Title: Men with prostate cancer and their family carers have unmet supportive and palliative care needs: a national survey

Running title Prostate cancer: unmet needs & person-centred care

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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 (EQ-VAS). 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-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 wellbeing*". 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: i) poor communication/information, including about palliative care; ii) poorly managed symptoms/concerns; iii) 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, inter-disciplinary working, and integrated palliative care should be resourced.

Key words: prostate cancer; supportive care; palliative care; survey

Key Messages Box:

What was already known?

- We know men with prostate cancer can have poor quality of life, but know little about their *unmet* needs, particularly in those with advanced disease.
- We know even less about the unmet needs of those providing informal care.

What are the new findings?

- Nearly two-thirds of men report unmet needs; more common in those with advanced disease. Unmet needs demonstrated a widespread burden with: i) poor communication/information, including about palliative care; ii) poorly managed symptoms/concerns; iii) poor care co-ordination
- Almost all carers reported at least one unmet need in relation to enabling them to care, and their own wellbeing and those with chronic health conditions themselves had more unmet need.

What is their significance?

- Lack of systematic, ongoing needs assessment and poor communication compound inadequate clinical pathways.
- Person-centred care, inter-disciplinary working, and integrated palliative care should be adequately resourced.

INTRODUCTION

Men living with prostate cancer report unmet needs across all domains of life[1] (physical, psycho-social, spiritual, financial etc.) with poor quality of life, [2] adverse impacts on work, [3] and informational needs.[4-6]

Informational needs span across diagnosis and treatment to treatment effects, expectations for progressive disease and symptom management.[4, 5, 7, 8] Informational needs remain unmet in up to a half of patients, [9, 10] continue after diagnosis, change over time,[9] are associated with lower physical, social and role functioning, higher levels of illness concern,[10] and ability to take part in treatment-decision making.[6]

Nearly all men with prostate cancer have at least some unmet supportive care needs[11], especially in those with greater psychological distress.[12] Needs increase in number and severity in progressive disease, seriously affecting quality of life.[2, 5] Health care professionals must be able to identify, assess and manage these needs using communication, symptom control and psycho-social 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 [14]), 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. Ethical approval prior to data collection was given by Hull York Medical School Ethics Committee.

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 URL 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 (SCNS-34)[15] 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" (7 items) and "Own wellbeing" (7 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 0-100mm 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 summarized 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 odds ratio estimates were reported with 95% CI and p values.

Carers
Descriptive statistics were produced, and CSNAT subscale scores calculated by summating 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 (MJ & 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 United Kingdom 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).

Table 1. Patient characteristics

Describe your cancer	Living with it	136 (63%)
	Cured/in remission	80 (37%)
Cancer stage	Early localized	48 (22.2%)
	Locally advanced	35 (16.2%)
	Advanced	45 (20.8%)
	Don't know/not to say	88 (40.7%)
Access to nurse specialist	Currently	111 (51.6%)
	In the past	73 (34.0%)
	Never	31 (14.4%)
Access to palliative care nurse specialist	Currently	12 (5.6%)
	In the past	8 (3.7%)
	Never	194 (90.7%)
Age	Mean (SD)	65.0 (8.5)
	Median (IQR)	66 (11)
Ethnic region	Asian	1 (0.5%)
	Mixed	2 (0.9%)
	White	212 (98.1%)
	Not to say	1 (0.5%)
Living region	England	194 (89.8%)
	Scotland	15 (6.9%)
	Wales	4 (1.9%)
	Northern Ireland	3 (1.4%)

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 Table 1; item level). Of 214 calculable SCNS scores, nearly two-thirds (133, 62.1%) 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.

Table 2. SCNS-34 questionnaire subscale summary

Subscale	**Category**	**N (%)**
	No need	64 (30.2%)

Psychological need (212 calculable)	Low need	44 (20.8%)
	Moderate to high need	104 (49.1%)
Health system & information needs (192 calculable)	No need	79 (41.1%)
	Low need	33 (17.2%)
	Moderate to high need	80 (41.7%)
Physical and daily living needs (214 calculable)	No need	121 (56.5%)
	Low need	31 (14.5%)
	Moderate to high need	62 (29.0%)
Patient care and support needs (198 calculable)	No need	111 (56.1%)
	Low need	33 (16.7%)
	Moderate to high need	54 (27.3%)
Sexuality needs (202 calculable)	No need	98 (48.5%)
	Low need	44 (21.8%)
	Moderate to high need	60 (29.7%)

Subscale level: If at least one item max score 4-5, then categorized as “moderate-high need”; If at least one item max score 3, then categorized as “low need”; If at least one item max score 1 or 2, then categorized as “no need”.

Predictors of patient unmet needs

Locally advanced/advanced cancer was associated with higher unmet need (Online 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 Table 3) Although not significant, access to nurse specialist was likely to contribute to better health status (mean VAS difference range 8.04 to 8.65, p values 0.07 to 0.08), adjusted for age, ethnicity (white vs non-white), cancer stage.

Carers

Characteristics are presented in Online Table 4. 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 on average 3.35 (SD=2.07) unmet needs.

Eighty-three (86%) respondents reported at least one unmet support need *relating to their own wellbeing*, 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 (r^2 =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 (i.e. high needs were associated with lower health status score) (r^2 =-0.187, n=83, p=0.09). *Unmet needs relating to own wellbeing* subscale scores was negatively and significantly associated with health status (i.e. high needs associated with lower health score) (r^2= -0.214, n=83, p=0.05).

Table 3: Carer Support Needs Assessment Tool scores

Domain 1: enabling the carer to care (n=97)	No need N (%)	A little bit more help N (%)	Quite a bit more help N (%)	Very much more help N (%)	Missing N (%)
Understanding their relative's illness	40 (41.2)	39 (40.2)	12 (12.4)	6 (6.2)	0 (0)
Managing their relative's symptoms, including giving medicines	66 (68)	24 (24.7)	6 (6.2)	1 (1)	0 (0)
Providing personal care (e.g. dressing, washing, toileting)	75 (77.3)	17 (17.5)	1 (1)	4 (4.1)	(0)
Knowing whom to contact when concerned	31 (32)	36 (37.5)	14 (14.4)	15 (15.5)	1 (1)
Equipment to help care for their relative	70 (72.2)	13 (13.4)	8 (8.2)	2 (2.1)	4 (4.1)
Talking with their relative about his/her illness	38 (39.2)	32 (33)	17 (17.5)	7 (7.2)	3 (3.1)
Knowing what to expect in the future when caring for their relative	22 (22.7)	34 (35.1)	22 (22.7)	15 (15.5)	4 (4.1)
Domain 2: Support in relation to own wellbeing (n=97)					
Looking after own physical health	53 (54.6)	26 (26.8)	12 (12.4)	4 (4.1)	2 (2.1)
Having time for oneself in the day	57 (58.8)	24 (24.7)	13 (13.4)	3 (3.1)	0 (0)
Any financial, legal, or work issues	64 (66)	20 (20.6)	4 (4.1)	9 (9.3)	0 (0)
Dealing with feelings and worries	17 (17.5)	40 (41.2)	24 (24.7)	16 (16.5)	0 (0)
Beliefs or spiritual concerns	80 (82.5)	12 (12.4)	1 (1.0)	1 (1.0)	3 (3.1)

Practical help in the home	67 (69.1)	17 (17.5)	7(7.2)	3 (3.1)	3 (3.1)
Getting a break from caring overnight	76 (78.4)	10 (10.3)	3 (3.1)	4 (4.1)	4 (4.1)

Predictors of Carer Self-reported Health Status
Health status (n=83/97) was poorer for those caring for someone with active disease *versus* remission: (active disease 67mm +/-22, n=67 *vs* remission 81mm +/- 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, -.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, -2.76; p<0.05) (data available on request).

Predictors of unmet care needs
After controlling for relationship to patient and own chronic illness, treatment modalities did not predict either domain of unmet carer support needs. The presence of a chronic illness significantly predicted unmet supportive care needs in relation to ones' own care needs (final models; Table 4).

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, 0.452	0.14	-1.29	-3.09, 0.5	0.16	-1.23	-3.03, 0.57	0.18
Chronic health problem (= yes)	0.944	-0.14, 2.03	0.09	0.82	-0.26, 1.9	0.13	0.84	-.236, 1.92	0.12
Treatment effect	-1.54	-4.05, 0.97	0.22	0.47	-1.2, 2.15	0.58	1.08	-1.42, 3.58	0.39
	Surgery			**Chemotherapy**			**Palliative Care**		
	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, 0.46	0.14	-1.25	-3.06, 0.56	0.17	-1.23	-3.02, 0.56	0.18
Chronic health problem (= yes)	0.88	-0.21, 1.97	0.11	0.82	-0.27, 1.91	0.14	0.9	-0.18, 1.98	0.1
Treatment effect	0.63	-2.02, 3.26	0.64	0.63	-1.99, 3.25	0.63	1.4	-1.02, 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, 1.87	0.95	0.09	-1.73, 1.91	0.92	0.11	-1.72, 1.94	0.9

Chronic health problem (= yes)	1.37	0.28, 2.46	**0.01***	1.28	0.19, 2.36	**0.02***	1.27	0.18, 2.35	**0.02***
Treatment effect	-1.57	-4.09, 0.95	0.22	-0.26	-1.95, 1.43	0.76	0.11	-2.42, 2.62	0.93
	Surgery			**Chemotherapy**			**Palliative Care**		
	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, 1.95	0.9	0.25	-1.53, 2.04	0.77	0.18	-1.63, 2.00	0.84
Chronic health problem (= yes)	1.25	0.15, 2.35	**0.03***	1.15	0.08, 2.12	**0.04***	1.33	0.25, 2.41	**0.02***
Treatment effect	-0.27	-2.92, 2.38	0.81	2.81	0.13, 5.48	**0.04***	1.36	-1.07, 3.78	0.27

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 Table 5).

Overall, free text responses were negative in character describing a story of persistently high symptom burden, particularly for those taking 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 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.

Table 5 Extended illustrative quotes from free text

Access to nurse support	*Although I have a named nurse contacting her is virtually impossible you can leave a message but it can be four or five days before she gets back to me. (patient 64)* *I have a specialist nurse but I do not get the support from her that I need. She is a nice enough person and tries to be upbeat about everything but …does not listen … I think a good specialist nurse who listens, has empathy and who is pro-active in arranging*

	support when it's needed or at least signposts me in the right direction would be the solution to many of the difficulties I encounter. (patient 79)
Difficulties in accessing person centred care	*The [hormone treatment] has had an increasing impact on my wellbeing and I feel alone and forgot about. (patient 32)* *My wife and I were not offered sexual health counselling. My GP appears uninterested in my post operative recovery as was my employer. (patient 19)* *Care I received for difficult and life-changing permanent after-effects of pelvic radiotherapy was almost non-existent. Medics seemed surprised, and not interested. (patient 69)* *No one prepares for how it feels to lose your [erectile] function or even wants to talk about it… I have struggled with this and I can't go through the pump and pills shit because it hurts my wife. (patient 103)* *Waiting 9 months for appointments to deal with the side effects of treatments, as I have done, is bad enough when you've got 50 years left but is a much bigger deal when you've been told you'll probably be dead in 5. (patient 79)*
Psychological support needed for patient and carer	*[It would have been good to have a] specific appointment given to husband to help him verbalise his emotional trauma brought on through changes of physical appearance, loss of male identity, feeling of weakness and vulnerability in no longer being alpha male able to defend himself and family.(carer 89)* *Prostate cancer often wrecks a couple's intimate relationship, support coming to terms with this and the changes in the person I care for. I felt so alone and struggled to manage my feelings of grief, anger, forever chasing up services over appointments, treatments etc., you are just left to your own devices. Services are often overstretched and can't offer the support people need.(carer 5)* *Being acknowledged as a carer and having someone ask how I am doing?(carer 162)*
Poor co-ordination of care and difficulties navigating the system	*Awareness of what financial assistance is available for provision of continence pads, etc. It took me 6 months to find out how to get these. (patient 193)* *Communication between different departments and institutions tends to not work well and I have to know what each departments wants other departments /institutions to do and I have to make sure it gets done.(carer 190)* *I've never received an appointment with a physio – I've used Youtube instead - phoning the hospital is hit or miss for help.(patient 84)* *There is a network of support groups across the UK that can help newly diagnosed men benefit from talking to the men that have received treatment. The medical profession needs to use this resource and it cost nothing! (patient 161)* *I find it difficult to contact the consultant to chase up when an appointment is due. It's also difficult to contact the Macmillan nurses as they are short staffed. I am still unsure*

	of future treatment and worry that it could be too late by the time decisions are made. (patient 227) *My GP seems reluctant to part with this information [PSA results… When you live your life in 12-week chunks getting the results ASAP [as soon as possible] is vital to m.e (patient 92)*
Poor communication re end of life	*How to cope when treatment fails. Feeling of abandonment... Some doctors lack empathy and understanding. They deliver life changing news and to some extent can be left floundering.(carer 292)* *One of the hardest things I had to deal with was not realising that he was actually going to die until it was too late and then having to deal with this and not realising what it would be like once he had died and how this would affect everyone in the family and how to cope with his death. Personally I think it would be helpful if Doctors tell 'the ugly truth' of what to expect in regard to what everyone is likely to go through and how horrendous it is to watch someone you love die in front of you/your family. I was not prepared for this at all and was particularly shocked at seeing how the body changed colour within minutes of death having experienced my lovely Dad dying in front of me gasping for his last breaths.(carer 71)*

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: i) poor communication across the cancer journey leaving serious information gaps, including about palliative care; ii) poor management of symptoms and multi-domain concerns leading to a sense of abandonment; iii) 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 carers[19] and of the Life After Prostate Cancer Diagnosis (LAPCD) UK survey.[20, 21] The LAPCD researchers found that problems were more likely with more advanced disease (stage II to 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-5D [22]) 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 amongst 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, albeit 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 elsewhere [23]) which presented a more balanced narrative. In the in-depth interviews, although many of these challenges were raised, beacons of excellence were also described: i) patients treated as an individual, with time for holistic patient and carer needs assessment with either direct support or referral to appropriate services, ii) 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.[23] Clinicians should not minimise early-stage disease, as some patients feel abandoned on “surveillance” with higher psychological distress than those receiving active treatment.[24,25] Most patients appreciate honesty in professionals allowing realistic expectations and adaptation. There is better patient experience when professionals appear to be patient.[23, 26] Poor or conflicting information about treatment side-effects, and a lack of discussion about treatments, leads to un-empowered choices and regrets.[23, 26] Referrals to relevant professional services are often not made. The LAPCD interviews also found examples of good care: doctors and specialist nurses practising empathic, 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.[26]

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 [27]. Regular systematic review must be built into follow up; relying on patients to volunteer concerns is insufficient.[28] 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.[23, 29]

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. [23, 30] 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 cancer [31] and non-malignant disease.[32] 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 i) holistic assessment, ii) symptom management and iii) 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.[33]

Limitations and strengths

This national survey was distributed *via* a charity and social media, so our response rate is unknown. Survey findings are not generalizable 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 (65 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 underrepresentation 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. [34, 35]

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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