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“It’s not just about prostate cancer, it’s about being a gay man”: a qualitative study of gay men’s experiences of healthcare provision in the UK.

ABSTRACT

Following a diagnosis of prostate cancer, men require information and support from healthcare providers which is tailored to their individual needs. Studies reporting on the needs of gay men with prostate cancer, and their experiences of healthcare provision, are lacking. This study highlights the issues affecting this group of men, and the implications for healthcare delivery in the United Kingdom. In-depth interviews were conducted with 12 gay men who had been diagnosed with prostate cancer. A phenomenological approach was used to collect and analyse data. Participants wanted, and expected, candid discussions with healthcare professionals, about how prostate cancer could affect their lives, sexual function, and how to access culturally relevant support before and after treatment. Participants perceived that their healthcare team had little knowledge about their needs, and if, or how, their experience differed due to their sexual orientation. Information provided was perceived as being misplaced, or informed by heteronormative assumptions. Consideration should be given to requesting sexual orientation when recording patient information, if patients are willing to disclose. If necessary, training should be provided for healthcare professionals to enable them to provide information and support that is culturally relevant at all stages of the consultation.

Keywords: prostate cancer; gay men; qualitative research; Phenomenology; healthcare provision.

Background

Over one million men worldwide were diagnosed with prostate cancer in 2012 (World Cancer Research Fund, 2016). By 2030, it is estimated that the proportion of men surviving this type of cancer for at least five years from diagnosis is expected to triple (Maddams, Utley, & Miller, 2012). The physical and psychological impact of prostate cancer and its treatment on men and their partners has been well documented (Thaxton, Emshoff & Guessous, 2005; Letts, Tamlyn & Byers, 2010; Goodewardene & Persad, 2010). However, most published research in relation to the disease reflects the experiences of heterosexual men and their partners. Hence, current guidelines (National Institute of Clinical Excellence [NICE], 2015) concerning appropriate treatment, provision of information, and support have been developed without recognising potential issues that may affect gay, bisexual or transgender prostate cancer patients

The National Cancer Patient Experience Survey (NCEP, 2016) highlighted several areas where the needs of all men with prostate cancer could be better met. These included: clearer explanations by healthcare staff in relation to cancer treatments and their side-effects; a more personalised approach within healthcare settings; practical advice about financial support and better information provision for family members or carers. Less than one third of men surveyed had been provided with a care plan. Although prostate cancer is likely to affect sexual minority patients in similar ways to heterosexual men, a growing body of evidence suggests that gay men may experience additional or unique challenges following a cancer diagnosis (Blank, 2005). Results from quantitative studies carried out in the United States of America (USA), comparing prostate cancer treatment side-effects, showed significant differences between heterosexual and gay men in terms of gay men's sexual functioning following anti-androgen treatment (Motofei et al. 2011) and poorer physical, sexual and psychosocial functioning following surgery (Latini, 2011). Other side effects including pain during anal sex and specific issues relating to ejaculation and libido loss have also been reported (Lee et al. 2015). Other studies suggest that oral phosphodiesterase 5 (PDE-5) inhibitor drugs (i.e. sildenafil [Viagra®]) which are frequently prescribed for erectile difficulties following prostate cancer treatment, are less effective for producing erections that are sufficient for anal sex (Cornell, 2005; Ussher et al. 2016).

Healthcare providers need to be aware of issues that affect gay men differently to heterosexual men. Currently, aftercare leaflets provided to men following transperineal biopsies or radiotherapy often advise that men abstain from sexual intercourse for a period of time following this procedure. However, it is unclear whether this information applies to both anal and vaginal intercourse (Prostate Cancer UK, 2012). It is also important that

healthcare providers are knowledgeable about the issues that may be relevant to gay men in order to signpost them to appropriate services, such as peer support groups. Traditional and familial support networks for gay men following prostate cancer treatment may be limited compared to those of heterosexual men, given that gay men are far less likely to have a regular partner than heterosexual men as they age, and are four times less likely to have children (Department of Health [DOH], 2005). Therefore, healthcare providers are regarded as key sources of support for men in this patient group.

Gay men are more likely to conceal their sexual orientation in health settings and support groups if they suspect they may experience heteronormative attitudes, homophobia or discrimination (Hart et al.2014). Other studies conducted in the USA have reported that gay men with prostate cancer are more dissatisfied with their medical care and can experience a 'sense of not belonging' in some healthcare settings (Filiault, Drummond & Smith, 2008). Current guidelines in the UK and the USA place emphasis on aspects of communication between patients and their healthcare providers, who have a duty to provide information regarding procedures, treatment and follow-up care that is 'tailored to individual needs.' (NICE, 2015). However, little is known about the experiences of gay men with prostate cancer in the UK, as the patient monitoring system does not routinely collect or record information about sexual orientation (Stonewall, 2012).

There is a lack of evidence about the impact of prostate cancer on gay men (Blank, 2005; All Party Parliamentary Group [AAPG] 2009). Current guidelines from the UK's National Institute of Clinical Excellence (NICE), and The American Cancer Society lack information about the experiences of gay men, and how healthcare providers can best meet their needs. This qualitative study aimed to explore issues affecting gay men with prostate cancer and the implications for healthcare delivery.

Methods

Design

We conducted a qualitative study underpinned by hermeneutic phenomenology (Heidegger,1962) and guided by the approach and framework developed by the work of van Manen (1990). Phenomenology is an ideal approach for exploring topics of an exploratory nature, to uncover that which is taken for granted in everyday life (Creswell, 2007). This approach also aims to convey the meanings that individuals attach to their experiences as they are lived, rather than how they are conceptualised (Benner, 1994).

Ethical Considerations

All study procedures and materials were approved by the University of Central Lancashire Research Ethics Committee. Participants gave written consent prior to participation. All data were anonymised and participants' identity protected through the use of pseudonyms. Participants are identified in this paper with identification numbers.

Recruitment

To gain a broad range of perspectives, purposive sampling was used to recruit participants. Inclusion criteria included men who self-identified as gay, had received a diagnosis of prostate cancer, and were not in the acute phase of treatments e.g. radiotherapy, brachytherapy and chemotherapy, or recovering from surgery. As we were unable to identify patients on National Health Service (NHS) databases, due to the absence of routine monitoring of sexual orientation, it was necessary to employ alternative recruitment strategies. These included: advertising our study, along with contact details for the researcher, on charity websites / forums and social media, and utilising snowball sampling. Adverts were also emailed to key contacts of local prostate cancer support groups across England for group circulation. We excluded men who could not understand or speak English, as funds were not available for interpreters. As gay and bisexual men may have distinct needs regarding health issues, and should not be perceived as a homogenous group (Clarke, Ellis & Riggs, 2013), bisexual men were also excluded. Despite the wide range of recruitment strategies which were implemented over a period of several months, it proved difficult to recruit participants using these approaches, and perhaps highlighting the need for researchers to explore alternative methods of recruiting within this population. Potential participants who showed interest in the study, mainly through snowball sampling, contacted the researcher who explained the project in detail and carried out eligibility screening. An information sheet and consent form were posted out to those who met the eligibility criteria. After gaining written consent, an interview was arranged at a time and place of the participants' choice.

Sample

Twelve gay men who had received a diagnosis of prostate cancer consented to take part in the study, and were recruited from various geographical locations across the North and South of England. Participants ages ranged from 49-82 with a mean of 61. The average age of initial diagnosis was 56 years, and time from diagnosis ranged from one to 16 years. Seven of the participants were employed, five were retired. Ten participants had undergone at least one form of active cancer treatment since being diagnosed, including surgery, radiotherapy, and brachytherapy. Two men had chosen to be monitored on active surveillance. Two participants had tested positive after acquiring Human Immunodeficiency Virus (HIV).

Data collection

In-depth, semi-structured interviews were used to explore the men's experiences. This type of interview is most favoured in phenomenological research, as it enables the researcher to seek understanding and interpretation and encourages participants to reflect on specific experiences, as opposed to generalisations (Benner, 1994). A topic guide was developed using open-ended questions and prompts in line with a phenomenological approach (van Manen 1990; Rubin & Rubin, 2005). Questions were designed to elicit lived experience as opposed to opinion. e.g. *Can you tell me what it was like for you when you were diagnosed with prostate cancer? How did it feel? What incidents and people stand out for you when you think back to this time?* Although several topics were covered during the interviews, this paper focuses solely on interactions and experiences which have direct relevance to healthcare settings and providers. Issues and concerns that were mentioned by participants were probed and explored in further detail. Interviews were conducted in participants' homes, or at a location of their choice and ranged in duration from 64 minutes to 164 minutes. Consent was given for interviews to be digitally recorded, which were subsequently transcribed verbatim.

Data analysis

In keeping with a hermeneutic approach, data collection and analysis were undertaken simultaneously to determine how initial themes or concepts contributed to the emerging phenomenon. Researchers who employ a phenomenological approach are often advised to 'bracket' their own pre-conceptions or assumptions about the topic under study, to enable a new way of seeing the emerging phenomena (LeVasseur, 2003). Hence, a reflective diary was kept throughout the study to challenge assumptions, conscious biases and pre-existing knowledge. Interview transcripts were uploaded in MAXQDA version 10 (a software package for organising qualitative data). Initial analysis involved the lead researcher reading and re-reading each transcript to identify selected words and phrases that could have important meaning to the participant. The hermeneutic process involved going back and forth between each interview and considering what these themes meant in isolation, and within the wider context of the dataset as a whole. A subset of transcripts was read and coded by all other authors independently; this coding was compared and discussed during analytical meetings, to inform the final themes.

Findings

Four broad themes emerged from the interviews, which have direct implications for healthcare provision during each stage of the cancer trajectory: Information needs; relationships with healthcare providers; support networks,

and relationships. The impact of treatment on sexual wellbeing appeared to affect every aspect of the participants lives and is a consistent thread throughout the findings.

Information needs

During the diagnosis phase, participants wanted information about the implications of prostate cancer for gay men, but they found that this was not available. Participants perceived that they were poorly informed due to a lack of information directly relevant to gay men in the educational material provided within clinics and online. Participants frequently turned to the internet in the hope of finding information that made reference to gay men and what they may need to know or ask their healthcare providers. There was also a lack of information for gay men about resuming sex following a transperineal biopsy. Although leaflets included advice about when it was safe to resume sex following the procedure, men were unsure whether this only applied to those who engaged in vaginal intercourse.

“...that caused me inflammation of the prostate... there are sexual practices that could have actually aggravated that... because they never talk about that, you know, when I said to them in the beginning, is there anything sexually I should be aware of, they said no, carry on. The thing is, they don't ask you what your sexual practices are.” (ID 4)

“I'd read somewhere ... that really men should wait about 3-4 weeks before resuming anal sex but I cannot find that literature anywhere on the NHS or Bupa [private health insurance company] I have scoured the internet.” (ID 1)

“There wasn't anything for us to read, we did all our own research...it was very geared to heterosexual [men] ... I needed something specific.” (ID 5)

When faced with a choice of treatment options, men wanted information about how each treatment might affect aspects of their sexual activity, which, in turn could also affect their partners. Men were particularly concerned about the preservation of ejaculation as it played a demonstrable role during intercourse for both partners. One participant perceived that the role of ejaculation was different for gay men.

“So that's a real cultural thing...this is the nub of the problem... guys end up dry cumming [dry ejaculation], or retro-ejaculation, or none. With gay guys faking it, it's not an option, we need to see other options of ways of providing climactic endings to our sex, love making.” (ID 4)

A participant delayed surgery until he found a surgeon who was willing to listen to his concerns and who would agree to perform nerve-sparing surgery.

“...he could see that the nerve sparing was for me, such a big thing because I was open about being gay. I sort of explained, I’d just split up with a partner, you know, because that’s what, you know, what I felt was, oh shit, you know, I’ve now got prostate cancer and erectile dysfunction, how am I going to go and find another partner like that?” (ID 3)

Unpartnered men were particularly concerned about the implications of potential treatment choices due to the emphasis and expectations placed on sex within the gay community. This led men to seek information from the internet and attempt to locate other gay men who had already been treated for prostate cancer in order to gain as much information as possible about different treatments.

“...no-one is going to want to have sex with a six foot four straight looking gay bloke who can't get an erection.” (ID 1)

“...that is what was needed I think, when I was diagnosed, was contact with other gay men, either individually or as a group, to talk through, oh what happened to you?” (ID 9)

The ambiguity surrounding information specific to gay men was apparent for those who had chosen to remain on active surveillance. Despite acknowledging that he may need to consider active treatment in the future, one participant was uncertain whose responsibility it was to raise concerns about how certain treatments could affect his ability to receive anal sex.

“Yes, I suppose in an ideal world if I felt erm, I needed to ask then I would ask... equally I’m sure the consultant would have found some way of saying... You see I don’t know because I’ve never seen, never read anything that’s mentioned it. So, do I infer from that that it isn’t an issue? That if that’s what you want to do, go ahead and do it?” (ID 5)

Some men also expressed annoyance, when they did eventually locate information and support specific to their needs, due to the time it had taken to find it. Several men wanted information earlier from their healthcare providers to help them understand the impact of different treatments and would have welcomed support from forums for gay men. They felt that they should have been signposted to relevant sources of information and support and not have to search for it themselves.

“If there had been a gay men’s support group, I would have gone to it. If there’d have been a gay men’s contact telephone line, I would have made use of it. If there’d been any publications I would have done, but there wasn’t. And to a great degree, there’s not now.” (ID 9)

“Oh wow, I’ve found something with gay on it and prostate, and then it made me angry because it’s like it’s taken me so long to find.” (ID 1)

A lack of available information about the aetiology of prostate cancer also led to some misconceptions about the disease in relation to sexual orientation “*I’ve got this thing; will people not wanna be with me cos I might catch prostate cancer?*” (ID 9). Older men had assumed that their sexual orientation was somehow connected to developing prostate cancer, and would have appreciated knowing that their sexual lifestyle choices were not causative factors in their diagnosis.

“...also, we thought, an element may be because of our lifestyle, sexually I’m talking about, over many, many years. Could that have contributed to the disease?” (ID 9)

Information concerning medication and devices to aid or enhance sexual function was frequently sought using the internet. Men used forums to discover which sex aids were the most suitable or how to use mechanical pumps more effectively. Websites also offered medication for erectile dysfunction, which one participant found useful upon hearing he would only be prescribed a limited number of tablets by his doctor. Despite being nervous about taking such medication, he considered this his only option and was reluctant to discuss the situation with his healthcare providers.

“I was really nervous about trying them... you get them online and they make you do this prescription, do you suffer from this, do you suffer this? And they charge you twenty-five pound for that bit and then you can order as many as you want... they’re not cheap...but it seems that’s quite a long time before my next appointment at the hospital... I’m not telling my consultant when I get there that I’ve tried it.” (ID 3)

Relationships with healthcare providers

The men who were interviewed placed a great deal of importance on relationships with their healthcare providers. Men reported feeling comfortable disclosing their sexuality to specialist nurses. Nurses were frequently described as ‘*angels*’ or ‘*diamonds*’ who provided practical and psychosocial support to the men when they became distressed, and who ‘*picked up the pieces*’ after they had finished a consultation with a medical practitioner. Nurses were also a first line of contact when men raised concerns about sexual matters, a topic, men were less inclined to discuss with doctors, who tended to be male: “*she [the nurse] did some sort of sex clinic, so I feel that I would ask her because she seems to be completely sort of open and available.*” (ID 2)

Choosing how, and when, to reveal sexuality was raised by participants and not usually instigated by medical staff. Despite the potential for awkwardness or embarrassment, some men felt it necessary to raise the subject

directly upon suspecting it may be an important factor to consider. Some doctors were described as “brilliant” and “practical.” However, the reaction from other doctors left some men feeling disappointed and frustrated.

“I said, if I can’t be honest and open with you, or ask you relevant questions, who do I go to? I said, you’re the guy with the answers I hope...so of course I’m going to talk to you about it. I didn’t feel particularly comfortable, but I felt it was sufficiently important for me not to miss this. I mean where was I going to go after I’d left [the hospital] to find the information out?” (ID 6)

“So, I actually told him I’m gay and all the rest of it, but it didn’t make any impression on him...he was more embarrassed...it was something that he wouldn’t want to deal with, you know, an additional complication...” (ID 3)

Age was also a pertinent factor for the men in terms of their relative age compared to the age of health professionals they dealt with age. One of the oldest participants (aged 82 years) recalled the difficulty of disclosing to his consultant over two decades earlier “...if an older guy, say sixty-five, seventy, thought he had prostate cancer, he wouldn’t necessarily tell the consultant. But I don’t know how you get over that...” (ID 7). However, since becoming an ambassador to promote awareness of prostate cancer in recent years, the same man now realised the importance of disclosing to health professionals to ensure patients receive the best care “It is necessary that people can come out you know, they should definitely tell their consultant, and the consultant should ask.” (ID 7)

Younger health professionals were generally perceived as being more open about gay issues, whereas older health professionals were viewed as more reluctant or embarrassed to engage in conversations, even when they were initiated by participants.

“... it wasn’t difficult at all to talk about that sort of thing. I mean I can still be embarrassed about talking to doctors... I was lucky to get a young consultant, the older one was unapproachable really.” (ID 3)

Participants described the need for male health professionals to show sensitivity and understanding by offering information and advice “Not as a consultant, but as a man” (ID 1) and expressed dismay when health professionals appeared to lack empathy about their situation, or engage with them during consultations. Some felt that that health professionals were homophobic, or that they inadvertently made assumptions about their sexuality that were inaccurate and, on some occasions, offensive.

“...he said, you’ll be dead within six months... ...he didn’t really engage with [first name of partner] very well. I don’t know whether he didn’t do the gay couple bit or what, I don’t know, but he was just

rude... there was no empathy, there was no element of consideration or compassion from him at all.”
(ID 5)

“This guy was just so off hand with me, I felt like he was homophobic, maybe I was wrong, but he didn’t treat me in any way that I felt respectful.” (ID 6)

“...it was incredibly difficult to talk to the doctor...That was another reason why I didn’t like the urologist because he made the joke, it [digital rectal examination] wouldn’t be painful for me... I can remember word for word, he said, ‘well somebody like you, it won’t make a lot of difference to somebody like you’.” (ID 5)

Support networks

Support sources for the men in the study were important and included close friends, partners, family and healthcare providers. Despite this, the majority of men reported that they attended medical appointments alone. Partners were absent from appointments for several reasons; some men were currently un-partnered, others had partners who worked, some had been uncertain about whether same-sex partners would be welcomed by healthcare staff.

“I was given no warning as to how traumatic it [biopsy] would be ...I barely got to the bus getting back and by the time I was home I wished I’d got a taxi. I was given no warning, no suggestion that I had somebody with me to bring me home.” (ID 7)

The outpatient clinic was frequently mentioned as a place where support structures were noticeably different for gay men, who noticed that other men waiting for appointments or treatment were usually accompanied by their female spouses. Men who attended radiotherapy sessions over a prolonged duration of time were especially attuned to these differences.

“I sat in the waiting room day after day, every day for eight weeks...there were very few people on their own. I think the only guy I saw on his own once, was a chap who told me why he was on his own. But most people were there with their wives. I felt a bit lonely I suppose at that time. And it just brought back to me the kind of oddness of the whole situation really when you’re gay. And you sort of have to live a slightly kind of... a bit of a shadowy life in some ways, you know?” (ID 8)

Participants reported that some healthcare providers picked up on social cues and encouraged men to bring a friend or partner to future appointments who could potentially offer emotional or practical support.

“...the interesting thing was [the consultant] asked me about my personal life, because he knew I wasn’t married. And he said, was I in a partnership? And I said, yes. And he suggested my mate

came several times with me, for a series of consultations that he should sit in on them. And I think that's very, very good...I think health professionals, and this is heterosexually as well by the way, should suggest to a man, a gay man especially, look, have you got a friend, a partner, call it what you like, to sit in on the discussion?" (ID 9)

Men who discovered prostate cancer support groups in their local area, tended to have strong opinions about the structure and purpose of such groups and were unanimous in their view that they were not suitable for their needs. Most participants conveyed a strong sense of “*not belonging*” and were frustrated at the reluctance of group members to initiate discussions about common issues to affect all men with prostate cancer, regardless of their sexual orientation. The presence of female partners within some groups also prevented men from speaking candidly about sexual matters, and they were uncomfortable about discussing gay-specific issues concerning relationship dynamics or sex, that may not have been experienced by heterosexual men.

“For a fifty-year-old out gay man who has, you know, quite a lot of experience with that in other areas, it [support group] was as far removed and fit for purpose as you'd possibly get. It just wasn't, for me, what I needed and what I wanted.” (ID 5)

“...I mean to us, going to a gay bar, picking up, us going off, splitting up, you know, with other guys, having a bit of sex, having a drink, it's just fun for us, but God...just sort of discussing at that group, even in just sort of very straight factual terms about not being able to [ejaculate], I suppose you just don't know what the reaction will be. But if you were with a group of gay men, where things are much more open and talked about...” (ID 12)

During the course of this study, a support group, specifically for gay men with prostate cancer, took place in a charitable organisation within the UK. Participants who had attended this group described the relief they felt from connecting with gay men who were in similar situations. Most men had found this group through online forums and networking as opposed to signposting within the NHS. Despite having to travel considerable distances to attend a group meeting of this nature, men were willing to undertake this journey in order to gain information and support that was not perceived as being available elsewhere.

“...that was a wonderful thing; that guys were able to talk really openly and not think that oh, someone's gonna be offended, because gay guys will talk and be far more open emotionally, far more open about the language they use than heterosexual men... It's not just about prostate cancer, it's about being a gay man.” (ID 4)

Several men described needing psychological support for issues that had been triggered since their cancer diagnosis. *“The thing above all I think, with prostate cancer for gay men, is the fear of what's going to happen, what people will say, and the support, you see... that's the trouble.” (ID 9)*. They spoke candidly about their

mortality and how developing the disease had triggered emotions and feelings associated with their past, and specifically their sexuality or 'coming-out' experience. Some had sought counselling from NHS services to help deal with their inner conflicts and were grateful for the opportunity to put their current situation into some context.

"Prostate cancer triggers a lot of the shit... I've thought that I've felt a bit of a fraud sometimes, cos I've had some counselling, and I'm thinking this has got nothing to do with my prostate. It's been about sex and relationships and I'm thinking that's been with me ever since I can remember." (ID 1)

"I said yes, I would like to see a counsellor, and that was probably the best thing I did actually. Because I had a lot of issues in the past unresolved and it's one of those sorts of things that before the diagnosis, it was like I'd better go and see a psychiatrist or something like that..." (ID 12)

Living with HIV, or supporting a partner with HIV was conveyed as an additional burden to contend with. One participant who lived with a partner who was HIV positive described their situation as 'a bit of a trade-off,' whereby both partners had a shared understanding of living with the side-effects and emotions associated with illness. Participants who were HIV positive felt there was a stigma attached to having both diseases, and found the control it placed upon their lives exhausting. One 50-year-old participant, who was still in employment, described dealing with mental health issues, which only compounded his situation.

"I feel like, you know in Trivial Pursuit, you know you get that cake thing, which you get all the different portions on, it's like I've got one of those but I've got sixteen bits of pie all mushing around at the same time... all of these drugs have to be balanced, so my HIV drugs all have to be balanced with my mental health drugs..." (ID 10)

Relationships

Challenges were apparent in relationships between men and their partners, and those who were actively seeking a partner within the gay community. Erection problems for men who enjoyed being part of the gay scene were particularly distressing; given the perceived emphasis on youth, body image and sex "a lot of our history and a lot of our presence is dealt around sex and sexual identity and the sex act and the imagery of sex. However, we dress that up, it's there." (ID 4). Some men perceived that they now had less value within the gay community and were unable to compete with healthier men "...you think, well, you know, nobody's going to want to go out with a bloke that can't get an erection in the gay environment." (ID 3)

Several men accepted that they could no longer meet the sexual needs of their partners. As distressing as this was, they were open-minded about the possibility of partners finding sexual satisfaction with other men, in an effort to keep other important aspects of their relationships intact.

“I have some concern whether it might bother [first name of partner] because he’s a lot younger. And I would hope, and I have no indication of this, that if occasionally he looked for sex somewhere else, I wouldn’t be upset or anything like that because I would understand his need, which I now can’t meet.” (ID 9)

Two participants compensated for changes to their sex lives by occasionally inviting a third person to join their sexual encounters when it was deemed appropriate. Both participants described the importance of being honest with partners about the situation and agreeing boundaries.

“...we’ve come to sort of an understanding. It’s fine, it’s a perfectly mutual sort of thing, but we’ve actually started to pick up other guys for like a threesome or whatever...And that’s worked out really well, you know. And I think we’ve sort of come to the conclusion that we both like doing that. It’s something else to the mix, you know. And the two people I’ve found, it’s not been a problem at all, you know, for them, it’s worked out alright. And that I found very confidence building and reassuring.” (ID 12)

Discussion

We conducted in-depth interviews to explore issues affecting gay men with prostate cancer and their implications for healthcare delivery. To our knowledge, this is the first in-depth study in the UK to examine the perspectives of gay men with prostate cancer.

Due to the lack of routine sexual orientation monitoring in health settings across Europe and the USA, the responsibility for raising issues concerning sexuality is ambiguous. Participants in this study would have liked healthcare professionals to raise the issue of sexuality. However, most felt that it was their responsibility to initiate a conversation about their sexual orientation, and were uncertain how this information would be received. Given that a large proportion of gay men choose not to disclose their sexuality to healthcare providers in general (Stonewall, 2012), the findings from this study suggest that gay men consider sexual orientation to be a relevant factor following a diagnosis of prostate cancer, and have a need to understand how it may impact on every aspect of their cancer journey.

Participants perceived that healthcare professionals had limited, or no knowledge, about sexual orientation, or about the potential impact of cancer treatment on gay men. Information about procedures, treatments and treatment

side-effects was presented from a heteronormative perspective. Participants would have welcomed information from the outset of their diagnosis, which clearly outlined issues that may affect gay men. As sexual activities differ amongst gay men, and can include stimulation of the prostate, participants wanted information that had considered their concerns and potential needs. This included: reassurance that they had not developed prostate cancer as a result of their sexual orientation; what precautionary measures to take following trans-rectal procedures; whether anal sex was safe to resume following treatment; and where they could access appropriate peer support. Current guidelines for prostate cancer (NICE, 2015), recommend that men with prostate cancer are 'provided with individualised information tailored to their own needs by a consultant or specialist nurse.' In addition, the guidelines highlight that information and support resources should be checked to ensure their content is clear, reliable and up to date. The findings from this study suggest that gay men are not currently provided with appropriate and relevant information. Healthcare providers should endeavour to ascertain at an early stage of the diagnosis whether men are likely to need additional information based on their sexuality.

The findings reveal that most participants felt unsupported by healthcare professionals, particularly doctors, and perceived that they were embarrassed when discussing issues associated with sexual orientation and sexual function. Communication barriers between healthcare professionals and patients are not uncommon (Fish, 2006). However, research has highlighted the harmful impact on sexual minority patients when they feel inclined to constantly gauge what they can or cannot say to their healthcare providers, for fear of receiving a neutral or negative response (Filiault, Drummond & Smith, 2008). Moreover, healthcare professionals may not always feel prepared or sufficiently informed to instigate a conversation about sexual orientation, or do not consider sexual orientation to be relevant to a health needs (Horden & Street, 2007). Medical staff who specialise in prostate cancer could benefit from additional training on issues that may affect gay and bisexual men, and to enable them to confidently converse with men about such issues. Training could also feature more prominently within the medical curriculum. LGBT organisations e.g. Stonewall are constantly developing information and training materials to support healthcare staff and sexual minority patients. Health messages and policies that promote non-discrimination and confidentiality in relation to sexual orientation could be displayed in clinical settings such as waiting rooms to promote inclusiveness and acknowledge diversity. Most participants were happy to discuss personal issues with nurses, including those of a sexual nature. As part of the UK's Nurses Competency Framework, nurses acquire communication and interpersonal skills and are trained to act on their understanding of how people's lifestyles and environments influence their health and wellbeing (Nursing and Midwifery

Council, 2015). For this reason, specialist nurses could be best placed to deliver holistic care at the time of diagnosis which may encourage men to discuss their concerns prior to treatment.

Healthcare professionals should recognise that ejaculation can have a different significance for gay men (Prestage, Hurley & Brown, 2013). Conversations about cancer treatment side-effects that specifically result in dry orgasms, or loss of ejaculation, should take place at an early stage as this may impact on their choice of treatment. Psychosexual counselling could be offered to men if it appears likely that loss of ejaculation is inevitable. Several participants in this study were open to finding adaptive ways to ensure they continued to have a healthy sex life following treatment and were open to exploring sexual flexibility. Our findings concur with past research which found men who had previously adopted an insertive role during anal sex were able to shift to a receptive role (Dowsett et al. 2014). Seven percent of heterosexual men in the same study revealed that they had also engaged in anal intercourse following prostate cancer treatment. Hence, information pertaining to the safety of anal sex post-operatively should be routinely provided as it has relevance for all men.

Despite the growing number of support groups available for men with prostate cancer in the UK, these mainstream groups were unable to meet the needs of the participants in this study. They were perceived as being geared towards providing support for heterosexual men and their female spouses. Participants considered it inappropriate to raise topics associated with their own sexual identity, for fear of embarrassing others, and were reluctant to endure the experience of 'coming out' to a group of heterosexual men. The commonality of gay identity for the men in this study was as equally important as the commonality of having prostate cancer. Most men did not continue to attend mainstream groups following their first visit, resulting in feelings of isolation and frustration. Since this research was conducted, three support groups within the UK, specifically for gay and bisexual men with prostate cancer, are now operating in three major cities: London (Metro Walnut); Manchester (Out with Prostate Cancer) and Birmingham (Midlands Gay, Bi, and Trans Prostate Cancer Support Group). These groups encourage patients to use Skype facilities if they are unable to attend in person and have buddying systems in place which help to forge peer support for those who need or want it. Similarly, organisations and forums in other countries e.g. MALECARE, (cancer website and forum) have been created which enable gay and bisexual men to network with each other. Healthcare providers should signpost patients to such groups and have information at hand for the nearest group.

Patients living with prostate cancer and HIV may also require additional support to enable them to successfully manage two chronic conditions. Findings from this study reveal that there is an element of stigma attached to both

diseases for gay men, and treatment side-effects from prostate cancer are compounded by the necessary adherence to HIV medication. As the population of men with HIV over the age of 50 is increasing each year, due to the success of antiretroviral drugs (Joseph Rowntree Foundation, 2010), it is likely that a significant number of men will face challenges associated with a dual diagnosis of prostate cancer and HIV in the future.

Strengths and limitations

This qualitative study provides rich accounts of the experiences of 12 gay men living within the UK who were diagnosed with prostate cancer. The broad age range of participants and personal circumstances such as living with HIV emphasise that men from sexual minorities are not a homogenous group. To date, little research has been conducted with this patient group, and our findings add to the growing body of literature in cancer research about how minority groups navigate care within an increasingly busy healthcare system.

The sample size in this study is in line with the tenets of phenomenological research. Therefore, the findings from this qualitative study may not be generalisable for all gay men with prostate cancer. Moreover, despite using a range of recruitment methods, very few men initiated contact with the researcher to request details about the study. This highlights the difficulties associated with recruiting from a population deemed 'hard to reach'. Historical attitudes towards homosexuality may have prevented more older men from participating. Our study also failed to recruit any men from ethnic minorities. Black and Asian men have a one-third chance of dying from prostate cancer yet little is known about the views of those who identify as gay. Until routine monitoring of sexual orientation is implemented across health services, further studies should explore how subgroups within gay society can be included in research, and how barriers can be sensitively addressed.

Conclusion

Guidelines for the diagnosis and treatment of prostate cancer currently make no reference to the needs of sexual minority patients and healthcare providers may be unaware that gay men have unique needs and concerns. Given the UK Government's plans to introduce sexual orientation monitoring across UK health services in the future, the findings from this study suggest that this will only be successful if healthcare providers find effective ways of demonstrating genuine inclusiveness towards sexual minority patients, and provide information that resonates with the sexual orientation of the individual. Training for healthcare professionals to enable them to find ways of initiating conversations about sexuality, and feel confident in addressing issues about lifestyle and sexual activity, that may differ from their own, are recommended.

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Conflict of Interest The authors declare they have no conflict of interest

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