Sexuality After Colorectal Cancer Treatment: A Narrative Synthesis

by

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Abstract

Sexuality and sexual health are often implicated due to treatment for colorectal cancer (CRC). The aim of this thesis was to understand how CRC treatment impacts the sexual health experiences of survivors, and how sex and gender-related factors shape these experiences. Narrative synthesis was chosen to examine relevant literature, and a sex and gender-based analysis framework was used to account for sex and gender throughout the research process. Findings generated a framework that shows the impact of treatment includes three aspects: sexual, psychosocial, and relational impact. Individual and relational characteristics, coping strategies, and interventions can influence the severity of the impact of treatment. This synthesis identified several gaps in the literature. Few studies examined men's and couples' sexual experiences. More intervention research is needed to understand what kinds of interventions are advantageous for survivors. Future guidelines should incorporate sex-specific management strategies to help improve sexual, relational, and psychosocial health.

List of Abbreviations Used

CRC	Colorectal Cancer
SGBA	Sex and Gender Based Analysis
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
ED	Erectile Dysfunction
QOL	Quality of Life
EORTC	European Organization for Research and Treatment of Cancer
IIEF	International Index of Erectile Function
FFSI	Female Sexual Function Index
CADTH	Canadian Agencies for Drug and Technologies in Health

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Chapter One Introduction

Colon and rectal cancers are two of the most common cancers in North America (Goldzweig et al., 2009), almost equally affecting men and women (Canadian Cancer Society, 2013). According to the Canadian Cancer Society (2013) 20,700 new cases of colorectal cancer (CRC) were diagnosed in 2012. Further, treatments for colon and rectal cancers (otherwise known as colorectal cancer) have improved over the years due to advancements in surgical techniques and increased rates of accessibility to radiation therapy and chemotherapy (Canadian Cancer Society). Due to these medical improvements, CRC survival rates are increasing (Bober et al., 2009); mortality rates in men have declined 2.7% per year since 2004 and 1.8% per year in women since 2000 (Canadian Cancer Society, 2013). Overall, approximately 65% of individuals with CRC will survive for five years or more after diagnosis (Canadian Cancer Society). Improved methods of cancer treatment have changed the course of illness from a short, often fatal trajectory, to a chronic illness allowing individuals to live for years after treatment (Sjövall, Gunnars, Olsson, & Thome, 2011). Although finishing treatment typically signifies the termination of the cancer, it does not mean the end of the illness experience. Side effects of treatment are often long-term and can impact many aspects of health, including sexuality and sexual health for both men and women (Bober, 2009).

The often-damaging physiological and sexual side effects of CRC treatment are well documented. These side effects typically include dyspareunia in women and erectile dysfunction in men (Cornish et al., 2007; Donovan, Thompson, & Hoffe, 2010; Ellis, Smith, Wilson, Warmington, & Ismail, 2009; Engel et al., 2003; Hendren et al., 2005; Morino et al., 2009; Quah, Jayne, Eu, & Seow-Choen, 2002; Schmidt et al., 2005;

Schmidt et al., 2010; Zippe et al., 2006). Hendren et al. (2005) examined sexual life post CRC treatment and found that 94% of women and 92% of men report one or more new sexual problems that were not present before treatment. In addition to the physical impact of treatment, the psychological, psychosocial, and psychosexual impact of CRC has been well outlined in the literature (Cecil, McCaughan, & Parahoo, 2010; Emslie et al., 2009; Goldzweig et al., 2009; Grant et al., 2011; Hagedoorn, Buunk, Kuijer, Wobbes, & Sanderman, 2000; Hagedoorn, Sanderman, Boks, Tuinstra, & Coyne, 2008; McCaughan, Prue, Parahoo, McIlfatrick, & McKenna, 2012; McCaughan, Prue, & Parahoo, 2009; Northouse, Mood, Templin, & Mellon, 2000; Rosmovitz & Ziebland, 2004; Schmidt et al., 2010). In addition, the impact and experience of treatment will manifest for men and women in deeply gendered ways. For example, distress regarding altered sexual functionality is sometimes prevalent in men (Bokhour et al., 2001; Emslie et al., 2009; Gilbert, Ussher & Perz, 2012), while significant anxiety regarding altered body image appears to be more significant for women (Grant et al., 2010; Gilbert et al., 2012).

Men and women sometimes undergo psychosocial and/or psychosexual therapy for treatment of sexual health issues because this has been shown to help with optimal recovery and management of cancer-related side effects (Guo, 2013; Rehse & Pukrop, 2003). Psychosocial interventions can play a role in reducing distress in cancer patients (Guo, 2013), improving quality of life (Osborn, Demoncada, & Feuerstein, 2006), and increase survivorship (Andersen et al., 2008). The most effective therapeutic techniques to address sexual health issues tend to be couple-focused and include treatment components that educate both partners about the cancer and treatments, promote couples' dyadic coping processes, and include specific sexual therapy techniques to address sexual and body-image difficulties (Scott & Kayser, 2009). However, findings pertaining to how men and women recovering from cancer respond to psychosocial interventions specifically pertaining to sexual health issues are limited and tend to vary considerably (Brotto, Yule, & Breckon, 2010). For example, a meta-analysis of 37 randomized controlled studies by Rehse and Pukrop (2003) demonstrated that psychosocial interventions appear to be more profitable for men than they are for women. The authors speculate this may be true because women are usually psychosocially better adjusted to illness. Conversely, there is a significant body of research that shows that women often access psychosocial support services, and tend to benefit from these services substantially more than men (Grande, Myers, & Sutton, 2006; Nelolaichuk, Cumming, Turner, Yuskchyshyn, & Sela, 2011; Steginga et al., 2008).

Overall, research shows that health professionals are not meeting the sexual health needs of men and women who have been treated for cancer (Hordern & Street, 2007). This lack of sexual health-focused care and support is exacerbated by the lack of explicit guidelines or policies in Canada that delineate how health care professionals should help CRC survivors to manage sexual health issues. Given that there are increased rates of survival among those diagnosed with CRC, an acknowledgment of the various quality of life issues— including sexuality and sexual health—has become more important than ever.

Purpose & Research Question

There is a large volume of literature examining the sexual health experiences of survivors of CRC. However, there are no synthesis papers that analyze this body of literature from a sex and gender specific perspective. To address this gap, I used a novel knowledge synthesis methodology as a way to synthesize relevant literature while simultaneously illuminating gaps in the literature. The purpose of this research was to critically examine how men and women with CRC experience sexual health as a result of treatment, and to understand how sex and gender-related factors influence survivors' sexual experiences. In an effort to encapsulate the complex gendered experience, a sex and gender-based analysis (SGBA) framework was used to guide the analysis of the synthesis findings. According to the Canadian Institutes of Health Research (CIHR) (2000) sex and gender are important variables to include in all health research, and a focus on gender can contribute to a sex-specific and gendered understanding of how men and women both socially and culturally respond to illness. Ultimately a greater understanding of how CRC treatment impacts sexual health could contribute to the formation of future policies or guidelines to guide this aspect of practice, and could help to influence health care professionals working with CRC survivors to recognize the importance of addressing sexuality as an aspect of long-term health management.

Therefore, the following questions guided a review of the literature:

What is the impact of CRC treatment on the sexual health experiences of survivors? How is this experience shaped by gender-related factors?

Summary

CRC survivorship has greatly improved in the last decade due to medical advancements in treatment. However, although individuals are living longer, often men and women will suffer long-term sexual side effects from chemotherapy, radiation therapy, and surgery. Due to the increased lifespan of survivors there is a need to engage in research that will address long-term quality of life issues for this patient population, one most salient aspect being sexuality and sexual health. Therefore, several researchers have inquired into the experience of CRC treatment and the impact treatment has on sexual health and sexuality. Generally, these studies show that men and women experience are challenged by alterations to their sexuality post treatment for cancer and experience sexual health issues in distinct, multifaceted ways.

There is a relatively developed body of literature evaluating the experience and impact of sexual health after CRC treatment. There are few guidelines or policies informing the care of this patient population, and often health professionals overlook the sexual needs of cancer patients. In order to address this gap, a synthesis methodology guided by a sex and gender-based analysis framework was used to analyze this body of literature from a sex and gender specific perspective, with the hopes of influencing future health policy and the formation of guidelines to address this aspect of quality of life.

Chapter Two Literature Review

This chapter will review the relevant literature and identify and define key concepts pertaining to the research question.

Defining Key Concepts

The concepts of gender, sex, sexuality, sexual health, and psychosocial health are complex and multifaceted. Unpacking these concepts and providing a clear definition of each term is necessary as they are central to this research. Gender is acknowledged to be the socially constructed characteristics considered appropriate by society for men and women. By definition, human sexuality is inclusive of sexual orientation, values, beliefs, and how we choose to express ourselves as men and women (World Health Organization, 2006). It will ebb and flow as we develop and encounter new experiences. Sexual health is highly dependent on physical and psychosocial well-being. It is intertwined with sexuality in the sense that sexual health cannot be obtained without a fulfilled sense of sexuality. Please refer to Table 2.1 below for more detailed definitions.

Table 2.1 Review of key concepts in this research

Sexuality	Experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors (WHO, 2006, p. 3).

Sexual Health	A state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence (WHO, 2006, p. 3).
Psychosocial Health	Psychosocial health hugely impacts quality of life and encompasses a broad spectrum of issues in cancer care including physical, social, cognitive, spiritual, emotional and role functioning, as well as psychological symptomology (Legg, 2011).
Gender	Gender is considered to be the socially constructed characteristics considered appropriate by society for men and women (WHO, 2013). Gender is not who we are but something that we do (Courtenay, 2000; Gerson & Peiss, 1985; Moynihan, 1998). Generally, gender-related factors are viewed as androgynous, fluid, challenging to define, and subject to change depending on context (Bruns, 2011; Kimmel, 1995).
Sex	Sex is considered to be the biological and physiological characteristics that define men and women (WHO, 2013). It refers to the anatomical, physical, genetic and hormonal variations that exist in species (Johnson & Repta, 2012).

Sexuality and Gender: A Review

It is helpful to review how gender is intertwined with sexuality and sexual health of men and women in order to begin to understand the experience of cancer treatment on sexuality. Here I review gender relations theory and how this theoretical perspective has guided the formation of my research question and focus. I will also review masculinity and femininity, and will introduce less constraining and more contemporary outlooks of gender and sex.

Gender relations. Raewyn Connell's (1987; 1995; 2005; 2009; 2011; 2012) conceptualization of gender relations is widely renowned, as researchers have made widespread uses of the concepts (Schippers, 2007). Connell (1987) conceptualizes gender relations as an aspect of dynamic social life enacted through daily interactions, whereby individual actions collectively constitute and re-create governing understandings of masculinities and femininities; however, this is done in a highly individual manner, as not all men and women will construct gender the same way. Connell also asserts that masculinity and femininity should be recognized as closely related concepts, one often impacting the influence of the other (Connell & Messerschmidt, 2005). Further, Connell (2012) outlines that much of the research attempting to encapsulate the impact of gender on health specifically outlines sex differences and diversity between men and women; she dubs this practice 'categorical thinking', where men and women are recognized and defined by sex-specific characteristics present in the media, government policy, and normative images of the family (Ridgeway & Correll, 2004). A significant weakness of categorical thinking is the lack of appreciation for the more subtle gender-related influences within gender categories and how these influences implicate health and illness.

Overall, gender relations theory is beneficial to help researchers move beyond the dyadic binary gender order that has dominated much of health research (Bottorff et al., 2012). In fact, this theory is useful to assist researchers in capturing the diverse ways in which men and women experience health and illness (Bottorff et al.). Connell's gender relations theory has been central to the consideration of gender related factors which attribute to the complex ways in which men and women experience sexual health after CRC treatment. This theoretical perspective has influenced the formation of the research question, focus of this proposed research project, and has helped to guide my understanding of gender throughout data collection and analysis phases.

Masculinity. Hegemonic masculinity is a central concept of gender relations theory. It functions as a network of power relations to signify a position of authority and leadership (Connell, 1995). Hegemonic masculinities operate through the subordination of other masculinities and also through the marginalization of femininity (Connell, 1995; Schippers, 2007). Connell (1987; 1995; 2005; 2009) uses the term hegemonic masculinity to mean that while there are multiple types of masculinities, there is always one that is hegemonic (i.e. superior) to the rest and acts to marginalize others in a gender hierarchy (Appelrouth & Edles, 2011). In addition, Connell emphasizes that often the hegemonic form is not the most common form. In fact, hegemonic masculinity is only enacted by a minority of men in society (Connell & Messerschmidt, 2005). Further, hegemonic masculinities are not fixed in nature; this is to say that men can adopt hegemonic masculinities when it is convenient for them, and can distance themselves from hegemony in times when it is needed. Therefore, masculinity doesn't necessarily represent a certain type of man but how a man chooses to position and represent himself in everyday situations (Connell & Messerschmidt, 2005). For example, many men align with hegemonic forms of masculinity that signify being successful, capable, reliable, and in control (Cheng, 1999). Some seek to emulate hegemonic characteristics such as domination, aggressiveness, competitiveness, sexual and athletic prowess, emotional control and stoicism (Oliffe, 2005; Moynihan, 1998).

Researchers have identified that hegemonic masculinities of western societies can be detrimental to health (Courtenay, 2000; Levant, Wimer, Williams, Smalley, & Noronha, 2009). Men are less likely than women to seek help for problems as diverse as depression, substance abuse, physical disabilities, and stressful life events (Husaini, Moore, & Cain, 1994; Levant et al., 2009; McKay, Rutherford, Cacciola, & Kabasakalian-McKay, 1996; Padesky & Hammen, 1981; Thom, 1986; Weissman & Klerman, 1977). Men who ascribe to hegemonic ideologies are more likely to engage in risky behaviors such as high-risk sexual activity, and also tend to experience higher levels of anger and stress (Levant et al., 2009). In addition, masculine characteristics such as inexpressiveness (Doyal, 2001) and refusal to admit weakness may prevent men to seek medical attention and participate in positive health practices (Addis & Mahalik, 2003; Harrison et al., 1992).

Some scholars argue that the notion of hegemonic masculinity has been widely over emphasized and overused (Wedgewood, 2009), because men tend to differ in how much significance they place on hegemonic masculine characteristics (Connell, 1995; Courtney, 2000; Good, Borst, & Wallace, 1994). In fact, a minority of men enact hegemonic masculinity (Connell & Messerschmidt, 2005). Howson (2006) introduced other forms of masculinities such as complicit, marginalized, protest, and subordinate that and are said to operate in society in relation to hegemonic masculinity to varying degrees.

Male sexuality and sexual health. For many men, masculinity is portrayed via the body and by the way it looks and works (Donaldson, 1991; Lee & Owens, 2002; Sabo, 1986). From a young age, most men learn to value their physical appearance, particularly idealized characteristics such as muscularity, athleticism, discipline, and power (Connell, 1995; Martino, 2003), and learn that their manhood is tied to their penis, specifically their ability to have and use erections for pleasure and to have sex with partners (Tepper, 1999; Zilbergeld, 1992). Most men value the meaning and the sexual pleasure associated with the sensations of an erection. In the context of sexuality and heterosexual relationships, hegemonic masculinities suggest that the male partner should initiate sexual activity, resulting in the successful penetration of the female. Inability to initiate sex or a lack of desire to do so can result in feelings of inadequacy among men, because they are unable to "live up to" a culturally embedded expectation (Lee & Owens, 2002). Men who are unable to accomplish the dominant ideals of sexual progression from erection to ejaculation tend to experience stigma, and a loss of a sense of manhood (Zilbergeld, 1992). Some men who are unable to perform sexually are affected in deeply gendered ways (Oliffe, 2005). Potts (2000) states that the impotent man feels "feminized, and –like a woman—he has no control over his body: there is no mind over matter" (p. 94). The inability to attain an erection resembles aspects of feminine sexuality (i.e. softness, slowness, and inferiority), and does not align with the idealized notions of masculinity (Potts, 2000). For men who are unable to live up to notions of masculinity, attempts to engage in sex may lead to anger, frustration, relationship conflict (Janssen, McBride, Yarber, Hill, & Butler, 2008), shame and despair (Flood, 2002; Lee & Owens, 2002; Tiefer, 1987).

Some researchers have challenged the dominant notions of sexuality among men. For example, in a study conducted by Janssen et al. (2008) focus groups were used to examine the factors that influence men's sexual activity. Findings indicated that men often experience sexual arousal without obtaining an erection. Further, the importance of body image emerged as an important factor in promoting or inhibiting sexuality; because many men feel believed willingness to engage in sex was significantly lower when they felt unattractive. In addition, participants were highly individual in their accounts of need for intimacy, and the importance they placed on the meaning of an erection. While some felt as though their ability to obtain and sustain an erection was closely tied to their masculinity, others did not. This study supported the body of thought that complexities of male sexuality are pronounced and diverse. Specifically, the findings help to illuminate that perhaps the importance placed upon the male erection may not be as closely tied to male sexuality as previously assumed.

Femininity. Socio–cultural constructions of idealized femininity normalize women as thin, young, and sexually appealing (Charlebois, 2011). These constructions support a component of gender relations theory, i.e. what is known as 'emphasized femininity' (Connell, 1987, p. 183), a socially constructed ideal of what constitutes a desirable woman. However, expressions of femininity take many forms. These forms include: emphasized femininity (as noted above, i.e. women support the gender hierarchy of hegemonic masculinities); ambivalent femininity (i.e. women who neither accept or reject hegemonic masculinities, and ebb and flow between resistance and co-operation with hegemonic ideals; and protest femininity (i.e. those who choose to challenge the basis of gender order, and promote notions of social justice to oppose the foundations of masculinities and femininities) (Howson, 2006). This conceptualization of femininity is useful to challenge constructs of masculinity and femininity as binary opposites while concurrently illuminating the diversity within the gender categories, and the relational gender dynamics in society (Bottorff, Oliffe, Robinson, & Carey, 2011). Generally, femininity is constructed as subordinate to masculinities, and it is through this subordination that gender hegemony is formed and maintained (Connell, 1987).

Female sexuality and sexual health. Sexuality has been highly debated, discussed, and dissected in many feminist works over the past decades. In the context of heterosexual relationships, women are sometimes viewed as sexual objects rather than sexual subjects, and will often disregard their own sexual needs and preferences in light of the needs of their male partner (Wood, Mansfield, & Koch, 2007). In line with hegemonic masculinities, female sexuality is sometimes reduced to an expression of male dominance. Flax (1987) outlines that gender socialization is the process through which women come to identify themselves as sexual beings to serve the needs of men. Societal influences such as magazine articles, television, and movies indicate to women that sustaining penetrative sex is a key component of the normative heterosexual relationships (Hyde, 2007). Due to the arguably lower social and economic position of women, many struggle to negotiate for their own sexual needs to be met and also may be challenged to refuse the sexual demands of men (Hyde, 2007).

According to Tiefer, Hall, and Tarvis (2002), if a woman perceives herself as unable to meet cultural norms regarding the notions of sexual attractiveness, sexual orientation, fantasies, or ideal sexual response, she may act in sexually avoidant ways or express feelings of distress. Furthermore, women who experience significant changes to their sexuality tend to experience socially produced anxiety (Hyde, Nee, Drennan, Butler, & Howlett, 2011). This anxiety could stem from the humiliation of being unable to live up to what society projects as normative heterosexual relations.

Sexual function in women has been highly scrutinized since the published works of Masters and Johnson (1966) which largely depicted the female sexual response cycle as linear and biologically determined, with little to no attention to the psychological aspects of sexual function (Levin, 2008). The notion that women will engage in sexual activity only if they feel the desire to do so has also been highly debated in literature. Basson (2005) argued that women have several reasons for engaging in sexual activity, and motivation for doing so is complex and multifaceted. Further, many feminist theorists have shunned the biological notions of sexual function in women, and instead support notions of sexual plurality, equality, justice, and diversity (Hyde et al., 2011), defined by choice and preference more than by biology.

Physiologically and culturally, women's sexuality has been shown to vary from that of men in multiple ways. Some women tend to have more nonspecific patterns of sexual arousal than men (Chivers, Riger, Latty, & Bailey, 2004), and tend to participate less in sexual activities such as self-stimulation (Hald, 2006; Oliver & Hyde, 1993; Peplau, 2003). Some studies have shown that women value committed relationships as a context for sexuality more so than men (Peplau, 2003; Regan & Berschid, 1999). Women tend to show higher levels of sexual plasticity; this means that women's sexual behaviors tend to be more susceptible to alteration depending on cultural, social, and contextual factors (Peplau, 2003). While this statement is not definitive, it is possible to infer that women's sexuality and sexual health may be at higher risk in light of a life threatening illness.

Physiological Impact of Treatment on Sexual Health

In order to begin the examination of how cancer survivors experience sexuality, a brief examination of the physiological sexual impact of cancer treatment is required. According to the Canadian Cancer Society (2013), cancers affecting the rectum, and the ascending, transverse, descending and sigmoid colon are considered within the spectrum of colorectal cancers. Typically, treatment options and care trajectory for individuals with CRC will be similar, including surgery, chemotherapy, and radiation therapy.

Surgery and sexual health. Surgery is the mainstay of CRC management, and remains the only curative therapy (Bonjer et al., 2007). In men, nerve damage caused by CRC surgery can compromise the ability to obtain an erection and can impair the ability to ejaculate. For women, nerve damage is related to decreased ability to achieve orgasm (Havenga et al., 1996), and decreased vaginal lubrication, which can result in dyspareunia (Daniels, Woodward, Taylor, Raja, & Toomey, 2006).

Radiation therapy and sexual health. Research shows that radiation therapy for the treatment of CRC significantly impacts long-term sexual functioning for both sexes (Donovan et al., 2010). Side effects such as erectile dysfunction can potentially impact sexual functioning of men (Canadian Cancer Society, 2013). Radiation therapy can cause onset of menopause, vaginal atrophy, fibrosis, adhesions, and shortening of the vagina (Canadian Cancer Society).

Chemotherapy and sexual health. Chemotherapy can induce menopause, low libido, and vaginal dryness among women (Canadian Cancer Society, 2012), and produce lower sperm counts in men (Stewart, Lee, & Kim, 2008). Men may also experience the inability to orgasm and challenges in maintaining an erection (Canadian Cancer Society, 2012).

Experience of Sexuality following Colorectal Cancer Treatment

The following section will expand beyond physical symptoms and will focus on the experience of sexuality post treatment as well as the psychosocial impact of treatment on sexuality and sexual health.

The male experience. How men experience illness has been increasingly recognized as socially constructed (Charmaz, 1995; Connell, 1995, 2000; Courtenay, 2000; Gordon, 1995; Gordon & Cerami, 2000; Huggins, 1998; Moynihan, 1998; Oliffe, 2002). Some research shows that men often downplay the significance of the side effects of cancer (McCaughan et al., 2012) by indicating that the long-term effects have a minimal impact on their life and everyday functioning (Foley et al., 2006; McCaughan et al., 2012). Conversely, some research shows that men do experience significant negative changes to their sexuality and sexual health post cancer treatment. Hendren et al. (2005) uncovered that 45% of men reported that treatment for CRC caused them to experience a significant negative change to their sex lives.

Altered functionality. Some researchers argue that men are highly concerned with altered functionality of their body post treatment for CRC. Studies show that men experience alterations to their sense of masculinity due to impaired sexual function (Dowswell et al., 2011; Fergus, Gray, & Fitch, 2002; Hendren et al., 2005). In a study of men following treatment for cancer, participants reported a diminished sense of manliness, self-worth and confidence that stemmed from fear and embarrassment associated with changes in functional sexual ability (Bokhour et al., 2001). Gilbert et al. (2012) conducted semi-structured interviews with 44 cancer survivors and their partners to understand the experience of changes to sexuality after cancer treatment. The central finding of this study was that both survivors and partners tended to be concerned about the men's loss of sexual functionality.

Erectile dysfunction (ED) is a widely researched aspect of physical functionality and has been shown to produce anxiety (Sugimori et al., 2005) and depressive symptoms in men (Araujo, Durante, Feldman, Goldstein, & McKinlay, 1998; Makhlouf, Kparker, & Niederberger, 2007; Seftel, Sun, & Swindle 2004; Shabsigh et al., 1998). ED has also been correlated to loss of self-esteem, and deterioration of multiple aspects of quality of life (Laumann, Paik, & Rosen, 1999; Sanchez-Cruz et al., 2003; Tomlinson & Wright, 2004; Wagner, Fugl-Meyer, & Fugl Meyer, 2000). To date there has been little published research describing the experiences of erectile dysfunction (ED) in men with CRC (Hendren et al., 2005). However, many studies examined men after surgery for prostate cancer, which provides some useful insights into the experience of ED and its impact on quality of life for men and their partners (Dowswell et al., 2011). Some men with ED describe experiencing reductions in the quality of sexual intimacy, sexual fantasy, perceptions of masculinity, and general social interactions with women (Davison, So, & Goldenberg, 2007). Fergus et al. (2002) uncovered in their exploratory study that some men express feeling stigmatized regarding their sexual difficulties, while others report feeling devastated, depressed, shameful, and embarrassed. Some research has shown that while the impact of ED is significant, it does depend in large part on an individual man's unique sexual history. This is to say that men who associate sexuality with masculinity pre-treatment tend to voice greater struggles with ED (Fergus et al., 2002 ; Gray et al., 2002).

Other functional concerns in men include the formation of a stoma and the use of an ostomy to eliminate waste. Rosmovitz and Ziebland (2004) outlined that the loss of control over bodily functions signifies a disentitlement of the individual as a thoroughly socialized, civilized human being in society. Anxieties and fears regarding the presence of a stoma, the noise associated with the stoma, odor, and leakage are concerns among men (Nagpal & Bennet, 2013). In one study, negotiating sex after stoma surgery was confirmed as a challenge because men's narratives suggested that the presence of a stoma had a long lasting negative effect on their intimacy more so than in women (Emslie et al., 2009). Participants in the narrative described loss of professional identity, loss of ability to socialize, loss of dignity, privacy and independence, and disruption of sexual identity as factors having a profound impact on their lives after obtaining an ostomy. Discomfort with sexual identity and fear of rejection persisted among participants for many years, and even participants who had good partner support outlined challenges in maintaining their sexual identity (Emslie et al., 2009).

Men recovering from treatment for cancer often experience psychosocial distress as a consequence of their changed sexual functionality. According to a large prospective study with 519 men and women, men experienced worse alterations to their sexual lives compared to women, which also translates into greater levels of emotional distress for men (Schmidt et al., 2010). Similar findings were outlined in a cross sectional study by

Goldzweig et al. (2009); results showed that the men experience significantly higher levels of psychosocial distress compared to women regarding their altered sexual function.

Body image. Body image is a key aspect of psychosocial health and encompasses an individual's feelings and attitudes toward their body (DeFrank, Mehta, Bahn, Stein, & Baker, 2007; Krebs, 2006). It is shaped by personal and social experiences (Cash, 2002; Paquette & Raine, 2004; Tiggemann & Lynch, 2001). Illnesses and disease that impact mobility and physical activity (i.e. cancer) can be affect body image, as lack of mobility can inhibit sexual desire, resulting in decreased interest in sexual activity (Lewis et al., 2004). While challenges to body image have traditionally been associated with women, body image issues are also a concern among men, although it appears this has not been widely researched. One exploratory by Davison and McCabe (2005) examined 437 healthy men and women ages 18-86 years to understand the impact of body image on psychological, social, and sexual functioning. Comparatively, men and women did not differ in their ratings of the importance of body image on physical attractiveness, body image importance, or level of engagement in efforts to improve their bodies. Men were as likely as women to denote their physical attractiveness as poor, and attribute significant importance to physical appearance. Men were also just as likely as women to report engaging in efforts to improve their outward physical appearance, and also make efforts to conceal their changed bodies with non-revealing clothing (Davison & McCabe).

Changes to symbolic, gendered body parts may inflict body image disturbances on male cancer survivors (Harrington, 2011). While research pertaining to CRC and body image is limited, there is some research pertaining to other cancers. Harrington identified that body image is a significant indicator of quality of life among prostate cancer survivors. ED, ejaculatory dysfunction, weight gain, and surgical scars are all aspects of treatment that can negatively affect male self image (Harrington, 2011; O'Shaughnessy & Laws, 2009). In a study conducted by Cecil et al. (2010) with eight men who underwent treatment for various types of cancer including prostate, bowel, and leukemia, body image issues emerged as a notable concern among participants. Aesthetic body changes such as weight gain were of prime concern for some and they also expressed a sense of loss of masculinity, attributing these concerns with loss of libido (Cecil et al.).

Coping. Emslie et al. (2009) conducted a secondary analysis of 17 men treated for CRC in an attempt to explore the experience of coping. Men expressed coping through avoidance of engaging in sex with their partners. Men enacted protective behaviours by resisting sexual activity to guard their partner from their altered erectile function and sense of body image. The narratives of the participants aligned with concepts of hegemonic masculinities as some participants outlined the importance of their roles as providers and protectors. Similar findings were uncovered in a longitudinal study by McCaughan et al. (2012). Men in this study were concerned that if they expressed emotions they would be viewed as emotional beings, acting in a way that is not congruent with 'masculine practice'. These findings support the notion that socially defined gender roles can substantially impact and/or inhibit coping mechanisms post cancer treatment.

There is a prevalent body of literature which supports that more often than not men will redefine their sexuality and preference for penetration when erectile function is lost (Gray, Fitch, Fergus, Mykhalovskiy, & Church, 2002; Oliffe, 2005). When a man encounters changes to his sexuality or sexual health there are two main options to cope outside of complete withdrawal from sexual activity. Firstly, the afflicted man can try to reinstate his previous level of functioning using the best that modern technology offers (i.e. medications or erectile aids), or secondly, he can work to alter his expectations and expand his notions of what constitutes acceptable sexual expression beyond the restrictive imperative of penetration accompanied by ejaculation and orgasm (Fergus et al., 2002). Men often enact the latter option; studies show that men who are afflicted with alterations to their sexuality will redefine their sense of masculinity in an attempt to reconcile their sense of sexual identity (Fergus et al., 2002; Gray et al., 2002).

Experience of men who have sex with men. In an effort to encapsulate the diversity of the male experience, it is important to account for the sexual experiences of men who have sex with men (MSM) undergoing treatment for cancer. There are multiple reasons that support the inclusion of MSM in the context of this research. According to Black, Gates, and Sanders (2000), due to the significant numbers of men diagnosed with CRC per annum in Canada, research pertaining to quality of life issues should be as deeply rich and textured as the range of men in our society, and should relate to the range of masculinities and sexualities among men. In addition, an aspect of a sex and gender-based analysis is the inclusion of diverse perspectives in the area of proposed research (Spitzer, 2006).

Overall, there is very little research examining the experience of MSM with CRC. Therefore, much of the research presented in the following section supporting the experience of MSM will be from the perspective of prostate cancer, because this has been relatively well researched.

Loss of sexual ability. Loss of sexual ability (i.e. loss of erectile function) may translate into high levels of distress among MSM. Erections and their importance to homosexual sexual activity varies from that of heterosexuality as often the erectile function suitable for oral or anal penetration differs from that of vaginal intercourse. Further, MSM may demonstrate concerns regarding other aspects of sexual intercourse, for example, if he considers himself to be primarily anal receptive he may be concerned about the impact of radiation therapy on bowel function and rectal irritation (Blank, 2005).

An exploratory study by Fergus et al. (2002) examined a sample of heterosexual and homosexual men after treatment for prostate cancer. The men who identified as gay in this study experienced a sense of pressure to perform which align with societal expectations, and concerns that they would disappoint their sexual partners as a result of their altered sexual functionality. Further, participants expressed a feeling as though they carried an invisible stigma related to their sexual issues; some men expressed this stigma as feeling as though they were carrying around a dark secret, unknown to the general public. In addition, findings showed that openly discussing sexual issues with partners is a challenge for gay men. Concerns of being mocked, ridiculed, and gossiped about by their partner and peers are other distresses (Fergus et al., 2002).

Expressions of masculinity. Asencio, Blank, DesCartes, and Crawford (2008) conducted focus groups with gay men to ascertain their knowledge of the potential sexual consequences associated with cancer and treatment. Findings show that sex is an integral part of homosexual relationships, and many gay men support the notion that a focal point of sexuality is the penis— particularly in terms of its size and function— as they constructed the penis as central to physical pleasure, identity, and masculine sexual prowess.

According to Fergus et al. (2002), gay men refer to sexual performance as a symbolic expression of manhood. Further, both the gay and straight men who participated in this study commonly defined sexuality in ways of "conquest and competition" (p. 310). This is achieved through the 'conquering' of sexualized others, and through sexually focused competitiveness with other men. Furthermore, suffering from sexual issues (i.e. erectile dysfunction) signified a sense of inferiority to participants, because they felt as though didn't quite measure up compared to other men. This was particularly expressed among gay men as they compared themselves to their sexually functioning partners.

The female experience. Some research shows that women report significantly higher levels of psychological distress compared to men in the light of a CRC diagnosis and subsequent treatment (Grant et al., 2011; Hagedoorn et al., 2000; Hagedoorn et al., 2008; McCaughan, et al., 2009; Northouse, Mood, Templin, & Mellon, 2000; Tuinstra et al., 2004). Women recovering from cancer typically report more problems in their work, family, and social life. They also tend to report lower levels of marital satisfaction within the first year following treatment for CRC (Northouse et al., 2000).

From a traditional viewpoint, women are typically responsible for juggling multiple roles (such as mother and partner) and it has been proposed that their sense of identity is deeply impacted by a life threatening diagnosis; therefore, they experience greater disruption to their sense of self in comparison to men (McCaughan et al., 2012). Emslie et al. (2009) suggested that socially defined gender roles influence the ways in which women recover from treatment. Findings of this study align with hegemonic femininities, reflected in participants need to organize domestic work and childcare, and were concerned with returning to caring roles as soon as possible after completion of treatment. It has been suggested that the impact of cancer treatment may not be as apparent in men as they do not have the same roles to fulfill in the context of family relations (Emslie et al., 2007; Northouse et al., 2000).

Altered functionality. Sexual intercourse post treatment can be a painful experience for women. Dyspareunia (painful sexual intercourse), vaginal pain, abdominal pain, and pelvic pain are all possible side effects of treatment (Hendren et al., 2005), however there has been very little research examining how women with CRC experience this pain. Platell, Thompson, and Makin (2004) examined sexual health concerns among women post treatment for rectal cancer and uncovered that women experience altered genital functionality (i.e. decreased vaginal elasticity and vaginal pain) when they attempted to engage in sexual activity. Tierney (2008) asserted that if a women experiences dyspareunia she may quickly lose her desire for sex in order to avoid a painful sexual encounter.

Fear of incontinence or leakage from an ostomy appliance was a prevalent finding in a narrative study by Andersson (2010), as women outlined how this fear limited their daily life and social interactions. Many women find engaging in sexual activity challenging because of psychological issues pertaining to the presence of the stoma and/or ostomy appliance (Grant et al., 2011). Hendren et al. (2005) conducted large retrospective study with 100 women to assess sexual function and quality of life (QOL) after surgery for rectal cancer. Results showed that women with an ostomy felt as though the appliance made their sex life worse. Further, women who experience a change of bowel functionality because of the formation of an ostomy feel ashamed of their bodies, and they believe their partners find them less attractive, resulting in loss of sexual spontaneity (Hendren et al., 2005; Platell et al., 2004). In addition, maintenance of the appliance is challenging for many as it requires the woman to reconcile her feelings of discomfort pertaining to her changed body prior to becoming sexually intimate (Manderson, 2005).

Body image. Women are generally considered to express more negative body image than men (Feingold & Mazzella, 1998). In addition, Davison & McCabe (2005) found that women have lower levels of satisfaction with their bodies and a greater tendency to conceal their bodies. Women also report higher levels of social physique anxiety, indicating that they are more concerned than men about others negatively evaluating their appearance (Davison & McCabe, 2005). Women who are highly concerned with their body image tend to report lower levels of sexual intimacy, and typically feel less comfortable and confident about sexuality and sexual interactions (Accard, Kearney-Cooke, & Peterson, 2000; Cash, Maikkula, & Yamamiya, 2004; Davison & McCabe, 2005; Wiederman & Hurts, 1997).

The impact of cancer treatment on female body image is direct and substantial. Cancer treatments (chemotherapy, radiation therapy and surgery) are known to induce long-term and sometimes permanent negative effects on sexual arousal and desire, vaginal lubrication (Jensen et al., 2004), menopausal status (Rasmusson & Thome, 2008), and the experience of painful intercourse (Gilbert, Ussher, & Perz, 2010). Butler et al. (1998) outlined these side effects as factors which promote “invisible assaults to femininity" (p. 685), and are associated with both poor body image and self-perceived attractiveness in women (Burns, Costello, Ryan-Woolley, & Davidson, 2007). Grant et al. (2011) conducted eight focus groups to discuss the challenges of living long term with CRC, and the experience of living with an ostomy as a result of treatment. These focus groups findings demonstrated that problems with body image and depression were prevalent in women. Participants expressed how their outward physical appearance (i.e. clothing selection) changed as result of their altered body image. Clothing that fit too tight was deemed too revealing was no longer an option for many participants. Gilbert et al. (2012) conducted a qualitative study with men and women and their partners to explore post-cancer treatment experiences of embodied sexual subjectivity. The primary concern among women was related to body image changes. Specifically, changes to weight made it difficult for some women participants to 'look in the mirror' and feel sexually attractive. Women also outlined additional challenges such as the inability to feel outwardly feminine owing to hair loss caused by chemotherapy treatments.

Coping. Some studies have shown that coping practices of women with CRC are less than optimal. Grant et al. (2011) reported that coping and adjustment difficulties pertaining to body image and formation of a stoma are common concerns. Women also encountered difficulties with sleep, and adjustment to life and sexual dysfunction after treatment. Baider, Perez, and De-Nour (1989) examined how couples experience and adjust to colon cancer. Men were shown to adjust better compared to women, reporting significantly lower levels of emotional distress post treatment. Conversely, Baider and Denour (1999) noted that women tend to adjust better to the disease in terms of sexual, social, and work-related functioning.

Not all research indicates that women cope poorly. McCaughan et al. (2012) found that women typically experience long-term treatment side effects, but adjust to these side effects and develop effective strategies to manage them. Ramirez et al. (2010) examined the experiences of women with an ostomy. Results showed that over time, women were able to adjust to changes in their physical appearance and overall health. This was helped by positive partner support; women placed a high level of value on the affirmation provided from their partner confirming their sexual desirability. In addition, some research demonstrates that women possess specific coping skills that help them to adjust more readily to side effects of treatment. Based on a meta-analysis, Tamres, Janicki, and Helgeson (2002) concluded that women are more likely to seek emotional support, engage in coping strategies, and use positive self talk. Further, women may be more apt to cope and adjust to illness more effectively because they tend to be more comfortable than men in discussing their emotional distress (Northouse et al., 2000). McCaughan et al. (2012) uncovered that it is possible that both men and women suffer from the same or similar distress post treatment for CRC. However, men who participated in this study were not as willing to share their experiences for fear of portraying themselves as less of a man. One can infer from these findings that coping and adjustment to illness is a gendered experience, influenced by gender roles and practices.

Experience of lesbian women. A systematic review by Brown and Tracy (2008) evaluating disparities among breast, cervical, ovarian, lung, and CRC literatures concluded that there is very little literature focusing on lesbians in the context of CRC. Generally, the majority of research focuses on the experience of lesbians undergoing accessing health care for screening and testing for various cancers (Brown & Tracey). However, there has been a growing body of literature addressing the experience of lesbians in the context of breast and gynecologic cancers; therefore this section will focus on this research with the assumption that some of the core findings may be transferable to lesbian women with CRC.

Body image and sexuality. After treatment for cervical cancer lesbian women often express feeling undesirable as sexual beings, and consequently brand themselves as 'bad investments' for their partner (Herzog & Wright, 2007). In addition, some research suggests that lesbian culture places less emphasis on physical size, body weight, and visual aspects of physical appearance (Fobair et al., 2001). For example, Loulan (1984), Herzog et al. (1992), and O'Hanlan (1995) are some researchers who suggest that in lesbian culture there may be less focus on appearances or sexual anatomy, with more focus on an individual's personality traits. In a study by Fobair et al. (2001) examining experiences of heterosexual women and lesbian women with breast cancer, survey data revealed that lesbian women were significantly more comfortable showing their body both before and after having breast cancer, suggesting that lesbians may be more comfortable with their body image. While these findings are noteworthy, they cannot be generalized to all lesbian women; although, they do suggest that the experience of lesbian women could be markedly different than that of heterosexual women.

Coping and support. Fobair et al.'s (2001) descriptive study comparing the experiences of breast cancer found that coping mechanisms differed between heterosexual and lesbian women. Lesbians reported significantly less cognitive avoidance behaviours compared to heterosexual women. However, lesbians were significantly more likely to report expressions of their anger, and reported lower levels of ‘fighting spirit’. Findings also demonstrated that heterosexual and lesbian women report similar levels of anxiety and feelings of helplessness or hopelessness as they recover from treatment for cancer.

Some studies show that lesbian women experience more stress associated with diagnosis, lower satisfaction with care, and lower satisfaction with the available emotional support (Matthews, Peterman, Delaney, Menard, & Brandenburg, 2002). However, according to Herzog and Wright (2007), regardless of how a cancer diagnosis may complicate and disrupt personal relationships, lesbians have reported that facing cancer together strengthens their relationships. In addition, Fobair et al. (2002) reported that lesbian partners were found to provide higher love and care and willingness to listen compared to heterosexual couples. Findings uncovered that lesbians’ support systems tended to extend beyond partners based on reports that lesbian patients tended to rate their friends as significantly more likely to give advice. Similar findings were uncovered by others (Bradford, Ryan, & Rothblum, 1994), who concluded that while lesbians may not have the same degree of family social support, they sometimes develop a broad chosen family that provide a supportive network of relationships.

Transgenderism and sexual health after cancer. Transgender is an umbrella term that describes several distinct gender identities including transsexual, transvestite, androgyne, intersex, hermaphrodite, and the states of crossgender (American Public Health Association, 1999; Israel & Tarver, 1997). Cancer research examining transgender populations is limited, which is not surprising given that in general, transgendered individuals are poorly researched compared to lesbian, gay, and bisexual populations. As a consequence, one of the most significant barriers transgender individuals face in health care is that most health professionals lack the necessary knowledge about transgender identity and sexuality, which acts as a barrier to the provision of optimal health services (Dean et al., 2000).

It has been said that transgendered men and women struggle with their reproductive anatomy and biological sex because it does not match their personal gender identity (Dutton, Koenig, & Fennie, 2008). Since CRC treatment has been shown to exert detrimental side effects to sexual health it is possible to infer that the sexual health experiences of transgendered persons are highly complex. Largely, health providers have little to no knowledge about how transgendered individuals experience the extent of their physical transitions, what specific health care issues they need to have addressed, nor how to provide culturally competent care (Dutton et al., 2008). Therefore the sexual health experiences of transgendered men and women post treatment for cancer are largely unknown, and it can be assumed that provision of sexual health supports for this population are likely haphazard and inadequate.

The couple experience. The experience of couples managing treatment and recovery for cancer is complex. This section will attempt to unpack the common experiences of couples challenged with cancer treatment and recovery.

Maintaining a healthy relationship throughout the diagnosis, treatment, and recovery stages of cancer is critical. Men and women who have low social support tend to be at greater risk for poor psychological adjustment after treatment for CRC (Chambers et al., 2011; Rhodes & Lakey, 1999). Research indicates that positive social relationships are an important aspect of psychological well-being, and spousal support has been shown to be a crucial component of optimal recovery from cancer treatment (Emslie et al., 2009; Piwonka & Merino, 1999). A longitudinal study comparing colon cancer patients' use of resources, concurrent stress, and overall psychosocial adjustment during the first year post-op, noted that high levels of martial satisfaction are correlated with high levels of psychosocial adjustment for both men and women (Northouse et al., 2000).

Cancer and the relationship. There is substantial research that shows that when a male or female partner is afflicted with a cancer diagnosis the psychological well-being of both the individual with cancer and their partner is significantly impacted (Manne, 1998). Often, couples face distress when undergoing and recovering from cancer treatment, and when patients are distressed their partners tend to be distressed as well (Carlson, Bultz, Speca, & St. Pierre, 2000; Manne, 1998). This increased distress is likely to impact sexuality, sexual health, and sexual well-being. In fact, research shows that individuals and partners afflicted with cancer tend to experience changes to sexuality and sexual functioning including decreased sexual desire, lack of interest in sex, pain during sex, erectile dysfunction, and body image concerns (Fergus et al., 2002; Gilbert, Ussher, & Hawkins, 2009; Gilbert et al., 2010; Gilbert et al., 2012; Jensen et al., 2004; Mercadante et al., 2010). Further, sexual satisfaction contributes to a relationship's stability (Sprecher & Cate, 2004). If a partner is unable to perform sexually due to the side effects of cancer treatment, one can infer that without a good quality sex life as perceived by both partners, the quality of the relationship could be jeopardy.

Men and women value relationships and sexuality in the context of cancer treatment in some similar ways. Research shows that men who report high levels of relationship satisfaction are more likely to report sexual fulfillment, while men who report low levels of relationship satisfaction are more likely to report sexual health difficulties (Cameron, Rosen, & Swindle, 2005; Rowland, Van Diest, Incrocci, & Slob, 2005). Comparably, research shows that women who report having a supportive and stable relationship are able to maintain feelings of sexual desirability after treatment (Altschuler et al., 2009; Manderson, 2005; Ramirez et al., 2010). In addition, Altschuler et al. (2009) uncovered that women value positive support from their partner, because it is central to their psychosocial adjustment after surgery. Generally the benefits of a stable, satisfactory relationship are prevalent for both men and women.

Researchers have looked into role differences with respect to dealing with cancer and have illuminated the importance of factoring gender roles into research with couples. Levels of psychological distress seem to be influenced by being male or female and being the patient or partner, and tend to vary considerably depending on gender and role (Tuinstra et al., 2004). Hagedoorn, Buunk, Kuijer Wobbes, and Sanderman (2000) examined levels of psychological distress among 173 couples in a cross sectional study. They showed that being the patient or partner makes little difference in terms of levels of distress in women, although there was a noted difference in men. Women partners and patients both perceive similar high levels of distress, while men patients perceive higher levels of distress compared to men partners. Hagedoorn et al. account for these differences by stating that women tend to be more relationship-oriented and will, therefore, be more strongly influenced by the condition of their partner.

The partner experience. Generally, partners experience more negative feelings, emotional distress, anxiety, and depression about the cancer diagnosis compared to patients (Northouse, Schafer, & Tipton, 1999; Persson, Severinsson, & Hellstrom, 2004). However, similar to findings by Hagedoorn et al. (2000) above, some research has indicated that female partners are more vulnerable to the negative side effects of a cancer diagnosis (Northouse et al., 1999; Northouse et al., 2000), reported higher levels of stress and burden (Blood et al., 1994; Tuinstra et al., 2004), and more demands associated with the illness (Stetz, 1987) than male partners. Northouse et al. (2000) revealed in their longitudinal study that female partners had the highest level of concurrent stress and the lowest level of support at each assessment time. However, these findings are not definitive, the authors suggest it could be related to the idea that women tend to be more open and comfortable in disclosing their emotional distress in comparison to men (Northouse et al., 2000).

There has been very little research done to examine the partner experience of cancer-induced alterations to sexuality. Persson et al. (2004) conducted a qualitative descriptive study with nine partners of patients who had undergone surgery for rectal cancer. A resounding theme of this study was the presence of a stoma highly influences the ways that partners view their sick partner. According to the findings, partners often describe the altered physical body and feel ‘disgust’ with the presence of the stoma. This was especially prevalent among women, who tended to view their partners changed bodies as less masculine and sexually desirable. In addition, partners often feel as though they sustained changes to their sexual relationship, and feel increasingly withdrawn from intimacy.

Altered sexual functionality, specifically challenges with erectile dysfunction (ED), can impact sexual satisfaction in partners (Butler et al., 2000; Fisher, Rosen, Eardley, Sand, & Goldstein, 2005; Shindel, Quayle, Yan Yan, Husain, & Naughton, 2005). Fisher et al. (2005) surveyed 293 female partners to ascertain their perspectives of male partners with ED. Findings showed that women generally experience a significant change to their own sexual activity, sexual desire, arousal and ability to orgasm. In addition, ED affects relationship satisfaction levels; women feel as though their sexual lives and experiences are negatively impacted by their partners' inability to attain or sustain an erection.

Role of the caregiver. Although not all partners will undertake the role of caregiver to their ill partner, often partners will assume the role of informal caregiver with little to no support from others (Gilbert et al., 2009; Northouse, 1988). Some research shows that this change in relationship dynamic can be harmful to couples' intimate relations. In a grounded theory study conducted by Gilbert et al. (2009), the impact of the caring role was examined in relation to the sexuality and sexual health of partners' caring for their partner post-cancer diagnosis. The findings of this study indicate that partners' experiences of sexuality are shaped not only by the physical changes in their partner but also the stress and exhaustion of the caregiver role. Additionally, many participants viewed their partner with cancer as child-like, or as an asexual sick patient. Activities such as help with personal care limited the ability of partners to view their partner as a sexual person. Ultimately, this changed view led partners to feel as though engaging in sexual activity was inappropriate or unacceptable (Gilbert et al., 2009).

Coping and negotiating intimacy. There is a growing body of literature examining the coping skills and adjustment of persons with cancer and their partners.

Much of this research shows that cancer poses a major stressor for couples, and that couples are highly involved in each other's coping and support processes (Hagedoorn et al., 2008). Coping with cancer is considered to be dyadic; peoples' adjustment to an altered self is affected by their partners' behavior and adjustment (Berg & Upchurch, 2007; Hagedoorn et al., 2008; Hagedoorn et al., 2011; Manne & Badr, 2008). In addition, coping is enhanced through sexuality, as sexual intimacy is crucial to enhance couple closeness and support, and to make the recovery process more manageable (Schultz & Van de Wiel, 2003; Scott & Kayser, 2009). Sexual intimacy can reaffirm life and vitality and bring a reassuring sense of normalcy to the lives of the couple afflicted with cancer (Kayser & Scott, 2008).

Gilbert et al. (2012) found that couples who experience various cancers including breast, brain, colorectal, liver and prostate outline undergoing a re-negotiation of sexual practices and relational closeness by finding other ways to be intimate. This includes the exploration of other sexual practices including: masturbation, mutual genital touching, massage, hugging and kissing and oral sex. Some couples express that the changes to sexuality brought on by cancer treatment actually provide an opportunity to feel closer as a couple.

Summary of the Literature Review

In summation, men and women who experience treatment for CRC find their sense of sexuality and sexual health to be physically and psychosocially challenged in significant, gendered ways. The findings of some studies examining the experience of treatment on sexuality and sexual health align with hegemonic masculinity, as themes of embarrassment, loss of manliness or masculinity, loss of sexual ability, avoidance, and protectiveness are present in narratives as men speak to the experience of treatment. Gay men face many of the same struggles as heterosexual males; however, erections and their importance to homosexual sexual activity varies from that of heterosexuality because often the erectile function suitable for oral or anal penetration may differ from vaginal intercourse. Men refer to the challenges pertaining to body image, including engaging in efforts to improve their outward physical appearance, and also making efforts to conceal their changed bodies with non-revealing clothing because they are concerned regarding their perceived attractiveness to others. These findings denote that not all men will align with hegemonic narratives; in fact, many findings give voice to men who align with the subordinated and marginalized forms of masculinity.

It has been proposed that a woman's sense of identity is deeply impacted by a life threatening diagnosis; therefore, it is possible women experience disruption to their sense of femininity. Study findings show that women with cancer report significantly higher levels of psychological distress. Further, women experiencing CRC show aspects of femininity and many women express challenges in fulfilling gender roles in the context of family relations (i.e. stress regarding organizing child care and returning to domestic work). In line with notions of femininity, women outline feeling ashamed of their changed bodies, and they believe their partners find them less attractive, resulting in alterations to sexuality and sexual activity. Lesbian women encounter some of the same challenges; however some research shows that lesbian women are less concerned with altered body image and outward physical appearance. In addition, lesbian women are said to experience more stress associated with the cancer itself.

The experiences of couples are highly complex, levels of psychological distress are contingent on being male or female and being the patient or partner, and tend to vary considerably depending on gender and role. Often, women partners and patients both perceive higher levels of distress compared to men. This has been explained to be the case since women tend to be more relationship-oriented and will therefore be more strongly influenced by the condition of their partner. Coping with cancer is considered to be a dyadic process, and often couples will work together to renegotiate intimate activities to include non-genital forms of intimacy and increased relational closeness. In fact, some couples feel as though changes to sexuality brought on by cancer treatment provide an opportunity to facilitate increased relational closeness.

The body of literature examining the experience of sexuality for those afflicted with CRC is diverse and substantial. Generally, the literature shows that the influence of sex and gender-related factors on recovery from CRC treatment is significant, although findings are varied and inconsistent. Often, men and women experience alterations to their sexuality in ways that are embedded in theoretical perspectives of femininity and masculinity. Therefore, undertaking a synthesis methodology, guided by a sex and gender-based analysis, was an effective strategy to systematically synthesize and interpret this body of literature. The final product contributes to a deeper understanding and interpretation of how cancer treatment impacts the sexual experiences of CRC survivors, and also offers an interpretation of how this experience is shaped by gender-related factors such as self perceived concepts of masculinity and femininity.

Chapter Three Methodology

This chapter will review the narrative synthesis approach and will outline how this methodology was utilized in the context of this study. It will include a detailed review of the methodology, data collection methods, and strategies used for data analysis.

Knowledge Synthesis: A range of methods

The need for a systematic method to examine and critique large bodies of literature became relevant in 1980's when the flaws of the traditional literature review were made apparent. The main issue of the traditional review was the tendency of reviewers to focus on a small subset of literature without appropriate critique and comparison of all relevant literature pertaining to a topic of inquiry. In addition, the 1980s brought an increasing interest in the randomized control trial (RCT) (Dixon-Woods et al., 2006). Subsequently, in 1992 the internationally recognized Cochrane Collaboration was founded; its purpose was defined as a way to systematically identify, critique, and summarize clinical trials pertaining to medical issues (Grant & Booth, 2009).

Scholars argue that a major flaw of the Cochrane review methodology is the disregard for most studies lying outside the realm of RCTs, particularly studies of a qualitative nature. Critics recognize that the Cochrane methodology promotes reductionist and standardized results that fail to recognize individual factors or contextual variables (Culpepper & Gilbert, 1999; Dixon-Woods et al., 2006; Forbes & Griffiths, 2002). Therefore, in more recent years, Noyes, Popay, Pearson, Hannes, and Booth (2008) of the Cochrane Collaboration have supported the inclusion of evidence from qualitative studies in order to uncover the experiences of those involved in receiving interventions (Arai, Roen, Roberts, & Popay, 2005; Mays, Pope, & Popay, 2005). Furthermore, there has been increased recognition of the importance of qualitative research to ensure that systematic reviews are of maximum relevance to policy, practice, and consumer decision-making (Mays et al., 2005). As a result, several methods of knowledge synthesis inclusive of qualitative data have been delineated in recent review literature. Some of the methodologies that are used specifically to synthesize qualitative evidence include: critical interpretive synthesis, meta-ethnography, meta-study, meta-summary, and qualitative evidence synthesis (Noyes et al., 2008). In addition, multiple methods of synthesis considering both qualitative and quantitative evidence are also recognized. These include narrative synthesis, realist synthesis, and meta-narrative approaches (Grimshaw, 2009).

Overall, there is an ever-growing list of different methods appropriate to synthesize different types of evidence for different types of research synthesis (Grant & Booth, 2009). However, the various synthesis methodologies share similar goals and objectives. According to Grimshaw (2009): "knowledge syntheses are important for establishing the key messages from the global evidence in a research field prior to knowledge translation and to inform the design and conduct of new research (p. 4)". In addition, knowledge syntheses are useful to help identify gaps in a specified body of literature, identify repetitions or redundancies in the literature, and identify potential sources of biases in primary studies (Grimshaw). Further, the various knowledge synthesis methodologies also follow a broadly similar approach to the research process; however, there is a need for researchers to be able to distinguish between these methods and to select the method that is the most appropriate to address the research question.

Table 3.1 provides further clarity about the main objectives of some of the most common approaches to knowledge synthesis.

Table 3.1 Review of qualitative and mixed method knowledge syntheses

Methodology	**Description**
Meta-ethnography	Involves 'putting together' written interpretive accounts of ethnographic studies using three distinct methods of synthesis. The overarching goal of this method is to produce a theory with great explanatory power (Barnett-Page & Thomas, 2009).
Meta-study	Iterative and reflexive methodology involving three components to analysis prior to the synthesis. Preliminary analysis includes: a meta-data analysis (analysis of the findings), meta-method (analysis of the methods), and meta-theory (analysis of theory) (Barnett-Page & Thomas, 2011). This process creates a new interpretation of included qualitative research accounting for all three elements of the analysis (Paterson, Thorne, Canam, & Jillings, 2001).
Critical Interpretive Synthesis	Draws on components of grounded theory and meta-ethnography. This approach involves synthesizing multi-disciplinary and multi-methods qualitative research using an iterative approach. It critically approaches the literature in an effort to deconstruct research traditions and theoretical assumptions in order to contextualize findings (Barnett-Page & Thomas, 2009).

Methodology	Description
Meta-summary	Meta-summary is a way of producing a 'map' of the contents of qualitative studies, and asserts a way to calculate the effects sizes for qualitative findings (Sandelowski & Barroso, 2007).
Realist synthesis	Realist reviews examine qualitative and quantitative research in an attempt to provide an explanatory analysis of what sort of interventions work for people, how do they work and in what circumstances do they work (Grimshaw, 2009).
Meta-narrative	Includes synthesis of research from a wide range of disciplines, designs, and theoretical perspectives in order to synthesize evidence in a way that will inform multidisciplinary, complex policy related decisions (Barnett-Page & Thomas, 2009).
Narrative synthesis	According to Popay et al. (2006) "Narrative synthesis refers to an approach to the systematic review and synthesis of findings from multiple studies that relies primarily on the use of words and text to summarize and explain the findings of the synthesis" (p. 5). This method is also referred to as "a form of story telling" (Popay et al., p. 5), and can use both qualitative and quantitative research to address a wide range of research questions. Telling the story of the findings in a trustworthy, rigorous, systematic, and convincing manner is the nature of this research methodology.

Why A Narrative Synthesis?

To complete this research, narrative synthesis methodology was selected. According to Noyes et al. (2008) a narrative synthesis inclusive of qualitative research is useful to explore questions such as: how people typically experience illness, how interventions work, for whom do interventions work, and what circumstances influence their effectiveness. Researchers who use narrative synthesis methodology are part of a story telling culture, with an overarching goal of assimilating evidence in a textual fashion to narrate why something needs to be done, or needs to be stopped (Popay et al., 2006). The defining characteristic of this methodology is that it adopts a textual approach to compare, contrast, describe, and tell the story of the findings from the included studies (Popay et al., 2006). A narrative synthesis offered an opportunity to comprehensively address the lived experience of both men and women with CRC.

In addition, narrative synthesis was the methodological approach selected for this research because any review question inclusive of a wide range of research designs can benefit from this methodology (Popay et al., 2006). With this method I was seeking to evaluate and synthesize various types of literature, including both published and grey literature sources pertaining to the impact of CRC treatment on the sexual experience. The benefits of including diverse sources of evidence when exploring a particular clinical query are significant, as the integration of diverse data can highlight different areas of interest (Mays et al., 2005), and, therefore, could potentially contribute to a greater understanding of the variables impacting the patient experience. Overall, a narrative synthesis was a valuable method to critically examine various types of evidence while simultaneously accounting for disparities and differences in the sex and gender-related factors, which shape the experience of cancer treatment on sexuality and sexual health.

Review of Sex and Gender-Based Analyses Framework

Since the late 1990s the Canadian federal government has supported the conduct of sex and gender-based analyses (SGBA) in health research (Armstrong & Armstrong, 2001). The Federal Plan for Gender Equality (1995) recognized the need to speak to sex and gender disparities in the context of health care, and outlined the need for more research pertaining to sex differences in disease (Spitzer, 2006). Subsequently, in 1996, the Status of Women Canada introduced *Gender-Based Analysis: A Guide for Policy-Making*, a comprehensive document to increase levels of awareness of gender as a way of looking at the world (Status of Women Canada, 1995). Health Canada (2003) has elaborated on the notions of SGBA and gender sensitive research in the context of health-based research. They define gender-based analysis as a research tool used to better illustrate how gender impacts health and to identify opportunities to maintain and improve the health of men and women in Canada. In 2001, The Canadian Institutes of Health Research (CIHR) established the Institute of Gender and Health as one of its 13 Institutes of health research. CIHR has expressed continual support of the conduct of SGBA through the creation of a guide to aid in conducting appropriate SGBA (Spitzer, 2006).

Conducting a SGBA. The overall aim of a SGBA is to examine the biological and social related factors influencing women and men, and analyze how they relate to a particular health problem (Spitzer, 2006). A SGBA challenges us to disregard the assumption that ‘one size fits all’, and reminds us to consider questions about the similarities and differences between men and women (Clow, Pederson, Haworth-Brockman, & Bernier, 2009), while simultaneously accounting for the diversity that exists within femininities and masculinities. It is considered an analytic approach to research that takes both men and women into account using a variety of quantitative and qualitative data. The inclusion of both quantitative and qualitative research methodologies in sex and gender analysis is recommended because quantitative data can provide insight into the effectiveness of interventions while qualitative work can provide deeper insight into the personal experience (Hebert, 2003).

Bottorff, Oliffe, and Kelly (2012) noted that research pertaining to men's and women's health often erratically incorporates gender and sex related factors into research designs, resulting in the inability of research to fully capture the nuances that a gender analysis can provide. Incorporating sex and gender into empirical, theoretical, and methodological aspects of research could contribute to better science by helping to explain the experience of health and disease while also providing evidence about which interventions can be improved and inequities corrected (Johnson, Repta, & Kaylan, 2012). Further, Johnson et al. state that "the inclusion of sex and gender in research is therefore a matter of ethics, as to deny or overlook the impact of these health determinants can ultimately and dramatically affect the well-being of individuals and groups." (p. 32).

CIHR released a resource guide to help researchers consider sex and gender and how they are applicable to their proposed research project (Spitzer, 2006). This document provides guiding questions to ensure each section of the research process considers and addresses notions of gender and sex. Ultimately, this document includes a checklist that outlines how a researcher can incorporate sex and gender in every aspect of the research approach. This checklist was used in the formation of the research question, the research approach and was also used to guide the data extraction and analysis portion of this research project. See Appendix A for more information regarding how a SGBA was conducted in the context of this research.

Review Methods

The process of undertaking a quantitative-based systematic review is grounded in a set of well-defined rules that have been largely documented by multiple scholars (Centre for Reviews and Dissemination, 2009; Higgins & Green, 2011; Khan, Kunz, Kleijnen, & Antes, 2003; Wright, Brand, Dunn, & Spindler, 2007). Concrete, step-by step methods for synthesizing both qualitative and quantitative literature have proven to be far more challenging to define. I chose to align with Popay et al.'s (2006) internationally recognized works entitled *Guidance on the Conduct of Narrative Synthesis in Systematic Reviews,* as this guidance provides a step by step approach to the narrative synthesis method, suitable for novice researchers. The guidance identifies six main elements critical to the process of undertaking a narrative synthesis in a robust and trustworthy manner. These include: 1) identifying the focus, preliminary research question, and mapping the available evidence; 2) specifying the review question; 3) identifying studies to include in the review; 4) data extraction and study appraisal; 5) analysis; 6) reporting the results and dissemination (Popay et al.). Figure 3.1 presents these steps and provides further detail about the sequence of how they were accomplished in the context of this research.

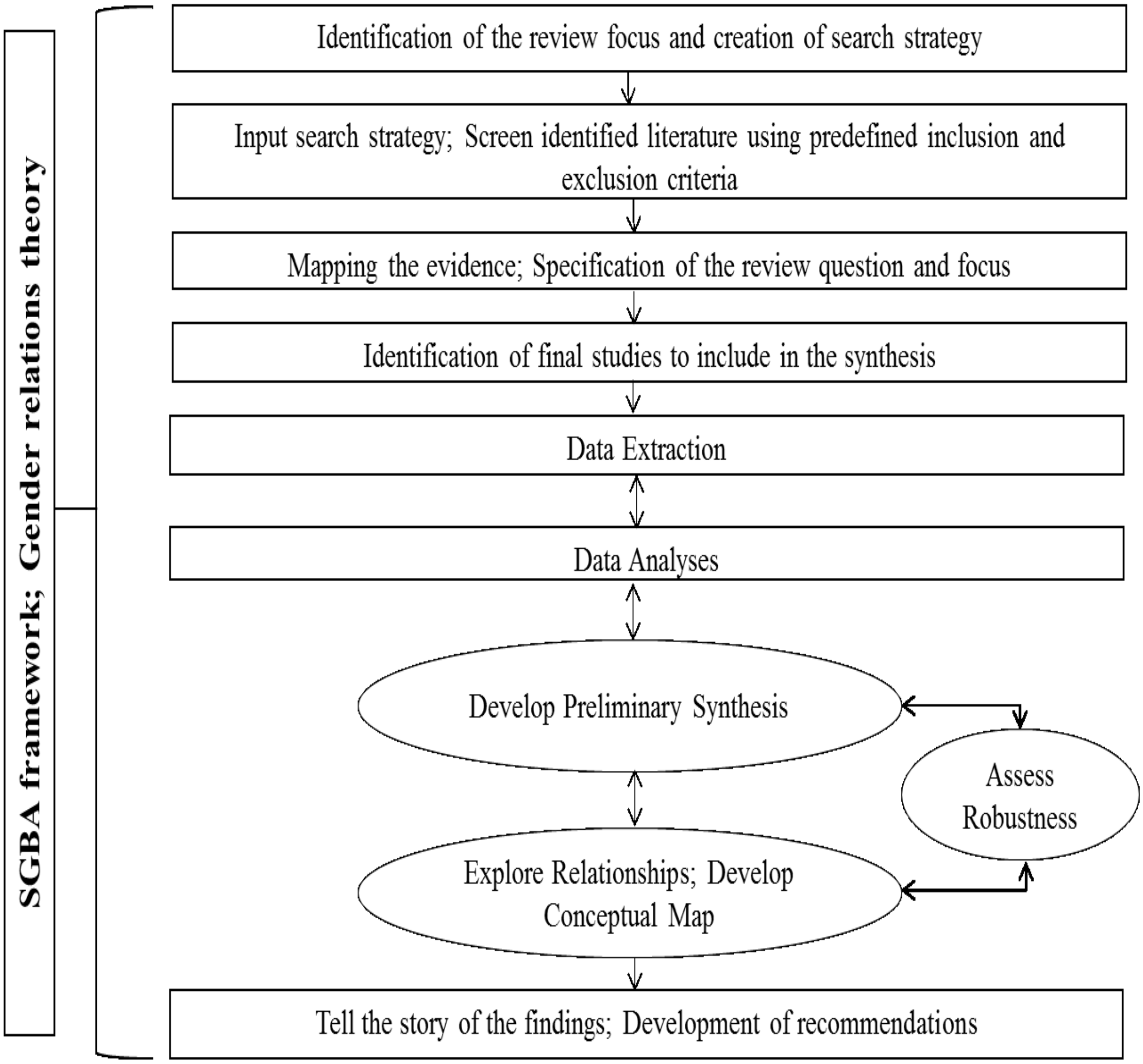

Figure 3.1 Sequence of methods for narrative synthesis

Procedures: Identifying the review focus (step one). An integral component of the systematic review process is the formation of the research question, which according to Popay et al. (2006) and Mays et al. (2005), should be distinguished at an early stage, prior to beginning the review. Often, initial research questions are broad and multi-faceted. Predefined research questions typically act to identify the study designs to be included, populations of interest, and outcomes of interest (Popay et al.). As the study proceeds, the research question may need to be altered and refined as the process of data collection and analyses are undertaken (Mays et al.). The process of formulating a research question is iterative (Popay et al.); the scope of the review can become more precise as the reviewer becomes more familiar with the body of literature pertaining to the query.

In the initial stages of this review, a broad and inclusive preliminary research question was formulated. This initial research question used to define the scope of this work (note it was slightly altered after completion of the mapping exercise, see results section) was defined as follows: *What is the gendered experience of sexuality after treatment for colorectal cancer, and the gendered response to psychosexual intervention for sexual health problems?*

Procedures: Formulating a search strategy (step one). A synthesis entails devising a detailed search strategy used to navigate and extract relevant studies from the body of available literature. A search strategy includes an accumulation of relevant terms used to comprehensively search several databases. It requires the researcher to define key terms and synonyms pertaining to the research question and assemble them in a manner that will yield the most relevant results from an existing body of literature. Significant effort is required to ensure that a comprehensive search strategy is formulated and refined as needed, as the search strategy is critical to encapsulating all relevant literature pertaining to the research topic (Mays et al., 2005).

To create the search strategy I elicited the guidance of a librarian scientist (i.e. Robin Parker, committee member and information services librarian). The Cochrane Collaboration (i.e. Naumann, 2007) has developed a document outlining how to formulate an appropriate and inclusive search strategy. The formation of the search strategy for this narrative synthesis was accomplished by following this step-wise approach. The step-by-step approach included: a) define relevant text words; b) determine synonyms for text words; c) control for different spellings of appropriate truncations; d) perform test searches; e) identify keywords; f) decide on whether to perform an exploded or a focused search; g) spell check; h) combine search terms; i) perform a second test search; j) customize the syntax of search strategy (Naumann, 2007).

Procedures: Preliminary search (step two). A search for relevant studies usually begins with the searching of multiple electronic databases (Hopewell, Clarke, & Mallet, 2005). A comprehensive synthesis depends on multiple data sources including: online search engines (i.e. PubMed or PsycInfo); specialized databases (i.e. Cochrane database, or government reports); manual hand searches of the references in articles (Fink, 2010); and grey literature searches (Hopewell et al., 2005). In consultation with Robin Parker, I selected a wide range of databases to capture the diverse body of literature (Table 3.2). See Appendix B to view the specific search strategies inputted into the included databases.

Table 3.2 Online databases selected to find relevant literature

Online Databases	
• PubMed • PsycInfo • CINAHL	• EMBASE • Proquest (dissertations and theses) • Sociological Abstracts

Search terms used to uncover relevant citations within the various databases included: colon OR rectal neoplasm OR tumor OR tumour OR carcinoma AND sex OR sexual behavior OR sexuality OR sexual health OR body image OR sexual dysfunction OR sexual intercourse OR femininities OR intimacy OR gender identity AND treatment OR chemotherapy OR radiation therapy OR surgery OR aftercare OR therapeutics (see Appendix B for more detail).

Grey Literature. Finding grey literature pertaining to a research question is often challenging and time-consuming. However, it is an important component of the systematic review, as grey literature is helpful to overcome some of the problems pertaining to publication bias (Hopewell et al., 2005). Grey literature is assumed to be literature that has not been formally published, has limited distribution, or is not available through established channels. Some examples include: conference abstracts, book chapters, research reports, unpublished data, dissertations, policy and guideline documents, and personal correspondence (Hopewell et al., 2005). Grey literature can be found in databases such as CINAHL (in the form of conference abstracts or dissertations), Proquest (dissertations and theses), and PsycInfo (in the form of book chapters or dissertations); however, I expanded on the use of database searching by using techniques such as snowballing and forwards citation gathering to help uncover non-indexed literature for relevant articles. Snowballing involved taking an article that currently exists in order to find out which relevant articles the selected paper cites. The next step was to check if those articles cite any other relevant articles, retrieve those articles, and continue this process until there are no more relevant articles. In addition, this process can be implemented in reverse, hence ‘forwards’ citation gathering. To do this, I used Google Scholar’s citation tracking feature by entering a known article within this database. This displayed more recent articles that cite the article of interest. In addition to these strategies, I also used the CADTH (Canadian Agencies for Drug and Technologies in Health, 2014) *Grey Matters: A Practical Search Tool for Evidence Based Medicine* as a guide to access various national and international grey literature sources (i.e. unpublished government documents and reports) that are inaccessible via bibliographic databases (CADTH, 2014).

Procedures: First round of screening to identify literature (step three). The results of the preliminary search strategy were imported into a citation manager (i.e., Refworks) for the initial title and abstract screening procedure. Wright et al. (2007) recommend that at least two reviewers should independently review titles and abstracts, because this will help to minimize the introduction of bias. In addition, Mateen, Oh, Tergas, Bhayani, and Kamdar (2013) compared the effectiveness of screening titles of articles versus screening titles and abstracts simultaneously. The authors concluded that the precision of identifying appropriate articles for inclusion was much higher when the researchers reviewed both titles and abstracts. Therefore, to extract relevant literature two researchers independently completed screening of titles and abstracts as well as full text screening.

The first round of screening required both researchers (main researcher and co-researcher) to review all titles and abstracts from the preliminary database searches. Using a specific, predefined set of inclusion and exclusion criteria (Table 3.3), each citation was designated as either include or exclude to move on to the second round of screening. A table in Microsoft Excel was used to keep track of whether or not a researcher designated to include or exclude the articles based on the preliminary title and abstract review. Once the screening of the titles and abstracts was complete, the researchers met to discuss any incongruence. A third party researcher reviewed discrepancies between reviewers to break the tie.

Table 3.3 Initial inclusion and exclusion criteria

Inclusion	**Exclusion**
• Can be any design, qualitative or quantitative. • Needs to examine aspects of the male or female sexual experience **or** the male or female response to psychosexual intervention. • There is no limit pertaining to the year of publication. • Can include male or female (or both-if data disaggregated) participants. • No age restrictions. • Must look at the experience of the treatment and/or recovery stages from CRC as the primary outcome.	• Studies in any language except English. • Studies that focus on diagnosis or pretreatment phases of cancer. • Studies that examine various types cancer together and do not examine CRC patients' data explicitly from the rest. • Studies that do not focus on the sexual *experience* of treatment and recovery. • Studies that report the experiences of men and women as a group (i.e. do not make explicit the findings pertaining to men and women).

Procedures: Second round of screening to identify literature (step four). Once the initial title and abstract screening procedure is complete, a more in depth and critical round of screening occurred. Full text articles of all included citations were retrieved and saved in PDF format and again, the main researcher and the co-researcher reviewed the full text articles independently. The same inclusion and exclusion criteria outlined (Table 3.3) were applied to this round of screening. An Excel spreadsheet was used by each researcher to track include versus exclude designations; however, in this round when an article was deemed to be excluded, a reason was also stated as to why the article is not appropriate for inclusion. On completion of the second round of screening, the researchers convened to discuss any discrepancies. When a consensus was not achieved, a third researcher was consulted to review the full text articles to resolve any discrepancies. A PRISMA diagram (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) (Moher, Liberati, Tetzlaff, & Altman, 2009) was used as a flow chart to represent the full screening and inclusion process of the literature (Figure 4.1).

Procedures: Mapping the evidence. Popay et al. (2006) outlines the mapping process (otherwise known as the scoping search) as an important step in ensuring the research question is answerable and relevant to key stakeholders. Mapping the evidence is often referred to as a first step in undertaking a large synthesis, and can be used to guide or refine the scope of the narrative synthesis project (Popay et al.). It provides an opportunity to briefly summarize a range of evidence in order to assess the depth and breadth of a particular area of interest (Levac, Colquhoun, & O'Brien, 2010). Further, it also a way to rapidly map key concepts and identify main sources and types of evidence available pertaining to a specific research area (Mays, Roberts, & Popay, 2001), as well as to begin to unpack the types of research designs and interventions previously evaluated in the available body of literature (Popay et al. 2006). To accomplish this step, once screening of the articles was complete, brief summaries of the included articles (i.e. author, date, sample, study designs, key findings) were logged in Microsoft Excel. These summaries were useful to provide an initial overview of the included body of literature and were also used to redefine the search strategy and research question as necessary. In addition, the mapping exercise was also helpful to support data extraction.

Procedures: Study appraisal. Study appraisal (otherwise known as validity assessment) refers to a process of assessing the quality of the methodological approaches in the included studies. Study appraisal is an important step in the production of the synthesis as it can impact the results of the individual studies and ultimately the conclusions reached from the final synthesis product (Popay et al., 2006).

I undertook study appraisal in the initial stages of this research to assess the overall quality of the included literature. According to Popay et al. (2006), it is important to establish trustworthiness of the final synthesis product, and study appraisal is a critical piece to establish trustworthiness of the findings. This trustworthiness depends on the methods used in the synthesis, including measures taken to minimize bias. For example, one way to minimize bias of the final product is to ensure that included studies judged to be of equal technical quality are given equal weight, or if not, providing justification for not doing so (Popay et al., 2006). In this research all studies were recognized to be of equal value, and I did not exclude studies based on their quality; however, Popay et al. outlines that regardless of whether or not a researcher chooses to exclude studies, it is important to clearly differentiate between more and less robust research. Studies that received a low quality score were grouped, and statements about findings of these studies were not drawn in instances where they presented outlying findings that were not supported by other included studies. Furthermore, Popay et al. states that it is particularly important that the appraisal of study quality be completed in a systematic manner.

Therefore, the research criteria for assessing qualitative studies included: assessing the research question and study design, integration of theory, sampling strategy, study findings, themes and concepts, and conclusions (Mays & Pope, 1996; 2005).

In addition, as the aim of this narrative synthesis was to include both quantitative and qualitative research findings, a rigorous approach to assess study quality for quantitative research was also warranted. Recent recommendations from the Cochrane Collaboration (2011) state that the evaluation of experimental research for the purposes of review methodoloies should focus on a risk of bias assessment and not an assessment of study quality (Higgins et al., 2011). However, because only one intervention study was ultimately included in this synthesis, it was decided that a risk of bias tool would not be appropriate to assess this methodologically diverse body of quantitative literature. Therefore, study quality of all quantitative studies were assessed using a Cochrane collaboration tool, produced by the Cochrane Public Health group and includes assessment for selection bias, study confounders, validity and reliability of the data collection methods, withdrawals and dropouts, and quality of analytic methods (Thomas, Ciliska, Dobbins, & Micucci, 2004). Using these criteria, a scoring system that provided a systematic and reproducible means of assessing the quality of research was applied to the included studies in an effort to differentiate between higher quality research and lower quality research. Scoring systems for study appraisal are not widely supported as a combined quality score is recognized by some to be an unreliable way to account for the quality of primary research (Whiting, Harbord, & Kleijnen, 2005). For this narrative synthesis it was felt that an overall score would be acceptable as studies were not being excluded based on lower scores. See Appendix B for more information of study appraisal criteria and how these criteria were evaluated in this research.

Several guidelines and policies were uncovered as a result of extensive grey literature searches. The Appraisal of Guidelines for Research and Evaluation II (AGREE II) instrument (Brouwers et al., 2010) was used to complete quality appraisal on these guidelines. This instrument evaluates six main domains as a way to assess the methodological rigour and transparency in which guidelines are developed. These domains include: a) scope and purpose; b) stakeholder involvement; c) rigour of development; d) clarity of presentation; e) applicability; f) editorial independence (Brouwers et al.).

Procedures: Data extraction. Data extraction was performed in an iterative manner; I progressed through screening, data extraction, and data analysis in a way that allowed for each element to inform the other if needed. I (along with a co-researcher) undertook data extraction using a pre-defined data extraction form created in close consultation with my thesis supervisors. In addition, Popay et al. (2006) outline that it is valuable to assess the volume of relevant literature, describe the types of interventions that have been evaluated in the literature, and describe the types of designs used. Ultimately several variables within the included studies were captured as a result of a systematic approach to data extraction (Table 3.4).

In order to facilitate data extraction a standardized electronic form on Microsoft Excel was used. This standardized form ensured the data extraction and retrieval process was as streamlined as possible (Wright et al., 2007). The first step in this process was to read the first included article and extract the relevant data using the pre-defined data extraction form. We then compared extraction findings to ensure accuracy. Any differences noted in extraction will be resolved by discussion or the involvement of a third reviewer. Data extraction proceeded in this fashion until extraction of all articles was complete. The two researchers met after every fifth article to ensure extraction was proceeding in an accurate and congruent manner.

Table 3.4 Items for data extraction

Items for Data Extraction	
• Date of publication. • Location of publication. • Setting of the study (hospital, community etc.). • Target Population. • Sample (i.e. sex, gender, age of participants). • Time since cancer treatment. • Type of cancer treatment(s).	• Aim of the study. • Primary & Secondary Outcomes. • Theoretical perspectives. • Study design. • Types of intervention. • Findings (sex-specific if applicable, accounts of gender factors if applicable).

Review Methods: Data Analysis

The next step in the narrative synthesis process was to complete data analysis. Popay et al. (2006) identify four main elements in the analytic process, all of which were included in this research. These elements were as follows: develop a preliminary synthesis of findings of included studies; explore relationships in the data; and lastly, assess the robustness of the synthesis. Of note, these components did not occur in sequence; the analytic process was very much iterative with each element informing the next (Popay et al.). In the following section I review specific strategies of how each of these four elements were accomplished in this synthesis.

Procedures: Developing a preliminary synthesis. A preliminary synthesis is one of the key components in the completion of a narrative synthesis, as it gives researchers an opportunity to provide a comprehensive description of the included studies and organize these results into clusters or patterns (Popay et al., 2006). Popay et al. outlines several tools and techniques to developing a preliminary synthesis. According to Popay et al. some of these items may be designated as appropriate for use while others may not, and the selection of appropriate tools and techniques will depend on the type of data and types of studies included. Once the scoping search was completed, tools and techniques to accomplish the preliminary synthesis were selected in close consultation with the thesis supervisors. Tools and techniques that were ultimately chosen included textual descriptions, tabulation, groupings and clusters, and thematic analysis (Table 3.5). The paucity of intervention studies that were included in this synthesis rendered some techniques such as: shaping data into a common rubric and vote counting inappropriate to synthesize this body of literature.

Table 3.5 Tools and techniques used to generate a preliminary synthesis

Technique	Description	Included / Excluded
Textual Description	Textual descriptions were a starting point to describe the included studies. Descriptions were brief and completed systematically. Each description contains the same information for all studies. Descriptions were useful to become familiar with the studies and to begin to compare findings (Popay et al., 2006).	Included. Each textual description included: study design, total participants, theoretical approach, outcomes, findings, and sex and gender specific findings if applicable.

Technique	Description	Included / Excluded
Vote Counting	Vote counting is conducted with quantitative studies and statistical data. Popay et al. (2006) recognize vote counting to be a complex task, defined in multiple ways by various scholars. Some researchers argue that categorizing the data by statistical significance can provide answers regarding the effects of the intervention, as the category containing the largest number of studies has been said to represent the true direction of the relationship (Curlette & Cannella, 1985).	Excluded on account of the lack of intervention studies within the included body of literature.
Tabulation	Tabulation is a common strategy used in all types of systematic reviews to portray qualitative and quantitative data (Popay et al., 2006). Tabulation can be particularly useful to provide visual representations of study design and outcome measures, among other results.	Included. Tabulation tables were used to visually organize data in table form, and to create several groupings and clusters to organize the included studies (Appendix G).

Technique	Description	Included / Excluded
Groupings and Clusters	Involves organizing the included studies into smaller groups to make the pool of data more manageable. Often, this is done at an early stage of the review, however as the synthesis progresses, it may be necessary to refine these initial groups. According to Popay et al. (2006), it is important to use the research question(s) to inform decisions about how to group the included studies. Studies can be grouped in multiple ways, according to one or a combination of the following: the type of intervention being studied; the setting or context for the intervention; the group at whom it is being directed (sex for example); the study design; and/or the nature of the results being reported (i.e. reported outcomes) (Popay et al.).	Included. Firstly, tabulated data was separated by overarching type of research approach in order to be able to analyze data in homogenous groups. Secondly, data was aggregated by sex, i.e. clustering studies that examine men, studies that examine women, and studies that examine both. This extracted data was further sorted in to groups of clusters based on various other characteristics (Appendix H). Excel tables were used to organize data and were uploaded into NVivo 10.

Technique	Description	Included / Excluded
Shaping Data into a common rubric	Involves transforming raw data results into a common numerical/statistical rubric. In large systematic reviews or statistical meta-analyses, pooling of statistical data involves the pooling of raw data to elicit an overarching statistical estimate of effect (Popay et al., 2006). However, in the context of a narrative synthesis, this type of data pooling is not expected nor recommended; although, Popay et al. advises that transforming statistical data into a common rubric will elicit an opportunity to summarize study results in a robust way, allowing for an assessment of the range of effects from a particular intervention.	Excluded on account of the lack of intervention studies that were ultimately included in this synthesis.

Technique	Description	Included / Excluded
Translating Data: Thematic Analysis	By definition, thematic analysis is a search for themes that emerge as valid or important to the description of a specific phenomenon (Daly, Kellehear, & Gliksman, 1997). By its very nature, thematic analysis is assumed to be an iterative and reflexive process (Fereday & Muir-Cochrane, 2006). According to Popay et al. (2006) thematic analysis in the context of a narrative synthesis is particularly useful to inductively and systematically identify the main, most important themes and/or concepts across the pool of included studies.	Included. Thematic analysis was undertaken using NVivo 10, all of the literature included in this synthesis was coded, including grey literature sources. Themes and related subthemes occurring within the included studies and across tabulated data were identified using Braun and Clarke's (2006) rigorous and inductive open coding techniques.

Procedures: Exploring relationships in the data. The next element is to explore relationships within and between the data. The purpose of this stage of the synthesis is to consider the factors that might explain any differences in the barriers and facilitators to successful implementation across included studies, and to gain a deeper understanding of the phenomenon of interest. Exploring relationships requires the reviewer move beyond identifying, listing, and tabulating results, to exploring and understanding relationships within and across the included studies. Techniques used to explore relationship included conceptual mapping, examining variability, qualitative case descriptions, and triangulation (Table 3.6). Other techniques such as examinations of moderator variables and subgroup analyses were not appropriate given the lack of intervention research.

Table 3.6 Tools and techniques used to explore relationships

Technique	Description	Included /Excluded
Conceptual mapping	Conceptual mapping serves to group and cluster findings that reviewers decide are empirically or conceptually similar, and to outline the relationships between these groupings and clusters. This involves a visual representation to help identify specific relationships between key concepts (Popay et al., 2006).	Included. Conceptual mapping was a critical strategy to begin the formulation of a framework to explicate the sexual experiences of CRC survivors. This exercise was conducted in collaboration with the thesis committee.

Technique	Description	Included /Excluded
Examining Variability	Examinations of variability are critical to understand the relationships between study results and key aspects of the primary studies. This involves comparing and contrasting relationships across studies (Popay et al., 2006). Examinations of this kind are helpful to understand how future interventional, observational and qualitative research can and should be conducted.	Included. Throughout the synthesis, examinations of variability were completed including examining variability in study outcomes, study designs, study settings, and barriers and facilitators.
Moderator Variables and Subgroup Analyses	This technique is concerned with evaluating the impacts of interventional studies. To do this, Popay et al. (2006) suggest analyzing moderator variables, defined as the variables that are expected to moderate and influence the main effects and outcomes examined by the review. Specifically, it is seeking to uncover what works, for whom and in what circumstances does the intervention work.	Excluded. The lack of intervention studies rendered this technique irrelevant in the context of this synthesis.

Technique	Description	Include /Excluded
Qualitative Case Descriptions	Qualitative case descriptions are a way to present descriptive data from studies included in a review. They can be used to try to explain differences in statistical findings, and also to summarize and critically reflect on both qualitative and quantitative findings (Popay et al., 2006). Generally, qualitative case descriptions allow researchers to re-examine textual descriptions and flesh out previous descriptions to check the previous stages of analysis for accuracy. Case descriptions allow the researcher re-evaluate any aspects of individual studies that may not have seemed relevant at the start of the synthesis, but have become of interest during the subsequent stages of describing and exploring the study data (Popay et al., 2006).	Included. Textual descriptions were thoroughly reviewed prior to completing the concept map to ensure all data was captured in each study. Any new information that was found was incorporated into these textual descriptions at this time. Qualitative case descriptions were critical to inform the concept map (Appendix F).

Technique	Description	Include /Excluded
Investigator Triangulation	Begley (1996) was the first to conceptualize investigator triangulation in nursing research, stating that the heterogeneity present in study results is associated with the diverse approaches undertaken by different researchers. Largely, triangulation functions from the understanding that each disciplinary likely approached a research query with differing epistemological positions (Begley). Analyzing study data in relation to the context in which the study was produced (specifically the disciplinary perspectives and expertise of the researchers) is a way to account for any gaps in a specific body of literature (Popay et al, 2006).	Included. For this synthesis, the various disciplines of the first (primary) authors were compiled and categorized according to discipline and setting of where the research was conducted. In addition, I was mindful of the investigator and methodological variation, throughout the synthesis process and considered how these variations may apply and impact the final synthesis product (Appendix I).

Procedures: Assessing robustness. Assessing robustness of the synthesis product can be done in many ways. Most simply, robustness can be established by evaluating the quality of the primary studies included in the review and/or the trustworthiness of the product of the synthesis process (Popay et al., 2006). According to Popay et al. (2006) it is particularly important that the appraisal of the methodological quality of included studies be completed in a systematic manner to ensure reproducibility. As stated previously in this chapter, a predefined set of quality criteria was used to assess the study quality of included research (See Appendix C).

Another less direct aspect of robustness that can impact the trustworthiness of the final synthesis product is the extent to which researchers have enough information to judge that individual studies meet the criteria for inclusion (Popay et al., 2006). Authors of primary studies under review sometimes fail to provide sufficient information on the intervention or phenomenon they are focusing on and there can be inconsistency between studies in the definition of what constitutes a particular intervention or phenomenon (Popay et al., 2006). Therefore, strict inclusion and exclusion criteria are necessary as a way to find relevant articles specifically pertaining to the research question and the phenomenon under study. In the context of this research, only relevant studies were included in the synthesis as a result of the strict inclusion and exclusion criteria.

Popay et al. (2006) outlines other ways to establish robustness and assess the strength of the evidence produced including critical reflection and member checking. Both of these techniques were used to ensure robustness of the final synthesis product.

Critical reflection. I engaged in critical reflection throughout the research process. A process log was kept to prospectively document discussions with the supervisors as well as full committee meetings. This log outlined details about input from the supervisors and committee, and also explicated rational for decisions and actions taken at each stage of the synthesis process.

According to Busse et al. (2002) critical reflection should also include the following: limitations of the methodology of the synthesis used (with a specific focus on its limitations and potential influence on the results), a critique of the evidence used (i.e. quality and validity) with an emphasis on the possible sources of bias from the sources of evidence used and their potential influence on the final synthesis product, and any assumptions made throughout the process. A log was kept detailing limitations of the method as well as critiques of the evidence included in this synthesis. In addition, personal biases and assumptions made throughout the process were also tracked in this log.

Member checking. Lastly, to enhance the robustness of the completed synthesis, I completed member checking as final step to ensure the findings of this research are valid and relevant. Popay et al. (2006) suggests that member checking, or consultation with the authors of included studies, is a valuable way to test the validity of the interpretations developed during the synthesis, and to verify the extent to which they are supported by the primary data. Therefore, to accomplish this, I contacted a selected group of authors whose studies were included in my synthesis. Authors were contacted via e-mail as provided in the contact information section often included in many research articles. An effort was made to contact authors inclusive of various types of study designs and outcomes as well as authors who specialize in men's health versus women's health. I requested a meeting with the authors to present my findings (via telephone) to these authors. To do this, I sent them a standard e-mail with a brief summary of the study findings enclosed and requested a meeting at their earliest convenience. During this meeting I was able to request feedback, pose questions, and gain insight into my findings from these experts. I took detailed notes of the meeting and reviewed them to gain further understanding. Findings of the member checking exercise are included in the results section of this research.

Summary of Methodology

The aim of this research was to understand how CRC treatment impacts the sexual experiences of survivors and to also gain insight into how sex and gender related factors might shape this experience. A SGBA framework was applied to this research to ensure that considerations of sex and gender were accounted for at each stage of the research process. Narrative synthesis was selected as a method to critically examine the relevant literature because the defining characteristic of this methodology is that it adopts a textual approach to compare, contrast, describe, and tell the story of the findings from all included research. For this reason, narrative synthesis was recognized as an effective method to gain insight into the ways in which CRC survivors experience their sexuality and sexual health post treatment, and to understand the sex and gender factors that shape these experiences.

The conduct of this research was guided by an iterative, methodical approach that included six main elements: 1) identifying the focus, preliminary research question, and mapping the available evidence; 2) specifying the review question; 3) identifying studies to include in the review; 4) data extraction and study appraisal; 5) analysis; 6) reporting the results and dissemination of findings.

The first step in this synthesis was to carry out the detailed search strategy and screen through all relevant literature. The two reviewers who screened this literature applied rigorous inclusion and exclusion criteria. On completion of screening, a scoping search was done and all relevant literature was mapped according to study design and outcomes. This necessitated minor changes to the inclusion and exclusion criteria as well as the research question. Once these changes were made, the refined body of literature underwent data extraction whereby two reviewers extracted relevant data and inputted this data into a table. Findings from data extraction were the building blocks to several analytic strategies, tools and techniques. The techniques used to create a preliminary synthesis of the literature included textual descriptions, tabulation, grouping and clustering, and thematic analysis. After completion of the preliminary synthesis portion of this study, relationships between and within the studies were further explored by conceptual mapping, examining variability of study outcomes, study designs, barriers, and study settings, and investigator triangulation. Lastly, robustness of the final synthesis product was established through three techniques: study appraisal, critical reflection, and member checking.

Chapter Four Results

This chapter will outline the narrative synthesis findings. It will include a detailed discussion of the systematic search results, results of data management techniques, and will review prominent themes in the included body of literature.

Search Results

Table 4.1 outlines the results of the comprehensive search. Methods used to find relevant literature included: database searches, forwards citation gathering, and snowballing. An extensive search was also performed in an effort to find unpublished grey literature using the CADTH grey literature tool.

Table 4.1 Final Search Results

Database	**Number of Results**
CINAHL	534
PubMed	850
Embase	899
PsycInfo	182
Sociological Abstracts	27
ProQuest (Dissertations and Theses)	76
Grey Literature Search (CADTH)	10
Other (snowballing etc.)	14
Duplicates = 402	
Total = 2,592	
Total (without duplicates) = 2,190	

Identifying relevant literature. A total of 2,568 citations were identified using the online database search strategies. An additional 14 citations were identified by other methods (i.e. snowballing). Ten guidelines and policies were identified through extensive grey literature searches. These 10 guidelines were screened and analyzed separately; results of grey literature can be found in section 4.3. Thus, 2,190 citations were retrieved and abstracts were independently screened by two reviewers using specific inclusion and exclusion criteria (Table 3.4). Refer to Figure 4.1 for a visual representation of the search process (PRISMA diagram).

RefWorks was used to track and store the citations. In the first round there were 40 discrepancies between reviewers. Reviewers met to discuss these discrepancies, and all were resolved on discussion. After the first round of screening, 2,008 citations were excluded. A total of 182 papers remained after title and abstract screening, and were assessed in full text. Twenty discrepancies existed after the second round of screening, and consensus for inclusion or exclusion was determined between reviewers for 10 citations. The remaining 10 discrepancies were reviewed by a third party for inclusion. Of the 182 citations reviewed in full text, 35 studies met the original criteria for inclusion in this narrative synthesis (Table 4.3) (Allal et al., 2005; Altschuler et al., 2009; Andersson, Engström, & Söderberg, 2010; Au, Zauszniewski, & King, 2012; Ball et al. 2011; Ball et al., 2013; Cotrim & Pereira, 2008; Da Silva et al., 2008; Dazio, Sonobe, & Zago, 2009; Devlin, Plant, & Griffin, 1971; Di Fabio, Koller, Nascimbeni, Talarico, & Salerni, 2008; Dowswell et al., 2011; Grant et al. 2011; Heras, Hatzopoulos, & Kritikos; Krouse et al., 2010; Li, 2009; Li et al., 2013; MacDonald & Anderson, 1985; Mahjoubi et al., 2012; Milbury, Cohen, Jenkins, Skibber, & Schover, 2013; Neuman, Park, Fuzesi, & Temple, 2012; Neuman et al., 2011; Nowicki, Kula, Rzepka, & Zegarski, 2011; Ohlsson-Nevo, Andershed, Nilsson, & Anderze´n-Carlsson, 2011; Platell, Thompson, & Makin, 2004; Ramirez et al., 2009; Reese, Porter, Somers, & Keefe, 2012; Rozmovitz &

Zielbland, 2004; Schmidt, Bestmann, Küchler, Longo, & Kremer, 2005; Schmidt, Daun, Malchow, & Küchler, 2010; Sharpe, Patel, & Clarke, 2010; Sprangers, Taal, Aaronson, & Velde, 1995; Traa, De Vries, Roukema, & Den Oudsten, 2012; Wirsching, Druner, & Herrmann, 1975; White, Faithfull, & Allan, 2013).

Mapping the literature (scoping search results)

The scoping search (i.e. mapping the literature) proved to be a useful strategy to refine the research question and overall focus of this narrative synthesis. This section will outline the initial results of the scoping search and explicate how mapping the literature contributed to the refinement of the research questions and inclusion criteria.

Thirty-five articles were included in the scoping search (Table 4.2). All of this literature was published from 1971-2013, with the highest number of articles published from 2005-2013 (n= 24; 66%). The 35 studies were published in various journals (Table 4.2), the most common of which was *Diseases of the Colon and Rectum* (n=3). Oncology-specific journals were common (n=6), as were journals specific to psychology, psychosocial or psychosexual health (n=4). Several journals were nursing focused (n=5).

Table 4.2 Scoping search: List of journals included in the synthesis

Journals (N=20)
Nursing-focused (n = 5) • *Journal of Wound Ostomy Continence Nursing* (Altschuler et al., 2009; Li., 2009) • *International Journal of Nursing Practice* (Andersson et al., 2010) • *Oncology Nursing Forum* (Au et al., 2012; Grant et al., 2011) • *European Journal of Oncology Nursing* (Cotrim & Pereira, 2008) • *Journal of Clinical Nursing* (Ohlsson-Nevo et al., 2011)

Journals (N=20)

Psychology/Psychosocial/Psychosexual-focused (n = 4)

- *Journal of Sexual Medicine* (Ball et al., 2011)
- *Journal of Sex & Marital Therapy* (Reese et al., 2012)
- *Psycho-Oncology* (Li et al., 2013; Sharpe et al., 2010)
- *Psychotherapy and Psychosomatics* (Wirsching et al., 1975)

Cancer-focused (n = 6)

- *Journal of Cancer Education* (Ball et al., 2013)
- *Journal of Clinical Oncology* (Krouse et al., 2009)
- *Supportive Care in Cancer* (Milbury et al., 2013)
- *European Journal of Surgical Oncology* (MacDonald & Anderson, 1985)
- *Annals of Oncology* (Heras et al., 2010; Traa et al., 2012)
- *International Journal of Radiation Oncology Biology Physics* (Allal et al., 2005)

Non-English Journals (n = 4)

- *Revista Latino-Americana de Enfermagem* (Dazio et al., 2009)
- *Tumori* (Di Fabio et al., 2008)
- *Wspolczesna Onkol* (Nowicki et al., 2011)
- *Deutsches Arzteblatt International* (Schmidt et al., 2010)

Gender-Specific (n = 1)

- *Women & Health* (Ramirez et al., 2009)

A variety of countries were represented in the included studies (Table 4.3). Results of the scoping search showed the highest percentage of the included literature were conducted in America (n= 13, 36%) (Altschuler et al., 2009; Ball et al., 2011; Ball et al., 2013; DaSilva et al., 2008; Grant et al., 2011; Krouse et al., 2009, Li, 2009; MacDonald & Anderson, 1985; Milbury et al., 2013; Neuman et al., 2011; Neuman et al., 2012; Ramirez et al., 2009; Reese et al., 2012). Studies published in Europe represented a large portion of the papers (n=16, 44%), four of which were published in the United Kingdom (Devlin et al., 1971; Dowswell et al., 2011; Rozmovitz & Ziebland, 2004; White et al., 2013), three in Germany (Schmidt et al., 2005; Schmidt et al., 2010; Wirsching et al., 1975), and two in the Netherlands (Sprangers et al., 1995; Traa et al., 2012). Additional European countries included: Sweden (Ohlsson-Nevo et al., 2011; Andersson et al., 2010), Switzerland (Allal et al., 2005), Portugal (Cotrim & Pereira, 2008), Greece (Heras et al., 2010), Italy (Di Fabio et al., 2008), and Poland (Nowicki et al., 2011). Two studies were published in Australia (Platell et al., 2004; Sharpe et al., 2011). Other locations included China (Li et al., 2013), Taiwan (Au et al., 2012), Tehran (Mahjoubi et al., 2012), and Brazil (Dazio et al., 2009).

The studies included in the scoping search utilized various settings in order to recruit participants and conduct the study itself (Table 4.3). Most often, urban hospitals were cited as the study setting (n=10) (Altschuler et al., 2009; Au et al., 2012; Da Silva et al., 2008; Dowswell et al, 2011; Li et al., 2013; Mahjoubi et al., 2012; Platell et al., 2004; Schmidt et al., 2005; Schmidt et al., 2010; Sharpe et al., 2011). Cancer centres were another common setting (n=6) (Ball et al., 2011; Ball et al., 2013; Neuman et al., 2011; Neuman et al., 2012; Nowicki et al., 2011; White et al., 2013), and academic hospitals (n=5) were also common (Allal et al., 2005; Di Fabio et al., 2008; Milbury et al., 2013; Ohlsson-Nevo et al., 2011; Reese et al., 2012). Other settings included: large health regions (Grant et al., 2011; Krouse et al., 2009; Ramirez et al., 2009), outpatient departments (Cotrim & Pereira, 2008; Dazio et al., 2009; Devlin et al., 1971), and rural hospitals (MacDonald & Anderson, 1985; Rozmovitz & Ziebland, 2004).

The initial included body of literature represented diverse methods (Table 4.3). Twenty studies were quantitative in nature, the majority of which used cross sectional methods to examine the sexual experiences of CRC survivors (n=12) (Au et al., 2012; Cotrim & Pereira, 2008; Di Fabio et al., 2008; Heras et al., 2010; Krouse et al., 2009; Li et al., 2013; MacDonald & Anderson, 1985; Mahjoubi et al., 2012; Milbury et al., 2013; Nowicki et al., 2011; Platell et al., 2004; Schmidt et al., 2005). Four studies used longitudinal designs to capture the prolonged sexual experiences of survivors (DaSilva et al., 2008; Neuman et al., 2011; Schmidt et al., 2010; Sharpe et al., 2011). Reese et al. (2012) used an intimacy enhancement intervention to help couples make cognitive and behavioral shifts within their intimate relationships. Three studies were systematic reviews (Li, 2009; Sprangers et al., 1995; Traa et al., 2012). Two studies utilized mixed methods designs (Altschuler et al., 2009; Wirsching et al., 1975). Eleven studies used qualitative methodologies to understand the sexual experiences of men and women (Andersson et al., 2010; Ball et al., 2011; Ball et al., 2013; Dazio et al., 2009; Dowswell et al., 2011; Grant et al., 2011; Neuman et al., 2012; Ohlsson-Nevo et al., 2011; Ramirez et al., 2009; Rozmovitz & Zielbland, 2004; White et al., 2013). Four of these qualitative studies present data specific to women and their experiences with intimacy, sexuality, body image, self-esteem, and sexual health (Andersson et al., 2010; Ball et al., 2011; Ramirez et al., 2004; White et al., 2013). Two qualitative studies examine men’s experiences with erectile dysfunction and explored how men manage sexual dysfunction post treatment (Ball et al., 2013; Dowswell et al., 2011), and one study examined the meanings men attribute to living with an ostomy (Dazio et al., 2009).

Table 4.3 Scoping search: Study characteristics

Author	Date	Country	Setting	Design
Allal et al.	2005	Switzerland	Academic Hospital	Longitudinal
Altschuler et al.	2009	USA	Urban Hospital	Mixed Methods
Andersson et al.	2010	Sweden	Unsure	Qualitative
Au et al.	2012	Taiwan	Urban Hospital	Cross Sectional
Ball et al.	2011	USA	Cancer Centre	Qualitative
Ball et al.	2013	USA	Cancer Centre	Qualitative
Cotrim & Pereira	2008	Portugal	Outpatient Department	Cross Sectional
Da Silva et al.	2008	USA	Urban Hospitals	Longitudinal
Dazio et al.	2009	Brazil	Outpatient Department	Qualitative
Devlin et al.	1971	UK	Outpatient Department	Mixed Methods
Di Fabio et al.	2008	Italy	Academic Hospital	Cross Sectional
Dowswell et al.	2011	UK	Urban Hospital	Qualitative
Grant et al.	2011	USA	Health Region	Qualitative

Author	Date	Country	Setting	Design
Heras et al.	2010	Greece	Unsure	Cross Sectional
Krouse et al.	2009	USA	Health Region	Cross Sectional
Li	2009	USA	NA	Integrative Review
Li et al.	2013	China	Urban Hospital	Cross Sectional
MacDonald & Anderson	1985	USA	Rural Hospital	Cross Sectional
Mahjoubi et al.	2012	Tehran	Urban Hospital	Cross Sectional
Milbury et al.	2013	USA	Academic Hospital	Cross Sectional
Neuman et al.	2012	USA	Cancer Centre	Qualitative
Neuman et al.	2011	USA	Cancer Centre	Longitudinal
Nowicki et al.	2011	Poland	Cancer Centre	Cross Sectional
Ohlsson-Nevo et al.	2011	Sweden	Academic	Qualitative
Platell et al.	2004	Australia	Urban Hospital	Case Control
Ramirez et al.	2009	USA	Health Region	Qualitative
Reese et al.	2012	USA	Academic Hospital	Intervention
Rozmovitz & Zielbland	2004	UK	Rural Hospital	Qualitative

Author	Date	Country	Setting	Design
Schmidt et al.	2005	Germany	Urban Hospital	Cross Sectional
Schmidt et al.	2010	Germany	Urban Hospital	Longitudinal
Sharpe et al.	2011	Australia	Urban Hospital	Longitudinal
Sprangers et al.	1995	NL	NA	Review
Traa et al.	2012	NL	NA	Review
Wirsching et al.	1975	Germany	Unsure	Mixed Methods
White et al.	2013	UK	Cancer Centre	Qualitative

Refining the scope of the synthesis. On completion of the scoping search it was collectively decided between the researcher and supervisors that the initial pool of articles was not specific enough to the research question. In fact, several of the studies were focused on measuring sexual functionality of men and women and did not include measures to capture how survivors experienced alterations to sexuality after treatment. There was no explicit criteria addressing the exclusion of these functionally focused studies; therefore, it was decided that the inclusion and exclusion criteria were not specific enough to allow removal of these articles where sexual functionality and dysfunction were the primary foci. As a consequence, the inclusion and exclusion criterion was further refined to become more explicit (Table 4.4). Specific items were added as follows: the exclusion of studies that primarily focused on comparing and contrasting various types of treatment modalities (i.e. abdominoperineal resection surgery vs total mesorectal excision surgery) and their outcomes on sexuality, as these studies are not explicitly focused on examining the experience of sexual outcomes. A second item was the exclusion of studies that use the European Organization for Research and Treatment of Cancer quality of life instrument (i.e. EORTC-QLQ-C 30 scale) (Aaronson et al., 1993) and/or the EORTC QLQ 38 supplement scale (Sprangers, Te Velde, & Aaronson, 1999) without using additional tools or measures to examine sexuality or sexual health. This item was included because it was collectively decided that the EORTC tools on their own do not provide sufficient insight into the sexual experience as they are primarily focused on sexual function. Lastly, emphasis was placed on the need for sexuality or sexual health to be either a primary focus of each included study or a key finding. Wording was altered to capture these changes in criteria (Table 4.4).

Table 4.4 Refined inclusion and exclusion criteria

Inclusion	**Exclusion**
• Studies can be any design. • Book chapters, conference proceedings and dissertations and theses can be included. • There is no limit pertaining to the year of publication. • Study samples can include male and/or female participants of any age. • Studies must look at the experience of recovering from treatment and/or long-term recovery stages of colorectal cancer. • Sexual health/ sexuality must be listed as a primary outcome or key focus (quantitative studies) OR Sexuality/ sexual health must be listed as a key finding (qualitative studies).	• Studies that focus on diagnosis or pre-treatment or treatment phases of cancer. • Studies that examine various cancers together and do not report data pertaining to CRC explicitly from the rest. • Studies that do not list aspects of the experience pertaining to sexuality or sexual health as a primary outcome or key finding. • Studies that primarily focus on comparing and contrasting various types of treatment modalities (i.e. APR surgery vs TME surgery) and their outcomes on sexuality. • Studies that use the EORTC-QLQ-C 30 scale and/or the EORTC QLQ 38 supplement scale without using further tools or techniques to examine sexuality or sexual health.

Refining the research question. The changes to the inclusion and exclusion criteria led to the need to alter the research question(s) to ensure clarity of the scope of the search. The original question guiding this research project was: *What is the gendered experience of sexuality after treatment for colorectal cancer, and the gendered response to psychosexual intervention for sexual health problems?*

On completion of the scoping search, the research question was altered to reflect the search findings and body of literature. The subsequent questions which guided the conduct of the narrative synthesis are: *What is the impact of CRC treatment on the sexual health experiences of survivors? How is this experience shaped by sex and gender-related factors?*

PRISMA diagram: Summary of search process. A visual summary of the search process was compiled as recommended by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Statement (Moher, Liberati, Tetzlaff, & Altman, 2009). This diagram is outlined in Figure 4.1

Results of the Narrative Synthesis

This section will outline the findings of the narrative synthesis, including a thorough description of the final included studies, results of study appraisal, and a discussion of prevalent themes and findings within this body of literature.

Overview of final included studies. A total of 21 primary research studies and 10 grey literature sources were deemed final inclusions for this synthesis. Therefore, the refined inclusion and exclusion criteria (Table 4.4) yielded a total of 15 additional exclusions from the initial pool of included studies included in the scoping search. The excluded articles include: Allal et al. (2005); Dazio et al. (2009); Devlin et al. (1971);

DiFabio et al. (2008); Heras et al. (2010); Krouse et al. (2009); Li (2009); Li et al. (2013); MacDonald & Anderson (1985); Mahjoubi et al. (2012); Rozmovitz & Ziebland (2004); Sprangers et al. (1995); Traa et al. (2012); White et al. (2013).

All final included research articles (n=21) are directly related to the research question, and provide accounts of the sexual experiences of CRC survivors. The majority of the studies were found using the comprehensive database searches (n = 19). Two studies (n=2) were found using alternative methods, i.e. snowballing (Neuman et al., 2011; Sharpe et al., 2011).

All of the studies were published from 1975-2013. Eighteen were published from 2009-2013 (n = 18). The studies represented diverse methodologies (Table 4.5). Eight of the papers use qualitative methods, eleven use quantitative methodology, and two used mixed methods. Very few of the qualitative studies explicitly state the qualitative approach used to guide the research (n=3). One study used a narrative approach (Andersson et al., 2010), one used grounded theory (Neuman et al., 2012), and one applied an explorative phenomenological approach (Ramirez et al., 2009). The most common type of design was cross sectional (n = 6) (Au et al., 2012; Cotrim & Pereira, 2008; Milbury et al., 2013; Nowicki et al., 2011; Platell et al., 2004; Schmidt et al., 2005).

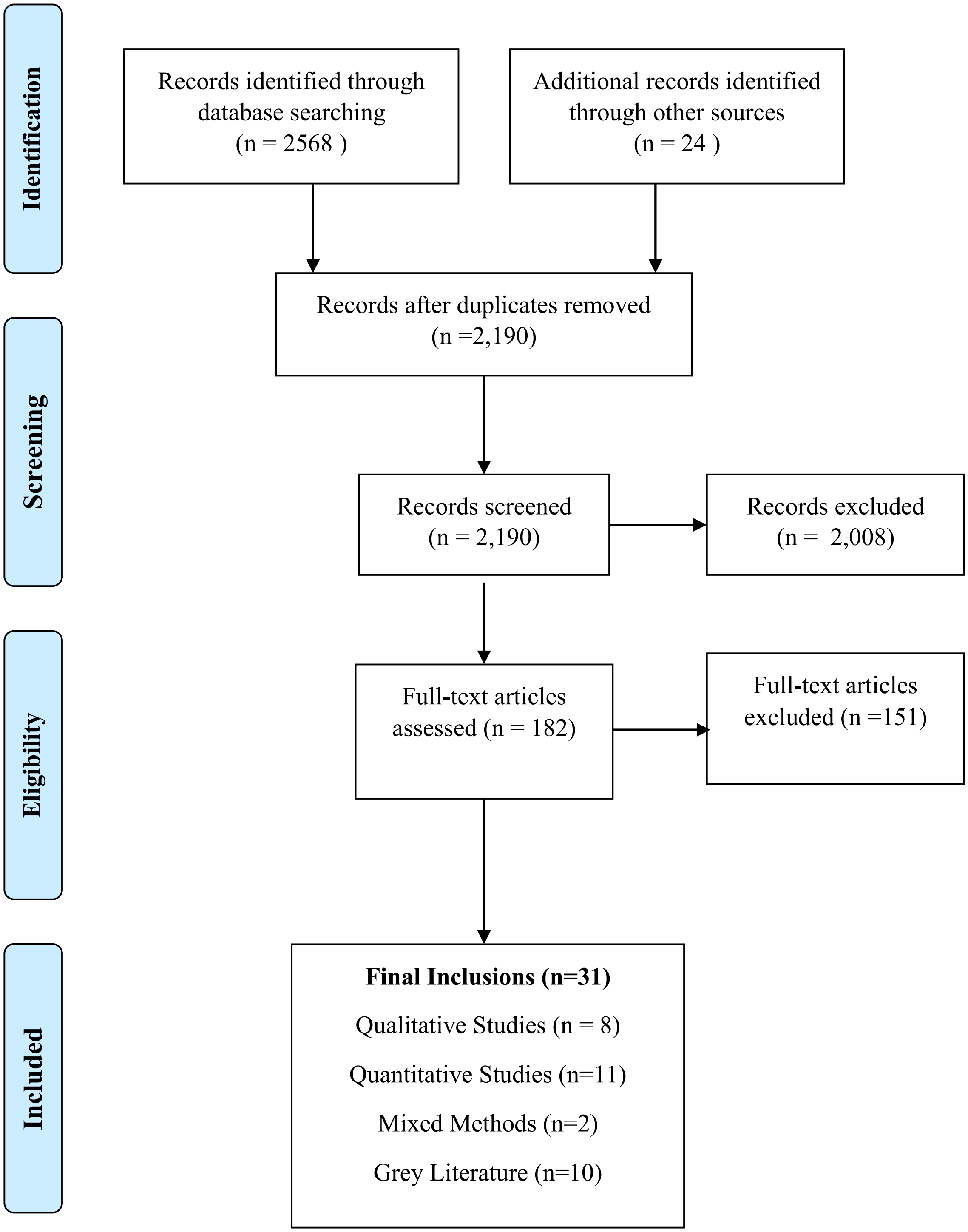

Figure 4.1 PRISMA diagram

Table 4.5 Review of final included primary research

Author	Year	Design
1. Altschuler	2009	Mixed Methods
2. Andersson	2010	Qualitative (narrative)
3. Au	2012	Cross Sectional
4. Ball	2011	Qualitative
5. Ball	2013	Qualitative
6. Cotrim	2007	Cross Sectional
7. Da Silva	2008	Longitudinal
8. Dowswell	2011	Qualitative
9. Grant	2011	Qualitative
10. Milbury	2013	Cross Sectional
11. Neuman	2011	Longitudinal
12. Neuman	2012	Qualitative (grounded theory)
13. Nowicki	2011	Cross Sectional
14. Ohlsson-Nevo	2011	Qualitative
15. Platell	2004	Cross Sectional
16. Ramirez	2009	Qualitative (phenomenology)
17. Reese	2012	Intervention
18. Sharpe	2010	Longitudinal
19. Schmidt	2005	Cross Sectional
20. Schmidt	2010	Longitudinal
21. Wirsching	1975	Mixed Methods

Grey literature. Ten policies and guidelines were included in this synthesis (Howell et al., 2011; Institute of Medicine [IOM], 2008; National Breast Cancer Centre, 2003; National Comprehensive Cancer Network, 2013; National Institute for Health and Cancer Excellence [NICE], 2011; New Zealand Guidelines Group, 2011; NICE, 2004; Patwardhan et al., 2006; The Association of Coloproctology of Great Britain and Ireland, 2007; The Cancer Council Australia, 2005). The majority of these documents briefly mentioned the sexual health issues and recommendations for care of cancer survivors; however, others were extensive in their accounts of appropriate management of this population. Most provided explicit recommendations for care of sexual issues for men and women with CRC. Many of the policies/guidelines were specific to colorectal cancer management; however some were more general cancer guidelines applicable to various cancers (Table 4.6). The general cancer guidelines were included as they provided detailed instructions pertaining to the management of sexual health issues and psychosocial care of men and women with cancer and could be generalized to CRC survivors.

Table 4.6 Included policies and guidelines (grey literature sources)

Colorectal Cancer Specific	**General Cancer Guidelines**
• *Clinical practice guideline for the prevention, early detection, and management of colorectal cancer.* The Cancer Council Australia/Australian Cancer Network (2005) • *Clinical Guideline. Colorectal cancer: the diagnosis and management of colorectal cancer.* National Institute for Health and Cancer Excellence (NICE) (2011)	• *Clinical practice guidelines for the psychosocial care of adults with cancer* National Breast Cancer Centre & the National Cancer Control Initiative (2003) • *Cancer Care for the Whole Patient. Meeting Psychosocial Health Needs.* Institute of Medicine (IOM) (2008)

Colorectal Cancer Specific	General Cancer Guidelines
• *Guidelines for the Management of Colorectal Cancer: 3rd edition.* The Association of Coloproctology of Great Britain and Ireland (2007) • *Management of Early Colorectal Cancer.* New Zealand Guidelines Group (2011) • *Guidance on Cancer Services Improving Outcomes in Colorectal Cancers*. National Institute for Health and Cancer Excellence (NICE) (2004) • *Cancer Care Quality Measures: Diagnosis and Treatment of Colorectal Cancer.* Duke Evidence-based Practice Center (Patwardhan et al., 2006)	• *NCCN Clinical Practice Guidelines in Oncology: Survivorship.* National Comprehensive Cancer Network (NCCN) (2013) • *Pan-Canadian Guidance on Organization and Structure of Survivorship Services and Psychosocial-Supportive Care Best Practices for Adult Cancer Survivors.* Canadian Association of Psychosocial Oncology (CAPO) (Howell et al. 2011)

Three guidelines were produced in the United States, three in the United Kingdom, two in Australia, one in New Zealand, and one in Canada (Table 4.7). Two guidelines were focused on enhancing psychosocial care of cancer survivors (IOM, 2008; National Breast Cancer Centre & the National Cancer Control Initiative, 2003). The remaining guidelines focused on improving survivorship (Howell et al., 2011; NCCN, 2013) and management of CRC (New Zealand Guidelines Group, 2011; NICE, 2004; NICE, 2011; Patwardhan et al., 2006; The Association of Coloproctology of Great

Britain and Ireland, 2007; The Cancer Council Australia, 2005). Guidelines were analyzed using NVivo 10 for prevalent themes, and were categorized accordingly to highlight sections of these documents addressing the experiences of men and women and recommendations for care of CRC survivors. These results are outlined further in the thematic analysis section of this research.

Table 4.7 Summary and characteristics of included grey literature

Name and Date of the Guideline	Country of Origin	Prepared by
Clinical practice guidelines for the psychosocial care of adults with cancer (2003)	Australia	National Breast Cancer Centre & the National Cancer Control Initiative
Clinical practice guideline for the prevention, early detection, and management of colorectal cancer (2005)	Australia	The Cancer Council Australia/Australian Cancer Network
Clinical Guideline. Colorectal cancer: the diagnosis and management of colorectal cancer (2011)	United Kingdom	National Institute for Health and Cancer Excellence (NICE)
Cancer Care for the Whole Patient. Meeting Psychosocial Health Needs (2008)	United States	Institute of Medicine (IOM)
Guidelines for the Management of Colorectal Cancer: 3rd edition (2007)	Ireland	The Association of Coloproctology of Great Britain and Ireland

Name and Date of the Guideline	**Country of Origin**	**Prepared by**
NCCN Clinical Practice Guidelines in Oncology: Survivorship (2013)	United States	National Comprehensive Cancer Network
Management of Early Colorectal Cancer (2011)	New Zealand	New Zealand Guidelines Group
Guidance on Cancer Services Improving Outcomes in Colorectal Cancers (2004)	United Kingdom	National Institute for Health and Cancer Excellence (NICE)
Cancer Care Quality Measures: Diagnosis and Treatment of Colorectal Cancer (2006)	United States	Duke Evidence-based Practice Center Patwardhan et al. (2006)
Pan-Canadian Guidance on Organization and Structure of Survivorship Services and Psychosocial-Supportive Care Best Practices for Adult Cancer Survivors (2011)	Canada	Canadian Association of Psychosocial Oncology (CAPO) Howell et al. (2011)

Results of study appraisal. I undertook study appraisal in the initial stages of this research to assess the overall quality of the included quantitative, qualitative, and mixed method literature. Quality appraisal was also completed for the included guidelines. This literature was assessed in terms of overall quality according to specific criterion included in validated study appraisal tools.

Study appraisal: Quantitative studies. Observational studies were assessed for quality using five specific criterions according to an appraisal tool by the Cochrane Public Health Group (Thomas et al., 2004). The five criterions included: selection bias, presence of confounders, tools used, number of withdrawals, and analysis. Each criterion was scored from 0-2, with the highest possible score as 10/10 and the lowest score 0/10. An overall quality score was attributed to each study so that studies that scored 0-4 were deemed weak, scores of 5-7 were moderate, and scores of 8-10 were strong (Table 4.8).

The intervention study included in the synthesis (Reese et al., 2012) was assessed out of a possible 14 points using the same criteria as above. In addition, because it was an intervention study, it was judged on blinding of study participants, as well as the quality of the intervention (Table 4.9).

Table 4.9 Results of study appraisal: Intervention study

Criteria	**Reese et al. (2012)**
Bias	Moderate (1)
Confounders	Weak (0)
Blinding	Weak (0)
Tools	Strong (2)
Withdrawals	Moderate (1)
Analysis	Moderate (1)
Intervention	Strong (2)
Overall Quality	Moderate (7/14)

Table 4.8 Results of study appraisal: Observational studies

Author	Bias	Confounders	Tools	Withdrawals	Analysis	Overall
Au	Weak (0)	Moderate (1)	Strong (2)	Strong (2)	Strong (2)	Moderate 7/10
Cotrim	Weak (0)	Weak (0)	Strong (2)	Strong (2)	Moderate (1)	Moderate 5/10
Da Silva	Weak (0)	Strong (2)	Strong (2)	Weak (0)	Moderate (1)	Moderate 5/10
Milbury	Strong (2)	Strong (2)	Strong (2)	Strong (2)	Moderate (1)	High 9/10
Neuman 2011	Weak (0)	Strong (2)	Strong (2)	Weak (0)	Moderate (1)	Moderate 5/10
Nowicki	Weak (0)	Weak (0)	Moderate (1)	Strong (2)	Moderate (1)	Low 4/10
Platell	Weak (0)	Weak (0)	Moderate (1)	Strong (2)	Moderate (1)	Low 4/10
Schmidt 2005	Moderate (1)	Strong (2)	Strong (2)	Strong (2)	Moderate (1)	High 8/10
Schmidt 2010	Moderate (1)	Strong (2)	Strong (2)	Weak (0)	Moderate (1)	Moderate 6/10
Sharpe	Strong (2)	Strong (2)	Strong (2)	Strong (2)	Strong (2)	High 10/10

Overall, quality ratings for the quantitative studies averaged moderate (n = 6) (Au et al., 2012; Cotrim & Pereira, 2008; Da Silva et al., 2008; Neuman et al., 2011; Schmidt et al., 2010; Reese et al., 2012) to high (n = 3) (Milbury et al., 2013; Schmidt et al., 2005; Sharpe et al., 2011). Few quantitative studies were deemed low quality (n = 2) (Nowicki et al., 2011 & Platell et al., 2004). On completion of the study appraisal exercise, some patterns were found among the included studies. Many studies explicitly outlined the validity and reliability of the data collection tools and techniques used (Au et al., 2012; Cotrim & Pereira, 2008; Da Silva et al., 2008; Milbury et al., 2013; Neuman et al., 2011; Schmidt et al., 2005; Schmidt et al., 2010; Sharpe et al., 2011). Lastly, a common finding was that very few studies provided a power or sample size calculation as a rationale for the sample size (n=8) (Cotrim & Pereira, 2008; DaSilva et al., 2008; Milbury et al, 2013; Neuman et al., 2011; Nowicki et al., 2011; Platell et al., 2004; Schmidt et al., 2005; Schmidt et al., 2010).

The overall quality of the intervention study (Reese et al., 2012) was deemed moderate. A significant drawback of this study was that it did not use a control group. It also did not account for ostomy status as a potential confounder influencing study results. The overall quality and explanation of the intervention was deemed strong as the description of the four-part intervention was detailed, and the majority of participants followed through and completed the whole intervention.

Study appraisal: Qualitative studies. Qualitative studies were assessed for eight specific criterion outlined by Mays & Pope (1996, 2005) (Appendix C). Each criterion was answered as either yes or no. 'Yes' answers gained one point, 'No' answers gained zero points. Studies were scored out of a total possible rating of eight. Studies that scored 0-3 were deemed weak, scores of 4-6 were moderate, and scores of 6-8 were strong. Generally, the eight qualitative studies varied in appraisal scores (Table 4.9.1).

Half of the qualitative studies included in this synthesis were of moderate quality (n = 4) (Andersson et al., 2010; Ball et al., 2013; Dowswell et al., 2011; Ohlsson-Nevo et al., 2011). A few of studies were deemed strong (n = 3) (Grant et al., 2011; Neuman et al., 2012; Ramirez et al., 2009) and one was scored as weak (n = 1) (Ball et al., 2011). Few qualitative studies (n = 3) mentioned the use of an explicit theory to guide the research process and interpretation of study findings (Grant et al., 2011, Neuman et al., 2012; Ramirez et al., 2009). For this reason, many studies scored low for certain criteria including presence and integration of theoretical framework, and overall flow of ideas. Two studies were vague regarding the strategy undertaken to garner the appropriate sample for the research (Andersson et al., 2010; Ball et al., 2011). All studies clearly outlined the research question guiding the study. Most studies clearly described the context of the study (n = 6) (Ball et al., 2011, 2013; Dowswell et al., 2011; Neuman et al., 2012; Ohlsson-Nevo et al., 2011; Ramirez et al., 2009). As well, most presented a sufficient amount of raw data and evidence to justify the findings (n = 7) (Andersson et al., 2010; Ball et al., 2013; Dowswell et al., 2011; Grant et al., 2011; Neuman et al., 2012; Ohlsson-Nevo et al., 2011; Ramirez et al., 2009).

Table 4.9.1 Results of study appraisal: Qualitative studies

Criteria	**Andersson**	**Ball 2011**	**Ball 2013**	**Dowswell**	**Grant**	**Neuman 2012**	**Ohlsson-Nevo**	**Ramirez**
Framework	No	No	No	No	Yes	Yes	No	Yes
Research Question	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Context	No	Yes	Yes	Yes	No	Yes	Yes	Yes
Sampling Strategy	No	No	Yes	Yes	Yes	Yes	Yes	Yes
Fieldwork Collection & Analysis	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes
Themes & Concepts	Yes	No	No	Yes	Yes	Yes	Yes	Yes
Flow of data	No	No	Yes	No	Yes	Yes	No	Yes
Amount of Evidence	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes
Overall	5/8 Moderate	2/8 Weak	6/8 Moderate	6/8 Moderate	7/8 Strong	8/8 Strong	6/8 Moderate	8/8 Strong

Study appraisal: Mixed methods. Only two mixed methods studies were included in this synthesis (Table 4.9.2). Criteria for appraisal were derived from the Pluye, Gagnon, Griffiths, and Johnson-LaFleur (2009) scoring system for appraising mixed methods in primary research (Appendix C).

Table 4.9.2 Results of study appraisal: Mixed methods

Author	Justification of design	Combination of methods	Integration of data	Overall
Altschuler	3/10	10/10	8/10	21/30 Strong
Wirsching	0/10	5/10	5/10	10/20 Weak

Quality apprasial: Guidelines. All ten included guidelines were subjected to intensive quality appraisal using the AGREE II instrument (Brouwers et al., 2010). Gudielines were scored in six different quality domains: scope and purpose, stakeholder involvement, rigor of development, clarity of presentation, applicability, and editorial independence (Appendix E). Several trends were noted in the quality of these six domains across included guidelines. Most guidelines (n=6) scored between 88%-100% (range 61-100%) in the scope and purpose domain, indicating that most guidelines were explicit in defining the scope and purpose of guidelines (Howell et al., 2011; National Breast Cancer Centre & the National Cancer Control Initiative, 2003; NICE, 2011; New Zealand Guidelines Group, 2011; The Cancer Council Australia, 2005; Patwardhan et al., 2006). Another domain where many guidelines scored high was clarity of presentation;

eight of the ten guidelines scored from 83-100% (Howell et al., 2011; National Breast Cancer Centre & the National Cancer Control Initiative, 2003; NICE, 2011; NICE, 2004; NCCN, 2013; New Zealand Guidelines Group, 2011; The Cancer Council Australia, 2005; Patwardhan et al., 2006). One domain where guidelines tended to score poorly was the applicability domain (n=9 scored below 70%) (Howell et al., 2011; National Breast Cancer Centre & the National Cancer Control Initiative, 2003; NICE, 2011; NICE, 2004; NCCN, 2013; New Zealand Guidelines Group, 2011; The Cancer Council Australia, 2005; Patwardhan et al., 2006). These guidelines did not provide advice or tools on how recommendations could be utilized nor did many present ongoing moniorting and auditing criteria for outcome measures. Scores pertaining to rigor of development varied widely from 35%-90%, indicating some guidelines were produced using systematic techniques while others lacked rigorous techniques (Appendix E).

Results of data extraction. Multiple iterations of an appropriate tool for data extraction were discussed with the thesis supervisors. To ensure accuracy and reliability of the collected data, two reviewers independently completed data extraction and compared findings as extraction progressed. Items for extraction included the study author, date, target population, type of treatment, time since treatment, sample, aim, design, theory, outcome measures, findings, and sex-specific findings (when applicable). See Appendix D detailed results of data extraction.

Data extraction: Theory. The lack of explicit theory guiding the included studies was noted as a significant limitation of the included body of literature. Theories and theoretical frameworks guiding these studies were not included in the data extraction tables as very few studies (n=5) explicitly addressed theory as guiding the research.

Theories or frameworks used within the studies included Schlotfeldt’s (1975) health-seeking model (Au et al., 2012), The City of Hope (2004) Four Dimensional Framework (Altschuler et al., 2009; Grant, 2011), Response Shift Theory (Neuman et al., 2012) and an anthropological perspective (Ramirez et al., 2009).

Results of analysis: Preliminary synthesis. There are several tools and techniques that are helpful to generate a preliminary synthesis (Popay et al., 2006). Analytic strategies used to develop the preliminary synthesis included: textual descriptions, tabulation, groupings and clusters, and thematic analysis.

Textual Descriptions. Textual descriptions of each included study were completed early in the preliminary synthesis (during data extraction) as a strategy to become as familiar as possible with the included studies (Appendix F). Descriptions were compared to data extraction tables to ensure collected data was comprehensive and accurate. Descriptions were also used to re-familiarize the researcher with the included studies, and were often referred to as a resource.

Tabulation, grouping, and clustering. Tabulation and grouping studies were taken on simultaneously in the context of this research. Tabulation was used as a strategy to visually organize quantitative and qualitative data in table form (Appendix G). Tabulation tables were used to create several groupings and clusters to organize the included studies (Appendix H). The next several pages provide an overview of the findings from these groupings/clusters.

Groupings and clusters: Outcomes. Groupings and clusters were a helpful strategy to visually portray, organize, and summarize all primary and secondary outcomes of the included studies within a common table. This was necessary as the studies outlined a variety of outcomes, all seemingly different in their aim to capture some aspect of the sexual experience of CRC survivors. Grouping all study outcomes supported the examination of variability of outcomes and the formation of four main categories to condense and summarize the main outcomes of the included studies. These categories include primary and secondary outcomes that measure:

- How the ostomy impacts sexuality, self-esteem, self-concept or body image (Altschuler, et al., 2009; Andersson et al., 2010; Grant et al., 2011; Platell et al., 2004; Ramirez et al., 2009; Sharpe et al., 2011).
- Correlations between sexuality (i.e. sexual function, body image) and HRQOL - i.e. emotional, mental and physical health (Da Silva et al., 2008; Neuman et al., 2011; Neuman et al., 2012; Schmidt et al., 2005; Schmidt et al., 2010).
- Understanding the sexual experience (Ball et al., 2011; Ball et al., 2013; Dowswell et al., 2011; Neuman et al., 2012; Ohlsson-Nevo et al., 2011; Wirsching et al., 1975).
- How psychosocial or psychological factors influence sexual function or body image - i.e. dyadic adjustment, martial satisfaction, anxiety, distress, spirituality & resourcefulness (Au et al., 2012; Cotrim et al., 2007; Milbury et al., 2013; Nowicki et al., 2011; Reese et al., 2012).

Groupings and clusters: Sex-specific. Studies were grouped according to sex, for example studies examining men (n=2) were grouped together, and studies examining women (n=6) were grouped separately (Table 4.9.3). This allowed for comparison of study designs, sample characteristics, and study findings pertaining to men and women.

Almost all of the studies, which specifically examined men or women, did so using qualitative methods (n = 6) (Altschuler et al., 2009; Andersson et al., 2010; Ball et al., 2011; Ball et al., 2013; Dowswell et al., 2011; Ramirez et al., 2009). The two remaining studies used cross sectional designs (Da Silva et al., 2008; Platell et al., 2004) to examine the sexual health experiences of women.

Overall, sex-specific groupings were useful to contest any assumptions that sexual experiences of men and women are similar. In fact, this grouping (while not definitive) demonstrated that concerns with partner acceptance and issues with self-esteem and body image were more prevalent for women. The two studies, which examined men indicated that diminished sexual functioning and erectile dysfunction was a significant experience for men, and often became problematic once other side effects of the cancer treatment subsided (Ball et al., 2013; Dowswell et al., 2011).

Table 4.9.3 Groupings: Sex specific studies

Studies Specific to Men	**Studies Specific to Women**
• Ball et al. (2013) • Dowswell et al. (2011)	• Altschuler et al. (2009) • Andersson et al. (2010) • Ball et al. (2011) • Da Silva et al. (2008) • Platell et al. (2004) • Ramirez et al. (2009)

Overall, the majority of the included studies examined both men and women who underwent CRC treatment (n=13). One study was a pilot intervention study (Reese et al., 2012), five were cross sectional (Au et al., 2012; Cotrim & Pereira, 2008; Milbury et al., 2013; Nowicki et al., 2011; Schmidt et al., 2005), and three were longitudinal (Neuman, et al., 2011; Schmidt et al., 2010; Sharpe et al., 2011). Three studies used qualitative methods to examine men and women (Grant et al., 2011; Neuman et al., 2012; Ohlsson-Nevo et al., 2011), and one used mixed methods (Wirsching et al., 1975).

Some studies (n= 8) examined sex-related differences in the sexual experiences of survivors (Au et al., 2012; Grant et al., 2011; Milbury et al., 2013; Nowicki et al., 2011; Reese et al., 2012; Schmidt et al., 2005; Schmidt et al., 2010; Wirsching et al., 1975), while some did not account for sex or gender differences whatsoever (Cotrim & Pereira, 2008; Neuman et al., 2011; Neuman et al., 2012; Ohlsson-Nevo et al., 2011; Sharpe et al., 2011). The eight studies that examined sex differences were grouped together to look for common trends in findings (Au et al., 2012; Ball et al., 2013; Dowswell et al., 2011; Grant et al., 2011; Milbury et al., 2013; Nowicki et al., 2011; Reese et al., 2012; Schmidt et al., 2005; Schmidt et al., 2010; Wirsching et al., 1975). Ultimately, these findings varied. Three of these studies outlined that men tend to show higher levels of distress caused by sexual changes (Schmidt et al., 2005; Schmidt et al., 2010; Wirsching et al., 1975), particularly as they relate to erectile dysfunction (Ball et al., 2013; Dowswell et al., 2011). Women have lower levels of sexual enjoyment post treatment for CRC compared to men (Milbury et al., 2013). Women were also found to experience challenges with body image, self-esteem, and increased concerns with the quality of martial relationships (Au et al., 2012; Grant et al., 2011; Nowicki et al., 2011; Wirsching et al., 1975).

The two major areas where the experiences of men and women differed most included experiences of changed body image and coping. For example, some of the evidence indicated that women are able to cope in resourceful ways to manage the after effects of cancer more so than men (Au et al., 2012). In addition, men may adopt stoic and avoidant behaviors to manage sexual changes (Ball et al., 2013; Dowswell et al., 2011), while women seem to be particularly dependent on partner support to help cope with sexual changes (Altschuler et al. 2009; Andersson et al., 2010; Nowicki et al., 2011; Ramirez et al., 2009). Changes to body image often manifested in relation to erectile dysfunction and are said to influence men's identities (Dowswell et al., 2011). For women, changed body image was strongly related to the presence of an ostomy, which many struggled to adjust to and manage post treatment (Ramirez et al., 2009). The discussion of sex-specific results are expanded in the thematic analysis findings outlined in the next section of this thesis.

Groupings and clusters: Ostomy-specific. It became clear early on in this research that the impact of the ostomy on the sexuality and sexual health of CRC survivors was significant. Several studies (n = 7) aimed to capture life with an ostomy, or how intimacy, relationships, body image, and/or sexuality were impacted by the presence of an ostomy (Altschuler et al., 2009; Andersson et al., 2010; Grant et al., 2011; Neuman et al., 2011; Neuman et al., 2011; Nowicki et al., 2011; Ramirez et al., 2009) (Table 4.9.4). Grouping these studies together revealed that the presence of an ostomy increases survivors' risk for sexual problems, including cessation of sexual relations (Nowicki et al., 2011), changes to body image and self-esteem (Grant et al., 2011; Neuman et al, 2011; Neuman et al., 2012), and changes to martial and intimate relationships (Altschuler et al., 2009; Andersson et al., 2010; Ramirez et al., 2009).

Table 4.9.4 Groupings: Ostomy specific studies

Ostomy-Specific Studies
Altschuler et al. (2009) Andersson et al. (2010) Grant et al. (2011) Neuman et al. (2011) Neuman et al. (2012) Nowicki et al. (2011) Ramirez et al. (2009)

Groupings and clusters: Comparison studies. Similar to studies that focused on ostomy-specific outcomes, some studies compared experiences of CRC survivors with ostomies to those without (n = 4) (Cotrim & Pereira, 2008; Da Silva et al., 2008; Sharpe et al., 2011; Wirsching et al., 1975). These studies provided further compelling evidence that men and women with ostomies tend to experience more severe sexual side effects. Survivors with ostomies demonstrated significantly lower HRQOL scores (Cotrim & Pereira, 2008) and more pronounced disturbances to sexual function (Cotrim & Pereira, 2008), body image, anxiety, depression, loneliness, and distress (Da Silva et al., 2008; Sharpe et al., 2011; Wirsching et al., 1975).

Groupings and clusters: Cancer-specific. On examination of the body of included literature, it was noted that several studies (n = 9) explicitly studied survivors with rectal cancer (Andersson et al., 2010; Au et al., 2012; Ball et al., 2011; Ball et al., 2013; Neuman et al., 2011; Neuman et al., 2012; Nowicki et al., 2011; Schmidt et al., 2005; Schmidt et al., 2010). No studies explicitly evaluated colon cancer patients.

Regardless, studies were grouped according to type of cancer (CRC or rectal cancer only) to determine if any patterns existed within this grouping (Table 4.9.5).

Table 4.9.5 Groupings: Rectal cancer vs. colorectal cancer

Study focus: Rectal cancer (n = 9)	**Studies focus: CRC (n = 11)**
• Andersson et al. (2010) • Au et al. (2012) • Ball et al. (2011) • Ball et al. (2013) • Neuman et al. (2011) • Neuman et al. (2012) • Nowicki et al. (2011) • Schmidt et al. (2005 & 2010)	• Altschuler et al. (2009) • Cotrim & Pereira (2008) • Da Silva et al. (2008) • Dowswell et al. (2011) • Grant et al. (2011) • Milbury et al. (2013) • Ohlsson-Nevo et al. (2011) • Ramirez et al. (2009) • Reese et al. (2012) • Sharpe et al. (2011) • Wirsching et al. (1975)

One study (Platell et al., 2004) evaluated sexual health comparing rectal cancer patients and colon cancer patients. This study provided some evidence that rectal cancer patients were more likely to feel less attractive after surgery; however, no other significant differences were noted. It is worth noting that this study was rated a low overall quality, therefore these results should be interpreted with caution. Overall, comparing studies that examined rectal cancer patients only with studies that focused on CRC patients yielded no significant differences in the severity and experience of sexual problems.

Groupings and clusters: Length of survivorship. Studies were organized according to the length of time from when participants had undergone treatment until the conduct of the study itself (Table 4.9.6). This was an important comparison primarily because of the range of time frames and varied lengths of survivorships represented among participants in the included studies. Studies were clustered in these groups according to the most commonly researched time frames including: 0-2 years (n=9) (Cotrim & Pereira, 2008; DaSilva et al., 2008; Neuman et al., 2011; Neuman et al., 2012; Ohlsson-Nevo et al., 2011; Reese et al., 2012; Sharpe et al., 2011; Schmidt et al., 2005; Schmidt et al., 2010), over 2 years (n=5) (Altschuler et al., 2009; Ball et al., 2013; Grant et al., 2011; Ramirez et al., 2009; Wirsching et al., 1975), varying lengths of survivorship (n=4) (Andersson et al., 2010; Au et al., 2012; Milbury et al., 2013; Platell et al., 2004) and unspecified survivorship (n=3) (Ball et al., 2011; Dowswell et al., 2011; Nowicki et al., 2011).

Researchers that examined survivors within two years of completing treatment included four longitudinal studies that examined the first 12-24 months post treatment. These studies showed that alterations to body image and self-esteem (Da Silva et al., 2008; Neuman et al., 2011; Sharpe et al., 2011) and impaired sexual function and sexual strain/distress (Schmidt et al., 2010) were quick-onset concerns experienced by survivors. In particular, body image was often impacted, and one study showed that it worsened over time (Neuman et al., 2011; Sharpe et al., 2011). The remaining studies examining survivors within two years (n=5) included research of a variety of designs (Cotrim & Pereira, 2008; Neuman et al., 2012; Ohlsson-Nevo et al., 2011; Reese et al., 2012; Schmidt et al., 2005). Findings of these studies further supported the harmful influence of CRC treatment, as all produced findings indicating the impact of cancer treatment on multiple aspects of sexuality and sexual health in this time frame. The successful implementation of the intimacy enhancing intervention by Reese et al. (2012) indicated that couple-focused interventions within the first two years of survivorship could be of value to improve sexual and relationship outcomes.

Studies examining longer-term survivors (i.e. those examining survivors over two years) were mostly qualitative (n = 3) (Ball et al., 2013; Grant et al., 2011; Ramirez et al., 2009), although two were mixed methods (Altschuler et al., 2009; Wirsching et al., 1975). Generally, these studies were focused on the sexual experiences and mechanisms of coping among CRC survivors. Grant et al. (2011) examined survivors five or more years post diagnosis and found that sexual issues, including functional changes and changes to sexual relationships, were substantial concerns for men and women. In addition, women were more likely to refer to challenges with body image and depression (Grant et al., 2011).

Generally, findings of the studies examining longer-term survivors indicated that alterations to sexuality wavered in significance, as sexual changes were not significant for some, and some survivors were able to cope with changes more readily than others. In fact, two studies indicated that coping among women was highly dependent on quality of partner support (Altschuler et al., 2009; Ramirez et al., 2009). Men, on the other hand, are able to cope with sexual changes by evaluating sexuality within their current life context, and attributing age as the primary factor impacting sexuality (Ball et al., 2013).

Some studies evaluated participants with a variety of lengths of survivorship (n = 4) (Andersson et al., 2010; Au et al., 2012; Milbury et al., 2013; Platell et al., 2004). These studies used varied methodologies, one was qualitative (Andersson et al., 2010), and three were cross sectional (Au et al., 2012; Milbury et al., 2013; Platell et al., 2004).

Two of these studies were specific to female survivors and examined the impact of the ostomy (Andersson et al., 2010; Platell et al., 2004). Au et al. (2012) examined resourcefulness, sexual self-concept, and spirituality in a variety of survivors and showed that these concepts are strongly interrelated as men and women who had greater resourcefulness had higher scores on measures of sexual satisfaction and sexual self-concept. Lastly, Milbury et al. (2013) found that better sexual function was associated with better QOL outcomes, dyadic adjustment, and body image. Generally, grouping studies in this manner did not provide substantial evidence that the sexual experiences of survivors are worse either in the short-term or long-term. All produced findings indicating that the influence of treatment on sexual health is significant, and impacts survivors on both a shorter term and longer-term basis.

Table 4.9.6 Groupings: Length of survivorship

Length of Survivorship	**Studies**
Survivors (1-2 years) (n=9)	Cotrim & Pereira (2008); Da Silva et al. (2008); Neuman et al. (2011); Neuman et al. (2012); Ohlsson-Nevo et al. (2011); Reese et al. (2012); Sharpe et al. (2011); Schmidt et al. (2005); Schmidt et al. (2010)
Survivors (2 + years) (n=5)	Altschuler et al. (2009); Ball et al. (2013); Grant et al. (2011); Ramirez et al. (2009); Wirsching et al. (1975)
Combination (n=4)	Andersson et al. (2010); Au et al. (2012); Milbury et al. (2013); Platell et al. (2004)
Unspecified (n=3)	Ball et al. (2011); Dowswell et al. (2011); Nowicki et al. (2011)

Groupings and clusters: Couple-based. Two studies (Ohlsson-Nevo et al., 2011; Reese et al., 2012) were focused on evaluating couples' experiences and outcomes post treatment for CRC. Cancer treatment resulted in sexual changes that both patient and partner coped with together, and many couples were able to adjust to changes in their sex life, either through cessation of sex or reconfiguration of intimacy (Ohlsson-Nevo et al., 2011). In the intervention study by Reese (2012), which focused on enhancing sexual communication and intimacy among couples, both patients and partners benefitted from structured sexual interventions as the intimacy enhancing intervention improved sexual communication, dyadic adjustment, and intimacy. Results of the qualitative study by Ohlsson-Nevo et al. (2011) examining the couple experience one year post treatment showed that some couples expressed the potential benefits of sexual health interventions to improve intimacy and sexual communication (Ohlsson-Nevo et al., 2011).

Grouping and clusters: Study quality. Lastly, studies were grouped according to overall quality. Six studies were of high quality (Altschuler et al., 2009; Grant et al., 2011; Milbury et al., 2013; Ramirez et al., 2009; Sharpe et al., 2011; Schmidt et al., 2010), eleven were deemed moderate quality (Andersson et al., 2010; Au et al., 2012; Ball et al., 2013; Cotrim & Pereira, 2008; Da Silva et al., 2008; Dowswell et al., 2011; Neuman et al., 2011; Neuman et al., 2012; Ohlsson-Nevo et al., 2011; Reese et al., 2012; Schmidt et al., 2005), and four were low quality (Ball et al., 2011; Nowicki et al. 2011; Platell et al., 2004; Wirsching et al., 1975) (Table 4.9.7).

Significance of study findings was also included in this table. A summary of the studies that produced statistically significant findings, and the appraisal score they achieved, provided insight into the overall quality and reliability of the significant findings. For example, if a study outlined significant findings and the appraisal score of this study was weak, the findings of this study may not be as reliable as a study that achieved a strong rating. Grouping studies in this fashion was helpful to determine quality of the included evidence, and contributed to determining the overall quality of the final synthesis product.

Table 4.9.7 Groupings: Study quality

Author	**Significant/Non Significant Findings**	**Appraisal Score**
High Quality Studies N= 6		
Altschuler et al. (2009)	Not Applicable	Strong
Grant et al. (2011)	Not Applicable	Strong
Milbury et al. (2013)	Significant Findings	Strong
Ramirez et al. (2009)	Not Applicable	Strong
Sharpe et al. (2011)	Significant Findings	Strong
Schmidt et al. (2010)	Significant Findings	Strong
Moderate Quality Studies n= 11		
Andersson et al. (2010)	Not Applicable	Moderate
Au et al. (2012)	Significant Findings	Moderate
Ball et al. (2013)	Not Applicable	Moderate
Cotrim & Pereira (2008)	Significant Findings	Moderate
Da Silva et al. (2008)	Significant Findings	Moderate
Dowswell et al. (2011)	Not Applicable	Moderate

Author	**Significant/Non Significant Findings**	**Appraisal Score**
Neuman et al. (2011)	Significant Findings	Moderate
Neuman et al. (2012)	Not Applicable	Moderate
Ohlsson-Nevo et al. (2011)	Not Applicable	Moderate
Reese et al. (2012)	Significant Findings	Moderate
Schmidt et al. (2005)	Significant Findings	Moderate
Low Quality Studies n=4		
Ball et al. (2011)	Not Applicable	Weak
Nowicki et al. (2011)	Significant Findings	Weak
Platell et al. (2011)	Significant Findings	Weak
Wirsching et al. (1975)	Significant Findings	Weak

Results of thematic analysis. Thematic analysis is a useful strategy to inductively and systematically identify the main, most important themes and/or concepts across the pool of included studies (Popay et al., 2006). Five overarching themes encapsulate the literature included in this synthesis: 1. individual characteristics, 2. relational impact (i.e. couple experience), 3. sexual impact, 4. psychosocial impact, and 5. coping with sexual changes.

Individual characteristics. Findings from the included studies described a multitude of individual influences on sexuality and sexual health post treatment for CRC including: physical factors (age, stoma status, type of cancer), culture/ social discourse, religion, psychosocial factors, mental health and social/partner support.

Age. Age is a factor that impacted sexuality for men and women alike. Several studies used measures such as the female sexual function index (FFSI) and the international index of erectile function (IIEF) scale, stoma QOL scales, and body image scales to capture the sexual experiences of survivors (Milbury et al., 2013; Neuman et al., 2012; Schmidt et al., 2005, 2010). Often, results of these measures indicated that advancing age was correlated to significant alterations to sexuality and sexual health (Milbury et al., 2013; Schmidt et al., 2005, 2010). However, while older survivors may experience more changes to sexual health, they do not appear to be as distressed by it when compared to younger survivors. Schmidt et al. (2010) uncovered that young survivors (i.e. those under the age of 70) experienced significantly greater levels of emotional distress due to altered sexuality when compared to those of older ages ($p<.05$).

One study showed that age appeared to be an important factor dictating emotional distress for women (Schmidt et al., 2005). Younger women (under 65 years) suffered greatly and considerably more from impairment of sexuality and emotional distress caused by sexual dysfunction compared to women older than 65 years in this study. This was not found in men, as men of all ages were shown to suffer deeply from emotional distress as a result of their altered sexuality (Schmidt et al., 2005).

Studies found that many survivors attribute changes to sexuality and sexual health after treatment to age. Many older women reported that sexual intercourse is no longer important to them, and attributed the lack of interest in sex to growing older. Changes to their sexual lives were not particularly distressing, as most learned other ways to maintain intimacy with their partner (Ramirez et al., 2009). Older age was also identified as an important factor that influenced and promoted different ways of coping in men (Ball et al., 2013; Dowswell et al., 2011). For example, the presence of erectile dysfunction (ED) or sexual concerns post treatment are often credited to advancing age, leading men to assume that changes to sexual health are a result of aging, and therefore some men will not seek medical attention for sexual problems, nor feel as though it is appropriate to engage in sexual activities. Perpetuating this mindset is the fact that some health care professionals are ageist in their management of sexual health (Dowswell et al., 2011). Often, sexual health issues are overlooked in older men, while younger men are offered the most information to help with sexual changes (Dowswell et al., 2011).

Colon vs. Rectal cancer. Studies were grouped to compare findings of studies which examined CRC patients versus those who only examined patients with rectal cancer. This analytic strategy did not yield any significant differences of sexual health outcomes between these patient populations in the context of this synthesis.

A couple of studies acknowledged the impact of the specific location of the cancer, stating that worse outcomes are often reported for rectal cancer patients compared to those with colon cancer (Milbury et al., 2013; Ohlsson-Nevo et al., 2011). However, only one study found that rectal cancer patients have worse sexual outcomes. This study compared sexual health outcomes of women who had surgery for colon cancer versus rectal cancer and found that women who had undergone pelvic surgery for rectal cancer experienced more impairment of sexual health compared with controls who had undergone abdominal surgery for colon cancer ($p=0.039$). (Platell et al., 2004). It is important to note that this study obtained a low score of overall quality, therefore the results should be interpreted with caution.

Stoma status. Not all CRC survivors require an ostomy. For those who do require one, in some instances they are temporary, while others are permanent. Overall, several studies included in this synthesis that evaluated the impact of the ostomy showed that it is an important factor that influences sexual function and body image among survivors (Andersson et al., 2010; Da Silva et al., 2008; Grant et al., 2011; Neuman et al., 2011; Neuman et al., 2012; Nowicki et al., 2011; Ramirez et al., 2009; Sharpe et al., 2011). Generally, the presence of an ostomy has been shown to cause body image disturbance and is linked to anxiety, distress, and depression in both men and women (Cotrim & Pereira, 2008; Sharpe et al., 2011). According to a longitudinal study by Sharpe et al. (2011), ostomy patients showed more body image disturbance ($p =.001$), and this disturbance tended to worsen over time for up to six months after completion of treatment, compared to those without osomties (Sharpe et al., 2011).

Women with ostomies often experienced changes to their sexual lives and substantially lower mental health scores compared to those without ostomies (DaSilva et al., 2008). Data specific to men showed that men with stomas experienced significant changes to frequency of intercourse, high rates of depression, and loss of self-esteem (Wirsching et al., 1975). Further detail of the impact of the ostomy is provided in the themes “sexual impact” and “psychosocial impact.”

Cultural factors or dominant social discourse. According to Ramirez et al. (2009) cultural notions of sexual decline in advancing age dominate sexual health discourse among those with CRC. Cultural assumptions pertaining to worsening of sexuality with age influenced the sexual expectations of men and women with CRC, and also influenced the ways in which men and women perceived and choose to cope with their sexual health post treatment.

Cultural influences of the stoma were shown to impact ways in which women chose to evaluate their femininity and manage the stoma during intimate relations (Ramirez et al., 2009). The influences of powerful cultural norms (hegemonic masculinity) were also shown to prevent men from admitting weakness or vulnerability post treatment in one study (Dowswell et al., 2011). These were also said to impact the ways in which men chose to manage their sexual health issues post treatment, and affirmed that silence is typically the dominant and safest approach for men adjusting to sexual issues. The influence of gender-related factors (i.e. masculinity and femininity) are further discussed as they relate to the themes “psychosocial impact” and “coping.”

Religion and spirituality. The study by Au et al. (2012) was the only study included in this synthesis that outlined the potential impact of religion or spirituality on the sexual experiences of CRC survivors. Findings of the study by Au et al. (2012) showed that men and women with low levels of spirituality experience less satisfactory sexual relationships ($p<0.001$) and lower self-concept compared to those with higher levels of spirituality (men: $p=0.000$; women: $p=0.007$) (Au et al., 2012).

Psychosocial factors. Psychosocial factors such as body image and self- esteem are individual aspects of psychosocial health which can influence the sexual impact and subsequent psychosocial impact of CRC treatment. Sharpe et al. (2011) determined in a longitudinal study that body image disturbance predicted psychological distress in both male in female survivors with ostomies up to the end of adjuvant treatment.

Capacity to cope (i.e. resourcefulness) can significantly and positively impact sexual health outcomes including better communication, more satisfying sexual relationship, and more positive sexual self-concept in men and women (Au et al., 2012). Resourcefulness is defined as: “a repertoire of the individual’s learned behavioral skills, which include personal and social resourcefulness for coping with stressful events such as cancer and its treatment” (Au et al., 2012, p. E392). Sex differences were noted for resourcefulness, lower resourcefulness was associated with men, while women were noted to have greater capacity for resourcefulness.

Social support and partner support. Current partnerships and presence of social support are two factors which influenced the sexual domain in both men and women (Milbury et al., 2013; Nowicki et al., 2011). In general, partner status was shown to improve sexual function, as both men and women in a committed relationship have been shown to score higher on measures of sexual function compared to single participants ($p<0.0001$) (Milbury et al., 2013). Partner support is noted as important in several studies as a way to facilitate coping and adaptation to sexual changes (Altschuler et al., 2009; DaSilva et al., 2008; Milbury et al., 2013; Nowicki et al., 2011; Ohlsson-Nevo et al., 2011; Platell, et al. 2004).

The importance of social support was especially prevalent for men in one study (Milbury et al., 2013) as findings showed lack of support was associated with poorer erectile function scores even when other variables (age and medical factors) were controlled for. This finding could reflect men's greater dependence on dyadic relationships (Milbury et al., 2013), and/or greater pressure for performance when not feeling secure in an established relationship.

Findings of this synthesis indicated that dyadic relationships (i.e. relationship quality) are highly influential for women (Altschuler et al., 2009; DaSilva et al., 2008; Ramirez et al., 2009). Partners' demonstration of support (or lack thereof) had a considerable positive or negative impact on the psychosocial adjustment of women post treatment (Altschuler et al., 2009). For example, according to the longitudinal study by Da Silva et al. (2008) that examined only women, those in a committed relationships had better self-image compared to single women after treatment.

Women who felt they were unable to communicate about cancer-related problems with their partner described feelings of loneliness (Ohlsson-Nevo et al., 2011). Some women who were in committed relationships expressed concerns that their partner will not accept their changed sexual self-post treatment (Nowicki et al., 2011). This lack of acceptance often played an important role in ceasing sexual lives of women with CRC (Nowicki et al., 2011; Platell et al., 2004). This finding did not hold for men, as men in one study were substantially more concerned with their decreased sexual drive and changed sexual function, and not their partner’s acceptance of their changed sexual selves (Nowicki et al., 2011). Of note, this study (Nowicki et al.) obtained a low score of quality and therefore the results of this study should be interpreted cautiously.

Mental health. Interestingly, few studies (n=3) reported findings pertaining to the impact of various mental health factors (i.e. anxiety, depression, or distress) on sexuality or sexual health. Da Silva et al. (2008) studied a group of female survivors and uncovered that superior sexual functioning up to one year post treatment was seen in participants with higher mental health scores. Cotrim and Pereira (2008) examined men and women post CRC treatment and uncovered very similar findings. On the other hand, Milbury et al. (2013) found that mental health scores were not significantly associated with altered sexual functionality (i.e. IIEF or FSFI scores). Based on these findings, Milbury et al. (2013) argued that the role of mental health and sexual relations is limited, and the underlying issues in sexual changes appear to be destructive cancer treatment and older age.

Sexual Impact. Men and women alike experienced alterations to sexual function post treatment for CRC, which manifested in both similar and dissimilar ways. This theme is organized to first describe general findings pertaining to the sexual experiences of survivors without ostomies. It then presents ostomy specific findings and outlines sex-specific findings pertaining to the sexual experiences of men and women post CRC treatment.

General sexual impact: Non sex-specific findings. The various authors included in this synthesis used several terms to capture the sexual impact of CRC treatment, all of which refer to changes in sexual function. Some of this terminology included: sexual strain, sexual impairment, sexual changes, sexual distress, sexual satisfaction and cessation of sex. Within this theme, these are all captured under 'sexual impact'.

Engaging in sexual relations (i.e. sexual intercourse) was often challenging for men and women alike because men had erection problems, and women experienced sex differently after surgery with less sensitivity or too much pain for intercourse (Milbury et al., 2013). For many, sex was a challenge; however, both men and women were often able to adjust and note improvements over time (Ohlsson-Nevo et al., 2011). Milbury et al. (2013) found that sexual function among CRC survivors was significantly better when the individual experienced good dyadic adjustment (i.e. relationships adjustment), and positive body image (p<0.0001) (Milbury et al., 2013). In addition, Milbury et al. (2013) found that men and women who had self-reported good sexual function also experienced better overall QOL (p<0.001).

Sexual impact of the ostomy: Non sex-specific findings. The presence of an ostomy compounds the negative impact of treatment on sexual health in CRC survivors, and many studies address the debilitating impact of the ostomy (Alstchuler et al., 2009; Andersson et al., 2010; Grant et al., 2011; Neuman et al., 2011; Neuman et al., 2012; Nowicki et al., 2011; Ramirez et al., 2009). Several studies showed that survivors with ostomies have poorer sexual lives (i.e. sexual activity/dysfunction and sexual capacity) than those without (Cotrim & Pereira, 2008; Da Silva et al., 2008; Neuman et al., 2011; Neuman et al., 2012). Often, changes to sexual life after the formation of an ostomy occur in the form of altogether ceasing or limiting sexual relationships (Nowicki et al., 2011). The ostomy is also correlated to a distinct lack of interest and satisfaction with sexual activity (Neuman et al., 2012). Neuman et al. (2012) reported that 53% of men and women with ostomies “frequently” or “always,” do not enjoy sexual activity, and an additional 20% report that they “occasionally” do not enjoy sexual activity.

Sexual impact: Specific to women. Changes to sexual functionality manifested as distressing for some women. Treatment can alter physiology of the vaginal canal, which caused one women in the study by Ramirez et al. (2009) to express significant emotional and relationship distress:

> Then because of the way it tilts [vaginal canal]…It [husband's penis] never goes in all the way. I have to be able to get my face to where it doesn't show pain, and it's difficult. It really is. [participant near tears.]…When he knows it hurts, it's in

> the back of his mind constantly. I know that that makes it more difficult for him to have an orgasm, because he's worried about me…He's like, `I'm trying'…And then I literally just, I want to roll over and cringe and just die…The one thing that we used to love to do together and it's kind of gone. And it's been gone for a long time. (p. 5)

According to Ramirez et al. (2009), the woman quoted above expressed a sense of great sadness on reflection of her altered sexual capacity. This distress was said to occur in part because sexual intercourse had played such an important role in her relationship with her partner prior to undergoing treatment (Ramirez et al., 2009). On the other hand, other studies found that sexual changes were not a big problem for some women with CRC, and were something they could manage (Andersson et al., 2010; Platell et al., 2004). In fact, 60% of women in the study by Platell et al. (2004) were not at all distressed by their changed sexual function post CRC treatment; however, this study obtained a low score of quality and therefore findings should not be considered in that light.

Some studies indicated that female survivors with ostomies experience poorer sexual health compared to those without (Da Silva et al., 2008; Ramirez et al., 2009), because of the common surgical placement (i.e. the lower abdomen) which can present particular difficulties for sexual activity (Ramirez et al., 2009). Female sexual function was related to the presence of an ostomy, as well as poor mental health scores, and worsening sexual function for up to a year after treatment (DaSilva et al., 2008). Generally, these findings corroborated that women with an ostomy have inferior sexual health and emotional quality of life compared to those without an ostomy (mean 39.6). (DaSilva et al., 2008).

However, not all of the evidence indicated that women with ostomies experience significantly worse sexual health. According to Platell et al. (2004) having an ostomy is not significantly related to sexual changes among female CRC survivors. This study compared sexual health among women with and without ostomies to find that there were no differences them in terms of taking the initiative in sexual activities, satisfaction with their partner as a person and as a lover, views on the importance of sex, thoughts of sex over the past six months, and whether their longing for sex had declined since surgery. It is difficult to know whether the unique and opposing findings of this study are representative of women's sexual experiences post treatment because it obtained a low score of quality and should therefore be interpreted with caution.

Sexual impact: Specific to men. For some men, sexual issues do not become a concern until well after completion of treatment, as often men are concerned with first and foremost tackling the cancer as a main objective (Dowswell et al., 2011). Some recognized changes to sexual capacity as a tradeoff to enhance survivorship, as illustrated in the quote below:

> Well, it was a matter of choices, you know. The operation is necessary to save your life. There is a chance that this can happen; it wasn't like there wasn't another option. So that you needed to take the chance, it was a matter of weighing the risks. The alternative would be a guaranteed active sex life but it would be a matter of only a year or two to live, so you kind of have to go with it (Ball et al., 2013, p. 497).

Men appeared to be challenged by changes to sexual capacity more so than women, and they more often reported sexual concerns (Grant et al., 2011; Schmidt et al., 2005, 2010) including erectile dysfunction and sexual impairment (Schmidt et al., 2005, 2010). Men also experienced worse sexual strain, and sexual and emotional distress caused by impaired sexual function than women (Schmidt et al., 2005, 2010). Further, emotional and sexual distress tended to persist and worsen over time for men, up to 24 months (2 years) after completion of treatment ($p<0.05$) (Schmidt et al., 2005).

Evidence outlining the specific sexual impact of the ostomy in men is very much lacking within the included studies. While several studies examined both men and women and outlined the detrimental impact of the ostomy (Cotrim & Pereira, 2008; Neuman et al., 2011; Neuman et al., 2012; Nowicki et al., 2011; Reese et al., 2012; Wirsching et al., 1975), only two reported these findings according to sex (Cotrim & Pereira, 2008; Nowicki et al., 2011). Findings of one of these studies indicated that the ostomy influenced sexual activity in men on a greater scale than women, because sexual function problems post treatment were found to be more prevalent in men (Cotrim & Pereira, 2008).

Psychosocial Impact. This theme outlines the psychosocial impact of CRC treatment on male and female survivors both with and without ostomies. Sex-specific data and gender-related factors, which influence these experiences are also presented.

General psychosocial impact: Non sex-specific findings. The psychosocial impact of treatment manifested among survivors as alterations to self- esteem, body image (Sharpe et al., 2011) and self-concept (Au et al., 2012). Studies that examined the experiences of survivors showed that changes to body image, alterations to self-concept and self-esteem were common experiences (Cotrim & Pereira, 2008; Neuman et al., 2012; Nowicki et al., 2011; Reese et al., 2013), that can worsen for up to six months after completion of treatment for some (Sharpe et al., 2011). In addition, changes to body image influenced anxiety, depression (Sharpe et al., 2011; Wirsching et al., 1975) and worse emotional QOL in many survivors (Cotrim & Pereira, 2008). Changed body image was also significantly correlated to sexual satisfaction in men and women, indicating that survivors who were able to gain a positive body image experienced satisfaction in their sexual lives ($p<0.001$) (Cotrim & Pereira, 2008).

Psychosocial impact: Specific to men. Sex-specific evidence outlining the impact of the ostomy on men's body image, self-esteem, and self-concept was very much lacking among the included studies. In spite of this lack of evidence, findings of some studies suggested that body image, self-esteem, and self-assessment could be affected on completion of treatment (Nowicki et al., 2011; Wirsching et al., 1975). In one study, changes to self-esteem and deteriorated self-concept were noted as significant reasons for limitation or cessation of sexual contact and relationships in a minority of male participants ($p<0.05$) (Nowicki et al., 2011). The prevalence of low self-esteem and low self-concept was found to be more prevalent for women in this study, and concerned men at much lower level. These findings should be interpreted with caution given the low quality scores attributed to this study (Nowicki et al.).

Sexual changes after treatment, specifically erectile dysfunction (ED), were shown to have profound consequences and to challenge men's identities, body image, and mental health (Dowswell et al., 2011). ED also impacted the quality of the men's relationships, for example, one survivor outlined the impending fall out of his relationship caused by ED:

> We enjoyed a good sexual relationship. The relationship isn't the same, it isn't the same. You can sense it isn't the same and the frustration, you know, it creates frustration. So the relationship, it hasn't broke down yet but I suspect it will (Dowswell et al., 2011, p. 4).

The ways in which men communicated with partners in this study regarding changes to sexuality varied as some men had not even discussed ED with their partners (Dowswell et al., 2011).

Men's sense of self-concept and body image appeared to be closely tied to their erectile function. Men who experienced ED reported depressed mood, distress, and changes to sexual function, which often lead to negative changes in men's sexual self-image (Dowswell et al., 2011) and possibly a loss of intimacy in relationships. Feelings of anxiety and depression are commonly associated with men who experience ED (Ball et al., 2013). Depression can become so severe, that one man in the study by Dowswell et al. (2011) contemplated suicide, and wondered whether life was worth living with ED.

Gender-related factors that influence male psychosocial health. Expressions of masculinity were present in the ways that men outlined stressful consequences from ED that challenged their sense of identity (Dowswell et al., 2011). For example, some expressed feeling incomplete and concerns about a loss of manliness, feeling as though ED impacts their ability to act as a complete and proper man (Dowswell et al., 2011). One survivor in the study by Dowswell et al. (2011) stated:

> I'd like to sort of feel that I was a complete man really and you don't feel like you're a complete man really and it's not a very nice feeling. It's like, I don't know, you can imagine how these women feel who have a breast op, they don't feel they're a complete woman I would imagine. It's like a piece of you is not there, you're not quite a full person are you? (p. 4)

A minority of men accepted erectile difficulties with a degree of silence, avoidance, stoicism, and avoided seeking help for erectile dysfunction (Dowswell et al., 2011). This behavior is in line with hegemonic masculinity. Dowswell et al. (2011) described the findings of this study as highlighting "the dynamic and contextual nature of masculinity …although this also affirms that silence is usually the dominant and safest approach for men adjusting to erectile dysfunction". (p. 6)

Psychosocial impact: Specific to women. Significant alterations to body image, self- esteem, and self-concept are shown to be common side effects of CRC treatment for female survivors with and without ostomies (Au et al., 2012; Cotrim & Pereira, 2008; Da Silva et al., 2008; Grant et al., 2011; Milbury et al., 2013; Neuman et al., 2012; Platell et al., 2004; Ramirez et al., 2009). Body image and self-esteem are said to be two factors which strongly correlate to women's sexuality and quality of life. In one study, women with high body image and self- esteem experienced significantly better sexual functioning, and overall QOL compared to women with lower body image and self-esteem ($p=0.0043$) (Da Silva et al., 2008). Since poor body image is often common among female survivors, these linkages signify that women with negative body image may experience challenges in their sexual lives. In spite of the substantial changes women experience to body image, over time (i.e. one year post treatment), improvements to body image frequently occurred among female survivors (Da Silva et al.).

Women with ostomies faced substantial alterations to their sense of self and body image as they often tended to have worse body image than women without ostomies (Da Silva, 2008). In addition, women with ostomies experienced more problems with body image compared to men with ostomies (Grant et al., 2011). Studies that explicitly focus on the sexual experiences of female CRC survivors with ostomies strongly suggested that alterations to body image manifested in significant ways. Some showed that women's experiences emphasized the distinct challenges women with ostomies encounter with their altered physical bodies (Andersson et al., 2010). Some felt a sense of shock that occurred at the moment of confrontation with the stoma (Wirsching et al., 1975), others felt a sense of alienation toward the ostomy (Andersson et al., 2010), and some felt a sense of disgust and disgrace regarding the ostomy and its various odours (Ramirez et al., 2009). The formation of an ostomy impacted the ways in which women perceived their level of attractiveness, and consequently altered the ways they viewed themselves sexually (Neuman et al., 2012). Both the smell and look of the ostomy caused women to grapple with the ability to feel sexual with their changed sense of body image (Ramirez et al., 2009). A quote from a participant in the study by Neuman et al. (2012) illuminated this finding well:

> Because you don't feel sexy, it is an ugly little thing to have to have on your body. It gets in the way for intercourse, so that I didn't like. You have a bag on you, that bag is never clean… There is always something in it, you feel like there is… you know you are not going to feel attractive. (p. 1120)

Platell et al. (2004) outlined that women who have undergone surgery and ostomy formation were significantly more likely to feel less attractive than those who do not have an ostomy. No studies in this synthesis document this finding for men. From a cultural point of view, Nowicki et al. (2011) argued that outward appearance is more important for self-esteem in women than for men. This finding was supported as challenges with deterioration of self-esteem is a significant reason for limitation or cessation of sexual contact by women with ostomies, and this finding was found on a much lesser scale in men (Nowicki et al., 2011).

Gender-related factors that influence female psychosocial health. For women, expressions of femininity are evidenced in the ways that women experienced their sexual selves in the presence of an ostomy. Women with ostomies experienced difficulties managing their altered sexual lives post treatment, as the pressure to maintain a normative sex life and upholding martial traditions were sometimes prevalent (Ramirez et al., 2009). Regular sexual intercourse was often recognized as an ideal expression of marital intimacy. Ramirez et al. (2009) found that one woman felt a sense of failure owing to her inability to uphold a normative sexual life, a gendered expectation that women should remain sexual and capable to engage in sexual activity to please their partner.

Conversely, Altschuler et al. (2009) outlined that the ways in which women described their sexuality post treatment showed that alterations to their sexual lives did not result in feeling as though their value as a woman was diminished when positive partner support was present. In fact, positive partner support was shown to influence the ways in which women adjusted to the ostomy and their sense of self and body image post treatment. Women described positive support as helping them to feel normal and whole, and not diminished as women in their various roles (Altschuler et al.). While partner support is likely also an influencing factor among men and the ways they identify with their gender, no studies explicitly outlined how men's identities are shaped by their partner.

Single women experienced gender related influences, which impact their sense of identity or sense of self. Gendered assumptions delineate that single women who do not participate in sexual or intimate acts could be considered "un whole" (Ramirez, 2009, p. 9). However, this was shown to be largely untrue as notions of an incomplete self do not adequately capture the true experiences of single women. Remaining celibate and avoiding sexual activity with a partner was often a way for single women to cope with sexual changes and manage the ostomy, because many felt avoiding sexual contact is less complicated than negotiating their altered sexual self with a partner (Ramirez et al., 2009).

Ultimately, both men and women experienced substantial challenges with body image and identity post CRC treatment, however, these manifested in very different ways. For men, challenges with body image and male identity were strongly tied with sexual and erectile dysfunction (Dowswell et al., 2011). For women, body image and sense of femininity appeared to be associated with the presence of the ostomy (Ramirez et al., 2009).

Relational Impact. This theme refers to the relational (or couple) specific experience of CRC survivors. Findings explicit to the relational experiences of sexuality were limited in this synthesis as only two studies specifically examined the experiences of couples after CRC treatment (Ohlsson-Nevo et al., 2011; Reese et al., 2012). Neither of these studies outlined the impact of the ostomy on sexuality, therefore the findings outlined in this theme should be viewed as general, and non-ostomy specific.

Sexual experiences of couples vary, as some couples are able to resume the same sex life post treatment, others will begin a different sex life, and some will cease their sex life altogether. However, both survivors and their partners experienced changes in intimacy within one year after surgery for CRC (Ohlsson-Nevo et al., 2011). Alterations to the patient's physical condition post CRC treatment was shown to profoundly impact the quality of couples' relationships, as well as their ability to maintain sexual intimacy. For some couples, sexual intercourse was replaced by other forms of intimacy and closeness, i.e. sensual touching or trying new sexual activities (Ohlsson-Nevo et al., 2011; Reese et al., 2012).

There is a statistical correlation between sexual function and dyadic adjustment ($p<0.005$), indicating that partnered men and women who are able to collectively adjust to the impact of treatment have better sexual outcomes (Milbury et al., 2013). In a different cross sectional study, survivors who were able to adjust to the sexual and psychosocial impact of CRC treatment (i.e. changes to body image) were shown to experience high marital satisfaction ($p<0.001$) (Cotrim & Pereira, 2008). This indicates that survivors who are able to engage in positive sexual relations and obtain a positive body image will experience better quality of their marital relationships (Cotrim & Pereira).

Couples experience irritation and tension due to the unwanted change in sexual relations caused by the treatment. Some survivors expressed feeling a sense loneliness as they felt unable to discuss their sexual concerns with their partners (Ohlsson-Nevo et al., 2011), and some were hesitant to discuss problems of a sexual nature because they are embarrassed (Reese et al., 2012). Generally, the ways in which couples managed and communicated the side effects of treatment varied. Dialogues about cancer, sharing worries and existential thoughts could strengthen relationships, while others found a sense of mutual togetherness and strength through silence (Ohlsson-Nevo et al., 2012).

Coping with sexual changes. Several studies described ways in which men and women were able (or not) to cope with alterations to sexual health post CRC treatment. These are first introduced according to general (non-sex specific) findings. Afterwards the specific coping experiences of men, women and couples are described.

Response shift. Survivors acknowledged a number of difficulties related to living with CRC. The impact of the cancer was often felt to be less significant when interpreted within the context of the cancer diagnosis and the associated risk of cancer-related mortality (Neuman et al., 2012). Both men and women often acknowledged a shift in perspective resulting in a complete reconceptualization of what QOL, sexuality, and sexual health means after CRC treatment. This shift in perceived overall QOL occured as a recalibration of the survivors' internal standards of what optimal QOL means and/or a reprioritization of values (i.e. the same life goals matter, but have changed in relative importance) (Neuman et al., 2012).

Coping with the side effects of the ostomy. Survivors with ostomies often discussed ways to modify and their outward appearance to conceal the ostomy itself (Grant et al., 2011; Neuman et al., 2011; Neuman et al., 2012). Grant et al. (2011) examined men and women with varying levels of health related quality of life and found that modifying clothing worn was a topic discussed in all of these groups. Specifically, survivors expressed the need to protect the ostomy from being pressed too tightly or irritated during sexual encounters (Grant et al.), and emphasized the need to wear loose clothing to accommodate the ostomy itself so it is not visible to others (Grant et al.; Neuman et al., 2011; Neuman et al., 2012).

Coping: Women's experiences. Some studies indicate that women may have a greater capacity to cope with alterations to sexuality post CRC treatment (Au et al., 2012; Wirsching et al., 1975). Women were shown to have greater resourcefulness compared to men (Au et al., 2012), and possessed a greater ability to manage depression and changes to social life (Wirsching et al., 1975).

Coping with the ostomy and adjusting to a post-surgical body was shown to be problematic for women (Ramirez et al., 2009). Some studies indicate the ostomy adds a more profound level of complexity to coping with sexual alterations (Altschuler et al., 2009; Ramirez et al., 2009). Women often engaged in carefully orchestrated ostomy management techniques prior to engaging in sexual activity. This included various ways to manage altered sexuality through specific techniques to manage intimate relations (i.e. hiding the ostomy bag), or the complete avoidance or cessation of sexual relationships altogether (Ramirez et al., 2009).

Women described coping through reconfigurations of their sexual lives to maintain new ways of intimacy (Ramirez et al., 2009). Other erotic activities, such as oral sex, can replace intercourse. Women who chose to cope with their altered sexual selves by avoiding sexual relations with a partner, sometimes found it effective to reconfigure their sexual lives to include self-stimulation (Ramirez et al., 2009).

While many negative changes occurred in the women's sexual lives related to the ostomy, women felt they could manage these changes if they chose to view them as an opportunity to survive the cancer itself. Often, women viewed the ostomy as a detrimental, foreign object, but over a long period of time (i.e. five years or more) this perspective shifts and changed, and the ostomy was recognized as a chance to live (Altschuler et al., 2009). Some recognized that while the ostomy interferes with sexual activity and the ability to procure a sexual relationship, it was a reasonable compromise for a chance to survive (Ramirez et al., 2009).

A similar attitude, assumed by some women, was a forceful acceptance of their changed sexual lives, and coming to terms with life as a celibate person (Ramirez et al., 2009). Even among those who wished to remain sexual, an outward acceptance of altered sexuality was sometimes present. For example, one woman consistently stated: "you just have to accept it." (Ramirez et al., 2009, p. 7). This was not a perspective readily employed by all women; some were unable to outwardly accept their altered sexuality, and therefore suffered emotional distress (Ramirez et al., 2009).

Some studies found that partners' demonstration of support or lack thereof can have a considerable positive or negative impact on the sexual and psychosocial adjustment of female CRC survivors (Altschuler et al., 2009). Partnered women often recognized the value of a positive relationship and being able to talk about emerging quality of life problems (Andersson et al., 2010), including issues pertaining to altered sexuality and sexual health. Many women attributed their ability to resume sexual activity to a supportive partner who accepted their altered sexual selves (Ramirez et al., 2009). In one study, positive partner support, both instrumental and emotional, was meaningful to women adjusting to altered body image and sexual self-concept and was important in helping women to feel a sense of normalcy post treatment. Women in this study who experienced negative support or a withdrawal of support altogether outlined poor coping and adjustment to changed QOL post treatment (Altschuler, 2010).

Studies showed that single women chose to cope and managed their changed sexuality by avoiding sexual encounters (Grant et al., 2011; Ramirez et al., 2009). This coping mechanism was used because some single women believed that finding a partner would be exceedingly difficult, particularly among those who had an ostomy as a result of treatment. While single women often felt as though celibacy was not necessarily an ideal state or way to manage altered sexuality, it was recognized as less complicated than having to negotiate a transformed body with potential sexual partners (Ramirez et al., 2009).

Gender related factors that influence female coping. Expressions of femininity and feminine values influenced the ways in which women were able to manage alterations to their sexual health. Partner support influenced how women with ostomies coped with their changed perception of femininity and sexuality post treatment. For example, Altschuler et al. (2009) found that many women valued ongoing support from their partners as a significant factor that helped them to feel "normal and whole, and not diminished as women in their various roles" (p. 6). Ultimately positive partner support as a coping mechanism could be related to the ways in which female CRC survivors experienced their femininity and sense of value as a woman post treatment.

Impact of intervention and provision of information: Women. Studies outlined the importance of providing factual, comprehensive information to women regarding the impact of treatment on sexuality and sexual health at a very early stage in the treatment process, in order to expedite and facilitate coping (Andersson et al., 2010; DaSilva et al., 2008; Nowicki et al., 2011; Ramirez et al., 2009).

Over 80% of women in the study by Da Silva et al. (2008) outlined that discussing sexual issues with health care professionals was either extremely or somewhat important to them. Preferably, women wished this conversation would happen prior to surgery and treatment as opposed to after the fact (Da Silva, 2008; Ramirez, 2009). Women also preferred this conversation be initiated by the health professional rather than themselves.

Many women with CRC expressed interest in participating in a sexual intervention to improve QOL (Ball et al., 2011). According to Ramirez et al. (2009) educational interventions provided at well-timed moments in the course of CRC care are suitable for women who express a desire to continue an active sexual life. Only one intervention study was included in this synthesis. It consisted of a telephone intervention focused on enhancing couple-based coping skills, implemented within the first year of treatment. It was shown to have a large effect size in improving female sexual function (≥.80). The intervention also improved intimacy (.20 to .30) and sexual communicaton (≥.80) (Reese et al., 2012).

Coping: Men's experiences. Male survivors have varying capacities to cope and manage alterations to sexuality. Lower resourcefulness was associated with men in one study (Au et al., 2012). This suggests there are possible constraints associated with the male sex that inhibits the ability to tap into personal and social resources to cope with sexual difficulties post CRC treatment.

Some men evaluated and managed their sexual dysfunction within their current life context. For example, some men attributed their sexual problems to their age and the cancer itself, which helped to ease coping and adjustment to altered sexual health (Ball et al., 2013). Another coping mechanism shown to be readily employed by men is the outward acceptance their altered sexual selves, and adjusting their expectations of their sexual lives. This consisted of readjusting sexual performance expectations, and the outward acceptance of new levels of sexual ability (Ball et al.).

The data outlining the impact of partner support on the coping experiences of men was not as strong as it was in women. However one study found that men in a committed relationship demonstrated higher levels of sexual functioning compared to single men (Milbury et al., 2013), which supports the notion that the presence of a partner can influence sexual activity post treatment and by association helps men to manage their altered sexual lives in a positive way.

Gender related factors that influence male coping. Expressions of masculinity were prevalent in the ways to which men chose to manage alterations to their sexual health, particularly the presence of erectile dysfunction (ED). Some men adopted stoic attitudes in line with hegemonic masculinity in an effort to accept their ED (Dowswell et al., 2011). Avoidance of sexual relationships and avoidance of seeking help for sexual problems were ways for some men to cope and manage their sexual changes (Dowswell et al.). Some believed that there is nothing that can be done to help with altered sexuality (Grant et al., 2011), and therefore avoided seeking help from health care professionals (Dowswell et al., 2011).

Impact of intervention and provision of information: Men. Generally, the care men do receive for sexual health problems is thought to be uncoordinated, and appropriate timing of information or intervention for sexual health concerns is recognized as an important contributor to the ways in which men manage and cope with their sexuality (Dowswell et al., 2011). Many men expressed interest in receiving information regarding the potential for sexual changes prior to undergoing treatment (Ball et al., 2013; Dowswell et al., 2011). This is recognized as important because those who were unaware of potential sexual side effects tended to avoid initiating conversations with health care providers regarding sexual symptoms post-treatment, and therefore attributed such symptoms to other factors, such as age (Ball et al., 2013). Men also believed the best time to start a psycho-educational sexual health intervention would be approximately two to three months after completion treatment to allow for adequate time to physically and emotionally heal from the side effects of treatment (Ball et al., 2013).

Coping: The couple experience. Both survivors and their partners often described a change in intimacy after surgery. Some couples discovered new forms of sexual intimacy (Ohlsson-Nevo et al., 2011), which included oral sex, sensual touching, holding hands, kissing, and cuddling.

Impact of intervention and provision of information: Couples. The intervention study included im this synthesis was shown to be largely useful, as 72% of participants found the intimacy enhancing intervention helpful to improve coping through intimate relations (Reese et al., 2012). The intervention introduced specific strategies to help couples cope and manage sexual changes and create new forms of sexual intimacy. These strategies included: doing something to increase sexual desire, engaging in sensual touching and other intimacy-building activities, trying new sexual activities, and trying specific strategies to solve a sexual problem (i.e., using lubricant or Viagra) (Reese et al., 2012). Overall, the intervention produced large to medium effects on nearly all sexual and relationship outcomes, including sexual distress, sexual communication, intimacy, and dyadic adjustment (Reese et al.). To help with the interpretation of the results of this intervention study, it is important to note that it was rated moderate overall quality. This score indicates that the impact of this intervention on sexual outcomes may be skewed.

Grey literature themes. Grey literature was analyzed for general literature findings, as well as, specific recommendations for the management of sexual health issues, including body image, stoma-related complications, sex-specific recommendations, and psychosocial recommendations.

General literature findings. Very little of the literature included within these guidelines provided substantial insight into the sexual experiences of men and women with CRC. However, the literature included in these documents largely supported the themes extracted for the purposes of this synthesis. For example, NICE (2004) reviewed multiple cross-sectional studies comparing survivors with ostomies to those without. Findings suggested that men and women with ostomies experience impaired social functioning, including emotional problems such as depression and loneliness. Sexual issues were also found to be prominent, specifically body image problems which were found in two-thirds of survivors with ostomies, and poor quality relationships with partners which was also more common among those with ostomies (NICE, 2004).

Recommendations for survivors with ostomies. Few guidelines explicitly addressed the management of sexual health issues for men and women with ostomies.

Specific recommendations were briefly mentioned in the NICE (2004) *Improving Outcomes in Colorectal Cancers* guideline. According to these recommendations, men and women who receive an ostomy as a consequence of treatment should be counselled before surgery by a clinical nurse specialist (CNS) with expertise in ostomy care to discuss the implications of the ostomy. After completion of treatment, the same CNS should be available to provide ongoing assistance to survivors pertaining to the management of the various physical, social, sexual and emotional problems associated with the ostomy (NICE, 2004). This guideline may be subject to some bias, as it scored low (40%) in the editorial independence domain of critical appraisal. This indicates that the authors of this guideline did not specify whether the views of the funding body influenced the final recommendations, nor did they explicitly outline whteher the guideline development group possessed any competing interests.

Body image recommendations. Treatment for CRC often causes a change in bowel function, which can be distressing for survivors and have other negative effects, including changes in body image and sexual function (Australian Cancer Network Colorectal Cancer Guidelines Revision Committee, 2005).

The National Breast Cancer Centre and National Cancer Control Initiative (2003), *Clinical practice guidelines for the psychosocial care of adults with cancer* recommended specific management of body image issues for cancer survivors. Generally, this guideline scored high in critical appraisal, however, it was noted to be lacking in descriptions of how the authors systematically identified literature and synthesized evidence for recommendations. Therefore these recommendations outlined in this guideline should be interpreted with caution. According to this guideline, the health professional should inquire into the degree of distress body image changes are causing, as well as the extent to which the survivor avoids situations such as catching sight of themselves or allowing their partner to see them naked or undressing (National Breast Cancer Centre and National Cancer Control Initiative, 2003). This guideline outlined that it is beneficial to sensitively explore body image concerns of survivors as a way to examine the severity and impact of body image on the quality of relationships. Specific open-ended questions are recommended to initiate conversation. For example:

> We don't often talk about it, but cancer certainly changes how we feel about ourselves. Many people tell me that they do have concerns about how they will look, and how they will feel about themselves after treatment. Is this something that you feel you could discuss with me? (National Breast Cancer Centre and National Cancer Control Initiative, 2003, p. 87)

General sexual health recommendations. New Zealand Guidelines Group (2011) *Clinical practice guidelines for the management of early colorectal cancer* and the Australian Cancer Network Colorectal Cancer Guidelines Revision Committee (2005) *Guidelines for the Prevention, Early Detection and Management of Colorectal Cancer* both recommended that the initial psychosocial information that survivors receive should include the possible effects of cancer and its therapy on sexual functioning and marital or partner relationships. Survivors should also receive information about resources available in their community (i.e. support groups), and websites designed to help survivors manage the various side effects of cancer (Jacobsen, 2009). Ongoing support for cancer survivors and their families/caregivers should also be provided (Institute of Medicine, 2008).

The National Comprehensive Cancer Network (NCCN) (2013) recommends that a baseline survivorship assessment for men and women is provided to all survivors and should include specific questions pertaining to sexual function and concerns regarding altered sexuality (NCCN, 2013). Skillful communication on part of the health professional can make it easier for survivors to disclose their sexual concerns. However, many health professionals feel reluctant to broach the subject of sexual problems (National Breast Cancer Centre and National Cancer Control Initiative, 2003). One guideline provided specific recommendations for how providers can initially approach sexuality and sexual health issues with survivors, for example:

> Cancer affects so many parts of people's lives, yet we often don't talk about things that are very important to us. When I ask them, many people admit that the cancer has affected their relationships and sex life – yet they usually don't talk about it unless I ask them. It would be important for me to hear if there are any concerns that you have about issues like this, as there are quite a few ways of helping. (National Breast Cancer Centre and National Cancer Control Initiative, 2003, p. 88)

In guidelines, providers are advised that all survivors should be asked directly if they have any sexual concerns or are experiencing any challenges with sexual health regardless of age. According to the Institute of Medicine (IOM) Guidelines (2008) *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*, providers should not assume that older survivors and their partners are uninterested in sexuality and intimacy. Appropriate referrals should be made if necessary to address sexual issues for men and women of all ages (IOM, 2008). The IOM (2008) guideline scored relatively high in all domains of quality appraisal except for editorial independence (33%). The authors did not specify that the interests of the funding body did not influence the final recommendations; therefore it is possible this guideline was subject to some bias.

The Canadian guidelines released by CAPO (Howell et al., 2011) provided broad sexual health recommendations for all cancer patients. This guideline recommended that health professionals use structured assessment processes (i.e. the PLISSIT model) to assess the sexual health of survivors. Other recommendations included that health professionals should have the capacity provide education and support about changes in sexual health and offer appropriate referrals as necessary. In addition, this guideline specified that survivors should have early access to psychoeducational-based care regarding changes in sexual health and function. This included psychoeducational interventions addressing changes in sexual health during and after treatment, and should involve both the cancer survivor and the survivor's partner (i.e. couples therapy) in order to promote healthy post treatment sexual health and optimal function. Early management of sexual health concerns is strongly encouraged for survivors with prostate or gynecologic cancers, as the management of alterations in sexual functioning is critical during treatment to influence long-term recovery for these patients (Howell et al., 2011). The CAPO guideline obtained high scores in all domains of quality appraisal except for the applicability domain (42%). This indicates that this guideline was lacking in explanations of how to integrate the recommendations to practice, including potential resource implications and ongoing monitoring criteria. In addition it is important to note that this guideline does not include specific management strategies for survivors with CRC, limiting the applicability of the recommendations to this population.

Recommendations for female survivors. The American-based NCCN (2013) survivorship guidelines were the only grey literature source that explicitly outlined sex-based management strategies. This guideline provides step-by-step management criteria for sexual issues including an algorithm that depicts diagnostic evaluation and ongoing assessment techniques that health providers can implement in practice. In general, this guideline is concerned with diagnosing and managing sexual function; however, it does provide useful insights into the management of other sexual or psychosocial health concerns.

Criteria for the management of women's sexual health issues on part of the health care provider includes asking about sexual activity at regular intervals and reviewing past and present sexual activity to ascertain how treatment has impacted sexual function and intimacy. Should a woman experience present issues or concerns for her sexuality, a detailed sexual history should be done and the women referred to psychotherapy, and/or sexual or couples counseling as needed. Ongoing evaluation involves regular check-ins regarding sexual concerns. This guideline also recommended that health providers should offer ongoing encouragement for women to engage in partner communication and open dialogue regarding sexual issues (NCCN, 2013). The NCCN (2013) guideline obtained a high score in many domains of quality appraisal including clarity of presentation as well as editorial independence. It scored low (70%) in the applicability domain because it did not describe barriers and facilitators to its application in practice nor did it address the potential resource and financiual implications of applying the recommendations.

The Australian Cancer Network Colorectal Cancer Guidelines Revision Committee (2005) exerted that body image problems appear to be greater in women. Therefore, specific management may require additional intervention and innovative solutions to manage body image and self-concept particularly among female survivors.

Recommendations for male survivors. Recommendations specific to the management of sexual health for male survivors follows a similar trajectory as women, however the NCCN (2013) guideline is heavily focused on the ongoing management and treatment for erectile dysfunction and associated emotional sequelae. Similar to the management of women, this guideline recommended that sexual health should assessed at regular intervals, including questions pertaining to sexual history, anxiety, depression, and relationship issues. Initial treatment for ED should involve medication intervention and referral to psychotherapy or sexual/ couples counseling as needed. Second tier management includes the reinforcement of referrals if initial management of ED is ineffective (NCCN, 2013).

Exploring relationships. One of the final elements of the narrative synthesis process is to explore relationships within and between included literatures. Ultimately, exploring relationships seeks to uncover the factors that could explain any differences in the facilitators and/or barriers across included studies (Popay et al., 2006), and also helps to identify aspects of a particular body of literature which require further research and development. Strategies used to explore relationships included: examinations of variability between studies, investigator triangulation, qualitative case descriptions, and conceptual mapping as a way to visually represent the findings of the synthesis.

Examining variability. Examinations of variability were critical to understand the relationships between study results and key aspects of the primary studies. Throughout the synthesis, examinations of variability were completed including examining variability in study outcomes, study designs and study settings. Examining variability was also a useful way to understand the various barriers and facilitators that both impeded and facilitated the conduct and findings of the included studies. Examinations of the various barriers and facilitators were helpful to understand how future interventional, observational and qualitative research can and should be conducted to address the sexual health needs of survivors. Ultimately this technique was useful to begin understand the similarities between studies and was helpful to identify gaps and areas for future research.

Examinations of variability: Barriers and facilitators. QSR NVivo 10 was used to code all barriers and facilitators noted by each study. Several studies identified barriers and facilitators which impacted the implementation of the studies and influenced the findings.

Discomfort with discussing sexual issues. Several studies noted the discomfort many participants and non-participants experienced in discussing sexual issues (Dowswell et al., 2011; Platell et al., 2004; Ramirez et al., 2009; Schmidt et al., 2005). This discomfort with discussing sexual health likely influenced the underreporting of sexual issues (Schmidt et al., 2005), or presented challenges for recruitment (Platell et al., 2004). In one study, some women noted that the subject matter was “too personal” to discuss (Ramirez et al., 2009). Platell et al. (2004) stated that discussing sexuality was especially difficult with a group of women who were of older ages (average age 65 years), since women of this age were less likely to discuss matters of sexual health compared to the younger cohort. ED was noted as an uncomfortable and sensitive subject matter for men, which likely influenced their ability to be explicit when discussing sexual issues (Dowswell et al., 2011).

Homogeneity of study samples. Homogeneity of the study participants was often noted as a drawback to the generalizability of the findings among the included studies (Ball et al., 2013; Dowswell et al., 2011; Grant et al., 2011; Milbury et al., 2013; Ramirez et al., 2009). Generally, studies in this synthesis evaluated the sexual experiences of Caucasian men and women, which caused a lack of sufficient diversity of the findings. One study acknowledged that the lack of diversity pertaining to age (Altschuler et al., 2009). The predominantly older age of participants in this study (over 65) is a noted limitation in this study, and the ability to apply these findings to the sexual experiences of younger women presents a challenge for future research. No studies examined the sexual experiences of gay men or lesbian women, another significant limitation to the generalizability of the synthesis findings.

Barriers to the intervention. Barriers to the successful implementation of interventions for CRC patients or couples were outlined in the one intervention study by Reese et al. (2012). Recruitment and retention rates were a significant challenge in this telephone-based intervention study, over 35% of participants did not complete the entire intervention, however Reese et al. (2012) argued that this was comparable to retention rates in other couple-based intervention studies (Baucom et al., 2009; Given et al., 2004; Kurtz, Kurtz, Given, & Given, 2005; Manne et al., 2005). The small sample size and lack of control group in this study contributed to low generalizability of the findings. The use of the convenient telephone based intervention was noted as a substantial facilitator that eased convenience in the implementation of this study (Reese et al., 2012).

Other substantial barriers of the intervention study included the low number of participants included in the effect size calculations for sexual function, which caused the author to recommend that findings should be interpreted with caution (Reese et al., 2012). Lastly, because the author included both sexually active and sexually inactive participants, it is possible that any recommencement of sexual activity artificially inflated the intervention's effects (Reese et al., 2012).

Investigator Triangulation. Triangulation is the consideration of the extent to which heterogeneity in study results may be attributable to the diverse disciplines of researchers. It involves analyzing the data in relation to the context in which they were produced, noting the disciplinary perspectives and expertise of the researchers producing the data. Investigator triangulation works from the understanding that each disciplinary approach may have produced different kinds of findings (Popay et al., 2006). Triangulation facilitated an examination of heterogeneity within the included studies and contributed to understanding gaps and potential areas for future research and development.

For this synthesis, the various disciplines of the primary authors were compiled and categorized. Researchers fell within one of four categories including: research conducted by Registered Nurses (n=7) (Altschuler et al., 2009; Andersson et al., 2010; Au et al., 2012; Cotrim & Pereira, 2007; Grant et al., 2011; Nowicki et al., 2011; Ohlsson-Nevo et al., 2011), research from psychology or behavior sciences (n=8) (Cotrim & Pereira, 2007; Milbury et al., 2013; Ramirez et al., 2009; Reese et al., 2012; Sharpe et al., 2011; Wirsching et al., 1975), research conducted by physicians or CRC surgeons (n=8) (Da Silva et al., 2008; Dowswell et al., 2011; Neuman et al., 2011, 2012; Platell et al., 2004; Schmidt et al., 2005, 2010), and research conducted by experts within oncology/cancer centers (n=5) (Ball et al., 2011, 2013; Milbury et al., 2013; Neuman et al., 2011, 2012) (Appendix I).

Qualitative case descriptions. Qualitative case descriptions (Appendix F) were developed using the existing textual descriptions (developed during the preliminary synthesis). Essentially, the goal of this exercise was to review the included studies in order to gain a deeper understanding of study findings and explore differences between study findings. All textual descriptions were reviewed after completion of the preliminary synthesis, and any information that was missing was added if needed. Qualitative case descriptions were compared to thematic analysis findings, and helped guide the formation of the concept map.

Concept Map. Conceptual mapping was a key strategy to visually represent the sexual experiences of CRC survivors; therefore it was named *sexual survivorship in CRC* (Figure 4.2). It was also a critical strategy to begin the formulation of a conceptual framework to explicate how CRC treatment impacts the sexual experiences of survivors. Conceptual mapping was completed in close consultation with the thesis committee. Ultimately, nine key concepts were generated as a result of the conceptual mapping exercise: a) individual and relationship characteristics; b) treatment; c) relational impact; d) sexual impact; e) psychosocial impact; f) intervention; g) coping; h) quality of life (QOL); and i) sex and gender related factors.

This conceptual map demonstrates that the impact of treatment on sexual health includes three main impacts: relational impact, sexual impact, and psychosocial impact. These three impacts are closely tied to QOL; results showed that if one is affected than often QOL is implicated. Several individual and relationship characteristics shape the overall impact of treatment. Treatment-related factors (such as stoma status) also influence how treatment impacts sexual health outcomes. Coping and interventions for sexual health were shown to dicatate the severity to which survivors experience sexual, relational, and psychosocial outcomes. Lastly, this concept map demonstrates that sex and gender-related factors were shown to mediate the entire sexual survivorship experience after CRC treatment.

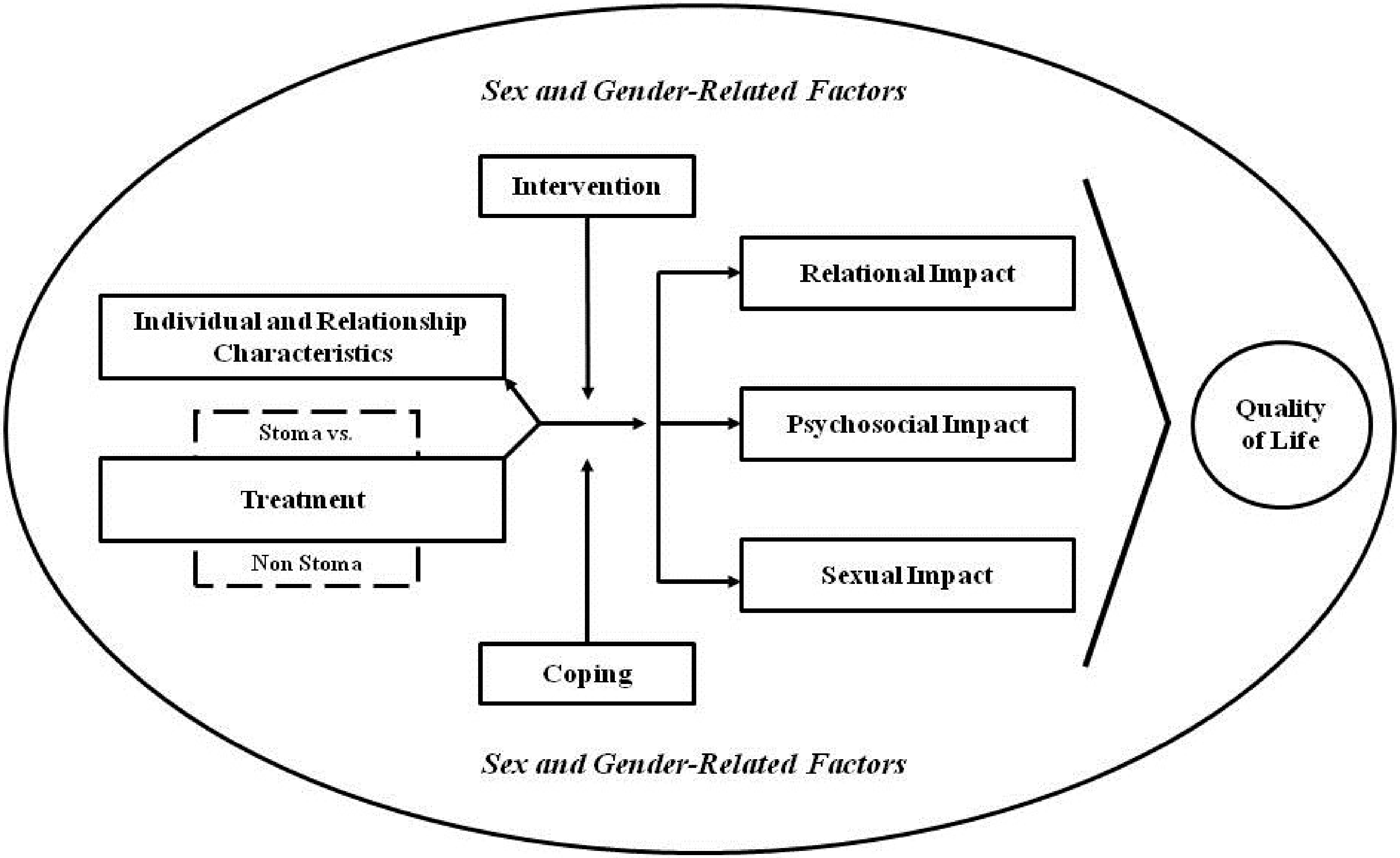

Figure 4.2 Conceptual framework: *Sexual survivorship in CRC*

Assessing Robustness. The final elements of the narrative synthesis process was assessing robustness of the final synthesis product. Strategies to assess robustness included the completion of study appraisal, member checking, and critical appraisal.

Study appraisal. Study appraisal was a useful strategy to judge the overall quality of the qualitative studies and risk of bias in quantitative studies. Generally, study quality ranged from moderate to strong, with very few studies obtaining a low score of overall quality. These ratings added to the overall quality and strength of the final synthesis product, indicating the conclusions are largely based on moderate to strong evidence.

Member checking. Lastly, to enhance the robustness of the completed synthesis, member checking was completed to test the validity of the interpretations developed during the synthesis, and to verify the extent to which they are supported by the primary data. A total of 16 authors were contacted via e-mail. Three authors agreed to speak about their research and were contacted via telephone to discuss their interpretation of the synthesis findings and conceptual map.

Dr. Marcia Grant, primary author of *Gender Differences in Quality of Life Among Long-Term Colorectal Cancer Survivors With Ostomies* (Grant et al., 2011) conducted her research study with male and female long term survivors (five or more years post diagnosis). Data was collected from four separate focus groups using patients from the Kaiser Permanente health regions in the United States: 1) women with high health related quality of life (HRQOL) 2) men with high HRQOL 3) women with low HRQOL and 4) men with low HRQOL. Using the City of Hope Four Dimensional Framework, the focus of this study was to examine general quality of life under four domains: physical, psychological, social, and spiritual. However, sexuality and challenges with body image were grouped under the social domain, and were commonly outlined by survivors as challenges they experienced for 5 + years after diagnosis. Challenges with body image were particularly prevalent for women, especially women with LQOL scores.

There were several findings of Dr. Grant's work that contributed to the findings of this synthesis and the formation of the concept map. Most notably, the long-term impact of CRC treatment was a key finding. This study shows that longer-term survivors (5-30 years post diagnosis) experience ongoing sexual issues, including functional changes and changes to sexual relationships. In addition, this study found that women were more likely to refer to challenges with body image associated with the ostomy, which supports findings of this synthesis that men and women experience changes to their body image in different ways.

Key findings of this synthesis were shared with Dr. Grant in an effort to test the validity of the interpretations developed during this synthesis and to verify the extent to which they are supported by the primary data. Dr. Grant was very supportive of this research, and indicated that the conceptual map specifically resonated with her personal expertise in the area of QOL and colorectal cancer.

Dr. Andrea Altschuler, primary author of *The Influence of Husbands' or Male Partners' Support on Women's Psychosocial Adjustment to Having an Ostomy Resulting from Colorectal Cancer* (Altschuler et al., 2009) focused this study on examining the how partners affect psychosocial adjustment and HRQOL for female survivors with ostomies. This study examined longer term survivors (five or more years since diagnosis). Ultimately this study found that partner support has a considerable positive or negative impact on psychosocial adjustment of long term female survivors with ostomies.

The study findings support the need for couple focused educational/ counseling materials or interventions to teach partners or husbands' skills to provide support, particularly for women whose relationships might not be particularly supportive. These findings have been woven into the concept map, particularly under the concepts *relational impact*, *coping,* and the *individual characteristics*. An explanation of the synthesis findings was provided to Dr. Altschuler, with positive feedback pertaining to the main concepts and overall setup and relationships in the concept map.

Dr. Katherine Duhamel, corresponding author of the study titled *Men's Experience with Sexual Dysfunction Post-rectal Cancer Treatment: A Qualitative Study* (Ball et al., 2013), was the final expert who participated in member checking. This study focused on understand the sexual dysfunction experiences of men following CRC treatment to give insight into how future interventions can be designed and implemented. This study was one of two studies that explicitly examined men; therefore findings of this study were critical in this synthesis to gain insight into men's sexual experiences. Sexual dysfunction (i.e. ED) was very common among men in this study (92%) and many attributed erectile dysfunction to age not the treatment. In addition, this study illuminated the complexities involved in male coping and was key in understanding how future interventions should be structured for men. Ultimately these findings are present under the *sexual impact*, *coping,* and *intervention* theme. A brief review of study findings and a summary of how this research fits into the conceptual framework was provided. Findings of this research resonated with Dr. Duhamel's clinical experience in this area.

Summary of Results

A total of 2,190 citations were identified for screening using the online database search strategies, berry picking, backwards citation tracking, and extensive grey literature searches. After two rounds of extensive screening by two researchers, 36 articles were deemed inclusions in the scoping search. This initial included body of literature represented diverse methods, settings, outcomes and countries of origin. On completion of the scoping search it was collectively decided that the initial pool of 36 articles was not specific enough to the research question, as several of the studies were focused on measuring sexual functionality of men and women and did not include measures to capture how survivors experienced changes to sexuality after treatment. As a result, the inclusion and exclusion criteria were further refined to allow removal of these articles where sexual functionality and dysfunction were the primary foci. The research question was also altered to reflect the search findings and body of literature. Ultimately a total of 31 primary research studies and grey literature sources were deemed final inclusions for this synthesis.

Once final inclusions were identified, all of the sources (primary research and grey literature) underwent rigorous data extraction. Items for extraction included the study author, date of the study, target population, type of treatment, time since treatment, sample, aim, design, theory, outcome measures, findings, and sex-specific findings. Study appraisal was also completed for all primary research. Generally studies scored from moderate quality to high quality.

The next step of this method was to generate a preliminary synthesis (Popay et al., 2006). Analytic strategies used to develop the preliminary synthesis included: textual descriptions, tabulation, groupings and clusters, and thematic analysis. Data were arranged in tables and grouped according to types of outcomes, sex-specific studies, couple-focused studies, ostomy specific studies, and length of survivorship. Grouping studies was a valuable exercise to understand and describe major patterns within and across these groups. Groupings showed that a number of factors influenced how CRC treatment impacts the sexual experiences of men and women, including: sex of the survivor as well as their stoma status. Groupings also showed that both longer and shorter term survivors will experience detrimental sexual side effects post treatment including changes to sexual function, body image, and partnered relationships. Adding further depth to these findings, thematic analysis of the included articles produced five major themes outlining the sexual experiences of men, women and couples: 1) individual characteristics; 2) relational impact; 3) sexual impact; 4) psychosocial impact; and 5) coping.

After completion of the preliminary synthesis portion of this study, relationships between and within the studies were further explored by conceptual mapping, examining variability of study outcomes, study designs and study settings, examining barriers/facilitators, and investigator triangulation. These techniques were helpful to illuminate heterogeneity among the included studies, as well as prevalent gaps in the literature. The conceptual mapping exercise involved linking multiple pieces of evidence from the individual studies to construct a model highlighting key concepts or issues and representing the relationships between these. Findings of thematic analysis, textual descriptions, groupings and clusters, examinations of variability lead to the generation of a theoretical framework that encapsulates the sexual survivorship experiences of male and female CRC survivors. This framework was constructed in close consultation with the thesis supervisor and committee, and includes seven key concepts: individual characteristics, intervention, coping, sexual impact, relational impact, psychosocial impact, and quality of life.

Lastly, robustness of the final synthesis product was established through three techniques. The first of which was study appraisal, completed early in the synthesis, determined that the overall quality of the 21 included articles was moderate to strong, indicating the conclusions drawn from the final product are based on good quality evidence. The second technique was critical reflection. A final technique was member checking where conclusions drawn from this synthesis were distributed to three authors in an effort to test the validity of the interpretations developed during the synthesis and the extent to which the experts in the field of CRC survivorship support them. Generally, member checking was successful in validating the *sexual survivorship in CRC* framework and key findings of this synthesis.

Chapter Five Discussion

The purpose of this research was to examine the impact of CRC treatment on the sexual experiences of survivors and to explore how these experiences are shaped by sex and gender related factors. To the best of my knowledge, this study is the first of its kind to use knowledge synthesis methodology to explore the literature pertaining to the sexual impact of treatment. This research is also unique because it uses a sex and gender based framework (Spitzer, 2006) – an underused framework in cancer literature (Moynihan, 2002) – as a way to understand how sex and gender related factors shape the sexual experiences.

The findings of this narrative synthesis indicate that the impact of CRC treatment on sexuality and sexual health is substantial and complex. Presently, there are no explicit frameworks that theorize how survivors experience their sexual health after treatment. This research resulted in the formulation of a conceptual framework, named *'sexual survivorship in CRC'*. This framework provides a conceptual overview of how treatment impacts sexual health, psychosocial health, quality of relationships, overall quality of life, and the ways in which sex and gender related factors shapes sexual outcomes (Figure 4.2). It is expected that this framework will be a useful tool to inform future research.

The defining characteristic of a narrative synthesis is the textual description that results, telling the story of multiple types of evidence to illuminate why something needs to be done in research and practice (Popay et al., 2006). This chapter discusses the framework developed in this synthesis and situates the findings in light of what is already known about the sexual experiences of CRC survivors.

Review: What is the Impact of Treatment?

Findings indicate that treatment exerts detrimental impacts on three main aspects of survivors' sexuality. These three aspects are the sexual impact, psychosocial impact, and relational impact.

Sexual impact. For men, the main sexual impact of treatment is erectile and/or ejaculatory dysfunction, whereas women can experience the decreased ability to achieve orgasm (Havenga et al., 1996), and decreased vaginal lubrication, which can result in dyspareunia (Daniels, Woodward, Taylor, Raja, & Toomey, 2006).

Several studies in this synthesis that included both men and women noted that men experience worse sexual function and more distress related to altered sexual function compared to women (Milbury et al., 2013; Schmidt et al., 2005; Schmidt et al., 2010). This finding is supported by a large cross sectional study that examined 794 men and women post CRC treatment, which also found that men experienced worse sexual function post operatively compared to women (Jayne et al., 2005).

Psychosocial impact. Colorectal cancer treatment significantly impacts psychosocial health. Psychosocial health encompasses a broad spectrum of factors including physical, social, cognitive, spiritual, emotional, psychological, and role functioning (Legg, 2011). Findings of this synthesis revealed that the psychosocial impact in relation to sexuality manifested as alterations to self- esteem, body image, and self-concept. This synthesis found that alterations to self-esteem were common for women and men with ostomies (Da Silva et al., 2008; Sharpe et al., 2011; Wirsching et al., 1975). Findings also supported that men and women can experience aspects of psychosocial health in different ways. Erectile dysfunction (ED) often resulted in changes to body image that impacted men's identities (Dowswell et al., 2011). There were no studies identified in this synthesis that examined the impact of the ostomy on men's body image or self-concept, however, some studies found that women's changed body image was strongly associated with the presence of an ostomy (Altschuler et al., 2009; Ramirez et al., 2009). These sex-specific findings align well with the general cancer literature. According to Franzoi (1995), men and women are socialized to different interpretations of their body. For women, the body is conceptualized "as an object of discrete parts that others aesthetically evaluate" (p. 417). For women with CRC, this synthesis found the presence of an ostomy appliance impacts women's personal self-image as well as perceived attractiveness to others (Neuman et al., 2011; Manderson, 2005; Platell et al., 2004). Conversely, for men the body is conceptualized "as a dynamic process where function is of greater consequence than beauty" (Franzoi, 1995, p. 417). In men with prostate cancer, Harrington (2011) argued that changes to symbolic, gendered body parts inflicts body image disturbances in survivors. Harrington supported findings of this synthesis that changes to body image are closely tied to functional changes such as erectile dysfunction (ED) and ejaculatory dysfunction.

Relational impact. The impact of cancer and cancer treatment extends beyond the person with cancer (Hawkins et al., 2009), and often takes a toll on intimate relationships (Fergus & Gray, 2009). Couples are challenged to return to a normal life post treatment (Silver, 2004), and one of the tasks couples face is resuming a sexual relationship (Manne & Badr, 2008). Studies in this synthesis showed that the detrimental impact of treatment can cause survivors to experience changes to relational aspects of health including changes to sexual communication (Reese et al., 2012), intimacy

(Ohlsson-Nevo et al., 2011), dyadic adjustment (Au et al., 2012; Cotrim & Pereira, 2008; Milbury et al., 2013; Nowicki et al., 2011; Reese et al., 2012), partner support (Altschuler et al., 2009; Ramirez et al., 2009), and marital satisfaction (Cotrim & Pereira, 2008; Milbury et al., 2013).

Review: Factors that Impact Sexual, Psychosocial and Relational Health

As reflected in the *sexual survivorship in CRC* framework, the sexual, psychosocial and relational impact of CRC treatment are highly influenced by individual and relationship characteristics, treatment (i.e. precense of a stoma), coping strategies, and interventions to promote sexual health.

Individual and relationship characteristics. Findings of this synthesis suggested that there are various individual and relationship characteristics that influenced the ways in which CRC treatment impacts relationships, psychosocial and sexual health, and overall QOL of survivors. For example, this synthesis found that age is an individual characteristic that negatively impacted sexual function post treatment.

Synthesis findings also suggested that relational factors such as presence of partner support and partner status also impact sexual, psychosocial, and relational outcomes post treatment (Altschuler et al., 2009; Milbury et al., 2013; Ramirez et al., 2009). General cancer literature supports these linkages, as the benefits of a stable, satisfactory relationship are prevalent for both men and women. For example, men who report high levels of relationship satisfaction are more likely to report sexual fulfillment compared to those with low levels of relationship satisfaction (Cameron et al., 2005; Rowland et al., 2005). Research findings also show that women who report having a supportive relationship are able to maintain feelings of sexual desirability after treatment

(Manderson, 2005). Studies also indicate that high levels of martial satisfaction are linked with positive psychosocial adjustment for CRC survivors (Northouse et al., 2000), and spousal support has been shown to be a key component of recovery from cancer treatment (Emslie et al., 2009; Piwonka & Merino, 1999).

Treatment. The synthesis found that the type of treatment can play a substantial role in influencing sexual health outcomes. In particular, survivors who underwent surgery for the placement of the ostomy often experienced more negative outcomes because several studies in this synthesis showed that presence of an ostomy compounds the negative impact of treatment on sexual health in CRC survivors (Alstchuler et al., 2009; Andersson et al., 2010; Grant et al., 2011; Neuman et al., 2011; Neuman et al., 2012; Nowicki et al., 2011; Ramirez et al., 2009). This is supported by cancer literature; several studies have found that survivors with ostomies experience worse sexual function post treatment (Lange et al., 2009; Ross et al., 2007; Traa et al., 2012). Synthesis findings also highlighted some sex and gender-specific experiences pertaining to the ostomy. Findings suggested that women with ostomies faced substantial alterations to their sense of self and body image (Altschuler et al., 2009; Da Silva, 2008; Ramirez et al., 2009). According to one study, women with ostomies in one study experienced more problems with body image compared to men with ostomies (Grant et al., 2011).

Coping. The synthesis also revealed that coping strategies also influenced the ways in which men and women experienced the sexual, psychosocial, and relational impact of treatment. Cancer literature outlines that survivors' coping strategies can include components of logical analysis, positive reappraisal, guidance/support, problem solving, cognitive avoidance, and resigned acceptance (Moorey, Frampton, & Greer, 2003; Chan, Ng, Lee, Ngan, & Wong, 2003). This synthesis found that CRC survivors engaged in similar strategies, which is not surprising as the general cancer experience often involves similar situations with which to cope, such as painful symptoms, uncertainty for the future, and changes to relationships (Dunkel-Schetter, Feinstein, Taylor, & Falke, 1992). Synthesis findings revealed that common coping strategies utilized by CRC survivors to cope with sexual changes are: management of sexual issues by attributing issues to other factors (such as older age), avoidance of sexual issues, and reconfigurations of sexual QOL. These coping strategies can either improve or impede the sexual, psychosocial, and relational impact of treatment.

There were some sex-specific ways and gender-related influences that influenced the ways in which men and women were able to cope with sexual changes after treatment. For men, coping with ED was a common struggle. Some men wanted to actively engage in treatment opportunities to help improve erectile function while others engaged in avoidant stoic attitudes to cope with erectile changes (Dowswell et al., 2011). Women on the other hand, struggled to cope with alterations to body images and changes to their perceieved femininity. Many women tended to value positive support from partners to help them manage and reconcile their changed outward appearance and perceieved sense of self (Altschuler et al., 2009; Ramirez et al., 2009).

Interventions to promote sexual health. One of the most important contributions of the behavioral sciences during the last 40 years has been the development of effective interventions to facilitate positive psychosocial adjustment in cancer care (Redd, Montgomery, & DuHamel, 2001). Substantial evidence now exists that supports the usefulness of interventions in reducing distress in cancer patients (Guo, 2013), improving recovery of sexual health (Redd et al., 2001), and improving overall quality of life (Osborn, Demoncada & Feuerstein, 2006). The one intervention included in this synthesis used a psycho educational, intimacy enhancing intervention, which was shown to be highly effective and improved sexual, psychosocial, and relational outcomes for coupled survivors (Reese et al., 2012).

The effectiveness of the intervention study included in this synthesis could be predicated on the fact that it was focused on both the patient and partner (Reese et al., 2012). According to a systematic review by Regan et al. (2012), couple-focused interventions are significantly more efficacious because patients and partners manage cancer in a mutual way, often as an interdependent system; therefore interventions targeting the couple as a unit are often of high relevance for survivors who are in a relationship. A second component of the intervention study that may have contributed to the success was that it utilized elements of psychoeducation to improve intimacy among couples. Psychoeducation combines education with elements of psychological therapy, and has been found to substantially improve frequency of sexual activity (Capone, Good, Westie, & Jacobson, 1980), improve self-esteem (Helgeson, Leopore, & Eton, 2006), increase compliance with sexual rehabilitation, and improve overall sexual knowledge (Robinson, Faris, & Scott, 1999) in those with cancer.

Linkages among the Key Concepts

As reflected in the *sexual survivorship in CRC* framework, this synthesis shows that nine concepts (individual and relationship characteristics, treatment, relational impact, psychosocial impact, sexual impact, QOL, intervention, coping, and sex and gender related factors) are interconnected and influence one another in several ways.

This section will describe these linkages and situate these findings in light of what is already known about the sexual experiences of CRC survivors.

Linkages: Sexual, psychosocial, and relational impacts of treatment. The sexual, psychosocial, and relational impacts of CRC treatment are all closely related; in fact, findings of this synthesis show that if one aspect of sexuality is affected, often the other two aspects are also implicated (Figure 4.2).

The sexual influences the psychosocial. Both the sexual impact and psychosocial impact are linked because body image is linked to sexual satisfaction in men and women with CRC, indicating that survivors who have a positive body image will often experience satisfaction in their sexual lives (Cotrim & Pereira, 2008). This synthesis also found that negative body image is linked with poor sexual function in women (Da Silva et al., 2008; Platell et al., 2004). Similar findings have been well outlined in research that has examined survivors with other cancers. For example, according to Taylor, Basen-Engquist, Shinn, and Bodurka (2004) body image plays a substantial role in the sexual functioning of gynecological survivors. In addition, in the general population, there is also a relationship between positive body image and good sexual function. For example, in a recent study by Pujos, Meston, and Seal (2010), 154 women participated in an Internet survey that assessed sexual functioning, five domains of sexual satisfaction, and several body image variables. Results indicated significant positive relationships between sexual functioning, sexual satisfaction, and all body image variables, indicating that several aspects of body image predict sexual activity and satisfaction in women.

Studies in this synthesis showed that alterations to sexual function after treatment influenced psychosocial health and sense of body image and male identity, as findings suggest that men's sense of self concept and body image are closely tied to their erectile function (Dowswell et al., 2011). According to the cancer literature, men with ED often report depressed mood, distress, and changes to sexual function, which often leads to negative changes in men's sexual self-image (Andersen, Cyarnowski, & Espindle, 1999; Ball et al., 2013; Nelson, Deveci, Stasi, Scardino, & Mulhall, 2010; Nelson, Mulhall, & Roth, 2010).

The sexual and psychosocial impact the relational. According to synthesis findings, changed sexual function or body image influenced the quality of couples' relationships. For example, partnered survivors who were able to attain a positive body image post CRC treatment experienced greater marital satisfaction (Cotrim & Pereira, 2008). Research shows that sexual satisfaction contributes to relationship stability (Sprecher & Cate, 2004). Synthesis findings showed a strong relationship between sexual satisfaction and marital satisfaction in patients with CRC (Cotrim & Pereira, 2008), as well as a correlation between sexual function and dyadic adjustment ($p<0.005$), so that survivors in committed relationships with high relationship satisfaction were able to collectively adjust to the impact of treatment, and experienced better sexual function outcomes post treatment (Milbury et al., 2013).

Generally, sexual intercourse is recognized as an integral part of most romantic relationships (Sprecher, Christopher, & Cate, 2006). In fact, some studies in this synthesis suggested that some survivors who were unable to engage in intercourse experienced substantial problems in their relationships (Dowswell et al., 2011; Ramirez et al., 2009). In one of these studies, some men felt as though ED caused deterioration of their relationships (Dowswell et al., 2011). Similarly, another study in this synthesis found that some women with dyspareunia expressed relationship distress resulting from changed function post treatment (Ramirez et al., 2009). Overall, this synthesis found that sexual function changes were related to quality of the relationship or relationship distress.

Linkages: Sexual, psychosocial, relational, and QOL. In addition to the linkages among the three areas (sexual impact, psychosocial impact, and relational impact) the synthesis revealed that QOL was an important concept to capture in the framework because several studies showed QOL is highly influenced by any changes to sexual function, body image, and quality of relationships (Cotrim & Pereira, 2008; Da Silva et al., 2008; Milbury et al., 2013; Neuman et al., 2011; Schmidt et al., 2005, 2010; Sharpe et al., 2011).

Literature supports the close relationship between QOL and aspects of sexuality and sexual health. While there is some debate regarding the meaning of the term QOL (Hunt, 1997), generally, it is recognized as a multidimensional construct incorporating (at minimum) four broad domains: physical health, psychological health, social relationships, and environment (World Health Organization Quality of Life Group, 1995). According to WHO QOL (1995) sexuality and sexual health are interwoven within the physical domain (sexual function), the psychological domain (body image, self-esteem), and the social relationships domain (personal or intimate relationships) of QOL. Literature specific to CRC supports the idea that sexual, psychosocial, and relational impacts of treatment are key QOL issues that are often measured in research examining CRC survivors (Sprangers, 1995). This synthesis found that at least three tools exist to assess the impact of treatment on QOL with components of sexuality and sexual health as critical components to be measured (Baxter et al., 2006; Grant et al., 2004; Sprangers, Te Velde, & Aaronson, 1999). Two studies administered The City of Hope Quality of Life (COH-QOL)-Ostomy questionnaire, which is designed to assess quality of life in CRC survivors (Altschuler et al., 2009; Grant et al., 2011). It contains several questions pertaining to sexual activity and body image as QOL components (Grant et al., 2004). Two studies in this synthesis (Neuman et al., 2011; Neuman et al., 2012) implemented the validated stoma quality of life survey (SQOLS) complied by Baxter et al. (2006) includes one scale that is specific to measuring sexual function and body image as aspects of QOL. In addition, the European Organization for Research and Treatment of Cancer (EORTC) released the EORTC QLQ-CR38 scale, a standardized QOL questionnaire tailored to the needs of CRC survivors that includes a sexual functioning scale, a body image scale, and a sexual problems scale (Sprangers, Te Velde, & Aaronson, 1999). Several studies in this synthesis administered this questionnaire (Cotrim & Pereira, 2008; Da Silva et al., 2008; Milbury et al., 2013, Neuman et al., 2011; Schmidt et al., 2010). Ultimately, general literature and findings of this synthesis strongly supports the close relationships between QOL and sexual function, body image, and quality of relationships, indicating the QOL is an essential concept to capture as it relates to survivors sexual experiences.

Linkages: Factors that impact the sexual, psychosocial, and relational. Most of the studies in this synthesis examined the individual sexual experiences of cancer survivors. This is not surprising as cancer research has traditionally focused on the impact of cancer on individual survivors; increasingly over the last 20 years researchers and clinicians working in oncology have recognized the importance of viewing cancer within the relational context, and significant attention has been paid to the experiences of both survivors and their partners (Girgis & Lambert, 2009; Manne & Badr, 2007). Overall, the body of literature that examined the relational (or couple-based) experience of CRC is not as extensive as other cancers, such as breast or prostate for example.

This synthesis found relationships between several individual, relational, and treatment related factors that influenced the sexual, psychosocial, and relational impact of treatment. Specifically, factors such as physical characteristics (i.e. age, sex, mental health), treatment factors such as stoma status, and gender-related factors, all impacted sexual, psychosocial, and relationship outcomes post CRC treatment (Alstchuler et al., 2009; Andersson et al., 2010; Da Silva et al., 2008; Dowswell et al., 2011; Grant et al., 2011; Neuman et al., 2011; Neuman et al., 2012; Nowicki et al., 2011; Ramirez et al., 2009; Reese et al., 2012; Schmidt et al., 2005, 2010). Relational characteristics such as partner status and partner support were also factors that exerted an effect on the sexual, relational, and psychosocial impact of treatment (Altschuler et al., 2009; Milbury et al., 203; Ramirez et al., 2009). In the subsequent paragraphs I will review these factors in further detail.

Age. Synthesis findings revealed that advancing age was an important factor that influenced worse sexual function after CRC treatment (Milbury et al., 2013; Schmidt et al., 2005; Schmidt et al., 2010). According to literature, advancing age may influence a decline in sexual function because often aging and illness impact mobility and tolerance to physical activity, reducing sexual desire (Camacho & Reyes-Ortiz, 2005). Studies in this synthesis showed that men and women with CRC who are over 70 have worse sexual functioning compared to younger survivors (Milbury et al., 2013; Schmidt et al., 2005; Schmidt et al., 2010). Similar findings were noted in a large four-year prospective study that examined 329 CRC survivors. In this study, sexual functioning was noted as consistently worse for patients greater than 70 years of age than for those who were younger (Engel et al., 2003). These findings are also similar to studies that have examined the general population. In a large cross sectional study that examined sexual function and advancing age in over 3000 men and women between the ages of 57 and 85, the likelihood of engaging in partnered sex was shown to decline steadily with age. These findings support that age is a variable that is associated with changes to sexual function in both the general population as well as cancer survivors.

According to the findings of this synthesis, while older survivors experienced more changes to sexual function, they may not be as distressed by it compared to younger survivors. Studies showed that younger survivors identified more emotional distress about their changed sexual function compared to older survivors (Milbury et al., 2013; Ramirez et al., 2009; Schmidt et al., 2005, 2010). This is in line with other literature; according to a qualitative study that compared the cancer experiences of survivors according to age, younger survivors were often more likely to emphasize the impact of cancer on their lifestyle and career, while survivors of older ages (65 years and older) were more likely to accept that the changes were a part of life (Foley et al., 2006).

However, not all studies in this synthesis found that older survivors passively accepted sexual changes. Younger survivors in the study by Schmidt et al. (2010) were more emotionally affected by impaired sexual function, however, older survivors (men and women greater than 70) also recognized the importance of sexual intimacy as a part of life, and experienced a sense of loss as a result of their changed sexual function (Schmidt et al.). Lindau et al. (2007) found that even though sexual function decreased with age in the general population, many older adults highly valued intimacy with their partner. Ultimately evidence in this synthesis indicated that advancing age influenced the sexual impact of CRC treatment; however, this is not conclusive. The sexual experiences of CRC survivors should not be assumed nor discounted solely based on age.

Psychological health. This synthesis produced some conflicting results pertaining to the linkages between mental health and the sexual and psychosocial impact of treatment. One study in this synthesis that examined both male and female survivors using the Center for Epidemiological Studies-Depression (CES-D) Scale (Radloff et al., 1977) and The Brief Symptom Inventory-18 (BSI-18) (Zabora et al., 2001) found that mental health scores were not at all associated with sexual functionality (Milbury et al., 2013). Based on these findings, Milbury et al. (2013) argued that the influence of mental health on sexual relations is limited. On the other hand, studies in this synthesis that used the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983) to measure anxiety and depression in survivors, found that changes to body image are related to individual mental health, and often survivors who experienced body image changes experienced high levels of anxiety and depression (Sharpe et al., 2011; Cotrim & Pereira, 2008). These findings are supported in the general literature as well as cancer specific literature. For example, one large, cross sectional study that examined 228 adults found that body image dysfunction was strongly related to social anxiety for both men and women (Cash, Thériault, & Annis, 2004). In another study that examined breast cancer survivors, depression and anxiety were both found to be significantly correlated to negative body image in moderate sample of 120 women (Karakoyun-Celik et al., 2010). Lastly, one study that examined body image alterations and corresponding anxiety in head and neck cancer patients after surgery found that alterations to body image were correlated to anxiety levels, so that individuals who experienced better body image experienced lower anxiety compared to those with poor body image (Dropkin, 1999).

Sex-specific data in this synthesis indicated there is a relationship between sexual function and mental health in both men and women. According to findings, feelings of anxiety and depression were commonly associated with men who experience ED (Ball et al., 2013; Dowswell et al., 2011). General literature shows that men who experience sexual functional changes (i.e. erectile dysfunction) also experience poor mental health outcomes (Sanchez-Cruz et al., 2003), including high anxiety (Sugimori et al., 2005), and depression (Araujo, Durante, Feldman, Goldstein, & McKinlay, 1998). One longitudinal study in this synthesis measured mental health in a group of female survivors using the Short Form-36 (SF-36) (Ware & Sherbourne, 1992) found that superior sexual functioning was common in participants with higher preexisting mental health scores (DaSilva et al., 2008). This indicates there is a close relationship between preexisting mental health and female sexual function. This is also a common finding in cancer research that examines female survivors. According to a study examining 232 women with ovarian cancer, higher preexisting anxiety was associated with greater sexual discomfort and lower sexual frequency post treatment. Higher depression was also associated with greater discomfort during sex and lower sexual frequency for women in this study (Taylor et al., 2004).

Ultimately findings from this synthesis as well as findings in the literature support the relationship between mental health and better sexual and psychosocial outcomes for CRC survivors; however there is some conflicting evidence. Some of the inconsistencies present in this data could be attributed to the wide variety of scales and tools used across studies to measure mental health outcomes within the included body of literature.

Treatment: Stoma Status. According to researchers, an estimated 18%–35% of CRC survivors receive temporary or permanent intestinal ostomies as part of their cancer treatment (Gastingern et al., 2005; Schmidt et al., 2005; Sun et al., 2013). According to the *sexual survivorship in CRC* framework, the creation of a stoma as a result of treatment is linked to worse sexual, psychosocial, and relational outcomes post treatment. For example, studies in this synthesis found that survivors with ostomies had significantly lower HRQOL scores (Cotrim & Pereira, 2008), more pronounced disturbances to sexual function (Cotrim & Pereira, 2008), as well as higher levels of anxiety, depression, loneliness, and distress (Da Silva et al., 2008; Sharpe et al., 2011; Wirsching et al., 1975) compared to survivors without ostomies. These findings align well with other research that has examined global QOL of CRC survivors. For example, according to a systematic review by Jansen, Koch, Brenner, and Arndt (2010), CRC survivors with ostomies had worse global health scores, poorer physical functioning, and more sexual function problems for up to five years post treatment compared to those without ostomies.

There are some inconsistencies in the literature about the degree to which survivors with ostomies experience changes to their psychosocial health. Research indicates that both male and female survivors with ostomies experience changes to their body image (Brown & Randle, 2005; Jenks et al. 1997; Persson & Hellstrom, 2002; Salter, 1992). However, studies included in this synthesis found that an ostomy was only shown to be highly associated with women's body image and self-concept, not men. Specifically, the formation of an ostomy was shown in many studies to impact the ways in which women perceived their attractiveness, and consequently altered the way women view themselves sexually (Andersson et al., 2010; Neuman et al., 2011; Ramirez et al., 2009; Wirsching et al., 1975). There were no studies identified in this synthesis that extended understanding of the impact of the ostomy on men's body image or self-concept. This could be because the majority of the studies that examined body image included only women, suggesting some gender bias.

However, some research does support the idea that women with ostomies will experience worse body image when compared to men. For example, Nordstrom & Nyman (1991) reported from their interviews with urostomists that women considered body-image-related issues to be the most negative aspect of the urostomy; men in this study were substantially less concerned with their body image. Another study by Kilic, Taycan, Belli, and Ozman (2007) found that women who had ostomies for multiple illnesses experienced significantly worse body image disturbance after surgery in comparison to men. Based on these findings, it seems that women may experience more body image disturbance with an ostomy, although more research is needed to understand men's experiences in the context of CRC.

Sex-related factors. In this synthesis, the use of a sex and gender-based framework (SGBA) (Appendix A) was helpful to understand the sex-related factors that may impact sexual health. Findings of this synthesis showed that an individual's sex plays a substantial role in influencing their sexual experiences post treatment. The use of a SGBA framework was also a novel way to gain a deeper understanding of how gender shapes survivors' sexual experiences, specifically how men and women culturally respond to changes to sexual, psychosocial, and relational health.

The most notable physiological differences between the sexes are contained within the reproductive organs (WHO, 2013). CRC treatment is unique in that it almost always impacts the physiology of reproductive organs for males and females, albeit in different ways. This synthesis revealed compelling evidence that supported that the anatomical changes (i.e. erectile dysfunction and dyspareunia) caused distinctive, sex-specific sexual experiences. For example, synthesis findings revealed that men often experienced ED, which results in more sexual function-related concerns (Grant et al., 2011; Schmidt et al., 2005; Schmidt et al., 2010) including cessation of sex (Nowicki et al., 2011), sexual impairment, and sexual strain compared to women (Schmidt et al., 2005; Schmidt et al., 2010). Other research shows similar findings. For example, in a systematic review by Traa, DeVries, Roukema, and Oudsten (2012), which reviewed over 80 studies to determine the prevalence of sexual dysfunctions in patients with colorectal cancer, a trend was found that indicated men experienced more sexual dysfunction compared to women for up to two years after surgery. This indicates that CRC treatment impacts men's sexual function on a greater scale than women.

Less is known about the sexual impact of CRC treatment in women (Milbury et al., 2013), because female sexual dysfunction is recognized as more challenging to quantify (Rosen et al., 2000). Studies included in this synthesis generally found that women were not as concerned with their altered sexual function and changed sexual anatomy compared to men (Andersson et al., 2010; Grant et al., 2011; Nowicki et al., 2011; Platell et al., 2004; Schmidt et al., 2005; Schmidt et al., 2010). These findings may not be entirely accurate as some measures of sexual function are not always representative of female sexual function. According to Basson et al. (2004), female sexual function is not as linear as male sexual function, because in many instances female sexual dysfunction is a consequence of physical or anatomical changes as well as psychosocial and/or interpersonal difficulties. This aligns well with findings of this synthesis that supported positive body image and interpersonal relationships (i.e. partner support) are linked to optimal sexual function in women (Altschuler et al., 2009; Andersson et al., 2009; Cotrim & Pereira, 2008; Da Silva et al., 2008; Ramirez et al., 2009).

Overall, based on the findings of this narrative synthesis, it is evident that men and women have unique, sex-specific sexual experiences post CRC treatment; however more research is needed to understand the complexities of female sexual dysfunction after CRC treatment and how contextual and relational factors can impact these experiences. Findings of this synthesis help to understand the sex-specific experiences of men and women, and also help to confirm that the physiological and anatomical differences between men and women can shape the ways in which they experience their sexual, psychosocial, and relational health post treatment.

Gender-related factors. Masculinity and femininity can mean different things for individuals. From a constructionist perspective, women and men think and act in the ways that they do because of conceptualizations about femininity and masculinity that are highly influenced by their culture (Pleck et al., 1994). This is to say that gender is constructed based on one’s culture and as a consequence can shift and vary, depending on the time and context (Kimmel, 1995). Few studies in this synthesis explicitly accounted for the ways in which culture influences masculininity and feminininty; however, one study found that cultural influences of the stoma impacted the ways in which women evaluated their sexuality and femininity after treatment (Ramirez et al., 2009). This is supported in the literature, as the presence of an ostomy has been said to violate the cultural notion that a component of adult hood is to maintain control of bodily functions (Manderson, 2005). Given our culture’s aversion to feces, it is often challenging for women to partake in sexual intercourse, become aroused, and desire sex (Ramirez et al., 2009). More research is needed to see if the cultural influences of the stoma impact men and masculininity post treatment because no studies in this synthesis addressed this connection.

Findings of this synthesis also suggested that an individual’s personal belief of what constitutes masculinity or femininity is a considerable factor that shaped the ways that men and women experienced their sexual, relational, and psychosocial health post treatment. In addition, the sexual, psychosocial, and relational impact brought on by CRC treatment influenced how women and men perceive their gender identities. Studies in this synthesis that accounted for the ways in which masculinity or femininity can shape the sexual experiences of survivors were all qualitative studies (Altschuler et al., 2009; Dowswell et al., 2011; Ramirez et al., 2009).

Femininity and sexuality. According to synthesis findings, the values women hold regarding their femininity and sexuality affected the ways they experienced the psychosocial and sexual impact of treatment. For example, this synthesis found that some women experienced alterations in the ways that they perceive their bodies and sense of sexuality and femininity after receiving an ostomy (Ramirez et al., 2009; Neuman et al., 2011). Specifically, in one study, many reported concerns that the presence of the ostomy impacted their sense of body image, and sense of attractiveness to others (Ramirez et al., 2009). Similar findings were shown in a study by Manderson (1999) that examined the impact of cancer surgery on gender identity of survivors from multiple cancers. This study found that ostomy surgery was closely associated with the loss of femininity. Participants felt less sexually attractive or desirable due to the ostomy and felt that others perceived them in the same way (Manderson, 1999).

Many women with ostomies are particularly concerned about how their changed physical and sexual self is perceived by their partner (Altschuler et al., 2009; Ramirez et al., 2009). This aligns well with general sexuality literature; some women ascribe to the gendered notion that a woman's role as a visual stimulus for her partner is dependent on her level of attractiveness as a sexual partner (Wiederman, 2002), therefore their sense of femininity and sexuality is closely tied to the ways in which they are perceived by others. A study in this synthesis by Altschuler et al. (2009) found that women highly value relational support and affirmation from their partner that they still view them as attractive. This affirmation helped women to cope with changes to their sense of femininity, to feel normal and whole, and not diminished as women in their various roles (Altschuler et al., 2009). Ultimately positive partner support is a key coping mechanism that may influence women to reconcile their sense of femininity in a positive way.

Masculinity and sexuality. For many men, masculinity embodies how the body functions and looks (Donaldson, 1991; Sabo, 1986; Lee & Owens, 2002). Societal influences manipulate how men of young ages learn to value their physical appearance, particularly idealized characteristics such as muscularity, athleticism, discipline, and power (Connell, 1995; Martino, 2003). Many learn that their manhood is tied to their penis, specifically their ability to have and use erections for pleasure and to have sex with partners (Tupper, 1999; Zilbergeld, 1992). The cultural values that some men may hold in relation to masculinity and their sexuality could influence how they experience the sexual impact of CRC treatment.

This synthesis found that changed masculinity or male identity was connected to erectile function in men with CRC. ED was shown to challenge men's sense of male identity and changes in erectile function also resulted in some men feeling incomplete, less of a man, and concerned about a loss of manliness (Dowswell et al., 2011). Relationships between erectile function, masculinity, and male identity are well supported by various studies in the cancer literature (Bokhour et al., 2001; Fergus, Gray, & Fitch, 2002; Gilbert et al., 2012; Oliffe, 2006). One study of men following treatment for cancer found that a diminished sense of manliness, self-worth, and confidence was common and stemmed from fear and embarrassment associated with changes in functional sexual ability (Bokhour et al., 2001). Another exploratory study that examined prostate cancer survivors found that sexual function was very closely related to sense of male identity (Fergus et al., 2002). Similarly, another study that examined men's experiences of prostate cancer, found that male identity is highly influenced by physical, sexual, and social changes (Oliffe, 2006).

Hegemonic masculinity (or hegemonic masculinities) refers to a set of practices and societal norms that are recognized as masculine and that are dominant in society

(O’Brien, 2009). Gender studies literature outlines that men in Western societies who ascribe to the ideals of dominant hegemonic masculinity often enact characteristics such as inexpressiveness (Doyal, 2001), refusal to admit weakness, toughness, stoicism, and avoidance (Wall & Kristjanson, 2005). Synthesis findings affirmed that gender norms (in this case, hegemonic masculinity) were shown to prevent some men from admitting weakness or vulnerability related to their changed erectile function post treatment (Dowswell et al., 2011). Other studies that have examined masculinity and prostate cancer have found similar results. For example, a study by Gray et al. (2000) that aimed to describe the experiences of men with prostate cancer during treatment, found that men enacted a hegemonic masculinity by working hard to control their emotions regarding their altered sexuality, and chose to hide this vulnerability from their partner.

Scholars have argued that the notion of hegemonic masculinity has been widely over emphasized and overused (Wedgewood, 2009), as a man's concept of his masculinity will ebb and flow throughout his life and can vary greatly, influenced by multiple factors, including sociocultural background (Kiss & Meryn, 2001), age, and ethnicity (Connell, 1995). Findings of this synthesis highlighted this dynamic and contextualized experience of masculinity, in that hegemonic ideals of masculinity did not dominate the sexual experiences of men with CRC. For example, in the study by Dowswell et al. (2011), only a minority of participants accepted their ED with a degree of silence, avoidance, and stoicism, while many men actively engaged in seeking treatment and help to manage their erectile dysfunction (Dowswell et al.).

Overall, the use of a SGBA highlighted the fact that sex and gender are critical factors that were generally erratically incorporated in the studies in this synthesis. Only two studies explicitly aimed to understand linkages between sex, gender, and the sexual health experiences of CRC survivors (Grant et al., 2011; Milbury et al., 2013). One of these studies used focus groups to account for the ways in which gender shapes the concerns and adaptations of long-term CRC survivors (Grant et al., 2011). The other study identified how demographic factors (i.e. sex) and psychosocial risk factors explain a significant proportion of the variance in male and female sexual function in CRC survivors (Milbury et al., 2013). According to Johnson et al. (2012) incorporating sex and gender into empirical, theoretical, and methodological aspects of research contributes to better science by helping to explain the experience of health and disease while also providing evidence about which interventions can be improved and inequities corrected. It was challenging to draw strong conclusions about how sex and gender influenced sexual health post treatment due to a distinct lack of sex and gender-specific data included in this synthesis. Therefore, future research investigating the relationships between sex, gender, and sexuality in cancer survivors is needed to address gaps in understanding of how sex and gender shapes CRC survivors sexual experiences.

Relational factors: Partner status. This synthesis indicated that relational factors such as current partnerships and presence of social support are factors that influenced the sexual impact of CRC treatment in both men and women. In general, findings showed that partner status improves sexual function, as both men and women in committed relationships show higher scores on measures of sexual function compared to single participants (Milbury et al., 2013).

According to Hagedoorn et al. (2008), individuals who are in a relationship when confronted with cancer maintain some advantage over individuals without a partner.

However, only one qualitative study in this synthesis examined the sexual experiences of single as well as coupled survivors (Ramirez et al., 2009), specifically women with ostomies. The authors found that the experiences of single women differed from those of partnered women. Avoiding sexual activity altogether was often a way for single women to deal with sexual changes, and some felt that avoiding sexual activity was less complicated than negotiating their altered sexual self with a partner (Ramirez et al., 2009). Similar findings have been outlined in the literature pertaining to breast cancer survivors. One prospective study (Ganz, 1996), which examined a large sample of both partnered and single breast survivors three years after treatment, found that over half of single women reported they would have difficulty telling a prospective partner about the cancer, compared to one fourth of partnered women who experienced communication problems with their partner. In addition, one third of the sample of single women felt afraid to initiate a sexual relationship. Partnered women in this study did not experience as many sexual difficulties; in fact one third actually felt their sexual relationship with their partner had improved over time (Ganz, 1996).

No studies in this synthesis looked at the experiences of single men; however, prostate cancer literature supports the idea that presence of a partner can influence sexual outcomes. Bertero (2001) conducted a phenomenological study to describe the impact of prostate cancer and its treatment on men's sexuality and intimate relationships. Partner status was noted as a critical factor to help men manage their sexual changes, as many stressed that it was easier to accept changes because they had a consistent wife or partner for many years. In addition, some participants also stated that they would consider the sexual alterations brought on by cancer treatment as more serious if they were single

(Bertero, 2001). A qualitative exploratory study found that single men with prostate cancer experienced social interactions with women in new ways (Bokhour et al., 2004). The sexual dysfunction brought on by cancer treatment diminished their sexual confidence, and caused some to withdraw from social interactions in order to avoid the possibility of a sexual encounter (Bokhour et al., 2004).

Generally, literature shows the sexual, psychosocial, and relational impact of CRC treatment differs in single men and women compared to partnered survivors. Without the presence of a partner, remaining celibate and avoiding sexual activity altogether is often a way for single survivors to deal with sexual changes brought on by treatment. In addition, it is evident that single survivors' sexual experiences are highly complex, possibly more so than coupled survivors, therefore health care professionals working with single CRC survivors should be prepared to offer additional intervention and/ or support services to this population.

Relational factors: Partner support. This synthesis found that the presence of positive partner support and survivors' satisfaction with their partner influenced high levels of sexual satisfaction compared to survivors with low marital satisfaction (Cotrim & Pereira, 2008). These findings are in line with the literature about general populations, which shows that positive partner support is an important factor that influenced good sexual function in the general population (DeLamater & Karraker, 2009; Lindau et al., 2007).

Many studies in this synthesis highlighted the value women place on partner support to improve the psychosocial and sexual impact of treatment (Altschuler et al., 2009, Ramirez et al., 2009). Further, women who reported having a supportive and stable relationship were able to maintain feelings of attractiveness, sexual desirability, and femininity after treatment (Altschuler et al., 2009; Ramirez et al., 2009). The importance of partner support to help women improve psychosocial and sexual health has also been well studied in breast cancer. It appears that breast cancer survivors experience similar benefit from partner and spousal support compared to women with CRC. According to Fergus and Gray (2009), who conducted a qualitative study with 30 women to understand the impact of breast cancer on heterosexual relationships, breast survivors identified spousal support as a factor that promoted positive body image and helped to manage sexual function changes (Fergus & Gray). Relationships between positive partner support and coping were not as well defined in men given the lack of comparable research for men.

Linkages: Coping and the sexual, psychosocial, and relational. Coping was a key concept in this synthesis, as it influenced the ways in which men and women experienced the sexual, psychosocial, and relational impact of treatment. This synthesis found that survivors engage in similar strategies including response shift, avoidance, forceful acceptance, and coping in context. In addition, there were also some sex and gender-specific differences in the ways that men and women coped with sexual changes. Couples coped with changed sexuality by finding new ways of intimacy.

Evaluating sexuality in current life context. Lazarus and Folkman (1984) described one of the most popular frameworks for understanding adjustment to life stressors, such as cancer, in their seminal work titled *Stress, Appraisal, and Coping*. In this work, Lazarus and Folkman (1984) described coping as an active process, shaped by the context in which stressors arise. According to stress and coping theory, evaluating a threatening life event by recognizing the longer-term perspective (or the big picture) can be an effective coping mechanism to diminish this threat (Moos & Schaefer, 1993; Park & Folkman, 1997). This coping tactic is called situational meaning, whereby individuals interpret global meaning in the context of specific life events and occurrences (Park & Folkman, 1997).

Several studies in this synthesis found that survivors' coped by interpreting the sexual impact of treatment in relation to their life context. For example, by attributing sexual function changes to age, both male and female survivors were able to reconcile their feelings about their changed sexual function and body image (Ball et al., 2013; Ramirez et al., 2009). Another study in this synthesis found that cancer treatment side effects were experienced as less significant in comparison to the more significant threat of death (Neuman et al., 2011).

Avoidance. Avoidance or distancing includes behaviours such as denial (Lazarus, 1993), keeping feelings to oneself, refusing to think about the problem, and going on with life as the cancer was not happening (Dunkel-Schetter, Feinstein, Taylor, & Falke, 1992). Avoidance is a common coping mechanism among men and women with cancer. For example, in a cross sectional examination of 600 cancer survivors, distancing was noted to be the most common coping strategy utilized by men and women with various types of cancers (Dunkel-Schetter et al., 1992). In this synthesis, studies found that survivors used avoidant coping strategies by adopting the attitude that there is nothing that can be done to help with sexual function and body image changes; therefore one must accept these changes and move on (Ball et al., 2013; Ramirez et al., 2009). In these studies, avoidance was recognized as a useful strategy to help survivors cope with their changed sexual lives. However, according to Folkman, Lazarus, Dunkel-Schetter Delongis & Gruen (1986) and Lazaurs (1993), distancing oneself from the problem at hand is not always an effective coping strategy. In some scenarios, distancing as a strategy when one should be attending to the problem can be destructive.

Response shift. Response shift is a psychological coping process that allows individuals to maintain acceptable quality of life in the face of deteriorating health or a chronic health illness (Sharpe et al., 2011). Sprangers and Schwartz (1999) originally proposed response shift theory to explain how changing internal standards, values, and the conceptualization of quality of life (QOL) can enhance coping and adaptation to chronic illness. Response shift has been well researched in chronic illness and is generally recognized as a positive coping strategy to help people manage QOL changes (Schwartz et al., 2006). A systematic review that examined breast cancer survivors found that response shift was a common coping mechanism; many breast cancer survivors noted a shift in their priorities, and sexual intercourse became of less important to quality of life because their main aim was survival (Schultz & Van De Wiel, 2003). This synthesis found that response shift was a valuable way for men and women with CRC to cope with the sexual and psychosocial impact of treatment. One qualitative study identified that CRC survivors engaged in a shift in perspective resulting in a complete reconceptualization of what QOL and sexual health means after CRC treatment. In this study, response shift was acknowledged as a valuable coping strategy that helped survivors reprioritize their sexual lives in order to adjust to and maintain an acceptable QOL post treatment (Neuman et al., 2012).

Sex and gender related factors that affect coping. This synthesis found that men and women with CRC coped with sexual changes in different ways. In addition, findings indicated that there are gender related factors that influence coping styles.

Men and coping. Masculinity was recognized to be a factor that influenced the ways that men coped with the sexual impact of CRC treatment. Some men adopted stoic and avoidant attitudes in an effort to accept their changed sexual function (Dowswell et al., 2011). Similar findings were reported in a qualitative study by Emslie et al. (2009) that explored the coping experiences of 17 men with CRC. Men in this study coped by altogether avoiding sex and resisting sexual activity with their partners (Emslie et al., 2009).

Women and coping. Some studies in this synthesis indicated that women might have a greater capacity to cope with the impact of CRC treatment (Au et al., 2012; Wirsching et al., 1975). For example, women were shown to have greater resourcefulness compared to men (Au, 2012), and possessed a greater ability to manage depression and changes to social life (Wirsching, 1975).

Resourcefulness is described as a repertoire of learned behavioral skills, including personal and social resourcefulness for coping with stressful events (Rosenbaum, 1990; Zauszniewski, 2006). Women are often described as very resourceful in coping with adversity. For example, in a cross sectional study by Krouse et al. (2009), women with CRC were shown to seek more social support than men to manage HRQOL changes post treatment. Similarly, a systematic review by Tamres et al. (2002) found that women were more likely than men to engage in coping strategies by seeking emotional support from friends, family, or health providers. Women were also more likely to engage in the use of personal skills such as positive self-talk to help them cope (Tamres et al., 2002). Ultimately research that measures resourcefulness as a proxy for coping may be biased towards women's ways of coping, as women by nature may be more resourceful than men in this sense.

Relational coping: New ways of intimacy. Some couples living with CRC cope with sexual changes by finding new ways of intimacy including oral sex, sensual touching, holding hands, kissing, and cuddling (Ohlsson-Nevo et al., 2011). Similar findings were reported in another study by Gilbert et al. (2012) that examined couples with various cancers including breast, brain, colorectal, liver, and prostate cancers. Many couples in this study re-negotiated sexual practices to include non-genital forms of intimacy and increased relational closeness. Although some couples were able to cope with sexual changes, this was not always the case. A number of couples in this study reported that sexual changes caused a sense of "sexual dys-embodiment" (p. 608), characterized by feelings of loss, lack of acceptance, depression, anxiety and stress (Gilbert et al., 2012).

Linkages: Interventions and the sexual, psychosocial, and relational. Research shows that interventions are essential to facilitate positive psychosocial adjustment in cancer care (Redd, Montgomery, & DuHamel, 2001). Only one intervention study was identified for inclusion in this synthesis (Reese et al., 2012). Overall, this intervention significantly improved outcomes including sexual communication, dyadic adjustment, and intimacy. The effectiveness of this intervention is not surprising given the overwhelming amount of evidence that supports that couple focused, psychosocial interventions with educational components can improve sexual function (Taylor, Harley, Ziegler, Brown, & Velikova, 2011), body image, dyadic coping processes (Scott & Kayser, 2009), couple communication, psychological health, and overall relationship functioning among cancer survivors and their partners (Regan et al., 2012).

Based on the findings of this narrative synthesis, it is important for future experimental research to incorporate sex-specific strategies to improve sexual health after treatment, as sex and gender were recognized as important factors that mediate the overall treatment experience. Despite the fact that the one intervention study included in this synthesis did not account for sex or gender, incorporating specific startegies to aid men with erectile dysfunction, and women with issues around the ostomy and body image may be of particular importance and hold potential for enhancing effectiveness of any future interventions. Other research that has examined the potential impact of interventions among men and women with cancer supports the notion that different, sex and gender-specific intervention strategies are needed to influence positive health outcomes in men and women (McQueen, Vernon, Meissner, & Rokowski, 2008; Ussher, Perz, Hawkins, & Brack, 2009).

Optimal delivery methods for intervention. The intervention study included in this synthesis used the telephone as a means to deliver the intervention, which was well received by study participants (Reese et al., 2012). Several other studies have implemented telephone interventions for cancer patients, and also found that they are well received (Beaver et al., 2009; Cox & Wilson, 2003; Gotay, 1998), and are particularly suitable for participants who have mobility issues or those who live in more rural areas that require travelling long distances for care (Beaver et al., 2009; Cox &

Wilson, 2003). Telephone interventions may also be beneficial for patients who are uncomfortable in discussing sensitive topics (such as sexual issues) face-to-face (Gotay, 1998). It may also be beneficial for future research to explore the benefits of online interventions. Since internet-based interventions are a fairly recent innovation (Griffiths, Lindenmeyer, Powell, Lowe, & Thorogood, 2006), few studies exist that examine the effectiveness of such interventions in the cancer population, particularly as they relate to sexual outcomes. One recent randomized controlled trial by Schover et al., (2012), which examined the effectiveness of traditional counseling compared to internet-based sexual counseling, found promising results that indicate that the internet-based program was as effective as traditional sex therapy in producing long-lasting improvements in sexual outcomes for prostate cancer survivors and their partners.

Timing of the intervention. While the benefits of couple-focused interventions were made clear in this synthesis, optimal timing of such interventions was not clear. The timing of the intervention study by Reese et al. (2012) varied; some participants began the intervention immediately post treatment, while for others it was 4-6 months later, and for one couple the intervention was implemented over one year after treatment. There was no indication in this study that the intervention was more effective at one time versus another.

On the other hand, some studies in this synthesis supported that early psycho-educational intervention would be well received by CRC survivors. Several observational studies in this synthesis stated that the survivors prefer factual, comprehensive information at early stages of the treatment process regarding the impact of treatment on sexuality and sexual health in order to facilitate coping post treatment

(Andersson et al., 2009; Ball et al., 2011; Ball et al., 2013; DaSilva et al., 2008; Nowicki et al., 2011; Ramirez et al., 2009). This is a common patient preference supported in general cancer literature. According to a randomized control trial that examined the timing and provision of information showed that cancer patients preferred receiving information early on in the treatment process (Mohide et al., 1997).

According to a systematic review by Stanton (2006), the majority of psycho-educational interventions have been directed towards survivors during the early diagnostic and treatment phases of cancer. Consequently, few experimental studies have focused on longer-term survivors (Stanton, 2006), a substantial gap in the literature and an area for future research and development. The need for this research is well supported by findings of this synthesis. Studies were clustered in these groups according to the most commonly researched time frames post diagnosis including: 0-2 years (Cotrim & Pereira, 2008; DaSilva et al., 2008; Neuman et al., 2011; Neuman et al., 2012; Ohlsson-Nevo et al., 2011; Reese et al., 2012; Sharpe et al., 2011; Schmidt et al., 2005, 2010), and over 2 years (Altschuler et al., 2009; Ball et al., 2013; Grant et al., 2011; Ramirez et al., 2009; Wirsching et al., 1975) (Table 4.9.7). The sexual side effects of treatment did not appear to be more severe during either timeframe, findings of these groupings substantiated that that the influence of treatment on sexual health is significant, and impacts survivors on both a shorter-term and longer-term basis. Experimental research implemented both in the short and long term may be beneficial to improve sexual outcomes of survivors.

Summary

This research was successful in formulating a framework depicting the complex ways in which CRC treatment impacts the sexual experiences of survivors. This *sexual survivorship in CRC* framework contributed to a more profound understanding of how treatment impacts sexual health, psychosocial health, quality of relationships, and overall quality of life. It also contributed to understanding what factors are important in influencing these experiences.

The *sexual survivorship in CRC* framework highlights three overarching components of sexuality and sexual health that are often implicated as a result of treatment. These include the relational, sexual, and psychosocial impact of treatment. These three components are closely linked to QOL; therefore change to any one can impact perceived QOL of survivors. In addition, there are various individual, relational, and treatment characteristics that influence the ways in which survivors experience their sexual, psychosocial, and relational health post treatment. Coping strategies and the provision and types of interventions that are implemented for survivors post treatment are also factors that can impede and/or promote adjustment to any alterations in sexual, relational, and psychosocial health. Sex and gender-related factors play a substantial role in shaping sexual, relational, and psychosocial health post treatment. These factors also impact the ways in which survivors are able to cope with sexual health changes, and should be considered in future interventional research because they liekly impact the efficacy of sexual health interventions between the sexes.

Chapter Six Conclusion

Findings of this synthesis facilitated the generation of several recommendations for future research and practice. This chapter outlines the theoretical and practical implications of this work, and will also identify areas for future research as well as strengths and limitations of the methodological approach and synthesis findings.

Theoretical Implications of this Research

The sexual survivorship framework. To date, there is no explicit theory that explains how cancer survivors experience their sexuality after treatment for cancer. This narrative synthesis generated a conceptual framework s*exual survivorship in CRC*, which presents the key elements of sexual survivorship described in the literature and offers beginning hypotheses about how these elements related to each other. In an attempt to validate this framework, authors of key studies included in this research were contacted to test the interpretations derived from this work. Largely, the framework was well received and the three authors who participated in member checking felt that the framework resonated with their expert knowledge of this phenomenon. Since this framework is preliminary and untested in practical and research settings, more primary research is needed to test the linkages and correlations within and between the key concepts that make up this framework in order to move the framework to theory.

This framework could be applied in other areas of cancer research in addition to colorectal cancer. For example, it could be particularly applicable for men with prostate cancer and women with gynecological cancers because long-term sexual issues have been documented in at least 50% of those treated for breast, prostate, colorectal, and gynecological cancers (Schover, 2005). In addition, according to Hordern and Street

(2007), diagnosis and subsequent treatment for cancer may dramatically impact a survivor's intimate and sexual world, irrespective of their cancer type. A cross sectional study by Schag, Ganz, Wing, Sim, and Lee (1994) demonstrates this well, as they found that the sexual, relational, and psychosocial domains were all influenced by treatment for survivors with prostate, colorectal, and lung cancers, suggesting the impact of treatment is highly similar in these three cancers. More research is needed to evaluate the potential validity of the framework in the context of other cancers.

Sex and gender based analysis framework. The use of a SGBA framework (Spitzer, 2006) was a novel way to understand the sexual experiences of CRC survivors because there is very little understanding of how sex and gender influence the ways in which men and women experience cancer survivorship (Moynihan, 2002). According to the Canadian Institutes of Health Research (CIHR, 2000) sex and gender are important variables to include in all health research, and can contribute to a deeper understanding of how men and women both socially and culturally respond to illness (CIHR). This synthesis was successful in achieving this deeper understanding, and was also effective in understanding the ways in which perceived masculinity and femininity shapes the sexual experiences of survivors. This knowledge will be useful in constructing future interventions, particularly with respect to targeting changes in body image issues, whereby masculinity was noted to be strongly tied with men's erectile dysfunction, while femininity was linked to the presence of an ostomy in women.

Overall, the use of a SGBA framework was a valuable contribution to this research. Future studies examining survivors with CRC would benefit from the use of a SGBA framework as a way to test the interpretations developed by this synthesis. In addition, research that examines sexuality in survivors with other cancers through the lens of a SGBA would be valuable, particularly in cancers where both men and women can be affected (i.e. lung, head and neck, and anal cancers).

Implications for Guideline Formation and Future Research

Implications for future guidelines in Canada. Several grey literature sources were included in this synthesis, all of which were explicit policies and guidelines from various countries that provide recommendations for the management of sexual health issues, including body image, stoma-related complications, sex-specific recommendations, and/or psychosocial recommendations. Many of the policies and guidelines were specific to colorectal cancer management; however some were more general cancer guidelines applicable to survivors of various cancers.

Several countries including the UK, USA, New Zealand, and Australia have produced comprehensive guidelines to address the sexuality and survivorship concerns of CRC survivors. At present, there are no guidelines that provide specific recommendations to help manage the psychosocial or sexual health of CRC survivors in Canada. One of the grey literature sources was produced in Canada; however it was a general psychosocial guideline, not specific to CRC or sexuality or sexual health. Without guidelines, it is likely that the management of sexual health issues for CRC survivors in Canada will vary from one institution to the next (Howell et al., 2011). This highlights the need to produce guidelines to manage CRC survivorship in Canada. The findings of this synthesis could be a starting point in creating a CRC survivorship guideline in our health system. This section will review the implications of the findings of this synthesis and how these could contribute to future guidelines or policy formation.

In line with the findings of this synthesis, a pan-Canadian guideline to manage sexual survivorship would need to encompass a broad review of the sexual, psychosocial, and relational implications of CRC treatment, as well as specific management strategies to attend to any changes to these three aspects. In addition, a clear explanation of the various individual and relational characteristics that can impact the sexual experiences of survivors would also be a critical piece of this guideline, particularly an explanation of how sex, gender, stoma status, and mental health can influence sexuality post treatment. Specific management techniques to help survivors with ostomies adjust to their changed sexuality and sexual health would also be critical, and sex-specific recommendations and management strategies should also be included.

Assessment of general sexual issues. According to some of the guidelines included in this synthesis, it is recommended that health providers (i.e. primary care physicians, registered nurses, interdisciplinary oncology teams, occupational therapists, physiotherapists, psychosocial or supportive care specialists, spiritual care providers, or other health or supportive care professionals) complete a baseline survivorship assessment for men and women with cancer. This assessment should include specific questions pertaining to sexual function and concerns regarding altered sexuality (Howell et al., 2011; NCCN, 2013). The Canadian guideline released by CAPO (Howell et al., 2011) recommended that health professionals use the PLISSIT (Permission, Limited Information, Specific Suggestions, and Intensive Therapy) model as a first step in assessing the psychosocial health of survivors.

The PLISSIT model, first developed by Annon (1976), can guide health providers to understand the level of intervention that might be appropriate to meet the sexual healthcare needs of patients. The effectiveness of the PLISSIT model in guiding health professionals caring for patients with stomas was examined in a case-control study by Ayaz and Kubilay (2009). The PLISSIT model was shown to be effective as a starting point to decrease sexual problems; therefore, an intervention plan based on the PLISSIT model could guide health providers in solving sexual problems of individuals with stomas, and help to integrate sexual health issues in care (Ayaz & Kubilay, 2009). Inclusion of this model in future guidelines and policies along with specific step by step instructions for its use may be a useful starting point to help providers assess and manage sexual health issues of CRC survivors.

Management of psychosocial issues. In addition to the use of the PLISSIT model, specific assessment and management of body image issues should be a routine part of survivorship care. The National Breast Cancer Centre and National Cancer Control Initiative (2003) recommended that health providers sensitively explore body image concerns of survivors as a way to examine the severity and impact of body image on the quality of relationships. This guideline provided specific open-ended questions that can be implemented into practice to initiate conversation about sexual function changes and body image changes. Inclusion of specific questions to initiate conversation could be beneficial in future guidelines, because some research has shown that health professionals are limited in their understanding of patient sexuality and sexual function after treatment for cancer, and some hold stereotypical assumptions about patient sexuality, based on age, sex, culture, and partnership status (Hordern & Street, 2007). If a guideline were to provide examples of gender-sensitive open-ended questions that health providers can utilize in their own practice, this may be useful to streamline the process to ensure all survivors are being asked about their sexual health post treatment.

Management of relational issues. Few guidelines included in this synthesis explicitly outlined ways to manage relational issues that occur as a result of cancer treatment. According to the general cancer survivorship guidelines produced by the Canadian Association of Psychosocial Oncology (CAPO), interventions to help survivors manage their sexuality and sexual health should include both the cancer survivor and the survivor's partner (i.e. couples therapy) in order to promote healthy post treatment sexual health and optimal function (Howell et al., 2011). This recommendation should be included in CRC specific guidelines to ensure that survivors who are partnered are being offered the best possible care.

Management of survivors without partners. None of the guidelines outlined how to provide care for single survivors. Explicit management techniques to help this population should be included in future guidelines, because the results of this synthesis indicate that single survivors can experience more sexual concerns and challenges with coping to changed sexuality compared to partnered survivors. Health providers should be aware of this fact and be prepared to refer patients to further counseling as necessary.

Ostomy-specific recommendations. Another important factor that would need to be addressed in a Pan-Canadian guideline of CRC survivorship would be an acknowledgement of the sexual and psychosocial experiences of CRC survivors with ostomies. For future guidelines it would be important to present evidence that survivors with ostomies tend to experience worse sexual function, mental health (i.e. anxiety, depression, distress), and trends towards worse body image and self-concept (particularly in women). Sharing this information in a guideline would be of value to ensure that health providers are aware of the implications of the ostomy, and are prepared to refer male and female ostomy survivors to appropriate services (such as sexual or psychological counseling) if needed.

In addition, it may also be important to recommend both pre-surgery and post-surgery counseling to ostomy patients by a clinical nurse specialist with expertise in ostomy care. According to the NICE (2004) guidelines which were included in this synthesis, pre surgical counseling should include the implications of the ostomy, and post-surgical counseling should pertain to the management of the various physical, social, sexual, and emotional problems associated with the ostomy (NICE, 2004). Ongoing management of this kind could help survivors to adjust to the sexual implications of the ostomy, and should be considered as a criterion for inclusion in future Pan-Canadian guidelines.

Sex-specific recommendations. Based on the findings of this synthesis, sex-specific research findings should contribute to the creation of policies or guidelines specific to the sexual health management of CRC survivors. The American-based NCCN (2013) survivorship guidelines were the only grey literature source that explicitly outlined sex-specific management strategies. This guideline provides step-by-step management criteria for sexual issues including an algorithm, which depicts diagnostic evaluation and ongoing assessment techniques that health providers can implement in practice. This guideline is primarily concerned with diagnosing and managing sexual function. For future guideline formation, an algorithm may be viable option to streamline sex-specific sexual survivorship care, however it will likely need to include more broad management strategies that address not only changes to sexual function, but also to psychosocial, and relational health.

In addition to the algorithm, it would also be beneficial to include an explanation of the sex and gender-related factors that can impact the sexual lives of survivors. For example, an explanation about the ways in which men and women experience body image would be helpful. Future guidelines should also specify differences in sexual function by drawing attention to the evidence that supports that men experience more sexual dysfunction. Imparting this knowledge would help health professionals manage these concerns or make referrals for counseling in a timely and efficient manner.

Gaps in the knowledge and areas for future research. A benefit of using a knowledge synthesis methodology is that it identifies gaps in a specified body of literature (Grimshaw, 2009). Therefore as a result of this research, several gaps were identified that exist in the body of research pertaining to the sexual experiences of male and female CRC survivors post treatment. The prevalence of gaps in this literature is not surprising as the body of literature examined is generally quite new; the vast majority of the studies in this synthesis were published from 2009-2013. As an up and coming area of cancer research, considerations of the following areas for future research is critical to expand knowledge of CRC survivorship.

Probably the most notable gap that impacts generalizability of the synthesis findings is the lack of included studies that examined the male perspective. In fact, only two studies in this synthesis were specific to men (Ball et al., 2013; Dowswell et al., 2011). More male-focused research is needed, particularly relating to how men experience changes to body image post treatment and the impact of the ostomy on sexual function and body image. In addition as investigations about how partner support does (or does not) help men to cope with changes to sexual and psychosocial health would be valuable.

It was challenging to fully understand how sex and gender related factors could impact the sexual experiences of survivors given that sex and gender were not incorporated into the majority of studies included in this synthesis. Future research should inquire into the linkages between sex, gender, and sexuality in cancer survivors, as it was challenging in this synthesis to draw conclusions regarding how sex and gender shaped experiences due to a lack of data.

Very few studies were couple focused; most of the studies in this synthesis examined the individual sexual experiences of cancer survivors. The body of literature that examines the relational (or couple-based) experience of CRC is not as thoroughly researched as other cancers, such as breast or prostate for example. More couple-focused research is essential to understand the couple experience of CRC cancer as well as how couples are able to cope with sexual changes brought on by the ostomy and treatment.

There was a lack of diversity within the included literature that limits the generalizability of the findings of this synthesis to various populations. Most studies in this only evaluated the sexual experiences of Caucasian, heterosexual, partnered men and women. Future research should focus on examinations of survivors from of different ethniticities and cultural backgrounds. Further, since very little research in this synthesis examined single men and women with CRC, future research should focus on exploration of the experiences of single survivors. In addition, another noted gap in this literature is the lack of studies that address the sexual experiences of gay, lesbian, bisexual, transgendered, or queer individuals. None of the included research explicitly outlined the sexual experiences of survivors who do not identify as heterosexual. This was not surprising, as a systematic review by Brown and Tracy (2008) concluded that there is very little literature focusing on lesbians in the context of CRC. Similarly, very little research exists examining the experience of gay men with CRC, although some studies have been conducted that include gay men with prostate cancer (Blank, 2005; Fergus et al., 2002). Research exploring the experiences of diverse populations including LGBTQ individuals is critical to illuminate the array of sexual experiences and should be a consideration for future research.

In general, there was a substantial lack of experimental studies specific to enhancing sexual survivorship of CRC survivors. The intervention study by Reese et al. (2012) that was included in this synthesis showed promise and should be tested further in larger samples in more robust designs such as clinical trials. However, in general, more experimental work is needed in this area, and it would be beneficial for future experimental research to explore various ways to deliver sex and gender-sensitive psychosocial interventions for CRC survivors and their partners. The lack of included experimental research limited the scope of this synthesis and impeded the ability to explore critical questions such as: how interventions work, for whom do interventions work, and what circumstances influence their effectiveness. The paucity of intervention studies included in this synthesis also limited the ability to engage in specific analytic techniques including examinations of moderator variables, vote counting, and pooling of statistical estimate effect, which can contribute to the breadth of findings and an understanding of what sort of interventions work for this population.

Strengths and Limitations of this Research

The findings of study appraisal are a limiting factor impeding the robustness of this research. Generally, quality scores of most of included research were moderate to high, although some studies were scored as low quality. It was decided early on in the synthesis process that studies would not be excluded based on their quality, therefore it is possible that these lower quality studies impacted both the results of the individual studies and ultimately the conclusions reached in the final synthesis product. To counteract this possible effect, all studies of lower quality were grouped and an effort was made to recognize lower quality studies throughout analysis, and conclusions were not drawn from these lower quality studies in instances where they presented outlying findings that were not supported by the rest of the included studies.

The majority of studies in this synthesis identified several barriers and limitations to the implementation and findings of individual studies. It is possible that some of these limitations also impacted the conclusions drawn from this synthesis. For example, a common barrier identified within several of the included studies was the discomfort that many participants experienced in discussing sexual issues that could have caused the underreporting of sexual issues or presented challenges for recruitment (Dowswell et al., 2011; Platell et al., 2004; Ramirez et al., 2009; Schmidt et al., 2005), thus impacting the final conclusions drawn from this synthesis.

A potential strength of this research is the methodological diversity of included literature. A benefit of utilizing narrative synthesis methodology is the capacity to synthesize multiple different types of evidence in a systematic way. According to Evans (2002), merging findings generated by a heterogeneous pool of studies can increase the robustness and transferability of the results (Evans, 2002). Therefore because this synthesis was successful in synthesizing a considerably heterogeneous body of literature including qualitative research, observational studies, and grey literature, these findings are likely accurate, robust, and relevant to CRC survivors and health providers. Another strength of this synthesis is the diversity that exists within the included studies according to discipline of the primary author. The differing epistemological standpoints of the disciplines including physicians, nurses, and behavioral scientists likely contributed to a more diverse, richer understanding of the sexual experiences of survivors.

Summary

The purpose of this research was to examine the impact of CRC treatment on the sexual experiences of survivors and to explore how these experiences are shaped by sex and gender- related factors. This study is the first of its kind to use a narrative synthesis method to explore this phenomenon. Synthesizing various types of evidence including primary research and grey literature sources illuminated that survivors' relational, psychosocial, and sexual health is impacted immensely post treatment. These impacts contribute to substantial alterations to the survivors overall quality of life. The severities of these impacts are mediated by several factors including individual and relational characteristics, the availability and types of interventions the survivor receives, and personal coping skills or strategies.

Sex and gender are important variables to include in health research, as they can contribute to a deeper understanding of how men and women both socially and culturally respond to illness. By using a sex and gender based framework, this synthesis found that men often experience worse sexual function and more distress related to altered function compared to women. Findings also supported that men and women can experience psychosocial health in gendered ways. Erectile dysfunction can result in changes to body image that impacted men's identities. Findings of this work highlighted that women's changed body image and perceived sense of femininity was strongly associated to the presence of an ostomy. This knowledge will be useful in constructing future studies, particularly experimental research targeting changes to body image and improving sexual function.

Men and women also engage in gendered ways of coping post treatment for CRC. It appears masculinity is a key factor that influences the ways that men cope with the sexual impact of treatment as some adopt stoic and avoidant attitudes in an effort to accept their changed sexual function. Findings also suggest that women may have a greater capacity to cope with the impact of treatment, as women have greater capacity for resourcefulness compared to men. Ultimately sex and gender were erratically incorporated into the studies included in this synthesis; therefore, it was challenging to fully understand how sex and gender related factors can impact the sexual experiences of survivors.

This study was successful in identifying several key areas for future research. There is a paucity of research that examines men's and couple's sexual experiences post CRC treatment. More research in these areas is essential. There is also a pronounced lack of research evaluating interventions pertaining to CRC survivors. Rigorous evaluations of couple-focused, psycho educational interventions for survivors would provide as a useful starting point because these apporoaches appear to be the most efficacious for this population. Identifying ways to integrate emerging understandings of sex and gender related influences shaping CRC survivors sexual experiences in these interventions holds potential for enhancing effectiveness. Future research should also explore innovative ways to deliver psychosocial interventions for CRC survivors and their partners including telephone and online delivery methods. Lastly, there was a distinct lack of diversity within the included literature that limits the generalizability of these findings. More research is need that examines survivors of various ethnicities, as well as studies that address the sexual experiences of LGBTQ individuals.

The contributions of this study to current knowledge are twofold. Firstly, to depict the complexities within this experience, a novel conceptual framework titled *sexual survivorship in CRC* was generated to represent this phenomenon. This framework will be a useful tool to inform the design of future quantitative and qualitative research. Secondly, this research contributes to a substantial gap in our health care system. At present, health professionals are struggling to provide sexual health-focused support, as there are no Canadian-based guidelines or policies that delineate how health professionals should manage CRC survivorship. This research resulted in the foundation of key aspects of care that must be included in future survivorship guidelines as a way to streamline care in our health system and help health professionals manage the complex sexual, psychosocial, and relational impact of CRC treatment for survivors.

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Appendix A: Applying Sex and Gender-Based Analysis (Spitzer, 2006)

Research Question

- Are sex and/or gender identified and defined? Are the definitions supported by recent academic literature?
- Does the proposal demonstrate awareness of what is known about sex, gender and diversity (i.e. sexual orientation) in this area of research? Are the concepts of sex, gender and diversity taken into account in the development of the research question(s)?
- Are the concepts of sex, gender and diversity applied clearly and appropriately?
- If used in the study, does the researcher identify and justify the choice of the sex of cells, cell lines, and/or animals?
- If the applicant asserts that sex and/or gender and diversity are not relevant to the proposed research, what evidence is presented?
- Does the research question reflect the diversity in and among females and males?

Data Collection

- Does the sex/gender/diversity composition of the sample reflect the research question?
- Does the sample match the researchers' plans for generalizing from the data?
- Have research instruments (i.e., surveys, measurements) been validated to reflect gender/sex and diversity?
- If sex is used as a proxy for weight, height and body fat/muscle ratios, is there an explicit explanation and analytical strategy provided for employing this approach?

- In the case of clinical trials: Does the sample reflect the distribution of the condition in the general population? For proposed clinical trials, are sufficient numbers of women and men included in the sample to enable safety as well as efficacy analysis? Where appropriate, how will the clinical trial track and account for female menstrual cycles? Does the applicant plan to analyze results in the context of known sex-specific adverse effects, height-weight-sex relationships, and interactions with commonly used drugs?

Data Analysis and Interpretation

- Will the researchers disaggregate and analyze data by sex/gender?

- Does the use of gender as a variable mask or intersect with other potential explanatory factors such as socioeconomic status, physical attributes and/or ethnicity?

- What assumptions are being made about gender and/or sex-especially as they intersect with other diversity indicators such as ethnicity, sexual orientation, socioeconomic class, etc.-while formulating the research problem, sampling, data collection, analysis and interpretation?

Appendix B: Search Strategies

Pub Med

((((sexualitat[tiab] OR sexualitatsfragebogen[tiab] OR sexualite[tiab] OR sexualities[tiab] OR sexualities'[tiab] OR sexuality[tiab] OR sexuality'[tiab] OR sexuality"[tiab] OR sexuality's[tiab] OR sexualityandu[tiab]) OR ("sexuality"[MeSH Terms] OR "sexual behavior"[MeSH Terms]) OR "psychosexual development"[MeSH Terms] OR "coitus"[MeSH Terms] OR Sex Counseling[tiab] OR "sex counseling"[MeSH Terms] OR Marital therapy[Title/Abstract] OR "spouses"[MeSH Terms] OR spouses[Title/Abstract] OR "sexual partners"[MeSH Terms] OR sexual partners[Title/Abstract] OR "sexual dysfunctions, psychological"[MeSH Terms] OR sexual dysfunction[Title/Abstract] OR sexual dysfunctioning[Title/Abstract] OR sexual dysfunctions[Title/Abstract] OR "erectile dysfunction/psychology"[Mesh Terms] OR "sexual behavior"[MeSH Terms] OR "dyspareunia/psychology"[Mesh Terms] OR erectile dysfunction[Title/Abstract] OR erectile dysfunctions[Title/Abstract] OR dyspareunia[Title/Abstract] OR body image[tiab] OR "body image"[MeSH Terms] OR sexual behaviour[Title/Abstract] OR sexual behavioural[Title/Abstract] OR sexual behaviours[Title/Abstract] OR sexual behavior[Title/Abstract] OR sexual behavioral[Title/Abstract] OR sexual behaviors[Title/Abstract] OR libido[tiab] OR libido[MeSH Terms] OR gender identit*[tiab] OR gender identity[MeSH Terms])) AND ((chemotherap*[Title/Abstract] OR radiotherap*[Title/Abstract] OR therap*[Title/Abstract] OR surger*[Title/Abstract] OR surgical*[Title/Abstract] OR treatment*[Title/Abstract] OR therapy[subheading] OR therapeutics[MeSH Terms] OR surgery[subheading] OR drug therapy[subheading] OR drug therapy[MeSH Terms] OR chemotherapy, adjuvant[MeSH Terms] OR radiotherapy, adjuvant[MeSH Terms] OR radiotherapy[subheading] OR survivor*[Title/Abstract] OR survivors[MeSH Terms] OR aftercare[MeSH Terms] OR aftercare[Title/Abstract]))) AND (("Gastrointestinal Neoplasms"[MeSH Terms]) OR (Gastrointestin*[tiab] OR colon*[tiab] OR rectal[tiab] OR rectum[tiab] OR colorectal[tiab]) AND (cancer[tiab] OR neoplasm*[tiab] OR tumour*[tiab] OR tumor*[tiab]))

Embase

colon*:ab,ti,de OR rectal:ab,ti,de OR rectum:ab,ti,de OR colorectal:ab,ti,de AND (cancer:ab,ti,de OR neoplasm*:ab,ti,de OR tumor*ti:ab,de OR tumour*ti:ab,de OR carcinoma*ti:ab,de) AND

'sexual behavior':ab,ti,de OR 'sexual behaviour'/exp OR 'sexual behaviours':ab,ti,de OR 'sexual behaviors':ab,ti,de OR 'sexuality':ab,ti,de OR 'sexualities':ab,ti,de OR 'libido':ab,ti,de OR 'sexual health':ab,ti,de OR 'body image':ab,ti,de OR 'male sexual dysfunction':ab,ti,de OR 'female sexual dysfunction':ab,ti,de OR 'psychosexual disorder':ab,ti,de OR 'psychosexual disorders':ab,ti,de OR 'sexual intercourse':ab,ti,de OR 'marital therapy':ab,ti,de OR 'sexual counseling':ab,ti,de OR 'masculinity':ab,ti,de OR 'masculinities':ab,ti,de OR 'femininity':ab,ti,de OR 'femininities':ab,ti,de OR 'spouse':ab,ti,de OR 'spouses':ab,ti,de OR 'intimacy':ab,ti,de OR 'gender identity':ab,ti,de

OR 'gender identities':ab,ti,de AND 'treatment':ab,ti,de OR 'chemotherapy':ab,ti,de OR 'adjuvant chemotherapy':ab,ti,de OR 'cancer chemotherapy':ab,ti,de OR 'cancer adjuvant therapy':ab,ti,de OR 'drug therapy':ab,ti,de OR 'cancer radiotherapy':ab,ti,de OR 'radiotherapy':ab,ti,de OR 'radiation therapy':ab,ti,de OR 'therapeutic':ab,ti,de OR 'therapeutics':ab,ti,de OR 'aftercare':ab,ti,de OR 'survivor':ab,ti,de OR 'survivors':ab,ti,de OR 'cancer survivor':ab,ti,de OR 'surgery':ab,ti,de OR 'surgical':ab,ti,de

CINAHL

(TI Gastrointestin* OR AB Gastrointestin* OR TI colon* OR AB colon* OR TI rectal OR AB rectal OR TI rectum OR AB rectum OR TI colorectal OR AB colorectal) AND (TI cancer OR AB cancer OR TI neoplasm* OR AB neoplasm* OR TI tumour* OR AB tumour* OR TI tumor* OR AB tumor*) AND MH Psychosexual disorder* OR TI psychosexual OR AB psychosexual OR TI impotence OR AB impotence OR MH impotence OR TI body image OR AB body image OR MH body image OR MH attitude to sexuality OR TI dyspareunia OR AB dyspareunia OR MH dyspareunia OR TI sexualit* OR AB sexualit* OR MH sexuality OR TI sex* counseling OR AB sex* counseling OR MH Sexual counseling OR MH couples counseling OR TI couples counseling OR AB couples counseling OR TI spouse* OR AB spouse* OR MH spouses OR TI sex* partner* OR AB sex* partner* OR MH sexual partner OR TI sexual dysfunction* OR AB sexual dysfunction OR MH sexual dysfunction, male OR MH sexual dysfunction, female OR MH Intimacy Positions OR TI intimacy OR AB intimacy OR TI Sex Role* OR AB sex role* OR MH sex roles OR MH Sex Factors OR TI Gender Identit* OR AB gender identit* OR MH gender identity OR MH Sexual and Gender Disorders OR TI Coitus OR AB coitus OR MH coitus OR TI sexual health OR AB sexual health OR MH sexual health

PsycInfo

(TI Gastrointestin* OR AB Gastrointestin* OR TI colon* OR AB colon* OR TI rectal OR AB rectal OR TI rectum OR AB rectum OR TI colorectal OR AB colorectal) AND (TI cancer OR AB cancer OR TI neoplasm* OR AB neoplasm* OR TI tumour* OR AB tumour* OR TI tumor* OR AB tumor*) AND TI body image OR AB body image OR SU body image OR TI body image disturbances OR AB body image disturbances OR SU body image disturbances OR TI sexualit* OR AB sexualit* OR SU sexuality OR TI sex* partner* OR AB sex* partner* OR SU sexual partner OR TI gender identit* OR AB gender identit* OR SU gender identity OR TI sex therap* OR AB sex therap* OR SU sex therapy OR TI sex role* OR AB sex role* OR SU sex roles OR TI sexual arousal OR AB sexual arousal OR SU sexual arousal OR TI spouse* OR AB spouse* OR SU spouses OR TI couple* OR AB couple* OR SU couples OR TI couples therapy OR AB couples therapy OR SU couples therapy OR TI masculinit* OR AB masculinit* OR SU masculinity OR TI femininit* OR AB femininit* OR SU femininity OR TI erectile dysfunction* OR AB erectile dysfunction* OR SU erectile dysfunction OR TI dyspareunia OR AB dyspareunia OR SU dyspareunia OR AB sexual function disturbances OR TI sexual function disturbances OR SU sexual function disturbances OR

TI interpersonal relationships OR AB interpersonal relationships OR SU interpersonal relationships OR TI sexual intercourse OR AB sexual intercourse OR SU sexual intercourse OR TI sexual health OR AB sexual health OR SU sexual health OR TI male orgasm OR AB male orgasm OR SU male orgasm OR TI female orgasm OR AB female orgasm OR SU female orgasm OR TI sexual attitudes OR AB sexual attitudes OR SU sexual attitudes OR TI sex drive OR AB sex drive OR SU sex drive

Sociological Abstracts

((gastrointestinal* OR colon* OR rectal OR rectum OR colorectal) AND (cancer OR neoplasm* OR tumour* OR tumor*)) AND (sex* OR sexual health OR sexual experiences OR sex counseling OR sex therapy OR erectile dysfunction OR sex roles OR gender identity* OR dyspareunia OR masculinity OR femininity OR body image OR impotence OR interpersonal relationships OR sexual intercourse OR sexual attitudes OR sex drive OR couples OR psychosexual disorder OR sexual dysfunction* OR sexual partner OR sexual behaviour* OR sexual behavior*)

Proquest (Dissertations and Theses)

(AB,TI(gastrointestinal*) OR DISKW(gastrointestinal*) OR AB,TI(colon*) OR DISKW(colon*) OR AB,TI(rectal) OR DISKW(rectal) OR AB,TI(rectum) OR DISKW(rectum) OR AB,TI(colorectal) OR DISKW(colorectal)) AND (AB,TI(cancer) OR DISKW(cancer) OR AB,TI(neoplasm*) OR DISKW(neoplasm*) OR AB,TI(tumour*) OR DISKW(tumour*) OR AB,TI(tumor*) OR DISKW(tumor*)) AND AB,TI(sexuality) OR DISKW(sexuality) OR AB,TI(sexual health) OR DISKW(sexual health) OR AB,TI(sex counseling) OR DISKW(sex counseling) OR AB,TI(sex therapy) OR DISKW(sex therapy) OR AB,TI(erectile dysfunction) OR DISKW (erectile dysfunction) OR AB,TI(sex role*) OR DISKW(sex role*) OR AB,TI(gender identity*) OR DISKW(gender identit*) OR AB,TI(dyspareunia) OR DISKW(dyspareunia) OR AB,TI(masculinity) OR DISKW(masculinity) OR AB,TI(femininity) OR DISKW(femininity) OR AB,TI(body image) OR DISKW(body image) OR AB,TI(impotence) OR DISKW(impotence) OR AB,TI(Interpersonal relationships) OR DISKW(interpersonal relationships) OR AB,TI(sexual intercourse) OR DISKW(sexual intercourse) OR AB,TI(sexual attitudes) OR DISKW(sexual attitudes) OR AB,TI(sex drive) OR DISKW(sex drvie) OR AB,TI(couples) OR DISKW(couples) OR AB,TI(sexual partners) OR DISKW(sexual partners) OR AB,TI(spouses) OR DISKW(spouses) OR AB,TI(psychosexual disorder*) OR DISKW(psychosexual disorder*) OR AB,TI(sexual dysfunction*) OR DISKW(sexual dysfunction*) OR AB,TI(sexual behaviour*) OR DISKW(sexual behaviour*) OR AB,TI(sexual behavior*) OR DISKW(sexual behavior*) OR AB,TI(coitus) OR DISKW(coitus)

Appendix C: Criteria for Study Appraisal

Table C1 Study Appraisal Criteria

Quantitative Studies			
Criteria for Observational Studies	**YES**	**NO**	**Unclear**
1. **Selection Bias**: Are the individuals selected to participate in the study likely to be representative of the target population?			
2. **Selection Bias:** What percentage of selected individuals agreed to participate?	%		
3. **Confounders:** Were the confounders adequately managed in the analysis?			
4. **Confounders**: Were there important confounders not reported?			
5. **Data Collection Methods:** Were data collection tools shown or known to be valid for the outcome of interest?			
6. **Data Collection Methods**: Were data collection tools shown or known to be reliable for the outcome of interest?			
7. **Withdrawls and Drop Outs:** Indicate the percentage of participants completing the study.	%		
8. **Analysis:** Is there a sample size calculation or power calculation?			
9. **Analysis**: Are the statistical methods appropriate?			
Criteria for Intervention Studies. Followed same criteria as above, in addition assessed:	**YES**	**NO**	**Unclear**
1. **Allocation Bias**: i) Is the method of random allocation stated? ii) If the method of random allocation is stated is it appropriate? iii) Was the method of random allocation reported as concealed?			
2. **Blinding**: Was (were) the outcome assessor(s) blinded to the intervention of participants?			

Criteria for Intervention Studies	**YES**	**NO**	**Unclear**
3. **Intervention Integrity**: i) What percentage of participants received the allocated intervention or exposure of interest? ii) Was the consistency of the intervention measured? iii) Is it likely that subjects received an unintended intervention (contamination or cointervention) that may influence the results?			
Qualitative Studies			
Criteria (Mays & Pope, 1996; 2005)	**YES**	**NO**	**NA**
1. Did the researcher take into account the theoretical framework and methods throughout the research?			
2. Is the research question clear? Is the design of the study an appropriate approach to answer the question?			
3. Was the context clearly described?			
4. Was the sampling strategy clearly described and justified? Was the sampling strategy theoretically comprehensive to ensure generalizability of the analysis? a. For example, was there a diverse range of individuals and settings?			
5. How was the fieldwork undertaken, and was it described in detail? Were data collection and analysis procedures systematic and clearly described?			
6. How were the themes and concepts identified from the date? How well did the analysis succeed in incorporating the observations, and to what extent did the analysis develop concepts and categories in order to explain key processes or participants accounts or observations?			

<table>
<tr><th>Criteria (Mays & Pope, 1996; 2005)</th><th>YES</th><th>NO</th><th>NA</th></tr>
<tr><td>7. Was it possible to follow the iteration between the data and the explanations of data (i.e. theory)? Did the researcher actively search for opposing cases in the data?</td><td></td><td></td><td></td></tr>
<tr><td>8. Was a sufficient amount of evidence provided so the reader could assess whether analytical criteria were met? Did the researcher self-consciously assess the likely impact of the methods used on the collected data?</td><td></td><td></td><td></td></tr>
<tr><td colspan="4">Mixed Method Studies</td></tr>
<tr><td>Criteria (Pluye et al., 2009)</td><td colspan="3">Score out of 10</td></tr>
<tr><td>1. Justification of the mixed methods design</td><td colspan="3"></td></tr>
<tr><td>2. Combination of qualitative and quantitative data collection-analysis techniques or procedures</td><td colspan="3"></td></tr>
<tr><td>3. Integration of qualitative and quantitative data or results</td><td colspan="3"></td></tr>
</table>

Appendix D: Data Extraction Findings

Table D1 Data Extraction: Population, Aim & Design

Author	Date	Target Pop.	Type of TX/Time since TX	Sample	Aim	Design
Altschuler	2009	Women with CRC and ostomy	Survivors five years post surgery	30 women	To understand how a range of aspects of intimacy and sexuality are affected by having an ostomy as a result of CRC.	Mixed Methods
Andersson	2010	Women with rectal CA & colostomy, still at work.	Survivors 1-6 years post surgery	5 women	To describe the experiences of women living with a colostomy as a result of rectal CA.	Qualitative
Au	2012	Men and women with Rectal CA who had surgery.	Short-term survivors. Diagnosed 1-3 years previous. 52% had surgery only.	120 32 women / 88 men	To examine relationships between two health-seeking behaviours spirituality and resourcefulness, as well as demographics, cancer-related factors and sexuality indicators.	Cross Sectional
Ball	2011	Women following rectal CA TX	Survivors	9 women	To understand sexual dysfunction following rectal cancer treatment.	Qualitative

Author	Date	Target Pop.	Type of TX/Time since TX	Sample	Aim	Design
Ball	2013	Men 2 years post TX for rectal CA	Survivors, median 6.4 years. Surgery 100%, 53% chemo, and 38.5% RT.	13 men	To understand men's perceptions of how RC treatment impacts their sexual functioning and how men manage sexual dysfunction. Also to receive feedback about utility of intervention.	Qualitative
Cotrim	2007	Men and women with CRC	Short-term survivors, all had TX within 6-8 months. 30% had ostomy.	153 103 men /50 women)	To assess the impact on quality of life of patients with colorectal cancer undergoing surgery.	Cross Sectional
Da Silva	2008	Women who had either pelvic or abdominal surgery for CRC	Short term Survivors- 6 to 12 months post surgery. All had combined TX. 57% had stoma, 84% of which were closed.	93 women	To evaluate women's sexual function, self-esteem, body image, and quality of life after CRC surgery. A second aim was to compare the results between patients who had pelvic dissection with those without to assess sexual dysfunction.	Longitudinal

Author	Date	Target Pop.	Type of TX/Time since TX	Sample	Aim	Design
Dowswell	2011	Men with erectile dysfunction after surgery for CRC.	Unsure of timing. 85% Surgery, 71% chemo, 46% RT, 46% stoma.	28 men	To describe the experiences of men after surgery for CRC and to ascertain whether or not the provision of information could be improved.	Qualitative
Grant	2011	Men and women with CRC and ostomies.	Survivors. 5-27 years post diagnosis. All had surgery.	33 17 men / 16 women	To describe how gender shapes the concerns and adaptations of long-term CRC survivors with ostomies.	Qualitative
Milbury	2013	Men and women with CRC.	Survivors 1-6 years. 64% men RT, 46% women RT, 80% chemo, 100% surgery.	261 144 men / 117 women	The goal was to identify demographic, medical, and psychosocial risk factors that explain a significant proportion of the variance in male and female sexual function in CRC survivors.	Cross Sectional
Neuman	2011	Men and women with rectal CA and temporary stoma.	Short term survivors, 6 months after TX. 100% surgery	60 27 women / 33 men	The goal was to perform an in-depth exploration into patients' experiences to determine the impact of a stoma on their QOL.	Longitudinal

Author	Date	Target Pop.	Type of TX/Time since TX	Sample	Aim	Design
Neuman	2012	Men and women with rectal CA and temporary stoma	Short-term. 6 months after TX. 100% surgery	26 12 women / 14 men	To explore the experiences of patients with rectal cancer who have a temporary ileostomy to better understand the discordant findings of previous quantitative quality-of-life studies.	Qualitative
Nowicki	2011	Men and women with rectal CA and stoma.	Unsure of timing. 100% surgery. 100% combined TX.	50 20 women / 30 men	Self-assessment of physical rehabilitation and psychosexual problems in patients with rectal carcinoma and stoma was the main objective.	Cross Sectional
Ohlsson-Nevo	2011	Couples with CRC who lived with same partner for past year.	Short-term survivors. 100% had surgery one-year prior.	13 6 women / 7 men	To describe the first year after surgery from both the perspective of persons treated for CRC and partners.	Qualitative descriptive
Platell	2004	Women with rectal CA who has abdominal or pelvic surgery.	Short-term survivors. 6 months after surgery. 53% with temporary ostomy.	41 women22 rectal CA; 19 colon CA	The aim of this study was to evaluate sexual health in women undergoing pelvic surgery for rectal cancer.	Observational

Author	Date	Target Pop.	Type of TX/Time since TX	Sample	Aim	Design
Ramirez	2009	Women with CRC and ostomy.	Survivors at least 5 years post diagnosis	30 women	Explore a range of experiences related to sexuality among female survivors with permanent ostomies.	Qualitative
Reese	2012	Men and women with CRC, partnered.	Short-term survivors. 1-24 months. 22% had surgery, 11% SX and RT, and 67% had SX, RT, chemo.	14 couples 7 men / 7 women	To collect preliminary data on the feasibility and efficacy of the intervention.	Intervention
Sharpe	2010	Men and women with CRC	Short-term survivors. 6 months post TX. 31% stoma. 100% surgery.	99 61 men / 39 women	To investigate the effect of having a stoma on body image in patients with CRC and to determine whether disturbances in body image predicted distress.	Longitudinal

Author	Date	Target Pop.	Type of TX/Time since TX	Sample	Aim	Design
Schmidt	2005	Men and women with rectal CA who had surgery.	Short-term survivors. 12-18 months after surgery. 100% surgery, 45.2% RT and chemo. 7% unknown.	261 136 men / 125 women	To assess the patients' postoperative sexual function and quality of life over time, with special attention to the important factors that influence sexual function.	Cross Sectional
Schmidt	2010	Men and women with rectal CA who had surgery.	Short term survivors. 1 year post op. 100% surgery, 13.1% chemo, 48% RT.	368 185 men/ 183 women	To determine to what extent sexuality was influenced by surgery and what impact it had on perceived QOL. To determine how factors, such as age, gender, type of surgery influenced sexuality.	Longitudinal
Wirsching	1975	Men and women with CRC who had surgery.	Mix of short term and long-term survivors (1-30 years). 100% had surgery	330 116 men/ 98 women 214 study group ostomy 110 control	Compare those with permanent colostomy with those who do not. To report the preliminary findings comparing the patient's own assessment of his health, the preoperative emotional state, social contacts and change in sexual activities.	Mixed Methods

Appendix D: Data Extraction Findings

Table D2 Data Extraction: Outcome Measures and Findings

Author	Outcome Measures	Findings	Sex-Specific
Altschuler	Relationships between women's perceptions of partners support on HRQOL & how having an ostomy affected intimacy and sexuality.	Three themes: 1) Positive Support From Husbands; 2) Withdrawal of Support From Husbands; or 3) Mixed Support From Husbands or Partners. Most women described positive support from their husbands as being central to adjusting to changes in sexual life.	See findings
Andersson	Impacts of ostomy on daily life, relations, work, body image and sexuality.	Two Themes: Insecurity about life & A Bridge to Life. Sexual restrictions were not a big problem for the women and were something they could 'live with' as long as they viewed it as an opportunity to survive cancer.	See findings

Author	Outcome Measures	Findings	Sex-Specific
Au	Spirituality, resourcefulness, sexual function sexual self-concept communication and sexual relationship.	Lower resourcefulness was associated with lower spirituality, sexual satisfaction, and sexual self-concept. Spirituality was positively and significantly correlated with better communication ($p < 0.001$) and sexual relationship ($p<0.001$).	- Women: Spirituality was correlated with female sexual self-concept ($p=0.007$). - Men: Spirituality was correlated to male sexual self-concept ($p=0.000$).

Author	Outcome Measures	Findings	Sex-Specific
Ball (2011)	Determine usefulness of a sexual intervention for women following rectal CA.	Women reported that a sexual intervention would be helpful post TX because it would provide them with education of their sexual problems and treatments to help (n = 8, or 89%). Also expressed the benefit of being able to talk to a professional regarding anxiety, which negatively impacts their sexual health, post TX (n = 6, or 67%).	See findings
Ball (2013)	Men's concerns and expectations about sexual function, prior experiences with help for sexual function, preferences for receiving care to improve function & to assess utility of sexual intervention.	Four themes: Prioritizing cancer survival at diagnosis; diminished sexual and bowel functioning; desire for greater education regarding impact of treatment on sexual functioning; and endorsement of the psycho-educational health intervention. Men had not focused on potential impact of TX at the time of diagnosis. Interest in sex quickly reemerged once the fear of cancer diminished and side effects resolved. Men evaluated sexuality within their current life context, which facilitated coping.	See findings

Author	**Outcome Measures**	**Findings**	**Sex-Specific**
Cotrim	Psychological morbidity in stoma versus non-stoma, Psychological morbidity of patients, Body image / sexual satisfaction /marital satisfaction	A strong relationship between sexual satisfaction and marital satisfaction ($p<0.001$) was found in stoma patients', also found in non-stoma but it was lower. Non-stoma had a significant relationship between body image and both sexual and marital satisfaction ($p<0.001$). Regression analysis shows type of patient X body image is a predictor of QOL.	No sex-specific findings
Da Silva	Women's pre treatment and post treatment sexual function, self-esteem, mental health, body image, and physical health.	Self-esteem did not change significantly after surgery. Women with worse body image scores (10) had lower self-esteem (mean 14.3, n 8). Women with better self-esteem ($p=0.043$) and higher body image scores had significantly better sexual functioning. Body image improved over time, with changes at 6 months and significant improvement at 12 months compared to baseline ($p<0.05$). At 6 months, mental health scores were higher for patients with good body image scores and higher self-esteem. However, at 12 months patients who had a stoma and low sexual function scores also had lower mental health scores (mean 39.6).	See findings

Author	Outcome Measures	Findings	Sex-Specific
Dowswell	Beliefs about erectile dysfunction (ED), impact on self-perception and relationships, satisfaction with information, and experience of treatment.	Four themes: Experience of ED; Experience of TX for ED; Inadequacies of care, & information before during and after TX. The sexual experience was profound and stressful. Once men began to recover from the effects of cancer, many began to take an interest in ED. ED challenged the men's identities, affected mental health and undermined relationships. Some men accepted these changes philosophically and with a degree of stoicism.	See findings
Grant	Identify specific challenges ostomates face, adaptation processes, and the strategies they adopted for self care. QOL Similarities and Differences by Gender.	Four themes: Social, Physical, Psychological AND Spiritual well-being. Sexuality was coded 17 times across focus groups. One or two comments indicated sexual relationships were not problematic and a number of comments in each group about sexuality and intimacy problems related to complications of surgery or radiation therapy.	- Only women mentioned body image & depression. Women coded sexuality 5 times. - Men coded sexuality 11 times.

Author	Outcome Measures	Findings	Sex-Specific
Milbury	Sexual functioning, global QOL, psychosocial functioning, social support & dyadic adjustment	Sexual function was associated with better QoL (p<0.001). Those in a relationships scored higher on the sexual function scale compared to single participants (committed relationship, 40.74 vs. single, 14.15, p<0.0001). Better sexual function was associated with better QoL outcomes (-.27); dyadic adjustment (-.27); and body image scores (-.22). Mental health and marital satisfaction were notassociated with sexual function.	- Men: body image was not significantly associated with IIEF scores.
Neuman (2011)	Impact of stoma on QOL before treatment, before stoma reversal and 6 months after.	A statistically significant decrease in body image (p = .03) between baseline and stoma closure time points. Diminished body image persisted after stoma reversal. Sexual activity was the most commonly cited problem, 53% reporting ‘‘frequently’’ or ‘‘always,’’ and 20% reporting that they ‘‘occasionally’’ did not enjoy sexual activity. Discomfort in clothing was a problem for (34%), and feeling unattractive (31%).	No sex specific findings

Author	**Outcome Measures**	**Findings**	**Sex-Specific**
Neuman (2012)	Experience with the stoma, perceived impact of the stoma on QOL, and changes in perception if the stoma were to become permanent.	Two themes: Stoma-related difficulties & Perceived response shift. The impact of the ostomy on sexuality was variable, some reported no limitations, and others felt that their sexual activities were curtailed. Many emphasized clothing changes to accommodate the stoma. Stoma impacted patients' sexuality and body image, but also posed a physical challenge that needed to be negotiated. The response-shift theory argues that CRC patients accommodate by shifting the meaning of their evaluation of QOL.	No sex-specific findings
Nowicki	Patients' feelings about the psychosexual domain, reasons for cessation of sex.	One third stopped or limited their sexual relationships ($p < 0.05$). Both genders had shame and fear of dirt and unpleasant smell as reasons for limiting sexual relationships. Changes in sexual life occurred in the form of ceasing sexual relationships in 36%.	Men: Most common reason for cessation of sex: decreasing sex drive 95%. Women: Lower self-esteem (55%) influence sexual life for women ($P<0.05$).
Ohlsson-Nevo	Life in general, how cancer affected the couple and experience of support in connection with the illness.	One theme: Life is back to normal and yet not. Couples described a change in intimacy after surgery. Some couples could resume the same sex life, others had a different sex life and some had no mutual sex life at all. Sex was for some replaced by another form of intimacy and closeness. The absence of sexual intercourse made some feel incomplete.	No sex-specific findings

Author	**Outcome Measures**	**Findings**	**Sex-Specific**
Platell	Compare Body image, sexual awareness, libido, arousal, physical difficulties during intercourse and sexual activity among women with colon vs. rectal cancer.	Study group (rectal CA) more likely to experience feelings of being less attractive after surgery (p=0.039). Most were not distressed that their longing for sex had decreased in the past 5 years. Six in the study group felt moderately to severely distressed by the thought that their limitations in sexual activity. Decrease in sexual activity related to partner in five women. Many (n= 12) felt 'less attractive' / 'unglamorous'.	See findings
Ramirez	Experiences of Body image, gender, and sexuality	Four themes: No long-term sexual difficulties (n=11), Long-term sexual difficulties (n=7), Age-related changes in sexuality (n=3), and No partnered sexual experience post surgery (n=9). For some women, sexual changes created a great deal of emotional distress, but for others, it did not appear to be particularly problematic. Several women described orchestrated ostomy management techniques when engaging in sexual activity.	See findings

Author	Outcome Measures	Findings	Sex-Specific
Reese	Patient and spouses' sexual distress, sexual function, sexual communication, dyadic adjustment, and intimacy.	Intervention had large effect sizes (≥.80) for patients' sexual distress and sexual communication; a medium effect size (.30 to .60) for dyadic adjustment; and small effect sizes (.20 to .30) for intimacy.	- Women: Intervention had large effect size (≥.80) for female sexual function. - Men: Sexual function showed little improvement
Sharpe	Body image satisfaction, anxiety and depression, distress, effect of changes in stoma status over time on psychosocial outcomes, and differences between stoma versus non-stoma groups.	There was a significant difference between groups for body image disturbance (p=.0005) as stoma patients showed more body image disturbance (p =.001). There was a main effect for time (p=.007) and stoma (p=.004). Over time, those with an initial stoma became more disturbed about their body image (p<0.005). Body image disturbance predicts anxiety (p=. 046) and follow-up distress (p<0.001). There were significant differences between groups for anxiety, favoring the non-stoma group (p=. 02).	No sex specific findings

Author	Outcome Measures	Findings	Sex-Specific
Schmidt (2005)	Age and Differences in Sexuality and QoL, Gender Differences and QoL. How age, gender, type of surgery and adjuvant treatment impact sexuality.	Men and women with rectal cancer experienced limitations in their sexual life.	-Women: Comparing the effect of age on sexuality a correlation between age, sexual impairment, and sexual strain ($P < 0.001$) was found only in females. -Men: showed significant higher scores on "sexual impairment" and "distress caused by sexual impairment."
Schmidt (2010)	Long-term Functional QOL, symptom QOL and sexuality measured before surgery, at discharge and 3,6,12 and 24 months later.	Both sexes experienced an impairment of their sexuality, men more than women. Patients under 70 years old experienced a mild improvement of their sexuality over time, yet experienced stronger emotional distress due to impaired sexuality, and this distress worsened up to two years after surgery. Younger patients were found to be more severely affected than older patients by both of these over the entire period of time covered by the study ($p<.05$).	-Men: Emotional distress in men worsened up to 24 months after surgery ($p<0.05$).

Author	**Outcome Measures**	**Findings**	**Sex-Specific**
Wirsching	Compare 1) Patients own assessment of his or her health 2) The perioperative emotional state 3) Social Activity and 4) changes in sexual activities.	Loneliness was correlated with overall state of health, seldom leaving home, fear of reoccurrence and sexual activity(i.e. loneliness is correlated to no sexual activity).	Men: Some had sexual disturbance and expressed loss of self-esteem and feelings of castration. These men show higher rates of depression. Men w ostomies show severe decrease of intercourse rate. ($p < 0.01$). Women: Had worsening of martial relationships (linked with low sexual frequency) & a greater capacity to cope with alterations to sexuality.

Appendix E: Quality Apprasial Results: Guidelines

Domain / Guideline	CAPO 2009	IOM 2008	NBCC 2003	NICE 2011	NZGG 2011	NICE 2004	CCA 2005	ACBGI 2007	AHRQ 2006	NCCN 2013
Domain 1: Scope and Purpose (Scores 1-7)										
Objectives	5	6	7	7	7	7	7	7	7	7
Questions	7	7	6	7	7	4	7	4	7	2
Population	7	4	6	7	6	5	6	3	6	7
Total Percentage	88%	77%	88%	100%	94%	72%	94%	61%	94%	72%
Domain 2: Stakeholder Involvement										
Relevant persons	7	7	7	6	5	7	4	7	6	7
Views and preferences	7	7	7	7	6	7	6	2	5	4
Target users	7	5	7	7	7	5	6	3	5	7
Total Percentage	100%	88%	100%	94%	83%	88%	72%	50%	72%	83%
Domain 3: Rigor of Development										
Systematic methods	7	7	4	7	7	6	7	2	7	5
Selection criteria	7	5	1	6	7	5	7	1	7	2
Strengths /limitations	6	5	5	4	7	4	6	2	7	2
Formulating recommendations	6	5	3	7	7	6	6	4	4	7

Domain / Criteria	**CAPO 2009**	**IOM 2008**	**NBCC 2003**	**NICE 2011**	**NZGG 2011**	**NICE 2004**	**CCA 2005**	**ACBGI 2007**	**AHRQ 2006**	**NCCN 2013**
Domain 3: Rigor of Development										
Benefits, risks	5	6	6	7	6	4	6	5	7	7
Linkages	7	7	7	5	7	2	7	4	7	7
Expertly reviewed	7	7	7	7	6	5	7	2	3	7
Updating	4	1	5	4	4	3	5	5	7	7
Total Percentage	85%	73%	62.5%	81%	89%	56%	89.5	35%	85%	75%
Domain 4: Clarity of Presentation										
Specific	7	4	7	6	7	7	7	4	7	7
Differing opinions	5	6	7	6	5	4	5	4	6	7
Clarity	7	5	7	7	7	7	7	4	7	7
Total Percentage	88%	66%	100%	88%	88%	83%	89%	44%	94%	100%
Domain 5: Applicability										
Barriers/ facilitators	4	7	6	5	2	4	3	2	5	5
Advice/ tools	6	7	4	7	1	6	4	4	5	7
Resource implications	1	7	4	6	2	7	7	2	2	2
Monitoring /auditing	3	3	2	2	2	3	2	2	2	7
Total Percentage	42%	83%	66%	66%	12.5%	70%	50%	29%	42%	70%

Domain 6: Editorial Independence

Domain / Criteria	**CAPO 2009**	**IOM 2008**	**NBCC 2003**	**NICE 2011**	**NZGG 2011**	**NICE 2004**	**CCA 2005**	**ACBGI 2007**	**AHRQ 2006**	**NCCN 2013**
Views of funding body	7	4	4	7	4	4	7	1	1	7
Competing interests	7	2	2	7	7	4	7	1	1	7
Total Percentage	100%	33%	33%	100%	83%	40%	100%	0%	0%	100%
Overall Quality (Domain Averages)	**83%**	**70%**	**75%**	**88%**	**75%**	**68%**	**82%**	**36.5%**	**64.5%**	**83%**

Appendix F: Qualitative Case Descriptions

Altschuler (2009)

This study is part of a larger parent study where the authors conducted a mailed survey to 117 women. The aim of this study was to investigate the ways in which husbands and male partners affect psychosocial adjustment and HRQOL of female CRC patients with permanent ostomies in order to better understand how a range of aspects of intimacy and sexuality are affected by having an ostomy as a result of CRC. The authors used comprehensive sampling to identify a sample of 30 women to participate in this qualitative interview study. All women were heterosexual, 5 years post diagnosis with permanent ostomies. The city of Hope Quality of Life for Ostomy surgery provided the framework for this study. A semi structured interview guide was used to gain insight into the women's perceptions of their husbands or partner's support and their global HRQOL following ostomy surgery. Most women who participated were married/partnered at time of surgery (22/30). The analysis yielded 3 main themes: Positive Support from Husbands, Withdrawal from husbands or partners and Mixed Support from husbands or partners. Only husbands (not unmarried partners) were reported as providing positive support by women. Husbands were central to the provision of instrumental and emotional support allowing women to feel a sense of normalcy, allowing them to feel loved post-surgery and feeling as though the ostomy did NOT diminish their value as a woman. Women who reported their husbands withdrew post op experienced a negative impact on their adjustment to the ostomy. For women who received mixed support from partners felt sporadic support and withdrawal of attention. Overall findings suggest that partners' demonstration of support or lack thereof can considerably impact intimacy, sexuality and psychosocial adjustment for women with ostomies.

Andersson (2010)

This study aimed to describe the experiences of women living with a colostomy after rectal cancer surgery. A purposive sample of 5 women aged 60-65 years was selected. An interview guide was used to elicit life before cancer diagnosis, surgery itself, life after illness, living with the colostomy and its impact on daily life, relations, work, body image and sexuality. Thematic content analysis yielded 2 main themes. The first is Insecurity about life, which was broken up into 2 subthemes including: Feeling restricted by the colostomy and cancer is frightening. Women felt sad and scared about the cancer diagnosis and found it was hard to wait for examinations, treatment and the surgery itself. Women claimed the stoma had impacted their daily life in several limiting ways. Body image was a concern, choosing clothing was a particular challenge as clothes needed to fit in a way that concealed the bag. Sex was altered after surgery, the women claimed it was very important to have a good relationship in order to be able to discuss sexual issues; however, sex was often not possible because of scars and pain. Women hoped to receive help with sexual problems at a subsequent time. The second theme: A bridge to life, was broken into 3 subthemes including: receiving good information, being able to work again and a chance to survive. Overall the women viewed the stoma as a chance to survive and an opportunity to live, sexual and body concerns were not an immediate concern nor a serious issue for women.

Au (2012)

This secondary analysis used a cross sectional design to assess the relationships between HSBs (health seeking behaviours), demographic variables, cancer related factors, and indicators of sexuality in patients with rectal cancer. This study used Schlofeldt's health seeking model as a guiding framework. 120 participants (32 women/ 88 men) were in this study. 96% were married, 63% had been diagnosed with rectal cancer 1-3 years previously. All had undergone either abdominoperineal resection or low anterior resection for rectal cancer. Some were receiving adjuvant treatment at the time of the study. Six measures were used and included examinations of resourcefulness, spirituality, sexual self concept, sexual satisfaction, sexual relationship and female & male sexual functioning. Overall findings showed that spirituality was positively and significantly correlated with better communication ($r = 0.47$, $p < 0.001$), sexual relationship ($r = 0.48$, $p < 0.001$), male sexual self-concept ($r = 0.44$, $p = 0.000$), and female sexual self-concept ($r = 0.47$, $p = 0.007$), indicating that both men and women with a lower sexual self-concept, less communication, and a less satisfactory sexual relationship had low spirituality. Resourcefulness was significantly and positively associated with better communication ($r = 0.22$, $p = 0.017$), more satisfying sexual relationship ($r = 0.43$, $p = 0.001$), and more positive sexual self-concept in men ($r = 0.36$, $p = 0.001$) and women ($r = 0.5$, $p = 0.004$). The findings indicated that men and women who had greater resourcefulness had higher scores on measures of sexual satisfaction and sexual self-concept. Women were noted to have greater overall resourcefulness when compared to men ($p=0.005$). Overarching finding of this study was the fact that lower resourcefulness was associated with lower spirituality, sexual satisfaction, and sexual self-concept in both genders.

Ball (2011)

This qualitative study aimed to better understand women's experience with sexual dysfunction following rectal CA treatment, and to investigate barriers and promoters that could influence their participation in an intervention for sexual health. Seven women partook in semi structured interviews and two women participated in a focus group for a total of nine participants. Findings showed that survivors feel as though an intervention via telephone would be helpful to enhance QOL post TX and would improve their sexual function. Participants expressed the benefits of being able to talk to a professional regarding anxiety. Barriers included geographical distance to the clinic and risk of embarrassment.

Ball (2013)

The aim of this qualitative study was to understand men's perceptions of how rectal cancer treatment impacts sexual functioning and how men manage sexual dysfunction. Secondary goals were to seek feedback regarding the content and utility of a proposed sexual health intervention. Semi structured interviews and focus groups were used as methods of data collection. Thirteen men participated, 6 participated in interviews, 7 in focus groups. Interviews and focus groups were focused on exploring the sexual experiences of men post treatment. Thematic analysis of the transcripts showed four primary themes including: prioritizing cancer survival at diagnosis, diminished bowel and sexual functioning, desire for greater education regarding impact of cancer treatment on sexual function, and endorsement of the psycho-educational health intervention. Sexual dysfunction was common among 92% of participants, and many attributed erectile dysfunction to age not TX. Participants viewed their sexual dysfunction within their current life context. The study found that participants prioritized survival at the time of diagnosis; however interest in sex quickly emerged once post-treatment side effects were resolved. Men reported learning methods of coping with dysfunction over time. This included acceptance of their current level of decreased sexual function and adjusting their expectations. Participants reported avoiding initiating the topic of sexual functioning with their healthcare providers due to embarrassment surrounding their sexual needs. They were interested in educational information regarding how to improve sexual functioning after cancer treatment.

Cotrim (2008)

The aim of this cross sectional study was to identify and assess the impact of surgery on QOL of colorectal CA patients while simultaneously assessing the burden of the illness on families of patients. Participants answered a set of surveys 6-8 months post op including surveys to assess QOL, body image, sexual satisfaction and anxiety and depression. Caregivers were also recruited and answered questionnaires pertaining to burden, depression, and anxiety. About 28.1% of participants had been submitted to surgery, 48.4% surgery and chemotherapy and 22.2% surgery, chemotherapy and radiotherapy. Approximately 30.1% had undergone ostomy surgery. Results of the 133 participants (103 men/50 women) were analyzed according to stoma vs non-stoma. Stoma patients had more depression ($P = 0.003$) than non stoma patients (mean = 9.80 (75.87). There were no significant differences between the groups in terms of anxiety. A strong relationship between sexual satisfaction and marital satisfaction (P<0.001) was found in the stoma patients' group. In the group of non-stoma patients, a relationship was also found but it was lower (P<0.001). In the latter group, a significant relationship between body image and both sexual and marital satisfaction was found (no raw data). Linear regression revealed that body image corresponded to overall emotional and physical QOL. For the interaction Type of Patient X Body Image, when there is more dissatisfaction with body image, stoma patients present a worse quality of emotional life when compared with non-stoma patients (-0.360). Sex/ gender was not found to have any significant correlation with the variables. Results in the present study showed that stoma patients have decreases in their functionality, more symptoms, worst general health and overall quality of life when compared with non-stoma patients. There were also significant differences in sexual function, social life, body image and psychological morbidity between the two groups.

Da Silva (2008)

The aim of this cohort study was to prospectively evaluate women's sexual function, self esteem, body image, and HRQOL after CRC surgery. A second aim was to compare the results between patients who had pelvis dissection to those without to assess whether pelvic dissection would impose greater risk for sexual problems. 93 women were evaluated using 3 different questionnaires at six and 12 months post-surgery. 61.3 % of participants underwent pelvic and 38.7% underwent abdominal procedures. 57 patients had a stoma; 84% were temporary and 15 % permanent. The majority were married (79%) and Caucasian (85%). Main outcome measures included sexual function, self esteem, body image and general health. Findings showed that there was a significant deterioration in sexual functioning (p=0.02). Self-esteem did not differ between groups nor showed a significant change post op. Body image improved with significant changes at 12 months (p=0.05), this was more pronounced in the pelvic group (p=0.037) who had worse body image going in to surgery. At 12 months, those not demonstrating a worsening in sexual function, and whose mental ability scores largely improved by at least 11.3 points, tended to show a large improvement in body image score (mean change= 13.3). Although patients with stoma tended to have worse body image, this was not statistically significant (P= 0.06). Those with better self-esteem and body image scores had significantly better sexual functioning (p=0.043). Superior sexual functioning was seen in participants w higher MCS and PCS scores. The different surgical procedures were compared there showed no statistically significant difference. Over 80% of participants stated it is extremely or somewhat important to discuss sexual issues pre-operatively.

Dowswell (2011)

This qualitative study aimed to examine the experiences of men after treatment for CRC and to identify barriers to accessing services, and suggest improvement to providing information in primary and secondary care. Purposive sampling was used to select 28 men treated for CRC. Participants varied in age, IIEF scores, adjuvant therapy, and stoma status. Most participants were white, married, and heterosexual. Semi structured interviews were conducted to elicit the men’s beliefs and experiences on ED as the interviews focused on beliefs on ED, impact on self perception and relationships, satisfaction with info and experience of treatment. Thematic analysis showed that men often attributed ED to the effects of treatment for colorectal cancer, psychological factors or age. Men often did not deal with ED before and during treatment because fighting cancer was the main objective. It wasn't until the aftercare stage when men began to recover where many took an interest in ED and at this point many were unsure of where to turn to for information. Profound and stressful consequences were reported as erectile dysfunction challenged the men's identity, affected mental and physical health, and undermined relationships. 13/28 men never sought help for ED while 9/28 sought no further help after unsuccessful treatment. Reticence was the most common explanation for not seeking help. This encompassed simple embarrassment (four men), a lack of confidence, a general fear of looking stupid, and waiting to be asked rather than raising the subject themselves. Participants believed HCPs were too busy, not interested in ED or that ED was offensive or was not on the clinical agenda and therefore they did not seek help. Of those who did ask for help with ED men's experiences were diverse, some were given treatment with success while others were unsuccessful in their attempt to treat ED. The authors recommend patients be subjected to care pathways similar to those with prostate cancer.

Grant (2011)

This qualitative study aimed to describe how gender shapes the concerns and adaptations of long-term CRC survivors (greater than 5 years) with ostomies. 33 participants (17M/16W) formed 4 female (2 HRQOL and 2 LQOL) and 4 male focus groups (2 LQOL & HQOL). Most participants were white and married or partnered. Focus groups were conducted to identify specific challenges ostomates face, their adaptation processes, and the strategies they adopted for self-care. Content analysis was based on the City of Hope 4 dimensional framework, data were placed into four domains including physical, psychological, social and spiritual well-being. Findings were described by gender and high vs. low related quality of life. Men and women identified specific challenges with sexuality and intimacy (under the social well-being domain) and sexuality was discussed across all focus groups, with one or two comments that indicated sexual relations were not problematic and a number of comments in each group about sexuality and intimacy problems related to complications of surgery or radiation therapy. Sexual issues were coded 6 times by the HQOL men's group, 2 times by the HQOL women's group, 5 times by the LQOL men's group, and 3 times the LQOL women's group. Modifying clothing worn (i.e. wearing clothing so the ostomy pouch was not visible) was a topic discussed in all the groups. Body image was discussed under the theme of psychological well-being; however only women in the low HRQOL group.

Milbury (2013)

This cross sectional study aimed to identify demographic, medical, and psychosocial risk factors that explain a significant proportion of the variance in male and female sexual function in colorectal cancer survivors. Patients who received surgery at least 6 months prior and completed treatment at least 1 month prior were eligible. A total of 261 (144 men/ 117 women) patients participated. Sexual function, QOL, depression, anxiety, dyadic adjustment, psychological distress, and medical outcomes were assessed. The EORTC QLQ CR-38 was used to capture global QOL. Findings show that men were more likely to be in a committed relationship compared to women. 65.5 % of men had ED while 42.3 % of women had sexual dysfunction. Men had higher sexual satisfaction scores compared to other studies while women had poorer satisfaction scores. Both men and women in a committed relationship scored higher on the CRC QLQ-38 "sexual function" scale compared to single participants ($P<0.0001$). Interestingly, mental health and marital satisfaction were not significantly associated with IIEF or FSFI scores. With older age, sexual function decreased, both men and women of older ages had lower sexual function scores and less sexual enjoyment. Sexual outcomes subscales were correlated with global QOL scales showing that sexual function was associated with better QOL ($p<0.01$). Better sexual function was associated with: better QOL outcomes (-.27); dyadic adjustment (-.27); body image (-.22); global QOL (-.32). For men, body image was not significantly associated with IIEF scores. Women reported less sexual enjoyment than men (women, 52.0 vs. men, 66.7, $P<0.007$). For men and women, increasing age was significantly correlated to sexual function.

Neuman (2011)

This cohort study is the first half of a large mixed methods study. It prospectively evaluated QOL for patients with rectal cancer undergoing sphincter-preserving surgery (SPS) with a temporary diverting stoma. The goal of this study was to perform an in-depth exploration into patients' experiences to determine the impact of a stoma on their QOL. Main outcome measures included: HRQOL (EORTC QLQ-C 30 & EORTC CR-38), work/social function, financial impact, skin irritation, sexuality/body image, and stoma function (SQOL scale). 60 (27 women/ 33 men) participants with stage I-III rectal cancer completed the QOL questionnaires pre-op, at stoma closure, and 6 months later. 72% were married, most (90%) had neoadjuvant therapy, and 82% underwent chemotherapy. Longitudinal data showed that sexual activity was the most commonly cited problem, with 53% reporting ‘‘frequently’’ or ‘‘always,’’ and an additional 20% reporting that they ‘‘occasionally’’ did not enjoy sexual activity. Additional areas of difficulty reported as ‘‘frequently’’ or ‘‘always’’ included concerns about leakage (39%), discomfort in clothing (34%), worry about privacy in emptying the pouch (32%), and feeling unattractive (31%). Further a statistically significant decrease in body image (P = .03) was observed between baseline and stoma closure time points; the mean change was 9.2. Diminished body image persisted after stoma reversal. A significant correlation was also observed for work/social function, sexuality/body image, and stoma function subscales ($p<0.01$). Overall, stoma-related difficulties were present despite the reportedly good global QOL reported by study participants. Areas of particular concern were sexuality, body image (difficulty with clothing, feeling unattractive), and practical concerns related to the stoma itself, such as finding privacy to empty the pouch and problems with leakage.

Neuman (2012)

This qualitative study is the second part of a larger mixed methods study aimed to explore the experiences of patients with rectal cancer who have a temporary stoma in order to better understand the discordant findings of previous quantitative QOL studies. 26 (12 women/14 men) participated in interviews to examine patients’ preoperative expectations regarding the temporary stoma, their overall experience with the stoma, the perceived impact of the stoma on their QOL, and changes in perception if the stoma were to become permanent. Two major themes were identified through the content based analysis including: stoma related difficulties and perceived response shift. Stoma related difficulties included: limitations in exercise and recreational activities, sleep, body image, sexuality, and social activities, as well as a number of issues specific to caring for the ostomy. Sexuality was identified as a key stoma related difficulty, although the impact of the ostomy on sexuality varied. Some reported difficulties based on personal or partner preferences, while others reported no limitations. Overall, the stoma impacted patients' sexuality and body image, but also posed a physical challenge that needed to be negotiated. Patients emphasized clothing changes to accommodate the stoma. Several categories emerged during the qualitative analysis suggesting that patients' perception of their QOL may have "shifted" during their time with a temporary stoma. Findings showed evidence of a complete reconceptualization of what QOL means, as well as a recalibration of the internal scale on which patients measured QOL. Although patients acknowledged a number of difficulties related to living with a stoma, these were felt to be less significant when interpreted within the context of their cancer diagnosis and the associated risk of cancer-related mortality.

Nowicki (2011)

The aim of this cross-sectional study was to assess physical rehabilitation and psychosexual problems of patients with rectal cancer and a stoma. 50 patients (20 women/30 men) with stomas were given a 24 item survey pertaining to social-demographic data, patients' assessment of physical rehabilitation and their feelings about the psycho-sexual domain. All participants had undergone combined treatment procedures, although some had a temporary stoma while others had a permanent stoma. Measured outcomes included patient's knowledge about rehabilitation, self assessment of physical rehab, intensity of emotions and psychosexual disturbances. Findings showed that the patients' lifestyle changes radically after stoma creation in most cases. Changes in sexual life after stoma creation occurred in the form of ceasing sexual relationships in 18 patients (36%) ($p<0.05$). Sex life was unchanged for 32%. Decreasing sex drive was the most common reason among men and women for cessation of sex (Men: 95% Women: 70% $p<0.05$). Deterioration of self-esteem was another main reason for limitation or cessation of sexual contact by women (55% of women: $p<0.05$) although not among men (16%). Other reasons included fear shame, fear of smudging and unpleasant smell, and depressive mood. Women were more concerned with their partners acceptance compared to men (40% v. 7%). Above half of men (62%) would not be ashamed of searching for help in order to resolve their sexual problems. 92% of patients did not use advice from psychologists or sex therapists.

Ohlsson-Nevo (2011)

This qualitative study aimed to describe the experience of life the first year after surgery from both the perspective of persons treated for CRC and their partners. Participants were men and women and their partners who had undergone CRC surgery one year previously. Seven patients were men and six were women. A total of 13 hetero sexual couples participated, five with rectal cancer and eight with colon CA. Six had a stoma. Patients and partners were interviewed separately, an interview guide was used to ensure covering issues such as life in general, how the diagnosis had affected relationships in the marriage and social life, and the experience of information and support in connection with the illness. Content analysis revealed one main theme: “Life is back to normal and yet not” with three subthemes: ‘Life has a shadow of death’, ‘The treated body sets the rules’, and ‘To share or not share the illness’. Both patients and their partners described a change in intimacy after surgery. Some couples could resume the same sex life, others had a different sex life and some had no mutual sex life at all. Sex was for some replaced by another form of intimacy and closeness. Male patients could have erection problems, and female patients could experience sex differently after surgery with less sensitivity or too much pain for sexual intercourse. The absence of sexual intercourse made some patients feel incomplete, missing an important part of life, but none of the partners expressed it as a great loss. Partners felt as though sexual problems were the patient’s responsibility and did not want to pressure them to seek medical advice. Overall, this study highlights that sexual activity of both patients and partners is often affected. Patients suffered from the loss, while the partners expressed an indifferent attitude towards the change.

Platell (2004)

This case control study aimed to document the prevalence of sexual dysfunction in women after low anterior resection or abdominoperineal resection for rectal cancer. Women with colon cancer (who had not received pelvic surgery) acted as the control group while women with rectal cancer acted as the study group. All participants in the study group had undergone surgery for rectal cancer and were disease free at least 6 months after surgery. Those in the study group were significantly younger than the control group. A total of 41 women participated in the survey which included outcome measures such as body image, sexual awareness, libido, arousal, physical difficulties during intercourse and sexual activity. There was no difference between the groups in relation to overall satisfaction with their sexuality and sex life, and the influence of their sexual difficulties on well-being. Findings showed that 9/22 in the study group were not sexually active, 6 of whom were not interested. With regards to questions on body image and sexual awareness, patients in the study group were significantly more likely to experience feelings of being less attractive after surgery (p=0.039). However, there were no significant differences between the groups in terms of taking the initiative in sexual activities, satisfaction with their partner as a person and as a lover, views on the importance of sex, thoughts of sex over the past 6 months, and whether their longing for sex had declined since surgery and what impact this had on their lives. A majority of women in both groups were not at all distressed that their longing for sex had decreased during the past 5 years. However, six of the 22 rectal CA women felt moderately to severely distressed regarding their sexual limitations. The reduction in sexual activity was related, to some degree, to their partner in five women. A common comment pertaining to sexual health made by participants in both groups was that the woman felt less attractive or ‘unglamorous’ owing to physical scarring which influenced self-esteem and sexuality.

Ramirez (2009)

This exploratory, phenomenological qualitative study was part of a larger mixed methods parent study to measure HRQOL among CRC survivors. An anthropological perspective was used as a guiding framework. Younger women were targeted to participate in this study (younger than 60 yrs.) although the median age of participants was 74. 30 women participated, all of who were 5 year + survivors with permanent ostomies. Semi structured interviews focusing on body image, gender, and sexuality were conducted. Analysis was done using grounded theory and findings revealed four different groups of sexual experience: 1) No long-term sexual difficulties N=11, 2) Long-term sexual difficulties N=7, 3) Age-related changes in sexuality N=3, 4) No partnered sexual experience post surgery N=9. Group 1: Women in this group reported that their ostomies did not interfere in the long-term with their sexual participation, which was primarily discussed in terms of heterosexual intercourse. Partner status in this group varied. Some were currently sexually active with partners, while others were not. Most experienced difficulties shortly after their surgery, but were ultimately able to resume intercourse with only a few minor modifications. Ostomy management was critical before sexual activity using strategies such as cleaning, changing the bag or hiding the bag. Many women attributed their ability to resume sex to their supportive spouse/partner. Group 2 experienced significant difficulty with pain or inability to have sex due to treatment affects and physical changes. Some were distressed by this while other did not find it particularly distressing. Some were able to orchestrate new levels of sexual activity that felt manageable for their changed bodies. Group 3 represented women who were partnered and reported that sex was no longer important to maintain a harmonious martial relationship. Their discussions of how sexuality had changed did not revolve around surgical difficulties but reflections on how getting older has affected the physical expressions of sexuality, although aging did not appear to affect the care and intimacy shown to one another. Group 4 reported that they had not engaged in any partnered sexual activity post surgery. While all had been involved in sexual relationships earlier in their lives, most did not have partners at the time of their surgery. The women in this group tended to believe that having an ostomy would make it exceedingly difficult to have a sexual partner. Other women in this group were older and widowed when they had their surgery. They did not resume sexual relationships, believing that this time of their life had passed. Ultimately, the surgery allowed these women to continue living. As such, altered sexual participation with partners or having no partner seemed a reasonable trade off as many believed they had a lot to live for.

Reese (2012)

This pilot feasibility study was concerned with collecting preliminary data on the feasibility and efficacy of an intervention that targeted sexual concerns of CRC patients and their partners. The intervention included 4 weekly sessions and was designed to help couples make cognitive and behavioral shifts in their intimate relationships. Participants were patients who had undergone treatment for CRC and their partners. All had some degree of sexual concerns which were assessed prior to the intervention. There were 4 telephone based interventions focused on intimacy enhancement. Participants were measured before participation and on completion. Outcome measures included sexual distress, sexual function, sexual communication, intimacy, and dyadic adjustment. A total 9 couples (5 men/4 women patients) completed all 4 interventions. Findings showed large effect sizes (≥.80) for sexual distress, female sexual function, and sexual communication; a medium effect size (.30 to .60) for dyadic adjustment; and small effect sizes (.20 to .30) for intimacy. For male patients, male sexual function showed little improvement. Data from spouses shows large effect sizes (>.80) for female sexual function and medium effect sizes for sexual distress, male sexual function, sexual communication, intimacy and dyadic adjustment. Overall, all of the outcomes saw some form of positive impact from the intervention. The majority of the participants had practiced skills taught in the program during the week they completed the post treatment measures. The skills that emerged as the most helpful to participants were those that were behavioral in nature and that were most heavily emphasized throughout the program, including communication, engaging in sensual touching and other intimacy-building activities, and trying new sexual activities. This study offered an examination of the preliminary efficacy of this protocol. Effect size analyses showed large to medium effects on nearly all sexual and relationship outcomes, with the largest improvements seen for sexual distress, sexual function for female participants, and sexual communication.

Schmidt (2005)

This retrospective (historical) cohort study aimed to determine to what extent sexuality was influenced by surgery and what impact it had on perceived QOL among patients at least 12-18 months post surgery for rectal cancer. Consecutive historical cohorts were identified by mailing all patients alive 1 year post op the QOL questionnaire (EORTC QLQ c-30) and tumor specific module. Main outcomes measures included HRQOL, functional status, role function, general symptoms, cognitive, emotional, social functioning, financial strain, fecal incontinence, diarrhea, sexual disorders, strain through impaired sexuality, and colostomy- related problems. A total of 261 patients (136 men/

125 women) responded to the survey. Participants had undergone various treatments/surgeries. Findings compared type of surgery and quality of life, gender differences and QOL, age difference in sexuality and QOL and adjuvant therapy and complications. Both men and women experienced limitations in sexual life but men had significantly high scores compared to women. There was a correlation between age, sexual impairment and sexual strain ($P<0.001$) but only in women. Women under 65 suffered more from impaired sexuality and distress from dysfunction compared to women over 65. This was not observed in men. Male patients showed significant higher scores on “sexual impairment” and “distress caused by sexual impairment.”($p<0.05$). Adjuvant therapy had an effect on the patients general QoL but not on their sexuality. Overall, significant differences were seen between females and males.

Schmidt (2010)

This aim of this longitudinal study was to assess rectal cancer patients’ postoperative sexual function and quality of life over time, with special attention to the important factors that influence sexual function. A total of 368 (183 women/185 men) participated. The EORTC QLQ C 30 and the supplementary module was used to assess Quality of life was through questionnaires administered at discharge from the hospital, 3, 6, 12, and 24 months later. Two questions specific to sexuality were also posed to participants. Outcome measures included comparing sexuality between men and women, and comparing age groups and surgical techniques. Both sexes experienced an impairment of their sexuality, men more severely than women ($p<0.05$). The associated emotional distress in men worsened up to the last time point 24 months after surgery; in men, the values for emotional distress were significantly worse at 24 months than at 3 months ($p<0.05$). Patients under 70 years old experienced a mild improvement of their sexuality over time, yet they nonetheless experienced stronger emotional distress due to impaired sexuality, and this distress worsened up to two years after surgery ($p<0.05$). The comparison of the two surgical techniques, AR and APR, revealed that patients who underwent APR experienced a significantly worse impairment of sexuality than patients who underwent AR ($p<0.05$). Emotional distress was greater in the APR patients than in the AR patients. Overall, women were especially burdened by the medical treatment itself, while, for men, impaired sexuality played a major role and was also associated with greater emotional distress than in women.

Sharpe (2011)

This prospective cohort study aimed to determine whether having a stoma is associated with increased body image disturbance, and whether body image disturbance predicts other psychosocial outcomes for CRC patients. A total of 79 patients participated, 25 had a stoma, and 54 did not have a stoma. Patients were measured at two points: within 9 weeks of surgery and at the end of adjuvant treatment (approximately 6 months). Main outcome measures included: body image, depression, anxiety and distress. Participants were analyzed according to stoma status (stoma v. non stoma), and results were compared between groups. Findings show that stoma patients showed more body image disturbance at baseline ($P=.001$). However, there were no significant differences at baseline for anxiety, depression, or general distress. At 6 months post op the stoma group maintained significantly worse body image ($P=.0005$). There was also a significant difference for anxiety, non-stoma patients demonstrated higher levels of anxiety compared to stoma patients (p=0.02) but not depression or general distress (P=.08). Furthermore a time X stoma effect was uncovered. Over time, those with a stoma became more disturbed about their body image. According to the multiple regression analysis stoma status did not significantly predict depression (P=.417). However, body image disturbance did significantly predict baseline depression (P=.0005), and it accounted for 22% of the variance in depression. Similar findings were found for anxiety, body image disturbance accounted for a 28% variance in baseline anxiety levels. Overall- patients who had a stoma reported more body image disturbance than those who did not. There was no improvement in body image disturbance over time, rather body image disturbance increased at follow-up in the stoma group whereas the reverse was true in the group without a stoma. Body Image disturbance was shown to be a predictor of levels of anxiety and distress after treatment.

Wirsching (1975)

This mixed methods study was conducted to compare 330 (116 men / 98 women) patients with permanent colostomies to those without through questionnaires and interviews. Outcome measures included self-reported health questionnaires were used to examine the patient's own assessment of his health, the preoperative emotional state, social contacts and change in sexual activities. This study used a control and study group; the study group comprised of 214 men and women who had surgery for CRC with ostomy formation, the control group was comprised of 110 men and women who surgery but NO colostomy. The 200 item Heidelberg colostomy questionnaire examining multiple items including sexual activities was used. Emotional state after surgery was shown to be statistically worse in colostomy patients for depression ($p<0.001$). This was particularly prevalent among young women. Sexual intercourse was shown to be worse among men colostomates ($p<0.001$) as 25% of male colostomates had no decrease in intercourse compared to 61% in the control group. Linkage analysis shows that life age, loneliness, and telling other of being a colostomist for women with worsening of martial relationships is linked with low frequency of intercourse in the age of 30 -40. Time since operation resumption of work, social activity and occurrence of spillage are also related to sexual activity. The assumption of the authors is that men must express loss of self-esteem and feelings of castration as these are revealed in the findings. These men show higher rates of social impotence, negative social resonance and depression. Among women there is no difference among colostomy patients on control group, which can lead to the assumption that women cope more effectively with lost sphincter control.

Appendix G: Tabulation Tables for Data Analysis

Items	Author A	Author B
Year		
Setting		
Location		
Target Population		
Type of Treatment/Time since Treatment		
Aim		
Study Design		
Theoretical Framework		
Outcomes		
Findings		
Gender-Specific Findings		
Quality Grade		
Direction of Effect (if applicable)		

Appendix H: Groupings and Clusters

Table H1 Findings specific to men

Author	Date	Target Population	Type of TX/Time Since TX	Sample Characteristics	Aim	Study Design	Outcome Measures	Key Findings	Direction of Effect (if applicable	Apprasial Score
Ball	2013	Men who were at least 2 years post-TX for stage I-III rectal cancer with an anastomosis at 15 cm or below, no evidence disease or recurrence, were 21-years of age or older, and spoke English.	Median post-TX time was 6.4 years; types of TX that participants received included: surgery (n=13; 100 %), chemo (n=7; 53.8 %), and RT (n=5; 38.5 %). 7/ 13 participants had temporary ostomies that were reversed prior to enrollment.	13 MEN. Caucasian (n=13; 100 %); 57 % percent were married, and 87 % were college educated. Ages 47-82.	To understand men's perceptions of how RC treatment impacts their sexual functioning and how men manage sexual dysfunction. Second, we sought to receive feedback about the content and utility of our proposed psycho-educational sexual health intervention.	Qualitative exploratory	Concerns and expectations about sexual functioning post-rectal cancer therapy, Prior experiences and satisfaction with help for post-cancer sexual function, Preferences for receiving education in improving sexual function & to assess content and utility of proposed sexual intervention.	**Priortizing cancer survival at diagnosis; diminished sexual and bowel functioning; desire for greater education regarding impact of treatment on sexual functioning; endorsement of the psycho-educational health intervention.** Participants said they had not focused on potential impact of cancer TX at the time of diagnosis. However, the interest in sex quickly reemerged once the fear of cancer diminished and other post-treatment side effects were resolved. Participants seemed to evaluate sexuality within their current life context. (i.e. most of the men attributed their sexual dysfunction to age), which facilitated their coping.	NA	Moderate
Dowswell	2011	Men with erectile dysfunction after surgery for colorectal cancer	Surgery/Chemo/RT complete--unsure of timing. Most had undergone colorectal cancer surgery (n=24). Chemo (n=20), RT (n=13), Stoma (n=13).	28 MEN-- ages 29-80; Most were married, white, and heterosexual. 9 had rectal cancer. IIEF scores varied.	Describe the experiences of men after surgery for CRC and to ascertain whether or not the provision of information could be improved so that it is flexible, responsive to individuals coping strategies and information choices.	qualitative: interviews/ thematic analysis	Beliefs about erectile dysfunction, impact on self perception and relationships, satisfaction with information, and experience of treatment.	THEMES: **Experience of ED; Experience of treatment for ED; Inadequacies of pt care, & information before during and after cancer tx.** The experience was profound and stressful for men. 2 men associated the casual factors of ED with ED to be associated with the undermining of their masculinity. ED challenged the mens identities, affected mental health and undermined relationships. One extreme-suicide was contemplated. A minority of men accepted these changes philosophically and with a degree of stoicism. When the men began to recover from the effects of cancer and its treatment, many began to take an interest in ED. Experiences w treating ED were diverse.	NA	Moderate

Table H2 Findings specific to couples

Author	Date	Target Population	Type of TX/Time Since TX	Sample Characteristics	Aim	Study Design	Outcome Measures	Key Findings	Direction of Effect (if applicable)	Apprasial Score
Ohlsson-Nevo	2011	Patients who had undergone CRC surgery one year previously and had lived with the same partner during the past year. Exclusion criteria were persons with difficulties understanding and speaking Swedish.	Surgery (all one year prior)	13 couples (7 M / 6 W)-- all heterosexual (five rectal CA; eight colon CA) Ages 39-86. Six had a stoma.	The aim of the study was thus to describe the experience of life the first year after surgery from both the perspective of persons treated for CRC and their partners.	Qualitative descriptive	Life in general, how the diagnosis had affected relationships in the marriage and social life and the experience of information and support in connection with the illness.	Life is back to normal and yet not. 3 subthemes: 'Life has a shadow of death', 'The treated body sets the rules' and 'To share or not share the illness'. Both patients and their partners described a change in intimacy after surgery. Some couples could resume the same sex life, others had a different sex life and some had no mutual sex life at all. Sex was for some replaced by another form of intimacy. Absence of sexual intercourse made some patients feel incomplete, but none of the partners expressed it as a great loss. Some partners expressed sexual problems as the patient's responsibility and did not want to pressure them to seek medical advice.	NA	Moderate
Reese	2012	All participants were 21 years of age or older, married or living with a partner for at least 1 year, had undergone surgery or other treatment for CRC. Inclusion was limited to patients with some degree of sexual concerns.	Surgery/other TX: 22% has surgery only; 11% had surgery and radiation and 67% had surgery, RT and Chemo. Range of completion from 1 month- 24 months.. All DX within 5 years. 22% w stage I; 56% w stage II; 22 % w stage IV. 22% had past ostomy; 33% w current ostomy.	14 heteosexual couples (7 M/ 7 W)-- (11 participating in at least one session and 9 completing all sessions and assessments-- 56% men (n=5), 44 % women (n=4). Ages: 47-76. 67% w rectal CA.	The purpose of the current pilot study was to collect preliminary data on the feasibility and efficacy of the intervention.	Pilot intervention study	Use of skills, program evaluation; Sexual distress, sexual function, sexual communication, dyadic adjustment, intimacy-- FSFI, IIEF AT BASELINE AND POST INTERVENTION.	Patient data showed large effect sizes (≥.80) for sexual distress, female sexual function, and sexual communication; a medium effect size (.30 to .60) for dyadic adjustment; and small effect sizes (.20 to .30) for intimacy.	Positive	Moderate

Table H3 Findings specific to women

Author	Date	Target Population	Type of TX/Time Since TX	Sample Characteristics	Aim	Study Design	Outcome Measures	Key Findings	Direction of Effect (if applicable)	Apprasial Score
Altschuler	2009	Female CRC patients with permanent ostomies	Survivors at least 5 yrs post surgery w ostomy.	30 WOMEN age: 44-93; White Non- Hispanic (N=22), Asian/Pacific Islander (N=5), African American (N=2), and Hispanic (N=1). 22 were married or partnered at the time of surgery or shortly thereafter, 8 were single	To better understand how a range of aspects of intimacy and sexuality are affected by having an ostomy as a result of CRC.	Mixed Methods -- cross sectional / interviews	Relationships between women's percepctions of partners support on global HRQOL and how having an ostomy affected intimacy and sexuality.	**1) Positive Support From Husbands; 2) Withdrawl of Support From Husbands; or 3) Mixed Support From Husbands or Partners.** Women describe positive support from their husbands as being central to their psychosocial adjustment, including adjustments to sexuality and changes in sexual life.	NA	Strong
Andersson	2010	Women w rectal cancer who had colostomy surgery and were still at work.	Survivors 1-6 yrs post surgery w colostomy	5 WOMEN age 60-65; 4 of them lived with a partner.	To describe the experiences of women living with a colostomy as a result of rectal CA.	Qualitative narrative approach	Experiences of life before cancer, the surgery itself, life after illness, (i.e. how living with colostomy impacts on daily life, relations, work, body image and sexuality).	**Insecurity about life & A Bridge to Life** . . . Sexual restrictions were not a big problem for the women and were something they could 'live with'. Body changes were also noted as a non-serious issue. They could live with these changes as they viewed it as an opportunity to survive cancer. The women's sex life changed after the rectal amputation. Those with partners thought it was important to have a good relationship and be able to	NA	Moderate
Ball	2011	Women following Rectal CA treatment	'survivors'	9 WOMEN treated at Memorial Sloan-Kettering Cancer Center (MSKCC) for rectal cancer. Ages: Unsure	To better understand women's experience with sexual dysfunction following rectal cancer treatment, and to investigate barriers and promoters that may influence their participation in a sexual health intervention after receiving treatment for rectal cancer.	Qualitative: Interviews & Focus Groups	Understand the women's experience with sexual dysfunction following tx and to investigate barriers/promoters that would influence their participation in a sexual health intervention.	Survivors reported that a sexual intervention would be helpful to improve their QOL post TX because it would provide them with an education of the etiology of their problem and treatments to reduce their dysfunction (N = 8, or 89%). Also expressed the benefit of being able to talk to a professional regarding anxiety, which negatively impacts their sexual health post TX (N = 6, or 67%)	NA	Weak
Da Silva	2008	Female patients undergoing surgery of the colon and/or rectum from 3 different institutions between 2001 and 2003 were prospectively enrolled in this study. Those undergoing anal surgery were excluded.	All pts underwent Surgery/Chemo/RT. Seven patients (7.5%) in the pelvic group had radiation therapy. Fifty-seven (61.3%) patients underwent stoma formation, 48 (84.2%) of which underwent subsequent closure. They were evaluated at 6-12 months after initial surgery; also evaluated pre op . . . The patients were divided in 2 groups for comparison: Pelvic Group and the Abdominal Group.	93 WOMEN age 32-54; mean age of 43.0 .Of the 93 patients, 57 (61.3%) patients underwent pelvic and 36 (38.7%) underwent abdominal procedures.	Prospectively evaluate women's sexual function, self-esteem, body image, and quality of life after colorectal surgery using validated tools. A second aim was to compare the results between patients who had pelvic dissection with those without pelvic dissection to assess whether pelvic dissection would impose greater risk for sexual dysfunction in women as seen in men.	prospective (cohort) design	Sexual function, self-esteem, body image, and general health (mental and physcial health) & Importance of Discussing Sexual Issues & To compare the results between patients who had pelvic dissection with those without to assess whether pelvic dissection would impose greater risk for sexual problems.	Self-esteem did not differ between groups and did not change significantly after surgery. Women with worse body image scores had lower self-esteem. Women with better self-esteem (P 0.043) and body image scores had significantly better sexual functioning. Body image improved over time, with significant improvement at 12 months (P 0.05). At 6 months, MCS scores were higher for patients with good body image. At 12 months patients who had a stoma and low sexual function score also had lower MCS scores. 81.4% of the women stated its important to talk about sexual issues	Positive	Moderate
Platell	2004	Age greater than 18 years; a diagnosis of rectal cancer; surgery that included ABD resection or low anterior resection; disease stage I- III, and alive and disease free at least 6 months after surgery. control group-Colon CA, included if had undergone surgery for colonic cancer, but had not had pelvic surgery.	At LEAST 6 months after Surgery. Study group: 18 underwent Low anterior resection and four ABD resection. All who had LAR had temp. ostomy which was subsequently closed. Eight received pre operative RT.	22 WOMEN (study group--rectal CA) 19 women (control group--colon) Age: unsure. Patients in the study group were younger than those in the control group. Majority of patients were over 60 yrs.	The aim of this study was to evaluate sexual health in women undergoing pelvic surgery for rectal cancer.	Case control design	body image, sexual awareness, libido, arousal, physical difficulties during intercourse and sexual activity. The questionnaire evaluated symptom occurrence, intensity and duration, and also considered the relevance of a symptom to each patient.	Study group was more likely to experience feelings of being less attractive after surgery (p=0.039). A majority of women were not distressed that their longing for sex had decreased. Six women in the study group felt distressed by the thought that their limitations in sexual activity and problems with faecal incontinence during intercourse would persist for the rest of their lives. Reduction in sexual activity was related to the partner in five women.	Somewhat Positive	Weak
Ramirez	2009	Women; colon and rectal cancer survivors (at least 5 years postdiagnosis) w permanent ostomies who were identified from NCI-certified tumor registries during the years 2000 through 2006 were eligible	Survivors (at least 5yrs post dx)	30 WOMEN --- 44 to 93 years; median age was 74. White Non-Hispanic (N=22), Asian (N=3), Pacific Islander (2), African American (N=2), and Hispanic (N=1). 22 were married or partnered at the time of surgery or shortly thereafter, and 8 were single at the time of surgery and continued in that status after the surgery.	Explore a range of experiences (using an anthropological perspective) related to sexuality among female survivors with permanent ostomies.	Qualitiative: phenomenology	Examined issues regarding body image, gender, and sexuality in female CRC survivors with ostomies.	1) No long-term sexual difficulties (n=11), 2) Long-term sexual difficulties (N=7), 3) Age-related changes in sexuality (N=3), 4) No partnered sexual experience post surgery (N=9). For some women, sexual changes created a great deal of emotional distress, but for others, it did not appear to be particularly problematic. Several women described carefully orchestrated ostomy management techniques when engaging in sexual activity.	NA	Strong

Table H4 Outcomes

Author	Date	Target Population	Aim	Study Design	Outcome Measures	Key Findings (specific to Sexuality/Sexual Health)
How the ostomy impacts sexuality, self-esteem, self-concept or body image (Altschuler, 2009; Andersson, 2010; Grant, 2011; Platell, 2004; Ramirez, 2009 & Sharpe, 2010).						
Altschuler	2009	Female CRC patients with permanent ostomies	To better understand how a range of aspects of intimacy and sexuality are affected by having an ostomy as a result of CRC.	Mixed Methods -- cross sectional / interviews	Relationships between women's percepctions of partners support on global HRQOL and how having an ostomy affected intimacy and sexuality.	**1) Positive Support From Husbands; 2) Withdrawl of Support From Husbands; or 3) Mixed Support From Husbands or Partners.** Women describe positive support from their husbands as being central to their psychosocial adjustment, including adjustments to sexuality and changes in sexual life.
Andersson	2010	Women w rectal cancer who had colostomy surgery and were still at work.	To describe the experiences of women living with a colostomy as a result of rectal CA.	Qualitative narrative approach	Experiences of life before cancer, the surgery itself, life after illness, (i.e. how living with colostomy impacts on daily life, relations, work, body image and sexuality).	**Insecurity about life & A Bridge to Life** . . . Sexual restrictions were not a big problem for the women and were something they could 'live with'. Body changes were also noted as a non-serious issue. They could live with these changes as they viewed it as an opportunity to survive cancer. The women's sex life changed after the rectal amputation. Those with partners thought it was important to have a good relationship and be able to talk about emerging problems.
Grant	2011	Colorectal Cancer w ostomy, patients with CRC who were 18 years or older. The goal was to recruit four to eight participants for each gender- and HRQOL-based focus group.	To describe how gender shapes the concerns and adaptations of long-term (i.e., more than five years) colorectal cancer survivors with ostomies.	Qualitative: content analysis / focus groups	Identify specific challenges ostomates face, their adaptation processes, and the strategies they adopted for self care. Quality-of-Life Similarities and Differences by Gender including physical, social, spirtual and psychological well being.	**Social Physical Psychologcial AND Spirtual well-being.** Sexuality was coded 17 times accross focus groups (2nd highest code under social domain!). HQOL men coded sexuality 6 times; LQOL men coded sexuality 5 times. Body image and depression were mentioned only by women. Body image was only discussed in the LQOL female group. HQOL women groups coded sexuality 2 times; 3 times for LQOL women. Sexuality was discussed across all focus groups, with one or two comments that indicated sexual relationships were not problematic and a number of comments in each group about sexuality and intimacy problems related to complications of surgery or radiation therapy.
Platell	2004	Women; greater than 18 years; a diagnosis of rectal cancer; surgery that included ABD resection or low anterior resection; disease stage I- III, and alive and disease free at least 6 months after surgery. control group-Colon CA, included if had undergone surgery for colonic cancer, but had not had pelvic surgery.	The aim of this study was to evaluate sexual health in women undergoing pelvic surgery for rectal cancer.	Case control design	Body image, sexual awareness, libido, arousal, physical difficulties during intercourse and sexual activity. The questionnaire evaluated symptom occurrence, intensity and duration, and also considered the relevance of a symptom to each patient.	Study group was more likely to experience feelings of being less attractive after surgery (p=0.039). Majority of women were not at all distressed that their longing for sex had decreased during the past 5 years. Six women in the study group felt moderately to severely distressed by the thought that their limitations in sexual activity and problems with faecal incontinence during intercourse would persist for the rest of their lives. Reduction in sexual activity was related to their partner in five women. There was no difference between in relation to overall satisfaction with their sexuality and sex life, and the influence of their sexual difficulties on well-being. The most frequent comment (12 women) felt 'less attractive' / 'unglamorous', owing to physical scarring.
Ramirez	2009	Women; colon and rectal cancer survivors (at least 5 years postdiagnosis) w permanent ostomies who were identified from NCI-certified tumor registries during the years 2000 through 2006 were eligible	Explore a range of experiences (using an anthropological perspective) related to sexuality among female survivors with permanent ostomies.	Qualitative: phenomenology	Examined issues regarding body image, gender, and sexuality in female CRC survivors with ostomies.	**1) No long-term sexual difficulties (n=11), 2) Long-term sexual difficulties (N=7), 3) Age-related changes in sexuality (N=3), 4) No partnered sexual experience post surgery (N=9)**. For some women, sexual changes created a great deal of emotional distress, but for others, it did not appear to be particularly problematic. Several women described carefully orchestrated ostomy management techniques when engaging in sexual activity.
Sharpe	2010	Adult patients with a diagnosis of stage A to D colorectal (colon or rectal) from seven hospital sites between March 2005 and September 2006	This study aimed to investigate the effect of having a stoma on body image in patients with colorectal cancer and to determine whether disturbances in body image predicted distress.	Prospective Cohort Study	Body Image Satisfaction; Anxiety and Depression; Distress; investigate the effect of changes in stoma status over time on psychosocial outcomes, examine Time×Stoma Effects, examine Differences between stoma versus non-stoma groups at Time 1& 2 (baseline/follow-up).	Between Stoma and Non stoma: There was a significant difference between groups for body image disturbance at baseline (P=.0005). Stoma patients showed more body image disturbance at baseline (p =.001). There was also a significant difference for anxiety, favoring the non-stoma group [P=.02], but not for depression or general distress (P=.08,). For body image disturbance, there was a main effect for time (P=.007) and stoma (P=.004). Body image was more disturbed for those who had a stoma initially. Over time, those with an initial stoma (and not those without) became more disturbed about their body image. Body image disturbance did predict baseline depression (P<.0005) & anxiety (P=.0005) and follow-up distress (p=.001).

Table H4 Outcomes continued (1)

Sexuality and HRQOL - i.e. emotional, mental, and physical health (Da Silva, 2008; Neuman, 2011; Neuman, 2012; Schmidt, 2005 & Schmidt, 2010).						
Da Silva	2008	Female patients undergoing surgery of the colon and/or rectum from 3 different institutions between 2001 and 2003 were prospectively enrolled in this study. Those undergoing anal surgery were excluded.	Prospectively evaluate women's sexual function, self-esteem, body image, and quality of life after colorectal surgery using validated tools. A second aim was to compare the results between patients who had pelvic dissection with those without pelvic dissection to assess whether pelvic dissection would impose greater risk for sexual dysfunction in women as seen in men.	Prospective (cohort) design	Sexual function, self-esteem, body image, and general health (mental and physcial health) & Importance of Discussing Sexual Issues & To compare the results between patients who had pelvic dissection with those without to assess whether pelvic dissection would impose greater risk for sexual problems.	Self-esteem did not differ between groups and did not change significantly after surgery. Postop, patients with worse body image scores (10) had lower self-esteem (mean 14.3, n 8). Women with better self-esteem (P=0.043) and body image scores had significantly better sexual functioning. Body image improved over time, with slight changes at 6 months and significant improvement at 12 months compared with baseline (P <0.05). At 6 months, MCS scores were higher for patients with good body image scores of 5 or less (mean 52.9) and higher selfesteem. However, at 12 months patients who had a stoma and low sexual function score (FSFI 22.9) also had lower MCS scores (mean 39.6). When asked about the importance of discussing sexual issues, 81.4% said its important.
Neuman	2011	Patients with stage I–III rectal cancer who received a temporary stoma. Patients were eligible for participation if they had rectal CA underwent surgery and follow- up, spoke English, and had no evidence of distant metastatic disease.	The goal was to perform an in-depth exploration into patients' experiences to determine the impact of a stoma on their QOL.	Prospective/ Longitudinal	Overall QOL, and Impact of Stoma of QOL before tx, before stoma reversal and 6 months after.	A statistically significant decrease in body image (P = .03) between baseline and stoma closure time points; the mean change was 9.2; approaches definition of a clinically meaningful difference. Diminished body image persisted after stoma reversal. Sexual activity was the most commonly cited problem, with 53% reporting ''frequently'' or ''always,'' and 20% reporting that they ''occasionally'' did not enjoy sexual activity. Discomfort in clothing was a problem for (34%), as well as feeling unattractive (31%). There was no clinically significant difference btween sexuality/body image as measured by the stoma QOL scale at the three diff. time points.
Neuman	2012	Patients with stage I - III rectal cancer who received a temporary diverting stoma between 2006 and 2008.	This study aimed to qualitatively explore the experiences of patients with rectal cancer who have a temporary ileostomy to better understand the discordant findings of previous quantitative quality-of-life studies.	Qualitative: Interviews/ grounded theory	The overall experience with the stoma, the perceived impact of the stoma on their QOL, and changes in perception if the stoma were to become permanent.	**Stoma-related difficulties & Perceived response shift.** The impact of the ostomy on sexuality was variable. Although some reported no limitations, others felt that their sexual activities were curtailed, either because of personal or partner preference. Stoma impacted patients' sexuality and body image, but also posed a physical challenge that needed to be negotiated. Pts emphasized clothing changes to accommodate the stoma. The response-shift theory argues that patients accommodate to a life-threatening or disabling illness by changing the meaning of their self-evaluation of QOL.
Schmidt	2005	Patients with Rectal CA who had a resection w curative intent at least 1 year previously from 1992-2002.	The goal of the present study was to assess the patients' postoperative sexual function and quality of life over time, with special attention to the important factors that influence sexual function.	Cross Sectional	Age and Differences in Sexuality and QoL, Gender Differences and QoL, How age, gender, type of surgery and adjuvant tx impact sexuality.	Comparing the effect of age on sexuality for both genders, we found a moderate correlation between age, sexual impairment, and sexual strain (r = −0.423; P < 0.001) only in females. Both experienced limitations in their sexual life, but male patients showed significant higher scores on "sexual impairment" and "distress caused by sexual impairment."
Schmidt	2010	Pts who had undergone tx with curative intent for CA of the rectum or of the rectosigmoid junction from 1997 - 2003	The main purpose was to determine to what extent sexuality was influenced by surgery and what impact it had on perceived QoL. A secondary purpose was to determine how factors, such as age, gender, type of surgery, and adjuvant treatment, influenced sexuality and QoL in these patients.	Prospective/ Longitudinal	Functional QOL, symptom QOL and sexuality. EORTC before surgery, at DC and 3,6,12 and 24 months later.	Both sexes experienced an impairment of their sexuality, men more than women. Emotional distress in men worsened up to to 24 months after surgery (p<0.05). Patients under 70 years old experienced a mild improvement of their sexuality over time, yet experienced stronger emotional distress due to impaired sexuality, and this distress worsened up to two years after surgery. Younger patients were found to be more severely affected than older patients by both of these over the entire period of time covered by the study (p<.05).

Table H4 Outcomes continued (2)

Understanding the sexual experience (Ball, 2011; Ball, 2013; Dowswell, 2011; Ohlsson-Nevo, 2011 & Wirsching, 1975).						
Ball	2011	Women following Rectal CA treatment	To better understand women's experience with sexual dysfunction following rectal cancer treatment, and to investigate barriers and promoters that may influence their participation in a sexual health intervention after receiving treatment for rectal cancer.	Qualitative: Interviews & Focus Groups	Understand the women's experience with sexual dysfunction following tx and to investigate barriers/promoters that would influence their participation in a sexual health intervention.	Survivors reported that a sexual intervention would be helpful to improve their QOL post TX because it would provide them with an education of the etiology of their problem and treatments to reduce their dysfunction (N = 8, or 89%). Also expressed the benefit of being able to talk to a professional regarding anxiety, which negatively impacts their sexual health, post TX (N = 6, or 67%)
Ball	2013	Men who were at least 2 years post-TX for stage I-III rectal cancer with an anastomosis at 15 cm or below, no evidence disease or recurrence, were 21-years of age or older, and spoke English.	To understand men's perceptions of how RC treatment impacts their sexual functioning and how men manage sexual dysfunction. Second, we sought to receive feedback about the content and utility of our proposed psycho-educational sexual health intervention.	Qualitative exploratory	Concerns and expectations about sexual functioning post-rectal cancer therapy, Prior experiences and satisfaction with help for post-cancer sexual function, Preferences for receiving education in improving sexual function & to assess content and utility of proposed sexual intervention.	**Priortizing cancer survival at diagnosis; diminished sexual and bowel functioning; desire for greater education regarding impact of treatment on sexual functioning; endorsment of the psycho-educational health intervention.** Participants said they had not focused on potential impact of cancer TX at the time of diagnosis. However, the interest in sex quickly reemerged once the fear of cancer diminished and other post-treatment side effects were resolved. Participants seemed to evaluate sexuality within their current life context. (i.e. most of the men attributed their sexual dysfunction to age), which facilitated their coping.
Dowswell	2011	Men with erectile dysfunction after surgery for colorectal cancer	Describe the experiences of men after surgery for CRC and to ascertain whether or not the provision of information could be improved so that it is flexible, responsive to individuals coping strategies and information choices.	qualitative: interviews/ thematic analysis	Beliefs about erectile dysfunction, impact on self perception and relationships, satisfaction with information, and experience of treatment.	**Experience of ED; Experience of treatment for ED; Inadequacies of pt care, & information before during and after cancer tx.** The experince was profound and stressful for men. 2 men associated the casual factors of ED with ED to be associated with the undermining of their masculinity. ED challenged the mens idenitties, affected mental health and undermined relationships. One extreme- suicide was contemplated. A minority of men accepted these changes philosophically and with a degree of stoicism. When the men began to recover from the effects of cancer and its treatment, many began to take an interest in ED. Experiences w treating ED were diverse.
Ohlsson-Nevo	2011	Patients who had undergone CRC surgery one year previously and had lived with the same partner during the past year. Exclusion criteria were persons with difficulties understanding and speaking Swedish.	The aim of the study was thus to describe the experience of life the first year after surgery from both the perspective of persons treated for CRC and their partners.	Qualitative descriptive	Life in general, how the diagnosis had affected relationships in the marriage and social life and the experience of information and support in connection with the illness.	**Life is back to normal and yet not. 3 subthemes: 'Life has a shadow of death', 'The treated body sets the rules' and 'To share or not share the illness'**. Both patients and their partners described a change in intimacy after surgery. Some couples could resume the same sex life, others had a different sex life and some had no mutual sex life at all. Sex was for some replaced by another form of intimacy and closeness.The absence of sexual intercourse made some patients feel incomplete, missing an important part of life, but none of the partners expressed it as a great loss. Some partners expressed sexual problems as the patient's responsibility and did not want to pressure them to seek medical advice.
Wirsching	1975	Colorectal CA/ unsure of target	Compare pts with permanent colostomy through questionnaire and interview with pts who do not have colostomy. To report the preliminary findings comparing the patient's own assessment of his health, the preoperative emotional state, social contacts and change in sexual activities.	Mixed Methods: case control (surveys) / interviews	Comparing 1) Patients own assessment of his health; 2) The periop emotional state 3) Social Contacts 4) change in sexual activities.	Lonliness was correlated w state of health, seldom leaving home, fear of reoccurence and sex-bound correlations exist to the size of community and sexual activity(i.e lonliness correlated to no sexual activity). The male group shows sexual disturbances it cannot be due to only organic damage, but is an expression of loss of self esteem and feelings of castration. These men show higher rates of social impotence, and depression. Men w colostomies show most severe decrease of intercourse rate. (p<0.01). Women showed worsening of martial relationships (linked w low sexual frequency) & greater capacity to cope

Table H4 Outcomes continued (3)

How psychosocial or psychological factors influence sexuality (Au, 2012; Cotrim, 2007; Milbury, 2013; Nowicki, 2011 & Reese, 2012)						
Au	2012	Rectal CA, 20 years or older, sexually active, classified as Dukes A–C (i.e. TNM system stage I–III). Had surgery, may have been receiving adjuvant treatment, and were receiving regular follow-up.	To examine the relationships between two health-seeking behaviours (HSBs), spirituality and resourcefulness, as well as demographics, cancer-related factors and sexuality indicators, within the context of Schlotfeldt's health-seeking model in rectal cancer survivors.	Cross Sectional (secondary analysis)	Spirituality, resourcefulness, sexual function, sexual self-concept, communication and sexual relationship.	The major finding of this analysis was that **lower resourcefulness was associated with lower spirituality, sexual satisfaction, and sexual self-concept in both genders.** Spirituality was positively and significantly correlated with better communication ($p < 0.001$), sexual relationship ($p<0.001$), male sexual self-concept ($p = 0.000$), and female sexual self-concept ($p = 0.007$).
Cotrim	2007	Patients with CRC, who had surgery, older than 18 years, and of both genders. Exclusion criteria were the presence of respiratory, cardiac or hepatic dysfunctions. Caregivers were also recruited when possible.	To identify and assess the impact on quality of life of patients with colorectal cancer undergoing surgery. To identify and assess the burden of illness on the families of patients' with colorectal cancer.	Cross Sectional	Socio-demographic and disease / treatment-related characteristics; Psychological morbidity in stoma versus non-stoma ; Psychological morbidity of patients; Body image/sexual satisfaction /marital satisfaction; & Burden of caregivers scale	A strong relationship between sexual satisfaction and marital satisfaction ($P<0.001$)was found in the stoma patients' group. In the group of non-stoma patients, a relationship was also found but it was lower ($P<0.001$). Non stoma pts had a significant relationship between body image and both sexual and marital satisfaction ($p<0.001$). Regression analysis also shows that type of patient (i.e. stoma) X body image is a predictor of patients QOL.
Milbury	2013	CRC pts. 18 years or older, competent in English, diagnosed with colon or rectal cancer stage I–III, and had received surgery at least 6 months earlier and completed all TX at least 1 month earlier. Patients w hereditary CRC were excluded.	The goal was to identify demographic, medical, and psychosocial risk factors that explain a significant proportion of the variance in male and female sexual function in colorectal cancer survivors.	Cross Sectional	Sexual functioning (IIEF FOR MEN AND FSFI FOR WOMEN) secondary: global QOL, psychosocial functioning, social support, dyadic adjustment	Both sexual outcome subscales were significantly associated with global QoL ($P<0.01$) so that better sexual function was associated with better QoL. Both men and women in a committed relationship scored higher on the CRC QLQ-38 "sexual function" scale compared to single participants (committed relationship, 40.74 vs. single, 14.15, $P<0.0001$). Better sexual function was associated with better QoL outcomes (-.27); dyadic adjustment (-.27); body image (-.22); global QOL (-.32); and sex. function (-.53) all correlated to sexual function. Interestingly, mental health and marital satisfaction were not significantly associated with IIEF or FSFI scores. For men, body image was not significantly associated with IIEF scores.
Nowicki	2011	Patients w Rectal carcinoma and stoma.	Self-assessment of physical rehabilitation and psychosexual problems in patients with rectal carcinoma and stoma was the main objective of this work.	Cross sectional	Patients' feelings about the psycho-sexual domain.	One third of pts stopped or limited their sexual relationships (< 0.05). Both genders had shame and fear of dirt and unpleasant smell as reasons for limitating sexual relationships. Changes in sexual life occurred in the form of ceasing sexual relationships in 36%. MEN: Reasons for cessation of sex: deteriorated selfassessment (n/%) 5/16; fear of lack of acceptance fr partner 2/7; shame 3/11; fear of smudging of dirt and unpleasure smell 3/11; decreasing sex drive 28/95 WOMEN: Lower self-esteem and fear of a lack of acceptance fr the partner play an important role in ceasing sexual life in about half of women (< 0.05). Deteriorated self assessment 11/55; fear of lack of acceptance 8/40; shame 3/15; fear of dirt/smell 3/15; decreasing sex drive 14/70; depressive mood 3/15.
Reese	2012	All participants were 21 or older, married or living with a partner for at least 1 year, had undergone surgery or other treatment for colorectal cancer. Inclusion was limited to patients with some degree of sexual concerns.	The purpose of the current pilot study was to collect preliminary data on the feasibility and efficacy of the intervention.	Pilot intervention study	Use of skills, program evaluation; Sexual distress, sexual function, sexual communication, dyadic adjustment, intimacy	Patient data showed large effect sizes ($\geq .80$) for sexual distress, female sexual function, and sexual communication; a medium effect size (.30 to .60) for dyadic adjustment; and small effect sizes (.20 to .30) for intimacy.

Table H5 Ostomy specific studies

Author	Date	Target Population	Type of TX/Time Since TX	Sample Characteristics	Study Design	Outcome Measures	Key Findings	Direction of Effect (if applicable)	Apprasial Score
Altschuler	2009	Female CRC patients with permanent ostomies	survivors (at least 5 yrs post surgery w ostomy)	30 WOMEN age: 44-93; White Non- Hispanic (N=22), Asian/Pacific Islander (N=5), African American (N=2), and Hispanic (N=1). 22 were married or partnered at the time of surgery or shortly thereafter, 8 were single	Mixed Methods --- survey/ interviews	Relationships between women's percepctions of partners support on global HRQOL and how having an ostomy affected intimacy and sexuality.	3 THEMES: POSITIVE SUPPORT FROM HUSBANDS; WITHDRAWL OF SUPPORT FROM HUSBANDS OR PARTNERS; MIXED SUPPORT FROM HUSBANDS OR PARTNERS. Women descirbe positive support from their husbands as being central to their psychosocial adjustment, including adjustments to sexuality and changes in sexual life.	NA	Strong
Andersson	2010	Women w rectal cancer who had colostomy surgery and were still at work.	survivors 1-6 yrs post surgery w colostomy	5 WOMEN age 60-65; 4 of them lived with a partner.	Qualitative narrative approach	Experiences of life before cancer, the surgery itself, life after illness, (i.e. how living with colostomy impacts on daily life, relations, work, body image and sexuality).	2 MAIN THEMES: **Insecurity about life & A Bridge to Life** . . . Sexual restrictions were not a big problem for the women and were something they could 'live with'. Body changes were also noted as a non-serious issue. They could live with these changes as they viewed it as an opportunity to survive cancer. The women’s sex life changed after the rectal amputation. Those with partners thought it was important to have a good relationship and be able to talk about emerging problems.	NA	Moderate
Grant	2011	Colorectal Cancer w ostomy, patients with CRC who were 18 years or older. The goal was to recruit four to eight participants for each gender- and HRQOL-based focus group.	Survivors (at least 5yrs post dx) Years since surgery varied from 5-27 yrs.	33 (17 M/ 16 W) ---- 8 FG were formed, based on gender and HRQOL scores. Age: 18 years and older. Primairly Caucasian, one African American participant, one Hispanic, and one w a multiethnic background. Sociodemographic characteristics varied across groups.	Qualitative: content analysis/focus groups	identify specific challenges ostomates face, their adaptation processes, and the strategies they adopted for self care. Quality-of-Life Similarities and Differences by Gender including physcial, social, spirtual and psychological well being.	4 THEMES: SOCIAL,PHYSICAL, PSYCHOLOGICAL AND SPRITUAL WELL-BEING. Body image and depression were mentioned only by women. Body image was only discussed in the LQOL female group. HQOL women groups coded sexuality 2 times; 3 times for LQOL women. Sexuality was discussed across all focus groups, with one or two comments that indicated sexual relationships were not problematic and a number of comments in each group about sexuality and intimacy problems related to complications of surgery or radiation therapy.	NA	Strong
Neuman	2011	Patients with stage I–III rectal cancer who received a temporary stoma between December 2006 and December 2008.	All had Surgery/ 90% neoadjuvant therapy (measured at time of surgical consent, prior to stoma reversal, and 6 months after reversal)-- Median duration after stoma placement was 190 days (range, 54–490 days); All patients in the study cohort underwent a diverting loop **ileostomy.**	60 (27 W / 33 M)---Ages 25-85. Median age 55. (45%) were female; a majority were married (72%). Nodal metastases were evident in 36 patients (60%).	Prospective/ Longitudinal (studied before tx, before stoma reversal and 6 months after)	in-depth exploration into patients’ experiences, Overall QOL, and Impact of Stoma of QOL	A statistically significant decrease in body image (P = .03) was observed between baseline and stoma closure time points.. There was no clinically significant difference btween sexuality/body image as measured by the stoma QOL scale at the three diff. time points. Diminished body image persisted after stoma reversal. Sexual activity was the most commonly cited problem, with 53% reporting ‘‘frequently’’ or ‘‘always,’’ did not enjoy sexual activity. Discomfort in clothing was a problem for (34%), and feeling unattractive (31%).	Positive	Moderate
Neuman	2012	Patients with stage I to III rectal cancer who received a temporary diverting stoma between December 2006 and 2008.	Surgery--received a temporary diverting stoma-- interviewed after initial surgery but prior to reversal. Sixty-five percent had stage III disease, Neoadjuvant therapy, n (%) 23 (88); Adjuvant therapy, n (%) 18 (69)	26 (12 W / 14 M-- interviews) Ages 36-85. (54% male, median age 54)	qualitative study: Interviews/ grounded theory	Preoperative expectations regarding the temporary stoma, their overall experience with the stoma, the perceived impact of the stoma on their QOL, and changes in perception if the stoma were to become permanent	Two Themes: Stoma-related difficulties & Perceived response shift. The impact of the ostomy on sexuality was variable. Although some reported no limitations, others felt that their sexual activities were curtailed, either because of personal or partner preference. Stoma impacted patients’ sexuality and body image, but also posed a physical challenge that needed to be negotiated. Pts emphasized clothing changes to accommodate the stoma. The response-shift theory argues that patients accommodate to a life-threatening or disabling illness by changing the meaning of their self-evaluation of QOL.	NA	Moderate
Nowicki	2011	PTS w Rectal carcinoma and stoma	All underwent Surgery (perm. & temp. stomas)/combined TX / unsure of exact timing. A permanent stoma was created in 78%, temporary in 12%. All underwent combined tx procedures.	50 (20 W /30 M)---- Ages 44-72.	Cross sectional	Social-demographic data, patients’ self assessment assessment of physical rehabilitation and their feelings about the psycho-sexual domain.	One third of pts stopped or limited their sexual relationships (< 0.05). Changes in sexual life after stoma creation occurred in the form of ceasing sexual relationships in 36%. MEN: Reasons for cessation of sex: deteriorated selfassessment (n/%) 5/16; fear of lack of acceptance fr partner 2/7; shame 3/11; fear of smudging of dirt and unpleasure smell 3/11; decreasing sex drive 28/95; depressive mood 0) p<.05 for all. WOMEN:lower self-esteem and fear of a lack of acceptance fr the partner play an important role in ceasing sexual life in about half of women (< 0.05).	Positive	Weak
Ramirez	2009	All colon and rectal cancer survivors with permanent ostomies who were identified from certified tumor registries during the years 2000 through 2006 were eligible.	Survivors (at least 5yrs post dx)	30 WOMEN --- 44 to 93 years; median age of participants was 74 years. White Non-Hispanic (N=22), Asian (N=3), Pacific Islander (2), African American (N=2), and Hispanic (N=1) 22 were married or partnered at the time of surgery or shortly thereafter (20 were married, 2 were partnered), and 8 were single at the time of surgery and continued in that status after the surgery.	qualitiative interview (phenomenology)-coded using principles of grounded theory	examined issues regarding body image, gender, and sexuality in female CRC survivors with ostomies.	4 groups: 1) No long-term sexual difficulties (n=11), 2) Long-term sexual difficulties (N=7), 3) Age-related changes in sexuality (N=3), 4) No partnered sexual experience post surgery (N=9). For some women, sexual changes created a great deal of emotional distress, but for others, it did not appear to be particularly problematic. Several women described carefully orchestrated ostomy management techniques when engaging in sexual activity.	NA	Strong

Table H6 Comparison Studies

Author	Date	Target Population	Type of TX/Time Since TX	Aim	Study Design	Outcome Measures	Key Findings	Direction of Effect (if applicable)	
Cotrim	2007	Patients with CRC, who had surgery, older than 18 years, and of both genders. Exclusion criteria were the presence of respiratory, cardiac or hepatic dysfunctions. Caregivers were also recruited when possible.	Surgery/chemo/RT 6-8 months prior. About 28.1% had been submitted to surgery, 48.4% surgery and chemotherapy and 22.2% surgery, chemotherapy & radiotherapy. 30.1% had ostomy surgery.	To identify and assess the impact on quality of life of patients with colorectal cancer undergoing surgery. To identify and assess the burden of illness on the families of patients' with colorectal cancer.	Cross Sectional	Socio-demographic and disease / treatment-related characteristics; Psychological morbidity in stoma versus non-stoma ; Psychological morbidity of patients; Body image/sexual satisfaction/marital satisfaction; & Burden of caregivers scale (depression & anxiety measures)	A strong relationship between sexual satisfaction and marital satisfaction (P<0.001)was found in the stoma patients' group. In the group of non-stoma patients, a relationship was also found but it was lower (P<0.001). Non stoma pts had a significant relationship between body image and both sexual and marital satisfaction (p<0.001). Regression analysis also shows that type of patient (i.e. stoma) X body image is a predictor of patients QOL	Significant findings	STOMA v. NON STOMA
Da Silva	2008	Female patients undergoing surgery of the colon and/or rectum from 3 different institutions between 2001 and 2003 were prospectively enrolled in this study. Those undergoing anal surgery were excluded.	All pts underwent Surgery/Chemo/RT. Seven patients (7.5%) in the pelvic group had radiation therapy. Fifty-seven (61.3%) patients underwent stoma formation, 48 (84.2%) of which underwent subsequent closure. They were evaluated at 6-12 months after initial surgery; also evaluated pre op . . . The patients were divided in 2 groups for comparison: Pelvic Group and the Abdominal Group.	Prospectively evaluate women's sexual function, self-esteem, body image, and quality of life after colorectal surgery using validated tools. A second aim was to compare the results between patients who had pelvic dissection with those without pelvic dissection to assess whether pelvic dissection would impose greater risk for sexual dysfunction in women as seen in men.	prospective (cohort) design	Sexual function, self-esteem, body image, and general health (mental and physcial health) & Importance of Discussing Sexual Issues & To compare the results between patients who had pelvic dissection with those without to assess whether pelvic dissection would impose greater risk for sexual problems.	Self-esteem did not differ between groups and did not change significantly after surgery. Postop, patients with worse body image scores had lower self-esteem. Women with better self-esteem (P 0.043) and body image scores had significantly better sexual functioning. Body image improved over time, with significant improvement at 12 months compared with baseline (P 0.05). At 6 months, MCS scores were higher for patients with good body image scores and higher selfesteem. However, at 12 months patients who had a stoma and low sexual function score also had lower MCS scores. 81.4% of the women state it to be important to talk about sexual issues.	Positive	PELVIC v. ABD SURG
Platell	2004	Age greater than 18 years; a diagnosis of rectal cancer; surgery that included ABD resection or low anterior resection; disease stage I- III, and alive and disease free at least 6 months after surgery. control group-Colon CA, included if had undergone surgery for colonic cancer, but had not had pelvic surgery.	At LEAST 6 months after Surgery. Study group: 18 underwent Low anterior resection and four ABD resection. All who had LAR had temp. ostomy which was subsequently closed. Eight received pre operative RT.	The aim of this study was to evaluate sexual health in women undergoing pelvic surgery for rectal cancer.	Case control design	body image, sexual awareness, libido, arousal, physical difficulties during intercourse and sexual activity. The questionnaire evaluated symptom occurrence, intensity and duration, and also considered the relevance of a symptom to each patient.	Study group was more likely to experience feelings of being less attractive after surgery (p=0.039). A majority of women were not distressed that their longing for sex had decreased. Six women in the study group felt moderately to severely distressed by the thought that their limitations in sexual activity would persist for the rest of their lives. Reduction in sexual activity was related to their partner in five women. There was no difference between in relation to overall satisfaction with their sexuality and sex life, and the influence of their sexual difficulties on well-being.	Some significant findings	RECTAL v. COLON
Sharpe	2010	Adult patients with a diagnosis of stage A to D colorectal (colon or rectal) from seven hospital sites between March 2005 and September 2006	Surgery (examined pre surgery or within 9 weeks of surgery and then again approx. 6 mos later at completion of adjuvant tx). 34 w stoma (type of tx: none--aside from surgery (48%); neoadjuvant 10%; chemo 32%; & RT 10%. 65 wo stoma (type of TX: none--aside from surgery (46%); neoadjuvant = 5%; chemo= 49%; RT =0%.	This study aimed to investigate the effect of having a stoma on body image in patients with colorectal cancer and to determine whether disturbances in body image predicted distress.	Prospective Cohort Study	Body Image Satisfaction; Anxiety and Depression; Distress; investigate the effect of changes in stoma status over time on psychosocial outcomes, examine Time×Stoma Effects, examine Differences between stoma versus non-stoma groups at Time 1& 2 (baseline/follow-up).	Between Stoma and Non stoma: There was a significant difference between groups for body image disturbance at baseline (P=.0005). Stoma patients showed more body image disturbance at baseline (p =.001). There was also a significant difference for anxiety, favoring the non-stoma group [P=.02], but not for depression or general distress (P=.08,). Over time, those with an initial stoma (and not those without) became more disturbed about their body image. Body image disturbance did predict baseline depression (P<.0005) & anxiety (P=.0005) and distress (p=.001).	Significant findings	STOMA v. NON STOMA
Wirsching	1975	Colorectal CA/ unsure of target	Surgery (1-30 yrs). Mean interval between surgery and follow-up was 9.7 yrs for the colostomy group and 8.1 yrs for the control.	Compare pts with permanent colostomy through questionnaire and interview with pts who do not have colostomy. (self reported health questionnaires). To report the preliminary findings comparing the patient's own assessment of his health, the preoperative emotional state, social contacts and change in sexual activities.	Mixed Methods: case control (surveys) / interviews	Comparing 1) Patients own assessment of his health; 2) The periop emotional state 3) Social Contacts 4) change in sexual activities.	Lonliness was correlated w state of health, seldom leaving home, fear of reoccurence and sex-bound correlations exist to the size of community and sexual activity (i.e lonliness correlated to no sexual activity). The male group shows sexual disturbances it cannot be due to only organic damage, but is an expression of loss of self esteem and feelings of castration. These men show higher rates of social impotence, and depression. Men w colostomies show most severe decrease of intercourse rate. (p<0.01). Women showed worsening of martial relationships (linked w low sexual frequency) & greater capacity to cope	Significant findings	STOMA v. NON STOMA

Table H7 Type of Cancer (colorectal/rectal)

				Rectal n=10		
Author	Date	Target Population	Aim	Study Design	Outcome Measures (related to Sexuality/Sexual Health)	Key Findings (specific to Sexuality/Sexual Health)
Andersson	2010	Women w rectal cancer who had colostomy surgery and were still at work.	To describe the experiences of women living with a colostomy as a result of rectal CA.	Qualitative narrative approach	Experiences of life before cancer, the surgery itself, life after illness, (i.e. how living with colostomy impacts on daily life, relations, work, body image and sexuality).	**Insecurity about life & A Bridge to Life** . . . Sexual restrictions were not a big problem for the women and were something they could 'live with'. Body changes were also noted as a non-serious issue. They could live with these changes as they viewed it as an opportunity to survive cancer. The women's sex life changed after the rectal amputation. Those with partners thought it was important to have a good relationship and be able to talk about emerging problems.
Au	2012	Rectal CA, 20 years or older, sexually active, classified as Dukes A–C (i.e. TNM system stage I–III). Had surgery, may have been receiving adjuvant treatment, and were receiving regular follow-up.	To examine the relationships between two health-seeking behaviours (HSBs), spirituality and resourcefulness, as well as demographics, cancer-related factors and sexuality indicators, within the context of Schlotfeldt's health-seeking model in rectal cancer survivors.	Cross Sectional (secondary analysis)	Spirituality, resourcefulness, sexual function, sexual self-concept, communication and sexual relationship.	The major finding of this analysis was that **lower resourcefulness was associated with lower spirituality, sexual satisfaction, and sexual self-concept in both genders.** Spirituality was positively and significantly correlated with better communication ($p < 0.001$), sexual relationship ($p<0.001$), male sexual self-concept ($p = 0.000$), and female sexual self-concept ($p = 0.007$).
Ball	2011	Women following Rectal CA treatment	To better understand women's experience with sexual dysfunction following rectal cancer treatment, and to investigate barriers and promoters that may influence their participation in a sexual health intervention after receiving treatment for rectal cancer.	Qualitative: Interviews & Focus Groups	Understand the women's experience with sexual dysfunction following tx and to investigate barriers/promoters that would influence their participation in a sexual health intervention.	Survivors reported that a sexual intervention would be helpful to improve their QOL post TX because it would provide them with an education of the etiology of their problem and treatments to reduce their dysfunction (N = 8, or 89%). Also expressed the benefit of being able to talk to a professional regarding anxiety, which negatively impacts their sexual health, post TX (N = 6, or 67%)
Ball	2013	Men who were at least 2 years post-TX for stage I-III rectal cancer with an anastomosis at 15 cm or below, no evidence disease or recurrence, were 21-years of age or older, and spoke English.	To understand men's perceptions of how RC treatment impacts their sexual functioning and how men manage sexual dysfunction. Second, we sought to receive feedback about the content and utility of our proposed psycho-educational sexual health intervention.	Qualitative exploratory	Concerns and expectations about sexual functioning post-rectal cancer therapy, Prior experiences and satisfaction with help for post-cancer sexual function, Preferences for receiving education in improving sexual function & to assess content and utility of proposed sexual intervention.	**Priortizing cancer survival at diagnosis; diminished sexual and bowel functioning; desire for greater education regarding impact of treatment on sexual functioning; endorsment of the psycho-educational health intervention.** Participants said they had not focused on potential impact of cancer TX at the time of diagnosis. However, the interest in sex quickly reemerged once the fear of cancer diminished and other post-treatment side effects were resolved. Participants seemed to evaluate sexuality within their current life context. (i.e. most of the men attributed their sexual dysfunction to age), which facilitated their coping.
Neuman	2011	Patients with stage I–III rectal cancer who received a temporary diverting stoma between 2006 -2008. Patients were eligible for participation if they had rectal CA underwent surgery and follow- up at Memorial Sloan-Kettering Cancer Center, spoke English, and had no evidence of distant metastatic disease.	The goal was to perform an in-depth exploration into patients' experiences to determine the impact of a stoma on their QOL.	Prospective/ Longitudinal	Overall QOL, and Impact of Stoma of QOL before tx, before stoma reversal and 6 months after.	A statistically significant decrease in body image ($P = .03$) between baseline and stoma closure time points; the mean change was 9.2; approaches definition of a clinically meaningful difference. Diminished body image persisted after stoma reversal. Sexual activity was the most commonly cited problem, with 53% reporting ''frequently'' or ''always,'' and 20% reporting that they ''occasionally'' did not enjoy sexual activity. Discomfort in clothing was a problem for (34%), as well as feeling unattractive (31%). There was no clinically significant difference btween sexuality/body image as measured by the stoma QOL scale at the three diff. time points.
Neuman	2012	Patients with stage I - III rectal cancer who received a temporary diverting stoma between 2006 and 2008.	This study aimed to qualitatively explore the experiences of patients with rectal cancer who have a temporary ileostomy to better understand the discordant findings of previous quantitative quality-of-life studies.	Qualitative: Interviews/ grounded theory	The overall experience with the stoma, the perceived impact of the stoma on their QOL, and changes in perception if the stoma were to become permanent.	**Stoma-related difficulties & Perceived response shift.** The impact of the ostomy on sexuality was variable. Although some reported no limitations, others felt that their sexual activities were curtailed, either because of personal or partner preference. Stoma impacted patients' sexuality and body image, but also posed a physical challenge that needed to be negotiated. Pts emphasized clothing changes to accommodate the stoma. The response-shift theory argues that patients accommodate to a life-threatening or disabling illness by changing the meaning of their self-evaluation of QOL.
Nowicki	2011	Patients w Rectal carcinoma and stoma.	Self-assessment of physical rehabilitation and psychosexual problems in patients with rectal carcinoma and stoma was the main objective of this work.	Cross sectional	Patients' feelings about the psycho-sexual domain.	One third of pts stopped or limited their sexual relationships (< 0.05). Both genders had shame and fear of dirt and unpleasant smell as reasons for limitating sexual relationships. Changes in sexual life occurred in the form of ceasing sexual relationships in 36%. MEN: Reasons for cessation of sex: deteriorated selfassessment (n/%) 5/16; fear of lack of acceptance fr partner 2/7; shame 3/11; fear of smudging of dirt and unpleasure smell 3/11; decreasing sex drive 28/95 $p<.05$ for all. WOMEN: Lower self-esteem and fear of a lack of acceptance fr the partner play an important role in ceasing sexual life in about half of women (< 0.05). Deteriorated self assessment 11/55; fear of lack of acceptance 8/40; shame 3/15; fear of dirt/smell 3/15; decreasing sex drive 14/70; depressive mood 3/15. (All $p<0.05$)
Platell	2004	Women; Age greater than 18 years; a diagnosis of rectal cancer; surgery that included ABD resection or low anterior resection; disease stage I- III, and alive and disease free at least 6 months after surgery. control group- Colon CA, included if had undergone surgery for colonic cancer, but had not had pelvic surgery.	The aim of this study was to evaluate sexual health in women undergoing pelvic surgery for rectal cancer.	Case control design	Body image, sexual awareness, libido, arousal, physical difficulties during intercourse and sexual activity. The questionnaire evaluated symptom occurrence, intensity and duration, and also considered the relevance of a symptom to each patient.	Study group was more likely to experience feelings of being less attractive after surgery ($p=0.039$). A majority of women were not at all distressed that their longing for sex had decreased during the past 5 years. Six women in the study group felt moderately to severely distressed by the thought that their limitations in sexual activity and problems with faecal incontinence during intercourse would persist for the rest of their lives. Reduction in sexual activity was related to their partner in five women. There was no difference between in relation to overall satisfaction with their sexuality and sex life, and the influence of their sexual difficulties on well-being. The most frequent comment (12 women) was that the woman felt 'less attractive' / 'unglamorous', owing to physical scarring.
Schmidt	2005	Patients with Rectal CA who had a resection w curative intent at least 1 year previously from 1992-2002.	The goal of the present study was to assess the patients' postoperative sexual function and quality of life over time, with special attention to the important factors that influence sexual function.	Cross Sectional	Age and Differences in Sexuality and QoL, Gender Differences and QoL, How age, gender, type of surgery and adjuvant tx impact sexuality.	Comparing the effect of age on sexuality for both genders, we found a moderate correlation between age, sexual impairment, and sexual strain ($r = -0.423$; $P < 0.001$) only in females. Both experienced limitations in their sexual life, but male patients showed significant higher scores on "sexual impairment" and "distress caused by sexual impairment."
Schmidt	2010	Pts who had undergone tx with curative intent for CA of the rectum or of the rectosigmoid junction from 1997 - 2003	The main purpose was to determine to what extent sexuality was influenced by surgery and what impact it had on perceived QoL. A secondary purpose was to determine how factors, such as age, gender, type of surgery, and adjuvant treatment, influenced sexuality and QoL in these patients.	Prospective/ Longitudinal	Functional QOL, symptom QOL and sexuality. EORTC before surgery, at DC and 3,6,12 and 24 months later.	Both sexes experienced an impairment of their sexuality, men more than women. Emotional distress in men worsened up to to 24 months after surgery ($p<0.05$). Patients under 70 years old experienced a mild improvement of their sexuality over time, yet experienced stronger emotional distress due to impaired sexuality, and this distress worsened up to two years after surgery. Younger patients were found to be more severely affected than older patients by both of these over the entire period of time covered by the study ($p<.05$).

Table H7: Type of Cancer (colorectal/rectal) (continued)

				Colorectal n=11		
Author	Date	Target Population	Aim	Study Design	Outcome Measures (related to Sexuality/Sexual Health)	Key Findings (specific to Sexuality/Sexual Health)
Altschuler	2009	Female CRC patients with permanent ostomies	To better understand how a range of aspects of intimacy and sexuality are affected by having an ostomy as a result of CRC.	Mixed Methods -- cross sectional / interviews	Relationships between women's percepctions of partners support on global HRQOL and how having an ostomy affected intimacy and sexuality.	**1) Positive Support From Husbands; 2) Withdrawl of Support From Husbands; or 3) Mixed Support From Husbands or Partners.** Women describe positive support from their husbands as being central to their psychosocial adjustment, including adjustments to sexuality and changes in sexual life.
Cotrim	2007	Patients with CRC, who had surgery, older than 18 years, and of both genders. Exclusion criteria were the presence of respiratory, cardiac or hepatic dysfunctions. Caregivers were also recruited when possible.	To identify and assess the impact on quality of life of patients with colorectal cancer undergoing surgery. To identify and assess the burden of illness on the families of patients' with colorectal cancer.	Cross Sectional	Socio-demographic and disease / treatment-related characteristics; Psychological morbidity in stoma versus non-stoma ; Psychological morbidity of patients; Body image/sexual satisfaction/marital satisfaction; & Burden of caregivers scale (depression & anxiety measures)	A strong relationship between sexual satisfaction and marital satisfaction (P<0.001)was found in the stoma patients' group. In the group of non-stoma patients, a relationship was also found but it was lower (P<0.001). Non stoma pts had a significant relationship between body image and both sexual and marital satisfaction (p<0.001). Regression analysis also shows that type of patient (i.e. stoma) X body image is a predictor of patients QOL (.360..significant**)
Da Silva	2008	Female patients undergoing surgery of the colon and/or rectum from 3 different institutions between 2001 and 2003 were prospectively enrolled in this study. Those undergoing anal surgery were excluded.	Prospectively evaluate women's sexual function, self-esteem, body image, and quality of life after colorectal surgery using validated tools. A second aim was to compare the results between patients who had pelvic dissection with those without pelvic dissection to assess whether pelvic dissection would impose greater risk for sexual dysfunction in women as seen in men.	prospective (cohort) design	Sexual function, self-esteem, body image, and general health (mental and physcial health) & Importance of Discussing Sexual Issues & To compare the results between patients who had pelvic dissection with those without to assess whether pelvic dissection would impose greater risk for sexual problems.	Self-esteem did not differ between groups and did not change significantly after surgery. Postop, patients with worse body image scores (10) had lower self-esteem (mean 14.3, n 8). Women with better self-esteem (P 0.043) and body image scores (18) had significantly better sexual functioning (mean 31.3). Body image improved over time, with slight changes at 6 months and significant improvement at 12 months compared with baseline (P 0.05). At 6 months, MCS scores were higher for patients with good body image scores of 5 or less (mean 52.9) and higher selfesteem. However, at 12 months patients who had a stoma and low sexual function score (FSFI 22.9) also had lower MCS scores (mean 39.6). When asked about the importance of discussing sexual issues, 81.4% of the women stated it to be important.
Dowswell	2011	Men with erectile dysfunction after surgery for colorectal cancer	Describe the experiences of men after surgery for CRC and to ascertain whether or not the provision of information could be improved so that it is flexible, responsive to individuals coping strategies and information choices.	qualitative: interviews/ thematic analysis	Beliefs about erectile dysfunction, impact on self perception and relationships, satisfaction with information, and experience of treatment.	THEMES: **Experience of ED; Experience of treatment for ED; Inadequacies of pt care, & information before during and after cancer tx.** The experince was profound and stressful for men. 2 men associated the casual factors of ED with ED to be associated with the undermining of their masculinity. ED challenged the mens idenitties, affected mental health and undermined relationships. One extreme- suicide was contemplated. A minority of men accepted these changes philosophically and with a degree of stoicism. When the men began to recover from the effects of cancer and its treatment, many began to take an interest in ED. Experiences w treating ED were diverse.
Grant	2011	Colorectal Cancer w ostomy, patients with CRC who were 18 years or older. The goal was to recruit four to eight participants for each gender- and HRQOL-based focus group.	To describe how gender shapes the concerns and adaptations of long-term (i.e., more than five years) colorectal cancer survivors with ostomies.	Qualitative: content analysis / focus groups	Identify specific challenges ostomates face, their adaptation processes, and the strategies they adopted for self care. Quality-of-Life Similarities and Differences by Gender including physcial, social, spirtual and psychological well being.	**Social Physical Psychologcial AND Spirtual well-being.** Sexuality was coded 17 times accross focus groups (2nd highest code under social domain!). HQOL men coded sexuality 6 times; LQOL men coded sexuality 5 times. Body image and depression were mentioned only by women. Body image was only discussed in the LQOL female group. HQOL women groups coded sexuality 2 times; 3 times for LQOL women. Sexuality was discussed across all focus groups, with one or two comments that indicated sexual relationships were not problematic and a number of comments in each group about sexuality and intimacy problems related to complications of surgery or radiation therapy.
Milbury	2013	CRC pts. 18 years or older, competent in English, diagnosed with colon or rectal cancer stage I–III, and had received surgery at least 6 months earlier and completed all TX at least 1 month earlier. Patients w hereditary CRC were excluded.	The goal was to identify demographic, medical, and psychosocial risk factors that explain a significant proportion of the variance in male and female sexual function in colorectal cancer survivors.	Cross Sectional	Sexual functioning (IIEF FOR MEN AND FSFI FOR WOMEN) secondary: global QOL, psychosocial functioning, social support, dyadic adjustment	Both sexual outcome subscales were significantly associated with global QoL (P<0.01) so that better sexual function was associated with better QoL. Both men and women in a committed relationship scored higher on the CRC QLQ-38 "sexual function" scale compared to single participants (committed relationship, 40.74 vs. single, 14.15, P<0.0001). Better sexual function was associated with better QoL outcomes (-.27); dyadic adjustment (-.27); body image (-.22); global QOL (-.32); and sex. function (-.53) all correlated to sexual function. Interestingly, mental health and marital satisfaction were not significantly associated with IIEF or FSFI scores. For men, body image was not significantly associated with IIEF scores.
Ohlsson-Nevo	2011	Patients who had undergone CRC surgery one year previously and had lived with the same partner during the past year. Exclusion criteria were persons with difficulties understanding and speaking Swedish.	The aim of the study was thus to describe the experience of life the first year after surgery from both the perspective of persons treated for CRC and their partners.	Qualitative descriptive	Life in general, how the diagnosis had affected relationships in the marriage and social life and the experience of information and support in connection with the illness.	**Life is back to normal and yet not. 3 subthemes: 'Life has a shadow of death', 'The treated body sets the rules' and 'To share or not share the illness'**. Both patients and their partners described a change in intimacy after surgery. Some couples could resume the same sex life, others had a different sex life and some had no mutual sex life at all. Sex was for some replaced by another form of intimacy and closeness.The absence of sexual intercourse made some patients feel incomplete, missing an important part of life, but none of the partners expressed it as a great loss. Some partners expressed sexual problems as the patient's responsibility and did not want to pressure them to seek medical advice.
Ramirez	2009	Women; colon and rectal cancer survivors (at least 5 years postdiagnosis) w permanent ostomies who were identified from NCI-certified tumor registries during the years 2000 through 2006 were eligible	Explore a range of experiences (using an anthropological perspective) related to sexuality among female survivors with permanent ostomies.	Qualitiative: phenomenology	Examined issues regarding body image, gender, and sexuality in female CRC survivors with ostomies.	**1) No long-term sexual difficulties (n=11), 2) Long-term sexual difficulties (N=7), 3) Age-related changes in sexuality (N=3), 4) No partnered sexual experience post surgery (N=9)**. For some women, sexual changes created a great deal of emotional distress, but for others, it did not appear to be particularly problematic. Several women described carefully orchestrated ostomy management techniques when engaging in sexual activity.
Reese	2012	All participants were 21 years of age or older, married or living with a partner for at least 1 year, diagnosed from 2003 to 2008, had undergone surgery or other treatment for colorectal cancer, and and were able to read and write English. Inclusion was limited to patients with some degree of sexual concerns.	The purpose of the current pilot study was to collect preliminary data on the feasibility and efficacy of the intervention.	Pilot intervention study	Use of skills, program evaluation; Sexual distress, sexual function, sexual communication, dyadic adjustment, intimacy-- FSFI, IIEF AT BASELINE AND POST INTERVENTION.	Patient data showed large effect sizes (≥.80) for sexual distress, female sexual function, and sexual communication; a medium effect size (.30 to .60) for dyadic adjustment; and small effect sizes (.20 to .30) for intimacy.
Sharpe	2010	Adult patients with a diagnosis of stage A to D colorectal (colon or rectal) from seven hospital sites between March 2005 and September 2006	This study aimed to investigate the effect of having a stoma on body image in patients with colorectal cancer and to determine whether disturbances in body image predicted distress.	Prospective Cohort Study	Body Image Satisfaction; Anxiety and Depression; Distress; investigate the effect of changes in stoma status over time on psychosocial outcomes, examine Time×Stoma Effects, examine Differences between stoma versus non-stoma groups at Time 1& 2 (baseline/follow-up).	Between Stoma and Non stoma: There was a significant difference between groups for body image disturbance at baseline (P=.0005). Stoma patients showed more body image disturbance at baseline (p =.001). There was also a significant difference for anxiety, favoring the non-stoma group [P=.02], but not for depression or general distress (P=.08,). For body image disturbance, there was a main effect for time (P=.007) and stoma (P=.004) and an interaction effect (P=.04). Body image was more disturbed for those who had a stoma initially. Over time, those with an initial stoma (and not those without) became more disturbed about their body image. Body image disturbance did predict baseline depression (P<.0005) & anxiety (P=.0005) and follow-up distress (p=.001).
Wirsching	1975	Colorectal CA/ unsure of target	Compare pts with permanent colostomy through questionnaire and interview with pts who do not have colostomy. (self reported health questionnaires). To report the preliminary findings comparing the patient's own assessment of his health, the preoperative emotional state, social contacts and change in sexual activities.	Mixed Methods: case control (surveys) / interviews	Comparing 1) Patients own assessment of his health; 2) The periop emotional state 3) Social Contacts 4) change in sexual activities.	Lonliness was correlated w state of health, seldom leaving home, fear of reoccurence and sex-bound correlations exist to the size of community and sexual activity(i.e lonliness correlated to no sexual activity). The male group shows sexual disturbances it cannot be due to only organic damage, but is an expression of loss of self esteem and feelings of castration. These men show higher rates of social impotence, and depression. Men w colostomies show most severe decrease of intercourse rate. (p<0.01). Women showed worsening of martial relationships (linked w low sexual frequency) & greater capacity to cope

Table H8 Length of Survivorship

Survivors (0-2 YRS) (n=9)

Author	Date	Type of TX/Time Since TX	Sample Characteristics	Aim	Outcome Measures	Key Findings (specific to Sexuality/Sexual Health)	Direction of Effect (if applicable)
Cotrim	2007	Surgery/chemo/RT 6-8 months prior. About 28.1% had been submitted to surgery, 48.4% surgery and chemotherapy and 22.2% surgery, chemotherapy and radiotherapy. 30.1% had ostomy surgery.	153 (103 M/ 50 W)---- (47 rectal CA 46/stoma 106/ colon CA). age: 27-88. The mean age was 64.64 years 67.3% of the sample had colon cancer, 32.7% rectal cancer. Ninety-six caregivers were also recruited.	To identify and assess the impact on quality of life of patients with colorectal cancer undergoing surgery. To identify and assess the burden of illness on the families of patients' with colorectal cancer.	Socio-demographic and disease / treatment-related characteristics; Psychological morbidity in stoma versus non-stoma ; Psychological morbidity of patients; Body image/sexual satisfaction/marital satisfaction; & Burden of caregivers scale (depression & anxiety measures)	A strong relationship between sexual satisfaction and marital satisfaction (P<0.001)was found in the stoma patients' group. In the group of non-stoma patients, a relationship was also found but it was lower (P<0.001). Non stoma pts had a significant relationship between body image and both sexual and marital satisfaction (p<0.001). Regression analysis also shows that type of patient (i.e. stoma) X body image is a predictor of patients QOL.	Significant Findings
Da Silva	2008	All pts underwent Surgery/Chemo/RT. Seven patients (7.5%) in the pelvic group had radiation therapy. Fifty-seven (61.3%) patients underwent stoma formation, 48 (84.2%) of which underwent subsequent closure. They were evaluated at 6-12 months after initial surgery; also evaluated pre op . . . The patients were divided in 2 groups for comparison: Pelvic Group and the Abdominal Group.	93 WOMEN age 32-54; mean age of 43.0 .Of the 93 patients, 57 (61.3%) patients underwent pelvic and 36 (38.7%) underwent abdominal procedures.	To evaluate women's sexual function, self-esteem, body image, and quality of life after colorectal surgery using validated tools. A second aim was to compare the results between patients who had pelvic dissection with those without pelvic dissection to assess whether pelvic dissection would impose greater risk for sexual dysfunction.	Sexual function, self-esteem, body image, and general health (mental and physcial health) & Importance of Discussing Sexual Issues & To compare the results between patients who had pelvic dissection with those without to assess whether pelvic dissection would impose greater risk for sexual problems.	Self-esteem did not differ between groups and did not change significantly after surgery. Postop, patients with worse body image scores (10) had lower self-esteem (mean 14.3, n 8). Women with better self-esteem (P=0.043) and body image scores had significantly better sexual functioning (mean 31.3). Body image improved over time, with slight changes at 6 months and significant improvement at 12 months compared with baseline (P <0.05). At 6 months, MCS scores were higher for patients with good body image scores of 5 or less (mean 52.9) and higher selfesteem. However, at 12 months patients who had a stoma and low sexual function score (FSFI 22.9) also had lower MCS scores (mean 39.6). When asked about the importance of discussing sexual issues, 81.4% of the women stated it to be important.	Significant Findings.
Neuman	2011	All had Surgery/ 90% neoadjuvant therapy. All patients in the study cohort underwent a diverting loop **ileostomy.**	60 (27 W / 33 M)---Ages 25-85. Median age 55. (45%) were female; a majority were married (72%). Nodal metastases were evident in 36 patients (60%).	The goal was to perform an in-depth exploration into patients' experiences to determine the impact of a stoma on their QOL.	Overall QOL, and Impact of Stoma of QOL before tx, before stoma reversal and 6 months after.	A statistically significant decrease in body image (P = .03) between baseline and stoma closure time points; the mean change was 9.2; approaches definition of a clinically meaningful difference. Diminished body image persisted after stoma reversal. Sexual activity was the most commonly cited problem, with 53% reporting ''frequently'' or ''always,'' and 20% reporting that they ''occasionally'' did not enjoy sexual activity. Discomfort in clothing was a problem for (34%), as well as feeling unattractive (31%). There was no clinically significant difference btween sexuality/body image as measured by the stoma QOL scale at the three diff. time points.	Signifcant Findings.
Neuman	2012	All had Surgery & received a temporary diverting stoma. Sixty-five percent had stage III disease, Neoadjuvant therapy, n (%) 23 (88); Adjuvant therapy, n (%) 18 (69)	26 (12 W / 14 M) Ages 36-85. Median Age 54.	This study aimed to qualitatively explore the experiences of patients with rectal cancer who have a temporary ileostomy to better understand the discordant findings of previous quantitative quality-of-life studies.	The overall experience with the stoma, the perceived impact of the stoma on their QOL, and changes in perception if the stoma were to become permanent. (interviewed before stoma reversal)	**Stoma-related difficulties & Perceived response shift.** The impact of the ostomy on sexuality was variable. Although some reported no limitations, others felt that their sexual activities were curtailed, either because of personal or partner preference. Stoma impacted patients' sexuality and body image, but also posed a physical challenge that needed to be negotiated. Pts emphasized clothing changes to accommodate the stoma. The response-shift theory argues that patients accommodate to a life-threatening or disabling illness by changing the meaning of their self-evaluation of QOL.	NA
Ohlsson-Nevo	2011	Surgery (all one year prior)	13 couples (7 M / 6 W)-- all heterosexual (five rectal CA; eight colon CA) Ages 39-86. Six had a stoma.	The aim of the study was thus to describe the experience of life the first year after surgery from both the perspective of persons treated for CRC and their partners.	Life in general, how the diagnosis had affected relationships in the marriage and social life and the experience of information and support in connection with the illness.	**Life is back to normal and yet not. 3 subthemes: 'Life has a shadow of death', 'The treated body sets the rules' and 'To share or not share the illness'**. Both patients and their partners described a change in intimacy after surgery. Some couples could resume the same sex life, others had a different sex life and some had no mutual sex life at all. Sex was for some replaced by another form of intimacy and closeness.The absence of sexual intercourse made some patients feel incomplete, missing an important part of life, but none of the partners expressed it as a great loss. Some partners expressed sexual problems as the patient's responsibility and did not want to pressure them to seek medical advice.	NA
Reese	2012	Surgery/other TX: 22% has surgery only; 11% had surgery and radiation and 67% had surgery, RT and Chemo. Range of completion from 1 month-24 months.. All DX within 5 years. 22% w stage I; 56% w stage II; 22 % w stage IV. 22% had past ostomy; 33% w current ostomy.	14 heteosexual couples (7 M/ 7 W)-- (11 participating in at least one session and 9 completing all sessions and assessments-- 56% men (n=5), 44 % women (n=4). Ages: 47-76. 67% w rectal CA.	The purpose of the current pilot study was to collect preliminary data on the feasibility and efficacy of the intervention.	Use of skills, program evaluation; Sexual distress, sexual function, sexual communication, dyadic adjustment, intimacy-- FSFI, IIEF AT BASELINE AND POST INTERVENTION.	Patient data showed large effect sizes (≥.80) for sexual distress, female sexual function, and sexual communication; a medium effect size (.30 to .60) for dyadic adjustment; and small effect sizes (.20 to .30) for intimacy.	Positive Relationship btwn intervention and outcomes.
Sharpe	2010	Surgery (examined pre surgery or within 9 weeks of surgery and then again approx. 6 mos later at completion of adjuvant tx). 34 w stoma (type of tx: none--aside from surgery (48%); neoadjuvant 10%; chemo 32%; & RT 10%. 65 without stoma (type of TX: none--aside from surgery (46%); neoadjuvant = 5%; chemo= 49%; RT =0%.	99 (61 M/ 39 W)---- Ages 52-78; various stages of illness: A=23%, B=33%, C=27, D=7%. Various types of surgery (several). 20 men w stoma; 41 men without stoma, 11 women w stoma and 28 without stoma.	This study aimed to investigate the effect of having a stoma on body image in patients with colorectal cancer and to determine whether disturbances in body image predicted distress.	Body Image Satisfaction; Anxiety and Depression; Distress; investigate the effect of changes in stoma status over time on psychosocial outcomes, examine Time×Stoma Effects, examine Differences between stoma versus non-stoma groups at Time 1& 2 (baseline/follow-up).	Between Stoma and Non stoma: There was a significant difference between groups for body image disturbance at baseline (P=.0005). Stoma patients showed more body image disturbance at baseline (p =.001). There was also a significant difference for anxiety, favoring the non-stoma group [P=.02], but not for depression or general distress (P=.08,). For body image disturbance, there was a main effect for time (P=.007) and stoma (P=.004) and an interaction effect (P=.04). Body image was more disturbed for those who had a stoma initially. Over time, those with an initial stoma (and not those without) became more disturbed about their body image. Body image disturbance did predict baseline depression (P<.0005) & anxiety (P=.0005) and follow-up distress (p=.001).	Significant Findings
Schmidt	2005	Examined 12-18 months after surgery. 100% had surgery; 5% chemo; 45.2% RT AND CHEMO; 7% unknown.	261 (QOL data; 136 M/ 125 W)-- 561 total demographic data (264 M/ 252 W) Ages 53-78.	The goal of the present study was to assess the patients' postoperative sexual function and quality of life over time, with special attention to the important factors that influence sexual function.	Age and Differences in Sexuality and QoL, Gender Differences and QoL, How age, gender, type of surgery and adjuvant tx impact sexuality.	Comparing the effect of age on sexuality for both genders, we found a moderate correlation between age, sexual impairment, and sexual strain (r = −0.423; P < 0.001) only in females. Both experienced limitations in their sexual life, but male patients showed significant higher scores on "sexual impairment" and "distress caused by sexual impairment."	Significant Findings
Schmidt	2010	Surgery-- various operative techniques. 13.1% chemo; 48% RT; 4.6 % unknown.	368 (183 W/ 185 M) --- Mean age 64.9	The main purpose was to determine to what extent sexuality was influenced by surgery and what impact it had on perceived QoL. A secondary purpose was to determine how factors, such as age, gender, type of surgery, and adjuvant treatment, influenced sexuality and QoL in these patients.	Functional QOL, symptom QOL and sexuality. EORTC before surgery, at DC and 3,6,12 and 24 months later.	Both sexes experienced an impairment of their sexuality, men more than women. Emotional distress in men worsened up to to 24 months after surgery (p<0.05). Patients under 70 years old experienced a mild improvement of their sexuality over time, yet experienced stronger emotional distress due to impaired sexuality, and this distress worsened up to two years after surgery. Younger patients were found to be more severely affected than older patients by both of these over the entire period of time covered by the study (p<.05).	Significant Findings

Table H8 Length of Survivorship (continued) (1)

			Longer Term Survivors (2 + YRS) (n=5)				
Author	Date	Type of TX/Time Since TX	Sample Characteristics	Aim	Outcome Measures	Key Findings (specific to Sexuality/Sexual Health)	Direction of Effect (if applicable)
Altschuler	2009	Survivors at least 5 yrs post surgery w ostomy.	30 WOMEN age: 44-93; White Non- Hispanic (N=22), Asian/Pacific Islander (N=5), African American (N=2), and Hispanic (N=1). 22 were married or partnered at the time of surgery or shortly thereafter, 8 were single	To better understand how a range of aspects of intimacy and sexuality are affected by having an ostomy as a result of CRC.	Relationships between women's percepctions of partners support on global HRQOL and how having an ostomy affected intimacy and sexuality.	**1) Positive Support From Husbands; 2) Withdrawl of Support From Husbands; or 3) Mixed Support From Husbands or Partners.** Women describe positive support from their husbands as being central to their psychosocial adjustment, including adjustments to sexuality and changes in sexual life.	NA
Ball	2013	Median post-TX time was 6.4 years; types of TX that participants received included: surgery (n=13; 100 %), chemo (n=7; 53.8 %), and RT (n=5; 38.5 %). 7/ 13 participants had **temporary** ostomies that were reversed prior to enrollment.	13 MEN. Caucasian (n=13; 100 %); 57 % percent were married, and 87 % were college educated. Ages 47-82.	To understand men's perceptions of how RC treatment impacts their sexual functioning and how men manage sexual dysfunction. Second, we sought to receive feedback about the content and utility of our proposed psycho-educational sexual intervention.	Concerns and expectations about sexual functioning post-rectal cancer therapy, Prior experiences and satisfaction with help for post-cancer sexual function, Preferences for receiving education in improving sexual function & to assess content and utility of proposed sexual intervention.	**Priortizing cancer survival at diagnosis; diminished sexual and bowel functioning; desire for greater education regarding impact of treatment on sexual functioning; endorsment of the psycho-educational health intervention.** Participants said they had not focused on potential impact of cancer TX at the time of diagnosis. However, the interest in sex quickly reemerged once the fear of cancer diminished and other post-treatment side effects were resolved. Participants seemed to evaluate sexuality within their current life context. (i.e. most of the men attributed their sexual dysfunction to age), which facilitated their coping.	NA
Grant	2011	Survivors (at least 5yrs post dx) Years since surgery varied from 5-27 yrs.	33 (17 M/ 16 W) ---- Age: 18 years and older. Primairly Caucasian, one African American participant, one Hispanic, and one w a multiethnic background. Sociodemographic characteristics varied (i.e. income, marital status before surgery and currently, and employment status) Education level was similar across groups.	To describe how gender shapes the concerns and adaptations of long-term (i.e., more than five years) colorectal cancer survivors with ostomies.	Identify specific challenges ostomates face, their adaptation processes, and the strategies they adopted for self care. Quality-of-Life Similarities and Differences by Gender including physcial, social, spirtual and psychological well being.	**Social Physical Psychologcial AND Spirtual well-being.** Sexuality was coded 17 times accross focus groups (2nd highest code under social domain!). HQOL men coded sexuality 6 times; LQOL men coded sexuality 5 times. Body image and depression were mentioned only by women. Body image was only discussed in the LQOL female group. HQOL women groups coded sexuality 2 times; 3 times for LQOL women. Sexuality was discussed across all focus groups, with one or two comments that indicated sexual relationships were not problematic and a number of comments in each group about sexuality and intimacy problems related to complications of surgery or radiation therapy.	NA
Ramirez	2009	Survivors (at least 5yrs post dx)	30 WOMEN --- 44 to 93 years; median age was 74. White Non-Hispanic (N=22), Asian (N=3), Pacific Islander (2), African American (N=2), and Hispanic (N=1). 22 were married or partnered at the time of surgery or shortly thereafter (20 married, 2 partnered), and 8 were single at the time of surgery and continued in that status after the surgery.	Explore a range of experiences (using an anthropological perspective) related to sexuality among female survivors with permanent ostomies.	Examined issues regarding body image, gender, and sexuality in female CRC survivors with ostomies.	**1) No long-term sexual difficulties (n=11), 2) Long-term sexual difficulties (N=7), 3) Age-related changes in sexuality (N=3), 4) No partnered sexual experience post surgery (N=9**). For some women, sexual changes created a great deal of emotional distress, but for others, it did not appear to be particularly problematic. Several women described carefully orchestrated ostomy management techniques when engaging in sexual activity.	NA
Wirsching	1975	Surgery (1-30 yrs). Mean interval between surgery and follow-up was 9.7 yrs for the colostomy group and 8.1 yrs for the control.	330 (116 M/ 98 W) --214 in colostomy & 110 control (no colostomy)--Ages: over 60. 46 men and 64 women completed the survey. Interviews were conducted with 17 M and 14 W from study group; and 7 patients from the control group.	Compare pts with permanent colostomy through questionnaire and interview with pts who do not have colostomy. (self reported health questionnaires). To report the preliminary findings comparing the patient's own assessment of his health, the preoperative emotional state, social contacts and change in sexual activities.	Comparing 1) Patients own assessment of his health; 2) The periop emotional state 3) Social Contacts 4) change in sexual activities.	Lonliness was correlated w state of health, seldom leaving home, fear of reoccurence and sex-bound correlations exist to the size of community and sexual activity(i.e lonliness correlated to no sexual activity). The male group shows sexual disturbances it cannot be due to only organic damage, but is an expression of loss of self esteem and feelings of castration. These men show higher rates of social impotence, and depression. Men w colostomies show most severe decrease of intercourse rate. (p<0.01). Women showed worsening of martial relationships (linked w low sexual frequency) & greater capacity to cope	Significant Findings.

Table H8 Length of Survivorship continued (2)

Combination (varying lengths of survivorship) (n=4)

Author	Date	Type of TX/Time Since TX	Sample Characteristics	Aim	Outcome Measures	Key Findings (specific to Sexuality/Sexual Health)	Direction of Effect (if applicable)
Andersson	2010	Survivors 1-6 yrs post surgery w colostomy	5 WOMEN age 60-65; 4 of them lived with a partner.	To describe the experiences of women living with a colostomy as a result of rectal CA.	Experiences of life before cancer, the surgery itself, life after illness, (i.e. how living with colostomy impacts on daily life, relations, work, body image and sexuality).	**Insecurity about life & A Bridge to Life** . . . Sexual restrictions were not a big problem for the women and were something they could 'live with'. Body changes were also noted as a non-serious issue. They could live with these changes as they viewed it as an opportunity to survive cancer. The women's sex life changed after the rectal amputation. Those with partners thought it was important to have a good relationship and be able to talk about emerging problems.	NA
Au	2012	63% of individuals had been diagnosed with rectal cancer 1-3 yrs previously. The remaining were still undergoing TX.	120 (32 W/ 88 M) age: 29-85 mean= 60 yrs. 96% were married. 60% were in the Dukes A or B cancer stage (TNM system stage I or II), and 52% of them were treated with surgery only. 52% had no comorbid conditions. Only 9% of participants used medicine or other substances to enhance sexual activity.	To examine the relationships between two health-seeking behaviours (HSBs), spirituality and resourcefulness, as well as demographics, cancer-related factors and sexuality indicators, within the context of Schlotfeldt's health-seeking model in rectal cancer survivors.	Spirituality, resourcefulness, sexual function, sexual self-concept, communication and sexual relationship.	The major finding of this analysis was that **lower resourcefulness was associated with lower spirituality, sexual satisfaction, and sexual self-concept in both genders.** Spirituality was positively and significantly correlated with better communication ($p < 0.001$), sexual relationship ($p<0.001$), male sexual self-concept ($p = 0.000$), and female sexual self-concept ($p = 0.007$).	Significant Findings
Milbury	2013	Surgery at least 6 months prior & complete all TX at least one month earlier. Years since diagnosis: MEN: 1.55 -4.75 yrs. WOMEN: 0.77-5.83. Years since TX : MEN: 1.22-4.04 yrs. WOMEN: 1.11-3.73. RT TX: MEN (N, %) 93 (64.6 %); WOMEN 54 (46.2 %) ; ChEMO: (N, %) MEN 115 (80.4 %) WOMEN 94 (80.3 %)	261 (144 M/ 117 W) Ages; 49-74. MEN: Colon 52 (36.1 %) & Rectal 92 (63.9 %) WOMEN: Rectal 56 (47.9 %) & Colon 61 (52.1 %) Ostomy MEN: 29 (20.3 %) WOMEN: 11 (9.5 %).	The goal was to identify demographic, medical, and psychosocial risk factors that explain a significant proportion of the variance in male and female sexual function in colorectal cancer survivors.	Sexual functioning (IIEF FOR MEN AND FSFI FOR WOMEN) secondary: global QOL, psychosocial functioning, social support, dyadic adjustment	Both sexual outcome subscales were significantly associated with global QoL ($P<0.01$) so that better sexual function was associated with better QoL. Both men and women in a committed relationship scored higher on the CRC QLQ-38 "sexual function" scale compared to single participants (committed relationship, 40.74 vs. single, 14.15, $P<0.0001$). Better sexual function was associated with better QoL outcomes (-.27); dyadic adjustment (-.27); body image (-.22); global QOL (-.32); and sex. function (-.53) all correlated to sexual function. Interestingly, mental health and marital satisfaction were not significantly associated with IIEF or FSFI scores. For men, body image was not significantly associated with IIEF scores.	Significant Findings.
Platell	2004	At LEAST 6 months after Surgery. Study group: 18 underwent Low anterior resection and four ABD resection. All who had LAR had temp. ostomy which was subsequently closed. Eight received pre operative RT.	22 WOMEN (study group--rectal CA) 19 women (control group--colon) Age: unsure. Patients in the study group were younger than those in the control group. Majority of patients were over 60 yrs.	The aim of this study was to evaluate sexual health in women undergoing pelvic surgery for rectal cancer.	Body image, sexual awareness, libido, arousal, physical difficulties during intercourse and sexual activity. The questionnaire evaluated symptom occurrence, intensity and duration, and also considered the relevance of a symptom to each patient.	Study group was more likely to experience feelings of being less attractive after surgery ($p=0.039$). Majority of women were not at all distressed that their longing for sex had decreased during the past 5 years. Six women in the study group felt moderately to severely distressed by the thought that their limitations in sexual activity and problems with faecal incontinence during intercourse would persist for the rest of their lives. Reduction in sexual activity was related to their partner in five women. There was no difference between in relation to overall satisfaction with their sexuality and sex life, and the influence of their sexual difficulties on well-being. The most frequent comment (12 women) felt 'less attractive' / 'unglamorous', owing to physical scarring.	Somewhat Significant Findings for body image /feeling attractive. No significant findings for anything else.

UnSpecified (n=3)

Author	Date	Type of TX/Time Since TX	Sample Characteristics	Aim	Outcome Measures	Key Findings (specific to Sexuality/Sexual Health)	Direction of Effect (if applicable)
Ball	2011	'survivors'	9 WOMEN treated at Memorial Sloan-Kettering Cancer Center (MSKCC) for rectal cancer. Ages: Unsure	To better understand women's experience with sexual dysfunction following rectal cancer treatment, and to investigate barriers and promoters that may influence their participation in a sexual health intervention after receiving treatment for rectal cancer.	Understand the women's experience with sexual dysfunction following tx and to investigate barriers/promoters that would influence their participation in a sexual health intervention.	Survivors reported that a sexual intervention would be helpful to improve their QOL post TX because it would provide them with an education of the etiology of their problem and treatments to reduce their dysfunction (N = 8, or 89%). Also expressed the benefit of being able to talk to a professional regarding anxiety, which negatively impacts their sexual health, post TX (N = 6, or 67%)	NA
Dowswell	2011	Surgery/Chemo/RT complete--unsure of timing. Most had undergone colorectal cancer surgery (n=24). Chemo (n=20), RT (n=13), Stoma (n=13).	28 MEN-- ages: 29-80; Most were married, white, and heterosexual. 9 had rectal cancer. IIEF scores varied.	Describe the experiences of men after surgery for CRC and to ascertain whether or not the provision of information could be improved so that it is flexible, responsive to individuals coping strategies and information choices.	Beliefs about erectile dysfunction, impact on self perception and relationships, satisfaction with information, and experience of treatment.	Experience of ED; Experience of treatment for ED; Inadequacies of pt care, & information before during and after cancer tx. The experince was profound and stressful for men. 2 men associated the casual factors of ED with ED to be associated with the undermining of their masculinity. ED challenged the mens idenitties, affected mental health and undermined relationships. One extreme- suicide was contemplated. A minority of men accepted these changes philosophically and with a degree of stoicism. When the men began to recover from the effects of cancer and its treatment, many began to take an interest in ED. Experiences w treating ED were diverse.	NA
Nowicki	2011	All underwent surgery and combined treatment procedures. Unsure of exact timing. A permanent stoma was created in 78%, temporary in 12%.	50 (20 W /30 M)-- Ages 44-72.	Self-assessment of physical rehabilitation and psychosexual problems in patients with rectal carcinoma and stoma was the main objective of this work.	Patients' feelings about the psycho-sexual domain.	One third of pts stopped or limited their sexual relationships (< 0.05). Both genders had shame and fear of dirt and unpleasant smell as reasons for limitating sexual relationships. Changes in sexual life occurred in the form of ceasing sexual relationships in 36%. MEN: Reasons for cessation of sex: deteriorated selfassessment (n/%) 5/16; fear of lack of acceptance fr partner 2/7; shame 3/11; fear of smudging of dirt and unpleasure smell 3/11; decreasing sex drive 28/95 WOMEN: Lower self-esteem and fear of a lack of acceptance fr the partner play an important role in ceasing sexual life in about half of women (< 0.05). Deteriorated self assessment 11/55; fear of lack of acceptance 8/40; shame 3/15; fear of dirt/smell 3/15; decreasing sex drive 14/70; depressive mood 3/15.	Significant Findings

Table H9 Study Quality (high quality studies)

Author	Date	Aim	Study Design	Outcome Measures	Key Findings (specific to Sexuality/Sexual Health)	Direction of Effect (if applicable)	Aprasial Score
Altschuler	2009	To better understand how a range of aspects of intimacy and sexuality are affected by having an ostomy as a result of CRC.	Mixed Methods -- cross sectional / interviews	Relationships between women's percepctions of partners support on global HRQOL and how having an ostomy affected intimacy and sexuality.	**1) Positive Support From Husbands; 2) Withdrawl of Support From Husbands; or 3) Mixed Support From Husbands or Partners.** Women descirbe positive support from their husbands as being central to their psychosocial adjustment, including adjustments to sexuality and changes in sexual life.	NA	Strong
Grant	2011	To describe how gender shapes the concerns and adaptations of long-term (i.e., more than five years) colorectal cancer survivors with ostomies.	Qualitative: content analysis / focus groups	Identify specific challenges ostomates face, their adaptation processes, and the strategies they adopted for self care. Quality-of-Life Similarities and Differences by Gender including physcial, social, spirtual and psychological well being.	**Social Physical Psychologcial AND Spirtual well-being.** Sexuality was coded 17 times accross focus groups (2nd highest code under social domain!). HQOL men coded sexuality 6 times; LQOL men coded sexuality 5 times. Body image and depression were mentioned only by women. Body image was only discussed in the LQOL female group. HQOL women groups coded sexuality 2 times; 3 times for LQOL women. Sexuality was discussed across all focus groups, with one or two comments that indicated sexual relationships were not problematic and a number of comments in each group about sexuality and intimacy problems related to complications of surgery or radiation therapy.	NA	Strong
Milbury	2013	The goal was to identify demographic, medical, and psychosocial risk factors that explain a significant proportion of the variance in male and female sexual function in colorectal cancer survivors.	Cross Sectional	Sexual functioning (IIEF FOR MEN AND FSFI FOR WOMEN) secondary: global QOL, psychosocial functioning, social support, dyadic adjustment	Both sexual outcome subscales were significantly associated with global QoL ($P<0.01$) so that better sexual function was associated with better QoL. Both men and women in a committed relationship scored higher on the CRC QLQ-38 “sexual function” scale compared to single participants (committed relationship, 40.74 vs. single, 14.15, $P<0.0001$). Better sexual function was associated with better QoL outcomes (-.27); dyadic adjustment (-.27); body image (-.22); global QOL (-.32); and sex. function (-.53) all correlated to sexual function. Interestingly, mental health and marital satisfaction were not significantly associated with IIEF or FSFI scores. For men, body image was not significantly associated with IIEF scores.	Significant Findings.	Strong
Ramirez	2009	Explore a range of experiences (using an anthropological perspective) related to sexuality among female survivors with permanent ostomies.	Qualitiative: phenomenology	Examined issues regarding body image, gender, and sexuality in female CRC survivors with ostomies.	**1) No long-term sexual difficulties (n=11), 2) Long-term sexual difficulties (N=7), 3) Age-related changes in sexuality (N=3), 4) No partnered sexual experience post surgery (N=9)**. For some women, sexual changes created a great deal of emotional distress, but for others, it did not appear to be particularly problematic. Several women described carefully orchestrated ostomy management techniques when engaging in sexual activity.	NA	Strong
Sharpe	2010	This study aimed to investigate the effect of having a stoma on body image in patients with colorectal cancer and to determine whether disturbances in body image predicted distress.	Prospective Cohort Study	Body Image Satisfaction; Anxiety and Depression; Distress; investigate the effect of changes in stoma status over time on psychosocial outcomes, examine Time×Stoma Effects, examine Differences between stoma versus non-stoma groups at Time 1& 2 (baseline/follow-up).	Between Stoma and Non stoma: There was a significant difference between groups for body image disturbance at baseline ($P=.0005$). Stoma patients showed more body image disturbance at baseline ($p=.001$). There was also a significant difference for anxiety, favoring the non-stoma group [$P=.02$], but not for depression or general distress ($P=.08$,). For body image disturbance, there was a main effect for time ($P=.007$) and stoma ($P=.004$) and an interaction effect ($P=.04$). Body image was more disturbed for those who had a stoma initially. Over time, those with an initial stoma (and not those without) became more disturbed about their body image. Body image disturbance did predict baseline depression ($P<.0005$) & anxiety ($P=.0005$) and follow-up distress ($p=.001$).	Significant Findings. (very pronounced differences btwn groups..)	Strong
Schmidt	2005	The goal of the present study was to assess the patients’ postoperative sexual function and quality of life over time, with special attention to the important factors that influence sexual function.	Cross Sectional	Age and Differences in Sexuality and QoL, Gender Differences and QoL, How age, gender, type of surgery and adjuvant tx impact sexuality.	Comparing the effect of age on sexuality for both genders, we found a moderate correlation between age, sexual impairment, and sexual strain ($r = -0.423$; $P < 0.001$) only in females. Both experienced limitations in their sexual life, but male patients showed significant higher scores on “sexual impairment” and “distress caused by sexual impairment.”	Significant Findings	Strong

Table H9 Study Quality (moderate quality studies) continued (1)

		Moderate Quality Studies n= 11					
Author	Date	Aim	Study Design	Outcome Measures	Key Findings (specific to Sexuality/Sexual Health)	Direction of Effect (if applicable)	Apprasial Score
Andersson	2010	To describe the experiences of women living with a colostomy as a result of rectal CA.	Qualitative narrative approach	Experiences of life before cancer, the surgery itself, life after illness, (i.e. how living with colostomy impacts on daily life, relations, work, body image and sexuality).	**Insecurity about life & A Bridge to Life** . . . Sexual restrictions were not a big problem for the women and were something they could 'live with'. Body changes were also noted as a non-serious issue. They could live with these changes as they viewed it as an opportunity to survive cancer. The women's sex life changed after the rectal amputation. Those with partners thought it was important to have a good relationship and be able to talk about emerging problems.	NA	Moderate
Au	2012	To examine the relationships between two health-seeking behaviours (HSBs), spirituality and resourcefulness, as well as demographics, cancer-related factors and sexuality indicators, within the context of Schlotfeldt's health-seeking model.	Cross Sectional (secondary analysis)	Spirituality, resourcefulness, sexual function, sexual self-concept, communication and sexual relationship.	The major finding of this analysis was that **lower resourcefulness was associated with lower spirituality, sexual satisfaction, and sexual self-concept in both genders.** Spirituality was positively and significantly correlated with better communication ($p < 0.001$), sexual relationship ($p<0.001$), male sexual self-concept ($p = 0.000$), and female sexual self-concept ($p = 0.007$).	Significant Findings	Moderate
Ball	2013	To understand men's perceptions of how RC treatment impacts their sexual functioning and how men manage sexual dysfunction. Second, we sought to receive feedback about the content and utility of our proposed psycho-educational sexual intervention.	Qualitative exploratory	Concerns and expectations about sexual functioning post-rectal cancer therapy, Prior experiences and satisfaction with help for post-cancer sexual function, Preferences for receiving education in improving sexual function & to assess content and utility of proposed sexual intervention.	**Priortizing cancer survival at diagnosis; diminished sexual and bowel functioning; desire for greater education regarding impact of treatment on sexual functioning; endorsment of the psycho-educational health intervention.** Participants said they had not focused on potential impact of cancer TX at the time of diagnosis. However, the interest in sex quickly reemerged once the fear of cancer diminished and other post-treatment side effects were resolved. Participants seemed to evaluate sexuality within their current life context. (i.e. most of the men attributed their sexual dysfunction to age), which facilitated their coping.	NA	Moderate
Cotrim	2007	To identify and assess the impact on quality of life of patients with CRC undergoing surgery. To identify and assess the burden of illness on the families of patients' with CRC.	Cross Sectional	Socio-demographic and disease / treatment-related characteristics; Psychological morbidity in stoma versus non-stoma ; Psychological morbidity of patients; Body image/sexual satisfaction/marital satisfaction; & Burden of caregivers scale (depression & anxiety measures)	A strong relationship between sexual satisfaction and marital satisfaction ($P<0.001$)was found in the stoma patients' group. In the group of non-stoma patients, a relationship was also found but it was lower ($P<0.001$). Non stoma pts had a significant relationship between body image and both sexual and marital satisfaction ($p<0.001$). Regression analysis also shows that type of patient (i.e. stoma) X body image is a predictor of patients QOL (.360..significant**)	Significant Findings	Moderate
Da Silva	2008	Prospectively evaluate women's sexual function, self-esteem, body image, and quality of life after colorectal surgery using validated tools. A second aim was to compare the results between patients who had pelvic dissection with those without pelvic dissection to assess whether pelvic dissection would impose greater risk for sexual dysfunction.	prospective (cohort) design	Sexual function, self-esteem, body image, and general health (mental and physcial health) & Importance of Discussing Sexual Issues & To compare the results between patients who had pelvic dissection with those without to assess whether pelvic dissection would impose greater risk for sexual problems.	Self-esteem did not differ between groups and did not change significantly after surgery. Postop, patients with worse body image scores (10) had lower self-esteem (mean 14.3, n 8). Women with better self-esteem ($P=0.043$) and body image scores had significantly better sexual functioning (mean 31.3). Body image improved over time, with slight changes at 6 months and significant improvement at 12 months compared with baseline ($P <0.05$). At 6 months, MCS scores were higher for patients with good body image scores of 5 or less (mean 52.9) and higher selfesteem. However, at 12 months patients who had a stoma and low sexual function score (FSFI 22.9) also had lower MCS scores (mean 39.6). When asked about the importance of discussing sexual issues, 81.4% of the women stated it to be important.	Significant Findings.	Moderate
Dowswell	2011	Describe the experiences of men after surgery for CRC and to ascertain whether or not the provision of information could be improved so that it is flexible, responsive to individuals coping strategies and information choices.	qualitative: interviews/ thematic analysis	Beliefs about erectile dysfunction, impact on self perception and relationships, satisfaction with information, and experience of treatment.	**Experience of ED; Experience of treatment for ED; Inadequacies of pt care, & information before during and after cancer tx.** The experince was profound and stressful for men. 2 men associated the casual factors of ED with ED to be associated with the undermining of their masculinity. ED challenged the mens idenitties, affected mental health and undermined relationships. One extreme- suicide was contemplated. A minority of men accepted these changes philosophically and with a degree of stoicism. When the men began to recover from the effects of cancer and its treatment, many began to take an interest in ED. Experiences w treating ED were diverse.	NA	Moderate
Neuman	2011	The goal was to perform an in-depth exploration into patients' experiences to determine the impact of a stoma on their QOL.	Prospective/ Longitudinal	Overall QOL, and Impact of Stoma of QOL before tx, before stoma reversal and 6 months after.	A statistically significant decrease in body image ($P = .03$) between baseline and stoma closure time points; the mean change was 9.2; approaches definition of a clinically meaningful difference. Diminished body image persisted after stoma reversal. Sexual activity was the most commonly cited problem, with 53% reporting ''frequently'' or ''always,'' and 20% reporting that they ''occasionally'' did not enjoy sexual activity. Discomfort in clothing was a problem for (34%), as well as feeling unattractive (31%). There was no clinically significant difference btween sexuality/body image as measured by the stoma QOL scale at the three diff. time points.	No Signifcant Findings.	Moderate
Neuman	2012	This study aimed to qualitatively explore the experiences of patients with rectal cancer who have a temporary ileostomy to better understand the discordant findings of previous quantitative quality-of-life studies.	Qualitative: Interviews/ grounded theory	The overall experience with the stoma, the perceived impact of the stoma on their QOL, and changes in perception if the stoma were to become permanent.	**Stoma-related difficulties & Perceived response shift.** The impact of the ostomy on sexuality was variable. Although some reported no limitations, others felt that their sexual activities were curtailed, either because of personal or partner preference. Stoma impacted patients' sexuality and body image, but also posed a physical challenge that needed to be negotiated. Pts emphasized clothing changes to accommodate the stoma. The response-shift theory argues that patients accommodate to a life-threatening or disabling illness by changing the meaning of their self-evaluation of QOL.	NA	Moderate
Ohlsson-Nevo	2011	The aim of the study was thus to describe the experience of life the first year after surgery from both the perspective of persons treated for CRC and their partners.	Qualitative descriptive	Life in general, how the diagnosis had affected relationships in the marriage and social life and the experience of information and support in connection with the illness.	**Life is back to normal and yet not. 3 subthemes: 'Life has a shadow of death', 'The treated body sets the rules' and 'To share or not share the illness'**. Both patients and their partners described a change in intimacy after surgery. Some couples could resume the same sex life, others had a different sex life and some had no mutual sex life at all. Sex was for some replaced by another form of intimacy and closeness.The absence of sexual intercourse made some patients feel incomplete, missing an important part of life, but none of the partners expressed it as a great loss. Some partners expressed sexual problems as the patient's responsibility and did not want to pressure them to seek medical advice.	NA	Moderate
Reese	2012	The purpose of the current pilot study was to collect preliminary data on the feasibility and efficacy of the intervention.	Pilot intervention study	Use of skills, program evaluation; Sexual distress, sexual function, sexual communication, dyadic adjustment, intimacy-- FSFI, IIEF AT BASELINE AND POST INTERVENTION.	Patient data showed large effect sizes (≥.80) for sexual distress, female sexual function, and sexual communication; a medium effect size (.30 to .60) for dyadic adjustment; and small effect sizes (.20 to .30) for intimacy.	Positive	Moderate
Schmidt	2010	The main purpose was to determine to what extent sexuality was influenced by surgery and what impact it had on perceived QoL. A secondary purpose was to determine how factors, such as age, gender, type of surgery, and adjuvant treatment, influenced sexuality and QoL in these patients.	Prospective/ Longitudinal	Functional QOL, symptom QOL and sexuality. EORTC before surgery, at DC and 3,6,12 and 24 months later.	Both sexes experienced an impairment of their sexuality, men more than women. Emotional distress in men worsened up to to 24 months after surgery ($p<0.05$). Patients under 70 years old experienced a mild improvement of their sexuality over time, yet experienced stronger emotional distress due to impaired sexuality, and this distress worsened up to two years after surgery. Younger patients were found to be more severely affected than older patients by both of these over the entire period of time covered by the study ($p<.05$).	Significant Findings	Moderate

Table H9 Study Quality (low quality studies) continued (2)

		Low Quality Studies n=4					
Author	Date	Aim	Study Design	Outcome Measures	Key Findings (specific to Sexuality/Sexual Health)	Direction of Effect (if applicable)	Apprasial Score
Ball	2011	To better understand women's experience with sexual dysfunction following rectal cancer treatment, and to investigate barriers and promoters that may influence their participation in a sexual health intervention after receiving treatment for rectal cancer.	Qualitative: Interviews & Focus Groups	Understand the women's experience with sexual dysfunction following tx and to investigate barriers/promoters that would influence their participation in a sexual health intervention.	Survivors reported that a sexual intervention would be helpful to improve their QOL post TX because it would provide them with an education of the etiology of their problem and treatments to reduce their dysfunction (N = 8, or 89%). Also expressed the benefit of being able to talk to a professional regarding anxiety, which negatively impacts their sexual health, post TX (N = 6, or 67%)	NA	Weak
Nowicki	2011	Self-assessment of physical rehabilitation and psychosexual problems in patients with rectal carcinoma and stoma was the main objective of this work.	Cross sectional	Patients' feelings about the psycho-sexual domain.	One third of pts stopped or limited their sexual relationships (< 0.05). Both genders had shame and fear of dirt and unpleasant smell as reasons for limitating sexual relationships. Changes in sexual life occurred in the form of ceasing sexual relationships in 36%. MEN: Reasons for cessation of sex: deteriorated selfassessment (n/%) 5/16; fear of lack of acceptance fr partner 2/7; shame 3/11; fear of smudging of dirt and unpleasure smell 3/11; decreasing sex drive 28/95 WOMEN: Lower self-esteem and fear of a lack of acceptance fr the partner play an important role in ceasing sexual life in about half of women (< 0.05). Deteriorated self assessment 11/55; fear of lack of acceptance 8/40; shame 3/15; fear of dirt/smell 3/15; decreasing sex drive 14/70; depressive mood 3/15.	Significant Findings	Weak
Platell	2004	The aim of this study was to evaluate sexual health in women undergoing pelvic surgery for rectal cancer.	Case control design	Body image, sexual awareness, libido, arousal, physical difficulties during intercourse and sexual activity. The questionnaire evaluated symptom occurrence, intensity and duration, and also considered the relevance of a symptom to each patient.	Study group was more likely to experience feelings of being less attractive after surgery (p=0.039). Majority of women were not at all distressed that their longing for sex had decreased during the past 5 years. Six women in the study group felt moderately to severely distressed by the thought that their limitations in sexual activity and problems with faecal incontinence during intercourse would persist for the rest of their lives. Reduction in sexual activity was related to their partner in five women. There was no difference between in relation to overall satisfaction with their sexuality and sex life, and the influence of their sexual difficulties on well-being. The most frequent comment (12 women) felt 'less attractive' / 'unglamorous', owing to physical scarring.	Significant Findings for body image /feeling attractive. No significant findings for anything else.	Weak
Wirsching	1975	Compare pts with permanent colostomy through questionnaire and interview with pts who do not have colostomy. (self reported health questionnaires). To report the preliminary findings comparing the patient's own assessment of his health, the preoperative emotional state, social contacts and change in sexual activities.	Mixed Methods: case control (surveys) / interviews	Comparing 1) Patients own assessment of his health; 2) The periop emotional state 3) Social Contacts 4) change in sexual activities.	Lonliness was correlated w state of health, seldom leaving home, fear of reoccurence and sex-bound correlations exist to the size of community and sexual activity(i.e lonliness correlated to no sexual activity). The male group shows sexual disturbances it cannot be due to only organic damage, but is an expression of loss of self esteem and feelings of castration. These men show higher rates of social impotence, and depression. Men w colostomies show most severe decrease of intercourse rate. (p<0.01). Women showed worsening of martial relationships (linked w low sexual frequency) & greater capacity to cope	Significant Findings.	Weak

Appendix I: Investigator Triangulation

Discipline/ Context	Author
Research conducted by RN's (n=7)	1. Altschuler et al. (2009) RN PhD 2. Andersson et al. (2010) MSc RN Enterostomal-therapist, 3. Au et al. (2012) RN PhD 4. Cotrim & Pereira (2007) RN 5. Grant et al. (2011) RN, DNSc, FAAN 6. Nowicki et al. (2011) Department of Oncological Nursing 7. Ohlsson-Nevo et al. (2011), RN, Doctoral Student, Department of Surgery.
Research from psychology or behavior sciences (n=8)	1. Cotrim & Pereira (2007) RN Department of Psychological Institute 2. Ball et al. (2011) (2013) Department of Psychiatry and Behavioral Sciences, Memorial Sloan-Kettering Cancer Center 3. Milbury et al. (2013) Department of Behavioral Science, The University of Texas MD Anderson Cancer Center 4. Ramirez et al. (2009) PhD, MPH University of the Sciences in Philadelphia Department of Behavioral and Social Sciences 5. Reese et al. (2012) Department of Psychiatry and Behavioral Sciences, The Johns Hopkins University School of Medicine 6. Sharpe et al. (2011) School of Psychology, The University of Sydney 7. Wirsching et al. (1975), MD Psychosomatical clinic, department of psychoanalytic basic research and family therapy, and department of surgery

Discipline /Context	**Author**
Research conducted by physicians or CRC surgeons (n=9)	1. Da Silva et al. (2008), MD, Department of Colorectal Surgery, 2. Wirsching et al. (1975), MD Psychosomatical clinic, department of psychoanalytic basic research and family therapy, and department of surgery 3. Dowswell et al. (2011) research fellow Primary Care Clinical Sciences, University of Birmingham 4. Neuman et al. (2011) (2012) MD University of Wisconsin, Memorial Sloan-Kettering Cancer Center 5. Platell et al. (2004), Department of Colorectal Surgery at Fremantle Hospital, University of Western Australia, Fremantle 6. Schmidt et al. (2005)(2010), M.D Department of General and Thoracic Surgery, University of Kiel, Kiel, Germany
Research conducted by researchers affiliated with oncology/cancer centers (n=5)	1. Ball et al. (2011) (2013) Department of Psychiatry and Behavioral Sciences, Memorial Sloan-Kettering Cancer Center 2. Milbury et al. (2013) Department of Behavioral Science, The University of Texas MD Anderson Cancer Center 3. Neuman et al. (2011) (2012) MD University of Wisconsin, Memorial Sloan-Kettering Cancer Center