

Contemporary Consumer Perspectives on Prostate Cancer Survivorship: Fifty Voices

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Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ABSTRACT

Objective: To describe contemporary consumer perspectives about prostate cancer survivorship in order to inform the development of survivorship guidelines.

Method: In a cross-sectional qualitative design, semi-structured interviews were undertaken with fifty prostate cancer support group leaders (50% response) across urban and rural/regional Australia. An interpretative phenomenological approach was applied to guide the identification of experiences and priorities of survivorship from participants.

Results: Three themes were identified for informing the development of prostate cancer survivorship guidelines: (1) The Experience of Diagnosis and Treatment; (2) Priorities for Survivorship; and (3) Mechanisms for Support. Four priorities for prostate cancer survivorship were identified: delivering person and men-centred care; improving communication; improving care coordination; and facilitating access to care. Mechanisms for support were peer support; advocacy; prostate cancer specialist nurses; and communication training for health professionals.

Conclusions: The lack of progress in changing prostate cancer survivorship outcomes for men will become increasingly problematic as this patient population group grows. Co-production provides a way forward to ensure relevance and accessibility for future survivorship initiatives.

INTRODUCTION

Cancer is a disease that from ancient times has been associated with dread, fear and a search for a seemingly elusive cure. As researchers and clinicians searched to better understand cancer and find effective treatments civil society organisations, such as the American Cancer Society (ACS), formed to galvanise efforts and provide funds for medical research importantly bringing the lay voice in to the crusade against cancer.(1) In the 1970s the language of cancer begins to change with Nixon's 'war' against cancer, the National Cancer Act of 1971(2), and the ACS slogan "cancer is a word not a sentence". It was not however until the 1980s that the concept of cancer survivorship emerged in the literature(3), and the idea that how a person survived after cancer was important finally came into focus in the clinical world. In 1986 the National Coalition for Cancer Survivorship was founded by cancer survivors to advocate for all people affected by cancer, defining survivorship as extending from the time of diagnosis and for the balance of life, a definition now expanded to include family, friends and caregivers.(4) A decade later, the National Cancer Institute established the first Office of Cancer Survivorship with an overarching goal to improve the quality of survival of all individuals diagnosed with cancer and their families.(5)

Importantly, cancer advocacy driven by cancer survivors preceded these institutions and forged national and global initiatives. In 1952, Terese Lasser founded Reach to Recovery, a peer support program for women with breast cancer, as a response to her personal experience of lack of support after her mastectomy.(6) This program was adopted by the American Cancer Society and then became global supported by the International Union Against Cancer with programs spread across the Asia-Pacific, North and South America, and Europe.(7) In Australia in the early 1990s a grass roots prostate cancer survivorship movement emerged in response to lack of support for men living with prostate cancer and perceptions of stigma and invisibility in the national health services agenda, later joining and forming the backbone of the Prostate Cancer Foundation of Australia (PCFA).(8) In sum, cancer survivors have been and continue to be driving forces in determining how their care should be delivered and what areas of focus are most important from their perspective.

However, the voice of the cancer survivor is not routinely visible in survivorship care initiatives and guidelines, and services developed in the absence of a patient voice risk being inaccessible or irrelevant to the individuals they seek to serve. This is a particular issue for patient groups who by virtue of their illness type or sociodemographic and cultural background may be less likely to advocate on their own behalf. Mitigating this risk by actively

engaging cancer survivors in the development and delivery of survivorship care initiatives is encapsulated in the concept of co-production. Shifting from the traditional bio-medical view of health care as a 'product' delivered by clinicians to passive patients, to health care as a 'service' co-produced collaboratively between patients, clinicians and health care systems embeds a role for patients as actors in their own health care.(9-11) Applying this to cancer survivorship care should help ensure that the health system and professional response is responsive and relevant to the priorities of patients and their families.

In contrast to co-production, clinical practice guidelines are most often built upon the highest level scientific evidence available, preferably systematic reviews and meta-analyses and randomised controlled trials, and incorporating expert consensus opinion.

Problematically, patient or consumer involvement in such guidelines tends to be poor, with most organisations involved in guidelines production not requiring consumer input, and as few as one in five developing consumer versions of these scientific documents.(12) In the case of existing prostate cancer survivorship guidelines (13), it is not clearly stated what input was obtained from survivors, and indeed such consultation appears to have been absent. Further, gaps in evidence for these existing guidelines suggest further consideration of content is needed.(14)

Accordingly, and to address this gap in knowledge, a nation-wide and in depth consultation process about survivorship priorities was undertaken with men previously treated for prostate cancer who were involved in community support, advocacy and education for prostate cancer survivors across both urban and rural settings.

METHOD

Study Design

This study used a cross-sectional qualitative design involving semi-structured interviews with prostate cancer support group leaders. Consistent with the aim of the study, we employed an interpretative phenomenological approach to guide the identification of experiences and priorities of survivorship from participants.

Participants

Eligible participants were required to be able to speak and read English, provide informed consent, and be either men who had experienced a prostate cancer diagnosis or a partner of these men who were leaders of support groups endorsed by the PCFA. Participants were purposively sampled to include metropolitan and regional areas as well as groups for younger men, gay and bisexual men, men with advanced disease.

Procedure

The study was approved by the University of Southern Queensland's ethics board (H18REA192). One hundred support group leaders affiliated with the PCFA were sent an email invitation to participate in a semi-structured telephone interview to obtain their perspectives on prostate cancer survivorship in the Australian context. Fifty support group leaders (50% response rate), expressed interest and consented to participate in the study. Following informed consent, interviews were scheduled and conducted between November 2018 and January 2019 by two interviewers with experience in collecting qualitative data from cancer survivors. An interview protocol informed the conduct of interviews with probing techniques used to facilitate expansive or specific responses. Interviews ranged from 22 minutes to 55 minutes with an average interview time of 34 minutes. Questioning included examples as follows:

- *Tell me about your experience as a support group leader*
- *Define the experience of prostate cancer survivorship, from your perspective as a support group leader*
- *What are the key prostate cancer survivorship issues facing your support group members?*
- *What prostate cancer survivorship issues would you tell an audience of politicians, health professionals and everyday Australians to act on?*

Data Analysis

Recorded interviews were transcribed verbatim by a professional transcriptionist. Demographic data were obtained via self-report and analysed using descriptive statistics. Before coding, data familiarisation occurred by a process of reading the transcribed interviews, reflecting on field notes taken during interviews to assist in the interpretation of meaning, and re-listening to audio-recorded interviews to develop an understanding of participant experiences and perspectives. Data were then inductively analysed using open coding(15), categorised, and built into themes by five coders independently (NR,JD,SKC,LZ, LE). Coders were qualified in social and behavioural science (JD,SKC,LZ,LE) and nursing (NR,SKC) with 2 to 20 years of experience working in prostate cancer survivorship. Coders used Braun and Clarke's approach to thematic analysis(16) to code data and identify themes. Two researchers (LZ,LE) created a preliminary coding schema by coding all transcripts. This coding scheme was further refined by a third researcher (NR) and finalised by additional team members (JD,SKC) with the description of saturated themes and sub-themes arrived at

through coding, synthesis and discussion. Coding was undertaken using NVivo 12 (QSR International, 2018). Reporting of data conforms with Consolidated Criteria for Reporting Qualitative Studies (COREQ) guidelines.(17)

RESULTS

Demographics

The participants were on average 71.8 years of age (SD=7.9; range 47.8-87.6). Average length of time since diagnosis was 9.9yrs (SD=5.1; range 2-20 years). Overall, participants had been performing their volunteer roles within the support group for 5.9 years (SD=3.6;range 1-18 years). The average size of the support groups was 84 members (SD=28.2;range 23-167) with 48 groups supporting both partners and their patients; 1 group for gay or bisexual men; and 1 for men with advanced prostate cancer. An equal proportion of participants living in either an urban (50%) or non-urban (50%) area.

Themes

Following data analysis, three themes emerged. These included: (1) the Experience of Diagnosis and Treatment; (2) Priorities for Survivorship; and (3) Mechanisms for Support. Within these themes were a series of sub-themes as outlined in Figure 1 and Supplementary File 1.

Theme 1: The Experience of Diagnosis and Treatment

Perceptions of prostate cancer survivorship were strongly characterised by participants' experience of diagnosis and treatment with frequent reference to challenges including: (1) physical and psychosocial burdens; (2) financial distress; (3) loss of masculinity; (4) lack of information; (5) lack of access to services; (6) decisional uncertainty; and (7) feeling discounted.

Participants referred to sustained physical and psychosocial burdens associated with prostate cancer and its treatment throughout the illness experience. They described the ongoing challenge of managing multiple cancer-related symptoms and side-effects including urinary incontinence, sexual dysfunction and bowel problems as well as treatment side-effects such as muscle-wastage, hot flushes, sleep disturbance, fatigue, weight gain and shrinkage of genitalia. Additionally, men linked the physical effects of prostate cancer and its treatment with extensive and ongoing psychosocial burden such as depression; distress; cognitive impairment; fear of recurrence associated with ongoing PSA testing; social withdrawal due to the potential for embarrassment from symptoms such as urinary incontinence; and partner distress after their cancer diagnosis.

The prostate cancer diagnosis and treatment also affected the ability of men to earn an income, with financial distress commonly described by participants. After diagnosis men reported the need to reduce work hours leading to lower income and financial stress. This situation was exacerbated by out-of-pocket healthcare expenditure and/or the cost of having to travel for treatment or move closer to treatment centres. Facing extensive changes to physical and psychological health, work status and typical social roles, men struggled with a loss of masculinity and felt that prostate cancer led to a “*loss of identity*” and “*loss of control*”.

Against a context of high needs, participants sought personalised information and support, however, they faced both a lack of information about how to manage their cancer-related problems and a lack of access to services to support them in their current situation. Additionally, men identified that care was often delivered by treating professionals who were “*in their own little silos*” resulting in specific problems not being referred or comprehensive follow-up care not being provided. Without the direction they needed, men reported feeling like “*just another number*” and referred to being “*lost within the system*”. In this context, being informed about a new diagnosis or worsening condition resulted in decisional uncertainty about how to address the challenges associated with treatment choices. Accordingly, they expressed a desire for “*consistency of care*” to help them navigate through the challenges of their prostate cancer survivorship experience and “*regain a sense of dignity*”, of “*self*” and of “*control*”.

With unmet needs and in the absence of adequate decision support, men reported feeling discounted as they made life-changing decisions with limited support. Subsequently, participants argued that prostate cancer survivors were a “*forgotten*” group and argued that the disease is “*far less visible and far less supported despite having just as much, if not more impact on Australians, than breast cancer*”. In addition, openly and socially discussing prostate cancer-related issues such as sexual dysfunction, genital shrinkage and urinary incontinence was seen as “*taboo*” due to social norms attached to discussing male symptoms of an intimate nature.

Theme 2: Survivorship Priorities

For participants, the challenges associated with prostate cancer diagnosis and treatment were linked with four priorities for addressing survivorship: (1) delivering person and men-centred care; (2) improving communication; (3) improving care coordination; and (4) facilitating access to care.

As part of *delivering person and men-centred care*, participants identified four components for improving the experience of prostate cancer survivors: educating men about their prognosis and treatment options including side-effects; tailoring support for men at diagnosis and as their prognosis changes; regularly communicating with men about their disease; and developing a plan to support men throughout their survivorship experience. Participants called for health professionals to focus on men's preferences for how they would prefer to receive care; in what ways their family/carers would be involved; what support they needed; and, which treatments they preferred. Additionally, men wanted a "*full explanation*" of which treatment and support options were available to them, their side-effects and the likely prognosis associated with each treatment.

Participants stressed the importance of improving communication at all stages of the disease experience because of emotional distress, information overload, and insufficient time between being informed of their options and needing to choose treatments. When informed of their therapeutic options, some men felt they were not informed appropriately or supported to make a decision that was best for them. Some men reported bewilderment at being subjected to "*information overload*" and "*forced*" to think about treatments while they were still processing a major life event. Men called for the need to extend conversations beyond the physical symptoms of cancer and its treatment to a broader array of challenges they faced including psychological stressors, financial problems and relationship difficulties.

Participants saw a need for improved access to care for prostate cancer survivors by providing a full range of interdisciplinary care to meet the full spectrum of men's' needs. Ongoing psychosocial issues among men with prostate cancer were linked with low access and availability of allied health services, such as psychologists and social workers for survivors. The importance of providing improved access to care was particularly emphasised as a means for addressing disparate survivorship outcomes for men in regional or socioeconomically disadvantaged areas.

In addition to improving access, participants identified care coordination as a priority. Required elements of care coordination included: regularly providing education on survivorship treatment options; documenting a survivorship care plan for every man; referring men to a comprehensive range of healthcare services to assess and treat survivorship needs; allocating a "*care coordinator*" to prostate cancer survivors; multidisciplinary communication to facilitate awareness and delivery of care tailored to men's needs, and tailoring the inclusion of partners, carers and/or families in care planning to men's preferences.

As an additional survivorship priority, participants spoke of the need for advocacy as a necessary step towards addressing inequalities in the way prostate cancer is perceived and supported in Australia. Challenging public misconceptions about the disease was a common topic with participants believing prostate cancer was poorly understood in the public setting. Participants therefore called for population-level awareness campaigns to inform people about the seriousness of prostate cancer, the importance of supporting men with the disease, and the need for men to “*get tested*”. By raising public awareness, participants hoped political support could be built leading to government-funded public health campaigns, increased funding for research, and achieving funding equity with women’s cancers.

Theme 3: Support Mechanisms

Participants identified several support mechanisms for improving the experience of diagnosis and treatment and addressing survivorship priorities including: (1) peer support; (2) advocacy; (3) prostate cancer specialist nurses; and (4) communication training for health professionals.

The role of peer support groups in empowering men with the disease was seen as a vital initiative to men with prostate cancer. Participants emphasised the need to refer men to support groups to share their experience and learn from other men with prostate cancer. Participants argued that men coped with prostate cancer better when sharing and receiving ideas and practical advice about their illness experience. Additionally, improved partner and carer support was endorsed with the need to discuss relationship and social challenges associated with prostate cancer survivorship and learn how others have coped in similar situations

The need for peer support and advocacy stemmed from a recognition that effectively engaging men was complex with marginalised populations seen to be particularly at risk. Therefore, appealing to men with prostate cancer individually was seen as an undertaking that required stronger community involvement. The need for men with prostate cancer to “*feel comfortable*” talking about their needs required a groundswell of community support. Men with prostate cancer were seen to be “*poor patients*” by participants as many were believed to be not proactive about their health and failed to comply with treatment or ask for support despite it being available. The need for “*man-friendly*” health education, health systems and communities were highlighted by participants as a key plank in improving health literacy, positive changes to health behaviours and subsequent improvements in survivorship outcomes. Participants also expressed concerns about vulnerable marginalised populations including men who are younger, indigenous, speak little or no English, live rurally, or are

incarcerated. Improved health service design and mass-marketing campaigns were identified as strategies to increase health literacy in men with prostate cancer. The need for workplace health promotion programmes also emerged strongly during interviews as a key strategy towards improving the palatability of men talking about prostate cancer and creating a culture that facilitated men to cope with the disease.

Participants also called for prostate cancer specialist nurses to coordinate care by acting as a link to multi-disciplinary care and community programs. Prostate cancer specialist nurse services were seen to be readily accessible to men who were reluctant to engage in the “*hassle*” of booking a specialist or general practitioner’s appointment and just “*wanted someone available right then, who could point me in the right direction at the right time*” to community-based care, services and support.

Building on the need for improved communication as a survivorship priority, participants called for communication training to be provided to health professionals to improve skills in supporting men. Clearer communication was also desired about the use of the PSA test both as a diagnostic indicator for prostate cancer and as part of survivorship assessment. Participants further identified the need to improve communication among specialists both in terms of conveying the implications of a prostate cancer diagnosis and the pros and cons of available treatments in an unbiased fashion.

DISCUSSION

This study is a key part of re-positioning consumers to the forefront of the co-production of prostate cancer survivorship priorities. Of great concern, men identified physical and psychosocial burden that included decisional uncertainty, feeling discounted; financial distress; a loss of masculinity; and a lack of information and access to services. The persistence of these problems despite decades of both descriptive and intervention research for men with prostate cancer speaks to a lack of translation of research into practice that is of great concern.(18-21) Participants identified four prostate cancer survivorship priorities to guide health care planning and delivery: (1) delivering person and men-centred care; (2) improving communication by health professionals; (3) improving care coordination; and (4) facilitating access to care. They also identified ways in which consumers can be further engaged in co-producing survivorship care through involvement in the creation of “*man-friendly*” or men-centred health education, health systems and communities.

Men with prostate cancer in Australia have historically stepped in to provide community-based care when action by the health system lagged.(8) As health systems adjust

and work to catch up there is a risk that this voice will be lost or overridden by the health professional perspective. At the heart of co-production is the need to shift from traditional approaches that privilege the expertise and knowledge of clinicians and view health care as a 'product' to be delivered, to health care as a 'service' co-produced by patients and clinicians as contributing partners.(10, 22) Traditional forms of encouraging consumer participation through 'patient voice' and 'patient voice' are important but not enough by themselves to challenge and change the dominant health system model.(11, 23) Achieving system-wide co-production of health care delivery requires going beyond solely seeking 'patient voice' and facilitating 'patient choice', to actively positioning consumers as co-producers of health services and systems.(23, 24)

As a grassroots voice for prostate cancer survivorship in Australia, support group leaders' responses flag a failure of personalised care and care coordination. A recent review identified a lack of follow-up care as a key reason why men with prostate cancer are left with unmet needs.(25) This issue is made more problematic by the lack of review-based evidence for care coordination and surveillance for recurrence.(14) Notably, participants in the present study eschewed traditional viewpoints associated with men avoiding thinking about their disease or desiring engagement in their care.(26) By contrast participants expressed a desire to direct their survivorship experience and called for a system which included them, consulted with them and advocated broadly for them.

LIMITATIONS

Strengths of the current study include a well characterised sample each with a lived experience of prostate cancer across a range of timespans, such that these shared perspectives are a broad representation of the state of survivorship care in Australia. Additionally, these survivorship priorities likely have high ecological validity given the continuing involvement of support group leaders in the community of men with the disease, and their current personal involvement in, or discussion about men's local experiences of care. Nevertheless, these perspectives may not match priorities for men with prostate cancer from low and middle income countries, or those with markedly different health systems to that in the present study. We were however able to recruit men from regional and rural Australia and this speaks to the consideration of the poorer disease outcomes that are prevalent in these geographic areas.(27)

CLINICAL IMPLICATIONS

The experience of prostate cancer remains characterised by loss and feelings of being discounted in the health system, with gaps in services that exacerbate the challenges of diagnosis and treatment. Men-centred survivorship care that includes effective care

coordination, enhanced health professional communication, and improved access to services is needed to improve outcomes for men and their families.

CONCLUSION

In conclusion, men are very clear about the challenges they face after prostate cancer and what is needed to address these. In Australia and elsewhere men with prostate cancer have demonstrated readiness to act on their own behalf, with or without health professional support.⁽⁸⁾ A key challenge to co-production is the potential for clinicians to revert back to viewing health care as a product to be delivered and centrally controlled.^(11, 22) Supporting consumers to actively co-produce guidelines to direct health care delivery is one important system-wide approach to help change health care culture. We strongly advocate for this approach to become standard practice in any initiatives that seek to meaningfully improve outcomes for people living with cancer.

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