Discussing the sexual consequences of treatment in radiotherapy and urology consultations with couples affected by prostate cancer

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Accepted for publication 20 January 2011

INTRODUCTION

About 35,000 men are diagnosed with prostate cancer in the UK each year [1]. Despite rising detection rates, mortality has remained static at ~10,000 per annum [1]. Thus the number of men living with prostate cancer is likely to impact on the public health burden significantly, with treatment-related side-effects presenting a particular challenge. Men are likely to experience a range of symptoms related to the disease and deterioration in sexual functioning as a consequence of surgery, radiotherapy and hormone treatment.

Despite growth in psychosexual research, most studies in prostate cancer have focused on biomedical management of erectile dysfunction (ED) as an iatrogenic consequence of radical prostatectomy. Surgery is a major treatment method [2], but is known to result in ED [3,4], often for upward of 5 years after treatment [5]. Even nerve-sparing surgery affects sexual functioning [6], although less invasive surgical techniques are being championed to reduce side-effects [7]. ED is also a known treatment effect of external beam radiotherapy (EBRT) [8]. In contrast a follow-up study of men treated with EBRT reported that erectile function recovery after treatment was correlated with sexual function before EBRT and decline in sexual functioning appeared to stabilise by 24 months after EBRT [9]. Studies suggest that the overall impact on sexual functioning is likely to be underestimated in the health-related quality of life (HRQL) literature [10]. Despite these data, the impact on sexual functioning was discussed infrequently in both clinic settings. Despite the presence of partners in nearly half of consultations, involvement of the partner tended to be minimal.

CONCLUSION

Given the potential burden of symptoms and side-effects, there is a need to include discussions of sexual recovery and rehabilitation in consultations, and to provide opportunities to discuss the sexual consequences of treatment with men and their partners.

KEYWORDS

sexual dysfunction, cancer, treatment effects, survivorship

Study Type – Attitude/patient experience analysis (retrospective cohort)
Level of Evidence 2b

What’s known on the subject? and What does the study add?

Men with prostate cancer are likely to experience a range of treatment-related side-effects including deterioration in sexual functioning as a consequence of surgery, radiotherapy and hormone treatment.

Despite the clear links between treatments and changes in sexual functioning, sexual concerns are infrequently discussed in clinic settings.

Data indicate the need to use clinical consultations appropriately to support both patient and partner in sexual recovery and rehabilitation, going beyond discussions of assistive technologies to offer psychosexual couple support.
functioning has been described as neglected by urology physicians [11]. Research and clinical practice developments have tended to focus on the use of assistive technologies such as vacuum pumps or pharmacological interventions, e.g. on-demand or regular dosing with phosphodiesterase-type 5 inhibitor drugs to prevent or manage ED [12].

Social attitudes to masculinity tend to place value on the ability to obtain erections and studies have confirmed the value placed on acceptable levels of sexual function by men with prostate cancer [13]. Similarly, framing prostate cancer treatment's impact in a biomedical and mechanistic way has led to studies focusing only on the experiences of patients, but the views of those closest to them have been less obvious [9,13,14].

Several studies are beginning to identify that prostate cancer impacts on both the patient and their partner [15,16]. However, very few studies have sought the views of partners directly, depending instead on proxy reports from patients. Partners are understood to play a role in the sharing of the disease experience [15,17]. Indeed, some studies report that the psychological impact of the disease is greater for partners, as indicated through higher scores on depression and anxiety scales [18] when compared to patients. Other studies have identified age and developmental life-stage differences in how couples respond to prostate cancer [19] with those aged >65 years faring better than younger couples.

The present study aimed to report the impact of prostate cancer treatment on couple's sexual relationships. This study defined sexual expression broadly to include penetrative sex, masturbation and oral sex, while intimacy included features such as emotional expressiveness, and non-sexual bodily functions such as urination.

The study's aim was to explore the content and process of discussions on sexual functioning for men and their partners in urology and oncology settings. Two clinics were selected to describe how communication about sexual concerns took place in each setting, and to identify differences in disciplinary and organisational culture between urological surgery and radiotherapy treatment settings.

**PATIENTS AND METHODS**

An ethnographic non-participant observation study was conducted in clinics in two NHS Trust Cancer Centres in South East England. Clinic A was a clinical oncology clinic and Clinic B was a prostate cancer urology clinic. Observations were made of clinic sessions led by a consultant or specialist registrar in clinical oncology, consultant urologists and a nurse practitioner in men's health.

Ethnography was selected as the methodology of choice, as it provides a framework for the exploration of social phenomena, focusing on a small number of cases where there has been limited theorising [20]. It originates from anthropology, and has been adopted in medical sociology research as a method of describing and interpreting social groups and practices. The ethnographic method emphasises non-participant observation, whereby the researcher observed clinic appointments. The term 'non-participant observation' is applied in this paper to describe the role adopted by the researcher, which recognises that while their presence may have shifted the nature of some interactions, as the researcher did not have an active clinical or supportive role within the clinic, the extent of change was minimised.

Sampling in ethnography proceeds initially through the selection of sites; thus sampling occurred as an outcome of the focus on clinical oncology and urology clinics. As the study was essentially exploratory, due to the limited published data in this field, purposive sampling was adopted to gain exposure to the widest range of patients within these clinic settings. The final sample included men at different stages of the cancer treatment pathway. The range of time points allowed identification of discussion about treatment-induced sexual concerns from the point of diagnosis, during active surveillance, through to treatment consequences associated with EBRT, brachytherapy and urological surgery.

The study received ethical approval from the NHS Research Ethics Committees serving sites were advised by the nurse or doctor before the start of the consultation that there was a researcher present. Patients were informed that they could opt-out of an observed consultation if they wished, with no impact on their treatment. No patients opted out of the study, although on one occasion a consultant requested that the researcher not be present for a consultation that was to focus on breaking 'bad news'.

Detailed observational notes were made by the researcher that meticulously identified the physical lay-out of clinics, including the display of posters or leaflets providing information related to ED and the sexual impact of treatment. Brief notes were made during consultations, which were augmented at the end of each clinic to record more extensive accounts of each patient-clinician interaction. Data collection proceeded for 4 months and was terminated when saturation had been achieved, that is, whereby no new information about the range of topics relating to sexual activity was being elicited.

Interpretative and descriptive analysis drew on the principles of ethnography [20]. Analysis of ethnographic data can be described as having two components. The first component is the quantifying of qualitative data [21], the second is the detailed description of each case and setting [22]. Frequency counts were recorded of the number and types of conversations pertaining to sexual consequences of treatment. Detailed observational notes recorded the nature and range of topics discussed and whether it was the patient, partner or healthcare professional who had raised the subject of sexual recovery. Observational descriptions also recorded how the conversation was managed, what topics dominated, and what topics were deemed permissible subjects for discussion in either setting.

**RESULTS**

In all, 60 consultations were observed; 37 in the urology clinic and 23 in the clinical oncology setting, comprising a total of 48 h of observation over an 18-week period. The clinical oncology clinic was staffed by one consultant, and one specialist registrar in clinical oncology, seeing an average of 30 patients per clinic session. The urology clinic was staffed by one consultant urologist and one nurse practitioner in men's health seeing an average of 11 patients per clinic session.

All men receiving treatment and follow-up for prostate cancer were seen in a single urology clinic, compared with clinical oncology where patients with various cancer diagnoses.
treated by radiotherapy were seen. This diversity of patient population in the clinical oncology setting appeared to demand a broader perspective in patient assessment and treatment evaluation terms within the conduct of the radiotherapy clinic.

PATIENT CHARACTERISTICS

The mean age of patients attending the clinics was 70 years in both clinics, with similar age ranges of 50–86 years. However, the median age of men attending the consultations differed, at 70 years in the clinical oncology and 65 years in the urology setting. Medical records identified most patients as White British, which accounted for 48 of the 60 consultations observed. Eight men were African-Caribbean, three were Turkish or Turkish-Cypriot and one man was Chinese.

Less than half of consultations were attended by the patient and partner (Table 1). All patients presented in heterosexual couples, although in one consultation a man was accompanied by a male friend, and the verbal and non-verbal interactions suggested this may have been a same sex partnership although overt disclosure of this did not take place.

Despite the presence of partners in nearly half of consultations, involvement of the partner tended to be minimal except in consultations where the man appeared frail or had significant mental or physical co-morbidities. At times, partners accompanied the patient to the hospital but did not take part in the consultation itself. The presence or absence of a partner did not appear to influence whether or not discussion of sexual issues occurred in the clinic.

It was more common to see newly diagnosed men within the urology setting, where discussions focused on treatment options; Table 2 outlines the stage of pathway for each clinic. The duration of consultations was often >30 min and the men were encouraged to read relevant booklets related to prostate cancer and its treatment and to have more than one discussion with their consultant before reaching any treatment decision.

WHO INTRODUCES SEXUAL FUNCTION AS A TOPIC WITHIN CONSULTATIONS?

Sexual functioning was primarily raised by healthcare professionals as a topic for discussion, with patients rarely doing so, particularly in the clinical oncology setting. Perhaps surprisingly given the prevalence of ED after prostate cancer treatment, sexual functioning or recovery was not raised at all in about half of the consultations observed. Table 3 records consultations where discussion occurred and the initiator of the topic.

Consultations where sexual issues were not raised appeared to be characterised by a number of key features. Patient demographics or illness factors accounted for some of this variability, including when the patient had an advanced stage of cancer, disease relapse, multiple co-morbid conditions (including physical and/or mental frailty) or when ongoing physical problem(s) dominated the consultation (for example discussions on pain or incontinence).

The following field note extract is from an observed consultation between a married man and a consultant. The extract typified interactions where discussion focused solely on the clinical, physical and non-sexual elements of prostate cancer and its treatment:

‘White Caucasian gentleman in his 70s who was in midst of diagnostic process, post transrectal biopsy attended alone. Result obtained and confirmed as a Gleason 4 + 4. Patient had already been commenced on hormone therapy as management. Discussed the positive effects of hormone therapy on urinary outflow obstruction (presented in urinary obstruction and has been taught intermittent self-catheterisation). Zoladex injection administered in clinic. Consultant asked patient if he had any further questions arising from confirmation of diagnosis and need for hormone therapy. Patient focused on impending bone scan, regularity of PSA testing and arrangements for hormone injection administration for future. No mention of sexual impact of disease either for self or partner’. White British man attending clinic alone, clinic
vaginal penetration. No suggestions were made regarding sexual difficulty and there were no enquiries regarding impact on his partner. African-Caribbean man attending alone, for a review after brachytherapy.

In the example above, the patient’s description of an inability to achieve intercourse did not lead to a discussion on how to manage this, or a wider psychosexual understanding of how this was affecting his relationship with his partner. In other instances, the consultant introduced the topic of sexual function. This extract from observation notes highlights a more direct approach by healthcare professionals to the discussion of possible sexual consequences of treatment:

‘The consultant mentioned orgasmic and ejaculatory alterations and the wife asked some questions regarding retrograde ejaculation and absence of ejaculation after surgery’. White British man and partner, newly diagnosed, clinic appointment to discuss treatment options.

Talk of sexual activity was sometimes accompanied by humour to manage potential discomfort: ‘Communication appeared to be open with a mainly appropriate use of humour to cope with mild embarrassment on the part of the patient’, Urology clinic. White British man and partner, clinic appointment to discuss ED.

IN WHAT CONSULTATION CONTEXT DOES TALK ABOUT SEXUAL ACTIVITY OCCUR?

Sexual dysfunction and its management often formed part of the consultation discussion in relation to expected side-effects of treatments. Table 4 presents the number of consultations where sexual function was discussed, rather than a frequency count of all instances of talk about treatment-induced sexual concerns.

Discussions about treatment options and their side-effects would sometimes, but not routinely, lead to conversations about the impact of treatment choice upon the man’s subsequent sexual function. The following excerpt from field notes in the urology clinic shows this feature together with the impact of the researcher’s presence on the outcome of the consultation:

‘While the pros and cons of orchidectomy vs hormone treatment had been mentioned, neither [the patient] nor his doctor had explored the sexual consequences of each option. The doctor’s pager went off. When she left to answer it, [the patient] asked me about my research. I replied it was early days, but I felt awkward and thought there was an element of benevolent coercion in recommending irreversible surgery without discussing the sexual consequences. As a non-participant observer, what was my role in helping him to discuss this new concern with his doctor?’

‘He was in the middle of telling me about sex when his doctor re-entered the room. [The patient] turned to her and said ‘So will this make me impotent?’ She looked surprised, sat upright and asked ‘Do you mean this operation would make me impotent? I felt awkward and thought there was an element of benevolent coercion in recommending irreversible surgery without discussing the sexual consequences. As a non-participant observer, what was my role in helping him to discuss this new concern with his doctor?’

TABLE 4 Discussion context for sex as a topic

<table>
<thead>
<tr>
<th></th>
<th>Clinic A</th>
<th>Clinic B</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-treatment function</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>Treatment side-effect</td>
<td>9</td>
<td>15</td>
</tr>
<tr>
<td>ED management</td>
<td>5</td>
<td>11</td>
</tr>
<tr>
<td>Advice about resuming sexual contact</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

TABLE 5 Sexual concerns discussed in clinics

<table>
<thead>
<tr>
<th></th>
<th>Clinic A</th>
<th>Clinic B</th>
</tr>
</thead>
<tbody>
<tr>
<td>Loss of desire</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>ED</td>
<td>9</td>
<td>12</td>
</tr>
<tr>
<td>Low desire and ED</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Reduced ejaculation/ orgasm</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Postoperative penile shortening</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Relationship dynamics</td>
<td>2</td>
<td>1</td>
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</tbody>
</table>

appointment to discuss diagnosis and treatment options.

Thus, despite the use of hormone therapy and its associations with impaired erectile functioning, no mention of this was made by the consultant, consequently no discussion was held about this side-effect. In contrast, a minority of men raised the issue of sexual functioning themselves, without any prompt from the healthcare practitioner:

‘The patient spontaneously mentioned he had noticed an altered orgasmic sensation. The consultant enquired with regard to expulsion of ejaculate. He then discussed the development of retrograde ejaculation and reduced pressure of ejaculate as an explanation for altered orgasmic sensation.’ White British man attending alone.

When patients themselves wished to speak of sexual functioning, both nurse practitioners and physicians often responded by providing medical explanations, and pharmacological interventions to aid sexual recovery. However, the detail and intent of some patient’s views were not always attended to:

‘Questions regarding the penile curvature elicited that the patient was able to get spontaneous erections without need for any medication, but that the curvature prevents vaginal penetration. No suggestions were made regarding sexual difficulty and there were no enquiries regarding impact on his partner’. African-Caribbean man attending alone, for a review after brachytherapy.

In the example above, the patient’s description of an inability to achieve intercourse did not lead to a discussion on how to manage this, or a wider psychosexual understanding of how this was affecting his relationship with his partner. In other instances, the consultant introduced the topic of sexual function. This extract from observation notes highlights a more direct approach by healthcare professionals to the discussion of possible sexual consequences of treatment:

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instance, opening up a space for discussion of the impact of treatment on sexual functioning. Although side-effects had been discussed, a transparent conversation about the impact on ED clearly had not been broached in a way that was meaningful and accessible to the patient.

THE RANGE AND TYPE OF SEXUAL CONCERNS

The content of conversations about sexual consequences of treatment focused largely on ED and reduced ejaculation. Discussions were therefore primarily about physical or organic sexual dysfunction rather than being framed as psychological or relational concerns.

In addition to the range of sexual concerns summarised in Table 5, other intimate treatment-induced changes that could affect sexual identity and masculinity were also raised by participants, such as breast tenderness or enlargement associated with hormone therapy.

Observation of a consultation with a man receiving hormone therapy exemplifies patient communication practices around non-sexual side-effects, which were also sensitive in nature. Sexualised language such as the term ‘titties’ was used to describe breast tenderness and drew attention to this delicate and potentially embarrassing issue:

...White Caucasian couple (aged 74) attended the clinic. The gentleman had been treated with hormone therapy (Zoladex and stilboestrol) for advanced prostate cancer, but his PSA was still rising. The patient led the discussion with regard to his recent ureteric stent insertion. He then mentioned that his ‘titties’ were tender, referring to a side-effect of his stilboestrol therapy. The consultant responded to him by acknowledging how he was feeling in himself before discussing the loss of control of his prostate cancer progression from stilboestrol therapy. [...] The wife remained silent throughout the consultation, although she was sitting alongside her husband. There was no discussion of sexual issues by either party. White British man and partner.

Thus, while the patient raised an issue which could be interpreted as being connected to an alteration in masculinity or intimacy, the physician did not attend to this as an invitation to talk about other related issues such as sexual functioning or relationship concerns. One feasible interpretation is the fear of embarking on a conversation that may threaten to expend more time than is available.

DISCUSSION

Through observation of these clinic settings, it became apparent that the opportunity for prolonged or detailed discussion of sexual concerns was shaped both by the volume and diversity of patient workload within the clinic. In the clinical oncology setting an average of 30 patients were seen by two healthcare professionals over a 3-h period, compared to 11 patients between two healthcare professionals over a similar time frame in the urology setting. Thus, there was greater patient throughput in the clinical oncology setting, resulting in less time for each patient encounter. Perhaps not surprisingly, consultations were focused mainly on disease surveillance and treatment response issues, meaning that psychosocial and psychosexual concerns were not prioritised in the time available between healthcare practitioner, patients and partners.

The range and depth of discussion related to sexual recovery varied considerably, and at times sensitive conversations did occur. However, frequently patients and partners were not invited to reflect on this aspect of their cancer experience, despite receiving treatment anticipated to cause changes in different aspects of sexual function. Only rarely were partners invited to be active participants in the consultation by the healthcare practitioners. This may further inhibit the sense of appropriateness for either party to raise sexual concerns especially if the role of the spouse/partner is not endorsed through overt three-way communication [22].

Sexual function has been identified as declining with age, and with the incidence of co-morbid conditions, notably cardiovascular conditions and diabetes [11]. Meanwhile other data indicates that many men aged in their 70s and 80s continue to engage in sexual activity as long as they have access to a willing partner or other forms of stimulation [23]. The data from the present study indicates that despite evidence of conceptualising sexual activity to be constitute significantly more than erectile function [24], there may only be very limited opportunities for men and their partners to discuss the specific impact of prostate cancer and its treatments on sexual functioning within the context of prostate cancer follow-up clinics.

The cross-sectional design of the present study meant that it is unclear whether sexual functioning had been discussed in previous clinic appointments. Clinicians informed the researcher that there was no distinct appointment where sexuality would routinely be discussed and therefore the clinics observed for this study form an opportunistic insight (which is likely to be representative of routine clinical practice). The sample is small and the study was time-limited; however, the findings were obtained in the most naturalistic method possible to enhance the study’s reliability.

Given the potential burden of symptoms and side-effects, there is a need to question supportive care provision in relation to sexual recovery and rehabilitation and to provide opportunities to discuss the sexual consequences of treatment with men and their partners. Where necessary, healthcare professionals should be supported to develop a more nuanced understanding of how to work with individual men or couples within the constraints of clinical practice. Healthcare professionals may also require educational support about how best to raise sexual function changes as topics of clinical conversation, so that these topics are given adequate gravitas. In addition to the physical and bio-medical model of approaching sexual rehabilitation after cancer (e.g. medication and assistive technologies), there should be an equal emphasis on systemic couple-focused communication skills.

Adopting this approach may help conversations in clinic to begin to connect medical and psychosexual concerns, e.g. how the use of medication or vacuum constriction devices may be integrated into a couple’s sexual and relationship repertoire when planning to be sexually active together.

CONFLICT OF INTEREST

None declared.
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Abbreviations: ED, erectile dysfunction; EBRT, external beam radiotherapy; HRQL, health-related quality of life.