## ORIGINAL ARTICLES

# Sexuality after Treatment for Early Prostate Cancer

## Exploring the Meanings of "Erectile Dysfunction"

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OBJECTIVE: To explore perceptions of the impact of erectile dysfunction on men who had undergone definitive treatment for early nonmetastatic prostate cancer.

DESIGN: Seven focus groups of men with early prostate cancer. The groups were semistructured to explore men's experiences and quality-of-life concerns associated with prostate cancer and its treatment.

SETTING: A staff model health maintenance organization, and a Veterans Affairs medical center.

PATIENTS: Forty-eight men who had been treated for early prostate cancer 12 to 24 months previously.

RESULTS: Men confirmed the substantial effect of sexual dysfunction on the quality of their lives. Four domains of quality of life related to men's sexuality were identified: 1) the qualities of sexual intimacy; 2) everyday interactions with women; 3) sexual imagining and fantasy life; and 4) men's perceptions of their masculinity. Erectile problems were found to affect men in both their intimate and nonintimate lives, including how they saw themselves as sexual beings.

CONCLUSIONS: Erectile dysfunction, the most common side effect of treatment for early prostate cancer, has far-reaching effects upon men's lives. Assessment of quality of life related to sexual dysfunction should address these broad impacts of erectile function on men's lives. Physicians should consider these effects when advising men regarding treatment options. Physicians caring for patients who have undergone treatment should address these psychosocial issues when counseling men with erectile dysfunction.

KEY WORDS: prostate cancer; erectile dysfunction; quality of life; qualitative methods.

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uality-of-life considerations and patients' values have been gaining significance in determining treatment choices and evaluating the outcomes of care for early, nonmetastatic prostate cancer. Patients now find themselves presented with several distinct primary therapy options (e.g., radical prostatectomy, radical external beam radiotherapy, brachytherapy, cryosurgery, and hormonal ablation therapy). However, choices may be difficult. While most patients survive five years, cancer treatment carries significant uncertainty. Each option that a patient might choose is associated with long-term side effects, including urinary incontinence, bowel problems, and sexual dysfunction, which, in turn, may cause further psychosocial distress. Their physicians have an important role to play as counselors, both to help them choose a treatment and then, over the long term, as they live with the outcomes.

Erectile dysfunction is the most common long-term side effect of active therapy for early prostate cancer. While some reports of surgical case series have documented rates of significant erectile dysfunction (i.e., erections that were inadequate for intercourse) as low as 28%, studies using patient-based survey methods have reported rates ranging between 60% and 93% after radical prostatectomy and between 67% and 85% following external beam radiotherapy. <sup>1-4</sup> While post-treatment erectile dysfunction may not be associated with declines in overall quality of life, <sup>3.5</sup> several studies have found that men report that it is substantially problematic, <sup>4.6</sup> may be perceived as more distressing than other side effects such as urinary incontinence, <sup>7.8</sup> or causes a loss of self esteem. <sup>9</sup>

However, the full range of impacts of erectile dysfunction in these patients remains poorly characterized. The assessment of sexual function in prostate cancer patients tends to focus largely on erectile function, augmented in some studies with assessments of interest, desire, satisfaction, arousal, and orgasm<sup>2.6,10-14</sup> along with a rating of how much of a problem sexual dysfunction presents. Although erectile dysfunction has been found to be associated with diminished emotional functioning as measured by the SF-36,<sup>6</sup> most assessments yield no specific information about the psychosocial changes that men may experience with sexual dysfunction, that is, what men may mean when

they indicate, as they often do, that sexual dysfunction is a "moderate to big problem."<sup>3,9</sup>

While sexual functioning certainly declines with age, sexuality remains a significant aspect of men's lives well into their older years. <sup>15–18</sup> Accordingly, their sense of themselves as sexual beings remains important. We would expect that men who experience erectile dysfunction after treatment for prostate cancer might perceive a significant loss. We would also expect that men faced with a treatment choice might anticipate a significant change in the quality of their lives. The psychosocial significance of sexual dysfunction in this context warrants careful attention, beginning with a close examination of the ways in which prostate cancer patients characterize the changes they experience. Thus, in this paper we describe the meanings of sexual dysfunction for men who have undergone treatment for early prostate cancer.

The data we present are from the first, qualitative phase of a more broadly focused study to develop patientcentered measures of the quality-of-life outcomes of prostate cancer treatment. We conducted focus groups in order to give men an opportunity to engage in an openended discussion of their experiences with prostate cancer, the effects of treatment on their lives, and how they were coping with these changes. Given the paucity of information about how men perceive the outcomes of treatment, focus groups provided an appropriate mechanism for opening an exploration. They would elicit accounts from patients in their own words, developed through a discussion of individual and shared experiences. Discussion of erectile dysfunction was a major topic of discussions that encompassed a wider range of issues, such as the behavioral problems of living with urinary and bowel dysfunction and the persistent uncertainty that accompanies surviving any cancer. This paper focuses on sexual dysfunction, as perceived by these men, in the context of other psychosocial changes.

## **METHODS**

## **Participants**

Focus group participants were recruited from lists of patients treated for early prostate cancer at two sites: Harvard Vanguard Medical Associates (HVMA), a staff model health maintenance organization in Boston, and the Veterans Affairs Medical Center (VAMC) in Washington, DC. Together, these sites serve a diverse population: largely middle class and white at HVMA; largely low income and African American at the Washington VAMC. Recruitment was limited to patients treated between 12 and 24 months previously in order to avoid those who were dealing with the acute effects of treatment and to focus on men who were likely to be coming to terms with long-term side effects. <sup>19</sup>

Potential participants were contacted via telephone and asked whether they would be willing to participate in a focus group at a given time. They were told the focus group discussion would be about the impact of prostate cancer on

their lives. A total of 130 patients were contacted, 48 agreed to participate, with most refusals being due to scheduling conflicts. All but one of the participants, who had opted for expectant management, had undergone radical prostatectomy, radical external beam radiotherapy, or brachytherapy (radioactive seed implant). All of the participants were heterosexual. They were not selected for a history of erectile dysfunction; however, in the course of the discussions, 26 did report significant erectile problems. Participants were asked for written signed consent at the time of the focus group prior to the beginning of the discussion. They were informed that the group discussion would be audio- and videotaped. The study was approved by the Human Studies Committee at both Harvard Vanguard Medical Associates and the Veterans Affairs Medical Center.

#### **Data Collection**

Seven focus groups were conducted. They were designed to be homogenous with respect to race (white or African American) and age (50 to 69 years old or 70 to 79 years old) in order to facilitate within-group discussion and between-group comparisons with respect to these social characteristics. Four to eight men participated in each 90-minute group session. Sessions were conducted at the medical centers at which the men received their care and were jointly led by a medical sociologist (JAC) and a medical oncologist (JAT). The discussion protocol was designed to explore patients' overall perceptions of their quality of life following treatment, including urinary, bowel, and sexual dysfunction, as well as changes in interpersonal relationships, concerns about the effectiveness of treatment, and other psychosocial effects. The discussions were semistructured. They began with asking each man to tell his story of his experiences with diagnosis and treatment and a general question, "Tell us what it's been like having been diagnosed and treated for prostate cancer." Follow-up questions addressed urinary, bowel, sexual function, relationships, and cancer worry, along with questions probing topics that emerged in the ensuing dialogue.

### **Analysis**

Complete, verbatim transcripts of the focus groups were analyzed qualitatively, using procedures informed by grounded theory methods. <sup>20</sup> We identified passages in the transcripts that represented topics and categories in the content of the discussions that suggested distinct domains of quality of life. The major domains included issues with urinary function, bowel function, uncertainty about the status of the cancer and treatment, and issues of sexuality. Then through the use of The Ethnograph (Scolari/Sage Productions, Thousand Oaks, Ca), a computer program that facilitates the coding, sorting, and management of qualitative data, a set of analytic codes was developed to account for these topics and domains. Segments coded as 'sexuality' were further subdivided into nine, internally consistent subcategories. Segments of coded text were

systematically reviewed, and categorical assignments were revised through a consensus-building process involving a psychologist (BGB), sociologist (JAC), and physicians with expertise in primary care internal medicine (TSI), and genitourinary oncology (JAT). These codes were then reviewed and revised in discussions with a collaborating geriatrician and medical oncologist, resulting in collapsing the nine subcategories into four domains affected by erectile dysfunction.

#### **RESULTS**

Most of the men who participated in these focus groups highlighted the cardinal importance of changes in their sexuality. One man offered tersely, "I would say the most significant aspect of the postoperative was the impotence." Others in the focus groups did not identify erectile problems associated with treatment. Several stated that they had not been sexually active prior to treatment and had experienced a gradual loss of interest in sex as they aged.

However, for the majority who attributed erectile dysfunction to their cancer treatment, their accounts, our questions, and the questions they raised with each other and with us led to in-depth conversations about the difficulties they encountered. Interestingly, none of the men used the clinical term "erectile dysfunction," and rarely spoke of a "weak" or "inadequate" erection. Men talked of erectile problems, but almost always in terms of their sexual relationships and with reference to how their lives had been affected more broadly. Moreover, they made a distinction between the quality of their erections and the more complex issues of the quality of their sex lives, as one man suggested in commenting on some initial questions we had asked.

It is very easy for me to answer a question saying are you satisfied or has getting and keeping an erection been a problem for you. Obviously it has and that is easy to answer. But then to ask, are you satisfied with your sex life, I am not quite sure the best way in answering that.

The ensuing discussion articulated the broader concerns of these men regarding their sex lives, extending beyond the question of having or not having erections. They articulated how changes in erectile function affected how they saw themselves and their relationships with their intimate partners. They described changes in their interpersonal relationships with women and other men that they attributed to sexual side effects of prostate cancer. Our analysis identified four major domains of men's sex lives that were affected by erectile problems (Table 1): the qualities of sexual intimacy, their everyday relationships with women, their sexual imagining and fantasy life, and their masculinity, that is their perceptions of themselves as men.

#### **Sexual Intimacy**

The focus group participants equated erectile dysfunction with diminished ability to perform sexually and

Table 1. Domains of Quality of Life Affected by Erectile Dysfunction

Sexual performance

Anxiety about satisfying a partner and oneself Hesitation in initiating physical intimacy Feeling that sex is awkward and unnatural Relationships with women

Awareness of loss of potential for sexual intimacy Disquieting absence of a sexual element in everyday interaction

Qualitative shift in interactions with women Sexual imaginings

Distressing lack of physical or emotional response to attractive women

Loss of pleasant pastime: fantasizing about sexual intimacy Masculinity

Sense of oneself as a man is diminished Loss of sexual function means loss of a defining feature of manhood

thereby enjoy intimate relations. Whereas erectile function is often assessed in mechanical terms of firmness for penetration, these men highlighted the significance of erections for accomplishing an intimate experience that was satisfying for both themselves and their partners. They also indicated that impaired performance ability could disable emotional and physical intimacy, since getting close was often assumed to lead normally to intercourse. They were apprehensive about intimate contact with their wives or partners, fearing that it might lead to an awkward, embarrassing performance or as one man put it, "starting a fire you can't put out." Further, as the following quote indicates, diminished confidence in one's sexual ability was associated with fear of embarrassment, should one attempt sexual activity and fail to receive or provide satisfaction.

I have been to that point when I was saying, I would like to but I would be real embarrassed if I really couldn't.

Men further expressed concern with the ways in which they did engage in sexual activity, even in the absence of a spontaneous erection. Men felt awkward when using mechanical assistive devices or injected medications, such as transurethral alprostadil, resulting in feeling that sexual intercourse had become unnatural.

[it] is extremely painful...doesn't seem to work too well. [sildenafil] doesn't work at all. So, yes, there is a sex life, but it's a rather unnatural one. But you've got to make do with what you've got or, as you say, you have to play it as it lies, right?

A natural expected course of events that would begin by getting an erection spontaneously now eluded this man. He went on to say that he and his partner had found other ways in which to be intimate and in fact had found ways to come to a sense of climax in these encounters, yet he still experienced a deep sense of loss. Physical intimacy with his wife was no longer a comfortable, familiar experience. Thus, using assistance to obtain an erection was not only inadequate at times, but also left men feeling

vulnerable and awkward. Another man added that the ineffective use of alprostadil suppositories could evoke rather painful feelings for an otherwise confident and capable adult man.

And then I really didn't get that much of an erection on it. I felt as if I were more fondling with myself, as I would as a teenager trying to get an erection on, and nothing, but in this case nothing happened. I mean it wasn't so much, it was that it just, it was ineffective, let me put it that way.

The experience of attempting intimacy was unsatisfying for this man as he tried to use the prescribed device for enhancing his erections.

## Relationships with Women

Men also described changes in the ways in which they related to women outside of their intimate relationships. They were aware of the absence of a subtle element of sexuality that had once characterized many of their interactions with women. This was especially true for men who were not married or in a monogamous relationship. They said that before they had prostate cancer they would have been aware of and perhaps attentive to the potential for sexual intimacy with women they met. Now they experienced social interactions with women in a new way.

[Before] you didn't know what was going to happen. Someone just walk by and you talk and have a nice conversation. But you got yourself together and you talk nice and talk right, you might keep her there. But now you don't try to keep her there because why, for what? You be nice to her and you all have a nice conversation then you got to go your own way because there's nothing you can do for her but be nice to her and have a nice conversation.

Whereas previously sexual intimacy may have been possible, consciously considered or sensed somewhere in the back of his mind, it was now well out of the question. He would focus now on avoiding a potentially embarrassing situation and finding ways to retreat from the interaction before the possibility of a sexual encounter was raised. He felt a change in how he was able to relate to women in everyday social situations, now defining himself and those interactions as nonsexual. Another man, echoing this self-consciousness, expressed a sense of reluctance to engage with women he would meet because, as he put it, "Within myself, I didn't feel the total confidence that I might have done the job well." Instead he withdrew from such interactions and avoided the possibility of a sexual encounter.

The men may not have been actively pursuing sexual relationships in every encounter with a woman, yet there had been a sexual undercurrent in most of their interactions. Now, their sexual confidence was diminished and they felt their relationships to be on new footings.

### **Sexual Imaginings**

The men became nostalgic when they described how they once enjoyed thinking about sex, now a lost pastime. They disclosed that they no longer enjoyed sexual feelings in response to seeing an attractive woman. They also expressed a profound sense of loss associated with a loss of a fantasy life in which they were able to imagine themselves as potential sexual partners. They were sadly conscious of their diminished libidos.

Several men lamented that they no longer could imagine approaching a woman, that they no longer gained pleasure in fantasizing about a sexual encounter. One participant was reminded of this when he realized that he no longer obtained an erection when he saw an attractive woman across the street.

Participant 1: It seems funny like sometimes you can see a real good-looking girl with a short skirt on, you know she's good-looking, and a year ago if I had seen her, you know, it would get hard. It don't get hard anymore.

Moderator: You still think about her, though?

Participant 2: Of course he does.

Participant 1: It's hard to think. I mean a year ago I'd be thinking of her all the time, but I can see a good-looking girl now and it don't even faze me at all because I can't.

Participant 3: That's why I asked about your libido. That's what libido is. And I mean I feel the same way. I look at a woman, I know she's a good-looking woman and it doesn't faze me.

Being "fazed" by an attractive woman was a small, ordinary pleasure of a sense of arousal, one for which they now have a sense of nostalgia. The men expressed a longing for that feeling again, seeking a sense of themselves as sexual in a way they previously had in their daily social lives. Although these men did not state that they had ever acted on such desires, even those men who were monogamous agreed that these fantasies had been part of their lives. The experience of being aroused by an attractive woman was something that they had identified as part of their lives as men. In the above example, the emphatic, "Of course he does," in response to the moderator's questioning of another man's thinking about women is indicative of the ubiquity of men's approach to this topic; being a man means being aroused by an attractive woman.

Even when men weren't sexually active, they were concerned with testing their sexual capability. One man stated that he was "curious to see how it feels" to be with a woman now because he "would still like to find out" if he were capable of a sexual relationship with a woman. Despite the fact that he had not been sexually active prior to his surgery, the knowledge that he could have been if he had so desired was important for him. This feeling was expressed in another group when one man said:

Well, at this point in my life, I think it's more psychological than anything else. It's the knowledge that you cannot perform, and it's that knowledge, I think, that's more disturbing than maybe the actual fact. . After all, it's a capacity you've had all your life and then suddenly it's gone.

Although they had lost the capacity for sex, it was not out of mind. Each of the following statements, expressed in several groups, was voiced with a wistful, plaintive, or bitter intonation.

"It never goes out of your mind."

"You don't forget about it."

"You think about it, but that's as far as you can go."

"I still have that great desire."

"You cannot get rid of your sex life."

These statements reveal that men do not stop being sexual beings just because they are unable to have an erection; sexuality remains a pervasive aspect of men's lives and an integral part of how they see themselves. Despite the loss of erections, sexuality remained part of their lives, and the ways in which men thought about themselves as sexual beings required redefinition.

The ways in which sexuality is embedded in the imaginings of men in everyday social life is nowhere more evident than in the ways men talk about their fantasizing about women. The pleasure of seeing women walking on the street had changed for many men, in that they no longer saw themselves as potential partners for those women, even in a fantasy world. While some men simply lamented the loss of a fantasy life, others no longer even felt comfortable fantasizing. One man said he had "sort of ruled [himself] out" as he thought about other women. He went on to say,

If you go to a conference or something, you're going out, whatever, I'm not now fantasizing about how I could sneak away and be with some other woman who's free and whatever...It's kind of sad because that was part of the fun of going to those conferences. I used to at least imagine.

This man lost a fantasy life, one in which he had derived much pleasure. Even if, as he said, he had not acted on any of these fantasies in the past, the knowledge now that he could not act on them now distressed him.

## Masculinity

Changes in the realms of sexual intimacy, interactions with women, and everyday musings were perceived as undermining men's masculine identities. The inability to connect with women sexually as well as the knowledge that they had lost their sexual capabilities led men to feel as if they had lost their manhood, making statements such as, "You lose that feeling that you are a whole man." One gentleman felt that his loss of sexual function led to a profound change in self worth.

It's a small, but it's a self-definitional thing...You might be on the auction block, but when somebody looked you over, they wouldn't want, they wouldn't pay anything for you.

In response, a second participant reinforced this notion that an ability to project self-confidence depended

on an underlying sexual capability; impairment in one disabled the other.

I think probably for a good bit of your life you're either defined by your feelings about your sexuality or it gets defined for you by the popular culture. And I know what he's saying. I mean something might happen, someone might say "I'm interested in you," and you couldn't pull it off, you know?...And I think, you know, this is our manhood we're talking about, you know? And it can be pretty hard to deal with it, but I think that's been a big thing for me and I think probably other people have experienced it.

In other words, the feelings that one might not be able to "pull it off," led men not only to doubt their sexual ability, but also provoked questions about their manhood. Thus, both the fear of embarrassment and the changes in the ways in which men imagined their interactions with a potential partner led them to question their own identity as a man in the same ways in which they had defined themselves prior to having erectile problems. Sexuality is seen here as a substantial part of what defines an individual as a 'man,' and men who had lost sexual function were finding themselves challenged to redefine themselves as masculine in our society.

#### **DISCUSSION**

The substantial incidence of erectile dysfunction in men treated for early prostate cancer is well described, as is its pathophysiology, but the impact of erectile dysfunction on men's lives has been less well explored. 6 We have begun to characterize the manifold effects of erectile dysfunction on men's experiences of intimacy with their partners, their relationships with women in social situations, and their self images as sexual beings. The men with whom we talked emphasized the breadth of their sexual lives, while scarcely mentioning the mechanics of erectile dysfunction. Thus, for these men the significance of this complication resided in its psychosocial implications, reaching far beyond the actual ability to have erections and well into the realm of social relationships and sexual self-concept. Difficulty engaging with a partner sexually was part of a broad set of problems concerning their sexuality that also included interactions with women, their fantasy life, and the ways in which they saw themselves as men.

Clearly our findings are limited. They are based on seven focus groups with 48 men. By selecting men 12 to 24 months post treatment, we were able to learn much about how men perceived the long-term side effects of prostate cancer treatment as they were encountering them. Our findings might have been different had we interviewed men a few years further out from treatment, at which time erectile problems might have had different implications for men, particularly for those who might have been facing indications of cancer recurrence. Nonetheless, our findings highlight important issues that have received scant attention in previous research on the outcomes of treatment for prostate cancer. Previous studies have found that sexual

dysfunction is a substantial problem, but have not described the nature of the problems men experience in a precise or meaningful way. Asking whether or not erectile dysfunction is a problem for men may be inadequate to appreciate the extensive impact on men's sexuality and sense of self and may in fact close off the opportunity for further discussion of the issue. In the focus groups, men did not identify erectile dysfunction as a problem that could be fixed. Rather they saw it as a new change in their lives that implied a shift in the ways in which they thought of themselves and in their interactions with others.

The focus group format provided men with an opportunity to discuss their common experiences, ask one another questions, and build on one another's comments, rather than solely responding to questions from a researcher. Although these are not easy issues to discuss, we found men in focus groups quite willing to talk, apparently facilitated by shared experiences and the knowledge that they were not alone. While some may have welcomed the forum and felt emboldened to share problems, the group discussion may have inhibited some disclosures because of fear of embarrassment in front of unfamiliar men, and this may limit our findings. Nonetheless, much was disclosed and multiple layers of meaning of sexual dysfunction articulated when men were given an opportunity to talk about these matters. Thus, as men spoke about their sexuality and expressed issues that are not often easily disclosed, the meanings they ascribed to their erectile problems were elucidated.

Focus groups are not designed to estimate prevalence or identify sources of variation in quality of life. Our findings suggest ways in which the assessment of qualityof-life outcomes in patient surveys might be improved, with more finely grained measures of the psychosocial impacts of treatment-related erectile dysfunction. They also suggest ways to ask about erectile dysfunction in connection with health-related quality of life. The men with whom we spoke described complex problems, but they did not think of erectile dysfunction as a health issue. Thus, erectile dysfunction may not be correlated with measure of disease and illness-related quality of life. For example, Litwin and his colleagues<sup>6</sup> reported that men find their erectile problems "bothersome," and that the emotional impact of erectile problems is significant. They also reported modest correlations between the severity of sexual dysfunction and scales of the SF-36. Our findings further elucidate the nature of the bother experienced by men and the extent to which they are affected by sexual dysfunction in their everyday lives. They also suggest that men may be experiencing substantial problems with sexuality, while reporting to their doctor that their "health" or their overall quality of life is good. Moreover, these problems may coexist with feelings of satisfaction with their decisions to pursue treatment to control their cancer and thus ensure their continued good health.

Thus, our findings should prove to be useful to physicians who wish to both advise men who must cope

with a diagnosis of prostate cancer and choose a course of treatment, and to help men who are living with the physical consequences of treatment. We have highlighted some of the issues that men confront when encountering erectile dysfunction, issues that impact upon the quality of their lives. As clinicians begin to appreciate the broad ways in which men assign meaning to erectile dysfunction in their social lives as well as in the context of intimacy, they may find new ways of helping men. As Litwin<sup>6</sup> argues, sexual performance is not the same as the emotional impact of erectile dysfunction; men do not equate the rigidity of their erections with the quality of their sexual lives. We know that patients seek the guidance of physicians in regard to what one can discuss and disclose in clinical interactions.<sup>21</sup> Hence, when physicians ask men solely about erectile function they may in effect foreclose further discussion of the impact of sexual problems on men's lives. Noted discrepancies between physicians' and patients' recollections of discussions about treatment options and side effects, particularly erectile dysfunction, 22 may reflect the limited attention given to this sensitive issue.

Our findings provide some guidelines as to how physicians may open up the discussion to address the extensive emotional impact of erectile dysfunction on men's lives, both when helping patients make treatment choices and when caring for men long after treatment has taken place. Physicians may need to extend the conversations beyond statements of possibilities of erectile problems to more in-depth discussions of the far-reaching impacts we have described. For some men, erectile functioning may already be compromised prior to treatment.<sup>23</sup> Thus, an assessment of men's functioning and the value they place on sexual functioning may be beneficial to helping men make truly informed decisions. By opening up the conversation, asking men about how active their sexual lives are, if they have a sexual partner or have an interest in pursuing a sexual relationship, and how important sexuality is to them, physicians may be able to better counsel men on how to think about their treatment options. Physicians will not be able to make the decision for men; however, raising issues such as men's sense of masculinity, their fantasy life, and the potential loss of sexual response on a daily basis may allow patients to more carefully reflect on the potential impact of erectile dysfunction on their lives.

Moreover, as many men opt for treatment that does render them impotent, primary care physicians are ideally positioned to help manage the consequences. Even though some of these men may not regret their decision for aggressive treatment, they may experience extensive psychosocial and emotional responses to finding new ways of being sexual. Since sexuality remains an important aspect of men's lives, men with erectile dysfunction may find themselves re-evaluating their sexuality, possibly discovering themselves to be on new footing with respect to the women in their lives. While the cancer itself may precipitate a re-evaluation of men's lives, <sup>24,25</sup> erectile dysfunction may

further challenge men's identities. Erectile dysfunction may precipitate an "identity dilemma" for men<sup>24</sup>—changes in how men see themselves as sexual beings and as men in our society.

Physicians, subsequently, need to appreciate the increasingly complex psychosocial issues that men attribute to their erectile dysfunction. In counseling men, physicians may need to probe beyond the mechanics of erectile function, and ask questions about men's feelings about their sexual lives and relationships. Prescribing interventions such as transurethral alprostadil or sildenafil may have broad-reaching implications for men, because they may find the use of assistance to be unnatural. These are not easy issues to discuss, and the clinical interaction often does not lend itself to extended discussions of such sensitive topics. Nonetheless, addressing concerns about sexuality issues in counseling men with new diagnoses is becoming increasingly important<sup>26</sup> as men continue to have active sex lives well into their later years. Although men are often reticent, as evidenced by the extensive discussions in our focus groups men may reveal much about their sexual dysfunction if given the opportunity to talk about these matters. Physicians thus need to be candid about both the physical and the psychosocial aspects of erectile dysfunction as they advise men about treatment choices and as they work with men seeking new ways of adjusting to these changes in their lives. When men reveal that they no longer can get a 'hard-on,' it is up to physicians to create an opportunity for men to discuss the impact of this upon their lives.

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#### **REFERENCES**

- Walsh PC, Epstein LI, Lowe FC. Potency following radical prostatectomy with wide unilateral excision of the neurovascular bundle. J Urol. 1987:138:823-7.
- Talcott JA, Rieker P, Clark JA, et al. Patient-reported symptoms after primary therapy for early prostate cancer: results of a prospective cohort study. J Clin Oncol. 1998;16:275–83.
- 3. Smith D, et al. Quality-of-life outcomes for men with prostate carcinoma detected by screening. Cancer. 2000;88:1454–63.
- Stanford J, et al. Urinary and sexual funcion after radical prostatectomy for clinically localized prostate cancer. JAMA. 2000;283:354–60.
- Clark JA, Rieker P, Propert KJ, Talcott JA. Changes in quality of life following treatment for early prostate cancer. Urology. 1999;53(1):161–8.
- Litwin MS, Nied RJ, Dhanani N. Health-related quality of life in men with erectile dysfunction. J Gen Intern Med. 1998;13(3):159–66.

- Helgason AR, Fredrikson M, Adolfsson J, Steineck G. Decreased sexual capacity after external radiation therapy for prostate cancer impairs quality of life. Int J Radiat Oncol Biol Phys. 1995;32(1): 33–9.
- 8. Helgason AR, Adolfsson J, Dickman P, Fredrikson M, Arver S, Steineck G. Waning sexual function—the most important disease-specific distress for patients with prostate cancer. Br J Cancer. 1996;73(11):1417–21.
- Roach M III, Chinn DM, Holland J, Clarke M. A pilot survey of sexual function and quality of life following 3D conformal radiotherapy for clinically localized prostate cancer. Int J Radiat Oncol Biol Phys. 1996;35(5):869-74.
- Helgason AR, Arver S, Adolfsson J, Dickman P, Granath F, Steineck G. 'Potency': the validation of information from a selfadministered questionnaire using objective measurements of night-time erections and test-retest reliability. Br J Urol. 1998;81(1):135-41.
- 11. Perez MA, Meyerowitz BE, Lieskovsky G, Skinner DG, Reynolds B, Skinner EC. Quality of life and sexuality following radical prostatectomy in patients with prostate cancer who use or do not use erectile aids. Urology. 1997;50(5):740–6.
- 12. Miles BJ, Giesler B, Kattan MW. Recall and attitudes in patients with prostate cancer. Urology. 1999;53(1):169–74.
- Talcott JA, Rieker P, Propert KJ, et al. Patient-reported impotence and incontinence after nerve-sparing radical prostatectomy. [see comments]. J Natl Cancer Inst. 1997;89(15):1117–23.
- 14. Wei JT, Dunn RL, Litwin MS, Sandler HM, Sanda MG. Development and validation of the expanded prostate cancer index composite (EPIC) for comprehensive assessment of health-related quality of life in men with prostate cancer. Urology. 2000;56: 899–905.
- 15. Marsiglio W, Donnelly D. Sexual relations in later life: a national study of married persons. J Gerontol. 1991;46(6):338S–344S.
- Marsiglio W, Greer RA. A gender analysis of older men's sexuality: social, psychological and biological dimensions. In: Thompson EH, ed. Older Men's Lives. Thousand Oaks, Calif: Sage Publications; 1994:122–40.
- Feldman HA, Goldstein I, Hatzichristou DG, Krane RJ, McKinlay JB. Impotence and its medical and psychosocial correlates: results of the Massachusetts Male Aging Study. J Urol. 1994;151(1): 54–61.
- Schiavi RC, Mandeli J, Schreiner-Engel P. Sexual satisfaction in healthy aging men. J Sex Marital Ther. 1994;20(1):3–13.
- Talcott J, Rieker P, Propert K, Clark J, Kantoff P. Long-term complications of treatment for early prostate cancer: 2-year followup in a prospective, multi-institutional outcomes study. Proc Am Soc Clin Oncol. 1996;5:252.
- Glaser BG, Strauss AL. The Discovery of Grounded Theory; Strategies for Qualitative Research. Observations. Chicago: Aldine Pub. Co; 1967.
- Mishler EG, Clark JA, Ingelfinger J, Simon MP. The language of attentive patient care: a comparison of two medical interviews. J Gen Intern Med. 1989;4(4):325–35.
- 22. Crawford ED, Bennett CL, Stone NN, et al. Comparison of perspectives on prostate cancer: analyses of survey data. Urology. 1997;50(3):366–72.
- Zinreich ES, Derogatis LR, Herpst J, Auvil G, Piantadosi S, Order SE. Pretreatment evaluation of sexual function in patients with adenocarcinoma of the prostate. Int J Radiat Oncol Biol Phys. 1990;19(4):1001–4.
- 24. Charmaz K. Identity dilemmas of chronically ill men. In: Sabo DF, Gordon D, Men's Studies Association (U.S.), eds. Men's Health and Illness: Gender, Power, and the Body. Thousand Oaks, Calif: Sage Publications; 1995:266–89.
- Frank AW. The Wounded Storyteller: Body, Illness, and Ethics. Chicago, Ill: University of Chicago Press; 1995.
- Montie JE. Counseling the patient with localized prostate cancer. Urology. 1994;43(2 Suppl):36–40.