

Exploring the lived experience of gay men with prostate cancer: A phenomenological study

MCCONKEY, Robert W. and HOLBORN, Catherine <<http://orcid.org/0000-0002-2211-1022>>

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Introduction

Prostate cancer is the second most commonly diagnosed, non-cutaneous male cancer worldwide, and it is the most common cancer diagnosed in men in Europe (Cancer Research UK, 2014). In Ireland, 5 year survival rates are reported as greater than 91% (National Cancer Registry Ireland, 2016).

Sexual dysfunction, urinary incontinence (UI), bowel dysfunction, gynaecomastia, weight gain, depression, and fatigue are frequently reported distressing prostate cancer treatment side effects. They are experienced to varying degrees of severity and duration, and can have an appreciable burden, negatively impacting the quality of life (QOL) and psychosocial functioning of men treated for prostate cancer (Sanda et al., 2008, Bourke et al., 2015, Carlsson et al., 2016).

Most of the published literature regarding prostate cancer however, has been conducted primarily in heterosexual, mostly married, Caucasian men (Dowsett et al., 2015). The invisibility of the lesbian, gay, bisexual, and transgender (LGBT) community in cancer care generally (Blank, 2005), and of gay men with prostate cancer specifically, has been highlighted (Allensworth-Davies et al., 2015, Dowsett et al., 2015). Gay men will experience the same treatment side effects as heterosexual men, however the impact on gay men may be different, and in some ways 'unique' (Motofei et al., 2011, Dowsett et al., 2015, Ussher et al., 2016b).

Despite an emerging trend of research being conducted with this population, there remains a paucity of published literature on the experiences of gay men with prostate cancer. Therefore, the aim of this research was to describe the lived experience of gay men with prostate cancer in Ireland. The objectives were to add to the emerging body of literature on gay men with prostate cancer, to broaden the research base, and to increase healthcare professional (HCP) knowledge and understanding of the issues faced by gay men with prostate cancer.

Methods

Giorgi's descriptive phenomenological method (Giorgi, 1997, Giorgi, 2009, Giorgi, 2012) presented in Table 1 outlines the concrete steps involved in conducting the study, and was deemed the most appropriate mode of inquiry to answer the research question; 'What is the lived experience of gay men with prostate cancer in Ireland?'. The overarching question asked to each participant was; 'Can you describe to me your experience of what it is like being a gay man with prostate cancer in Ireland?'. Additional prompts were then used during the interviews to ensure the phenomena was fully explored; from their initial diagnosis through to living with the side effects of treatment and, for some, the ongoing management of their cancer. For example, some of the prompts included 'Can you tell me what influenced your treatment choice?', 'Can you describe how being a gay man influenced your treatment decision?', or 'How has the treatment affected your quality of life in terms of ...sexual relationships? ...masculinity? ...being a gay man?', 'Can you explain how that made you feel?'.

Employing the phenomenological attitude, or reduction, also referred to as bracketing, is fundamental for demonstrating rigour and validity in descriptive phenomenology (Dowling, 2006, Finlay, 2008, Giorgi, 2009, Creswell, 2013, Mann, 2016). Bracketing is widely acknowledged as a method of holding in abeyance ones pre-existing knowledge about a phenomenon by focusing critical attention to the participants lived experience (Giorgi, 2009, Creswell, 2013). A reflexive journal was maintained throughout the study and is advocated as a means of demonstrating reflexivity for the purposes of bracketing one's biases (Dowling, 2006, Chan et al., 2013).

Purposive sampling was used in this study which is synonymous with qualitative research. Additionally, chain referral sampling was also employed. This is an adaption of snowball sampling, which has been used as an efficient, culturally competent strategy commonly used by nurse researchers (Penrod et al., 2003, Sadler et al., 2010). It was considered appropriate given the characteristics of the population under study, which have been described as stigmatised, vulnerable,

geographically dispersed, and 'hard to reach' (Penrod et al., 2003, Bonevski et al., 2014, Simon Rosser et al., 2016).

Posters and advertisements providing information about the study, were deployed in a broad range of settings including prostate cancer support groups, urology clinical settings and waiting rooms, gay venues such as bars, clubs, sports and social organisations, and included both print and online distribution to their associated social media accounts. Additionally, two advertisements were promoted in the Gay Community News, Irelands leading gay monthly magazine both online and in print. After extensive recruitment efforts, the final sample size of 8 participants was considered sufficient and is similar to other qualitative studies with similar populations (Thomas et al., 2013, Hartman et al., 2014). As advocated by Guetterman (2015), a reflexive process was engaged where issues of sampling and theoretical data saturation were considered and continually assessed.

The average age of the men in this study at time of diagnosis was 55.6 years (range 49 – 66 years). There was wide heterogeneity in the treatments received and the average time since initial treatment was 5.9 years (range 3 – 10 years). Five of the eight men were in a same sex relationship at time of diagnosis and all but one was 'out' in their general lives. Six of the eight men had attended third level education. Participant demographics are presented in Table 2.

In-depth face to face interviews conducted in a neutral venue were the primary method of data collection, and are promoted as both a means of achieving greater depth and richness, and for sensing participant nuances (Englander, 2012). Due to personal circumstances, one of the interviews was offered and conducted by telephone. With the participants' consent, all interviews were recorded on both a Dictaphone, and a backup recording device. Field notes were maintained to capture and record insights deemed appropriate by the researcher. The recorded interviews were listened back in full on the same day as recording, and were transcribed verbatim by the researcher. The average length of an interview was 62 minutes

(Range 24 minutes – 111 minutes). Pseudonyms are used throughout this paper to ensure participant anonymity.

Ethical approval and indemnity was granted by the university ethics committee. Permissions were also sought, and granted, from organisations where recruitment material was posted.

Data Analysis

Data analysis followed the steps outlined in Giorgi's descriptive phenomenological method presented in Table 1. The researcher's disciplinary perspective and professional sensitivity guided the process (Giorgi, 1997). This perspective emanates from the context of the researchers fourteen years holistic urological nursing experience and having studied Giorgi's phenomenological method.

While assuming the phenomenological attitude, and maintaining it throughout, the initial step involved reading all the transcripts to get a general or global 'sense of the whole' (Giorgi, 1997, Giorgi, 2009). This is congruent with the holistic approach employed in phenomenology. The next step consisted of dividing the data into 'meaning units'. This involved physically marking the points on the page where a transition in the meaning occurred. Meaning units were then transformed from the language of the participants into the language of nursing science. Next, each meaning unit was made more explicit using a method called 'free imaginative variation' which helps determine essential intuitions congruent with the researcher's discipline and was expressed as a statement of the structure of the experience. This process was completed with each of the participants' data.

In Giorgi's final step, the structure of the phenomenon is expressed by once again using imaginative variation to decide which features are imperative for the phenomenon under study and which are unessential (Giorgi, 1997). It is through

this iterative process that synthesis of the essential structures of the participant's concrete lived experiences were described.

Validation & Reliability

Various strategies advocated by Creswell (2013) were employed to enhance the validity of the study and the credibility and trustworthiness of the findings (Darawsheh, 2014). As previously described, reflexivity was one of the means of demonstrating validity. Building rapport with the participants and providing detailed descriptions of their experiences, as well as articulating the methods and process of conducting the study enhances its validity (Creswell, 2013). The researcher also maintained field notes during the interview process, making notes of nuances in change of body language, or perceptions of attitudinal shifts by the interviewee. Reliability in qualitative health research refers to the congruence of responses by different coders to the analysis of the same data (Creswell, 2013), and was performed by the researcher's supervisor where transcripts and data analysis were reviewed in a systematic process until agreement was reached.

Findings

The general structure of the phenomenon 'the lived experience of gay men with prostate cancer in Ireland' emerged with three key themes representing the essence of the participants lived experience. The three key themes and subthemes to emerge are presented in Table 3.

The experience of diagnosis, treatment decision making, and the impact of treatment

Shock of Diagnosis

All the men described the incalculable shock they experienced at the time of diagnosis. Men who were alone at time of receiving the news described a sense of turmoil and distress "...I was totally shocked...I really don't know what I heard..." (P1 Steven, alone at time of diagnosis).

Treatment decision making

Information on treatment decision making was sought from a wide variety of sources; GPs, consultants, nurse specialists if available, cancer charities and gay community resources combined with intensive searching on the internet. The volume of information overwhelmed some and confused others. *"...you actually don't know where to start looking for information, and you look on the internet and you want to go out and hang yourself <laughs>, it's not the best place to look... so I think the initial problem was to try and find sources of information..." (P3 Paul), and "...WebMD on the computer...it was way out of my league, so I just, I said I'd go for the beads (brachytherapy) because, I dunno, it just...it looked the best option" (P2 Evan).*

Men who reported feeling comprehensively informed with full and frank disclosure around the treatment side effects and their potential impact, were less inclined to report distress, even by the younger men, or those who reported emotional difficulty with the treatment decision making process itself *"...I discussed everything with him... he knew that for gay sex ya know, you need a stronger erection, so he was quite open about all that..." (P8 Jim, treatment side effect discussion with his consultant).*

Conversely, a perceived information deficit resulted in anger, frustration and regret *"there's that kind of...I suppose it's kind of an anger that would be there from cancer anyway, but just...some of it is down to the lack of information that was provided ya know, and therefore people made decisions based on an incomplete picture, I think, I did anyway..." (P4 Kevin).*

Most felt it would be a good idea to speak with another gay man with prostate cancer not only at this time-point but at various stages throughout the journey *"...I thought it would be easier to talk to some gay people, ya know, you could be more open about it..." (P1 Steven).*

Treatment related side effects

Sexual dysfunction & Erectile dysfunction (ED)

Treatment related ED was reported to varying degrees by all the men in this study and resulted in some experiencing feelings of guilt for being unable to fulfil the needs of a partner, resignation to total celibacy, or experiencing a self-imposed exclusion from the gay community. Almost all the men reconciled a degree of ED to the ageing process, and some by recalling a fulfilling sexual life pre-treatment, allaying the emotional burden.

One man reported reversing his role in penetrative sex from being the insertive (the 'top') to the receptive (the 'bottom') partner to accommodate his desire to maintain a healthy and active sex life with his partner *"I became the bottom...there wasn't much of a choice really to be honest, it was either that or become a monk or give it up completely, so am, I just adapted myself to being the bottom in the relationship..."* (P6 Andy).

Most men engaged in a program of penile rehabilitation and reported varying degrees of success. The process was found to be impersonal, mechanical, and mostly absent of context or sensitivity from a gay man's perspective *"...so she never even dreamed of asking, ya know just sort of say what sort of sexual practice do you engage in or what , ya know, has this made a huge difference to your life, so she was talking in terms of the mechanics of how to get an erection whereas....it was no support in terms of....ya know like individually what does this mean...like she wasn't selling tins of beans to people..."* (P4 Kevin).

Another man described the impact of treatment being acutely realised when engaging in sexual activity with his partner and comparing his 'new self' to his partner; *"being a gay man...you are obviously with another man, and experiencing*

him, and comparing what I'm like compared to him there beside me...that sometimes hits me" (P8 Jim).

Orgasm and anejaculation

All the men described a diminished sensation and decreased intensity of post treatment orgasm with a consequential reduction in pleasure *"the release that was there prior to the surgery... that is not there anymore"* (P8 Jim), *"...there is no real pleasure to it..."* (P7 Jerry). Orgasm was not always achievable which led to feelings of frustration. Anejaculation was deeply distressing, especially in the younger men, and described as a significant loss which was intensified by the absence of support to discuss it *"sometimes like when my partner is ejaculating and that sort of stuff I'd be thinking wouldn't I love to be able to do that again and experience that again"* (P8 Jim), and *"...it's a huge loss...I really miss being able to ejaculate...who do you say that to, or where do you say that?"* (P4 Kevin).

Urinary incontinence

The men in this study had markedly differing experiences of UI ranging from a bearable inconvenience, to an intolerable and shocking event primarily in the first two years of recovery but moderating for most over time. Kevin (P4) described his incontinence as *"alarming and unbearable..."*, while Tony (P5) stated that it *"nearly drove me insane..."*. Some men felt forced to abandon cherished recreational pursuits such as swimming or cycling, social activities such as enjoying a drink with friends, and others were fearful and anxious at work in case a visible leak would occur.

Those who experienced climacturia found it both embarrassing and grievous, as Kevin (P4) put it *"I think dry orgasms are bad, as bad and all as they were, are better than when you are urinating on yourself or somebody else... I would be more embarrassed ya know if there is any element of urine coming out, it just, ya know, it would take me a month again before I would even contemplate doing anything"*, or as Jerry (P7) put it: *"...if I'm with somebody, all I'm trying to do is, ya know, stop from pissing on them..."*.

Penile Shortening

Three of the men made specific reference to the negative impact of penile shortening not only on their body image, but also as being embarrassing and a continuous reminder of *'being less than whole'* (P7 Jerry), which resurrected feelings of anger.

Impact on masculinity

Half of the men described the adverse impact of prostate cancer treatment on their masculinity associated with their experiences of sexual dysfunction including penile shortening, anejaculation, and especially ED. This was palpable in reports by Kevin (P4) of *"feeling less than a man"*; by Andy (P6) who felt at times that he wasn't a man anymore since he *"...can't even get a hard on..."*; and by Jerry (P7) who said that prostate cancer treatment *"....annihilated who I am...like someone took my manhood out ...just got it and took it away from me and I can't, I can't address that..."*. One man considered the assault by prostate cancer on his masculinity was further complicated by the public perception of gay men being less than masculine, indicating elements of stigma and minority stress as contributing factors *"I suppose as a gay man...there is always that thing that...people would say, sure gay men, you know, you are not really masculine, or you are not as masculine as a straight man anyway..."* (P4 Kevin).

Others denied any impact of treatment on their masculinity, one finding humour affording a protection to the threat, and another viewed masculinity as a multifaceted concept incorporating a person's whole personality and not being solely bound to sexual functioning. Yet another, in relation to masculinity, moderated the impact on his *'manly functions'* (P3 Paul) by considering it as inevitable, analogous to women experiencing menopause.

Impact on gay identity

Some of the men strongly felt the impact of prostate cancer on their identity as gay men, or within the gay community. For Andy (P6), prostate cancer imparted a threat to his gay identity related to his alignment with phallocentrism, leading to issues of low self-esteem and questioning his position within the gay community. This was acutely felt while he was single, a time when he harboured fears of loneliness and isolation from the gay community due to his ED being *"a very taboo subject"* for

which *“...you certainly don’t want to stand out in that community... and you certainly wouldn’t be broadcasting what was going on with you, especially if you are not in a relationship... and I suppose it changed my perspective in that now I knew that I am not the same as every other gay man that is walking around”*. Jerry (P7), who was single prior to, and since diagnosis, also expressed the impact on his gay identity in a similar fashion *“...as a gay man... it annihilated who I am...like who am I? ...I’m a eunuch...”*. This made him feel like an incomplete sexual being unworthy and incapable of offering a valuable relationship.

Most of the men however, denied any impact on their identity as gay men. Paul (P3) considered being a gay man as only a small part of his identity, and while hormone therapy had entirely robbed him of his libido, which he described as a strange feeling, he went on to state that *“...it wasn’t something that ya know, had me depressed...”*. Others, didn’t see themselves as ‘gay men’ with prostate cancer, just men with prostate cancer who happened to be gay, and therefore did not articulate the specific impact on their identity as gay men. For example, Tony (P5) said *“...it never came into it, you know, it was, it was just like everybody, it was just like any ordinary individual man being told they had prostate cancer... I never just really thought of myself as a gay man... I would think that probably if my ...my sexual life had been different it would have affected me more”*. And although Jim (P8) later went on to describe the ways it impacted him as a gay man in term of sexual expression, information, and support, he did not associate this specifically with his identity as a gay man *“not as a gay man, just ya know, obviously, the impact of it as a man really, just the whole experience of it and all that kind of a thing, nothing that is specifically because I am a gay man”*.

The experience of the healthcare service

Sexual orientation disclosure

While most of the men in the study were comfortable disclosing their sexual orientation to their HCPs, it was challenging for others due to fear of a negative reaction. Steven (P1) stated *“...I just thought, I dare not...I got a bit afraid...”*, and another man was apprehensive due to a historical lack of acceptance of members of the LGBT community *“...nobody of my generation is entirely comfortable...so I didn’t find it particularly easy...”* (P3 Paul). Most disclosure occurred as the participants

brought and introduced their male partner at time of diagnosis, and none experienced any negative reaction.

Communication with the healthcare team

Participants often described the importance of establishing rapport and building a trusting relationship with their HCPs. Communication around sexual side effects of treatment however was sometimes difficult resulting in unmet needs. For instance, Tony (P5) describes his experience of his sexual side effect discussion; “...*and when I ask questions about that...oh, well it was like taboo! They didn’t want to kind of talk about that...*”, and Jerry (P7) “...*I would call myself versatile leaning towards a top... that doesn’t mean that I haven’t had prostate massage... which is extremely pleasurable... that ceased in my life for the reason, well there is no prostate there, and anyhow I was terrified... what is there in terms of the mutilation?... now I was afraid to ask anybody, but it was a real question*” (P7 Jerry).

Two of the men reported on the effort by their consultants to understand their specific concerns related to gay sexual practices, such as penetrative sex requiring a firmer erection, and fears related to receptive anal intercourse (AI) in the absence of a prostate post-surgery. Others with similar concerns were reluctant to ask these types of questions of their HCPs and were at a loss as to who to ask, or from where they could source this information. Sometimes their information seeking on intimate topics was met with HCPs ambivalence, leading them to believe the subject was taboo, which resulted in distress and despair.

All the men reported positive experiences with their GPs to whom they were all out, with one exception, and they served as an important source of support.

Specialist nurses

Less than half of the men had access to a urology or prostate cancer nurse specialist. With one exception, these men described them as their greatest source of support in the healthcare system in terms of expertise, professionalism, and advocacy, however, some of the participants were critical of the mechanical focus of penile rehabilitation, an absence of knowledge of gay specific sexual concerns, and a deficiency in the provision of psychosexual support. When Kevin (P4) was looking

for support around restoring his sexual functioning he found the nurse specialist *“...didn’t have any of the language to talk about gay sex or...not even gay sex...I would have thought she might have done a bit of homework...I presume not everyone going into her was straight...I could hardly have been the first gay man she had met...and lots of people have different sexual practices, you know...it was kind of...she was just uncomfortable...”*.

Sources of support and means of coping

Significant others, family & friends

The participants in this study received support from various sources including family members, friends, and significant others. Men who were single or closeted report the lowest level and number of sources of support. They described an experience of going it alone, or engaging their own resources to cope, and believed there was no one who could understand their experience.

All the partnered men in this study reported their partner as being their main source of practical, informational and emotional support which mediated the impact of the disease. The significance placed on partner support is evident in the following participants descriptions; Andy (P6) who was single for a period of 18 months, 5 years after diagnosis stated that *“...my best would have been my partner...it’s a lonely place being a gay man without support like that, especially if you don’t have a partner...”*, Kevin (P4) *“absolutely, would be the rock”*, and Jim (P8) *“obviously my partner ya ya, absolutely 100%, it would have been a difficult journey without him... certainly having one by your side who is so understanding ya know makes a huge difference....”*.

Cancer Support Groups

Prostate cancer support groups were found to be mostly populated by older men, held heteronormative dyadic assumptions, discussed topics on a superficial level, and had no experience or materials related to the supportive care needs of gay men. As Steven (P1) explained *“...the men in the group... they’d be talking about their wives and the help their wives were”*. And Alan (P6) searched for a prostate cancer

support group *“to see if I could find someone like me, that would have been in the same position and there wasn’t ...they didn’t have any of that information”*.

Gay community resources

Most men searched for gay resources, primarily information sources or support for gay men with prostate cancer online. None of the men found any resources for gay men with prostate cancer originating in Ireland, leaving some to experience a sense of loneliness and isolation. This angered some men who contrasted the level of resources directed towards gay men’s sexual health related to Human Immunodeficiency Virus (HIV) or sexually transmitted infections (STI) *“...there is never anything in them about prostate cancer...they were supposed to be good on health...on the HIV and AIDs and that, there was never a mention of...prostate cancer at all” (P1 Steven)*, and *“that’s the thing, there is no resource, and I mean particularly for gay men, like gay men are as prone to prostate cancer as any other men...there was nothing to say oh, I’ll go to that, like there isn’t a resource there actually” (P4 Kevin)*.

Discussion

The findings suggest that prostate cancer negatively impacts gay men with prostate cancer in Ireland, at various time points in their journey. As evidenced in the narratives by the men in this study, the physical effects of the cancer and its treatment can impair their lives, both psychologically and socially, and affect the quality of life they experience. Distress appears to be compounded by deficits in HCP knowledge and communication skills concerning treatment decision making, aspects of gay men’s sexual practices, and from a deficit in community based support from leading cancer charities or from within the gay community. It is acknowledged that the more prevalent literature, which focuses on the experiences of heterosexual men, also reports similar experiences related to the shock at time of diagnosis, difficulty with treatment decision making, the impact on sexual functioning, and on masculinity. There are, however, obvious and notable differences which are

of particular significance to gay men that this, and other similar studies, have highlighted.

With regards to treatment decision making, HCP communication difficulties and information deficits within this population have been reported (Thomas et al., 2013, Dowsett et al., 2015, Ussher et al., 2016b, Speer et al., 2017). An apparent deficit in patient-centred care is consistent with findings of the experiences of other gay men with prostate cancer care (Wong et al., 2013) and in LGB patients in general (Hulbert-Williams et al. 2017). Inadequate patient-centred HCP training compounds a hetero-normative bias in both the education system and in healthcare provision in general (Wong et al., 2013, Dorsen and Van Devanter, 2016, Speer et al., 2017) resulting in less positive cancer care experiences (Hulbert-Williams et al., 2017). HCPs should be particularly cognisant to the needs of un-partnered or unaccompanied gay men at this time as they have reported greater dissatisfaction and psychological distress with HCP information provision and communication (Wong et al., 2013, Speer et al., 2017).

In terms of the role of erections, erectile dysfunction may mean that it is no longer possible for the man to be the 'active' partner in the relationship. Even those who regain some erectile function will require a firmer erection for anal penetration compared to vaginal sex (Ussher et al., 2016b). While role reversal from active to receptive partner is possible, flexibility such as this is acceptable only to a minority of men (Dowsett et al., 2014, Hart et al., 2014, Rosser et al., 2016, Ussher et al., 2016c). A possible reason for the low numbers of men adopting role reversal is that oral sex and mutual masturbation are more commonly practised by gay men (Dowsett et al. 2015), followed by anal intercourse (Lee et al. 2015) and is therefore not part of the repertoire of all gay men. Additionally, some men may be reluctant to adopt the receptive position due to anal discomfort post treatment (Ussher et al., 2016b).

Treatment associated sexual dysfunction has a clear psychological impact on gay men. For those experiencing ED, or diminished libido, this could result in a self-

imposed exclusion or disqualification from sexual engagement, leading to feelings of isolation and psychosocial distress (Dowsett et al., 2014,Ussher et al., 2016a,Ussher et al., 2016b). A perceived inevitable decline in erectile functioning due to the ageing process may mediate the distress and facilitate coping with the loss (Hartman et al., 2014,Dowsett et al., 2015,Ussher et al., 2016c). Another aspect relates to the psychological impact of treatment imposed ED when gay men compare themselves to their potent sexual partner (Fergus, Gray and Fitch 2002). Reports of a reduction in penile length have been negatively described in terms of gay identity, and changes in orgasmic sensation also causes anguish (Ussher et al., 2016b). Ejaculate, or 'cum play' is a source of particular enjoyment in gay sexual behaviour (Prestage et al., 2013). Consequent prostate cancer treatment related anejaculation is a distressing side effect also reported by other gay men (Wassersug et al., 2013,Ussher et al., 2016c) which results in a deep sense of loss and yearning, and adversely affects QOL (Hart et al., 2014). The absence of the prostate post-surgery was also lamented as a previous source of pleasure as the prostate has been described as the male 'G' spot (Filiault et al., 2008,Rose et al., 2016). HCPs need to be aware of the broad implications of sexual dysfunction in gay men treated for prostate cancer and its resultant impairment on QOL which appears to be more appreciated than in heterosexual men (Motofei et al., 2011,Hart et al., 2014, Lee et al., 2015).

The negative impact of UI on QOL in men treated for prostate cancer is well known (Johansson et al., 2011). UI, but more specifically climacturia, is a significant source of distress to gay men with prostate cancer (Ussher et al., 2016b). This contrasts with the results of other reports of men treated for prostate cancer which found that climacturia had little impact on bother scores for UI during sexual activity (Frey et al., 2014,O'Neil et al., 2014) despite prevalence rates of up to 38%. Neither study reported the sexuality of the participants however, and a heteronormative bias is assumed.

The effects of prostate cancer treatment on masculine identity and masculine self-esteem is well documented, predominantly in the heterosexual married population

(Fergus et al., 2002, Clark et al., 2003, Zaider et al., 2012). For gay men with prostate cancer the threat may also result in an identity crisis and self-imposed isolation from the gay community. The severity of sexual dysfunction, how closely aligned the participant's views were to the prevailing hegemonic phallogentric discourse, and their level of immersion in the gay community appears to influence the impact (Thomas et al., 2013, Simon Rosser et al., 2016, Ussher et al., 2016a). The threat is mediated not only by the sexual side effects, but how the man responds, and sometimes by the response of his social circle including intimate partners (Thomas et al., 2013, Dowsett et al., 2015, Simon Rosser et al., 2016). Additionally, some men experience a sense of stigma relating to sexual orientation (Thomas et al., 2013), along with associated levels of discomfort when debating disclosing sexuality to a HCP (Allensworth-Davies et al., 2015). Lower masculine self-esteem has been found to be a predictor of health-related QOL (Ussher et al., 2016a) and is therefore an important consideration for HCPs to understand when interacting with gay men with prostate cancer. Conversely, men who do not closely align their identity to their sexuality, or those who accept ED as part of the ageing process could experience less threats to masculinity (Ussher et al., 2016c).

Significant disparities and health inequities between lesbian, gay, bisexual and transgender people (LGBT) and heterosexuals have been identified in the literature (Boehmer et al., 2012). Attitudes toward the acceptability of LGBT people in society are divided (Kohut et al., 2013), intersecting with issues of historical and present day discrimination, stigma, and minority stress (Meyer, 1995, Altman et al., 2012, Meyer, 2013). While sexual orientation disclosure can be problematic for some gay men with prostate cancer (Rose, Ussher and Perz 2016), an affirming disclosure does not necessarily translate into an overall positive experience of healthcare provision. A system of sexual orientation monitoring such as that proposed in the UK (NHS North West, 2011) could assist in addressing the lack of evidence on LGBT healthcare needs and experiences (Hulbert-Williams et al., 2017), including those of gay men with prostate cancer. The practice of sexual orientation monitoring was found to be overwhelmingly acceptable to patients in the United States (Cahill et al., 2014).

Prostate cancer nurse specialists are a valuable resource for prostate cancer patients (Tarrant et al., 2008, Cockle-Hearne et al., 2013). However, medical, nursing, and allied HCPs receive inadequate clinical preparation in LGBT health education which may explain their lack of certainty or perceived ambivalence regarding the health needs of this population (Carabez et al., 2015, Sabin et al., 2015). Increasing education for HCPs regarding the health needs of LGBT patients, including how marginalisation and stigma impact on caring for vulnerable populations is recommended (Dorsen and Van Devanter, 2016).

Capistrant et al (2016) and Dowsett et al (2015) concluded that social support for gay men with prostate cancer is substantially provided by family and friends as opposed to partners, who predominantly provided the support in this study. The predominant literature focuses primarily on the female partners of married men as the main sources of support (O'Shaughnessy et al., 2013, Chambers et al., 2011), corroborating the assertion of a dyadic hetero-normative bias in the prostate cancer literature (Kelly et al., 2017). Single men may be more at risk of psychosocial dysfunction associated with low levels of support not only in single gay men (Thomas et al., 2013, Capistrant et al., 2016) but also in un-partnered men with prostate cancer in general (Matheson et al., 2016), although both remain underrepresented in most published studies. HCPs should remain cognisant to the nature of gay men's social and support structures which differ from traditional sources in published papers.

A hetero-normative bias exists in prostate cancer support groups, and lack of knowledge or understanding of gay men's prostate cancer specific needs from within gay community resources is psychosocially distressing and imparts a sense of taboo around the phenomenon (Wong et al., 2013, Dowsett et al., 2015, Rose et al., 2016). This study identified an area of service provision absent in both the Irish cancer charity sector, and within the gay community resources in Ireland.

Strengths

As far as is known, this is the first study to be conducted on the experience of gay men with prostate cancer in Ireland thereby giving a unique insight to their perceptions from diagnosis, through treatment, and into survivorship.

Another strength is the important contribution this study makes to the paucity of literature on the topic, thereby building and strengthening the evidence base and raising the profile of this under-represented population.

Limitations

While the sample was geographically diverse with men representing the four provinces of Ireland, a recent survey indicated that between 14% and 23% of the gay population in Ireland are foreign born (O'Donnell et al., 2016), yet all of the men recruited into this study were Irish, Caucasian, predominantly well-educated, most were partnered, and their HIV status was not disclosed, and therefore may be unrepresentative of the wider gay community.

Conclusions

As far as is known, this is the first study to investigate the lived experience of gay men with prostate cancer in Ireland. Consistent with the limited body of research conducted in this area, the findings of this study suggest that gay men with prostate cancer in Ireland experience universal feelings of shock at time of diagnosis, have unmet information and support needs at time of diagnosis, treatment decision making, and with regards to side effect management, particularly sexual rehabilitation. These impact on their psychosocial and sexual functioning with consequent impairment to QOL. Issues associated with heteronormativity, minority stress, and stigma, may influence how gay men interact with the health service or perceive the delivery of care.

Some of the issues identified that are of distinct relevance to gay men with prostate cancer include, but are not limited to, the role of ejaculate in gay sexual behaviour, the potential for role reversal in penetrative sex, the prostate as a source of pleasure, a firmer erection being required for penetrative sex, threats to gay identity, differences in social support structures, and an absence of formal support outside the healthcare service provided by the cancer charity sector or the gay community in Ireland. Deficits with communication and HCP knowledge and education may contribute to a perceived ambivalence towards gay men's issues or indicate to gay men that the subject matter is taboo, compounding issues of stigma and minority stress.

A general knowledge of gay culture and gay sexual practices will help HCPs to understand how aspects of prostate cancer treatments and their associated side effects uniquely impact on the lives of gay men. There is an onus on healthcare education providers to include these components in their curricula, and on healthcare service providers to ensure access to such training. HCPs who feel underequipped to adequately address the concerns of this population should engage in education and communication training to increase their confidence in the delivery of care, or refer on to providers who can. Ensuring a supportive environment can be an important first step in building confidence and establishing a trusting relationship.

While many aspects of the prostate cancer experience are shared with all men regardless of sexuality, conducting a comprehensive sexual history and assessment of the supportive care needs of this cohort will require an understanding of the issues identified here that are unique and of concern to gay men with prostate cancer to deliver an equitable culturally sensitive service.

Further research is warranted in all areas of how prostate cancer impacts gay men. Factors influencing treatment decision making, comparative studies of various treatments and their impact on gay men, the impact on partners, and on single gay men, have never been adequately researched.

References

- Allensworth-Davies, D., Talcott, J.A., Heeren, T., de Vries, B., Blank, T.O., Clark, J.A., 2015. The Health Effects of Masculine Self-Esteem Following Treatment for Localized Prostate Cancer Among Gay Men. *LGBT Health* 3, 49-56.
- Altman, D., Aggleton, P., Williams, M., Kong, T., Reddy, V., Harrad, D., Reis, T., Parker, R., 2012. Men who have sex with men: stigma and discrimination. *Lancet* 380, 439-445.
- Blank, T.O., 2005. Gay men and prostate cancer: invisible diversity. *J. Clin. Oncol.* 23, 2593-2596.
- Boehmer, U., Miao, X., Linkletter, C., Clark, M.A., 2012. Adult Health Behaviors Over the Life Course by Sexual Orientation. *Am. J. Public Health* 102, 292-300.
- Bonevski, B., Randell, M., Paul, C., Chapman, K., Twyman, L., Bryant, J., Brozek, I., Hughes, C., 2014. Reaching the hard-to-reach: a systematic review of strategies for improving health and medical research with socially disadvantaged groups. *BMC medical research methodology* 14, 42.
- Bourke, L., Boorjian, S.A., Briganti, A., Klotz, L., Mucci, L., Resnick, M.J., Rosario, D.J., Skolarus, T.A., Penson, D.F., 2015. Survivorship and improving quality of life in men with prostate cancer. *Eur. Urol.* 68, 374-383.
- Cahill, S., Singal, R., Grasso, C., King, D., Mayer, K., Baker, K., Makadon, H., 2014. Do ask, do tell: high levels of acceptability by patients of routine collection of sexual orientation and gender identity data in four diverse American community health centers. *PloS one* 9, e107104.
- Cancer Research UK, 2014. Prostate cancer incidence statistics. <http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/prostate-cancer/incidence> Accessed November 2016.
- Capistrant, B.D., Torres, B., Merengwa, E., West, W.G., Mitteldorf, D., Rosser, B., 2016. Caregiving and social support for gay and bisexual men with prostate cancer. *Psycho Oncology* 25, 1329-1336.
- Carabez, R., Pellegrini, M., Mankovitz, A., Eliason, M., Ciano, M., Scott, M., 2015. "Never in All My Years...": Nurses' Education About LGBT Health. *Journal of Professional Nursing* 31, 323-329.
- Carlsson, S., Drevin, L., Loeb, S., Widmark, A., Lissbrant, I.F., Robinson, D., Johansson, E., Stattin, P., Fransson, P., 2016. Population-based study of long-term functional outcomes after prostate cancer treatment. *BJU Int.* 117, E36-E45.
- Chambers, S.K., Pinnock, C., Lepore, S.J., Hughes, S., O'Connell, D.L., 2011. A systematic review of psychosocial interventions for men with prostate cancer and their partners. *Patient Educ. Couns.* 85, e75-e88.

Chan, Z.C., Fung, Y., Chien, W., 2013. Bracketing in phenomenology: only undertaken in the data collection and analysis process? *The Qualitative Report* 18, 1.

Clark, J.A., Inui, T.S., Silliman, R.A., Bokhour, B.G., Krasnow, S.H., Robinson, R.A., Spaulding, M., Talcott, J.A., 2003. Patients' perceptions of quality of life after treatment for early prostate cancer. *Journal of Clinical Oncology* 21, 3777-3784.

Cockle-Hearne, J., Charnay-Sonnek, F., Denis, L., Fairbanks, H., Kelly, D., Kav, S., Leonard, K., van Muilekom, E., Fernandez-Ortega, P., Jensen, B., 2013. The impact of supportive nursing care on the needs of men with prostate cancer: a study across seven European countries. *Br. J. Cancer* 109, 2121-2130.

Creswell, J.W., 2013. *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*. Sage publications, London.

Darawsheh, W., 2014. Reflexivity in research: Promoting rigour, reliability and validity in qualitative research. *International Journal of Therapy & Rehabilitation* 21.

Dorsen, C., Van Devanter, N., 2016. Open arms, conflicted hearts: nurse-practitioner's attitudes towards working with lesbian, gay and bisexual patients. *J. Clin. Nurs.* 25, 3716-3727.

Dowling, M., 2006. Approaches to reflexivity in qualitative research. *Nurse. Res.* 13, 7-21.

Dowsett, G.W., Lyons, A., Duncan, D., Wassersug, R.J., 2014. Flexibility in men's sexual practices in response to iatrogenic erectile dysfunction after prostate cancer treatment. *Sexual Medicine* 2, 115-120.

Dowsett, G.W., Prestage, G., Duncan, D., du Plooy, D.R., Waling, A., 2015. Moving on: mental health, resilience and sexual recovery among gay men living with prostate cancer. Australian Research Centre in Sex Health and Society (LaTrobe). Australia.

Englander, M., 2012. The interview: Data collection in descriptive phenomenological human scientific research. *Journal of Phenomenological Psychology* 43, 13-35.

Fergus, K.D., Gray, R.E., Fitch, M.I., 2002. Sexual dysfunction and the preservation of manhood: experiences of men with prostate cancer. *J. Health. Psychol.* 7, 303-316.

Filiault, S.M., Drummond, M.J., Smith, J.A., 2008. Gay men and prostate cancer: voicing the concerns of a hidden population. *Journal of Men's Health* 5, 327-332.

Finlay, L., 2008. A Dance Between the Reduction and Reflexivity: Explicating the "Phenomenological Psychological Attitude". *Journal of Phenomenological Psychology* 39, 1-32.

Frey, A., Sønksen, J., Jakobsen, H., Fode, M., 2014. Prevalence and Predicting Factors for Commonly Neglected Sexual Side Effects to Radical Prostatectomies: Results from a Cross-Sectional Questionnaire-Based Study. *The journal of sexual medicine* 11, 2318-2326.

Giorgi, A., 2012. The descriptive phenomenological psychological method. *Journal of Phenomenological Psychology* 43, 3-12.

Giorgi, A., 2009. *The Descriptive Phenomenological Method in Psychology: A Modified Husserlian Approach*. Duquesne University Press, Pennsylvania.

Giorgi, A., 1997. The theory, practice, and evaluation of the phenomenological method as a qualitative research procedure. *Journal of Phenomenological Psychology* 28, 235-260.

Guetterman, T., 2015. Descriptions of Sampling Practices Within Five Approaches to Qualitative Research in Education and the Health Sciences. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research* 16.

Hart, T.L., Coon, D.W., Kowalkowski, M.A., Zhang, K., Hersom, J.I., Goltz, H.H., Wittmann, D.A., Latini, D.M., 2014. Changes in sexual roles and quality of life for gay men after prostate cancer: challenges for sexual health providers. *The Journal of Sexual Medicine* 11, 2308-2317.

Hartman, M., Irvine, J., Currie, K.L., Ritvo, P., Trachtenberg, L., Louis, A., Trachtenberg, J., Jamnicky, L., Matthew, A.G., 2014. Exploring gay couples' experience with sexual dysfunction after radical prostatectomy: a qualitative study. *J. Sex Marital Ther.* 40, 233-253.

Hulbert-Williams, N.J., Plumpton, C.O., Flowers, P., McHugh, R., Neal, R.D., Semlyen, J., Storey, L., 2017. The cancer care experiences of gay, lesbian and bisexual patients: A secondary analysis of data from the UK Cancer Patient Experience Survey. *European Journal of Cancer Care* doi: 10.1111/ecc.12670. Epub 2017 Feb 27 .

Johansson, E., Steineck, G., Holmberg, L., Johansson, J., Nyberg, T., Ruutu, M., Bill-Axelsson, A., 2011. Long-term quality-of-life outcomes after radical prostatectomy or watchful waiting: the Scandinavian Prostate Cancer Group-4 randomised trial. *The Lancet Oncology* 12, 891-899.

Kelly, D., Sakellariou, D., Fry, S., Vougioukalou, S., 2017. Heteronormativity and prostate cancer: a discursive paper. *J. Clin. Nurs.* doi: 10. 1111/jocn. 13844. Epub 2017 Jul 28 .

Kohut, A., Wike, R., Bell, J., Horowitz, J.M., Simmons, K., Stokes, B., Poushter, J., Ponce, A., Gross, E.M., Barker, C., 2013. The global divide on homosexuality. *Pew Research Center* .

Lee, T.K., Handy, A.B., Kwan, W., Oliffe, J.L., Brotto, L.A., Wassersug, R.J., Dowsett, G.W., 2015. Impact of Prostate Cancer Treatment on the Sexual Quality of

Life for Men-Who-Have-Sex-with-Men. *The Journal of Sexual Medicine* 12, 2378-2386.

Mann, S., 2016. *The Research Interview. Reflective Practice and Reflexivity in Research Process*. Palgrave Macmillan, UK.

Matheson, L., Rivas, C., Nayoan, J., Wagland, R., Glaser, A., Gavin, A., Wright, P., Watson, E., 2016. Marginalised men with prostate cancer: a qualitative metasynthesis exploring the impact on younger, gay and unpartnered men with prostate cancer. *Psychooncology* 25, 4.

Meyer, I.H., 2013. Prejudice, social stress, and mental health in lesbian, gay, and bisexual populations: Conceptual issues and research evidence. *Psychological Bulletin* 129, 674.

Meyer, I.H., 1995. Minority stress and mental health in gay men. *J. Health Soc. Behav.* , 38-56.

Motofei, I.G., Rowland, D.L., Popa, F., Kreienkamp, D., Paunica, S., 2011. Preliminary study with bicalutamide in heterosexual and homosexual patients with prostate cancer: a possible implication of androgens in male homosexual arousal. *BJU Int.* 108, 110-115.

National Cancer Registry Ireland, 2016. Cancer trends No. 30. Prostate. <https://www.ncri.ie/publications/cancer-trends-and-projections/cancer-trends-30-prostate-cancer>. Accessed November 2016.

NHS North West, 2011. Everything you always wanted to know about sexual orientation monitoring ...but were afraid to ask. NHS North West, Manchester.

O'Donnell, K., Fitzgerald, M., Barrett, P., Quinlan, M., Igoe, D., 2016. MISI 2015: findings from the men who have sex with men internet survey. Health Service Executive, Dublin.

O'Neil, B.B., Presson, A., Gannon, J., Stephenson, R.A., Lowrance, W., Dechet, C.B., Tward, J.D., Myers, J.B., Brant, W.O., 2014. Climacturia after definitive treatment of prostate cancer. *J. Urol.* 191, 159-163.

O'Shaughnessy, P.K., Ireland, C., Pelentsov, L., Thomas, L.A., Esterman, A.J., 2013. Impaired sexual function and prostate cancer: a mixed method investigation into the experiences of men and their partners. *J. Clin. Nurs.* 22, 3492-3502.

Penrod, J., Preston, D.B., Cain, R.E., Starks, M.T., 2003. A discussion of chain referral as a method of sampling hard-to-reach populations. *J. Transcult. Nurs.* 14, 100-107.

Prestage, G., Hurley, M., Brown, G., 2013. "Cum play" among gay men. *Arch. Sex. Behav.* 42, 1347-1356.

Rose, D., Ussher, J., Perz, J., 2016. Let's talk about gay sex: gay and bisexual men's sexual communication with healthcare professionals after prostate cancer. *European Journal of Cancer Care* doi: 10.1111/ecc.12469 .

Rosser, B.S., Capistrant, B., Torres, B., Konety, B., Merengwa, E., Mitteldorf, D., West, W., 2016. The effects of radical prostatectomy on gay and bisexual men's mental health, sexual identity and relationships: qualitative results from the restore study. *Sexual and Relationship Therapy* 31, 446-461.

Sabin, J.A., Riskind, R.G., Nosek, B.A., 2015. Health Care Providers' Implicit and Explicit Attitudes Toward Lesbian Women and Gay Men. *Am. J. Public Health* 105, 1831-1841.

Sadler, G.R., Lee, H., Lim, R.S., Fullerton, J., 2010. Recruitment of hard-to-reach population subgroups via adaptations of the snowball sampling strategy. *Nurs. Health Sci.* 12, 369-374.

Sanda, M.G., Dunn, R.L., Michalski, J., Sandler, H.M., Northouse, L., Hembroff, L., Lin, X., Greenfield, T.K., Litwin, M.S., Saigal, C.S., 2008. Quality of life and satisfaction with outcome among prostate-cancer survivors. *N. Engl. J. Med.* 358, 1250-1261.

Simon Rosser, B., Merengwa, E., Capistrant, B.D., Iantaffi, A., Kilian, G., Kohli, N., Konety, B.R., Mitteldorf, D., West, W., 2016. Prostate Cancer in Gay, Bisexual, and Other Men Who Have Sex with Men: A Review. *LGBT Health* 3, 32-41.

Speer, S.A., Tucker, S.R., McPhillips, R., Peters, S., 2017. The clinical communication and information challenges associated with the psychosexual aspects of prostate cancer treatment. *Soc. Sci. Med.* 185, 17-26.

Tarrant, C., Sinfield, P., Agarwal, S., Baker, R., 2008. Is seeing a specialist nurse associated with positive experiences of care? The role and value of specialist nurses in prostate cancer care. *BMC Health Services Research* 8, 65.

Thomas, C., Wooten, A., Robinson, P., 2013. The experiences of gay and bisexual men diagnosed with prostate cancer: Results from an online focus group. *European Journal of Cancer Care* 22, 522-529.

Ussher, J.M., Perz, J., Kellett, A., Chambers, S., Latini, D., Davis, I.D., Rose, D., Dowsett, G.W., Williams, S., 2016a. Health-Related Quality of Life, Psychological Distress, and Sexual Changes Following Prostate Cancer: A Comparison of Gay and Bisexual Men With Heterosexual Men. *The journal of sexual medicine* 13, 425-434.

Ussher, J.M., Perz, J., Rose, D., Dowsett, G.W., Chambers, S., Williams, S., Davis, I., Latini, D., 2016b. Threat of sexual disqualification: The consequences of erectile dysfunction and other sexual changes for gay and bisexual men with prostate cancer. *Arch. Sex. Behav.* , 1-15.

Ussher, J.M., Rose, D., Perz, J., 2016c. Mastery, Isolation, or Acceptance: Gay and Bisexual Men's Construction of Aging in the Context of Sexual Embodiment After Prostate Cancer. *The Journal of Sex Research* , 1-11.

Wassersug, R.J., Lyons, A., Duncan, D., Dowsett, G.W., Pitts, M., 2013. Diagnostic and outcome differences between heterosexual and nonheterosexual men treated for prostate cancer. *Urology* 82, 565-571.

Wong, W., Lowe, A., Dowsett, G., Duncan, D., O'Keefe, D., Mitchell, A., 2013. Prostate cancer information needs of Australian gay and bisexual men. Prostate Cancer Foundation of Australia, Sydney, NSW .

Zaider, T., Manne, S., Nelson, C., Mulhall, J., Kissane, D., 2012. Loss of masculine identity, marital affection, and sexual bother in men with localized prostate cancer. *The journal of sexual medicine* 9, 2724-2732.