

Co-constructing sexual recovery after prostate cancer: a qualitative study with couples

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Background: Men are likely to experience deterioration in sexual functioning as a consequence of treatment for prostate cancer. Indeed, sexual difficulties are common across all treatment modalities.

Objective: To determine the impact of treatment for prostate cancer on intimacy and sexual expression/relationships from the perspective of couples.

Methods: An observational study was conducted including in-depth interviews with 18 people affected by prostate cancer; comprising eight couples and two individual men.

Results: Four categories were identified that illustrated the impact of prostate cancer on intimacy and sexual recovery. These related to social influences and language used to describe the loss or recovery of sexual activities; difficulties in discussing sexual activity with clinicians; the clash of individual impact of prostate cancer recovery versus the impact on the couple, and the re-integration of sexual activities into the relationship.

Conclusions: Though only one person in a partnership experiences cancer, these data indicated the extent to which prostate cancer treatment also impacts on partners. The study indicates that adjustment to erectile dysfunction (ED) takes time, but is a highly significant event in couples' lives and its importance should not be under-estimated. Consequently, we suggest that relational models of care should be considered, whereby side-effects are recognised as impacting on both members of the partnership (for example ED, or lack or ejaculate). Supportive care in this context, therefore, may best be based on a relational approach using language and interventions that are appropriate to the patient and their situation.

Keywords: Prostate cancer; sexuality; couples; survivorship

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Introduction

Prostate cancer is the highest incidence cancer diagnosis for men worldwide, with approximately 35,000 men diagnosed with the condition in the UK each year (1). Despite rising detection rates via increased public awareness and prostate specific antigen testing, however, mortality has remained static (1). Consequently, increasing numbers of men are surviving long beyond the original diagnosis and experiencing the long-term effects of the disease and its treatment. Sexual dysfunction presents a particular challenge, with men and their partners experiencing deterioration in sexual

functioning as a consequence of all treatment options.

Surgery is known to result in erectile dysfunction (ED) (2), with recovery of function often occurring up to five years following treatment (2). Even nerve-sparing surgery impacts on sexual functioning (3), though less invasive surgical techniques are being championed to reduce impact on sexual and urinary function (4). ED is also a known treatment consequence of external beam radiotherapy and brachytherapy (5). Studies suggest that the overall impact on sexual functioning is likely to be underestimated in the quality of life (QoL) literature (in part due to the methodological limitations of fixed questionnaire scales) (6),

Table 1 Socio-demographic and medical data of participants

Sample characteristic	N [%]
Ethnicity (n=18)	
White British and White Irish	10
African Caribbean, Australian, Chinese, Greek, North African, Filipino, Taiwanese	8
Employment (n=18)	
Retired	4
Housewife	4
Professional	5
Semi-professional	1
Manual	4
Sexual orientation (n=18)	
Heterosexual	14 [78]
Homosexual	4 [22]
The men's treatment (n=10)	
Prostatectomy	4 [40]
Hormone therapy	1 [10]
Radiotherapy/HIFU	1 [10]
Combination of two therapies	3 [30]
Combination of three therapies	1 [10]
Stage of treatment	
On treatment (hormone therapy)	2
Follow-up	8

HIFU, high-intensity focused ultrasound.

and emerge as a concern as men enter follow-up (3). Despite these data, the impact of prostate disease on sexual functioning has been described as an outcome that has been neglected by urologists (3,7). Research focus and clinical practice developments have tended to concentrate on the use of assistive technologies: primarily pharmacological interventions, to help some men achieve more normative erectile function (8). However, such responses are limited as they may lack integration with couple-focused strategies which, if delivered effectively, could enhance the success of biomedical interventions. Further, prostate cancer is often portrayed as a disease of individual men (9), whereas research has increasingly pointed to the shared nature of the experience within a unique couple dynamic (10-13), with evidence demonstrating poorer sexual functioning when compared to the general population (11). Studies have also started to emphasise partners as 'unpaid/unrecognised carers', indicating the need for a further

precedent to appreciate and address their needs in order to support and sustain their physical, emotional and caregiving role (11).

Despite the growth in prostate cancer research, the majority of studies in prostate cancer have focused on the impact of management of ED as an iatrogenic consequence of androgen therapy or radical prostatectomy (14). The impact on partners has been a more recent development but attention is being concentrated on this issue (15,16). In the latter study the issue of distress in female partners was examined and revealed the shared nature of the cancer event, and the need to reassess the situation once prostate cancer had been confirmed and to accept the challenges, threats and losses facing them, manage changes and create a meaningful intimate and social life (15). Furthermore there have been questionnaire studies exploring how prostate cancer couples rate each other's coping and distress. One study demonstrated that higher QoL, in both groups, was associated with higher education levels, lower avoidant coping, and higher relationship satisfaction (17).

The present study sought to document the intimate experiences of men and their partners post-treatment, focusing particularly on qualitative accounts of the impact in relation to sexual functioning and how these concerns were managed between themselves, and discussed in the clinic.

Materials and methods

In-depth interviews were conducted with participants recruited from two inner-city English hospitals. The study received ethical approval from the local NHS Research Ethics Committee.

Subjects

Interviews were conducted with respondents as couples, or individuals, depending on their stated preferences, recognising the benefits and constraints of individual versus dyadic interviews. Of the 18 participants, six couples agreed to a joint interview. Two couples provided individual accounts, and two men agreed to participate only without their partner.

Maximum variation sampling (18) encouraged a purposively heterogeneous demographic mix (*Table 1*), that included a diverse group of men with experience of a range of treatment options. Participants' ages ranged from 34 to 78 years and all were at least 2 years post surgery or radiation therapy, some were still on hormone therapy. The majority

of patients and partners were classified as White British, with the remaining 44% drawn from minority ethnic backgrounds including Greek, African Caribbean, Chinese, North African and Filipino. The sample was also purposively devised to ensure men had completed treatment at least two years before and were undergoing follow-up care at the time of the study. This allowed them, and their partners, to consider the enduring impact of cancer treatment.

Inclusion & exclusion criteria

Inclusion criteria were men (and their partners where possible) willing to provide written consent and living with a diagnosis of prostate cancer who have had experienced external beam radiotherapy, prostate surgery or androgen therapy at least 2 years previously. This was to ensure that short-term treatment effects were minimised and some adaptation to their situation had occurred. Exclusion criteria included men less than 2 years out of treatment, those unable/unwilling to provide written consent or those with co-morbidities that were likely to impact significantly on their experiences. Advice was sought from medical staff about the study and its aims, assistance with access to men was provided by Nurse Specialist or Consultants.

Procedure & interview focus

Interviews were carried out in participants' homes. They were intentionally exploratory in nature and all participants were invited to reflect on the cancer experience and its impact on their sex lives. They were advised at the time of recruitment that we wanted them to be as honest as possible and to use language that felt comfortable.

An experienced researcher with a background in mental health and communication skills education undertook all interviews (SML). The interviews followed a conversational style using series of prompts such as 'Can you tell me about the impact of prostate cancer on your relationship?'; 'How has this been experienced in terms of your sexual relationship?'; 'How has your partner been affected by this experience?'; 'Can you tell us how this was dealt with by the health care professionals you have met?'

Interviews were then transcribed in full and checked for accuracy by two members of the team (DK & SML).

Coding

Analysis proceeded with a full reading and discussion between

two of the researchers to support the organisation of the interview transcripts. Codes were developed in the process of defining categories and identifying recurring and less usual themes. Thus, categories were formulated and overarching themes were identified (for example gendered aspects of the disease, the shared nature of the event), to describe and explain the couples' and individuals' experiences of prostate cancer outcomes. Data were coded and comparisons made across the transcripts about couples' experiences since treatment, expectations and views of current service provision regarding recovery following prostate cancer treatment. This approach allowed the interviewer to remain focussed on what might help people in their situation, as well as illuminate the experience they have been through as a couple (19).

Results

Four categories were identified within the transcripts that represented core components of intimacy and sexual recovery following prostate cancer treatment. These related to social influences and language used to describe the loss or recovery of sexual activities; discussing sexual activity with clinicians; the clash of individual versus couple paradigms of prostate cancer recovery and the re-integration of sexual activities into the relationship.

Social influences and language used in relation to sexual expression

Social influences and language emerged as recurring features in these interviews. This included, for instance, the use of metaphors, the vocabulary chosen to describe sexual dysfunction or activity, and inherent culturally-derived expectations. There was evidence of frequent use of metaphors by both patients and partners. One partner, who found it difficult to express her frustration at her husband's ED, and his complacency towards it, related her dissatisfaction in terms of "I'm dying... of thirst... of food" and "A little cuddle?, No! I'm starving" (Female partner, couple 9, post surgery).

The expression "Rome wasn't built in a day" (Female partner, couple 8, post radiotherapy) was also used to demonstrate a partner's understanding of the gradual process involved in resuming sexual expression after prostate cancer treatment. Much of the language used by participants referred to ED and the failure of achieving an erection, for example: "it was floppy", "we had a small, fairly flaccid penis"—it was noteworthy that women would often

speak of the problem in joint terms rather than just the man's. More technical terms such as "*masturbation*" and "*ejaculation*" were used during the interviews rather than colloquial or slang terms. In social terms, this might be a sign of not seeming to appear crude or disrespectful in the interview context but, does raises an important point about the type of language that may be considered acceptable in clinical situations.

Underpinning the use of these terms were cultural expectations in relation to sexual dysfunction experienced predominantly from the patients' perspective. The focus was usually on problematic erectile function. One of the men had asked his male friends about failing sexual ability. Although he had very strong sexual desire, his "*orgasm, erection does not last for a long time, one to one and a half minutes... not very strong*" (Patient, couple 3, post surgery). He was prescribed a PDE5 inhibitor and claimed that he didn't want pleasure for just himself but for his wife as well, and felt that he was the one who should "*fix this problem*". The expectations of all patients (except two) was to resume full sexual activity as soon as practicable and this appeared to be a higher expectation than that held by partners who expressed the belief in taking things at a more steady pace.

One female partner explained this eagerness to please and to meet perceived expectations within the sexual relationship:

"He was too anxious to try to please me and nothing would happen at all and I would say, 'Don't be silly, you wait and see another couple of months will be fine and give it time and don't jump the gun too quick. You know, you're not ready yet'. After a while it was fine. I think it was a natural reaction." (Female partner, couple 1, post surgery).

At times, the choice of language of sex and intimacy could become a source of discomfort and tension within the medical consultation. The following quotation illustrates how one patient was asked to modify his language:

"Do you remember he said 'Have I had sex?' and I said 'Oh I'd had a shag twice' and he said 'Don't talk like that' or something...so I said 'Oh well better call it sexual intercourse.'" (Male patient, couple 4, post surgery).

This articulation of clinician discomfort is framed as related to the language that the patient chose to use, rather than avoidance of talking about sexual topics more generally. This does, however, signpost potential tensions in talking openly about sex and intimacy in a language which the patient, partner and clinician are comfortable with.

There were instances of remarkable frankness during data collection—one Arab couple spoke of their intimate relationship very openly with young children climbing

over them, another couple was interviewed as they lay on their bed together and the interviewer sat beside them. There was no sense of awkwardness about these situations; perhaps because the interviewer was comfortable with the discussion herself and so the participants felt able to vent their concerns and experiences. The social context within which disclosure takes place, therefore, may need to be considered. The home setting for this study seems to have encouraged openness—more so than had been achieved in clinical settings.

Discussions with clinicians about sexual activity

Talking with clinicians about intimacy and sex—either in a positive or a negative sense—was a common theme within these interview data. This included reflections on treatment decision-making, the range of topics that were discussed, and the ways in which clinicians communicated whether sex was an acceptable and appropriate topic for discussion within oncology outpatient clinics. Information about sexual functioning and the likely changes post-treatment were an expressed interest of both patients and partners.

Health care professionals in outpatient clinics had communicated their understanding of the expected pattern of sexual recovery of patients and their partners:

"We found ... (the nurse practitioner) very good and explained about sex life. Her information helped a lot." (Female partner, couple 1, post surgery).

Participants reflected on who had initially raised the topic of sex and concerns about ED:

Female partner: *(My husband's) erection was getting worse and worse... Now this isn't something he brought up with (consultant) really.*

Patient: *(Consultant) asked me about it I think, as opposed to the other way around.*

Partner: *He (my husband) didn't really want to bring up that topic, did you? (Couple 2, post surgery).*

Couples felt that talking about sex and intimacy was an important topic; requiring a senior clinician to give the topic the gravitas it deserved:

"I think you have to have a doctor or a nurse or somebody who's in a senior position who is quite sympathetic and knows how to be able to sit down and talk to a couple, because I think that's very important really, you know it's no good like the couple going in and seeing the consultant or the doctor or the nurse and they're just flippant with them, they don't explain things." (Partner, couple 1, post surgery).

The majority of this sample did not feel that clinicians

had discussed sexual functioning well, and reported that such concerns were not always appropriate to share with friends/family:

“Unconsciously, I was really scared. I wish I’d had somebody like you (the researcher), what I would call a professional that’s, because it’s not something that you can talk about to close friends because, it’s too intimate.” (Partner, couple 6, androgen therapy).

Limited opportunities were offered to individuals or couples to talk about their psychosexual needs; this was felt to be a considerable constraint of current service delivery:

Interviewer: *Do you think that your psychosexual needs had been met in terms of the care that you received after the treatment?*

Patient: *Well once I went off the hormonal drug, there was no, shall we say, counselling or anything.*

Interviewer: *Did anyone talk to you about it or mention it or was it...?*

Patient: *No, no, my oncologist in [another country] did say to me that once you’re off the drug things will get back to normal but what he didn’t tell me was how long, it was only after I asked a question when I got the result that it will take a year to eighteen months for your body to eliminate all the effects of the [treatment], that was all I was given.* (Patient, couple 6, androgen therapy).

Thus, while some information was provided, all of the participants felt that this stopped short of what they required to enter psychological recovery feeling adequately prepared for the timeframes over which physical recovery might take place.

At times, discussions about sex included directives about what sexual activities were permissible at specific time points during recovery. A minority of participants had offered leaflets about sexual functioning, and aids to EF recovery such as vacuum constriction devices, while others had not been given advice but felt that this would have been extremely helpful. Rarer in the data was an expression that discussions of ED and incontinence had guided treatment decision making. The following participant describes photo dynamic therapy (PDT) and high-intensity focused ultrasound (HIFU):

“He said ‘What are you going to do?’ so I said ‘I got two choices I need to do the PDT again... or I can do the HIFU and I don’t want to do the conformal, I don’t want to do the surgery or any others’ I said because ‘I don’t want to be impotent or incontinent and everything else’. And what I said was ‘Is it better to have ten years of fun or fifteen years of hell?’” (Patient 5, post radiotherapy).

Meanwhile, other patients were given so little information, that they were uncertain when they could resume regular sexual activity, without putting their health in danger:

“The thing that stopped me [having sex] was, first of all I

was, I couldn’t pee at all so I had to put the catheter in every few hours, and, we saw there was lots of blood coming out and this sort of thing...so I thought maybe I’d do myself some damage and that’s why... So it was a ‘damage I might do to myself’ scenario, and nobody said to me in the hospital, ‘Oh you can have sex whenever you feel like’ they just said ‘You’ve got to wait a week or a month.’” (Patient, couple 4, post surgery).

In other instances pre-treatment discussions of sexual functioning continued post-treatment, with some physicians asking about erectile functioning at follow-up appointments. The following participant reflects on how he was asked to describe his erections, following treatment:

“And I said ‘Oh it’s’, I said ‘the first time was a bit soggy... And the second one was okay’ I said ‘but only half an hour.’” (Patient, couple 4, post surgery).

The importance of transparent discussions with clinicians is underlined by the paucity of opportunities some participants seem to have had to talk about their sexual functioning elsewhere.

At an individual couple level, there were also examples of where the private impact had probably not been appreciated by health professionals. One of the members of the two gay couples who took part spoke of how his partner had become ‘very fat after the hormone therapy’ and said:

‘This was very hard to come to terms with, a fattish old man.’

His partner does not now ejaculate but:

‘Joint ejaculation had been very important to us, now he says I’m coming, I’m coming!, but there’s no visible signs.’ (Couple 6, androgen therapy).

The man also spoke of feeling guilty at finding his partner unattractive since hormone therapy but had felt unable to discuss this—certainly not with a health professional. He also had not been aware that it was possible for a man to have a powerful but dry orgasm without a full erection; this learning had been experiential rather than anything given to the couple as an information package associated with the treatment choices.

Another man spoke of having had erections and sexual dreams leading to orgasms in the post-surgical period in hospital. This had not been disclosed to staff but his attitude to this had been rather accepting and he described professionals doing such work in a matter of fact way:

“If you go to the butcher he know how to cut meat, if you go to the mechanic he fixes your car, so it’s your job...” (Patient 6, post surgery).

Regarding his erections and his sexual recovery, however, he spoke of masturbating into a cloth after surgery due to it being: *‘Bloody and so as not spread germ.’*

An individualistic model of care

Partners often reported feeling excluded from the events relating to the cancer and its impact. For instance, shortly after diagnosis one of the partners recalled:

“I would have liked, just once in a while, for the consultant to say, “How is your wife getting on? I really feel out of it and the fact was of course, I was affected.” (Partner, couple 2, post surgery).

Partners were rarely asked during clinics about their own needs in relation to the effects of the diagnosis and treatment outcomes. Thus, despite the sexual consequences of treatment having had a clear impact on the partner, they were rarely made to feel they had a genuine contribution to make to the medical consultation. The following excerpt illustrates this position of feeling under-supported, particularly in the context of being in a same-sex relationship:

Interviewer: *Did they ask you, questions in terms of you know, were you okay?*

Partner: *No they never did, they were very nice but I think the... medical establishment in general is still rather formal.*

Interviewer: *There’s no guidance, for same sex couples?*

Partner: *No, that’s right, and that really would have been very helpful.* (Partner, couple 6, androgen therapy).

Some couples told the interviewer that they had not talked with each other about sexual concerns either before or after treatment:

Interviewer: *Now did you talk about this before the operation?*

Partner: *No we didn’t actually. (...) I was very patient, because I think you have to be like that, you can’t just like click your fingers and everything’s going to come back to normal because it’s a big operation and he was very ill and it’s just basically if you love somebody enough it’s just, you just must sort of have patience and wait and then everything is fine.* (Female partner, couple 1, post surgery).

The above extract indicates that although the clinician had talked with him and his partner about sexual concerns, this did not mean that the couple would necessarily talk about it further together.

Re-integrating sex into the relationship

Couples found their own harmony in living with enduring changes such as moderate or severe ED and reflected on this with the interviewer:

“The only way it’s affected my sex life is not getting an erection, to begin, though now that’s not a problem now.” (Patient, couple 1, post surgery).

A further interviewee reflected on changes in erectile functioning as he recovered from treatment:

“Well it wasn’t really there because, there is no erection you know, as strong as I want it to be. (Patient, couple 3, post surgery).

Participants indicated the importance of regaining sexual functioning, with one man stating that he yearned for sex before his physical capability returned:

“I was dying for some sex” (Male, couple 4, post radiotherapy).

Couples discovered that although penetrative sex may not be possible, other forms of intimacy and sexual activity were still available, and again the issue of orgasm without full EF was mentioned:

“One thing that I picked up on, which I thought was quite extraordinary was that you can have an orgasm with a flaccid penis.” (Partner, couple 2, post surgery).

For one man, although he regained erections very quickly after surgery, however this was not something his wife was aware of. Indeed, several years after treatment he was still sexually active, but not with his wife. The following quotation was also used above to illustrate pre-cancer relationships, but speaks equally powerfully to this sense of (re)integrating sex into current lifestyle choices:

“Well she (wife) will believe, and she does still believe it, that, I am er...you know, I cannot make love. She accepted it...that the penis it never gets hard.” (Patient 5, post radiotherapy).

Discussion

The final quotation above may reveal one of the reasons why some professionals, who may be under time pressures in clinical situations, find the discussion of sexual dysfunction a challenging topic. Such conversations bring them closer to the social and psychological complexities of people’s lives in ways that go beyond the traditional focus of the biomedical model. By adopting a qualitative approach to this study we were exposed to aspects of the couple’s sexual lives which would have not been revealed by questionnaire methods. However, both approaches have a role to play to reveal the needs of larger samples of couples across different disease trajectories.

Although only one person in a partnership experiences cancer, these data clearly indicated that the disease and its treatments also impacts on the partner. There is evidence that adjustment to ED takes time, but is a highly significant event in couples’ lives following prostate cancer. Its importance should not be under-estimated (20). Consequently, there is not only a need for patient-centred care, but also relational models of care, whereby side-effects

are recognised to impact on both members of a partnership (for example ED, or lack of ejaculation). Supportive care is therefore important for both patient and partner but must be tailored using language that is appropriate to the context of their lifestyles and expectations (3).

A relational approach to couple-focused support will take into account an understanding of illness impact that extends beyond the individual (patient-centred) bio-medical model. Instead it views cancer as a life-changing event that affects not just individuals, but everyone in one's intimate, and wider, sphere of relationships. To truly understand and address the wider impact of prostate cancer, it is vital that it is accepted as a condition affecting both the patient and those with whom he relates. Importantly these relationships may be spousal, casual or committed (or multiple combinations of these possibilities). The danger for the professional is to make assumptions.

These data suggest that health professionals should be supported to develop a more nuanced understanding of how best to work with couples in the post-cancer situation. There are clear practice implications for professionals in being able to provide care for patients and partners in a morally neutral way, while maintaining confidentiality within and between the two (or more) parties in sexual relationships. Consequently, HCP education should explore culturally held assumptions related to aspects of social difference such as age, gender and sexual orientation. Beyond this ideological level, healthcare professionals should also receive practical support to raise sexual functioning and intimacy within clinical conversations, so that these topics are given adequate gravitas. In addition to the bio-medical model of resuming sex after-treatment using medication, assistive technologies and sex toys (20), there should also be an emphasis on the development of couple-working skills and disclosure of worrying symptoms; such as the impact of ED. Clinical trials are exploring ways to support men and partners after therapy (21,22).

Finding a vocabulary for these clinical conversations is critical, with the patient, partner and health professional finding a mutually acceptable lexicon for discussing sex and intimacy. This may include shifting between medicalised language and lay terms to accommodate varying levels of (dis)comfort at talking about sexual/intimate issues (19).

We must also acknowledge the limitations of this small, heterogenous sample. In qualitative studies the aim is to obtain depth of insight from smaller numbers.

However, we also wanted to include as mixed a group as possible. Whilst we can offer insights here we recommend larger scale studies are needed, using mixed research methods.

To return to the original impetus for this study about the impact of prostate cancer on couples, we are reminded of the fact that sexual expression is one of the most fundamental of human pleasures. It allows people to engage intimately, to derive pleasure from each other's body and reinforces the bonds that exist—and that become so important—when a life threatening illness is diagnosed. When we set out to cure or control cancer but, in the process, leave individuals unable to experience the pleasure of sexual intimacy then we must ask if we have really promoted their wellbeing. To some individuals this outcome may be very acceptable, whereas to others they may be left with a sense of regret.

Qualitative research methods can allow us insights into these issues and can reveal nuanced examples of the impact of cancer treatments. The primary message of this paper is that information and communication can help clarify what expectations might be acceptable, and achievable, and which are less likely. Previous research revealed that prostate cancer consultations, although focussing on the area of the body most associated with sexual function, did not always encourage the topic to be addressed. Instead the topic was most often raised by the patient, if it was at all, and some men (such as those with co-morbidities) were least likely to be asked about sexual concerns (19).

By not including this issue into routine practice we risk diminishing the importance of sexual function in the mind of patients and partners, and in doing so their anxiety may be magnified. Mitchell (23) captures this final sentiment well:

'Sexual pleasure, is also relative, and is often as much a product of expectation, of the symbolic meaning of the act, and of the emotional and relational context as it is of the physical experience' (p.60).

This is a useful reminder as we engage in curative work with increasing numbers of men, and their partners, following the diagnosis of prostate cancer (23,24).

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Footnote

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to declare.

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