Prostate cancer: unmet supportive and palliative care needs: national survey of patients and family carers

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ABSTRACT

Objectives Men living with prostate cancer have supportive and palliative needs. However, few studies detail unmet needs (vs quality of life measurement) or include data from those with advanced disease. We aimed to identify unmet needs of people living with prostate cancer (men, family carers), including those with advanced disease.

Methods Mixed-methods national survey (patient Supportive Care Needs Survey; Carer Support Needs Assessment Tool) and health status (EuroQol Visual Analogue Scale). Quantitative data were explored using regression analysis. Free text data were subjected to thematic analysis.

Results 216 men (mean age 65±8.5 years; active cancer 136 [63%]) and 97 carers (68 [70%] spouse/partner) provided data. 133 men (62%) reported moderate-to-high need which was more likely in advanced disease. Men’s health status was worse with active vs remitted disease (mean difference −11; 95% CI −17 to −5; p<0.001). 85 (88%) carers reported at least one unmet need relating to ‘enabling them to care’ and 83 (86%) relating to ‘their own well-being’. Carers with chronic illnesses had more unmet needs (p=0.01 to p=0.04) and patient receipt of palliative care independently predicted higher unmet carer needs (p=0.02). Free text data demonstrated widespread burden with: (1) poor communication/information, including about palliative care; (2) poorly managed symptoms/concerns and (3) poor care co-ordination. Incontinence, sexual dysfunction and hormone side-effects were serious problems, often left unaddressed.

Conclusions Many living with prostate cancer continue with wide-ranging concerns. Lack of systematic, ongoing needs assessment and poor communication compound inadequate clinical pathways. Person-centred care, interdisciplinary working and integrated palliative care should be adequately resourced.

INTRODUCTION

Men living with prostate cancer report unmet needs across all domains of life (physical, psychosocial, spiritual, financial, etc) with poor quality of life, adverse impacts on work and informational needs.

Informational needs span across diagnosis and treatment to treatment effects, expectations for progressive disease and symptom management. Informational needs remain unmet in up to a half of patients, continue after diagnosis, change over time, are associated with
lower physical, social and role functioning, higher levels of illness concern and ability to take part in treatment decision making.6

Nearly all men with prostate cancer have at least some unmet supportive care needs especially in those with greater psychological distress.11 Needs increase in number and severity in progressive disease, seriously affecting quality of life.2 3 Healthcare professionals must be able to identify, assess and manage these needs using communication, symptom control and psychosocial support skills, and identify those who need referral to specialist palliative care for complex and persistent problems at any stage of the disease trajectory, depending on need.13

However, relatively few studies present the breadth and detail of supportive and palliative care unmet needs (distinct from quality-of-life measurement), and data from those with advanced and progressive disease is sparse. We, therefore, sought to identify the unmet supportive and palliative care and informational needs of people living with prostate cancer (patient and carer), including people living with advanced disease.

METHODS

Summary design
This mixed-methods study used a national online survey with optional free text.

Survey development and data collection
The survey was developed from validated questionnaires with added questions to explore their experience of diagnosis, treatments received (now and previously) and access to a specialist nurse and piloted. The survey online link was advertised through an email invitation from Prostate Cancer UK to their members, and advertised via social media. A paper questionnaire was available on request. The survey was anonymous and completion taken as implied consent.

To assess patients’ needs we used the Supportive Care Needs Survey Short Form-34 (SCNS-SF34) with optional free text comments. The SCNS-SF34 is a validated 34-item measure assessing cancer patients’ unmet needs across psychological, health system information, physical and daily activity, patient care and support, and sexuality domains.

We collected demographic data from patients (age, ethnicity, metastatic disease or not, initial cancer treatment, current treatment, cancer nurse specialist and/or a palliative care nurse specialist access) and carers (age, sex).

Family members completed the Carer Support Needs Assessment Tool (CSNAT).16 Fourteen questions assess two domains of caring ‘support needed to be a carer’ (seven items) and ‘own well-being’ (seven items). A free text box was provided on both surveys to allow respondents to report other support needs. No character length was stipulated allowing respondents space to write as much or as little as they wished.

Health status was assessed using the 0–100 mm EuroQol Visual Analogue Scale (EQ-VAS) (100=best health imaginable; 0=worst health).

Sample size
To allow for modelling of associations between patient characteristics and survey responses, we aimed to recruit at least 200 participants.17

Data analysis
Carers and patient responses were analysed separately. Statistical analysis was conducted using SPSS (IBM, V24). Missing data were not imputed.

Patients
Descriptive statistical analyses summarised the needs of patient groups. SCNS-SF34 subscale scores were categorised according to maximum score (4 or 5 = ‘moderate-high need’; 3=‘low need’; 1 or 2 =‘no need’).

Ordinal logistic regression investigated associations between treatment type and level of patient need, adjusting for baseline demography (age, ethnicity), cancer stage and access to nurse specialist. The treatment types were: Active surveillance/watch and wait (yes/no); hormones (yes/no); radiotherapy treatment (yes/no); surgery (yes/no); chemotherapy (yes/no); palliative care (yes/no). Regression models explored associations between treatment type and health status, adjusting for these factors. Parameter and OR estimates were reported with 95% CI and p values.

Carers
Descriptive statistics were produced, and CSNAT subscale scores calculated by summing the subscale items, giving a range of 0–28 (higher score=greater unmet need). The scores were used for inferential analyses.

Independent t-test were performed to test for significant differences in unmet needs between carers of patients with active cancer and those in remission, and for differences in health status.

Regression analysis tested for significant associations between health status and level of unmet care needs adjusting for covariates: relationship to patient (spouse/other); presence of own chronic health problem (yes/no); cancer stage (active, early localised, locally advanced, metastatic). As cancer stage correlated with treatment modality, it was not included in these models. Due to the modest sample size separate models were calculated, each with one modality included as a third step after the covariates.

Free text were analysed using thematic analysis.18 Two authors (MJJ and MT) reviewed the free text responses and jointly developed a coding frame that one author (MT) applied to the dataset.

RESULTS
Sufficient data were provided by 216/249 men with prostate cancer and 97/110 carers.
Patients
Characteristics are seen in table 1. All cancer stages were represented although this was unreported by 41%. Most had not accessed a specialist palliative care nurse, and 14% had not accessed a prostate cancer nurse specialist. Most were of white ethnicity and lived in England although all UK nations were represented. The self-reported health status of patients was significantly worse for those living with active disease compared with those in remission (mean difference $-11; 95\%$ CI $-17$ to $-5; p<0.001$).

Patients reported multiple treatments, the most common current treatment was hormone therapy (86, 40%), then active surveillance (35, 16%), radiotherapy (27, 13%), chemotherapy (16, 7%), surgery (4, 2%) and palliative care (3, 1%). A further 11 (5%) reported ‘none’ which may refer to either active surveillance or palliative care; we, therefore, counted this group separately. The most common past treatment was hormones (90, 42%) then radiotherapy (84, 39%), surgery (79, 37%), active surveillance (60, 28%), chemotherapy (19, 9%) and palliative care (3, 1%).

Prevalence of unmet patient support needs
Table 2 presents the SCNS-34 survey subscale summary (online supplemental table 1; item level). Of 214 calculable SCNS scores, nearly two-thirds (133, 62%) had moderate-high need, 39 (18.2%) had low need and only 42 (19.6%) had none. Unmet needs were seen across all domains of experience, including men in remission.

Subscale level: If at least one item max score 4–5, then categorised as ‘moderate-to-high need’; If at least one item max score 3, then categorised as ‘low need’; If at least one item max score 1 or 2, then categorised as ‘no need’.

Predictors of patient unmet needs
Locally advanced/advanced cancer was associated with higher unmet need (online supplemental table 2). We found no evidence of association between treatment type and patient unmet needs, adjusted for age, ethnicity (white vs non-white), cancer stage, access to nurse specialist (yes/no).

Predictors of self-reported health status for patients
The self-reported health status of patients was significantly worse for those living with more advanced disease, but treatment type was not related (online supplemental table 3). Although not significant, access to nurse specialist was likely to contribute to better health status (mean VAS difference range 8.04–8.65, $p=0.07–0.08$), adjusted for age, ethnicity (white vs non-white), cancer stage.

Carers
Characteristics are presented in online supplemental table 1. Of all respondents, 84/97 carers were currently supporting someone with cancer; the remainder were living with someone in remission or had been recently bereaved. A few did not say. Most were spouse/partners of patients (68/97; 70%), then daughters (19/97; 19.6%). Three-quarters of carers were themselves living with a long-term condition.

Almost half were caring for someone with metastatic disease (46%), and 15% caring for someone receiving palliative care. Hormonal treatment was
the most common modality for both current and past treatments.

Prevalence of carer support needs

Reported unmet needs are presented in table 3. Eighty-five (88%) reported at least one unmet support need relating to enabling them to care, with an average 3.55 (SD=2.07) unmet needs.

Eighty-three (86%) respondents reported at least one unmet support need relating to their own well-being, with an average of 2.64 (SD=1.99) unmet needs.

The two most common unmet care needs linked to ‘enabling the carer to care’ were ‘knowing who to contact when concerned’ and ‘knowing what to expect in the future’. The two most common care needs related to ‘supporting the carers own well-being’ were ‘dealing with own feelings and worries’ and ‘looking after own health’.

There was a strong correlation between the subscale scores for the two types of carer needs (r²=0.753, n=96, p<0.01); individuals with unmet needs in one area were likely to have high unmet needs in both domains.

The Enabling them to care subscale score was negatively, but non-significantly correlated with poorer health status (ie, high needs were associated with lower health status score) (r²=−0.187, n=83, p=0.09).

Unmet needs relating to own well-being subscale scores was negatively and significantly associated with health status (ie, high needs associated with lower health score) (r²=−0.214, n=83, p=0.05).

Health status (n=83/97) was poorer for those caring for someone with active disease vs remission: (active disease 67mm±22, n=67 vs remission 81 mm±14, n=16; p=0.02). There was a significant negative correlation between unmet care needs (support in relation to own well-being) and health status but this relationship disappeared once carer characteristics (carer relationship and carer health) were added to the model (data not presented).

Carer self-reported health was poorer when they reported living with a chronic health problem (95% CI −12.25 to −0.36; p=0.04). Adding patient treatment modality did not add to the variance explained, except when the patient was receiving palliative care where treatment modality was associated with a reduction in health status for the carer of 15.97 points (95% CI −29.2 to −2.76; p<0.05) (summary data available on request).

Survey free text

Thirty-eight carers and 77 men with prostate cancer added free text comments. Notably, most data regarding palliative care came from written free text comments from carers. Illustrative quotes are seen in table 5 (an extended version is available as online supplemental table 5).

Overall, free text responses were negative in character describing a story of persistently high symptom burden, particularly for those taking...
Table 4  Final models predicting unmet care needs (carers)

**Predicting unmet care needs (Help needed to Care)**

| Active surveillance | Hormones | Radiotherapy |
|---------------------|----------|--------------|
| **Parameter estimates** | **95% CI** | **P value** | **Parameter estimates** | **95% CI** | **P value** | **Parameter estimates** | **95% CI** | **P value** |
| Relationship (spouse=yes) | $-1.33$ | $-3.11$ to $0.452$ | $0.14$ | $-1.29$ | $-3.09$ to $0.5$ | $0.16$ | $-1.23$ | $-3.03$ to $0.57$ | $0.18$ |
| Chronic health problem (=yes) | $0.944$ | $-0.14$ to $2.03$ | $0.09$ | $0.82$ | $-0.26$ to $1.9$ | $0.13$ | $0.84$ | $-0.236$ to $1.92$ | $0.12$ |
| Treatment effect | $-1.54$ | $-4.05$ to $0.97$ | $0.22$ | $0.47$ | $-1.2$ to $2.15$ | $0.58$ | $1.08$ | $-1.42$ to $3.58$ | $0.39$ |

**Surgery**

| Parameter estimates | **95% CI** | **P value** | Parameter estimates | **95% CI** | **P value** | Parameter estimates | **95% CI** | **P value** |
|---------------------|----------|--------------|---------------------|----------|--------------|---------------------|----------|--------------|
| Relationship (spouse=yes) | $-1.34$ | $-3.15$ to $0.46$ | $0.14$ | $-1.25$ | $-3.06$ to $0.56$ | $0.17$ | $-1.23$ | $-3.02$ to $0.56$ | $0.18$ |
| Chronic health problem (=yes) | $0.88$ | $-0.21$ to $1.97$ | $0.11$ | $0.82$ | $-0.27$ to $1.91$ | $0.14$ | $0.9$ | $-0.18$ to $1.98$ | $0.1$ |
| Treatment effect | $0.63$ | $-2.02$ to $3.26$ | $0.64$ | $0.63$ | $-1.99$ to $3.25$ | $0.63$ | $1.4$ | $-1.02$ to $3.82$ | $0.25$ |

**Predicting unmet care needs (own care needs)**

| Active Surveillance | Hormones | Radiotherapy |
|---------------------|----------|--------------|
| **Parameter estimates** | **95% CI** | **P value** | **Parameter estimates** | **95% CI** | **P value** | **Parameter estimates** | **95% CI** | **P value** |
| Relationship (spouse=yes) | $0.06$ | $-1.75$ to $1.87$ | $0.95$ | $0.09$ | $-1.73$ to $1.91$ | $0.92$ | $0.11$ | $-1.72$ to $1.94$ | $0.9$ |
| Chronic health problem (=yes) | $1.37$ | $0.28$ to $2.46$ | $0.01^*$ | $1.28$ | $0.19$ to $2.36$ | $0.02^*$ | $1.27$ | $0.18$ to $2.35$ | $0.02^*$ |
| Treatment effect | $-1.57$ | $-4.09$ to $0.95$ | $0.22$ | $-0.26$ | $-1.95$ to $1.43$ | $0.76$ | $0.11$ | $-2.42$ to $2.62$ | $0.93$ |

**Surgery**

| Parameter estimates | **95% CI** | **P value** | Parameter estimates | **95% CI** | **P value** | Parameter estimates | **95% CI** | **P value** |
|---------------------|----------|--------------|---------------------|----------|--------------|---------------------|----------|--------------|
| Relationship (spouse=yes) | $0.11$ | $-1.72$ to $1.95$ | $0.9$ | $0.25$ | $-1.53$ to $2.04$ | $0.77$ | $0.18$ | $-1.63$ to $2.00$ | $0.84$ |
| Chronic health problem (=yes) | $1.25$ | $0.15$ to $2.35$ | $0.03^*$ | $1.15$ | $0.08$ to $2.12$ | $0.04^*$ | $1.33$ | $0.25$ to $2.41$ | $0.02^*$ |
| Treatment effect | $-0.27$ | $-2.92$ to $2.38$ | $0.81$ | $2.81$ | $0.13$ to $5.48$ | $0.04^*$ | $1.36$ | $-1.07$ to $3.78$ | $0.27$ |

* statistically significant
hormone treatment. Symptoms were seen as inevitable, to be borne stoically. Support services were usually helpful, but varied in existence, accessibility and quality. Access to the Macmillan prostate nurse specialist was often difficult and one man described how formulaic responses without compassion and individual understanding did not provide what he needed. Those in rural areas were often physically and socially isolated.

Person-centred (vs disease-centred) care was not universal. Hospital services were seen as prohibitively busy and general practitioners (GPs) viewed as unhelpful. Problems with continence and sexual activity were crucially important to men, but these issues were bypassed by their clinicians.

Carers in particular highlighted the gaps in services where opportunities and space for patients to talk with clinicians about the devastating effects are needed but rarely provided. Carers often felt alone and unsupported in inadequately resourced services.

Poor coordination of services where patients and carers felt they had to navigate the chaotic system themselves, (‘forever chasing up services over appointments’) or be forgotten, was frustrating, tiring, and worrying in the context of a limited prognosis. Practical helpful things were often provided late, or not at all as patients and carers found their own way around the system or gained what they could from other sources.

Lastly, palliative care was seen as for the last few days of life only, but even then, was not always accessed or offered. One carer wrote poignantly that clinicians had not been clear about her father’s imminent death, or informed her what to expect.
DISCUSSION
Wide-ranging unmet needs were commonly experienced by men with prostate cancer and family carers (mainly women) and more likely with advanced disease. Poorer self-reported health was independently predicted by advanced disease stage.

The free text data illustrated burden from a life-changing disease, and treatment side effects against a backdrop of: (1) poor communication across the cancer journey leaving serious information gaps, including about palliative care; (2) poor management of symptoms and multi-domain concerns leading to a sense of abandonment; and (3) poor service configurations and care co-ordination with inadequate resources.

The range and prevalence of problems in this survey are consistent with a Pan-European survey of men with prostate cancer and their carers19 and of the Life After Prostate Cancer Diagnosis (LAPCD) UK survey.2 20 The LAPCD researchers found that problems were more likely with more advanced disease (stage II–IV) and that although half of respondents had sexual problems few had been offered support.2

Interestingly, the LAPCD survey found comparable health-related quality of life (EQ-5D21) to men in the general population and a quarter (23%) of men with stage 4 (only 11% of their sample) disease reported no limitations in any EQ-5D domain. However, the EQ-5D omits specific enquiry about sexual dysfunction, incontinence or hormone related side effects. In our data, the EQ-VAS global measure showed reduced health status in patients with active disease; similarly among carers. Over a third of our respondents had advanced disease, and we placed no limit on time since diagnosis. We also measured unmet needs rather than quality of life. The two approaches measure different, although overlapping, constructs;14 a man may have significant impairment but perceive this to be well-managed (no unmet need) or vice versa.

Our free text data were almost completely negative. However, we also conducted in-depth interviews with a sub-group sample of survey respondents (reported elsewhere22) which presented a more balanced narrative. In the in-depth interviews, although many of these challenges were raised, beacons of excellence were also described: (1) patients treated as an individual, with time for holistic patient and carer needs assessment with either direct support or referral to appropriate services; (2) services providing skilled empathic nurse specialists and support groups, and streamlined provision between healthcare settings (secondary, primary, palliative and charity groups). Even with restricted services, person-centred honest communication and coordinated care greatly ameliorated the impact of problems. Our written qualitative data delivered less favourable reports perhaps facilitated by perceived anonymity; talking to a (female) researcher may have inhibited some.

Giving patients information immediately following bad news can block out reception and reduce opportunities to access professionals with further issues.22 Clinicians should not minimise early-stage disease, as some patients feel abandoned on ‘surveillance’ with higher psychological distress than those receiving active treatment.23 24 Most patients appreciate honesty in professionals allowing realistic expectations and adaptation. There is better patient experience when professionals appear to be patient.22 25 Poor or conflicting information about treatment side effects, and a lack of discussion about treatments, leads to unempowered choices and regrets.22 23 Referrals to relevant professional services are often not made. The LAPCD interviews also found examples of good care: doctors and specialist nurses practising empathetic, non-rushed information giving and checking using a person-centre approach, with streamlined communication across healthcare setting, and streamlined investigation and follow-up backed up by good literature and other resource.25

Patients’ concerns change over time and unmet needs may persist with over a third of men reporting at least one unmet need at 15 years.26 Regular systematic review must be built into follow-up; relying on patients to volunteer concerns is insufficient.27 Our participants were reluctant to raise important concerns, because of embarrassment, or assuming no help was possible because their clinician did not ask. The Pan-European survey showed that 92% clinicians thought that they addressed patients’ quality of life concerns, but only 14% of patients agreed.19 Holistic knowledge of the patient is needed, achieved through continuity of care and easy patient access to key workers such as specialist nurses or patient navigators.22 28

Information about palliative care was avoided or poorly communicated leading to misconception and underuse. Many patients, members of the general public and clinicians believe ‘palliative care’ is synonymous with care in the last days/weeks of life.22 29 This is despite evidence that needs-based, rather than prognosis based, access to palliative care improves quality of life, symptom control, reducing unnecessary hospital admissions and invasive futile interventions in both cancer30 and non-malignant disease.31 Integrated working between prostate cancer and palliative care teams may help provide a safety net alongside other services providing clinical psychology, incontinence care and sexual function rehabilitation. However, clinicians need skills in (1) holistic assessment, (2) symptom management and (3) communication regarding progressing disease, advance care planning and palliative care referral, recognising that patients may misinterpret the offer.

Many participants perceived their GPs as unhelpful despite many being good communicators, skilled in palliative care. Poor communication between secondary and primary care renders this avenue of
care blocked with patients believing GPs, (who may concur) have no role in their care.\textsuperscript{32}

Limitations and strengths
This national survey was distributed via a charity and social media, so our response rate is unknown. Survey findings are not generalisable to all, but all disease stages, treatments and UK regions were represented. Findings were consistent with data from other countries. Our respondents were younger on average than the LACPD study (63 vs 71); older people with less online access, or less confident, may be less well represented.

Unexpectedly, few expressed concerns about pain; perhaps because clinicians are trained in pain relief and have effective treatments, or because those with bad pain were less able to respond. However, it also highlights that patients’ palliative care needs encompass more than pain control.

The mixed-methods approach allowed insights regarding the quantitative responses. Recruitment avoided identification through health service providers and may have minimised reporter bias. Few participants were non-white as with previous under-representation of Black African/Caribbean men in prostate cancer research despite their risk of aggressive tumours and perceived lack of support felt by their spouses/partners.\textsuperscript{33,34}

CONCLUSIONS
Many men with prostate cancer and their families live with serious long-term effects. Needs are not identified, assessed or addressed systematically. Inadequate clinical pathways and poor communication between clinicians and patients compounds this problem. Growing evidence suggests that despite beacons of good practice, there is a pressing need for person-centred care and better inter-disciplinary working, including integrated palliative care, to be the standard of care.

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