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Men's Experience with Sexual Dysfunction Post Rectal Cancer Treatment: A Qualitative Study

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Keywords

Rectal Cancer; Sexual Dysfunction; Erectile Dysfunction; Bowel Dysfunction

Introduction

It is estimated that approximately 40,340 new cases of rectal cancer (RC) will occur in the United States in 2013.¹ As a result of advances in surgical treatment and adjuvant therapy, the five year survival rate for RC has increased from 48% in 1975-1977 to 68% in 2002-2008 for all races.¹ With an increase in survival rates for RC, quality of life after treatment for RC patients has become an important issue for survivors.

Sexual dysfunction is a common problem among male RC survivors. The incidence and risk factors associated with sexual dysfunction in men post RC treatment are ill-defined; however, it is known that surgical treatment can impact the parasympathetic and sympathetic nerves responsible for erection and ejaculation.² Radiation treatment for RC may also cause damage to the nerves and blood vessels involved in erections. The buildup of fibrosis occurs at a gradual rate after radiation. For example, in men with prostate cancer, the rates of erectile dysfunction (ED) consistently increase up to 5 years after radiation treatment.³ Studies report that as many as 63% of men will have ED, and that 60% will have difficulty with ejaculation after treatment for RC.⁴⁻⁶ Mannaerts and colleagues reported in a recent study that out of 73 men who had received both radiation and surgery as treatments for their RC, only 10% reported that they could achieve a “quality erection” and only 10% could ejaculate post operatively.⁵ These sexual side effects often translate into a significant decrease in men's sexual activity.^{4, 7, 8} Hendren and colleagues reported that out of 99 men treated for RC using a nerve sparing surgical technique to preserve sexual functioning, 50% were sexually active post surgery compared to 91% before surgery; 45% reported that their sex life was worse after treatment, and 47% reported a loss of libido.⁴

Feelings of anxiety and depression are often associated with men who experience sexual dysfunction. Men who experience ED reported depressed mood, distress, and increased bother related to sexual dysfunction, which often leads to negative changes in men's sexual self-schema and loss of intimacy in their relationships.⁹⁻¹¹ Although there are effective treatments for ED, the data indicates that most men (50 to 80%) do not comply with ongoing medical ED interventions (i.e., medications, penile injections, vacuum devices) and only

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38% of men following treatment found them to be helpful in improving their sex lives. Thus, understanding men's attitudes and behavior regarding sexual function and treatments appears crucial for effective treatment.¹²⁻¹⁴

Little is known about the sexual health of male RC survivors, their methods of coping with sexual dysfunction, and their attitudes regarding treatments to improve their sexual functioning after cancer treatment. Because of the need to address these issues, we designed an exploratory study using qualitative methods with two research objectives. First, we aimed 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. This intervention is designed to improve sexual functioning among male RC survivors and is based on a revised intervention described by Canada and colleagues.¹² The educational intervention includes four individual sessions and brief booster calls between these sessions. The topics addressed include sexual dysfunction and a review of various treatment options tailored to the individual needs of the participants.

Methods

Strategy

We chose a qualitative design using both semi-structured individual interviews and focus groups to explore our research questions, so as to integrate a depth of information that can be elicited from participants via individual interviews as well as shared thoughts and beliefs that are gained via focus groups. Because of the sensitive nature of the topic, we wanted to include individual interviews in the event men did not feel comfortable sharing their experiences with sexual dysfunction in a focus group setting. Recruitment procedures, interview guides, and data analysis were carried out the same way for both the qualitative interviews and the focus groups.

Recruitment and Data Collection

The study was approved by the institutional review board at Memorial Sloan-Kettering Cancer Center (MSKCC). Thirteen male RC survivors participated: six survivors in individual semi-structured telephone interviews and seven additional men in one of two in-person focus groups at MSKCC. Four participants attended the first focus group and three participants attended the second focus group, each lasting approximately 1.5 hours. We continued to recruit participants until we believed that we had reached thematic saturation, and the number of participants chosen for this study is consistent with qualitative research guidelines indicating sample size needed to reach thematic saturation of findings.¹⁵

Eligibility criteria included that the participants were at least two years post treatment for stage I-III rectal adenocarcinoma or rectosigmoid cancer with an anastomosis at 15cm or below, had no evidence disease or recurrence, were 21 years of age or older, and spoke English. After eligibility was assessed, a research study assistant (RSA) approached potential participants either at their upcoming clinic appointment or by mailing an introductory letter to those patients that did not have an upcoming clinic appointment. Over the course of recruitment, 32 eligible male rectal or rectosigmoid cancer survivors were approached and 13 participants were enrolled to the study (41%). If men were interested and eligible to participate, the RSA obtained their informed consent either verbally by telephone ($n = 6$) or written in-person ($n = 7$). We provided each participant with a monetary incentive of \$20 for participation, and focus group participants were given an additional \$20 to cover travel expenses. Those who declined to participate in the study stated lack of time, discomfort with subject matter, and distance to MSKCC as reasons for refusal.

We explored the same set of topics in the interviews and focus groups (see Table 1 for a full overview of the questions included). A female qualitative methods specialist (ES) conducted the telephone interviews. The focus groups were run by experienced mental health professionals, and one of the focus groups was run by a woman (LJ), while the other was run by a man (CN) with female research assistants present. We did not use a software program to analyze the findings. Both the interviews and focus groups were audio recorded and transcribed by the research staff.

Data Analysis

The study data was comprised of six interview transcripts and two focus group transcripts. We used a targeted procedure of qualitative thematic text analysis to analyze both the interview and focus group data, which involved a focused review and interpretation of the transcripts.¹⁶⁻¹⁹ Our analysis process consisted of multiple phases. In Phase One, an analytical team consisting of the study investigators, a qualitative methods specialist, and a medical student read each transcript and highlighted content that was interesting or important to the goals of the research study, then noted their reflections in the margins of the transcripts, a process known as margin coding.²⁰ In Phase Two, each analysis team member wrote their thoughts about important findings in an analysis template and selected quotations from the transcript that best illustrated each observation. In Phase Three, analysis team members met to share their independent reflections and collectively generated a set of findings for the transcript. This iterative process was repeated until the transcripts of all interviews and focus groups had been read and synthesized into a summary of findings. In Phase Four, the team reviewed the synthesized findings produced for each transcript and generated descriptive and interpretive themes that represented the most salient findings.

The team assessed the salience of the thematic findings identified in Phase Four in two ways. First, there was consideration of whether multiple reviewers had reached similar conclusions regarding men's experience of sexual functioning post RC treatment. Also considered was their feedback regarding the psycho-educational sexual health intervention during their independent review and synthesis of the interview and focus group transcripts. This form of analyst triangulation, in which multiple analysts review and synthesize qualitative data, is suggested to enhance the credibility of findings.^{21, 22} Second, the degree to which thematic findings repeated and recurred across the eight transcripts were assessed and the conceptual themes identified were manifested in each interview and focus group.^{21, 23}

Results

Study Sample

The median post treatment time for the 13 participants was 6.4 years. The median age of the sample was 67 years old (range 47 to 82 years). All of the participants were Caucasian (n=13; 100%), 57% percent were married, and 87% were college educated. The types of treatment that participants received for RC included: surgery (n=13; 100%), chemotherapy (n=7; 53.8%) and radiation (n = 5; 38.5%). Additionally, 7/13 participants had temporary ostomies that were reversed prior to enrollment.

A total of 225 transcribed pages from both the qualitative interviews and the focus groups were reviewed for analysis. Through our analysis, four primary themes emerged: 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. We discuss these results below.

Prioritizing cancer survival at diagnosis

Participants reported that they had not been focused on potential impact of cancer treatments at the time of diagnosis. It has been well documented that receiving a cancer diagnosis is overwhelming and extremely disruptive; all other issues take a back seat behind survival²⁴ as illustrated by the following quote from a man who reported having dry orgasms:

“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.”

However, the interest in sex quickly reemerged once the fear of cancer diminished and other post treatment side effects, such as pain or fatigue, were resolved, as illustrated by the following quote by a participant who reported that he attributed 50% of his ED to his surgery:

“But as, as you know...as soon as the operation was over, as soon as you find that it was a success, and they got everything and you didn't have to have chemotherapy, then all of a sudden you go back to some of the other priorities which were smaller at the beginning but now they become bigger, and you say okay now, am I going to ever have a proper erection for the rest of my life?”

Diminished bowel and sexual functioning

Bowel dysfunction was prominent among our RC survivors (100%), with constipation and diarrhea as the chief complaints. Some participants expressed that problems with bowel functioning had a significant impact on their daily functioning. Frequent and unexpected bowel movements became a source of stress and uncertainty, and participants reported that aspects of daily life such as work and travel became disrupted. In terms of priorities during survivorship, participants expressed that gaining control over their bowel functioning took precedence over addressing issues with sexual dysfunction. Some participants reported that they were more concerned with colostomy reversal before they were ready to address any other side effects.

In response to the distress caused by bowel dysfunction, participants developed strategies to help manage the physical aspects of their bowel dysfunction. Such coping strategies included: modifying diet such as increasing fiber intake and creating structured eating times; having bowel movements at home, avoiding public restrooms when possible or planning activities outside the home to be close to a bathroom; developing a daily routine for bowel movements; and taking anti-diarrheal medications and fiber-based supplements.

Sexual dysfunction was another significant complaint among participants (92%). More specifically, ED was the most common complaint and the inability to ejaculate was a less common issue. Participants seemed to evaluate their sexual dysfunction within their current life context. For example, most of the men attributed their sexual dysfunction to age rather than cancer, which facilitated their coping with diminished sexual functioning during survivorship. Recurring perspectives regarding current sexual functioning among the sample were learning to cope and live with diminished functioning and readjusting expectations of sexual function. For example, one participant shared:

“And there was just this gradual decline...So there was this acceptance, as things diminished, that that's, the performance would just have to do, the expectations of the performance would have to taper off, and eventually you know you were hoping eventually it wouldn't go away completely.”

Similarly, several participants considered their cancer when considering their sexual deficiencies, with one man explaining,

“But in the scope of things I’m fine. Does it bother me? I guess it bothers me but I just live with it,” and another expressed, “...I think that the only thing that moves me quickly is the thought of cancer and, it’s (sexual functioning) not that big a deal, it’s an issue but it’s not a monumental issue.”

Desire for Greater Education Regarding Impact of Cancer Treatment on Sexual Function

Although participants reported that their primary concern at the time of receiving their RC diagnosis was cancer survival, many participants reported interest in receiving more information from their physicians about the potential impact RC treatment may have on their sexual functioning before cancer treatment commenced and having their treatment team take the initiative in asking about any sexual side effects at follow-up appointments. Some participants expressed a lack of understanding about a number of issues, including: what sexual functioning encompasses (e.g., sexual issues that may arise other than erectile dysfunction); sexual functioning norms for men by age; and how RC treatment may impact sexual functioning.

The majority of participants indicated that their doctors did not bring up treatment-related effects on sexual functioning at the time of diagnosis or during follow-up appointments. Similarly, most participants did not initiate discussions about sexual side effects with their oncologists for several reasons, including: focus on more pressing cancer issues, lack of attribution of sexual deficiencies to RC treatment, and a learned tendency to cope with deficiencies.

Endorsement of Psycho-educational Sexual Health Intervention

All participants reported that they would have participated in our proposed psycho-educational sexual health intervention after RC treatment had it been available to them. Overall, participants reported that the intervention was comprehensive in scope and it contained relevant content that would be useful for a man struggling with sexual deficiencies following RC treatment. A common attitude about the utility of the intervention is voiced by the following participant,

“For somebody having a problem I think that’s very, very, could be very helpful. ‘Cause you’re on your own otherwise, I mean...they [doctors] ask questions one at a time but having a process could be very, could mean a lot to people.”

Participants regarded the primary benefits of the intervention to be the opportunity to receive education about sexual functioning treatment options and causes of sexual dysfunction, including that RC treatment can affect functioning, and the opportunity to receive emotional support. Participants believed the best time for a man to start the psycho-educational sexual health intervention would be approximately two to three months after completion of his last treatment for RC, as this timeframe would not only allow adequate time for him to physically heal from treatment, but also would likely be when a man is emotionally ready to address any sexual dysfunction.

The barriers to intervention participation that men reported were more logistical in nature rather than substantive. A frequently reported barrier was men’s geographic distance from MSKCC. Other barriers included a perception that the intervention required a longer time commitment than desired and the potential embarrassment associated with discussing sexual functioning.

Discussion

This qualitative study was designed to better understand men's experience with sexual dysfunction following RC treatment to inform the adaptation of a psycho-educational sexual health intervention from male RC survivors and to investigate barriers and promoters that would influence their participation in a psycho-educational sexual health intervention. This study serves as the initial step for an NIH pilot randomized controlled trial for a sexual health intervention, which is currently in progress.

Based on 13 men's retrospective accounts of their thoughts and experiences at the time of diagnosis and during treatment for RC, the study found that participants prioritized survival at the time of diagnosis, learned with time to cope with bowel and sexual deficiencies resulting from cancer treatment, and were interested in educational information regarding how to improve sexual functioning after cancer treatment. Each of these findings is discussed below followed by a discussion of study limitations and clinical relevance.

Prioritizing Cancer Survival at Diagnosis

We found that although treatment for RC carried significant potential adverse effects in terms of bowel and sexual dysfunction, participants prioritized surviving the cancer over these potential risks. List and colleagues also found a similar phenomenon among their participants with stage IV head and neck cancer.²⁵ Being cured ranked the number one priority for List's participants, and quality of life issues, such as being pain free, able to chew, and keeping an unchanged appearance followed. Quality of life issues became a priority for participants once they had completed and recovered from treatment.²⁵ Our study similarly found that once participants were in remission and their fear of losing their life to the disease had dissolved, quality of life issues slowly became more important.

Coping with Diminished Bowel and Sexual Functioning

Bowel dysfunction was the most common treatment-related complaint among the survivors, with many reporting problems with constipation and diarrhea. All participants expressed concern about how their compromised bowel functions interfered with their quality of life. Arndt and colleagues also found a significant increase in bowel dysfunction compared to the general population following RC treatment.²⁶ Temple and colleagues developed an instrument to evaluate bowel dysfunction after sphincter preserving surgery for RC. The participants in that study reported that they had on average 3.5 bowel movements per day and 37% were dissatisfied with their bowel function. The most common symptoms reported in that study were incomplete evacuation, clustering, food affecting frequency, unformed stool, and gas incontinence.²⁷ The participants in our study complained of symptoms similar to those reported in the Temple study and sought help from their doctors to find effective strategies to alleviate these issues. For example, the men reported that they increased fiber in their diet as well as scheduled social events around their bowel movements. Bowel issues can also impact resuming sex after cancer treatment and add more difficulty to scheduling or planning sexual experiences.

The vast majority of our sample of male RC survivors reported sexual dysfunction after treatment for RC. This rate may be higher than the figures reported in other studies⁴⁻⁶ and may represent a self-selection bias as survivors were told during study recruitment that we would be discussing the topic of sexual dysfunction. Thus those who did not experience any sexual dysfunction may have self-selected out of participation. The most common complaint among participants was ED. Studies of men with cancer as well as without cancer have shown that men with ED experience increased frustration and symptoms of depression.²⁷⁻³⁰

Some of the participants were unclear as to whether their sexual dysfunction was a result of the surgery or their age. The ages of our participants are consistent with the average age of diagnosis of RC among men; however, younger men with this disease might express different concerns and have different ways of coping with their sexual dysfunction. Other studies have emphasized that younger men may have a greater investment in addressing issues related to sexual dysfunction.^{2, 10, 31, 32} Interestingly, a recent qualitative study examining the psychosexual needs of post treatment prostate cancer survivors suggests that many older men attribute their sexual dysfunction to be a consequence of their treatment, regardless of age, and participants reported that they believed they weren't asked about their sexual function during follow-up appointments because of their age.³³ Furthermore, participants reported avoiding initiating the topic of sexual functioning with their healthcare providers due to embarrassment surrounding their sexual needs. This illustrates the importance of assessing survivors' sexual needs based on their individual treatment history and associated risks rather than age.^{34, 35}

There is a vast amount of literature on the prevalence of sexual dysfunction after prostate cancer treatment; however, information on how men cope with such difficulties is limited. Penson and colleagues³⁶ compared health-related quality of life (HRQOL) in men with prostate cancer and ED to men with ED resulting from other non-malignant conditions. They found that men with prostate cancer appeared to have better HRQOL, despite reports of worse erectile and orgasmic function and lower intercourse satisfaction, as compared to those with ED due to other conditions. The authors hypothesized that the etiology of ED may play a role in how men perceive their sexual dysfunction and they may be able to cope by acknowledging that the treatment that caused their dysfunction also increased their chances of survival.³⁶ Men in our study reported similar methods of coping, which included accepting their current level of decreased sexual function and adjusting their expectations. It is clear that there is a need to further examine methods of coping in RC survivors.

Desire for Greater Education Regarding Impact of Cancer Treatment on Sexual Function

Survivors reported that they preferred to be told by their physicians prior to RC treatment about the possible negative symptoms they may experience as a result of their treatment. Many participants believed this knowledge would help them make more informed decisions about which type of treatment(s) to pursue as well as prepare them psychologically for the negative consequences. Survivors also found it helpful to learn about the side effects because it helped alleviate anxiety. The nature of patient-doctor communication has been found to be critical in influencing patient quality of life outcomes. For example, Kerr and colleagues found that patients who reported that the information regarding diagnosis and treatment provided by their doctor was unclear had a decreased quality of life when compared with those who communicated effectively with their health care provider.³⁷ Research suggests that patients may need education about side effects of treatment outside of the oncologist/patient interaction. These interactions are stressful for patients and focused specifically on the best treatments for cancer. Razavi and colleagues found that individuals who receive traumatic negative information (e.g., a diagnosis of cancer) repress other information at the time of cancer diagnosis in order to cope with the negative news.³⁸ A separate meeting with a surgeon, oncologist, or different member of the treatment team, such as a psychologist or nurse, may be helpful for education on side effects and how patients react to them.

Pre-treatment and follow-up visits are an advantageous time to address sexual functioning issues with patients on a number of fronts. Healthcare providers can use these visits to proactively ask men to report on their sexual functioning, which may be especially important for men who are embarrassed to initiate a conversation regarding their sexual functioning. Also, providers can educate patients about impact of RC treatments on sexual

functioning and how RC treatment can alter men's functioning. Additionally, providers can describe what normal sexual functioning looks like according to men's age and what sexual deficiencies include, as they are not solely limited to ED. Lastly, referral to a sexual health expert and education about different treatment regimens can be presented to men if they are experiencing sexual dysfunction.

Endorsement of Psycho-educational Sexual Health Intervention

After adequate healing time from RC treatments, survivors reported that they were ready to address their dysfunction and that an intervention would be helpful. Canada and colleagues also found that an intervention after prostate cancer significantly reduced sexual dysfunction.¹² The survivors in that study reported that the intervention should begin approximately two to three months post completion of treatment because it allowed for wound healing as well as enough psychological healing to pursue other issues. Although time is needed to psychologically heal from cancer treatments, medical literature reports that the earlier treatment begins for prostatectomy, the better result one experiences achieving erection later in recovery.^{25, 39} Because early treatment resulted in earlier and more frequent erections in prostate survivors, more research is needed to explore the possibility of extending this recommendation to RC survivors.

The participants in the study were eager to receive educational information regarding their dysfunction, and the sex of the person presenting the information did not appear to impair them from speaking about their issues in the focus groups or in the phone interviews. One of the focus groups was run by a woman, while the other had both a man and woman present. The phone interviews were all conducted by a woman, and the participants were open about their dysfunction despite any potential embarrassment of discussing sensitive issues with a member of the opposite sex. The participants were also unaffected by the different discussion formats: telephone interviews versus focus groups. Although the study's sample size was too small to systematically determine any difference in information gathered from either format, there were no noticeable differences in our transcript analysis. This is an indication that men feel comfortable discussing issues surrounding sexual functioning with both men and women and regardless of discussion setting.

Study Limitations

Limitations to the study include that the average time since participants completed RC treatment was over six years. This lengthy period may have influenced our findings, such that participants' recollection of interactions with their physicians discussing support for sexual dysfunction may be compromised. In addition, their sexual and bowel dysfunction were more likely to improve with time, thus limiting their affect on current quality of life. It is critically important to mention that all participants of this qualitative study were Caucasians who were treated at one cancer center, thus limiting the generalizability of these findings. Furthermore, we did not collect information pertaining to participants' sexual orientation. Future research is needed to explore this topic in a more diverse population of men including minority patients and patients with low socioeconomic status, as well as the Lesbian, Gay, Bisexual, and Transgender (LGBT) community. It is also important to note that there was no screening criterion for sexual dysfunction or pretreatment baseline assessment established for this qualitative study. Participants were informed that the study was about sexual function at time of recruitment so it is likely that only those survivors who had experienced issues related to sexual functioning volunteered to participate. We did not specifically inquire about stoma reversal and how this may have affected sexual activity. In addition, participants were not inquired about the quality of their relationship with their spouse or partner – a factor that is likely to have an effect on sexual dysfunction. Lastly, all participants reported that they would have participated in the proposed psycho-educational

sexual health intervention had it been offered to them after RC treatment. This finding may be influenced by sample bias since individuals who agreed to take part in qualitative interviews or focus groups for this study are probably more open to participating in an intervention program as compared to other male RC survivors who may not volunteer for this type of study.

Clinical Relevance

Communicating issues about sexual health and sexual dysfunction to clinicians may be difficult for patients, and there is sparse literature addressing the existing psycho-educational interventions for sexual dysfunction after RC. As such, it may be beneficial to educate clinicians on sexual side effects from cancer treatment and encourage them to initiate a conversation during follow up examinations and provide referrals as necessary. Many of the men reported that they would have preferred to have been informed of potential sexual side effects prior to the initiation of treatment. Greater patient education prior to cancer treatment can be beneficial in allowing patients to prepare for common post treatment side effects, thus reducing anxiety and uncertainty throughout treatment and following the treatment process. Repeated delivery of information may also be important, as men may not hear or retain information that is delivered around the time of diagnosis. Furthermore, if educational materials and other resources regarding treatment for sexual dysfunction following cancer treatment are made accessible both prior to and shortly after completion of treatment, it may help men address their sexual health issues as they experience them.

Conclusion

Although our findings indicate that survival is the primary concern during and after treatment, we also learned that as fears about cancer and mortality diminish, sexual function often re-emerges as a significant concern. The men in this study reported a lack of education about sexual issues associated with cancer treatment and expressed a desire to increase their knowledge about sexual concerns. Furthermore, since the participants reported that they were unaware of the potential sexual side effects as a result of treatment, they ceased to initiate conversations with their physicians regarding symptoms experienced post treatment and attributed such symptoms to other factors, such as age. Due to lack of awareness, male survivors likely do not have the information they need to address those issues that could potentially increase their quality of life. The findings also highlight the need to incorporate interventions and programs targeted to address these issues. In particular, providing education to patients about potential sexual side effects prior to initiation of RC treatment may help prepare them for what to expect after treatment. Additionally, post treatment follow ups that incorporate questions about sexual function can help patients to address those issues, especially for those that feel too embarrassed or uncomfortable to initiate these conversations. Patients who experience post treatment sexual dysfunction have the potential to significantly improve their functioning with various treatment options; however, they first need to be provided with the proper education regarding the potential issues that may arise as a result of cancer and treatment, what they can expect to experience, and what options are available to help improve their symptoms.

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References

1. American Cancer Society Facts and Figures. Cancers of the Colon and Rectum Key Statistics. 2013

2. Ho VP, Lee Y, Stein SL, Temple LK. Sexual function after treatment for rectal cancer: a review. *Diseases of the Colon & Rectum*. 2011; 54:113–25. [PubMed: 21160322]
3. Potosky AL, Davis WW, Hoffman RM, et al. Five-year outcomes after prostatectomy or radiotherapy for prostate cancer: the prostate cancer outcomes study. *J Natl Cancer Inst*. 2004; 96:1358–67. [PubMed: 15367568]
4. Hendren SK, O'Connor BI, Liu M, et al. Prevalence of male and female sexual dysfunction is high following surgery for rectal cancer. *Ann Surg*. 2005; 242:212–23. [PubMed: 16041212]
5. Mannaerts G, Schijven MP, Hendriks A, Martijn H, Rutten HJ, Wiggers T. Urologic and sexual morbidity following multimodality treatment for locally advanced primary and locally recurrent rectal cancer. *Eur J Surg Oncol*. 2001; 27:265–72. [PubMed: 11373103]
6. Moriya Y. Function preservation in rectal cancer surgery. *Int J Clin Oncol*. 2006; 11:339–43. [PubMed: 17058130]
7. Heriot AG, Tekkis PP, Fazio VW, Neary P, Lavery IC. Adjuvant radiotherapy is associated with increased sexual dysfunction in male patients undergoing resection for rectal cancer: a predictive model. *Ann Surg*. 2005; 242:502–10. discussion 10-1. [PubMed: 16192810]
8. Marijnen CA, van de Velde CJ, Putter H, van den Brink M, Maas CP, Martijn H, Rutten HJ, Wiggers T, Kranenbarg EK, Leer JW, Stiggelbout AM. Impact of short-term preoperative radiotherapy on health-related quality of life and sexual functioning in primary rectal cancer: report of a multicenter randomized trial. *J Clin Oncol*. 2005; 23:1847–58. [PubMed: 15774778]
9. Andersen BL, Cyranowski JM, Espindle D. Men's sexual self-schema. *J Pers Soc Psychol*. 1999; 76:645–61. [PubMed: 10234850]
10. Nelson CJ, Deveci S, Stasi J, Scardino PT, Mulhall JP. Sexual bother following radical prostatectomy. *J Sex Med*. 2010; 7:129–35. [PubMed: 20104671]
11. Nelson CJ, Mulhall JP, Roth AJ. The Association Between Erectile Dysfunction and Depressive Symptoms in Men Treated for Prostate Cancer. *J Sex Med*. 2010
12. Canada AL, Neese LE, Sui D, Schover LR. Pilot Intervention to Enhance Sexual Rehabilitation for Couples after Treatment for Localized Prostate Carcinoma. *Cancer*. 2006
13. Schover LR, Fouladi RT, Warneke CL, et al. The use of treatments for erectile dysfunction among survivors of prostate carcinoma. *Cancer*. 2002; 95:2397–407. [PubMed: 12436448]
14. Sundaram CP, Thomas W, Pryor LE, Sidi AA, Billups K, Pryor JL. Long-term follow-up of patients receiving injection therapy for erectile dysfunction. *Urology*. 1997; 49:932–5. [PubMed: 9187703]
15. Guest G, Bunce A, Johnson L. How many interviews are enough?: An experiment with data saturation and variability. *Field Methods*. 2006; 18:59–82.
16. Bernard, HR., editor. *Research Methods in Anthropology: Qualitative and Quantitative Approaches*. Sage Publications; Thousand Oaks: 1994.
17. Creswell, JW., editor. *Qualitative Inquiry and Research Design: Choosing Among Five Traditions*. Sage Publications; Thousand Oaks: 1998.
18. Green, JT.; N., editors. *Qualitative Methods for Health Research*. Sage Publications; London: 2004.
19. Patton, MQ., editor. *Qualitative Evaluation and Research Methods*. Sage Publications; Thousand Oaks: 2002.
20. Miles, MBH.; A. M., editors. *Qualitative data analysis*. 2nd ed.. Sage; Thousand Oaks: 1994.
21. Patton MQ. Enhancing the quality and credibility of qualitative analysis. *Health Serv Res*. 1999; 34:1189–208. [PubMed: 10591279]
22. Warren, CABK.; T.X.. *Discovering qualitative methods: Field research, interviews, and analysis*. Roxbury Publishing Company; Los Angeles: 2005.
23. Guba, EG. *Toward a methodology of naturalistic inquiry in educational evaluation*. University of California, Graduate School of Education, Center for the Study of Evaluation; Los Angeles: 1978.
24. Hubbard G, Kidd L, Kearney N. Disrupted lives and threats to identity: the experiences of people with colorectal cancer within the first year following diagnosis. *Health (London)*. 2010; 14:131–46. [PubMed: 20164162]

25. List MA, Stracks J, Colangelo L, et al. How Do head and neck cancer patients prioritize treatment outcomes before initiating treatment? *J Clin Oncol*. 2000; 18:877–84. [PubMed: 10673531]
26. Arndt V, Merx H, Stegmaier C, Ziegler H, Brenner H. Quality of life in patients with colorectal cancer 1 year after diagnosis compared with the general population: a population-based study. *J Clin Oncol*. 2004; 22:4829–36. [PubMed: 15570086]
27. Temple LK, Bacik J, Savatta SG, et al. The development of a validated instrument to evaluate bowel function after sphincter-preserving surgery for rectal cancer. *Diseases of the Colon & Rectum*. 2005; 48:1353–65. [PubMed: 15868235]
28. Araujo AB, Durante R, Feldman HA, Goldstein I, McKinlay JB. The relationship between depressive symptoms and male erectile dysfunction: cross-sectional results from the Massachusetts Male Aging Study. *Psychosom Med*. 1998; 60:458–65. [PubMed: 9710291]
29. Shabsigh R, Klein LT, Seidman S, Kaplan SA, Lehrhoff BJ, Ritter JS. Increased incidence of depressive symptoms in men with erectile dysfunction. *Urology*. 1998; 52:848–52. [PubMed: 9801112]
30. Shiri R, Koskimaki J, Tammela TL, Hakkinen J, Auvinen A, Hakama M. Bidirectional relationship between depression and erectile dysfunction. *J Urol*. 2007; 177:669–73. [PubMed: 17222655]
31. Smith DP, Supramaniam R, King MT, Ward J, Berry M, Armstrong BK. Age, health, and education determine supportive care needs of men younger than 70 years with prostate cancer. *J Clin Oncol*. 2007; 25:2560–6. [PubMed: 17577034]
32. Steginga SK, Occhipinti S, Dunn J, Gardiner RA, Heathcote P, Yaxley J. The supportive care needs of men with prostate cancer (2000). *Psychooncology*. 2001; 10:66–75. [PubMed: 11180578]
33. O'Brien R, Rose P, Campbell C, et al. "I wish I'd told them": A qualitative study examining the unmet psychosexual needs of prostate cancer patients during follow-up after treatment. *Patient Educ Couns*. 2010
34. Giesler RB, Given B, Given CW, et al. Improving the quality of life of patients with prostate carcinoma: a randomized trial testing the efficacy of a nurse-driven intervention. *Cancer*. 2005; 104:752–62. [PubMed: 15986401]
35. Lepore SJ, Helgeson VS, Eton DT, Schulz R. Improving quality of life in men with prostate cancer: a randomized controlled trial of group education interventions. *Health Psychol*. 2003; 22:443–52. [PubMed: 14570527]
36. Penson DF, Latini DM, Lubeck DP, Wallace K, Henning JM, Lue T. Is quality of life different for men with erectile dysfunction and prostate cancer compared to men with erectile dysfunction due to other causes? Results from the ExCEED data base. *J Urol*. 2003; 169:1458–61. [PubMed: 12629383]
37. Kerr J, Engel J, Schlesinger-Raab A, Sauer H, Holzel D. Doctor-patient communication: results of a four-year prospective study in rectal cancer patients. *Diseases of the Colon & Rectum*. 2003; 46:1038–46. [PubMed: 12907897]
38. Razavi D, Delvaux N, Hopwood P. Improving communication with cancer patients. A challenge for physicians. *Annals of the New York Academy of Sciences*. 1997; 809:350–60. [PubMed: 9103586]
39. Montorsi F, Guazzoni G, Strambi LF, et al. Recovery of spontaneous erectile function after nerve-sparing radical retropubic prostatectomy with and without early intracavernous injections of alprostadil: results of a prospective, randomized trial. *J Urol*. 1997; 158:1408–10. [PubMed: 9302132]

Table 1

Topics explored in interviews and focus groups

Topic Overview	Question Probes
Warm-up questions	<ul style="list-style-type: none"> •How many years are you post treatment? •How did your rectal cancer surgery go? •Have you experienced any side effects from the surgery on your bowel functioning?
Concerns and expectations about sexual functioning post rectal cancer therapy	<ul style="list-style-type: none"> •Please share with me what your sexual functioning is like now following treatment for your rectal cancer. •How satisfied/dissatisfied are you with your current sexual functioning? •What expectations/beliefs do you have about what your sexual functioning should be like following treatment for rectal cancer?
Prior experiences and satisfaction with help for post-cancer sexual function	<ul style="list-style-type: none"> •If you have experienced problems with sexual functioning as a result of your treatment for rectal cancer, have you ever sought information about how to improve sexual functioning? •Have you sought medical care for any post-cancer sexual issues?
Interviewer provides brief overview of intervention	<ul style="list-style-type: none"> • Interviewer describes content of intervention sessions and time commitment required
Preferences for receiving education in improving sexual function	<ul style="list-style-type: none"> • What reactions do you have to the intervention? •How interested would you be in participating in an intervention that may help men with rectal cancer improve their sexual functioning and quality of life? •Based on my overview of the intervention, what do you think would encourage you to participate in the intervention? •What do you think would hinder you from participating in the intervention?
Closing comments	<ul style="list-style-type: none"> • Do you have other thoughts regarding what would make a sexual health intervention attractive to you that we haven't already discussed?