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Exploring Unmet Needs in Prostate Cancer Care: A Cross-sectional Descriptive Study

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Article info

Abstract

Background and objective: Prostate cancer, the most common cancer among men worldwide, has significant impact on quality of life. Supportive care needs for those affected by prostate cancer are not well understood. This study aims to describe patient-reported unmet needs and explore supportive care priorities of men treated for prostate cancer.

Methods: A cross-sectional survey was distributed to all men who had accessed prostate cancer services (including surgical, radiation, and medical oncology treatment modalities) at a tertiary hospital. The survey included qualitative questions exploring patient experience and a validated patient-reported outcome measure (Supportive Care Needs Survey Short Form 34). Clinical information was collected. Analyses included, descriptive statistics, multivariate logistic regression models and qualitative analyses using a framework method.

Key findings and limitations: A total of 162 participants provided survey data. Domains about information, self-management, and sexual function were the highest ranked items with unmet needs. A qualitative analysis also identified "relationships", "information", and "the value of hindsight" constructs. Participants who identified three or more unmet needs expressed treatment regret (odds ratio 5.92, 1.98–22.23, p = 0.01).

Conclusions and clinical implications: Understanding the unmet needs of patients may better inform supportive care interventions that address what is important to patients. Importantly, participants valued relationships. There may be opportunities to better meet the needs of patients by improving access to information and self-management resources, particularly around sexuality. Further research is warranted.

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Patient summary: Prostate cancer and its treatment impacts are not well understood. Prioritisation of relationships and improving access to information and self-management resources are important. Further attention to prostate cancer supportive care in clinical practice is needed.

1. Introduction

Prostate cancer is the most common cancer among men worldwide [1]. The continuum of the prostate cancer trajectory has significant quality of life impacts [2]. For those treated for localised prostate cancer, quality of life can be compromised due to sexual, emotional, urinary, and bowel impacts [3,4]. For those being treated for advanced prostate cancer, these impacts may also extend to reduced functional capacity, fatigue, and impaired cognition [4,5]. Real-world registries identify that prostate cancer has persistent and problematic treatment impacts for up to 60% of those treated for the disease [6–8].

In a patient-reported outcome (PRO) study led by prostate cancer survivors, including participants from 25 European countries, the quality of life outcomes from prostate cancer were identified to be far worse than those reported in clinical trials [9]. There is also emerging evidence that clinician priorities do not necessarily align with those that are important to patients [10,11]. Work by Nyame and colleagues [12] in the USA investigated research priorities with prostate cancer survivors. In this study, 58.1% had localised prostate cancer, 16.1% had recurrent disease, and 24.4% had advanced prostate cancer. They identified a range of priorities across the prostate cancer continuum, with particular attention to research that could better inform treatment decisions, and support quality of life and on-going survivorship care.

The literature recognises that supportive care needs for those affected by prostate cancer across the disease trajectory are not well understood [2]. For this reason, we aimed to explore patient-reported prostate cancer unmet needs. Unmet needs are defined as a condition or symptom the treatment or diagnosis of which is not addressed adequately by available therapy or services, whether it be delayed or not received at all [13,14].

2. Patients and methods

This study was conducted in a large Australian public health service, which serves a geographical region with a population in excess of 1 million people. Potential participants had been treated at a large tertiary teaching hospital for prostate cancer. These services included surgical services for prostatectomy, radiation oncology, and medical oncology, including clinical trials across these service lines. All patients approached had undergone any type of treatment for prostate cancer in the past 12 months.

Ethical approvals were obtained from the local human research ethics committee (LNR/2020/QRBW/62920).

A cross-sectional survey was developed, which included the following: (1) the Supportive Care Needs Survey Short Form 34 (SCNS-SF34) [15], (2) clinical information, and (3) qualitative questions about perceived barriers and enablers regarding access to prostate cancer care. The SCNS-SF34 is a validated tool that has been used extensively in cancer care research internationally to assess supportive care needs, including prostate cancer supportive care clinical trials [16]. It has five domains, including psychological, health system and information, physical and daily living, patient care and support, and sexuality. Each question response has a scale from no needs to high unmet needs [15]. Additional questions were developed to capture participant clinical demographics and to understand perceived health service barriers and enablers to access prostate cancer care. Questions that asked about points of transition, such as at diagnosis and treatment decision-making, were identified as important through the pilot testing process.

Development consisted of four iterative steps, including question drafting, discussion with the study team, pilot testing with patients (n = 6) and consumer representatives (n = 4) known to the study team, and refinement of questions based on feedback. A summary of the final survey is presented in Figure 1 A patient information sheet was attached explaining the purpose of the survey, the voluntary nature of the study, and the contact details for the specialist nursing service in the hospital should they have questions or experience any worries as a result of participation. A reply-paid envelope was enclosed for potential participants to return the survey if they chose to participate.

Survey 1:

1. When where you first diagnosed with prostate cancer? (Please tick)

(1–3 mo, 3–6 mo, 6–9 mo, 9–12 mo, 1–2 yr, over 2 yr)

2. When you were first diagnosed, what worked well?

3. When you were first diagnosed, what could have been done better?

4. Where did you get your information about your diagnosis? Was it useful? Why?

5. What treatments have you had for your prostate cancer (you can tick more than one)

(Active surveillance; radical prostatectomy; radiotherapy; brachytherapy; hormone therapy; chemotherapy; other [please list])

6. How did you decide on your treatment? Is there anything you would change?

7. How do you think you are going at the moment? Why?

Survey 2:

Supportive Care Needs Survey Short Form 34 (SCNS-SF34)

Fig. 1 – Survey questions.

Table 1 – Methodological approach according to analysis type

Data analysis type and purpose	Approach taken
Descriptive statistics: To describe patient treatment groups, SCNS-SF34 scores, and quantity of needs	1. The number of participants in treatment group and any combination of treatments was described by counts 2. The average number of unmet needs, average score, and 95% CI were evaluated 3. The proportion of each level of unmet needs (none, low, moderate, high) for each treatment group and combination of treatment group was described
T test statistics: H0: There is no difference between treatment types and the number of unmet needs	1. All treatment modalities vs each treatment type was investigated 2. Each individual treatment type vs each treatment type alone was investigated 3. Radical prostatectomy and second-line treatment vs radiation therapy vs second-line treatment was investigated
Log model: H0: None of the coefficients, including time since diagnosis (>2 or <2 yr) and treatment type, have a statistically significant relationship with the number of unmet needs	For each question, a model included time since diagnosis (>2 or <2 yr), and treatment type
Qualitative analysis: Qualitative responses were then analysed into themes using the framework methods, with two independent researchers coding the data inductively and synthesising into key constructs	1. Codes were identified from qualitative responses by two independent researchers 2. A matrix was formed by synthesising codes in discussion with the research team 3. A table was developed with key constructs and corresponding quotes
Mixed methods analysis: Association between qualitative constructs and the number of needs (no needs, 1–2 needs, and ≥3 needs) were explored	1. Participant qualitative responses were consolidated into three groups using the number of needs they reported in the SCNS-SF34 (no needs, 1–2 needs, and ≥3 needs) 2. Key constructs in each group were identified 3. An association chi-square test was applied

CI = confidence interval; SCNS-SF34 = Supportive Care Needs Survey Short Form 34.

Descriptive analyses were firstly applied initially. T tests investigated differences between treatment modalities. A logistic regression investigated each domain of need as an independent variable, and modelling time since diagnosis and treatment modality. The R lme4 (version 4.09) package in R was used in analyses [17].

Qualitative responses were analysed using the framework method. Two independent researchers coded the data inductively and then synthesised into key constructs [18].

Finally, a mixed method analysis was completed using an embedded correlational model [19]. Qualitative constructs were listed for three groups according to the number of needs reported (those with no needs, one to two needs, and three or more needs). A chi-square test was applied to investigate whether the number of needs was associated with a construct.

Reporting has followed the Good Reporting of A Mixed Methods Study checklist [20].

A summary of the approach to analyses is presented in Table 1.

3. Results

A total of 387 surveys were distributed, from which 162 were returned and 153 (40%) were fully complete.

For the 153 participants (from metropolitan and regional locations), treatments included hormone therapy, radiation therapy, radical prostatectomy, brachytherapy, and chemotherapy, and any combination of these. All participants had received treatment, accessed as routine care and/or clinical trials in the past 12 months. Three participants did not to complete the SCNS-SF34, four did not complete the open text questions, and two surveys were returned blank. Of the seven participants who completed the demographics, two reported treatment for a radical prostatectomy alone, one received radiation therapy and hormone therapy, one had no treatment, and three reported radical prostatectomy/radiation therapy and other treatment lines.

Treatment characteristics are presented in Table 2.

3.1. Quantitative analysis

Across all the participants and all items on the SCNS-SF34 (n = 5202), the majority (68%) reported no unmet needs, with the remaining reporting low, moderate, or high unmet needs. Hormone therapy had a statistically significant association with the events of high unmet needs (p = 0.002) in multivariate analyses, both on its own as a treatment and as an adjuvant therapy.

Table 2 – Treatment characteristics reported by study participants

Treatments received	Number (%)
All patients	153 (100)
No treatment	6 (4)
Hormone therapy alone	12 (8)
Radiation therapy alone	16 (10)
Radical prostatectomy alone	29 (19)
Radical prostatectomy and hormone therapy	7 (5)
Radiation therapy and hormone therapy	27 (18)
Brachytherapy and other treatments	2 (1)
Radical prostatectomy and/or radiation therapy and other treatment lines	54 (35)

Table 3 – Ten highest ranked items due to the number of events

Ranked items	No need	Low need	Moderate need	High need
Being informed about the test results as soon as feasible	61	40	34	18
Being informed about the things you can do to help yourself get well	66	36	33	18
Being informed about cancer that is under control or diminishing	68	39	32	14
Concerns about the worries of those close to you	69	35	31	18
Worry that the results of treatment are beyond your control	81	40	22	10
Changes in sexual relationships	83	32	22	16
Changes in sexual feelings	84	33	23	13
Being given information (written, diagrams, drawings) about aspects of managing your illness and side effects at home	87	34	24	8
Being given explanations of those tests for which you would like explanations	87	34	24	8
Not being able to do the things you used to do	87	33	24	9
Reassurance by medical staff that the way you feel is normal	88	36	19	10

Table 4 – Log model of unmet needs >2 yr since diagnosis

Variable	OR	95% CI	p value
Being given information (written, diagrams, drawings) about aspects of managing your illness and side effects at home	5.67	2.92–78.53	0.001
Being given explanations of those tests for which you would like explanations	3.07	3.57–315.54	0.002
Being adequately informed about the benefits and side effects of treatments before you choose to have them	6.52	1.76–24.22	0.01
Being given information about sexual relationships	4.84	1.19–19.71	0.03
Being informed about things you can do to help yourself to get well	2.07	1.07–11.92	0.04
Changes in sexual feelings	4.00	0.98–16.33	0.05
CI = confidence interval; OR = odds ratio.			

Instrument items, ranked by frequency, are presented in Table 3. When unmet needs were ranked as independent variables, information need domains were reported in five of the top ten results. Relationship-related domains were reported in three of the top ten results. The impacts of prostate cancer on participant identity were presented in two of the top ten results.

Using a multivariate model, considering time (>2 yr since diagnosis), information needs (moderate and high) ranked the highest, followed by sexual needs. These data are presented in detail in Table 4.

3.2. Qualitative findings

From the qualitative responses, three key constructs were identified. Consistent with the SCNS-SF34 data, these also related to "information" and "relationships". The final was called the "value of hindsight" and related to the reflections shared by participants with the knowledge gained from their experience since diagnosis.

3.2.1. Theme 1: Information

Information was reported to be highly prized and important, and this construct was apparent across all open text responses. Some participants spoke about delays in receiving information, and that it was a source of worry, particularly when waiting for results due to the potential of the implications of these results. Information sources could come from many avenues, and participants appreciated having multiple media, such as booklets or support group contacts, and options available to them, increasing accessibility.

"Advice from urologists, advice from oncologists, materials provided, personal research, reading"

With the right information, participants were able to navigate their cancer journey and effects.

"You need to know the risks to accept them"

Resources of information were desirable as these supported independence and self-care. Relying on others without support and subsequently feeling vulnerable appeared undesirable from responses.

"More information on the side effects and what to do"

Having clinical space for informational conversations, providing opportunities to discuss challenges, and assessing the understanding of information were considered important by participants. Several participants detailed how appointments provided the opportune time to have these discussions.

"Plenty of opportunity to discuss things"

3.2.2. Theme 2: Relationships

Responses relating to relationships fell into three key areas, depending on what relationship they were talking about. These included relationships with loved ones, relationships with health care workers, and observed relationships between health care workers:

1. *Relationships with those people who participants cared about.* Some participants spoke of cherished support from their loved ones and how they valued these relationships. Others expressed concern at how prostate cancer and the subsequent treatments had also caused harm to those who they cared about.

"I want to be close to my wife again".

2. *Relationships between clinical teams and members.* If these relationships appeared to be functional, participants were positive in their observations; if these were negative, participants seemed to feel vulnerable.

"I want to know that they know what we are doing, not know they are disagreeing with each other".

3. *Relationships with those in the clinical team.* Some participants spoke of taking pride in developing their own personal relationships and referred to consultants and nurses by name, stating that they had a good relationship.

"I have a good relationship with everyone in the department and that gives me comfort".

3.2.3. Theme 3: The value of hindsight

This construct consolidated responses by participants that considered what they had learned, what worked for them, and what they would have done differently. They were reflective of the decisions they made and whether they could have done things better. These reflections were expressed openly in the written responses. Many of them placed great emphasis on the first decision they made for treatment, irrespective of treatment decisions that were likely to follow considering the treatments they reported.

"I made the best decision I could, but [unfortunately] that is what put me where I am now"

Staff was involved in making these decisions.

"Someone to discuss everything with"

The implications of what would come of the decision they made weighed heavily.

"It gets hard working out what to do"

3.3. Key findings of the mixed methods analysis

Participants who reported treatment regret were associated with three or more SCNS-SF34 unmet needs of any type ($p = 0.01$). We did not find other statistically relevant associations between the qualitative findings and the number of unmet needs reported.

4. Discussion

We conducted a study that aimed to build on the current PRO literature to better understand the unmet needs for patients diagnosed with and treated for prostate cancer. This study identified that participants ranked sexual needs, needs relating to mood, and needs relating to information highest. It appears that unmet needs are cumulative, with participants having greater unmet needs when they have had more than one line of treatment. Qualitative constructs of information, relationships, and the value of hindsight reflect the identified unmet needs reported in the quantitative SCNS-SF34 data. Participants with three or more unmet needs expressed "treatment regret". The use of a qualitative survey in conjunction with a validated tool is a novel approach.

From clinical trials, issues relating to urinary, bowel, and sexual function feature strongly after treatment for localised cancer [21–23]. Our data demonstrated that sexual functioning and mood have the greatest unmet needs, with information resources lacking broadly. For those living with advanced cancer, research tells us that these impacts do not go away, but subsequent treatments can enhance these side effects, with added layers of reduced functional capacity, fatigue, and cognition [24,25]. Real-world data tell us that these treatment impacts are worse in clinical practice than previously thought [9,26–28]. Qualitative studies tell us that even 10–15 yr after treatment, patients still live with these impacts and feel abandoned with little information or support [29,30]. Our study identified that information needs featured both in the qualitative open text responses and in the validated SCNS-SF34, particularly for those who had received a diagnosis >2 yr ago. Dunn and colleagues [31] have built a survivorship framework off an extensive evidence base, which may address some of the unmet needs identified here. Their research reports that personal agency is central to their survivorship framework, with information, the prioritisation of relationships, and a need to be self-determined with care and rehabilitation from treatment.

Mood featured with unmet needs in our study. The impacts of prostate cancer on mood have a strong evidence base in the literature, highlighting distress and suicide risk for those who are diagnosed with prostate cancer [32–35]. Our study did not formally assess anxiety or depression, or use the measures used in these studies. Similar to us, studies have also identified treatment regret in almost a quarter of men [36]. In the localised prostate cancer population, treatment regret has been associated with positive surgical margins, patient education, and impacts on masculinity and/or hormones [36,37]. We certainly identified that those treated with any androgen deprivation therapy had higher unmet needs universally, which was also identified by Ralph and colleagues [26] in their PRO study. Misunderstanding about shared decision-making and a lack of information or understanding have been reported in other studies [37].

The use of the SCNS-SF34 in our study brought a unique perspective to the current PRO data, and directly addressed the outcomes we were seeking. In particular, the use of a supportive care need survey with an accompanying qualitative survey was potentially a strength of this study. Both quantitative and qualitative analyses independently brought new insights. It is possible that the qualitative questions may have influenced the responses from the participants. There are other critical limitations of this study, primarily around the sample of participants. We did not ask participants whether they were currently undergoing treatment, their age, their functional status, other comorbidities, socioeconomic status, and social supports. In addition, we did not ask whether their treatment was for curative or palliative intent, but we received responses from a proportion of patients who had received more than one line of treatment. A selection bias may have influenced

the responses received, though we received incomplete surveys that demonstrated similar characteristics to those completed. The size of voluntary participants was relatively small for a PRO study, and the setting of a single health service, albeit large, was also a limitation. Our confidence intervals were wide, indicating that whilst the findings were significant, these are not stable, and further research is needed.

This study has potentially identified that there are opportunities to build further evidence on treatment decision-making for those diagnosed with prostate cancer and to better understand the mechanisms of treatment regret. Understanding information needs, delivery of information, and best access to information is an important area for future research, articulated in our study, with signals across the broader literature. The impacts on sexual function and also relationships featured strongly, and this is an area of emerging interest. Continued research and clinical care involving PROs hold promise for better evidence and relevant health care delivery.

5. Conclusions

Investigation of unmet needs is useful to better understand the impacts of a prostate cancer diagnosis and subsequent treatments. This cross-sectional study was descriptive and aimed to explore unmet needs. There are a number of limitations, particularly absent demographics such as age, socioeconomics, and the goals of treatment on responses, which can be addressed in future cohort studies. Further research can better inform health service delivery. Areas of attention could include optimisation of information needs and the development of interventions that consistently prioritise relationships for patients. Unmet needs may result in treatment regret for those treated for prostate cancer. The findings from this study warrant further attention to prostate cancer supportive care in clinical practice.

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