The unique information and communication needs of men affected by prostate cancer: a qualitative study of men's experience

Information need of prostate cancer patients

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DATA AVAILABILITY

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

CONFLICT OF INTEREST

The authors declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

AUTHOR CONTRIBUTIONS

MJ and MT conceptualised and designed the study. MT supervised the study. LJ and MT conducted the interviews. HC analysed and interpreted the data and wrote the original draft. MJ, MT and LJ validated the analysis. All authors reviewed and edited the manuscript and approved the final draft.

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Abstract

Objective: To explore the specific information and communication needs of men affected by prostate cancer to inform the development of educational materials for clinicians.

Methods: This is a qualitative descriptive study. A purposive sampling strategy was used to identify men at different cancer stages and with experience of different treatment regimens. Semi-structured interviews (25) were conducted with nineteen men and six carers over the phone. Interview data were analysed using a framework approach.

Results: Four themes emerged: gaps in the information provided by secondary care doctors and nurses; communication skills needed in effective clinical information provision; a need for individualised information; alternative information sources used to meet unmet needs. Regardless of cancer stage and treatment, men with prostate cancer and their carers found information regarding common and burdensome adverse effects of prostate cancer treatment particularly lacking, and their ongoing and changing information needs often overlooked. They needed information delivered in a compassionate and individually tailored manner, considering content, timing, and emotional support within the context of their unique life circumstances.

Conclusion: Clinicians often fail to recognise the need for or deliver patient-centred conversations about treatment, managing side effects and prognosis. The findings will be used to develop clinician-facing educational materials.

KEYWORDS

prostate cancer, patient, information need, communication skill, secondary care, symptom management

1. INTRODUCTION

Prostate cancer is the second most common cancer and the fifth leading cause of death from cancer in men worldwide (Bray et al., 2018). It is the most commonly diagnosed cancer among men in higher-income countries, with incidence rates highest where there is the widespread practice of prostate specific antigen (PSA) test. In the UK, as the most common cancer in men, it accounted for 26% of all new cancer cases in men in 2017 (Cancer Research, 2020), with incidence rates projected to rise by 12% by 2035 (Smittenaar et al., 2016).

Men with prostate cancer can experience a range of treatment-related adverse effects, such as urinary, bowel and sexual dysfunction (Appleton et al., 2015; Donovan et al., 2016; Jung et al., 2016; Ream et al., 2008), and associated psychological distress and depression (Bill-Axelson et al., 2013; Jung et al., 2016; Ream et al., 2008; Wootten & Siddons, 2013). Post treatment, many experience difficulties with body image, masculinity and self-esteem (Appleton et al., 2015; Harrington, 2011), and impaired quality of current and future partner/marital relationships and sexual intimacy (Appleton et al., 2015; Tucker et al., 2016). It has been found that in higher-income countries, including the UK, men commonly experience a range of unmet supportive care needs including informational, spiritual, emotional, social, or physical needs (King et al., 2015; Paterson et al., 2015; Ream et al., 2008).

There has been a growing body of qualitative research examining men's experience of and need for supportive care (Arrington, 2015; Bamidele et al., 2018; Chambers et al., 2018; Dunn et al., 2020; King et al., 2015; Kirkman et al., 2017; Netsey-Afedo et al., 2019; Paterson et al., 2015; Paterson et al., 2017; Schildmeijer et al., 2019). These studies helped to identify priority areas of unmet informational need, such as diagnostic tests (e.g. PSA), treatment

options and outcomes, prognosis, and adverse effects of treatment (short-term and long-term) and their management (Bamidele et al., 2018; Chambers et al., 2018; Dunn et al., 2020; King et al., 2015; Netsey-Afedo et al., 2019; Paterson et al., 2015; Paterson et al., 2017; Schildmeijer et al., 2019). Barriers to meeting men's information needs were also noted, such as information undersupply or overload, and communication problems men experienced with professionals (Bamidele et al., 2018; Chambers et al., 2018; Dunn et al., 2020; King et al., 2015; Kirkman et al., 2017; Netsey-Afedo et al., 2019; Paterson et al., 2015; Paterson et al., 2017; Schildmeijer et al., 2019). Moreover, studies have found that access to a specialist nurse meant the experience of supportive care was better (Dunn et al., 2020; King et al., 2015); and men used a variety of alternative information sources to meet their unmet needs (Arrington, 2015; Dunn et al., 2020; King et al., 2015; Kirkman et al., 2017; Schildmeijer et al., 2019).

In the UK, high-quality, accessible health information is widely recognised as one of the most important components of effective supportive cancer care (Department of Health and Social Care, 2012; Macmillan Cancer Support, 2019). The Prostate Cancer Diagnosis and Treatment guideline published by the National Institute for Health and Care Excellence recommends that men with prostate cancer and their partners are provided with adequate, tailored information about the consequences of treatment decisions, focusing on quality of life as well as survival; specifically, they should be informed about the impact of treatment on their sexual function, physical appearance, continence and other aspects of masculinity (NICE, 2014; 2019). Evidence on how well the recommendation has been implemented in clinical practice is sparse. However, a recent UK-wide, population-based study, which explored experiences of treatment decision-making among prostate cancer patients, found

that, still, information on potential side-effects was often reportedly inadequate (Wagland et al., 2019). This means that there is still scope for practice improvement.

The current educational resources for clinicians developed by the charity Prostate Cancer UK (PCUK) contain some information about palliative/supportive care needs and their management but an internal review determined these were insufficient, particularly in terms of patient information/communication needs and how they can be met. This study was undertaken on behalf of the charity, and the final goal was to develop *patient-informed*, palliative/supportive care education materials for health care professionals, which the charity would use to help improve the clinical practice. So far, few studies have focused exclusively on exploring men's experiences of information and/or communication in the UK secondary care setting. To design new educational materials that target the issues identified by the men themselves as important, we interviewed men affected by prostate cancer and their family members, aiming for a focused and in-depth understanding of men's experiences of and specific needs for information and communication.

2. METHODS

2.1 Study design

This is part of a mixed-methods study to explore the supportive and palliative care needs of men with prostate cancer and their family members. A national cross-sectional online survey (to be reported separately) was distributed by Prostate Cancer UK (PCUK), and through University social media platforms (e.g. Twitter, Facebook). A sample of survey respondents was interviewed to explore their experiences and needs in more depth. The study was approved by the Hull York Medical School Ethics Committee, University of Hull, Hull, UK (18 03 granted 05 February 2018).

2.2 Participants

Altogether, 216 men (mean age 65 +/-8.5 years; active cancer 136 [63%]) and 97 carers (spouse/partner 68 [70%]) responded to the online survey and provided sufficient data. In the survey, demographic data collected from men with prostate cancer included age, ethnicity, metastatic disease or not, initial cancer treatment, current treatment, and cancer nurse specialist and/or palliative care nurse specialist access; only age and gender were collected from carers. The survey provided the opportunity for respondents to leave their contact details and consent to contact, and 60 out of 216 (28%) men and 11 out of 97 (11%) carers volunteered to be interviewed, from whom interview participants were selected. A purposive sampling strategy was used (Palys, 2008), with the intention to gain maximum variation in views and experiences. Specifically, a predetermined sampling frame (Table 1) was used to select men at different cancer stages and with experience of different treatment regimens. Exclusion criteria included: insufficient English, not willing or unable to give informed consent, and meeting the criteria in the sampling frame that is already met. When eligible men were not available for interview, their carers were included instead.

2.3 Data collection

Our study aimed to address specific clinical issues and contribute to change and quality improvement in the practice setting. Therefore, we used a qualitative descriptive design (Bradshaw et al. 2017; Doyle et al. 2020). A qualitative descriptive design is commonly used in nursing and healthcare research to provide straightforward descriptions of experiences and perceptions (Doyle et al. 2020). In other words, it does not require a deeply theoretical context and aims to stay close to and describe participants' experiences. A topic guide was

developed based on existing literature and expert opinion from multidisciplinary perspectives, and revised following pilot interviews (APPENDIX 1). Consent forms were completed online or returned by post prior to interview. All interviews (25) were conducted over the telephone by LJ and MT (between May and September 2018) and audio recorded with consent. The interviews were transcribed verbatim and anonymised with a unique ID code and distinguishing features were removed.

2.4 Data analysis

Interview transcripts were analysed by HC using framework analysis (Gale et al., 2013; Ritchie & Spencer, 1994), with the aid of NVivo11. The initial coding and the development of an analytical framework (matrix) were validated by members of the multidisciplinary research team (i.e. Intercoder agreement and audit trail). This helped to ensure that the main analyst (with a background in public health) had not drawn exclusively from the data that confirmed her presumptions. The perspectives of colleagues from different disciplinary backgrounds (including psychology, medical sociology and palliative medicine) also added analytic depth to data interpretation. This kind of team effort improved the validity of interpretation and enhanced the credibility and relevance of the findings (Ritchie & Spencer, 1994).

A combined (deductive and inductive) approach was taken: to explore some specific issues informed by previous literature and the specifics of the research question while leaving space to discover other unexpected aspects of the participants' experience (see APPENDIX 2. Nodes (themes) in NVivo). The thematic framework (matrix) that the team developed was both case (individual participant) and theme based, i.e. a spreadsheet containing numerous cells into which summarized data were entered by themes (columns)

and cases (rows). The spreadsheet provided an intuitively structured overview of the data while situating each perspective in context by retaining the connection to other aspects of each individual's account (Gale et al., 2013). It made it easy to compare and contrast data across cases as well as within individual cases. As a result, commonalities and differences in the data were identified, as well as relationships between different parts of the data, thereby seeking to draw descriptive and explanatory conclusions clustered around themes.

2.5 Reporting

Standards for Reporting Qualitative Research (SRQR) was used to help us provide more complete information about the study and report it in a more explicit and transparent manner (O'Brien et al., 2014).

3. RESULTS

Nineteen men and six carers were interviewed about their experiences and views. Table 2 describes the demographic and clinical characteristics of the 24 men with prostate cancer who were selected for interview. However, not all of them could be interviewed directly (e.g. due to ill health), and so some carers were interviewed about their partner or parent's cancer experience. Specifically, 18 men with cancer took part in one-to-one interviews; 5 carers (3 spouses, 1 daughter and 1 son) were interviewed about their partner or parent's cancer experience; and in one interview, both the patient and his partner were interviewed (separately).

Carers included five females and one male; all white British (age not reported); and four spouses/partners, one daughter and one son. One carer was caring for a man with early localised cancer, two caring for a man with localised advanced cancer and one caring for a

man with advanced metastatic cancer; one carer was bereaved; information was missing for one carer. The men they cared for were receiving different treatments at the time of the interview: two men were receiving hormones only, one receiving hormones and chemotherapy, one watchful waiting, one palliative care only, and one deceased. Findings are presented under four themes: information gaps (3.1), professional communication skills (3.2), individualisation of information (3.3) and alternative information sources (3.4) (See Table 3 for themes and illustrative quotes).

3.1 Information gaps - "They don't give you any real information" (Participant [P]84, patient) Following the disclosure of diagnosis, all participants reported receiving information focused on the disease status and treatment options and plans from their secondary care professionals (mainly urologists, oncologists and nurses). Although participants appreciated such information, many also felt that they did not get all the information they needed (Table 3: 3.1.a.). Particularly, the information provided often featured textbook answers and population-level statistics, which were not interpreted into the "real-life" implications for the individual concerned, i.e. how the person's body, mind, daily life, relationships, and future was likely to change as the result of the disease and treatment (Table 3: 3.1.b.). The most often neglected were adverse effects of active treatments such as incontinence, erectile dysfunction, fatigue, hot flushes, emotional and psychological issues, although these were sometimes briefly mentioned alongside an explanation of the treatment plan (Table 3: 3.1.c. & 3.1.d.). Subsequently, many had a knowledge gap about self-care strategies and supportive professional services (Table 3: 3.1.e.).

Some acknowledged that professionals might focus on clinical outcomes due to time pressures or lack of (specialised) training in providing such information (Table 3: 3.1.f.).

However, they expected that professionals should signpost patients to reliable, alternative information and support services, but this often did not happen (Table 3: 3.1.g.). Those who were signposted to a support group or PCUK praised this practice.

Some participants with advanced cancer wanted more information about prognosis or "the worst-case scenario." However, doctors often avoided these conversations and focused on how they would control cancer growth instead (Table 3: 3.1.h.). No men reported receiving information about palliative care. Some were offered palliative care, but it was not explicitly labelled as such, e.g. it was sometimes referred to as care provided by Macmillan nurses (Table 3: 3.1.i.). Palliative care was commonly understood as comfort care provided when life-prolonging, active treatments run out and one was dying (last days to months) (Table 3: 3.1.j.). Perceptions were mainly based on the experience of a family member or a close friend, rather than discussions with healthcare providers.

Some pointed out that their need for information was emerging and ongoing rather than a one-off. Different information was needed at key points in time along the disease trajectory as the disease, treatments and side effects, and their life circumstances changed (Table 3: 3.1.k.). However, for many, most information was given to them at the initial diagnosis and treatment stage and rarely revisited; most were either unsatisfied with how their ongoing information needs, particularly in terms of supportive and palliative care, were met, or unsure of how such needs would be met when they arose in future (Table 3: 3.1.l.).

3.2 Professional communication skills - "It's got to be really good communication skills" (P33, carer)

At the time of diagnosis, many struggled to take in all the information offered because of "a scrambled brain" as they were feeling "sliding down the wall and your life is about to end"

(P24, patient). What many perceived as life wrecking news provoked such strong emotions that they blocked out much of the information provided (Table 3: 3.2.a.).

In retrospect, some participants thought it would have helped to have some time and space to process thoughts and feelings before essential information was given (Table 3: 3.2.b.). For others, what they needed when they were "at the lowest" was "a sort of metaphorical cuddle" (P251, patient), i.e. emotional support. Instead, professionals discounted their feelings and jumped straight into giving more information. They used words such as "understanding", "empathetic", "reassuring", "caring", or "compassionate" to describe the emotionally responsive communication they needed from professionals (Table 3: 3.2.c.). When offered, many appreciated being able to go back to professionals for clarification and further questions after they had come to terms with the diagnosis (Table 3: 3.2.d.).

In general, many regarded professionals' communication skills as pivotal in effective information provision. They gave examples of specific skills and qualities or lack of these that contributed to their good or bad care experience. Notably, professionals were most often praised for being "honest" or "every question was answered without any flannel about it at all" (P157, patient), i.e. not avoiding or concealing difficult information. Nonetheless, some questioned whether the problem was a lack of communication skills or time constraints prohibiting professionals from using their skills (Table 3: 3.2.e.). When professionals were not rushing and gave them adequate time to go through everything they needed to know, they were satisfied with their care.

3.3 Individualisation of information - "You want somebody that treats you as an individual" (P101, patient)

The need of participants to be treated as an individual was pronounced. They needed information that was tailored to their individual needs and given as and when needed. To justify this need, participants gave examples of different ways in which people differed from one another in living with prostate cancer. Particularly, disease complexity and various treatments, combined with “all sort of different dynamics to people” (P88, patient), led to differences in, for example, how people responded to the diagnosis, how their sexual intimacy and relationship with an existing or potential partner were affected, and what type of and how much information they needed (Table 3: 3.3.a. & 3.3.b.).

The “different dynamics to people”, as one participant summarised, boiled down to “their physical health, their mental health, their personal circumstances, their family situation, erm, you know, cultural, religious beliefs” (P96, patient). As such, some suggested that if a professional was to treat a patient as an individual, “the first thing is you need to know or you need to try and work out the patient” (P69, patient). In other words, it is within the context of a patient’s “whole life” that the unique information and support needs of the patient can be understood and addressed (Table 3: 3.3.c.).

To achieve “treats you as an individual”, many regarded easy access to and sufficient time with preferably the same professional throughout the cancer journey as necessary, for example, when patients were assigned a clinical nurse specialist (CNS) as their key worker or point of contact. Some participants described how this arrangement helped them build trust in the nurse and in time they opened up and communicated even the most sensitive issues; and it enabled the nurse to know them well enough to assess their unique information needs and provide tailored support (Table 3: 3.3.d.).

Some participants argued that patients should also take responsibility for soliciting individualised information. This included seeking clarification on the spot, reading what is

given, researching for extra, and going back to professionals to ask further questions (Table 3: 3.3.e.). However, some struggled to come up with questions to ask because “it's difficult to ask for something you don't know about” (P164, patient) and “the difficult thing is knowing, knowing what you should know” (P190, carer), i.e. knowing what information is (or will be) relevant and useful, therefore, should be sought. As such, they needed professionals to be both “responsive” and “proactive”. Most professionals seemed to do well in answering questions. It is, however, being proactive, that they appeared to be less capable of, in terms of gauging the correct amount and type of information and support to give (Table 3: 3.3.f.).

3.4 Alternative information sources - “I get information from Prostate Cancer UK” (P30, patient)

To meet their unmet information needs, participants used a variety of alternative information sources, particularly internet, charities and support groups. The internet was viewed as a useful and easily accessible source, but some felt overwhelmed by the amount of information available (Table 3: 3.4.a.); and some cautioned that there were risks of being misled because of inaccurate, incomplete or irresponsible information (Table 3: 3.4.b.). Some trustworthy websites were named- often those of the well-known cancer charities (e.g. Macmillan Cancer Support, Cancer Research UK and PCUK) where comprehensive information about cancer, treatments and side effects, self-care and coping strategies, and palliative and supportive care resources were available (Table 3: 3.4.c.).

Some participants joined a local support group which was often led by a specialist nurse and found it a reliable source for timely information. These groups organised professional (specialist nurses or invited medical speakers) led information and education sessions, and enabled members- people affected by prostate cancer, to connect with one another, thereby

providing members with continuing opportunities to get needed information (Table3: 3.4.d.).

Some participants used and strongly recommended getting a “second medical opinion”. Second opinions were used to better understand different treatments so as to choose the right one or confirm or “double-check” that they were “taking the correct road” regarding the chosen treatment (Table 3: 3.4.e.).

Many participants did not have “a point of reference that they felt they could trust and rely on” (P6, patient). Instead, they obtained information from several sources, often checking information from one source against another or “triangulating” bits of information from different sources. In this way, they felt reassured when they had doubts about certain information or found reliable information- confirmed by different sources (Table 3: 3.4.f.).

4. DISCUSSION

This study is the first to focus on and detail the unmet information and communication needs of men affected by prostate cancer. It adds to the literature on the specific information and communication needs of men at different stages of prostate cancer and who experienced different treatment, highlighting the ongoing, changing and individual needs along the cancer pathway. The study identified: significant gaps in the information provided by secondary care professionals (urologists, oncologists, and nurses); specific professional communication skills needed in effective information provision; the pronounced need for tailored information based on individual needs; and patterns of using alternative information sources to meet unmet needs. The findings largely reflect the

perspectives of men with prostate cancer as we only interviewed six carers, and the interviews with carers tended to be shorter and less rich.

In this study, information provision by secondary care professionals was found to be disease and treatment focused. Generally, there was insufficient information offered to participants to help them develop a realistic expectation of, cope with and adapt to the "whole-person" effects and impact of cancer and its treatment. Also, most information was given to them at the initial diagnosis and treatment stages with their emerging and ongoing information needs often overlooked. Studies looking at different cancers similarly found a lack of information at all stages of cancer journey particularly an undersupply of information at later points; and misalignment between when the information was needed and when it was actually provided (Carter et al., 2011; King et al., 2015; Macmillan Cancer Support, 2019; Paterson et al., 2017; Rutten et al., 2016; Schildmeijer et al., 2019).

Further, this study found a lack of information specifically regarding common and burdensome adverse effects of prostate cancer treatments (e.g. incontinence, erectile dysfunction, fatigue, hot flushes, emotional and psychological issues), and self-care strategies and professional services that help deal with these effects, mirroring other studies conducted in higher income countries (Carter et al., 2011; Chambers et al., 2018; Jung et al., 2016; O'Brien et al., 2011; Paterson et al., 2017; Ream et al., 2008; Schildmeijer et al., 2019; Walsh & Hegarty, 2010). Professionals in this study also avoided having difficult conversations about prognosis and the future with participants, in common with people with other cancers (Carter et al., 2011; Chen et al., 2019; van Weert et al., 2013). Subsequently, information about palliative care was not explicitly communicated if provided, and often totally avoided, even when participants had advanced cancer. Participants, therefore, did not understand what palliative care was, even though they were living with

unmet physical, psychological and other needs that could be addressed by the early integration of palliative care (Ferrell et al., 2017).

In this study, we found that patients were often given lots of information immediately after they had received bad news. However, this and other studies have found that patients' attention to and recall of information provided during bad news consultations is poor; and the emotional toll of bad news- increased levels of distress or anxiety, might be responsible for this hampered information processing (Maharaj et al., 2018; Netsey-Afedo et al., 2019; Speer et al., 2017; Tarrant et al., 2008; van Osch et al., 2014). Participants in this study found it helpful when professionals provided emotionally responsive communication, emotional support or opportunities to go back to them for clarification and further information.

Consistent with other studies (Carter et al., 2011; Jung et al., 2016; Tarrant et al., 2008), this study found that time was an important element in good communication; and patients had a better experience of care when professionals were not rushing and patiently answered their questions. Tarrant et al. (2008) found that lack of unconstrained time to talk things over, particularly after bad news, had a negative emotional impact on prostate cancer patients; and that the time-pressured clinical environment was thought to hinder patients' verbal communication abilities and capacity to retain and process information. Professionals also felt that the limited time they had with patients in 'pressurised environments' was one of the biggest communication barriers (Macmillan Cancer Support, 2019).

There were clearly unmet needs for individually tailored information and communication as found in this and other studies (Macmillan Cancer Support, 2019; Maharaj et al., 2018; Paterson et al., 2017; Speer et al., 2017). Further, this study found that to be able to tailor the information based on needs, professionals needed to know a patient well enough- as a whole person. Moreover, easy access to and sufficient time with preferably the same

professional, such as a dedicated clinical nurse specialist (CNS), was thought to facilitate knowing and treating a patient as an individual. Previous studies similarly found that seeing a CNS helped to improve patient experience as CNSs acted as patient advocates and source of supportive care (King et al., 2015). A study of CNS' role and value in prostate cancer care (Tarrant et al., 2008) found that CNSs provided information, advice, emotional and other essential support immediately post-diagnosis and during the course of treatment and follow-up. Several aspects of their role were seen as unique and highly valued. First, it was their availability to the patient in terms of both unconstrained time with them and availability for contact for advice and support throughout their care. Second, they helped patients to understand and come to terms with their diagnosis and treatment by communicating in a patient-centred way and using non-medical language. Third, they were more likely to address wider issues than simply the diagnosis and treatment.

Some participants in this study suggested that patients also need to take some responsibility for meeting their unique information needs by proactively eliciting information from their healthcare professionals. However, many others found it difficult to be proactive because they could not ask about things that they did not know exist or were relevant. Indeed, many may not have adequate health literacy to advocate for themselves in this way (Rowlands et al., 2015). Thus, as found in this study, professionals need to proactively give information, i.e. gauging the correct amount and type of information to offer to each individual at the right timing, as well as being responsive, i.e. answering questions fully, honestly and in accessible language.

Despite the reliance on professionals as a primary information source, participants in this study also used and appreciated alternative sources. Consistent with prior research, this study found that men with prostate cancer often obtained extra information from local

face-to-face support groups and regarded the informational or psychoeducational aspect of peer and professional support as a major benefit of such groups (Arrington, 2015; Chambers et al., 2018; Dunn et al., 2020; Huber et al., 2018; Jung et al., 2016; Maharaj et al., 2018; Thaxton et al., 2005). The internet was another frequently used alternative found in this and other studies (Arrington, 2015; Jung et al., 2016; Kirkman et al., 2017; Rutten et al., 2016). For some people, the abundance of information, the lack of trustworthiness and the question of relevance were obstacles to using the Internet. However, some reliable on-line sources, mainly those of the well-known cancer charities were recommended in this study.

By purposive sampling of men by cancer stage and treatment, we were able to explore some diversity in men's experience of and need for information and communication throughout the prostate cancer pathway and across various treatment modalities. This is the strength of this study. There are, however, several limitations. The survey was quite lengthy, so we decided to limit the demographic data we collected (i.e. age and ethnicity for men, and age and sex for carers) as we were concerned about the impact on response rates. The sampling frame was based on clinical characteristics only. As such, it is unclear whether or not our sample represents diverse experiences in terms of socioeconomic background such as education (and thus health literacy level), which may influence information needs. All participants are British White. The experiences of men from black and minority ethnic groups are not represented. All but one participant was heterosexual and most over 60 years. The experiences presented here are therefore unlikely to be a representation of all the significant populations particularly in terms of the impact of the disease and treatment on sexuality and relationships. Although we recruited via a range of media, most participants were members of Prostate Cancer UK; this came to light during the interviews when they talked about their experience of getting support from the charity. The implication of this

might be that the findings may represent men able to self-advocate and successful in seeking and engaging with support; non-members could have had different experiences, for example, in terms of social support. Carers' and patients' perspectives were not compared; therefore, we could not report the differences between the two groups. This is because only six carers were included as proxy informants when patients could not be interviewed, and they provided far less information than patients.

Despite the limitations, the findings suggest that regardless of cancer stage and treatment, men with prostate cancer can have ongoing and changing information needs throughout their cancer pathway, including not just at the time of diagnosis and treatment, but also post-treatment (to deal with side or aftereffects), after the active treatment and other times when specific needs arise. Also, they need information delivered in a compassionate and person-centred manner, considering content, timing and emotional support, as appropriate for the individual concerned within the context of his unique life circumstances. In meeting men's needs, effective communication skills are regarded as important as well as allowing adequate clinical time for information provision and communication. Professionals' availability for contact for information, advice and support throughout the cancer pathway could be instrumental in meeting individualised needs. The use of alternative information resources, particularly when guided and supported by professionals, can also be beneficial to patients, but should supplement, not replace clinical support. The findings of this study will be used to inform the content regarding patient information and communication needs in the professional-facing educational resources we will develop.

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Table 1: Sampling frame for qualitative interviews

Cancer stage	**Localised early**	**Localised advanced**	**Metastatic**	
Watch and wait/ Active surveillance	1- 2	n/a	n/a	
Hormonal treatment	n/a	2- 3	4- 5 +/- palliative RT	
Radiotherapy (external beam or brachytherapy)	3- 4	n/a		
Surgery	2- 3	2- 3	n/a	
Chemotherapy	n/a	2- 3	3- 4	
Total	6- 9	6- 9	7- 9	19 - 27

Table 2. Characteristics of men included (n=24)

	n
Age (50-80)	
50-59	4
60-69	10
70-79	6
80-89	3
Missing	1
Ethnicity	
British White	22
Missing	2
Cancer stage	
Remission	4
Early localised	5
Advance metastasis	8
Localised advanced	5
Missing	2
Current treatments	
Hormones	7
Chemotherapy	1
Surgery	0
Radiotherapy	0
Two of the above	5
Active surveillance	1
Watch and wait	2
Palliative care	1
None	6
Missing	1
Past treatments	
Active surveillance	0
Watch and wait	4
Hormones	3
Chemotherapy	0
Surgery	2
Radiotherapy	0
Two or more of the above	14
Palliative care	1

Note: 18 of these men were interviewed and 5 carers (3 spouses, 1 daughter and 1 son) were interviewed about another 5 men; for one man, both his partner and himself were interviewed (separately).

Table 3. Themes and illustrative quotes

Themes	Quotes
3.1 Information gaps "They don't give you any real information" (P84, patient)	a. You don't get all the information that you need at the time that you're diagnosed, they give you the basic like yes, you've got to have radiation treatment, you've got to have hormone treatment and the hormone treatment there might be a few side effects but they don't give you all the information you need. (P84, patient) b. What you're not really told is that actually it's going to have quite an impact on your relationship life. (P157, patient) c. I think doctors should be able to talk it through, not just the operation but the possible psychological effects of your sex life, whether you're going to be incontinent or not. (P101, patient) d. They ought to explain a bit more about the emotional roller coast side, because it is up and down like mad sometimes. (P155, patient) e. When I stop the radiotherapy, I was a bit leaky, well nobody suggested getting pads. (P157, patient) f. I've seen how they work and I can see the pressures they're under, I think they have to focus purely on trying to get the right clinical outcome and give the right treatment. I think trying to widen their remit too hard, they ain't going to have time to do it. (P298, patient) g. You need to be signposted to where you can go and get the information. (P101, patient) h. I said well what's the worse, what's the prognosis? And his answer was how long's a piece of string. . . . . all you got told was well, if things are going wrong and your PSA starts to climb or the cancer starts to spread, we change the treatment and you're thinking yeah, but is that going to make any difference? And nobody could answer obviously or nobody wanted to answer. (P179, patient) i. It hasn't been sort of something that's come up with all this prostate cancer, nobody's suggested it. Well not as palliative care, I mean they've said basically if you need any help or you want anything, back-up or whatever, we're here for you, which I suppose can be construed as something like that. (P227, patient)

	j. Palliative care could be anything from the obvious would be something like pain relief, but it could be a whole load of other things that improve their quality of life, during the process between, life-extending treatment finishing and their life ending. (P96, patient) k. The point at which I need to make a choice then I'll need more information to be able to make a choice, if that's four or five years down the line, even eighteen months down the line, then the weight of those options might have changed by then, the treatment might have changed by then, the research might have changed by then, well my condition will have changed by then, how relevant all of those things will be to me, is something that'll be important at the point in time that I have to make that decision, not now. (P24a, patient) l. Until things happen I don't know what my needs will be, if I'm incapacitated then of course I will need some sort of help but where I would go for that I'm afraid I don't know. (P183, patient)
3.2 Professional communication skills "It's got to be really good communication skills" (P33, carer)	a. Been told you've got prostate cancer, half of the information probably goes straight over your head because you weren't taking it in because you're still recovering from the fact somebody's told you you're now carrying, walking around with cancer inside you. (P227, patient) b. In actual fact I preferred to get that news at home because if I'm going to get upset and have a scrambled brain for a while, I'd rather do that than sitting in front of someone in an office. So that, for me, I can then go to the oncologist with a slightly clearer head and discuss it. (P69, patient) c. Empathy and good communication skills are just absolutely, I think they just need to be at the forefront, the ability to be able to give bad news in a compassionate way and not to avoid it, and not to dismiss people's feelings. (P33, carer) d. Just being told that they've got prostate cancer, is a bit of a blow, you don't take everything in, so she did say here's my phone number, here's my email, if there's something you've forgotten what I said or whatever, get back to me. (P227, patient) e. I don't think it's so much a matter of skills, a matter of time, back to having, not enough time for doing things. (P143, patient)

3.3 Individualisation of information "You want somebody that treats you as an individual" (P101, patient)	a. I said if a man's in a relationship, if he's married, he's been with his partner for some time and things change, it's just an adjustment in your relationship, things a little different, you're together, you still have intimacy but perhaps in a different way if you're not having penetrative sex or whatever and you still have that relationship, although it's adjusted. I said but if you're single, which I am, I said it's really quite a whole different dynamic. (P88, patient) b. The difficulty is, you can give people too much information, so to say you want more information, how much is more? And different people, my idea of more is different to your idea of more anyway. . . . . the advice that might be relevant for a gentleman in his seventies may well not be relevant for somebody who's only just been fifty. (P96, patient) c. They're beginning to, thank god, look at your whole life and hope that you are, what, do you have an active sex life? Are you gay, are you heterosexual? Whatever it may be. They should know enough about you to give you the right guidance. (P101, patient) d. We knew her [CNS] right from the beginning and, that's the way they do it there apparently and she's been almost part of the family, it was that. It was good because, I mean she, to be blunt when you're dealing with prostate, you've got to get rid of all your inhibitions. (P157, patient) e. Ask the right questions they're very good at telling you the right answers but lots of other men, A, don't want to ask anyway and B, don't know the right question to answer. (P164, patient) f. It was very much, what's the word, proactive, they [his wife's CNS] were, they said this is available, do you want to take it up? And my wife took up, first of all individual counselling and then we went for joint counselling because we just felt that was the best thing to do. Yet for me, when I was going through my cancer, never mentioned. (P164, patient)
3.4 Alternative information sources "I get information from Prostate Cancer UK" (P30, patient)	a. I do use the internet and sometimes I think you've got too much information on it. (P101, patient) b. If you're not careful in the wider context, if you go on the internet, and you've got, I don't know, you just said a bit under the weather, by the time you've finished internet, you're actually phoning the funeral director, so you've got to be very careful. (P164, patient)

	c. Just go on the Prostate Cancer UK website because they're the specialist area and that's where I've got virtually all sorts of my information from. (P298, patient) d. We [the support group] meet every two months. You've always got somebody there who's further down the journey, the road, they can pass on their information, every two months, every second meeting, the cancer nurse turns up and is there for any questions that we have, they also arrange for us to have specialist speakers in, people to give us health advice and also updates on new technology and improved treatment procedures. (P179, patient) e. If you're seeing a surgeon perhaps get a second opinion from radiotherapist or whatever, don't just take the first option that people throw at you. (P101, patient) f. I don't think any sources are reliable unless they're triangulated with other bits of information, so, I think what becomes reliable is when you hear it more than half a dozen times or read it more than half a dozen times. (P24a, patient)

Appendices

APPENDIX 1. Interview topic guide

LIVING WITH PROSTATE CANCER
INTERVIEW TOPIC GUIDE

Introduction

- Overview of the study
- Details of the funder
- Overview of who is being invited to take part, and why
- Explanation of how findings will be used

Aims of the discussion

- Informal discussion
- Remind participants they are not obliged to take part at all
- No right and wrong answers to the questions
- If they do not hear or understand a particular question, please ask for clarification
- They can choose not to answer a particular question, without needing to give a reason

Confidentiality

- Recording of interviews
- Information will remain anonymous

Tell me a little bit about yourself…

- Time since diagnosis, current and past treatments, support available to the patient (formal and informal)
- What are some of the issues you are dealing with now? (physical, financial, emotional, spiritual, practical)

Information needs

- Thinking about your current needs, what information have you needed?
    - Have you been able to find it/where from/useful/if not why not?
- Thinking back to when you/the person you care for was diagnosed, if you knew then what you know now, what (if anything) might you have done differently?
- Who should provide these different types of information? (Why/when)
- Probe about when different sorts of information should be given/offered (e.g. prognosis/palliative care/advanced directives) – if feel OK to do so

Emotions and feelings

- What has the psychological impact of living with/caring for someone who lives with PC have?
- How have you dealt with these emotions?

- What kinds of help (if any) did you seek out/receive? What services were most helpful? Least helpful?
- What kinds of assistance would you like to be available?

Support services

- What support services are you aware of, and have you used any? (e.g. palliative nurse specialist/palliative care)
- What do you think about palliative supportive services?
    - If positive ask why, if negative ask why and probe where information is from and whether any experience

Knowledge and skills of clinicians looking after you

- Given these issues **in addition to knowing about the cancer treatments** what do you think the doctors, nurses or other professionals need to know about, and how to help, the side-effects of the cancer treatment?
- Given these issues **in addition to knowing about the cancer treatments** what do you think the doctors, nurses or other professionals need to know about, and know how to help? NB.[note to interviewer – probe for issues mentioned above, but not in this question]

Living with prostate cancer

- What other kinds of support should be made available to men living with PC and their carers to help them manage their condition better?

APPENDIX 2. Nodes (themes) in NVivo

Nodes

What information is needed
Changing/emerging information needs
What is effective communication
Barriers or facilitators of communication
Expectation and perception about palliative care
Informing about palliative care
Obtaining, assessing, applying information from various sources
“Treats you as an individual”