Author/s:
Charlick, M;Murphy, M;Murphy, B;Ettridge, K;O'Callaghan, M;Sara, S;Jay, A;Beckmann, K

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Original Article

Sexual wellbeing support for men with prostate cancer: a qualitative study with patients

Megan Charlick[1], Michael Murphy[2], Barbara Murphy[2,3]^, Kerry Ettridge[4,5], Michael O'Callaghan[5,6,7], Sally Sara[8], Alexandar Jay[6], Kerri Beckmann[1]^

[1]Cancer Epidemiology and Population Health, University of South Australia, Adelaide, South Australia, Australia; [2]MMResearch, Melbourne, Victoria, Australia; [3]School of Psychological Sciences, University of Melbourne, Melbourne, Victoria, Australia; [4]Health Policy Centre, South Australian Health and Medical Research Institute, Adelaide, South Australia, Australia; [5]University of Adelaide, Adelaide, South Australia, Australia; [6]Flinders Medical Centre, Adelaide, South Australia, Australia; [7]Flinders University, Adelaide, South Australia, Australia; [8]Prostate Cancer Foundation of Australia, Adelaide, South Australia, Australia

Contributions: (I) Conception and design: M Charlick, K Beckmann; (II) Administrative support: M Charlick, B Murphy; (III) Provision of study materials or patients: None; (IV) Collection and assembly of data: M Murphy; (V) Data analysis and interpretation: M Charlick, M Murphy, B Murphy; (VI) Manuscript writing: All authors; (VII) Final approval of manuscript: All authors.

Correspondence to: Kerri Beckmann, PhD. Cancer Epidemiology and Population Health, University of South Australia, GPO Box 2471, Adelaide, South Australia 5001, Australia. Email: kerri.beckmann@unisa.edu.au.

Background: Sexual concerns remain the most frequently reported unmet need among men with prostate cancer. We aimed to explore patient's experiences seeking and receiving sexual wellbeing support after prostate cancer treatment, to ultimately identify areas which should be prioritised for improvement, as informed by the patients themselves.

Methods: Prostate cancer patients between 18–36 months post-treatment participated in semi-structured interviews. Interviews were conducted via video conference, transcribed verbatim, and thematically analysed. Interviews explored cancer experience, sexual support sought/received, and barriers to obtaining/receiving sexual wellbeing support.

Results: Most men relied on their treating clinician or specialist nurse for information about sexual wellbeing, though some consulted other professionals (physiotherapists, sexologists), peak bodies, the internet, or other men with prostate cancer. Information received was often fragmented, not specific to individuals' needs, or given at the wrong time or with limited follow-up. Barriers to help-seeking included the higher priority to be "cancer free", embarrassment, concerns about overburdening healthcare professionals, the perceived reluctance of clinicians to discuss sexual wellbeing and limited time for discussion. Continuity of care, accessibility of sexual-wellbeing experts, involvement of partners and personalised information were perceived as facilitating help-seeking for sexual health concerns.

Conclusions: To address the numerous shortcomings and barriers to seeking and receiving sexual wellbeing support, men with prostate cancer recommended that support should be provided both pre- and post-treatment, preferably by a healthcare professional trained to provide personalised and evidence-based sexual-wellbeing care. The sexual health needs of men with prostate cancer may be better met through ensuring men have continuing access to sexual wellbeing experts who can provide personalised support.

Keywords: Male; prostatic neoplasms; survivorship; sexual health; qualitative methods

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^ ORCID: Barbara Murphy, 0000-0002-6867-5819; Kerri Beckmann, 0000-0002-9798-1479.

Introduction

In 2024, prostate cancer was estimated to be the most commonly diagnosed cancer for men and Australians overall, affecting one in five men over their lifetime (1). Treatments include radical prostatectomy, radiotherapy and hormone therapy: all are highly effective in eliminating or reducing the progression of cancer (2). However, these treatments can significantly impact sexual function (3), as well as urinary and bowel function. The specific sexual-related side effects include erectile dysfunction, lack of ejaculation, changes in orgasmic function, loss of libido, and changes to penile length and girth (which also affects urinary function) (4,5). The types of sexual side effects and their trajectories vary by treatment type, with more immediate impacts among men who undergo prostatectomy and more gradual declines following radiotherapy which may not become apparent until 6–24 months after treatment (6).

Highlight box

Key findings

- This qualitative study explored men's experiences seeking help for sexual health issues after prostate cancer treatment. It identified several barriers to seeking help including: reluctance to discuss sexual health needs due to stigma, self-reliance, resignation, perceived discomfort of clinicians, not wanting to overburden healthcare professionals and limited time; a lack of continuity of care; limited knowledge and access to expert support services. Shortcoming of the information and support provided include that: it was given at the wrong time when the primary focus was on being 'cancer-free'; it was not personalised to men's individual needs; follow-up was often limited.

What is known and what is new?

- Sexual concerns are the most frequently reported unmet need among men with prostate cancer. Despite treatment and support options being available men often do not seek help for their sexual needs.
- Men interviewed in this study indicated some reluctance to discuss sexual concerns but also highlighted shortcomings in the information and support provide, including its timing, the impersonal nature that support, limited follow-up, and a lack of continuity of care.

What is the implication, and what should change now?

- Men with sexual health needs after prostate cancer treatment would benefit from being proactively offered access to relevant services at multiple time points after treatment.
- The sexual health needs of men with prostate cancer may be better met through ensuring they have continuing access to sexual wellbeing experts who can provide personalised support.

Sexual dysfunction can have a major impact on men's quality of life, self-esteem, mental health, relationships, and sense of masculinity (3,4,7). Sexual concerns are the most frequently reported unmet need among men with prostate cancer (8).

Men with prostate cancer can face challenges in seeking information and help for sexual difficulties. Previous qualitative research with prostate cancer patients highlights that men may feel embarrassed and uncomfortable initiating a discussion about their sexual dysfunction (9,10). Men who are unpartnered or who have depression are less likely than others to seek help for sexual dysfunction (8,11). Costs involved in attending appointments and purchasing sexual aids also inhibit help-seeking (12-14). Help-seeking behaviour is also strongly affected by the relationships men have with the healthcare professionals involved in providing treatment and care (13-16).

A recent publication of international guidelines for managing and supporting prostate cancer patients' sexual wellbeing emphasised provision of high-quality, evidence-based clinical care on sexual health as a key metric of prostate cancer care (17). Given sexually-related supportive care needs are the most commonly reported and intensely experienced unmet need among prostate cancer patients (13,18), further research to understand the barriers to seeking and receiving sexual wellbeing support, as well as shortcomings in current help-seeking pathways, is required. Qualitative research allows for these issues to be deeply explored and provides patients the opportunity to be involved in the process of improving patient-centred care. Given this, we aimed to explore men's experiences seeking and receiving sexual wellbeing support after prostate cancer treatment to identify areas which should be prioritised for improvement, as informed by the patients themselves. We present this article in accordance with the COREQ reporting checklist (available at https://tau.amegroups.com/article/view/10.21037/tau-2024-682/rc).

Methods

This study was conducted in accordance with the principles outlined in the Helsinki Declaration and its subsequent amendments. It received ethics approval by the Southern Adelaide Clinical Human Research Ethics Committee in November 2023 (No. LNR/23/SAC/146). All participants gave informed consent for the publication of information relating to them, including deidentified quotes.

Participants and recruitment

Participants were men with prostate cancer who had received radical treatment 18–36 months earlier and were enrolled on the South Australian Prostate Cancer Clinical Outcomes Collaborative registry (a clinical registry that includes both public and private patients treated across South Australia). Men who had previously completed a survey on sexual wellbeing and support could nominate to participate in a qualitative interview. After providing informed consent, potential participants were telephoned by B.M. to arrange a mutually convenient time for the interview. Invitations were continued until 20 participants were enrolled in the study, with saturation being reached. As per Braun *et al.*'s reflexive thematic analysis methodology (19), interviews aimed to deeply explore participant's experiences and opinions. An interview guide was prepared by the authors, informed by a literature review (15) and consultations with a consumer advisory committee (comprised of seven men with prostate cancer and one partner) and a research advisory committee (comprised of three researchers, a urologist and a prostate cancer nurse specialist). A semi-structured interview approach was used, using an interview guide to direct the conversation, with follow-up and probing questions used as required. No formal field notes were taken for analysis purposes.

Data collection

Individual one-to-one interviews were conducted with each participant by a male researcher M.M., who has over 30 years' experience conducting health and social qualitative research and holds a graduate diploma in psychology. The interviewer had no contact with the participants prior to the interviews, and introduced himself at the beginning of the interviews, detailing his experience and role in the study. Interviews were conducted via Zoom, which has been shown to provide data of comparable quality to that obtained through face-to face interviews (20). They were then digitally recorded with participants consent and transcribed verbatim. Interview duration was between 50 to 60 minutes.

Data analysis

Interview transcripts were analysed by authors M.M. and B.M., using a grounded theory approach (21) and Braun *et al.*'s reflexive thematic analysis methodology (19), with themes developed from the research objectives and emergent trends from the data. Reflexive thematic analysis involves six steps: (I) data immersion and familiarisation to the content; (II) initial coding of transcripts; (III) categorisation of codes; (IV) refinement of categories into meaningful themes; (V) formalisation of defined themes; and (VI) summarisation of themes with extracts from the data. Selected quotes refer to the participant number, age at interview, and treatment/s received. A summary of the themes was presented to participants for comment prior to publication.

Results

Sample

Twenty prostate cancer patients were interviewed (all of whom identified as male). Participants' ages at the time of interview ranged from 55 to 78 years. Time since diagnosis ranged from 2 to 7 years. Eleven participants had undergone prostatectomy, one had transitioned to radical prostatectomy after a several years on active surveillance and eight had received radiation as their primary treatment, three of whom also reported receiving hormone therapy. Most were partnered in a heterosexual relationship and were retired. Individual participant characteristics are shown in *Table 1*.

Overview of men's experiences and themes

The provision of sexual wellbeing support occurred along a continuum for most men in the study, beginning at diagnosis in relation to treatment decision making, and continuing years into post-treatment survivorship care. However, the support and information received and accessibility for patients varied considerably, as did the impact of treatment on sexual function. Men described a range of biological/physical, psychological, and social impacts on their sexual wellbeing. Physical impacts typically included loss of spontaneous erections, difficulty getting and/or maintaining an erection even when aroused, and changes in ejaculation including loss of sensation and/or dry ejaculation. Some men also reported changes in penile length and girth. Psychologically, men described feelings of frustration, disappointment, loss, and grief due to temporary or permanent changes in their sexual function.

> *You do mourn that loss. Because you tend to forget about the surgery, that's kind of behind you now. Life has moved on and you want to be who you were previously (Participant #13, 63 years, prostatectomy).*

Socially, changes in sexual function often led to changes

Table 1 Individual participant characteristics

Participant No.	Age at diagnosis, years	Age at interview, years	Partner status	Sexual orientation	Employment status	Treatment(s) received	Degree of bother about sexual function at interview[#]
1	64	66	Partnered	Straight	Retired	Prostatectomy	Small problem
2	57	60	Partnered	Straight	Retired	Prostatectomy	Moderate problem
3	65	69	Widowed	Straight	Retired	Radiation	Small problem
4	70	73	Single	Straight	Retired	Prostatectomy	Moderate problem
5	71	75	Partnered	Straight	Retired	Radiation, hormone therapy	Big problem
6	66	70	Widowed, partnered	Straight	Retired	Prostatectomy	Moderate problem
7	54	57	Partnered	Straight	Employed	Prostatectomy	Moderate problem
8	75	78	Partnered	Straight	Retired	Prostatectomy	Moderate problem
9	64	67	Partnered	Gay	Retired	Prostatectomy	No problem
10	67	70	Single	Straight	Retired	Radiation, hormone therapy	No problem
11	58	62	Single	Gay	Employed	Radiation	Small problem
12	69	73	Partnered	Straight	Retired	Radiation, hormone therapy	Big problem
13	61	63	Partnered	Straight	Employed	Prostatectomy	Moderate problem
14	64	71	Partnered	Straight	Retired	Prostatectomy	Small problem
15	68	71	Partnered	Straight	Retired	Prostatectomy	Big problem
16	71	73	Partnered	Straight	Retired	Radiation	Moderate problem
17	72	76	Partnered	Straight	Retired	Prostatectomy	Moderate problem
18	76	78	Partnered	Straight	Retired	Radiation	Moderate problem
19	53	55	Partnered	Straight	Employed	Radiation	No problem
20	53	57	Partnered	Straight	Employed	Prostatectomy	Moderate problem

[#], based on EPIC-26 question 12: overall, how big a problem has your sexual function or lack of sexual function been for you during the last 4 weeks. EPIC-26, Expanded Prostate Cancer Index Composite-26.

in sexual relationships and activity. For some, the impacts on their intimate relationship were considered negative and significant, whereas other couples navigated the sexual changes and found alternative ways of having sexual intimacy, such as using sexual aids.

The extent to which these physical, psychological, and social impacts affected men's overall recovery, emotional wellbeing, and intimate relationships was often moderated by other factors. These included the importance of his sex life, the degree of pre-treatment sexual decline already experienced, the quality of his relationship with his partner, and whether his recovery was in line with his expectations. Broadly speaking, men who had not experienced significant pre-treatment decline in sexual function and whose recovery of function followed a slower than expected trajectory tended to experience the sexual changes as more negatively.

> *It was important to me, and it is concerning. If you're asking 'do I miss that?' yeah, I absolutely do miss that (Participant #1, 66 years, prostatectomy).*

On the other hand, having a supportive partner and an evolving sex life tended to ameliorate some of the negative impacts. Men who had already experienced substantial

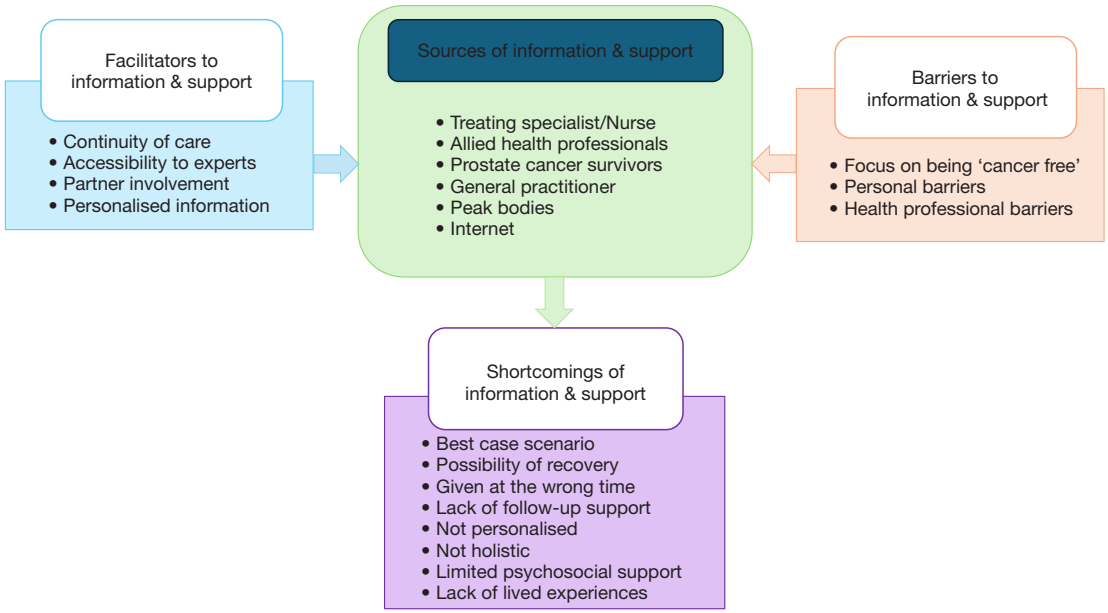

Figure 1 Overview of main themes relating to seeking and receiving sexual wellbeing information and support provided men with prostate cancer.

sexual decline prior to treatment did not tend to experience such significant additional impacts.

> *Even if it (prostate cancer) hadn't happened, it's probably not something that's of real interest to either of us now in our stage of life. We've been together 40 years, so it's not really that big an issue in our relationship (Participant #2, 60 years, prostatectomy).*

With these experiences in mind, men's help-seeking behaviour and perspectives on the support they received, was more specifically explored. From our interviews with men, we identified four major themes regarding help-seeking and support for sexual wellbeing after prostate cancer treatment. Theme 1 describes the various sources of information and support received and sought regarding sexual wellbeing. Theme 2 describes the participant's perspective on the shortcomings of the information provided. Themes 3 and 4 describe the barriers and facilitators identified for the access and uptake of sexual wellbeing support. An overview of these themes is depicted in *Figure 1*.

Theme 1: sources of information and support

Primary contacts (treating clinician/specialist nurse)

Most often the treating specialist (urologist, radiation oncologist) and prostate cancer nurse were the primary sources of information regarding treatment-related sexual impacts, with many men commenting that they were '*mostly reliant on my surgeon and the nurse*'. In cases where men had a positive relationship with these primary contacts, verbal information was provided in person prior to treatment, with written literature provided to take home. Some men talked about having undergone an 'induction session' with the urologist and a specialist prostate cancer nurse prior to making their decision about which treatments to proceed with. Some men indicated that, while these early conversations were not extensive, they did inform them enough to know that more detailed information was available further along the continuum if required.

> *I remember the urologist talking about sex but not in huge detail, just enough to let you know—well, there is assistance further down the track if you want it (Participant #8, 78 years, prostatectomy).*

For many, being in the care of a specialist nurse was critical in their access to information and support: '*to hold your hand*' through the process and to help '*filter the information*'. Some men identified the specialist nurse as '*the most helpful*' of the care team and felt comfortable contacting them at any time with questions or for support.

She was brilliant. I had two, maybe three sessions, and I phoned her a couple of times with the usual dumb questions. That's what you need, that sort of person. I was thrilled they had a prostate specific nurse that dealt just with those patients and that had just restricted knowledge of just that one thing. I thought that was amazing (Participant #11, 62 years, radiation).

However, some men reported negative experiences with their specialist prostate cancer nurse, describing '*unreturned phone calls*' and frustration due to unmet expectations of support. Some men highlighted a lack of consistency across different hospitals and sectors regarding the availability of a specialist prostate cancer nurse. A small number felt that the nurse assigned to them was not comfortable discussing sexual wellbeing.

All sorts of assurances were given about how accessible this person was but… my messages to the prostate nurse went unreturned. So it was a little bit frustrating. I didn't feel enough support really during that process (Participant #16, 73 years, radiation).

Allied health professionals

A small number of men were referred to, or personally sought out, a physiotherapist either pre or post treatment, to begin a regime of pelvic floor exercises to maintain and improve sexual function and urinary continence. Men who engaged with physiotherapists tended to be sexually active and sexually interested prior to their prostate cancer diagnosis, and reported returning to satisfactory sexual functioning after treatment.

I wanted to fast track it so I googled a physio who does pelvic floor exercises for erectile dysfunction. I did all those exercises, and that got me through to the last 5–10% [of functional recovery] (Participant #9, 67 years, prostatectomy).

Men were also occasionally referred to sexologists by primary contacts or sought them out themselves for additional support. Two specific websites run by sexologists were often mentioned and highly recommended; both websites included YouTube videos and information sheets on various topics, as well as stories and testimonials from other men with prostate cancer. Participants highlighted that these specialist websites helped by normalising the sexual dysfunction, providing a sense of reassurance as well as various strategies to assist recovery.

Survivors with lived experience

A small number of men talked about the value of discussing their sexual difficulties and potential solutions with other men with lived experience of prostate cancer. Through these connections, men found empathy, validation and guidance, particularly regarding the expected recovery trajectory. These connections tended to be relationships with personal friends rather than formal support groups.

I go to my peer group. I've got guys that are ahead of me in the prostate recovery journey. You go 'alright, is this normal? Am I expecting a dip here? Or should I be on the up? (Participant #20, 57 years, prostatectomy).

General practitioners (GPs)

Some men, particularly those without strong links to their urologist or a specialist nurse, indicated that they would seek information or advice from their GP if required. However, there was some hesitation and uncertainty about whether their GP would be adequately equipped to deal with sexual issues related to prostate cancer.

If I need some help in that area I'll go to my GP. I'd talk to my GP if I was particularly concerned about something (Participant #17, 76 years, prostatectomy).

I think GPs are really poorly informed. He was reluctant to give me the Cialis prescription repeat, he was reluctant to give me a Viagra prescription. I certainly wouldn't bother going there again (Participant #20, 57 years, prostatectomy).

Peak bodies

A small number of men talked about the value of information they had obtained through peak bodies such as the Cancer Council and Prostate Cancer Foundation Australia. Notably though, very few men had gone down this path. In fact, upon prompting, several men commented that this was not something they had considered.

It didn't cross my mind, to tell you the truth. Didn't even think of looking into those places (Participant #10, 70 years, radiation + hormone therapy).

Internet

Many men had turned to the internet and found '*a wealth of information*' regarding prostate cancer and the procedures

they had undergone or were recovering from. Some men indicated that they used the internet as '*a second opinion*' to verify information given by their health professionals. While having little interest in support groups, men generally valued watching, listening to, or reading testimonials on the internet from other men in similar situations.

> *I gained more from the internet than anything else. Just off the internet. There's a wealth of information on the internet now. There's forums, there's people talking there about it. There's a lot of things out there, just google 'prostate cancer' (Participant #3, 69 years, radiation).*

Importantly, some commented that information on the internet can be confronting, unreliable, or predatory.

> *The information is marketing. I discount most of it because I know that they're just interested in selling products. So it's not that helpful really (Participant #16, 73 years, radiation).*

Theme 2: shortcomings in information and support

Men reported many shortcomings in the type, quality and amount of information provided, and in how it was delivered. Some men indicated that the topic of sexual functioning was not raised or discussed at all by their treating specialists. Others indicated that the information they had been given was too broad and lacked detail. Common areas of misinformation or gaps in knowledge included possible loss of spontaneous erections and ejaculation, penile shortening, and the likelihood of loss of function after radiation treatment. It was also common for men to describe having hazy recollections of the sexual health information provided to them, indicating that the information was often not well-absorbed at a time of significant stress.

> *Nobody spoke about the sexual impacts of surgery, to be honest. So I didn't really have any understanding of that side of it. To my recollection there was never any discussion on it. I don't remember it being a discussion until afterwards, when I didn't have any sexual function. They may have said something about it, but I just wasn't listening (Participant #2, 60 years, prostatectomy).*

The following sections outline the specific gaps and shortcomings in information provided, and the factors that contributed to limitations in information provision.

Information painted a picture of 'best-case scenario'

In some cases, men felt that they had been given the 'best case scenario' rather than a realistic picture of the likely trajectory of sexual recovery, which in turn affected their expectations significantly. Some postulated the urologist might provide a best-case scenario so as not to dissuade people from having surgery.

> *I feel like I got a positive view, like best case scenario of how things would turn out. I don't feel like in hindsight it was a realistic one. It was a bit more of a positive spin on it than the reality. He presented the best-case scenario each time I've spoken with him (Participant #7, 57 years, prostatectomy).*

Lack of information that sexual recovery is possible

On the other hand, some men had not been given any positive or hopeful information about likely outcomes of treatment. A sense of resignation was present for many men who presumed that '*sexual decline is inevitable with prostate cancer*'. In a few cases, involvement in this research project was the first moment of realisation that regaining sexual functioning may be possible and that assistance was available.

> *Quite frankly, I didn't know that that sort of a person [sexual specialist being discussed in interview] existed. I've had nobody say to me 'would you like to sit down and talk about what's happening with a sex therapist'. I'd say, 'Yes, well, thanks very much!' (Participant #18, 78 years, radiation).*

Awareness of medication and sexual aids to assist with sexual dysfunction and sexual activity also varied. Men were somewhat aware of the existence of medications, and often received initial information from the treating clinician and/or specialist nurse. However, few men really absorbed this information until they were themselves experiencing sexual issues that they wished to address. Notably, some men were not given any information about the availability of medications or aids to address sexual dysfunction.

> *I didn't even know the medication was for erectile disfunction. I didn't know anything about sexual aids. I didn't know any of that stuff. That type of information would have been good (Participant #2, 60 years, prostatectomy).*

Information given at the 'wrong' time

Men commonly talked about having been provided information at a time that it was not perceived as relevant. If information was provided at '*the wrong time*' it was either dismissed or not absorbed. This occurred at a range of points along the care continuum.

In the pre-treatment period, men's focus tended to be on treating the cancer rather than on the impacts of treatment on sexual function. As a result, for many men the information provided prior to treatment was not absorbed at the time.

> *In hindsight it was very difficult for me to take all of that in when I knew that I had cancer and it needed to come out (Participant #7, 57 years, prostatectomy).*

Similarly, information provided in the early post-treatment phase was sometimes dismissed as not relevant. Recovery of urinary control was the major focus for many men in that period, whereas sexual issues were secondary:

> *This was not long after the operation. So it was probably not the right time. Too many other things to think about. I was still trying to get my bladder under control. My focus was on that (Participant #2, 60 years, prostatectomy).*

On the other hand, some men felt they had not been provided with information early enough, and that having information early on would have helped them to better prepare for any potential consequences of treatment.

> *It would be rather nice to know before the procedure that there was a service available in regard to your sexual wellbeing. It appears to me that nobody could give two hoots about your sexual functioning after this prostate treatment (Participant #18, 78 years, radiation).*

Lack of follow-up information and support

Participants indicated that access to information and support tended to reduce over time. Some mentioned that disconnection from the health system, and therefore from sources of information and support, occurred from the moment they left hospital. This was sometimes the case even when they had access to a specialist nurse:

> *It all evaporated once I started treatment. You drop off the radar for them. So now the ability to ask any questions doesn't seem to exist. I'd go to my GP and she would struggle to answer them (Participant #11, 62 years, radiation).*

Lack of personalised or tailored information or support

Almost all participants described being provided with written information after diagnosis and prior to treatment. While the amount of information provided was regarded as '*extensive*', several men commented on the limitations of written information, noting that it tended to be generic and impersonal.

> *They're 2-page fact sheets. They were just generic. And they cater to the masses. They're not catered to your individual situation (Participant #13, 63 years, prostatectomy).*

Indeed, several men commented on the lack of personalized information tailored to their specific situation and experiences. This was largely due to being provided in written and web-based formats without adequate discussion by health professionals.

> *It's more like 'read this, go home read this' sort of thing. They give you the pamphlets and you go away and read it (Participant #3, 69 years, radiation).*

Men noted a lack of opportunity to ask questions relevant to their specific circumstances, some listing the type of questions that had gone unanswered due to the lack of personalized or tailored conversations. One man commented that he had difficulty understanding the written information provided, due to both the high literacy level and its use of jargon.

> *Sifting through all that stuff, you'd last about 20 minutes then put the footy on. It is difficult to read, its pretty full on. Some of the language is pretty hard, the medical terminology. The average Joe kind of brick layer or truck driver will find it difficult going (Participant #19, 55 years, radiation).*

Lack of psychosocial support

Whilst participants acknowledged receiving information from the specialists about the likely sexual function outcomes, they expressed disappointment that it had not been discussed in relation to broader psychosocial impacts on relationships and wellbeing. This lack of psychosocial information and support exacerbated feelings

of abandonment for some men.

> *When I went to the surgeon, he asked me about my erectile function. But he didn't ask me about my sex life or, whether I had an active sex life or anything like that. I think it's probably worth talking about more about that (Participant #1, 66 years, prostatectomy).*

Lack of information from men with lived experience

Some men commented that they would have benefited from hearing stories from other men who had undergone prostate cancer treatments, for two major reasons. First, it was thought that this would have helped them prepare for likely consequences of prostate cancer treatments. Second, they believed that prostate cancer survivors would have direct experience of the same issues and challenges they were facing, and therefore would be able to provide understanding and empathy.

> *To talk to a survivor would be very good. A person who's been through it successfully. To sit down and say 'look, this is what happens'. Someone sensitive who can say 'I've been there, I know the process'. You need to be empathized with (Participant #9, 67 years, prostatectomy).*

Fragmentation and lack of holistic care

A small number of men pointed to the fact that they had received their information in a piecemeal and *ad hoc* manner from disconnected and disparate sources, indicating that each professional '*just does their little bit*'. From this perspective, information and support was not considered holistic, and lacked a sense of cohesion and continuity. One participant suggested support should be provided from a single information source, rather than multiple providers.

> *There's gaps because each piece of information is being put in a little package. You go to (different sources) and you're going to get a biased opinion. As opposed to going to one site or one therapist or one person that's going to be a lot more holistic (Participant #20, 57 years, prostatectomy).*

Theme 3: barriers to information and support

Focus on being cancer-free

The most common barrier to accessing and absorbing information about sexual wellbeing, particularly in the initial pre-treatment period, was a focus on being cancer free. Often the information offered at the time of diagnosis was not taken in due to an overwhelming priority to have the cancer removed. This was particularly the case regarding potential impacts of treatment, when the desire to be cancer-free outweighed any possible negative side effects.

> *I just wanted it friggin gone, you know? I would have worn incontinence pants, I would never had sex again, I just wanted it gone. That was the main thing for me. I just didn't want to have cancer. I was prepared to wear whatever the consequences were, as long as I was cancer-free (Participant #1, 66 years, prostatectomy).*
>
> *I said 'just cut it out', get rid of it'. I didn't have to worry about it then. All my questions were just focused on getting rid of the cancer. To me, it [sexual impacts] didn't even rate on my radar. It'd be hard to have sex if you're dead (Participant #2, 60 years, prostatectomy).*

Personal barriers

A small number of men commented that their tendency towards self-reliance made them unlikely to seek information or support for sexual wellbeing. For these men, seeking advice or help from others was out of character and not something they could comfortably do.

> *I could have got the support if I chose to… ego is probably the hardest thing. I tend to do things myself rather than ask for help, so that's probably the main reason why I haven't sought help. It's just my nature (Participant #7, 57 years, prostatectomy).*

Although not a commonly acknowledged barrier, several men talked about feeling uncomfortable discussing sex and sexual issues with their healthcare provider, particularly if they were female.

> *It's embarrassing. A female, I just don't think they're the right people to talk about erection problems. Talk with a male, a male will understand what's happening (Participant #9, 67 years, prostatectomy).*

A common barrier to help-seeking was that problems or losses in sexual function were not considered a high priority. Some men were resigned to their loss of sexual function and accepted it without needing to seek information or support to remedy it.

> *It was such a non-issue for me. Even if you give me all the information in the world, I probably wouldn't have been*

interested (Participant #2, 60 years, prostatectomy).

Some men expressed feeling inadequately prepared and informed about sexual wellbeing impacts and were unsure what and how to discuss the issue with their specialist. Others stated they were not sure who to speak to for support regarding sexual health.

I don't know where to go on this topic. Are there specialists who can assist in this area? Is there someone the GP can refer me to? What happens? There needs to be clearer indication that this is a topic I can explore further (Participant #16, 73 years, radiation).

Health professional barriers

For a small number of men, perceptions of their health professional attitude dissuaded them from seeking assistance for sexual issues. These barriers included perceptions that health professionals were uncomfortable discussing sexual issues and were reluctant to acknowledge negative side effects of treatments.

The urologists feel a bit awkward to me. They're very loathe to discuss much in detail about sexual function. He's a very polite, careful. He's a surgeon, he just wanted to do a good job at surgery. I think there's a lack of training in one-to-one patient relationships. He was just awkward in discussing this sort of stuff (Participant #15, 71 years, prostatectomy).

Some participants expressed concerns about over-burdening health professionals with their needs or questions. This view seemed to be related to a belief that their concerns were not serious enough to warrant attention, particularly when other patients might have more pressing needs, or if they were still 'early' in their recovery.

I don't know what it's (the sexual recovery period) meant to be. I have no idea other than what I was told earlier that it could take 2 or 3 years. Well, I'm still in that timeframe so I'm not gonna worry him over that (Participant #13, 63 years, prostatectomy).

Some men also talked about the limited time and opportunity to have in-depth discussions and to ask questions in their appointments with specialists or GPs.

My first appointment with the oncologist lasted 5 minutes. And the second appointment lasted 3! There's no real time for discussion (Participant #16, 73 years, radiation).

Theme 4: facilitators of information and support

Continuity of care through primary contacts

Some men talked about the importance of having someone available who could provide information and support when needed, as a reliable and approachable contact point. As noted earlier, most often this primary support person was a specialist nurse or, to a lesser extent, their urologist. Knowing that this person was available provided a great sense of security, and reassurance, and helped men feel less alone in their recovery. These primary contacts tended to be easily accessible by telephone at almost any time over the care continuum.

I think having the nurse who I could contact at any time to ask questions was probably the biggest part of it. The nurse was always available to me. She would regularly call me, ask me how I was going (Participant #7, 57 years, prostatectomy).

Access to sexual health experts

Several men commented on the importance of having someone available who had specialized knowledge and expertise in sexual health issues.

You want someone that's got that knowledge base. You want to get that from a professional. You really need someone who's a professional in sex (Participant #2, 60 years, prostatectomy).

Some men suggested that it would be ideal to receive a referral for sexual health counselling after a prostate cancer diagnosis as part of routine care:

I think it would be useful to have a (sexual) specialist that I can be referred to as a matter of course, not because I request it. I get exercise physiology, I get physiotherapy. So why not put into that equation sexual therapy, as a special component of the treatment plan? (Participant #16, 73 years, radiation).

Partner involvement

Some talked about the importance of involving the partner in appointments, decision making, information seeking and

addressing sexual issues and challenges as they arose.

> *It's important that 'partner' had as much to do with the operation as I did. I would have felt uncomfortable making the decision without her involvement. Cause it affects both of us. You got to work hard at it (resuming sex), you can't expect it to be automatic (Participant #8, 78 years, prostatectomy).*

Some men commented that they had realized in hindsight that having their partner more closely involved in their appointments with surgeons and nurses would have been beneficial.

> *At the time I didn't feel like my partner needed to be involved but in hindsight if that was encouraged, I imagine it would have made a difference (Participant #7, 57 years, prostatectomy).*

Personalised information

Some men commented specifically on the value of having tailored information provided in person by their healthcare team. Again, the importance of being able to ask personally relevant questions and have these answered in a tailored way was highlighted as particularly valuable.

> *The nurse was brilliant for the questions, like 'am I ever going to have sex again?' Questions that weren't answered in the booklet or weren't made clear enough. In the booklet, it's answered very generically. They've got to cater for everybody. But for things specific to me, it was the nurse (Participant #11, 62 years, radiation).*

Discussion

This qualitative study aimed to explore men's help-seeking experiences and satisfaction with sexual wellbeing support after prostate cancer treatment, and to identify priority areas for improvement from patients' perspectives. According to men interviewed, sexual wellbeing support was sought/received from several avenues, but primarily through a treating clinician, specialist nurse, or other prostate cancer survivors. Some men felt the information they were provided with was insufficient in several ways in that it did not match realistic experiences, was provided at inappropriate times or not followed up, did not address psychosocial wellbeing or was not tailored to individual circumstances.

Several of the barriers and facilitators identified in the present study have been reported in previous research. These include patient disinterest in sexual recovery immediately after diagnosis (10,14,22,23), embarrassment or discomfort discussing sexual wellbeing (10,14,24-26), and perceived discomfort of healthcare professionals in addressing sexual wellbeing (26-30). Facilitators for patients' help-seeking also reported in previous research include having a supportive partner (27,31) and receiving personalised care from the nurse/healthcare professional (22,24). Participants in our study whose sexual wellbeing support was provided as routine care by their provider early in their cancer journey described feeling satisfied with the support received and were comfortable seeking it. Other research has found that patients prefer clinician-initiated discussion of sexual wellbeing (28,32), which is now an expectation of all clinicians involved in patient care, according to the recently published Sexual Health Guidelines for Prostate Cancer (17). Participants in our study also described feeling more comfortable discussing their sexual health issues with a healthcare professional who was present throughout their cancer journey. A lack of continuity of care has been identified as a barrier to help-seeking for sexual wellbeing support in previous research (30,33), suggesting that patients who have ongoing access to dedicated supportive care professional are more likely to feel comfortable seeking and receiving sexual wellbeing support.

Overall, men had varied preferences regarding the timing of key information or support provision, with some feeling they could not absorb this at the time of diagnosis when treatment was their priority, while others indicated that immediately post-treatment was also not ideal. Some men felt abandoned after they were discharged from hospital, which is consistent with other research (9). Hence, it is likely some men would benefit from being actively offered access to relevant services at multiple time points from diagnosis and for some years after treatment, to ensure they know how and where to access help as sexual recovery became a priority.

Accessibility to a singular information source, either in person or online, was recommended by several study participants to improve care. For many, this source was the specialist nurse. In Australia, prostate cancer specialist nurses are responsible for facilitating multidisciplinary care through referrals, and provide expert specialist nursing care for men and their families at no financial cost (34). Prostate cancer specialist nurses are available in some but not all

public hospitals, and in a limited number of private facilities. Recently, the Prostate Cancer Foundation Australia launched a specialist telenursing helpline accessible to any person diagnosed with prostate cancer or family members, regardless of location or hospital referral. Access to nurse-led prostate cancer survivorship care has been shown to significantly reduce unmet needs (35), improve quality of life (36), and reduce emotional and psychological distress (37). While sexual care services and resources exist outside of hospital-based specialist nursing services, many come at financial cost, exist only online, or are simply unknown to patients. Given the growing evidence and support for specialised nurse-delivered survivorship care on patient outcomes (35,37), it would be ideal that all patients are afforded the opportunity to receive prostate cancer specialist nursing support as part of their routine care. While there has been significant growth in the number of prostate cancer specialist nurses in Australia, there are still insufficient numbers to ensure all men treated for prostate cancer have access to such a service.

Several participants recommended that all men receive personalised sexual wellbeing information both pre- and post-treatment. While very little research has evaluated the effect of pre-treatment sexual counselling on patient outcomes, randomised control trials investigating the effect of post-treatment nurse-led care suggests that it can significantly increase the use of erectile dysfunction treatment use (38,39). While other sexual wellbeing outcomes were investigated in these trials, no significant differences in patient's sexual function or sexual satisfaction were identified, which may be due to limited sample sizes and restricted follow-up periods of 1-year post-treatment or less. A model which may provide more accessibility and anonymity is telehealth or internet-based sexual wellbeing support and counselling. Emerging evidence suggests internet-based sexual counselling in prostate cancer is acceptable and feasible, and can improve patient sexual function, masculine self-esteem, sexual confidence, and sexual satisfaction (40,41). Thus, such care modalities warrant further investigation.

Limitations

Some limitations of this study should be considered when interpreting these results. Firstly, all participants resided in South Australia, Australia, where the majority of the population live in the capital city. Therefore, patient experiences, in addition to the supportive care services available, may not be reflective of those residing in rural and remote areas, other states or other countries, particularly those without government-funded medical care. Secondly, our study was somewhat limited with respect to participants' diversity, with all but two men identifying as heterosexual. Previous research suggests gay and bisexual prostate cancer patients often experience differences in seeking and receiving sexual wellbeing support (24,31), and therefore further exploration of their experiences is warranted. Finally, as this was a qualitative study, we were not seeking to quantify the number of men who experienced specific sexual problems or the number who found each experience distressing. Nor was this study designed to measure or compare the experiences of men who had undergone different treatments for prostate cancer. As such, the recruitment of men into the study was not stratified by treatment type, nor did we directly compare results according to treatments received.

Conclusions

This qualitative study explored the experiences of prostate cancer patients between 18–36 months post-treatment in seeking received support for their sexual wellbeing. According to the participants interviewed, support and information was gained through several avenues, but predominantly through healthcare professionals, other prostate cancer survivors, and the internet. However, shortcomings in the information and support received were identified by patients, such as poor timing, poor expectation setting by healthcare professionals, non-tailored nature of information, and lack of follow-up care. Continuity of care, personalisation of information, and having ongoing access to sexual health experts were perceived by men as being important for addressing their sexual health needs. Results indicate a strong preference for sexual wellbeing care to be provided by a healthcare professional specifically trained in personalised and evidence-based sexual wellbeing care to address men's unmet sexual health needs. Based on existing models of care and current evidence, specialist nurses are the well placed to provide this service. However, sustained funding and commitment by health services is required to ensure feasibility, sustainability, and equitable access to sexual wellbeing survivorship care.

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Footnote

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Conflicts of Interest: All authors have completed the ICMJE uniform disclosure form (available at https://tau.amegroups.com/article/view/10.21037/tau-2024-682/coif). M.M. declares that he is the owner of the research company MMResearch, who was commissioned to conduct the interviews with participants. B.M. declares that she is employee of the research company MMResearch, who was commissioned to conduct interviews with participants. The other authors have no conflicts of interest to declare.

Ethical Statement: The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. This study was conducted in accordance with the principles outlined in the Helsinki Declaration and its subsequent amendments. It received ethics approval by the Southern Adelaide Clinical Human Research Ethics Committee in November 2023 (No. LNR/23/SAC/146). All participants gave informed consent for the publication of information relating to them, including deidentified quotes.

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