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Unmet supportive care needs in prostate cancer survivors with advanced disease: A mixed-methods exploration

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ABSTRACT

Purpose: Men with advanced prostate cancer experience a wide range of side effects from the cancer and its therapies, which have a negative effect on their quality of life (QOL). Few studies have evaluated supportive care needs in these individuals. The purpose of this study was to conduct a holistic supportive care needs assessment among these survivors guided by the Supportive Care Framework for Cancer Care.

Methods: Using a convergent parallel mixed-methods approach, prostate cancer survivors with advanced disease ($n = 188$) completed a cross-sectional survey. A subset of these survivors ($n = 20$) participated in an interview to further explore their experience of unmet needs.

Results: Survivors reported unmet supportive care needs in every domain of the framework. Up to 95.2% of the survivors had at least one unmet need, with a mean of 14.9 (range: 0–42). Several areas of convergence among the quantitative and qualitative data (fatigue, sexual dysfunction, practical, and emotional/

psychological domains), as well as divergence (informational and spiritual domains, depression, urinary dysfunction) were found through the integration process.

Conclusions: This study confirms that prostate cancer survivors with advanced disease experience high rates of unmet supportive care needs. The findings also highlight the diversity of those unmet needs. These results may assist with future development of patient-centered supportive care interventions that better meet the specific needs of this vulnerable group of cancer survivors.

Keywords: prostate cancer; advanced disease; survivors; supportive care; unmet needs; quality of life; mixed-methods

INTRODUCTION

Despite extensive screening and novel treatments, the incidence of prostate cancer (PC) in the United States continues to increase (NCI, 2020). Furthermore, by 2040, its incidence is estimated to rise 33.6%, partly due to an increase in men greater than 65 years of age (Rawla, 2019). More than 3.6 million PC survivors are currently living in the U.S. A survivor is defined as any man with a history of PC, from the time of the initial diagnosis until the end of life (Delinger et al., 2015). Of note, about 30% of these men will experience progression or recurrence of their disease (i.e., an advanced PC survivor with regionally advanced, metastatic, or recurrent/refractory disease) (ACS, 2019; Holm et al., 2018; NCCN, 2020; PCEC, 2019). While treatment with curative intent is no longer an option for these men, management with a combination of therapeutic agents (e.g., chemotherapy, androgen-deprivation therapy [ADT]) is used to control symptoms or disease progression (Spratt, 2019; Zajdlewicz, 2017). However, these treatments are associated with long-term, negative effects that significantly compromise health outcomes and quality of life (QOL) (Carter et al., 2011; Crawford et al., 2017; Miller et al., 2019). Unmet physical, emotional, social, psychological, informational, spiritual, and practical supportive care (SC) needs often stem from these effects, increasing both burden and healthcare spending (Jacobsen et al., 2017; Miller et al., 2019).

SC needs are defined as survivors' desire for support to maximize QOL and minimize functional and psychosocial deterioration for a problem that arises from the illness or treatments (Paterson et al., 2018). Despite current cancer survivorship guidelines, between 33% and 81% of PC survivors report unmet SC needs (King et al., 2015; Watson et al., 2016). Specifically, survivors reported unmet emotional needs (52.9%), physical needs (47.1%), practical and spiritual needs (23.5%), and social needs (11.8%) (Nekhlyudov et al., 2017).

SC is a patient-centred approach that focuses on the prevention and proper management of the side effects of PC and its treatments; improvements in coping and decision-making

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skills; and reduction of functional impairments (Lo & Buss, 2019; Paterson et al., 2015; Paterson et al., 2017). The Institute of Medicine, the American Society of Clinical Oncology (ASCO), and the American Cancer Society (ACS) endorse SC as a way to improve QOL and rehabilitation and lessen the economic hardship of cancer care on healthcare systems (Paterson et al., 2015). However, the implementation of SC varies significantly across settings, partially due to survivors' SC needs remaining unknown generally across a range of cancer types (Nekhlyudov et al., 2017; Paterson et al., 2015).

Only two studies have focused on exploring the specific unmet SC needs of PC survivors with advanced disease. In the first study (Carter et al., 2011), priority unmet SC needs were related to bodily functions (i.e., urinary function, fatigue, sexual function), information and support, and emotional distress (i.e., sadness, anger, frustration). In the second study (Paterson et al., 2017), unmet SC needs were found in every domain (i.e., physical, psychological/emotional, intimacy/sexual, practical, informational, existential, and patient/clinician communication). Additionally, two studies aimed to assess specific unmet informational SC needs in PC survivors. Bermat et al. (2016) reported that 56% of PC survivors had unmet informational needs related to PC recurrence, effects on spouse/relationship, and long-term effects/recovery from cancer. Darwish-Yassine et al. (2014) found that older and White survivors reported that a clinician was their main source of PC information. In contrast, survivors with a college education or higher tended to go to the Internet for initial information.

Given the high prevalence of unmet SC needs among PC survivors living with advanced disease observed in the limited number of existing studies and the paucity of research on the assessment of SC needs in this population, a holistic needs assessment is warranted. Therefore, the purpose of this convergent parallel mixed-methods study was to characterize unmet SC needs in PC survivors with advanced disease using the Supportive Care Framework for Cancer Care (SCFCC) (Fitch, 2008), and examine potential areas of convergence and divergence of these unmet needs between the two methods. Study findings may be used to develop patient-centred SC interventions aimed at enhancing QOL of advanced PC survivors' living with advanced disease and reduce burdens to healthcare systems.

METHODS

Theoretical Framework

The SCFCC (Fitch, 2008) outlines a comprehensive taxonomy of seven domains (i.e., physical, emotional, social, spiritual, practical, informational, and psychological), and served as the guiding theoretical framework for this study. The SCFCC was initially developed as a tool to help clinicians understand the global and complex needs of diverse cancer patients throughout the illness continuum (Fitch, 2008). This framework has been used successfully in previous needs assessment studies with various types of cancer survivors, including PC (Fitch & Steele, 2010; Fitch, 2012). In this study, the SCFCC was used to guide the selection of validated instruments to measure unmet SC needs and informed the development of the qualitative interview guide (Cheah et al., 2016; Haynes-Lewis et al., 2018). Lastly, it guided the categorization and interpretation of the findings, identifying unmet SC needs

across domains that were prevalent and had the potential to negatively impact the overall health and QOL of PC survivors living with advanced disease.

Study Design and Settings

This study used a convergent parallel mixed-methods design. After obtaining an institutional review board waiver, cross-sectional quantitative and qualitative data were collected concurrently from PC survivors living with advanced disease between July and October 2020. We used a multichannel recruitment strategy to identify eligible survivors. Recruitment settings included an academic medical institution in the southern United States, Research Match (online research recruitment tool), various PC support groups and organizations, and social media. All recruitment procedures were conducted online due to the COVID-19 pandemic restrictions. All participants were provided with a written statement of the research that included information about what was involved in participation, and considerations of confidentiality.

Sample

In the quantitative phase, a convenience sample of PC survivors were enrolled if they met the following inclusion criteria: had advanced disease (i.e., stages III, IV, or recurrent); were ≥ 18 years; were able to read, understand, and speak English; and resided in the United States or its territories. Excluded were survivors who were enrolled in palliative or hospice care.

For the qualitative phase, we used a purposive sampling strategy to identify and select information-rich cases from enrolled survivors who completed the survey and indicated willingness to be contacted to participate in the qualitative interview. Diversity in sociodemographic and clinical factors (e.g., race, ethnicity, age, disease stage, treatments, time since diagnosis, level of education, marital status, geographical location) was prioritized to ensure maximum variation and to capture the perspectives of potentially neglected and underserved individuals. Recruitment continued until data saturation was achieved (i.e., inability to obtain new information has been attained) (Creswell, 2018).

Data Collection

Quantitative Data: An online survey to characterize unmet SC needs in PC survivors living with advanced disease was administered using Research Electronic Data Capture application (REDCap, n.d.). Survivors who completed the entire survey ($n = 188$) received a \$10 electronic gift card as compensation for their time and effort. The survey included three standardized validated measures that have been previously used in needs assessment studies of PC and other types of cancer.

Socio-demographic and clinical questionnaire. Self-reported data included age, race, ethnicity, marital status, employment, years of education, insurance status, state of residence, age and stage at diagnosis, treatments received, and current disease stage.

Supportive Care Needs Survey-Short Form 34 (SCNS-SF34). Unmet SC needs were assessed using the 34-item SCNS-SF34. The instrument maps five domains: physical and daily living, health care and information, psychological, patient care and support, and sexual. While this instrument has robust similarities with domains of the SCFCC (Boyes et al., 2004; Fong & Cheah,

2016), some domains are not separated within its subscales. For example, items measuring emotional needs are included in the psychological subscale. The items that measure psychological needs are included in two separate subscales (i.e., psychological, health system and information). Survivors reported the extent to which they needed help with each item over the past month using a 5-point Likert scale (1=no need, 2=had need but need for help was satisfied, 3=low need, 4=moderate need, 5=high need). All responses were summed within each need domain and standardized from 0 to 100, with higher scores representing higher levels of need (Okediji et al., 2017).

Supplementary SCNS PC Module. This 8-item module assesses PC-specific unmet needs. It is appropriate for use with patients at various stages of PC, treatment modalities, and time since the initial diagnosis. It has the same response set and scoring as that of the SCNS-SF34 (Okediji et al., 2017).

Functional Assessment of Chronic Illness Therapy – Spiritual Well-Being (FACIT-Sp 12). This 12-item instrument assesses the participants' spiritual well-being. Summary scores range from 0 to 48. A higher score indicates greater spiritual well-being (Muñoz et al., 2016).

European Organization for the Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30). The EORTC QLQ-C30 is an integrated system consisting of 30 items divided in five functional scales, three symptom scales, one global health/QOL scale and 6 individual symptom items. A four-point Likert response set was used for all the items except for the health status and QOL scales, measured on a 7-point scale. Scores were calculated by scale and transformed into a 0 to 100 summary score. A higher score represents higher QOL on the functional and global scales or higher level of symptomatology on the symptom scales/items (Fayers et al., 2001).

Qualitative Data: Sandelowski's approach guided the qualitative part of this study (Sandelowski, 2000). Semi-structured interviews were conducted via telephone after the script was developed by the principal investigator (PI). The script was informed by existing literature, the original study aims, and the SCFCC classification of supportive care needs, and reviewed by our multidisciplinary team with expertise in cancer care, survivorship, and qualitative methodology. The PI (ACS) contacted selected survivors to arrange the interview at a day/time of their convenience. Socio-demographic and clinical information were collected including age, race, ethnicity, education level, marital status, employment status, insurance status, PC stage at diagnosis, current PC stage, age at initial diagnosis, and treatments received. Then, the open-ended interview questions aimed at encouraging the survivors to voice their experiences of their unmet supportive care needs. Probes were used throughout the interview to elicit additional explanations (Creswell et al., 2018; Creswell & Poth, 2018). A reflective journal was also maintained by the interviewer to record impressions about the interview. Interviews lasted 15 to 52 minutes, were audio-recorded, and professionally transcribed verbatim.

Data Analysis

Quantitative Data. All statistical analyses were done using SPSS v25 (IBM, 2019). Descriptive statistics were used to

characterize the sample. To identify and calculate the unmet SC needs (i.e., frequency, proportion, mean, standard deviation, range) per domain and per item, we dichotomized the SCNS-SF34/PC-module (i.e., "Low Need" for scores <3 and "Some Need" for scores ≥3) as well as the FACIT-Sp items (i.e., "Low" for scores <3 and "High" for scores ≥3). Total scores for the FACIT-Sp and the EORTC-QLQ-C30 were calculated (i.e., mean value of all items, some items reversed). Missing data were reported; no imputation was carried out.

Qualitative Data. Descriptive statistics were used to summarize this sample's characteristics. The primary analyst (ACS) cross-checked and read each transcript for accuracy, removing any identifying information. Thematic analysis was conducted using NVivo12 to identify patterns within the collected data (Sandelowski, 2000; Vaismoradi et al., 2013). A first level of coding was performed line-by-line to develop descriptive themes. Then, the initial codes were categorized to develop analytical themes and generate higher level of conceptual themes about the unmet SC needs guided by the domains of the SCFCC (Cox et al., 2017). An iterative comparative method was used throughout the qualitative data collection and analysis until data saturation was achieved, comparing each interpretation with prior findings and using each interview's analysis to inform subsequent interviews (Creswell & Poth, 2018; Elo & Kyngas, 2007; Thorne, 2000).

The concepts identified by Lincoln and Guba were followed to ensure rigor (Luv, 2015). Credibility was established by providing a statement of research to each participant; by writing impressions about the interview; by conducting several levels of data coding; and by having two other members of the research team verify the transcripts and themes (S.N. and S.Q.). Dependability was achieved by keeping an audit trail of all decision-making processes. Confirmability was established through repetitive questioning and probes for clarification and by including direct quotes as evidence of the data collected. Transferability was ensured by the sampling strategy and documentation of the recruitment and data collection processes. Additional triangulation was performed by comparing and contrasting the quantitative and qualitative results and comparing these conclusions with prior studies (Carter et al., 2011; Creswell & Poth, 2018; Paterson et al., 2017).

RESULTS

Demographic and Clinical Characteristics

From the 670 PC survivors who accessed the quantitative survey, only 188 met our inclusion criteria (28.1% response rate). The remaining turned in incomplete surveys or did not meet our inclusion criteria (e.g., had localized PC). The mean (SD) age of the sample was 69.0 (8.8) years. Most men were White (93.1%), married (82.4%), college degree holders (79.3%), and retired (68.1%). The majority (63.5%) lived in southern states. Almost half of the participants (49.7%) reported having stage IV PC. The mean (SD) age at diagnosis was 61.6 (8.1) years. Most survivors had completed multiple treatments, such as ADT (74.5%), radiation (63.3%), or surgery (60.1%) (Table 1).

Table 1

Quantitative and Qualitative Sample Demographic and Clinical Characteristics

	Quantitative Survey Participants (N = 188) ^a		Qualitative Interview Participants (N = 20) ^a	
	n (%)	Mean (SD)	n (%)	Mean (SD)
Age	143 (73.1)	69.0 (8.8)	18 (90)	67.4 (8.3)
40–49	3 (1.6)		0 (0)	
50–59	17 (9)		4 (20)	
60–69	53 (28.2)		6 (30)	
70–79	53 (28.2)		7 (35)	
80–89	16 (8.5)		1 (5)	
90+	1 (0.5)		0 (0)	
Race	187 (99.5)		20 (100)	
White	175 (93.1)		18 (90)	
Black	9 (4.8)		2 (10)	
Native American/Alaskan	1 (0.5)		0 (0)	
Ethnicity	186 (98.9)		20 (100)	
Hispanic	2 (1.1)		0 (0)	
Non-Hispanic	184 (98.9)		20 (100)	
Marital Status	187 (99.5)		20 (100)	
Never Married	7 (3.7)		2 (10)	
Partnership	4 (2.1)		1 (5)	
Married	155 (84.4)		14 (70)	
Divorced	17 (9)		2 (10)	
Widower	4 (2.1)		1 (5)	
Level of Education	187 (99.5)		20 (100)	
High School or GED	11 (5.9)		1 (5)	
Some College	27 (14.4)		1 (5)	
Graduate & Beyond	149 (79.3)		18 (90)	
Employment Status	187 (99.5)		20 (100)	
Full Time	43 (22.9)		9 (45)	
Part Time	9 (4.8)		1 (5)	
Unemployed (actively looking)	1 (0.5)		0 (0)	
Unemployed	2 (1.1)		0 (0)	
Retired	128 (68.1)		10 (50)	
Disabled	3 (1.6)		0 (0)	
Geographical Location	181 (96.3)		19 (95)	
Northeast	19 (10.3)		1 (5)	
South	115 (63.5)		8 (40)	
Mid-West	19 (10.3)		2 (10)	
West	15 (8.1)		6 (30)	
Pacific	17 (9.2)		2 (10)	
Age at Diagnosis	184 (97.9)	61.6 (8.1)	19 (95)	59.4 (8.8)
30–39	1 (0.5)		0 (0)	
40–49	8 (4.3)		0 (0)	
50–59	63 (33.5)		11 (55)	
60–69	81 (43.1)		6 (30)	
70–79	29 (15.4)		2 (10)	
80+	2 (1.1)		0 (0)	
Treatments Received	188 (100)		20 (100)	
Surgery	113 (60.1)		17 (85)	
Radiation	119 (63.3)		14 (70)	
Chemotherapy	42 (22.3)		1 (5)	
ADT	140 (74.5)		11 (55)	
Brachytherapy	18 (9.6)		2 (10)	
Cryotherapy	7 (3.7)		1 (5)	
Current Cancer Stage	187 (99.5)		20 (100)	
Stage III	53 (28.2)		5 (25)	
Stage IV	93 (49.7)		8 (40)	
Stage Recurrent	41 (21.8)		7 (35)	

^aSome of the participants did not provide an answer for some of the sociodemographic and clinical characteristics.

Abbreviations: ADT, Androgen-Deprivation Therapy

Of the 43 survivors who were invited to participate in the semi-structured interview, 21 declined or were lost to follow-up. Of the 22 interviews that were performed, two were not included in the analysis because of a discrepancy in the current stage of disease. The mean (SD) age for the 20 participants was 67.4 (8.4) years. Most were White (90%), married (70%), retired (50%), and held a college degree (90%). Current disease stages of III, IV, and recurrent were somewhat evenly represented (25%, 40%, and 35%, respectively). The mean (SD) age at diagnosis was 59.4 (8.8) years. Surgery, radiation, and ADT were the most common treatments (Table 1).

Survivors' Perceptions and Prevalence of Supportive Care Needs

Unmet SC needs were reported in all seven domains. Over 95% of the PC survivors reported having at least one unmet SC need. The proportion of survivors reporting PC-specific unmet needs was 83.5%, with 79.8% endorsing emotional/psychological unmet needs, and 74.5% reporting sexual unmet needs. Unmet needs were identified in the physical (64.4%), informational (59.6%), practical (45.7%), and spiritual domains. The mean number of unmet SC needs was 14.9±10 (range 0 to 42).

Across all of the SCNS domains, among those who reported some unmet need (i.e., low, moderate, high) the highest unmet need was endorsed for the sexuality domain (mean 39.4±29.2), followed by the psychological domain (37.6±22.9) and the physical and daily life domain (29.9±23.4). In contrast, the lowest level of unmet need was for patient care and support (27.2±21.0). In three out of the six SCNS domains, over 50% of survivors reported *some level of need* in the psychological, sexuality, and PC-specific domains. In addition, 38.3% of the survivors who completed the spiritual well-being subscale expressed their level of peacefulness as "little" or "somewhat". The mean scores, frequencies, and percentages for the unmet needs are presented in Table 2. The 12 most common unmet SC needs are presented in Table 3. Five of these 12 unmet needs were in the emotional/psychological domain. The remaining were in the sexuality (2), PC-specific (3), and physical (2) domains.

Quantitative and Qualitative Findings for each SCFCC Domain

1.1. Unmet Physical Needs

Needs that stem from physical symptoms and the inability to carry out activities of daily life belong to the physical domain (Fitch, 2008). Almost 40% of the survivors reported some degree of unmet needs in the physical domain. The mean scores for the three subscales associated with the physical domain were 39.4±29.2 (sexuality), 29.9±23.4 (physical), and 29.6±19.4 (PC-module), ranking first, third, and fourth out of the six categories in this instrument respectively. The highest level of unmet need was related to the sexuality/intimacy (59% "changes in sexual feelings" and 45.2% "changes in sexual relationships"), followed by fatigue (49.4% "lack energy / tiredness" and 46.3% "not being able to do the things I used to do"), and "urinary incontinence" (44.1%). Additional unmet needs included "hot flushes" (43.1%), gastrointestinal problems (29.3%), and "pain" (25.5%).

In the qualitative interviews, the findings were similar. The men also reported urinary dysfunction, fatigue, and sexual problems during the interviews. Various forms of urinary dysfunction were reported by 14 survivors including: urinary frequency, incontinence, and caring for a urostomy. One survivor shared: "Urination, well, my urination, the doctor who removed the prostate left me incontinent and I worked real hard with physical therapy, didn't gain anything. So, I wear diapers and I have a penile clamp..."

Thirteen survivors reported fatigue that interfered with hobbies, daily, and social activities. While some men attributed fatigue to the aging process, some noted that it became more evident after their diagnosis and treatments, particularly after radiation or ADT. Loss of sexual function was a primary concern for half of the survivors. The causes were reported to be either surgery or taking ADT. While one survivor seemed content with his sexual function due to a new pumping prosthesis, others qualified sex as "inexistent" and talked about the deep effect that it had on their overall QOL and well-being: "Well, it has an effect on my sexual interest...And I didn't realize before the surgery, how important that was just to my well-being and my mental health".

Some of the survivors described physical needs not captured by the quantitative survey. Men talked about hot flushes at night, pain, weight gain after taking ADT, and sleeplessness, all of which impacted their daily life (Table 4). Although unpleasant, most had accepted these needs as expected consequences of advanced PC and its treatments.

1.2. Unmet Emotional Needs

Emotional needs arise from a lack of reassurance and comfort related to living in distress due to cancer (Fitch, 2008). The mean psychological subscale score was 37.6±22.9, with 44.4% of the survivors endorsing some unmet needs in this domain. The most common emotional unmet needs included: "fears about cancer spreading" (62.2%) and "uncertainty about the future" (58%), followed by "worry about results of treatment" (50%), "anxiety" (46.6%), and "depression" or "feelings of sadness" (42.6%).

During the interviews, men spoke of emotional health as one of the most affected areas. Some of the survivors were diagnosed a few years earlier and were still facing unresolved needs related to feelings of anxiety, fear, or depression, with four men expressing anger and regret about the decisions that they had made after the initial diagnosis. They believed that if they had been better informed, their outcomes, including emotional outcomes, would have been more optimal and they would not feel angry or regretful. One survivor shared: "And I wish I knew then what I know now, I guess is what I'm trying to say, regarding just the literal day-to-day, how is this going to affect your life."

Nine men spoke about the emotional consequences of advanced PC and its treatments, emphasizing that sometimes, existential concerns trigger excessive worry and loss of confidence about the future, mainly due to a possible loss of role within their family. However, only five survivors reported that disease recurrence in the near future was a source of fear (Table 4).

Table 2*Degree of Supportive Care Needs per Domain: "Some need" (N=120)^a*

Items by Domain	Mean (SD)	Range	Some Need n (%)			
			Low	Moderate	High	TOTAL
Physical & Daily Living	29.9 (23.4)	0–80				
Pain			31 (16.5)	13 (6.9)	4 (2.1)	48 (25.5)
Lack energy/tiredness			41 (21.8)	39 (20.7)	13 (6.9)	93 (49.4)
Feeling unwell a lot of time			38 (20.2)	17 (9.0)	4 (2.1)	59 (31.3)
Work around home			27 (14.4)	18 (9.6)	6 (3.2)	51 (27.2)
Not do things I used to do			41 (21.8)	31 (16.5)	15 (8.0)	87 (46.3)
Psychological	37.7 (22.9)	0–97.5				
Anxiety			55 (29.3)	26 (13.8)	6 (3.2)	87 (46.3)
Feeling down/depressed			52 (27.7)	20 (10.6)	6 (3.2)	78 (41.5)
Feelings of sadness			53 (28.2)	21 (11.2)	6 (3.2)	80 (42.6)
Fears about cancer spreading			63 (33.5)	37 (19.7)	17 (9.0)	107 (62.2)
Worry about results of treatment			46 (24.5)	33 (17.6)	15 (8.0)	94 (50.1)
Uncertainty about future			60 (31.9)	38 (20.2)	11 (5.9)	109 (58)
Learning to feel in control			51 (27.1)	25 (13.3)	4 (2.1)	80 (42.5)
Keeping positive outlook			42 (22.3)	18 (9.6)	10 (5.3)	70 (37.2)
Feelings about death/dying			45 (23.9)	22 (11.7)	10 (5.3)	77 (40.9)
Concerns about worries of those close			42 (22.3)	42 (22.3)	16 (8.5)	100 (53.1)
Health System & Information	27.2 (21.0)	0–100				
Be given information about important aspects of your care			27 (14.4)	13 (6.9)	6 (3.2)	46 (24.5)
Be given information (written, diagrams) about aspects of managing illness at home			30 (16.0)	21 (11.2)	4 (2.1)	55 (29.3)
Be given explanations of tests for which you would like explanations			17 (9.0)	15 (8.0)	10 (5.3)	42 (22.3)
Be adequately informed on benefits & side effects of treatments before you choose			21 (11.2)	22 (11.7)	12 (6.4)	55 (29.3)
Be informed about test results as soon as feasible			15 (8.0)	12 (6.4)	10 (5.3)	37 (19.7)
Be informed about cancer under control or diminishing (remission)			26 (13.8)	12 (6.4)	8 (4.3)	46 (24.5)
Be informed about things you can do to help yourself to get well			34 (18.1)	20 (10.6)	10 (5.3)	64 (34.0)
Have access to professional counseling e.g., psychologist, social worker) if your family/friends need it			32 (17.0)	20 (10.6)	10 (5.3)	62 (32.9)
Be treated like a person, not just a case			24 (12.8)	15 (8)	7 (3.7)	46 (24.5)
Be treated in a hospital/clinic as physically pleasant as possible			15 (8.0)	12 (6.4)	6 (3.2)	33 (17.6)
Have member of hospital staff with whom you can talk about all aspects of condition			26 (13.8)	18 (9.6)	14 (7.4)	58 (30.8)

continued...

Patient Care & Support	27.2 (21.0)	0–100				
More choice about cancer specialist you see			29 (15.4)	21 (11.2)	5 (2.7)	55 (29.3)
More choice about which hospital you attend			26 (13.8)	14 (7.4)	4 (2.1)	44 (23.3)
Reassurance by medical staff that the way you feel is normal			31 (16.5)	15 (8)	5 (2.7)	51 (27.2)
Hospital staff to attend promptly physical needs			26 (13.8)	12 (6.4)	4 (2.1)	42 (22.3)
Hospital staff to acknowledge/show sensitivity to your feelings & emotional needs			27 (14.4)	12 (6.4)	5 (2.4)	44 (23.5)
Sexuality	39.4 (29.2)	0–100				
Changes in sexual feelings			46 (24.5)	39 (20.7)	26 (13.8)	111 (59.0)
Changes in sexual relationships			32 (17.0)	30 (16.0)	23 (12.2)	85 (45.2)
To be given information about sexual relationships			30 (16.0)	21 (11.2)	9 (4.8)	60 (32.0)
Prostate Cancer-Specific Module	29.6 (19.4)	0–78.1				
Urinary incontinence			45 (23.9)	26 (13.8)	12 (6.4)	83 (44.1)
Difficulties passing urine			27 (14.4)	9 (4.8)	7 (3.7)	43 (22.9)
Hot flushes			44 (23.4)	26 (13.8)	11 (5.9)	81 (43.1)
Problems with bowel habits			40 (21.3)	11 (5.9)	4 (2.1)	55 (29.3)
Feeling as you going through a life like women			39 (20.7)	12 (6.4)	8 (4.3)	59 (31.4)
Feeling like you have lost part of manhood			40 (21.3)	34 (18.1)	25 (13.3)	99 (52.7)
Feeling like what you say is not taken seriously by others			25 (13.3)	14 (7.4)	4 (2.1)	43 (22.8)
Feeling like you have lost the ability to be aggressive			24 (12.8)	14 (7.4)	6 (3.2)	44 (23.4)
Spiritual Well-Being - FACIT-Sp Subscale^b	27.02 (9.2)	0–44				

^a Some of the participants did not provide an answer to some of the SCNS and FACIT questions.

^b Higher score represents better spiritual well-being.

Abbreviations: FACIT-Sp, Functional Assessment of Chronic Illness Therapy-Spiritual Well-being.

Table 3

Prostate Cancer Survivors Living with Advanced Disease - Top Unmet Supportive Care Needs (N=188)

Supportive Care Needs	n	Prevalence (%)	Domain
Fears about cancer spreading	107	62.2	Psychological
Changes in sexual feelings	111	59.0	Sexuality
Uncertainty about the future	109	58.0	Psychological
Concerns about worries of those close	100	53.1	Psychological
Feeling like you have lost your manhood	99	52.7	PC-module
Worry about results of treatments	94	50.1	Psychological
Lack of energy / tiredness	93	49.4	Physical & Daily Living
Not do things I used to	87	46.3	Physical & Daily Living
Anxiety	87	46.3	Psychological
Changes in sexual relationships	85	45.2	Sexuality
Urinary incontinence	83	44.1	PC-module
Hot Flushes	81	43.1	PC-module

Table 4

Unmet Supportive Care Needs: Direct Quotes from Qualitative Interviews

SCFCC Domain	Unmet SC Need	Qualitative Direct Quotes
PHYSICAL	Urinary Dysfunction	<i>“So the biggest thing would be urinary issues. Between surgery and radiation, I developed a bladder neck contracture,...And I have to self catheterize myself every night to keep that bladder contracture open...”</i>
	Fatigue	<i>“My muscles are very weak. So my hypothesis is that I get tired a lot earlier in the day...”</i>
	Sexual Dysfunction	<i>“I have erectile dysfunction now. I can’t have sex, and that’s a big deal”</i>
	Hot Flashes	<i>“I guess hot flashes quite a bit. I think this is what the major disruptor of my sleep”</i>
	Pain	<i>“So, the pain, in some ways, prohibits me from doing things that I would like to do. So, I’d say it’s a great impact...”</i>
	Insomnia	<i>“I have a lot of difficulty sleeping and relaxing”</i>
	Weight Changes	<i>“The side effect of the pills, the medications generally, are that I’ve gained quite a lot of weight”</i>
EMOTIONAL	Anger-Regret	<i>“When I was initially diagnosed, my doctor did not tell me about some other treatments that I should have had, and I didn’t know enough to ask about them and he didn’t offer them to me”</i>
	Existential Concerns	<i>“I was very bothered by the diagnosis. I was very concerned about my health and future and survival...”</i>
	Anxiety	<i>“There’s a lot of anxiety because it’s the first time I had to face mortality”</i>
	Depression	<i>“I’m depressed about the whole business of sexual function after the prostatectomy, and I would have elected different options if I had been better explained what my possibilities were and weren’t after the surgery”</i>
INFORMATIONAL	Deficiencies	<i>“Well, I didn’t know that advanced cancer really was a term that meant something”</i> <i>But the hormone therapy, the side effects from it, I had no idea what they were. I was told... I was kind of jokingly told that, “Oh, you’re going to have difficulty with a lot of things like sexual ability, et cetera</i>
	Problems with Information	<i>“...I wish I had a better understanding of what follow-on treatment strategy might be in store. And I understand that this is kind of an evolving thing here, but I feel unprepared for future possibilities”</i>
PRACTICAL	Home assistance	<i>“My basic household chores have been impacted by the joint pain and things like that that I have due to the therapy”</i>
	Finances	<i>“Prostate cancer cost me almost 30,000 bucks before I was on Medicare”</i>
	Transportation	<i>“And my partner can drive me, my wife can drive me places to drop me off if say I’m going for a long time and I don’t want to have to deal with parking”</i>
SPIRITUAL	Impact on Spirituality	<i>“I lost my faith for a while”</i>
SOCIAL	Impact on Social Life	<i>“...So that’s kind of where I see the most impact socially just in dating and again, how much of it that I’ll reveal in social interaction”</i>
	Lack Social Interaction	<i>“It’s nice to be around other people and in my business I’m rarely around other people, I’m generally by myself”</i>
PSYCHOLOGICAL	Coping	<i>“And let my mind wander to darker places and kind of feel a sense trend, sometimes it’s hard to do. There are times when I wake up in the middle of the night and it’s on my mind”</i>
	Body Image	<i>Like I told you about breast enlargement, the weight gain, and the muscle loss. Sure, I’m not happy about that at all.</i>
	Cognitive Dysfunction	<i>I think I have a lack of concentration, so that impacts the things that I like to do. Actually, it’s pretty pervasive.</i>

Abbreviations: SC, supportive care

Anxiety was a major problem for these survivors. Consciously or not, many experienced high levels of anxiety at some point during their advanced disease trajectory. One survivor said: “So, I guess it’s the not knowing what my status is, is producing some anxiety.” Depression was also a concern reported by a quarter of these men, primarily tied to the effects of surgery or as a consequence of prolonged ADT treatment (Table 4).

1.3. Unmet Informational Needs

Informational needs stem from a lack of or insufficient information for adequate decision-making and well-being (Fitch, 2008). Informational unmet needs were reported by 27.2% of the survivors. The mean score (29.5±21.5) for this domain was the second lowest. The top two unmet needs reported were: “be informed about things you can do to yourself to get well” (34%) and “have member of hospital staff with whom you can talk about all aspects of condition” (30.8%).

During the interview, all the survivors said that they had received information about advanced PC. The sources of information were both formal (e.g., pamphlets) and informal (e.g., support groups or online research). However, 16 men voiced repeated dissatisfaction with the type and/or amount of information they received throughout their journey. For some, the problem arose from the time of diagnosis: “...the conventional wisdom, the cliché that you’re going to get is, “Oh, prostate cancer’s no big deal...” For others, the information regarding the side effects of the treatments was not sufficient: “But the hormone therapy, the side effects from it, I had no idea what they were. I was told... I was kind of jokingly told that, “Oh, you’re going to have difficulty with a lot of things like sexual ability, et cetera...” Some reported a lack of information regarding available sources of support or insufficient guidance about more novel treatments and potential benefits. Of note, four survivors had issues understanding the information they received; not finding the information they were looking for; or feeling anxious about the information overload (Table 4).

1.4. Unmet Practical Needs

Practical needs are related to the cancer journey itself and the demands of the disease on the person and their daily life (Fitch, 2008). The patient care and support items had the lowest total prevalence among the various SCNS subscales, with a mean score of 27.2±21.0. In total, 25.1% of the survivors reported some unmet needs. Survivors endorsed having unmet needs with “hospital staff to attend promptly physical needs” (22.3%), as well as with “more choice about cancer specialist you see” (33%). While needs related to transportation or finances were not measured in the surveys, they were raised during the interviews.

Most survivors felt that they were sufficiently supported regarding their disease, whether it was by their medical team or the informal Internet support community. However, some reported having other unmet practical needs. Seven men explained that due to their illness and treatment-related side effects, they encountered difficulties working around the house. Some wished they had assistance with certain tasks:

“I do have difficulty bending over and picking things up. And so housework, a good stove... I get behind on the housework. I could use help there. That’s for sure.” In addition, transportation and finances were cited as a reason for worry in some cases. Most survivors expressed satisfaction about their insurance and monetary situation. However, nine interviewees said that paying the insurance premium or medical expenses was challenging at times (Table 4).

1.5. Unmet Spiritual Needs

Needs arising from a loss of meaning of life and changed personal beliefs (e.g., religion) are included under the spiritual domain (Fitch, 2008). The mean FACIT-Sp total score was 27.0±9.2 (range 0-48). Survivors expressed a high level of peace/meaning with a mean subscale of 22.9 (range 0-32). Their mean level of faith was 8.2 (range 0-16). Regarding individual items, 50% of the survivors endorsed “My illness has strengthened my faith/beliefs” and 38.3% endorsed “I find strength in my faith/spiritual beliefs” as none or little.

Interviews highlighted that 13 of the 20 survivors considered that spirituality had a prominent role in their lives despite individual differences in spiritual beliefs. Most did not experience any spiritual crises or changes in their relationship with God due to their cancer. For some, their level of faith grew throughout their cancer journey or returned after a brief turndown. None of the survivors blamed God for their cancer or searched for a higher meaning behind their diagnosis. Overall, their spirituality and related activities did not change, and they expressed belief that life was more precious since the time of diagnosis. However, for six men, being a survivor with advanced disease had a level of impact on their spirituality or personal beliefs: “Okay. I don’t hold on to my own life as fiercely as I once did. I’m more content now to see myself as part of a much larger process...” (Table 4).

1.6. Unmet Social Needs

Social needs derive from affected social roles and/or lack of social support during the cancer experience (Fitch, 2008). Aside from one isolated item included under the health system and information subscale, “feeling like what you say is not taken seriously by others”, the social domain was not evaluated thoroughly in the quantitative data. However, this item was endorsed as a need by 22.8% of the survivors.

The qualitative data highlighted the limited impact of advanced PC on social well-being. The majority of survivors explained that their social life was maintained more or less as usual (e.g., going out to eat, visiting friends). Most survivors described having some sort of social support, whether it was family members, spouse, friends, church, or the medical or Internet communities. However, five out of the 20 interviewees acknowledged advanced PC having some level of impact on their social life, whether it was in the form of intimacy changes, lack of understanding from family or friends, or changes in socialization: “...having cancer is like living in a different world that a lot of people don’t understand and will never” (Table 4).

1.7. Unmet Psychological Needs

According to the SCFCC, psychological needs are associated with inappropriate coping styles or problems with changes in body image (Fitch, 2008). While the SCNS and PC modules do not measure any changes in body image, they evaluate coping using three items. The item “learning to feel in control” had 42.5% of respondents expressing some degree of unmet need. The other two items, “keeping a positive outlook” and “have access to professional counseling”, was reported as an unmet need in 37.2% and 32.9% of the respondents, respectively.

Survivors explained that they did not have much difficulty coping with the disease. Coping mechanisms were varied and included learning to live with it, considering advanced PC a wake-up call in life, trying to keep a positive attitude, praying, exercising, or showing resignation. However, four men described having some problems with their coping, with two survivors admitting seeking professional help. One survivor shared: *“In terms of coping with the psychological aspect, I realized pretty early on that I was mentally going into a very bad place, dark place. I knew that I needed to reach out to someone...”* Additional unmet needs arose from changes in body image and cognitive impairment as a consequence of the treatments (Table 4).

Integration of Results

Integration of quantitative and qualitative data increases the value of mixed methods research (Creswell & Plano, 2011; Fetters et al., 2013). Therefore, after analyzing and organizing

the data separately, an integration at the interpretation and reporting level was performed using a joint display approach. As illustrated in Figure 1, while the left side provides the quantitative mean ratings of the survivors’ SC needs, the right side provides illustrative quotes from the qualitative interviews. Both sides were organized based on the SCFCC domains and were color-matched to help visualize the distinct constituent domains. The ultimate goal of the integration process was to explore potential areas of convergence and divergence among the two sets of data (Fetters et al., 2013).

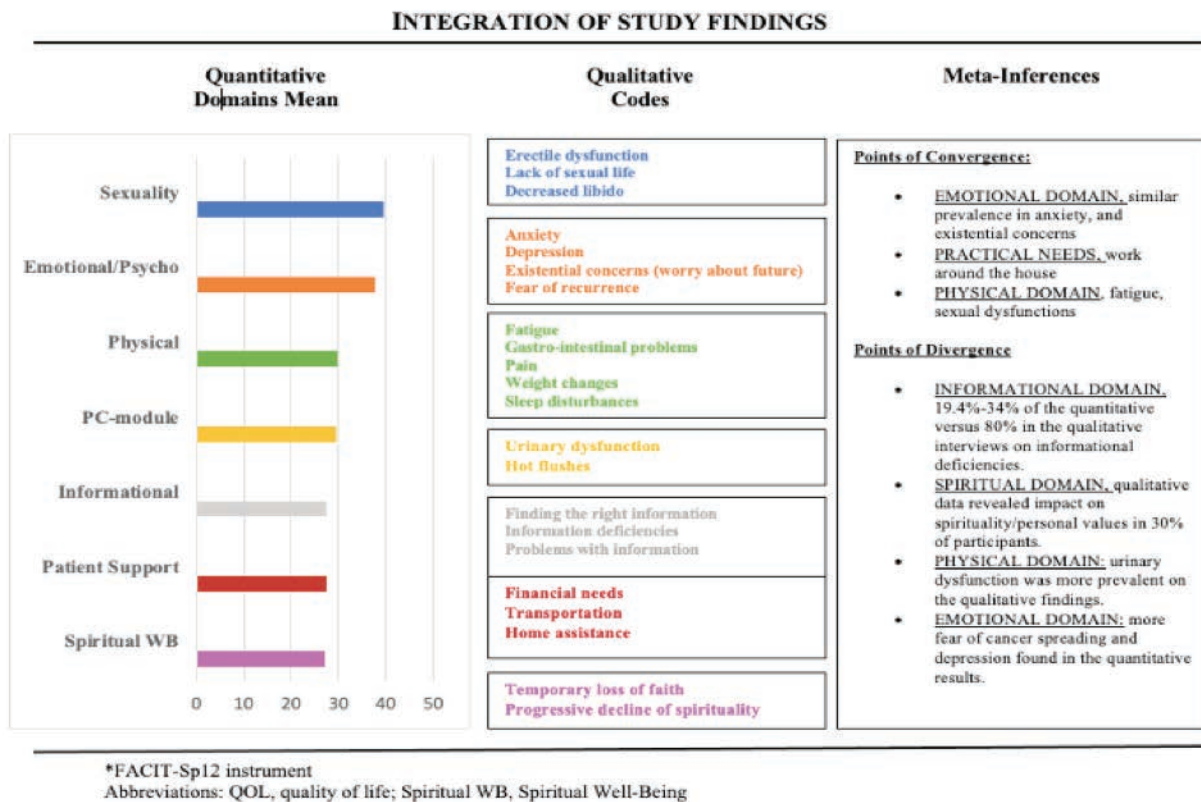
DISCUSSION

This study is the first to categorize the prevalence and types of unmet SC needs in PC survivors living with advanced disease in the United States. Of note, survivors had unmet needs in every domain of the SCFCC. In addition, 30% of the survivors endorsed unmet needs for more than 50% of the items. Our findings are important for two reasons. First, the unmet needs were identified in both the quantitative and qualitative parts of this study. Second, the prevalence of unmet needs exceeds the threshold suggested by the SCFCC, which suggests that these unmet needs are not being addressed by the healthcare system (Cheah et al., 2016; Fitch, 2008).

Several areas of convergence were found between the two sets of data. Consistent with prior research reporting high prevalence rates for fatigue and sexual dysfunction among PC survivors living with advanced disease (Cockle-Hearne et al., 2013;

Figure 1

Integration of Quantitative and Qualitative Results



Lintz et al., 2003), both survey and interview respondents identified these symptoms as unmet priority physical SC needs. In addition, they explained how both fatigue and sexual issues interfered with daily life, leading to a range of negative feelings. Regarding fatigue, most of the survivors explained that they tried to continue with life as usual despite its complex and multidimensional effects. Some even described becoming more aware of their health and making appropriate lifestyle changes (e.g., nutrition). Also consistent with previous reports (Lintz et al., 2003; Paterson et al., 2017), sexual dysfunction was one of the most troubling unmet physical need for 50% of these survivors. The survivors explained that they would have opted for alternative treatments other than prostatectomy or ADT if they had known the impact on libido and sexuality. Decision regret is a common experience reported by many PC survivors living with advanced disease. Of note, decision regret is associated with a lack of literacy or utilization of the Internet as a primary source of information (Joyce et al., 2020; Shaverdian et al., 2018). To ensure that treatments are aligned with survivors' expectations and preferences, clinicians must provide individualized information about the expected impact of the various treatments on sexual function in a proactive manner (Shaverdian et al., 2018; Wollersheim et al., 2020).

Another area of convergence included the emotional and psychological domains. Many survivors felt fortunate about having PC over other types of cancer. As in prior reports, they acknowledged several coping mechanisms in dealing with the disease, including acceptance or looking at the disease in a more positive light (Maharaj et al., 2018). However, some men experienced anxiety and fear about: their own mortality, the cancer spreading, the future, and the results of treatments. These findings are consistent with previous studies that found that 54% of PC survivors living with advanced disease manifest uncertainty, anxiety, or regret about treatment decisions (Paterson et al., 2020; Ralph et al., 2020). More research is needed to determine which SC interventions may contribute to a better psychological burden control (Kuon et al., 2019; O'Shaughnessy et al., 2015). On the surface, the convergent findings regarding physical and emotional unmet needs appear to be consistent with the extant literature suggesting that advanced PC therapies are associated with fatigue, pain, decreased libido, impotence, anxiety, and existential concerns (Chambers et al., 2019; Holm et al., 2018; Steentjes et al., 2018; Paterson et al., 2015; Bermat et al., 2016). However, these high rates may be clinically relevant because, despite the impact of these unmet SC needs and the current guidelines, the SC beyond routine clinical care appears to be suboptimal at best (Handberg et al., 2018; Lo & Buss, 2019; Nekhlyudov et al., 2017; Paterson et al., 2020).

Practical unmet SC needs were found in both the quantitative and qualitative data. Survivors voiced needs related to treatment choices, healthcare team communication, and transportation being sufficiently met throughout their disease trajectory. However, a few men encountered difficulties with housework and finances. In a previous U.S study (Darwish-Yassine et al., 2014), the survivorship phase of the cancer continuum was found to be the most expensive of all phases for individuals. The few survivors who were employed struggled with medical expenses or insurance premiums. These unmet

needs are likely to persist, as they need additional treatments to keep advanced PC under control (Bauer et al., 2020). More research is needed on how to prevent and/or mitigate financial toxicity among PC and other cancer survivors living with advanced disease.

Several areas of divergence were found during the integration process. While survey results highlighted low levels of unmet informational SC needs, 80% of the interviewees voiced informational deficiencies at some point during the care process. While a few survivors were satisfied with the amount and type of information they received from their medical team, many highlighted the importance of self-education, as a way to cope with their illness. Others noted that information about treatment side effects affecting QOL and/or novel therapies were not provided and made them "*feel unprepared for future possibilities.*" This finding is consistent with past reports on variability in the amount and quality of information that is given to PC survivors living with advanced disease (Bobridge et al., 2015). Plausible explanations for these informational deficiencies include providers seeing large amounts of PC survivors, clinicians prioritizing survival to SC, information overload, or patient-related stoicism or lack of readiness to learn (Albaugh et al., 2017; Ball et al., 2013; Maharaj et al., 2018). Additional research is warranted to determine the specific unmet needs and appropriate timing for education in this vulnerable group.

Findings regarding the spiritual domain were somewhat inconsistent. Advanced cancer may lead to a loss of hope that affects an individual's body, mind, and soul (Hatamipour et al., 2015). Up to 79% of Americans identify with some type of spiritual doctrine despite differences in what spirituality may mean to them (Busolo & Woodgate, 2016). Many patients with advanced cancer rely on spirituality to cope with their disease, suggesting that higher levels of spirituality are associated with better overall QOL and lower prevalence of unmet SC needs (Matthews et al., 2012). The majority of our survivors described a number of coping strategies and identified that spirituality played an active role in their life. While the peace and faith subscale scores were above average, 30% spoke about the conversion of spiritual health into a different process: "*I'm more content now to see myself as part of a much larger process...*" Additional empirical evidence is needed to determine the impact of advanced PC on spirituality, a domain that continues to be relatively under investigated (Paterson et al., 2015).

Additional areas of divergence included urinary dysfunction (physical domain) and depression (emotional domain). While only 44% of the survey respondents reported urinary dysfunction, 70% of those interviewed noted urinary unmet SC needs as a priority. Our qualitative findings are congruent with another study that found that urinary functional needs are an unavoidable consequence of some of the most common treatments for PC (Carter et al., 2011). In terms of depression, between 25% and 42.6% reported this unmet need. Depression may occur with ADT, as well as during evaluations for recurrent disease (Carter et al., 2011). Both of these unmet needs may require referrals to specialized care.

Findings from this study highlight the magnitude of unmet SC needs in PC survivors living with advanced disease. While most unmet needs stem from the adverse effects of the

treatments, some may be related to other factors: lack of physical activity; insufficient contact with an oncology nurse; not having a life partner; not knowing about the availability of specific treatments or counseling; and lack of knowledge (Cockle-Hearne et al., 2013; Darwish-Yassine et al., 2014; Ralph et al., 2020). For example, previous studies found that PC survivors with advanced disease who exercised on a regular basis or saw oncology nurses throughout the care process reported higher vitality scores, improved sexual functioning, lower anxiety, and higher well-being (Hart et al., 2017). In addition, married or partnered survivors were more likely to seek help when needed (Olliffe et al., 2015).

Strengths and Limitations

One of the primary strengths of this study was the use of the SCFCC (Fitch, 2008). This framework addresses a broad array of SC needs experienced by PC survivors living with advanced disease and provides a robust structure to be able to conduct a holistic needs assessment. In addition, the use of a convergent mixed-methods design allowed for a more in-depth exploration of the unmet needs of PC survivors living with advanced disease.

However, several limitations warrant consideration. The study was cross-sectional. While the sample size was adequate, survivors were primarily White, married, retired, and held a college degree, so our results may not be generalizable to all PC survivors living with advanced disease. While the use of a single coder to analyze both types of data is a limitation, the tables and the codebook were developed in collaboration with all members of the research team. In addition, regular meetings were held to enhance trustworthiness. To be consistent with the other instruments used in this study, the time frame for the SCNS-PC module was changed from seven days to one month, so that all the questions related to the same specific timeframe (Gjersing et al., 2010). Finally, a female researcher conducted all the data collection. A male researcher may have prompted different responses from some of these survivors.

Implications for Practice

This study provides a more comprehensive picture of the multifaceted unmet SC needs in this population and highlights some variations compared to previous work. While most survivors expressed high levels of satisfaction with the overall survivorship care they have received, unmet SC needs were present in a relatively large proportion of survivors regarding physical, and emotional/psychological domains and, to a

lesser degree, the informational and spiritual domains. These results support further SC research in PC survivors living with advanced disease to determine specific unmet needs that can be met with existing and future SC interventions. In addition, there is a need to evaluate if these unmet SC needs are associated with survivors' demographic and clinical characteristics. Nurses, particularly oncology nurses, could play an important role in identifying and conducting routine assessments in survivors at increased risk for a lower QOL.

CONCLUSION

This study provides comprehensive information to understand the prevalence and types of unmet SC needs in PC survivors living with advanced disease. This needs assessment confirms and extends previous work describing the specific unmet SC needs of this vulnerable population. The development and implementation of adequate SC is essential, as the prevalence of unmet needs remains high, especially among the physical, informational, and emotional/psychological domains. To improve functional and QOL outcomes, clinicians need to research ways to develop and implement SC that is individualized, multidisciplinary, and dynamic to ensure that every PC survivor's need is met.

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ETHICAL APPROVAL

All procedures performed in this study involving human participants were in accordance with the ethical standards of the institutional review board at the Medical University of South Carolina and with the 1964 Helsinki declaration and all its amendments.

INFORMED CONSENT

Informed consent was waived under the institutional review board Category II.

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