

Addressing sexual dysfunction in colorectal cancer survivorship care

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Abstract: Despite the high prevalence of sexual dysfunction in survivors of colorectal cancer, studies have shown that patients and providers rarely discuss how these symptoms may be influencing overall quality of life. The type and severity of symptoms of sexual dysfunction can vary greatly depending on the type of colorectal cancer and treatment, and assessment of sexual dysfunction is key to understanding how patients may be affected by these symptoms. Although patients would like to discuss these issues with their provider, they are often reluctant to ask questions about sexual functioning during appointments. Likewise, health care providers may hesitate to address sexual dysfunction due to time limitations or lack of knowledge regarding treatment of sexual problems. Health care providers can facilitate discussion of sexual dysfunction by (I) assessing sexual functioning throughout treatment; (II) initiating discussions about symptoms of sexual dysfunction at each appointment; and (III) maintaining adequate referral resources for treatment of sexual dysfunction.

Keywords: Colorectal cancer; sexual dysfunction; psychosocial factors; sex counseling

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Introduction

Sexual dysfunction is one of the most common long-term effects of colorectal cancer treatment, yet studies consistently show that this issue is rarely discussed among patients and their providers (1). Colorectal cancer survivorship has increased significantly in recent years due to advances in surgical techniques and adjuvant therapy, and the majority of colorectal patients will become long-term cancer survivors (2). Increasing survival rates in colorectal cancer have shifted the focus of patient health care needs from treating malignancies to addressing survivors' long-term quality of life, which includes sexual functioning (1). When sexual issues are not addressed, it can have a significant negative impact on the quality of life of survivors (3). To improve the quality of survivorship care in colorectal cancer, the sexual health needs of patients require assessment and treatment at all stages of care (4-6).

Sexuality is an important component of quality of life, given that the majority of colorectal cancer survivors will remain sexually active following treatment (7). Changes in

sexual functioning in colorectal cancer survivors can affect not only patients, but their partners as well (1). Although colorectal cancer survivors often report that their overall quality of life (QOL) is good, both men and women report significant problems with sexual functioning following treatment (6,8-11).

Prevalence of sexual dysfunction in colorectal cancer survivors

Forty-one percent of all cancer survivors experience a decrease in sexual functioning and 52% experience changes in body image (12). In patients with colorectal cancer, the rates of sexual dysfunction can be even higher given the physiological changes that can result from surgery, chemotherapy, and radiation therapy (*Table 1*). For example, patients who have undergone surgery for rectal cancer are significantly less likely to be sexually active than prior to surgery, and their sexual problems can be complex and multi-factorial (4). The type of surgery can impact sexual function as well. For example, one study found that women

Table 1 Potential impact of colorectal cancer treatments on sexuality			
Physiologic changes	Radiation therapy	Chemotherapy	Surgery
Vascular, sensory, and continence	Vascular scarring—decreased genital blood flow (erection dysfunction; decreased vaginal lubrication)	Change in senses—taste bud changes; increased sensitivity to smells; peripheral neuropathy changes sensation of touch	Urinary/fecal incontinence—type of surgery affects risk
Skin changes	Skin changes—texture/color changes can affect body image; can remind partner of patient's diagnosis. Although tattoos are small, they can be a reminder to the patient or partner of diagnosis	Skin sensitivity changes—some chemo causes extreme reaction to cold which affects food that can be eaten on dates; neuropathy affects enjoyment of skin touch; hand/foot (palmar/plantar) syndrome can affect enjoyment of activity with partner/affect ease of touching partner if skin peeling off hands; skin rash can occur; affect color of nails	Surgical scars—body image changes; affect partner's ease in being with patient
Fatigue	Affects social interaction, libido	Affects social interaction, libido	Affects social interaction, libido
Vaginal vault changes	Shortening of vagina; decreased lubrication; risk of dyspareunia; vaginal stenosis	Decreased lubrication; risk of dyspareunia; increased risk of vaginal infection from tiny tears; Mucositis—can affect oral or vaginal cavity	Postoperative adhesions if they occur do not usually affect the vaginal vault unless surgery was done in that specific location
Sexual pattern alterations	If fatigue, may need to change usual positions or time of day for activity; affect spontaneity; if decreased lubrication will need to use artificial lubricant to avoid tears and possible infection; if XRT causes diarrhea, will affect usual pattern if apprehensive re: fecal incontinence	If nausea/vomiting, will decrease desire; affects dating pattern; if taste bud changes, may avoid French kissing/oral stimulation; if fatigue, may need to change usual positions or time of day for activity; affect spontaneity; if decreased lubrication will need to use artificial lubricant to avoid tears and possible infection	If stoma will need to remember to empty appliance prior to sexual activity; perhaps wear cover on appliance to prevent it 'sticking' to body; if patient irrigates, may decide to do prior to activity so can wear smaller 'security pouch'; change in usual position so appliance can lie to the side; if waterplay activity part of sexual pattern may want to irrigate, prior so do not have to wear appliance; avoid 'gassy' food on date or use 'gas filters'; loss of rectal sexual pleasuring if rectum removed
Nerve damage	Skin sensitivity decreased; decreased vaginal lubrication/erection dysfunction	Skin sensitivity decreased; decreased vaginal lubrication/erection dysfunction	Skin sensitivity decreased; decreased vaginal lubrication/erection dysfunction
Urethral irritation	Depends on radiation treatment field	Hormonal changes may cause thinning and inflammation of tissues around the vaginal opening; if using spermicidal as birth control, can cause urethral irritation	None

Table 1 (continued)

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Physiologic changes	Radiation therapy	Chemotherapy	Surgery
Hair pattern	Alopecia—(only of site of radiation treatment) affects body image; daily reminder of treatment/diagnosis; if loss of pubic hair may be pleasurable OR may be emotionally upsetting to pt or partner if pt feels 'childlike'	Alopecia/hair thinning—affects body image; if single, may affect desire to date; daily reminder of treatment/diagnosis; if loss of pubic hair may be pleasurable OR may be emotionally upsetting to pt or partner if pt feels 'childlike'	Alopecia/hair thinning—none
Fertility impact	Location/dose affect risk; premature ovarian failure	Type/dose affect risk	Usually not for colorectal cancer; abdominal adhesions can increase risk of female infertility post-tx; pelvic exenteration (hysterectomy); A/P resection = retrograde ejaculation
Fear of recurrence	Impacts libido of patient and/or partner	Impacts libido of patient and/or partner	Impacts libido of patient and/or partner
Delayed complications	Risk of fecal or urinary incontinence due to fibrosis (risk factors for postoperative incontinence included preoperative incontinence, female gender, perioperative blood loss, preoperative bladder emptying difficulties, autonomic nerve damage, and presence of a permanent stoma)	Peripheral neuropathy may be permanent and it can affect sensations/enjoyment; taste bud changes may be permanent and will affect sexuality	Adhesions can cause pelvic pain during coitus; nerve damage may be permanent and affect sensations

who had abdominoperineal excision (n=73) for rectal cancer were less sexually active, had less frequent coitus, and were less likely to achieve arousal or orgasm than women who had anterior resection (n=222) (13). In males, one study found that total mesorectal surgery (n=49) affected erection (80%) and ejaculation (82%), while another study by Sartori and colleagues found less impact on erection and ejaculation (n=35) (14,15). Other studies have found that stoma creation does not always negatively impact on sexual function. For example, the meta-analysis by Ho, Lee, Stein and Temple found mixed results in terms of the relationship between stomas and sexual dysfunction. Despite the lack of conclusive evidence, the authors recommended that patients be informed that surgery might affect sexual functioning (6).

Sexual dysfunction in colorectal cancer survivors can also be related to medications (e.g., hormonal treatment or psychotropic medications) or changes in body weight during the course of treatment (16-19) (Table 1). Prior sexual history, age, partner status, socioeconomic status,

cultural beliefs surrounding sexuality, global quality of life and comorbid medical conditions can all have an impact on sexual functioning in survivors (20). Any symptoms of sexual dysfunction can also be exacerbated by symptoms of anxiety, depression, and fatigue which are common among survivors of cancer (21).

Although there is evidence to suggest that high rates of sexual dysfunction are reported among colorectal cancer survivors, very few studies have compared the prevalence of sexual dysfunction in this population with normative control groups. One of the few recent comparative studies of colorectal cancer survivors with a normative sample reported that male survivors of rectal cancer experienced higher rates of erectile dysfunction (54%) than those with colon cancer (25%) or those within the normative sample (27%) (4). Males with rectal cancer also reported higher rates of ejaculation problems (68% rectal versus 47% of colon cancer survivors). Female rectal and colon cancer survivors reported significantly more vaginal dryness (35%

rectal; 28% colon) than the normative population (5%) and pain during intercourse (30% rectal; 9% colon; 0% normative) (4).

Patient-provider communication about sexual dysfunction

Providing education, informational support, and treatment options can help to improve sexual functioning in colorectal survivors (11). Despite the high prevalence of sexual dysfunction reported by colorectal cancer survivors and increasing awareness of the sexual health needs of patients, sexual functioning is often not adequately addressed by health care providers (22,23). Patients often express reluctance to raise sexual issues during appointments, and many report feeling embarrassed or ashamed to ask questions related to sexual health (24). Discussing sexual issues may be a new experience for many cancer patients who may not have felt the need to address this topic with health care providers in the past (25,26). This can result in patients feeling unsure how to broach and describe sexual issues for the first time. Health care providers may also be reluctant to discuss sexual functioning due to time limitations, lack of knowledge regarding treatment for sexual problems, and beliefs about the appropriateness of discussing sexuality within the context of cancer treatment (1).

Recent studies have identified issues related to patient-provider communication for patients with many types of cancer, including colorectal cancer. For example, Flynn and colleagues found that in a survey of 819 patients with cancer and cancer survivors, 78% of participants felt that it was important to discuss how cancer may impact sexual functioning and 64% believed that it was helpful to include partners in discussions with providers about their sex life (5). However, only 29% of participants reported that they had asked their health care provider about problems with their sex life, and 45% reported that they had never received any information from their providers about how cancer or cancer treatment may affect their sexual functioning. Although most patients (59%) who did not ask their providers about sexual problems reported that they did not have any questions, 21% felt that the problems with their sex life were “not bad enough” to discuss, and 9% reported that they felt too shy or embarrassed to bring up the topic. Focus group participants in that study reported that it would be helpful for the oncology provider to initiate discussions about sexual problems (5).

A recent qualitative study of patients (n=21), their

partners (n=9), and their health care providers (n=10) assessed sexual health needs for colorectal cancer survivors from their perspective (1). This study sought to identify potential barriers and facilitating factors to communication about sexual functioning through a combination of focus groups and questionnaires. As with the Flynn *et al.* study, participants in this study were not always able to recall if they had received information about sexual functioning after treatment. Patient/partner knowledge about the availability of treatment for sexual problems was also limited (1). The patients and partners noted that having more information about potential sexual problems and health care options may have facilitated further discussion about sexual functioning with their health care providers. The patients and partners also noted that they felt embarrassed to bring up sexuality with their providers, and many felt that it was inappropriate to discuss sexual problems if the treatment goal was patient survival.

Traa and colleagues reported that health care providers identified a number of barriers to providing adequate sexual health care including knowledge and competence in the area of sexuality, beliefs about sexuality, and attitudes towards discussing sexuality (1). In the Traa *et al.* study, most providers noted that they did not feel sufficiently prepared to have detailed discussions about sexuality or did not consider it to be within the scope of their care. Health care providers echoed some of the same concerns expressed by patients/partners by noting that as providers they felt it was inappropriate to discuss sexuality if the main treatment goal was survival. They also expressed concern that the potential for causing discomfort or embarrassment for the patient and/or their family members might have an adverse effect on overall treatment.

Additionally, sexuality may be considered “irrelevant” for certain patients due to their age, gender, or relationship status (1,10). For example, health care providers may consider elderly or widowed patients as having less sexual health care needs. This is similar to prior studies of communication regarding sexuality in primary care settings that have identified cultural factors (e.g., gender, age, race/ethnicity, or sexual orientation differences) as barriers to openly discussing sexual functioning (22).

Improving communication about sexual dysfunction in survivorship care

Given the high rate of reported sexual dysfunction among colorectal cancer survivors and the limited patient-provider

Table 2 Interviews and self-report questionnaires to assess sexual functioning

Questionnaire	Description
CSFQ	35-item clinician-administered questionnaire for males and females that assesses medication-related changes in sexual function in the following domains: sexual pleasure, sexual desire, arousal, and orgasm
DIFS	25-item clinician-administered questionnaire for males and females that assesses sexual cognition, sexual behavior, orgasm, and sexual drive
SIDI-F	13-item clinician-administered questionnaire for female to assess symptoms of hypoactive sexual desire
IIEF	15-item self-report questionnaire for men to assess erectile function, intercourse satisfaction, orgasmic function, sexual desire and overall satisfaction with sexual functioning
FSFI	19-item self-report questionnaire for women to assess sexual desire, arousal, lubrication, orgasm, satisfaction, and pain

CSFQ, Changes in Sexual Functioning Questionnaire (27); DIFS, Derogatis Interview for Sexual Functioning (28); SIDI-F, Sexual Interest and Desire Inventory (29); IIEF, International Index of Erectile Functioning (30); FSFI, Female Sexual Function Index (31).

communication about sexual functioning in oncology settings, there is a need to address barriers to sexual functioning discussions in order to improve the quality of life aspect of survivorship care. Althof & Parish have identified a number of patient-centered communication skills that may help providers to improve interactions regarding sexual functioning, while taking into consideration the time constraints of appointment time (24). For example, using a combination of clinical interview and questionnaire techniques can help to screen for potential sexual problems, gather information about patients' sexual functioning, and help patients to feel more comfortable addressing questions about sexual functioning with their provider (24).

A number of assessment tools related to sexuality have been developed that can help providers to gather data about sexual functioning quickly prior to meeting with patients (Table 2). Although self-report questionnaires are not sufficient to fully evaluate a patient's symptoms of sexual dysfunction, they can provide a useful way to begin conversations about sexuality. Often survivors who have not brought up sexual issue concerns with providers will disclose those concerns on a self-report symptom list (22). Using open-ended questions to help patients to elaborate on their sexual functioning concerns can help to clarify sexual problems and identify potential areas for treatment. Open-ended questions can be particularly helpful in eliciting information about how sexual problems are impacting patient functioning (24).

Overall, sexual dysfunction is prevalent among colorectal cancer survivors and an important aspect of quality of life for health care providers to consider. Despite patients' report of the importance of discussing sexuality with their

providers, it is often not addressed during appointments. In order to improve patient-provider communication regarding sexual functioning, the following recommendations may be helpful to consider:

Recommendations for providers:

- (I) *"As part of clinical practice, screening and assessment of sexual functioning should be included early in treatment for all patients and continue during all stages of care"* (22). Regardless of age, sexual orientation, or partner status, sexual functioning is an important aspect of the quality of life for all patients that should be made part of clinical practice with assessments being done frequently and continuing during all stages of treatment. As recommended by Althof & Parish, a combination of physical examination, clinical interview, and questionnaires may help to improve assessment, engage patients in a conversation that they may be reluctant to initiate, and, as appropriate, elicit patient concerns (24). Even if patients do not report changes in sexual functioning after treatment has been completed, it is important to re-assess the patients as they may experience delayed onset of sexual problems after treatment or develop new problems over time;
- (II) *"Patients may be reluctant to raise the topic of sexual functioning during appointments. Initiating conversations about sexual functioning as part of standard clinical care can help to facilitate discussions about these issues"*. Patients consistently state that they feel more comfortable if providers bring up the topic of sexual functioning (5). Asking permission to discuss sexuality may help patients

Table 3 Web based resources on sexuality and cancer

American Association of Sexuality Educators, Counselors, and Therapists: www.aasect.org
National Institutes of Health, National Institute on Aging: www.nia.nih.gov : "Health Information" for Sexuality in Later Life brochure
Wound, Ostomy and Continence Nurses Society: www.wocn.org : locate a certified WOC Nurse near you
American Cancer Society: www.cancer.org : pamphlets about sexuality and cancer
American Cancer Society United Ostomy Association, Inc: www.ostomy.org
Fertile Hope: www.livestrong.org/we-can-help/fertility/risks/ for information re: risk of infertility
Mary-Helen Mautner Project for Lesbians with Cancer: Mautnerproject.org
American Psychosocial Oncology Society: www.apos-society.org
WOC, wound, ostomy and continence.

to feel more comfortable answering questions about their current functioning and provide them with language to help them describe and report their symptoms. Involving sexual partners in these discussions (with patient permission) may also help to facilitate a more open dialogue among patients, partners, and providers throughout treatment;

- (III) "Maintain referral resources and information regarding treatment options for sexual dysfunction for patients and their partners". Health care providers report that lack of knowledge about treatment options and concerns about treating sexual dysfunction within their scope of practice may limit their ability to discuss these issues with patients (1). In multidisciplinary care settings, it may be possible to consult with another provider with expertise in sexual functioning in the event that a practitioner's knowledge and skill sets are limited in this area (32). If these options for referral are not available, being aware of local external referral sources for treatment of sexual dysfunction can also facilitate further treatment for patients. There are also a number of patient resources that may provide valuable information about sexual dysfunction and help patients to make informed decisions about seeking treatment for sexual problems (Table 3).

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