



The clinical communication and information challenges associated with the psychosexual aspects of prostate cancer treatment



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ABSTRACT

Rationale: Prostate cancer and its treatment have significant sexual side effects that necessitate timely patient information and open communication with healthcare professionals. However, very little is known about men's experiences of talking to clinicians about the psychosexual difficulties associated with the disease.

Objective: This study aims to advance understanding of men's perceptions of the communication and information challenges associated with the psychosexual aspects of prostate cancer and its treatment.

Method: Between October 2013 and April 2014, semi-structured interviews were conducted with 21 men from the UK who had been treated for prostate cancer. Interview transcripts were analysed using thematic analysis.

Results: Three themes describe the communication challenges men face: (1) It can be too soon to talk about sex; (2) the psychology of sex is missing; (3) communication is not individually tailored.

Conclusions: Clinicians might usefully (1) consider and discuss with patients how their psychosexual communication needs and information processing abilities may fluctuate across the cancer timeline; (2) initiate discussions about the consequences of treatment that extend beyond biological and mechanical aspects to include emotional and relational factors; (3) tailor communication to the dynamic mix of attributes that shape men's individual psychosexual needs, including their relationship status, sexual orientation, sexual motivations and values. Skills-based training in communication and psychosexual awareness may facilitate the proactive and permissive stance clinicians need to discuss sexual side effects with a heterogeneous group of patients.

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1. Introduction

Prostate cancer (PC) is one of the most prevalent forms of cancer in the developed world, with an estimated 1.1 million cases diagnosed worldwide in 2012 (Ferlay et al., 2015). There is a strong age component to the etiology of PC, with most cases occurring in men aged 50 years and older (Prostate Cancer UK PCUK, 2013). Incidence has increased significantly in recent years due to an ageing

population and wider availability of the prostate specific antigen screening test (Quinn and Babb, 2002). In the UK it is estimated that one in eight men will get PC at some point in their lives (PCUK, 2013). However, survival rates are favourable: In the USA, following active treatment, the 5-, 10- and 15-year cancer specific survival rates are 95%, 90%, and 79%, respectively (Ward et al., 2005). Consequently, the disease constitutes a significant “public health burden,” with management of treatment-related sexual side effects posing “a particular challenge” (Forbat et al., 2012, p. 98).

Men diagnosed with PC face difficult choices between treatment options that can result in incontinence, infertility, feminisation, and chronic changes to sexual functioning, including erectile dysfunction, penile atrophy, and loss of libido (Chung and Brock, 2013; Donovan et al., 2016; PCUK, 2012). For many, these side effects will “be less acceptable than the disease itself” (National Institute for Health and Care Excellence NICE, 2014, p. 117), causing chronic psychological distress (Wooten and Siddons, 2013), difficulties with body image, masculinity and self-esteem (Harrington, 2011;

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Oliffe, 2005), and impaired quality of current and future partner/marital relationships and sexual intimacy (Beck et al., 2009; Penson and Nelson, 2009; see also Tucker et al., 2016).

The unique psychosexual challenges posed by PC and its treatment mean that a man's trajectory from diagnosis through treatment and to post-treatment and recovery is a difficult and complex journey; one that necessitates collaborative and open communication with healthcare professionals (Brandenburg and Bitzer, 2009; Hordern and Street, 2007). Effective communication "profoundly affects" a patient's cancer experience (Department of Health, 2011, p. 48; Independent Cancer Taskforce, 2015): It can promote patient satisfaction, psychological functioning, and overall health outcomes, including cancer survivorship (Arora, 2003; Epstein and Street, 2007; Fallowfield and Jenkins, 1999; National Cancer Survivorship Initiative, 2013; Street et al., 2009). Consequently, UK guidelines and policy directives recommend that healthcare professionals must be adequately skilled in communication to support patients and empower them to make informed decisions about their care (Department of Health, 2011; Independent Cancer Taskforce, 2015; NICE, 2014). This includes the need to provide men and their partners with adequate, tailored information about the sexual consequences of treatment decisions, focusing on quality of life as well as survival (NICE, 2014, p. 14). Specifically, patients should be informed about the impact of treatment "on their sexual function, physical appearance, continence and other aspects of masculinity" (NICE, 2014, p. 14; PCUK, 2012, p. 15), and be offered "the opportunity to talk to a healthcare professional experienced in dealing with psychosexual issues at any stage of the illness and its treatment" (NICE, 2014, p. 14).

Evidence suggests that there is variability in how well this is achieved in clinical practice and that clinicians inadequately address cancer patients' sexual information and support needs (Tucker et al., 2016; Flynn et al., 2012; Gilbert et al., 2016; NICE, 2014, p. 115; Ussher et al., 2013; Watson et al., 2015; Zhou et al., 2016). For example, in their observational study of communication in British PC clinics, Forbat et al. (2012, p. 98) note that patients' psychosexual concerns are often side-lined by clinicians, with limited opportunities "to discuss the specific impact of prostate cancer and its treatments on sexual functioning."

Clinicians may be reticent to talk about psychosexual issues with cancer patients because they lack sufficient time, knowledge, confidence, and comfort, think it is someone else's responsibility, or assume a patient's age or relationship status render sexual concerns irrelevant (Hordern and Street, 2007; Park et al., 2009; Ussher et al., 2013). Likewise, patients may be reluctant to disclose psychosexual concerns due to embarrassment and perceptions that clinicians lack the time to discuss such issues, regarding them as trivial compared with survival (e.g., Carr, 2007; Flynn et al., 2012; Stead et al., 2003).

To date, no study has specifically asked men about their experiences of talking to clinicians about the psychosexual aspects of PC and its treatment. This study aims to address this gap, generating new understandings of the psychosexual information and communication challenges faced by men with PC.

2. Methods

This study adopted a qualitative, semi-structured interview-based approach to give men the freedom to reflect upon and describe their experiences of talking to clinicians in their own words (Barriball and While, 1994). The University of Manchester Research Ethics Committee granted ethics approval. Participants were 21 men aged 18 years or over who had received a diagnosis of PC and were undergoing or had undergone active treatment. Participants were excluded from the study if they had untreated PC or

their disease was managed by expectant management (watchful waiting) or active surveillance. Based on previous research, an interview sample of 20 patients is optimal for achieving data saturation (Speer and McPhillips, 2013). Most men ($n = 17$) described their stage of disease as localised or locally advanced wherein the cancer had grown just outside of the prostate gland but was not metastatic. The remainder ($n = 4$) had advanced, metastatic cancer. All participants were English speakers and able to provide written informed consent. Participants were White-British and ranged in age from 52 to 78 years. Further demographic and clinical details are presented in Table 1.

At the outset the research team did not know how difficult it might be to recruit men willing to discuss psychosexual communication needs with researchers. Therefore, in order to maximise sample size, participants were recruited using opportunity and snowball sampling methods. First, SS identified potential participants through existing contacts from patient and public involvement work in the community. These men had consented to being contacted to take part in future research. One of these existing contacts identified as an advocate for gay men within the PC community. He was specifically approached to participate in this study in view of calls for research that examines the communication experiences of gay men with PC (Tucker et al., 2016). Participants were also identified through the PC Support Federation registry of patient-led support groups in the Northwest of England. Support group facilitators disseminated written details of the study on behalf of the researchers or consent was granted by facilitators for the researchers to attend and present the study to potential participants.

Between October 2013 and April 2014, two female researchers (ST or RM) conducted in-depth, semi-structured interviews with 21 men, five of whom were accompanied, at their request, by their female partner who also gave their consent and actively participated in the interview. The interview guide was informed by public involvement work in the community. It was divided into three sections: (1) Background, in which disease history and treatment were discussed; (2) questions about general clinical communication and information needs; (3) questions about clinical communication and information needs in respect of the psychosexual aspects of prostate cancer and its treatment. Participants were interviewed in their preferred location and paid £20 for their time. Each audio-recorded interview lasted between 50 and 170 min, was transcribed verbatim, and identifying details changed. See [online supplement](#) for interview guide.

Transcripts were analysed qualitatively using thematic analysis to identify the core patterns within men's descriptions (Braun and Clarke, 2006). Coding and theme development proceeded in an inductive fashion without reference to a pre-existing model or framework (Boyatzis, 1998; Braun and Clarke, 2006). Transcripts were read and re-read, with initial ideas noted. Interesting features of the data were systematically coded at the descriptive, semantic level, reflecting men's own language, meaning, and concepts (Braun and Clarke, 2006). Using the list of all identified codes, features of the data that were similar were clustered to create sub-themes. Finally, sub-themes that represented patterns were collated to form themes. Reliability was enhanced through an iterative process in which authors discussed and refined codes and themes until they reached agreement (Boyatzis, 1998). Themes were subject to on-going analysis and refinement to ensure they were cohesive against the coded extracts and data set.

3. Results

The analysis identified three themes that describe the predominant information and clinical communication challenges men

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