

# Sexual Side Effects and Prostate Cancer Treatment Decisions

## *Patient Information Needs and Preferences*

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**Abstract:** Prostate cancer treatment decision making requires complex trade-offs among treatment outcomes, and sexual function is a central consideration for most men. Although sexual function is included in prostate cancer decision models, survival and fear of recurrence and cancer progression weigh more heavily in these decisions for many men than concerns about treatment impact on sexuality. In this article, we discuss the importance of sexuality in men's treatment decisions for prostate cancer. We focus on men's preferences for maintaining sexual function and their needs for information about the risk of sexual side effects with prostate cancer treatment. Our review suggests that among men diagnosed with prostate cancer sexual function is less important to men than concerns about survival, but is more highly valued than other side effects and treatment characteristics. However, there is evidence that concerns about sexuality are not in proportion with the associated risk for sexual problems with prostate cancer treatment and men acknowledge unmet needs for information about sexuality in making prostate cancer treatment decisions.

**Key Words:** prostate, cancer treatment, sexual side effects

(*Cancer J* 2009;15: 41–44)

Each year in the United States, several hundred thousand men are diagnosed with prostate cancer and asked what they would prefer: To possibly give up some degree of sexual function? To probably experience some level of urinary incontinence? To live with cancer without treatment? Treatment options differ in side effects, but for most men no alternative is clearly advantageous in prolonging survival. The choice of management strategy involves complex trade-offs that represent difficult decisions for men, their significant others, and their clinicians.<sup>1,2</sup> The common primary treatments (ie, radical prostatectomy, external beam radiation therapy, brachytherapy) have associated side effects including sexual dysfunction, urinary incontinence, and bowel problems.<sup>3,4</sup> Anxiety about cancer progression and recurrence is frequently a concern in the trade-off along with side effects.<sup>5–7</sup> Among all the considerations that patients weigh in making prostate cancer treatment decisions, concern about sexual function is central in the choice of treatment for localized prostate cancer.<sup>8,9</sup>

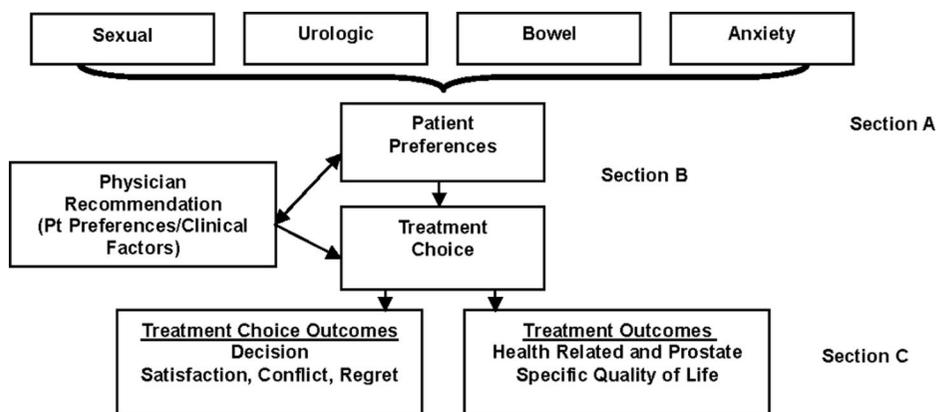
It is clear that patients would like to have their goals and values related to their sexuality considered in prostate cancer treatment decision making.<sup>10,11</sup> Typically, models of prostate cancer

decision making include sexual function, urinary function, bowel function, and anxiety about survival as the important preferences for prostate cancer treatment decision making.<sup>12,13</sup> Most conceptual models of prostate cancer treatment decisions place sexual function centrally as a concern of most patients. As shown in Figure 1, these models assume that the choice of treatment for prostate cancer can only be judged in reference to the patient's goals and values for treatment. The patient's goals and values for treatment are defined as the patient's treatment-related preferences that are associated with attributes of treatment outcomes (eg, disease-free time, survival), treatment-related side effects (eg, urinary incontinence, sexual dysfunction), and other qualities of the treatment itself (eg, invasiveness of the procedure, recovery time). The figure shows the influence of these domains of concerns or preferences (ie, sexual function, urinary function, bowel function, anxiety) on the choice of treatment in Section A. In addition to these domains of patient preferences, the physician recommendation, based on the physician's understanding of patient preferences and clinical factors, such as the patient's age and comorbid conditions, has a reciprocal relationship with patient preferences (Section B). We assume that ultimately both the patient's preferences and the physician's recommendation influence treatment choice. The treatment choice, in turn, contributes to both treatment choice outcomes such as satisfaction or regret with the decision and treatment outcomes such as quality of life (Section C).

Although sexual function is widely thought to be important in prostate cancer treatment decisions, the physician alone is not the best judge of how a man may value sexuality in making this choice. Studies of patients and urologists have found that treatment priorities differ across these groups. For example, both patients and urologists identified treatment effectiveness as the most important treatment goal, but patients noted quality of life issues such as sexual function (45%) as the top concern in selecting treatment in contrast to urologists who noted treatment efficacy.<sup>14</sup> Physician characteristics, such as specialty, have also been shown to influence their perspectives on prostate cancer treatment recommendations.<sup>15</sup> Physician judgments of their own patients' preferences do not correspond to patient judgments of their own preferences when assessed either by utilities or rank order elicitation methods.<sup>16–19</sup> There is little correlation between patient-rated utilities and physician ratings when utilities are elicited by a time trade-off (TTO) method and the physicians were asked to complete the TTO as they thought their patients would. When patients and physicians were asked to rank order attributes associated with prostate cancer treatment (ie, sexual function, bowel and bladder problems) in terms of their importance to the patient there was little relationship between patient and physician ratings. This relationship did not increase even when patients perceived that their physicians had actively solicited their preferences.<sup>16–19</sup> Therefore, to understand how a patient's concern about sexuality is weighed with other potential treatment outcomes, such as survival and urinary function, it is necessary to ask the patient directly.

Thus, to know how to support men in making prostate cancer treatment decisions, it is critical to understand men's need for

Received for publication November 19, 2008; accepted December 3, 2008.  
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ISSN: 1528-9117/09/1501-0041



**FIGURE 1.** Conceptual framework for understanding patient preferences and outcomes. Section A depicts the contribution of attribute domains to patient preferences. Sexual function is included in most models of prostate cancer treatment decisions. Section B shows the relationship between patient preferences and treatment choice, and the effect of physician recommendation on preferences and choice. Section C illustrates several potential outcomes associated with treatment choice.

information about sexuality and prostate cancer and men’s preferences for maintaining sexual function as compared with other aspects of well-being, such as urinary function and anxiety. In this article, we discuss the research findings on the need for information about sexuality among men making prostate cancer treatment decisions and the value that men place on sexual function in their choices of treatment for prostate cancer. We examine the potential for current decision aids to inform patients and clarify values, and we point to directions for future research.

### INFORMATION NEEDS AND SEXUALITY

Although a man’s goals and values are critical considerations in prostate cancer treatment, men need information about the treatments and their expected outcomes to fully understand or predict their own preferences. For example, information about how several treatments influence erectile dysfunction or sexual desire would be expected to influence a man’s preferences with respect to those treatments. A number of studies have identified information needs among men diagnosed with prostate cancer and suggest that information on sexual function is important in prostate cancer treatment decisions. However, the relative importance of information on sexuality varies considerably, compared with information on urinary function and survival.<sup>20</sup>

Feldman-Stewart et al<sup>21</sup> identified a wide range of information needs among men recently diagnosed with prostate cancer (6–12 months). Among the many questions that men raised, those concerning sexuality that were evaluated as essential to address in making prostate cancer treatment decisions were options to manage impotence (61%) and the impact of treatment on sexual function (55%). In contrast, questions about survival, cure, recurrence, and spread of prostate cancer were rated as essential to address before making a treatment decision by 80% or more of the sample. Questions about loss of bladder control were rated as essential to address by 74% of the sample.

Other studies suggest that information on sexuality is an unmet need among men diagnosed with prostate cancer. For example, in a study of 500 men diagnosed with localized prostate cancer in the United States, the 3 most frequently endorsed support needs were related to the impact of prostate cancer and its treatment on sexual activity or sexuality (ie, support/counseling on when/how to return to sexual activity, support in dealing with your loss of interest in sex, support in dealing with the cancer’s impact on your sex life, support in dealing with feelings of “loss of manhood”).<sup>22</sup> In a qualitative study of informational needs among men treated for prostate cancer, Maliski et al<sup>23</sup> similarly found that men were not prepared for sexual side effects such as penile numbness, perineal soreness, and dry ejaculation.

### THE VALUE OF SEXUALITY IN PROSTATE CANCER TREATMENT DECISIONS

Compared with the literature on information needs, a more extensive body of empirical work exists that has examined the relative value of sexual function compared with other preferences that influence the choice of prostate cancer treatment. Conventional measures of preferences yield utilities, numbers that range from 0.0 to 1.0 where a health state of 1 is equivalent to perfect health and those near 0.0 represent states near death. Utilities provide a means to compare preferences across health states (eg, sexual function, urinary function) and people. Most studies that have measured utilities using methods such as the standard gamble (SG), time trade off (TTO), and visual analog scale have found that both sexual functioning and urinary functioning are valued highly. Albertsen et al<sup>24</sup> studied 50 men diagnosed with prostate cancer and, using TTO, found utilities of 0.91 for current health, 0.898 for sexual function, 0.892 for urinary function, and 0.978 for bowel function. Another study of men diagnosed with prostate cancer obtained utilities of 0.91 for current health, 0.95 for sexual function, 0.98 for urinary function, and 0.99 for bowel function.<sup>25</sup> Other findings are similar for men diagnosed with prostate cancer.

In contrast to studies of men diagnosed with prostate cancer, both men who have not been diagnosed with prostate cancer and men diagnosed with prostate cancer and asked to predict utilities for future health states provide markedly lower utilities.<sup>25,26</sup> Utilities of 0.71 for sexual function and 0.62 for urinary function have been found for men seen in primary care clinics with no history of prostate cancer.<sup>26</sup> In a study using SG to elicit utilities in a sample of older men 52% of whom had been previously diagnosed with prostate cancer, impotence (0.89) was evaluated as better than urinary difficulty (0.88), urinary incontinence (0.83), and bowel problems (0.71).<sup>27</sup> Despite the relative importance of sexual function in prostate cancer treatment decision, concern about survival and removal of the prostate cancer is an important driving factor in decisions to seek active treatment and this seems to outweigh concerns about sexual function.<sup>28</sup>

Thus, whether or not men are diagnosed with prostate cancer influences how they value sexual functioning compared with other side effects associated with prostate cancer treatment. Studies of which men value what prostate cancer outcomes more highly than others suggest that some predictors influence utilities across all domains, including the domain of sexual function. For example, men diagnosed with prostate cancer who are generally healthy have higher utility for quantity of life as compared with men who are less healthy who value quality of life concerns such as sexual function.<sup>25</sup> In another study, older men, compared with younger, showed a greater concern about maintaining quality of life domains relative to

living longer.<sup>15</sup> However, Smith et al<sup>29</sup> have reported that age, race, and comorbid conditions did not predict utilities in their study of 209 men who had surgical treatment for prostate cancer.

While general health seems to be related to utilities for sexual function and other potential side effects associated with prostate cancer treatment, a related question is whether current sexual function influences how sexual function is valued. In a study of predictors of prostate cancer utilities, Saigal et al<sup>25</sup> found little relationship between sexual functioning and the utility of maintaining sexual function. In contrast, other studies have showed a relationship between sexual behavior and utilities for sexual function. Men who reported more frequent sexual activity had lower utilities for living with erectile dysfunction than did those reporting less activity.<sup>15</sup> Similarly, Smith et al found a relationship between sexual function and how men value sexuality. In this study, those with increased urinary and sexual bother and those with only sexual bother were willing to give up more life years to obtain perfect sexual function than those reporting less current burden due to sexual side effects.<sup>29</sup>

Qualitative research, as compared with utilities, provides a more nuanced view of the importance of sexuality in prostate cancer treatment choices. A study of prostate cancer narratives in men who had undergone definitive treatment for prostate cancer identified 4 domains of sexuality—sexual intimacy, interactions with women, sexual fantasy, and perceptions of masculinity—that are profoundly impacted by prostate cancer treatment.<sup>8</sup> These impacts on sexuality are broad and it is not clear that they are well articulated to men during the treatment decision-making process. Rather than guided by careful assessment of the risks of side effects such as sexual dysfunction, another study found that men's preferences relevant to prostate cancer treatment options were based on initial uninformed assumptions and fear about prostate cancer.<sup>6</sup> These fears motivated rapid treatment with post-treatment sexual side effects justified by earlier misunderstandings about treatment benefits and harms. Diefenbach et al reported similar findings in a quantitative study of beliefs and perceptions in 654 men diagnosed with localized prostate cancer. Those seeking surgical treatment were more likely than men selecting radiation therapy to see prostate cancer as serious and as likely to spread.<sup>30</sup>

It should be noted that the studies reviewed for the most part have investigated localized disease. Adjuvant treatment for localized prostate cancer and treatments for locally advanced and advanced disease often involve the addition of hormone therapies. These involve sexual side effects such as reduced sexual interest and desire that have not been evaluated extensively in studies of patient preferences for prostate cancer treatment outcomes. Similarly, little is known about how other hormone therapy side effects such as gynecomastia and hot flashes influence sexual function and how these outcomes are valued in the treatment decision-making trade-offs.

## DECISION AIDS AND SEXUALITY IN PROSTATE CANCER TREATMENT CHOICES

Based on the evidence of unmet educational needs among men making prostate cancer treatment decisions, a variety of decision aids have been developed and disseminated to provide information on prostate cancer, its treatments, treatment outcomes, and the risks and benefits of the options available to manage prostate cancer.<sup>31–34</sup> The standards for the development of decision aids advocate that an assessment of patient values related to treatment outcomes be included in the decision aid, either through a formal preferences assessment or a task used to clarify patient values.<sup>35,36</sup> Several decision aids have been developed for prostate cancer treatment decisions and include information on the impact of prostate cancer treatment on sexuality.<sup>2,18,32,34,37–39</sup>

In a 2004 review of materials used for decision making in early-stage prostate cancer, Fagerlin et al<sup>40</sup> identified 44 sets of

patient education materials publicly available in print, video, electronic media, and Web-based formats. These materials include descriptions of the sexual side effects expected to occur with common treatments for prostate cancer. Information on sexual side effects were included in 84% of the materials for radical prostatectomy, 81% for radiation therapy, and 72% for hormone therapy. These rates are similar to that for the inclusion of information on urinary function. Few of the materials distinguished the temporary and permanent sexual side effects (34% for radical prostatectomy, 30% for radiation therapy, and 7% for hormone therapy). None of the materials included ways to help patients understand their preferences or values related to sexual function and other outcomes. Because of the absence of preference assessment and values clarification methods, these investigators concluded that these materials could not be considered as decision aids.

## CONCLUSIONS

The results of studies of the relative value of maintaining sexual function compared with prolonging life and avoiding other side effects are mixed, but several limited conclusions may be drawn from this work. First, sexual function seems to be an important consideration for men making prostate cancer treatment decisions. It is clear that men value maintaining sexual function at levels similar to how they value maintaining urinary function. For many men, survival seems to be the most highly valued factor influencing prostate cancer treatment decisions. Thus, although sexual problems are important to men in prostate cancer treatment decisions, and sexual difficulties impact the lives of men deeply when they occur, fears about cancer survival, recurrence, and progression can overshadow considerations related to sexuality out of proportion of the actual risk.<sup>41</sup> Inadequate understanding of the risk of sexual problems or a man's lack of insight into the importance of sexual functioning in his life can contribute to poorly informed decisions about prostate cancer treatment.<sup>42</sup> Unfortunately, regret about prostate cancer treatment is not rare and has been related to post-treatment concern about sexual function.<sup>4,43</sup> Second, despite inconsistencies in findings on the predictors of utilities for sexual function, several findings stand out including the influence of general health and current sexual function on how important men feel it is to maintain sexual function after prostate cancer treatment. Men in good general health and those experiencing increased sexual bother due to prostate cancer treatment place a higher value on maintaining sexual function.

It is important to note that a limitation of studies of patient preferences is the incomplete conceptualization of sexuality as a value. For many persons, sexuality is a highly personal and nuanced experience. As a biopsychosocial construct, sexuality is complex and multifaceted. It encompasses a variety of constructs including, but not limited to, self-concepts, attitudes, preferences, desires, behaviors, activities, relationships, and functions. In contrast to the construct of sexuality, most measures of patient preferences for sexual function are one-dimensional and therefore limited in their ability to assess preferences. A related measurement issue is that most utilities elicitation approaches ask about impotence, erectile function, or sexual function. Treatments can be disruptive to a variety of sexual functions (eg, erectile, ejaculatory), to sexual desire and interest, and to sexual relationships. It is difficult to know what research participants are thinking about when they answer questions about trade-offs concerning sexual function. Like measures of preferences for sexual function, existing decision aids are limited in terms of the presentation of sexual side effects. Some content is covered by most educational programs, but this does not distinguish among the variations of sexual experience that are impacted by prostate cancer treatment. Qualitative studies suggest that consideration of sexuality as a complex construct may provide important

insights about how men's concerns about sexuality influence the choices that are made in prostate cancer treatment. Decision aids have yet to incorporate the more nuanced information on sexuality suggested by studies of men's narratives.

In conclusion, for many men, next to survival, sexuality is one of the most important considerations in prostate cancer treatment decision making. It is clear that men value sexuality as highly as urinary control, and these concerns are more important than many other side effects and treatment characteristics that influence the final choice of management strategy. However, there are unmet needs for information about sexuality among men diagnosed with prostate cancer, and this is particularly concerning because of the potential for regret about the decision. Additional research is needed to better understand how to educate men about prostate cancer and its treatments, so that men are able to make informed decisions that fully incorporate their values about sexuality as a multidimensional experience.

### ACKNOWLEDGMENTS

S.J.K. is supported by a Veterans Administration (VA) Health Services Research and Development award (IIR02-142-1) and her work on this article was supported by the resources and facilities of the interdisciplinary Program to Improve Care for Veterans with Complex Comorbid Conditions at the San Francisco VA Medical Center.

This material is partly the result of work supported with resources and the use of facilities at the Health Services Research & Development Center of Excellence (HFP90-020), Michael E. DeBakey Veterans Affairs Medical Center. D.M.L. is supported by Mentored Research Scholar Grant 06-083-01-CPPB from the American Cancer Society.

The contents of this work are solely the responsibility of the author and do not necessarily represent the official views of the Department of Veterans Affairs.

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