



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

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**Purpose:** Gay men with prostate cancer are an 'invisible species' in the research literature despite concerns that the impact of treatment may be more profound and in some ways unique compared to heterosexual men. The aim of this research is to explore the lived experience of gay men with prostate cancer.

**Method:** In-depth interviews were recorded and transcribed verbatim from a purposive sample of eight gay men treated for prostate cancer in Ireland. A qualitative methodological approach employing Giorgi's descriptive phenomenological method was used to collect and analyse data.

**Findings:** Three key aspects emerged representing the essence of the participants lived experience; The experience of diagnosis, treatment decision making, and the impact of treatment, with sub-themes of shock of diagnosis, the generalist nature of information, sexual side effects and incontinence, and masculinity and gay identity. Secondly, the experience of the healthcare service with sub-themes of sexual orientation disclosure and communication with the healthcare team; and thirdly, sources of support and means of coping which included significant others, family & friends, cancer support groups, and gay resources and support services.

**Conclusion:** Gay men with prostate cancer have unmet information and supportive care needs throughout their prostate cancer journey, especially related to the impact of sexual dysfunction and associated rehabilitation, negatively impacting their quality of life. Issues associated with heteronormativity, minority stress, and stigma may influence how gay men interact with the health service, or how they perceive the delivery of care. Healthcare education providers should update prostate cancer education programmes accordingly.

### 1. 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.

### 2. Methods

Giorgi's descriptive phenomenological method (Giorgi, 1997, 2009,

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**Table 1**  
Concrete steps in Giorgi's phenomenological method.

1. Collecting phenomenological data
2. Reading whole descriptions
3. Breaking descriptions into meaning units
4. Transforming meaning units
5. Identifying the essential features of phenomena
6. Integrating features into structures (essences) of phenomena

(Giorgi, 1997, 2009, 2012).

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.

**Table 2**  
Participant demographics.

Participant No./ Pseudonym	Age at diagnosis	Treatment	Years since initial treatment
P1 Steven	58	Open prostatectomy followed by radiotherapy 5 years later for biochemical recurrence	10
P2 Evan	51	Brachytherapy & Radiotherapy	3
P3 Paul	61	Radiotherapy & hormone therapy	4
P4 Kevin	47	Radical prostatectomy. Hormone treatment. Radiotherapy. Chemotherapy & Hormone therapy	4
P5 Tony	61	Open prostatectomy	6
P6 Andy	52	Hormone therapy, open prostatectomy and radiotherapy	12
P7 Jerry	66	Robot assisted laparoscopic prostatectomy	5
P8 Jim	49	Robotic assisted laparoscopic prostatectomy	3

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 min (Range 24 min–111 min). 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.

### 3. 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, 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.

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