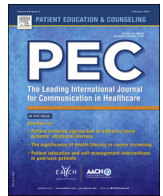




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Physical and emotional health information needs and preferences of long-term prostate cancer survivors

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ABSTRACT

Objective: Many men diagnosed with prostate cancer (PC) will experience physical and psychosocial late effects of treatment. Their interest/preferences for receiving information about addressing common sequelae is not well understood. We examined long-term PC survivors' level of interest, whether this differed based upon symptomatology, and their preferred coping information source.

Methods: N=615 PC survivors (3–8 years post-diagnosis) completed a survey on physical and psychological health and their information interests and preferences related to late effects of cancer treatment.

Results: Over half of PC survivors reported interest in information about late effects of treatment or sexual health, while approximately a quarter were interested in emotional health information. Survivors preferred to receive information about late effects of treatment from their oncologists, sexual health information from their primary care providers (PCP), oncologist, or written/online resources, and emotional health information from their PCP. Information needs were more commonly reported among men with poorer domain-specific health functioning.

Conclusion: Long-term PC survivors report significant interest in receiving information about their physical, sexual, and emotional health.

Practice implications: Medical providers caring for these men should inquire about survivors' information needs and future intervention efforts should consider who delivers the information, dependent upon the type of dysfunction reported.

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1. Introduction

In 2015, over 220,000 Americans were diagnosed with prostate cancer (PC) making it the most common non-skin cancer in men. Improvements in early detection and treatment of PC have resulted in 5-year relative survival rates of almost 100% for those diagnosed with a localized disease [1]. However, curative treatments for PC (e.g., radical prostatectomy, radiation therapy, and hormonal therapy) are commonly associated with decrements to urinary,

bowel, and sexual functioning that can result in significant psychological distress [2,3].

There have been ongoing efforts to develop interventions that target the physical and psychosocial sequelae of PC that men commonly report following treatment. These programs include those seeking to improve stress management skills, relationship functioning, mood, and quality of life among other endpoints [4–8]. Researchers have tried to improve the availability of these interventions beyond the academic medical center setting by delivering these programs using telehealth, web portals, and non-doctoral level providers [8–12]. Though these attempts are well-intentioned, several recent systematic reviews of supportive care interventions for PC survivors have indicated that there is “a lack of robust evidence for supportive care interventions for men with prostate cancer” [13] due to significant limitations in study design and implementation [8,13].

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In particular, it is acknowledged that one size does not fit all when it comes to psychosocial interventions in chronic illness populations [14]. It is imperative to better understand what patients are interested in learning about, as well as how and from whom they would like to receive that information. Specifically in PC survivors, there are multiple issues that require attention as efforts are made to improve their long-term well-being. First, not all PC survivors report poor physical or emotional health [15] and recognizing those at risk can be challenging. Little is known about the degree to which PC survivors desire additional information about how to cope with the multiple individual domains of function that can be affected by treatment, such as sexual dysfunction or emotional disturbances. Secondly, despite evidence indicating that some PC survivors have unmet informational needs about coping with these side effects of treatment [16–18], it is unclear as to how these men prefer to receive this information about coping with their post-treatment sequelae. Research indicates that cancer patients are open to receiving information about their cancer-related care from a variety of sources [19,20], but there is a limited understanding of how PC survivors specifically want to receive information about their multiple needs, and from whom they wish to receive this information [21]. In the current study, we sought to improve our knowledge of the unique information needs and preferences of long-term PC survivors across three key domains (coping with the late effects of PC treatment, sexual dysfunction, and emotional health) by inquiring about their level of interest in receiving further coping information, whether their interest level was associated with their level of symptomatology, and their source of support preferences.

2. Methods

The current findings are part of a larger study querying demographics, medical history, and physical and emotional health. The survey was mailed to 979 PC survivors, 3–8 years post-diagnosis and who were seen for at least one medical visit at a comprehensive cancer center. A total of 707 men returned their survey, for a response rate of 72.2%. Our concerted efforts to achieve this level of participant response (e.g., use of Priority Mail, repeat survey mailings) are described elsewhere [22]. In the current study, we excluded participants who did not respond to items querying their information needs, resulting in a final sample of 615 PC survivors. Study responders did not significantly differ from non-responders ($p \geq 0.05$) on demographic (age, ethnicity, marital status, education, household income) or study outcome (SF-12 Physical and Emotional Quality of Life, EPIC-26 Sexual Domain) variables. Current study participants were an average of 66.9 years of age (range=47–91; SD=7.9), and 5.0 years post-diagnosis (SD=1.7). They were mostly Non-Hispanic males who were married, well-educated, and reported having a high household income. The majority of participants reported having had prostate surgery, among other treatments, and were an average of 5.0 years post-PC treatment. Some participants received PC treatment within the past 12 months (18.7%), with the majority undergoing hormonal therapy (12.3%). See Tables 1 and 2 for further information. The study protocol was approved by the cancer center's IRB. A full discussion of study recruitment and methodology has been previously reported [23,24].

Study participants provided demographic information about their age, marital status, ethnicity, education, and household income. To understand PC-related symptoms, participants responded to the EPIC-26, a 26 item questionnaire inquiring about symptoms associated with PC treatment in four domains (urinary, bowel, sexual and hormonal) [25]. Further, general health-related quality of life was assessed using the Short Form-12 (SF-12), which is a 12-item measure assessing the individuals'

Table 1
Prostate cancer survivor demographic profile.

	No.	Mean	Percent	Standard Deviation
Age (Years)	615	66.9		7.9
Ethnicity	612			
Non-Hispanic White	585		95.6%	
African-American	14		2.2%	
Other	13		2.1%	
Marital Status	614			
Married	540		87.9%	
Never Married	18		2.9%	
Divorced/Separated	35		5.7%	
Widowed	21		3.4%	
Education	614			
High school diploma or less	68		11.1%	
Some College	121		19.7%	
College Graduate	188		30.6%	
Post-Graduate	237		38.6%	
Household Income	595			
≤\$49,999	82		13.8%	
\$50,000–\$99,999	224		37.6%	
>\$100,000	289		48.6%	

Table 2
Prostate cancer survivor disease-specific and quality of life profile.

	No.	Mean	Percent	Standard Deviation
Time Since Diagnosis (Years)	615	5.0		1.7
Prostate Surgery	609			
Yes	350		57.5%	
No	259		42.5%	
Radiation Therapy	611			
Yes	294		48.1%	
No	317		51.9%	
Hormonal Therapy	610			
Yes	224		36.7%	
No	386		63.3%	
Chemotherapy	610			
Yes	51		8.4%	
No	559		91.6%	
EPIC-26 Prostate Treatment Specific				
Sexual Domain	603	31.8		28.1
Bowel Domain	604	93.4		12.6
Hormonal Domain	603	89.4		14.4
Urinary Incontinence	606	80.3		24.0
Urinary Irritative	600	90.6		11.8
SF-12 Quality of Life				
Physical	597	50.3		9.1
Emotional	597	53.2		8.7

health status in both the physical and emotional domains [26]. The SF-12 and EPIC-26 have been validated and used extensively in studies examining health outcomes for PC survivors [27] (Table 2).

Each participant's health information needs were assessed by asking them to indicate their level of interest in receiving information about 1) "Coping with side effects of prostate cancer therapy," 2) "Sexual health and function," and 3) "Emotional health (including depression, anxiety, and alcohol/drug use" with options being "Not at all," "A little bit," "Somewhat," and "Very much." They were then asked to indicate their first choice for how they would prefer to receive each type of information, with 7 options including in-person conversations with their primary care provider (PCP),

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