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The experiences of men diagnosed with advanced prostate cancer: a qualitative study

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The authors declare there are no competing interests to declare.

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Abstract

Objective: To explore men's lived experience of advanced prostate cancer (PCa) and preferences for support.

Design: Cross-sectional qualitative study applying open-ended surveys and interviews conducted between June and November 2016. Interviews audio-recorded, and transcribed verbatim and analysed from a phenomenological perspective.

Setting: Australia, nation-wide.

Participants: 39 men diagnosed with advanced PCa (metastatic or castration-resistant biochemical regression) were surveyed with 28 men subsequently completing a semi-structured in depth telephone interview.

Results: Thematic analysis of interviews identified two organising themes; lived experience and supportive care. Lived experience included 6 super-ordinate themes: regret about late diagnosis and treatment decisions; being discounted in the health system; fear/uncertainty about the future; acceptance of their situation; masculinity; and treatment effects. Supportive care included 5 super-ordinate themes: communication; care coordination; accessible care; shared experience/peer support; and involvement of their partner/family.

Conclusions: Life course and the health and social context of prostate cancer influence men's experiences of advanced disease. Multimodal interventions integrating peer support and specialist nurses are needed that more closely articulate with men's expressed needs.

Strengths and limitations of this study

- Extends previous research in men with advanced PCa to describing how masculinities, life course, and the broader social and public health context influence support needs
- Robust and transparent study method and the application of a phenomenological theoretical approach
- Valid and reliable and transferable within the Australian setting
- Cross-sectional design is a study limitation

Keywords
Prostate cancer, advanced cancer, metastatic, masculinities, supportive care needs, life course

Introduction

Prostate cancer (PCa) is the second most common cancer in males with the highest incidence in Australia/New Zealand and North America [1]. Most men present with localised disease or disease that has spread to regional lymph nodes with the relative 5-year survival rate for these men exceeding 95% [2 3]. However, 1 in 5 will progress to metastatic disease [4]. Approximately 5% of men are diagnosed with metastatic disease and the relative 5-year survival rate for these men is only 30% [3 5]. The mainstay treatment for advanced PCa is androgen deprivation therapy (ADT) that typically is followed by progression to metastatic castration-resistant PCa [6]. Once this occurs, median survival is less than 2 years [7], although recent therapeutic advancements such as abiraterone acetate and enzalutamide have shown potential for further slowing disease progression [8] with median survival up to 3 years [6]. The STAMPEDE [9] and LATITUDE [10] trials demonstrated a survival advantage for the combined use of abiraterone with commencement of ADT however this was offset by earlier and more prolonged androgen suppression and a higher risk of grade 3 to 5 adverse events.

Hence, while new treatments for advanced PCa prolong life, this means men are living longer with the effects of both treatment and disease progression including deteriorating bone health, pain, hot flushes, loss of libido, erectile dysfunction, increased fat mass, sarcopenia, fatigue, and cognitive decline [6 11]. Men with advanced PCa have poorer quality of life, higher levels of psychological distress, increased suicide risk, and more unmet supportive care needs compared to men with localised disease [12-15]. Approximately 1 in 4 experience regret about treatment decisions and this is associated with poorer quality of life and increased distress [16]. In sum, the burden associated with advanced PCa is substantial and further evolving as new treatments emerge.

Problematically, to date there is scant psychosocial or supportive care intervention research directly targeting men with advanced PCa; and the one randomised trial of scale completed by our team failed to prove effectiveness[17 18]. Researchers in Canada and Scotland have previously highlighted the persisting support services gap for men with advanced PCa and suggested more qualitative research elucidating men's experiences is needed if we are to develop effective supportive care interventions[19 20]. Carter et al in 2011 explored the supportive care needs of men with advanced PCa and concluded that functional issues, information needs, and emotional distress were the three domains of need that needed to be addressed [19]. More recently, Paterson et al (2017) interviewed eight men with advanced PCa describing a broader range of challenges extending to interpersonal and intimacy needs [20]. Both studies emphasised the gap in informational support for these men, however neither deeply explored issues related to masculinities or the broader social and public health context in which this illness experience is nested [21-23]. We sought to extend this previous work more specifically connecting our enquiry between men's challenges and their preferences for support within their social context. Accordingly, we explored the lived experience of men with advanced PCa (proven metastatic or castration-resistant biochemical regression) and their supportive care preferences applying a phenomenological approach.

Method

Study design

This study applied a cross-sectional qualitative design. In a preparatory first step, participants first reflected on their experience with advanced PCa via a mail administered open-ended survey. Responses informed development of a protocol which guided subsequent semi-structured in-depth telephone interviews. Consistent with the study aim to better understand men's experiences and unearth gaps in understanding we adopted a phenomenological perspective [24]. Ethical approval was obtained from the Griffith University Human Research Ethics Committee (Reference number 2016/418).

Participants and recruitment

Participants were recruited from an existing patient study cohort [14]. In June 2016 we contacted men who had not withdrawn from the cohort and were not to our knowledge deceased and had consented to be contacted about future research (N=141). In all, 39 men returned the survey (28% response) and of these 28 were available for telephone interview between September 2016 and November 2016 (72% response). Mean age of participants was 72.7 years (SD=8.5; range 58.2-94.6) and majority were born in Australia (75%), married (86%), and retired (79%). Mean time since diagnosis was 7.7 years (SD=5.0; range 2.1-22.8). Most men were treated with ADT (88%); 73% radiation therapy; 62% prostatectomy. Men who did not participate were either too unwell (n=4), had a hearing impairment (n=1), or did not consent (n=6). Table 1 reports sociodemographic characteristics and treatment information for each interview participant.

Data collection

Men responded to four questions in the open-ended survey about their PCa-related concerns or challenges; assistance or support accessed for these concerns and from whom; other support needed; and preferences for support for men. Thematic analysis [25] of survey responses (MH, KL, SC) indicated four areas that were challenging for men and in which they lacked support: information, medical care, side-effects, and the future. Three experienced female interviewers in a research fellow or research assistant position with post-graduate training in the behavioural sciences (ML, KL, EE) conducted telephone interviews to further explore the key areas identified. Interviews were on average 62.1 minutes in length (SD=19.2; range=29.2 to 111.9 minutes). Member checking occurred at the beginning of each interview during which the interviewer asked participants to comment on the accuracy of researcher interpretation of survey results and gave participants the opportunity to add anything they thought had been missed. Interview questions (Table 2) explored in greater depth the concerns previously identified in men's survey responses: health system concerns, supportive care needs, barriers to support and preferred approaches. Participants were also invited to discuss other aspects of their experience that they considered were important. Interviews were audio-recorded and transcribed verbatim.

Data analysis

Interview transcripts were analysed using thematic analysis [25]. Themes were derived inductively from the data without guidance a priori from theory. Coders had behavioural science (SC, MH, JD, KL), psycho-oncology (SC, MH, JD, KL), and nursing (SC) backgrounds. Once all interviews had concluded, interview transcripts were coded iteratively with constant comparison between the codes generated and the data to ensure that consistent and diverging responses were incorporated. Two research team members independently coded one-third of the transcripts and generated a preliminary coding scheme (MH, KL). This coding scheme was further refined with a third (SC) and fourth (JD) research team member. Once all interview transcripts were included the coding scheme was further reviewed and agreed upon by all coders. Exemplar responses were identified across transcripts to illustrate and confirm labelling of themes. Reporting of data is consistent with consolidated criteria for reporting qualitative studies (COREQ) guidelines [26].

Results

Thematic analysis identified two organising themes: lived experience and supportive care. The first organising theme reflected men's lived experience with advanced PCa, and within this six super-ordinate themes. The second organising theme captured elements of supportive care that men found challenging and their preferences for how care should be delivered, and within this five super-ordinate themes. Figure 1 depicts the coding structure. Tables 3 and 4 present illustrative quotes for each super-ordinate theme.

Lived experience

Men's lived experience with advanced PCa included six super-ordinate themes: regret about late diagnosis and treatment decisions; being discounted in the health system; fear/uncertainty about the future; acceptance of their situation; masculinity; and treatment effects (Table 3).

Regret about late diagnosis and treatment decisions

Men described feeling regret about late diagnosis or treatment and this was commonly attributed to delays by clinicians. Men perceived these delays were caused by general practitioners and/or specialists who would not perform digital rectal examinations (DREs) or prostate-specific antigen (PSA) testing; did not detect PCa until it was well advanced despite regular testing; and did not refer patients for further treatment or testing in a timely manner despite men's requests for them to do so. From this, some men were left with a distrust of the medical profession. Men also discussed regretting their treatment choices and not having had a second opinion so that they felt more adequately informed and clearly understood the outcomes of treatment, including side effects, and how these could be managed.

Being discounted in the health system

In their interactions with clinicians, men described their concerns, needs and autonomy as discounted or ignored. Men felt devalued and believed they were somehow less important in the broader health system. In their experience, PCa was the 'poor cousin' of breast cancer in terms of funding, research focus, and controversy over the value of PSA testing; and less effort by the government and non-profits to promote awareness of PCa. Men also considered that they and their cancer were less important due to their older age and community attitudes where PCa is considered a cancer that may not lead to death.

Fear/uncertainty about the future

An uncertain future was discussed in terms of men needing to make 'the unknowable' a known entity by understanding how much time they may have left to live; what lies ahead for disease progression and quality of life; potential treatment options; and next steps for support when all treatment options had been exhausted. This information was critical to men's ability to feel more in control and to prepare for the future both psychologically and practically while they were well enough to do so. By contrast, some men discussed not wanting to know what the future held in order to focus on their day-to-day life.

Acceptance

Men used their age as a frame to accept physical changes and the threat to their mortality. Other approaches men adopted to reach acceptance were focusing on 'getting on with it', and viewing ongoing physical effects of the disease or its treatment as part of life, an inevitable outcome of treatment or disease progression, and as a favourable alternative to death. Regarding sexuality, some men found changes in their physical capacity to have sex an ongoing cause of distress. Other men shifted their focus to other aspects of their relationships (e.g., expressing intimacy in ways that do not require an erection) as a way to accept their situation.

Masculinities

Male values and masculinities were discussed as central to men's experience of PCa, support, and coping. Men believed that as a group they do not look after themselves, go to the doctor, ask for help, or talk about their problems by comparison to women, and have a different view on their health, are less prepared to discuss their health, and gave health less attention. This reluctance to seek help or support or talk about their problems was ascribed to male values around being strong, capable, independent/autonomous, or stoic. Some men used avoidance as a coping approach by avoiding thinking or talking about their situation, and covering up or ignoring side-effects or a need for support. Some men expressed concerns that there would be negative consequences socially or in their employment if others knew about their cancer. Privacy and being embarrassed talking about personal issues were also raised. Viewing sexuality and sexual function as important to their identity as a man meant that some men were deeply troubled by changes in sexuality; and believed that their relationship with their partner now would be negatively impacted or that it would no longer be possible for them to start new relationships with women.

In their perceived role as 'the provider' and 'the protector', some men expected to give help rather than receive it. Men tried to protect their wives or their family by not talking about their problems and thus avoid worrying them. They also adopted approaches to promote adjustment including being optimistic and 'getting on with it'; taking responsibility for their health and well-being (e.g., remaining physically active); as well as an action-oriented approaches in which they identified and solved problems directly or sought help or support. In using these approaches, men saw themselves not constrained by masculine norms constraining help seeking. Some men devalued 'talk' as a way to obtain support and viewed psychologists as not able to provide the solutions they needed, also describing unfavourable attitudes towards support groups as an opportunity for self-pity or drama.

Treatment effects

Men discussed the effects of advanced PCa and its treatment that affected their quality of life, relationships, capacity to do daily tasks, and for some men were highly distressing. Prominent amongst these were physical effects and financial concerns. Physical effects included the inability to obtain an erection; lack of libido; urinary incontinence; changes in appearance and bodily structure including gynecomastia; weight gain; sarcopenia; decreased bone density; fatigue; dizziness; loss of balance; breathlessness; hot flushes; cognitive changes; and pain. Some men discussed no longer being well enough to work and that this negatively affected their income and retirement plans.

Supportive care

The organising theme supportive care included five super-ordinate themes: communication; care coordination; accessible care; shared experience/peer support; and involvement of their partner/family (Table 4).

Communication

Men had mixed experiences in their interactions and communication with health professionals. Four pivotal points in the care trajectory in which effective communication appeared most critical were: diagnosis; deciding on treatment options; treatment effects and symptom management; follow-up care. Some men described being unclear about the specifics of their diagnosis (e.g., staging, PSA). Other men appreciated the direct and honest approach adopted by their clinicians when communicating about the severity of their disease. When discussing treatment options, men desired more guidance and support in making a treatment decision; and for options to be more clearly communicated so that they could better understand long-term treatment effects. Some men were dismayed that their GPs or other health professionals did not seem to have specialised knowledge about PCa. Preferred decision support included clear, unbiased communication about the pros and cons of each treatment option and referral to other sources of information that men could consider in their own time.

Some men described confusion and frustration when they were given a treatment that they needed to self-administer (e.g., injections) but were not effectively instructed in how to do this. Men commonly discussed health professionals' communication about treatment side-effects as insufficient (e.g., told about treatment effects but not how to deal with them) and selective (e.g., told about immediate but not long-term treatment effects), and as a consequence felt unprepared and isolated in their experience. Men also described that they did not feel listened to when they raised their concerns or able to get clear answers to questions. Some men expressed that it was up to them to find solutions to manage their side-effects because clinicians did not adequately address these.

Care Coordination.

For some men, regular ongoing communication with their clinicians was a source of support, however other men felt out of touch and isolated due to the length of time between each consultation. GPs were important to some men in helping them feel connected with their care team. Men discussed the need for better coordinated care and information and this was focused on three aspects: communication between health professionals; having a 'middle man'; and integrating psychosocial support as part of routine care.

A lack of communication between specialist clinicians regarding treatment and referral was discussed as problematic. Men had mixed views as to who should be the central point of call for information and referral. Some men believed this should be their GP; others suggested their urologist or oncologist should have this responsibility. Patient advocates or navigators were also discussed as an option to help streamline and clarify the diagnostic and treatment process. Most commonly men discussed PCa nurses as being central to their care. Nurses provided informational, emotional, and practical support that clarified men's understanding of their situation; served as an intermediary between the patient or couple and other clinicians; and men believed PCa nurses were more likely to refer them to other beneficial services than other health care professionals. Men discussed that the best time to be connected with a PCa nurse was at diagnosis with continued access throughout treatment.

Men identified the need to integrate psychosocial support as part of routine care without relying on men themselves to raise emotional issues with clinicians. Alongside this, men also discussed the need for routine referral to support groups or information about the existence of local groups. Men also discussed exercise programs as helpful for weight gain and muscle wastage as well as with reducing feelings of loss of masculinity.

Accessible care

Men discussed three main barriers to accessible care: geographic location; ill health and financial cost of treatment. Solutions to overcoming accessibility issues were described. Men experienced difficulty accessing services because they resided in a regional or rural location where services were either not available or required them to travel long distances with resultant cost and inconvenience. Other men had difficulty or were prevented from accessing central or nearby services due to ill health or fatigue. Some men also discussed the high financial cost of treatment or drugs to manage side-effects such as erectile dysfunction and their uncertainty about how to cover these costs. To overcome accessibility issues, men suggested use of online or telephone services for those in rural or regional areas or who could not access care due to ill health; lobbying the government to subsidise financial costs of treatment; and increasing the availability of home-based medical care or practical assistance services where needed.

Shared experience/peer support

The opportunity to talk to other men in the same situation was commonly discussed by men as a source of support that they had or wished they had an awareness of and access to. Men described three aspects of shared experience/peer support: benefits; delivery preferences; and barriers. Shared experience was highly valued because it allowed men to talk to someone who had been through the same experience; obtain information or advice when weighing up treatment decisions or managing side effects; make positive upward (e.g., other men doing well and inspiring hope for recovery) or downward (e.g., other men are doing worse so I am ok) comparisons [27]; gave men a safe and confidential forum to express their concerns; and helped men to feel less alone. However, men did not always describe the concept of shared mutual experience as peer support or being connected to support groups. Mutual support also occurred through companionship with other men who did not have cancer such as at Men's Sheds and social or sporting clubs.

Men proposed different delivery methods for peer support (e.g., face-to-face, telephone, or online) to take into account individual differences and need for privacy or anonymity. Both structured (e.g., with a facilitator and an agenda) and unstructured (e.g., a chat over coffee) methods were acceptable. Some men preferred shared experiences specifically for men with advanced disease on the basis that men with localised disease have different treatments and cancer-related physical effects.

Finally, despite acknowledging the benefits of shared experience, men also discussed barriers to peer support use and availability. These included feeling uncomfortable to share in a group; the difficulty of sustaining support groups; death of peers; and the belief that support groups were focused only on emotional or psychological information.

Involvement of partner/family

In addition to shared experience, men identified partners and/or family and friends as sources of support that contributed to their emotional and physical wellbeing. For some men, female partners were their main source of emotional and practical support. Men discussed that partners were also impacted by the diagnosis and treatment of PCa and believed it was important to involve their partners in their care and available support. Men also commented that partners are often the catalyst for their involvement in support groups or seeking out information or support from other sources.

Men's broader family, friends and neighbours were also discussed as sources of support, often providing practical assistance.

Discussion

The present study extends previous research about the experience of men with advanced prostate cancer, adding an additional level of description that provides insight into how health context influences men's responses; the influence of life course; and ways in which masculinities is expressed in this setting. As in previous research, difficulties with accessible informational support about the disease and its treatment were highly evident [19 20]. That these problems persist and are remarkably similar in Canada [19], Scotland [20], and in our Australian data, is striking and suggests that globally there may be a gap in health systems' responses to advanced prostate cancer. Prostate cancer survivorship research has to date been underfunded by comparison to breast cancer[28]; a consensus about clinical care for advanced prostate cancer is just now emerging [29]; and the historical and persistent debate about the early detection of prostate cancer [23 30] are likely contributors to this. The men's reports in our study of prostate cancer having a less favourable public profile reflect this and show how the broader public health and social context can have a profound negative impact on an already difficult cancer experience.

The influence of life course in response to illness in terms of men's age and the expression of masculinities and masculine models of coping strongly emerged in this study and this has implications for the design of care models [31]. We propose that there is a need to newly conceptualise and then deliver what men actually want, rather than starting from a first principle of revising services already provided that are not meeting men's needs. Men underutilise psychosocial support services after cancer compared to women with breast cancer [32]; and previous research has suggested that interventions promoting self-management in men with cancer and other chronic diseases should include action oriented approaches if they are to be utilised [33 34]. With regards to providers of support, men in the present study proposed both peer support and nurse specialists as preferred care providers, confirming previous research [35].

Limitations of the present study include the cross sectional design. Recent qualitative research applying a prospective study design proposed that coping with advanced cancer evolves over time as symptoms progress and fluctuate [36]. Future research utilising a prospective case study design will add further depth to our understanding of men's experiences in the face of advancing prostate cancer. As well, the men in our study were not newly diagnosed with advanced disease and so reports of their experience at the time of diagnosis or initial disease progression are retrospective and subject to recall bias. Strengths include a robust and transparent study method and the application of a phenomenological theoretical approach such that our data can be considered valid, reliable, and transferable within the Australian setting. However, a high level of concurrence with previous research supports a wider application of our results to other similar health care settings.

Based on our previous research [17 37] and the present results we propose five key content elements for inclusion in supportive care interventions with men with advanced prostate cancer: decision support; treatment education with self-management and skills training for symptom effects, including exercise prescription; routine screening for psychological distress with referral; psycho-education with tailored distress management strategies; communicating with health professionals. Strategies to integrate peer support within the care team are needed. Finally, the prostate cancer specialist role presents as highly acceptable to men and should be central in supportive care delivery and care coordination.

In conclusion, supportive care services for men with advanced prostate cancer need to be multimodal and take into account the influence of life course on men's illness experience. More broadly there is a need for the health system to prioritise research and development in clinical prostate cancer care taking a more holistic approach than currently exists.

Author contributions

SC, JD and MH conceived the study, developed the interview protocol, undertook the analyses and interpretation, and led manuscript development. KL recruited and interviewed participants, undertook analysis and contributed to writing the manuscript. ML recruited and interviewed participants. MF, ID and AL contributed to data interpretation. All authors contributed to revisions and approved the final manuscript.

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Table 1

Sociodemographic characteristics and treatment information for participants completing an open-ended survey and telephone interview

N = No; NR = Not reported; W = Widowed (married at time of diagnosis); Y = Yes.

TABLE REMOVED TO PROTECT PARCIPANTS IDENTITY.

Table 2

Interview questions

Focus area	**Question**
Health system	Thinking about your medical treatment, what changes do you feel would make medical services better meet the needs of men with advanced prostate cancer?
Supportive Care Needs	Thinking about the treatment side effects that a man with advanced prostate cancer might experience, what sort of support would help most? Thinking about the future and the worries that face a man with prostate cancer that has advanced or recurred, what sort of support would help most?
Barriers	In developing services to help men cope or manage better with advanced prostate cancer, can you describe support approaches or ways of helping that would **not** be acceptable to men? For example, supportive approaches that would turn men off or away?
Preferred approaches	In developing services to help men cope or manage better with advanced prostate cancer, can you describe support approaches or ways of helping that would be more attractive to men?
Other	Thinking about what we have spoken about today, is there anything else we haven't covered that you think is important to supporting men with advanced prostate cancer?

Table 3

Lived experience organising theme and super-ordinate themes

Super-ordinate theme	**Exemplar quotes**
Regret about late diagnosis and treatment decisions	"I saw a GP and first of all, I think it was 1.9 was my PSA reading, and when it got to 14 I said to him – everything I read tells me that I should be seeing a specialist. And he said, "Oh you worrywart, don't worry about it," and then next time I said it, he said, "All right I'll send you to see […] he's a urologist." I went to see his specialist mate, and he said, "Bloody hell, where've you been, you should've been here three years ago." Because it'd been like that for three or four years. The prostate was full of cancer, and it escaped outside the prostate and went into my lymph nodes, because of all that time wasted." (P31)
Being discounted in the health system	"The men seemed to think that prostate cancer was a B grade compared to other cancers. Because it was older men, and they'd had their run probably. No-one's going to worry too much about it…Usually men who have got prostate cancer are old, older men and certainly you wouldn't all the funding going to the old men and not the young women, or middle-aged women. It wouldn't be fair would it. So we thought that the prostate cancer people were sort of the poor relations in both attitude, funding, in a lot of ways. But you can't change it." (P26)
Fear/uncertainty about the future	"I'd just like to know where I'm headed. I guess he can't tell me what's going to happen with the disease, but I'd imagine there must be a pattern, a reasonable pattern of what happens. I mean, with some illnesses you know this is going to progress from this to that, to that, but an article I saw recently in a support group pamphlet was, if you took Drug X tablets, when they stopped working, you took Drug Y tablets. When they stopped working, the next thing on the - on the ladder was death, d-e-a-t-h. Well, I've been taking Drug X for quite a while. I've been taking Drug Y for quite a while. Each had a definite effect on my PSA, each lost that effect. So really, the next thing that faces me is death. Now, so, it was four months ago that my oncologist gave me, he said, "You'll see your birthday." Well, that's only three months away, it's only two months away actually. What's going to happen between now and then?" (P6)

Acceptance	"I think acceptance. That would be the word that comes to mind. Not resignation, big difference in my mind between resignation and acceptance, but okay, I accept it, to live a bit longer, or feel a bit better. This is what happens, I've just got to come to terms with it the best way I can. I didn't handle it too well. I think even at that age, you think you're indestructible. Gees, it did happen. But, it's not the end of the world and that's the attitudinal part, I think, more so than – attitude in retrospect, acceptance and spirituality part of it...I can possibly liken it, sort of, something akin to grief counselling is what I needed. You know, there's anger, there's frustration, everything. The whole gambit. It's all there. It's like, okay, it's passed away now, you know, let it rest...I just assumed, pop a couple of Viagra, you'll be right. But, no. So, yeah, it's – yeah and that's a problem after being very active for such a long time with a beautiful wife, it's really hard, really hard to take." (P30)
Masculinity	"Partly, I think, the reluctance of men to talk about their health, or to talk about personal issues that the idea of maleness, being able to be stoic and cope, type of thing. And just in the idea of maleness, that, sort of, men don't cry, men are stoic, or you get on and cope with things, a lot of men have not been exposed to talking about personal matters and so find it difficult to do that." (P9)
Treatment effects	"I'm impotent, and that – put it this way, that's – honestly, that's something that I have an extremely hard time coming to terms with. My wife and I had a fantastic sex life but that's gone and there's now – yeah, it's probably as much my fault as hers but there's just nothing left of our marriage; we live together but that's about it." (P38) "I can't even walk down the beach, put out – not having to urinate a couple of times, I take my dog for a pretty long walk each day and I'm looking over my shoulder and I'm always thinking one day I'm going to get busted and someone's going to call me a dirty old man and are they going to even be prepared to listen to the fact that I've had prostate cancer and it's not my fault?" (P14) "Eating is a problem, I have a problem eating. I don't really want to eat but I more or less force myself to eat, because I have no energy, but I've lost, I think, it's 40 kilos all together, but that's over a period. When I look in the mirror I see this gaunt face looking at – I thought I was fairly good looking for an old bloke but now I really look bloody painful, I take notice, like, god I'm gaunt. And I really am thin." (P19) "The general fatigue, loss of energy, loss of muscle tone, the hormonal issues were probably the biggest ones. I've got osteoporosis because – it's only at the early stage, but my bone density is checked regularly, but it's dropping slowly even though I do exercise, walk a lot and keep my weight down and exercises up. I do that sort of thing all the time. But I'm probably holding it in check. But that one's always a bit of a concern. I've got to be careful I don't fall off the roof, I don't do something, don't break anything nowadays. In fact I – when I finished radiation therapy I felt all pretty smart and I went running on the rocks at the beach one day, and jumped from one rock to another, and snapped my ankle so badly it had to be screwed up with screws and braces." (P5)

	“I now have gynecomastia which I’ve discussed with my GP and my specialist. I was looking at having my breasts removed, unfortunately which I would’ve had to pay for, but I was told that if I did, they would come back so it would be a waste of time and effort and money doing it.” (P38) “I know the cancer’s spreading. I woke up this morning about 4 o’clock with pains in my pelvic, where it is, the pelvic bone where I suspect the cancer’s moving to. They said it would at the Cancer Clinic, so that gave me a bit of pain. But I find if I take Panadol, one of these Panadols – I take two at night and two in the morning and two midday, I keep the pain at a level that’s quite acceptable. But I didn’t take it last night and then I woke up at 4 o’clock and thought, oh, what’s going on here.” (P23) “I mean one of the biggest impacts is financial loss and that is not discussed full stop. That’s when you’re diagnosed with a terminal illness and there is no cure. They can slow the disease down, which they’ve successfully done in my case. But because of the side effect of loss of testosterone, so you’ve got less energy, muscle wastage and all of that. And the end resulted in me – I had to give up work. Now, that financial loss has been – made a big impact on my retirement and everything else.” (P3)

Table 4

Supportive care organising theme and super-ordinate themes

Super-ordinate theme	**Exemplar quotes**
Communication	"For me at my stage, or more advanced, or – I don't know at what stage I'm at. Whether I'm advanced or reasonable, or what. I don't have any – I don't have any real – I don't know what the symptoms are – if you do get advanced or more advanced, I don't know what the symptoms are really. I have no information in that regard. I don't know." (P17) "He's not exactly verbose, he doesn't say a great deal. And I got put on Drug Z and was more or less left to my own devices with my GP who I don't think he'd ever heard of it and it wasn't really until about three or four months ago that we managed to sort out how the injections should be given." (P10) "Openness, I think, for me for the treatment options. Probably the side effects were less discussed or less publicised. There was some, particularly in the radiation process, you could get burning, you could get itching, this, or that, but then later on you find out there was some others that they didn't mention…On that score, I think there's some minor explanation, you will get tireder, you will get hot flushes, but no advice - what can you do about a hot flush; go and have a cold shower. There's been nothing on that, and in terms of maybe a medication, is there something will help as it does for ladies, I've got no idea." (P35)
Care Coordination	"You just get the impression going through the process that the different stages of the process all have their own people, their own separate team altogether. I guess, I could sum it up in a word and that's coordination with all the different treatments and tests and results and everything to do with the treatment, all those things are there obviously, patients are being treated for a long, long time, but having been through the process I just find that even though you end up getting through it it's a bit of a minefield for the patient because they haven't got a clue really what's involved, what's coming next, what you've got to do." (P20) "It's got to be the doctors. The doctors, I think, it has to start at the GP level and go right through. This is, as I say, this is your life and they're doing the journey with you. That's a good way of putting it, they're doing the journey with you." (P15) "I'd say ideally at time of diagnosis, after you talk to the doctor the next step would be the prostate cancer nurse. Yeah. Into the treatment part of it, yes, as part of the treatment process. But, in some ways, I think, that if you've got, say, sort of a trusted person, so if it's a prostate cancer nurse providing good information and directing

	traffic, type of thing, and putting people in touch with resources, I think, that's probably going to help to overcome the difficulties." (P9) "I think this support idea needs to be built in at diagnosis level into the, well, the doctors would present this as, "This is a natural part of the treatment, we're not saying go there if we think you need it, you have been diagnosed with cancer, you need it, we would strongly recommend you take your – take the benefit of going to a group for," I don't know how many meetings, but a few. And I also think that - how you do it I don't know, but that it gets presented – it is presented to men as, "This is what you do, there is no loss of dignity in going and talking over your problems with people who are in the state – in the same position as you are."" (P39)
Accessible care	"Well I'm up in the country and when I got diagnosed there was really no services in my town and it was a, you know an hour and a half trip to the closest place where could get anything done…Well they certainly – they didn't even have chemotherapy services here. And they didn't have helpers such as prostate nurses etcetera, people that were specifically trained in this sort of cancer. My oncologist, my urologists are all down in Melbourne. I mean they're two hours away in a motor car." (P34) "It's about $40,000 a year. I think it's about four to 12, about $4,000 a month I think. Which the majority of people can't afford anyway. So he's got a number of other drugs, too. But that's the one he'd like to use next for me. So we've got to deal with that when we get there." (P5) "I definitely would [go to another support group]. The problem is I can't drive anywhere at the moment because of some of the drugs I'm on; so it makes it very difficult for me to get anywhere. And now the closest group other than this one, even that one I had to go by car, but the next area's group is probably about twice the distance away and nowhere near public transport." (P27)
Shared experience/peer support	"And I think that's – the big help that people need, and they are finding it here because they come to support group, it's looking for some comfort, I think, or some advice, or to talk to someone who's been there and done that. I think that a lot of trouble with the GPs and the surgeons, they – a lot of them don't have that first-hand experience, even though they work with it every day of their lives they don't – they haven't had the actual experience of living with the disease first-hand anyway." (P5) "I think if you had someone or a little group of people who could meet and talk and have – maybe even in a coffee shop, have a cup of coffee, even the pub, have a beer or coffee or something and discuss your problems because that's where you'll find out that most of the people have problems the same as you. You get some men together, you can have someone facilitate it at first, then you just leave them and come back later on." (P19)

	“Yeah, well face-to-face is the best way, but yeah, online, why not? Particularly with people in the country, assuming they know how to go online and handle IT and all that sort of thing. Yeah, somebody or some group of people that they can contact who do have the experience and have the understanding.” (P21) “From a personal standpoint of view, the normal sort of prostate cancer support group hasn’t been of any real benefit to myself or my wife. And the reason advanced prostate cancer for now, based in south east Queensland, which covers all of Australia and we have a monthly telephone conference and that is, yeah that’s quite beneficial. Because everybody in it has got advanced prostate cancer. It’s just that yeah, I’ve got advanced metastatic prostate cancer and that’s what this group is particular for, for men with advanced. Because we joke and say we among ourselves, “Dead Men Walking Club.” Warped sense of humour…” (P3) “And, I know, I found going to the support group, I walked into the room, I sat by myself and I didn’t sort of mix with the other men, but that unfortunately is me. I’m not a mixer, I’m not a conversationalist, although I seem to be talking pretty well to you. So I found them, it felt a bit uncomfortable. For those who have been there a long time, they were starting to hear the same thing over and over again. So I guess that might have been why I terminated going, one of the reasons. Very well run group, I just lost, I felt I was getting no benefit out of it and I wasn’t really comfortable there. That’s me, my particular makeup you can understand.” (P6)
Involvement of partner/family	“She (wife) senses my feelings, my moods, and she can tell if I’m feeling a bit negative by my comments or my talk, or mostly my body language. And she doesn’t beat around the bush, she just tells me to snap out of it, or, “Pull yourself together,” or “get yourself sorted”. Why don’t you do this, or why don’t you do that?” She doesn’t muck around, she really socks it to me, which is really good, it’s what I need. And I know that a lot of men say the same thing, they are always grateful for their partners in many, many cases, and we really live a lot longer with good wives, I can assure you. My wife is definitely the pinnacle. She’s the main support there.” (P5) “So, I get help with transport and I have someone come and help me clean once a fortnight and that, but I probably need help with shopping, but I have friends who will go and do the shopping or take me shopping. So, I’m fairly well off in that regard. …So, yeah, it’s good to have someone who will help you, you don’t want them mothering you, but take you and if I needed shopping we would go shopping after we’d been to the gym, heavy shopping, I need it, and bring it home.” (P19)

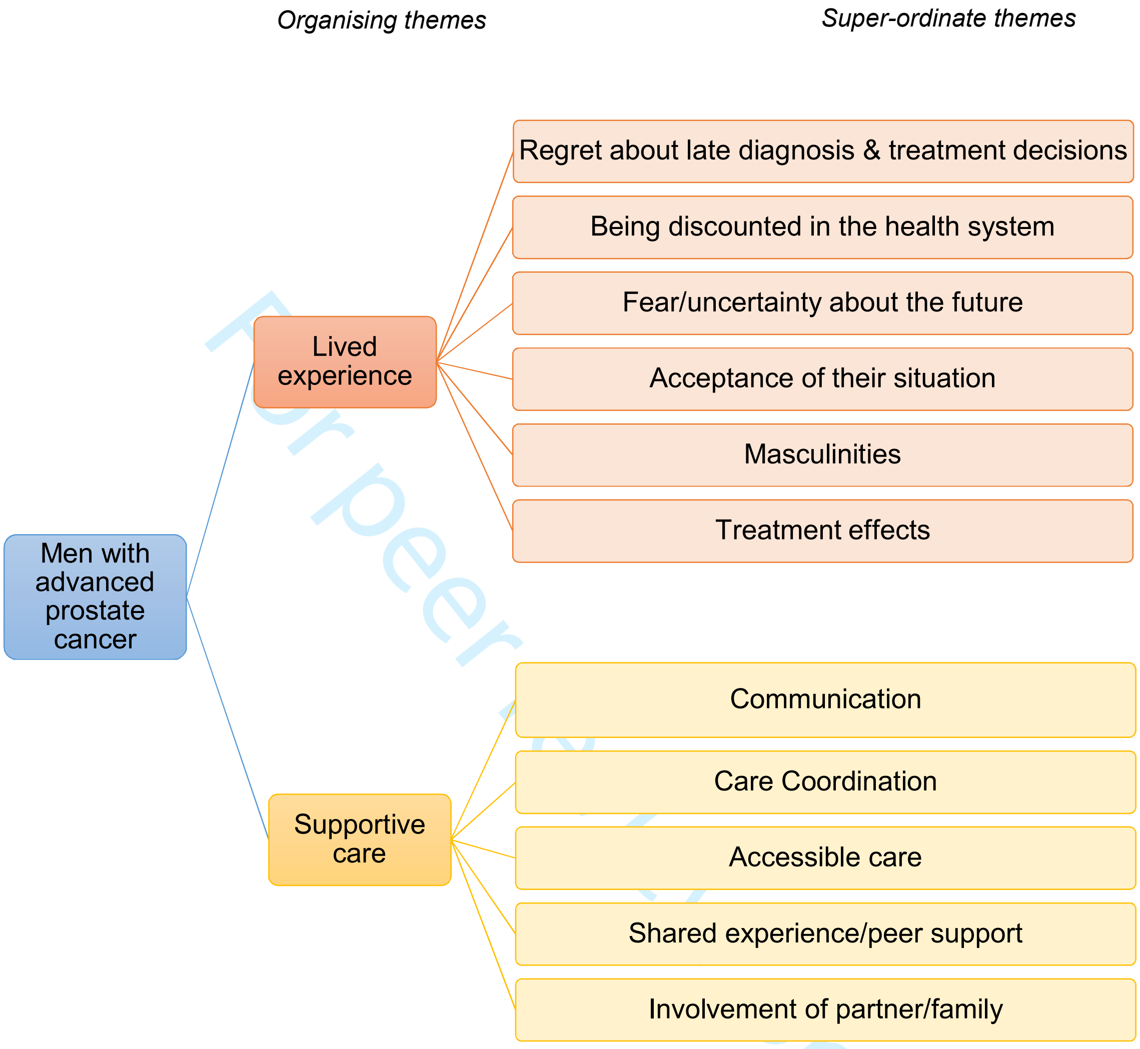

Figure 1. Coding structure derived from thematic analysis

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The experiences of men diagnosed with advanced prostate cancer: a qualitative study

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Abstract

Objective: To explore men's lived experience of advanced prostate cancer (PCa) and preferences for support.

Design: Cross-sectional qualitative study applying open-ended surveys and interviews conducted between June and November 2016. Interviews audio-recorded, and transcribed verbatim and analysed from an interpretive phenomenological perspective.

Setting: Australia, nation-wide.

Participants: 39 men diagnosed with advanced PCa (metastatic or castration-resistant biochemical regression) were surveyed with 28 men subsequently completing a semi-structured in depth telephone interview.

Results: Thematic analysis of interviews identified two organising themes; lived experience and supportive care. Lived experience included 6 super-ordinate themes: regret about late diagnosis and treatment decisions; being discounted in the health system; fear/uncertainty about the future; acceptance of their situation; masculinity; and treatment effects. Supportive care included 5 super-ordinate themes: communication; care coordination; accessible care; shared experience/peer support; and involvement of their partner/family.

Conclusions: Life course and the health and social context of prostate cancer influence men's experiences of advanced disease. Multimodal interventions integrating peer support and specialist nurses are needed that more closely articulate with men's expressed needs.

Strengths and limitations of this study

- Extends previous research in men with advanced PCa to describing how masculinities, life course, and the broader social and public health context influence support needs
- Robust and transparent study method and the application of a phenomenological approach
- Valid and reliable and transferable within the Australian setting
- Cross-sectional design is a study limitation

Keywords
Prostate cancer, advanced cancer, metastatic, masculinities, supportive care needs, life course

Introduction

Prostate cancer (PCa) is the second most common cancer in males with the highest incidence in Australia/New Zealand and North America [1]. Most men present with localised disease or disease with regional lymph nodes spread with the relative 5-year survival rate for these men exceeding 95% [2 3]. However, 1 in 5 will progress to metastatic disease [4]. Approximately 5% of men are diagnosed with metastatic disease and the relative 5-year survival rate for these men is only 30% [3 5]. The mainstay treatment for advanced PCa is androgen deprivation therapy (ADT) that typically is followed by progression to metastatic castration-resistant PCa [6]. Once this occurs, median survival is less than 2 years [7], although recent therapeutic advancements such as abiraterone acetate and enzalutamide have shown potential for further slowing disease progression [8] with median survival up to 3 years [6]. The STAMPEDE [9] and LATITUDE [10] trials demonstrated a survival advantage for the combined use of abiraterone with commencement of ADT however this was offset by earlier and more prolonged androgen suppression and a higher risk of grade 3 to 5 adverse events.

Hence, while new treatments for advanced PCa prolong life, this means men are living longer with the effects of treatment and disease progression including deteriorating bone health, pain, hot flushes, loss of libido, erectile dysfunction, increased fat mass, sarcopenia, fatigue, and cognitive decline [6 11 12]. Men with advanced PCa have poorer quality of life, higher levels of psychological distress, increased suicide risk, and more unmet supportive care needs compared to men with localised disease [13-16]. Approximately 1 in 4 experience regret about treatment decisions and this is associated with poorer quality of life and increased distress [17]. In sum, the burden associated with advanced PCa is substantial and further evolving as new treatments emerge.

To date there is scant psychosocial or supportive care intervention research directly targeting men with advanced PCa; and the one randomised trial of scale completed by our team failed to prove effectiveness[18 19]. Researchers in Canada and Scotland have previously highlighted the persisting support services gap for men with advanced PCa and suggested more qualitative research elucidating men's experiences is needed if we are to develop effective supportive care interventions[20 21]. Carter et al in 2011 explored the supportive care needs of men with advanced PCa and concluded that functional issues, information needs, and emotional distress were the three domains of need that needed to be addressed [20]. More recently, Paterson et al (2017) interviewed eight men with advanced PCa describing a broader range of challenges extending to interpersonal and intimacy needs [21]. Both studies emphasised the gap in informational support for these men, however neither deeply explored issues related to masculinities nor the broader social and public health context in which this illness experience is nested [22-24]. We sought to extend this previous work more specifically connecting our enquiry between men's challenges in facing advanced PCa and their preferences for support within their social context. Accordingly, we applied an interpretative phenomenological approach to describe the lived experience of men with advanced PCa (proven metastatic or castration-resistant biochemical regression) and their supportive care preferences.

Method

Study design

This study applied a cross-sectional qualitative design. In a first step, participants reflected on their experience with advanced PCa via a mail administered open-ended survey. These responses provided a context to inform development of a protocol to guide subsequent semi-structured in-depth telephone interviews. Consistent with the study aim to describe men's lived experiences in the context of advanced prostate cancer we adopted an interpretative phenomenological perspective [25 26]. Ethical approval was obtained from the Griffith University Human Research Ethics Committee (Reference number 2016/418).

Participants and recruitment

Participants were recruited from an existing patient cohort [15]. In brief, this was a cohort drawn from treatment centres across Australia with participants from five Australian states. In June 2016 we contacted men who had not withdrawn from the cohort and were not to our knowledge deceased and had consented to future contact (N=141). In all, 39 men returned the survey (28% response) and of these 28 were available for telephone interview between September 2016 and November 2016 (72% response). Similar to the cohort from which participants were drawn, the mean age of participants was 72.7 years (SD=8.5; range 58.2-94.6) with the majority born in Australia (75%), married (86%), and retired (79%); men resided across four Australian states. With regards to educational level, 7 men had a college degree; 15 had a trade or technical certificate/diploma; 2 had completed senior high school and four had completed junior high school. Mean time since diagnosis was 7.7 years (SD=5.0; range 2.1-22.8). Most men were treated with ADT (88%); 73% radiation therapy; 62% prostatectomy. Men who did not participate were either too unwell (n=4), had a hearing impairment (n=1), or did not consent (n=6). Table 1 reports sociodemographic characteristics and treatment information for each interview participant.

Data collection

Men responded to four questions in the survey about their PCa-related concerns; assistance or support accessed for these concerns and from whom; other support needed; and preferences for support for men. Thematic analysis [27] of responses (MH, KL, SC) indicated four areas that were challenging for men and in which they lacked support: information, medical care, side-effects, and the future. Three experienced female interviewers in a research fellow or research assistant position with post-graduate training in the behavioural sciences (ML, KL, EE) conducted telephone interviews to further explore the key areas identified. Interviews were on average 62.1 minutes in length (SD=19.2; range=29.2 to 111.9 minutes). Member checking occurred at the beginning of each interview during which the interviewer asked participants to comment on the accuracy of researcher interpretation of survey results and gave participants the opportunity to add anything they thought had been missed. Interview questions (Table 2) explored in greater depth the concerns previously identified in men's survey responses: health system concerns, supportive care needs, barriers to support and preferred approaches. Participants were invited to discuss other aspects of their experience that they considered were important. Interviews were audio-recorded and transcribed verbatim.

Data analysis

Interview transcripts were analysed using thematic analysis [27 28]. Themes were derived inductively from the data by reading and re-reading the interview narratives and from this developing an understanding of men's lived experience through their words. Coders had social and behavioural science (SC, MH, JD, KL), and nursing (SC) backgrounds with a wide range of experience from two to 20 years working in psycho-oncology and prostate cancer research and included male and female researchers. Transcripts were coded iteratively with constant comparison between the codes generated and the data to ensure that consistent and diverging responses were incorporated. Two research team members independently coded one-third of the transcripts and generated a preliminary coding scheme (MH, KL). This coding scheme was further refined with a third (SC) and fourth (JD) research team member. Once all interview transcripts were included the coding scheme was further reviewed and agreed upon by all coders. Exemplar responses were identified across transcripts to illustrate and confirm labelling of themes. Reporting of data is consistent with consolidated criteria for reporting qualitative studies (COREQ) guidelines [29].

Results

Thematic analysis identified two organising themes: lived experience and supportive care. The first organising theme reflected men's lived experience with advanced PCa, and within this six super-ordinate themes. The second organising theme captured elements of supportive care that men found challenging and their preferences for how care should be delivered with five super-ordinate themes. Figure 1 depicts the coding structure. Tables 3 and 4 present illustrative quotes for each super-ordinate theme.

Lived experience

Men's lived experience with advanced PCa included six super-ordinate themes: regret about late diagnosis and treatment decisions; being discounted in the health system; fear/uncertainty about the future; acceptance of their situation; masculinity; and treatment effects (Table 3).

Regret about late diagnosis and treatment decisions

Most men described feeling regret about late diagnosis or treatment and this was commonly attributed to delays by clinicians. Many men perceived these delays were caused by general practitioners and/or specialists who would not perform digital rectal examinations (DREs) or prostate-specific antigen (PSA) testing; did not detect PCa until it was well advanced despite regular testing; and did not refer patients for further treatment or testing in a timely manner despite men's requests for them to do so. From this, some men were left with a distrust of the medical profession. Many men also discussed regretting their treatment choices and not having had a second opinion so that they felt more adequately informed and clearly understood the outcomes of treatment, including side effects, and how these could be managed.

Being discounted in the health system

In their interactions with clinicians, most men described their concerns, needs and autonomy as discounted or ignored. Many men felt devalued and believed they were somehow less important in the broader health system. In their experience, PCa was the 'poor cousin' of breast cancer in terms of funding, research focus, and controversy over the value of PSA testing; and less effort by the government and non-profits to promote awareness of PCa. Some men also considered that they and their cancer were less important due to their older age and community attitudes where PCa is considered a cancer that may not lead to death.

Fear/uncertainty about the future

An uncertain future was discussed in terms of most men needing to make 'the unknowable' a known entity by understanding how much time they may have left to live; what lies ahead for disease progression and quality of life; potential treatment options; and next steps for support when all treatment options had been exhausted. This information was critical to their ability to feel more in control and to prepare for the future both psychologically and practically while they were well enough to do so. By contrast, some men discussed not wanting to know what the future held in order to focus on their day-to-day life.

Acceptance

Many men used their age as a frame to accept physical changes and the threat to their mortality. Other approaches adopted by many men to reach acceptance were focusing on 'getting on with it', and viewing ongoing physical effects of the disease or its treatment as part of life, an inevitable outcome of treatment or disease progression, and as a favourable alternative to death. Regarding sexuality, some men found changes in their physical capacity to have sex an ongoing cause of distress. Other men shifted their focus to other aspects of their relationships (e.g., expressing intimacy in ways that do not require an erection) as a way to accept their situation.

Masculinities

Male values and masculinities were discussed as central to most men's experience of PCa, support, and coping. Many men believed that as a group they do not look after themselves, go to the doctor, ask for help, or talk about their problems by comparison to women, and have a different view on their health, are less prepared to discuss their health, and gave health less attention. This reluctance to seek help or support or talk about their problems was ascribed to male values around being strong, capable, independent/autonomous, or stoic. Many men used avoidance as a coping approach by avoiding thinking or talking about their situation, and covering up or ignoring side-effects or a need for support. Some men expressed concerns that there would be negative consequences socially or in their employment if others knew about their cancer. Privacy and being embarrassed talking about personal issues were also raised by many men. Viewing sexuality and sexual function as important to their identity as a man meant that some men were deeply troubled by changes in sexuality; and believed that their relationship with their partner now would be negatively impacted or that it would no longer be possible for them to start new relationships with women.

In their perceived role as ‘the provider’ and ‘the protector’, some men expected to give help rather than receive it. Some men tried to protect their wives or their family by not talking about their problems and thus avoid worrying them. Many also adopted approaches to promote adjustment including being optimistic and ‘getting on with it’; taking responsibility for their health and well-being (e.g., remaining physically active); as well as an action-oriented approaches in which they identified and solved problems directly or sought help or support. In using these approaches, men saw themselves not constrained by masculine norms constraining help seeking. Many men devalued ‘talk’ as a way to obtain support and viewed psychologists as not able to provide the solutions they needed, also describing unfavourable attitudes towards support groups as an opportunity for self-pity or drama.

Treatment effects

All men discussed the effects of advanced PCa and its treatment that affected their quality of life, relationships, capacity to do daily tasks, and for many men were highly distressing. Prominent amongst these were physical effects and financial concerns. Physical effects included the inability to obtain an erection; lack of libido; urinary incontinence; changes in appearance and bodily structure including gynecomastia; weight gain; sarcopenia; decreased bone density; fatigue; dizziness; loss of balance; breathlessness; hot flushes; cognitive changes; and pain. Some men discussed no longer being well enough to work and that this negatively affected their income and retirement plans.

Supportive care

The organising theme supportive care included five super-ordinate themes: communication; care coordination; accessible care; shared experience/peer support; and involvement of their partner/family (Table 4).

Communication

Men had mixed experiences in their interactions and communication with health professionals. Four pivotal points in the care trajectory in which effective communication appeared most critical were: diagnosis; deciding on treatment options; treatment effects and symptom management; follow-up care. Many men described being unclear about the specifics of their diagnosis (e.g., staging, PSA) whereas, by contrast, some men appreciated the direct and honest approach adopted by their clinicians when communicating about the severity of their disease. When discussing treatment options, men desired more guidance and support in making a treatment decision; and for options to be more clearly communicated so that they could better understand long-term treatment effects. Some men were dismayed that their GPs or other health professionals did not seem to have specialised knowledge about PCa. Preferred decision support included clear, unbiased communication about the pros and cons of each treatment option and referral to other sources of information that men could consider in their own time.

Some men described confusion and frustration when they were given a treatment that they needed to self-administer (e.g., injections) but were not effectively instructed in how to do this. Men commonly discussed health professionals' communication about treatment side-effects as insufficient (e.g., told about effects but not how to deal with them) and selective (e.g., told about immediate but not long-term effects), and as a consequence felt unprepared and isolated in their experience. Some men described not being listened to when they raised their concerns or being unable to get clear answers to questions. Some men expressed that it was up to them to find solutions to manage their side-effects because clinicians did not adequately address these.

Care Coordination.

For some men, regular ongoing communication with their clinicians was a source of support, however other men felt out of touch and isolated due to the length of time between each consultation. GPs were important to some men in helping them feel connected with their care team. Most men discussed the need for better coordinated care and information and this was focused on three aspects: communication between health professionals; having a ‘middle man’; and integrating psychosocial support as part of routine care.

A lack of communication between specialist clinicians regarding treatment and referral was discussed by many men as problematic. Men had mixed views as to who should be the central point of call for information and referral. Some men believed this should be their GP; others suggested their urologist or oncologist. Patient advocates or navigators were also discussed by some men as an option to help streamline and clarify the diagnostic and treatment process. Some men discussed PCa nurses as being central to their care. Nurses provided informational, emotional, and practical support that clarified men’s understanding of their situation; served as an intermediary between the patient or couple and other clinicians; and were seen as more likely to refer them to other beneficial services than other health care professionals. These men discussed that the best time to be connected with a PCa nurse was at diagnosis with continued access throughout treatment.

Some men identified the need to integrate psychosocial support as part of routine care without relying on men themselves to raise emotional issues with clinicians. Alongside this, some men also discussed the need for routine referral to support groups or information about the existence of local groups; and exercise programs as helpful for weight gain and muscle wastage and managing feelings of loss of masculinity.

Accessible care

Many men discussed three main barriers to accessible care: geographic location; ill health and financial cost of treatment. Some men experienced difficulty accessing services because they resided in a regional or rural location where services were either not available or required them to travel long distances with resultant cost and inconvenience. Some men had difficulty or were prevented from accessing central or nearby services due to ill health or fatigue; and some men discussed the high financial cost of treatments or drugs to manage side-effects such as erectile dysfunction and uncertainty about how to cover these costs. To overcome accessibility issues, these men suggested use of online or telephone services for those in rural or regional areas or who could not access care due to ill health; lobbying the government to subsidise financial costs of treatment; and increasing the availability of home-based medical care or practical assistance services.

Shared experience/peer support

The opportunity to talk to other men in the same situation was discussed by most men as a source of support that they had or wished they had an awareness of and access to. Three aspects of shared experience/peer support: benefits; delivery preferences; and barriers were described. Shared experience was highly valued by most men because it allowed them to talk to someone who had been through the same experience; obtain information or advice when weighing up treatment decisions or managing side effects; make positive upward (e.g., other men doing well and inspiring hope for recovery) or downward (e.g., other men are doing worse so I am ok) comparisons [30]; gave men a safe and confidential forum to express their concerns; and helped men to feel less alone. However, some men did not always describe the concept of shared mutual experience as peer support or being connected to support groups. Rather, mutual support also occurred through companionship with other men who did not have cancer such as at Men's Sheds and social or sporting clubs.

Most men proposed different delivery methods for peer support (e.g., face-to-face, telephone, or online) to take into account individual differences and need for privacy or anonymity. Both structured (e.g., with a facilitator and an agenda) and unstructured (e.g., a chat over coffee) methods were acceptable. Some men preferred shared experiences specifically for men with advanced disease on the basis that men with localised disease have different treatments and cancer-related physical effects.

Finally, despite acknowledging the benefits of shared experience, many men also discussed barriers to peer support use. These included feeling uncomfortable to share in a group; the difficulty of sustaining support groups; death of peers; and the belief that support groups were focused only on emotional or psychological information.

Involvement of partner/family

In addition to shared experience, most men identified partners and/or family and friends as sources of support that contributed to their emotional and physical wellbeing. For most men, female partners were their main source of emotional and practical support. Many men discussed that partners were impacted by the diagnosis and treatment of PCa and believed it was important to involve and support partners in their care. Some men commented that partners are often the catalyst for their involvement in support groups or seeking out information/ support from other sources. Broader family and friends were also discussed by some men as sources of support, often providing practical assistance.

Discussion

The present study extends previous research about the experience of men with advanced PCa, adding an additional level of description that provides insight into how health context influences men's responses; the influence of life course; and ways in which masculinities is expressed in this setting. As in previous research, difficulties with accessible informational support about the disease and its treatment were highly evident [20 21 31]. That these problems persist and are remarkably similar in Canada [20], Scotland [21], and in our Australian data, is striking and suggests that globally there may be a gap in health systems' responses to advanced PCa. PCa survivorship research has to date been underfunded by comparison to breast cancer[32]; a consensus about clinical care for advanced PCa is just now emerging [33]; and the historical and persistent debate about the early detection of prostate cancer [24 34] are likely contributors to this. The men's reports in our study of PCa having a less favourable public profile reflect this and show how the broader public health and social context can have a profound negative impact on an already difficult cancer experience.

The influence of life course in response to illness in terms of men's age and the expression of masculinities and masculine models of coping strongly emerged in this study and this has implications for the design of care models [35]. We propose that there is a need to newly conceptualise and then deliver what men actually want, rather than starting from a first principle of revising services already provided that are not meeting men's needs. Men underutilise psychosocial support services after cancer compared to women with breast cancer [36]; and previous research has suggested that interventions promoting self-management in men with chronic diseases should include action oriented approaches if they are to be utilised [37 38]. With regards to providers of support, men in the present study proposed both peer support and nurse specialists as preferred care providers, confirming previous research [39].

Limitations of this study include the cross sectional design. Recent qualitative research applying a prospective study design proposed that coping with advanced cancer evolves over time as symptoms progress and fluctuate [40]. Future research utilising a prospective case study design will add further depth to our understanding of men's experiences in the face of advancing PCa. As well, the men in our study were not newly diagnosed with advanced disease and so reports of their experience at the time of diagnosis or initial disease progression are retrospective and subject to recall bias. Strengths include a robust and transparent study method and the involvement of men **across four** Australian states with varied sociodemographic backgrounds such that our data can be considered broadly relevant across the Australian setting. We do note that our participant group was not ethnically diverse and so likely does not represent these experiences, that have been well described elsewhere [41].

Based on our previous research [18 42] and the present results we propose five key content elements for inclusion in supportive care interventions with men with advanced PCa: decision support; treatment education with self-management and skills training for symptoms, including exercise prescription; routine screening for psychological distress with referral; psycho-education with tailored distress management strategies; communicating with health professionals. Strategies to integrate peer support within the care team are needed. Finally, the prostate cancer specialist role presents as highly acceptable to men and is ideally placed for supportive care delivery and care coordination [43].

In conclusion, supportive care services for men with advanced PCa need to be multimodal and take into account the influence of life course on men's illness experience. There is a need for the health system to prioritise research and development in clinical PCa care taking a more holistic approach than currently exists.

Author contributions

SC, JD and MH conceived the study, developed the interview protocol, undertook the analyses and interpretation, and led manuscript development. KL recruited and interviewed participants, undertook analysis and contributed to writing the manuscript. ML recruited and interviewed participants. MF, ID and AL contributed to data interpretation. All authors contributed to revisions and approved the final manuscript.

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Figure Legend

Figure 1. Coding structure derived from thematic analysis

Table 1

Sociodemographic characteristics and treatment information for participants completing an open-ended survey and telephone interview

N = No; NR = Not reported; W = Widowed (married at time of diagnosis); Y = Yes.

TABLE REMOVED TO MAINTAIN PARTICIPANTS CONFIDENTIALITY

Table 2

Interview questions

Focus area	Question
Health system	Thinking about your medical treatment, what changes do you feel would make medical services better meet the needs of men with advanced prostate cancer?
Supportive Care Needs	Thinking about the treatment side effects that a man with advanced prostate cancer might experience, what sort of support would help most?
	Thinking about the future and the worries that face a man with prostate cancer that has advanced or recurred, what sort of support would help most?
Barriers	In developing services to help men cope or manage better with advanced prostate cancer, can you describe support approaches or ways of helping that would **not** be acceptable to men? For example, supportive approaches that would turn men off or away?
Preferred approaches	In developing services to help men cope or manage better with advanced prostate cancer, can you describe support approaches or ways of helping that would be more attractive to men?
Other	Thinking about what we have spoken about today, is there anything else we haven't covered that you think is important to supporting men with advanced prostate cancer?

Table 3

Lived experience organising theme and super-ordinate themes

Super-ordinate theme	**Exemplar quotes**
Regret about late diagnosis and treatment decisions	"I saw a GP and first of all, I think it was 1.9 was my PSA reading, and when it got to 14 I said to him – everything I read tells me that I should be seeing a specialist. And he said, "Oh you worrywart, don't worry about it," and then next time I said it, he said, "All right I'll send you to see […] he's a urologist." I went to see his specialist mate, and he said, "Bloody hell, where've you been, you should've been here three years ago." Because it'd been like that for three or four years. The prostate was full of cancer, and it escaped outside the prostate and went into my lymph nodes, because of all that time wasted." (P31) "My only regret was that I didn't get enough information at the beginning, or, hey, maybe I did, but I was never comfortable with the fact that I had really learnt everything that there was to learn about it before I actually made decisions, and I may or may not have made the wrong one." (P32)
Being discounted in the health system	"The men seemed to think that prostate cancer was a B grade compared to other cancers. Because it was older men, and they'd had their run probably. No-one's going to worry too much about it…Usually men who have got prostate cancer are old, older men and certainly you wouldn't all the funding going to the old men and not the young women, or middle-aged women. It wouldn't be fair would it. So we thought that the prostate cancer people were sort of the poor relations in both attitude, funding, in a lot of ways. But you can't change it." (P26) "They treat you more as a joke, yeah, and the last time I spoke to him about it– I tried to find out am I going to have a lot of pain, is my bones going to break or whatever? He said: You'll probably die of pneumonia."(P6) "I just got the impression that the patient was just a number, the name didn't matter, in fact, we won't even involve the patient in the discussion, they're there but we've just got a number for him on the records and when they come around to your bed the team, which could be a half a dozen or 10 or even more depending on how many people they've got on the day, they just start talking about the condition you've got, absolutely nothing, no mention of you yourself being the patient, they don't even recognise you." (P20)
Fear/uncertainty about the future	"I'd just like to know where I'm headed. I guess he can't tell me what's going to happen with the disease, but I'd imagine there must be a pattern, a reasonable pattern of what happens. I mean, with some illnesses you know this is going to progress from this to that, to that, but an article I saw recently in a support group pamphlet was, if you took Drug X tablets, when they stopped working, you took Drug Y tablets. When they stopped working, the next thing on the - on the ladder was death, d-e-a-t-h. Well, I've been taking Drug X for quite a while. I've been taking Drug Y for quite a while. Each had a definite effect on my PSA, each lost that effect. So really, the next thing that faces me is death. Now, so, it was four months ago that my oncologist gave me, he said, "You'll see your birthday." Well, that's only three months away, it's only two months away actually. What's going to happen between now and then?" (P6)

Acceptance	"I think acceptance. That would be the word that comes to mind. Not resignation, big difference in my mind between resignation and acceptance, but okay, I accept it, to live a bit longer, or feel a bit better. This is what happens, I've just got to come to terms with it the best way I can. I didn't handle it too well. I think even at that age, you think you're indestructible. Gees, it did happen. But, it's not the end of the world and that's the attitudinal part, I think, more so than – attitude in retrospect, acceptance and spirituality part of it...I can possibly liken it, sort of, something akin to grief counselling is what I needed. You know, there's anger, there's frustration, everything. The whole gambit. It's all there. It's like, okay, it's passed away now, you know, let it rest...I just assumed, pop a couple of Viagra, you'll be right. But, no. So, yeah, it's – yeah and that's a problem after being very active for such a long time with a beautiful wife, it's really hard, really hard to take." (P30)
Masculinity	"Partly, I think, the reluctance of men to talk about their health, or to talk about personal issues that the idea of maleness, being able to be stoic and cope, type of thing. And just in the idea of maleness, that, sort of, men don't cry, men are stoic, or you get on and cope with things, a lot of men have not been exposed to talking about personal matters and so find it difficult to do that." (P9)
Treatment effects	"I'm impotent, and that – put it this way, that's – honestly, that's something that I have an extremely hard time coming to terms with. My wife and I had a fantastic sex life but that's gone and there's now – yeah, it's probably as much my fault as hers but there's just nothing left of our marriage; we live together but that's about it." (P38) "I can't even walk down the beach, put out – not having to urinate a couple of times, I take my dog for a pretty long walk each day and I'm looking over my shoulder and I'm always thinking one day I'm going to get busted and someone's going to call me a dirty old man and are they going to even be prepared to listen to the fact that I've had prostate cancer and it's not my fault?" (P14) "Eating is a problem, I have a problem eating. I don't really want to eat but I more or less force myself to eat, because I have no energy, but I've lost, I think, it's 40 kilos all together, but that's over a period. When I look in the mirror I see this gaunt face looking at – I thought I was fairly good looking for an old bloke but now I really look bloody painful, I take notice, like, god I'm gaunt. And I really am thin." (P19) "The general fatigue, loss of energy, loss of muscle tone, the hormonal issues were probably the biggest ones. I've got osteoporosis because – it's only at the early stage, but my bone density is checked regularly, but it's dropping slowly even though I do exercise, walk a lot and keep my weight down and exercises up. I do that sort of thing all the time. But I'm probably holding it in check. But that one's always a bit of a concern. I've got to be careful I don't fall off the roof, I don't do something, don't break anything nowadays. In fact I – when I finished radiation therapy I felt all pretty smart and I went running on the rocks at the beach one day, and jumped from one rock to another, and snapped my ankle so badly it had to be screwed up with screws and braces." (P5)

	"I now have gynecomastia which I've discussed with my GP and my specialist. I was looking at having my breasts removed, unfortunately which I would've had to pay for, but I was told that if I did, they would come back so it would be a waste of time and effort and money doing it." (P38) "I know the cancer's spreading. I woke up this morning about 4 o'clock with pains in my pelvic, where it is, the pelvic bone where I suspect the cancer's moving to. They said it would at the Cancer Clinic, so that gave me a bit of pain. But I find if I take Panadol, one of these Panadols – I take two at night and two in the morning and two midday, I keep the pain at a level that's quite acceptable. But I didn't take it last night and then I woke up at 4 o'clock and thought, oh, what's going on here." (P23) "I mean one of the biggest impacts is financial loss and that is not discussed full stop. That's when you're diagnosed with a terminal illness and there is no cure. They can slow the disease down, which they've successfully done in my case. But because of the side effect of loss of testosterone, so you've got less energy, muscle wastage and all of that. And the end resulted in me – I had to give up work. Now, that financial loss has been – made a big impact on my retirement and everything else." (P3)

Table 4

Supportive care organising theme and super-ordinate themes

Super-ordinate theme	Exemplar quotes
Communication	"For me at my stage, or more advanced, or – I don't know at what stage I'm at. Whether I'm advanced or reasonable, or what. I don't have any – I don't have any real – I don't know what the symptoms are – if you do get advanced or more advanced, I don't know what the symptoms are really. I have no information in that regard. I don't know." (P17) "He's not exactly verbose, he doesn't say a great deal. And I got put on Drug Z and was more or less left to my own devices with my GP who I don't think he'd ever heard of it and it wasn't really until about three or four months ago that we managed to sort out how the injections should be given." (P10) "Openness, I think, for me for the treatment options. Probably the side effects were less discussed or less publicised. There was some, particularly in the radiation process, you could get burning, you could get itching, this, or that, but then later on you find out there was some others that they didn't mention…On that score, I think there's some minor explanation, you will get tireder, you will get hot flushes, but no advice - what can you do about a hot flush; go and have a cold shower. There's been nothing on that, and in terms of maybe a medication, is there something will help as it does for ladies, I've got no idea." (P35)
Care Coordination	"You just get the impression going through the process that the different stages of the process all have their own people, their own separate team altogether. I guess, I could sum it up in a word and that's coordination with all the different treatments and tests and results and everything to do with the treatment, all those things are there obviously, patients are being treated for a long, long time, but having been through the process I just find that even though you end up getting through it it's a bit of a minefield for the patient because they haven't got a clue really what's involved, what's coming next, what you've got to do." (P20) "It's got to be the doctors. The doctors, I think, it has to start at the GP level and go right through. This is, as I say, this is your life and they're doing the journey with you. That's a good way of putting it, they're doing the journey with you." (P15) "I'd say ideally at time of diagnosis, after you talk to the doctor the next step would be the prostate cancer nurse. Yeah. Into the treatment part of it, yes, as part of the treatment process. But, in some ways, I think, that if you've got, say, sort of a trusted person, so if it's a prostate cancer nurse providing good information and directing

	traffic, type of thing, and putting people in touch with resources, I think, that's probably going to help to overcome the difficulties." (P9) "I think this support idea needs to be built in at diagnosis level into the, well, the doctors would present this as, "This is a natural part of the treatment, we're not saying go there if we think you need it, you have been diagnosed with cancer, you need it, we would strongly recommend you take your – take the benefit of going to a group for," I don't know how many meetings, but a few. And I also think that - how you do it I don't know, but that it gets presented – it is presented to men as, "This is what you do, there is no loss of dignity in going and talking over your problems with people who are in the state – in the same position as you are."" (P39)
Accessible care	"Well I'm up in the country and when I got diagnosed there was really no services in my town and it was a, you know an hour and a half trip to the closest place where could get anything done…Well they certainly – they didn't even have chemotherapy services here. And they didn't have helpers such as prostate nurses etcetera, people that were specifically trained in this sort of cancer. My oncologist, my urologists are all down in Melbourne. I mean they're two hours away in a motor car." (P34) "It's about $40,000 a year. I think it's about four to 12, about $4,000 a month I think. Which the majority of people can't afford anyway. So he's got a number of other drugs, too. But that's the one he'd like to use next for me. So we've got to deal with that when we get there." (P5) "I definitely would [go to another support group]. The problem is I can't drive anywhere at the moment because of some of the drugs I'm on; so it makes it very difficult for me to get anywhere. And now the closest group other than this one, even that one I had to go by car, but the next area's group is probably about twice the distance away and nowhere near public transport." (P27)
Shared experience/peer support	"And I think that's – the big help that people need, and they are finding it here because they come to support group, it's looking for some comfort, I think, or some advice, or to talk to someone who's been there and done that. I think that a lot of trouble with the GPs and the surgeons, they – a lot of them don't have that first-hand experience, even though they work with it every day of their lives they don't – they haven't had the actual experience of living with the disease first-hand anyway." (P5) "I think if you had someone or a little group of people who could meet and talk and have – maybe even in a coffee shop, have a cup of coffee, even the pub, have a beer or coffee or something and discuss your problems because that's where you'll find out that most of the people have problems the same as you. You get some men together, you can have someone facilitate it at first, then you just leave them and come back later on." (P19)

	“Yeah, well face-to-face is the best way, but yeah, online, why not? Particularly with people in the country, assuming they know how to go online and handle IT and all that sort of thing. Yeah, somebody or some group of people that they can contact who do have the experience and have the understanding.” (P21) “From a personal standpoint of view, the normal sort of prostate cancer support group hasn’t been of any real benefit to myself or my wife. And the reason advanced prostate cancer for now, based in south east Queensland, which covers all of Australia and we have a monthly telephone conference and that is, yeah that’s quite beneficial. Because everybody in it has got advanced prostate cancer. It’s just that yeah, I’ve got advanced metastatic prostate cancer and that’s what this group is particular for, for men with advanced. Because we joke and say we among ourselves, “Dead Men Walking Club.” Warped sense of humour…” (P3) “And, I know, I found going to the support group, I walked into the room, I sat by myself and I didn’t sort of mix with the other men, but that unfortunately is me. I’m not a mixer, I’m not a conversationalist, although I seem to be talking pretty well to you. So I found them, it felt a bit uncomfortable. For those who have been there a long time, they were starting to hear the same thing over and over again. So I guess that might have been why I terminated going, one of the reasons. Very well run group, I just lost, I felt I was getting no benefit out of it and I wasn’t really comfortable there. That’s me, my particular makeup you can understand.” (P6)
Involvement of partner/family	“She (wife) senses my feelings, my moods, and she can tell if I’m feeling a bit negative by my comments or my talk, or mostly my body language. And she doesn’t beat around the bush, she just tells me to snap out of it, or, “Pull yourself together,” or “get yourself sorted”. Why don’t you do this, or why don’t you do that?” She doesn’t muck around, she really socks it to me, which is really good, it’s what I need. And I know that a lot of men say the same thing, they are always grateful for their partners in many, many cases, and we really live a lot longer with good wives, I can assure you. My wife is definitely the pinnacle. She’s the main support there.” (P5) “So, I get help with transport and I have someone come and help me clean once a fortnight and that, but I probably need help with shopping, but I have friends who will go and do the shopping or take me shopping. So, I’m fairly well off in that regard. …So, yeah, it’s good to have someone who will help you, you don’t want them mothering you, but take you and if I needed shopping we would go shopping after we’d been to the gym, heavy shopping, I need it, and bring it home.” (P19)

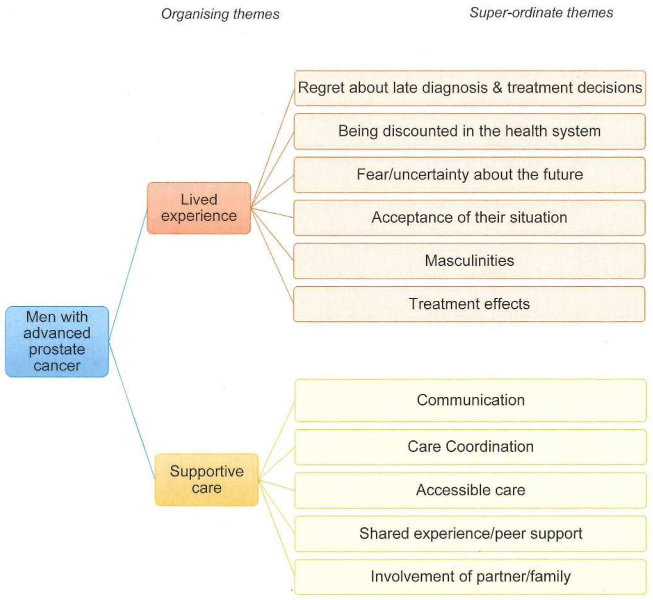

Figure 1. Coding structure derived from thematic analysis

Coding structure derived from thematic analysis

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The experiences of Australian men diagnosed with advanced prostate cancer: a qualitative study

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The experiences of Australian men diagnosed with advanced prostate cancer: a qualitative study

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Abstract

Objective: To explore men's lived experience of advanced prostate cancer (PCa) and preferences for support.

Design: Cross-sectional qualitative study applying open-ended surveys and interviews conducted between June and November 2016. Interviews audio-recorded, and transcribed verbatim and analysed from an interpretive phenomenological perspective.

Setting: Australia, nation-wide.

Participants: 39 men diagnosed with advanced PCa (metastatic or castration-resistant biochemical regression) were surveyed with 28 men subsequently completing a semi-structured in depth telephone interview.

Results: Thematic analysis of interviews identified two organising themes; lived experience and supportive care. Lived experience included 6 super-ordinate themes: regret about late diagnosis and treatment decisions; being discounted in the health system; fear/uncertainty about the future; acceptance of their situation; masculinity; and treatment effects. Supportive care included 5 super-ordinate themes: communication; care coordination; accessible care; shared experience/peer support; and involvement of their partner/family.

Conclusions: Life course and the health and social context of prostate cancer influence men's experiences of advanced disease. Multimodal interventions integrating peer support and specialist nurses are needed that more closely articulate with men's expressed needs.

Strengths and limitations of this study

- Extends previous research in men with advanced PCa to describing how masculinities, life course, and the broader social and public health context influence support needs
- Robust and transparent study method and the application of a phenomenological approach
- Valid and reliable and transferable within the Australian setting
- Cross-sectional design is a study limitation

Keywords
Prostate cancer, advanced cancer, metastatic, masculinities, supportive care needs, life course

Introduction

Prostate cancer (PCa) is the second most common cancer in males with the highest incidence in Australia/New Zealand and North America [1]. Most men present with localised disease or disease with regional lymph nodes spread with the relative 5-year survival rate for these men exceeding 95% [2 3]. However, 1 in 5 will progress to metastatic disease [4]. Approximately 5% of men are diagnosed with metastatic disease and the relative 5-year survival rate for these men is only 30% [3 5]. The mainstay treatment for advanced PCa is androgen deprivation therapy (ADT) that typically is followed by progression to metastatic castration-resistant PCa [6]. Once this occurs, median survival is less than 2 years [7], although recent therapeutic advancements such as abiraterone acetate and enzalutamide have shown potential for further slowing disease progression [8] with median survival up to 3 years [6]. The STAMPEDE [9] and LATITUDE [10] trials demonstrated a survival advantage for the combined use of abiraterone with commencement of ADT however this was offset by earlier and more prolonged androgen suppression and a higher risk of grade 3 to 5 adverse events.

Hence, while new treatments for advanced PCa prolong life, this means men are living longer with the effects of treatment and disease progression including deteriorating bone health, pain, hot flushes, loss of libido, erectile dysfunction, increased fat mass, sarcopenia, fatigue, and cognitive decline [6 11 12]. Men with advanced PCa have poorer quality of life, higher levels of psychological distress, increased suicide risk, and more unmet supportive care needs compared to men with localised disease [13-16]. Approximately 1 in 4 experience regret about treatment decisions and this is associated with poorer quality of life and increased distress [17]. In sum, the burden associated with advanced PCa is substantial and further evolving as new treatments emerge.

To date there is scant psychosocial or supportive care intervention research directly targeting men with advanced PCa; and the one randomised trial of scale completed by our team failed to prove effectiveness[18 19]. Researchers in Canada and Scotland have previously highlighted the persisting support services gap for men with advanced PCa and suggested more qualitative research elucidating men's experiences is needed if we are to develop effective supportive care interventions[20 21]. Carter et al in 2011 explored the supportive care needs of men with advanced PCa and concluded that functional issues, information needs, and emotional distress were the three domains of need that needed to be addressed [20]. More recently, Paterson et al (2017) interviewed eight men with advanced PCa describing a broader range of challenges extending to interpersonal and intimacy needs [21]. Both studies emphasised the gap in informational support for these men, however neither deeply explored issues related to masculinities nor the broader social and public health context in which this illness experience is nested [22-24]. We sought to extend this previous work more specifically connecting our enquiry between men's challenges in facing advanced PCa and their preferences for support within their social context. Accordingly, we applied an interpretative phenomenological approach to describe the lived experience of men with advanced PCa (proven metastatic or castration-resistant biochemical regression) and their supportive care preferences.

Method

Study design

This study applied a cross-sectional qualitative design. In a first step, participants reflected on their experience with advanced PCa via a mail administered open-ended survey. These responses provided a context to inform development of a protocol to guide subsequent semi-structured in-depth telephone interviews. Consistent with the study aim to describe men's lived experiences in the context of advanced prostate cancer we adopted an interpretative phenomenological perspective [25 26]. Ethical approval was obtained from the Griffith University Human Research Ethics Committee (Reference number 2016/418).

Participants and recruitment

Participants were recruited from an existing patient cohort [15]. In brief, this was a cohort drawn from treatment centres across Australia with participants from five Australian states. In June 2016 we contacted men who had not withdrawn from the cohort and were not to our knowledge deceased and had consented to future contact (N=141). In all, 39 men returned the survey (28% response) and of these 28 were available for telephone interview between September 2016 and November 2016 (72% response). Similar to the cohort from which participants were drawn, the mean age of participants was 72.7 years (SD=8.5; range 58.2-94.6) with the majority born in Australia (75%), married (86%), and retired (79%); men resided across four Australian states. With regards to educational level, 7 men had a college degree; 15 had a trade or technical certificate/diploma; 2 had completed senior high school and four had completed junior high school. Mean time since diagnosis was 7.7 years (SD=5.0; range 2.1-22.8). Most men were treated with ADT (88%); 73% radiation therapy; 62% prostatectomy. Men who did not participate were either too unwell (n=4), had a hearing impairment (n=1), or did not consent (n=6). Table 1 reports sociodemographic characteristics and treatment information for each interview participant.

Data collection

Men responded to four questions in the survey about their PCa-related concerns; assistance or support accessed for these concerns and from whom; other support needed; and preferences for support for men. Thematic analysis [27] of responses (MH, KL, SC) indicated four areas that were challenging for men and in which they lacked support: information, medical care, side-effects, and the future. Three experienced female interviewers in a research fellow or research assistant position with post-graduate training in the behavioural sciences (ML, KL, EE) conducted telephone interviews to further explore the key areas identified. Interviews were on average 62.1 minutes in length (SD=19.2; range=29.2 to 111.9 minutes). Member checking occurred at the beginning of each interview during which the interviewer asked participants to comment on the accuracy of researcher interpretation of survey results and gave participants the opportunity to add anything they thought had been missed. Interview questions (Table 2) explored in greater depth the concerns previously identified in men's survey responses: health system concerns, supportive care needs, barriers to support and preferred approaches. Participants were invited to discuss other aspects of their experience that they considered were important. Interviews were audio-recorded and transcribed verbatim.

Data analysis

Interview transcripts were analysed using thematic analysis [27 28]. Themes were derived inductively from the data by reading and re-reading the interview narratives and from this developing an understanding of men's lived experience through their words. Coders had social and behavioural science (SC, MH, JD, KL), and nursing (SC) backgrounds with a wide range of experience from two to 20 years working in psycho-oncology and prostate cancer research and included male and female researchers. Transcripts were coded iteratively with constant comparison between the codes generated and the data to ensure that consistent and diverging responses were incorporated. Two research team members independently coded one-third of the transcripts and generated a preliminary coding scheme (MH, KL). This coding scheme was further refined with a third (SC) and fourth (JD) research team member. Once all interview transcripts were included the coding scheme was further reviewed and agreed upon by all coders. Exemplar responses were identified across transcripts to illustrate and confirm labelling of themes. Reporting of data is consistent with consolidated criteria for reporting qualitative studies (COREQ) guidelines [29].

Results

Thematic analysis identified two organising themes: lived experience and supportive care. The first organising theme reflected men's lived experience with advanced PCa, and within this six super-ordinate themes. The second organising theme captured elements of supportive care that men found challenging and their preferences for how care should be delivered with five super-ordinate themes. Figure 1 depicts the coding structure. Tables 3 and 4 present illustrative quotes for each super-ordinate theme.

Lived experience

Men's lived experience with advanced PCa included six super-ordinate themes: regret about late diagnosis and treatment decisions; being discounted in the health system; fear/uncertainty about the future; acceptance of their situation; masculinity; and treatment effects (Table 3).

Regret about late diagnosis and treatment decisions

Most men described feeling regret about late diagnosis or treatment and this was commonly attributed to delays by clinicians. Many men perceived these delays were caused by general practitioners and/or specialists who would not perform digital rectal examinations (DREs) or prostate-specific antigen (PSA) testing; did not detect PCa until it was well advanced despite regular testing; and did not refer patients for further treatment or testing in a timely manner despite men's requests for them to do so. From this, some men were left with a distrust of the medical profession. Many men also discussed regretting their treatment choices and not having had a second opinion so that they felt more adequately informed and clearly understood the outcomes of treatment, including side effects, and how these could be managed.

Being discounted in the health system

In their interactions with clinicians, most men described their concerns, needs and autonomy as discounted or ignored. Many men felt devalued and believed they were somehow less important in the broader health system. In their experience, PCa was the ‘poor cousin’ of breast cancer in terms of funding, research focus, and controversy over the value of PSA testing; and less effort by the government and non-profits to promote awareness of PCa. Some men also considered that they and their cancer were less important due to their older age and community attitudes where PCa is considered a cancer that may not lead to death.

Fear/uncertainty about the future

An uncertain future was discussed in terms of most men needing to make ‘the unknowable’ a known entity by understanding how much time they may have left to live; what lies ahead for disease progression and quality of life; potential treatment options; and next steps for support when all treatment options had been exhausted. This information was critical to their ability to feel more in control and to prepare for the future both psychologically and practically while they were well enough to do so. By contrast, some men discussed not wanting to know what the future held in order to focus on their day-to-day life.

Acceptance

Many men used their age as a frame to accept physical changes and the threat to their mortality. Other approaches adopted by many men to reach acceptance were focusing on ‘getting on with it’, and viewing ongoing physical effects of the disease or its treatment as part of life, an inevitable outcome of treatment or disease progression, and as a favourable alternative to death. Regarding sexuality, some men found changes in their physical capacity to have sex an ongoing cause of distress. Other men shifted their focus to other aspects of their relationships (e.g., expressing intimacy in ways that do not require an erection) as a way to accept their situation.

Masculinities

Male values and masculinities were discussed as central to most men’s experience of PCa, support, and coping. Many men believed that as a group they do not look after themselves, go to the doctor, ask for help, or talk about their problems by comparison to women, and have a different view on their health, are less prepared to discuss their health, and gave health less attention. This reluctance to seek help or support or talk about their problems was ascribed to male values around being strong, capable, independent/autonomous, or stoic. Many men used avoidance as a coping approach by avoiding thinking or talking about their situation, and covering up or ignoring side-effects or a need for support. Some men expressed concerns that there would be negative consequences socially or in their employment if others knew about their cancer. Privacy and being embarrassed talking about personal issues were also raised by many men. Viewing sexuality and sexual function as important to their identity as a man meant that some men were deeply troubled by changes in sexuality; and believed that their relationship with their partner now would be negatively impacted or that it would no longer be possible for them to start new relationships with women.

In their perceived role as 'the provider' and 'the protector', some men expected to give help rather than receive it. Some men tried to protect their wives or their family by not talking about their problems and thus avoid worrying them. Many also adopted approaches to promote adjustment including being optimistic and 'getting on with it'; taking responsibility for their health and well-being (e.g., remaining physically active); as well as an action-oriented approaches in which they identified and solved problems directly or sought help or support. In using these approaches, men saw themselves not constrained by masculine norms constraining help seeking. Many men devalued 'talk' as a way to obtain support and viewed psychologists as not able to provide the solutions they needed, also describing unfavourable attitudes towards support groups as an opportunity for self-pity or drama.

Treatment effects

All men discussed the effects of advanced PCa and its treatment that affected their quality of life, relationships, capacity to do daily tasks, and for many men were highly distressing. Prominent amongst these were physical effects and financial concerns. Physical effects included the inability to obtain an erection; lack of libido; urinary incontinence; changes in appearance and bodily structure including gynecomastia; weight gain; sarcopenia; decreased bone density; fatigue; dizziness; loss of balance; breathlessness; hot flushes; cognitive changes; and pain. Some men discussed no longer being well enough to work and that this negatively affected their income and retirement plans.

Supportive care

The organising theme supportive care included five super-ordinate themes: communication; care coordination; accessible care; shared experience/peer support; and involvement of their partner/family (Table 4).

Communication

Men had mixed experiences in their interactions and communication with health professionals. Four pivotal points in the care trajectory in which effective communication appeared most critical were: diagnosis; deciding on treatment options; treatment effects and symptom management; follow-up care. Many men described being unclear about the specifics of their diagnosis (e.g., staging, PSA) whereas, by contrast, some men appreciated the direct and honest approach adopted by their clinicians when communicating about the severity of their disease. When discussing treatment options, men desired more guidance and support in making a treatment decision; and for options to be more clearly communicated so that they could better understand long-term treatment effects. Some men were dismayed that their GPs or other health professionals did not seem to have specialised knowledge about PCa. Preferred decision support included clear, unbiased communication about the pros and cons of each treatment option and referral to other sources of information that men could consider in their own time.

Some men described confusion and frustration when they were given a treatment that they needed to self-administer (e.g., injections) but were not effectively instructed in how to do this. Men commonly discussed health professionals' communication about treatment side-effects as insufficient (e.g., told about effects but not how to deal with them) and selective (e.g., told about immediate but not long-term effects), and as a consequence felt unprepared and isolated in their experience. Some men described not being listened to when they raised their concerns or being unable to get clear answers to questions. Some men expressed that it was up to them to find solutions to manage their side-effects because clinicians did not adequately address these.

Care Coordination.

For some men, regular ongoing communication with their clinicians was a source of support, however other men felt out of touch and isolated due to the length of time between each consultation. GPs were important to some men in helping them feel connected with their care team. Most men discussed the need for better coordinated care and information and this was focused on three aspects: communication between health professionals; having a ‘middle man’; and integrating psychosocial support as part of routine care.

A lack of communication between specialist clinicians regarding treatment and referral was discussed by many men as problematic. Men had mixed views as to who should be the central point of call for information and referral. Some men believed this should be their GP; others suggested their urologist or oncologist. Patient advocates or navigators were also discussed by some men as an option to help streamline and clarify the diagnostic and treatment process. Some men discussed PCa nurses as being central to their care. Nurses provided informational, emotional, and practical support that clarified men’s understanding of their situation; served as an intermediary between the patient or couple and other clinicians; and were seen as more likely to refer them to other beneficial services than other health care professionals. These men discussed that the best time to be connected with a PCa nurse was at diagnosis with continued access throughout treatment.

Some men identified the need to integrate psychosocial support as part of routine care without relying on men themselves to raise emotional issues with clinicians. Alongside this, some men also discussed the need for routine referral to support groups or information about the existence of local groups; and exercise programs as helpful for weight gain and muscle wastage and managing feelings of loss of masculinity.

Accessible care

Many men discussed three main barriers to accessible care: geographic location; ill health and financial cost of treatment. Some men experienced difficulty accessing services because they resided in a regional or rural location where services were either not available or required them to travel long distances with resultant cost and inconvenience. Some men had difficulty or were prevented from accessing central or nearby services due to ill health or fatigue; and some men discussed the high financial cost of treatments or drugs to manage side-effects such as erectile dysfunction and uncertainty about how to cover these costs. To overcome accessibility issues, these men suggested use of online or telephone services for those in rural or regional areas or who could not access care due to ill health; lobbying the government to subsidise financial costs of treatment; and increasing the availability of home-based medical care or practical assistance services.

Shared experience/peer support

The opportunity to talk to other men in the same situation was discussed by most men as a source of support that they had or wished they had an awareness of and access to. Three aspects of shared experience/peer support: benefits; delivery preferences; and barriers were described. Shared experience was highly valued by most men because it allowed them to talk to someone who had been through the same experience; obtain information or advice when weighing up treatment decisions or managing side effects; make positive upward (e.g., other men doing well and inspiring hope for recovery) or downward (e.g., other men are doing worse so I am ok) comparisons [30]; gave men a safe and confidential forum to express their concerns; and helped men to feel less alone. However, some men did not always describe the concept of shared mutual experience as peer support or being connected to support groups. Rather, mutual support also occurred through companionship with other men who did not have cancer such as at Men's Sheds and social or sporting clubs.

Most men proposed different delivery methods for peer support (e.g., face-to-face, telephone, or online) to take into account individual differences and need for privacy or anonymity. Both structured (e.g., with a facilitator and an agenda) and unstructured (e.g., a chat over coffee) methods were acceptable. Some men preferred shared experiences specifically for men with advanced disease on the basis that men with localised disease have different treatments and cancer-related physical effects.

Finally, despite acknowledging the benefits of shared experience, many men also discussed barriers to peer support use. These included feeling uncomfortable to share in a group; the difficulty of sustaining support groups; death of peers; and the belief that support groups were focused only on emotional or psychological information.

Involvement of partner/family

In addition to shared experience, most men identified partners and/or family and friends as sources of support that contributed to their emotional and physical wellbeing. For most men, female partners were their main source of emotional and practical support. Many men discussed that partners were impacted by the diagnosis and treatment of PCa and believed it was important to involve and support partners in their care. Some men commented that partners are often the catalyst for their involvement in support groups or seeking out information/ support from other sources. Broader family and friends were also discussed by some men as sources of support, often providing practical assistance.

Discussion

The present study extends previous research about the experience of men with advanced PCa, adding an additional level of description that provides insight into how health context influences men's responses; the influence of life course; and ways in which masculinities is expressed in this setting. As in previous research, difficulties with accessible informational support about the disease and its treatment were highly evident [20 21 31]. That these problems persist and are remarkably similar in Canada [20], Scotland [21], and in our Australian data, is striking and suggests that globally there may be a gap in health systems' responses to advanced PCa. PCa survivorship research has to date been underfunded by comparison to breast cancer[32]; a consensus about clinical care for advanced PCa is just now emerging [33]; and the historical and persistent debate about the early detection of prostate cancer [24 34] are likely contributors to this. The men's reports in our study of PCa having a less favourable public profile reflect this and show how the broader public health and social context can have a profound negative impact on an already difficult cancer experience.

The influence of life course in response to illness in terms of men's age and the expression of masculinities and masculine models of coping strongly emerged in this study and this has implications for the design of care models [35]. We propose that there is a need to newly conceptualise and then deliver what men actually want, rather than starting from a first principle of revising services already provided that are not meeting men's needs. Men underutilise psychosocial support services after cancer compared to women with breast cancer [36]; and previous research has suggested that interventions promoting self-management in men with chronic diseases should include action oriented approaches if they are to be utilised [37 38]. With regards to providers of support, men in the present study proposed both peer support and nurse specialists as preferred care providers, confirming previous research [39].

Limitations of this study include the cross sectional design. Recent qualitative research applying a prospective study design proposed that coping with advanced cancer evolves over time as symptoms progress and fluctuate [40]. Future research utilising a prospective case study design will add further depth to our understanding of men's experiences in the face of advancing PCa. As well, the men in our study were not newly diagnosed with advanced disease and so reports of their experience at the time of diagnosis or initial disease progression are retrospective and subject to recall bias. Strengths include a robust and transparent study method and the involvement of men **across four** Australian states with varied sociodemographic backgrounds such that our data can be considered broadly relevant across the Australian setting. We do note that our participant group was not ethnically diverse and so likely does not represent these experiences, that have been well described elsewhere [41].

Based on our previous research [18 42] and the present results we propose five key content elements for inclusion in supportive care interventions with men with advanced PCa: decision support; treatment education with self-management and skills training for symptoms, including exercise prescription; routine screening for psychological distress with referral; psycho-education with tailored distress management strategies; communicating with health professionals. Strategies to integrate peer support within the care team are needed. Finally, the prostate cancer specialist role presents as highly acceptable to men and is ideally placed for supportive care delivery and care coordination [43].

In conclusion, supportive care services for men with advanced PCa need to be multimodal and take into account the influence of life course on men's illness experience. There is a need for the health system to prioritise research and development in clinical PCa care taking a more holistic approach than currently exists.

Author contributions

SC, JD and MH conceived the study, developed the interview protocol, undertook the analyses and interpretation, and led manuscript development. KL recruited and interviewed participants, undertook analysis and contributed to writing the manuscript. ML recruited and interviewed participants. MF, ID and AL contributed to data interpretation. All authors contributed to revisions and approved the final manuscript.

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Figure Legend

Figure 1. Coding structure derived from thematic analysis

Table 1

Sociodemographic characteristics and treatment information for participants completing an open-ended survey and telephone interview

Participant ID	Age (years)	Time since diagnosis (years)	Received hormone treatment (Y/N/NR)
P3	70	8.0	Y
P5	67	NR	NR
P6	90	4.2	Y
P7	69	4.3	Y
P8	69	7.0	Y
P9	69	3.9	Y
P10	86	3.2	Y
P12	72	14.4	Y
P14	67	4.0	Y
P15	71	11.5	Y
P17	95	10.3	Y
P18	75	16.0	Y
P19	78	5.4	Y
P20	69	5.8	Y
P21	70	15.1	Y
P23	79	12.0	Y
P24	72	22.8	Y
P25	61	2.7	Y
P26	76	7.8	Y
P27	64	8.1	N
P30	58	6.0	Y
P31	59	4.8	N
P32	70	4.2	Y
P33	74	6.8	Y
P34	70	6.0	N
P35	78	4.4	Y
P38	76	NR	NR
P39	83	2.1	Y

N = No; NR = Not reported; Y = Yes.

Table 2

Interview questions

Focus area	Question
Health system	Thinking about your medical treatment, what changes do you feel would make medical services better meet the needs of men with advanced prostate cancer?
Supportive Care Needs	Thinking about the treatment side effects that a man with advanced prostate cancer might experience, what sort of support would help most? Thinking about the future and the worries that face a man with prostate cancer that has advanced or recurred, what sort of support would help most?
Barriers	In developing services to help men cope or manage better with advanced prostate cancer, can you describe support approaches or ways of helping that would **not** be acceptable to men? For example, supportive approaches that would turn men off or away?
Preferred approaches	In developing services to help men cope or manage better with advanced prostate cancer, can you describe support approaches or ways of helping that would be more attractive to men?
Other	Thinking about what we have spoken about today, is there anything else we haven't covered that you think is important to supporting men with advanced prostate cancer?

Table 3

Lived experience organising theme and super-ordinate themes

Super-ordinate theme	**Exemplar quotes**
Regret about late diagnosis and treatment decisions	"I saw a GP and first of all, I think it was 1.9 was my PSA reading, and when it got to 14 I said to him – everything I read tells me that I should be seeing a specialist. And he said, "Oh you worrywart, don't worry about it," and then next time I said it, he said, "All right I'll send you to see […] he's a urologist." I went to see his specialist mate, and he said, "Bloody hell, where've you been, you should've been here three years ago." Because it'd been like that for three or four years. The prostate was full of cancer, and it escaped outside the prostate and went into my lymph nodes, because of all that time wasted." (P31) "My only regret was that I didn't get enough information at the beginning, or, hey, maybe I did, but I was never comfortable with the fact that I had really learnt everything that there was to learn about it before I actually made decisions, and I may or may not have made the wrong one." (P32)
Being discounted in the health system	"The men seemed to think that prostate cancer was a B grade compared to other cancers. Because it was older men, and they'd had their run probably. No-one's going to worry too much about it…Usually men who have got prostate cancer are old, older men and certainly you wouldn't all the funding going to the old men and not the young women, or middle-aged women. It wouldn't be fair would it. So we thought that the prostate cancer people were sort of the poor relations in both attitude, funding, in a lot of ways. But you can't change it." (P26) "They treat you more as a joke, yeah, and the last time I spoke to him about it– I tried to find out am I going to have a lot of pain, is my bones going to break or whatever? He said: You'll probably die of pneumonia."(P6) "I just got the impression that the patient was just a number, the name didn't matter, in fact, we won't even involve the patient in the discussion, they're there but we've just got a number for him on the records and when they come around to your bed the team, which could be a half a dozen or 10 or even more depending on how many people they've got on the day, they just start talking about the condition you've got, absolutely nothing, no mention of you yourself being the patient, they don't even recognise you." (P20)
Fear/uncertainty about the future	"I'd just like to know where I'm headed. I guess he can't tell me what's going to happen with the disease, but I'd imagine there must be a pattern, a reasonable pattern of what happens. I mean, with some illnesses you know this is going to progress from this to that, to that, but an article I saw recently in a support group pamphlet was, if you took Drug X tablets, when they stopped working, you took Drug Y tablets. When they stopped working, the next thing on the - on the ladder was death, d-e-a-t-h. Well, I've been taking Drug X for quite a while. I've been taking Drug Y for quite a while. Each had a definite effect on my PSA, each lost that effect. So really, the next thing that faces me is death. Now, so, it was four months ago that my oncologist gave me, he said, "You'll see your birthday." Well, that's only three months away, it's only two months away actually. What's going to happen between now and then?" (P6)

Acceptance	"I think acceptance. That would be the word that comes to mind. Not resignation, big difference in my mind between resignation and acceptance, but okay, I accept it, to live a bit longer, or feel a bit better. This is what happens, I've just got to come to terms with it the best way I can. I didn't handle it too well. I think even at that age, you think you're indestructible. Gees, it did happen. But, it's not the end of the world and that's the attitudinal part, I think, more so than – attitude in retrospect, acceptance and spirituality part of it...I can possibly liken it, sort of, something akin to grief counselling is what I needed. You know, there's anger, there's frustration, everything. The whole gambit. It's all there. It's like, okay, it's passed away now, you know, let it rest...I just assumed, pop a couple of Viagra, you'll be right. But, no. So, yeah, it's – yeah and that's a problem after being very active for such a long time with a beautiful wife, it's really hard, really hard to take." (P30)
Masculinity	"Partly, I think, the reluctance of men to talk about their health, or to talk about personal issues that the idea of maleness, being able to be stoic and cope, type of thing. And just in the idea of maleness, that, sort of, men don't cry, men are stoic, or you get on and cope with things, a lot of men have not been exposed to talking about personal matters and so find it difficult to do that." (P9)
Treatment effects	"I'm impotent, and that – put it this way, that's – honestly, that's something that I have an extremely hard time coming to terms with. My wife and I had a fantastic sex life but that's gone and there's now – yeah, it's probably as much my fault as hers but there's just nothing left of our marriage; we live together but that's about it." (P38) "I can't even walk down the beach, put out – not having to urinate a couple of times, I take my dog for a pretty long walk each day and I'm looking over my shoulder and I'm always thinking one day I'm going to get busted and someone's going to call me a dirty old man and are they going to even be prepared to listen to the fact that I've had prostate cancer and it's not my fault?" (P14) "Eating is a problem, I have a problem eating. I don't really want to eat but I more or less force myself to eat, because I have no energy, but I've lost, I think, it's 40 kilos all together, but that's over a period. When I look in the mirror I see this gaunt face looking at – I thought I was fairly good looking for an old bloke but now I really look bloody painful, I take notice, like, god I'm gaunt. And I really am thin." (P19) "The general fatigue, loss of energy, loss of muscle tone, the hormonal issues were probably the biggest ones. I've got osteoporosis because – it's only at the early stage, but my bone density is checked regularly, but it's dropping slowly even though I do exercise, walk a lot and keep my weight down and exercises up. I do that sort of thing all the time. But I'm probably holding it in check. But that one's always a bit of a concern. I've got to be careful I don't fall off the roof, I don't do something, don't break anything nowadays. In fact I – when I finished radiation therapy I felt all pretty smart and I went running on the rocks at the beach one day, and jumped from one rock to another, and snapped my ankle so badly it had to be screwed up with screws and braces." (P5)

	"I now have gynecomastia which I've discussed with my GP and my specialist. I was looking at having my breasts removed, unfortunately which I would've had to pay for, but I was told that if I did, they would come back so it would be a waste of time and effort and money doing it." (P38) "I know the cancer's spreading. I woke up this morning about 4 o'clock with pains in my pelvic, where it is, the pelvic bone where I suspect the cancer's moving to. They said it would at the Cancer Clinic, so that gave me a bit of pain. But I find if I take Panadol, one of these Panadols – I take two at night and two in the morning and two midday, I keep the pain at a level that's quite acceptable. But I didn't take it last night and then I woke up at 4 o'clock and thought, oh, what's going on here." (P23) "I mean one of the biggest impacts is financial loss and that is not discussed full stop. That's when you're diagnosed with a terminal illness and there is no cure. They can slow the disease down, which they've successfully done in my case. But because of the side effect of loss of testosterone, so you've got less energy, muscle wastage and all of that. And the end resulted in me – I had to give up work. Now, that financial loss has been – made a big impact on my retirement and everything else." (P3)

Table 4

Supportive care organising theme and super-ordinate themes

Super-ordinate theme	Exemplar quotes
Communication	"For me at my stage, or more advanced, or – I don't know at what stage I'm at. Whether I'm advanced or reasonable, or what. I don't have any – I don't have any real – I don't know what the symptoms are – if you do get advanced or more advanced, I don't know what the symptoms are really. I have no information in that regard. I don't know." (P17) "He's not exactly verbose, he doesn't say a great deal. And I got put on Drug Z and was more or less left to my own devices with my GP who I don't think he'd ever heard of it and it wasn't really until about three or four months ago that we managed to sort out how the injections should be given." (P10) "Openness, I think, for me for the treatment options. Probably the side effects were less discussed or less publicised. There was some, particularly in the radiation process, you could get burning, you could get itching, this, or that, but then later on you find out there was some others that they didn't mention…On that score, I think there's some minor explanation, you will get tireder, you will get hot flushes, but no advice - what can you do about a hot flush; go and have a cold shower. There's been nothing on that, and in terms of maybe a medication, is there something will help as it does for ladies, I've got no idea." (P35)
Care Coordination	"You just get the impression going through the process that the different stages of the process all have their own people, their own separate team altogether. I guess, I could sum it up in a word and that's coordination with all the different treatments and tests and results and everything to do with the treatment, all those things are there obviously, patients are being treated for a long, long time, but having been through the process I just find that even though you end up getting through it it's a bit of a minefield for the patient because they haven't got a clue really what's involved, what's coming next, what you've got to do." (P20) "It's got to be the doctors. The doctors, I think, it has to start at the GP level and go right through. This is, as I say, this is your life and they're doing the journey with you. That's a good way of putting it, they're doing the journey with you." (P15) "I'd say ideally at time of diagnosis, after you talk to the doctor the next step would be the prostate cancer nurse. Yeah. Into the treatment part of it, yes, as part of the treatment process. But, in some ways, I think, that if you've got, say, sort of a trusted person, so if it's a prostate cancer nurse providing good information and directing

	traffic, type of thing, and putting people in touch with resources, I think, that's probably going to help to overcome the difficulties." (P9) "I think this support idea needs to be built in at diagnosis level into the, well, the doctors would present this as, "This is a natural part of the treatment, we're not saying go there if we think you need it, you have been diagnosed with cancer, you need it, we would strongly recommend you take your – take the benefit of going to a group for," I don't know how many meetings, but a few. And I also think that - how you do it I don't know, but that it gets presented – it is presented to men as, "This is what you do, there is no loss of dignity in going and talking over your problems with people who are in the state – in the same position as you are."" (P39)
Accessible care	"Well I'm up in the country and when I got diagnosed there was really no services in my town and it was a, you know an hour and a half trip to the closest place where could get anything done…Well they certainly – they didn't even have chemotherapy services here. And they didn't have helpers such as prostate nurses etcetera, people that were specifically trained in this sort of cancer. My oncologist, my urologists are all down in Melbourne. I mean they're two hours away in a motor car." (P34) "It's about $40,000 a year. I think it's about four to 12, about $4,000 a month I think. Which the majority of people can't afford anyway. So he's got a number of other drugs, too. But that's the one he'd like to use next for me. So we've got to deal with that when we get there." (P5) "I definitely would [go to another support group]. The problem is I can't drive anywhere at the moment because of some of the drugs I'm on; so it makes it very difficult for me to get anywhere. And now the closest group other than this one, even that one I had to go by car, but the next area's group is probably about twice the distance away and nowhere near public transport." (P27)
Shared experience/peer support	"And I think that's – the big help that people need, and they are finding it here because they come to support group, it's looking for some comfort, I think, or some advice, or to talk to someone who's been there and done that. I think that a lot of trouble with the GPs and the surgeons, they – a lot of them don't have that first-hand experience, even though they work with it every day of their lives they don't – they haven't had the actual experience of living with the disease first-hand anyway." (P5) "I think if you had someone or a little group of people who could meet and talk and have – maybe even in a coffee shop, have a cup of coffee, even the pub, have a beer or coffee or something and discuss your problems because that's where you'll find out that most of the people have problems the same as you. You get some men together, you can have someone facilitate it at first, then you just leave them and come back later on." (P19)

	"Yeah, well face-to-face is the best way, but yeah, online, why not? Particularly with people in the country, assuming they know how to go online and handle IT and all that sort of thing. Yeah, somebody or some group of people that they can contact who do have the experience and have the understanding." (P21) "From a personal standpoint of view, the normal sort of prostate cancer support group hasn't been of any real benefit to myself or my wife. And the reason advanced prostate cancer for now, based in south east Queensland, which covers all of Australia and we have a monthly telephone conference and that is, yeah that's quite beneficial. Because everybody in it has got advanced prostate cancer. It's just that yeah, I've got advanced metastatic prostate cancer and that's what this group is particular for, for men with advanced. Because we joke and say we among ourselves, "Dead Men Walking Club." Warped sense of humour…" (P3) "And, I know, I found going to the support group, I walked into the room, I sat by myself and I didn't sort of mix with the other men, but that unfortunately is me. I'm not a mixer, I'm not a conversationalist, although I seem to be talking pretty well to you. So I found them, it felt a bit uncomfortable. For those who have been there a long time, they were starting to hear the same thing over and over again. So I guess that might have been why I terminated going, one of the reasons. Very well run group, I just lost, I felt I was getting no benefit out of it and I wasn't really comfortable there. That's me, my particular makeup you can understand." (P6)
Involvement of partner/family	"She (wife) senses my feelings, my moods, and she can tell if I'm feeling a bit negative by my comments or my talk, or mostly my body language. And she doesn't beat around the bush, she just tells me to snap out of it, or, "Pull yourself together," or "get yourself sorted". Why don't you do this, or why don't you do that?" She doesn't muck around, she really socks it to me, which is really good, it's what I need. And I know that a lot of men say the same thing, they are always grateful for their partners in many, many cases, and we really live a lot longer with good wives, I can assure you. My wife is definitely the pinnacle. She's the main support there." (P5) "So, I get help with transport and I have someone come and help me clean once a fortnight and that, but I probably need help with shopping, but I have friends who will go and do the shopping or take me shopping. So, I'm fairly well off in that regard. …So, yeah, it's good to have someone who will help you, you don't want them mothering you, but take you and if I needed shopping we would go shopping after we'd been to the gym, heavy shopping, I need it, and bring it home." (P19)

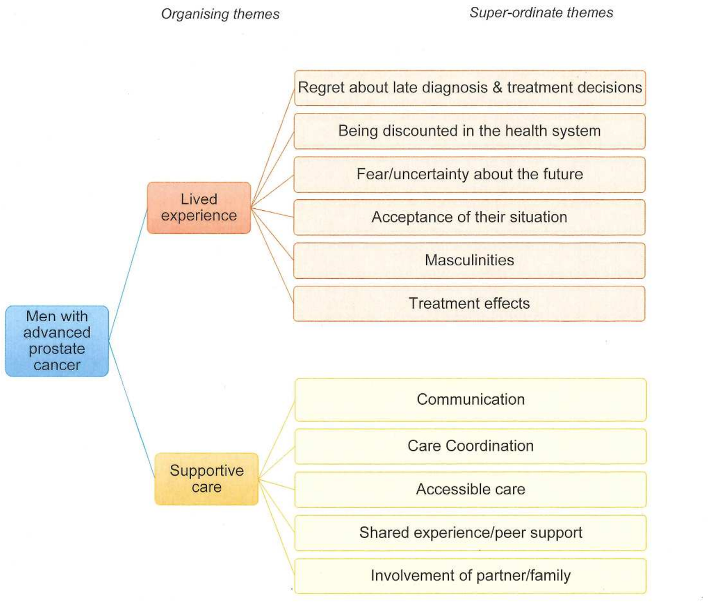

Figure 1. Coding structure derived from thematic analysis

Coding structure derived from thematic analysis

297x420mm (300 x 300 DPI)