

MEN'S SEXUAL HEALTH

What Patients and Partners Want in Interventions That Support Sexual Recovery After Prostate Cancer Treatment: An Exploratory Convergent Mixed Methods Study



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ABSTRACT

Introduction: Men treated for prostate cancer suffer from treatment-related sexual side effects that adversely affect their relationships and quality of life.

Aim: To investigate what prostate cancer survivors and their partners want from a sexual recovery intervention, and whether they consider an online tool acceptable for use in promoting sexual recovery.

Methods: This mixed-methods study included focus groups and interviews with both heterosexual and gay cancer survivors, as well as their partners. Focus groups and interviews probed experiences with treatment, side effects, and support received/needed for sexual recovery. Participants responded to proposed web-based intervention content. Interviews were analyzed with thematic content analysis. Their sexual function was assessed with validated measures.

Main Outcome Measures: Acceptability of online tools for promoting sexual recovery was evaluated.

Results: Participants included 14 patients and 10 partners (2 male). Patient and partner median age was 62 and 62.5 years, respectively. Treatment ranged from surgery alone to combined radiation and hormonal therapy. Qualitative data analysis yielded 5 main intervention needs: (i) pretreatment discussion of sexual side effects, rehabilitation, emotional impact and realistic expectations, (ii) improved sexual communication within couples, (iii) strategies for promoting sexual intimacy beyond penetrative intercourse, (iv) attentiveness to partners' needs, and (v) access to peer support. Gay men specifically expressed the need for improved provider understanding of their sexuality and experiences. Most considered a web-based approach to be acceptable.

Conclusion: Patients and partners value both pretreatment preparation for sexual recovery and support for sexual recovery for both after treatment. A web-based approach may help mitigate barriers to access to these support services. **Mehta A, Pollack CE, Gillespie T., et al. What Patients and Partners Want in Interventions That Support Sexual Recovery After Prostate Cancer Treatment: An Exploratory Convergent Mixed Methods Study. Sex Med 2019;7:184–191.**

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Key Words: Prostate Cancer; Sexual Dysfunction; Erectile Dysfunction; Cancer Survivorship; Sexual Partners; Web-Based Intervention; Sexual Recovery; Prostatectomy; Radiation Therapy; Health-Related Quality-of-Life Outcomes

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INTRODUCTION

The diagnosis and treatment of prostate cancer adversely impact the physical, mental, and emotional well-being of prostate cancer patients and their partners, irrespective of treatment modality.^{1–5} Sexual dysfunction is the most common health-related quality of life complaint among prostate cancer survivors,⁶ affecting patients and partners in distinct yet significant ways.⁷ The current literature demonstrates that sexual dysfunction, which encompasses not only erectile dysfunction, but also decreased libido, impaired arousal, and muted orgasm,⁸ can have wide-ranging implications for patient and partner intimacy,

communication, and relationship satisfaction. Untreated sexual dysfunction is associated with frustration, anxiety, and depression for both patients and partners, potentially culminating in separation, divorce, and even suicide.^{9–13} As a result, there is a growing interest in preserving and promoting the recovery of sexual function and sexual intimacy among prostate cancer survivors and their partners.

It is well recognized that partners play a critical role in the sexual recovery of prostate cancer survivors by providing both emotional and logistical support.¹⁴ Partners' sexual interest is positively correlated with patients' recovery of sexual function.¹⁵ Conversely, partners' level of depression is predictive of the patients' relationship satisfaction, sexual satisfaction, and perceived quality of communication.²

Interventions that promote sexual recovery after prostate cancer treatment are in short supply, especially those that take a broader perspective in simultaneously addressing both patients and partners in the functional, emotional, and relationship domains. Prior studies that have used these approaches have shown a number of positive outcomes, including reduced stress, increased use of pro-erectile aids, more realistic expectations about the recovery of sexual function, and higher levels of relationship satisfaction.^{16–20} However, these interventions have not been widely disseminated, and access to them is often geographically restricted. Furthermore, interventions are largely designed by experts with knowledge of sexual issues in prostate cancer, without the benefit of patient and partner input.

In recent years, telemedicine approaches have been tested to increase access to care for prostate cancer patients.^{19,21} We therefore performed an exploratory, convergent, mixed-methods study of men with prostate cancer and their partners to investigate the support they would have wanted before and after their treatment, as well as the acceptability of online approaches for delivering the support. The results of this study were used to inform the final design and implementation of the TrueNTH Sexual Recovery Intervention for Prostate Cancer Survivors and Their Partners ([ClinicalTrials.gov](https://clinicaltrials.gov/ct2/show/study/NCT02702453) Identifier: NCT02702453).

MATERIALS AND METHODS

In this exploratory, convergent, mixed-methods study, sexual function assessments with validated instruments (see “[Quantitative Data Collection](#)”) provided a context for participants' views expressed in the focus groups (F.G.) and interviews. Data were collected from prostate cancer survivors and their partners at a single time point after surgery or radiation treatment for prostate cancer. The study was approved by the institutional review boards at the University of Michigan and Emory University. All participants provided written informed consent before participation.

Study Sample

Study participants included single and partnered prostate cancer survivors, as well as their same-sex or opposite-sex

partners. Participants were recruited from outpatient Urology and Radiation Oncology clinics at 2 academic medical centers, in the U.S. Midwest and the South. The catchment areas of these centers included urban, suburban, and rural patients. To be eligible for study participation, patients had to be within 6–36 months of treatment for prostate cancer, with radical prostatectomy or radiation therapy (with or without androgen deprivation therapy), or androgen deprivation alone, able to speak and read English, and able and willing to provide informed consent for study participation. Similarly, partners had to be able to speak and read English, and be able and willing to provide informed consent. 4 focus groups of 6–8 participants each were planned: patients only, partners only, heterosexual couples, and same-sex couples. Diversity, both in terms of participant race/ethnicity, as well as treatment modality, was prioritized, to the extent possible, during recruitment for focus group participation. Focus groups with heterosexual couples and partners were conducted at the University of Michigan. A focus group with patients was conducted at Emory University. Due to challenges with recruitment for a full focus group involving same-sex partners, 2 same-sex couples participated in 2 separate semi-structured interviews via Skype.

Procedure

Quantitative Data Collection

All participants completed demographic questionnaires and functional measures prior to focus groups or interviews. Additionally, data related to the diagnosis and treatment of prostate cancer were abstracted from the patients' medical records.

Prostate cancer patients completed the Expanded Prostate Cancer Index Composite (EPIC), which evaluates health-related quality of life outcomes in men treated for organ-confined prostate cancer, across 5 domains (urinary incontinence, urinary irritability, sexual, bowel, and hormonal).²² Participants responded to a Likert scale; a higher total score reflects higher function. The validity, or internal consistency, of EPIC has been evaluated using Cronbach's alpha statistic. The value of the alpha coefficient ranges from 0–1, with most methodologists recommending a minimum value between 0.65–0.8 to ensure validity.²³ Validation of EPIC confirmed high internal consistency (Cronbach's alpha ≥ 0.8 for the urinary, bowel, sexual, and hormonal domain summary scores).²²

Female partners completed the Female Sexual Function Index (FSFI), which assesses 6 domains of sexual function in women (desire, arousal, lubrication, orgasm, pain, and satisfaction).²⁴ Participants respond to a Likert scale, with a higher score reflecting higher function. A high degree of internal consistency has been demonstrated for FSFI (Cronbach's alpha ≥ 0.82).²⁴

Male partners completed the International Index of Erectile Function (IIEF), which assesses 5 domains of sexual function in men (erectile function, orgasmic function, sexual desire, intercourse satisfaction, and overall satisfaction).²⁵ Participants

respond to a Likert scale, with a higher score reflecting higher function. A high degree of internal consistency has been demonstrated for each of the 5 domains (Cronbach's alpha ≥ 0.73), and for the total scale (Cronbach's alpha ≥ 0.91).²⁵ For all 3 sub-scales, a higher score indicates higher functioning.

Qualitative Data Collection

The focus group and interview guides for both patients and partners were based on the research question and previous research on couples' sexual recovery. Interview questions were prepared to assess 3 main domains: (i) experiences with prostate cancer treatment, treatment-related side effects, and the treatment's impact on themselves and their relationships; (ii) support received/needed for sexual recovery; and (iii) recommendations for an intervention that would aid sexual recovery after prostate cancer treatment. Example questions included the following:

- "Thinking about the sexual recovery process, what would you consider to be the 2 or 3 absolutely essential topics that the intervention should address?"
- "What do you think partners should know about your experience of ED [erectile dysfunction] and sexual recovery after your prostate cancer treatment?"
- "Are there some methods of presentation that would be uncomfortable either for you or your partner?"

Additionally, participants were specifically asked about the utility of a web-based intervention for sexual recovery. For example:

- "Imagine yourself in front of a computer or an iPad with your partner. You are both reviewing a website together, reading education material of sexual recovery, and being given some exercises to do. How do you think you and your partner would react?"
- "Can you think of any topics that would be uncomfortable for you to view online with your partner?"

Participants were also asked to review the educational content developed for the TrueNTH Sexual Recovery Study Protocol²⁶ and asked about the likelihood of responding positively to intimacy exercises. They were asked to suggest any additional information that should be included.

Focus groups were conducted by the study investigators and trained staff (A.M., T.G., C.C., D.W.), and lasted approximately 1.5–2 hours. Individual interviews were conducted by the principle investigator (D.W.), and lasted approximately 1 hour. Focus group and interview sessions were digitally recorded and transcribed verbatim.

Data Analysis

Quantitative Data

Demographic and clinical data were summarized using descriptive statistics. Functional data were scored, and means were calculated for patients and female partners. Functional data for male partners are reported individually.

Qualitative Data

Thematic analysis of interview and focus group transcripts was performed separately by the principle investigator and graduate students (K.H. and J.K.). Data were first coded as open codes, followed by higher conceptual level coding, and further categorized into final themes.²⁷ Data for patients, partners, and heterosexual and same-sex couples were analyzed separately. 3 qualitative analysts (D.W., K.H., J.K.) independently coded the data, discussed the findings, and agreed on a final coding schema, to ensure the quality of the data analysis. Findings were discussed and confirmed with the full research team. Combined quantitative and qualitative data were compared to determine whether focus group and interview content reflected participants' functional status. Together, they provided the experiential platform from which participants offered their advice on intervention content.

RESULTS

Sample Characteristics

14 patients and 10 partners (2 male) participated in 3 focus groups and 2 interview sessions. Mean patient and partner age was 62 and 63 years, respectively (Table 1). 9 of the 14 patients were white, and 5 were African American. All partners were white. 9 patients of 14 underwent a radical prostatectomy, 3 had radical prostatectomy and radiation therapy, 1 had radiation and hormonal therapy, and 1 had hormonal therapy only. Partners' husbands were treated with radical prostatectomy (n = 3), radiation and hormonal therapy (n = 1), and radical prostatectomy, radiation, and hormonal therapy (n = 1). The vast majority of patients (13 of 14) stated that they were in a committed relationship. 3 of the 14 patients had same-sex partners. Average number of years in a committed relationship was 19 for patients, and 39.5 for partners. Both patients and partners reported a variety of comorbidities, with hypertension and hypercholesterolemia being most common.

Functional Outcomes

Patient- and partner-reported sexual function is summarized in Table 2. On average, both patients and female partners reported low sexual function. The mean EPIC score for patients was 20.8, which indicates severe erectile dysfunction²⁸; the average FSFI score for female partners was 7.4, which indicates severe sexual dysfunction²⁴; and the 1 male partner's IIEF score was 38 of a possible 75, which indicates moderate sexual dysfunction.²⁵ 1 male partner did not return his IIEF questionnaire.

Interview Themes

Patient, partner, and couples' focus groups and interviews identified 5 related themes that they considered important to sexual recovery: (i) pretreatment preparation for sexual side effects, rehabilitation strategies, emotional reaction to the side-effects, and realistic expectations of outcomes; (ii) improved communication about sexual concerns within couples; (iii)

Table 1. Participants' characteristics

Characteristic	Patient	Partner
Gender		
Male, n (%)	14 (100)	2 (20)
Female, n (%)		8 (80)
Race		
Caucasian, n (%)	9 (64)	10 (100)
African American, n (%)	5 (36)	0 (0)
Age (mean, range)	(62, 51–84)	(63, 35–83)
Partnered status		
Partnered, n (%)	12 (93)	10 (100)
Education		
High school, n (%)	3 (21)	2 (20)
College degree, n (%)	10 (71)	7 (70)
Graduate degree, n (%)	3 (21)	2 (20)
Employment status		
Working, n (%)	7 (50)	6 (60)
Retired, n (%)	7 (50)	4 (40)
Disabled, n (%)	0 (0)	0 (0)
Income		
<\$60,000, n (%)	5 (36)	4 (40)
>\$60K,000, n (%)	8 (57)	4 (40)
Missing, n (%)	1 (7)	1 (20)
Comorbidities		
0–2, n (%)	5 (36)	7 (70)
3–4, n (%)	8 (57)	2 (20)
Missing, n (%)	1 (7)	1 (20)

strategies for promoting sexual intimacy beyond penetrative intercourse; (iv) attentiveness to partners' needs; and (v) access to peer support. Additionally, gay men specifically expressed the need for (vi) improved provider understanding of gay men's sexual identity and experiences.

Pretreatment Preparation

9 patients acknowledged limited pretreatment knowledge about the sexual side effects of prostate cancer treatments, due to their healthcare provider focusing on cancer control only, rather than the impact of cancer therapies on long-term quality of life. 1 patient stated: "My doctor was great about a lot of information, but that particular piece [around sexual side effects] was not really addressed" (Patients' FG participant).

Another patient stated:

I wasn't quite so sure about what happened, you know if I cure the cancer, what about the sexual aspect...with that stated I think full disclosure up front and working on removing not just the cancer but helping the patient get over the fact that...they have another battle to fight—that is, getting back online with your sexual performance (Patients' FG participant).

Table 2. Participants' sexual function

Sexual function (IQR)	Patient (n = 14)	Female partner(n = 10)	Male partner (n = 1)
EPIC	20.8 (8.3–53.6)	NA	38
FSFI or IIEF	NA	7.4 (3.1 –21.9)	NA

EPIC = Expanded Prostate Cancer Index Composite; FSI = Female Sexual Function Index; IIEF = International Index of Erectile Function; NA = not applicable.

Several patients reasoned that physicians may be unwilling to discuss the sexual side effects of treatment for fear that patients would be unwilling to undergo cancer treatment due to the potential side effects:

Some physicians opt not to say anything about what could happen afterwards because they know that the patient needs treatment, and that, if they say anything, they may not go through with it (Patients' FG participant).

The need for better pretreatment counseling about side effects and realistic expectations for recovery was widely echoed, with multiple patients explicitly outlining the need for a patient-provider discussion about penile rehabilitation, regardless of patient age or relationship situation. 1 patient specifically contrasted the relative lack of reliable information about the sexual side effects of prostate cancer treatment with that pertaining to women undergoing breast cancer treatment:

I'll put it into perspective; there is more information about women and breast cancer, to what happens before, what happens after, all widely disseminated. You don't see that type of information as it relates to prostate cancer (Patients' FG participant).

The need for emotional preparation was particularly strongly voiced in the partners' group:

I think for men, um, it is a loss, and almost like death, they, that they do need to address, that this is something in their lives that they can't keep pushing down; it's got to be addressed (Partners' FG participant).

Improved Communication Between Couples

Patients and partners alike expressed an interest in improved communication with each other, both to vocalize their concerns about treatment-related sexual side effects, and to understand each other's needs about the physical loss of sexual function, and the emotional changes associated with the onset of sexual dysfunction. 1 female partner stated: "He's talking in here more than he talks to me about it. He doesn't talk. He won't talk about it" (Couples' FG participant). Another partner added:

“You have to be both on the same page. If you aren’t, this doesn’t mean nothing” (Couples’ FG participant).

Men recognized the need to have partners more involved in the sexual recovery process and had a favorable recollection of instances when their physicians had involved their partners in the discussion about prostate cancer treatment and treatment-related expectations. One patient recalled: “My doctors were very good about looking at looking at my wife and saying, you know ‘What are your questions, what are your concerns’, and so that was really helpful to us” (Patients’ FG participant).

Strategies for Promoting Intimacy

Patients and partners expressed a wish that they would have had support for maintaining physical and emotional intimacy. Partners’ greatest disappointment appeared to stem not from the man’s loss of erectile function, but from the concomitant loss of other forms of intimacy, particularly in the context of hormonal treatment. As 1 female partner said: “He doesn’t just have no desire to have sex, he has no desire to hug me, kiss me, cuddle me. That’s what breaks my heart...that has always meant more to me than the actual...” (Couples’ FG partner participant). There was a consistent perception among patients and partners that sexual intimacy and sexual pleasure was important for couples to maintain, even in the setting of sexual dysfunction that prevented penetrative intercourse.

Attentiveness to Partners’ Needs

Multiple partners vocalized the sentiment that women can be just as interested in sexual activity as men are, but that female partners may be embarrassed to share this sentiment for fear of being negatively judged, especially in the setting of male erectile dysfunction:

Just an observation, I mean they always proclaim men as sexual creatures, but when it comes down to it, women are too, but they don’t want to advertise it because that would make them sound like something else, you know. (Couples’ FG partner participant)

Access to Peer Support

The vast majority of couples expressed an interest in peer support, group support, and counseling, in order to help navigate the physical and emotional challenges associated with treatment-related sexual dysfunction. 1 patient, who participated in a focus group, stated: “I think the group setting is very good...you wouldn’t sit at home and talk like this, but in a group setting you’ll spill your guts” (Couples’ FG patient participant). And a partner at a focus group agreed: “You feel comfortable when you know that there is somebody else going through the same thing that you are going through. I think that helps” (Couples’ FG partner participant).

Concerns of Gay Men and Same-Sex Partners

Although all participants endorsed the need for increased provider knowledge and comfort about sexual dysfunction, gay men in particular emphasized the need for providers to be comfortable talking about all types of sexual activity and attentive to the specific needs of gay men. They gave the following examples of the types of topics they would wish to discuss with their providers:

No, because...emotionally they couldn’t do it (change sexual roles)...in fact somebody who is not used to being on top tries to be on top, often they lose their erection. (Patient)

... Talking about having an orgasm, and not having any fluid being important for gay men vs um, a straight couple. (Partner)

... Um, but I also believe, and this is just my personal opinion, it is not scientific fact, but I believe that most gay men are used to the majority of gay men, I would say are not in a monogamous relationship. (Partner)

Both same-sex couples included in this study stated the importance of patients and partners being counseled together about side effects of prostate cancer treatment, with a frank discussion about sexual function and sexual practices.

Attitudes Toward a Web-Based Intervention

Most study participants were receptive of a web-based intervention to promote recovery of sexual function among prostate cancer survivors. For participants, the primary benefits of a web-based intervention were access to vetted, reliable information pertaining to the physical and emotional aspects of sexual function. For example, 1 patient stated:

I think if there was something that we would have liked differently with the whole procedure and recovery process is to have access to a website that has all of this stuff...that has the people that you can talk to, that has the video instruction, that has the imagery...outlets for emotional support, like, that kind of stuff would have really helped. (Same-sex couple patient)

Heterosexual and same sex couples participating in the study, and participants in the partners-only focus groups, were generally receptive to the design of a web-based intervention that included didactic information about sexual function and strategies for promoting intimacy after prostate cancer treatment. On the contrary, at least 3 participants in the patients-only focus group were opposed to the idea of a web-based intervention that required patients and partners to review sexually-explicit information together, preferring, instead, for their partners to review this information separately from themselves:

My wife and I are pretty open about talking about these kinds of things, but even with...us being able to communicate like that, I don't know, sitting side by side at a computer screen going through it together. I kind of lean towards more...if my doctor would have handed her a brochure and said, "You really need to look at this because this is what your husband is going to experience," and then I have some materials that I look through, and kind of deal with it on my own (Patients' FG participant).

Certainly, the hesitation on the part of these patients appeared to stem more from discomfort discussing their sexual function with their partners than with the idea of promoting sexual recovery.

DISCUSSION

Combining quantitative and qualitative findings, we found that, in the context of compromised sexual function, as demonstrated by the functional assessments of both patients and partners, patients and partners wished that they would have been prepared for the sexual side effects of prostate cancer treatment, as well as for their emotional impact and rehabilitation strategies. Irrespective of treatment type and sexual orientation, both patients and partners independently voiced the need for better communication with each other about their sexual concerns and were open to strategies designed to enhance sexual intimacy. Access to peer support, which included support for partners' needs, was also deemed important. Finally, most, but not all, participants considered a web-based approach for education, engaging in interactive activities with each other on the web and peer-support to be acceptable.

Our findings echo and extend the previously published literature in terms of patient-reported needs for health information after prostate cancer treatment,²⁹ including education and support related to treatment options for erectile dysfunction and relational issues.^{30,31} Prostate cancer treatment can result in a wide range of sexual problems, such that restoration of erectile function alone is not enough to improve the quality of life of prostate cancer survivors.⁸ Many men diagnosed with prostate cancer experience anxiety over the uncertainties of cancer prognosis, fear of cancer treatment, and diminished quality of life, as well as physical health impairment. This may be accompanied by decreases in sexual desire, and disorders of ejaculation and orgasm, which can affect partner sexual relationship and dynamics. Therefore, full sexual rehabilitation requires psychological and sexual counseling, in addition to medical and surgical therapies for erectile dysfunction.³²

The recent literature recognizes the need to include both patients and their partners in prostate cancer survivorship care plans.^{33–35} At least 11 interventions promoting sexual recovery after prostate cancer treatment have been developed and tested over the past 10 years, involving a variety of approaches

and outcome measures.³⁶ Earlier interventions took a psycho-educational approach, focusing on patients and use of erectile dysfunction treatments, and including partners as adjuncts. Later interventions were more likely to include partners as equal participants in the interventions and included behavioral assignments rather than erectile dysfunction treatments alone. Overall, these interventions succeeded in improving couples' knowledge about treatment-related sexual side effects, use of erectile dysfunction treatments, and partners' attitudes toward erectile dysfunction. However, their long-term impact on sexual function, relationship satisfaction, and intimacy has been modest.³⁶

The study shows that, in general, web-based interventions appear to be acceptable to patients and their partners. This approach may be promising because it allows for the intervention to be tailored, for example, based on treatment type, sexual orientation, and relationship status. This type of tailoring is likely important because our study showed that men want specific information from their health care providers based on the type of treatment that they received. As a case in point, the gay men in the study requested data that were specific to their lives and lifestyles. Despite increasing patient reliance on web-based resources for the acquisition of healthcare-related information, we found it interesting that not all focus group participants found this approach acceptable. Notably, some participants were embarrassed at the idea of discussing web-based content related to sexual function with their partners. These responses likely stem from the fact that long-term couples are unaccustomed to discussions about their sexual function and relationship.³⁷ These couples may need initial in-person counseling to help them recognize that sexual recovery after prostate cancer treatment requires communication, mutual acceptance, and support that had not been needed before the cancer experience.

This study has several limitations. The sample of gay men and their partners was small and may not be representative of the gay population at large. The study was also limited to 2 academic medical centers, which, although they were chosen to be geographically diverse, with a different racial and ethnic makeup in terms of the patient population they serve, may have impacted the responses we received. Nevertheless, we did find that the themes were quite similar across the focus groups and reflective of the research literature, which gives us some confidence that these findings are transferable. Focus groups were designed to foster communication among participations. It is possible that people willing to participate in focus groups may be more likely to endorse the need for peer support.

With these limitations and gaps in mind, we used the findings of this study to design a patient- and partner-oriented, tailored, web-based educational intervention to promote sexual recovery after prostate cancer treatment. This intervention is currently being tested in a randomized-controlled trial to assess its efficacy as a support tool for men and their partners who wish to recover sexual intimacy after prostate cancer treatment.²⁶

CONCLUSIONS

Patients and partners value both pretreatment preparation for sexual recovery and support for sexual recovery for both after treatment. A web-based approach may help mitigate barriers to access to these support services.

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