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Gay men and prostate cancer: voicing the concerns of a hidden population

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Keywords

Prostate cancer
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Abstract

Background: Prostate cancer (PCa) is of paramount concern to men's health, with a high prevalence in Western societies. While previous research has examined PCa from a variety of standpoints, this literature fails to take into account the difficulties encountered by marginalized groups of men, such as gay men. **Methods:** For this phenomenological, qualitative pilot study, we conducted interviews with two gay men with PCa and one long term romantic partner of a gay man with PCa so as to better understand their viewpoints on the disease. An inductive, thematic analysis of the interview transcripts was conducted. **Results and conclusions:** Major themes expressed included (1) concerns related to relationship changes and strains, (2) altered sexual function and associated implications for a gay identity, and (3) the perception of heteronormative attitudes in the health care system. Implications for health care delivery are discussed. © 2008 WPMH GmbH. Published by Elsevier Ireland Ltd.

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Prostate cancer (PCa) is the most common cancer diagnosed in Australian men apart from non-melanoma skin cancer, with 1 in 11 men contracting the illness [1]. Estimates from the United States are even higher, with a reported prevalence of 1 in 6 [2]. PCa thus represents a major concern within the field of men's health.

Although a number of treatment options are available to men with PCa, these courses of action often have serious side effects [3]. These include erectile difficulties and other sexual impairments [4]. Given the traumatic nature of a cancer diagnosis, and the undesirable side effects engendered by treatment, it is not surprising that many men diagnosed with PCa exhibit psychological distress and anxiety.

Indeed, in analyses of men diagnosed and treated for PCa, a number of research teams [5–7] have found heightened levels of depression and depressive symptoms, even several years post-treatment. Additionally, the PCa diagnosis may negatively impact on the perceived

quality of marital and romantic relationships, and increase relationship strain [7]. Finally, other studies [8–11] have demonstrated that men with PCa exhibit anxiety related to a dampened sense of masculinity, and frustration over their inability to live up to Western society's archetypal notions of what it means to be a man. While men might attempt to renegotiate their masculinity [10], this may not always be beneficial as frustration and anxiety related to identity renegotiation adds to the negative psychological state endured by many of these patients.

Wives and romantic partners may also be impacted by a PCa diagnosis. Couper et al. [5] reported a significant decline in marital satisfaction by female partners of men diagnosed with PCa. Therefore, research on the psychosocial impact of PCa should not only consider patients, but their partners as well.

While this past research is invaluable in understanding how a cancer diagnosis impacts a man's life, his relationships and the way in

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which he embodies masculinity, it uses a presumptive model of heteronormativity. That is, it assumes men with prostate cancer are heterosexual. Such an assumption, however, is unfounded. It perpetuates the heteronormativity that is all too common in men's health research and health services research more generally. Furthermore, it ignores the fact that there is a 31% probability that one or both of the men in a gay dyad will be diagnosed with PCa as compared to a 17% chance of a PCa diagnosis in a heterosexual dyad [3]. As such, calls have been made for research that explicitly investigates gay men's experiences relating to PCa diagnosis and treatment [12].

While it is likely that gay men experience some of the same concerns as their straight peers, there are also concerns that are unique to gay men and their partners due to their marginalized position within Western society, and the nature of male-male relationships and sexual encounters. Smith et al. [12] identified several potential areas in which a PCa diagnosis may differentially impact gay men. These potential concerns included the importance of the prostate as a site for sexual pleasure during anal sex; Western society's ambiguous views regarding the role of gay partners as caretakers; the impact of open or polyamorous relationships on some gay men's lives; and homophobia and heteronormative attitudes on the part of health care providers. Other potential complications for gay men, which were not reviewed by Smith et al. [12], include the need for a firmer erection for anal intercourse as compared to vaginal sex, and the potential for anal discomfort as a result of treatment for PCa [13,14]. However, Smith, et al. [12] did note that many of these potential concerns are speculative, and that future research was needed to ascertain the impact of PCa on the lives of gay men.

Due to the general silence surrounding gay men's, and their partners', experiences of PCa, and the potentially unique concerns described above, this qualitative, exploratory pilot study examines their experiences, frustrations, and perspectives.

Methods

This study was envisioned as a pilot study to investigate areas of concern to gay men with PCa. The research design employed was small-

N, qualitative, and inductive, as described below.

Recruitment and Participants

Ethics approval was given by the University of South Australia and the Royal Adelaide Hospital. Convenience and snowball sampling methods were used to access both gay men with PCa and their partners. Patton [15] describes both methods as ideal when targeting stigmatized social groups such as gay men. In particular, participants were recruited through announcements at a local centre for gay men's health, announcements via the state cancer council, and a small article in a local gay newspaper. Following their interview, participants were asked to pass along the researchers' contact information to anyone they thought might be suited for the study.

These sampling methods yielded a small participant pool. In total, three men participated: two men with PCa, and one partner of a man with PCa (who was one of the patients interviewed). This difficulty in recruitment may signal a reluctance on the part of gay men impacted by PCa to participate in health-related research. This reluctance, however, is understandable, given these men's poor experiences with the health care system, as explored in the 'Themes' section, below. That is, these men may be reluctant to further engage in a system they perceive as heteronormative and homophobic. Furthermore, as a general population, older gay men are difficult to recruit, and have been termed an 'invisible population' [16]. Prostate cancer adds another layer of invisibility [14], thus further complicating efforts at recruitment. This trend is worth future examination, though it is beyond the scope of the present article, which instead seeks to explore the perspectives of gay men impacted by PCa.

Although we recognize that three participants is generally regarded as a small participant pool, it is important to consider that qualitative research focuses on depth of information provided by informants, rather than attaining a large sample size [15]. Indeed, recent qualitative research suggests the power and utility of conducting small-N, qualitative research when conducting interview-based research with sub-populations of gay men [17]. Thus, although only a limited number of men participated in the present study, this

small-N does not diminish the power of their experiences, and the value of their perspectives when analyzing the place of gay men within contemporary, Westernised health care. However, given this small sample size, caution should be used when extrapolating these results to other individuals and populations. Future research is clearly needed.

Finally, as this was intended as a small scale pilot study, a large number of men was not required. Rather, the intent of the study was to gain an initial perspective on PCa from the vantage point of gay men impacted by the disease.

Conducting Interviews

Participants each provided written informed consent prior to their interviews. The two men with PCa participated in a small focus group type interview with the authors S.M.F. and J.A.S. Focus group interviews are recognized as being particularly advantageous in qualitative health research such as this [18,19]. The focus group interview was a semi-structured, person-to-person interview, designed to explore a specific set of themes and issues that relate to gay men's experiences of living with PCa.

It had originally been intended that a focus group would also be conducted for partners of men with PCa. However, after extensive recruitment efforts, only one such individual was willing to participate. That partner participated in an in-depth, semi-structured individual interview with S.M.F.

Both interviews were digitally recorded. These were then transcribed verbatim by S.M.F. This process ensured a high degree of familiarity with the interview content when the analysis began.

Methodology and Analysis

Transcripts were repeatedly examined by the investigators to determine the most prominent themes, a process known as thematic analysis [15]. Comparisons were made between investigators' thematic analyses to cross-check the emerging themes in the form of triangulation, which increases the reliability of the research [15].

Transcripts were analyzed inductively, through the methodological lens of phenomenology. Phenomenology seeks to understand the lived experiences of individuals with

regard to particular life events ('phenomena') in order to better understand what it is like to experience those events. It is a particularly potent methodology in health care research, as it seeks to understand what it is like to experience illness and disease, and be treated for those ailments [20]. Accordingly, a phenomenological perspective with respect to gay men and PCa seeks to understand what it is like to be a gay man diagnosed with PCa, or the partner of a gay man with the disease.

Themes

Three dominant themes emerged from the data: (1) Relationship changes; (2) gay sex and PCa; and (3) heteronormativity and health care. These themes are elaborated below, using descriptive data from the interview transcripts.

'We're not prepared for a diagnosis of cancer': Relationship Changes

Both the patients and the partner identified that they experienced strains and changes in their romantic relationships, and relationships with other gay men, as a result of the diagnosis of PCa. Part of this changed relationship dynamic, particularly for those men with partners, related to the ambiguous role of the partners in treatment and recovery.

This trend is best represented by the partner of a man with PCa who claimed that:

We both had a gut feeling something was wrong, and when he went to have these tests done, interestingly I was in denial about it all until . . . As all these tests were going forward, part of me denied it, thinking it's not cancer, it's just something that's, you know . . . easily fixed, no problem. And, of course, when he did tell me, I was devastated. We're not prepared for a diagnosis of cancer, whether it's yourself or your partner. And it took me a long time to come to terms with it. I went to have counseling, mainly because I wanted to be supportive to [partner]. I have a lot of difficulty coping, in stressful situations, and I didn't want to be a burden to [partner], I didn't want my . . . difficulties in coping to impact on [partner's] recovery.

Clearly, then, PCa impacts not just patients, but also their partners who love them. Comprehensive treatment should, therefore, not

only attend to the concerns of the patient, but also provide support for the partner. Of course, for this to happen requires a recognition on the part of the health care system that the gay partner has concern and interest in the well-being of his sick lover.

However, it is not just partnered men who experience changes to their relationships. The un-partnered man expressed differences in the manner in which he related to other gay men, particularly in a sexual context. The non-partnered patient said:

You've got scars on your abdomen where the robot, the Da Vinci robot actually did the surgery, that was . . . Like, you wanted to go on the beach and wear your bathers on the beach, or go to the sauna, that could be very, um . . . I mean I didn't really feel confident about going to a swimming pool or going to the beach for quite a few months after the operation. . . . For me, it was all about confidence approaching other gay men for sex, that was really sort of the thing, because of all that sort of emphasis on the body and not having an erection and all that sort of thing.

It is clear from these claims that PCa has a profound impact on gay men's sense of self, body image, and their ability and desire to relate to other gay men. Recognition of these factors is, therefore, critical to an understanding of gay men's experiences of PCa, especially given the centrality of sex and sexuality to many gay men's lives [e.g. 21, 22]. That difference was explicitly stated by one patient who identified that, 'for gay men, you know, there's a different culture about sex.' It is that difference, and the differences in sexuality enacted by PCa treatment, that informs the second theme.

'I always saw my prostate as a pleasure centre': Gay Sex and PCa

As previously identified, the patients in our research cited distinct changes to their libidos as a result of PCa treatment. One patient said:

The truth is that my libido has just vanished. You know, I don't have very much sexual urge at all anymore. You know, and every now and then I think I must do something out of, you know, out of habit. You know, I don't really have any urge anymore, and um and um and when I do have any sort of sexual activity whether it's masturbation or sex with my partner, it's uh, it's become

. . . more of, well I mean it's not entirely without pleasure, but it's it's become a bit of a bother actually. It's sort of, it's not something I lust for anymore, you know, which is a major thing. And I mean, and like uh I was not expecting that, I didn't, I wasn't prepared for that.

In addition to those changes related to libido and sexual interest, PCa is perceived as having a unique impact on gay men:

Well, I always saw my prostate as a pleasure centre. And I knew from sexual experiences that you know, massaging a prostate gland . . . could increase the pleasure of sexual intercourse enormously. And, you, to me, the prostate gland is a sort of major part of the male sexual experience.

Quite simply then, PCa, by the very nature of the organ it afflicts, carries a unique significance to gay men and their sense of sexuality. Therefore, any clinical discussion around PCa should recognise the meaning of the prostate gland in gay men's lives. It is noteworthy that recognition did not appear to exist when the patients discussed their sexuality with their health service providers. The partner explained:

Certainly [partner's] doctor did give him information, primarily about symptoms and what to expect, but it didn't give that specialized information about being gay and how does that impact on relationships.

Similarly, health service providers did not seem to appreciate the reality that many gay men are either not coupled, or engage in sex outside the primary relationship. This was identified by the single patient who claimed that:

Because a lot of gay men don't have that kind of, intimate kind of sexual contact [as do married heterosexual couples]. That sometimes it's more like meeting in saunas or things like that, or beats, or something like that. Where um, an erection is kind of like a very important part of the whole kind of social ritual.

Frank and open discussion about post-operative sexuality is uncommon. One patient in this research described the information provided regarding post-operative sexuality as 'disingenuous' and 'coy' while the other described it as 'Victorian'. Indeed, specific discussions regarding sex did not occur, while the literature provided to patients was not in the

least informative nor did it specifically address gay sex. However, a lack of frank information about sex was merely one aspect of a range of concerns the men faced in terms of the health care system and their sexuality.

‘He just assumed I was heterosexual’: Heteronormativity and Health Care

Not only did the men in our research project report a lack of discussion regarding the impact of PCa upon their sex lives, but they also developed a perceived sense of not belonging in certain health contexts given their homosexual status. That is, a common frustration among the men was the assumption by most health care providers that their patients are married and heterosexual. One of the men described such an experience with assumed heterosexuality.

They quite blatantly assumed in my case. I felt they quite blatantly assumed I was heterosexual. My urologist is a lovely guy, [name of doctor], and I have no criticism of him in terms of his professional practice and medical practices. But, um, he just assumed I was heterosexual and you know, he said, “Would you like to bring your wife, or . . . to these meetings?” I mean (A) Was I married? Didn’t ask. (B) Was I heterosexual? Didn’t ask.

Despite these assumptions of heterosexuality, the men did not correct their providers by disclosing their own sexuality. This ‘closetedness’ may have been due to the perception of homophobia in the health care system. One man said:

As far as like my experience of the whole going in and being told that you’ve actually got prostate cancer and all that, I felt very um, I don’t know. I suppose I see a hospital as a sort of heterosexual kind of place.

Another man concurred:

You fear, you’re frightened of the judgmental attitude of the doctor. You’re frightened that he might not have your best interest at heart. Better to be silent about it all, and not create waves.

With such negative attitudes toward the health care system evident among gay men, it is understandable they would not want to voluntarily place themselves in a vulnerable position by disclosing their sexuality. It is, therefore, the responsibility of health care

providers to adopt accepting, or at the very least tolerant, discourse and attitudes towards gay men, sexual practices and relationships in the context of prostate cancer. It is only through such open and compassionate dialogue that a hospital, and other health care facilities, may no longer be seen as ‘a sort of heterosexual kind of place’.

Conclusions

This pilot research demonstrates that gay men with prostate cancer, as well as their partners, must face a number of difficulties in terms of health care provision. These difficulties are significant given their inextricable ties with sexuality. Therefore, from a phenomenological perspective, it is clear that the meaning of PCa for gay men, both patients and partners, is different from that for a heterosexual male and his female partner because sexuality itself is experienced differently between these two populations. While the clinical aspect of treatment is identical, it is the humanistic elements that require attention.

The gay men in our study explained that their unique health care needs, at least in relation to their PCa diagnosis, were seldom acknowledged or addressed by health service providers. This was particularly evident with respect to discussion – or the lack of open discussion – about sexuality. Both patients and providers must be encouraged to directly address the sexual side effects of PCa treatment, especially dampened libido and erectile dysfunction. Failure to do so not only diminishes the client’s faith in the provider’s competency, but leaves the participant feeling vulnerable post-surgery and can threaten the sexual relationship they have with their partner.

Another key issue identified within our study included participants’ fear of reprisal when disclosing (if choosing to disclose) their sexuality. While this contradicts the very essence of empathy expected in health care encounters, it also limits the potential for health service providers to address the unique health care concerns of same-sex attracted individuals. That is, a tension exists between the fear of reprisal and patient responsibility to disclose their sexuality at the time of being diagnosed with PCa. It is redundant to

apportion blame at this intersection – both the patient and the health service provider have a responsibility to be open with each other. Furthermore, it is possible that this fear of reprisal, and sense of heteronormativity within health care, is what may have negatively impacted our recruitment efforts.

From this research it also appears that gay men with prostate cancer do not feel comfortable with the treatment process due to the heteronormative underpinnings that accompany it. Yet, there are simple strategies that can be employed to accommodate such concerns. For example, a starting point could be recognizing that not all partnered older men have ‘wives’. Similarly, understanding that their partners are likely to develop a sense of ostracisation due to heteronormativity is

equally important. Moreover, identifying the fact that the partners of gay men with PCa may also experience psychological distress related to the illness is worthy of further exploration. Indeed, our data suggests that more adequate support structures for gay couples to negotiate the PCa journey are needed.

The concerns raised in this pilot research project provide guidance for further research with medical practitioners, specialists and other health service providers who work with gay men with PCa. We have clearly shown that these must coincide with a more comprehensive understanding of the issues confronting gay men with respect to treatment options, relationships and sexual functioning, particularly if the implications for practice are to be adequately addressed.

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