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Figuring Out Sex in a Reconfigured Body: Experiences of Female Colorectal Cancer Survivors with Ostomies

Michelle Ramirez, PhD, MPH, Carmit McMullen, PhD, Marcia Grant, RN, DNSc, Andrea Altschuler, PhD, Mark C. Hornbrook, PhD, and Robert S. Krouse, MD

Abstract

Colorectal cancer (CRC) survivors with ostomies can face complex concerns regarding sexuality. We used an anthropological perspective to examine the experiences of 30 female CRC survivors with ostomies to shed light on the sexual challenges and adaptations made in the wake of cancer surgery and treatment. Participants fell into four categories with regard to their sexual experience post surgery; however, not all women found their altered sexuality to be particularly problematic. This type of phenomenological examination can inform a more patient centered, less biomedically focused paradigm for assessing and improving the sexual health of cancer survivors.

Keywords

cancer; sexuality; lifecourse; quality of life

INTRODUCTION

As more people survive cancer, greater attention is being given to health-related quality-of-life (HR-QOL) outcomes, including sexuality (Krouse et al. 2006; Krouse et al. 2007; Grant 1999; Nugent et al. 1999; Ramsey 2000). For people diagnosed with colorectal cancer (CRC), surgical treatment may result in an intestinal stoma. Intestinal stomas (or ostomies) are created through a surgical procedure in which a diseased part of the small or large intestine is removed. The remaining intestine is attached to an opening in the abdomen through which feces are expelled, most often into a pouch appliance. The surgical formation of a stoma often results in complex emotional, social, and physical concerns. Moreover, adjusting to a post-surgical body with an ostomy is often problematic (Kelly 1992; Klopp 1990; Notter and Burnard 2006; Salter 1992). Individuals typically learn to use a bag or appliance to care for the stoma, prevent skin irritation, manage accidental leakage, and overcome embarrassment related to sounds and smells (Annells 2006; Manderson 2005). Because of its common surgical placement—the lower abdomen—having an ostomy can present particular difficulties for sexual intimacy (Black 2004; Weerakoon 2001).

A notable amount of research examines the effects of ostomy surgery on male sexual functioning (Fazio et al. 1980; Sprangers et al. 1995; Yeager and Van Heerden 1980), but less is known about how it affects the sexual health of women (Camilleri-Brenan and Steele 1998; Ofman and Auchincloss 1992; Li 2009). However, various physiological changes have been documented among women who have undergone surgery and radiation as part of a CRC treatment plan. Dyspareunia, or painful intercourse, can result from operations in the pelvis that create scar tissue around the vagina. If the rectum is removed, the angle of the vaginal

canal can shift to such a degree that penetration can be painful or difficult (Sprunk and Alteneder 1999:86). Additionally, radiation therapy can cause vaginal stenosis, which is a narrowing of the vagina due to a build up of scar tissue (White and Faithfull 2006).

Adverse psychosocial outcomes have also been observed among cancer survivors who experience sexual difficulties. Ferrell and colleagues (1995) indicated that family distress and sexuality were reported as having the most negative influence on the social well-being of cancer survivors. Oncology care providers and researchers are concerned with designing interventions that can improve patient-provider communication regarding sexual matters (Hordern and Street 2007) and interventions to aid in the sexual rehabilitation of cancer survivors (Gallo-Silver 2000; Junkin and Beitz 2005). However, these interventions are often framed around resuming heterosexual intercourse (Grunberg 1986; Gloeckner 1991; Bordwell 1997). Hordern and Currow advocate a patient-centered approach and assert that sexuality is “inextricably linked to a sense of wholeness,” and “intrinsic to a sense of self” (2003:58).

In anthropological research specifically examining sexuality after ostomy surgery, Manderson (2005) asserts that managing an ostomy impacts self-image and sexual/social relationships, and proposes that an ostomy and its function breach normal bodily boundaries by externalizing fecal matter. Moreover, cultural aversions to feces require individuals living with an ostomy to reconcile or manage their own and others' experience of disgust when attempting to be sexually intimate. These practices highlight the importance of maintaining bodily aesthetics during sexual encounters. However, the author noted the positive psychosocial role played by spouses and partners who maintained sexual relationships with individuals post surgery.

The current discussion explores a range of experiences related to sexuality among female colorectal cancer survivors with permanent intestinal ostomies. Documenting male sexual function has been more amenable to scientific measurement. Because the effects on female sexuality have been more elusive, using qualitative methods to explore this poorly understood phenomenon is appropriate because these methods allow researchers to explore in depth the lived experience of individuals. Further, using an anthropological perspective provides some useful insights into the complex challenges faced by this patient population, and can also potentially inform more patient-centered, less biomedically focused paradigms for assessing and improving the sexual health of cancer survivors.

METHODS

Recruitment

In the parent study, a survey was mailed to 284 long-term CRC survivors to measure HRQOL among CRC survivors with ostomies; 117 of these participants were women. Study sites for the parent study were 3 Kaiser Permanente Regions: Northern California (KPNC), Northwest (KPNW), and Hawaii (KPH). A comprehensive sampling strategy was used to identify participants for the initial survey. All colon and rectal cancer survivors (at least 5 years post-diagnosis) with permanent ostomies who were identified from NCI-certified tumor registries in KPH, KPNC, and KPNW during the years 2000 through 2006 were eligible. Women who chose to participate in the current interview study had previously completed the HRQOL survey, and were patients from either KPNC or KPNW only.

Women were contacted in waves of recruitment from each site until the intended sample of 30 was filled. Potential participants received a recruitment letter inviting them to participate in an hour-long interview to discuss how having an ostomy affected them in terms of intimacy and sexuality. Those potential participants who expressed an interest in participating then received a follow-up call from the interviewer to confirm eligibility and to schedule an interview if appropriate. Electronic medical records were used to identify minority patients in the pool of

eligible participants to ensure some degree of minority representation. The project team also focused recruitment on younger women (<60 years of age) to ensure that a wide variety of experiences would be represented. The response rate to the initial mailed HRQOL survey was 52%. The median age of women survey participants was 74 years. Seventy-three female survey participants were contacted for the interview study, and 30 were interviewed, yielding a 41% response rate. Non-respondents stated that they did not have the interest or time to participate or could not be reached during phone follow up (see also Altschuler et al. 2009).

Materials

Members of the interdisciplinary research team collaboratively created the semi-structured, open-ended interview guide that examined issues regarding body image, gender, and sexuality in female CRC survivors with ostomies. Standard instruments were not used to measure these dimensions because of the exploratory and phenomenological nature of the study. Therefore, open-ended questions eliciting meaning and experience were used to capture the essence of patient experience (Morse 1994). Participants were given the choice of being interviewed in their homes, their local medical facility, or a location that was most convenient, and most chose to be interviewed in their homes. Prior to commencing the interview, informed consent was obtained from all study participants, and women received a \$25 gift certificate after completing the interview. Interviews were audio recorded and transcribed verbatim by a professional transcription service. The IRBs of each institution approved all study materials and protocols.

Data Analysis

Four of the six authors were involved in the coding of the data. Using grounded theory, the coders remained open to the theoretical possibilities in the data (Charmaz 2006). For purposes of validity, however, at least two authors independently reviewed and coded each transcript for major themes. Codes addressed issues such as comorbidities, complications, body image, ostomy care, sexuality, the nature of relationships with spouses, and sense of self and femininity (Table 3). When coding differences arose, the coding authors discussed the responses and came to consensus on the most appropriate codes for each response. Based on the initial coding of the interviews, and consistent with grounded theory's emphasis on data emergence, rather than data emanating from an earlier frame applied to the study (Charmaz 2006), the women's responses revealed four major categories of sexual experience after their surgeries. The first author then placed women into the group that most accurately reflected their experience. This categorization was reviewed by all members of the coding team to ascertain the validity of the four categories of sexual experience. No qualitative software was used in coding the interview data.

FINDINGS

While most participants were White Non-Hispanic (N=22), other racial/ethnic groups were represented: Asian (N=3), Pacific Islander (2), African American (N=2), and Hispanic (N=1) (Table 1). Participants ranged in age from 44 to 93 years (mean=70). Of the 30 respondents, 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. All of the women interviewed had been in heterosexual relationships at some point during their lives. None reported that they had ever been in a same-sex sexual relationship and framed their current sexual repertoire (or lack thereof) in terms of heterosexual experience. Participants fell into four different groups of sexual experience based on our analysis of their responses: 1) No long-term sexual difficulties, 2) Long-term sexual difficulties, 3) Age-related changes in sexuality, 4) No partnered sexual experience post surgery (Table 2). Each group is described in more detail below.

Group I: No Long-Term Sexual Difficulties (N=11)

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 women were currently partnered, others had deceased partners, and still others were either divorced or no longer lived with a sexual partner. 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 to their sexual repertoire.

Several women described carefully orchestrated ostomy management techniques when engaging in sexual activity. First, it was important to have either a new bag or a bag that had been recently emptied of all fecal matter before having sex. Sexual activity generally did not happen without the ostomy pouch in place for fear of accidents and leakage; thus, it became important to cover the pouch with various items such as towels, tube tops, or night gowns--covering their ostomy appliance before sexual activity simply became part of their sexual repertoire. Covering the ostomy served two important purposes: it kept the pouch stable, ensuring a greater degree of accident prevention, and it also kept the pouch hidden. Several women explained that not only did they not want their partner to see the pouch, but the women themselves did not want to see the pouch during sexual activity. Hiding the pouch from sight was in essence a way to minimize their own and their partner's disgust at "matter out of place" (Douglas 1966), i.e., feces during sex, which given our culture's aversion to feces, was seen by the participants as antithetical to sexual arousal and desirability. One participant described this process very succinctly:

So, when I'm in bed and I've got my lingerie on... I've got a clean bag. He can lay on top of me; it doesn't hurt. He's not feeling feces. That's another thing, sometimes he'll want to have sex and I have a little bowel...in my bag and I'll excuse myself and get another bag, because I don't want him to feel that when he's laying on top of me. That would make me feel gross. You know?

Several women in this group attributed their ability to resume sexual activity to a supportive spouse who accepted their reconfigured bodies. Indeed these men were described as a key component in these women's recovery and acceptance of their surgically altered bodies. For example, one woman with multiple health problems in addition to her cancer, found great comfort in her husband's support: "My husband is very loving and caring. He didn't have a problem with it, so that helped me a lot." To which she later added: "Knowing that someone else still feels that you're desirable makes all the difference in the world to me." Thus, remaining sexually desirable to her husband was paramount for this woman's acceptance of her changed body.

Group II: Long-Term Sexual Difficulties (N=7)

This group of women primarily framed the experience of sexual difficulty in terms of either painful intercourse or the inability to have intercourse, both due to vaginal changes as a result of cancer treatments. For some women, this created a great deal of emotional distress, but for others, it did not appear to be particularly problematic. The youngest woman in the sample (age 44), who had been married to her husband since she was 19, described the inability to have regular intercourse as an extremely difficult issue. This was in part because intercourse had played such an important role in their relationship prior to the surgery. After surgery, she and her husband tried different positions and lubricants but the pain she experienced during intercourse affected both partners' ability to enjoy sex. This ultimately created tremendous sadness when she reflected upon the loss:

And 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.

This participant and her husband continued to have oral sex although she reported that this was not a satisfactory reconfiguration for either partner. Prior to ostomy surgery she described a very active and mutually satisfying sexual life with her husband. Regular intercourse is often touted in the United States as an ideal expression of marital intimacy, indeed it is often seen to form the core affective bond in a conjugal relationship, which has been described by various scholars as a companionate model of marriage (Simmons 1979; Hirsch 2003). Therefore, it is not surprising that the current lack of sexual intercourse represented a profound disruption and loss to this woman. She reported that she had been advised to use a vaginal dilator to keep the walls of her vagina flexible post-surgery, but found inserting it to be extremely painful, and did not use it regularly. However, she discussed that had she been made more aware of the potential sexual difficulties, this information may have helped her to endure the pain the dilators caused in the early days of her cancer treatment. At several different times during the interview, this participant described that she wished she had been given more information and education prior to surgery about the potential long-term effects that surgery and radiation would have on her intimate life.

However, other participants reported that a lack of sexual intercourse was not particularly distressing. One 48-year-old woman, a mother of two adolescent boys, also experienced pain during intercourse post surgery, but felt reasonably satisfied having oral sex with her husband and occasionally masturbating. She reported that at times she missed having intercourse, but felt that it was not particularly important to resume, in part because it had never been a central part of the relationship for her even before the surgery. She knew her husband would prefer to resume intercourse, but he did not pressure her given that it was painful for her. This participant felt very grateful for her husband's understanding, but also reported that an additional obstacle was feeling undesirable because of the pouch appliance, stating, "No, I don't feel sexy with a bag of stuff hanging off the side of me." Thus, even with an understanding husband, this woman's discomfort with her ostomy was an obstacle in resuming intercourse. But again for this couple, it did not appear to be the profound disruption that it was for the participant discussed above. Indeed, this woman felt very grateful to have survived cancer, and while the pouch certainly interfered with intercourse, it was a reasonable compromise for her, in that she was alive and able to be a parent to her children.

Yet another woman, a divorced 69-year-old Asian woman, tried once to have intercourse and found it to be so painful that she has since abstained from intercourse all together, and any emotional or romantic entanglements that could potentially lead to intercourse. She reported masturbating on occasion and felt that this was a less complicated and more comfortable sexual release because she did not have to worry about how a sexual partner might feel about her body. In the process of recounting her lack of partnered sexual experience, this woman said, "You probably think I'm pathetic." This statement suggested this woman's sense of failure to uphold a "normative" sexual life, and illustrated the cultural pressure exerted on individuals to remain sexually active. In spite of this pressure, however, the women who reported long-term sexual difficulties as *unproblematic* to their wellbeing, or the well being of their relationships, were able to orchestrate new levels of sexual activity that felt manageable for their reconfigured bodies.

Group III: Lifecourse, Age-Related Changes in Sexuality (N=3)

Although very few women were included in this group, they represented an important dimension to understanding sexuality in this patient-survivor population. These individuals were currently partnered and reported that sexual intercourse was no longer important to maintain a harmonious marital relationship. One of the three had been sexually active with her husband post surgery at a younger age, but all three attributed their lack of interest in intercourse, or the importance of having intercourse at the current time, to growing older.

One participant, an 84-year-old woman, who was still married to her childhood sweetheart, described other acts of intimacy and love as part of her current relationship with her husband:

I: Did anything about your sexual life with your husband change?

R: No. Not at all. Nothing changed until we got just too old. [Both laugh.] Really. He has erection problems, and he accepted that because we're old. There's a LOT more to being in love than having sex. A LOT more. And it works out fine. We're perfectly happy.

I: Could you tell me about that? What are some of the other things about being in love other than having sex?

R: He'll go out in the garden and cut me a bouquet of flowers and bring them in, or he does things that he knows I'll do but it may bother me to do. He helps me with anything he can help me with, without being asked...

This woman had her surgery during the 1950s, which also included having her ovaries removed. Thus, having sex with her husband as a younger woman became even more enjoyable after surgery because she did not have to worry about unwanted pregnancies. At 84 years of age, however, intercourse no longer played the role that it once did at an earlier stage in her relationship.

Another woman when asked how important sexuality was to her, replied: "Hey, I'm close to seventy...So, I'm on the waning side. That's not a very important part of my life..." Although, this woman described what she considered to be a higher level of intimacy with her husband:

There is more intimacy at the mental level than at the physical level. That's what... *stays forever*...The physical part and some of the other areas aren't there forever. Just physical closeness is a good thing. You know, just holding hands, sitting together watching TV.

These women appeared to have an awareness of the ephemeral nature of youthful sexuality. Moreover, 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 IV: No Sexual Experience Post Surgery (N=9)

This group of women 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. One woman in this group was married at the time of surgery, but the relationship eventually ended because her husband believed that he could no longer provide care for what he perceived to be the participant's escalating health challenges.

The women in this group tended to believe that having an ostomy would make it exceedingly difficult to have a sexual partner. One 55-year-old woman indicated that she would very much like to have a sexual partner but believed that the way she smelled made her undesirable to a potential sexual/romantic partner. She recounted a time post-surgery when a friend tried to

reassure the participant about the way she smelled: “She was pretty denying. She said ‘you don’t smell bad, you’re not dirty.’ I smell bad to me, so it’s bad to me... This is part of the sexual thing... in ways I haven’t quite sorted out.” Unable to reconcile her own disgust regarding her ostomy, and its various odors this participant believed she had to either learn how to feel differently about herself to find a sexual partner, or come to terms with her life as a celibate person. While this woman had been single for a quite some time, she wanted to assure the interviewer that she was not a lonely person, that she had a good job, and an active social life which included community and political activism.

Another participant, a 60-year-old woman with multiple health problems, lived in a dark, rented room in her brother’s house, which was very cluttered. Her brother rented rooms to various people, and each appeared to have their own various health challenges. While this might seem like a less than optimal living situation, this woman, a retired ostomy nurse, felt that she had a lot to live for. This became apparent when she described a patient she once took care of who tried to destroy her ostomy by jabbing it with a fork. According to the retired nurse, her patient had behaved in such a self-destructive manner because, “she did not want to live” and for a person to adapt successfully to life with an ostomy, they must first know that they want to continue living. In spite of this participant’s many challenges, she knew she wanted to live. She had plans to de-clutter her room, take part in social activities with her church, and get rid of old clothing that no longer fit. This participant indicated that she had romantic relationships prior to her surgery, which she described as taking care of the partner and not vice-versa, but now felt that she would not know how to deal with a potential partner’s reaction to her condition:

I had boyfriends prior to, but I haven’t socially been active since then. I haven’t gone looking for any male counterparts since, because I’m not sure how they would adjust to it, to tell you the truth. It’s questionable that I could deal with their... emotional reaction to the ileostomy... I have to be honest about that.

During the interview this participant indicated that she also did not feel comfortable masturbating. She noted that had she been a younger person with an ostomy, being unable to garner a sexual relationship may have been more distressing for her. Thus, while having an ostomy at age 60 meant that she was unlikely to find a sexual partner, having the surgery was a reasonable trade off because it ultimately saved her life, a life she very much wanted to live.

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, in the same manner as the women described in Group III above. One 88-year-old participant, who had the surgery shortly after her husband died when she was in her early 60s, kept herself busy with volunteer activities to keep from thinking too much about sex. Her most frequent refrain during the interview was, “you just have to accept it.”

DISCUSSION

Examining the experiences of these CRC survivors provides important insights into how women living with ostomies restructure ideas of sexuality, that in many instances resist cultural imperatives for specific forms of sexual activity (Becker 1997; Hunt 2000). For some, having an ostomy did not present long-term challenges in maintaining a sexual relationship. Many women spoke of an initial phase of disruption when intercourse was painful. As time passed however, these women were ultimately able to reconfigure their sexual lives to eventually include intercourse. The various techniques employed to hide and manage the pouch appliance before, during, and after sex not only speaks to the adaptability and creativity of these women, but also reflects “cultural ideas of delicacy and aesthetics in relation to changed bodies and body function” (Manderson 2005: 406). Due to cultural aversions to feces, hiding the pouch

from both themselves and their sexual partner functioned to reconcile both parties' potential disgust with the ostomy appliance.

Moreover, having a supportive partner who accepted their surgically transformed body was integral in reaffirming sexual desirability after surgery for many of these women (Altschuler et al. 2009; Manderson 2005). Indeed, several studies have shown the positive role that spouses can play in a cancer survivors' recovery (Altschuler et al. 2009; Frick et al. 2006; Rozmovits and Ziebland 2004; Vacek et al. 2003). Using specific management techniques and having a particular kind of relationship with one's spouse allowed some women to resume a key component of companionate marriage—sexual intercourse. Companionate marriage is generally characterized by an intense psychological companionship or friendship, wherein sexual activity, particularly intercourse, is of fundamental importance to the conjugal relationship (Simmons 1979). Cross-cultural studies of marriage reveal that companionate marriage is not universally recognized as the function or purpose of marriage. However, it is the model upheld as the ideal in the United States, which can perhaps provide some insight into why the youngest woman in the sample found her altered sexuality to be so difficult. Before the surgery she enjoyed a very active and satisfying sexual life with her husband, thus upholding the marital ideal sanctioned by U.S. culture. However, the surgery and radiation permanently altered her anatomy, which prevented intercourse on most occasions or made it extremely painful. A recurring theme for this woman was that she had not received adequate information about the potential effects that cancer treatments would have on her sexuality, and indicated that the long-term effects of cancer treatments should have been clarified (Notter and Burnard 2006). The regular use of vaginal dilation can prevent or minimize these complications, but research indicates a lack of consistency in the content of patient education regarding this intervention (Lancaster 2004). Therefore, educational interventions at well-timed moments in the course of cancer care might be advisable for women who express a desire to continue having intercourse, particularly for those women who are likely to undergo radiation therapy in their pelvic region (Turnbull 2006; White and Faithfull 2006).

Several other women, however, reported that no longer having sexual intercourse was not particularly distressing. Other erotic activities, such as oral sex, took the place of intercourse and were reported as acceptable alterations in their sexual lives. Similarly, the women in the life-course/age-related changes group also reported that no longer having intercourse was unproblematic.

The debate over whether age-related sexual declines are normative or pathological (Camacho 2005) is complicated by popular conceptions that underestimate elders' sexual activity levels. For example, Katz (2007) challenged cultural assumptions about the asexual elderly and encouraged providers to recognize that many people remain sexual throughout their lives. In this study, many of the women had, earlier in their lives, been able to overcome the physical and emotional issues related to having an ostomy and resumed intercourse with their partners. At the time of the interview, however, they reported aging into a different stage of meaning with regard to sexuality. Women described other acts of intimacy and love that reaffirmed and maintained the couple's relationship. Indeed, a more companionable, as opposed to companionate model of marriage emerged for this group of women. Companionable marriage can perhaps be viewed as a complementary marital ideal that is featured at later stages in the life-course of a couple, when intercourse is no longer the centrifugal force upon which a marriage necessarily revolves and non-sexual intimacy and companionship are the key features of the conjugal bond (Ramirez 2006: 554). Further, even for some of the younger women in the sample, intercourse had never been a central feature in their relationship, therefore omitting it entirely after surgery was not particularly problematic. This points to a diversity of meaning with regard to marital relationships and suggests that resuming intercourse may not be a primary therapeutic goal for all cancer survivors.

It is the final group of women (Group IV) however, that fundamentally challenge biomedical, and even patient-centered paradigms of sexuality (Hordern and Currow 2003). According to the latter, the women who had not participated in sexual or intimate acts since the time of their surgery would be considered “un-whole” or perhaps missing some “intrinsic part of the self.” However, the women's accounts revealed that notions of an un-whole or incomplete self because they have not participated in sexual or intimate acts with another person may not adequately capture the lived experience of the celibate women in this study. For some of these women, being of an age they considered beyond sexual activity factored into their celibate status, while others were unable to reconcile their own experience of disgust or the potential reactions of a sexual partner to their ostomy. Even autoerotic sexual activities were reported to be uncomfortable by some. Catherine Bell and Elisa Sobo (2001) contend that examining celibacy cross-culturally “provides a useful lens through which to reconsider the significance of the body and of desire as *inherently social* rather than as biological givens upon which social practices are inscribed” (2001:6). Several of the women in our study found that celibacy was perhaps not an ideal state, but was less complicated than having to negotiate a transformed body with potential partners. Indeed, in a cultural setting fixated on “wrinkle-free, glamorous and penetrative sex, from which the frail, sick...or debilitated are generally excluded” (Hordern and Street 2007:1705), confronting the possibility of a sexual encounter wearing an ostomy appliance that can unpredictably fill up with feces, or worse—leak, may understandably present physical and emotional obstacles to garnering a new sexual partner. Ultimately, however, 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. Some of these women may have benefited from counseling or medical interventions to improve their sexual lives (Borwell 2009) but for others, celibacy was a desirable or acceptable sexual reconfiguration. In other words, neither sexual nor intimate acts were essential to the well-being for some women with ostomies in this study.

Limitations of This Study

As a qualitative study, a relatively small number of participants were interviewed. The smaller number and in-depth nature of the inquiry strives to explore a range of responses from which one could develop hypotheses, unlike quantitative methods that aim to extrapolate generalizable findings from a representative sample

At several points during the data gathering, the research team consulted to determine if and when data saturation occurred. After 30 interviews, it was determined that no new themes arose in the data. Nevertheless, selection bias in this qualitative research project cannot be ruled out – for example, women with more serious complications after surgery may have been less likely to participate. The low response rate, while troubling because of the potential for introducing participation bias and thus not including a full range of information about sexuality in colorectal cancer survivors, is somewhat understandable in light of the highly sensitive nature of the questions, and perhaps the older age of many in the target population. Indeed, some non-responders indicated that the subject matter was “too personal” to discuss with the interviewer. Although, the stated intent of the project in all of the recruitment material was to explore sexuality, several women chose to participate even though they had no partnered sexual experience after ostomy surgery. Their experiences therefore yielded important information regarding the various meanings of celibacy in a U.S. cultural context.

While the research team made significant efforts to ensure racial and ethnic diversity in the study sample, most participants were White Non-Hispanic women. Thus, while some minority women were included in this study, too few were included to make any claims regarding whether sexual adaptations to ostomy surgery differed by race/ethnicity. Much more research is needed to address issues faced by minority women in this patient population.

Conclusion

Research on cancer survivorship is a rapidly growing area of inquiry to reduce suffering and maximize well-being among this patient population. Recent attempts to incorporate sexuality as a distinct area of care to improve the quality of life among cancer survivors have tended to conform to culturally prescribed ideas of essential sexuality which can, in some instances, further burden survivors' post-treatment lives. Examining the lived experiences of female CRC survivors with ostomies in a North American cultural context illustrates a diversity of experiences that may in some instances conform, and in others, resist cultural models of sexuality. Ultimately, the experiences of the women in this study suggest that a more nuanced view of sexuality could broaden the range of research questions, outcome measures, and interventions for cancer survivors.

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Table 1

Participant Demographics:

MARITAL STATUS/AGE	Number
Married	22
Single	8
Age Range (years)	44–93 (average age 70)
RACE/ETHNICITY	
White (Non-Hispanic)	22
Asian	3
Pacific Islander	2
African American	2
Hispanic (White)	1

Table 2

Sexual Experience after Ostomy Surgery
No long-term sexual difficulties
Long-term sexual difficulties <ul style="list-style-type: none">• Problematic• Unproblematic
Age-related changes in sexuality <ul style="list-style-type: none">• Sexuality changes not attributed to ostomy
No partnered experience

Table 3

Major Codes	Description
Comorbidities	Additional cancers, other illnesses
Complications	Health complications attributed to ostomy: Radiation & chemotherapy complications Ostomy specific complications
Coping/Adjustment	Acceptance of ostomy, grateful for life, resuming normal activities
Body Image	Difficulty accepting changed body Feel “dirty” “smelly” Discussions of body size Other descriptions, i.e., “ugly”
Ostomy Specific Issues	Odor, irrigation, different adaptations (covering ostomy, no bag) Accidents and leakage
Sexuality	No sexual experience post surgery No difficulty with sex Masturbation Oral Sex Lifecourse changes (aging related) Orgasms Meanings of sexuality Strategies/solutions to help sexual relations (covering ostomy, new bag, etc.)
Sexual Difficulties	Pain with intercourse, anatomical changes in vagina (often attributed to radiation), ostomy gets in the way, fear of sexual rejection
Spousal Support	<i>Instrumental:</i> Changing bag, general help with ostomy care <i>Psychosocial:</i> Displays of empathy, assurance still same person, not displaying worry, assurances of normalcy, assurances of beauty (see Altschuler et al. 2009)
Sense of self/femininity	How ostomy affected participant's sense of self as a woman Life stage of ostomy-had participant been younger, may have been more difficult