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Original article

"I wish I'd told them": a qualitative study examining the unmet psychosexual needs of prostate cancer patients during follow-up after treatment

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Abstract

Objective: To gain insight into patients' experiences of follow-up care after treatment for prostate cancer and identify unmet psychosexual needs.

Methods: Semi-structured interviews were conducted with a purposive sample of 35 patients aged 59-82 from three UK regions. Partners were included in eighteen interviews. Data were analyzed using constant comparison.

Results: 1) psychosexual problems gained importance over time 2) men felt they were rarely invited to discuss psychosexual side effects within follow-up appointments and lack of rapport with health care professionals made it difficult to raise problems themselves 3) problems were sometimes concealed or accepted and professionals' attempts to explore potential difficulties were resisted by some 4) older patients were too embarrassed to raise psychosexual concerns as they felt they would be considered 'too old' to be worried about the loss of sexual function.

Conclusion: Men with prostate cancer, even the very elderly, have psychosexual issues for variable times after diagnosis. These are not currently always addressed at the appropriate time for the patient.

Practice Implications: Assessments of psychosexual problems should take place throughout the follow-up period, and not only at the time of initial treatment. Further research examining greater willingness or reluctance to engage with psychosexual interventions may be particularly helpful in designing future interventions.

Key words: Prostate; cancer, follow-up, psychosexual, qualitative, partners

1. Introduction

Follow-up after cancer treatment is used to identify and address psychosocial needs, as well as monitor any adverse effects of treatment and detect recurrence or progression of disease [1]. The Institute of Medicine has detailed different domains of psychosocial need that ought to be met throughout a patient's 'cancer journey' [2]. Prostate cancer patients are likely to share common concerns with other cancer sufferers [3, 4], but have reported some specific unmet psychosocial needs [5-14]. Patients have reported particular difficulties in the domains of self image, masculinities [15-17] and sexuality [18, 19] which appear to relate to losses consequent on treatments for prostate cancer. Radical curative treatments can result in nerve or tissue damage, either eradicating erections or taking up to two years for partial erections to be recovered [20] and hormonal treatments can result in side effects that might be experienced as challenging to masculinity (e.g. loss of libido and gynecomastia). Consequently, psychosocial assessment may have a particular focus on patients' psychosexual needs after treatment (i.e. psychological need arising from sexual dysfunction) [21]. The National Institute for Clinical Excellence (NICE) recommends that men and their partners are given the opportunity to discuss psychosexual problems before and after treatment [21]. However, there has not been any detailed exploration of men's varying responses to the psychosexual side effects of treatment or of their views on the delivery of psychosexual support during follow-up.

Male cancer patients typically access available psychosexual services at lower rates than female patients [14]. This raises questions about whether there might be improvements needed to existing psychosexual services and how best to facilitate

men's access to health care if they experience problems [22, 23]. Empirical evidence supports a popular belief that men encounter difficulties disclosing psychological difficulties during consultations [8, 24-26]. Health care seeking for mental health difficulties has been described as being particularly challenging to masculinities [27, 28], which may exacerbate problems in identifying and addressing patients' psychosexual needs. It has been suggested that GPs could have an important role in identifying men's needs and in offering psychosexual support [1, 29, 30]. However, it has been reported that some patients lack confidence in their GP's ability to provide this kind of support [31] and there may be little time for assessment of needs in practice [32-35].

Psychosocial support may be provided to cancer patients by family and friends [36, 37]. However, some men express concerns about burdening those closest to them and want to avoid seeming over-dependent on their partners. There may be good reason for such concerns as psychosocial morbidity in prostate cancer has been shown to be highly prevalent, not only among patients, but particularly among their partners [38, 39]. However, there is a paucity of psychosocial assessments and interventions currently available to patients and their partners [40-43].

This paper offers insight into patients' experiences of follow-up care, including the failure to address certain psychosexual needs, particularly those concerning sexual function. We thought it important to present the accounts of both younger and older men here, as to date most studies have emphasized younger men's 'greater' psychosexual needs [9, 44] and have commonly assumed that "the older the patient, the less the bother" [45]. However, one Swedish study found that elderly people still

regarded sexual activity as a natural part of their lives [46] and some of the accounts of older men presented here suggest that the psychosexual consequences of treatment may be relative to initial function, irrespective of age.

This qualitative study aimed to describe prostate cancer patients' experiences of current follow-up practices, seek explanations as to why needs went unmet (if this was perceived to be the case), and examine participants' perceptions of professional role changes and alternative models to hospital follow-up [47]. This research was complemented by an interview study examining the views of health care professionals (HCPs) on follow-up, along with a systematic review of international guidelines on prostate cancer follow-up [48].

2. Methods

2.1 Sample

Prostate cancer patients were recruited through nine general practices located in three regions across the UK (North Wales (NW) $n=10$, East Lothian (EL) $n=10$ and Thames Valley (TV) $n=15$) (ethical approval was granted). Each practice identified ten patients from their cancer register and a member of the research team (RO) discussed anonymized cases with a GP in each practice in order to select five to invite for interview. A total of 45 patients agreed to participate, exceeding the number we anticipated needing. Purposive sampling ensured maximum variation by: patients' age (59-82); socio-economic background; treatment (including those who had curative and hormonal treatments and patients undergoing monitoring); on who led the follow-up (primary, secondary or shared care) and modes (e.g. clinic, postal, telephone) and lengths of follow-up (ranging from 9 months to 14 years post-treatment) (See Table

1). This sample was designed to enable us to explore some diversity in men's experiences of follow-up as articulated by thirty-five participants.

Patients were sent postal invitations by their GPs and those consenting were telephoned by a member of the research team (RO). Men were asked to extend the invitation for interview to their partners if they wished, as there had been impromptu involvement of spouses in pilot interviews (Partners included $n=18$) (See [60] for a detailed discussion about the unplanned presence of spouses in interviews on cancer). Partners took varied roles in interviews: some observed while the participant spoke of his experience; others prompted forgotten details of follow-up; some described their own unmet psychological needs.

2.2. Interview design

Data were collected between March and September 2008. Exploratory interviews were conducted to inform the study topic guide (see Table 2), which drew on the literature, the original research questions, pilot data, with further amendments to account for emergent themes. The first author is a medical sociologist and was new to conducting cancer-related research. The study's multidisciplinary team included a senior cancer researcher (EW) and a GP (PR) who commented on emergent themes and areas that might be fruitful to probe in subsequent interviews. Field notes were written immediately after leaving participants' homes to note any unrecorded conversations before and after the 'formal' interview. They were also used to record early analysis (i.e. reflections on the main themes covered and their relationship to preceding interviews).

2.3. Description of interview

All interviews were conducted in participants' homes by RO who was responsible for the research process. Interviews were digitally recorded with participants' consent. Patient interviews began with an open non-directive question inviting men to speak at length about their diagnosis, current treatment, and experiences of follow-up care. Probes were then used to elicit greater detail on issues raised spontaneously by participants (in the order patients presented them and reflecting the language they used). More directive questions were utilized in the later stages of interview to explore any areas noted on the topic guide that had not already been covered. The most sensitive means of exploring men's experiences of psychosexual problems (and an effective strategy for prompting more detailed responses from those initially reluctant to discuss these matters in detail) was to normalize, rather than personalize, the loss of sexual function (e.g. 'some men find that a common side effect of treatment is impotence. Is this something you have experienced?'). This was a particularly effective technique when exploring the psychological consequences of the loss of sexual function (e.g. 'another man interviewed described having difficulties adjusting psychologically to being impotent. Is this something that has affected you?'). Partners' who were included in early interviews also spontaneously discussed their psychological needs and this was explored in greater depth in later interviews. However, a focus on patients' experiences of follow-up was necessarily prioritized given the original focus of the study.

2.4. Analysis

Recordings were transcribed verbatim, cross-checked for accuracy and identifying information was removed. RO coded all interviews using Nvivo7. Constant

comparison [49] was used to examine the commonalities and differences within and between transcripts. Broad themes were identified first and then broken down into sub-themes by RO who coded all data. Memoing was used to keep note of how themes were derived and whether the names of themes were given by the researcher or were coded *in vivo*. Some of the identified themes were driven by research questions (e.g. ‘ideas on what might help improve follow-up?’ and ‘views on the role of primary care’). Other themes were grounded in the data having either been: 1) transparent upon completion of an interview and noted in field notes (e.g. ‘unmet psychosexual needs of patients’ and ‘psychological problems described by partners’ or 2) emergent as coding of the data progressed (e.g. ‘variations in experiences of follow-up’ and ‘comparison of responses of younger/ older men’) [50].

The One Sheet of Paper method (OSOP) was used to summarize the data captured under particular themes in order to help identify patterns or common language used [51]. For example, under the broad theme of ‘psychological problems’, it was identified that psychological difficulties commonly manifested later on. The data presented here derive from a number of broader themes that were entitled ‘living with side effects’ (including sexual problems), ‘what happened in consultations (primary/secondary care)’, ‘health care seeking outside of formal follow-up appointments’, ‘problems with follow-up’, ‘men’s unmet psychological problems’ and ‘partner’s experiences of follow-up and unmet psychological needs’.

EW and PR each coded and analyzed a sample of interviews and the coding framework that RO, EW and PR developed independently of one other, was found to be a close match. RO then examined ‘relationships’ within and between themes e.g.

comparison of theme 1: *discussion within consultations* and theme 2: *living with side effects*, indicated that there was a disparity between the psychosexual side effects that patients described living with and what they were willing, or able, to raise within appointments. ‘Groups’ of participants, that were likely to share common experiences of follow-up (e.g. by age or treatment group), were also examined.

3. Results

3.1 Identifying men’s unmet psychosexual needs

3.2. Psychosexual needs manifested later on

The primary concern for all patients, regardless of age, was survival. However, in the case of younger patients, psychological needs relating to the loss of sexual function, surfaced after the imminent threat to their survival had passed.

Many of the younger participants had been offered counseling prior to radical curative treatment and this was perceived as preparing them well for the likely consequences of treatment. However, one man described how psychosexual problems manifested years after treatment:

*You simply don’t know how you’re going to react to it yourself....I think it’s only later on that I was affected emotionally by it.
(#46: Aged 64; FU 6 years; Radical Prostatectomy)*

Another patient perceived there to be a lack of support when psychosexual problems eventually arose:

*Immediately post-operatively the question of impotence doesn’t really come into your head. I think it’s only later on that you..have to...face-up psychologically to how you handle that....There’s not a lot of...counseling from either primary care or the hospital in terms of the psychological aspect.
(#61: Aged 61; FU 5 years; Prostatectomy)*

An older participant described how he had been offered various interventions by the hospital, in the form of pills, pumps and injections. He was critical of, what he perceived as, an emphasis on physical functioning:

The problem was it was switched off up here as far as I was concerned (indicates his mind). It sounds a strange thing to say, but it was. It was finished, dead, buried, gone...No I didn't use them (the Viagra he was prescribed) actually in the end. (#48: Age 74; FU 9 Years; Hormone).

3.3. Lack of rapport with staff

Other explanations for psychosexual needs not being identified within follow-up consultations, was provided a participant who had been routinely asked how he was coping. He felt that a lack of continuity of care during follow-up made it difficult for him to establish a relationship in which he would have felt comfortable disclosing problems with his 'sex life'. He described how follow-up might be improved to help overcome the difficulties he experienced:

I think if you saw the same person each time you would probably build up a rapport with that person. But seeing a stranger every time you're thinking 'oh my God. I'm not going to walk in there and start talking about my sex life with somebody I've never seen in my life before'I think I glossed over it (the psychological impact) (#51: Aged 59, FU 5 years; Radiotherapy)

An older participant described encountering similar difficulties in reporting psychosexual concerns during appointments:

It was quite a shock when you...go there and it's somebody else...Initially it affected me, 'oh I'm not seeing him again. I wish I'd see him'. But then having seen the other person I was put at ease and I was able to speak...I held nothing back sort of thing.. (about) the clinical side effects really. I don't think I spoke about my psychological problems...what was going in my mind, though. (#69: Age 75; FU 2 Years; Radiotherapy)

3.1.4. Concealment, resistance and acceptance of psychosexual problems

Other explanations for difficulties in identifying men's psychosexual needs were provided by participants who described how they had concealed emotional difficulties, resisted efforts on the part of health professionals to explore their feelings about the loss of sexual function, or reached a point where they accepted the loss of sexual function and no longer wished to seek support.

One participant stated that although he recognised that there was an implicit invitation to discuss his psychological and sexual difficulties when asked 'how are you feeling?', he had routinely presented himself as accepting of the loss of sexual function:

*They did...say 'how do you feel?' I said 'I've accepted it' because I was trying to make myself...feel better. But then after it I'd say 'oh I wish I'd told them'.
(#63: Age 62; FU 2 Years; Radical Prostatectomy)*

A urologist interviewed for the HCP study suggested that he could often detect men's seeming reluctance to talk about the psychosexual side effects of treatment. He spoke of the difficulties he had in 'opening men up' during follow-up consultations:

*I feel that they could do with opening up the discussion but they won't..discuss it...If they want to keep their head buried in the sand, that's their choice...You can mention it and they shrug their shoulders, some of them and say 'it doesn't bother me any more'. A large number of men will say that. Therefore, one feels that's the end of the discussion. They've closed it off.
(#9 Urologist, NE England)*

One participant described why he had resisted all efforts to explore how he felt about the loss of sexual function. He felt that 'talk about sex' was an unacceptable practice (for a man of a particular generation where such discussions were viewed inappropriate talk to have with strangers):

Men don't talk about things like that, well not the type of man that I go with...You don't talk about having sex...To me that's very personal and that's in that little box there and it's locked and there's no key to it.

(#40: Age 77; FU 14 Years; Radiotherapy/ Hormone)

However, others had conveyed to their GP and/ or consultant that they were open to being referred to a specialist psychosexual service in order to get support with the psychological difficulties in adjusting to the loss of sexual function. One man described his frustration when he was told there was no appropriate support available in his area:

For me the issue was psychological...I (asked) 'what can we do about this?' (the psychological impact of erectile dysfunction). It sounded much more...drug options rather than psychological. So I didn't pursue that.. I just decided to live with it.

(#55: Age 60; FU 2 Years; Radical Prostatectomy)

Another patient, who had never disclosed during follow-up appointments the depression he experienced following treatment, described a harrowing process before he came to accept the loss of sexual function:

Wife: It was difficult for you. It was

#63 Patient: You feel like...you're not a man anymore. That's the way I feel and at first I would just have a couple of cans (alcohol), you know, and all of a sudden it was more. But now I've stopped all that. I mean I still have a couple of cans but I dinnae drink as much as what I used to...I'm over all that (Wife: You have). I've accepted it now

(#63: Age 62; FU 2 Years; Radical Prostatectomy)

Younger men's accounts of follow-up highlight some of the difficulties there may be in encouraging men to disclose problems and in providing them with timely support.

3.2. Unmet psychosexual needs of older patients

Impotence was commonly perceived by men of all ages as a necessary sacrifice they had to make in order to survive prostate cancer. Most of the older participants appeared to accept that treatment had halted their sexual lives permanently and were unlikely to pursue further treatments in an effort to improve, or restore, erectile function. However, there were some exceptions who attached greater importance to sexual activity and described psychological difficulties in adjusting to the losses consequent on treatment. One couple had been married for sixty years and were particularly distressed at the prospect of treatment affecting sexual function:

*It shook me rigid when he (consultant) was telling us the effects of it (treatment), referring to it like being castrated. I was like 'oh God! Do we **have** to have that?' Your sex drive would be nil! So, it's sad.
(Wife of #73, Age 82; FU 3 years; Hormone)*

Another patient, who had remarried at the age of seventy-four, described how the loss of sexual function had profoundly affected his view of himself as a man:

*At first I felt in a sense that I was letting my wife down. As I say we've only been married five years and she's 20 years younger than me. I was hoping to have a.. satisfying sexual relationship with her.....I did feel that I was not fully a man not being able to sort of function 100%.
(#75: Age: 79; FU 5 years; Hormone therapy)*

He commented that he had not been asked about sexual function during follow-up appointments and believed this had been neglected because of his age:

*I don't know whether the team (at the hospital) took the attitude 'he's getting on for 80. It's not worthwhile bothering much with him'. They didn't ask me. I had to tell them that I just couldn't function sexually at all.
(#75: Age: 79; FU 5 years; Hormone therapy)*

There seemed to be particular concern (a commonly expressed view within the sample) that the onus had been on him to raise his sexual problems during an appointment. However, he felt confident about asserting his needs within consultations (he discussed how his work as a clergyman meant that he was used to discussing emotions). However, it was more common to hear from older participants that they avoided initiating discussions about their sexuality because they were too embarrassed to admit they still had sexual needs. A younger man stated that he also felt ‘too old’ to raise his concerns and worried about how this might be received by health care professionals: “I feel I shouldn’t be thinking about sex at my age” (#56: Aged 63, FU 8 Years; Watchful Waiting). In such cases, an invitation from a health care professional, to make it ‘acceptable’ for them to discuss sexual activity, would have been welcomed. One participant stated that while he thought it reasonable for health care professionals to assume some older men might be more accepting of the loss of sexual function, he thought it was important to assess men on the basis of their individual psychosexual needs and avoid assumptions based on age:

I think it would probably be useful to be offered (counseling) but it depends on each individual’s sexuality at the end of the day and how important that is...at different times of their life. I suppose like most people...you want to feel that you’re still sort of potent probably even when you’re 85
(#48: Age 74; FU 9 Years; Hormone)

Older participants described having more frequent contact with primary care than their younger counterparts, usually for hormonal injections and/ or regular Prostate Specific Antigen tests (PSA). However, it appeared that these rarely provided opportunities for men to discuss any concerns they had relating to their sexuality or psychological wellbeing. Rather, these visits were described as perfunctory, usually involving an appointment with a phlebotomist or practice nurse, who “*just takes the*

blood” (#58 Age 75; FU 6 years; Radiotherapy), suggesting to one man that there was “*no more than a technical interest*” in his disease (#48: Age 74; FU 9 Years; Hormone). One participant stated that his GP “*did ask ‘how do you feel’, ‘how am I?’....You see I’ve never thought perhaps of saying ‘oh I really feel...’ up here sort of thing, in my mind*” (#69: Age 75; FU 2 Years; Radiotherapy). Practice nurses, interviewed for the health professionals study, acknowledged the lack of psychosexual support currently offered to their patients. However, one nurse felt the regular contact she had with patients would be:

...an opportunity for them to discuss it because it isn’t something that you can discuss with anybody in the street, is it?...But it is an opportunity. I think if we had more information we may be able to give better support there.
(#6 PN, Thames Valley)

3.3. Partners’ psychological needs

Both partners and patients emphasised the toll that living with cancer had on spouses. Patients emphasised the difficulties of living with the psychosexual side effects of treatment long-term and there were few mentions of the psychological difficulties experienced in living with a cancer diagnosis. However, a number of spouses revealed that it had been important, immediately after diagnosis, to appear mentally strong for the ‘struggling’ patient. Despite describing the emotional toll that her husband’s illness had taken on her (her husband had also been critically ill with a perforated bowel prior to his cancer diagnosis), one partner described how she felt she also had to remain mentally ‘tough’ after her husband’s treatment:

I’m tough! (Laughs) (her eyes filled with tears)...You just have to get on with it....There’s no point in me lying down...Somebody has to be capable.
(Wife of #68: Age 61; FU 3 Years; Hormone/ Radiotherapy)

Another wife of a patient similarly emphasised the need for stoicism through treatment and during follow-up, stating that she felt she was “*the stronger of the two*” in coming to terms emotionally with the cancer and the side effects of treatment (Wife of #71: Age 71; FU 2 Years; Radiotherapy). However, some of the patients emphasised the fragility of their wives and felt a need to protect them, particularly from worry about cancer. One man observed that his wife might have benefited from some external support following his treatment:

When you're a cancer patient you're not at your best or you're not the best person to be around...It's..nice for them to get a bit of encouragement from an outside source.
(#42: Age 73; FU 7 Years; Watchful Waiting)

However, in the absence of such support one man described how he felt it was his protective duty as a man to “hide a lot..and... (because I’m) trying to be strong and brave for my family” (#64: Age 62; FU 2 Years; Radical Prostatectomy).

Most partners appeared to find it difficult to consider their own psychological needs in detail. However, one woman was able to state in the interview, if not within appointments, that she had felt a need for some formal psychological support following her husband’s surgery:

It had been a traumatic period for my husband. It had been a traumatic period for myself.... after they all went away (after treatment) I was on my own...I just cried I really did because I felt I needed help from somewhere..... That's what was missing really. A support. (RO: You felt a need for support?) Yes I did at the time...I needed the counselling.
(Wife of #74: Age 69; FU 3 Years; Radical Prostatectomy)

However, another of the partners felt that the only contact she had with professionals about her husband's cancer was within follow-up appointments. She was concerned that this was not an appropriate setting in which to raise the psychological difficulties she was experiencing: *"I feel they're talking to [husband]. I don't feel that I should be asking anything"* (Wife of #68). The data suggest that partners, in common with patients, would have welcomed an invitation to discuss their psychological needs in an appropriate setting when needs arose.

4. Discussion and conclusion

4.1 Discussion

This qualitative study offers insights into the psychosexual side effects of prostate cancer treatment, as articulated by thirty-five men. Their accounts offer some explanations as to why psychosexual needs were not currently being met by existing follow-up arrangements. Most prostate cancer patients seek support for sexual dysfunction at an early stage following treatment [52]. However, the data presented here show that the psychological consequences of the loss of sexual function may only manifest years after treatment when the imminent threat to survival passes [6, 53]. These data have important implications for the delivery of psychosexual support during follow-up, as current recommendations suggest that assessment of psychosexual needs should be targeted around the period close to diagnosis [54] and in the early months after treatment [9, 55, 56]. This study suggests that re-evaluations of men's psychosexual needs after treatment, regardless of perceived stability of disease, might improve the experience of follow-up care for some. Follow-up might be further enhanced by assessing patients based on individual psychosexual need, thus

avoiding assumptions about the possible meaning of the loss of sexual function for men of particular ages [57-59].

The findings presented here are based on the experiences of a small sample of patients and their partners and are therefore not generalizable. However, we have included a range of patients (by age, treatment and length of follow-up) to reflect some of the diversity in men's experiences of follow-up. As all patients were asked about their wish to include or exclude partners from interview, it was apparent from discussion prior to interview that a partners' participation in, or absence from, reflected their inclusion or exclusion (by patients) from follow-up consultations. The initial unplanned presence of partners in early interviews proved beneficial in eliciting greater details from patients regarding the content of follow-up appointments. This is perhaps unsurprising given family members' involvement in cancer care and their role (when present) in prompting, or relaying, important details within consultations [60]. The experiences of advanced cancer patients, and their partners, were not explored as fully as we had planned. Given that this is a much neglected issue this would benefit from examination elsewhere. The sample also reflects the limited ethnic diversity in the three study regions (North Wales, East Lothian and Thames Valley) and so the needs of Afro-Caribbean men, who have a higher incidence of prostate cancer, were not examined [61].

The main focus of the study was on patient's experiences of follow-up and inevitably there were limits to the exploration of partner's psychological needs. A maximum variation sample of partners would have enabled us to explore a wider range of their experiences in greater depth. The sexual lives of partners were largely omitted from

their discussions, which focused almost exclusively on their unmet psychological needs (by contrast sexual and psychological issues were intertwined in patient's accounts). In the few instances where partners and patients discussed their sexual relationships, partners sought to minimize the importance of the loss of patients' sexual function and dismissed the idea, when men expressed concerns, that this had a negative impact on their relationship. It may be that joint interviews may have hindered detailed exploration of the psychosexual needs of partners and may be more easily explored within individual interviews. Despite these limitations, a particular strength of the study was that it enabled us to incorporate these emergent findings, which have not received detailed attention elsewhere.

4.2 Conclusion

The data show that while the side effects of treatment may be similar for men, in terms of the impact on sexual function, they hold particular meanings and have different psychosexual consequences for patients of varying ages and different stages of follow-up. Practice-based research which develops and evaluates interventions designed to assist men in addressing any psychosexual problems is needed as there is a lack of proven psychosocial interventions for adult cancer patients. It would be useful to further explore whether existing psychosexual services are acceptable to those who identify themselves as in need of greater support. Further research, examining men's accounts of greater willingness or reluctance to engage with psychological interventions, may be particularly insightful. There is also a need for research that offers more detailed insight into the psychological consequences for partners in supporting patients throughout follow-up and to examine the possibility of wider psychosexual concerns.

4.3 Practice implications

An important finding of this study is that assessment of psychosexual needs has to take place throughout the follow-up period, and not only at the time of initial treatment. Patients may take time to identify that they have a need for psychosexual support and when they feel ready to raise concerns may need help in overcoming 1) embarrassment about discussing sexual function and 2) ideas that it is ‘unmanly’ to discuss emotions. The National Health and Medical Research Council, Australia, describe strategies being evaluated to improve psychosocial care of cancer patients [62]. These include educational workshops for health care professionals, patients and their families, designed to de-stigmatise psychosexual problems, legitimise expression of concerns, and raise awareness of the effectiveness of interventions. There may be a role for the GP in assessing wider psychosexual needs and signposting where to get help where needed. GPs may also be particularly well placed to offer partners encouragement to consider their psychological needs at a time when care is largely focused around the patient. However, it has been reported that physicians, while perceiving exploration of patients’ psychosexual needs as part of their role, may feel unprepared to identify and address these appropriately [63]. There may also be a preference, on part of health care professionals and patients alike, to draw on the services of allied care providers e.g. counsellors who have expertise in supporting men coming to terms with losses or challenges to masculinity as a result of illness and treatment.

The authors confirm all patient/ personal identifiers have been removed or disguised so the patient/ person(s) described are not identifiable and cannot be identified through the details of the story.

Contributions:

All authors contributed to the design and conduct of the study and commented on the paper. RO conducted all interviews and a detailed analysis of the data and prepared all drafts of the manuscript. EW and PR each coded a sample of the dataset. HM conducted a systematic review for a connected study and advised on appropriate sources to include in the paper.

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References

1. Neal, R. Management of prostate cancer in general practice. *Trends in Urology, Gynecology and Sexual Health*. 2008; 13: 27-80.
2. Institute of Medicine (IOM). *Cancer care for the whole patient: meeting psychosocial health needs*. Eds Adler, N & Page, A. Washington DC, National Academies Press. 2007.
3. Hedestig, O., Sandman, P & Widmark, A. Living with untreated localized prostate cancer. *Cancer Nursing*; 2003; 26(1): 55-60.
4. Ames, S., Tan WW., Ames GE., Stone RL., Rizzo TD Jr., Heckman, MG., Crook, JE., Clark, MM., Rummans, TA & Werch, CE. Quality of life of men with biochemical recurrence of prostate cancer. *J Psychosoc Oncol*. 2008; 26(2): 17-34.
5. Jakobsson, L., Hallberg, I & Loven, L. Met and unmet nursing care needs in men with prostate cancer. An explorative study. Part II. *European Journal of Cancer Care*. 1997; 6: 117-123.
6. Gray, R., Fitch, M., Phillips, C., Labrecque, M & Fergus, K. Managing the impact of illness: the experiences of men with prostate cancer and their spouses. *Journal of Health Psychology* . 2000; 5: 531-548.
7. Sanson-Fisher, R., Girgis, A., Boyes, A., Bonevski, B., Burton, L & Cook, P. The unmet supportive care needs of patients with cancer. *American Cancer Society*. 2000; 88: 225-36.
8. Helgason, A., Dickman, PW., Adolfsson J & Steineck G. Emotional isolation: Prevalence and the effect on well-being among 50-80-year-old prostate cancer patients. *Scandinavian Journal of Urology and Nephrology*. 2001; 35(2), 97-101.
9. Steginga, S., Occhipinti, S., Dunn, J., Gardiner, R., Heathcote, P & Yaxley, J. The supportive care needs of men with prostate cancer. *Psycho-oncology*. 2001; 10: 66-75.

10. Boberg, E., Gustafson, D., Hawkins, R., Offord, K., Koch, C., Wen, K., Kreutz, K & Salner, A. Assessing the unmet information, support and care delivery needs of men with prostate cancer. *Patient Education and Counseling*. 2003; 49: 233-242.
11. Lintz, K., Moynihan, C., Steginga, S., Norman, A., Eeles, R., Huddart, R., Dearnaley, D & Watson, M. Prostate cancer patients' support and psychological care needs: survey from a non-surgical oncology clinic. *Psycho-Oncology*. 2003; 12: 769-783.
12. Visser, A & Van Andel, G. Editorial: Psychosocial and educational aspects in prostate cancer patients *Patient Education and Counseling*. 2003; 49: 203-206.
13. Wallace, M & Storms, S. The needs of men with prostate cancer: results of a focus group study. *Applied Nursing Research*. 2007; 20:181-187.
14. Manii, D & Ammerman, D. Men and cancer: a study of the needs of male cancer patients in treatment. *Journal of Psychosocial Oncology*. 2008; 26(2): 87-102.
15. Ream, E., Quennell, A., Fincham, L., Faithfull, S., Khoo, V., Wilson-Barnett, J & Richardson, A. Supportive care needs of men living with prostate cancer in England: a survey. *British Journal of Cancer*. 2008; 98: 1903-1909.
16. Clark, J., Wray N., Brody B., Ashton C., Giesler B & Watkins H. Dimensions of quality of life expressed by men treated for metastatic prostate cancer. *Soc Sci Med*. 1997; 45(8): 1299-309.
17. Chapple, A & Ziebland, S. Prostate cancer: embodied experience and perceptions of masculinities. *Sociology of Health & Illness*. 2002; 24(6): 820-841.
18. Bokhour, B., Clark, J., Inui, T., Silliman, R & Talcott, J. Sexuality after treatment for early prostate cancer: exploring the meanings of 'erectile dysfunction'. *Journal Gen Intern Medicine*. 2001; 16: 649-655.
19. Beterö, C. Altered sexual patterns after treatment for prostate cancer. *Cancer Practice*. 2001; 9(5): 245-251.
20. Wittmann, D., Northouse, L., Foley, S., Gilbert, S., Wood, D. P., Jr., Balon, R & Montie, J. E. The psychosocial aspects of sexual recovery after prostate cancer treatment. *Int J Impot Research*. 2009; 21(2), 99-106.
21. National Institute for Health and Clinical Excellence (NICE). *Prostate cancer diagnosis and treatment*. Cardiff: National Collaborating Centre for Cancer. 2008
22. Moynihan, C., Bliss JM., Davidson J., Burchell L & Horwich, A. Evaluation of adjuvant psychological therapy in patients with testicular cancer: randomized controlled trial. *BMJ*. 1998; 316(7129)(Feb 7): 429-35.

23. Neese, L., Schover, L., Klein, E., Zippe, C & Kupelian, P. Finding help for sexual problems after prostate cancer treatment: a phone survey of men's and women's perspectives. *Psycho-Oncology*. 2003; 12: 463-473.
24. Balderson, N & Towell, T. The prevalence and predictors of psychological distress in men with prostate cancer who are seeking support. *British Journal of Health Psychology*. 2003; 8: 125-134.
25. Arrington, M., Grant, C & Vanderford, M. Man to man and side by side, they cope with prostate cancer: self-help and social support. *Journal of Psychosocial Oncology*. 2005; 23(4): 81-102.
26. Gray, R., Fitch, M., Phillips, C., Labrecque, M & Fergus, K. To tell or not to tell: patterns of disclosure among men with prostate cancer. *Psycho-Oncology*. 2000; 9: 273-282.
27. Kiss, A & Meryn, S. Effect of sex and gender on psychosocial aspects of prostate and breast cancer. *British Medical Journal*. 2001; 323(7320): 1055-1058.
28. O'Brien, R., Hunt, K & Hart, G. 'It's caveman stuff, but that is to a certain extent how guys still operate': men's accounts of masculinity and help seeking. *Social Science & Medicine*. 2005; 61: 503-516.
29. Sahay, T., Gray, R & Fitch, M. A qualitative study of patient perspectives on colorectal cancer. *Cancer Practice*. 2000; 8: 38-44.
30. Pascoe, S., Neal, R., Allgar, V., Selby, P & Wright, P. Psychosocial care for cancer patients in primary care? Recognition of opportunities for cancer care *Family Practice*. 2004; 21(4): 437-442.
31. Bradburn, J., Maher, J., Adwewuyi-Dalton., R, Grunfeld., E, Lancaster, T & Mant, D. Developing clinical-trial protocols: the use of patient focus groups. *Psycho-Oncology*. 1995; 4: 107-112.
32. Allen, A. The meaning of breast cancer follow-up experience for the women who attend. *Eur J Oncol Nurs*. 2002; 6: 155-161.
33. Beaver, K & Luker, K. Follow-up in breast cancer clinics: reassuring for patients rather than detecting recurrence. *Psycho-Oncology*. 2005; 14: 94-101.
34. Pennery, E & Mallet, J. A preliminary study of patients' perceptions of routine follow-up after treatment for breast cancer. *Eur J Oncol Nurs*. 2000; 4,138-145.
35. Koinberg, I., Holmberg, L & Fridlund, B. Satisfaction with routine follow-up visits to the physician. *Acta Oncologica*. 2001; 40(4), 454-459.

36. Emslie, C., Browne, S., Macleod, U., Rozmovits, L., Mitchell, E & Ziebland, S. 'Getting through' not 'going under': a qualitative study of gender and spousal support after diagnosis with colorectal cancer. *Social Science & Medicine* 2009; 68: 1169-1175.
37. Giarelli, E., McCorkle, R & Monturo C. Caring for a spouse after prostate surgery: the preparedness needs of wives. *Journal of Family Nursing*. 2003; 9(4): 453-485.
38. Cliff, AM & MacDonagh, RP. Psychosocial morbidity in prostate cancer: I. Design of a new questionnaire. *BJU Int* 2000; 86(7): 829-33.
39. Northouse, L., Mood, D., Montie, J., Sandler, J., Dandler, H., Forman, J., Hussain, M., Pienta, D., Sanda, M & Kershaw, T. Living with prostate cancer: patients' and spouses' psychosocial status and quality of life. *Journal of Clinical Oncology*. 2007; 25 (27): 4171-4177.
40. Northouse, L., Mood, DW., Schafenacker, A., Montie, JE., Sandler, HM & Forman, JD. Randomized clinical trial of a family intervention for prostate cancer patients and their spouses *Cancer* 2007; 110(12): 2809-2818.
41. Manne, S., Babb, J., Pinover, W., Horwitz, E & Ebbert, J. Psycho- educational group intervention for wives of men with prostate cancer. *Psycho-Oncology* 2004; 13(1): 37-46.
42. Sinfield, P., Baker, R., Agarwal, S & Tarrant, C. Patient-centered care: what are the experiences of prostate cancer patients and their partners? *Patient Education and Counseling* 2008; 73: 91-96.
43. Adams, E., Boulton, M & Watson, E. The information needs of partners and family members of cancer patients: a systematic literature review. *Patient Education and Counseling* 2009; 77(2): 179-86.
44. Smith, D., Supramaniam, R., King, M., Ward, J., Berry, M & Armstrong, B. Age, health and education determine supportive care needs of men younger than 70 years with prostate cancer. *Journal of Clinical Oncology*. 2007; 25(18): 2560-2566.
45. Litwin, M. S., Flanders, S. C., Pasta, D. J., Stoddard, M. L., Lubeck, D. P & Henning, J. M. Sexual function and bother after radical prostatectomy or radiation for prostate cancer: multivariate quality-of-life analysis from CaPSURE. *Cancer of the Prostate Strategic Urologic Research Endeavor*. *Urology*. 1999; 54(3): 503-8.
46. Beckman, N., Waern, M., Bustafson, D & Skoog, I. Secular trends in self reported sexual activity and satisfaction in Swedish 70 year olds: cross-sectional survey of four

- populations, 1971-2001. *BMJ* . 2008; 337(19 July): 151-163.
47. O'Brien, R., Rose, P., Campbell, C., Weller, D., Neal, R., Wilkinson, C & Watson, E. Prostate cancer patients' experiences of follow-up after treatment: a qualitative study. *British Journal of Urology International*. Online early 3 March 2010
48. McIntosh, H.M., Neal, R D., Rose, P., Watson, E., Wilkinson, C., Weller, D & Campbell, C. Follow-up care for men with prostate cancer and the role of primary care: a systematic review of international guidelines. *Br J Cancer* 2009;100(12): 1852-60.
49. Glaser, BG. The Constant Comparative Method of Qualitative-Analysis. *Social Problems* 1965;12(4), 436-445.
50. Kelle, U. The development of categories: different approaches in grounded theory. *The sage handbook of grounded theory*. Bryant, A & Charmaz, K. pp191-213. London Sage Publications. 2007
51. Ziebland, S., McPherson, A. Making sense of qualitative data analysis: an introduction with illustrations from DIPEX (personal experiences of health and illness). *Med Educ*, 2006. 40(5): p. 405-14.
52. Schover, L. R., Fouladi, R. T., Warneke, C. L., Neese, L., Klein, E. A., Zippe, C & Kupelian, P. A. Seeking help for erectile dysfunction after treatment for prostate cancer. *Arch Sex Behav* 2004; 33(5): 443-54.
53. O'Brien, R., Hunt, K & Hart, G. 'Standing out from the herd': renegotiating masculinity in relation to men's experience of illness. *International Journal of Men's Health*. 2007; 6 (3): 178-200.
54. Bisson, JI., Chubb, HL., Bennett, S., Mason, M., Jones, D & Kynaston, H. The prevalence and predictors of psychological distress in patients with early localized prostate cancer. *BJU Int* 2002; **90**(1): 56-61.
55. Visser, A., Van Andel, W., Voogt, E., Dijkstra, A., Rovers, P., Goodkin, K & Kurth, K. Changes in health-related quality of life of men with prostate cancer 3 months after diagnosis: the role of psychosocial factors and comparison with benign prostate hyperplasia patients. *Patient Education and Counseling*. 2003; 49 (3): 225-32
56. Smith, J. A., Filiault, S. M., Drummond, M. J & Knapman, R. J. The psychosocial impact of prostate cancer on patients and their partners. *Med J Aust* 2007; 186(3): 159-60
57. Smith, D. P., King, M. T., Egger, S., Berry, M. P., Stricker, P. D., Cozzi, P. Ward, J., O'Connell, D. L & Armstrong, B. K. Quality of life three years after

diagnosis of localized prostate cancer: population based cohort study. *BMJ* 2009; 339: b4817.

58. Lepore, S., Helgeson, VS., Eton, DT & Schulz, R.. Improving quality of life in men with prostate cancer: a randomized controlled trial of group education interventions. *Health Psychology*. 2003; 22(5): 443-452.

59. Giesler, RB., Given, B., Given, CW., Rawl, S., Monahan, P & Burns, D. Improving the quality of life of patients with prostate carcinoma: a randomized trial testing the efficacy of a nurse-driven intervention. *Cancer* 2005; 104(4): 752-762.

60. Speice, J., Harkness, J., Laneri, H., Frankel, R., Roter, D & Kornblith, A et al. Involving family members in cancer care: focus group considerations of patients and oncological providers. *Psycho-Oncology* 2000; 9(2): 101-112.

61. Ben-Shlomo, Y., Evans, S., Ibrahim, F., Patel, B., Anson, K., Chinegwundoh, F., Corbishley, C., Dorling, D., Thomas, B, Gillatt, D., Kirby, R., Muir, G., Nargund, V., Popert, R., Metcalfe, C & Persad, R. The risk of prostate cancer amongst black men in the United Kingdom: the PROCESS cohort study. *Eur Urol* 2008; **53**(1), 99-105.

62. National Health and Medical Research Council. *NHMRC Clinical practice guidelines for the psychosocial care of adults with cancer*. Campertown, NSW, National Breast Cancer Centre. 2003

63. Matthews Nichols, C & Barrett K. Female sexual dysfunction: a survey of Ob/Gyn resident education and experience. *Program of the Annual International Society for the Study of Women's Sexual Health*. Westin Casuarina, Las Vegas, NV, 248. 2005