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Disclosure of Diagnosis and Treatment Among Early Stage Prostate Cancer Survivors

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Abstract

Objective—Increased long-term survival rates have led to a greater focus on the health-related quality of life (HRQL) of prostate cancer survivors. This study assessed the motivations of prostate cancer survivors for disclosing their diagnosis and treatment to close others, and their perceptions of their own and others' responses to the disclosure.

Methods—Prostate cancer survivors (N = 35) who were 24–36 months post-treatment for localized disease completed a semi-structured telephone interview. Open-ended questions concerning disclosure of men's diagnosis and treatment and their perceptions of their own and others' reactions to the disclosure were included.

Results—Regarding men's motivations for disclosing their diagnosis and treatment, men reported that they were seeking social support (SS) and that others had a 'right to know.' Further, the receipt of emotional support and feeling a sense of positive emotions were common following disclosure about their diagnosis and treatment. Participants reported continuing to discuss their treatment side effects 2–3 years post-treatment.

Conclusion—Prostate cancer survivors reported an overall positive and supportive response following the disclosure of their diagnosis and treatment. Further examination of the relationship between SS and HRQL will be necessary to identify interventions to enhance the well-being of this growing population of survivors.

Practice Implications—Providers need to be aware of the extent and long-term nature of the side effects following treatment for prostate cancer. If providers encourage men to talk about their diagnosis, treatment, and side effects, providers may better understand men's experience with the disease, and men may be more likely to accept these commonly experienced changes, as well as seek treatment for them. These efforts may result in improved quality of life for survivors of prostate cancer

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(1) "I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story"

Keywords

Prostate cancer; Social Support; Health-related quality of life; Long-term side effects

1. Introduction

Prostate cancer (PCa) is the most frequently diagnosed non-cutaneous cancer among men in the United States, with an estimated 192,280 new cases expected in 2009 [1]. The majority of men are diagnosed with early stage disease, and five year survival rates for men with early stage disease approach 100% [1]. As a result, there are a substantial number of prostate cancer survivors who live for many years following their diagnosis and treatment.

There are a number of different treatments for early stage disease, including radical prostatectomy (RP), external beam radiation (EBR), brachytherapy, hormone therapy, a combination of these treatments, and watchful waiting. Each of the active treatments is associated with side effects, the most common of which include urinary, bowel and sexual dysfunction [2–4]. Given the very high survival rates associated with early-stage disease and the studies indicating that many men will experience long-term side effects, it is important to examine the health-related quality of life (HRQL) of these survivors [5,6]. These long-term side effects can be associated with negative psychological outcomes as men contend with the changes to their usual functioning [7,8].

1.1 Social Support and Prostate Cancer

Social support (SS) plays an important role in adjustment to cancer [9,10] and has been linked to better health outcomes [11–14]. SS has been described as a sense of belonging to a social network (i.e., one's family and friends), the giving and receiving of information, acts of affection, and provision of assistance [15–17]. SS is commonly classified into broad categories including: 1) Emotional support (provision of comfort and things done to make an individual feel appreciated and loved), and 2) Tangible support (giving and receiving information, advice and physical assistance) [18]. Importantly, SS has been positively associated with psychological well-being and may lower the risk for distress among PCa survivors [19,20].

Disclosing diagnosis and treatment information to members of one's social network may help prostate cancer survivors cope by influencing their perceptions of their condition, encouraging them to engage in more health promoting behaviors and by facilitating interactions with others [18,20–24]. Further, sharing information may help men accept the commonly experienced changes caused by treatment, including urinary, bowel and sexual dysfunction, thereby improving their quality of life.

1.2. Health-Related Quality of Life and Prostate Cancer

General HRQL has been defined as the extent to which one's physical, social/family, functional and emotional well-being are affected by a medical condition or associated treatment [25,26]. Several studies of general HRQL among PCa survivors have demonstrated the negative impact following diagnosis and treatment [6], but also a significant improvement within one year of treatment [27–29]. Prostate cancer-specific HRQL, defined as urinary, bowel, and sexual functioning and the bother caused by a change in function, is immediately adversely affected after treatment [5,27,28,30] and can persist for several years [2,5,6,27,30]. Longitudinal data from the Prostate Cancer Outcomes Study (PCOS) show that, depending on the treatment, some men experienced a high level of distress due to urinary, bowel, and sexual dysfunction [5,6].

Several qualitative studies have assessed men's HRQL following treatment for PCa [31,32], the HRQL of survivors and their spouses [33,34], the experience of the health care system [35], and the physical versus psychosocial aspects of HRQL [24]. Identified themes have included management of side effects, coping with changes in sexual functioning, and preventing the illness from interfering with everyday life. Interestingly, Korfage and colleagues [8] found that although men reported urinary, bowel and sexual dysfunction due to treatment, they did not consider these issues when reporting their *general* HRQL. Rather, the side effects were viewed as unavoidable consequences of treatment that men must learn to accept. The researchers suggested that being diagnosed and treated for a potentially life-threatening disease may have resulted in a change in men's definition of health [36].

In summary, both quantitative and qualitative studies have demonstrated the negative impact of PCa treatments, particularly on disease-specific HRQL. General HRQL may be positively influenced by psychological and social processes that unfold over time as men adjust to the changes caused by their diagnosis and treatment [22]. Enhancing SS may be one way to assist PCa survivors in their efforts to cope with the resulting changes that negatively impact their psychosocial and physical well being. There is little empirical work that has investigated why PCa survivors disclose or do not disclose their diagnosis and treatment to family and friends, and how they feel other people may respond to them. In addition, few studies have explored the role of SS in the context of PCa survivors. To address these gaps in the literature, we conducted a semi-structured interview with open-ended questions concerning PCa survivors' motivations for disclosure of their diagnosis and treatment to family and friends. We also asked men how they and others responded to this disclosure. By assessing men's long-term perspective of this period surrounding their diagnosis and treatment, we expected to gain information regarding the types of assistance men may benefit from most during this difficult period.

2. Methods

2.1. Overview

Participants in the current study were a convenience sample who had previously participated in a pilot intervention study that evaluated an automated, telephone-based, symptom monitoring system for PCa survivors. They had participated in the prior study when they were 12–18 months post-treatment for early stage PCa [37], and were 24–36 months post-treatment in the current study. Participants were accrued from the urology departments at Georgetown University Medical Center (GUMC) and at the Washington Hospital Center (WHC).

2.2. Sample

Of the 44 eligible participants from the pilot study, 4 (9.1%) declined due to unrelated health complications and lack of interest, 5 (11.4%) could not be reached by telephone or mail, leaving 35 (79.6%) who agreed to participate and completed the interview.

2.3. Procedures

Approval for this study was obtained from the Institutional Review Board of Georgetown University Medical Center (GUMC). An invitation letter was mailed and men were subsequently called to determine their interest in participating. After providing verbal consent, participants completed the 20–30 minute telephone interview utilizing a semi-structured questionnaire. The first author (TPJ) conducted all of the telephone interviews. He was not known to the participants as he had not participated in the original pilot symptom monitoring study. The interviewer recorded men's verbatim responses during each interview and typed the responses immediately following completion of the interview. The

written consent form was mailed to the participants to be signed and returned. Participants received a \$20 gift card to a local grocery store in appreciation for their participation. Men were accrued between December, 2007 and February, 2008.

2.4. Measures

2.4.1. Demographic and Prostate-Related Information—We assessed age, race, marital status, education, employment status, comorbidities, and type of prostate cancer treatment. In addition, we assessed prostate cancer–specific HRQL using the three ‘bother’ questions from the UCLA Prostate Cancer Index [38] for urinary, bowel and sexual function (i.e., How much are you bothered by ...), with a 1–5 response format. Due to the skewed nature of the responses, we dichotomized each item to reflect the percent of men reporting no bother vs. the percent reporting any bother.

2.4.2. Qualitative questions—We developed a series of open-ended questions that covered a range of issues: men’s perceptions of what influenced them to disclose their diagnosis and treatment to others, how people responded to the information, and men’s emotional response to the disclosure. Additionally, we asked what men shared with others about their side effects and whether men continued to share information about their diagnosis and treatment (Table 2). Although the interview included a series of questions, the interview process was flexible. For example, in response to a particular question, men frequently went on to discuss related issues. Often their response incorporated topics that were to be assessed later in the interview, and the interviewer noted the respondent’s answer at that time without repeating the question later.

2.5. Data Analysis

2.5.1. Thematic analysis techniques guided the analysis process [39,40]—Given our relatively small sample size, we did not use an electronic tool for data analysis [41,42]. Rather, we opted to manually analyze the data, which allowed coders to become extremely familiar with the data. The manual process ultimately facilitated the coding by providing the opportunity for coders to discuss all participant responses and the development of important themes [41]. During data analysis, two coders independently identified and coded the participant responses. First, while analyzing the responses, recurring themes were identified and became the basis by which we created a set of coding rules. Next, the two coders organized the themes into distinct categories and subcategories to describe the PCa survivorship experience. After the initial coding of responses, a third coder reviewed the open coding process to settle any disagreements and to help reach consensus. Throughout the coding process, descriptive notes were taken to assist in the recognition of emerging themes. These notes were later discussed among the three coders. From this systematic review and categorization process, two primary themes emerged: the experience of positive emotions and the receipt of social support (see Table 2).

3. Results

3.1. Sample Description

Participants (N = 35) were an average of 65 years old, over one-half were African-American (57%), and the majority were married/in a committed relationship (94%). Most men had undergone RP (75%) for their treatment (Table 1). Regarding treatment side effects, 51.4% reported having at least some urinary bother, 34.3% reported at least some bother related to bowel functioning, and 80% reported at least some bother due to sexual functioning.

3.2. Qualitative Findings

From the series of open-ended questions designed to elicit men's perceptions of their disclosure of their diagnosis and treatment, we have organized the data in chronological order: issues surrounding the decision to disclose the diagnosis and treatment, men's perceptions of others' responses to the disclosure, and men's own feelings after disclosure. The two predominant that emerged were the experience of positive emotions and the receipt of SS, particularly emotional support. Regarding the types of information disclosed at the time of the diagnosis and currently, the disclosure of side effects was the prevailing response. Table 2 presents the identified themes with exemplar responses, and below we have described the responses that emerged most frequently, along with additional examples from the data.

Decisions to disclose the diagnosis and treatment—Men often reported that they shared information about their diagnosis and treatment because of the nature of their relationship with family and friends. That is, men felt that their family and friends, “should”, “had the right to” or “ought to” know about their diagnosis and treatment. Another substantial portion of responses were coded as ‘benefit to oneself.’ Interestingly, the benefit men reported for themselves was both the receipt of emotional support from others and preventing the feeling that they were hiding anything from their loved ones. For example, one man described his disclosure as being due to the nature of his relationships and as a way to seek social support:

“Well my wife and children had a right to know, no reason not to tell them. You look for support and encouragement from them...and even sympathy to some degree. I told my brother because he is my brother. You tell friends who you know well and coworkers on a need to know basis.”

Another man described both his need for emotional support and not wanting to hide the diagnosis from others:

“I really felt that when I found out it was a shock to me. My confidence in my doctor allowed me to speak freely about it. I wanted someone else to know and I didn't want to hide it.”

Others' responses to the disclosure—Men's perceptions of others' responses primarily concerned their emotional and tangible support. For example, one man described receiving both forms of support:

“Everybody was concerned; typically the women expressed concern and sympathy. Men suggest how to deal with it, doctors they know to go and see.”

However, other responses also contained the expression of negative emotions after learning of the diagnosis and/or treatment. For example, one man stated,

“Initially, everyone was concerned whether I would live or die. When you talk about cancer it is frightening to everybody.”

Men's feelings following the disclosure—Regarding the way men felt after they shared their information with others, several different positive emotions were expressed. For example, one man said simply,

“I felt relieved. Definitely. I wouldn't be hiding anything.”

Similarly, many responses indicated reduced worries and/or increased positive emotions after talking about their diagnosis and treatment. However, several men indicated that either

they did not have any worries, or that talking about it did not change their worry. One survivor put it this way:

“It hasn’t affected any worries. I didn’t have any worries at all.”

Men’s disclosure of the side effects of treatment—Responses indicated that men shared mostly about urinary and sexual side effects, which reflects the two most common side effects following RP. However, some men shared about all three of the major side effects. Additionally, men often mentioned to whom they spoke about certain problems. One participant said:

“Just urinary to my best friend and the support group; of course, to my wife she knows about it. I never discussed the bowel side effects to anyone because I never associated it with prostate cancer. I talked about the sexual side effects with my wife and my best friend also.”

Of the men who reported that they were continuing to talk to others about their prostate cancer, the majority of comments concerned side effects and information about appointments and test results. Men also reported talking about it in order to help others, either by encouraging them to seek screening, or to help them cope with the diagnosis and treatment. For example, one man stated,

“In some respects I’m an advocate looking out for men. Somebody tells me when they have pain...you need to check your PSA with your doctor...I refer them to a site, just type in prostate and Google.”

4. Discussion and conclusion

4.1. Discussion

This study described the nature of PCa survivors’ disclosure about their diagnosis and treatment to members of their SS network. We assessed men’s motivations for disclosing their diagnosis and treatment, and men’s perceptions of others’ reactions and their own reactions following their disclosure. The majority of men reported that they told members of their social network about their disease and treatment because they felt it was “the right thing to do” and that their loved ones “deserved to know.” These responses reflected the way that men perceived their relationships. Of the men who stated they were influenced to tell others because of a benefit to themselves, many of the responses indicated that men were seeking emotional support. This was notable, as men appeared to welcome the receipt of emotional support and saw it as something that benefited them. This was further emphasized when men indicated how they felt after the disclosure and the predominant response revealed the experience of ‘positive emotions’ as a result. For example, men indicated that they had a sense of relief and a reduction of worries after they disclosed their experiences. In sum, the predominant responses included the experience of positive emotions and the receipt of SS, particularly emotional support.

Another aspect of men’s perceived benefit to themselves concerned the subcategory, “not wanting to hide anything.” This theme conveyed a desire to be open and to want to communicate about their cancer. Communication may be especially important for the PCa survivor facing problems such as sexual and urinary dysfunction [42,43], as these changes may significantly impact HRQL. Survivor disclosure may reduce distress, as it has proven beneficial for overall health and psychological well-being [21,23]. In this way, SS may improve HRQL for PCa survivors by facilitating coping with some of the immediate and long-term effects associated with treatment.

The narrative responses concerning treatment side effects, as well as the quantitative responses, indicated that side effects continued to be a significant problem 2–3 years following treatment. As is common following radical prostatectomy, sexual and urinary side effects were reported most often. When asked, “What information do you continue to share now,” the most common response concerned side effects, further highlighting the lasting impact of side effects long after the completion of treatment. These results suggest that interventions focused on facilitating men’s adjustment to long-term side effects such as sexual and urinary dysfunction may be useful and well-received by PCa survivors. Such interventions may help survivors accept the commonly experienced side effects as an expected consequence of treatment.

There were several limitations that should be considered in the interpretation of the results. The length of time since treatment (2–3 years) may have limited men’s ability to accurately recall the information they disclosed and others’ reaction to the disclosure. Further, men’s current functioning may have influenced the valence of their recollection. In addition, prior participation in the symptom monitoring intervention suggests that these participants may have been more open to discussing their symptoms, as well as sensitized to treatment side effects. Finally, although the manual recording of verbatim responses may not be viewed as an ideal technique for use during qualitative interviews, we did not find that the brief pauses required for writing disrupted the flow of the interview. The participants were generally motivated to tell their stories, and based on the richness of their responses, did not appear to mind that the interviewer paused to record their responses. Further, as the interviews were conducted by phone, the recording of the responses was less intrusive than if the interviews had been conducted in person. Further, there may have been a slight advantage for some participants who would have been uncomfortable knowing that they were being tape recorded.

This study contains several strengths, primary of which is the rich narrative describing men’s positive perceptions of their and others’ reactions to the disclosure about their diagnosis and treatment. Specifically, this study provided men’s descriptions of the importance of SS as they were coping with the long-term side effects of treatment. Assessing men’s long-term view provided an understanding of the lasting effects from that period of great uncertainty. This research is innovative in its focus on men’s disclosure of their diagnosis and treatment and the relationship between this disclosure, SS, and positive emotions. Encouraging newly diagnosed PCa patients to share this information may serve as an invitation to elicit SS from those close to them. Also, there is little available data that explores why prostate cancer survivors do or don’t disclose their diagnosis and treatment, or of men’s perceptions of this disclosure and how it relates to their own adjustment to the illness and treatment.

4.2. Conclusion

The results indicated that men received SS at the time of their diagnosis and treatment, and that they believe that it had a positive impact on their quality of life. The data also revealed that survivors felt that their SS network should be informed about their condition, and they continued to disclose information about side effects long after the completion of treatment. Receipt of emotional support was endorsed by many men, suggesting that while men may not necessarily ask for support, they appear to benefit from it well into survivorship when they have returned to their lives but are still being negatively impacted. Physicians may also encourage men to disclose their experiences about diagnosis and treatment as a way to potentially improve men’s HRQL. Overall, the results of this study suggest that additional research is needed to further examine the relationship between SS and HRQL in PCa survivors in an effort to improve men’s ability to cope with the long-term side effects that many men experience.

4.3. Practice implications

Given the reported benefits of emotional support and the association with positive adjustment, healthcare providers may be able to enhance survivors' well-being by asking men whether or not they have a support network. For those who do, providers can encourage men to talk to people about their experiences as a way to cope with the experience. For men who do not, providers can encourage men to seek out a support network. Prostate cancer-specific support groups (e.g., Us TOO (<http://ustoo.com/>)) have been beneficial for some men. If providers encourage survivors to talk about their diagnosis, treatment, and side effects with others, men may be more likely to exchange this type of information, which may result in better quality of life for many survivors of PCa.

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Table 1

Sample Characteristics

Demographic Characteristics	
Age (Mean, SD)	64.7 yrs (8.7)
	N
Race	
White	15
African American	20
Marital Status	
Married/committed Relationship	32
Divorced /widowed	2
Never married	1
Education	
At least 11 th grade	1
HS/GED	6
Some college	11
BA/BS	6
Advanced degree	11
Employment status	
Retired	13
Full time	21
Part time	1
Clinical information	
Comorbidities *	
No illnesses	3
1–2 illnesses	11
3+ illnesses	21
Type of treatment	
Radical prostatectomy	27
External beam radiation	1
Brachytherapy	6
Watchful waiting	1

* Comorbidities were gathered during the initial study

Table 2

Narrative Themes and Exemplar Quotes

Topic/Themes	Exemplars
<u>Influences on the decision to share thoughts and feelings about the diagnosis and treatment</u> Nature of the Relationship Benefit to others Benefit to oneself -Emotional Support -Tangible Support -Not Wanting to Hide Anything	<i>"It's just a natural thing to do. They have a right to know since it affects them. They need to know."</i> <i>"I wanted to urge the males around me to get checked."</i> <i>"They loved me. I knew they would pray with me over the situation."</i> <i>"With my friend it was to get his feedback how he dealt with his problem"</i> <i>"You shouldn't hide anything. Why should you hide a problem like that."</i>
<u>Others' responses to the diagnosis and treatment</u> Negative emotions Offer of emotional support Offer of tangible support Negative response toward cancer	<i>They felt pity for me...."</i> <i>"My wife got very upset...was a little fearful"</i> <i>"The first thing they said was, anything I can do to make you feel better,"</i> <i>I'm right here for you."</i> <i>"They asked if there was anything they could do, wanted to help with appointments and transportation back and forth to the hospital."</i> <i>"My brother was negative about it because the prostate had to be removed. His thing was the sex part."</i>
<u>Impact of disclosure on emotions</u> No change Emotional Support Positive Emotions -Not Hiding Anything -Relief -Other positive emotions	<i>"Felt the same as before, no change. If I have a problem, I go to get it fixed"</i> <i>"Talking about it didn't help."</i> <i>"Supported, loved."</i> <i>".... You feel better, more at ease not hiding important things from those that care about you."</i> <i>"At first I was tempted to not tell them at all. I didn't regret it[telling them]. I felt relieved I told them. Otherwise you're holding back something."</i> <i>"The more I talked the more I felt comfortable and accepted this as a part of me from now on and to move on."</i> <i>"I was glad to have people to share it with and glad to share information."</i> <i>"I felt happy...I was not alone, I felt like a burden was lifted, they know what I'm going through..."</i> " <i>I feel surrounded by a lot of good people. I guess I'm a lucky person."</i>
<u>Information disclosed about side effects (urinary, bowel, and sexual functions) experienced as a result of treatment</u> None or only treatment decisions	<i>"We just talked about treatment, we didn't talk about the side effects, didn't discuss the side effects with anyone."</i>

Topic/Themes	Exemplars
Urinary	<i>"...I can't seem to get my plumbing adjusted...I'm having some problems not controlling urine flow..."</i>
Bowel	<i>"... my bowel movements sting and burn, sometimes the burning sensation won't go away...asked my buddies...hey when does this stop."</i>
Sexual	<i>"...Sexual function. I discussed that with someone who had the same surgery." "Just the sexual functions to immediate family."</i>
All three side effects	<i>"I mentioned <u>urinary incontinence</u> with my family and close friend. <u>Sexual activity</u> with my wife, explained to her, talked about that, she is aware of consequences of radiation treatment creating my <u>bowel problem</u> and talked to my close friend we touch base and talk about that too."</i>
<u>Ongoing disclosure about diagnosis and treatment</u>	
Side effects	<i>"I've got some semblance of sexual control, I just need to get the timing...It's not quite as spontaneous."</i>
Appointments, test results, follow-up	<i>"Shared results of the test that came back from the doctor for PSA level with my coworker and my wife."</i>
Helping others (encouraging screening/treatment)	<i>"Well just with males, encouraging them to get checked. Early diagnosis really helps."</i>
Helping others (cope with diagnosis/treatment)	<i>"I talk to... others who have gone through prostate cancer. The overall health, the side effects, how they are coping with it, and what they deal with."</i>