

# Let's talk about gay sex: gay and bisexual men's sexual communication with healthcare professionals after prostate cancer

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**Let's talk about gay sex: gay and bisexual men's sexual communication with healthcare professionals after prostate cancer**

Although sexual changes after prostate cancer (PCa) have specific meanings and consequences for gay and bisexual (GB) men, little is known about how GB men navigate sexual well-being support. We surveyed 124 GB men with PCa and 21 male partners, and interviewed a sub-sample of 46 GB men and 7 male partners, to examine GB men's experiences of sexual communication with healthcare professionals (HCPs) since the onset of PCa. GB men perceived a number of deficits in HCPs communication: medical support dominated sexual and psychological support; heterosexuality of GB patients was often assumed; sexual orientation disclosure was problematic; and GB men perceived rejection or lack of interest and knowledge from a majority of HCPs with regard to gay sexuality and the impact of PCa on GB men. Facilitators of communication were acknowledgement of sexual orientation and exploration of the impact of PCa on GB men. In order to target improved support for GB men with PCa, it is concluded that HCPs need to address issues of hetero-centricism within PCa care by improving facilitation of sexual orientation disclosure, recognising that GB men with PCa might have specific sexual and relational needs, and increasing knowledge and comfort discussing gay sexuality and gay sexual practices.

*Keywords:* prostate cancer, psychological, sexuality, gay and bisexual men, sexual identity disclosure, communication with healthcare professionals.

It is widely recognised that sexual well-being and sexual relationships are important concerns for people with cancer and their partners (Hordern & Street 2007; Reese 2011). Healthcare professionals (HCPs) are increasingly recognising these concerns, positioning sexual well-being post-cancer as an important issue (Lindau *et al.* 2011;

Ussher *et al.* 2013). Despite this, a number of barriers to clinical discussions of cancer and sexuality have been identified, including deficits in HCPs knowledge, comfort, and confidence talking about sex (Ussher *et al.* 2013), as well as structural constraints, such as lack of time, education and privacy concerns (Hautamaki *et al.* 2007; Hordern & Street 2007). Although discussions of sexuality with HCPs have been found to be more common in the context of prostate cancer (PCa) compared to other cancer types (Hawkins *et al.* 2009), sexual well-being support for men with PCa has widely and consistently been reported as inadequate (King *et al.* 2015). This is a matter of concern, as current treatments for PCa carry with them a

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range of potential sexual side effects, including erectile dysfunction, loss of ejaculatory capacity, loss of libido, reduction in penis size, and urinary or bowel incontinence (Chung & Brock 2013).

Gay and bisexual (GB) men with PCa report higher dissatisfaction with PCa treatment than heterosexual men, associated with lower quality of life (Torbit *et al.* 2014; Ussher *et al.* 2016). One explanation for this dissatisfaction is that GB specific issues and concerns are often unaddressed by HCPs (Blank 2005). Sexual rehabilitation support in PCa care has been criticised for focusing on restoration of erectile function to achieve vaginal penetration, while overlooking the alternative sexual practices of GB men and many heterosexual men. However, the side effects of PCa treatment have been reported to hold specific meanings and consequences for gay sexual practices, gay relationships and gay identity (Thomas *et al.* 2013; Ussher *et al.* in press). These relate to the need for firmer erections for penetrative anal sex compared to penetrative vaginal sex (Goldstone 2005), the symbolic and erotic nature of visible semen exchange for many gay men (Prestage *et al.* 2013), potential loss of anal pleasure given that the prostate has been coined 'the male g-spot' (Asencio *et al.* 2009), potential discomfort during anal sex after PCa treatment (Wittmann *et al.* 2009), and the increased scrutiny claimed to be held by gay men with regard to the aesthetics and size of the penis (Drummond & Filiault 2007). Changes to erectile function and anal sensitivity or discomfort may also impact upon secondary self-labels such as 'top' (insertive partner) or 'bottom' (receptive partner), with unique implications for the identity of GB men after PCa. The nature of GB relationships, where many men are single, have casual sex or concurrent partners (Lyons *et al.* 2011), can also have specific implications for how changes to sexual well-being after PCa are experienced by GB men.

Healthcare professionals working with cancer patients have reported that the sexual concerns of lesbian, gay, bisexual, transgender (LGBT) patients are less likely to be addressed, due to lack of confidence and knowledge of LGBT sexuality and relationships (Perz *et al.* 2013; Ussher *et al.* 2013). However, research on communication between GB men with PCa and HCPs is scant, only addressed within two small-scale qualitative studies (Filiault *et al.* 2008; Thomas *et al.* 2013). In these studies, GB men perceived PCa support as heteronormative: HCPs often failed to discuss the physical and psychological impacts of treatment on gay men and their partners, often assumed gay patients were heterosexual, and communication by HCPs when discussing gay sexuality was described as 'disingenuous', 'coy' and 'Victorian' (Filiault *et al.* 2008).

Research on lesbians with breast cancer (Boehmer & Case 2004; Dehart 2008), and wider LGBT health research (Semp 2008; Rounds *et al.* 2013), suggest that patients frequently perceive interactions with HCPs as hetero-centric and at times homophobic and discriminatory. Disclosure of sexual orientation, in order to receive targeted information and support, can be a focus of difficulty. Although disclosing sexual orientation to HCPs is associated with positive mental health outcomes (Durso & Meyer 2013) and greater satisfaction with care (O'Hanlan *et al.* 1997), there is evidence that when sexual minority patients do disclose, responses from HCPs range from accepting to ignoring (Katz 2009), with some HCPs reticent to discuss sexuality or provide relevant sexual information in response to disclosure (Nusbaum & Hamilton 2002; Labig & Peterson 2006). It has been suggested that this is because of HCPs lack of knowledge and training regarding the sexual practices of sexual minorities (Stott 2013) and concern about appropriate use of language (Hinchliff *et al.* 2005; Ussher *et al.* 2013). Non-disclosure by sexual minority patients has been associated with fear of mistreatment, privacy concerns and uncertainty as to whether sexual orientation is important to medical care (Stein & Bonuck 2001; Boehmer & Case 2004; St Pierre 2012). However, to date no research has investigated sexual orientation disclosure by GB men with PCa.

The present study aims to examine GB men's experience of communication with HCPs after the onset of PCa, focussing on issues related to sexuality and changes in sexual well-being. The following questions were used to direct the research: What are GB men's experiences talking about sexuality and sexual well-being with HCPs since the onset of PCa? How do GB men with PCa negotiate sexual orientation disclosure with HCPs?

## METHOD

### Participants and procedure

One-hundred and twenty-four GB men who currently have, or have had, PCa, and 21 male partners of men with PCa completed an online or postal survey, part of a larger mixed methods study examining sexual well-being and quality of life after PCa in GB men and their male partners. Full demographic details are presented in Table 1. Participants were primarily recruited within Australia, with a minority recruited from the U.S.A., U.K. and New Zealand, through cancer support groups, cancer research databases, clinicians, social media, and GB community and health organisations. This type of purposive non-probability sampling has been widely used

**Table 1.** Socio-demographic characteristics

Variable	GB men ( <i>N</i> = 124)			Male partners ( <i>N</i> = 21)		
	<i>n</i>	M (SD)	Range	<i>n</i>	M (SD)	Range
Age*	119	64.25 (8.18)	45–89	21	55.67 (9.04)	40–67
Years since diagnosis	115	5.904 (5.03)	0–25	20	3.35 (2.85)	1–10
	<i>n</i>	%		<i>n</i>	%	
Sexuality						
Gay	99	81.15	–	19	90.48	–
Bisexual	20	16.39	–	1	4.76	–
Other	3	2.46	–	1	4.76	–
Ethnicity						
Anglo-Australian	84	67.74	–	12	57.14	–
Other	40	32.26	–	9	42.86	–
Relationship length						
Less than 2 years	13	14.49	–	2	11.10	–
More than 2 years	56	45.16	–	16	88.90	–
Sexual activity with						
Regular partner	50	40.32	–	16	76.19	–
Casual partner(s)	49	39.52	–	6	28.57	–

\*Where *N* < 124 = missing data.

to overcome the challenges of recruiting members of vulnerable or 'hidden' populations into research studies (Watters & Biernacki 1989), and is thus well suited to the present study. Two open-ended questions regarding sexual communication with HCPs were included in the survey: the first asked participants about their experiences of sexual identity disclosure and the second asked about experiences discussing sexual well-being. At the end of the survey, 62% of participants volunteered to take part in one-to-one semi-structured interviews, lasting approximately 1 h. Of these, we interviewed 46 GB men and seven partners to further examine the subjective experiences of sexual communication and perceived support from HCPs. Interview participants were purposively selected to ensure a broad sampling frame across age-groups, sexual orientations (gay/bisexual), relationship contexts (single/partnered; monogamous/non-exclusive) and experiences with PCa (e.g., years since diagnosis, self-reported severity of sexual changes). The interviews were conducted as an 'extended conversation' (Rubin, 2005, p. 96), with the timing and formatting of the questions used flexibly to suit the particular context and experience of the participants. Interviewees were offered a modest (AUD \$25) gift card as a reimbursement for expenses. In accordance with established protocols in qualitative research, sampling was discontinued when information redundancy was reached, and no additional information was forthcoming in three consecutive interviews (Miles & Huberman 1994). Ethics approval was granted by the University Human Research Ethics Committee and participating community organisations, and all participants provided specific consent.

## Analysis

The analysis of open-ended survey responses and interviews was conducted using thematic analysis (Braun & Clarke 2006). The style of analysis adopted was inductive with the development of themes being data driven, rather than based on pre-existing research or hypotheses. All of the interviews were audio-recorded and transcribed verbatim, with the resulting transcripts then read in conjunction with the audio recording, to verify for errors in transcription. A subset of the interviews were then independently read and reread by two of the authors to identify first order concepts or codes, such as 'sexual changes after PCa'; 'impact of sexual changes'; 'experiences of sexual orientation disclosure', 'HCPs perceived knowledge of GB sex and sexuality', 'interactions with HCPs' and 'what's missing from PCa care'. The entire data set was then coded using NVivo, a computer package that facilitates organisation of coded qualitative data. All of the coded data were then read through independently by two of the authors. Codes were then grouped into higher order themes, a careful and recursive decision making process, which involved checking for emerging patterns, for variability and consistency, and making judgements about which codes were similar and dissimilar, leading to the development of a thematic map of the data.

## RESULTS

Analysis of responses are presented through four themes: cancer-centred care negates sexual needs; HCPs assume heterosexuality; navigating sexual orientation disclosure

(an avoidant stance; a hesitant stance; a forthright stance); and HCP responses to disclosure and requests for gay-specific information (rejecting; lack of knowledge or interest; acknowledgement and interest). Assigned pseudonyms, information on age, identification as gay or bisexual, and partner status, are provided for substantive qualitative responses.

### **'It's a narrow view': Cancer-centred care negates sexual needs**

As a consequence of decline in sexual function due to PCa treatment, the majority of GB men reported experiencing a reduction in or cessation of sex, with loss of sexual activity described as 'really devastating', after which 'you end up a bit of a train wreck', with many participants 'feeling isolated', 'outside of the sexual community', 'inferior', 'faced with a big sense of failure', 'depressed' at the prospect of 'facing life alone', or as a 'liability' to partners as a result of sexual changes after treatment. Despite the importance of continued sexual activity to the majority of GB participants and the psychological strain PCa-related sexual decline placed on having or maintaining gay sexual relationships, the majority of interviewees told us they received inadequate sexual and psychological well-being support, with HCPs often described as failing to look beyond the medical aspects of treatment.

Communication with HCPs was repeatedly described as cancer-centred and medically focussed, which was perceived as deprioritising discussions of sexual well-being and negating consideration of the impact of PCa and its treatment on sexuality and sexual practices. For example, Scott (gay, 59) stated that 'the sexuality side of it was shelved, pushed to one side' by his urologist, and that 'the discussion was all to do with a piece of cancerised prostate and how to get it out'. Similarly, Matt (partner, 56) told us the support he and his partner Bruce (gay, 61) received around treatment was 'fantastic in the way of technical examination' but there was 'very little, if any, backup information regarding rehabilitation of erection and anything to do with sexuality or function other than the purely clinical aspects of the surgery'.

Follow-up care was also frequently described as lacking. For example, Sam (gay, 74) – who at a 5-year review with his urologist disclosed experiencing softer erections, loss of ejaculate, dysorgasmia, reduction in penis size, ongoing faecal incontinence and was unable to engage in receptive anal intercourse, told us his urologist said, 'well, the good news is your PSA is low, the bad news is I don't have to see you anymore'. Sam said, 'I felt that that instead of following up on all these side effects from the treatment, I

felt that he'd abandoned me'. Similarly, Mason (gay, 68) said 'I felt a little abandoned' because 'doctors tend to give the impression that getting rid of the cancer is the most important thing and the after effects, you've just got to live with them'. A few men provided accounts of how a purely technical or clinical stance adopted by some HCPs was experienced as dehumanising. For example, Graham (gay, 74) told us he felt like 'an object' while recovering in hospital following penile implant surgery:

I was just lying there in bed with my puffed up penis all wrapped up in bandages and the urologist walked in with some strange lady that I had no idea who she was, and without saying anything, he just grabs my bandaged thing and undid it and demonstrated how you puff it up. And I was really put out by that.

Interviewer: How did that make you feel?

Graham: Well, I feel like an – an object. The way they just did it – they didn't even treat me as a person, they just treated me as something with a – an operation.

The language used by HCPs to describe sexual changes was also experienced as a source of distress by some participants. Alan (partner, 67) told us his partner's treatment was described by HCPs as 'chemical castration', which 'totally freaked him out' and was reported to have increased his distress approaching further treatment. This is consistent with other participant reports of medical professionals failing to consider or address the emotional impact of loss of sexual function.

At the same time, several participants who independently sought psychological support following PCa treatment told us that the support was not targeted to their needs of adjusting to sexual changes. For example, Gordon (bisexual, 56) told us:

They [psychologist and psychiatrist] dealt with my depression as a mental illness and of course the nature of the mental illness was partly the sense of loss and mourning and grief over no longer having sexual function, and then after that no longer having sexual feeling or desire. But mainly it was treated as a clinical illness. You'd be treated with pharmaceuticals, with techniques for dealing with stress, and nothing at all with regard to sexual intimacy.

The 'compartmentalised' approach Gordon attributed to his mental health professionals echoes the cancer-centred support participants frequently described receiving from medical professionals, both 'over-focussed on [the] condition'.

### **'It's as though we're invisible': HCPs assume heterosexuality**

When sexual well-being was addressed by HCPs, participants described it as a 'one-size-fits-all approach' that was 'geared up for straight men', with little, if any, psychosexual support offered to cope with the impact of PCa on gay sexuality and relationships. As a result, our sample described being marginalised from support due to the fact that their PCa care was not only cancer-centric, but also hetero-centric. For example, Euan (gay, 66) said 'there was a whole lot of stuff that... does mean a lot to a gay man that wasn't fully explained' and Scott (gay, 59) told us there was 'no real questioning or trying to understand my position as a gay male'. Similarly, Jack (gay, 59) stated, 'with prostate cancer you get into the whole heterosexual world of discussion about it' with 'very little discussion or even mention of how it might affect gay men'. Within this 'heterosexual world of discussion', Henry (gay, 59) intimated that 'it's as though we're invisible. We're usually not considered. The assumption always seems to be that the man with prostate cancer sitting in front of them or on the end of the phone must be straight'. This 'assumption' was evident in several accounts of HCPs referring to sexual partners as women. For example, Drew (gay, 65) told us 'most of them [HCPs] cater for how you are adjusting with your wife' and Billy (gay, 72) recounted the following conversation with his urologist:

He said, 'Would I like to bring my partner along. What is she doing?' And I just said to him, 'Oh, my partner is male.' And he just sat there for a minute and his jaw dropped and he said, 'Oh, I haven't come across this before.'

Participant reports of the assumption of heterosexuality in clinical discussions were also reflected in printed material received from HCPs, as Tristan (gay, 62) stated: 'When you've been diagnosed with cancer, being presented with questions and forms that assume you to be heterosexual is very distressing'. Andy (gay, 61) told us 'all the literature is about having sex with your wife when you come out of hospital, and doing this and doing that... I just adjust the reading to make it more inclusive, but I shouldn't have to do that'. Consequently, contact with HCPs in the context of PCa often involved the added 'distress' of having to navigate 'a heterosexual world of discussion', with little information or support on how GB men might be affected differently by PCa. As such, participants described their experiences negotiating sexual concerns within a clinical environment unaccustomed to supporting the sexual well-being needs of GB men.

### **Navigating sexual orientation disclosure**

The perceived hetero-centric nature of PCa care necessitated GB men disclosing their sexual orientation to HCPs if they wanted to receive gay-specific sexual information or acknowledgement of their relationship context. Eighty per cent of survey respondents indicated that they had disclosed sexual orientation to at least one HCP since the onset of PCa. To gain deeper insight into sexual orientation disclosure in the context of PCa, we asked interviewees about their experiences of disclosing or not disclosing. Three different approaches to disclosure were reported by GB men: an avoidant stance, a hesitant stance and a forthright stance, as outlined below.

#### *'Why go down that track if you can avoid it?': An avoidant stance*

A minority (approximately one-fifth) of interviewees reported that they avoided disclosure of sexual orientation with HCPs. A few participants said non-disclosure was a product of limitations within clinical settings, that 'there didn't seem to be an appropriate time' and 'the consultations are always very short and rushed'. For a number of other men, avoiding disclosure was a more deliberate choice motivated by 'fear of rejection', 'reservations as to whether HCPs are accepting or not', not wanting 'to be lectured', 'privacy', and being 'too embarrassed', with disclosure positioned as a 'risk'. For example:

I have some reservations as to whether some professionals are accepting or not. Why go down that track if you can avoid it?... They may be less likely to be as assisting as I would like them to be. I just don't want to take that risk (Tony, gay, 74).

Some participants also told us they 'did not see the need to disclose' and 'it didn't seem relevant' during initial contact with HCPs; however, this often led to regret at a later stage when gay-specific sexual concerns arose. As Graham (gay, 74) stated, 'I should have just taken the bull by the horn and said it straight out, that I'm a gay man. I [then] wouldn't have to complain about their lack of communication on that subject'.

Given the discomfort, perceived risk and uncertain relevance associated with avoidance of disclosure, many participants frequently indicated that HCPs need to take greater responsibility to ask patients how they self-identify in terms of sexual orientation. For example, Jack (gay, 59) stated, 'it would almost take the medical profession or the treatment people to open up that avenue of conversation', and Michael (gay, 69) said it is 'important for all

HCPs' to take the initiative in ensuring targeted information is made available to GB men who may not be aware of the potential significance of PCa on gay sexuality:

I wish they had been open earlier. It's only this last year or so that I have realised how important it is for a gay man... and I really think it is important for all health professionals to try and ascertain whether a person is gay or straight, in a tactical way, and, of course, that person may not – may choose not to disclose.

*'It's a bit confronting, even after you've done it a thousand times': A hesitant stance*

The majority of interviewees (approximately three-fifths) adopted a hesitant stance to disclosure, indicating that disclosure of sexual orientation to HCPs was to some degree 'difficult' or 'uncomfortable', with men describing themselves as 'a little bit hesitant' and grappling with their 'duty of disclosure'. As Steve (gay, 65) stated:

You have to, sort of, basically come out to people all the time, each time you meet somebody. You have to explain and sometimes some people aren't really with it. Some people don't understand what it entails and so sometimes it's a bit confronting even after you've done it a thousand times.

As a result of the 'confronting' nature of disclosure, several participants reported relying on an 'unspoken awareness' of sexual orientation, disclosing indirectly to HCPs by bringing a male partner or gay friend to an appointment, by using humour, or dropping hints. For example, Colin (gay, 68) said:

I haven't just come right out and said, 'Hi, doctor. I'm gay,' but when [my partner] shows up with me I make inappropriate jokes and that's one of the strange ways I think that a lot of people deal with this is with a sense of humour.

Some HCPs were positioned positively in their responses to such indirect disclosures. As Alan (partner, gay, 67) said 'I went into an appointment with Derek to see a beautiful doctor, she's just been amazing, and her assumption was that we were gay.' Others reported that some HCPs 'would rather not deal with it, but will deal with it if they have to' (Alex, gay, 69), indicating that indirect disclosure can often fail to lead to desired discussions about sexuality:

My consultant and specialist nurse are very helpful... but they don't touch the particular issues

involving men who have sex with men... very odd, I give them the clues and they lead with them without any particular comment related to orientation... I feel just like a general case (Louis, gay, 56).

Such accounts suggest that men who adopt a hesitant stance might be to some extent reliant on how receptive HCPs are to indirect disclosure to pick up on patient 'clues' about GB status.

*'I have no hesitation to let them know I'm gay': A forthright stance*

A further minority (approximately one-fifth) of interviewees adopted a forthright stance, describing themselves as undeterred by anticipated reactions of HCPs to disclosure and actively revealed their sexual orientation as a matter of course. For example, participants told us: 'I've been absolutely open about my sexual orientation with every single health professional I've ever encountered' (Bruce, gay, 61) and 'I have no hesitation to let them know I'm gay' (Gary, gay, 52). Participants who adopted a forthright stance indicated it was the professional responsibility of HCPs to be open to discussing health issues specific to GB men. For example, Vincent (partner, gay, 62) stated:

I'm as comfortable as a train... and I don't have any problems at all talking about my sexuality or whatever with health professionals. If they get embarrassed, they shouldn't be in the bloody trade, for God's sake. They need to be able to cover the breadth of human health.

Additionally, some men who adopted a forthright stance told us it was a strategic move that enabled them to gauge the level of knowledge and comfort of their HCP in discussing gay sexual practices and relationships. For example, Rick (gay, 59) told us 'it [disclosure] also gives them [HCPs] an opportunity, if they're not comfortable for any reason, well I prefer not to be there.' As such, Rick employs a high level of agency as a patient who only engages with HCPs who are 'comfortable' in incorporating his sexuality into their care. A similar account from Clive (gay, 70) described disclosure as a means to assess HCP level of comfort and safeguard against dissatisfaction with care at a later stage:

I sort of tell them at the beginning. 'This is the way it is, are you comfortable talking to me? And are you quite confident that you understand the issues relating to me?' So what you're doing is, you might be sort of be moving into areas where they're not comfortable. Even though they are health profes-

sionals. And then they're supposed to understand the different issues. But they just – everyone's got their baggage and their limits.

The implication of this is that HCPs who are not 'confident' in 'understanding the different issues for GB men', or who have 'baggage' or 'limits' with regard to what they will discuss, may find some forthright GB men with PCa discontinue seeking their care.

### **HCP responses to disclosure and requests for gay-specific sexual information**

The reciprocal nature of HCP and patient discussions of sexuality following PCa were apparent in open-ended survey and interview accounts. Tailored information and support was described as highly contingent on HCP responses to sexual orientation disclosure and requests for gay-specific information, with HCP responses described as rejecting, lacking interest or knowledge, or positive, as outlined below.

#### *'I don't want to know anything about your sex life': Rejecting responses*

Several men recounted rejection of discussion of gay sexuality by HCPs following sexual identity disclosure and requests for gay-specific information. For example, Scott (gay, 59), after disclosing he was gay, recalled his urologist's response was 'let's just stick to what we're dealing with here, which is the prostate cancer'. Gareth (gay, 65) said his urologist told him 'I don't want to know anything about your sex life' after he asked for support regarding reduced penis size, leading Gareth to infer 'I think it was because I was gay'. Similarly, when Colin (gay, 68) asked a urologist about anal sex post-prostatectomy, he said the urologist 'looked as if I had maybe hit him in the face with a lemon meringue pie or that we were both in church and I had just broken wind and pointed at him'. Participants told us such responses from HCPs 'made me feel uncomfortable', 'annoyed', 'not natural' or 'not safe'. The implications of this are illustrated in the account below, where Rick describes feeling that he is 'not normal' or 'dirty' because of his urologist's reaction to a request for information about anal sex:

We started talking about anal intercourse and he said, 'ah look I can't go there I want to stop, you know, I'll stop the conv[ersation]' – and I thought well, okay, well it's important to me but I obviously can't talk to you about it... Well, you take it as well it's not normal, is he thinking it's dirty, and he obviously thinks it's not normal because I'm sure

he doesn't stop heterosexual men from talking about having intercourse with their wives (Rick, gay, 59).

Zachary (partner, 59) stated perceived discomfort from HCPs also reinforces social constructions of 'gay sexuality portrayed as the sort of, a bit smelly and on the sidelines... like a distasteful topic [laughs].' Additionally, experiences of rejection could result in a number of GB men avoiding future disclosure, with Colin (gay, 68) stating 'it is because of occurrences like that [perceived rejection] that I think a lot of gay men are very guarded', adding, 'what help is it if they [HCPs] know, but you don't feel safe in talking'.

#### *'I could have said it to the wall': Lack of knowledge or interest*

The majority of participants positioned HCPs as 'lacking interest' or 'reluctant' to discuss the specific needs of GB men in relation to PCa, with HCP knowledge of gay sexuality perceived as 'very sketchy'. For example, participants made comments such as 'I could have said it [disclosed] to the wall, he had no reaction whatsoever, he wasn't remotely interested' (Jerry, gay, 66), and 'the urologist at the time didn't seem to know much about the difference between gay sex and straight sex, or being gay, whether that would have any bigger impact on me' (Graham, gay, 74). A number of men stated that HCPs lack of knowledge and interest left them without answers to requests for gay-specific information, as illustrated in the accounts below:

Nobody has ever been able to tell me, however, how long one should wait after being the receptive partner before having a PSA test. There seems to be an alarming ignorance in the profession on this issue and other issues affecting men who have sex with men (Barry, gay, 61).

None of the registrars [medical residents] had any idea on how having a radical surgery would affect a gay man. Or how some of the side effects could impede on anal sex (Lucian, gay, 51).

A number of men described unanswered requests for gay-specific information led to them undertaking their own 'voyage of discovery', or having to 'make the primary connection' with referral sources for tailored support, which left them feeling 'anxious' and 'frustrated'. Others felt 'deflated' or 'disappointed' for still not having the answers:

Is to be a bottom going to be dangerous, you know, for somebody who's been a top because you've had to

have your prostate removed? All these sort of things I don't know, and I still don't know but he [the urologist] sort of wasn't going there (Euan, gay, 66).

Such accounts highlight the potential psychological consequences for GB men when their sexual well-being needs are not acknowledged or followed up by primary care HCPs. One bisexual man suggested HCPs were even less supportive of bisexual men:

People just don't understand what it's like to be bi, married, and not out. People understand gay and straight but bi guys don't fit so we seem to be ignored. It tears you apart internally and we get no help (Cameron, bisexual, 65).

As a consequence of unmet sexual and emotional needs, some participants stated they sought out gay or 'gay-friendly' HCPs: 'it should be with a male who is preferably gay' (Elijah, gay, 79); 'I probably would have felt more comfortable if I saw a gay urologist' (Scott, gay, 59). However, the need for all HCPs to be able to support GB men was also emphasised, due to issues of access – 'I live in rural area so it is very difficult even to see a gay-friendly health professional' (Andy, gay, 61) – and the need for increased cultural competency, as described below:

It'd be nice to have a gay specialist but I mean, do you really want the whole community to be split down the middle or fractured with 'I'll only go to a gay specialist'?... If you can sort of try and at least address the problem of surgeons and specialists in prostate cancer to at least have a tick box that they actually address the implications and talk about – I mean they might be uncomfortable doing it but I mean at the same time they're a medical professional, they should be able to go for it (Euan, gay, 66).

#### *'I found that quite comforting': Acknowledgement and positive support*

Several participants stated that some HCPs were responsive to sexual orientation disclosure and to requests for gay-specific information, openly and candidly discussing gay sexuality. For example, participants commented: 'she [urological nurse] was very interested in knowing about how gay men deal with this sort of thing and their sexual encounters' (David, gay, 64); 'she [psychologist] sort of wanted me to talk to her so that she had a better perspective of where I was coming from' (Clive, gay, 70); 'both my GP and specialist are open to frank discussions' (Timothy, gay, 65). These men reported that although some HCPs

often lacked the necessary knowledge and awareness to automatically answer requests for gay-specific information, they were interested in understanding GB men's concerns and sought information and resources to support them, as illustrated in the account below.

I have been fortunate in having a very caring professional who has gone the extra distance to improve his knowledge of how prostate cancer affects gay men and their relationships. He is shocked at the lack of resources and support available to gay men. He has ordered a number of resources for myself and my partner from overseas to help (Rick, gay, 59).

Healthcare professionals' efforts to explore the impact of PCa on gay male sexuality were reported to have a positive impact on psychological adjustment and feelings of 'comfort' post-cancer, as evidenced by Mason's account:

Part of the process should be that there is someone who deals with your psychological and emotional side of what's going to happen to you, just as much as the physical. They've been very interested to try and find information that is specific to gay people. They've been very interested in listening to my story the whole way through. And I found that quite comforting (Mason, gay, 68).

This suggests that positive responses to sexual orientation disclosure, and provision of targeted GB sexual information, have implications beyond the sexual domain.

## DISCUSSION

The present study adds to a growing body of literature in cancer research of unmet patient needs in communication about sexuality (Hordern & Street 2007; Hawkins *et al.* 2009; Gilbert *et al.* 2014). Reports of inadequate discussion of sexual and psychological needs with HCPs in the present study reflect prior research with predominantly heterosexual samples of PCa patients. However, a number of GB specific concerns were also identified, which have practice implications for HCPs working in PCa care, in order to inform targeted care for GB men.

### Psychosexual support

The finding that the sexual and psychological concerns of GB PCa patients are generally not addressed by HCPs in favour of medicalised cancer care reflects other qualitative studies reporting on the sexual support experiences of PCa patients (Ream *et al.* 2008; O'Brien *et al.* 2010; Galbraith *et al.* 2012). Negation of psychosexual aspects of care by



many HCPs might relate to socio-historical approaches to PCa and sexuality which include: urologists downplaying of the sexual side effects of PCa to encourage men to opt for treatment (Kubitschek 1994); patient rationalisation to treat and fight PCa, which renders sexual well-being as secondary to survival (Olliffe 2005); and the more recent medicalising (and marketing) of sexual dysfunction as primarily a physiological event (Klaeson *et al.* 2012). It has also been suggested that the dominance of hegemonic masculinity within men's health, where men are represented as stoical, strong, competent and assumed to be heterosexual, might negate acknowledgement of the diversity of men's sexual interests, as well as their emotional vulnerabilities post-PCa (Gray *et al.* 2002; Kelly 2009). Within the confines of hegemonic masculinity, a 'language of emasculation' has been associated with sexual dysfunction post-PCa treatment, which can evoke shame and silence when discussing sexual well-being (Wassersug *et al.* 2010). This silencing might reflect a 'dissociation of care' (Kampf 2013) between men with PCa and their HCPs, where men become stereotyped as self-sufficient or not wishing to receive help, and HCPs tend to avoid men's sexual difficulties due to fears of shaming or emasculating them. Reproduction of discourses and assumptions associated with hegemonic masculinity and biomedical approaches to cancer are key barriers to addressing the sexual and psychological well-being needs of GB men with PCa. This may also lead to a narrow view of heterosexuality, neglecting the diverse sexual needs of heterosexual men, such as those who have reported engaging in receptive and insertive anal intercourse before and after PCa treatment (Dowsett *et al.* 2014).

### The assumption of heterosexuality

Previous qualitative research investigating communication between sexual minority patients and HCPs found that cancer care was positioned as hetero-centric or dismissed the relevance of sexual orientation to care, resulting in reduced psychosocial support for sexual minorities (Sinding *et al.* 2004; Thomas *et al.* 2013; Ussher *et al.* 2013). It has been reported that HCPs working in cancer often remark 'I treat all my patients the same', a stance that potentially reifies hetero-centrism by assuming all patients are heterosexual (Quinn *et al.* 2015). This assumption can lead to the negation of the needs of GB men with PCa, and supports assertions that GB men with PCa are an 'invisible diversity' (Blank 2005) or 'hidden population' (Filiault *et al.* 2008). While HCPs need to acknowledge that each patient may have specific sexual needs, a proportion of the patients they see are GB men,

whose needs and concerns might differ from many heterosexual men, due to the impact of PCa on gay sexual practices, gay relationships and gay identities (Thomas *et al.* 2013; Ussher *et al.* in press). However, the success of bringing GB concerns into clinical discussions rests heavily on HCPs motivation to become culturally competent with regard to sexual orientation disclosure and discussion of gay sexual concerns.

### Sexual orientation disclosure

Rates of disclosure by GB men in the present study were similar to other sexual minority and health studies (Labig & Peterson 2006; Petroll & Mosack 2011). The finding that some GB men utilised disclosure as a tool to gauge HCP confidence and comfort discussing gay sexuality reflects prior research where GB men reported changing urologists if theirs was not 'gay-friendly' (Thomas *et al.* 2013). GB men's reasons for adopting an avoidant or hesitant stance to disclosure supports previous research where difficulties disclosing were associated with anticipation of disapproval based on past experiences of discrimination, concerns about medical mistreatment or privacy, and patient beliefs that disclosure is irrelevant to care (Stein & Bonuck 2001; Boehmer & Case 2004; Neville & Henrickson 2006). The hesitant stance to disclosure adopted by the majority of the sample supports prior sexual orientation disclosure research drawing on self-presentation theory (Barbara *et al.* 2001), which posits that individuals, wishing to present themselves favourably, often gauge the probability of a negative reaction before disclosing a potentially stigmatising characteristic.

A key aspect of culturally competent care to ameliorate these difficulties is HCP facilitation of sexual orientation disclosure (McNair & Hegarty 2010). This is for a number of reasons, which include: HCP-led facilitation of disclosure has been shown to allay fears of disapproval and improve care (Stein & Bonuck 2001); sexual minorities dislike it when healthcare providers presume that they are heterosexual, even if they are too fearful to disclose (Barbara *et al.* 2001); and incidents of disclosure are purported to foster greater self-acceptance (Schrimshaw *et al.* 2013), while reducing the negative health outcomes of internalised homophobia and concealment (Pachankis 2007; Durso & Meyer 2013). Additionally, if HCPs were to demonstrate GB cultural competency by explicitly acknowledging sexual orientation, this could resolve patient uncertainty as to the relevance of sexual orientation to PCa care and serve as a segue to discussing the potential impacts of PCa on GB patients. Previous research has suggested discussions of sexuality are often

absent in cancer care because some patients 'trust in the expert', believing HCPs will talk about sexuality if it is important (Hordern & Street 2007). This further reinforces the need for HCPs to take responsibility to educate GB men on the relevance of sexual orientation to PCa to bring relevant concerns to the attention of patients. In addition to verbal facilitation of disclosure by specifically asking patients how they self-identity in terms of sexual orientation, HCPs can support disclosure by fostering an inclusive clinical environment with 'gay-friendly' visual cues such as posters, brochures and information (McNair & Hegarty 2010). Such practices, if adopted by HCPs in the context of PCa, might offset GB men's perceptions that HCPs are unaware or disinterested in GB issues, and lead to increased discussion of GB sexual concerns.

### Talking about gay sexuality and gay sexual practices

A key aspect of culturally competent clinician–patient communication is an overtly non-judgemental, affirming attitude to sexual minorities (McNair & Hegarty 2010), which in this study, was perceived to be adopted by only a minority of HCPs. GB men with PCa perceived many HCPs lacked the skills, comfort, interest and knowledge, to communicate about gay sexuality. This supports prior research estimates that when HCPs know the sexual orientation of their sexual minority patients, less than 20% of HCPs provide medical information relevant to their sexual behaviours (Labig & Peterson 2006). Although limitations to discussing sex within clinical settings, such as time restraints, were perceived by patients, primary care physicians serve as an ongoing contact throughout PCa care. As such, education and training of HCPs into how to communicate about gay sexuality is needed. This would empower HCPs to provide information regarding a broad range of sexual practices, and to discuss the meanings of these changes in the context of both long-term and casual GB sexual relationships, to avoid heteronormative assumptions. HCPs need to ensure they are either resourced to provide relevant information regarding GB men and PCa, or seek out answers to GB men's concerns as they arise rather than ignoring them. In this view, information kits have recently been developed for GB PCa patients and their HCPs (Wong *et al.* 2013, PCFA 2014, Prostate Cancer UK 2014), as well as for LGBT patients across the cancer continuum (Buchting *et al.* 2015). Medical students within urology and oncology would also benefit from more training on PCa and sexuality, including a focus on GB needs and experiences. Increasing HCP confidence in discussing gay sexuality through education and access to resources may in turn reduce perceptions that

HCPs possess insufficient knowledge, interest or comfort, to discuss gay sexuality in the context of PCa.

### Strengths and limitations

The key strength of the present study is that it stands as the only study to date specifically investigating GB men's experience with HCPs in the context of PCa, and the largest study of the subjective experiences of communication between GB men and HCPs in the context of cancer. The limitations of the study include the use of a self-selected volunteer sample via multiple recruitment methods, which may have attracted participants motivated by negative experiences of sexual communication; the small proportion of bisexual men and male partners in the sample, despite concerted efforts to recruit such men; the predominantly Anglo-Australian-USA-UK sample, which may not represent views of GB men from other ethnic backgrounds; as well as the fact that HCPs were not surveyed or interviewed as part of the study, suggesting further research is needed in this area.

### CONCLUSION

This study indicates that GB men with PCa are potentially marginalised from support for sexual changes experienced post-cancer. To tailor increased support for GB men with PCa, HCPs need to address issues of hetero-centricism within PCa care by improving facilitation of sexual orientation disclosure, recognising that GB men with PCa might have specific sexual needs post-cancer, and increasing knowledge and comfort discussing gay sexuality and gay sexual practices. Further research is needed to inform improved HCP communication about PCa, sexuality, and sexual well-being to address these issues.

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