

# **The Lived Experience of Gay Men with Prostate Cancer**

**by**

**Dawn Doran**

A thesis submitted in partial fulfilment for the requirements for the degree of  
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## STUDENT DECLARATION FORM

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**School of Health**

## ABSTRACT

**TITLE:** The Lived Experience of Gay Men with Prostate Cancer

### Background

Prostate cancer affects over 40,000 men in the United Kingdom each year. The UK Government's pledge to reduce inequalities within cancer care, relating to prostate cancer, has predominantly focused on the experiences of heterosexual men and overlooked the experiences of gay men. Hence, current recommendations relating to prostate cancer care may not reflect the unique needs of this marginalised group.

### Aims

This study aimed to explore the impact of prostate cancer on gay men to understand how the disease affected their life and, identify any specific psychosocial or support needs.

### Methods

This interpretive phenomenological study was guided by van Manen's methodological and analytical approach. Twelve gay men were recruited from across the UK. Semi-structured interviews were conducted to explore participants' experiences of prostate cancer.

### Analysis

Interpretative data analysis incorporating hermeneutic principles identified themes and sub-themes which were reflected through the lens of Merleau-Ponty's four lifeworld existentials.

### Findings

The context in which prostate cancer is experienced is unique to gay men. Themes which convey the bodily impact of the disease (Corporeality) include '*violation of identity*', '*assault of the physical body*' and '*the power of potency*'. The changing sense of time (temporality) is revealed within themes of '*threat to eternal youth*', '*living in a state of flux*', '*disrupted lives*' and '*past, present and future horizons*'. Relationships with others (relationality) are illuminated through the themes '*the quest for mutual respect and equality*', '*locating information*', '*to tell or not to tell*', '*changes and challenges*' '*friendship*' and '*in pursuit of peers*'. Finally, the intimacy of space (spatiality) is uncovered within the themes '*yearning for community*', '*the power of proximity*' and '*isolation*'.

### Conclusions

This is the first UK study to explore the experiences of gay men with prostate cancer, and identified unmet needs unique to gay men diagnosed with prostate cancer which have implications for clinical practice, health policy and groups which provide support to men with prostate cancer.

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## **ABBREVIATIONS**

AIDS	Acquired Immune Deficiency Syndrome
APPGC	All Party Parliamentary Group on Cancer
CRUK	Cancer Research UK
DoH	Department of Health
GP	General Practitioner
HIV	Human Immunodeficiency Virus
LGBT	Lesbian, Gay, Bisexual and Transgender
LGF	Lesbian and Gay Foundation
MUSE	Medicated Urethral System for Erections
NCSI	National Cancer Survivorship Initiative
NHS	National Health Service
NICE	National Institute Clinical Excellence
PSA	Prostate specific antigen
TRUS	Trans-rectal Ultrasound Scan
WHO	World Health Organisation

## Chapter 1: INTRODUCTION

This research explores the experiences of gay men who are living with prostate cancer. The study developed from my personal and academic interests in men's health, and more specifically, how men adapt and cope when they are confronted with cancer. The study aims to determine how the disease and its subsequent treatments impact on various aspects of gay men's lives. A deeper understanding of their experiences provides insights into some of the challenges or barriers these men face whilst living with prostate cancer. In addition to contributing to the current body of prostate cancer literature and the topic of cancer more generally, this research also adds to the growing body of literature that is concerned with reducing health inequalities within the Lesbian, Gay, Bisexual and Transgender (LGBT) community as a whole.

This introductory chapter aims to provide a contextual backdrop for the study. It begins by outlining the global burden of cancer before moving on to describe how cancer currently affects people living within the United Kingdom (UK) in terms of incidence, mortality and survivorship. The chapter then focuses on the gender divide that exists in relation to cancer. This section outlines why males may face a greater risk of developing and dying from cancer than females and why it is important to study male's experiences of cancer and, more specifically, prostate cancer. Here, a summary about the disease is provided, which discusses the various treatment options that are available to men following diagnosis and the side-effects that are associated with these treatments. Finally, the chapter looks at the role of sexual orientation in relation to prostate cancer. This final section evaluates evidence which suggests that gay men may face additional and unique challenges following a diagnosis of prostate cancer and states why this study will have implications for patients, healthcare professionals and policy makers.

## **1.1. Cancer as a worldwide problem**

In 2012 it was estimated that over 14 million people worldwide were diagnosed with cancer, and a further eight million people died from the disease (Cancer Research UK (CRUK), 2014). Although there are over 200 types of cancer, four main types of cancer account for almost half of those diagnosed. The World Cancer Report (2014), published by the World Health Organization's (WHO) International Agency for Research on Cancer, reported that in 2012, lung cancer was the most common cancer (13%) followed by breast cancer (11.9%), colorectal cancer (9.7%) and prostate cancer (7.9%). The same report also estimated that the burden of cancer is likely to increase to 23.6 million new cases each year by 2030, based on predicted demographic changes, such as the growing proportion of elderly people and negative health behaviours associated with personal lifestyle choices.

### **1.1.1 Cancer within the United Kingdom**

The UK currently has the 23<sup>rd</sup> highest overall cancer rate, based on a list of 50 countries with the highest cancer rates in the world (World Cancer Research Fund, 2014). In 2011, an estimated 331,000 cases of cancer were reported in the UK; the two most common types being female breast cancer and prostate cancer (CRUK, 2014). Although mortality rates from cancer have dropped more than a fifth since the 1990's, cancer still claims over 150,000 lives in the UK each year (CRUK, 2014).

Despite the predicted global increase in cancer incidences, the extent to which this applies to the UK is still unclear. One major study, claimed that cancer incidences were likely to remain stable until 2030 (Mistry, Parkin, Ahmad, & Saseini, 2011). However, other reports have suggested that cancer incidence in the UK is likely to rise by 20% by 2021 (Bupa, 2011). More accurate reports of projected cancer incidences are needed to help determine how the burden of cancer will impact on the UK health system and wider economy in future years. In addition, it would be helpful if such reports included the predicted trends

of individual cancers as opposed to reporting an overall figure. This information could help to determine which cancers are likely to affect people in the future, thus ensuring that sufficient resources are in place to meet patient needs.

### **1.1.2 Survivorship and the growing cost of cancer**

Macmillan Cancer support (2014) estimate there are now two million people across the UK who are living with and beyond a cancer diagnosis. This figure is expected to double by 2030 as a result of better treatments and an ageing population which is continuing to increase (Macmillan Cancer Support, 2014). However, evidence has shown that many cancer survivors and their carers have unmet needs as a consequence of cancer treatment, which could be avoided or better managed (Department of Health (DoH), 2007). In addition to the emotional cost for patients and their families, the financial costs of failing to meet the needs of cancer survivors are significant to the National Health Service (NHS) and the wider economy. Currently, the annual estimated costs associated with cancer diagnosis and treatment, are around £18 billion, of which £13 billion is associated with loss of productivity and reliance on benefits (DoH, 2013). Hence, it is inevitable that the financial burden of cancer will continue to rise, based on the projected number of future cancer survivors.

In order to adequately address the needs of the growing number of people surviving cancer, one of the key initiatives of the Cancer Reform Strategy (2007) was to create the National Cancer Survivorship Initiative (NCSI). This partnership, between Macmillan Cancer Support and the DoH, aimed to ensure that cancer survivors in the UK received the best care and support deemed necessary to enable them to lead healthy and active lives for as long as possible (NCSI, 2014). Since its launch in 2008, the NCSI has continued to look for ways to improve the lives of cancer survivors, such as implementing interventions for patients and their carers to ensure they have better care planning once they complete

primary cancer treatment, and are provided with information and access to relevant support sources (NCSI, 2013). Moreover, whilst the initiative has delivered on many of the aims it set out during its 2008 launch, the NCSI also acknowledges that there is still much to be done in terms of identifying the needs of cancer survivors and finding the most appropriate way of meeting these needs.

## **1.2. Cancer incidence and the gender divide**

Upon examining the prevalence of cancer, a gender divide is apparent. Men face a significantly higher risk of developing non-gender specific forms of cancer than women and are 35% more likely to die from the disease (CRUK, 2013). In 2011, 167,487 men were diagnosed with cancer compared to 164,000 women. The most recent analysis of deaths in the UK found that there were 202 deaths for every 100,000 men compared to 147 for every 100,000 women in 2011 (CRUK, 2013). The reasons underpinning this gender division are complex, as even when gender-specific forms of cancer are accounted for, men still tend to have worse outcomes. Research indicates that survival rates for men at one, five and 10 year intervals are all worse than those of women (Edgren, Liang, & Adami, 2012).

The role of health beliefs and personal health practices may offer an explanation as to why a gender divide in relation to cancer exists. For example, men are less likely to engage in health-promoting behaviours than women, with the exception of physical activity (Lee & Owens, 2002). A survey undertaken by Saga (2013), revealed that men were less likely to contact their General Practitioner (GP) with a health problem and were less likely to accept an invitation to the bowel cancer screening programme, which was introduced across the UK in 2006, compared to their female counterparts. This finding is a major concern, given that bowel cancer rates among men increased by nearly 30% over the last 35 years compared to a 6% increase in women. Although the Saga survey revealed that men knew less about the symptoms of certain cancers than women, their reluctance to take part in

screening may, in part, reveal more about their attitudes towards the screening culture within the UK, since it has historically been weighted in favour of female cancers. For example, women are invited to routine screening for cervical and breast cancer from the age of 25 and 50 respectively, and have been for the past two decades. In contrast, men have only been included in the routine screening for bowel cancer from the age of 60 for the past eight years. Hence, it could be men have simply not yet become accustomed to the benefits and the culture of screening, in the way that women have over the past two decades.

Although lifestyle factors have been attributed to higher cancer incidence, mortality and survival rates amongst both sexes, men still appear to be at a greater risk of developing certain types of cancer that affect both sexes. Currently, over a quarter of men in the UK are considered to be obese and they are more likely to smoke tobacco and consume higher levels of alcohol compared to their female counterparts (General Lifestyle Survey, 2011). Hence, in order to understand why men are more likely to engage in negative health behaviours, it may be necessary to gain a better understanding of what it means to be a man.

### **1.2.1 Masculinity, health and cancer**

One way to attempt to understand why a gender divide exists in relation to cancer is to examine how the contexts in which men experience health and disease differ. Lee and Owens (2002) state that '*more important for men's health than any specific disease is the influence of social constructions of maleness*' (p. 5). Hence, the authors call for an understanding of the social and cultural contexts that influence men's health and their behaviours. Watson (2000) supports this view and highlights the need to better understand how masculinity and hegemonic traits influence health behaviours.

Hegemonic masculinity refers to the traditional view of men's behaviour and is prescriptive in that it characterises men by toughness, unemotionality, physical competence, competitiveness and aggression (Lee & Owens, 2002). Hence, when applied to health behaviours, men may place more importance on conforming to these traits than on their own health.

In respect of cancer, there is evidence to suggest that masculinity impacts on men's behaviour. Some men have been found to adopt a stoic approach to cancer and are more likely to hide a diagnosis of cancer from their peers for fear of being regarded as different (Hilton, Emslie, Hunt, Chapple, & Ziebland, 2009). Hence, this may risk limiting their support network and may result in men not wanting to ask for support in case it is perceived as a sign of weakness. The findings from an ethnographic study which explored cancer in relation to masculinity revealed that men felt less masculine as a result of not being able to work and look after their families (Cecil, McCaughan, & Parahoo, 2010). The masculinities of the men in this study were also affected in relation to their body image and the fact that they no longer felt "*like a man's man*".

The pressures that men place upon themselves and the potential for these pressures to have a detrimental impact on their health have obvious implications when they are diagnosed with cancer. Moreover, as the incidence rates of some male cancer are expected to increase, it is vital that we have a comprehensive understanding of the issues that men face when they receive a diagnosis of cancer, particularly as conforming to masculine traits clearly impacts on their experience. However, as Connell (2005) points out, men are not a homogenous group and multiple masculinities may exist. Therefore, it is imperative that healthcare providers and policy makers understand how different types or groups of men respond to health messages about cancer, access cancer support sources and experience cancer within the context of the social world they inhabit.

### **1.2.2 Male cancers and sexual orientation**

Just as a gender divide exists between men and women in relation to cancer, there is also some evidence to suggest that some men may face an increased risk of certain cancers based on their sexual orientation. An American study which investigated cancer incidences within a population of over 51,000 men who completed a general health survey, found that gay men were almost twice as likely to report a cancer diagnosis compared to heterosexual men (Boehmer, Miao, & Ozonoff, 2011). Although the reasons for this finding were unclear, the authors suggested that potentially higher rates of anal cancer amongst gay men may have contributed to this finding. This may be a plausible theory given that gay men are up to 20 times more likely to develop anal cancer compared to heterosexual men, as a result of exposure to the human papilloma virus (Anderson, Vajdic, & Grulich, 2004).

Gay men who are living with human immunodeficiency virus (HIV) face an even higher risk of developing anal cancer as a result of a weakened immune system (National LGBT Cancer Network, 2014). Moreover, as a survey by Stonewall (2012) reported that 33% of gay men are likely to smoke cigarettes, compared to 21% of heterosexual men, gay men may also have a greater risk of developing lung cancer.

Relatively little research exists in relation to how sexual orientation impacts on the experiences of gay men with cancer. A study by Snyder (2011), which aimed to determine the number of medical publications that reported studies addressing the LGBT community over a 50 year period, found that only 1.44% of publications had addressed cancer, as most publications were devoted to HIV/acquired immune deficiency syndrome (AIDS) and sexually transmitted infections.

### **1.3. Men and prostate cancer**

Prostate cancer is a malignant tumour that starts to grow within the prostate gland. Cancer may be confined within the prostate (localised) or may have spread to the tissues just beyond the prostate (locally advanced). Advanced or metastatic cancer occurs when the cancer has spread beyond the prostate gland to other parts of the body.

Prostate cancer is estimated to account for 7% of all new cancer cases worldwide (CRUK, 2012) and led to the deaths of around 254,000 men in 2007 (Crawford, 2009). The incidence of prostate cancer and its mortality rate varies greatly across continents. The highest rates are found in Australia and New Zealand, Western and Northern Europe have the highest incidence rates whereas South-Central Asia has the lowest incidence rate. Across Europe, Ireland had the highest incidence of prostate cancer with 183.2 new cases per 100,000 men and Greece had the lowest – 27.9 new cases per 100,000 men (Kaplan, 2013). In the UK alone, over 40,000 new incidences of prostate cancer were recorded in 2009 and 10,000 men died of the disease in the same year. It is also estimated that around 250,000 men are currently living with and beyond prostate cancer in the UK (Prostate Cancer UK, 2013) as men now have an 8 in 10 chance of surviving the disease compared to the 3 in 10 chance men had during the 1970's.

#### ***1.3.1 Screening for prostate cancer***

Because there is no national screening programme for prostate cancer in the UK, men are usually alerted to the possibility that they have prostate cancer when they experience symptoms and visit their GP, or it is detected by other means, e.g. through a routine blood test or other medical procedure. The current guidelines regarding health screening in the UK state that, whilst there is currently no organised screening programme for prostate cancer, an informed choice programme 'Prostate Cancer Risk Management' is in place. This programme is designed to ensure that men are provided with sufficient information about

the advantages and disadvantages of the 'prostate specific antigen' (PSA) blood test and outlines the treatment choices available to them for the disease (Burford, Kirby, & Austoker, 2009). However, whilst this information is detailed and may be considered informative by those men who do request further details on PSA testing, there is a possibility that not all men will be aware that this information, or indeed the programme, is available, especially as prostate cancer is often present in the absence of any symptoms. Hence, the debate concerning whether screening for prostate cancer should be implemented nationally is one of contention. Although there is some evidence to suggest that early detection of prostate cancer as a result of screening may save lives (Gomella et al., 2011), those who are opposed to routine screening argue that it leads to over-diagnosis and unnecessary treatment in a larger group of men, who would otherwise have remained healthy without treatment for many years (Moyer, 2012). Although routine screening is not available on the NHS, some private healthcare policies offer annual screening for prostate cancer to their clients. Bupa, for example, provides its clients with information designed to help men make an informed decision about whether they do want to be screened (Bupa, 2010).

### **1.3.2 Risk factors for prostate cancer**

The biggest risk factor for developing prostate cancer appears to be related to age. The disease is relatively uncommon in men under the age of 40. However, by the time men reach the age of 80 they have an 80% chance of either having or developing the disease (Burford et al., 2009). Men also face an increased risk of developing prostate cancer if they have a first degree relative with the disease, or if several family members have suffered from the disease (Prostate Cancer UK, 2014) Furthermore, Black African and Caribbean men are up to three times more likely to be affected by prostate cancer compared to other ethnic groups (NHS, 2014).

### **1.3.3 Symptoms of prostate cancer**

Several symptoms of prostate cancer are associated with presentation to a GP, who may perform certain medical tests to rule out the possibility of prostate cancer. Some of the more common symptoms present as problems associated with urinating. These include not being able to empty the bladder due to pressure being placed on the urethra by the presence of a tumour, or having to urinate more frequently. Other symptoms may include pain or blood in the urine, or the presence of back ache. Fatigue and weight loss are also signs that cancer may be present (Lange & Adamec, 2003). In contrast, some men do not experience any symptoms that would alert them or their GP to the presence of cancer. In such instances, the disease may only be detected as a result of undergoing medical tests or procedures for an unrelated medical problem.

### **1.3.4 Diagnosis of prostate cancer**

If cancer is suspected, a blood test will usually be carried out in order to determine whether a man's PSA level is raised. However, as other medical conditions or physical activities can also raise PSA levels, a digital rectal examination (DRE) may also be performed in order to detect abnormalities in the shape or size of the prostate gland. Depending on the results of one or both of these tests, a trans-rectal ultrasound scan (TRUS) may be carried out. During this procedure, biopsies from the lobes of the prostate are taken and sent for examination by a pathologist (Mason & Moffat, 2010).

### **1.3.5 The prostate biopsy**

A positive biopsy report provides information based on the findings of tissue samples and is described in terms of staging and grading (Mason & Moffat, 2010). Information about the stage of cancer is concerned with how advanced the cancer is. Further tests, such as a computed tomography (CT) scan, or a magnetic resonance imaging (MRI) scan, may also be requested in order to determine if, and to what extent, cancer has spread beyond the

prostate capsule. The most common form of staging uses the Tumour Node Metastasis (TNM) system, an effective process which is also used to stage several other cancers. Staging is based on the extent of the tumour (T), the extent to which it has spread to the lymph nodes (N), and the presence of metastases (M). An example of the staging criteria is shown in Table 1 as defined by the American Joint Committee on Cancer (AJCC, 2010), a system that is used internationally. (The classifications provided by the AJCC designed to aid staging are provided in Appendix 1).

**Table 1. TNM Classification for Prostate Cancer (AJCC, 2010)**

T = Description of the primary tumour.

TX	Primary tumour cannot be evaluated
T0	No evidence of primary tumour
Tis	Carcinoma in situ (early cancer that has not spread to neighbouring tissue)
T1–T4	Size and/or extent of the primary tumour

N = Presence of cancer in the nearby lymph nodes.

NX	Regional lymph nodes cannot be evaluated
NO	No regional lymph node involvement (no cancer found in the lymph nodes)
N1-N3	Involvement of regional lymph nodes (number and/or extent of spread)

M = Presence of metastases

M0	No distant metastasis (cancer has not spread to other parts of the body)
M1	Distant metastasis (cancer has spread to distant parts of the body)

In addition to staging, prostate cancer is also graded using the Gleason grading scale, which is now used by pathologists worldwide to determine whether the cancer tumour is aggressive or non-aggressive (Mason & Moffat, 2010). Its measurement is based on the appearance of cancer cells when they are viewed under a microscope. Where cells appear more distorted, they are likely to be more aggressive. Hence, a higher number of distorted cells are given a higher Gleason score (Lange & Adamec, 2003). The Gleason scale is

numbered 1-5 with 1 being the lowest score and 5 being the highest. Two samples of cells from different areas of the prostate are graded individually and then added together to provide an overall score. A score is firstly assigned to the cells from an area where the cancer is most prominent (primary grade) and a second score is assigned to the cells from the second most prominent area where cancer is present (secondary grade). Gleason scores totalling between 2 and 4 are considered to be very low in terms of the cancer's aggressiveness. Scores between 5 and 6 indicate a mildly aggressive cancer. A score of 7 indicates that the cancer is moderately aggressive and scores between 8 and 10 indicate that the cancer is of a highly aggressive nature (Lange & Adamec, 2003).

Once a diagnosis of prostate cancer has been confirmed and staging has determined how far the cancer has advanced, a discussion about the various treatment options which may be available to the patient will take place. At this stage, some men may be offered the choice of more than one type of treatment. Hence, decisions about the preferred option are often based on the treatment's efficacy and their potential side-effects. Some men may be advised to have more than one type of treatment during the course of their cancer journey. Men who agree to take part in clinical trials may be required to undergo a combination of treatments simultaneously. The treatments that are currently available for prostate cancer are summarised in Table 2. This also provides a brief description of each treatment and their potential side effects.

**Table 2. Prostate Cancer: Treatments and possible side-effects**

Treatment	Brief Description	Potential side effects
Radical Prostatectomy	Prostate gland removal. Only conducted when cancer has not spread beyond the prostate.	Impotence / problems associated with erectile dysfunction e.g. dry orgasms, Penile shortening Urinary Incontinence.

Treatment	Brief Description	Potential side effects
Radical Prostatectomy cont...		Urinary problems, tiredness and skin irritation. Longer term problems can include sexual problems and infertility.
Hormone Therapy	Hormones delivered by injections or tablet form to reduce testosterone. Occasionally, an operation known as a subcapsular Orchidectomy is performed to remove the part of the testicles that produces testosterone.	Hot flushes, weight gain, decreased libido, fatigue, strength and muscle loss, breast swelling, loss of body hair, mood changes, risk of bone thinning, heart disease and diabetes.
Active Surveillance	Active treatment is postponed and cancer is monitored until it progresses.	Potential increased need for biopsies.
Watchful Waiting	Similar to AS however, the end goal is to manage symptoms once they appear rather than commence active treatment.	As above.
Brachytherapy	Small radioactive seeds are inserted into the tumour. This treatment is usually given in combination with external beam radiotherapy.	Urinary and bowel problems.
Chemotherapy	Chemotherapy drugs are usually given intravenously with the aim being to shrink and control the cancer, and relieve symptoms.	Fatigue, nausea and vomiting, loss of appetite, bowel problems, hair loss, fluid retention, peripheral neuropathy, mood changes.
Cryotherapy	Cancer cells in the prostate gland are killed during a method that uses freezing and thawing.	Erectile dysfunction and urinary problems.

### **1.3.6 Prostate cancer and current policy guidelines**

Several policies consider the impact of prostate cancer within the UK. The NCSI seeks to find ways of supporting men who have completed primary treatment for prostate cancer and the National Institute for Health and Care Excellence (NICE), an independent organisation set up by the Government in 1999, has developed a national framework for diagnosing and treating prostate cancer. This provides clinical practice guidelines, which healthcare professionals are recommended to meet, in order to ensure men receive the best care. The current guidelines, published in January 2014 (NICE, 2014), offer in-depth guidance about each stage of the cancer journey. In particular, the policy places emphasis on aspects of communication between men and their healthcare providers, stating that information should be ‘tailored to their individual needs’. It also states that men should be given advice on how to access information and support from websites, local and national cancer information services, and support groups. Healthcare providers are also encouraged to seek feedback from men with prostate cancer and their carers about the information resources, thus ensuring they are receiving the highest quality information.

The guidelines also state that men should be adequately informed about the impact of prostate cancer on their sexual function and aspects of their embodied self / masculinity which may impact on their quality of life. Healthcare providers are also expected to discuss aspects of sexual dysfunction with men covering topics such as libido, ejaculation, and how clinical sexual aids or medication could be used in sexual rehabilitation.

Although the NICE guidelines are comprehensive, particularly in terms of staging and treatment, there are some areas in which the guidelines could be improved. For example, despite acknowledging that the impact of prostate cancer on masculinity may have a profound effect on men, there is very little guidance for healthcare providers about which aspects of masculinity may be affected. A draft report produced prior to the new guidelines

was not able to find an adequate definition of masculinity. Hence, a literature review on this important topic was not undertaken to form part of the report. Therefore, it is debatable whether healthcare providers can adequately inform and support men on some aspects of masculinity that may differ from their own engendered perspective. The NICE guidelines also acknowledge that little is known about men from ethnic minority groups in relation to masculinity, or the impact of prostate cancer on homosexual, bisexual or transgender women. Therefore, it is unlikely that healthcare professionals will have adequate knowledge about specific issues that affect these groups of men in order to ensure they have sufficient information. By failing to address the complex nature of masculinity, there is a risk that men may be viewed by policy makers and healthcare providers as a homogenous group. As prostate cancer only affects males, there is clearly a need for a better understanding of what concerns men have in relation to their masculinity.

#### **1.4. Prostate cancer and sexual orientation**

As highlighted by the NICE consultation guidelines, little is known about the impact of prostate cancer on homosexual, bisexual and transgender women (NICE, 2014). A policy briefing for health and social care staff by the DoH (2007), stated that gay men with prostate cancer were more likely to have difficulties dealing with oncologists and urologists. Although the guidelines did not offer too much detail concerning these difficulties, the report stated that these may be based on assumptions made by healthcare providers that all men have a female partner. The report also acknowledged that non-heterosexual men may experience sexual problems following treatment that may differ from heterosexual men. Moreover, a response from Prostate Cancer UK to a call for evidence by the All Party Parliamentary Group on Cancer (APPGC) also highlighted the dearth of research amongst this group and suggested further research is needed to reduce potential inequalities (Prostate Cancer UK, 2009).

### **1.4.1 Prostate cancer and gay men**

Since cancer registries do not collect data about sexual orientation, it is not known exactly how many gay men are currently affected by prostate cancer within the UK. However, given that around 40,000 men are diagnosed each year, it is inevitable that a significant number of these men will be gay.

There is some evidence to suggest that gay men may face additional or unique challenges throughout various stages of their prostate cancer journey. Preliminary results from two separate studies comparing prostate cancer treatment side-effects showed significant differences between heterosexual and gay men (Latini, 2011; Motofei, Rowland, Popa, Kreienkamp, & Paunica, 2011). One study that compared the effects of the anti-androgen drug bicalutamide reported significant reductions in all aspects of gay men's sexual functioning compared to heterosexual males (Motofei et al., 2011). Similarly, Latini (2011) found that gay men who underwent a radical prostatectomy reported statistically significant worse physical, sexual and psychosocial functioning following surgery than heterosexual men. This led Latini (2011) to speculate whether these findings may be related to medications commonly prescribed for erectile dysfunction, such as phosphodiesterase-5 inhibitors, for example, Viagra. However, as these medications were designed to produce erections firm enough for vaginal intercourse, they may not be as effective in producing erections firm enough for anal penetration (Latini, 2011). Clearly, this requires more in-depth exploration to better understand the reasons for these interesting findings.

A closer inspection of the literature in this area also reveals that much of what has been written in relation to this group of men is speculative. Blank (2005) discusses several challenges that gay men are likely to face following a prostate cancer diagnosis, compared to heterosexual men, focusing on key differences such as culture, lifestyle and the

underpinning of heteronormative assumptions within healthcare settings. For example, prostate cancer literature frequently refers to the supportive role of wives and families during a man's prostate cancer journey, whereas emotional support structures for many gay men are known to differ as friends often play a major role in the men's lives as opposed to family members (Clarke, Ellis, Peel, & Riggs, 2013). In contrast to the traditional monogamous relationships commonly associated with heterosexual couples, gay men are far less likely to have a regular partner as they get older and are four times less likely to have children that can offer familial support (DoH, 2007). It has also been suggested that the prostate gland may have a greater significance for gay men compared to heterosexual men and closely associated with their sense of sexuality and masculinity (Blank, 2005). Hence, for some gay men, surgical procedures which involve the removal of the prostate gland may have different implications in terms of how gay men reconcile their identity. Blank (2005) contends that heterosexually orientated practitioners may be oblivious to the needs and concerns of their gay patients. A health survey by Stonewall (2012), undertaken with gay and bisexual men, revealed that a high proportion of gay men in the UK are still reluctant to disclose their sexuality to healthcare providers due to the fear of discrimination and homophobia. Moreover, a collection of personal narratives (Perlman & Drescher, 2005), penned by gay men from the USA who have experienced prostate cancer, suggest that the gay men's experience of the disease may differ on account of their culture. Although opinion-based papers are helpful in terms of highlighting the potential challenges that gay men may face when diagnosed with prostate cancer, empirical research to support or refute the issues outlined within these articles is limited. Furthermore, although personal accounts of gay men's experiences of prostate cancer have provided insights into the lives of American men who have experienced the disease, the absence of any methodological processes and cohesive analysis of these narratives makes it difficult to draw out themes and conclusions that could help to influence health policies.

## **1.5. Conclusion**

This chapter has provided some context to the present study, by discussing how current cancer policy has failed to adequately reflect the needs of gay men with cancer, and more specifically, those with prostate cancer. I have also provided an overview of prostate cancer in order to illuminate the impact of this disease on men as a result of the invasive treatments they must undergo, in order to eradicate or manage the disease. I have also provided an overview of why it may be important to consider the needs of gay men in respect of prostate cancer. However, there is clearly a need to discover what their unique needs are in order to determine whether any gaps in service provision exist, that may impact on their experiences.

In the next chapter I present the literature review that was conducted in order to determine what is currently known about gay men with cancer.

## Chapter 2: **THE LITERATURE REVIEW**

In the previous chapter I presented the background to the study in relation to the importance of studying male cancers, and specifically prostate cancer. I also discussed why it may be necessary to consider sexual orientation in respect of male cancers and highlighted the lack of research that has been conducted in this area. Finally, I examined several literature sources in relation to gay men and prostate cancer, which suggested that further research is needed in order to understand their experience and identify their needs.

### **2.1. Introduction**

In this chapter, I have provided an outline of the steps that were taken in order to conduct a comprehensive literature review. I begin by identifying the essential components that are necessary in order to undertake a comprehensive literature review, before outlining the strategy that was taken to identify relevant literature for the purpose of the present study. I move on to discuss how a critical appraisal tool was chosen and then applied to the literature. Finally, I present the findings from the papers that were included in the review and critically discuss the main themes that arose from the literature.

#### **2.1.1 *The importance and purpose of a literature review***

The literature review is a purposeful and essential component of the research process, as it provides an objective, thorough and critical summary of a range of literature relating to the area being studied and should present a clear rationale as to why further research is warranted (Hart, 1999; Carnwell & Daly, 2001; Cronin, Ryan, & Coughlan, 2008). Prior to conducting the literature review for the present study, it was necessary to determine which style would best illuminate the key concepts and theories about the experiences of gay men with prostate cancer, and consider the strengths and weaknesses of previous studies. Although traditional, narrative reviews are popular across many academic disciplines, it has

been argued that they may contain bias (Petticrew & Roberts, 2006). Adopting this type of format means that researchers are relatively free to 'cherry pick' literature they feel is relevant to their topic. Hence, the lack of a clear audit trail or justification about why literature has, or has not, been included, may inadvertently lead to the inclusion of studies which support the researchers own findings (Petticrew & Roberts, 2006). For this reason, a literature review style that adopted a more systematic approach to searching for literature was the preferred choice for the present study.

One of the most stringent types of literature reviewing styles common across many domains of healthcare research is the systematic review. This approach is particularly useful, albeit time-consuming and sometimes costly, for assessing clinical and cost effectiveness (Hemmingway & Brereton, 2009). They provide an up-to-date overview of the current state of a given topic and can highlight where gaps in research need to be addressed. This review style also provides transparency as an audit trail of the search strategy employed by the researcher is often included within the final review, enabling future replication. Strict criterion is usually applied to such reviews. Hence, the need for a well-structured research question and clear inclusion and exclusion conditions for retrieval of relevant studies is paramount prior to the search (Petticrew & Roberts, 2006).

One disadvantage to conducting a review with such strict boundaries is that they may not allow room for the research question to change. According to Boell and Cecez-Kecmanovic (2010), a deeper understanding of the research problem may only become apparent as the literature review progresses. For this reason, I decided that applying a narrow research question and strict inclusion / exclusion criteria prior to searching for literature, may inadvertently screen out studies that may have some relevance to my area of research. Instead, I chose to incorporate a strategy advocated by Boell and Cecez-Kecmanovic (2010). This strategy involves searching for literature in a systematic fashion, to ensure that all key

terms are included. However, a degree of flexibility allows subsequent terms that turn out to be relevant further along the search process to be incorporated into future searches.

### **2.1.2 Search strategy**

The literature review focused on studies relating to gay men and their experiences of prostate cancer. Electronic databases including CINAHL (Cumulative Index to Nursing & Allied Health Literature), Ovid Medline (in process and other non-indexed citations 1946 to May 2012), Psychinfo and EMBASE (Excerpta Medica Database) were searched and limited to dates between January 1996 and May 2012. The decision to include studies conducted after 1996 was based on the recommendations set out in the Calman-Hine report, A Policy Framework for Commissioning Cancer Services (DoH, 1995). This report highlighted the need for the acknowledgement and provision of psychosocial support for cancer patients and their carers. Hence, most research in this topic area emerged following this publication. Comprehensive searches using syntax and key terms, specific to each database, were built using words related to experiences and aspects of a psychosocial nature. However, given the breadth of terms that fall under the psychosocial spectrum, a combination of Mesh headings, database specific terms and free text words were collected and subsequently built into each database search. This process entailed checking all retrieved and relevant articles for further Mesh headings, determining whether they would yield relevant papers and then adding the term to the final search string (see Appendix 2 for an example of search terms used). Other potential literature sources such as Google Scholar and the library bookshelves were also searched to capture studies that may not have appeared within the electronic databases.

### **2.1.3 Initial search**

Following an initial search for qualitative and quantitative literature specifically related to terms relating to gay men and prostate cancer, it became evident that literature on this

topic was scarce. The search revealed just one primary study focused on this population. Moreover, whilst the search returned several papers that referred to gay men in the context of prostate cancer, they consisted mostly of professional review articles, conference abstracts and a series of personal narratives penned by gay men with the disease. Whilst these articles contained rich and interesting information in relation to the topic, they were not considered suitable for inclusion within the literature review based on their lack of any methodological framework and interpretation of findings. However, it was decided that several of these literature sources should be included within the introduction chapter as a means of highlighting the potential issues concerning this population of men.

#### **2.1.4 Revised search**

As the literature search did not produce enough studies relating to gay men and prostate cancer, alternative ways of approaching the literature review were considered. One potential solution would have been to base the literature review around gay men's experiences of chronic illness, including HIV. However, it was feared that this would not have reflected the unique challenges that may be associated with cancer for this group, specifically for prostate cancer. Therefore, a decision was made to widen the literature search to include papers about all men diagnosed and treated for prostate cancer, regardless of their sexual orientation. Despite some initial concerns that this would lead to a review predominantly reflecting the experiences of heterosexual men, as opposed to the population under study, the benefits of widening the search were soon realised. In addition to highlighting the lack of research about gay men and prostate cancer, encompassing the experiences of all men with the disease would provide a rich context in which to compare and debate new findings that arose in the current study.

The decision to widen the literature search and include all men with prostate cancer posed a further challenge, in that the revised search, returned over several thousand 'hits'. As research into prostate cancer has proliferated over the last three decades a high number of qualitative and quantitative hits was anticipated. Hence, in order to reduce the number of studies to a more manageable size, several filters and limiters were applied to the searches in an attempt to screen for any studies that were not relevant to the current research objective. This included omitting studies that focused on screening for prostate cancer in addition to papers that focused on risk, genetics or interventions relating to the experience of the disease. Although this resulted in a reduced number of hits, the number of papers relating to experiences of prostate cancer was still very high. Hence, after consulting with my supervision team and a member of staff within the university with expertise in systematic searching, a decision was made to narrow the search to look for qualitative studies only. As the present study aimed to focus on the 'lived experience' of gay men, narrowing the search to qualitative studies meant that the literature review would reflect a rich and comprehensive, yet manageable account, of men's personal experiences of prostate cancer, and would enable the findings from the present study to resonate within the existing body of qualitative research in this field.

Incorporating a qualitative filter (see Appendix 2.1) within the search strategy meant that any studies that had adopted qualitative approaches would also be retrieved. Hence, words related to such approaches e.g. 'grounded theory', 'phenomenology' and 'interview' were included to ensure that all types of qualitative studies were captured within the search. The ensuing number of hits across the four databases was considerably lower. However, as the filter did not fully remove all quantitative studies, the studies were individually screened again to ensure that only qualitative studies remained. In order to aid guidance on the inclusion of qualitative studies, a definition of qualitative research was sought. Several

definitions have been debated, as to what best describes qualitative research. Schmid (1981) considers the approach to be:

*“...the study of the empirical world from the viewpoint of the person under study”*

Van Maanen’s<sup>1</sup> (1979) definition incorporates the techniques used by researchers when conducting qualitative research.

*“An umbrella term covering an array of interpretive techniques which seek to describe, decode, translate and otherwise come to terms with the meaning, not the frequency of certain more or less naturally occurring phenomena in the social world.”*

For the purpose of identifying literature that had the potential to be included in this review, both of these definitions were deemed to be useful. Hence, during the screening of each abstract, the following questions were also used as a preliminary guide to ensure that the paper considered information that was relevant to the current study.

- Does the article explore what it is like to experience prostate cancer from the patient’s perspective?
- Is the article’s main aim to illuminate how physical or psychological factors relating to prostate cancer impact on men’s lives following treatment?

A total of 238 papers were retrieved for further reading, as it was not always clear from the study’s abstracts if they met the inclusion and exclusion criteria, which is outlined in Table 3. A rationale for the exclusion / inclusion criteria will now be discussed.

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<sup>1</sup> John van Maanen - Not to be confused with references made to Max van Manen throughout the thesis.

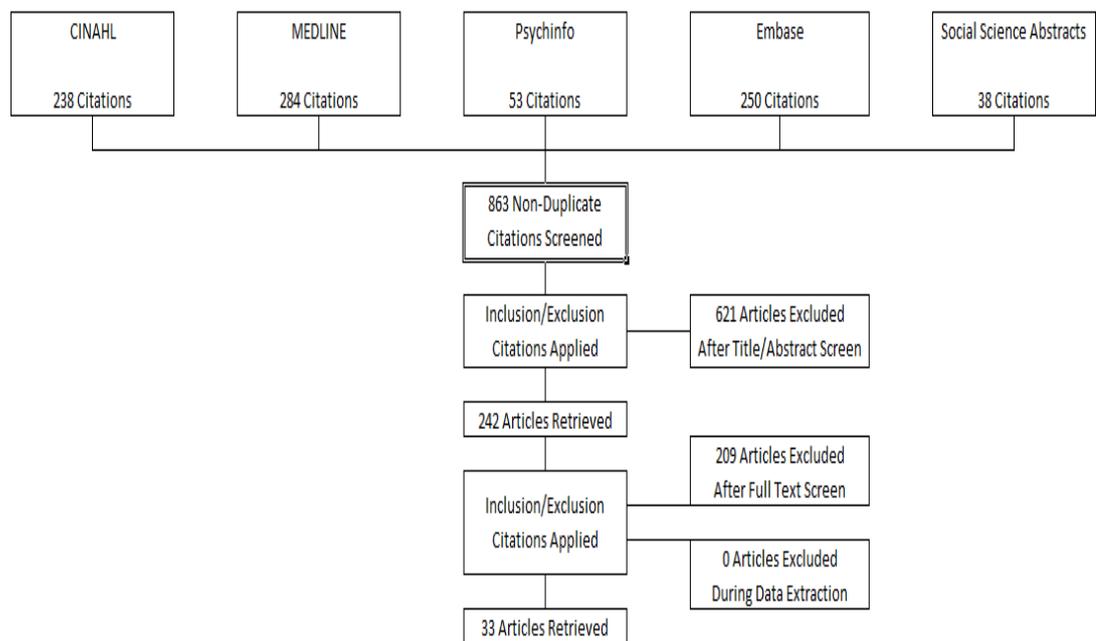
**Table 3. Inclusion and Exclusion criteria.**

Inclusion criteria	Exclusion criteria
Published qualitative studies that report on the experiences of being treated for prostate cancer from the patients' perspective.	Quantitative or studies which use mixed methods.
Studies focused on men who have already undergone a form of treatment for prostate cancer.	Studies where the main focus is on the following: diagnosis/pre-treatment/palliative stages of prostate cancer; the evaluation or comparison of treatment interventions; the predictive, risk, screening or genetic aspects of prostate cancer, purely physical aspects of prostate cancer.
Studies reported in English.	Studies focused on the experience of couples.

The decision to include only qualitative studies has already been outlined. However, whilst several mixed method studies containing a qualitative component could have also been included within the literature review, it was felt that the number of purely qualitative studies would adequately reflect the range of issues experienced by men with Prostate cancer. Studies focusing on couples were also excluded. Despite the advantages of joint interviewing within studies such as establishing rapport, there is a tendency for couples to express a 'collective' account of their cancer journey (Taylor & de Vocht, 2011). Findings from professional review articles were excluded as these risked being opinion based rather than substantiated with actual findings.

As the present study aimed to explore men's experiences of prostate cancer following treatment; studies where the main focus of the paper was on the diagnosis/ pre-treatment of prostate cancer were excluded, as were studies of a biomedical nature. Several other types of studies were also excluded on account of the 'survivorship' stage that men were deemed to be at. Therefore, studies focused on the palliative stages of prostate cancer

were excluded on the grounds that the present study seeks to explore how individuals experience cancer from the perspective of those patients who have completed treatment, and are now considered to be within the survivorship stage of rehabilitation and monitoring. Studies which focused on men who had recently undergone surgery or radiotherapy within the previous 12 months were excluded on account of them still being in the ‘acute’ phase of their cancer journey. Following completion of surgical treatment, men are less likely to have the clinical support they had during the acute phase and challenges become more apparent as they attempt to ‘get back to normal’ and renegotiate their future (Foster & Fenlon, 2011). Moreover, as a result of radiotherapy, many men only start to develop and experience ‘late effects’ several months after they have completed their treatment (Wittmann et al., 2009).



**Figure 1. Flowchart illustrating the literature search strategy**

## **2.2. Quality appraisal**

After applying the inclusion and exclusion criteria, a total of 33 papers were included within the literature review. As each of these studies had adopted qualitative approaches, it was important to understand the key issues surrounding qualitative appraisal techniques prior to choosing an appropriate critical appraisal tool, particularly as the present study was adopting a qualitative approach.

Quality appraisal is a process whereby the methods, results and findings from individual research studies are critically assessed for quality (Petticrew & Roberts, 2006). In order to aid this process, appraisal tools, which usually take the form of guides or checklists, are frequently employed by consumers of research to provide analytical evaluations of key elements within the study. These include methodological and ethical issues, rigour, validity and reliability in addition to the overall presentation and synthesis of the research (Hannes, Lockwood, & Pearson, 2010). Critical appraisal of research studies ensures that best practice within the healthcare sector is grounded in best evidence (Long & Godfrey, 2004). Hence, study findings are not simply taken at face value but examined to check whether the conduct of research and conclusions derived from it, are both credible and reliable enough to form judgements which have the potential to impact on care and treatment.

Due to the dominance of quantitative methods in health research, many critical appraisal tools have been constructed to provide criteria aimed at detecting issues and biases relating to research design, sampling, statistical procedures and their results (Long & Godfrey, 2004). However, since qualitative research is now widely recognised for its potential to enhance understanding and provide rich insights into experiences (Popay, Rogers, & Williams, 1998), many academics contest the practicality of applying the same appraisal procedure to qualitative studies (Barbour, 2001; Meyrick, 2006). Hence, a tool specifically designed to appraise qualitative research is necessary.

Combined with the diversity of philosophical assumptions that underlie qualitative approaches and the lack of need to generalise findings, assessment of rigour, reliability and validity of qualitative studies invariably differs to quantitative studies. Therefore, Lincoln and Guba (1985), proposed that qualitative studies should instead be evaluated on whether the study is trustworthy by establishing the following four principles: credibility: confidence that the study's findings contain 'truth'; transferability: that the findings could be applied in other contexts; dependability: that findings are consistent and repeatable; confirmability: evidence that the findings are shaped by participants as opposed to the researcher. The added problem here, particularly for novice researchers, is that evidence of these principles is not always obvious upon initial reading of a paper. Hence, well designed critical appraisal tools are credited with helping to guide researchers through this process (Newton, Rothlingova, Gutteridge, LeMarchand & Raphael, 2011). The principles above are discussed in more detail within the methodology chapter.

A systematic review identified 121 published critical appraisal tools, of which only seven were specifically constructed for the appraisal of qualitative studies (Katrak, Bialocerkowski, Massy-Westropp, Kumar, & Grimmer, 2004). Since then, further reviews of qualitative appraisal tools have been undertaken (Walsh & Downe, 2006; Hannes et al., 2010) reflecting the growing interest in this topic. Despite making interesting comparisons between tools, most authors seem to agree that there is no '*gold standard*' in terms of which one to use. Instead, they merely attempt to point out the strengths and weaknesses of each tool and provide some context relating to how or why the tool was conceived. For example, Hannes et al. (2010) discuss the growing popularity of the Critical Appraisal Skills Programme (CASP, 2012) tool amongst health researchers, yet at the same time, highlight its limitations in evaluating methodological quality compared to other tools. Walsh and Downe (2006) point out that the framework underlying the development of the CASP tool is not as robust as other appraisal tools and are critical of its lack of criteria relating to

researcher reflexivity. On the other hand, well developed tools, such as those developed by Spencer, Ritchie, Lewis and Dillon (2003) or Sandelowski and Barroso (2007), have been criticised for being too detailed and lengthy (Walsh & Downe, 2006). Therefore, researchers can only weigh up the merits of each tool and ensure that their justifications for using it are well supported.

### **2.2.1 Rationale for the critical appraisal tool used within the present study**

The decision to use the critical appraisal framework developed by Walsh and Downe (2006) (see Appendix 2.2) in the present study was made for several reasons. Firstly, the theoretical framework that helped to develop this tool was considered to be particularly robust, as it was based on a review of previous literature and pre-existing frameworks. By removing non-essential criteria through a process of elimination, a condensed checklist for essential criteria was created that was both inclusive yet concise. Secondly, the framework offers a clear set of guiding principles in order to aid the reviewer to determine methodological quality. Newton (2011) pointed out that the availability of '*anchors*' (forms of guidance) can facilitate critical appraisal, particularly for novice researchers, therefore, this was deemed to be important. Finally, the researchers point out that their appraisal framework should be used flexibly rather than prescriptively. This is a particularly important point, especially as some researchers urge caution when rejecting studies purely on the grounds of poor methodology (Sandelowski & Barroso, 2007; Pawson, 2006). Their main arguments contend that a study with a flawless methodology may not provide particularly novel findings. Conversely, studies containing flaws in their methodology may provide compelling findings which are worthy of discussion. Hence, Sandelowski and Barroso (2007) highlight the importance of also applying common sense during the appraisal process.

Critical appraisal commenced with an initial reading of each study. During the second reading of each study, a comprehensive summary, outlining how each stage of the framework had been demonstrated within the study was then written up (an example of a completed study appraisal can be found in Appendix 2.3). Furthermore, in order to help determine the overall quality of each paper, a later enhancement to the chosen critical appraisal tool, in the form of a grading criterion, was also adopted (Downe, Simpson, & Trafford, 2007). Therefore, each study was assigned a grade between A and D depending on how the flaws in each study impacted on its quality (see Appendix 2.4 for grading criteria).

### **2.2.2 Quality of included studies**

A total of 33 papers were included within the review (a summary of the included studies which details their main findings is provided in Appendix 3). All the studies were qualitative and focused on how prostate cancer and various treatments had impacted on the men's lives. Despite the varying nature of the studies aims, their objectives were to understand the men's experiences from their own perspective. Studies were conducted by authors from a range of disciplines including nursing, medicine, sociology and psychology.

### **2.2.3 Participants**

The participants included in the studies all had a diagnosis of prostate cancer. However, the participant's cancer type in terms of staging, e.g. local/advanced inevitably varied within each study. Several studies explored the experiences of men with prostate cancer specifically in relation to their treatment. Four studies focused on active surveillance, a further four focussed on men who were undergoing hormone treatment and three focused on men's experiences after undergoing surgery. The remaining 22 studies included men who had undergone a range of treatments. Hence, it was not always possible to where specific findings applied to men who had undergone certain treatments. Socio-

demographic information was provided in many of the studies and included information such as the men's ages, marital status and time since diagnosis. Overall, the cultural and ethnic differences of participants were adequately described. However, although sexual orientation was explicitly mentioned within four of the studies, most papers made no reference of this factor.

#### **2.2.4 *Methods used within the studies***

A total of 25 studies had employed face-to-face interviews to seek the patient's perspective. A further five had gathered data from focus groups and three studies collected data from both focus groups and through one-to-one interviews. Interview types ranged from semi-structured to unstructured and examples of questions and probes were included in several studies. All of the included studies had adopted a qualitative design. Nine studies had adopted a phenomenological approach, two studies used grounded theory, four studies utilised an ethnographic approach and three described using descriptive methods. The remaining studies did not specify a particular approach and applied a broad range of analytical methods upon collecting data.

#### **2.2.5 *Data extraction, analysis and synthesis***

Following quality appraisal, findings were extracted from each paper following guidelines by Sandelowski and Barroso (2007). Findings from each individual paper were first separated and then grouped into common themes. A larger synthesis of findings from all studies then followed which led to similar themes being grouped together. Contradictory findings were also identified using this method. Initially, many potential themes were identified relating to the experiences of men with prostate cancer. However, after regrouping the findings several times, they were eventually condensed into six themes, which were synthesised in order to reflect the main issues experienced by men with prostate cancer. It is worth noting that several of these themes are inter-related and may

overlap in some themes. For ease of reading, several themes contain separate headings to separate the main issues being discussed.

- **Relationships with healthcare providers**
  - Communication
  - Information
  - Decision making
  
- **Masculinity**
  - Sexual function
  - Language
  - Culture
  - Reconciling masculinity
  
- **Support Networks**
  - Wives and partners
  - Healthcare providers
  - Support from friends
  - Peer support
  
- **Living with Treatment outcomes**
  - Body image
  - Additional health issues
  - Sexual difficulties
  
- **Recovery, adaption and acceptance**
  
- **Uncertainty**

### **2.3. Relationships with healthcare providers**

The relationships that patients developed with their healthcare providers was a dominant theme across the literature. However, the nature of this relationship, due to the expected roles that healthcare providers were expected to fulfil at different time points during the men's cancer journeys, was often subject to change. This was mainly due to communication problems, a perceived lack of information, and issues that arose during the decision making process. These three points have been discussed separately for ease of reading. However, there is an unavoidable degree of overlap, which perhaps highlights the pivotal role that healthcare providers play in the lives of men with prostate cancer.

### **2.3.1 Communication**

Several studies suggest that men's early interactions with healthcare providers form an important part of their cancer journey (Ng, Kristjanson, & Medigovich, 2006; Ervik, Nordoy, & Asplund, 2010; Jones et al., 2011). A study conducted in Ireland, by Walsh and Hegarty (2010) investigated the experiences of eight men who had undergone a radical prostatectomy following prostate cancer. The findings revealed that the participants viewed their diagnosis as '*the first of several defining moments*' during their cancer journey. Consequently, men were still able to vividly recall details about this moment several years later, such as the words that were used by the consultant and the emotions they experienced at this time. Several men in this study revealed that the shock of hearing they had cancer had been lessened when the news was delivered with kind words from their consultant. However, others remembered the news being communicated in an 'off-hand manner' and were not asked how they felt after receiving their diagnosis. Ervik et al. (2010) stressed the use of words by consultants to describe cancer, e.g. 'aggressive', should be explained to patients as a way of ensuring the context of the word is understood. Effective, interpersonal communication between healthcare providers and patients clearly has the potential to help patients form positive memories about their cancer experience during their recovery (Walsh & Hegarty, 2010).

An American study by Filiault, Drummond and Smith (2008) which explored the experiences of gay men with prostate cancer, emphasises the potential power of non-verbal cues associated with communication, as the participants in this study appeared to avoid verbal communication with their healthcare providers. The men in this study described experiencing a sense of '*not belonging*' within some health contexts; they felt that healthcare was provided based on heterosexist assumptions. Moreover, as they did not feel comfortable in discussing their sexuality with their consultants, for fear of discrimination, healthcare providers may have simply been unaware that the men may

have required information tailored to their needs. However, although the authors of this study advocate the need for healthcare providers to be inclusive and provide a space in which gay patients feel able to communicate openly, about issues that may uniquely concern gay men with prostate cancer, the findings from this study also highlight the potential challenges, and barriers, that may arise for both patients, and healthcare providers, if patients choose not to disclose their sexual orientation. Hence, this study raises important questions concerning how sexual orientation should be broached during initial appointments, and by whom. One of the main limitations of this study was the small sample size, as the findings only reflect the experiences of two gay men with prostate cancer.

Cultural issues as a result of ethnicity also have the potential for miscommunication between healthcare providers and patients as a study of 16 African-Caribbean men living with prostate cancer within the UK illustrated Nanton and Dale (2011). Participants in this study took part in focus groups and frequently reported that consultants lacked sensitivity when delivering their cancer diagnosis. The interviewers noted that rather than reacting with shock and fear, as might be expected, the participants described how they reacted calmly upon hearing they had cancer. They were also reluctant to ask questions at this time, which the authors suggest may have been interpreted by consultants as '*indifference.*' They go on to suggest that consultants may have assumed that the men did not want to engage in further discussion. As it is not known from the findings whether communication difficulties continued throughout the men's cancer journey, it is not clear to what extent these early interactions impacted on the way future appointments were conducted. However, the findings do suggest that healthcare providers may misinterpret cultural characteristics based on their own pre-understandings. One of the main strengths of this study was the researcher's decision to employ interviewers who were from the same cultural background as the participants. However, whilst this resulted in rich and

detailed findings, the omission of any reflection by the interviewers, makes it difficult to determine how their role and status as 'cultural insiders' may have impacted on the data.

### **2.3.2 Information**

Relationships between healthcare providers and patients appeared to be perceived more negatively in those studies where patients felt that they had not been provided with sufficient information. As several studies found that successful adaptation to prostate cancer could be partly mediated by the provision of sufficient information (Kelly, 2009; Ervik et al., 2010; Carter, Bryant-Lukosius, Blythe, & Neville, 2011), this would suggest that healthcare providers have a key role to play in ensuring that patients know how to access relevant information sources. In addition to procuring information from their healthcare providers, men also sought information from a variety of sources including the media and internet, friends and family or advice from other men who had personally experienced prostate cancer (Kelly, 2004; 2009; Heidesteg, Sandman, Tomic, & Widmark, 2005a; Heidesteg, Sandman, Tomic, & Widmark, 2005b; Wallace & Storms, 2007; Ervik et al., 2010; Carter et al., 2011; Kazer et al., 2011a).

Two specific time points were frequently highlighted across most of the studies, suggesting that men's need for information were greater at these times. The first time point occurred around the time men were presented with several different treatment options to consider. The second time point occurred at a later stage during the men's cancer journey, when sexual difficulties were likely to become more salient following treatment.

During the first time point, men who had been offered several treatment options tended to seek information that could help them make an informed decision about which one they should choose. A study by Bertero (2001) highlighted the burdensome nature of having to make this decision as it was viewed by some men as a '*choice of consequence*.' However, whilst information concerning treatment efficacy was clearly a concern for men across the

literature, several studies suggest there was a greater need for men to be provided with information that would help them to understand how the side-effects of treatment, such as erectile dysfunction and incontinence, would impact on them long-term; information that several studies reported men did not always receive prior to undergoing treatment (Bertero, 2001; Fergus, Gray, & Fitch, 2002; O'Shaughnessy & Laws, 2009). Men's frustrations, which were often directed at consultants in relation to the information they felt should have been provided, were discussed in a study by Hagen, Grant-Kalischuk and Sanders (2007). This phenomenological study explored the experiences of 15 Australian men who described '*fumbling in the dark*' when attempting to obtain information from their healthcare providers. The participants in this study raised an important question concerning the role of specialist nurses, as it was suggested that they may be better placed to provide information to patients, given the time constraints of consultants.

The second time-point at which men tended to have an increased need for information occurred during the post-treatment phase, when sexual problems as a result of treatment became more salient. One of the key issues raised by men across several studies referred to the initiation of conversations about sexual matters with healthcare providers (Hagen et al., 2007; Ervik et al., 2010; Carter et al., 2011). A Canadian study, conducted by Letts, Tamlyn and Byers (2010), explored the impact of prostate cancer on men's sexual wellbeing with 19 men. The findings revealed that generally, the onus was on patients, rather than healthcare providers, to bring up sexual matters and request information relating to these issues during hospital follow-up appointments. Moreover, this appears to be a widespread problem. A UK study found that older men were often too embarrassed to admit they still had sexual needs (O'Brien et al., 2011). Hence, conversations regarding sexual matters were not initiated by either party. Those men who did attempt to initiate conversations with clinical staff felt that that this was not something they were keen to discuss and preferred to keep matters focused on the men's treatment. Given the prevalence of

prostate cancer amongst older men, the findings from this study, suggest that could be a widespread problem. A Norwegian study by Ervik et al. (2010) offers an alternate viewpoint. This study reported that their participants observed 'silence' from healthcare services. Unlike the men in O'Brien et al.'s (2011) study who described initiating conversations, the men in this study simply trusted that their healthcare providers would provide them with information, if it was necessary. Hence, men did not seek information from additional sources. A recommendation, made by O'Brien et al. (2011) which suggests that healthcare professionals should receive specific training to better enable them to broach sexual matters, appears to be well justified.

Few studies were able to comment of whether information concerning sexual needs for gay men was considered. The findings from Filiault et al.'s (2008) study suggest that they were not. However, the concerns raised in this study were not able to be given sufficient consideration, mainly due to a lack of data about this issue. Furthermore, although a three further studies made reference to having gay men within their samples, (Fergus et al., 2002; Kelly, 2004; Filiault et al., 2008; O'Shaughnessy & Laws, 2009) the majority of men in these three studies were heterosexual. Therefore, it is not clear whether information relating to sexual orientation was offered to the gay men in these studies, or indeed requested.

The timing and quality of information provided by healthcare providers may be important factors, in addition to the information itself, as highlighted by an American study by Letts et al. (2010). Although most men in this study reported that they not feel prepared prior to their treatment, the findings revealed that men who did feel they *were* prepared, still expressed a sense of frustration at the lack, or quality of information provided by their consultant. Fergus et al. (2002) suggested that men may be fairly reluctant to know the extent to which they may be sexually impaired prior to treatment, as some men in their

study admitted that knowing about long-term issues may have simply added to their burden. However, a study by O'Brien et al. (2011) offers an alternative explanation. This study, which interviewed a sample of 35 men of varying ages, suggests that the psychological consequences of prostate cancer treatment may be only manifest after the imminent threat to survival passes. Hence, information given at the start of treatment may not appear that relevant at the time. The authors of this study conclude that the timing of when discussions should take place will inevitably vary, depending on the individual's needs. On this basis they recommend that assessment for psychosexual needs should take place throughout the follow-up period, as opposed to pre-set time points.

### **2.3.3 Decision making**

Another recurring theme across several of the studies centered on the difficulties that were encountered between patients and their healthcare providers during the decision making stage of their cancer journey (Ng, 2006; Bailey, Wallace, & Mishel, 2007; Wallace & Storms, 2007; Walsh & Hegarty, 2010; Kazer et al., 2011a). Kelly (2004), found that men's ability to cope with prostate cancer was, in part due to them being in control of the decisions to be made about treatment. However, the extent to which some men wanted to be involved in the decision making stage of their cancer journey appeared to vary. Two studies offered evidence to suggest that certain groups of men may want to have less involvement than others. Kazer et al. (2011a) suggested that due to the weight of responsibility around treatment choice, older men may be happier to adopt a more passive role in this process, due to their overriding trust in the consultant's authority role. Findings from Nanton and Dale's (2011) UK study also support this view, but suggest that culture, as well as age, may be a factor. Only one man from their sample of 16 African-American men who were interviewed for this study had been actively involved in the decision making process. Furthermore, as the one man who was actively involved in the process had private health

insurance, it is not clear whether this was directly related to his involvement in the decision making process as this is not stated within the findings. The remaining 15 men reported receiving limited information from their healthcare providers and only three of the men probed their healthcare providers for further information. The authors of this study suggest that the lack of questioning by this patient group, combined with the men's 'intrinsic' perception of the consultant's authority role, may have led healthcare providers to assume they preferred a passive role. Hence, cultural issues and missed cues may inadvertently prevent men from being more involved in their treatment decision.

#### **2.4. Masculinity**

One of the dominant themes across many of the studies concerned the impact of prostate cancer, and the effects of treatment, on men's sense of masculinity (Bertero, 2001; Bokhour, Clark, Inui, & Talcott, 2001; Chapple & Ziebland, 2002; Fergus et al., 2002; Navon & Morag, 2003; Broom, 2004; Oliffe, 2005; Oliffe, 2006; Hagen et al., 2007; Maliski, Rivera, Connor, Lopez, & Litwin, 2008; Kelly, 2009; O'Shaughnessy & Laws, 2009; Gannon, Guerro-Blanco, Patel, & Abel, 2010). Men who had undergone radical prostatectomy said that they no longer felt like 'whole men' and described feeling mutilated (Heidesteg et al., 2005a). Men receiving hormone treatment frequently experienced particularly distressing side-effects, including loss of libido; breast enlargement (gynecomastia); weight gain; decreased muscle mass and reduced penis/testes mass (Oliffe, 2006).

Broom (2004) revealed that potency became an important factor for men when they were contemplating treatment. This study found that some men were prepared to choose inferior treatments if they had the potential to retain potency, as opposed to those that would offer the best chance of cure. Similar findings were reported by Kelly (2004) in respect of men who wished to avoid impotence and incontinence.

The impact of clinical procedures associated with prostate cancer on men were discussed in an ethnographic study by Kelly (2009). Observations noted by the researcher, whilst one participant underwent a transrectal ultrasound scan, conveyed the traumatic nature of this procedure. Moreover, Kelly noted the “boundaries of interpersonal intimacy” between the patient and health professional during this interaction, highlighting the vulnerability of the patient at this time. Broom (2004), suggested that medical procedures which involve anal penetration are difficult for some men to endure as they “compromise masculinity”. Moreover, as some men may associate penetration with homosexual behaviour, Broom (2004) concedes these procedures go against ‘maleness’, and may be worse for those men with higher cultural codes relating to masculinity. As gay men’s experiences of transrectal procedures were not fully explored in the studies that were selected for this review, it is difficult to ascertain whether they would be likely to find them equally, or less traumatic.

#### **2.4.1 Sexual function**

There are conflicting opinions across the literature, regarding the extent to which men feel their masculinity has been compromised as a result of prostate cancer and its treatment. Fergus et al. (2002), suggested that “above all, men with prostate cancer are primarily concerned with the “preservation of manhood – striving to retain one’s masculinity in the face of a decidedly de-masculating experience”. Several studies reported that masculine identity was strongly linked with sexual performance, particularly a capacity for penetrative sex (Gannon et al., 2010). However, other studies, such as Letts et al (2010) and Carter et al. (2011) found some men did not consider that, sexual changes had impacted on their masculinity. Findings by Fergus et al. (2002) suggest that men who were able to perceive sexual function as a distinct or isolated entity, as opposed to an integral component of their male identity, were more able to cope with the loss of sexual function. Hence, this suggests

that perceptions of masculinity differ amongst men, which may explain why some studies report opposing findings.

Two studies, which included detailed accounts of the research process and researcher reflexivity, suggest that there may be additional issues to consider when attempting to elicit authentic accounts of masculinity, within a research context. Kelly (2009) discussed the dynamics of conducting interviews with men whose masculinities have been threatened as a result of prostate cancer. He reflected on how his own presence, as a male, may have led some participants to feel judged or “less masculine” by him during the interview. An earlier study by Chapple and Ziebland (2002), adds further weight to this suggestion. A total of 52 participants in this study were offered the choice of a male or female interviewer yet interestingly, only one man chose to be interviewed by a male. Although the researchers in both studies stressed that not all men chose to discuss intimate concerns during the course of their interviews, these findings may have some application to health settings, in relation to how men with prostate cancer interact with male healthcare providers.

#### **2.4.2 Language**

Several studies noted how the language used by some men revealed the importance they placed on certain masculine ideals. O’Shaughnessy and Laws (2009) found that some men preferred to communicate using metaphors when discussing sexual ability. Phrases or words associated with male strength, e.g. ‘fighting spirit’, ‘courage’, ‘survivorship’ were frequently referred to across studies (Broom, 2004; Oliffe, 2006). However, Navon and Morag (2003) pointed out that men’s intentions to adopt strategies centred on a ‘fighting spirit’ attitude were often thwarted for men on hormone therapy, as this treatment stripped them of the capacity and the energy to deploy such strategies. In contrast, other words and phrases were associated with the perceived notion that men should fulfil the

masculine role of 'family protector', 'breadwinner' or 'provider' were also common, especially amongst men from certain ethnic groups (Maliski et al., 2008).

### **2.4.3 Culture**

Cultural differences in relation to ethnicity and masculinity were evident within the literature. A comparison of Latino and African-American men's experiences of prostate cancer revealed that they were more concerned with losing the ability to connect with a partner rather than the need to prove their masculinity through sexual conquest. However, masculine ideals between the two groups of men differed. Whereas Latino men viewed masculinity in terms of being the family provider, African-American men spoke more about sexual prowess and their sense of connectedness in their community (Maliski et al., 2008).

Less is known about how prostate cancer and treatment impacts on gay men. However, the four gay men who took part in Fergus et al.'s (2002) study, were particularly concerned about 'not measuring up' sexually, due to the expectations from lovers who expected that sex should match physical stature. Retrograde ejaculation and dry orgasms, had led one man to perceive he was not only "lesser male" but also "lesser gay". Although Filiault et al.'s (2008) study did not specifically address the impact of treatment on masculinity; the two men in this study reported that cancer had a profound impact on their identity and their ability to relate to other gay men. Hence, there may be some aspects of masculinity that are unique to gay men in addition.

### **2.4.4 Reconciling masculinity**

Several studies reported on the various ways men attempted to reconcile their masculinity following treatment. Bokhour et al. (2001) found that whilst normalising discourses, whereby men attributed changes in their sexual ability to the ageing process, were

adaptive for some men, they were not for others who then had to deal with forming a new identity as an 'older man'. Conflicting perspectives were also found in relation to men who compared their identities pre-treatment and post-treatment. Navon and Morag (2003) found that Israeli men who attempted to maintain their pre-treatment social identity only served to intensify their confusion concerning sexuality. Hence, those who experienced feminising side-effects as a result of hormone treatment, reconstructed their identity as not belonging to either gender and relegated sex to a former part of their lives. In contrast findings by a UK study by Kelly (2004) found that men who reflected on their former selves and questioned their masculine assumptions, became closer to understanding their own situation, which Kelly interpreted as a coping strategy that allowed men to view the cancer as less threatening. The participants in Navon and Morag's (2003) study may have been unable to reconcile their former identity due to the on-going bodily changes they were confronted with on a daily basis, as a result of hormone treatment.

One important finding in Broom's (2004) study in relation to masculinity, suggests that there may be too much emphasis on sexual 'function' within clinical settings. The authors point out that providing men with sexual aids that are focused on penetration is, in some respects, colluding with the powerful discourses that exist about masculinity. Hence, they recommend that healthcare providers could encourage men to find alternative but equally acceptable ways of achieving sexual pleasure. This finding may partly explain why findings from other studies, such as Bokhour et al. (2001), reported that a significant number of men were not satisfied with sexual aids, as they may serve as an added reminder of what they have lost.

## **2.5. Support networks**

### **2.5.1 *Wives and partners***

Several sources of support were cited across the literature yet differed based on intrapersonal and interpersonal factors. The supportive role of wives and partners of men with prostate cancer was a dominant theme across most of the studies. During the early stages of prostate cancer, spouses appear to be instrumental in helping men to understand the importance of preserving life over potency (Bertero, 2001; Ng et al., 2006). Moreover, men were more likely to accept an altered sex life post-treatment if their wives or partners were also accepting of the situation (Bertero, 2001; Fergus et al., 2002; Letts et al., 2010). This was particularly common for men who had been partnered for many years, although older men with younger wives voiced more concern about this issue (Bertero, 2001). However, contradictory findings from one particular study suggests that not all wives and partners find it easy to readily accept their partner's disease, or assume a supportive role. In a study of 15 Israeli men undergoing hormone treatment, over half of the men in the sample stated they were negatively affected by their wives' attitude and felt that they lacked support (Navon & Morag, 2003). For the men in question, their wives openly showed "*revulsion*" towards their husbands' bodily changes and physically distanced themselves, fearing infection. The depth of detail provided within this study was one of its key strengths. In addition to conveying how cultural differences within relationships have the potential to alter the experience of illness for patients, the findings and conclusion also challenge some of the perhaps more widely held assumptions about the role of female carers within Western society.

Very few studies explored the support role in the context of same-sex relationships. However, a phenomenological study, conducted with two gay men and one partner, reported that relationships were prone to strain, and subsequently changed, due to the ambiguous role of the partner during the men's treatment and recovery (Filiault et al., 2008). However, one of the main limitations to this study was that it did not fully explore what led to ambiguity within the role, or uncover the specific factors that caused the

relationship to become strained. It is also unknown whether the men in this study utilised other forms of support from their social networks or families. Nonetheless, these findings highlight that relationship dynamics within gay relationships may differ from those of their heterosexual counterparts. Moreover, as it is conceivable that men in a gay relationship could both experience cancer at the same time, they may face additional challenges when attempting to seek support from one another.

### **2.5.2 Healthcare providers**

The findings from several studies show that doctors are regarded as an important source of support during men's recovery particularly for widowers or particularly frail men who had less social contact (Jonsson, Aus, & Bertero, 2010; Walsh & Hegarty 2010; Nanton & Dale, 2011; Kazer et al., 2011a). These men were cited as being more reliant on formal social care agencies and less aware of the full range of services available to them due to referral procedure complexities. Unpartnered men in Kazer et al's. (2011a) study were also more reliant on medical staff. Confidence in their doctors provided the men in this study with an effective way of coping, highlighting the value of good communication between healthcare providers and men who have smaller support networks. However, as the findings in this study only appear to reflect the experiences of heterosexual men who *did* have confidence in their healthcare providers, it is difficult to know what impact this might have had on unpartnered men in terms of coping, regardless of their sexual orientation. An Australian study of 20 participants conducted by Ng et al. (2006), reported that the relationships the men had with their healthcare providers determined how they responded to each phase of treatment and what strategies they used to cope. Hence, patients clearly benefit from those healthcare providers who consider their holistic needs.

### **2.5.3 Support from friends**

Friendship networks were mentioned by men in several studies (Navon & Morag, 2003; Ng et al., 2006; Maliski et al., 2008; Carter et al., 2011; Grunfield, Halliday, Martin, & Drudge-Coates, 2012). However, less importance appears to be placed on men's friendships in terms of the support they offer, compared to that provided by the men's wives or partners. Even men who were unpartnered were less likely to rely on their friends for support and instead, turned to ex-partners or sought support from health professionals (Kazer et al., 2011). The main reason why men are less likely to seek support from friends appears to centre on the men's reluctance to be perceived as weak, dying, or less masculine (Oliffe, 2006; Gannon et al., 2010). Fergus et al. (2002) found that some men who were concerned about how they were perceived by their friends were more likely to use normalising strategies, or impression management skills. For example, when matters of a sexual nature were being discussed amongst a group, men would give others the impression they were still potent. This finding suggests that conforming to masculine ideals, even when facing a life threatening disease is an important part of the men's identity and may help them to cope with social pressures. On the contrary, over-use of impression management strategies has been shown to be counterproductive. Navon and Morag (2003) revealed that when men engaged in this type of behaviour, an awareness of their own self-deceit, combined with the emotional labour required to keep up the façade served to estrange men further from their friends. However, as few studies focused exclusively on the role of male friendship in relation to prostate cancer, it is not clear whether there are specific elements of male friendship that are more beneficial than the support they receive from other sources.

### **2.5.4 Peer support**

Peer support in the form of support groups was mentioned within several studies (Heidesteg et al., 2005; Ng et al., 2006; Hagen et al., 2007; Kelly, 2009; Ervik et al., 2010; Carter et al., 2011). A study by Wallace & Storms (2007), conducted with focus groups discovered that men who attended such groups found benefits in terms of making decisions about treatment, acquiring new information about the disease and simply being able to share mutual experiences with other prostate cancer sufferers, who were regarded as being in the same '*subculture*', on account of their disease status. However, other studies revealed that some men preferred not to attend such groups. Participants in a study by Heidesteg et al (2005), considered that prostate cancer was a deeply personal and private matter. Other studies identified the negative aspects of attending support groups, as men inevitably encountered distress upon witnessing the deterioration and subsequent deaths of men they had befriended (Kelly, 2009; Ervik et al., 2010). Although it may be assumed that unpartnered men may be more inclined to attend support meetings, considering they have fewer forms of support sources available to them, a study investigating the experiences of this population found this was not the case. Only two out of the 15 men in the study used support groups as a support source. Interestingly, the men who took part in this study were noted for being self-reliant and having an enhanced capacity for coping, compared to partnered men. None of the studies considered gay men's experience of peer support groups

Faith and spirituality were cited as important sources in three studies. Kazer et al. (2011a) found that older men were more likely to rely on the church than younger men. As this study focused on the experiences of partnered men, this suggests that older unpartnered men may have fewer support sources than younger men more generally. The other two studies were conducted with men were conducted with men from ethnic minority groups. The African-Caribbean participants who took part in Nanton and Dale's (2011) study, drew strength from their life-long religious beliefs during their cancer journey and regarded the

church as the most highly valued form of support outside of their family. A study of 23 African-American men, by Jones et al. (2011) reported that those living in rural areas were more likely to rely on faith than those living in urban areas. However, as the author of this study highlights, it is not clear whether this difference is due to communal differences or a lack of alternate forms of support in urban areas.

## **2.6. Living with treatment outcomes**

Issues concerned with living with treatment outcomes were a dominant theme across all of the studies, and reflected the challenges that men faced in their daily lives, and the impact they subsequently had on their sense of self. Several studies highlighted the troublesome nature of urinary incontinence (Bertero, 2001; Navon & Morag, 2003; O'Shaughnessy & Laws, 2009; Nanton & Dale, 2011). Unlike erectile dysfunction, which to some extent was regarded as an invisible side-effect, incontinence issues were more salient. The social lives of men were severely affected, due to worry associated with leakage and odour, and the necessity to plan trips around the location of public conveniences (Maliski et al., 2008; O'Shaughnessy & Laws, 2009). Maliski et al (2008), revealed that the embarrassing nature of incontinence had resulted in some men refraining from social activities, or having to give up work. Moreover, although incontinence had a negative effect on men and their relationships, unpartnered men in Kazer et al.'s (2011) with problems relating to either urinary or bowel incontinence were identified as a barrier to those who contemplating new relationships.

### **2.6.1 *Body image***

Several studies discussed themes concerning men's body image after cancer treatment. Although some men mentioned body image in relation to surgery, e.g. O'Shaughnessy and Laws (2010), themes relating to body image were most evident within studies of men undergoing hormone therapy. For these men, changes to their body, were particularly

devastating as they affected both physical and psychological aspects of their lives and were deemed to be feminising. The most frequently mentioned side effects of hormone therapy included night sweats, disrupted sleep patterns, gynaecomastia (breast enlargement), impotence, weight gain, loss of muscle, hair loss, reduction in penis size, all of which resulted in feelings of embarrassment (Navon & Morag, 2003; Ng et al., 2006; Oliffe, 2006; Hagen et al., 2007; O'Shaughnessy & Laws, 2009; Ervik et al., 2010; Carter et al., 2011; Grunfield et al., 2012). A UK study found that men were reluctant to disclose these problems to those around them and to some degree, suffered in silence (Grunfield et al., 2012). The study made recommendations for the provision of alternative forms of support to be made available for men undergoing this type of treatment, which do not threaten their masculinity. A study by O'Shaughnessy and Laws (2009) highlights how body image may be closely related to masculinity as while some men in this study were concerned by scarring as a result of surgery, other men reframed their scars in a positive light as the scars reminded them they had survived cancer.

### **2.6.2 *Psychological and additional health Issues***

The studies conveyed the challenges of living with the long-term effects of prostate cancer. Men repeatedly wished for the life they had prior to prostate cancer (Ervik et al., 2010) and in some cases felt as though they had been left with a new or changed body. Kelly (2004) reported that some men felt as though they had relinquished a former part of themselves, in order to be cured. Findings from a British study conducted by O'Brien et al. (2011) also suggested that psychological support was lacking when men wished to discuss the impact of treatment on their sex lives and personal relationships. Men in this study stated that whilst they would have welcomed an opportunity to discuss psychological needs relating to sexual matters, a lack of rapport with staff combined with inopportune moments, meant that their psychosexual issues remained unaddressed. Furthermore, as findings from this

study were gained from participants from three different UK regions, this suggests that psychosexual issues may not be given high priority during men's follow-up consultations.

A study by Carter et al. (2011) also revealed that men on hormone therapy may have additional health issues to contend with. In this study, two groups of men undergoing different types of hormone therapy were compared. Men in the group who were receiving hormone sensitive therapy reported comorbidities such as cardiovascular problems, hypertension, diabetes and arthritis whereas comorbidities were not mentioned by those taking hormone refractory therapies. However, there are two issues which would benefit from further clarification. Firstly, it is not clear whether the comorbidities mentioned by the men were present as a direct result of taking hormone treatment, or they were pre-existing conditions. Secondly, the variation in data collection methods for each group may have simply generated different types of data. Men who disclosed their comorbidities were interviewed individually, whereas those in the group that made no mention of comorbidities were interviewed together. Hence, the men who were interviewed alone may have been more willing to disclose personal information than those who were in a focus setting amongst other men.

### **2.6.3 Sexual difficulties**

Prior to treatment, sex was perceived by the men in some studies as a means to pleasure and achieving intimacy with their partner (Letts et al., 2010). Hence, the negative impact of prostate cancer treatment on men's sex lives was a dominant theme across all but one study (Carter et al., 2011), where men had undergone active treatment. Sexual difficulties were often mediated by factors such as age, marital status and the nature of their personal relationships prior to, and during, their cancer experience. The main problems described across the majority of studies were reflected in a study by Letts et al. (2010) and included: full or partial loss of erection, reduced force of ejaculation, decreased orgasm, loss of libido

and decreased emotional changes, in addition to other relationship changes. The extent to which men experienced these problems varied across the studies. Furthermore, whilst men stated that they were usually aware of the potential risks to potency prior to their treatment, many were clearly unprepared for the extent to which it occurred after they had been treated and the initial threat of survival had passed, as outlined earlier (Fergus et al., 2002).

Issues concerning men's libido were also apparent. Whilst an intact libido, combined with the loss of sexual function was viewed as bothersome for some men, it was not as much of an issue for others. Letts et al. (2010) found that despite not being able to act on their sexual urges, some men felt that their intact libido was a reminder that at least something related to their sexuality had remained unchanged. In contrast, an intact libido left some men feeling frustrated as they were unable to physically act upon their desire. The absence of libido and sexual ability was also problematic, particularly for men undergoing hormone therapy. In these instances, the loss of both elements of sexual experience for men was compounded (Chapple & Ziebland 2002; Navon & Morag 2003; Ng et al., 2006). On the other hand, Oliffe (2006) found that the absence of libido helped some men to accept impotence. These men were less frustrated about their physical inability to perform sexually, as they were void of any desire. For the two gay men interviewed within a study by Filiault et al. (2008), distinct changes in their libido were noted as being distressing, given the centrality of sex in the participant's lives as gay men. However, despite emphasising that the prostate gland is viewed as a site for pleasure for gay men, the researchers do not explain why the centrality of sex is so significant in the lives of gay men. Nonetheless, one gay man in Kelly's (2004) study revealed that he had rejected treatments in order to preserve sexual function, which may suggest that sex may have specific value for some gay men.

Men's psychological adjustment to sexual difficulties is also apparent across several studies. Kelly (2004) and Letts et al. (2010) conveyed the sense of loneliness and isolation felt by some men who were inclined to view erectile dysfunction as 'their problem.' participants within both of these studies expressed relief at being able to share their worries for the first time with the interviewer. Hence, Letts et al. (2010) recommends the use of multidimensional assessments during follow up appointments to capture men's emotional, as well as physical, state of health. The findings from an American study by Bokhour et al. (2001), which conducted seven focus group sessions, each consisting of seven men, suggests that erectile dysfunction may be more embedded within the social context of men's lives than previously thought. Although the men in this study described complex issues relating to their sex lives, they did not necessarily view erectile dysfunction as a 'health issue'. Hence, the researchers suggested that measurement outcomes aimed at determining disease and illness related quality of life, may not adequately reflect the wider range of emotional problems that may be associated with sexuality.

Several studies revealed that not all men were overly concerned by the loss of sexual function and that others were resigned to the permanent changes in their sex lives (Hagen et al., 2007; O'Shaughnessy & Laws, 2009; Walsh & Hegarty 2010). The use of erectile aids and medication designed for rehabilitation and improvement of the men's sex lives were also frequently discussed across the studies. However, men's satisfaction with their effectiveness varied. Whilst many men were initially open to the idea of trying out aids and had accepted them as a normal part of their sexual repertoire (Kelly, 2004), others were uncertain about the appropriateness of treating erectile dysfunction (Oliffe, 2005). For example, a study of Latino and African-American men with prostate cancer by Maliski et al. (2008) found that Latino men were more hesitant regarding the use of medication, although they did not explain their hesitation. On the other hand, African-American men reported that they were willing to try anything that could help them retain some form of

sexual functioning. Although these findings may suggest a cultural difference in attitudes between the two groups of men in this study, the authors also acknowledge that they findings may also be attributed to the higher ratio of single men in the African-American sample, who may have been more concerned about maintaining an active sex life in the future. Fergus et al. (2002) highlighted the sense of hope experienced by men, who initially felt confident that technology would restore their sex lives. However, these men soon realised the reality of using erectile aids was different to what they expected and often came with a cost. Complaints about medications and erectile aids were synonymous across most studies that discussed this issue. Some men described feeling pain when attempting to use them. However, the most common complaints centred on the lack of spontaneity when men wanted to use them and disappointment with their overall effectiveness (Bokhour et al., 2001; Chapple & Ziebland, 2002; Fergus et al., 2002; Heidesteg et al., 2005; Letts et al., 2010; Walsh & Hegarty, 2010).

Another dominant theme in relation to sexual difficulties concerned the men's relationships with their wives or partners. Partnered men described feeling wary about initiating signs of affection towards their partners, for fear that this would lead to an expectation of sexual intimacy, which they were then unable to fulfil (Bokhour et al., 2001; Letts et al., 2010). Other men expressed regret about the effect of sexual difficulties on their relationships (Hagen et al., 2007; Letts et al., 2010; Grunfield et al., 2012) as communication between themselves and their partners had become awkward. Letts et al. (2010) suggests that this is because some men did not know how their wives or partners felt about the changes in their sexual relationships, as whilst some men discussed sexual matters with their partners at the time of diagnosis, it was rarely spoken about following treatment. Once again, this finding reiterates the need for psycho-sexual matters to be broached throughout the men's cancer journey by healthcare providers as this may afford

more opportunities for men and their partners to discuss issues as they become more salient.

Four studies found that unpartnered men, or those not sexually active prior to surgery were also affected by changes to their sexual functioning (Bokhour et al., 2001; Fergus et al., 2002; Letts et al., 2010; Kazer et al., 2011a). Therefore, these findings emphasise how sexuality is not only about 'function' but is an integral part of a man's sense of sexual self.

For some men, sexual difficulties were experienced with a sense of stigma. This was particularly evident in studies where gay men, single men and those from ethnic minorities were represented in their study samples (Fergus et al., 2002; Navon & Morag, 2003; Jones, et al., 2011; Kazer et al., 2011; Nanton & Dale, 2011). For Caribbean men, their high investment in sexual performance meant that it was difficult for them to recover emotionally after treatment (Jones, et al., 2011). For single men, the fear of shame and embarrassment meant that disclosure of sexual difficulties was delivered with hesitation and apprehension (Fergus et al., 2002; Letts et al., 2010; Kazer et al., 2011).

Gay men, who were included within four studies, reported additional concerns to those experienced by heterosexual men (Fergus et al., 2002; Kelly, 2004; Filiault et al., 2008; O'Shaughnessy & Laws, 2009). However, although gay men were grossly under represented within study samples, their experiences were similar across all four studies and therefore, worthy of discussion. One gay man equated his diagnosis of prostate cancer to having HIV (Fergus et al., 2002) Unlike heterosexual men who often turn to partners for support, this man anticipated rejection by potential lovers and worried about ridicule and gossip, likening the need to disclose his diagnosis to the 'coming out' process that many gay men experience (Fergus et al., 2002). Likewise, Filiault et al. (2008) found that gay men were troubled by the prospect of not measuring up, particularly as unlike female partners, these men's partners were sexually functioning men of the same sex to whom gay men could

visually compare themselves to. Furthermore, one gay man stated that the way he related to other gay men had changed, particularly in a sexual context. This echoes descriptions by heterosexual men who reported qualitative shifts in the way they interacted with women since undergoing treatment (Bokhour et al., 2001).

For the one gay man included in O'Shaughnessy and Law's (2009) study, the inability to sustain an erection had a particularly negative impact on his sexual identity. Short term and multiple relationships afforded few opportunities for him to explain impotence in a way that would invite empathy or patience. However, similar to other studies that include gay men, this study fails to explain how relationships amongst gay men differ, to those amongst heterosexual men. Therefore, conclusions and recommendations by researchers who have included gay men within their studies are generally based around the experiences of men with female partners.

## **2.7. Recovery, adaptation and acceptance**

In order to adapt and finally accept the long term changes that occurred following cancer treatment, men used several strategies to help achieve this. Reclaiming a sense of normality was common for men interviewed in one study (Walsh & Hegarty, 2010). The men achieved this by going back to work, retaining the same public image and keeping family dynamics the same as they were prior to their treatment. For some men with a positive outlook, acceptance of permanent changes as a consequence of treatment was perceived as a 'trade-off' for being alive (Bertero, 2001; Heidesteg et al., 2005; Oliffe, 2006). Others attributed erectile difficulties to the natural ageing process and were grateful that prostate cancer had not struck at a younger age. This is apparent within several studies and was emphasised by those who had fathered children as a sense of '*servicing their purpose*' (Maliski et al., 2008). Some men felt that by educating others about prostate cancer they could turn their own experience into one that would help and inform others

(Hagen et al., 2007). Humour was also frequently cited as an effective way of helping cope with bodily changes, particularly those experiencing the feminising side-effects related to hormone therapy (Bertero, 2001; Fergus et al., 2002; Grunfield et al., 2012) although this appeared to be easier for some men than others. Several studies found that men often chose to adopt healthier lifestyles following their cancer treatment (Heidesteg et al., 2005). For some, this meant changing their diet to more natural products or avoiding those linked to prostate cancer risk such as red meat or dairy products (Ng et al., 2006). Others chose to introduce exercise into their daily lives to increase their strength or engage in physical work – an activity which was cited as allowing men to regain a renewed sense of worth (Maliski et al., 2008). Men also spoke about the need to take up new activities within and outside of their relationships as an alternative way of dealing with prostate cancer (Fergus et al., 2002; Heidesteg et al., 2005)

Several men spoke about reframing their cancer experience in order to find some positive meaning from this life-changing situation. In some cases, men re-examined their lives (Kelly, 2004; Hagen et al., 2007). Instead of constantly focusing on the negative outcomes of treatment, they began to appreciate the positive changes that had occurred within their marital relationships. By managing to separate sex from love, Heidesteg et al. (2005) suggests that men were able to find new ways of remaining close to their partners. This was particularly evident in a study of men undergoing hormone therapy (Olliffe, 2006), as men experienced a range of emotions traditionally associated with femininity such as a heightened sense of sentimentality, being more open to touch and feeling and more maternal feelings towards family members. Despite their single status, Kazer et al. (2011a) found that unpartnered men demonstrated an increased potential for coping, compared to partnered men. These men highlight the benefits to be gained for adopting a positive attitude towards life following prostate cancer.

In contrast, whilst men frequently discussed the positive lessons they had learnt from their cancer experience, some men failed to see any meaning in their experience. For these men, prostate cancer had not changed their outlook on life and it continued to negatively impact on most aspects of their day-to-day lives (Hagen et al., 2007).

## **2.8. Uncertainty**

Uncertainty was a common theme across several studies as the negative experiences of some men had led them to develop a sense of uncertainty about their future. This often centred on the potential recurrence of prostate cancer and the fear of enduring a long, drawn out death (Ng et al., 2006). Men undergoing hormone ablation were particularly affected as their treatment was a constant reminder that their disease was still present. Hence, it is particularly understandable why there is no form of closure for these men (Ng et al., 2006).

Findings from two studies suggest that PSA levels may help to manage uncertainty for some men. Whereas Ng et al.'s (2006) suggests that men use PSA levels as a way of monitoring their responses to treatment; Heidesteg et al. (2005) suggested that by knowing their PSA values, patients are afforded some security and control over their illness. This was found to be particularly beneficial for those men undergoing active surveillance.

Moreover, as the findings from these studies indicate that men share their PSA values with fellow patients they meet in healthcare settings or support groups, it appears that the PSA value has some informational value amongst a group of men who appreciate and understand its significance.

Uncertainty was a particularly dominant theme within studies that explored the experiences of men undergoing active surveillance or watchful waiting (Olliffe, Pickles, & Mroz, 2009). A phenomenological study conducted by Heidesteg et al. (2003), which sought to uncover the meaning that seven men attributed to being placed on active surveillance,

revealed that the men saw themselves as *“living under a dark shadow”*, indicating that the men were never certain if, or indeed when, the disease might progress. This study also reflected how uncertainty may lead to a sense of loneliness. Men in this study chose not to share their thoughts and feelings with those closest to them, instead preferring to seek out men in similar situations.

Healthcare providers appear to play an important role for those patients experiencing feelings related to uncertainty. Findings from Ervik et al.'s (2003), illuminated the experiences of men treated with either endocrine therapy or active surveillance. The findings revealed that some men felt a sense of ambivalence towards their healthcare providers, as they had not been offered a form of curative treatment. This underscores the need for healthcare providers to ensure that patients understand why delaying curative treatment may be in their best interest. In contrast, other studies have noted that patients undergoing active surveillance tend to develop a trusting relationship with their healthcare providers (Heidesteg et al., 2003; Bailey et al., 2007). Hence, in the absence of certainty, men may feel a strong sense of reassurance from their healthcare providers, particularly as they may need to be monitored more frequently.

Although some studies have reported the negative aspects of living with uncertainty when men are undergoing active surveillance, others have attempted to explore whether any aspects of uncertainty can be adaptive. One such study, by Kazer et al. (2011b) found that experiencing uncertainty led some men to adopt healthier lifestyles, in an attempt to stay healthier for longer. As this study excluded men under the age of 65, it is difficult to know whether men of a younger age would have also adopted similar habits. However, the study demonstrate that some men are able to reframe their lives, by adopting a more positive attitude. Moreover, a study which used Mishel's Reconceptualised Uncertainty in Illness model (Mishel, 1990) to analyse data acquired from 10 interviews with men undergoing

active surveillance, offers a potential explanation for these findings (Bailey et al., 2007). This study explored whether the extent to which negative or positive thoughts translate to danger or opportunity respectively. The study found that men anxiety was heightened amongst those men who felt a strong sense of denial about living with a disease that is commonly associated with pain and suffering. In contrast, other men, who considered themselves thankful to be healthy, despite having cancer that was being untreated, were more able to reframe their diagnosis in a positive light. The study suggests that men may have to learn how to integrate uncertainty into their lives, in order to function healthily and normal in the future. Studies that discussed aspects of uncertainty shed light on how undergoing active surveillance has its own unique challenges compared to those experienced with other forms of treatment. Although patients may not have endured the unpleasant side effects associated with active treatment, they are forced to contemplate the possibility of experiencing them in the future nonetheless. One of the main limitations of the studies that have discussed uncertainty is their tendency to focus on men over the age of 65. Hence, it is not clear how younger men experience uncertainty in their everyday lives.

## **2.9. Summary**

The purpose of this literature review was to identify research that illuminated the experiences of gay men with prostate cancer. As the initial literature search retrieved only one study focused exclusively on the experiences of gay men, the review sought to identify research to reflect the experiences of all men with prostate cancer. The themes described from the findings provide a comprehensive understanding of the multidimensional nature of prostate cancer and how side-effects that many men live with as a result of treatment, impact on various aspects of their lives.

Gay men's experiences were under-represented which suggest that the overall findings from this review predominantly reflect the experiences of heterosexual men. Only four studies explicitly stated they had included gay men within their samples. Therefore, gay men accounted for just 1.3% of the total number of men who took part in all of the studies.

Findings reported within the four studies that did include gay men in their samples, suggest that whilst some of their experiences are similar to those of heterosexual men, others may differ.

The studies suggest that there is a greater emphasis on the centrality of sex for gay men. However, apart from one study, which revealed how one gay man had chosen inferior treatment in order to preserve sexual function (Kelly, 2009), it is not clear what short and long-term implications this may have for gay men. Moreover, although a central theme in the review was centred on the need for information about sexual issues, the findings did not explore whether gay men require specific information in relation to their own sexual preferences.

The findings also revealed that relationship dynamics may differ for gay men. Those shared with healthcare providers appeared to be more difficult on account of heterosexist norms within health settings (Filiault et al., 2008). The two gay men in this study described a sense of 'not belonging'. However, as neither had not disclosed their sexual orientation to their healthcare provider, the experiences of men who do choose to disclose their sexual orientation are not known. Furthermore, despite suggesting that personal relationships may also suffer following a diagnosis of prostate cancer (Filiault et al., 2008), it is unclear what factors led the men's relationships to become 'strained'. Unpartnered men in a study by Fergus et al. (2002) were also concerned that their disease status would prevent them from embarking on new relationships on account of 'not measuring up'.

The findings also suggest that gay men experience a sense of stigma, shame and embarrassment upon being diagnosed with prostate cancer (Fergus et al., 2002; Filiault et al., 2008). However, as both studies do not probe this issue further, it is unclear what impact this has on men and what strategies, if any, they adopt to overcome this.

There are also several other important points in the literature review which merit further study. For example, the extent to which gay men value support sources, such as friendships and support groups was not reflected in the findings, nor whether their experience of transrectal procedures differs to heterosexual men; given that Broom (2004) suggested that such procedures for heterosexual men are closely associated with homosexual behaviour.

Finally, although one of the dominant themes in the literature review was based around masculinity, the findings mostly reflect heterosexual masculinity. However, a comment by a man in one study in which he described not only feeling "*lesser male*", but also "*lesser gay*" suggests that there are unique aspects of gay identity that also impact on the men's sense of self which require further exploration.

Based on the gaps in research, as outlined within this summary, it is necessary to examine the experience of prostate cancer from the perspective of gay men who are living with the disease. Thus, the aims of the present study are described below.

## **2.10. Study aims**

The primary aim of the present study is:

- To explore the lived experiences of gay men with prostate cancer

The Objectives therefore are:

- To explore patients' experiences of prostate cancer to determine how it impacts on various aspects of their lives.

- To determine whether gay men report any additional or unique psycho-social support needs.

## Chapter 3: **METHODOLOGY**

In the previous chapter, the main themes arising from current literature in relation to the experiences of men with prostate cancer were discussed. In addition to outlining the challenges that men are faced with during their cancer journey, the literature review highlighted a need for further research into the experiences of gay men who have been diagnosed with prostate cancer.

### **3.1. Introduction**

In this chapter I begin by stating the aims of the research and provide an overview of the research paradigm that underpins this study. I then discuss the potential suitability of several qualitative approaches, before giving a justification as to why an interpretive phenomenological approach was considered to be the best approach for answering the study's research question. An introduction and overview of phenomenology then follows. This provides an historical background to the approach and compares the various schools of thought, along with the key scholars who have shaped the phenomenological movement over the past century. I then go on to highlight the contributions of the modern scholar Max van Manen, who continues to develop and refine a methodological framework, designed to assist researchers in the '*doing*' of phenomenology in research. Finally, I conclude by justifying why I decided to adopt Max van Manen's (The Dutch / Utrecht tradition) approach for the present study.

#### **3.1.1 *The research paradigm underpinning the study***

A research paradigm is an interpretative framework, shared by communities of researchers, which is guided by "*a set of beliefs and feelings about the world and how it should be understood and studied.*" (Guba & Lincoln, 1994; Weaver & Olsen, 2006).

Although various research paradigms exist, each one is characterised by different

ontological (what is reality), epistemological (how do we know something) and methodological (how do we go about finding something out) assumptions in their approaches to conceptualising and conducting research (Guba & Lincoln, 1994; Crotty, 1998; Weaver & Olsen, 2006) Hence, it is important that these differences and assumptions are made explicit within a study and are embedded throughout the research process (Creswell, 2007).

The principles underlying the research paradigm for the purpose of this study are based on social constructionism and interpretivism. Unlike objectivist epistemological perspectives such as positivism, which assume that meaning and meaningful reality exist apart from human consciousness (Crotty, 1998), social constructionism takes the stance that meaning and meaningful reality are constructed when an individual encounters realities (or phenomenon) that exist within the world. For example, despite the fact that concrete objects, such as plants, trees and mountains already exist when we enter the world, meaning is only truly ascribed to them upon encountering them. (van Manen, 1990) However, one must also consider the context in which these objects are experienced as prior knowledge, culture and personal beliefs have the capacity to change the manner in which meaning is constructed. On this basis, it must be accepted that multiple meanings exist for each object or experience, for each individual (Crotty, 1998).

Researchers who take a social constructionist perspective acknowledge how these multiple meanings are formed. They consider factors such as interactions that transpire between individuals, the context in which they live and work and, importantly, the cultural and historical background that have helped to shape them as an individual (Creswell, 2007, p. 21). When researchers embark on a qualitative study from this vantage point, there is an acknowledgement that they too have constructed meaning about the world based on their own cultural background and experiences.

### **3.2. Research design**

Due to the epistemological grounding and the nature of this study, a qualitative research design, utilising in-depth interviews was considered to be the most fitting when considering a methodological approach. Firstly, due to the paucity of knowledge relating to prostate cancer and its impact on gay men, the study sought to seek rich informative data that would illuminate their experiences. Moreover, issues surrounding recruitment were identified in the early stages of the study early on during the study as the difficulties of recruiting through the NHS, due to the absence of sexual orientation monitoring had already been realised. This was compounded by the knowledge I was researching within a population who have been perceived as a 'hard to reach' group in terms of research (Flanagan & Hancock, 2010). Hence, I felt that gaining access to a hard to reach group, combined with the additional prerequisite of a prostate cancer diagnosis could potentially reduce opportunities to recruit from this population even further. As a consequence of all of these factors, a qualitative approach was considered to be more appropriate than a quantitative approach.

Qualitative methods are increasingly used within clinical and healthcare research (Cohen & Crabtree, 2008) and have proliferated in the past decade. Studies utilising qualitative approaches can provide substance and explanation to numerical data generated within quantitative studies and offer rich insights into how patients experience disease and treatment. They also have the distinct advantage of helping researchers and healthcare professionals to better understand the setting and context in which illness and treatment are experienced. Moreover, qualitative research is useful in terms of its ability to develop and enhance theory; particularly when current theories do not adequately reflect or explain the complex problems faced by certain societal groups or individuals (Creswell, 2007).

Prior to choosing a qualitative approach for this study, it was important to consider a range of qualitative approaches that would ensure the approach taken could do justice to the research question being posed. A researcher's epistemological position will naturally eliminate some of the approaches available to them and subsequently lean towards others. I considered the merits of four different qualitative approaches before finally deciding that I would apply the use of phenomenology. I now outline the other three approaches I considered, prior to making that decision. I then go on to offer a short rationale as to why phenomenology was considered to be the most suitable approach upon which to conduct this research.

### **3.2.1 *Grounded Theory***

Grounded Theory has the distinct advantage of being an inductive approach which aims to generate and advance theories, as well as provide explanations of social processes (Charmaz, 2006). Data is generated through the use of observations, interactions and materials that relate to the topic being studied. Following a methodical process of coding, memo writing, and rigorous analysis that demands a strict set of codes and principles, concepts and ideas begin to develop, which may then go on to form the foundations on which theories can be built (Streubert-Speziale & Carpenter, 2003),

Although I was initially attracted to this approach due to the eclectic use of methods to obtain data, it was felt that theoretical sampling, a key feature within the grounded theory approach, may not be achievable within the study's timeframe. Theoretical sampling requires the researcher to obtain data that explicates categories that emerge as a direct result of data gathering (Charmaz, 2006). Thus, a broad, diverse and wider sample of participants is normally required for grounded theory research to ensure that a concrete description of an experience, in all its guises, is achieved. Given that I was recruiting from a sub-section of a minority group, this approach was rejected.

### **3.2.2 Case study approach**

Case Study methods are particularly useful when a researcher wishes to explore an issue within a bounded system, i.e. within a particular setting or context (Stake, 2005). Data collection typically involves gathering multiple sources of rich information about an event or experience that occurs within a setting, often over a period of time. This approach may also include the views of significant people who are closely involved or attached to the person or experience being studied (Yin, 1999). One of the main advantages for using this approach is that it can help to yield a rich and rounded perspective of an issue, due to the various sources it draws information from. Hence, cases can then be compared or applied across other settings. When I initially considered how this approach could be applied to the study, I envisaged that gaining the perspectives of healthcare professionals and support group leaders, in addition to the family and friends of the men being studied, may help to build rich cases that would reflect both the experiences of prostate cancer and the various contexts in which it is experienced. However, a concern with using this approach was that there would not be sufficient time to conduct and analyse data, based on the amount of sources that may have been required to build multiple cases as the process would have undoubtedly required staged ethical approval. Furthermore, there was also a concern that the depth of analysis required to uncover the lived experience of the men under study may have been somewhat diluted as a result of the potential quantity of data collected from other sources. For these reasons, a decision was made to discount a case study approach.

### **3.2.3 Narrative Inquiry**

As the present study aimed to explore experience, a narrative approach was also considered. Narrative inquiry yields life stories, past histories and weaves together the past, present and future experiences of those being studied (Crossley, 2000). Emphasis is given to the way participants narrate their stories. The types of stories they tell can reveal

how individuals view their lives based on their past experiences and how they make sense of their present situations. However, although narrative inquiry and phenomenology share some commonalities, in that they pursue stories, in the hope of shedding light on what they mean to the individual concerned, they both differ. Whereas a narrative study aims to explore the life story of an individual and show how stories help to shape their experiences, a phenomenological study reduces individuals' experiences with a phenomenon to a '*description of the universal essence*' (Creswell, 2007). That is, what an experience is like for an individual and what makes it unique to the group as a whole. Due to the dearth of current research on gay men as a group, I considered that focusing on the phenomena of the men's experiences in relation to prostate cancer was of central importance. Hence, a narrative approach was discounted in favour of a phenomenological approach.

### **3.2.4     *Justification for an interpretive phenomenological approach***

Phenomenology is considered to be an ideal approach for exploring topics of an exploratory nature (Creswell, 2007). This inductive approach has been widely used across several disciplines within health research and has offered rich insights into the perspectives of patients, which have ultimately helped to improve care (Thomson, Dykes & Downe, 2011). The main advantage of using a phenomenological approach to explore how illness is experienced, is that it aims to convey the meanings that individuals attach to their experiences, as they are lived, rather than how they are conceptualised (Benner, 1994). Hence, by employing in-depth interviews, the approach can help to reveal the essential features of a phenomenon; those things that capture it in its most general sense, and how, in some situations, it may vary (Holloway & Todres, 2005). Another advantage of this approach is that it offers researchers a lens through which they are encouraged to look beyond 'taken for granted' assumptions and acknowledge how their own view of the world may impact on the research process. After considering several methodological approaches,

it was deemed that a phenomenological approach would be the best approach for conveying the lived experience of gay men with prostate cancer. Hence, I now offer an introduction to phenomenology and describe its application to the present study.

### **3.3. Introduction to phenomenology**

Phenomenology is an inductive qualitative research tradition, the origins of which are deeply rooted within philosophy (Mackay, 2005; Reiners, 2012). Phenomenology is primarily concerned with how humans experience their world, within the world and what it means to be human. Therefore, constructionism and phenomenology are naturally compatible (Crotty, 1998). Phenomenology poses the question *'what is this or that kind of experience like?'* It attempts to gain insights into how everyday things in the world are experienced (van Manen, 1990, p. 9). As phenomenology endeavours to uncover and describe the essence of an experience or phenomena, this in turn allows the nature of the experience to be shown in a much deeper and fuller manner than it may have been previously shown (van Manen, 1990).

As a philosophy, phenomenology was developed around the turn of the 20th century by Edmund Husserl (1859-1938), at a time when some philosophers had started to question whether metaphysics and the quest for certainty were the only ways of viewing the world (Moran, 2000). Following an 'interpretive turn' within the philosophical sciences, scholars of phenomenology, amongst those within other interpretive practices such as critical social theory, feminism and postmodernism, began to pose questions concerned with the ways of being human; questions that were related to the meaning and understanding of 'being' (Heidegger, 1962).

Although there are several variations within current phenomenological practices and methods, they have been primarily guided by two main schools of thought and their respective founders. Descriptive phenomenology is attributed to Edmund Husserl and

hermeneutic or interpretive phenomenology is associated with Martin Heidegger. A table outlining the key differences to both approaches can be found in Appendix 4. Here I discuss some of their similarities and differences in more detail and provided a synopsis of key figures who have drawn and built upon the work of both approaches within their own phenomenological work.

### **3.3.1 Edmund Gustav Albrecht Husserl (1859-1938)**

Husserl was a German philosopher who is widely regarded as being the founding father of phenomenology (Zahavi, 2003). Many of his ideas were derived from past influential figures such as Georg Wilhelm Friedrich Hegel, William James and Franz Brentano. Disillusioned with the way in which psychology attempted to study human issues using methods borrowed from the natural sciences, Husserl turned his attention to the *“life-world”* (Lebenswelt). He saw the lifeworld as *“the world in which we are always already living and which furnishes the ground for all cognitive performance and all scientific determination”* (Husserl, 1938, p. 41). Husserl’s vision was that philosophy should become a recognised and rigorous science in its own right that would enable the study of human concerns using phenomenology as its foundation (Streubert-Speziale & Carpenter, 2003).

In Husserl’s view, consciousness is the condition of all experience. However, he goes on to argue that as humans, we are unable to reflect upon experience ‘as it is given to us’, due to our prior knowledge of the world, and our on-going engagement within it (Moran, 2000). In other words, if access to the experience of a phenomenon is derived through conscious interpretation ‘with’ the world, the construction of meaning becomes an obvious problem for those trying to gain access to the phenomenon in question, in order to see it clearly (Moran, 2000; Lavery, 2003). This realisation led Husserl to develop what is known as ‘the phenomenological reduction’ or ‘epoche’; a process undertaken by the researcher which involves temporarily suspending or ‘bracketing out’ their everyday assumptions or

extraneous thoughts, in order to isolate the central features of the phenomena under investigation (Moran, 2000; Holloway, 2005). For Husserl, insight into conscious processes could only become possible through the use of 'reduction' (Reiners, 2012).

By practicing 'reduction', Husserl proposed that objects could be described as they appear to consciousness (Lavery, 2003). Utilising a process he names as 'intuiting', which requires the researcher to imaginatively think and wonder about data and the descriptions given, Husserl believed that a common understanding or accurate interpretation of the phenomenon being explored could eventually be reached (Streubert-Speziale & Carpenter, 2003). When applied to research, naïve descriptions of experience are obtained through open-ended questions and dialogue with a participant. Using these descriptions, the structures and essences of experience would be described in detail based on reflective analysis and interpretation of the research participant's account or story (Giorgi, 2008).

The subject of reduction in phenomenological research remains a contentious and widely debated issue. Whereas some contemporary phenomenological scholars for example Giorgi (1985) remain true to Husserl's reductive approach, others outwardly reject it and take Heidegger or Gadamer's stance that reduction is not possible and perhaps even unhelpful. Other scholars such as Max van Manen (1990), advocate the use of reduction, but approach it with caution. Van Manen suggests that personal biases and prejudices should be explicated prior to commencing research as well as personal views or recollections that emerge throughout the research. Hence, the researcher is aware of how his/her own preconceptions of the phenomena being explored.

### **3.3.2     *Martin Heidegger (1889 – 1976)***

Martin Heidegger was a former student of Husserl's at Freiburg University in Germany. During his time there, Heidegger spent many years reading his mentor's work whilst developing his own ideas of how phenomenology should question and approach the notion

of 'being' (Dasein) and the being of others. Although Heidegger drew on many of Husserl's original phenomenological concepts initially, he opposed and finally rejected the reductive attitude which is a hallmark of Husserl's approach. The notion of distancing oneself from the world and its objects through the process of reduction was not something Heidegger considered to be possible, given that as humans, we are 'thrown' into the world (Smythe, Ironside, Sims, Swenson, & Spence, 2008). Central to his approach, is the belief that humans inherently bring a degree of 'pre-understanding' to a situation or experience that cannot be eliminated or set aside (bracketed), since it is already in the world (Koch, 1995). Heidegger also challenged Husserl's claim that phenomenology should be a purely descriptive philosophy. In Heidegger's view, the actuality of any description being void of interpretation, regardless of how it is told or retold, is an impossibility (Mackey, 2005). Hence, Heidegger incorporated hermeneutics into his approach.

The term 'hermeneutics' derives from the Greek word 'hermenein' which refers to explanation or interpretation and is associated with the Hermes, the Greek God who helped humans to grasp the unknowable, through his discovery of language and writing (Crotty, 1998, p. 88). By incorporating hermeneutics, the philosophy of interpretation, into his studies, Heidegger asks 'what is it like to mean to be a person?' (Leonard, 1989). His approach focuses on 'being in the world' rather than simply knowing about the world (Reiners, 2012). When a researcher engages in hermeneutic inquiry, their quest is to uncover and reveal that which is taken for granted in everyday life.

### **3.3.3 Hans – Georg Gadamer (1900 – 2002)**

Gadamer was another German philosopher who studied under Heidegger. Drawing upon both Heidegger and Husserl's influences as well as the writings of Plato and Hegel, Gadamer began to develop his own philosophical concepts. His philosophical stance is that humans are situated in the world historically and tied to tradition (Crotty, 1998). He also

positions language as being the core of understanding (Crotty, 1998). For Gadamer, the world is brought into consciousness through the use of language as it reveals 'being' (Crotty, 1998), and in turn, 'being' is what makes language possible (Koch, 1999). Both are inextricably bound. In his major work, *Truth and Method* (1960), language is perceived as 'the medium in which substantive understanding and agreement take place between two people' (Gadamer, 1962). This leads us to explore another of Gadamer's key concepts; 'horizons'.

When Gadamer talks about horizons, they are horizons that are connected to the past, the immediate present and the subsequent fusion of both (Crotty, 1998). Here, Gadamer is trying to point out that 'understanding' is a result of the interplay that occurs when we use past knowledge as a way of making sense of the present. As the interplay unfolds, a mediation of what was known and may be known, results in a 'fusion of horizons'.

However, Gadamer states that horizons are not fixed "*horizon is... something into which we move and that moves with us. Horizons change for a person who is moving*" (Gadamer, 1960, p. 304) implying that horizons have fluidity. Hence, the fusion of horizons can be likened to the circular process that occurs within the hermeneutic circle.

Gadamer also focused on the concept of prejudgement or '*prejudices*'. These preconceptions we hold are part of the linguistic experience that help to make understanding possible. Thus, inherited notions which are derived from our culture help us to make sense of the world (Dowling, 2007). For this reason, Gadamer also opposes Husserl's concept of reduction, citing it as not only unnecessary but impossible. He goes on to reject the concept further by stating any attempt to eliminate personal prejudices could interfere with the interpretation process (Dowling, 2007).

### **3.3.4 Maurice Merleau-Ponty (1908-1961)**

Merleau-Ponty was a French philosopher who viewed philosophy as a means to reawaken the understanding of how humans come to awareness of the world (Moran, 2000). In a similar vein to Husserl, Merleau-Ponty attempts to show that experience should be viewed in a new light without relying on our reflective experience. However, Merleau-Ponty also emphasised the need for us to understand how we normally experience 'experiences' in a world that is already there (Mackey, 2005). Merleau-Ponty's phenomenology is 'existential' in that it lays emphasis on the human presence and their individual, independent and conscious existence within the world. His approach also centres on perception and the world it discloses, in terms of the way we think about, anticipate and ponder in all its mystery (Carman, 2008). Like Gadamer, Merleau-Ponty also recognises the importance of language as he believes that word and thought cannot be separated (van Manen, 2014).

Perception, according to Merleau-Ponty, *'is not just born anywhere but emerges in the recesses of a body'* (Carman, 2008, p. 9). He views body and consciousness as being meaningfully involved and inextricably bound (van Manen, 2014). Hence, what makes a perspective concrete and finite is its rootedness in our bodily orientation and behaviour (Carman, 2008).

In relation to the lifeworld, Merleau-Ponty proposes four domains (existentials) in which the bodily orientation of humans are situated. These encompass lived space (spatiality), lived body (corporeality), lived time (temporality) and lived human relation (relationality or community) (van Manen, 1990). Van Manen has frequently adopted these existential themes in both his own research and to further the methodological framework he developed to assist researchers during their own pursuit of lived experience.

### **3.3.5 Dutch School (Utrecht tradition)**

The Dutch School has made an important contribution to the international phenomenological movement (Levering & van Manen, 2002). The 'school' was formed just after the end of World War II and was pioneered and initially led by the chair of psychiatry at the University of Utrecht, Henricus C. Rimke. As well as including phenomenologists, the Dutch school also comprised like-minded academics from across a range of disciplines. These included psychologists, educators and pedagogues as well as sociologists, criminologists and jurists (Levering & van Manen, 2002). However, rather than viewing phenomenology as a philosophy, these scholars were interested in phenomenology as a reflective and practical method that could be applied within their professional disciplines (van Manen, 2007).

Leading scholars of the Utrecht school went on to publish many books and journal articles relating to phenomenology which continue to provide an important source of guidance to modern day phenomenologists. Today, the Dutch school is perceived as being a collected school of thoughts and ideas stemming from its original scholars. Consequently, developments that originally derived from the Dutch school continue to be taken forward by phenomenologists both within and outside of the Netherlands. However, the scholar who has been most influential in continuing to refine phenomenological methods that are ground in understanding the concrete experiences of everyday life is Professor Max van Manen, Professor Emeritus at the University of Alberta, Canada.

### **3.3.6 Max van Manen (1942 - present)**

Max van Manen was born and raised in the Netherlands, before moving to Canada at the age of 25, in order to complete his PhD within the Faculty of Education at the University of Alberta. Van Manen's personal research interests mostly centre on aspects of pedagogy and the development of phenomenology as a research method for use in human science

inquiry. As well as being influenced by Husserl, Heidegger, Gadamer and Merleau-Ponty, van Manen was heavily influenced by the phenomenological style of writing produced by Utrecht scholars from the Dutch school such as Langeveld, Linschoten and Buytendijk. These influences encouraged van Manen to pursue phenomenology in a way that bridges its philosophical underpinnings with a working methodological framework that can be applied to research.

Van Manen (1990) perceives phenomenology as an enquiry that is not governed by a set of investigative procedures. He argues that restrictive procedures run the risk of thwarting phenomenology's unique ability to reveal the essence of the phenomenon being studied, implying that the essence of phenomenology itself may also be compromised.

Paradoxically, van Manen also recognises the need for researchers to have a methodological and practical foundation upon which to practice phenomenological research. Hence, rather than following a rigid set of rules, van Manen proposes that human science research embracing hermeneutic phenomenology, can be pursued by making use of flexible guidelines, or during each stage of the research process. As a result, the researcher has the capacity to '*encourage inventiveness and stimulate insight*' (van Manen, 1990, p. 30).

### **3.4. The Hermeneutic circle**

The process used to help achieve understanding in phenomenology is known as the 'hermeneutic circle'. Narratives are examined in a simultaneous fashion, between its parts and the text as a whole. The circular motion occurs when further narratives are generated, examined and become 'parts' themselves. Upon entering the hermeneutic circle, the researcher is required to revisit or re-examine all of the texts' parts, as a way of comparing meanings, in a way that is not usually linear (Crist & Tanner, 2003). As new meanings emerge, this cyclic process continues and understandings are continually challenged.

### **3.5. Rationale for choosing van Manen's phenomenological approach**

The current study is informed by interpretive phenomenology and is guided by the approach and framework developed by the work of Max van Manen. I chose to adopt van Manen's approach as opposed to other phenomenological approaches, as it draws upon the work of several influential philosophers and incorporates the central tenets of their work into a practical methodology. I was also drawn to the flexibility offered within van Manen's framework, as he points out that research does not always proceed sequentially. This framework consists of six steps. Each step is designed to help the researcher elicit the phenomena of lived experience during each stage of their research. Van Manen (1990) also suggests using a reflective lens during the research process, in the form of four lifeworld elements that can be applied to most aspects of human existence, as a way of helping to illuminate how experience is embodied in everyday life. These encompass Merleau-Ponty's lifeworld existentials: spatiality (lived space), temporality (lived time), relationality (lived relations) and corporeality (lived body). Within the next chapter, I discuss the application of van Manen's approach to the research methods used to elicit the lived experience of gay men with prostate cancer.

## Chapter 4: **APPLIED METHODS**

In the previous chapter, I discussed the research paradigm underpinning the present study and evaluated the strengths and weaknesses of several qualitative approaches that could have been utilised for this research. An historical overview of phenomenology and the key figures who have influenced this discipline over the past century provided a contextual background in which to place the study. The chapter concluded with a rationale for choosing van Manen's phenomenological approach as opposed to other descriptive and interpretive phenomenological approaches.

### **4.1. Introduction**

In this chapter, I discuss the research methods that were applied during the course of the study in the sequential order they were undertaken. I begin by discussing a range of ethical issues that were identified and addressed, before moving on to discuss sampling and recruitment strategies. This is followed by an overview of the steps that were taken prior to and during the data collection phase in which participants were actually recruited into the study. Finally, an in-depth overview of van Manen's six step approach is provided which explains how each of the steps helped to guide the research during the data collection and analytical phases of the study. Finally, I conclude by addressing how methodological rigour was demonstrated throughout the course of the research.

### **4.2. Ethical issues**

Prior to conducting any aspect of research, several ethical issues were identified, which were considered and addressed prior to seeking and subsequently gaining ethical approval from the University Ethics Committee (see Appendix 5). These concerns centred on issues of safety, informed consent and confidentiality/anonymity of the participants, the handling

and storage of data and safety issues concerning myself as a lone researcher. These issues will now be discussed in more detail.

#### **4.2.1 *Informed consent***

A main aspect of ethical consideration concerns the issue of informed consent. Informed consent is necessary to ensure that participants are fully cognisant of issues related to confidentiality, anonymity and the use of their data following completion of the project. All participants were provided with an information sheet prior to the arrangement of an interview (see Appendix 6). Hence, participants were given at least 48 hours to decide if they wanted to be interviewed. As interviews were arranged sometimes days or weeks in advance, participants were always asked once again, prior to the interview, if they were still happy to consent and proceed. If this was the case, participants were asked to sign a consent form (see Appendix 7).

#### **4.2.2 *Participant safety***

In addition to the researchers contact details, the information sheet also contained contact details for the lead supervisor of the project and the Dean of Health within the university. Hence, if they wished to discuss any concerns they had about the conduct of the researcher or any aspect of the interview, they were able to do so. Due to the sensitive nature of the topic, it was envisaged that some participants may become distressed during the interview whilst recalling their past experiences. Prior to commencing the interview, it was agreed that if this should happen, the interview could be paused or terminated.

#### **4.2.3 *Researcher safety***

As it was likely that most of the interviews would be conducted either at the participant's home or somewhere located near to them for ease of access, a University risk assessment was completed. In line with the University's lone worker policy, a 'buddy' system was also

put in place to ensure that there was regular contact between myself and a member of the supervision team prior to, and following each interview. As it was anticipated that there may be some occasions where interviews continued for longer than initially anticipated, due to the in-depth nature of phenomenological interviews and informal chatting that often takes place prior to the interview, it was agreed that a short text message would be sent to a member of the supervision team during a toilet break, to inform them that the interview was going well and contact would be made upon leaving the participant's home.

#### **4.2.4 Data handling and storage**

Storage of data was adhered to in line with the requirements of the University of Central Lancashire. All documentation related to the project was kept locked away in a filing cabinet within the postgraduate base room. All participants' transcripts were checked to ensure identifying features were omitted and names were replaced with pseudonyms. Where external transcription services were used, they were affiliated by the University and interview audio data were sent and received via encrypted ZIP files. Any electronic data relating to the study was stored on the University secure server or a personal laptop; both of which were password protected.

#### **4.3. Sampling**

Within phenomenological inquiry, purposive sampling is usually used in order to gain access to participants who have had direct experience of the phenomena being explored (Crotty, 1998). It was therefore decided that gay men who had received a diagnosis of prostate cancer would be recruited to take part in the study, providing they were not in the acute phase of treatment following surgery or radiotherapy. Phenomenology does not attempt to provide irrefutable evidence nor to prove or disprove (Smythe et al., 2008). Instead, phenomenological research aims to evoke awareness and provoke thinking. Furthermore, as large amounts of data are often yielded as a result of the preferred style of

in-depth interviewing within phenomenological research, the sample size is generally smaller. Benner (1994) advocates that the size of a sample can be considered adequate when new participants fail to reveal new findings and meanings found in previous participants stories. Smythe & Spence (2012) suggest that a sample of 12-20 participants is adequate for doctoral level research, although many of van Manen's doctoral students have recruited fewer than five participants for their studies<sup>2</sup>. It is also accepted that some participants may need to be interviewed on multiple occasions, particularly if their initial interview requires further clarification or new meanings need to be probed further. Alternatively, participants who are experiencing ill health may tire easily and an in-depth interview in one sitting may not be in their best interests. For example, in a study by Wright and Hacking (2012), several participants (anorexic females) were interviewed several times, but for very short periods. In the present study, the participants were informed that the interview would proceed at their pace and could be paused and reconvened at a later date, if they were to tire or felt unable to continue.

#### **4.4. Recruitment**

Researchers who explore the experiences of individuals who have experienced cancer often request ethical approval to recruit within the NHS. This way, potential participants can be identified by clinical staff who also ensure that they meet the suitability criteria by accessing their medical notes or records. However, as sexual orientation is not a demographic that is routinely captured and monitored across the NHS at present, a decision was made to employ alternative strategies in order to identify and recruit potential participants. These included contacting national and local organisations and

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<sup>2</sup> During my attendance at the Utrecht Summer School in the Netherlands, I was able to discuss the issues relating to sampling sizes with Max van Manen face-to-face and who kindly gave students access to some completed studies which contained small sample sizes.

charitable groups across the UK as well as 'snowball sampling' and making use of the social media site 'Twitter'. These strategies will now be discussed in further detail.

#### **4.4.1 Recruitment issues to consider**

A number of decisions were made prior to the recruitment stage to ensure the phenomenon of gay men with prostate cancer could be reflected as accurately as possible using an interpretive approach. I considered how appropriate it was to potentially interview men who were still actively receiving treatment to minimise any distress. As outlined in the introduction, certain types of treatment for prostate cancer, such as hormone therapies, are often prescribed to patients for several years. Moreover, watchful waiting and active surveillance are both considered to be active treatments. It was eventually decided that men who were actively receiving, or recovering from the most invasive forms of treatment including surgery, radiotherapy, brachytherapy and chemotherapy would be excluded.

Another recruitment issue to consider was the possibility that bisexual men may want to participate in the study. Health research into the experiences of the LGBT population frequently groups non-heterosexual men together, however it is important to remember that they are not a homogenous group and treating them in this way is not always considered to be helpful (Clarke, Ellis, Peel, & Riggs, 2013). The needs and challenges faced by bisexual and gay men may also differ from each other due to social structures relating to their sexual orientation (Clarke et al., 2013). On this basis, it was decided that the phenomenon of bisexual men with prostate cancer may be different from that of gay men and that bisexual men would possibly benefit from being studied separately in the future, in order to illuminate their own unique experiences. Hence the inclusion and exclusion criteria was as follows:

### **Inclusion Criteria**

- Men who self-identified as gay and were aged 18 or over
- Men who have received a diagnosis of prostate cancer
- They were able to speak and understand English

### **Exclusion Criteria**

- Men under the age of 18
- Heterosexual men
- Men who could not speak and understand English
- Men who were currently undergoing, or about to undergo active treatments such as surgery, radiotherapy, brachytherapy and chemotherapy or had undergone treatment during the past six months.

#### ***4.4.2 Promoting the study through organisations and support groups***

Following ethical approval, I made contact with several key charitable organisations including Stonewall, Prostate Cancer UK, The Lesbian and Gay Foundation and The Terence Higgins Trust. They each offered advice on how best to recruit from within the gay community. Following this advice, I began to search and list additional sources who could potentially promote the study. This resulted in me making contact with over 200 organisations, charities, and support groups, in addition to individuals from academic institutions who were recommended to me during the earlier stages of the study. I composed a generic email (see Appendix 8) outlining the study with a request for their support. Each email was then personalised to the recipient prior to it being sent. This resulted in an excess of 50 replies, most of which were positive and with agreements to promote the study, either by putting up a poster that was created (see appendix 9) or posting the details on their websites, forums or social media sites. Recruitment posters were subsequently emailed or posted to those contacts who agreed to promote the study

and acknowledgment emails were sent to those who stated that they were unable to help, thanking them for their response. Promotion of the study using this method yielded seven participants.

#### **4.4.3 Snowball sampling**

Snowball sampling is a popular recruitment method, especially when used to recruit participants who are considered 'hard to reach' (Johnston & Sabin, 2010). This strategy involves asking active participants if they know of any other individuals, within their own circle of contacts, who may be interested in taking part in the study. Although this recruitment method has been criticised for its potential to yield certain 'types' of participants (Browne, 2005), its value for accessing participants belonging to hard to reach groups cannot be disputed.

Snowball sampling proved to be an effective recruitment strategy for the purpose of this study. In addition to contacting various organisations by email, I was also invited to attend a workshop run by Prostate Cancer UK and Stonewall in September 2012. The purpose of the workshop was to discuss ways in which the needs of gay and bisexual men with prostate cancer could be best met and promoted within the charity. During this session, I met a potential participant, whom I later interviewed and who went on to be involved with the first support group in the UK for gay and bisexual men with prostate cancer. As I was invited to attend the first gathering of this group, I was able to recruit a further two men who were in attendance. One of the men also informed me of another man who had expressed interest in taking part. Snowball sampling resulted in the recruitment of three men into the study.

#### **4.4.4 Recruiting via social media**

The value of social media platforms such as Twitter and Facebook is now recognised as having the unique ability to promote and communicate research related material to large groups of people worldwide. Most organisations, charities, political parties and academic institutions now have their own Twitter 'feeds' on which they post (tweet) regular up-to-date news items and events to their hundreds or thousands of 'followers'. Followers can be individuals or other organisations with their own Twitter accounts, who usually have an interest in the news items being generated by other Twitter users. Once they have read a news item, they are then able to 'retweet' this to their own dedicated group of followers.

In terms of promoting research studies or aiding recruitment, Twitter can be used to target specific organisations or charities who may, if requested, retweet a recruitment poster or message to their followers. The hope is that a 'domino effect' will transpire and the message will be subsequently viewed by potential participants and those interested in the research being promoted.

To support my own research topic and to promote the study, I joined Twitter and subsequently followed organisations, charities and academics who were interested in prostate cancer research. I then began following various charities, LGBT groups and organisations that I thought may have followers who would be interested in taking part in the study. After several months, I had accumulated several hundred followers and was, in turn, following over 700 different Twitter accounts. I tweeted my recruitment poster and details about the study to my followers and asked several prominent organisations to retweet it. The recruitment poster reached over half a million people, based on the accumulation of followers from organisations who retweeted my original message.

The use of social media as a way of recruiting did not directly lead to anyone contacting me for an interview during the recruitment phase. Hence, the use of social media for directly recruiting participants as opposed to advertising research may be an interesting area to

explore in the future. Nevertheless, due to the accumulation of Twitter followers to my account, I was eventually contacted by two men with prostate cancer after data collection had ended, who expressed an interest in taking part in any future research relating to this topic. Expressions of interest for my study were also received from a variety of academic sources globally. I was also contacted for advice by other PhD and Master's students studying in similar fields who were experiencing recruitment issues. Hence, Twitter may be a quick and informative form of social media in terms of knowledge transfer amongst those who share an interest in specific academic fields.

I now go on to outline the procedure that was undertaken following promotion of the study through various means and after I had been contacted by potential participants for further information.

#### **4.4.5 Recruitment procedure**

Following the promotion of the study, several men contacted me by email to request further details about the study or to say they would be interested in taking part. Those who simply requested further details about the study were sent a reply, thanking them for their interest and requesting whether they would prefer a copy of the information sheet and consent form by post or by email. I also explained within the email that if they decided they would like to take part in the study, I would need to clarify whether they were eligible based on their current health status (i.e. if they were undergoing treatment) and that it would be useful to speak to them by telephone if they decided they would like to take part. Upon receiving the information, they were asked to contact me by email or telephone. This procedure was repeated for men who expressed an interest in taking part in the study. However, upon sending an information sheet and consent form, I stated that I would contact them after 48 hours to check if they still wanted to proceed and arrange a telephone call to check their eligibility.

Telephone calls were arranged between myself and those men who agreed to take part in the study. Although the main purpose of the phone call was for me to check eligibility by asking several questions from an eligibility screening form I had created (see appendix 10), on reflection, the phone calls played an instrumental role in terms of establishing trust between myself and the men. Upon establishing that the men were eligible to take part in the study, I took the opportunity to try and get to know the men a little better and to let them get to know me. Spradley (1979), who developed guidelines on the art of ethnographic interviewing suggested that rapport building during the early stage of an interview can pay enormous dividends. Hence, the phone calls were friendly and informal and I encouraged the men to talk about the topic of research and any concerns they may have had about it. The most common question I was asked was asked by the men was why, as a female, I was particularly interested in conducting this piece of research. This gave me an opportunity to express my own passion about the topic and why I thought it was important and I sensed that explaining my motivations allayed any fears the men may have had about being potentially exploited. Several telephone calls lasted up to an hour and the reciprocal exchange of information during this time helped to form a solid basis for the main interview.

Due to the distance that participants may have needed to travel in order to be interviewed at the host institution, and given that some men are known to suffer varying levels of incontinence following treatment for prostate cancer, I thought that it was only fair to ask the participants where they felt most comfortable being interviewed. Hence, a mutually convenient time and location was arranged for an interview to take place. As locations required me to travel to other parts of the country, it was agreed that I would contact the men again, the day prior to the interview, to ensure that our meeting arrangements were still in place. Once again, this phone call offered a further opportunity to build rapport and

on this occasion, several men offered to meet me from train stations and invited me to share lunch at their home upon arriving.

Due to rapport we had built during our phone calls, the conversation between the men and myself when the interview finally took place was relaxed and informal. Some men were surprised that I had travelled so far to hear about their experiences and they were happy to share local knowledge about the area in which they lived, and their lives more generally.

Following a period of informal conversation, discussion naturally turned to the purpose of my visit. At this point, formalities surrounding consent were reiterated and I simply asked the men to tell me about their experiences. Details about the interview schedule and subsequent data collection are discussed later in this chapter in relation to van Manen's six step approach. It is also important to point out that during the time I spent with the participants, I was not afraid to express interest and to some extent, a degree of cultural ignorance, if and when they discussed aspects of gay culture that I was unfamiliar with. The men were happy to explain concepts or situations I had no prior knowledge of, in order to ensure their experiences were reflected accurately.

#### **4.4.6 Ethical amendment**

The unhelpful nature of labelling individuals with categories based on their sexual orientation became clear once recruitment had commenced. Hence, I was forced to look again at the blurred boundaries that exist between gay and bisexual men. This was as a result of being contacted by one man after a call for participants had been posted on a cancer forum. This man explained that, although he was an outwardly heterosexual man, married with children, internally he identified himself as a gay man who embarked on relationships with other men. This was complicated by the fact that he assumed he would be regarded as a bisexual man in terms of the research project, due to his dual relationship

status. This led me to consider how many other men could be in similar situations as a result of social norms, labelling and expectations. To overcome this dilemma, ethical approval was sought to change the inclusion criteria to 'men who self-identify as gay'. Furthermore, to ensure that there was an element of flexibility, as a result of the issue raised by the individual who initially contacted me, the term 'bisexual men' was also removed from the official exclusion criteria on the ethics form. However, it should be noted that bisexual men were not actively recruited and the title of the study on the recruitment poster remained the same.

After outlining the steps that were taken prior to the recruitment of men to the study, and discussing issues that arose during this stage of the research, I now move on to discuss van Manen's six step approach in more detail. In order to highlight how the framework was applied to the study during the data collection and analysis phase, I will continue to outline and discuss the methods that were employed during both of these phases within the context of each of the six research activities proposed by van Manen.

## **4.5. Van Manen's six step approach**

### **4.5.1 Introduction**

As previously stated, phenomenology is suited to exploration of what an experience is like, and means, to those who have lived, or are currently living through it. Unlike descriptive phenomenology, hermeneutic phenomenology endeavours to illuminate, interpret and understand, as opposed to simply describing and explaining the features of a particular experience or phenomenon (Giorgi, 1985). Hence, van Manen's approach is based on the '*dynamic interplay among six research activities of human science*' (van Manen, 1990, p. 30). The approach offers six flexible guidelines that may assist researchers during their pursuit for the lived experience.

The six research activities are not necessarily sequential and van Manen emphatically denies that a systematic or procedural approach can be followed; he insists that “*critical moments of inquiry are ultimately elusive to systematic explication*” (van Manen, 1990, p. 34).

The six activities are briefly outlined before each one is discussed in relation to how it was applied to the study.

- Turning to a phenomenon which seriously interests us and commits us to the world
- Investigating experience as we live it rather than as we conceptualise it
- Reflecting on the essential themes which characterise the phenomenon
- Describing the phenomenon through the art of writing and rewriting
- Maintaining a strong orientated pedagogical relation to the phenomenon
- Balancing the research context by considering the parts and the whole

(van Manen, 1990, p. 30)

#### **4.6. Turning to a phenomenon which seriously interests us and commits us to the world.**

A starting point for phenomenological research is to identify a deep interest and recognise this interest as an experience that human beings live through (van Manen, 1990). By orienting oneself to a phenomena, the researcher does not simply pose a research question, but rather ‘lives’ and ‘becomes’ this question – interrogating it until it finally reveals something about its essential nature, with the resulting account being one which is able to ‘pull’ the reader and evoke a sense of wonder and questioning (van Manen, 1990, p. 43).

Within this first step, van Manen discusses the importance of employing the use of bracketing. As previously discussed, bracketing is commonly associated with Husserl and his adoption of the Greek word ‘epoche’ (abstention, to stay away from) and ‘reduction’

deriving from the word 're-ducere' (to lead back) (van Manen, 2014). For van Manen, the attentive turning to the world with an open state of mind is desirable. Therefore, rather than attempting to forget what we already know, van Manen suggests that by acknowledging and making explicit the understandings, assumptions, personal beliefs and theories that we hold about a phenomena, we can deliberately hold them at bay and turn this knowledge against itself at a later stage (van Manen, 1990).

#### **4.6.1 Application to the study: Bracketing**

The limitations of 'bracketing' in its purest form within Husserl's approach to phenomenology have been widely debated in the literature (LeVasseur 2003; Tufford & Newman 2010). It is acknowledged that for individuals to be initially interested in a phenomenon, they inevitably hold some assumptions towards it, regardless of their accuracy (Tufford & Newman, 2010). For this reason, Heidegger argued that 'bracketing' was largely unachievable. Similarly, Gadamer argued that to try and escape from one's own concepts in this way was '*manifestly absurd*' (Gadamer, 2004, p. 398). Nevertheless, it is possible for a happy medium to be reached for phenomenological researchers who feel that bracketing has a useful purpose. By temporarily setting aside one's own assumptions and pre-conceptions, prior to data collection through a process of self-reflection, participant's accounts can be approached with a more open mind (Starks & Trinidad, 2007).

On the surface, my initial limited knowledge of both gay culture and prostate cancer would suggest that bracketing, in the Husserlian sense, may have been achievable. However, I agree with both van Manen and Gadamer who acknowledge that any attempt to simply 'un-know' what is already known, regardless of how little knowledge that may involve, is not always possible. I was also mindful that I had previously undertaken a literature review prior to collecting any data. As there is some disagreement about when literature should be

consulted when undertaking a phenomenological study, the next section provides a brief discussion about the difficulties this entails for doctoral students and researchers.

#### **4.6.2 *Bracketing and literature reviews within phenomenology***

Views differ on the role of the literature review within some qualitative approaches such as phenomenology (Carnwell & Daly 2001). Researchers who employ a phenomenological approach are often advised to 'bracket' their own pre-conceptions or assumptions about the topic under study, to enable a new way of seeing the emerging phenomena (LeVasseur 2003). Hence, some researchers may choose to perform their literature review following data collection or after the post-analytic phase. They may also advocate including any source of literature that 'provokes thinking' (Smythe & Spence 2012). However, this can be problematic. Novice researchers, e.g. those undertaking a PhD, are required to produce a proposal clearly outlining a need for their research. Hence, a literature review is necessary in order to demonstrate the projects original contribution to knowledge and to highlight gaps in previous research (Hart, 1999). Likewise, experienced researchers are also required to demonstrate their familiarity with the subject area when applying for project funding.

As I had already read literature relating to prostate cancer experience for men and the experiences of gay men and health issues more widely, this inevitably meant that I made some assumptions about how some aspects of this experience may have impacted on men in gay relationships. Therefore, I engaged in reflection and wrote what I thought I knew about gay men in relation to prostate cancer as an attempt to bracket out my assumptions, conscious biases and pre-existing knowledge. I had also already started to reflect on my experiences prior to finalising my chosen research topic. Therefore, many of my preconceptions and assumptions were recorded during this time (this bracketing statement can be found in Appendix 11). Throughout the data collection phase, I continued reflecting by noting down anything that seemed to be particularly meaningful or important prior to,

and following, each participants interview. In addition, I made notes after phone calls I exchanged with participants or people connected to my topic and wrote about how my own thought process may have changed since commencing the research.

#### **4.7. Investigating experience as we live it rather than as we conceptualise it**

Turning to the phenomena of lived experience means re-learning how we look at the world by re-awakening the basic experience of the world (Merleau-Ponty, 1962). The process of doing this requires the researcher to 'gather' or 'collect' lived experience material (van Manen, 1990). Interviews that are grounded in the philosophical hermeneutic tradition are the most common forms of gathering data in phenomenological research (Moustakas 1994; Cohen, Khan & Steeves, 2000). The aim of the interview is to uncover what it means '*to be*' as it shows up or reveals itself through the stories that participants choose to share (Vandermause & Fleming, 2011).

##### **4.7.1 *Application to the study: Construction and use of the phenomenological interview schedule***

Interpretive phenomenology seeks to interpret concealed meaning in phenomena (Dinkins, 2005). Thus, a phenomenological approach to interviewing focuses on the experiences of participants and the meaning they make of them (Seidman, 2013). The interview structure most favoured in phenomenological research is one that yields a story or narrative, as these can encourage participants to reflect on specific experiences as opposed to generalisations (Benner, 1994). When constructing an interview schedule, Smythe (2011) recommends crafting questions that inspire participants to recount an experience and stay as close to it as possible. Whereas some researchers may choose an unstructured interview format, I favoured a loose semi-structured format comprising of five open ended questions. This provided a structure to fall back on, in the event that the interview veered off course, yet offered enough flexibility to explore the significance of certain issues should they occur

during our conversation. Probes, as suggested by Rubin and Rubin (2005) were also used throughout the interview.

Just prior to commencing the interview, I explained to each participant that it would be helpful if they could answer my questions in a way that could best help me to relive their experience whilst recounting it and to tell me how they felt during that experience. In order to gain some socio-demographic characteristics from the men, I posed questions of this nature in an unstructured conversational style, as a way of opening the interview as opposed to in a list-wise fashion. After this information had been provided, this gave me an opportunity to open the interview more formally by asking the first question.

To encourage participants to use words that help shape, colour and bring texture to their experience, Smythe (2011) recommends posing questions or prompts to participants that start with 'tell me about....' Therefore, my first question asked participants to 'Can you tell me what it was like for you when you were first diagnosed with prostate cancer'. The remaining four interview questions continued as follows:

- What effect has prostate cancer had on your life?
- Do you think that being gay has made a difference?
- Have other people in your life been affected? If so, how?
- How has cancer affected your outlook on life?

In keeping with phenomenological methods, the interview schedule served its purpose in that it was used as a guide (Smythe, 2011). A series of probes were also used to encourage the participants to elaborate or expand on their experiences (see Appendix 12 for interview guide and probes). The questions and probes changed naturally during the data collection phase, partly as a response to what the participants decided to share with me, and as a

result of the participants spontaneously offering answers to the questions included in the interview schedule, without being specifically asked.

#### **4.8. Reflecting on essential themes which characterise the phenomenon**

Phenomenological reflection helps us to '*grasp the essential meaning of something*' (van Manen, 1990, p. 77). However, whilst this may appear to be easy on the surface, the '*something*' may not always be tangible. Van Manen uses time as an example of a '*something*', as time is a phenomenon that most of us can grasp, despite the complexities of its situational meaning.

##### **4.8.1 Application to the study: Being immersed in the data**

For the present study, finding meaning entailed listening to each interview, reading and re-reading the participant's transcript to identify selected words and phrases that could have important meaning to the participants within the context of their interview, both as a whole and then what they might mean when placed in the wider context of the other participant's interviews.

#### **4.9. Describing the phenomena through the art of writing and rewriting**

In order for phenomenological text to 'show' the reader what something is like, the meaning, similar to that which is conveyed through poetry, must be expressed in a way that the reader can be responsive to (van Manen, 1990). If words are all we have to describe experience, they must be chosen carefully if they are to move us or deepen our understanding of something we may not have personally experienced. When we write, we make our implicit thoughts and ideas explicit. Van Manen suggests that the art of writing allows us to take a step back from the immediate lived world and lets us see our thinking in a more objectified way. This happens when we edit until we are happy with our description of something. Seeing our thoughts on paper, or on screen, gives us a separation from that which we are attempting to describe. This separation allows the space for us to apply yet

another layer of thought onto the initial thought. Each subsequent thought layer is refined until we are happy that it reflects what it meant to us implicitly.

#### **4.9.1 Application to the study: Organisation of data**

Twelve interviews were conducted and transcribed either by myself or by a University approved external transcriber. Once these were checked, edited and identifying features removed, they were uploaded into the qualitative computer software management program MAXQDA. The decision to use this programme over manual organisation of data or other available software programmes such as NVIVO was made for two reasons. 1) The combined time of the interviews was in excess of 25 hours. Hence, it was considered that this amount of data would have been difficult to manage purely by hand when going back and forth through the interviews in order to identify a potential phenomenon. 2) MAXQDA is acclaimed for its ease of use in terms of coding and clustering significant aspects of phenomenon. It also contains a unique feature that enables the transformation of data to a spread-sheet format, making it easier to share the process with all members of the supervision team. Using MAXQDA, experiential descriptions within the data were initially coded with a theme that described the meaning that could have been ascribed to that experience. During the hermeneutic process of going back and forth between each interview and considering what these themes meant in isolation and within the wider context of the dataset as a whole, the themes were eventually condensed. This process entailed building up many such themes before they were eventually condensed.

#### **4.10. Maintaining a strong orientated pedagogical relation to the phenomena**

Phenomenological research demands a deep level of engagement with the research topic and a commitment to stay close to the phenomenon being explored. In order to do the topic justice, van Manen (1990) asserts that researchers should not separate theory from

life. Hence, when exploring a topic, it is important that researchers stay orientated to that topic and true to what the experience means for those who own that experience. What van Manen means here, is that researchers must be vigilant and, if necessary, find ways to ensure they stay orientated throughout the research process. Finding some way of reflecting is a useful way of staying focused. I chose to frequently update an online secure diary which I found useful to look back through from time to time. Reflecting on past thoughts during the analysis process is useful and it continues the process of the '*reduction.*'

#### **4.10.1 Application to the study: The reflective diary**

The ability to be reflective *and* reflexive is considered to be a fundamental pillar of 'critical' qualitative research (Sandelowski & Barroso, 2002; Fontana, 2004). Whereas reflection is the process of 'thinking about' something that takes place after an event (Finlay, 2002), reflexivity entails the ability to inwardly reflect on the ways in which our own view of the world has the ability to influence the research findings of any inquiry (Sandelowski & Barroso, 2002).

Researchers are encouraged to engage in continuous reflection throughout the research process as a way of acknowledging that their own position and values within the social world may inadvertently impact on both the research process itself, and also the findings (Jootun, Maghee & Marland, 2009). In order to reduce bias, Etherington (2004) suggests that a journal can help researchers to explicate what they experience as a result of undertaking research and encourage them to be reflexive. The result being this can help them to separate their own views and interpretations of the data from those whose views and interpretations are being sought. I chose to keep a secure online journal from the start of the PhD process, as a way of reflecting back on the experience as a whole. Prior to and following each interview, I made notes about the participants which included my

impressions of them during our meeting, their body language as well as my own reaction to their experiences and the manner in which they relayed them. This was a particularly worthwhile activity, as I noted how my own body language or reaction to certain topics, particularly during earlier interviews, impacted on the participant. A sample of some entries taken from my reflective journal can be found in Appendix 13.

#### **4.11. Balancing the research context by considering the parts and the whole**

In quantitative studies, data analysis is generally undertaken once all data has been collected. However, qualitative studies differ, in that to some extent, researchers may begin to analyse or interpret their data once the gathering process begins, even though this may be unintentional. If, as Merleau-Ponty posits, we are continually making sense of the world (Carman, 2008), this will inevitably apply within an interview situation, as we listen intently to another person describing their own experience within the world. Once again, this emphasises the need for reflexivity during the early stages of any study. In order to make sense of the data, I was guided by the work of Gadamer (1962) and van Manen (1990). During the process, I also sought guidance by reading the work of other phenomenological health researchers (Benner, 1994; Holloway, 2005; Finlay, 2011; Wright & Hacking, 2012). Finlay (2011) acknowledges that any approach to analysis is neither linear nor clear-cut. Hence, she considers “*dwelling, wonder, evidencing, and ambivalence*” to be essential for “*engaging in analysis*” to ensure that “*analysis is engaging*” (p. 242).

Van Manen (1990; 2014) offers three methods of reading textual data as a way of capturing themes and insights which may point to phenomenological meaning. These include: the *wholistic reading approach*; the *selective reading approach* and the *detailed reading approach*. I chose to use a combination of these methods. Hence, I will now present a step by step outline of how each one was applied to the data, in the order they were

undertaken. I also highlight where Gadamer's influence was drawn upon during the process.

#### **4.11.1 Application to the study: Detailed reading, selective reading and wholistic reading**

During this approach, the researcher is advised to do a line by line reading of each sentence within an anecdote or passage and ask "*what does this sentence say about...[the experience of gay men with prostate cancer]*" (van Manen, 2014, p. 322). On the very first reading of the transcript, I preferred to read it on paper as opposed to a computer screen. I am not sure why this made such a difference yet I felt more connected with the men when reading their words on paper. I highlighted key words or text parts and made reflective notes within the margins of the pages. As the software programme, MAXQDA also offers a highlighting and noting function which meant that I could transfer notes over and they would be stored electronically. During this approach, I initially found it difficult to not automatically be drawn towards 'themes' of a superficial nature. For example, 'communication issues' were frequently mentioned across several interviews. However, this clearly does not provide any meaning or lived thoroughness in terms of what it meant to the men, in a certain context, at a certain time. It took some practice to look beyond what initially appears to jump out from the text and look at what lies beneath. I held onto van Manen's warning that as phenomenological researchers, we must not separate real life from theory (van Manen, 2014). Gadamer's concepts of prejudice and tradition also come into play during this process. Although Gadamer views both concepts as both inherent and necessary, since we can never really view anything from a tradition-free stance (Gadamer, 1975), I had to remind myself that both concepts risked labelling things I did not fully understand at this point. To continue without this acknowledgement may have led to looking for data that would then fit those labels, as opposed seeing meaning driven by the epoche and the reduction (van Manen, 1990).

After a detailed read through of each transcript and after listening back through the participant's interviews whilst doing so, I began to engage in the process of selective reading. During this approach, it is recommended researchers ask '*what statement(s) or phrase(s) seem particularly essential or revealing about the phenomenon or experience being described?*' (van Manen, 1990; 2014). This type of reading often led to snap-shot stories being highlighted within the text. These stood out as poignant experiences, captured in full detail and then retold in their entirety. Van Manen (1990; 2014) perceives these powerful passages as anecdotes and advocates their use to convey meaning in phenomenological writing.

The word anecdote has Greek origins and means 'things unpublished' (Eilifsen, 2011). Therefore, anecdotes reveal things that are known but not explicit. Hence, Eilifsen suggests that anecdotes are functional in that they reveal things that are not yet published to the self; things that slip our consciousness or reflections. They have the capacity to stir a sense of recognition about an experience, even if the reader may not have directly experienced it for his or her self. Within the context of phenomenological writing, an anecdote is used as a device which evokes a sense of meaning within the reader. One of its hallmarks is the 'Punctum', this being the final few words or line at the end of an anecdote which brings the story to a poignant and often bitter end.

Some researchers advocate the changing of wording within an anecdote, as a way of better illuminating the sense of recognition and meaning it conveys (Eilifsen, 2011; van Manen, 2014, p. 321). Van Manen even goes so far as to suggest that once an experience is shared, it ceases to belong to the narrator (van Manen, 2014); which to some extent, gives the researcher a licence to enhance it as he or she sees fit. However, whilst some editing was necessary in order to remove repetition, and to ensure the experiences conveyed through the use of quotes, had a logical flow of ease, I did not deem it necessary to embellish the

men's experiences in any way. Those I have included, in my opinion, fulfil the role of an anecdote and present a true lived-through experience.

As the word 'wholistic' suggests, this method involves reading the text as a whole rather than viewing it in separate parts. This involved asking '*How can the eidetic, originary<sup>3</sup>, or phenomenological meaning or main significance of the text as a whole be captured?*' (van Manen, 2014, p. 320). Gadamer's concept of the hermeneutic circle came in to sharp focus during this approach as I had to constantly incorporate the thoughts and themes drawn through selective and detailed reading and place them in light of the bigger picture.

Sometimes, this meant having to try and bracket out what I knew about the individual parts of the text I had already picked apart, in order to try and gain some separation, and to find the overall meaning as opposed to a sum of its parts. Thus, this entailed recognising that a 'fusion of horizons' (Gadamer, 2004) must occur as a way of bridging what was "*known previously*", to what was "*known now*", examining the data.

When undertaking phenomenological research, the researcher is required to continually question how meaning within individual parts of texts, fits with what is being reflected from the texts as a whole. This can be likened to the hermeneutic circle, as described earlier, in which the researcher goes back and forth between texts in an iterative fashion, to determine how initial themes or concepts contribute to the emerging phenomenon. However, this process needs structure. Hence, van Manen (1990) offers several ways of applying structure to this back and forth process in order to produce a written phenomenological account which is textually organised and exemplifies that which has been explored, for example, the four existentials provide a way of describing the participant's lived experience and enable meaning to be applied to the participant's

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<sup>3</sup> Van Manen's term which means tracing the meaning of a phenomena to its originary character or source

experiences in relation to lived time, body, space and their relationships with others. It is also useful to question how concepts and meanings that differed from the text as a whole were understood and how these also contributed to the phenomenon. As the hermeneutic circle is never ending, it is difficult to completely know when to stop engaging with the data. The word saturation, which is frequently applied to qualitative research, is one that does not easily lend itself to phenomenological texts. The more one looks, the more one can find, as reinterpretation is an inevitable consequence of a probing and inquisitive mind.

#### **4.12. Establishing rigour and the decision Trail**

One of the controversial debates surrounding qualitative research has been whether it can demonstrate the scientific rigour found in quantitative research (Mays & Pope, 1995). Hence, the debate surrounding this issue has been briefly covered earlier within this chapter. Here, I outline the processes that were undertaken to establish and demonstrate rigour during the present study following the guidance of evaluative criteria techniques developed by Lincoln and Guba (1985). This framework consists of four key areas, each of which can demonstrate the trustworthiness of a qualitative study. They include; credibility (confidence in the 'truth' of the findings); Transferability (showing that the findings can apply to other contexts); Dependability (the findings are consistent and could be repeated) and Confirmability (showing how the findings have been arrived at via the inquiry) (Koch, 1993; Cohen & Crabtree, 2006).

##### **4.12.1 Credibility**

To demonstrate credibility, Guba and Lincoln (1985) suggest prolonged engagement in the field being researched. This is a strategy most often aligned with an ethnographic approach. I was unable to spend any time observing participants in specific settings or in their own social settings. However, I did familiarise myself with several aspects of gay culture as a way of gaining a broader understanding of the social world some men spoke about, and as a way

of determining some of the deeper issues concerning their health. I attended a gay pride event with Prostate Cancer UK, where I was able to speak to men in the gay community about prostate cancer and their concerns more generally. I also went along to events within the gay village in Manchester, one of which I was invited to by one of the participants. Additionally I attended several events at the Lesbian and Gay Foundation in Manchester, both as a visitor and an invited speaker to discuss my research with the community and community health workers. I also attended two meetings for the first UK prostate cancer support group meetings for gay and bisexual men and was able to observe interactions within this setting for several hours.

The explication of negative cases also enhances credibility. Hence, the data was also searched for experiential accounts which were different from those frequently mentioned across the interviews as a whole. An example of this is where one participant perceives there to be some advantages to taking hormone therapy, due to the physical impact it had on his own personal sense of embodiment.

Although member-checking is also suggested as a way of demonstrating credibility, it is not a practice that is widely advocated in phenomenology (McConnell-Henry, Chapman, & Francis, 2011). There are several drawbacks to the process of member checking which may lead participants to change their experiential accounts upon reading a transcript of their interview (Sandelowski, 1993; Morse, 1991). Moreover, as phenomenological research aims to gain access to experiences that are pre-reflective, I considered it even more important to take the participant's experiences 'as given,' in the time and space they were recounted. Instead, I sought 'the phenomenological nod' (Munhall, 1994) of the men who attended the support group for gay and bisexual men with prostate cancer, some of whom had participated in the study. During this session, I share some of the themes I had developed and asked the men in attendance to comment on any aspect of what I was

describing. I received a unanimous 'nod' of agreement from the men who described being able to identify with the findings I was able to share with them.

I also demonstrated confirmability through the process of peer debriefing. This took place within regular PhD supervision meetings with three academics. During these meetings I was challenged on a number of issues relating to every aspect of my research. These included how I related phenomenological concepts to the development of themes and being challenged on a number of assumptions or ideas I had along the way.

#### **4.12.2 *Transferability***

Transferability refers to the study's ability to be applied to wider contexts other than the setting it has been conducted in, and the extent to which a reader can derive meaning and apply that meaning to their own experiences (Guba & Lincoln, 1985; Sandelowski, 1986). Hence, the inclusion of 'thick description' (Guba & Lincoln, 1985) allows other researchers to gain a sense of how this could apply within settings other than that in which the research has been conducted. Hence, as opposed to including a superficial account of what the participants have experienced, the interpretations attempt to convey the meaning of experiences. In the context of this study, this meant providing additional context to situations such as explanations of cultural norms. Hence, this level of thick description may enable the reader to apply the meanings to other settings.

#### **4.12.3 *Dependability***

Dependability can be demonstrated within qualitative research by providing a decision trail during each stage of the research process (Guba & Lincoln, 1985). This should provide evidence of the decisions and choices that were made during the various stages during the research process and clearly explicate why they were made (Koch, 1993). The study is deemed to be 'auditable' when the trail of processes is sufficiently clear enough to enable

another researcher to follow the trail and reach a similar conclusion (Ryan, Coughlan & Cronin, 2007).

As stated previously, a reflective diary was updated regularly throughout the present study as a way of documenting any decisions that were made regarding the choice of methods or any issues that arose during the course of the research. This was exemplified during the decision that was made to readdress the inclusion/exclusion criteria in relation to sexual orientation labelling, where an ethical amendment was sought. In addition, decisions relating to aspects of the study were raised and documented during monthly meetings with my supervision team. Hence, these documents contained precise accounts of what was discussed and are able to show how some decisions were formulated through informed debate.

#### **4.12.4 Confirmability**

Confirmability requires the researcher to clearly explicate how interpretations and conclusions arising from the data have been reached (Lincoln & Guba, 1984; Ryan, Coughlan & Cronin, 2007). Moreover, this is usually established when other criteria associated with rigour have been met. Confirmability has been demonstrated within the present study by the inclusion of longer quotes, as opposed to short quotes. By including longer quotes and anecdotes, it is possible for other researchers to see how the interpretations were reached. Reflexive notes and a bracketing statement formed an important part of this study. They are able to reveal how any biases or preconceptions may have impacted on the data.

#### **4.13. Summary**

This chapter has provided a comprehensive overview of the steps and processes that were undertaken in order to conduct this study. In addition to explaining why van Manen's phenomenological approach was deemed to be most suitable for exploring the research aim and objectives, this chapter also offers a detailed outline of how the six steps

suggested by van Manen were applied to the various stages of the research. This chapter has concluded by outlining how it has achieved rigour and trustworthiness throughout the process, in preparation for the next two chapters.

## Chapter 5: **FINDINGS**

### **5.1. Introduction**

The purpose of this chapter is to present the findings of the study through the four lifeworld existentials proposed by Merleau-Ponty (1962), as guided by van Manen (1990). The chapter opens with a breakdown of both personal and disease characteristics of the participants, which are presented in table form. A short introduction to each of the participants follows, in order to provide some context to their lives. Following a brief recapitulation of Merleau-Ponty's existential framework, the themes derived from analysis of the data are presented visually in the form of an illustrated figure. The findings from the data are then presented in sub-chapters and are aligned to the existential categories of Spatiality, Corporeality, Temporality, and Relationality. Each of the four sub-chapters will consist of a brief description of how each respective existential lens was utilised to view the data and place the resultant themes. Each theme will then be presented, described and supported with direct quotes and anecdotes from the participants' interviews.

### **5.2. Characteristics of the study sample**

Twelve participants were recruited from several geographical locations across the UK. These ranged from areas within the Northwest of England and Yorkshire regions, down to the West Midlands and South East of England. The participants were all Caucasian men aged between 49 and 82, with the mean age being 61. The average age of initial diagnosis was 56 years. Ten men had undergone at least one form of active cancer treatment since being diagnosed, whilst the remaining two had been placed on active surveillance and had not received any further treatment at the time of interviewing. Two participants were also being treated for HIV\*. Seven of the participants reported being employed or self-employed and five were retired. See Table 4 for a detailed breakdown of the study sample.

**Table 4. The Participants: Personal and Disease Characteristics**

Name	Age	Treatment	Time since diagnosis (years)	Length of interview (minutes)
Christopher	59	Hormone Therapy, Radiotherapy, Radical Prostatectomy	5	162
Alan	64	Active Surveillance	5	92
Joshua	53	Radical Prostatectomy, Radiotherapy	1	103
Elliot	51	Active Surveillance	2	164
Ian	53	Chemotherapy & Radiotherapy, Hormone Therapy	3	113
Charles*	70	Radiotherapy	7	136
Jerry	73	Radiotherapy, Hormone Therapy	8	134
Francis	60	Chemotherapy, Hormone Therapy	1	143
Anthony	77	Radical Prostatectomy	16	105
Hugo*	49	CyberKnife treatment, Hormone Therapy	3	159
William	75	Radiotherapy, Hormone Therapy	3	64
Matthew	51	Radiotherapy, Hormone Therapy	3	143

### 5.3. Introducing the participants

The lifeworlds of the men who took part in this study were uniquely shaped by their past experiences and relationships, in addition to their cancer experience. A short synopsis for each participant has been provided, in preparation for making reference to them throughout this chapter. Background details include their age, geographical location, treatment and relationship status. Where it was deemed to be of relevance, their

employment status was also included. Each participant was given a pseudonym to maintain confidentiality. Pseudonyms were also given to all individuals who were mentioned by the participants, e.g. partners, health professionals, etc. Additionally, any features that could personally identify participants have been changed or removed.

### **5.3.1 Christopher**

Christopher, a 59 year old man living in the North West of England, discovered he had prostate cancer in 2008 whilst undergoing tests at his local genitourinary medicine (GUM) clinic for an unrelated problem. The diagnosis came as a shock to Christopher, especially after learning that a radical prostatectomy would offer the best outcome based on his cancer type. Following surgery, he endured several weeks of radiotherapy and spent a further two years on hormone suppression treatment. This resulted in Christopher experiencing erectile dysfunction and loss of libido. Despite several bouts of worry and frustration, Christopher tried to frame his cancer journey as a positive experience; one that had facilitated personal growth, led him to discover the joys of sensuality in place of sex, and grow more holistically as a gay man. Christopher had been proactive in searching out various sources of support and information for himself, and for other men with prostate cancer. However, after attending support groups and speaking to other men, he perceived there were certain taboos that prevented men talking about the disease which still needed to be addressed. At the time of our interview, Christopher had recently split up with his partner and was living alone. He was still experimenting with different methods available to aid erectile function, in order to continue enjoying sex. Christopher was also keen to raise awareness and offer support to other gay men who were concerned about the disease.

### **5.3.2 Alan**

Alan, from Yorkshire, was 59 when he was diagnosed with prostate cancer, after undergoing tests to ascertain why he needed to urinate more frequently during the night. A

biopsy revealed that Alan had localised prostate cancer, although it was found to be growing at a very slow rate. As his consultant did not think that it warranted immediate treatment, Alan chose to be placed on active surveillance. He considered that this would provide him with sufficient time to explore all other treatment options for the future and to live a relatively normal life until his prognosis changed. Alan had been retired from work for a year when he was diagnosed. Yet, despite becoming anxious prior to the six monthly PSA tests that checked to ensure his cancer remained stable, Alan described himself as a “glass half full” person. Having successfully recovered from a different type of cancer five years earlier, Alan made the decision not to disclose his prostate cancer diagnosis to his immediate family, unless it became necessary to do so. Alan admitted that he often felt burdened by this decision but had made it in order to prevent his elderly family from worrying. Alan lived with his male partner John, in a relationship spanning almost 20 years.

### **5.3.3 Joshua**

Joshua, from London, was 51 when he was diagnosed with advanced localised prostate cancer. His father had died from the disease 18 years earlier and Joshua was encouraged to have a PSA test as a precautionary measure on the advice of his brother. A raised PSA and biopsy results indicated that Joshua had an aggressive form of cancer, despite being asymptomatic. After initially taking hormone treatment, Joshua opted to undergo nerve-sparing surgery, which was followed by a seven week course of radiotherapy. Joshua was single when he was first diagnosed and had assumed he would have no chance of finding a partner again, given the prominence and expectations of sex within the gay scene<sup>4</sup>. However, he did subsequently meet a supportive partner called Daniel, who he shared a home with. Although he was still trying to come to terms with some of the problems

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<sup>4</sup> The commercial, physical aspect of gay community, characterised by gay bars, nightclubs, saunas, restaurants etc... (Barker, 2002, p. 189).

associated with erectile dysfunction, Joshua remained optimistic about the future and continued to seek out alternate and inventive ways of achieving sexual and sensual pleasure with his partner Daniel.

#### **5.3.4 Elliot**

Elliot, from the South of England, was just 41 when he began having his PSA levels tested, due to his father being diagnosed with prostate cancer whilst in his fifties. Although his levels remained stable for several years, a biopsy confirmed the presence of localised prostate cancer after his PSA levels started to slowly rise. Elliot was given several treatment options due to the cancer's slow growing nature. Although initially hesitant, Elliot opted for active surveillance to delay active treatment, which would give him the time to consider alternative treatment options. Despite being in a committed relationship with his male partner, Samuel, for almost 20 years, Elliot craved support from other gay men with prostate cancer as he considered that their experience may help him make a decision about what treatment to undergo, if and when it became necessary to do so.

#### **5.3.5 Ian**

Ian, a 53 year old man from the West Midlands, was informed he had prostate cancer when he was 50, a few days following his civil partnership to his long term male partner of 16 years, Neil. He had been treated for prostatitis several months prior to his diagnosis and had assumed that this was a sports related problem. Due to the aggressive nature of the cancer, he was advised to have a radical prostatectomy. This was a devastating prospect for Ian, given his relatively young age; however, his clinical team eventually decided that Ian was eligible to take part in a clinical trial combining radiotherapy, chemotherapy and hormone treatment. Ian found this to be a gruelling experience. However, he revealed that overall, his relationship with his partner Neil had been strengthened by his cancer experience. Despite some on-going changes to their sex life, they found new ways to

overcome this in order to remain intimate. Ian found that having cancer had helped him to re-evaluate his life following his cancer diagnosis and hoped that a better support network to support newly diagnosed gay men would become available in the future.

### **5.3.6 Charles**

Charles, a 70 year old man from the North West of England, was diagnosed with prostate cancer in 2007. This was preceded by a long series of investigations and a transurethral resection of the prostate stemming from repeated bouts of prostatitis. After initially being told a radical prostatectomy would be the best treatment option, Charles decided that more time was needed before making a decision and embarked on a quest to investigate alternative treatments that would not be as invasive. In the meantime, Charles discovered he was HIV positive. Therefore, Charles and his consultant agreed that he should undergo a seven week course of radiotherapy, in order to avoid the surgical complications associated with being HIV positive. Although Charles still lived with his ex-long-term male partner, Ken, they shared a purely platonic and open relationship. One of Charles' main concerns was how his subsequent erectile dysfunction, in addition to being HIV positive, would be perceived by future partners.

### **5.3.7 Jerry**

Jerry, a 73 year old man from the South of England, was diagnosed with prostate cancer in 2005, following tests for a bladder condition. He subsequently underwent a course of radiotherapy followed by hormone treatment. Notably, Jerry's cancer journey was conveyed as being one of frustration and disruption, due to the long delays between appointments and administrative errors within the health service. Jerry would have welcomed an opportunity to speak to other gay men with the disease, both prior to and following his treatment, as he struggled to find the support he needed within his local area. Moreover, although a support group was eventually established locally, Jerry felt it did not

offer him the type of support he required. Jerry shared his life with Tom, his male partner of 10 years.

### **5.3.8 Francis**

Francis was a 60 year old man living in the South East England. He had been diagnosed with advanced prostate cancer, one year prior to our interview, following a routine blood test that reported a high PSA reading; a biopsy confirmed the diagnosis. He subsequently took part in a clinical trial which combined chemotherapy and hormone therapy, before undergoing a course of radiotherapy. Prior to his illness, Francis worked for a Christian organisation, but felt he had been pressured into taking early retirement by his employers, mainly due to the demanding and stressful nature of his job. This decision had resulted in Francis feeling “*role-less*”, despite him acknowledging that he may have experienced some difficulties fulfilling his obligations to his employers whilst undergoing treatment. Francis had been in a supportive and loving relationship with his long-term partner David for over 30 years, despite them not living together. As David also worked for a Christian organisation on a full time basis, Francis frequently experienced bouts of loneliness due to his partners work commitments.

### **5.3.9 Anthony**

Anthony, a 77 year old man from the South of England, was diagnosed with prostate cancer in 1998, following a routine company medical check, which revealed a higher than average PSA reading. Sixteen years after undergoing a radical prostatectomy, Anthony considered himself to be “*a success story*”. In his spare time he was involved in promoting awareness about prostate cancer to both gay and heterosexual men. Anthony felt strongly about the need for men to be provided with enough information and support upon receiving a cancer diagnosis, as he felt this was missing when he was first diagnosed. Anthony said he would like to attend a prostate cancer support group where he could be open about his sexual

orientation, and where Calvin, his male partner of 35 years, would be made to feel welcome. Anthony still worried about the impact that his surgery had on his sex life, and its impact on Calvin, who was 12 years younger. Anthony was a man of strong Christian faith, which he credited for helping him get through his cancer experience.

### **5.3.10 Hugo**

Hugo, a 49 year old man from London, was the youngest participant in the study. He had been diagnosed with prostate cancer in 2010 after a painful episode of prostatitis. He was shocked upon learning he had developed the disease at such a young age, particularly as there had been no family history of prostate cancer. Determined that he did not want to be left facing impotency and incontinence as a result of surgery, Hugo fought a lengthy battle with his local council to secure the funding necessary in order for him to undergo CyberKnife treatment. He finally completed his treatment in 2012 and, at the time of interview, had no clinical signs of recurrence. Hugo had also been diagnosed with HIV 11 years prior to his cancer diagnosis and took medication for this condition as well as chronic anxiety. Although Hugo was in a relationship with his male partner upon receiving his cancer diagnosis, Hugo did not receive the support he needed from him whilst undergoing treatment. As a result, their relationship deteriorated and finally ended. At the time of our interview, Hugo still lived with his ex-partner. However, this arrangement was purely for convenience and their relationship was not amicable.

### **5.3.11 William**

William, a retired 75 year old man from London, was diagnosed with localised prostate cancer in 2010, after a routine blood test for an unrelated problem revealed a high PSA reading. Following research on the internet, William was adamant that he would prefer radiotherapy as opposed to surgery, to which his consultant agreed, providing William completed a six month course of hormone treatment beforehand. As William was already

receiving hormone treatment for gender dysphoria at that time, he did not find the side-effects of the hormone treatment too distressing. On the contrary, they had, what he perceived to be, some positive benefits, such as breast enlargement. During our interview, William was keen to point out that he did not agree with the labels attributed to sexual orientation, perceiving it more as a “*continuous spectrum*” than any fixed category. Hence, during our interview he stated that if he was forced to apply a standard term to describe his own sexual orientation, this would be “bisexual”.

### **5.3.12 Matthew**

Matthew was a fifty one year old man, from the South East of England. He was diagnosed with localised advanced prostate cancer when he was 48, after suffering from what he initially thought were bladder problems relating to an enlarged prostate. Following a course of hormone therapy, he underwent radiotherapy and was informed that he would have to continue on hormone therapy for the foreseeable future. Matthew had been in a civil partnership with his male partner, Lee, for six years, although they had known each other for many years. Lee was also present during our interview and it was evident that they shared a strong and supportive relationship with one another. Matthew described ‘coming out<sup>5</sup>’ in his thirties. Hence, being diagnosed with prostate cancer at a young age had resulted in him feeling that his gay identity had been cut short. Nevertheless, experiencing cancer had also altered Matthew’s perspective on life. He frequently spoke about some of the “positives” that had occurred as a consequence of his diagnosis, such as dealing with past, unresolved issues.

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<sup>5</sup> To openly declare one’s sexuality to others (Baker, 2002, p. 101)

#### **5.4. The Findings viewed through the four fundamental lifeworld existentials**

Merleau-Ponty (1962) stated that *'the body is our general medium for having a world'*.

Therefore, our experiences of people, places, and moments in time, are experienced bodily and through our embodied actions, albeit at a pre-conscious level (van Manen, 2014). In order to make contact with those experiences, to try and really understand what the experience looks like, or feels like, van Manen (1990) suggests using the four fundamental structures that Merleau-Ponty (1962) proposed make up our lifeworld. These encompass how we experience our lived body ('Corporeality'); our lived perception of time ('Temporality'); our lived relations with others, ('Relationality'); and how we encounter the lived spaces we inhabit ('Spatiality'). By taking a lived moment in time from a dataset and describing how it was experienced, when viewed through one of the aforementioned structures, van Manen (1990) maintains that it is possible to achieve a vivid and detailed description of the experience. By using specific quotes and anecdotes, it then becomes possible to convey the essence of this experience to others, who, despite not living through the experience themselves, are still able to recognise its central features and relate to it based on their own experiences of being in the world.

The remainder of this chapter presents the findings from the dataset. Figure 2 illustrates the themes that were generated following data analysis. Whilst the four lifeworld existentials of lived body, lived space, lived time and lived relation can each be differentiated, they cannot be separated (van Manen, 1990, p. 105). Therefore, it is inevitable that some components of the essential themes within one chapter may be comparable to those in another. For example, several points within the theme 'Yearning for community', featured within the existential 'Spatiality', overlap with the theme 'In pursuit of peers', which features within the existential 'Relationality'. Moreover, although a greater number of subthemes were identified within 'Relationality', this merely reflects the

multifaceted structure of this particular existential. Hence, despite having more sub-themes, it has equal weighting, in terms of importance, as the other three existentials.

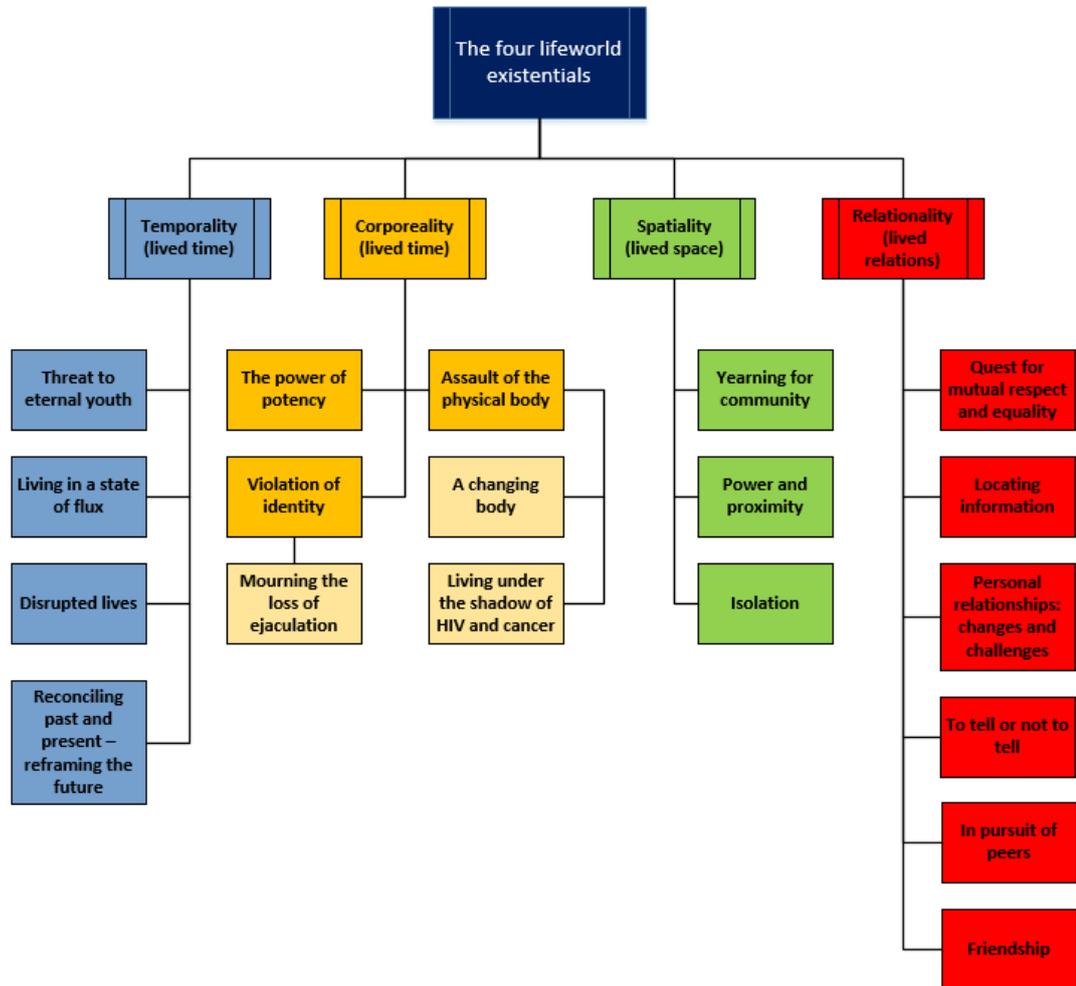


Figure 2. Themes generated from the dataset viewed through the four lifeworld existentials

#### **5.4.1 Findings viewed through the existential lens of Corporeality (Lived Body)**

Corporeality refers to the fact that we are always bodily in the world (van Manen, 1990).

Although we may not always be consciously aware of it, we experience and react to situations in the world through our physical bodies. We are able to identify with others because we know what it is like to have a body. We experience the pleasure and pain derived through its sensory receptors such as the flush of heat rising in our cheeks upon feeling pride or shame when we are watched or judged by others.

Given that illness has a direct impact on the physical body, it was not difficult to find examples within the data that reflected the men's corporeal experiences of living with prostate cancer. Hence, the theme '*assault of the physical body*' focuses on the meaning of this to the men. The two subthemes '*a changing body*' and '*living under the shadow of HIV and cancer*' reflect the uniqueness of the men's experiences of their own bodies as gay men, as does the theme '*violation of identity*'. Finally, the theme '*the power of potency*' centres on the meaning of potency for the men and encompasses their sense of lost potential, as well as their perceived loss of masculine status.

#### **5.4.2 Assault of the physical body**

When I asked the participants to tell me how cancer had impacted on their lives, participants often automatically chose to describe experiences which related to the physical impact of cancer. In some instances they reflected on the problems they had experienced prior to their diagnosis, which related to their symptoms or medical procedures such as biopsies. Several men described their shock at seeing blood or "*brown sauce*" in their semen, something they considered being "unacceptable" for a gay man. However, most problems the men discussed were those associated with physical post-operative issues and treatment side-effects. Charles described how medical procedures

whilst he was a patient in hospital had left him feeling somewhat dehumanised. He perceived that his physical body (“*my body*”) had been treated separately from himself as a whole person (“*me*”).

*“I didn’t feel like a human being, I felt like some kind of a machine walking around with this thing attached to my leg, it was just horrible. I mean what it does to you mentally and emotionally, something like that, is quite difficult to describe really, but I was in a mess...I feel like my body’s just been blasted with no thought to what it’s been doing to me”.*

(Charles)

When Christopher described his experience of undergoing a radical prostatectomy, he likened the removal of his prostate to the removal of an electrical socket, in an attempt to convey how the physical removal of the prostate had invisible, yet far reaching consequences on his body as a whole.

*“...I liken it to a light socket, you see that socket on the wall, if that was my prostate it sounds like we’ll just undo the screws and we’ll take the plate off and undo the wires and there you go we’ve taken your prostate out. No, no, no, no, no! When you pull that plate off the wall you’re pulling all the wires with it, and the light bulbs, and the power supply, and the cooker... and that’s what happens when you take the prostate out”.*

(Christopher)

Issues concerning incontinence were problematic for some men and there was an overwhelming sense that losing control over their bodily functions was “*something that should not happen to adults*”. The lack of control that the men had over their own bodies was further heightened when they were in the presence of others. Ian described the distress he felt following an incident that occurred during one of his radiotherapy sessions, upon realising he was unable to control his bowel movements whilst actively undergoing treatment.

*“...it happened on the table when I was having my radiotherapy, and I was completely distraught, I’ve spent most of my life crying.*

*And I remember just feeling so ashamed, I just felt really embarrassed by it. And she'd got three students with her, on the day that this had happened"*

(Ian)

Compared to most of the other men's experiences, William's view of how cancer treatment had impacted on his own body was less emotional and he spoke about it in a matter of fact manner. William refuted the popular notion that cancer should be perceived as a "heroic battle" and instead, viewed the disease as something within his body that simply needed to be fixed.

*"...the heroic battle? I didn't have a heroic battle, I just had something that was treated and cured. I don't know what all the fuss was about. Yes, it might have been life threatening but the way it's portrayed in the media and so on... Just like when I had a broken hip. So they stuck it back together and I was on crutches and then it was alright. I didn't fight a brave battle with a broken hip"*

(William)

### **5.4.3 A changing body**

Coming to terms with bodily changes that were out of their control was distressing for most men. Physical changes, as a result of hormone treatment, had a pronounced effect on the way they perceived themselves, not only as men, but as gay men within gay society. Men found weight gain particularly problematic and this was frequently mentioned within several interviews. Christopher described how weight gain had impacted on his own view of his body and how this made him feel when he was interacting with potential partners.

*"I'm really proud of my body, when I used to go out with guys, I used to really enjoy getting undressed and they'd go how old? Bloody hell how old are you? wow, no testosterone, gay man, getting older as well, muscle tone, I put on one and a half stone in weight, most of it was fat, don't wanna get undressed in front of people, don't touch me you know, I feel all flabby..."*

(Christopher)

Matthew had also struggled to come to terms with the changes to his body, after losing his body hair as a result of taking hormone treatment. He was concerned about how this might look to others and pointed out how problematic the loss of body hair is for men who identify themselves as part of the gay subculture known as “bears”. Like Christopher, Matthew was also concerned about gaining weight as a consequence of the treatment and discussed the emphasis that is placed on physical appearance within gay society.

*“I’ve started noticing I’m putting on weight round my middle, more so than I did before, and that’s quite depressing... one thing I’ve learnt about the gay world is that there is, there can be quite a lot of emphasis on the way you look.”*

(Matthew)

In addition to experiencing aesthetic bodily changes, some men were also trying to come to terms with the less outwardly noticeable changes, such as fatigue. Ian described how the side effects from radiotherapy were still affecting him three years after his treatment had ended.

*“...three years on, I’m still feeling the effects of it. So I mean my muscle pain, my sort of, you know, being quite lethargic at times. Not so much my mood anymore because by nature I’m quite, you know, not one of those people. But getting up in the morning, it’s like, you know, a 90 year old getting out of bed sometimes, where I ache!”*

(Ian)

The loss of libido was also an invisible change that some men, like Francis, were still learning how to adjust to.

*“...I mean having the hormone therapy and everything, there’s absolutely no, there’s absolutely no sexual interest at all now and I do find that quite strange... There are other side effects, you know, the hot sweats and everything. I mean, you kind of have to sort of live with those I suppose. It’s just, you know, it’s facing a kind of permanent change I suppose really”.*

(Francis)

When Christopher talked about the loss of his libido, he had mixed views on the physical changes that had occurred as a result of hormone treatment. On one hand, he described how the loss of libido affected his physical body and, in turn, how this had wider implications for meeting a potential partner. However, Christopher also acknowledged that, while cancer had impacted on his identity, his loss of libido had one positive aspect in that it had led to the discovery of sensuality. Subsequently, Christopher spoke about how he had become more in touch with the emotional, in addition to the physical aspect of his own body. His quote conveys part of the personal journey he frequently mentioned.

*“...no libido and no blood going into it, looks like me little finger, oh my God, no-one is going to want to have sex with a six foot four straight looking gay bloke who can't get an erection - are you not interested or what....you know? I felt my identity and sexuality was at an end, my libido was totally destroyed, utterly taken out. Another guy who I got to meet, not a gay guy, he was on the same treatment as me, had exactly the same journey type of thing and his libido was fine, but mine was utterly and totally switched off. That said, I suddenly discovered sensuality....for two years I had no testosterone and my dick didn't rule me”.*

(Christopher)

#### **5.4.4 Living under the shadow of HIV and cancer**

In addition to being diagnosed with prostate cancer, Hugo and Charles were also HIV positive. Hugo had contracted HIV several years prior to discovering he had prostate cancer, unlike Charles, who discovered he was HIV following his cancer diagnosis. Balancing the physical, psychological and social impact of two chronic diseases had taken its toll on both men. Hugo describes experiencing a similar feeling when he was first informed he had HIV as he did upon hearing he had cancer. He was also aware how being someone who has both diseases might appear to others.

*“And that was the same thing, that was that feeling, you know that sort of cinema deep based bump goes through your soul, it was*

*that sort of feeling for both HIV and for prostate cancer. It was that sort of out of control, oh fuck, what does this all look like?"*

(Hugo)

Due to a culmination of health and personal problems, Hugo was also receiving treatment for some mental health issues, including severe anxiety. The amount of medication Hugo was required to take on a daily basis meant that he experienced a certain lack of control over his life.

*"I still have to take all my tablets every day and I know if I stop taking those tablets I will get ill. And it's, you know, it's very restricting, all the time you have to think, my tablets, my tablets, everything you do you have to think, my tablets. Oh let's go to Brighton for the day, oh I've got to be home by eight so I can take my tablet, you know... You can't be as impulsive as you might like to be. I can get fed up at some point, and I've got beepers, I've got alarms, my phone goes off, it tells me when to take the tablets... I get sick of the control it has over me."*

(Hugo)

For Charles, the perceived stigma of having cancer and HIV had made him wary about getting into relationships with people, who he thought may expect more of him than he was capable of giving. Following some bad experiences with men he had met, Charles eventually decided that future partners would have to accept him as he was; a man with HIV and prostate cancer.

*"From now on, when I get involved with anybody, there are two things that they need to know; one I've had cancer, I've had treatment for cancer, it affects me physically, and I also have HIV. So if you're taking me on, you have to be aware of those things".*

(Charles)

Although only two men in the sample had HIV, several other participants had current partners, or had been in relationships with partners, who were HIV positive. Joshua described his partners HIV diagnosis as being a "bit of a trade-off," since both men had specific, but distinct issues they had to contend with, in relation to their respective

illnesses. Elliot on the other hand, drew strength from having formerly lived with a partner who was HIV positive. He revealed that his ex-partners death had helped him to make sense of his own cancer experience.

*“I knew what Joe [ex-partner who died] was like, that he had confronted HIV as you know, he’d been on television, panorama, hard talk he’d been on and talked about being HIV positive from 1991 he was on ACT, on all those type of things that were just coming in at that time and he was like someone was stepping off a cliff out into the aether and er, it was such sort of brave thing and it was such a profound experience actually... because of that, when the whole thing with prostate cancer came round, it was my version. You know, we lived together for twenty years... And so the whole thing with prostate cancer for me, is really important as a thing to erm look at as a way of learning from and because Joe did not let it define him, but he used it. He bloody well used being HIV positive”.*

(Elliot)

#### **5.4.5 Violation of identity**

The men described ways in which their identity had been affected in one way or another at different points during their cancer experience. Elliot, who had chosen to undergo active surveillance, had gone to great lengths to seek out information that would help him make an informed choice about treatment in the future. In doing this, he was able to gain a clear insight into how prostate cancer and the side-effects of treatment would impact on him as a gay man, in addition to the impact on his physical body.

*“The whole thing about having prostate cancer and being a gay man, it’s not just about prostate cancer, it’s about being a gay man... I don’t see myself as top or bottom, I like everything...I’m very conscious of my own prostate and whether that’s because of the prostate cancer, I don’t think it is...”*

(Elliot)

When Ian described how cancer impacted on his own sexual identity, he was quick to point out that this identity was something quite separate from his sense of masculinity.

*“I don’t think it really affected my masculinity. I think it affected my humanness, if that makes sense, as a male, but as a gay male, not as a heterosexual male... as an out gay man I’ve always been very comfortable in my own skin, but I don’t think it affected my masculinity in the same way...”*

(Ian)

When I probed Ian a little further on the issue of masculinity in a gay context, he offered more detail and attempted to help me understand how it may differ from the way masculinity may operate in a heterosexual context.

*“I’ve never been too concerned about my masculinity. I think being gay helps you, again, compartmentalise that. This isn’t about masculinity at all. I’ve dealt with lots of men across the board, predominantly heterosexual men in my work...and the restraints and the constraints of being heterosexual and the expectations placed on you, I’m not saying that you escape it as a gay man, although you do, but it’s not the same level, where, you know, you have to be this great performer, you have to be this great person and all the rest of it... I don’t think this is particularly linked to masculinity, but I think it’s to do with sexuality, that you do feel un-sexual, you know, because you can’t guarantee that things are going to happen... it was about a year before I had any full erectile sufficiency, and that was quite difficult because you do feel that your sexuality has been compromised, not your masculinity, the two are separate.”*

(Ian)

As a result of only coming out relatively late in his life, Matthew, the youngest man in the sample, described the loss of an identity he had only been able to experience and enjoy for a relatively short period of time.

*“It’s like you’ve lost something within yourself because it took me so fucking long to come out, it took me so long to get the confidence... I went to Manchester and I had a bloody good time, you know, doing everything that gay men do. And it was such a boost to my self-confidence. And it was like, it’s almost now like a brief window, I mean it was certainly a few years, it’s like that’s over now, potentially, and with the prostate op as well...That’s part of me, that was suppressed for so many years, and now I don’t have that anymore”.*

(Matthew)

#### 5.4.6 Mourning the loss of ejaculation

The impact of cancer treatment on the meant that some men now experienced dry orgasms during intercourse. Some men found this particularly distressing, as some men considered the visual and physical aspects of ejaculating were to be an integral part of their sexual identity.

*“It’s a sort of rejection thing, isn’t it? I was having to say to him, I can’t cum anymore. And he was fine about it but it’s that, it’s the old rejection thing, isn’t it...if I’m honest, that’s the thing maybe I miss the most. Yes, if I was absolutely honest, I could put up with the lack of libido, but I do miss that [ejaculation]. That was so much a part of me, it was, well you know, it’s such a, your brain almost explodes, it’s so intense and it just doesn’t quite happen like that...”*

(Matthew)

Christopher described a sexual encounter in which he had been videoed ejaculating. Being able to watch himself experiencing something he could no longer achieve was expressed as being a small comfort to Christopher, as it connected him to an important aspect of this former self.

*“I’m just so glad I videoed it ‘cause I didn’t know at the time I’d lose it. And then I get to see how important it is for other blokes and I watch, I watch blokes coming and I watch other muscular activity in the abdomen and the heart rate and the breathing...”*

(Christopher)

Although Joshua admitted that being unable to ejaculate had been a major issue for him, he had accepted that this was an inevitable side-effect if he were to remain cancer free.

*“It’s the same, you know, your muscles still clench and all the rest of it but you don’t ejaculate. And that has been a really big thing for me...I enjoy somebody else coming, you know, but I still, you know, I’ve got away, hopefully, with not having cancer. So that, for me, is a small price to pay, you know, you’ve got to balance it out. If I’m still getting the same feeling, ok. So I don’t make a mess everywhere, you know, that I can live without, but as long as the feelings still the same...”*

(Joshua)

#### **5.4.7 The power of potency**

Issues relating to potency were frequently mentioned, or alluded to, both in the physical sense; referring to the men's ability to function sexually, and in a subjective sense; relating more to the men's loss of potential regarding their future as lovers or sexual partners. Elliot had been on active surveillance for several years at the time of our interview, yet he had become more aware that potency was something that he needed to appreciate whilst he was in the world right now and still able to function sexually.

*“But the whole sexual side for me, in the last two years, I've become far more, makes me sound like an old pervert. I've been far more interested in sex but it's become bloody important because the thought of actually losing it, and so from that point of view, to me, my own sexual being has become really important. Really, really important”.*

(Elliot)

Men were also concerned how potency, or lack of potency, impacted on their partners. Despite being in a long-term relationship, Francis described how the loss of potency had affected him, it was obvious that he was worried about how this impacted on his partner.

*“I think the fact that the potential suddenly is now gone, that's been quite hard really I think. And I do find that hard with him because I feel, and I do ask him all the time, whether I'm letting him down with things really, you know, on that. And he says, oh for goodness sake, you know, we've been together thirty years. But I say, well I know, but there's the possibility...when all the cares in the world are gone and, you know, you're lying in a hotel room, you know, no clothes on and it's hot, you know, and things happen, you know. But I think sort of the fact that I can't now, I mean I think it's been quite strange really for me. And I do try to kind of, and he doesn't say much about all that and I do sort of, he assures me that there's no problem, I hope there isn't.”*

(Francis)

As Joshua was still fairly active within the gay scene, loss of potency had changed the way he felt when he was in the company of other men. Although Joshua was very optimistic about his overall experience of cancer, a big part of his social life had been affected.

*“I do feel that if I see pornography or something like that, guys with big erections or my mates talking about going to a naked party or whatever and all that sort of thing, or just in gay conversation, people are all about erections and hard-ons and things. And I do feel a bit deflated when I hear that, it just sort of brings it back, you know. I think I’m very lucky in that I’ve got a partner and all the rest of it. But you keep hearing that thing...and you think, well that option’s not there anymore, you know”.*

(Joshua)

For Hugo, potency was something that was profoundly intertwined with the ‘male’ role.

Hugo commented that he did not plan to have children, but still regarded his ability to maintain the choice to do so as an important aspect of “*being a man*”.

*“There’s something about potency...it’s a big part of what makes you a man... I believe I’m still producing sperm, I’ve not had it magnified or tested or anything. So I don’t, I mean I don’t think I’m sterile, not that that’s important, I’m not going to have children. But in a way it is important because there’s something about being a man, you know... I’ve been careless with it and given it away for nothing, for a pint of lager and a packet of crisp, in my time. But, you know, it’s a big part of you for it not to work and not to function”.*

(Hugo)

## **5.5. Findings viewed through the existential lens of Spatiality (Lived Space)**

Within a phenomenological context, spatiality or lived space refers to the qualitative nature of space, as opposed to the dimensional and environmental aspects that are often associated with the term more generally. In describing Heidegger’s position on spatiality, Polt (1999) points out that Heidegger viewed space as a place where things and people ‘*belong or do not belong*’ (Polt, 1999, p. 59); it is about how space ‘*feels*’ to an individual (van Manen, 1990, p.102). This may incorporate their subjective worldview or bodily experience of being in, or interacting within, that space as opposed to actual space itself. Lived space has been described by van Manen as the most abstract of the four existentials, as it is not an entity that is overtly reflected upon (van Manen 1990, p. 102). Yet the way

we experience space can often have a profound effect on our feelings; in the same way that our feelings can also influence our perception of space. As a result, “*we become the space we are in*” (van Manen, 1990, p. 102).

When applied to the present study, utilising the existential lens of spatiality meant looking for the unique ways men experienced specific moments or contexts, at certain times during their cancer journey. The first of three themes to emerge, ‘*Yearning for community*’, focuses on how shared, communal space is experienced by men within support group settings. The second theme, ‘*The power of proximity*’, is more concerned with the spatial experience of personal boundaries and the invisible barriers men encountered within health settings. The third theme ‘*Isolation*’ relates to the sense of space that humans experience when they are lost in their own thoughts, despite being in the presence of others.

### **5.5.1 *Yearning for community***

With the exception of Hugo, all of the participants described their experiences of attending at least one type of cancer support group during their cancer journey. However, not all participants continued to attend the groups after their first session. Although their reasons for this varied, many men stated that they felt out of place and detached from the other group attendees. The following quote was taken from Christopher’s interview, who described his experience of attending a support group set up by his local health authority. The group had been set up specifically for men with prostate cancer, but also permitted wives or partners of the men to attend. Importantly, the quote reveals that there was no sense of belonging for Christopher within this particular group.

*“I don't belong... these groups are just full of ‘old men’ in inverted commas. Even though I'm 59 now and you know, I'm more than middle aged and going into you know, being classed as an old man but not like seventy, eighty, I'm thinking, I don't belong here, these are guys who I don't dress like them, my attitude's not like them, I*

*don't wanna talk like them you know, I don't wanna act like them, that doesn't mean to say I'm better than them.. But I wanna be around guys who say 'Christopher, can you wank? Can you ejaculate? What was it like having sex? Does the end of your knob not get as hard as the other thing when you inject it?' But I'm thinking I can't say this, their wives are there.."*

(Christopher)

Christopher was very proactive in seeking out group support from other men with prostate cancer, in an attempt to arm himself with as much information as possible for the future. Despite feeling as though he did not “belong”, Christopher was one of the few men in the study who continued to attend his local support group on a regular basis. However, he described feeling somewhat alienated from the group. He was frustrated at having to stifle the urge to speak openly and in the candid way he was used to when discussing sexual matters amongst men in his own social milieu. This frustration was also expressed by other participants.

*“...you see this is the other thing, is that, you know, we couldn't possibly, I mean all that we've talked to you today, I mean to us, going to a gay bar, picking up, us going off, splitting up, you know, with other guys, having a bit of sex, having a drink, it's just fun for us, but God...just sort of discussing at that group, even in just sort of very straight factual terms about not being able to cum, I suppose you just don't know what the reaction will be. But if you were with a group of gay men, where things are much more open and talked about...”*

(Matthew)

Descriptions of support groups varied for other men too. Alan felt obliged to attend a support group as it was led by a Macmillan nurse who was involved in his care. However, he described his first encounter with this group as “a heterosexual men's meeting”. Another participant, Ian, realised that his local support group would not be the appropriate place for him to speak openly and frankly in the presence of others. Ian also expressed frustration at the reluctance of other men to initiate discussions about the most common issues to affect all men with prostate cancer, regardless of their sexual orientation; namely

erectile dysfunction, as well as other issues related to sexual matters. Ian's description of the proverbial 'elephant in the room' illustrates how the topic of sex was considered to be a taboo topic amongst the men in attendance.

*"It's having an environment when you know if you bring those conversations to the fore that it will be picked up and worked with. There's no way I would have done that at that. I knew from the first one [support group] that it wasn't for me, by the second one it was a definite no-no; that it was never going to happen. Because it was the elephant in the room...It was the elephant, the rhinoceros and the lion all in one fell swoop..."*

(Ian)

When I asked Ian to tell me about his experience of support groups, his description of the group setting, the leadership and the attendees was somewhat disdainful. It accentuated a void that existed between what he wanted and required in terms of support, and what he perceived to be on offer within the group. Ian went on to describe how a sense of community may exist for heterosexual men, but that he did not see himself as being part of this community, nor did he want to be. For Ian, the individual characteristics of the group resulted in the opinion that the group "was not fit for purpose" as his anecdote reveals.

*"... white middle class heterosexual males of a certain age, who really felt, I think, very uncomfortable hearing from an 'out' gay man, in terms of, you know, his experience and the support needs that I required....And an environment where, I think, other gay and bisexual men could meet to talk openly because, you know, it's not everybody that you can talk about sex. They didn't talk about sex at that group. It was peripheral drabble, I use the term here sometimes with work, when people will go through the motions of something, and I call it, articulated incompetence. It sounds absolutely fantastic, when you scrape beneath the surface its meaningless dribble... And it was a bit like articulated incompetence, it sounded good to the uninitiated, somebody who's just been diagnosed, going through treatment, if they're white heterosexual males, probably would have fitted and be fit for purpose. For a fifty year old out gay man who has, you know, quite a lot of experience with that in other areas, it was as far removed and fit for purpose as you'd possibly get. It just wasn't, for me, what I needed and what I wanted."*

(Ian)

Jerry's experience of attending a support group was less about it being geared towards heterosexual men and more about the concept of support. For Jerry, the main element of a support group was missing and did not meet his own personal needs.

*"One of the reasons I didn't continue, regarding this particular support group as a priority, is it's not mainly geared to support. It's mainly geared, which isn't to say it doesn't give support, it does, you know, at an individual level I'm quite sure it does. But it's mainly geared to men who are retired and enjoy golf, who enjoy other things, fund raising for a good cause. It's that type, that's the ethos of it. And it prides itself on having raised quite a lot of money from the sort of social events that I'm personally not that interested in. I mean I had helped to get a stall in [place name] to sort of rattle tins...so it's more a fundraising group of men who've got a common problem. Fundraising to support diagnosis and treatment, which is a very worthy worthwhile cause, but it's not mainly geared as a support group..."*

(Jerry)

During the data collection phase of the study, I was invited to the first prostate cancer support group meeting to be specifically created for gay and bisexual men in the UK. I later recruited two of the men who attended that meeting and they were able to convey the importance of having a space where they were able to speak freely about the issues they deemed to be important. Elliot, one of the youngest participants in the study, was overcome with emotion during this meeting. Having completed a 500 mile round trip in order to attend the two hour session, I asked him about his experience of the meeting during our subsequent interview to ascertain why it had been an important day for him.

*"...that was a wonderful thing that guys were able to talk really openly and not think that oh, someone's gonna be offended, because gay guys will talk and be far more open emotionally, far more open about the language they use than heterosexual men."*

(Elliot)

### **5.5.2 The power of proximity**

The men frequently discussed how they perceived and interacted with the health professionals charged with their care. They were able to vividly recall where specific

interactions had taken place, and, to some extent, their descriptions helped to convey how the space around them felt. All of the men remembered the time they were diagnosed. They also remembered how they felt when undergoing tests or procedures of an intimate nature. For Josh, there was an acute sense of awareness that the space around him, and what lay beyond the curtain, had the potential to take on new meaning, depending on the outcome of the meeting about to take place.

*“I walked in there and before I walked in to see him through the sort of curtains I thought, oh I wonder if I’m going to be seeing a lot of this place, you know, that sort of feeling. It’s a funny sort of feeling that, you know, this could be it. I might be visiting there quite a lot”.*

(Joshua)

Men sometimes became more aware of how the space around them felt during physical examinations due to the inevitable need for bodily exposure. Charles described how the proximate space between the consultant, the female nurse and himself, both prior to and during his digital rectal examination, had resulted in him feeling “small”. Although the following anecdote clearly overlaps with Charles’ corporeal, and relational experience of the procedure, it also reveals how the combination of both resulted in Charles having to endure an uncomfortable personal experience, which deeply affected how he felt about himself at that moment.

*“He [medical consultant] sat behind his desk... he was exceedingly smart, lots of gold jewellery and a gold pen, he was just a bit disdainful. And my partner was with me, who he didn’t really pay much attention to. And he wanted to examine me, you know, with the rubber glove and the finger and all the rest of it. So he took me into another room. And I was very conscious of the fact that there was a woman nurse, and I know they have to have somebody there, and she’s standing, watching. Now, it might be perfectly apparent to you, I’m seventy one, and you don’t normally have this [hair] colour being seventy one, I tint my hair. As he’s got his finger up my backside, he leans forward and he says to me, ‘do you dye your hair?’ And I said, ‘what?’ He said, ‘do you dye your hair?’ I said, ‘well yes as it happens’..... ‘Oh right; that explains it.’ And I just thought, how appallingly, you know, obnoxious, unnecessary and rude, you know, it just made me feel so small. I mean if*

*somebody's got their finger up your bottom, you know, they come out with something like that, and it was very uncomfortable, very embarrassing. I just felt they were laughing at me."*

(Charles)

Although Charles recalled several negative accounts of incidents that had taken place in confined spaces, where the power balance was not equally weighted, positive experiences by Charles were also recalled. Here, he described his first encounter with a new female GP, and conveyed the way he felt 'comfortable' he felt talking to her, compared to the male doctors who worked within the practice.

*"And she [GP] sat and listened to me with a big smile on her face. And I said, I don't suppose many men come and talk to you about stuff like this, do they? And she chuckled and she sort of said, well, she said, I wouldn't be most men's first choice, she said, to come and discuss this kind of a problem with. She said, you know, there are men here you can talk to about it. I said, I'm not actually comfortable with most of the men here. I said, I don't feel comfortable with them. I said, I do feel comfortable talking to you about it. She said, well that's fine"*

(Charles)

Likewise, Joshua, one of the youngest men in the sample found that unlike some of the other consultants he had dealt with, he eventually found one that he felt able to be "open" with.

*"I was open about being gay and pretty much, yes I wasn't backward at all. He [consultant] was a young bloke, it wasn't difficult at all to talk to about that sort of thing. I mean I can still be embarrassed about talking to doctors, particularly in London... I was lucky to get a young consultant, the older one was unapproachable really."*

(Joshua)

### **5.5.3 Isolation**

Most of the men in the study described times when they had felt isolated or vulnerable as a result of living with the knowledge they had cancer. This was often portrayed as a difficult aspect of the disease to live with.

*“It’s interesting because you’re not alone but you’re incredibly lonely. That’s how I’d describe it. So you’ve got people around you, I had Neil, thank God, but you’re actually, this is about you and so you have to face your, you know, your own mortality almost.”*

(Ian)

Francis made several references to the overwhelming sense of loneliness and isolation he experienced during his cancer journey. In addition to losing his mother just days after being diagnosed, he also felt abandoned by the Christian organisation he had dedicated his life to and by the community he had supported for much of his life. Early retirement had resulted in him feeling empty and “*role-less.*”

*“My mum dies, I’m diagnosed. I’m on my own. Suddenly I’m on my own. All my kind of foundation stones have gone really.... I felt so dark and so low. I just got myself in a terrible state really. And I spoke to the Chaplain lady and I said, you know, this is strange, you know... I spend my life kind of giving and going round seeing people who are dying of cancer and, you know, bereaved families, and suddenly here am I, on my own with all this...”*

(Francis)

From what Francis discussed in his interview, it was evident that working life was an important part of his identity. He was forced to accept that life would be quite different without the responsibilities and social aspects that had been a central aspect of his work. During his weekly visits to the hospital to receive radiotherapy, Francis continued to endure the same sense of isolation, despite being amongst a group of men who were going through a similar experience.

*“I sat in the waiting room day after day, every day for eight weeks, having radiotherapy feeling, you know, kind of like this. And nobody asked what I did for a living because I suppose most of them were retired... so they didn’t ask what I did for a living and they didn’t particularly sort of ask me if I was married or anything. So I just sort of, was quite a bit anonymous really I suppose, which is a bit odd when you go every day for eight weeks... I felt a bit lonely I suppose at that time. And it just brought back to me the kind of oddness of the whole situation really when you’re gay. And you sort of have to live a slightly kind of, still a bit of a shadowy life in some ways, you know.”*

(Francis)

Several men described a feeling of not being able to escape themselves. They carried a burden that could not be mentally compartmentalised in the way that general day to day problems could be. They described how a familiar space in the home such as the bath, a space they associated with putting troubles aside and relaxing in, was no longer somewhere they could escape to. The cancer simply “followed” them there.

*“I remember the feeling I had was basically, I’d walk from this room into the bedroom and it would follow me, you know. It was like, you can’t get away from it; you’re thinking about it all the time and you just want to shut it off. And I’d walk in there, the bedroom, I’d lie down on the bed and I’d try and go to sleep, you can’t get away from it, it just follows you around...”*

(Joshua)

## **5.6. Findings viewed through the existential lens of Temporality (Lived Time)**

Temporality is considered to refer to subjective time, rather than clock or objective time (van Manen, 1990), and is a fundamental structure of human existence (Heidegger, 1962). Meaning is focused on the experience or quality of time during a lived moment. For example, we may not be aware of how fast time passes when we find ourselves lost in a good book for several hours, yet we become painfully aware of how long a minute takes to pass when waiting for a bus to arrive on a bitterly cold day.

Utilising the lens of temporality pointed to certain moments during the men’s lives where their sense of time was altered. As a result, four essential themes emerged. The first theme, ‘*The threat to eternal youth*’, refers to the men’s perceptions of their own sense of youth, whilst living with a disease commonly associated with an older generation. The second theme, ‘*Living in a state of flux*’, is centred on the ambiguous position that men found themselves in upon realising that they could not return to the past but were not

quite sure how to move forward. The third theme, *'Disrupted lives'*, centres on how prostate cancer obstructed normality in the men's lives. Finally, the fourth theme, *'Reconciling past and present – reframing the future'*, focuses on the how men attempted to make some sense of their present lives, by reflecting on the past and reframing their outlook for the future.

### **5.6.1 Threat to eternal youth**

The prominence of youth and youthfulness within gay culture was frequently mentioned. Men fondly recalled the experiences they had enjoyed as young men on the gay scene, in which they had enjoyed feeling liberated and desired. Hence, the manifestation of time on the body and the men's appearances was more apparent as a result of prostate cancer.

*"The gay community is youth orientated, physically orientated you know, looks and all that stuff and orientated toward the quick fix of whether it's sex or experience of drinking... there is still hope for older gay men and those of them who have prostate cancer to be included..."*

(Elliot)

Not surprisingly, being diagnosed with a disease associated with an older generation, posed an element of threat to the men's sense of their own youth. Despite being the same age as his heterosexual counterparts at a support group meeting, Alan conveyed a sense of otherness and felt as though a "generation gap" existed between himself and the men he encountered.

*"And you're surprised when you think they are the same age as you and you think, I hope I don't look like that, I hope I don't dress like that...So even though you're the same age do you feel there is a generation gap...Yes, I feel as though these are old men and I'm not, I'm not an old man..."*

(Alan)

Alan observed how the men adopted a “*uniformed*” look, with some presenting themselves as being ‘*twenty years older than they actually are*’. Moreover, this view was not one just restricted to the younger men within the sample. Seventy five year old Jerry appeared to feel little kinship with the men who attended his local support group.

*“It was a very stiff upper lip, five/ten years older than me, generational, been through military service and ‘know what it’s like’ type attitude, style. Now you’d be much, much less likely to find that if it was mainly, it doesn’t have to be exclusive, but if it was mainly of gay men.”*

(Jerry)

Charles, who was still socially active within the gay scene, shared several experiences that revealed how important it was for him to retain a sense of youth. Charles looked several years younger than his seventy years, which was reflected both in his fashion taste and his physical appearance. As a result, he still enjoyed dating younger men and did not always feel it necessary to disclose his own age. Youthful company clearly helped Charles to retain a sense of his own youth as his anecdote conveys. There is also some overlap in this anecdote with the existential structure ‘spatiality’, as the closeness Charles feels when in bed with the person he describes is a stark contrast from the proximate space he experiences with his consultant.

*“I would have been sixty seven, he hadn’t a clue how old I was. And I was thinking, here I am at the age of sixty seven, clinging on to this hunk on the back of a motorbike, being driven around, with all the fountains lit up thinking, wow, this is amazing. And I’m thinking, oh shit, I’ve forgot to take my pills tonight. But I had an amazing time with him and he just, he just, he gave me back my belief in myself. Because I thought life was over. I thought, I’ve got cancer, I’ve got AIDS, you know, who’s going to be interested, what have I got to look forward to? And here is this guy, he’s intelligent, handsome, caring...And I woke up in the morning, the sun was streaming through the windows, he was asleep, and he’d got his arm around me. And I just looked up at him, I thought, my god, this is what I have been missing. This is what’s been missing from my life for about ten years really, just this intimacy, just being in bed with somebody, you know. It wasn’t about the sex, it was just being in bed with somebody who was holding me, who was comfortable with me, warts and all, or in my case, HIV and*

*cancer, you know. And here was this caring man who just enjoyed being with me, enjoyed having sex with me, and was now cuddling me and was fast asleep in bed with me. I thought, this is just brilliant, it was just wonderful. And I came back home, I mean it was like being reborn”.*

(Charles)

### **5.6.2 Living in a state of flux**

Although there was a sense that prostate cancer had become a permanent aspect of the men’s lives, even for those who had completed their treatment, frequent bouts of uncertainty about the future meant that time was not always experienced in the linear, carefree way it had been prior to their diagnosis. During Ian’s interview, it was evident that he was still coming to terms with having cancer three years later.

*“I’m constantly in some sort of emotional element that, you know, in three years, has not gone away completely...”*

(Ian)

Several men described how they felt at certain time points. For example, the lapse between Joshua’s initial diagnosis and the need to make a decision about his treatment was described as a *“ticking time bomb”*. Following treatment, time was frequently perceived as being more unpredictable as the men had to find their own way of living in the moment. This was the case for Francis who, having been treated with hormone therapy, was still uncertain as to how long things would remain the same for him.

*“In a sense I suppose I’m tempted to think of it as now it’s the end of all that. But in a sense, I might be in the middle of all that, I don’t know.”*

(Francis)

For Alan and Elliot, who had chosen to remain on active surveillance, the feeling of unrest became more salient as their check-ups to detect potential changes in their PSA levels approached. Both men were aware that their situation could change leading up to this time

point and carried a feeling of uncertainty around with them which increased until their check-up was over.

*“...you go through these periods of you know you’ve had a high-ish reading, what will the next one be? And as the next date draws closer you become quite anxious of what’s going to happen now? And then when it’s when the reading’s down it’s a huge sense of relief...you just don’t know whether you’re going to survive this, you don’t know if you’re going to get through it and what the end product will be.”*

(Alan)

Matthew was also living in a similar state of flux. After being informed by his consultant that he was not eligible for surgery, Matthew assumed he was a “gonner”, as this meant that although the cancer could be shrunk and kept under control with hormone treatment, it could not be fully removed. When Matthew described how he felt upon hearing this news, he conveyed a sense of being ‘stuck’; not able to go back to life as it was before, but also not able to move forward and contemplate the future.

*“I didn’t see anything, any point in planning anything... I wouldn’t even turn up for work... what I did find was each time I went to see the consultant in the early days, I thought, right I’m going in and he’s going to say, right you’ve got a week to go or a month, and that’s how I would be mentally thinking. You’re thinking weeks or months or, you know... my thought, is that I’ve got virtually no time left, even though they’d not said anything like that.”*

(Matthew)

However, as time passed, Matthew started to come to terms with his prognosis, and the routine of taking oral and intravenous medication intermittently became more familiar to him. Hence, time took on more regularity than it had for many months and Matthew became more accustomed to living in the present moment.

*“...there’s more certainty to our lives now, you know, because we know what the treatment is. Before it was, oh when are we getting this, when am I getting that? So I know, there’s a pattern now, tablets, injection, tablets, injection, which is ok... I find it easy just to, not easy, I find it cope-able to think, right this is the situation, this is how things are, so we adapt our situation to do this now.*

*And I don't tend to think, oh it was so much better before or what's going to happen when? I just sort of think, well right, at the moment this is the way things are and so this is how we deal with it."*

(Matthew)

### **5.6.3 Disrupted lives**

Disruption for the men in this study meant that their usual busy and active lives were subject to change, in order to accommodate the men's differing circumstances, especially around the time of diagnosis and most certainly during treatment. Disruption for Jerry meant that his usual orderly life was turned into one of "chaos". Throughout our interview, Jerry relayed many dates and times for appointments he had been asked to attend for various tests and investigation, or subsequent phone calls he had made to the hospital in an attempt to chase up results. It was evident that for Jerry, his experience of cancer had been largely defined by a long time-line of specific events and non-events within the NHS spanning several years. Jerry was less concerned about how his sexual orientation had impacted on his experience.

*"...my story is more about a man facing up to prostate cancer, without good professional support, and with a hospital, which in its early stages, handled me badly".*

(Jerry)

Unlike Jerry, who was retired, more than half of the men in the sample were still employed and needed to continue working to remain financially independent. Therefore, disruption of daily routines as a result of cancer treatment, for those still in employment, often had both personal and professional consequences. Hugo described how he compartmentalised his life and time into smaller chunks, in order to be able to deal with each issue separately, without becoming overwhelmed. Being self-employed also meant that Hugo was feeling some financial strain in addition to problems relating to his health as the following anecdote revealed.

*“I feel like, you know in Trivial Pursuit, you know you get that cake thing, which you get all the different portions on, it’s like I’ve got one of those but I’ve got sixteen bits of pie all mushing around at the same time... the prostate cancer has sort of been one more for the pile. I didn’t get completely absorbed in it, I just took it, that’s another thing I’ve got to deal with, quite pragmatically... I didn’t get too emotionally involved in it. I mean, there have been times when I’ve got upset about it, there are times when I feel frightened. But in the majority of cases, I’ve been more worried about what I’m going to eat next week or how I’m going to pay next month’s mortgage, which at the moment is one of the biggest problems in my life, you know, that’s horrific. So it’s this roulette wheel that goes round in my head.”*

(Hugo)

The impact of prostate cancer for Francis was especially far reaching. It had disrupted several aspects of his life, which he now saw as being “coloured”. In addition to having to retire from a job he had dedicated his life to, he was also forced to move house and come to terms with the possibility that future plans he had made for himself and his partner may not turn out as planned.

*“It’s like a barrier a lot of the time. But the sort of long term thing... I’m kind of going along all the time thinking that we’ll plan for a long retirement or something, but I can’t do it, you know. It is very difficult. It’s hard, David’s fifty eight... they moved the retirement age for [says workplace], so you’ve got to go on to sixty eight. Now he’s got no money, so he’s got to go on for another ten years. And that’s quite hard, because I think if we were both retired and we were looking forward to sixty five or something and retiring and having a nice, doing something, you know. But he’s actually going to have to work for another eight years after I retire officially at sixty five, you know. And that’s a shame in a way, so I’ve always got that sort of, he’s busy and I’m not. I suppose that happens to people, people in retirement generally, but it’s sort of wanting to grab all the time we can really.”*

(Francis)

‘Planned time’ was also disrupted for the men in terms of things they looked forward to in the future. Planned time encompassed those days or weeks in the calendar that were set aside in advance for holidays, or special occasions that were looked forward to beforehand. Holidays abroad were frequently mentioned as something enjoyable that were now

impossible, due to the cost of travel insurance which was considered to be “off the radar”. However, whereas some men had cancelled their plans to travel overseas on account of costs involved, others were prepared to take the risk of travelling abroad without adequate insurance cover, as Alan revealed.

*“It’s very hard to get holiday insurance at a reasonable price...I have now changed my mind ‘cause I’ve got two forms of cancer which so far, aren’t going anywhere...I have now just got general insurance which doesn’t cover my health, my known health issues, so I’m taking a risk now...as far as I’m aware, you know nothing will happen overnight...I thought it was a bit unreasonable, given that I’ve not had treatment, I’ve had no operations. You answer the questions and the computer says yes or no.”*

(Alan)

Disruption for Christopher and Joshua meant that the sexual spontaneity they had formerly enjoyed and taken for granted, had been replaced with a need to now plan ahead.

Christopher, who was single and a regular user of the dating application ‘Gaydar’, was sometimes rebuffed by potential sexual partners if he was not immediately available for sex.

*“...somebody will say oh, do you fancy having sex? And I get me diary and go yeah, can we make it in a couple of days’ time? Phrrr, delete. They’ve deleted me, they want it now.”*

(Christopher)

Although Joshua was mindful that he need to plan ahead if he wanted to enjoy sex with his partner, he found that verbalising his needs earlier in the day felt unnatural.

*“That’s the other thing that’s difficult is, even like the MUSE tablets, is organising it because you’ve got to plan for it, you know, like this weekend, we didn’t quite get around to it and then by the time you start thinking about doing it it’s too late. You think, well if I do one it’s going to be erect for a while and it’s just too much... You can’t just say I’m feeling... I have to tell him if I’m feeling randy basically, which I find awkward. I can’t show an interest in the way I used to. And you think that they think you’re not interested in them.”*

(Joshua)

#### **5.6.4 Reconciling past and present – reframing the future.**

In many respects, facing a life threatening illness had resulted in a 'reframing' of time for the men, and in some cases, a reframing of their outlook on the future. Several men described how they no longer allowed themselves to become depressed over "things that really don't matter" or reported being "not so assiduous at work". Others described how they allowed themselves to indulge more than before and had adopted more of a "bugger it" attitude. The men spoke about their lives in retrospect and often shared their 'coming out' stories. These were incredibly poignant as these were clearly defining moments in each of the men's lives. On some occasions, specific features of stories from their past became intertwined with their cancer experience in the present.

Several men described how being diagnosed with prostate cancer had been a trigger for revisiting past issues relating to their sexuality. Christopher described being in the midst of a "personal growth journey" before he was diagnosed with cancer. Hence, continuing on this journey during and beyond his cancer treatment had empowered Christopher to face his fears, frustrations and helped him to deal with some past issues which had, until this point in his life, been unresolved.

*"So, what am I saying.....what I'm really saying is..... I came out when I was twenty seven. Sex in my family was a very difficult, very taboo subject, if I hadn't have had prostate cancer... I don't think I would have resolved some past hurt, past...things I've covered up because.. I never realised they'd been hidden...I'm still on a personal growth journey and it will never stop, allows me to explore who I am, my foibles, my faults, my good things, my reality, the people I wanna be with... I think my prostate cancer has allowed me to grow much more holistically as a gay man....what comes up for me, witnessing it now rather than getting sucked down into it, witnessing, if I didn't have prostate cancer, I've got a lot of shit. Prostate cancer triggers a lot of the shit".*

(Christopher)

Hugo, Ian and Matthew also described revisiting feelings from their past since receiving their cancer diagnosis. Hugo likened the disclosure of his prostate cancer to friends and family to his coming out experience.

*“I came out, not came out, it was nothing to be ashamed of with this one. Oh that sounds dreadful, doesn’t it? But there was, it did feel like that when I came out being gay, it felt like I was ashamed of it. It felt like it was something I had to, had been ashamed of all my life. But with the prostate cancer there wasn’t that big overwhelming cloud of shame, it was just something that happened.”*

(Hugo)

Matthew described coming to terms with issues from his past which had remained unresolved prior to his cancer diagnosis. Seeking help from a counsellor finally helped Matthew to stop looking back. He was now more able to look forward and was more self-accepting.

*“...that was probably the best thing I did actually. Because I had a lot of issues in the past unresolved and it’s one of those sort of things that before the diagnosis, it was like I’d better go and see a psychiatrist or something like that. And I suppose what you think is, well it’s not that big a deal, you know, a lot of people have got worse issues. So you put it off, you don’t do anything about it. And the counsellor was fantastic, she was so good, got loads of stuff off my chest about my past. And that for me was a really good thing for the diagnosis because I thought, as the time’s gone on, that idea of, oh I haven’t got long to live, it begins to get, the timeline changes and changes and changes. It was moving forward, now I can think about planning things. And I don’t think about, oh I haven’t got long to go, it’s a different mental change really.”*

(Matthew)

As Matthew continued to talk about his past and how it impacted on the present, verbalising his thoughts resulted in him being able to articulate how he wanted to view the future.

*“But then that thing I want to put in place, as I said, that’s not me thinking, oh well I’ve got a short time. That’s me thinking, actually, I’ve just thought of it now actually, for me that’s something new in my life and that’s something new I want to work*

*on. So it's a projection of how I want things to go, rather than thinking, oh, you know, it's not long now..."*

(Matthew)

For Charles, there seemed little to be gained by looking too far into the future. Instead, he was thankful for the positive encounters he had experienced and was philosophical about the future.

*"I suppose it's made me realise that nothing's certain, you know. You go along and every day you think is going to be like the day before and, of course, it never is...What do I think of the future? I don't know, and I get through each day literally day by day. I just keep thinking, I'm somewhat more reassured by what's happened to me recently. Thinking, well you never know what can happen, maybe things are going to get much better. If they don't get any worse I'll be quite happy, that would be good."*

(Charles)

## **5.7. Findings viewed through the existential lens of Relationality (Lived other)**

Relationality refers to the relationships we maintain with others in the interpersonal space we share with them (van Manen, 1990). Relationships refer to those people we are close to, such as family and friends. Equally, they also encompass the relationships we have with people that we encounter on a day to day basis, or those who we make formal and informal connections with through the workplace, or who provide a service.

When utilising the lens of relationality, moments where relations with others had significant meaning to the men were identified. Although there were many references to the relationships men had with others, four main themes emerged. The first theme, '*The quest for mutual respect and equality*', centres on the relationships that men formed with the health professionals charged with their care. This also contains the sub-theme '*Looking for information*', which conveys the men's desire to be provided with information that they deemed to relevant to them, not only as men, but as gay men. The theme '*To tell or not to*

*tell'* presents findings relating to the secrecy that surrounded disclosure of prostate cancer for some men. The final theme, '*Personal relationships – changes and challenges*' reveals how the men's relationships with their partners or potential partners had altered as a result of having prostate cancer.

### **5.7.1 The quest for mutual respect and equality**

All of the men who took part in this study described the ways in which they interacted with health professionals they had encountered along their cancer journey. As previously illustrated in the existential spatiality, some encounters were more unpleasant than others. Several men described situations where they felt disrespected by health professionals on account of their sexual orientation. Ian recalled how one senior consultant assumed that a rectal examination would not be problematic for Ian, because he was a gay man.

*"I can remember word for word, he [medical consultant] said, 'well somebody like you, it won't make a lot of difference to somebody like you', that's what he said to me".*

(Ian)

Ian went on to describe how nervous he was about this procedure due to the sexual abuse he had been subjected to when he was younger. Moreover, Ian disclosed that he did not receive anal sex from his partner. This incident made such a lasting impression on Ian that he refused to have anything more to do with the consultant in question during the remainder of his care.

*"... if this comes back, I don't care who you get, even if you have to get someone from another hospital, I'm not ever seeing him [consultant] again, that's non-negotiable, I won't even acknowledge him. And I saw him once or twice when he came onto the ward when I was admitted. And I wouldn't... and I said to the staff nurse, I don't remember her name, if he's on the rounds don't bring him to me because I won't engage with him."*

(Ian)

Charles also described several occasions where he felt it was necessary to explain to health professionals why it was important for them to listen to some of the concerns he had about being a gay man with prostate cancer. The following anecdote describes one of these occasions and the frustration that Charles felt.

*“He [the consultant] came out with a comment that I was only the second gay man he had ever met in all his career. And I just said, that’s got to be rubbish, you know, I said, that can’t possibly be right. I said, you work and operate in a city which has one of the highest populations of gay men in the country. I said, you can’t possibly have only seen two gay men. And he sort of looked a bit thoughtful and he said, well when you put it like that, he said, I suppose you must be right. He said, it’s just that men don’t normally tell me that they’re gay. I said, well this is my life we’re talking about, you know. I said, if I can’t be honest and open with you, I said, or ask you relevant questions, who do I go to? I said, you know, you’re the guy with the answers I hope. I said, so of course I’m going to talk to you about it. But it was perfectly obvious that nobody else had ever approached him about this subject. And there must be hundreds and hundreds of gay men out there, who are afraid to say, you know, how is this going to affect my sex life? Will I ever be able to have sex again? It’s too embarrassing for them to ask”.*

(Charles)

The men also described how some healthcare professionals made their experiences within healthcare settings much easier. Nurses were described by several men as “lovely” and for the most part, they were portrayed as being the most approachable members of clinical staff encountered by them.

*“And Emma, who was my clinical nurse, who was with him at the time, who has turned out to be, you know, like an angel. She was absolutely brilliant to me.”*

(Ian)

In contrast, whilst consultants were appreciated in terms of their expertise and knowledge, their manner towards the men was described as being more “straight laced” and “dismissive.” Joshua struggled to find a consultant who he felt comfortable about disclosing his sexuality to. However, realising that not disclosing may be detrimental to his health in

terms of the treatment option he had been advised to take, Joshua decided to broach it with someone he perceived to be “a sort of consultant God character”.

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

(Joshua)

Joshua described feeling “lucky” when he found a younger consultant who he felt comfortable enough to be open with and raise some of the issues that concerned him as a gay man.

*“I was lucky that I had the fallback of going to the other surgeon you see...he made me quite sort of angry really and I thought, sod it, I’m not going to have him, I’ll have [first name of consultant] do it. So I was lucky that I had that option. If I hadn’t have done, then I think I would have been very uncomfortable and not knowing what to do, you know. If you kick up a stink and then go out and try and find another surgeon, because you’re able to choose whoever you want to do it, you can go to any hospital you like and have it done, but do you really want to sort of do that when you’re faced with this ticking time bomb? So that guy I found particularly approachable, even on gay issues. With [consultant’s name], the good guy, you know, you could talk to him about anything, you know, you could ask him questions”*

(Joshua)

Christopher, who had been very proactive in asking for help when he needed it, described how he had planned to open up a conversation with his consultant about issues concerning his sexuality, but did not get the reaction he had hoped for.

*“I said to er, my Macmillan nurse who I get on well with, very well, I said I’m going to ask Mr [surname of doctor], him, as a man, what’s it like... er, about testosterone and having orgasms, not as a consultant but as a man, and... [first name of Macmillan nurse] burst out laughing, because Mr [surname of doctor] was straight laced, I’m a consultant, you know, don’t mess with me type of thing. Nice guy, got to know him a little bit now and er... I went in and I nodded to [the Macmillan nurse] as if to say, I’m going to ask him now and he didn’t, didn’t like that... he just evaded the question”.*

(Christopher)

Charles spoke about the assumptions that he felt were made by health professionals as a result of him being open about his sexuality. In the following quote, Charles described how he had phoned a nursing organisation, as he felt he could not relate to anyone sexually. He enquired whether he could be prescribed a liquid form of Cialis (a phosphodiesterase type 5 inhibitor similar to Viagra) that would not irritate his stomach as the tablet form had.

*“I said, no, no, it’s not Viagra. I said, it’s the same sort of thing. I said, but Cialis, I said, unfortunately, when I’ve had it in the past, I said, it gives you terrible headaches and stomach ache. I said, but I believe it can be supplied in a liquid form or like a jelly. Oh she said, I think that’s too much information don’t you? And I suddenly felt that big, you know. And I twigged where her mind was at. And I said, it’s a jelly that you swallow, that you actually take orally. I said, I don’t know what you were envisaging...that’s not support that was judgemental, it was just horrible. So I never contacted them again. So I went on for two or three years dealing with the ins and outs of the HIV virus and the medication for that, and with the prostate.”*

(Charles)

In contrast, when health professionals did show an interest in the issues that were of specific concern to the men in terms of their sexuality, this was greatly appreciated.

William, who had been receiving treatment for gender dysphoria, prior to his cancer diagnosis, described how his consultant was interested in his past history and had been supportive.

*“...she was very supportive, very interested in er my other history I suppose. Yeah she was tickled pink when I told her that the bicalutamide was having a marvellous effect on my breast growth”.*

(William)

### **5.7.2 Locating information**

With the exception of one man, all the participants desired information that they deemed to be relevant to their needs as a gay men. Anthony, who considered himself a ‘success story’ recalled the lack of information or support that was available to him when he was

initially diagnosed 15 years earlier; something he did not feel had improved within that time.

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

(Anthony)

Ian, confirmed the current lack of available literature created for gay men. However, despite finding a resource from Macmillan Cancer Support, Ian wanted information that was specific to the type of cancer he had.

*“There wasn’t anything for us to read, we did all our own research. And that was very generalised, as you say, it was very geared to heterosexual. There was a very limited amount of, I think Macmillan did one gay men and cancer, which was very good, but talked in very generalised terms. You know, and for me, I needed something specific”*

(Ian)

Alan, one of the two men on active surveillance, had not needed any specific information about how treatment would impact on any aspect of his sex life and had not yet sought it at the time of our interview. However, when I asked what type of information he may perhaps ask for in the future, his first concern was about whether anal sex may be problematic. Despite stating he would ask for information if necessary, Alan assumed that his health care providers would inform him about anything he may need to know.

*“I suppose the issue of sex-acts, I’ve never asked and nobody has ever mentioned it... I suppose in an ideal world if I felt I needed to ask then I would ask, I’ve never felt I needed to ask but it’s just a question of, I wonder whether anal sex is something... equally, I’m sure the consultant would have found some way of saying... You see I don’t know because I’ve never seen, never read anything that’s mentioned it. So do I infer from that that it isn’t an issue? That if that’s what you want to do, go ahead and do it?”*

(Alan)

Elliot, was also undergoing active surveillance. However, unlike Alan, Elliot expressed a heightened need for information so he could be better informed to make a treatment decision in the future. After undergoing a transperineal biopsy which resulted in an inflamed prostate, Elliot made the connection that his own sexual practices could have a detrimental impact on his health after undergoing such procedures, but was astounded that his health care providers were not aware of this risk.

*“I had a transperineal biopsy... the way they monitor is excellent, you can't fault it. But apparently, that caused me inflammation of the prostate now, there are sexual practices that could of actually aggravated that whatever, and... because they never talk about that, you know when I said to them in the beginning, is there anything sexually I should be aware of, they said no, carry on. The thing is, they don't ask you what your sexual practices are... It's like someone's sexual practices and what they do are going to have implications, you know...”*

(Elliot)

Several men described asking for information from their health care providers but that it was not always forthcoming. However, Christopher admitted that he may have been provided with answers to the questions he asked his consultant, but may not have digested what they were being told, resulting from the shock of being diagnosed. Christopher was one of the few men who had a urology nurse present at that time. Hence, he recalled how she was able to remind him that certain pieces of information had been provided to him but he may have forgotten.

*“My urology nurse...a few times when I've been crying to her about certain things, I'd say why didn't [consultant] tell me that... 'Here, [mimics voice of nurse] he's told you eight times Christopher.' So, I might have missed it, if I gave him the benefit of the doubt. There's a piece of my radar that says no, I don't think I missed it, he never sat down and said, I'll give you twenty minutes Christopher, thirty minutes, whatever; what's it like to be gay with this diagnosis? Never had that conversation. Never ever, ever said would you like me to help you find somebody who's gay, never... I think because I was dealing with, oh my god I'm gonna die, that was probably very low on my priority list. When that, oh I'm gonna die got moved off, I moved into a different area where I was kicking the doors down. I was asking for psychosexual stuff, I was asking to see an endocrine consultant because I wanted to know, what does testosterone*

*do? What it's like when, if my body needs testosterone and I've not got it? What's it doing to me not having it?"*

(Christopher)

Charles also remembered being given information at the time of his diagnosis.

*"I do remember, he talked to me about radiotherapy... he may have mentioned chemotherapy, he certainly talked about the surgery. He described the surgery and he drew little diagrams. And he talked about what happened afterwards and he talked about the nurses, none of it went in. And I'm not stupid, you know, I'm quite an intelligent guy I think, but not one iota of it went in, I was just so shocked. All I could see was a big letter C and, oh god, I've got cancer, that's all you can think about, nothing registered*

(Charles)

Since being diagnosed, the internet had become one of Joshua's main support sources for locating support from other gay men with prostate cancer and for seeking information about sexual aids, and drugs that could help to improve his sexual function. He described turning to the internet in an attempt to acquire more medication than his own medical team were prepared to prescribe. His quote describes the sense of apprehension he experienced prior to ingesting one and highlights that there may be potential dangers for men who use the internet for information as opposed to their healthcare providers.

*"You know, they make their money, they're not cheap. It's like fifteen pound a shot. So I got eighteen, well I had, my bloody boyfriend nicked one didn't he, he didn't tell me, in one of these sessions with a bloke. And he tried one, I was really nervous about trying them, he was either drunk or had drunk a bit too much, or whatever, he was worried about not getting an erection, so he did it. I have to lock it away. But anyway, so I tried it and, so, yes you get them online and they make you do this prescription, do you suffer from this, do you suffer this? And they charge you twenty five pound for that bit and then you can order as many as you want. Next time you order you've got to pay the twenty five pound for them and that's the cheap one, and it's about the same price or even cheaper in America, they're not cheap. But it seems that that's quite a long time before my next appointment at the hospital... I'm not telling my consultant when I get there that I've tried it".*

(Joshua)

### 5.7.3 *Personal relationships: changes and challenges*

Some biggest changes and challenges faced by the men in the context of relationships, were those that impacted on their personal and intimate relationships. Those who were in relationships, or civil partnerships, were aware of how their partners were affected both emotionally and sexually. Christopher described the frustration both he and an ex-partner Tim experienced due to Christopher's inability to perform sexually. Their relationship became more problematic when Christopher discovered Tim had chatting to men on the internet.

*“With some guys it absolutely doesn't matter. Tim, my boyfriend said Christopher, it doesn't matter...something I've learnt with Tim, is that when you've said it doesn't matter, underneath that it does matter, and you're trying not to hurt me by saying it doesn't matter, but what I really want from you is the truth, not so you can beat you up and I can beat you up and reject you or whatever, it's so I can only deal with the truth. And when we've had spats and fallen out he's said yeah, actually Christopher, it does matter, when you can't get your dick up when you can't get an erection, you can't screw me...it really does.”*

(Christopher)

Joshua and his partner Daniel, attempted to overcome some of the challenges they experienced by, on some occasions, introducing a third party into their sexual relationship. They found this to be a positive experience.

*“...we've come to sort of an understanding. It's fine, it's a perfectly mutual sort of thing, but we've actually started to pick up other guys for like a threesome or whatever, and twice, involving the same bloke twice as well. And that's worked out really well, you know. And I think we've sort of come to the conclusion that we both like doing that and, you know, if we do it like once a month or something, that's going to be quite a good addition really because somebody else is there with a proper erection and all the rest of it. It's something else to the mix, you know. And the two people I've found, it's not been a problem at all, you know, for them, it's worked out alright. And that I found very confidence building and reassuring”.*

(Joshua)

Matthew described some of the challenges he now faced as a younger man with prostate cancer. During our interview, Matthew's partner Neil was also present. Matthew described a recent night out that both men would have gained immense pleasure from prior to Matthew's diagnosis. This entailed both of them going out to a gay club, separating for part of the evening, in which time both men would take part in sexual activities with other men in the club, before meeting up again later to go home as a couple. I asked Matthew what the experience of going to gay clubs with his partner was like for him now, especially since hormone treatment had lowered his libido. Matthew went on to describe a brief moment in which he experienced a sudden sense of vulnerability concerning his partner, after seeing him engaging with another man.

*"... just for a minute I thought, I felt a bit de-masculated and it's like because I can't, I haven't got the libido or I can't cum anymore. And I thought, if I'm honest I felt a bit vulnerable, not that I don't think you [speaks to partner Neil] would ever go off with anybody... But just for a minute it was just like, you know, I can't do what I used to do... it wasn't jealousy, it's never been jealousy, it's just fleetingly I felt sadness... And maybe now it's that, there's a slight part of me that feels a bit, oh I don't know, vulnerable or disappointed that if the situation could arise again, these really attractive guy or guys, and I'm just thinking, oh, you know, I can't respond to it like I used to..."*

(Matthew)

Although Ian acknowledged that his relationship with his partner had changed as a result of prostate cancer, he described how his relationship with his partner had changed for the better. However, he also admitted that they had faced challenges. Having to make plans in the event of Ian's death had led them to discuss some difficult past truths.

*"Neil is probably the most important because whilst we've got over having those conversations of a practical nature, we then had to talk about the emotional bit. And although we've been together nineteen years, we went through a really rough patch in year seven. I had an affair and we'd never really talked about that at all. And that forced the issue, in terms of, because he was really angry about it and he'd never been able to tell me how angry he was, but it all came out... it was incredibly uncomfortable, it was incredibly uncomfortable because, it was uncomfortable for all*

*sorts of reasons. I don't know if it cleared the air as such, I think it just put things into context for us both, you know."*

(Ian)

Not all the men's relationships withstood the strain placed upon them during this difficult time. Hugo's relationship broke down because he felt unsupported by his partner whilst he was undergoing cancer treatment.

*"... useless, he was useless, and that's not me being vindictive, he just was useless. Whilst I was having my treatment, you would be there, you would be there, you would go with the person, you would, even if it was a friend of mine I'd be doing that, you know. He should have been in the car beside me on the way up... he didn't even get out of bed or stir, he was still asleep when I got up to go. I used to get picked up about seven thirty in the morning to get taken up, it was a long way..."*

(Hugo)

Elliot, who described being in a loving and committed relationship, expressed sadness and frustration on account of his partner not wanting to talk openly about Elliot's emotions and his worries about the future. Elliot found this frustrating as his partner's father had also been diagnosed with prostate cancer several years earlier. He had wrongly assumed his partner would be more understanding.

*"My partner is ten years younger than me and what's ironic and he doesn't seem to get it... You know, we've had real massive arguments and all the time I'm really aware that because I've read so much about cancer generally, about the corticoids and about stress... and I sort of said this to him; I don't need the stress, I really don't need this and I can feel, because I do get very stressed out, I am very passionate about things and I said about integrity and more about rights and getting things sorted. Actually, that sort of support needs to be forthcoming and if you can't, and it's understandable, maybe it's too close. Being a partner that to get that sort of support and their having to dress it in their own way themselves, you know if you were heterosexual then you are sharing something with the wife, they're not going to share prostate cancer."*

(Elliot)

Personal relationships were not the only ones subject to change. Following his diagnosis, Francis' relationship with his employers became strained after he felt that he was pressured into taking early retirement. The nature of his job meant that Francis was required to provide pastoral care to a fairly large community. Hence, his employers were concerned that he may not be well enough to fulfil his duties whilst undergoing treatment.

*“My immediate boss came round to see me within days and said, I'm sorry, we can't have this, we need to sign you off. And I said, well, you know, why? Because I can manage, I'll be alright, I like to do things. No, it's not fair to anyone, we can't have this...when they sort of opened the briefcase and got out a letter, I'm thinking, God they're obviously sort of thinking, we can't let him go on with this. And I'm sure in a way they had the best intentions at heart, but I did feel as if I was being kind of pushed into something a little bit...”*

(Francis)

Francis' working life was, in many ways, bound up with his personal life as accommodation was provided by his employer. Leaving his job meant that he would have to move house, in order to enable his successor to move in, and away from a community he had come to feel part of.

*“I'm feeling quite depressed at times because I suppose I feel psychologically not prepared for retirement and I wanted to go on. And as I feel better, I feel as if I could do things and I'm a bit fed up. And I feel sort of sad that I left them all, even though I was, you know, I was beginning to think it might be time to move on from there. But that terrible sense of not having a role anymore is very strange when we retire...I've invested so much into it, yes and I just suddenly feel role-less and kind of quite empty at the moment. And I just need to find something to do, if I'm going to be alright, I've obviously got to be okay with all this, you know.”*

(Francis)

#### **5.7.4 To tell or not to tell**

For several men, having prostate cancer was something that they chose to disclose to other people, depending on their personal circumstances. Christopher preferred to tell potential sexual partners that he had undergone removal of a tumour that had affected his erectile

nerves. Alan had been particularly guarded about who he disclosed his diagnosis to. Having already been diagnosed and treated for one form of cancer several years earlier, he was mindful that he did not want to “fall into a victim scenario”.

*“I think people would put me into it. You know, some people look at me and say well there’s the man with prostate cancer... the people I have told have been friends who were not close to my family, yes and not my friends in [says hometown], apart from one friend, but it’s you know, how to, people who will be discreet and erm, but there is a need to be able to tell people, even though I didn’t want to tell everybody. You know ‘cause it’s, erm, you know there’s just a sort of you have to say, you know when things bad happen to you, you have to unburden yourself somehow and I, I selected people to tell”.*

(Alan)

Anthony considered that having cancer was a personal matter for him and his partner Calvin. Therefore, they decided they would not tell anyone until Anthony was admitted to hospital for surgery. However, Anthony also admitted that he was also concerned that others may question whether his sexuality may have been a contributing factor for him developing the disease.

*“There was also, we thought, an element may be because of our lifestyle, sexually I’m talking about, over many, many years. Could that have contributed to the disease? Do you understand what I mean?”*

(Anthony)

### **5.7.5 Friendship**

In addition the support that men received from their partners, they also described how their friendships with others had impacted on their lives and during their cancer experience. Some men were aware of how having cancer impacted on their friends who they felt did not always understand and maybe did not want to understand what it was like living with this disease.

*“Obviously, we’ve got gay friends, not a lot because we don’t move, you know, in the gay club circuit, you know. We might have done when we were younger but not now. Most of them, I would say, are uneducated about this, it’s not uneducated themselves, uneducated about the disease. And they don’t really understand, a lot of them don’t like me explaining anyway, this fear element again. They don’t really understand and I don’t think they really want to know...”*

(Jerry)

Charles was also very aware of how having cancer impacted on others and had been shocked at the reaction of people he had considered to be his friends.

*“I think the same as anybody who gets told that they’ve got cancer, your immediate friends and family are all very frightened for you. Interestingly enough, there were people who, when I got diagnosed with cancer, just dropped me. That came as such a shock. I never anticipated that. And, you know, you make excuses for them. You think, oh well maybe they can’t handle it or whatever. But it’s not good enough actually, there’s something lacking. I don’t know what it is”*

(Charles)

Alan was particularly grateful to the friends when he was diagnosed with prostate cancer as he had made a conscious decision not to tell his family, in order to prevent them from worrying. Hence, he was careful which friends he did disclose to, to minimise the risk of his family discovering his diagnosis.

*“...the people I have told have been friends who were not close to my family, yes and not my friends in [names town], apart from one friend but it’s you know, how to people who will be discreet and erm, but there is a need to be able to erm, tell people, even though I didn’t want to tell everybody. You know ‘cause it’s erm, you know there’s just a sort of you have to say, you know when things bad happen to you, you have to unburden yourself somehow and I, I selected people to tell. Or people who pressed me, you know some people pressed me and I thought yes, I will tell them...”*

(Alan)

Ian described the reciprocal investment that considered to be a necessary component of genuine friendship. He spoke highly of the close network of friends he had and the importance he placed upon them both prior to and following his cancer experience.

*“For the people who I have invested in, who have invested in me, they’ve become my focal point. And that’s not necessarily my complete family, I’ve got friends, who we tend to call, family, which is a combination of friends and family, who are probably far more important to me than some members of my immediate family.”*

(Ian)

For Hugo, who was living with both HIV and prostate cancer, his friends had become a central part of his life. Given that Hugo’s relationship had broken down due to the lack of support he had received from his partner, Hugo was able to recognise specific values in the friendships he had developed since coming out as a gay man in his twenties, and the unique qualities they offered him at specific times of his life.

*“When I came out as gay, I lost all my friends... I didn’t lose any friends over the prostate cancer, in fact, if anything, it’s helped develop some friendships... I don’t have lots of friends, but the friends that I do have are very good friends and have been there for years. I probably have a handful of five very good, very close friends that I can talk to about anything and everything. And I know that if I was to pick the phone up and say, I need you, they would drop everything, as much as they could do, and they would be there as soon as they could. And that’s a lovely feeling and each of them bring me different things. For example, my friend [friend’s name], who I did talk to about my prostate cancer, and he was very supportive, but he’s not emotionally intelligent, he doesn’t, he’s never had relationships, he doesn’t understand the complexities about emotions and that sort of thing. So he never says, how do you feel? He’ll say, what time’s your appointment? Not how do you feel about your appointment coming up. So I know that about him, you know, that’s useful to some extent”*

(Hugo)

### **5.7.6 In pursuit of peers**

Although most men described having a wide and supportive social network when it came to discussing issues relating to prostate cancer, they communicated a distinct need to be able to access and speak to gay men who had been through the same experience.

*“But also, just sort of discussing at that group, even in just sort of very straight factual terms about not being able to cum, I suppose you just don’t know what the reaction will be. But if you were with a group of gay men, where things are much more open and talked about...And I think there may well be other guys in similar situations, the same age, who think, may go along, go to one meeting and think... I feel out of place, I feel this is too old for me, what am I getting out of it? And maybe even, you know, have a negative effect.”*

(Joshua)

This sentiment was echoed by most participants. They described needing to be amongst men who would implicitly understand what it was like to live as a gay man. Jerry alluded to this implicitness when we were discussing the issue of support groups.

*“We don’t sort of talk as gay, we just know that...”*

(Jerry)

The men wanted to be with other men would understand issues concerning their community that Elliot suggested would “go over a lot of heterosexual guys’ heads”.

Moreover, they conveyed a need to be around those who used, understood and accepted the necessity for using colloquial language, where terms such as “poppers” (amyl nitrate) or slang terms for the male anatomy and sexual practices did not have to be explained.

*“I think if you had a gay group like in Manchester... that was a wonderful thing that guys were able to talk really openly and not think that oh, someone’s gonna be offended, because gay guys will talk and be far more open emotionally, far more open about the language they use than heterosexuals”*

(Elliot)

The men referred to their history, the stigma of being a gay man in previous decades, and to the HIV and AIDs epidemic which had forced them to take ownership of their own

health. Ian described how these events had empowered gay men to be more open amongst themselves, about health and sexual issues more generally.

*“We’ve had to have those conversations, when the HIV virus hit and safer sex practices and all those sorts of things, that we’ve been both educated and exposed in a way that heterosexual men haven’t to those issues, you know...”*

(Ian)

## **5.8. Summary**

This chapter has outlined the findings from this study. The quotes and anecdotes that have been presented offer a glimpse into the men’s lifeworlds and convey their experiences of living with a diagnosis of prostate cancer, or, in the case of two participants, prostate cancer and HIV. The following chapter will offer an interpretation and discussion of these findings and describe what meanings were attached to the men’s experiences.

## Chapter 6: **DISCUSSION**

### **6.1. Introduction**

The aim of this phenomenological study was to explore the lived experience of gay men with prostate cancer. The objectives were to gain insights into how the disease impacted on various aspects of their lives, and to determine whether they reported any unique psychosocial and support needs. In achieving its aim and objectives, this study has made an original contribution to knowledge in several ways. By extending what is currently known about living with this disease more widely, the study offers an insight into what it is like to be a gay man, in the UK, living with prostate cancer. It also highlights the need for healthcare providers to develop a better understanding of some of the unique issues that may impact on the lives of these men, and to develop culturally relevant information. The study has also made an important contribution to knowledge, by highlighting the extent to which cultural identity may serve to alter the embodied experience of cancer, thus emphasising the need for a diverse and accepting healthcare system, which continues to develop ways of identifying and acknowledging individualism and practicing person-centered care.

This chapter discusses the findings of the study in relation to the aims and objectives that were outlined at the outset. The findings will be discussed in relation to several of the themes that emerged from the literature review and, more recent or relevant, literature sources will be incorporated to give context to the findings. The limitations of the current study are discussed within this chapter, as are the recommendations for future research, health practice and the implications this study has for current and future policy. The findings resulted in six themes, which are listed below and will be discussed separately. However, there may be an unavoidable degree of overlap within some themes, due to the natural, cyclical way they are experienced in everyday life.

- Filling the void: Gaps in information and the need for reassurance
- The altered self: Prostate cancer and gay identity
- Seen but not heard: Negotiating heterosexism and the taboo topic of sex
- For better or for worse: Changing relationships
- Brothers in arms: The role of kinship and 'family' support
- Finding the rainbow: Looking beyond cancer

## **6.2. Filling the void: Gaps in information and the need for reassurance**

The findings suggest that upon hearing of their cancer diagnosis, the men in this study experienced a defining moment, during which the four fundamental structures of their lifeworlds and taken for granted existence were temporarily suspended. Some men heard what was being said by those around them, yet were unable to listen. Others described how their own bodies reacted, describing that they had been dealt 'a body blow' or been 'hit'. Within seconds of hearing the news, the participants had already taken a step from an old life, into a new and very different way of being.

Following their diagnosis, time was experienced with a heightened sense of urgency. The men tried to rapidly educate themselves about a disease they had little prior knowledge of, in order to evaluate how the treatments they had been presented with would impact on their lives. On the surface, this finding concurs with those reported in previous studies, which have shown that men have a heightened need for information just following diagnosis (Hagen, Grant-Kalischuk, & Sanders, 2007). However, despite being given several sources of information by their healthcare providers, the men in this study felt that something important was missing; but, as several men pointed out, they were not quite sure what this was. Closer inspection of the data revealed that the men in this study needed information which would allow them to make sense of how prostate cancer would

affect them not only as men, but as gay men. Hence, the ambiguous nature of suspecting, but not really knowing, if there were things they should know, fuelled the men's need to acquire more specific information.

Several men went on to describe how, and where, they looked for information. Some, but not all, men asked their healthcare providers if there was anything they should know in terms of how treatment may affect their sexual functioning as gay men, but reported that their questions were often met with embarrassment. However, whereas the men assumed this embarrassment was associated with their disclosure about being gay, it is also possible that consultants simply were not able to answer their questions due to their own lack of knowledge about issues relating to sexual orientation. The potential for miscommunication between healthcare providers and patients during early interactions, on account of cultural differences, was discussed in Nanton and Dale's (2011) study. Their research, which explored the experiences of African-Caribbean men with prostate cancer within the UK, emphasised the need for healthcare providers to have intercultural competence, in preparation for dealing with men from minority groups. Although this particular study focused on cultural differences based on ethnicity, the findings from this study indicate that similar barriers may exist for consultants as a result of sexual orientation. Hence, future studies exploring prostate cancer amongst gay men may benefit from incorporating the views of medical staff, in order to determine whether healthcare professionals would welcome training on issues that are of concern to gay men.

The findings from this study also suggest that the timing of information for some men may have also been a factor in them not 'hearing' what information may, or may not, have been given to them at certain times. O'Brien et al. (2009) reported similar findings, suggesting that information associated with issues that were not related to survival may need to be raised at a separate time in order for men to appreciate its relevance. Nevertheless, a

systematic review, undertaken as part of the development of UK guidance on the management of erectile dysfunction following treatment for prostate cancer, recommends that discussions should take place with patients and their partner both prior to and following treatment (White et al., 2014). By sufficiently preparing men and their partners for the dysfunction they may encounter in their sex lives, the authors maintain that this can ensure that their expectations of recovery are realistically managed.

As the participants in this study were uncertain of what questions they should pose to their healthcare providers, they sought information from other sources. Despite the plethora of information about prostate cancer within the public domain, the men were disappointed to discover that few made reference to, or portrayed imagery that they could identify with as gay men. Information concerning sexual function was clearly targeted at men who engaged in vaginal sex and omitted potential problems that may occur for those engaging in anal sex. Hence, the internet was cited as the most useful source of information for most men. An Australian report published since the interviews for this study were conducted, stated that prostate cancer materials are not serving gay and bisexual men, or presented in a manner that is relevant (Wong, Lower, Dowsett, Duncan, O'Keefe & Mitchell, 2013) The authors condemn the 'one size fits all' approach in terms of information provision. Instead, they emphasise the need for culturally relevant information that uses language and imagery, which gay men can identify with, something that the men in the present study expressed a longing for.

By joining website forums designed to help men with prostate cancer, the participants were able to post questions in the hope that someone would be able to answer. Some men had more success in this than others, based on how competent they were in locating relevant internet sites. These findings support those reported in a study conducted by Thomas (2013), which examined posts placed on two internet discussion boards,

specifically created for men with prostate cancer. Whilst posts from one discussion board were taken from a website targeted at the general population of men, posts from the second discussion board were taken from a website aimed at gay men. The findings revealed that gay men were significantly more likely to pose questions relating to sexual function, incontinence, psychosocial problems and the side-effects of treatments than heterosexual men. In contrast, heterosexual men were more likely to pose questions based on types and choices of available treatments. The findings from this study and those reported by Thomas (2013) not only have implications for gay men with prostate cancer, but may also apply to the LGBT community more widely. Given the large body of literature within the field of cancer relating to information needs, healthcare providers and researchers may need to ensure that information reflects the needs of sexual minorities, whose concerns about cancer may differ from their heterosexual counterparts.

On the occasions where men were able to connect with other gay men who had received a diagnosis of prostate cancer, they experienced a great sense of relief. In addition to procuring information regarding questions they may want to ask their healthcare providers, the men were also able to catch a glimpse of what their own futures may be like, as gay men with prostate cancer. From an existential perspective, it is possible that the need to understand the experience of cancer from another gay men's perspective, was the only way that the men could start to make sense of the journey they were about to embark on. Moreover, this highlights some of the difficulties that we, as humans, encounter when we attempt to envisage ourselves in an altered body that has undergone cancer treatment, whilst inhabiting one that is currently well. This can be compared to the paradoxical state experienced by participants in Bailey et al.'s (2007) study, whereby men on active surveillance experienced a sense of confusion about the silent nature of their cancer, a disease which is so commonly associated with pain and suffering. Furthermore, this may also have some parallels with the concept that renowned pedagogics Max van Manen and

Bas Levering spoke about in relation to 'touching' and 'being touched'. They argue that it is impossible to experience both sensations at the same time, since we experience ourselves as either the 'toucher' or 'the being touched', but never really both (van Manen & Levering, 1996). When applied to the participants in this study, it may be that seeking out others that they could wholly identify with was the only way that the men could grasp what their future might be like following treatment, given the lack of inclusiveness through other generic sources.

Following their treatment, sexual issues became more salient. Hence, the men in this study expressed that the nurses and specialist nurses they came into contact with were more approachable in terms of being able to ask them for information. They also conveyed that nurses were often able to direct them to other relevant support sources, e.g. psychosexual counsellors. Fergus et al.'s (2002) participants suggested that specialist nurses may have been better positioned to provide them with information during their cancer journey. This finding is also advocated by those reported in a recent study which examined the role of the clinical nurse specialists who care for patients with prostate cancer (Lopes & Higa, 2014). This paper found that nurse specialists were uniquely placed to offer several types of support to men with prostate cancer, which could be delivered through telephone helplines. Hence, the findings from the present study suggest that specialist nurses may also benefit from training on issues affecting gay men with prostate cancer, which may be easier to implement given the time constraints of consultants.

Regarding the provision of information for gay men, the findings from this study add considerable weight to the debate about whether LGBT people require health information specific to their sexual orientation (The National Cancer Equality Initiative, 2010). They also highlight that it is perhaps important that LGBT patients have some way of knowing that their needs have been considered and taken into account, even if there are no specific

issues to report. For the men in this study, the element of 'not knowing' if their needs had been considered put them in the ambiguous position of having to clarify this through other means, and may have placed additional and unnecessary stress on them in the process.

The findings also highlight that there is a need for health writers to produce culturally relevant information about prostate cancer that is inclusive of the needs of gay men, and indeed other non-heterosexual men, particularly as sexual dysfunction is a frequent side-effect of treatment. Prostate Cancer UK have already gone some way into making this happen, following the publication of a recent booklet aimed at gay and bisexual men (Prostate Cancer UK, 2014). However, there are still some gaps in knowledge that need addressing. For example, it is unclear whether some NHS patient information leaflets, e.g. information about the prostate biopsy (Surrey and Sussex Healthcare Trust, 2012), whether the needs of gay men have been considered. The advice on this information leaflet recommends that men refrain from sexual intercourse for around 24 hours. However, it not clear whether 'sex' only refers to vaginal sex. As men undergoing a prostate biopsy face an increased risk of infection following the procedure, it is very important for men who enjoy anal sex with their partner to know when it is safe for them to resume. Moreover, given that men who are HIV positive face a higher risk of infection due to their lowered immunity, the guidelines need to be clearer. This could be addressed by producing materials that are culturally specific or by simply including additional sections within existing material that can reassure all men, regardless of sexual orientation, about issues they may need to consider.

### **6.3. The altered self: Prostate cancer and gay identity**

The findings revealed that the impact of prostate cancer for gay men often extended beyond their corporeal experience of the disease. Cancer affected their whole sense of self and was frequently reflected back to them through the eyes of others. This resonates with

phenomenological literature by Sartre (1956) who spoke about how our silent bodies are to ourselves until they are viewed by another; at which point, we are likely to judge ourselves by what we think the 'other' may see. Sartre also suggests that the mere thought of 'the look' by others has the ability to alter our perceptions of self. Hence, it is unsurprising that the men in this study and patients in a more broad sense, experience a diminished sense of self when they are experiencing illness.

The men frequently spoke about how they were 'before' compared to who they perceived themselves to be 'now,' highlighting the temporal crack that had created a split in the way the men now experienced a life they had once taken for granted. Embodied changes, as a result of cancer treatment, meant that men were forced to acknowledge that their bodies were now different and to some extent, had betrayed them, especially given the extent to which treatment side effects had impacted on important domains of their lives. Even when changes were not always visible to the naked eye, their presence was still felt. Moreover, these changes became more or less salient, depending on the company that men were in at any given time. These findings strongly resonate with studies which have explored how men feel about their changing bodies as a result of cancer (Bertero, 2001; Kelly, 2009)

Changes to the men's corporeal sense of self became most apparent when bodily changes were visible, either to themselves or to others. Weight gain, as opposed to weight loss, was a common side effect as a result of hormone treatment, which several of the men found particularly distressing. Although some of the men outwardly expressed they did not subscribe to the popular notion attached to 'the gay ideal' – a lean and muscular physique, they also contradicted themselves at times. For example, one participant (Christopher) commented that he was not interested in maintaining a certain image. However, he later commented that his body was something he had always been proud to display when he

attended the gym, as younger men whose bodies were not as muscular were surprised when he revealed his true age.

The investment and value placed on body image and has received much attention within discourses relating to gay culture (Wright, 2001; Brekhus, 2003). Clarke et al. (2013) discuss how the prominence of youth within gay society shuns ageing. Hence, this may explain why some men in this study felt it necessary to hold on to their sense of youth. Kane (2010) argues that gay men experience their bodies differently to heterosexual men, as the object of their physical attraction and desire, shares the same gender as themselves. Hence, it perhaps natural that the men in this study were particularly concerned by how they were viewed within their own social milieu, especially if they, themselves had been prone to placing a certain value on the appearance of other men, prior to their own cancer diagnosis.

Less visible bodily changes were brought into sharp focus within gay spaces when men actively sought sexual partners. For some men, the absence of an erection meant that they were no longer able to use this non-verbal form of communication as a way of conveying their interest to potential sexual partners. In these situations, men had to find a way around this problem, which often meant having to reveal something about themselves, and exposed them to the possibility of rejection. It was on these occasions that men realised that an integral part of their identity which had previously helped to define them, was now relegated to their past. Navon and Morag (2003) discussed how invisible changes to men on hormone therapy affected their sense of self. The participants in their study described how they attempted to use normalising strategies in order to convince others they were well. However, as this strategy was not congruent with how they perceived themselves, it was counter-productive.

Given the location and function of the prostate within the male body, and the effects of subsequent cancer treatment on men's virility, it is unsurprising that one of the main findings from past and current research centres on the impact of cancer on men's sense of masculinity. Chapple and Ziebland (2002) revealed that participants in their study made comments relating to masculinity spontaneously without being prompted. Other studies noted how men's language reflected their own views of masculinity, as they would often use words associated with hegemonic masculine traits such as strength, or the role of protector and breadwinner (Broom, 2004; Nanton and Dale, 2011). Whilst analysing the data, it was evident that language directly relating to hegemonic elements of masculinity tended to be used more by myself as a researcher, than the men themselves. This was revealing on two levels. Firstly, it revealed a degree of naivety on my part in assuming that all men, regardless of sexual orientation, would instinctively identify with the 'traditionally held' view of masculinity; that being my own entrenched view of the construct. Moreover, when the men were asked how cancer had impacted on their masculinity, some of the men struggled to answer this question, or reframed the question in order to ensure they provided an answer they felt comfortable with. They placed emphasis on the fact that cancer had affected them, firstly and foremost, as human beings. Comments made by the men focused less on the traits traditionally associated with masculinity, and more towards aspects of identity, which were congruent with their own personally held views. Hence, although past research on masculinity has revealed differences amongst men from ethnic groups, e.g. Nanton and Dale (2011); Jones et al. (2011) the findings from this study suggest that unique aspects of sexual orientation may also influence how men choose to portray themselves, which may impact on the importance they place on certain types of treatment.

The notable absence of references to hegemonic masculinity and the men's own interpretation of what it was to be a man with prostate cancer was also revealing as it gave an insight into how the men chose to define themselves. From a Heideggerian perspective,

it would seem that the men were choosing to be authentic (Heidegger, 1962). When Heidegger talks about the authentic versus inauthentic self, he is referring to an individual's choice not to be directed towards the things which concern others, but towards their own way of existing (Polt, 1999, p.61). As the men in the current study were openly gay and proud of their sexuality, this may explain why they felt less inclined to conform to the hegemonic traits that are commonly found within the narrative accounts of heterosexual men with prostate cancer. The findings also suggest that attempting to define the term masculinity is, as Connell (2005) posits, fraught with difficulties, given that it is culturally derived.

#### **6.4. Seen but not heard: Negotiating heterosexism and the taboo topic of sex**

The findings revealed that the men experienced both positive and negative encounters within health care settings as a result of their sexual orientation. When the participant's sexuality was acknowledged and accepted by health care providers, the men conveyed a sense of relief and to some extent, gratitude, for not being misunderstood or at worse, judged. One of the participants in the present study, who described having gender dysphoria, recalled how he enjoyed the conversations he had with his female consultant, as she expressed an interest in the potential benefits he experienced as a result of the hormone drugs he was required to take. For this man, recognition of his 'otherness' resulted in him feeling that he had been valued as an individual. This finding draws attention to the fact that the continuum for sexual orientation is complex, as this participant did not want to 'fit' into a label. Moreover, a study of transsexual women with prostate cancer by Wasserug and Gray (2011) serves as a reminder that there are different groups of individuals who may experience prostate cancer in a unique way.

Filiault et al. (2008) reported that the gay men in their study felt a sense of 'not belonging' in some health contexts. However, the frustration felt by men in this study was directed

more towards individuals as opposed to places. This may be due to the fact that the men in Filiault's study were not open about their sexuality to their health care providers. Hence, this may have led them to assume that places, as opposed to people were generally unaccepting. In contrast, the men in the present study were openly gay men who attributed heteronormative attitudes to individuals. Consultants were frequently perceived to be those who made assumptions about the men. However, whereas some simply assumed the men were heterosexual, those who the men shared their sexual orientation with were then prone to making assumptions based on their own stereotypical perceptions of gay men. When assumptions were made at inopportune moments, such as during trans-rectal procedures, a sense of trust was perceived as being breached and perhaps different types of interpersonal boundaries from those described by Kelly (2009), were crossed due to the recognition of 'difference' between the two individuals. Moreover, Broom (2004) suggested that heterosexual men may associate trans-rectal procedures with homosexual activity. Whilst some of the men in this study acknowledged that the physical nature of the procedure itself was not as distressing, given their sexual practices, the psychological experience was still experienced as embarrassing; especially when it was assumed that as gay men, they should "not find it a problem".

Fish (2006) has written extensively about heterosexism within health and social care. In addition to highlighting the barriers that LGBT people face due to a lack of specific information about their needs, Fish also highlights the harmful impact that heterosexist assumptions can have on individuals who have to constantly gauge what they feel they can or cannot say to their healthcare provider, for fear of receiving a neutral or negative response. She goes on to state if patients feel that they will receive a negative response, they are far less likely to disclose their sexual orientation. The findings from the present study strongly resonate with the writings of Fish (2006), as although the men in this study

were happy to disclose their sexual orientation to medical staff, they often expressed regret at having done so.

The findings also revealed that health care providers were reluctant to engage in open conversations about issues of a sexual matter, despite the men's attempts at initiating these conversations. However, this issue is not one that is just confined to gay men. Previous and more recent studies have highlighted the need for more open discussion about sex in the context of illness and particularly in the context of prostate cancer, where erectile dysfunction is common (Ervik et al., 2010; Letts et al., 2010; O'Brien et al., 2011). The reluctance of some health care providers to initiate discussions around the taboo topic of sex has been examined in previous literature. A study by Forbat, White, Marshall-Lucette and Kelly (2011) revealed that healthcare professionals are generally reluctant to raise the topic with patients for several reasons. They point out that busy workloads may prevent healthcare professionals from engaging in such conversations and, suggest that additional support may be necessary to help them to broach issues that they may find embarrassing. The findings from this study support this suggestion and highlight the need for any type of support to reflect the needs of gay men. Moreover, given the Government's plans to eventually extend sexual orientation monitoring across the whole of the NHS, the findings suggest that this will only be successful if healthcare providers find effective ways of demonstrating genuine inclusiveness towards LGBT patients.

### **6.5. For better or for worse: Changing relationships**

The findings revealed that for some men, prostate cancer is a shared experience. This was evident though the way that partnered men spoke about the impact of their disease on the men they shared their lives with. This, in turn, affected their outlook on life and how they reframed the changes to their relationship. Unpartnered men shared their hopes about meeting new companions and lovers who would accept them for who they were now, as

some men perceived there was an element of stigma in having prostate cancer. Their fears of not living up to the expectations of other gay men sexually were also realised as some men wondered if they would now be perceived as less valuable, given the changes to their sex lives. These findings echo the concerns of both gay and heterosexual men within several studies that have explored the impact of prostate cancer on relationships (Bertero, 2001; Navon & Morag, 2003; Letts et al., 2010; Kazer et al., 2011). However, the findings particularly resonate with past literature that has included gay men within their samples (Fergus et al., 2002; Filiault et al., 2008).

### **For better...**

The dyadic nature of prostate cancer between heterosexual couples has been well documented in past literature. Fergus (2011) explored the corporeal impact on what she described as 'the communal body' of couples with prostate cancer. This study highlighted how each partner's identity and sense of self were intricately tied. This was certainly true for the men in this study for those whose relationships remained intact. The men's partners were conveyed as anchors, and offered a sense of stability and normality to the men in what was a turbulent and confusing period within their lives. Participants who reported that their relationships had been strengthened as a result of their cancer experience appeared to renegotiate and reaffirm their roles with each other at various stages of the disease trajectory. Hence, time played a role in helping the men to reflect and prepare for the next part of the journey that lay ahead.

The men's capacity to enter into open and honest conversations with each other helped each partner to accept their current situation, especially when issues of a sexual nature needed to be addressed. This finding diverges somewhat from those found in previous studies whereby men are often embarrassed to talk openly to their partners about impotence (Letts et al., 2010). Rather than simply accepting that sex was now something that had to be relegated to their past, the men were open to finding ways of adapting their

sex lives. A third of the men in the present study revealed how they attempted adapt their sex lives by considering inviting a third person to become involved in some of their sexual activities. However, whereas two men had already put this into action and reported that it had enhanced their relationships, two men spoke about this scenario in terms of it being a last resort they were willing to arrange for their partners, if it meant that they would not then have to look for sex outside of the relationship. These findings concur with those reported in a recent study which explored the experiences of three gay couples' concerning sexual dysfunction after radical prostatectomy (Hartman et al., 2014). The study found that two of the couples they interviewed had also opened up their relationships as a way of keeping their sexual relationship intact. This notion has been described in past literature about gay couples which have challenged the ambiguous role of monogamy in gay relationships in relation to prostate cancer (Blank, 2005; Asencio, Blank, Descartes & Crawford, 2009). Moreover, as some of the men in the present study spoke candidly about using openness as an adaptive strategy, these findings support the views of research that has explored this topic in other illness contexts, such as HIV, e.g. Hoff and Beougher (2011).

Findings from a recent Australian study revealed that non-heterosexual men living with erectile dysfunction following prostate cancer treatment were more open to the notion of being more flexible in terms of their sexual practices (Dowsett, Lyons, Duncan & Wasserug, 2014). The authors found that some men who had previously adopted an insertive role during anal sex were able to shift to a receptive role. This meant they were still able to re-establish a sex life that was not dependent on them having an erection. Another important finding from this study was the use of flexibility in sexual practice by heterosexual men. Seven percent of heterosexual men surveyed revealed that they had also practiced anal intercourse following prostate cancer treatment. Hence, this finding perhaps challenges the widely held assumption that the practice of anal intercourse is only enjoyed by non-heterosexual men.

The unique ability to be able to separate sex from those emotions that may traditionally lead to a sense of jealousy within heterosexual dyad may also be as a result of the men's shared existence. The notion of a shared existence amongst the men and those they shared, or had shared, close intimate relationships was evident in the way they spoke about how HIV had impacted on their past and current relationships. Although two men in this study were HIV positive, HIV still featured in their lives as some had partners or close friends with the disease, or had been in relationships with partners who were HIV positive, yet they expressed a genuine need to look after each other. Previous literature suggests that gay men have developed resilient coping skills as a result of caring for others with HIV and based on their history as gay men who, to some extent, have had to deal with much oppression throughout their lives (Munro & Edward, 2008), Hence, the dominant presence of HIV in some gay men's lives more widely may better prepare them for meeting the needs of each other when prostate cancer strikes.

#### **For worse...**

Although several men spoke about how their relationships were enhanced as a result of their cancer experience, contrasting findings revealed how the strain of living with cancer had negatively impacted on their relationships. Three of the men's relationships had broken down since developing cancer and another man revealed that he and his partner had experienced communication difficulties effectively with his partner since being diagnosed. The breakdown of relationships for two of them men was due to the perceived lack of emotional or practical support from their partners. This was demonstrated through their partner's reluctance to engage in conversations about the fears and emotions they were experiencing, or their partner's unwillingness to accompany participants to hospital appointments or treatment sessions. Hence, this resulted in men feeling isolated, rejected

and bitter that their partners either could not, or would not, identify with what they were experiencing.

Although partners were not interviewed as part of this study, it is worth considering why men's partners were unable to provide the support to their partners they so desperately wanted and needed. Firstly, they may simply not have been prepared to step into the informal carer role that so many wives and spouses adopt automatically when their husbands are diagnosed with prostate cancer. The role of wives and female partners is well documented in past literature and they are widely considered as being the cornerstone of the men's care (Ervik et al., 2010; Hagen Jones et al., 2011; Nanton & Dale., 2011).

Moreover, the stressors associated with this caring role have also been widely acknowledged in prostate cancer literature where it has been suggested that wives and partners may also need support during their husband or partner's cancer journey (Resendes &McCorkle, 2006). However, as most literature relating to the caring role in the context of prostate cancer literature, centres reflects the dynamics of female-male dyads, it may be inappropriate to assume that the findings from the main body of carer literature in relation to cancer easily translated in the context of caregiving within male dyads.

Secondly, two of the men whose relationships had broken down were HIV positive – as were their partners. Hence, although the extent to which this may have been a factor was not explored further in the interviews in this study, the impact of living with two chronic diseases may have been a contributing factor as to why the men's partners were not able to support the secondary needs of additional disease. Further research is clearly warranted concerning this issue, particularly as the population of men with HIV over the age of 50 is increasing each year, due to the success of antiretroviral drugs (Joseph Rowntree Foundation, 2010). Hence, it is likely that a significant number of these men will also have to face the challenges of being diagnosed with prostate cancer in the future.

For those men who were un-partnered in the present study, contemplating future relationships meant wondering whether they would be accepted or rejected by potential partners as a result of not being able to live up to their perceived expectations in terms of sex. Some men described how the physical presence of erections was a necessary and demonstrable way for them to interact within the gay scene. Hence, whereas past literature suggests that men use hegemonic traits to hide sexual problems, e.g. Navon and Morag (2003), this is more problematic for gay men where the visibility of sex may be used as gain initial access to other men. Moreover, the value placed on ejaculate was high for the men in this study compared to the general findings within the literature review. The men in the current study emphasised that ejaculating had been a way of expressing satisfaction to their partners. Hence, there was a deep sense of loss for those men who experienced 'dry orgasms'. This finding resonates with past research which has explored the significance of semen for gay men. Several studies have argued that actual exchange of semen is integral to their sense of self and is symbolic of intimacy and social connection (Prestage, Hurley & Brown, 2013). This may explain why so many men in this study and the gay man in a study by Kelly (2009) were so reluctant to undergo procedures that would, in essence, eradicate an integral part of themselves. Hence, these findings perhaps highlight why it is important for health care providers to recognise the significance of these cultural factors when men are making decisions concerning treatment.

## **6.6. Brothers in arms: The role of kinship and 'family' support**

### **Kinship and community**

The findings revealed that the men drew upon an eclectic network of individuals for support, from both within and outside of the gay community. The utility of peer support and support groups was discussed in several studies within the literature review, which

suggested that men's decisions to attend support groups are influenced by several factors (Heidesteg, 2005; Kelly, 2009; Ervik et al., 2010). Nevertheless, regardless of what support sources were available to the men in this study most men in this study expressed a deep need to have contact with other gay men who had experienced prostate cancer. The findings from this study resonate most with those reported in Wallace and Storm's (2007) study, in which some men described themselves as belonging to a 'subculture' of other men. However, whereas the men in Wallace and Storm's study conveyed the need to belong to a subculture based on the commonality of prostate cancer, it was equally important for the men in the present study to belong to a subculture based on the commonality of gay identity.

Although nearly all of the men in this study accessed mainstream support groups, their descriptions of their experiences within these groups revealed that they did not identify with those in attendance. Their descriptions of the men who attended these groups clearly highlighted how they saw themselves as being different; not just in terms of attitude, but also in terms of being physically different. Despite sharing space with men of a similar age group, the men in the present study felt that a generation gap existed between themselves and the other men. Instead of inhabiting in a space which would allow them to be 'open' about discuss their fears and concerns, these spaces were conveyed as 'closed'.

Interestingly, the men in this study noticed differences, but overlooked similarities. For the men in this study, the only commonality they had with the other men was their diagnosis of prostate cancer.

There are several reasons as to why the men in this study experienced a deep sense of 'not belonging' (Filiault et al., 2008) in mainstream (and predominantly heterosexual) support groups; Firstly, the presence of female spouses, combined with language which was underpinned by heterosexist norms appeared to lead some men to believe that this

environment excluded them. Secondly, the sense of otherness towards other men present within the group experienced may have been as a result of their own preconceptions about heterosexual men; a finding which is supported by a recent study that explored the role influence of sexual orientation within support groups more widely (Provence, Rochlen, Chester & Smith, 2014). The findings from this particular study revealed that gay men identified feelings of heterophobia and distance prior to attending the group, which influenced their perceptions, expectations and likelihood in participating. The authors revealed that several factors underpinned the men's attitudes which commonly included past homophobic experiences. They were also fearful that they would be stigmatised upon disclosing their sexual orientation as this was perceived to be another 'coming out' process for some men which is often a notably difficult time for gay men and has a long-lasting impact on many aspects of their lives (Alderson, 2000; Clarke, et al., 2013). These are important findings, and extend beyond the context of prostate cancer. Given that so much emphasis is placed on the value of peer support following a cancer diagnosis, it may be important for support group leaders to better understand how factors relating to sexual orientation can impact on how support is delivered and received. By acknowledging *why* some men may experience heterophobia, this may be result in better group adherence for LGBT patients more generally.

Another explanation may centre, once again, on the notion of shared identity. Research on support groups more generally has identified that diseases which are considered to be stigmatising are generally more well attended than those which are less stigmatising, but more prevalent. A study by Davison et al. (2000) reported that people with AIDS were 250 times more likely to attend support groups than those with e.g. hypertension, which is far more common. The authors' explanation for why so many people attended AIDS support groups, centred on the human need to make social comparisons, a theory put forward by Festinger (1954). Festinger's theory posits that in the absence of expertise, patients

compare similarities and differences between themselves and others, as a way of making judgements about their own status. If this theory is applied to the current study, it may be that the gay men who attended heterosexual support groups were only able to compare differences rather than similarities. This may partly explain why it was so important for them to seek out men they were able to compare themselves to in terms of equal weighting. Moreover, it is also worth considering why kinship and a sense of belonging amongst others may be determining factors for groups to elicit positive support amongst those they are designed to help.

In order to understand why having a shared sense of identity in terms of sexual orientation may be so important, when faced with a disease such as prostate cancer, it is useful to compare the findings from the current study with those found in a study by Persson and Richards (2008), which explored how heterosexual men and women coped with living with HIV. The findings revealed that perceived stigma and a lack of cultural resonance about HIV within the heterosexual community, led to them feeling ostracised. In turn, support within the wider HIV community was not adequate. The HIV community was perceived as 'alienating' due to the language, imagery commonly used within the HIV sector, and the dominant focus on LGBT communities and practices. Paradoxically, the authors suggest that their participants were, in many ways, 'in the closet' – a representation commonly associated with homosexuality, and its denial, as a result of persecution. Whilst the authors of the study did not set out to look at the potential value of culturally supportive spaces for this marginalised group, their interpretation of the findings using Michael Foucault's notion of 'heterotopia' is one that could be applied to those in the present study that relate to the men's search for kinship and community.

Heterotopia is a term originally derived from the study of anatomy and referring to parts of the body that are 'out of place'. Merleau-Ponty's concept of spatiality relates to embodied

experience of space, whereas Foucault's concept of heterotopia related to spaces or worlds of 'otherness'. For Foucault, heterotopias are real and physical interpretations of utopian spaces that exist within society; distinguished by their difference from the social world and the social order within it (Hetherington, 1997). Heterotopias for the heterosexual participants in Persson and Richard's study were portrayed as micro-worlds or cultures, in which they personally inhabited both temporally and spatially. Permission to access these worlds however, was based more on trust amongst the participant's personal and professional connections and less on the need for shared identity. In contrast, the findings from the present study suggest that shared identity is a central component of the heterotopic world of gay men with prostate cancer. Moreover, unlike the participants in Persson and Richard's study who did not seek to find a united heterotopic space for themselves as a group, the participants in the present study sought to create one of their own. Hence, the following section shares some parallels with Searle's phenomenon of collective intentionality, a state whereby individuals share intentional states such as beliefs, desires and intentions (Searle, 1995, p. 23). Such capacities can then lead to collective action whereby collective goals are set and the collective will work to achieve.

Almost 18 months after this study began, the first British support group for gay and bisexual men with prostate cancer was launched in Manchester. This group was formed after several gay men, who had personal or indirect experience of prostate cancer, made contact and agreed that peer support delivered within their own social milieu, would help to foster the conditions necessary, in order for a support network to be effective.

Due to the nature of my research and the previous contact I had with those who had put the group together, I was invited to their first meeting. This took place within an LGBT organisation and although initially apprehensive about encroaching on their space as a heterosexual female, I was accepted by the group members as someone who understood

their desire for kinship. During this meeting, there was an outpouring of emotion from the men who attended, some of whom had travelled several hundred miles to experience this sense of kinship. There appeared to be a sense of relief amongst the men as they spoke candidly and openly about past and on-going issues they were experiencing; not only as a result of prostate cancer, but as a result of being a gay man living with the disease.

Conversations in relation to aspects of gay culture were implicitly understood amongst the men who could readily identify with each other's experiences. The immediate benefits for men attending this group were tangible.

These findings highlight that men with prostate cancer are not a homogenous group and less so within the context of peer support groups. Group settings may emphasise this and social comparison theory may go some way in explaining why group dynamics within self-help groups have to meet certain conditions if support is to be given and received. Men's cancer experiences are inextricably bound to their culture. Hence, it appears that support has some value when it can be delivered within the context of that culture. They also highlighted the difficulties gay men faced in terms of accessing relevant types of peer support, and why extra measures, such as adequate sign-posting, may be necessary to ensure gay men, their partners, or their chosen family networks, receive the type of support they deem to be useful following a cancer diagnosis.

### **The importance of 'family'**

The findings highlighted the important role ascribed to the men's friendships or, as one man described; "*family*". This term was used to describe friends who were like family; who were deemed to be as important as family, with the only difference being, that these people were chosen members of the men's families, as opposed to those prescribed by lineage. Contrary to the findings from previous research which appear to suggest that heterosexual men are reluctant to seek out support from their friends, in order not to

appear weak (Olliffe, 2006; Navron & Morag, 2003; Gannon et al., 2010), the friends of men in this study were relied upon for practical and emotional support. The men were not afraid to ask for support from this important source and this was reciprocated whenever possible. The important role of non-familial support networks for gay men has been highlighted, primarily in the context of HIV. In one report, which examined the impact of HIV on older adults, friends were cited as the primary source of support for gay men (Karpiak, Shippy & Cantor, 2006). However, as the carers in this particular study were also more likely to have a diagnosis of HIV themselves, informal caregiving placed additional demands on these men. Hence this relates to an earlier discussion as to whether prostate cancer is a demand too many for some men who are living with HIV.

The men in this study were more likely to turn to 'Family' as opposed to some blood relatives when revealing their cancer diagnosis as many of the men were quite secretive about who they shared their diagnosis with. Past literature in relation to issues that prevent men from disclosing they have prostate cancer have revealed that they often choose not to disclose, as a way of retaining normality, this appeared to be for the sake of others as opposed to themselves (Fergus et al., 2002). Some men in the present study chose not to disclose their diagnosis to family members, as a way of protecting them from worry. Elderly parents and close relatives were often shielded. Hence, men used their friends as a way of unburdening their load. On the other hand, some men simply thought that cancer was a private matter. A study by Navron and Morag (2003) which explored the experiences of heterosexual Israeli men with prostate cancer found that men chose not to discuss problems relating to their disease with other men due to a desire to conform to hegemonic traits. The men in the Navon and Morag (2003) study used impression management strategies to avoid being seen as weak or less manly in front of friends, thereby putting the needs of others before themselves. However, the men in this study also chose to be secretive about their diagnosis in order not to be stigmatized by their

peers. This was especially true of those men with an existing diagnosis of HIV, or those who suspected that others may assume that being gay was a factor for them developing prostate cancer. Given that there stigma is often experienced amongst men who are HIV positive in the gay community (Smit et al, 2012), it is perhaps not that surprising that some men were afraid of being doubly stigmatized

These findings suggest that friendship dynamics, or 'families of choice' (Clarke et al., 2013) are unique for men in the gay community in that they appear to offer similar levels of support as that found within close families. However, the levels of burden placed upon these individuals may be much greater. Hence, further research may help to uncover whether this group of invisible carers may also have support needs when supporting men with prostate cancer.

### **6.7. Finding the rainbow: Looking beyond cancer**

Past research into the adaption process following a diagnosis of prostate cancer has revealed how many men use adaptive strategies to find a way of moving forward in an attempt to find some meaning from the experience (Kelly, 2004; Hagen et al., 2007). One of the most striking features of the findings was the men's resilience, and their ability to recognise that whilst cancer may have altered the way they perceived themselves, it did not define them. They had a unique ability to reframe their past negative experiences as life-lessons for the future, although the process for this to take place required time and work on the men's part. This was a temporal process which often entailed the men reconciling some aspects of their past which they had not felt able to deal with prior to their cancer diagnosis. For some, this meant revisiting their lives prior to them coming out as gay men, for others it meant accepting that some of their feelings associated with stigma were as a result of their past conflicts resulting from internalised homophobia.

Nevertheless, regardless of the men's pasts, there was a clear sense that the men knew

that in order to contemplate their future, they had to find a way of fusing cancer into their present lives.

From a Gadamerian perspective, it could be considered that some of the men experienced a 'fusion of horizons'. Gadamer believed that understanding happens when our present understanding (or horizon) is moved to a new understanding (or horizon) by a particular encounter. Hence both horizons fuse into something of living value (Gadamer, 2004). This was clearly a valuable process for the men who took part in this study. By verbalising their thoughts during their interview, a 'new horizon' was sometimes adopted as some men appeared to gain a further sense of clarity about their situation or suddenly realised as one participant (Matthew) did, how he actually wanted to move his life forward. By applying Gadamer's theory to interactions that take place within healthcare settings, Fergus (2011) suggests that a similar level of understanding between patients and healthcare professionals could be achieved. Thus, enabling patients to find ways of looking ahead following their cancer diagnosis as opposed to looking back.

## **6.8. Implications for health care practice**

In order for health care professionals to be in the best position to offer advice tailored to the needs of gay men, it is important that they are aware of a patients' sexual orientation. Hence, plans that are underfoot by the government to introduce sexual orientation monitoring across all health trusts (Stonewall, 2014) are clearly warranted and should be implemented sooner rather than later. Moreover, in the event that all NHS trusts do implement monitoring, it is inevitable that some patients will still not feel comfortable enough to disclose their sexual orientation. Within the context of prostate cancer, it is important that healthcare providers work towards cultivating an inclusive environment in which gay men would be more likely to disclose, or discuss issues of concern relating to their sexuality. This means that a training package may need to be designed and

implemented to ensure that all staff members, regardless of their position, are aware that they have a duty to ensure they promote inclusiveness to all patients, and suspend any personally held judgements they may hold during professional interactions. Training could incorporate workshops and role play scenarios, specifically designed to help individuals become more aware of how their attitudes, language and non-verbal gestures can directly influence a patient's experience.

Promoting an inclusive atmosphere may mean that health professionals, including consultants and urology nurses, who are specialise in issues directly related to prostate cancer, may need to be better educated on issues that affect LGBT patients and their partners, to ensure that patient centered care, as per the NICE guidelines, is adhered to. Specific health Issues affecting LGBT populations could also feature more prominently during the course of student medical and nursing training. Including topics about these issues on examination papers may also mean that students would be less likely to skip recommended reading around this issue and be better prepared for dealing with LGBT patients that they deal with in the future.

Promoting an inclusive atmosphere could also include ensuring that there are sufficient sources of printed information available for gay men who do not wish to verbally discuss their sexuality. However, this may mean that health trusts may have to rethink how health promotion information is produced and subsequently displayed. For example, a simple solution would be for clinical departments to display posters that let men know that they are a gay friendly organisation. However, posters designed to relay messages regarding prostate cancer could use more inclusive imagery. They could also include persuasive health messages that encourage gay men to ask their health care providers how prostate cancer may affect some aspects of their lifestyle. Leaflets or booklets about prostate cancer should include specific advice that is relevant to gay men following biopsies e.g. when to

resume anal sex. Healthcare providers need to ensure they direct men to culturally relevant sources of support e.g. support groups, forums etc... For example, Prostate Cancer UK have now included an information page on their website specifically for gay and bisexual men with prostate cancer and since published an accompanying booklet that can be obtained free of charge (see Appendix 14). Alternatively, men could be signposted to one of the three support groups specifically created for gay and bisexual men in the UK. Those who do not live in the vicinity of the groups could be given their website details to connect with other men on their online forum.

Issues concerning the potential impact of prostate cancer on all aspects of sexual function should be raised by the health care provider as a matter of course. Although this is an issue that is being tackled more widely in other domains of health, it should be a non-negotiable topic in respect of prostate cancer and other urological cancers where sexual function is directly affected. Enhanced training to help health care professionals feel more comfortable and confident about raising the issue of sex should be considered, particularly around taboo issues such as anal sex as this is a sexual practice that is not exclusive to the gay community.

Third sector organisations who provide services for LGBT people could follow the lead of The Lesbian and Gay Foundation (LGF) by creating additional sources of support for men with prostate cancer. This could be by way of setting up a regular support group meeting, or perhaps implementing a 'buddy system' for those who are unable to attend groups. This would entail setting up a peer mentor system were men were able to contact each other by telephone or email in confidence. Moreover, given the prevalence of prostate cancer, LGBT organisations should do more to make it more visible within their publications so that men are more aware of the symptoms of the disease and what to ask their GPs if they are worried about the disease.

## **6.9. Implications for improving policy**

Policy guidelines and specifically those published by NICE should ensure that sufficient information is made available to gay men, bisexual men or men who have sex with men (MSM) concerning several aspects of their care. This advice specifically relates to those points found within section 1.1: Information and decision support for men with prostate cancer, their partners and carers of the NICE 2014 Guidelines for Prostate Cancer which emphasises patient centered care and outlines that men should be given information tailored to their needs and advice on how to access support groups. The current guidelines still fail to acknowledge the potential impact on men as a result of their sexual orientation. Whilst health care providers clearly strive to be inclusive, and demonstrate equality through the correct use, or absence of labels or terminology, the findings from this research suggest that the term 'equality', may serve to be unhelpful in certain context of prostate cancer care as the findings from this study as it confirms the misconception that men are a homogenous group. Although men should be treated with equal respect and care, they findings highlight that they do have some concerns that may need to be acknowledged separately from those of heterosexual men. Hence, it is imperative that the NICE guidelines for prostate cancer outline why it is important to treat gay men, based on their individual needs and endeavour to meet them.

Current guidelines and briefings regarding treatment and aftercare need to state that issues of a sexual nature, should be raised with patients, both prior to and following trans-rectal procedures. This will ensure that they are given ample opportunity to voice any concerns they may have with their health care providers, in relation to aftercare and resumption of sex, regardless of whether this is vaginal or anal sex and regardless of their sexual orientation.

Policies, such as The National Cancer Equality Initiative (2010) and the NCSI should recognise that there are some contexts in which health information specifically targeted to LGBT patients, such as the issues that have been outlined within this study, is wholly necessary. The Equality Act (2010) also needs to acknowledge the unique role of carers in male dyads and do more to identify practical ways in which health care and support services can better identify and support those that may have health problems of their own, as a result of chronic illnesses such as HIV, but are concerned about discrimination. Policies such as the Department of health briefings on equality and diversity (DOH, 2007) should include specific briefings on diseases such as prostate cancer, where there is evidence to suggest that specific differences may be reported or experience during the disease trajectory, as a direct result of an individual's sexual orientation. Future policies that are developed between the government and the third sector could consider developing educational material relating to prostate cancer or cancer more generally that specifically targets men in the gay community. This would include the use of colloquial language and imagery as a salient way of raising awareness of the disease amongst members of the gay community.

### **6.10. Unique contributions of the study**

The study had made a unique contribution in terms of what it adds to the existing body of prostate cancer literature and extends what is currently known about the experiences of gay men with prostate cancer. It also adds to the body of psycho-oncology literature which has already started to acknowledge the importance of exploring and reflecting the unique needs of non-heterosexual populations in relation to various types of cancer. The study makes an important contribution to the body of literature concerned specifically with sexuality and cancer by highlighting some of the factors which may need to be taken into account when gay men undergo treatment for cancer as opposed to heterosexual men. It

also adds to the body of cancer survivorship literature and associated policies that have previously outlined a distinct lack of research on marginalised groups.

The study has made a unique contribution to LGBT literature in relation to health and ageing and underscores the need for individuals working with men with HIV to be mindful that prostate cancer may place additional burdens on those with a HIV diagnosis, or who may be looking after someone with a HIV and prostate cancer diagnosis.

The study has also made a unique contribution to research by reflecting the various ways researchers can access groups that are considered as being 'hard to reach'. Although social networking sites such as Twitter have not been widely used in terms of advertising and recruiting participants for research, the use of it in this study demonstrates the potential such sites have in helping to reach large groups of people across the country and indeed across the globe that may not be accessible by any other means.

### **6.11. Strengths of the study**

This is one of the first in-depth studies to explore the experiences of gay men with prostate cancer in the UK. As such, it offers perspectives from a broad age range of men who have experiences of being patients in the current Government's national healthcare system, as opposed to alternative types of health care systems in Westernised countries, such as the USA or Australia. By adopting a phenomenological approach to explore the lived experience of gay men with prostate cancer, this study was able to provide an in-depth and embodied account of what living with this disease meant to this group of men. Moreover, as the study was conducted with gay men from different regions within the UK, the findings offered diverse and contextual perspectives which served to accentuate the essence of the phenomenon being sought.

One of the main strengths of using a phenomenological approach and a flexible interview structure, as opposed to qualitative approaches that utilise a more structured forms of questioning, was that it enabled the participants to give a personal account of what they deemed to be important in respect of prostate cancer, as opposed to any presumptive notions held by the researcher. Hence, as a cultural 'outsider' exploring a relatively unexplored area, many of the topics the participants chose to bring into the interview may have been overlooked or omitted, if a more prescriptive approach had been chosen. I also consider that my status as a heterosexual female, researching the lives of gay men was a strength of this study. As well as aiding the bracketing process which is borrowed from Husserl and a central component to van Manen's approach, it also meant that I was less likely to overlook implicit meanings that a cultural 'insider' may have. Given the interview style adopted for phenomenological research, the men's interviews were unstructured enough to allow them to share their experiences in a way that felt natural to them. As a researcher, allowing oneself to be taken on a journey through another's lived experience, from the beginning to end, helps when attempting to relay the essence of that experience to others.

Furthermore, as all but one of the men were interviewed alone, they were able to describe the impact of cancer on their relationships without fearing how their partner might react. Using the existential framework of Merleau-Ponty, when analysing the data, helped to draw attention to the multiple facets of Dasein, that, as humans, we are too busy to recognise in ourselves, despite their immeasurable effect on our psyche.

### **6.12. Limitations of the study and recommendations for future research**

One of the obvious limitations of this study is its small sample size. Although phenomenological studies, like other qualitative approaches, do not attempt to generalise their findings (Benner, 1994), it would be interesting to determine whether the findings

reflect the issues of gay men on a broader scale. For this reason, it would be useful to undertake a national survey. This could help to determine whether there specific issues affect men in different parts of the country, e.g. urban areas, or whether ethnicity poses any unique challenges. Moreover, an anonymous survey may help to capture the views of older gay men still prefer to remain silent about their sexual orientation on account of the persecution they may have experienced when homosexuality was viewed as a crime. Given that prostate cancer affects so many older men, it is perhaps even more pressing that researchers find an acceptable way of obtaining their views. The demographic information gathered from a survey method could also help to pinpoint specific areas within the UK where support groups could be implemented or determine whether a 'buddy system' whereby men could contact each other through other means was feasible. Furthermore, as this field of research is of interest to researchers in other parts of the world, a larger international study incorporating a quantitative element may now be more feasible than when it was anticipated at the outset of this study.

The sample characteristics of the participants in this study could also be a viewed as limitation, in relation to the phenomenon that has been reflected in this study. All of the participants were white, openly gay, Caucasian men and were financially independent. Hence, the experiences of gay men from black and ethnic minority groups, or those from different social backgrounds have not been reflected. Furthermore, the experiences of bisexual men and transsexual women were not captured. Although the UK is multicultural and accepting of differences relating to race, religion and sexual orientation, men from the 70 countries throughout the world where homosexuality is still illegal and, in eight countries, punishable by death, may face the added problem of gaining relevant types of support from within their own communities. Future research could explore the most appropriate ways of accessing gate keepers to these groups and sensitive ways of recruiting and engaging with gay men within these groups. As some BME groups are more prone to

developing prostate cancer, it is particularly important that their experiences are recognised and reflected within prostate cancer literature.

This study has highlighted that the use of labels to describe sexual orientation may be problematic when conducting research, in terms of who may, or may not, identify with those labels. Researchers need to find innovative ways of ensuring that potential participants are not excluded from taking part in research aimed at improving their cancer experience. Employing a methodological approach, e.g. action research, whereby participants and providers of care are actively engaged in the research process, may offer a solution to this problem. As action research involves consulting participants at each stage of the research process and actively working with them at various phases, this could help to ensure that research is conducted sensitively, and in a way that is culturally acceptable to those being studied.

Another limitation was the absence of those individuals who inevitably helped to shape the participant's lived experience. Although only one interview in this study was conducted with the man's partner present, it introduced an interesting dynamic to the interview, in terms of what was revealed by the participants and possibly concealed. Moreover, as the participants expressed the ways in which cancer had impacted on their partners and their relationships, future research that includes partner perspectives may help to shed more light onto how male dyads cope when one, or perhaps both men are diagnosed with prostate cancer. Interviewing health professionals who care for men with prostate cancer should also be explored. If communication between gay men and healthcare providers is to improve in the future, it will be necessary to determine what the current barriers and challenges that prevent adequate communication between the two parties are, and how they can be better addressed. Insights from both carers and health professionals would provide a holistic account of the prostate cancer for men in the gay community.

Finally, although I personally considered that being a cultural outsider whilst conducting this type of research may be advantageous, in terms of uncovering implicit norms, or everyday experiences that cultural insiders may take for granted, I do also acknowledge that there are some limitations to this status. Past research highlights the benefits of having inside knowledge as a researcher (Meezhan & Martin, 2009). Hence, it is difficult to know whether a researcher who had inside knowledge or identified with the participants would have been privy to parts of the men’s experience that I was not. I also accept that my own preconceptions and female status may have also influenced how the men interacted with me and what they chose to share. It will be of interest to compare the current study’s findings with future studies whereby the researcher has a cultural advantage. Studies of this nature may offer insights into how both roles can be improved upon when conducting research with groups that are perceived as being ‘hard to reach.’

### **6.13. Plan for dissemination of findings**

The findings of this study will be shared with national and local organisations, charities and support groups, from which participants were recruited, by way of a short report and summary of the findings. A copy of the report will also be sent to those participants who expressed an interest in receiving one following completion of the study. This report will be available by July 2015. Where it is feasible to do so, the findings will also be presented in person.

The findings of this research will also be disseminated in peer reviewed publications in academic journals and it is anticipated that between four and five articles will be subsequently produced by 2018. These are outlined as follows:

<b>Article content</b>	<b>Intended audience</b>	<b>Timeframe following PhD completion</b>
Findings of the study	NHS stakeholders, health care professionals, policy makers, researchers, patients	12 months

Article content	Intended audience	Timeframe following PhD completion
Literature review	Researchers, health care professionals, policy makers	12-18 months
Choosing an appropriate qualitative appraisal tool	Researchers, students	18-24 months
Methodology: Recruiting 'hard to reach' groups	Academics	18-24 months
Gay masculinity and prostate cancer	Researchers, patients, health care professionals, policy makers	24-36 months

Finally, as the findings of the study are of key importance to the NHS and associated stakeholders, abstracts will be submitted to national and international conferences associated with cancer care and survivorship. A list of current published abstracts and oral / poster presentations resulting from this study can be found in Appendix 15.

#### **6.14. Conclusion**

This study has provided a rich insight into how gay men with prostate cancer experience prostate cancer. This was the first in-depth study to be undertaken within the UK and captured data during an historical era in which gay marriage was legalised and the first ever support group for gay and bisexual men with prostate cancer was created. Since the beginning of this study, research into the unique needs of LGBT patients with cancer has caught the attention of health care providers, researchers and policy makers across the country. In addition, men who I met during the course of this study have empowered themselves by setting up support networks and groups that now also welcome bisexual men and transsexual women. It is hoped that the findings from this study will go some way to reducing inequalities within health care and help to encourage healthcare providers to recognise that experiencing prostate cancer, as a gay man, is a unique experience.

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## APPENDICES

## Appendix 1: TNM Classification for Prostate Cancer

Table 1. TNM Classification for Prostate Cancer

<b>Primary tumor (T)</b>	
TX	Primary tumor cannot be assessed
T0	No evidence of primary tumor
T1	Clinically inapparent tumor not palpable or visible by imaging
T1a	Tumor incidental histologic finding in $\leq 5\%$ of tissue resected
T1b	Tumor incidental histologic finding in $> 5\%$ of tissue resected
T1c	Tumor identified by needle biopsy (because of elevated prostate specific antigen [PSA] level)
T2	Tumor confined within prostate; tumors found in 1 or both lobes by needle biopsy but not palpable or reliably visible by imaging
T2a	Tumor involves one-half of 1 lobe or less
T2b	Tumor involves more than one-half of 1 lobe but not both lobes
T2c	Tumor involves both lobes
T3	Tumor extends through the prostatic capsule; invasion into the prostatic apex, or the prostatic capsule is classified not as T3 but as T2
T3a	Extracapsular extension (unilateral or bilateral)
T3b	Tumor invading seminal vesicle(s)
T4	Tumor fixed or invades adjacent structures other than seminal vesicles (eg, bladder, levator muscles, and/or pelvic wall)
<b>Pathologic (pT)*</b>	
pT2	Organ confined
pT2a	Unilateral, involving one-half of 1 lobe or less
pT2b	Unilateral, involving more than one-half of 1 lobe but not both lobes
pT2c	Bilateral disease
pT3	Extraprostatic extension
pT3a	Extraprostatic extension or microscopic invasion of the bladder neck
pT3b	Seminal vesicle invasion
pT4	Invasion of the bladder and rectum
*Positive surgical margin should be indicated by an R1 descriptor (residual microscopic disease).	
<b>Regional lymph nodes (N)</b>	
<i>Clinical</i>	
NX	Regional lymph nodes were not assessed
N0	No regional lymph node metastasis
N1	Metastasis in regional lymph node(s)
<i>Pathologic</i>	
PNX	Regional nodes not sampled

pN0	No positive regional nodes
pN1	Metastases in regional nodes(s)
<b>Distant metastasis (M)*</b>	
M0	No distant metastasis
M1	Distant metastasis
M1a	Nonregional lymph nodes(s)
M1b	Bone(s)
M1c	Other site(s) with or without bone disease
*If more than 1 site of metastasis is present, use the most advanced category (pM1c).	

Table 2. Histopathologic grade

GX	Gleason score cannot be assessed
Gleason $\leq 6$	Well differentiated (slight anaplasia)
Gleason 7	Moderately differentiated (moderate anaplasia)
Gleason 8-10	Poorly differentiated or undifferentiated

Table 3. Anatomic stage/prognostic groups

Stage	T	N	M	PSA*	Gleason
I	T1a-c	N0	M0	PSA < 10	Gleason $\leq 6$
	T2a	N0	M0	PSA < 10	Gleason $\leq 6$
	T1-T2a	N0	M0	PSA X	Gleason X
IIA	T1a-c	N0	M0	PSA < 20	Gleason 7
	T1a-c	N0	M0	PSA $\geq 10$ but < 20	Gleason $\leq 6$
	T2a	N0	M0	PSA < 20	Gleason $\leq 7$
	T2b	N0	M0	PSA < 20	Gleason $\leq 7$
	T2b	N0	M0	PSA X	Gleason X
IIB	T2c	N0	M0	Any PSA	Any Gleason
	T1-2	N0	M0	PSA $\geq 20$	Any Gleason
	T1-2	N0	M0	Any PSA	Gleason $\geq 8$
III	T3a-b	N0	M0	Any PSA	Any Gleason
IV	T4	N0	M0	Any PSA	Any Gleason
	Any T	N1	M0	Any PSA	Any Gleason
	Any T	Any N	M1	Any PSA	Any Gleason

\*If PSA or Gleason is not available, grouping should be determined by T stage and/or either PSA or Gleason, as available

## Appendix 2: Example of MESH terms used for searching literature and qualitative filter

xpProstatiNeoplasms/  
2prostatecancer.mp.  
3prostatetumour  
4expAdaptation,Psychological/  
5Stress,Psychological/  
6"HealthServicesNeedsandDemand"/  
7NeedsAssessment/  
8SexualBehaviour/  
9"QualityofLife"/px[Psychology]  
10PatientSatisfaction/  
11BodyImage/  
12expSocialSupport/  
13expLifeChangeEvents/  
14expEmotions/  
15AttitudetoHealth/  
16"ActivitiesofDailyLiving"/  
17expSelfConcept/  
18spirituality/or resilience,psychological/  
19livedexperience.mp.  
20spirituality.mp.orSpirituality/  
21psychosocial.mp.  
22need\$.mp.  
23Homosexuality,Male/  
24gay.mp.  
25homosexual.mp.  
26 lgbt.mp.  
27 sexuality.mp. or Sexuality

### Appendix 2.1: Qualitative Filter

28 (((("semi-structured" or semi structured or unstructured or informal or "in-depth" or in-depth or "face-to-face" or structured or guide) adj3 (interview\* or discussion\* or questionnaire\*)) or (focus group\* or qualitative or ethnograph\* or fieldwork or "field work" or "key informant")).ti,ab. or interviews as topic/ or focus groups/ or narration/ or qualitative research

## Appendix 2.2 : Summary criteria for appraising qualitative research studies.

Walsh, D; Downe, S. (2006). Appraising the quality of qualitative research. *Midwifery*. 22(2):108-19.

Stages	Essential Criteria	Specific Prompts
<b>Scope and Purpose</b>	Clear statement of, and rationale for, research questions/aims/purpose	Clarity of focus demonstrated Explicit purpose given, such as descriptive/explanatory intent, theory building, hypothesis testing Link between research and existing knowledge demonstrated
	Study thoroughly contextualised by existing literature	Evidence of systematic approach to literature review, location of literature to contextualise the findings, or both
<b>Design</b>	Method / design apparent, and consistent with research intent	Rationale given for use of qualitative design Discussion of epistemological/ontological grounding Rationale explored for specific qualitative method (e.g. ethnography, grounded theory, phenomenology) Discussion of why particular method chosen is most appropriate/sensitive/relevant for research question/aims Setting appropriate
	Data collection strategy apparent and appropriate	Were data collection methods appropriate for type of data required and for specific qualitative method? Were they likely to capture the complexity/diversity of experience and illuminate context in sufficient detail? Was triangulation of data sources used if appropriate?
<b>Sampling Strategy</b>	Sample and sampling method appropriate	Selection criteria detailed, and description of how sampling was undertaken Justification for sampling strategy given Thickness of description likely to be achieved from sampling Any disparity between planned and actual sample explained
<b>Analysis</b>	Analytical approach appropriate	Approach made explicit (e.g. Thematic distillation, constant comparative method, grounded theory) Was it appropriate for the qualitative method chosen? Was data managed by software package or by hand and why? Discussion of how coding systems/conceptual frameworks evolved How was context of data retained during analysis

		<p>Evidence that the subjective meanings of participants were portrayed</p> <p>Evidence of more than one researcher involved in stages if appropriate to epistemological/theoretical stance</p> <p>Did research participants have any involvement in analysis (e.g. member checking)</p> <p>Evidence provided that data reached saturation or discussion/rationale if it did not</p> <p>Evidence that deviant data was sought, or discussion/rationale if it was not</p>
<b>Interpretation</b>	Context described and taken account of in interpretation	<p>Description of social/physical and interpersonal contexts of data collection</p> <p>Evidence that researcher spent time 'dwelling with the data', interrogating it for competing/alternative explanations of phenomena</p>
	Clear audit trail given	Sufficient discussion of research processes such that others can follow 'decision trail'
	Data Used to support interpretation	<p>Extensive use of field notes entries/verbatim interview quotes in discussion of findings</p> <p>Clear exposition of how interpretation led to conclusions</p>
<b>Reflexivity</b>	Researcher reflexivity demonstrated	<p>Discussion of relationship between researcher and participants during fieldwork</p> <p>Demonstration of researcher's influence on stages of research process</p> <p>Evidence of self-awareness/insight</p> <p>Documentation of effects of the research on researcher</p> <p>Evidence of how problems/complications met were dealt with</p>
<b>Ethical Dimensions</b>	Demonstration of sensitivity to ethical concerns	<p>Ethical committee approval granted</p> <p>Clear commitment to integrity, honesty, transparency, equality and mutual respect in relationships with participants</p> <p>Evidence of fair dealing with all research participants</p> <p>Recording of dilemmas met and how resolved in relation to ethical issues</p> <p>Documentation of how autonomy, consent, confidentiality, anonymity were managed</p>
<b>Relevance and Transferability</b>	Relevance and transferability evident	<p>Sufficient evidence for typicality specificity to be assessed</p> <p>Analysis interwoven with existing theories and other relevant explanatory literature drawn from similar settings and studies</p> <p>Discussion of how explanatory propositions/emergent theory may fit other contexts</p> <p>Limitations/weaknesses of study clearly outlined</p>

		Clearly resonates with other knowledge and experience Results/conclusions obviously supported by evidence Interpretation plausible and 'makes sense' Provides new insights and increases understanding Significance for current policy and practice outlined Assessment of value/empowerment for participants Outlines further directions for investigation Comment on whether aims/purposes of research were achieved
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## Appendix 2.3: Completed study appraisal

<p><b>Title of study and reference:</b>          Australian men's long term experiences following prostatectomy: A qualitative descriptive study          O'Shaughnessy and Laws (2009)          Contemporary Nursing 34 (1) 98-109</p>
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Scope and Purpose	Comments	Grade
Clear statement of, and rationale for research questions /aims/purposes	Aims to describe men's long term recovery following prostatectomy as study wants to identify the effects of unresolved post-surgical morbidity. Explicit purpose given as there is less known about the long term effects after prostatectomy – hence, men are not fully informed about the long term side effects before they actually have their surgery. The study suggests that some men regret their decision to have surgery but only years later. Good literature review and evidence that it has been approached in a systematic fashion	A
Study thoroughly contextualised by existing literature	See above – also, the study points out why other studies have failed to adequately address this issue. For example, other methodologies have failed to outline how long men had been treated for and have pointed out limitations with conducting telephone interviews as body language and expressions cannot be accounted for. Mentions how literature review was approached, which most studies do not however, this is a PhD candidates paper and this may reflect the instilled lessons of methodology that are taught at this level.	A
Design	Comments	Grade
Method/design apparent and consistent with research intent	Qualitative methods. Although no specific approach is outlined, the rationale for using qualitative methods is adequately discussed including the benefits of conducting focus groups and individual interviews. There was no discussion of epistemological and ontological grounding. No discussion of particular method as qualitative is too vague to discuss if no specific approach. The setting for research design was appropriate however, as participants were recruited from men who had mostly attended support groups, it is uncertain whether could be considered a representative sample of men as it could be argued that support groups attract men who are comfortable in sharing their experiences.	B
Data collection strategy apparent and appropriate	Data collection methods were appropriate for the type of data required and fit a qualitative approach (despite there being no specific approach) Both focus groups and interviews were likely to capture the diversity of experience in sufficient detail and this form of triangulation is more than many studies have offered.	A

<b>Sampling strategy</b>	<b>Comments</b>	<b>Grade</b>
<b>Sample and sampling method appropriate</b>	The selection criterion for sampling is explained well. The justification for the purposive sampling strategy is outlined and supported by evidence however, it is noted that 'most' of the men had attended one of two prostate support groups. As previously mentioned, not all men want to attend support groups and therefore, may have underlying issues of a sensitive nature which these men may not have experienced. However, thickness of description is likely, especially as focus groups and interviews were employed. It is not clear where the men who had not attended the focus groups were recruited from. Also, class, race, sexuality were not discussed and no demographics were taken. The fact that a gay man highlighted his sexuality was coincidental but shows that there may be other issues from this perspective which may have given the researcher an alternative view.	<b>B</b>
<b>Analysis</b>	<b>Comments</b>	<b>Grade</b>
<b>Analytical approach appropriate</b>	Analysis was undertaken using content analysis and is appropriate for qualitative methods. It has to be assumed that data was analysed by hand and there is some discussion of the framework and approach taken to explore and generate categories. Context of data and subjective meanings of participants were retained and portrayed adequately and there is evidence of more than one researcher. Additionally, rigour was enhanced as researchers offered participants the opportunity to comment on the researcher's summary although it is not stated whether any participants took up this offer. To ensure that saturation point was reached, a researcher identified information redundancy by constant comparison of data which did not identify any new themes. However, as only two focus groups were conducted – each containing 4 men, it is hard to know or compare whether a different group would have thrown up new information. It was not clear that there were two focus groups and this had to be assumed by reading in between the lines. No evidence that deviant data was sought.	<b>A</b>
<b>Interpretation</b>	<b>Comments</b>	<b>Grade</b>
Context described and taken into account of interpretation	Some discussion of context of data collection and it is evident (in my opinion) that the researcher spent time dwelling with the data.	<b>A</b>
Clear audit trail given	Yes, there is a clear audit trail so others can follow decisions made by the researcher.	<b>A</b>
Data used to support interpretation	Use of field note entries and verbatim quotes are used to support findings although field notes are not as extensive as quotes. There is a clear exposition of how interpretation led to conclusions. Particularly as the researcher links theory to his findings during the analysis as well as in the discussion	<b>A</b>

Reflexivity	Comments	Grade
Researcher reflexivity demonstrated	Discussion of relationship between researcher and participants is discussed and reasons for including other people present during the focus group are discussed. There is some evidence of self-awareness as groups were selectively grouped and reflexivity is mentioned. The researcher notices small detail such as eye contact being made between participants and when one man discloses his sexuality (the response by other men) Effects on the researcher are not mentioned	A
Ethical dimension	Comments	Grade
Demonstration of sensitivity to ethical concerns	There is an acknowledgement that the dignity and wellbeing of participants took precedence over the expected benefits of knowledge, indicating that there was a transparent and mutual respect for the men who took part. All participants were advised about the processes of data transcription, analysis and dissemination and ethical approval was gained from 3 organisations prior to data collection	A
Relevance/transf erability	Comments	Grade
	There is sufficient evidence for typicality specificity to be assessed and the rigour given to this study helps to support this further. Analysis is interwoven with existing theories and literature throughout and there is some discussion about how the findings may link to ensuring men with PC are given enough information prior to choosing their treatment. Limitations are not discussed although further directions for investigation are touched upon. The study clearly resonates with other research in this area and interpretation 'makes sense' and are supported well by evidence. The study provides new insights and understandings to some extent and the aims and purposes of this research were, in my opinion, achieved.	A

## Appendix 2.4: Grading Guidance

Downe, S; Simpson L; Trafford K. (2007). Expert intrapartum maternity care: a meta-synthesis. *Journal of Advance Nursing*, 257(2):127-40

For each study, questions are answered using **Y= yes, N=no** or **UC=unclear**

Each study is graded using the following grading system (Walsh & Downe. 2006; Downe et al., 2007):

**A:** No, or few flaws. The study credibility, transferability, dependability and confirmability is high.

**B:** Some flaws, unlikely to affect the credibility, transferability, dependability and /or confirmability of the study.

**C:** Some flaws that may affect the credibility, transferability, dependability and /or confirmability of the study.

**D:** Significant flaws that are very likely to affect the credibility, transferability, dependability, and /or confirmability of the study.

**Use the following codes:** Y: yes; N: no; UC; unclear

Author, Year & Country	Aims Clear	Participants: Appropriate for question	Design: Appropriate for aims and theoretical perspective	Methods : Appropriate for design	Sample: Size and sampling justified	Does the data analysis fit with the chosen methodology	Reflexivity present	Study ethical	Do the data presented justify the findings	Is the context described sufficiently	Is there sufficient evidence of rigour	Grade

### Appendix 3: Studies included in the literature review

Study, Setting	Treatment	Scope, Purpose	Design, Methods	Sampling Strategy, Participants	Analytical Strategy	Overview of Findings	Grade
Bailey, Wallace & Mishel (2007)  USA	Watchful waiting / Active surveillance	To explore the problems of older men with prostate cancer who have undergone watchful waiting.	Qualitative descriptive design	N = 10 Purposeful sampling Aged 64-88	Content analysis	Men lived with a sense of uncertainty.  Men had to contend with the prospect of choosing treatment and felt doubtful when contemplating these decisions.  Men who could bracket the fact they had cancer adopted a more positive view of life.	B
Bertero, (2001)  Sweden	Various	To explore and identify the impact of prostate cancer and its treatment on men's sexuality and intimate relationships	Qualitative design  Phenomenology In-depth interviews	n = 10 Men aged 63-76 (mean 67.6 years)  Purposeful sampling  Interviewees received diagnoses between 2-7 years prior to study. Demographic data provided	Heideggerian approach followed	Men's sexual patterns altered as result of treatment  Men are still hopeful that their sex lives will be restored.  Wives play a key role in a man's acceptance of altered sexuality.  Masculinity is affected by prostate cancer.	A
Bokhour, Clark, Inui, & Talcott, (2001)  USA	Radical Prostatectomy Radical external beam radiation Brachytherapy	To explore perceptions of the impact of erectile dysfunction on men who had undergone treatment for early nonmetastatic Prostate cancer.	Qualitative design  Focus Groups	n = 48 (White or African American heterosexual men aged 50-79)  7 focus groups (matched for age either 50-69 or 70-79 and race)  Patients treated for PC either 12 or 24 months previously.	Analysed using procedures informed by grounded theory methods	Sexual dysfunction impacts negatively on men's quality of life.  Sexual intimacy is disrupted as are sexual fantasies.  Everyday interactions with women are disrupted  Men's perceptions of masculinity are altered	B
Broom (2004)  Australia	Various	To qualitatively explore a group of men's experiences of being tested, investigated and treated for prostate cancer.	Qualitative design  Focus Groups	n = 33  Twenty five recruited from 3 support groups and a further 8 men who responded to a local magazine article.  Aged 40-85  Demographic data provided	Qualitative interpretive traditions (Rubin & Rubin, 1995)	Cultural stereotypes and perceptions of masculinity shape men's views of health.  Loss of potency is the most difficult aspect of PC during the post treatment stage.  Loss of potency closely related to men's gender identities.  Some men prioritise potency over cure, some men.	B

Study, Setting	Treatment	Scope, Purpose	Design, Methods	Sampling Strategy, Participants	Analytical Strategy	Overview of Findings	Grade
Carter, Bryant-Lukosius, Blythe, & Neville, 2011  Canada	Hormone treatment	To better understand the priority supportive care needs of men with advanced prostate cancer	Qualitative design  Description Method (Sandelowski, 2000) 5 Focus Groups 10 Individual Interviews 1 Dual interview	n = 29 (12 men with hormone-sensitive prostate cancer and 17 with hormone-refractory prostate cancer.  Recruited through multiple sampling strategies e.g. advertisements, recommendations  Age range 59-88  Demographics provided	Analysis outlined in detail. Assumed to be part of Sandelowski's description method although this is not made explicit.	Men struggle to do 'what they want to do' due to functional issues such as side-effects of treatment.  Men had consistent information needs relating to treatments, medications, side effects and alternative therapies.  Men experienced emotional distress due to uncertainty and consequences of advanced cancer as well as anger and frustration due to unresolved issues about their diagnosis and treatment decisions at this time.	B
Chapple & Ziebland (2002)  UK	Variety of all known therapies	To look at the way in which prostate cancer affects men's bodies, their roles and sense of masculinity.	Qualitative design  Unstructured interviews (approx. 3 hours each)	n = 52  Purposive Sampling. Men recruited through GP's, hospital consultants and support groups  Age range 50-85  Demographics provided	Analysis used NUD*IST	Masculinity prevented some men from seeking help when they developed symptoms.  Treatment resulted in disturbing side effects which impacted on men's lives, impotence was a real issue for many as well as bodily changes from hormone treatment  Work and sport became an issue for men following treatment	C
Ervik, Nordoy, & Asplund (2010)  Norway	Endocrine therapy and active surveillance	To illuminate men's experiences of being diagnosed with PC and their experiences of treatment.	Qualitative design  Phenomenology  Interviews lasting between 1-1.5 hours	n = 10  Sampling strategy appears to be purposeful although not clearly stated  4 men aged 60-70  4men aged 70 – 80  2 men aged over 80	Hermeneutic interpretation	Men found it difficult to discuss sexuality with health professionals  Men expressed a need for more information and expressed uncertainty  Most men received support from wives  Support groups were important to men	B

Study, Setting	Treatment	Scope, Purpose	Design, Methods	Sampling Strategy, Participants	Analytical Strategy	Overview of Findings	Grade
Fergus, Gray & Fitch (2002)  Canada	Various treatments	To explore the experiences of men living with sexual dysfunction after cancer.	Qualitative design  Semi-structured interviews (multiple in some cases) lasting between 45-90 mins	n = 18  Ethnographically diverse sample 14 heterosexual men 4 gay men  Age range 57-75  Time since diagnosis 3.7 yrs	Constant comparison	Men viewed treatment as trading in sex for the chance to live.  Sexual dysfunction was a major disruption for men  Adopting certain attitudes helped men to adapt to illness and loss of sex.  Prostate cancer perceived by some men as an invisible stigma. Single and gay men worried about disclosure with potential partners	A
Filiault, Drummond, & Smith (2008)  Australia	Not stated	To examine the experiences, frustrations and perspectives of gay men with PC	Qualitative design  Phenomenology  1 focus group 1 interview	n = 3 ( 2 gay men & 1 partner)  Snowball sample recruited through local centre for gay men and local gay newspaper	Inductive analysis through methodological lens of phenomenology	Relationship dynamics were threatened as a result of prostate cancer Changes in libido and sex has a specific impact on gay men's sense of sexuality  Gay men experienced heteronormativity in healthcare settings	C
Gannon, Guerro-Blanco, Patel, & Abel (2010)  UK	Radical prostatectomy	To investigate how men attempt to reconstruct masculinity following RP	Qualitative design  Semi-structured interviews (45-2hrs)	n = 8 (demographics provided)  Sampling not explicit  7-15mth post-surgery	Foucauldian discourse analysis (Willig)	Men's ability to be sexually active is central to their identity.  Masculinity is challenged by when men feel a sense of vulnerability.  Attributing changes to factors such as age helped men to normalise.	B
Grunfield, Halliday, Martin, & Drudge-Coates (2012)  UK	Andropause deprivation therapy (ADT)	To explore the experience and impact of ADT symptoms amongst men with metastatic PC	Qualitative design  Phone interviews / face to face interviews  (27-48 mins long)	n = 21  Sampling strategy unclear  Aged between 68-92	Framework approach	Men avoided social situations as a result of treatment side effects.  Sexual dysfunction a major concern Adaptation was helped when some men attributed their decline in health to their age and used humour.  Conflict in marriage was an issue for some men.  Alternative methods to gain erections were problematic.	B

Study, Setting	Treatment	Scope, Purpose	Design, Methods	Sampling Strategy, Participants	Analytical Strategy	Overview of Findings	Grade
Hagen, Grant-Kalischuk, & Sanders (2007)  Canada	Various treatments	To explore the lived experiences of men with PC, their symbolic meaning their experiences of healing	Qualitative design  Phenomenology  Interviews	n = 15  Sampling strategy unclear however pts. recruited through PC support groups, adverts, word of mouth.	Phenomenological analysis	Masculinity threatened when men receive diagnosis for prostate cancer.  Side effects that are difficult to cope with.  Lack of information is frustrating.  Spouse and family main source of support but peer support also important.  Men re-evaluated their lives were transformed in a positive way.	A
Heidesteg, Sandman, Tomic, & Widmark, (2005)  Sweden  (Heidesteg, Sandman, Tomic, & Widmark (2005)  Sweden	a) Radical prostatectomy  b) External beam radiation therapy (EBRT)	To illuminate the experience of living after a) radical prostatectomy b) EBRT for localised PC	Qualitative design  Interviews	a) n = 10 b) n = 10  Sampling not outlined but men were recruited from a database  All men aged between 61-69	Content analysis	Bodily changes due to treatment impact on daily living.  Men were confused when choosing treatment and turned to other men for help Talking to other patients was helpful Men.  Treatment left men feeling exposed, especially with female health professionals.	A
Heidesteg, Sandman, Tomic, & Widmark (2003)  Sweden	Active Surveillance	To illuminate the meaning of being a patient living with untreated localized prostate cancer.	Qualitative design Hermeneutic phenomenology  Interviews	N = 7 Purposeful sampling Aged 62-69	Hermeneutic methods	Men felt alone with the disease yet this was due to a choice to not worry family or be viewed as someone with an illness by others.  Coping was used and men attempted to screen off the illness as a separate part of their lives.  Men lived with an overriding sense of uncertainty and worry about the prospect of treatment in the future.  Masculinity was affected for some but not others in relation to erectile function.  Relationships with physicians were very important due to time spent with them due to increased monitoring.	A

Study, Setting	Treatment	Scope, Purpose	Design, Methods	Sampling Strategy, Participants	Analytical Strategy	Overview of Findings	Grade
Jones et al., (2011)  USA	Various treatments	To examine social and economic barriers relating to cancer care and assess who participants relied on for financial support or other resource issues during diagnosis and treatment	Qualitative design  Hermeneutic phenomenology  Focus groups	n = 23  African-American PC survivors 11 rural based 12 urban based  Multiple sampling strategies	Thematic Analysis	Family members, particularly wives are important to men. Men in rural areas used spirituality more than men in urban areas Trust in healthcare providers was important when men were deciding on treatment When men had a better understanding of the disease, they had more control and less anxiety. Health insurance was vital to minimising financial strain and worry	B
Jonnsson, Aus, & Bertero (2010)  Sweden	Various treatments	To provide information if and how PC affects men's daily lives 2 years after diagnosis	Qualitative design  Phenomenology  Interviews (lasting between 25-45 mins)	n = 22  Sampled from a previous baseline study but no details provided  Aged between 50-85 no other demographics given	Hermeneutic interpretation (Gadamer approach)	Men were able to be positive and reassess their current life situation Although men felt healthy, they reported fatigue and sense of uncertainty Relationships with physicians differed - some positive, some negative Identity associated with sexual activity regardless of age.	C
Kazer et al (2011a)  USA	Various treatments	To expand the understanding of the phenomena of living with PC for unpartnered men	Qualitative methods  Telephone interviews	n = 17  Stratified purposeful sampling  Aged 47-72 (other demographics provided)	Not clear however, interviews transcribed by 3 investigators and themes generated.	In absence of partner, men rely on physician more or turned to the church Support groups were not utilised by most men Men who are self-reliant have the potential for enhanced coping Positive attitudes were adopted by men as a way of coping	B
Kazer et al (2011b)  USA	Active surveillance	To determine the psychosocial and educational needs of men undergoing active surveillance	Qualitative design  Two focus Group with open ended questions	n = 7 Purposeful sampling  Criteria: No previous treatment and aged ver 65	Content analysis	Few found support groups helpful Information on active surveillance was limited Men became tired of constant monitoring Men attempted to adopt healthy behaviours	B
Kelly a (2004) Kelly b (2009)  UK	Unknown (although radiotherapy is mentioned)	a) To explore the impact of PC on the sexual dimensions of men's lives.  b) To examine masculine embodiment in the context of PC	Qualitative methods  Ethnography (Included interviews with participants, health professionals and observations)	n = 14 men with PC n = 5 health professionals  Opportunistic sampling	Interview analysed using Miles and Huberman (1994) approach  Observational data used 'place, actors, event' framework	Men experienced uncertainty when making decisions about treatment – treatment choice was shaped by men's feelings around impotence and incontinence Some men felt it was important to retain sexual function, others regarded it as less important Masculinity is reshaped following illness Male sexuality is shaped by cultural, personal and social factors One gay man rejected surgery and radiotherapy to preserve sexual function	C  A

Study, Setting	Treatment	Scope, Purpose	Design, Methods	Sampling Strategy, Participants	Analytical Strategy	Overview of Findings	Grade
Letts, Tamlyn, & Byers (2010)  Canada	Various treatments	To enhance understanding of mens lived experiences of the impact of PC on aspects of sexual wellbeing	Qualitative methods  Phenomenology  Interviews (45mins - 2hrs)	n = 19  Purposeful sampling  Aged between 54-79 (other demographics provided)	Framework approach (Richie & Spencer)	Some but not all aspects of sexual wellbeing are affected. Most men reported no changes in affection, romance or self-concept as a man Men's perceptions of their partners response to sexual changes helped adaptation Discussions about sex were mostly rare 8/19 men found sexual aids ineffective	A
Maliski, Rivera, Connor, Lopez, & Litwin (2008)  USA	Various treatments	To develop a descriptive model of processes used by low-income African-American and Latino men to maintain masculine identity with PC related symptoms	Qualitative design  Grounded theory  Interviews (combination of face to face or telephone)	n = 78  Multiple sampling strategies including adverts in newspapers, support groups etc...	Grounded theory approach (Strauss & Corbin)	Men renegotiate their masculinity after cancer treatment. Masculinity influenced by cultural and social factors Work and physical strength tied to masculine values Men were embarrassed by erectile dysfunction Some viewed erectile dysfunction as part of the ageing process or a trade-off for life Men shifted their priorities and re-evaluated life others could not do this however	A
Nanton & Dale (2011)  UK	Various treatments	To investigate the experiences of African-Caribbean men with a diagnosis of PC	Qualitative design  Interviews (60-90 mins each) using flexible approach	n = 16  Snowball sampling  Aged between 50-83 All men lived in UK for 40yrs +	Unclear  Generation of themes	Wives played a central role in men's lives as did faith and the community Reluctance to seek help due to cultural issues and this impacted on daily life Men were generally unhappy with communication with healthcare providers Men were concerned about sexual dysfunction	B
Navon & Morag (2003)  Israel	Hormonal therapies	To examine the coping strategies employed by advanced cancer PC patients receiving hormone therapy to learn from the experiences about potential solutions to their non-medical needs	Qualitative design  In-depth interviews (multiple interviews with participant)	n = 15  Sampling strategy not made explicit although appears to be purposeful.  Men aged between 57-85	Constant comparison (Glaser,1998) (Strauss & Corbin, 1990)	Men were embarrassed by the side effects of hormonal treatment and were repulsed by their bodily changes Men were reluctant to disclose sexual problems to others, particularly male friends Some men viewed loss of sex as trade-off for being alive Not all partners were supportive as male role was not being fulfilled Men mostly coped alone	B

Study, Setting	Treatment	Scope, Purpose	Design, Methods	Sampling Strategy, Participants	Analytical Strategy	Overview of Findings	Grade
Ng, Kristjanson, & Medigovich (2006)  Australia	Hormone ablation  (either alone or prior to or following other forms of treatment)	To provide an understanding of the experiences of men living with PC and the ways in which hormone ablation affects their experiences	Qualitative methods  Phenomenology  Interviews & Field notes	n = 20  Sampling strategy not clearly outlined  Men aged between 50-70	Method followed by Streubert & Carpenter (1995) Content analysis	Men used their PSA levels to monitor their responses to treatment Men reported different ways of living with outcomes following treatment – some adopted positive coping strategies such as healthier lifestyles and positive outlook Support from wives was important as were support groups Importance placed on relationships with health professionals	B
O'Brien et al (2011)  UK	Various treatments	To describe patients experiences of follow-up practices, seek explanations as to why needs were unmet	Qualitative design  Interviews	n = 35  Purposeful sampling of men across 3 UK regions  Aged between 59-82	Constant comparison (Glaser, 1998)	Survival is main priority but Psychosexual problems became more of an issue over time, Communication an issue for men in healthcare settings - sex problems are rarely discussed in follow up appointments and onus is on patient to raise these issues. Older men were often too embarrassed to discuss sexual needs Men expressed the toll of their illness on their spouses	A
Oliffe a (2005)  Oliffe b (2006)  Australia	a) Radical prostatectomy  b) Androgen therapy	To explore men's experience of impotence following prostatectomy To describe the finding of men treated with ADT for advanced PC	Qualitative design  Ethnographic approach  Interviews	a) n = 15 average age 57 b) n = 16 average age 67  Multiple sampling strategies inc media, support groups, adverts on PC internet sites	Interpretation of concepts developed (Sandelowski, 1995; Spradley, 1980)	Men could rationalise the threat of impotency prior to surgery as a way of surviving. Following surgery, diverse reactions were experienced. Men abandoned treatments for erectile dysfunction due to their artificial nature Older men were less reliant on penetrative sex and attributed it to ageing Men on hormone treatment were embarrassed by bodily changes and this affected masculinity, social activities, Hegemonic masculinity helped men to 'fight' prostate cancer	A
Oliffe, Pickles & Mroz (2009)  Canada	Active surveillance	To describe men's active surveillance related practices and psychosocial issues	Qualitative design  Interpretive description	n = 25  Purposeful sampling based on diagnosis  Age range 48-77 Average age - 68	Constant comparative analysis	Uncertainty was dominant within the men's lives both implicitly and explicitly Some men made lifestyle modifications and gained from doing something extra to improve their wellbeing Men sometimes felt pressure from family to defend their choice of treatment	B

Study, Setting	Treatment	Scope, Purpose	Design, Methods	Sampling Strategy, Participants	Analytical Strategy	Overview of Findings	Grade
O'Shaughnessy & Laws (2009)  Australia	Prostatectomy	To describe men's long term recovery following prostatectomy for the purpose of identifying the effects of unresolved post-surgical morbidity	Qualitative design  Descriptive  Focus groups (n = 8) and individual interviews (n = 3)	n= 11  Purposeful sampling  Men's ages not outlined	Content analysis	Men expressed that incontinence and impotence were a major source of emotional tension Men expressed regret over the lack of information accessible to them for evaluating risk of long-term problems Men's social lives were affected Some men could emotionally adapt to changes in sexual function Most men acknowledged and altered body state and state of self One gay man found that short and long term relationships afforded few opportunities for him to explain impotence in a way that could allow potential partners to respond with patience and empathy	B
Wallace & Storms (2007)  USA	Unclear	To explore the psychosocial and educational needs of men diagnosed with PC and the effectiveness of existing support services for this population	Qualitative design  Grounded theory  Focus groups	n = 16  Convenience sampling which utilised multiple sampling strategies  Men aged between 49-81	Constant comparison	Physicians referred to as the best source of information but not for psychosocial support Men would have like to have known more about prostate cancer prior to getting a diagnosis Treatment decisions were most difficult part of cancer experience Men relied on discussions with wives to decide on treatment The disease had been life changing for men Men on hormone treatment were constantly reminded that cancer was present	C
Walsh & Hegarty (2010)  Ireland	Radical prostatectomy	To provide a retrospective view of men's experiences of the PC treatment journey from diagnosis through to completion of surgery and beyond	Qualitative design  Descriptive  Interviews (lasting between 1-4hrs)	N = 8  Sampling strategy not stated  Men's ages and other demographics unknown	Thematic analysis	PSA testing a significant feature in men's treatment journey Support considered as central throughout the men's cancer experience although the sources of support differed for men Men experience 'defining moments' at various stages of their journey Erectile dysfunction a primary concern Loss of sexual function linked to loss of sense of identity as a man Incontinence a concern for men as is facing their mortality	B

## Appendix 4: Key differences between Husserlian and Heideggerian

### Phenomenological approaches. Adapted from Lavery (2003)

Husserlian Phenomenology	Heideggerian Phenomenology
Descriptive phenomenology	Philosophical hermeneutics Hermeneutic phenomenology Interpretive
Epistemological	Existential-ontological
Concerned with questions of knowing	Concerned with being, experiencing and understanding
How do we know what we know	What does it mean to be in the world
Cartesian duality: mind and body split	Dasein
A mechanistic view of the person	Person as self-interpreting being
Mind-body person live in a world of objects	Person exists as a 'being' in and of the world
Ahistorical	Historicity
Analysis looks at the meaning given to subject	Analysis looks at the transaction between situation and the person
What is shared is the essence of the conscious mind	What is shared is culture, history, practice and language
Starts with reflection of mental states	We are already in the world in our pre-reflective states
Meaning is not affected by the interpreter's own world view	Interpreter is also a participant in making the data
Participants meaning can be reconstituted in interpretive work by insisting data speak for themselves	With the fore-structure of understanding interpretation can only make explicit what is already understood
Claim that following specific techniques and procedures guarantee validity of interpretation	Establishes own criteria for trustworthiness of research
Bracketing defends the validity or objectivity of the interpretation against self-interest	The hermeneutic circle acknowledges that background, co-constitution, pre-understanding are intertwined

## Appendix 5: Ethical approval



16<sup>th</sup> January 2013

Kinta Beaver & Dawn Doran  
School of Health  
University of Central Lancashire

Dear Kinta & Dawn

**Re: BuSH Ethics Committee Application**

**Unique Reference Number:** BuSH 078

The BuSH ethics committee has granted approval of your proposal application 'The Lived Experience of Gay Men with Prostate Cancer'.

Please note that approval is granted up to the end of project date or for 5 years, whichever is the longer. This is on the assumption that the project does not significantly change, in which case, you should check whether further ethical clearance is required

We shall e-mail you a copy of the end-of-project report form to complete within a month of the anticipated date of project completion you specified on your application form. This should be completed, within 3 months, to complete the ethics governance procedures or, alternatively, an amended end-of-project date forwarded to [roffice@uclan.ac.uk](mailto:roffice@uclan.ac.uk) quoting your unique reference number.

Yours sincerely

Vice Chair

**BuSH Ethics Committee**

## **Appendix 6: Participant information sheet**

### **Participant Information Sheet**

#### **Title of study: The Lived Experience of Gay Men with Prostate Cancer**

*Research Team: Dawn Doran, Prof Kinta Beaver, Dr Susan Williamson, Karen Wright*

The study is being conducted as part of a research degree at the University of Central Lancashire. To help you decide if you would like to be involved in the study, please take some time to read the following information carefully. It is important that you understand what is required of you before you agree to take part. If you have any further questions after reading the information and would like to discuss them further, please do not hesitate to contact me. You should be fully satisfied that you have all the information you need before you decide to be involved with the study.

#### **The Research**

Research relating to men's experiences of prostate cancer has mostly focused on the experiences of heterosexual (straight) men. Therefore, the potential issues and challenges that gay men may experience, following diagnosis and treatment for prostate cancer, are not clear. The purpose of this study is to explore the impact of prostate cancer on gay men. We want to find out what gay men experience when faced with prostate cancer. We intend that the findings of this study will provide important information to healthcare professionals and the charitable organisations that support gay men so that they can best meet the needs of gay men with prostate cancer.

#### **Why would I be suitable?**

I am interested in hearing about the experiences of gay men who have been diagnosed and treated for prostate cancer. I am interested in how the disease has affected different aspects of your life and whether there are any issues that you have found particularly challenging. This information will help to raise current awareness about issues relating to gay men and prostate cancer and will ultimately lead to increased knowledge within the wider gay community and for the healthcare professionals who are involved in your care.

#### **What is involved?**

You will be invited to take part in a face to face interview at a mutually convenient place and time. It is expected that the interview will last about 60 minutes, but this can be shorter or longer depending on you. With your permission, I will start by asking you to share some personal details including your age, the type of cancer

you were diagnosed with, the length of time since your initial diagnosis and what type of treatments you have undergone. This information will be used to provide a brief overview of your cancer journey within my thesis. With your consent, you may be contacted again to ask if you wish to take part in a further interview. A further interview would provide an opportunity for me to make sure that I have understood some of the points you might raise in the first interview or it may be that you want to say more about your experiences.

**What if I consent to be interviewed but then change my mind?**

Even if you consent to take part in an interview, you are under no obligation to proceed. You will be able to withdraw from the study however; data withdrawal will only be possible up until final analysis has been undertaken. If you decide that you no longer wish to take part you will not have to give a reason for doing so. If you wish to withdraw from the study after you have been interviewed you will be asked to give permission for any information that has already been collected to be used when reporting on the study, All identifying features (e.g. names) will be removed from any information that you provide .

**Will what I say during the interview be treated as confidential?**

Yes, please be assured that all information about you will be strictly confidential. With your permission, each interview will be recorded. All recordings will be securely stored within electronic files at the University which are password protected. If you agree to your interview being recorded, you can ask for the recorder to be stopped at any time during the interview or you can ask for any part of the recording to be deleted. Your interview will be transcribed (typed up) by me. Any details of your experience that could identify you (e.g. place of work or names) will be deleted when your interview is typed up. You will have a unique identification number (ID number) for the study. Therefore, if any comments that you make are used in written reports about the study, the ID number will be used. Any information that may directly identify you will not be used.

**What information will be held about me after the study?**

At the end of the study, your interview recording will be destroyed and any other information, such as your transcript, will be safely stored in a secure archive for five years in keeping with standard research practice at the University. At the end of this period all your data will be destroyed in a secure manner. This is in accordance with University of Central Lancashire's storage of data policy.

**What if there is a problem?**

It is appreciated that during the course of the interview, some issues that you recall may be potentially distressing for you. If you do feel upset at any point during our conversation, I will ask if you would like me to temporarily stop the interview, until you feel ready to continue. The interview can also be stopped if you feel unable to continue for any reason at all. I can also give you the contact

details for appropriate support groups and organisations if you feel that this would be helpful.

**Can I discuss this study with friends or family before I agree to take part?**

Yes, of course. If any members of your family or friends have any questions they would like to ask about the study I will be happy to answer them, with your permission.

**Who has reviewed the study?**

This research study has been registered and approved by the Research Degrees Sub-Committee at University of Central Lancashire. It has also been approved by their Ethics Committee.

**Do I need to consider any further information about this study?**

After the interview you may wish to ask me some questions about the interview or research study. You will have plenty of time to ask any questions and I will also leave my contact details in case you think of anything else you would like to ask at a later date. This information pack contains the contact details of my research supervisor.

**If I decide to be interviewed, what should I do?**

If you provided your contact details when you requested an information pack and agreed to be contacted 48 hours after receiving it, I will phone to ask if you have any further questions about the study. If you are satisfied that you have enough information and feel happy about taking part, we can then arrange a mutually convenient time for you to be interviewed. However, if after speaking to me you decide that you would like to have a little more time to think about taking part in the study, I can arrange to contact you a couple of days later when you have had more time to think about it.

**What do I do if I have any concerns or issues about the study?**

If you have any concerns or issues about the study that you feel I am unable to resolve, you can contact my project supervisor (Prof Kinta Beaver) or the University School Dean (Nigel Harrison). Their contact details are provided below.

**Thank you for taking the time to read this information sheet.**

**If you have any further questions about the project please contact:**

**Dawn Doran (PhD student)**

School of Health, Brook Building, University of Central Lancashire, Preston PR1 2HE

Email: [Ddoran@uclan.ac.uk](mailto:Ddoran@uclan.ac.uk)

**Professor Kinta Beaver (Project Supervisor)**

School of Health, Brook Building, University of Central Lancashire, Preston PR1 2HE Email: [KBeaver@uclan.ac.uk](mailto:KBeaver@uclan.ac.uk)

**Nigel Harrison (Dean and Head for The School of Health)** Brook Building, University of Central Lancashire, Preston PR1 2HE

Email: [NHarrison@uclan.ac.uk](mailto:NHarrison@uclan.ac.uk)

## Appendix 7: Participant consent form

### Participant Consent Form

#### Title of Study: The Lived Experience of Gay Men with Prostate Cancer

If you are happy to consent to each statement, please place your initials in each box here



1	I confirm that I have read and understood the Participant Information sheet version 2 dated 2.12.13 about the above study. I have had the opportunity to ask questions and I am satisfied with the answers to any questions I may have asked.	
2	I have had enough time to think about whether I want to be interviewed or not	
3	I understand that I am under no obligation to agree to being interviewed and taking part is voluntary. I understand that I am free to withdraw at any time, without giving any reason.	
4	I agree to the audio-recording of my interview and understand that I can ask for the recording to be stopped at any time and I can ask for any part of the recording to be deleted.	
5	I understand that the information I give will remain confidential and my name or other identifying features will be removed when the interviews are typed up (transcribed).	
6	I agree that some of my comments may be used in written reports on the study but my name or any other identifying features will not be used.	
7	I agree to being interviewed as part of the above study	
8	I understand that I may be contacted again by the researcher after my interview and may be asked to agree to a further interview. I understand that I am under no obligation to agree to any further interviews and I do not need to give a reason for refusal.	
9	I understand that if I withdraw from the study, any information that has already been collected will not be used without my permission.	

Name of Participant	Date	Signature
Name of researcher	Date	Signature

#### Contact Details

Researcher: Dawn Doran, PhD student, School of Health, Brook Building (Room 247) University of Central Lancashire, Preston, PR1 2HE

## Appendix 8: Example of email to support groups / organisations

Dear.....

My name is Dawn Doran and I am a PhD research student at the University of Central Lancashire, based within the Cancer and Supportive Palliative Care Group within the School of Health. I found your details on the Prostate Cancer UK website and wondered whether your support group would be able to help promote a piece of research that I am currently working on for my PhD?

My research is exploring the impact of prostate cancer on gay men. Despite this being the most common male cancer, very little research has been conducted to reflect the potential challenges that some gay men may face after being diagnosed with the disease. Hence, what has been written about this topic so far is largely opinion based. The findings from my research aim to highlight those issues which are centrally important to gay men, following diagnosis or treatment for prostate cancer, and raise awareness of those issues amongst health professionals who are charged with their care.

As so little is known about this topic, I am hoping to conduct in-depth interviews with gay men, across the UK, who have experienced prostate cancer. However, as I cannot recruit men through the NHS, due to the lack of sexual orientation monitoring, I am contacting various groups and organisations that could potentially promote my study - either through their website, or by mentioning the study within a newsletter or weekly / monthly group meeting.

If you are able to help in any way I would be most grateful. The study has received ethical clearance from the University Ethics Committee and I can send you an A4 promotion poster (by email or by post) which outlines the study and provides my contact details for anyone who may be interested in taking part. Following completion of this research, I will also provide you with a summary of the findings if this is something you would be interested in receiving.

I look forward to hearing from you,

Kind regards,

Dawn Doran

**Are you are a gay man who has experienced  
prostate cancer?**

**If so, I would really like to hear your story**

I am a PhD Student at the University of Central Lancashire. I am looking for volunteers who are willing to take part in the following study:

**“The Lived Experience of Gay Men with Prostate Cancer”**

As a participant in this study, I would like to interview you and would ask you to share your experiences of prostate cancer and describe how it has impacted on various aspects of your life since diagnosis and treatment.

**If you would like to take part in this study or simply find out a bit more about what is involved, please contact me for an informal chat or to request an information pack which contains further details.**

If you would like more information about this study please contact:

**Dawn Doran (PhD student)  
Brook Building  
University of Central Lancashire  
Preston  
Lancashire  
PR1 2HE  
Tel: 07551952003  
Email: [DDoran@UCLan.ac.uk](mailto:DDoran@UCLan.ac.uk)**

This study has been reviewed by, and received ethics clearance through, the Office of Research Ethics, University of Central Lancashire

## Appendix 10: Eligibility criteria form

(All participants must meet eligibility criteria based on the inclusion/exclusion criteria detailed in the proposal / ethics application)

**ID Number (purely for screening log)** \_\_\_\_\_

**Date form completed:** \_\_\_\_\_

<b>Inclusion Criteria (Must answer yes to all questions)</b>		<b>Yes</b>	<b>No</b>
1. Have you previously received a diagnosis of prostate cancer?			
2. Would you describe your sexual orientation as being exclusively gay?			
3. Are you aged 18 or over?			
4. Can you speak and understand English well enough to take part in an interview?			
<b>Exclusion Criteria (Must answer no to all questions)</b>		<b>Yes</b>	<b>No</b>
1. Are you undergoing or about to undergo any active forms of cancer treatment such as surgery, radiotherapy or chemotherapy?			
2. Have you been diagnosed with any form of cognitive impairment that may severely affect your ability to recall your past experiences? (e.g. Alzheimer's disease)			
<b>Does the potential participant meet the eligibility criteria? If so, continue to the next section</b>		<b>Yes</b>	<b>No</b>
Are you happy to provide some contact details so I can post or email an information pack to you?			
Name	Address		
Email			
And finally, are you happy for me to contact you after 48 hours after receiving the information pack?		<b>Yes</b>	<b>No</b>
How would you prefer me to contact you? (Please tick)	<b>Telephone</b>	<b>Email</b>	<b>Letter</b>
Telephone Number:	Best time to call		

## **Appendix 11: Bracketing statement**

This is a statement in which I acknowledge what I know about my topic area (or think I know about it) from both an academic and personal perspective.

Although I am aware that writing this statement will not ultimately enable me to forget anything I think or know, I do feel that it will be helpful to refer back to in order to ensure that the participants accounts and experiences are theirs and not mine.

### **Academic literature**

My knowledge of gay men with prostate cancer is limited to what I have found whilst looking for literature on the topic. Hence, the so far from Thomas Blank's paper (2005) and the monographs contained within Pearlman and Drescher's book about gay men with prostate cancer. These papers say that the experience for gay men is different based on their sexual orientation and I have taken this to mean that they may face some discrimination from people based on their personal choice of partner, or they may have some problems in disclosing their sexuality. I get the impression that sex is more important for gay men compare to heterosexual men, given that most literature I have read relating to gay men highlights sex as being a central aspect of their lives.

### **My personal experiences and encounters with gay men.**

My knowledge of gay men and the type of lives they lead is very limited. Growing up in a working class town with working class parents, issues about sexuality just never cropped up. I was in my late teens when I first heard of anyone being gay, I think it was around the time when pop stars had started to really come out and the HIV/AIDs crisis drew attention to the population of gay men. I can honestly say that my feelings towards gay people at this time were pretty neutral. My family were also a bit naïve when it came to homosexuality. They didn't have any views on it either, or if they did then they did not share them with me. I guess I was lucky as nobody around me discriminated against them so I did not either. The first gay man I ever met was someone I worked with in 1989. I was 19. He was never open about his sexuality, it was just something everyone knew. I came across very few gay men until I worked for an organisation a few years later. For the most part, these men were not open about their sexuality, it was simply 'known' that they were gay by their work colleagues and it wasn't

regarded as a big deal by anyone. I have liked and respected the gay men I have worked with. However, a lot of my knowledge about the lives gay men has been acquired from the media.

## Appendix 12: Interview and topic guide / probe examples

### Initial Questions

**Can you tell me what it was like for you when you were diagnosed with prostate cancer?**

*Prompts*

*How did it feel?*

*What incidents and people stand out for you when you think back to this time?*

**What effect has prostate cancer had on your life?**

*Prompts*

*What thoughts stand out for you?*

*How did that experience make you feel?*

*What has that been like for you?*

**Do you think that being gay has made a difference?**

*Prompts*

*Within health settings or support groups*

**Have other people in your life been affected? If so, how?**

*Prompts*

*How did / does that make you feel?*

**How has cancer affected your outlook on life?**

### Example Probes: Rubin & Rubin (2005)

Type of Probe	Purpose	Example
Continuation Probes	To encourage the interviewee to continue talking about the present subject	“Mmm hmm. So...” “Then what?” “And...?”
Elaboration Probes	Encourage the interviewee for more detail or explanation of a particular concept	“Such as?” “Could you give me an example?” “Can you tell me more about that?”
Attention Probes	These let the interviewee know they are being listened to carefully which encourages elaboration.	“Ok, I understand” “That is interesting”
Clarification Probes	Asks the interviewee to explain something that the interviewer does not follow or understand	“Could you run that by me again?” “Could you explain that to me again in a bit more detail?”
Steering Probes	To get back onto a topic that has gone off track	“Sorry I distracted you with that question, you were talking about...” “So you were saying earlier that... let’s explore that...”
Sequence Probes	To explore causation or when event sequences are blurred	“Could you tell me what happened step by step?” “When did this happen?”
Evidence Probes	Asks what a person knows and how they came to their conclusions	“Could you give me an example?” “Are there specific instances when this happened?”
Slant Probes	Help the interviewer to determine the lens through which people see and interpret their worlds	“How did you feel about (the incident / topic)?” Describe how that felt

### Appendix 13: Reflective journal extracts

*I am having a conversation with a male researcher from another university today and I am very nervous about talking to him on the phone. I am worried about using the wrong terminology. Do I say the word homosexual, is it offensive? I don't know what the etiquette is and I don't want to offend him. I hope he does not think I am odd because I want to research gay men when I am a straight female... Spoke to the researcher. He was very nice but thinks I will have some issues getting gay men to open up to me as I am not an insider. He advised me to clarify things I do not understand and wished me good luck.*

*[Participant's name] was very open with his use of language. I was aware this might happen and I thought that I would be very embarrassed of someone describing intimate details of their sex lives and their fantasies with me. However, I was surprised by my own reaction as I didn't blush once, I didn't flinch and I wasn't openly or secretly shocked by anything [participant] said. I would say fascinated and somehow relieved that someone was allowing me to get a glimpse into a world I will never inhabit. There is so much I want to say about [participant] in terms of my thoughts throughout the interview. On the odd occasion, I did wonder whether he considered himself to be an actor who was used to saying these words in this way, or was this merely an example of someone who literally has no inhibitions and does not feel the need to think about something before he says it. I have thought about this all the way home and it maybe says more about my suspicion towards other people in general. The words journey and personal growth came up a lot during the interview and the fact that [participant] said he was excited upon first hearing his diagnosis was particularly revealing. This evoked a feeling of recognition for myself and I suddenly remembered the same feeling I had several years earlier upon being told I to undergo emergency surgery. I also had that same sense of excitement – is it excitement or is it just a momentary way of handling fear? Of course, reality soon sets in as it did for [participant] yet I can't help but feel that prostate cancer has been a friend as well as a foe to [participant] as it has forced him to go deeper on his journey.*

....Part way through the interview, I sensed that there was a sense of discomfort when we touched on the issues that might concern his sex life if he chose to have treatment. I noticed how his arms folded and how he shifted on his chair. This invariably impacted on the way I responded and continued with the interview as I was acutely aware that the dynamics in the interview might take an uncomfortable shift I were to continue probing this topic. After reflecting on this later I suddenly became aware of how a whole generation gap and my own presence as a female researcher may have felt for Alan. I imagined how my own father may have felt in the same situation and for the first time I was forced to consider how my gender and sexuality had the capacity to impact on my research in a potentially negative way. Reflecting also made me question why I had even felt the need to bring up the matter of sex. Alan had not undergone treatment for his cancer and therefore his sex life had not been affected. I realised that I had not been able to 'bracket' what I already knew. The interview prior to Alan's was focused on sexual experience and function and I had wrongly assumed that this would be an important aspect of Alan's experience in much the same way....it wasn't.

....The look in [participant's name] eyes stayed with me all the way home and for the rest of the evening, and I found myself feeling quite upset on the train. A feeling of hopelessness about cancer more generally washed over me. What is it like to live with something that changes you for the rest of your life?...He had gone to the support meeting looking for answers yet come away feeling worse than before he went.

....Something else also happened during the interview. I stopped seeing [participant's name] as a 'gay man.' This had also happened during my interview with [participant's name] but even more so with [participant's name]. He was a man with a story to tell and it didn't matter that I was a PhD student studying gay men with prostate cancer. He ceased to become a gay man with prostate cancer, he was a man expressing his whole life, his views of the world and in some ways, was coming to terms with what it is to be a man in his own world generally.

I have noticed that I am starting to feel a bit uncomfortable about telling some people about my research project and the fact I am starting to feel uncomfortable is not a nice feeling. I went to a seminar today and we had to go around the room

*and tell each other about our research. One lady asked me in private why I wanted to research gay men. She was a health practitioner already but said that she did not agree with homosexuality in any way and she could not understand why I would choose to research this topic. I don't know what she expected me to say really but I was shocked that as a health professional, working in the UK, she even had a right to say that to me. Is it any wonder gay men might feel discriminated against?*

## Prostate facts for gay and bisexual men



## About this booklet

This booklet is for gay and bisexual men, and men who have sex with men. In many ways, prostate cancer and other prostate problems are the same for men whatever their sexuality – gay, bisexual or heterosexual.

But if you are gay, bisexual or a man who has sex with men, you might have some specific questions or concerns. We provide information that may be more relevant to you. There's also information about the support available to you.

Everyone is different, so if the information here isn't what you're looking for, you should be able to find what you need in our Tool Kit fact sheets and other booklets. If you have any other questions or need more support speak to our Specialist Nurses, in confidence, on 0800 074 8383.

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The following symbols appear throughout the booklet to guide you to sources of further information:



Prostate Cancer UK Specialist Nurses



Prostate Cancer UK publications



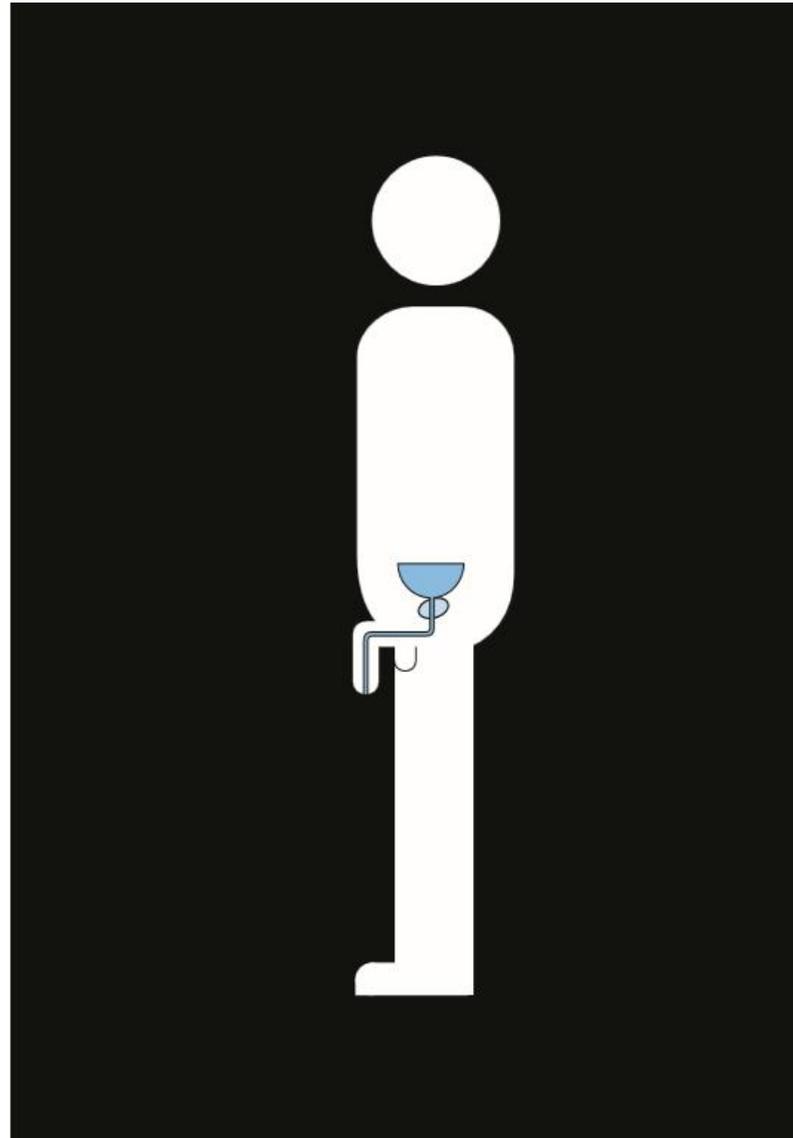
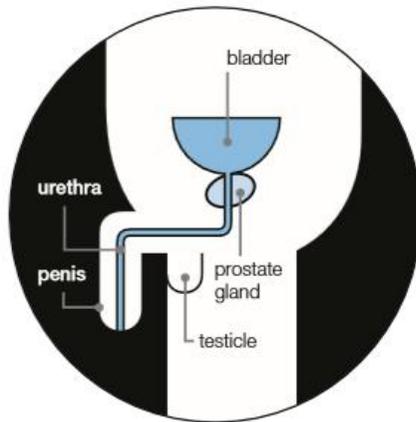
Watch men tell their own stories in our online videos:  
[prostatecanceruk.org](http://prostatecanceruk.org)

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## What is the prostate?

Only men have a prostate gland. The prostate is usually the size and shape of a walnut and grows larger as you get older. It sits underneath the bladder and surrounds the urethra, which is the tube that men pee and ejaculate through. Its main job is to help make semen, which is the fluid that carries sperm.



## Prostate problems and prostate cancer

The three most common prostate problems are:

- an enlarged prostate – this is the most common prostate problem
- prostatitis – an inflammation or infection of the prostate
- prostate cancer.

For some men, problems urinating could be a sign that they have a prostate problem, usually an enlarged prostate. Or it might be an infection or inflammation of the prostate, called prostatitis. Early prostate cancer doesn't usually cause problems urinating.

Problems with urinating could also be caused by another health problem, such as diabetes, or by any medicines you are taking, such as anti-depressants.

If you have symptoms, get them checked out by your doctor.

There's no evidence that gay or bisexual men are more likely to get prostate cancer or other prostate problems. But prostate cancer is the most common cancer in men in the UK. About 1 in 8 men will get prostate cancer at some point in their lives.

You may be more likely to get prostate cancer if:

- you are aged 50 or over
- you are Black
- your father or brother has had it.

If you are more at risk of prostate cancer, or if you have symptoms such as problems peeing, you might want to get further advice or a check-up at your GP surgery.



Read more about prostate problems, symptoms and your risk of prostate cancer in our booklet, **Know your prostate: A guide to common prostate problems.**



## Testing for prostate cancer

There is no single test to diagnose prostate cancer, but there are a number of tests which can be used to see if you have a prostate problem. These include a blood test known as the PSA test, physical examination of your prostate (called a digital rectal examination or DRE), and a prostate biopsy.

 Read more about tests for prostate cancer in our Tool Kit fact sheet, **How prostate cancer is diagnosed.**

### The PSA test

The PSA test measures the total amount of prostate specific antigen (PSA) in your blood. PSA is a protein produced by the prostate. It's normal to have a small amount of PSA in your blood, and the amount rises as you get older. A raised PSA level may suggest you have a problem with your prostate, but not necessarily cancer.

A PSA test alone can't tell you whether you have prostate cancer, and there are pros and cons to having one. If you're thinking about having a PSA test, it's important to find out more about it first, so you know the facts before you decide.

Certain things might cause your PSA level to rise for just a short while – and make the test results misleading. This includes being the receptive partner (the 'bottom') during anal sex or stimulation of the prostate, so it might be wise to avoid this in the week before a PSA test.

 Find out more about the PSA test in our booklet, **Understanding the PSA test: A guide for men concerned about prostate problems.**

### Digital rectal examination (DRE)

The DRE is a common way of helping to diagnose a prostate problem. Your doctor or nurse will feel the prostate gland through the wall of the back passage (rectum).

The doctor or nurse will slide their finger into your back passage. They will wear gloves and put some gel on their finger to make it more comfortable.

This may be uncomfortable, and some men find it embarrassing but it will be over quickly.

Find out more about the DRE in our Tool Kit fact sheet,



**How prostate cancer is diagnosed.**

### Prostate biopsy

If your test results suggest you may have a problem with your prostate, your GP will refer you to a hospital specialist who will then decide if you need further tests, such as a biopsy. A prostate biopsy takes tiny pieces of the prostate to look at under a microscope for signs of cancer.

The biopsy involves having an ultrasound probe inserted into the rectum (back passage) to scan the prostate. A needle is then inserted through the wall of the back passage into the prostate using the ultrasound image as a guide.

There are some short-term effects of a biopsy. One side effect is blood in your semen – some men have a bit of blood, others have a lot. Your semen may look blood-stained. Wear a condom if you are having sex during this time.

If you are the receptive partner ('bottom') during anal sex, ideally wait for around six weeks after a biopsy before having sex. Ask your doctor or nurse at the hospital for further advice. Read more about speaking with health professionals on page 19.

Read more about the biopsy in our Tool Kit fact sheet,



**How prostate cancer is diagnosed.**



**The results came back. From the physical examination of my prostate the doctor had found some lumps, and my PSA was raised.**

A personal experience

## Treatment for prostate cancer

Your treatment options will depend on whether your cancer is contained within the prostate gland (localised), has spread just outside of the prostate (locally advanced) or has spread to other parts of the body (advanced).

You may have a choice of treatments. Your doctor or nurse will explain all your treatment options, and help you to choose the right treatment for you.

Each treatment has its own pros and cons. Your personal preferences are very important – think about how the treatment and its side effects will fit into your life.

You might find it helpful to get support, information and advice before choosing a treatment. Speak to your doctor or nurse, or you can call our Specialist Nurses.



For more information about the different treatments for prostate cancer, read our **Tool Kit** fact sheets.



## Side effects of prostate cancer treatment

Depending on what treatment you have, side effects can include:

- problems with erections
- urinary problems (for example leaking urine)
- bowel problems
- tiredness.

You'll have your own reasons for choosing one treatment over another, including how side effects could affect your lifestyle. For example, if you are the receptive partner ('bottom') during anal sex and you're thinking about having radiotherapy, you might want to find out how radiotherapy can affect the bowel and the back passage.

Speak to your doctor or nurse about your treatment options and side effects. Think about letting them know about your sexuality and lifestyle so they know how treatment might impact on you, so they can give you specific information and support. You might also find it helpful to discuss your treatment options with your partner, family or friends.

Find out more about speaking to health professionals on page 19.

Read more about treatment side effects and ways to manage them in our **Tool Kit** fact sheets.



## Sexual side effects

Having treatment for prostate cancer can affect:

- how you feel about yourself sexually
- your desire to have sex (libido)
- your ability to get an erection (erectile function)
- your ability to ejaculate and have an orgasm
- your sexual satisfaction
- your fertility
- the appearance of your body
- your relationships.



For more detailed information about the risk of sexual problems for each different prostate cancer treatment, read our **Tool Kit** fact sheets.

The way that sexual side effects affect you could depend on your approach to sex, sensuality and intimacy. Not all gay and bisexual men have anal sex – but if you do, then the impact of side effects will depend on whether you identify as a ‘top’, a ‘bottom’ or ‘versatile’.

### Experience of sex

If you have a partner or you are sexually active then coping with cancer and side effects may change your relationship and the way you have sex.

Your sex life is unlikely to be the same as it was before cancer – but you don’t have to give up on having closeness, pleasure or fun. Keeping some kind of physical closeness alive, in whatever ways possible, can protect or even improve your relationship.

If you are the receptive partner (‘bottom’) during anal sex a lot of the pleasure comes from the penis rubbing against the prostate, and for this reason it is often referred to as the male g-spot.

Some men who are the receptive partner during anal sex find that if they have surgery to remove their prostate (radical prostatectomy) or radiotherapy, their experience of sex changes.

With all sexual changes you may be able to find ways to work through this and find new ways of giving and receiving pleasure and keeping closeness or intimacy alive.



Our booklet **Prostate cancer and your sex life** provides practical tips to help with your sex life, further information about sex therapy and specific information for partners.

You could also get advice about the impact on your sex life at a Genito-urinary Medicine (GUM) clinic or sexual health clinic. They know a lot about sexual issues, and may be able to advise about what can help.



### Watch Martin's story

For one gay man’s experience of dealing with the impact of prostate cancer on sex and relationships.

### Erection problems

To be the active partner (the ‘top’) during anal sex you normally need a strong erection, so erection problems can be a particular issue. You could try using a constriction ring around your penis together with another treatment like tablets (such as Viagra®), to help keep your erection hard enough for anal sex.

There are also other treatments for erection problems such as vacuum pumps, injections and pellets.

Speak to your GP or doctor or nurse at the hospital to find out more about treatments for sexual problems. They might refer you to a specialist service such as an erectile dysfunction (ED) clinic.

Find out more about speaking to health professionals on page 19.

### Bowel problems and anal sensitivity

If you are the receptive partner ("bottom") during anal sex, then bowel problems after radiotherapy may be a particular issue. Some men also find that the skin inside their anus is more sensitive after radiotherapy.

If you are experiencing bowel problems or sensitivity in this area then wait until these issues have improved before trying anal play or sex. Although short-term problems in the back-passage usually settle-down within six weeks of finishing treatment, there can be some permanent changes in the anal canal.

It's wise to be cautious and perhaps less adventurous than you were before your treatment. Talk to your doctor or nurse for further advice. Find out more about speaking with health professionals on page 19.

Use a condom and try extra lubrication once any sensitivity settles down. Use water soluble or silicone-based lubricants. Never use oil-based lubricants such as body lotions, massage oils, or Vaseline, as they can make the condom break.

Cleaning yourself before sex can make you feel more comfortable, but douching can irritate the lining of your back passage, making it more likely to get infections. So you may prefer to just clean the external area, rather than cleaning inside. The gay men's health charity GMFA provide more general advice about douching.

Find out more about managing bowel problems in our booklet, **Living with and after prostate cancer: A guide to physical, emotional and practical issues**. Read more about radiotherapy in our Tool Kit fact sheets, **External beam radiotherapy** and **Permanent seed brachytherapy**.

### Ejaculation and orgasm

After surgery for prostate cancer (radical prostatectomy) you will no longer be able to ejaculate semen, although you will still be able to have an orgasm. This sometimes also happens after radiotherapy. Some men say that this changes their experience of sex, but after time some men can adapt to it.

Read more about surgery in our Tool Kit fact sheet, **Surgery: radical prostatectomy**.



**I didn't realise how much significance as a gay man I put on having an erection. But I actually discovered I could really enjoy something new, which was sensuality.**

A personal experience

## HIV and prostate cancer

HIV (human immunodeficiency virus) doesn't only affect gay and bisexual men, but as a population gay and bisexual men are more likely to be affected by HIV. This information answers particular questions that gay and bisexual men have asked us about HIV and prostate cancer.

There is evidence that some cancers – such as anal cancer, lung cancer and some lymphomas – are more common in people living with HIV. Researchers have looked at whether men with HIV are more likely to develop prostate cancer. At the moment, we don't know for sure. But there is research that shows that men with HIV can still benefit from treatments for prostate cancer like surgery and radiotherapy. And these men don't seem to get more side effects.

Some medicines used to treat cancer can affect medicines to treat HIV or conditions associated with HIV. If you do have HIV and prostate cancer, it's important that health professionals specialising in HIV and cancer discuss the best treatment options for you. It is also very important that your doctors know about all the medication you take, including over-the-counter and herbal remedies and any recreational drugs.

## Speaking to health professionals

Some men find that their doctor or nurse assumes that they are heterosexual. Health professionals don't record people's sexuality as a standard. But it can help to let your doctor or nurse know about your sexuality and bring your partner to appointments.

Most health professionals will have had equality and diversity training and the NHS has a legal duty to treat people fairly. This means it's illegal to discriminate against you because of your sexual orientation. It is your right to have the same standard of care and treatment as heterosexual men.

But if you feel these rights are not being respected, you can complain.

- If you live in England, contact your nearest Patient Advice and Liaison Service (PALS) at your local hospital or through NHS Choices.
- If you live in Scotland, get more information from NHS National Services Scotland.
- If you live in Wales, Health in Wales has more information.
- If you live in Northern Ireland, get more information from nidirect.

You can get information and support from Stonewall's Information Service, or your local Citizens Advice Bureau.

### Including your partner

If you are in a civil partnership then you have the same healthcare rights as a married couple. A civil partnership also gives your partner the right to be your nearest relative. This means that they can be involved in decisions about your healthcare.

If you're not married or in a civil partnership but do have a boyfriend, then you can nominate them as your point of contact or 'next of kin.' Next of kin can be anybody in your social or family network. Staff must respect your wishes about who this is.

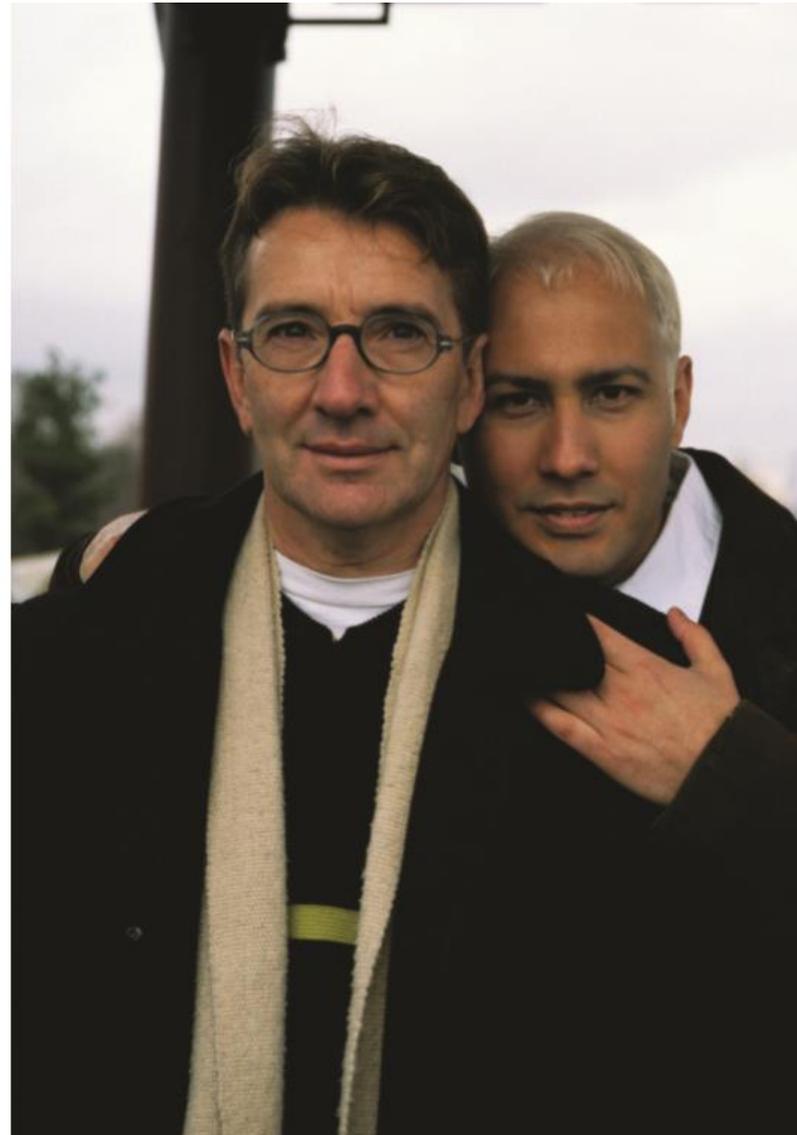
If you give permission, your partner, boyfriend or friend can:

- be involved in medical appointments
- be included in discussions about your diagnosis, treatment and care
- make sure your wishes are represented.



**Having an understanding, supportive partner, who can communicate and share his feelings, and allow me to share my feelings with him – that to me is so powerful.**

A personal experience



## Getting more support

All Prostate Cancer UK services are open to everyone, whether you are gay, bisexual, transgender, heterosexual, single or in a relationship. Partners can also use our services.

### Who can help?

#### Gay and bisexual organisations

You may want to talk to gay and bisexual organisations such as:

- The Lesbian and Gay Foundation
- GMFA – the gay men’s health charity
- Stonewall
- Health with Pride
- LLGS (London Lesbian and Gay Switchboard) Helpline
- Malecare.

#### Your medical team

It could be useful to speak to your nurse, doctor, GP or someone else in your medical team. They can help you understand your diagnosis, treatment and side effects, listen to your concerns, and put you in touch with other people who can help.

#### Our Specialist Nurses

Our Specialist Nurses can answer your questions, help explain your diagnosis and go through your treatment options with you. They’ve got time to listen to any concerns you or those close to you have about living with prostate cancer. Everything is confidential. To get in touch:

- call our Specialist Nurses on **0800 074 8383**
- email from our website at **prostatecanceruk.org** (click ‘We can help’).

#### Trained counsellors

Counsellors are trained to listen and can help you to find your own answers and ways to deal with things. Many hospitals have counsellors or psychologists in their team who are specialists in helping people with cancer – your doctor or nurse at the hospital will be able to let you know if this is available.

There are different types of counselling available. Your GP may be able to refer you to a counsellor, or you can see a private counsellor. To find out more contact the British Association for Counselling & Psychotherapy.

#### Support groups

At local prostate cancer support groups men get together to share their experiences of living with prostate cancer – you can ask questions, offload worries and know that someone understands what you’re going through. Some groups have been set up by local health professionals, others by men themselves. Many also welcome partners, friends and relatives. To find your nearest prostate cancer support group:

- visit our website at **prostatecanceruk.org** (click ‘We can help’)
- ask your nurse
- call our Specialist Nurses on **0800 074 8383**.

There are also some support groups in the UK for gay and bisexual men with prostate cancer. Find details of these support groups on our website at **prostatecanceruk.org** (click ‘We can help’).

- **Out with Prostate Cancer Manchester.** It offers a safe and confidential environment to discuss your concerns and experiences with other gay and bisexual men who deal with the same problems.

- **Out with Prostate Cancer Midlands Gay, Bisexual and Trans Prostate Cancer Support Group** is based in Birmingham. It provides the opportunity to meet and talk to others who share or understand your experience of prostate cancer.
- **METRO WALNUT** is open to gay and bisexual men, and men who have sex with men and their partners. It is also open to any transsexual women on a one to one basis and to the main group by invitation. It's based in London.

#### Our one-to-one support service

Our one-to-one support service is a chance to speak to someone who's been there and understands what you're going through. They can share their experiences and listen to yours. You could discuss treatment options, dealing with side effects, or telling people about your cancer – whatever's important to you.

Our Specialist Nurses will try to match you with a trained volunteer with similar experiences. Let us know if you'd prefer to talk to a gay or bisexual man. Family members can also speak to partners of men with prostate cancer. To arrange it:



- call our Specialist Nurses on **0800 074 8383**
- visit our website at **prostatecanceruk.org** (click 'We can help').

#### Our online community

Our online community is a place to talk about whatever's on your mind – your questions, your ups and your downs. Anyone can ask a question or share an experience. It's a place to deal with prostate cancer together.

Sign up on our website at **prostatecanceruk.org** (click 'We can help').

## More information from us

### The Tool Kit

The Tool Kit information pack contains fact sheets that explain how prostate cancer is diagnosed, how it's treated and how it may affect your lifestyle. Each treatment fact sheet also includes a list of suggested questions to ask your doctor. Call our Specialist Nurses for a personally tailored copy.

### Leaflets and booklets

We have a range of other leaflets and booklets about prostate cancer and other prostate problems.

### To order publications:

All our publications are free and available to order or download online. To order them:

- Call us on **0800 074 8383**
- Visit our website at **prostatecanceruk.org/publications**

### Call our Specialist Nurses

If you want to talk about prostate cancer or other prostate problems, call our Specialist Nurses in confidence. You can also email the nurses using the contact form on our website. Visit **prostatecanceruk.org** and click on 'We can help'.



**Speak to our  
Specialist Nurses**  
**0800 074 8383\***  
**prostatecanceruk.org**

\* Calls are recorded for training purposes only. Confidentiality is maintained between callers and Prostate Cancer UK.

## Other useful organisations

### Citizens Advice Bureau

[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

Online advice [www.adviceguide.org.uk](http://www.adviceguide.org.uk)

Advice on a wide range of issues including financial and legal matters. Find your nearest Citizens Advice Bureau in the phonebook or online.

### GMFA

[www.gmfa.org.uk](http://www.gmfa.org.uk)

Provides health information for gay men.

### Health in Wales

[www.wales.nhs.uk](http://www.wales.nhs.uk)

Information about health and health services in Wales.

### Health with Pride

[www.healthwithpride.nhs.uk](http://www.healthwithpride.nhs.uk)

Online health resource for lesbian, gay, bisexual and transgender people. Includes information on cancer issues and erection problems.

### LLGS London Lesbian and Gay Switchboard)

[www.llgs.org.uk](http://www.llgs.org.uk)

Helpline: 0300 330 0630

Free and confidential support and information for lesbian, gay, bisexual and transgendered communities throughout the UK.

### Malecare

[malecare.org](http://malecare.org)

American male cancer charity. Provides information and support for gay, bisexual and transgender people and men who have sex with men, including an online forum.

### NHS National Services Scotland

[www.nhsnss.org](http://www.nhsnss.org)

Supports the NHS in Scotland. Provides information about making a complaint about NHS services in Scotland.

### nidirect

[www.nidirect.gov.uk](http://www.nidirect.gov.uk)

Information about government services in Northern Ireland, including health services.

### Stonewall

[www.stonewall.org.uk](http://www.stonewall.org.uk)

Infoline: 0800 050 20 20

Information for anyone looking for details about gay rights.

### The Lesbian and Gay Foundation

[www.lgf.org.uk](http://www.lgf.org.uk)

Helpline: 0845 330 30 30

Information, advice and support for lesbian, gay and bisexual people.

## About Prostate Cancer UK

Prostate Cancer UK fights to help more men survive prostate cancer and deal with other prostate diseases so they can enjoy a better life. We support men by providing vital information and services. We find answers by funding research into causes and treatments and we lead change, raising the profile of all prostate diseases and improving care. We believe that men deserve better.

At Prostate Cancer UK, we take great care to provide up-to-date, unbiased and accurate facts about prostate diseases. We hope these will add to the medical advice you have had and help you to make decisions. Our services are not intended to replace advice from your doctor.

References to sources of information used in the production of this booklet are available at [prostatecanceruk.org](http://prostatecanceruk.org)

### **This publication was written and edited by:**

Prostate Cancer UK's Information Team.

### **It was reviewed by:**

- Dawn Doran, PhD Researcher, "The lived experience of gay men with prostate cancer", University of Central Lancashire, Preston, Lancashire
- Darryl Mitteldorf, Licensed Clinical Social Worker, Executive Director, Malecare Cancer Support, New York, USA
- Mark Pedder, Macmillan Urology & Oncology CNS, Luton & Dunstable Hospital, Luton
- Sean Ralph, Health and Care Professions Council registered Therapy Radiographer & Out with Prostate Cancer support group Treasurer, Manchester

- Dr. Daniel Saunders, Consultant in Clinical Oncology, Nottingham University Hospitals NHS Trust
- James Taylor, Senior Health Officer, Stonewall, London
- Dr Tim Wong, Senior Project Officer – Awareness and Education, Prostate Cancer Foundation of Australia
- Prostate Cancer UK volunteers and other gay and bisexual men affected by prostate problems and prostate cancer
- Prostate Cancer UK Specialist Nurses

### **Tell us what you think**

If you have any comments about our publications, you can email: [literature@prostatecanceruk.org](mailto:literature@prostatecanceruk.org)



## Donate today – help others like you

Did you find this information useful? Would you like to help others in your situation access the facts they need? Every year, 40,000 men face a prostate cancer diagnosis and millions more face other prostate diseases. Thanks to our generous supporters, we offer information free to all who need it. If you would like to help us continue this service, please consider making a donation. Your gift could fund the following services:

- £10 could buy a Tool Kit – a set of fact sheets, tailored to the needs of each man with vital information on diagnosis, treatment and lifestyle.
- £25 could give a man diagnosed with a prostate problem unlimited time to talk over treatment options with one of our specialist nurses.

To make a donation of any amount, please call us on **0800 082 1616**, visit [prostatecanceruk.org/donations](http://prostatecanceruk.org/donations) or text **PROSTATE to 70004\***. There are many other ways to support us. For more details please visit [prostatecanceruk.org/get-involved](http://prostatecanceruk.org/get-involved)

\*You can donate up to £10 via SMS and we will receive 100% of your donation. Texts are charged at your standard rate. For full terms and conditions and more information, please visit [prostatecanceruk.org/termsprostatecanceruk.org/terms](http://prostatecanceruk.org/termsprostatecanceruk.org/terms)



The quotes with the photos in this booklet are not the words of the people who appear.



**Speak to our  
Specialist Nurses**

**0800 074 8383\***

**prostatecanceruk.org**



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**🐦 Follow us on Twitter: @ProstateUK**

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To be reviewed November 2015

**Call our Specialist Nurses from Mon to Fri 9am - 6pm, Wed 10am - 8pm**

\* Calls are recorded for training purposes only.  
Confidentiality is maintained between callers and Prostate Cancer UK.

Prostate Cancer UK is a registered charity in England and Wales (1005541)  
and in Scotland (SC039332). Registered company number 2653887.

2674 GAY/JU/2014

## **Appendix 15: Presentations, abstracts and articles resulting from the study**

### **Published abstract**

Doran D, Beaver K, Williamson S, Wright K (2013). An Exploration of the Psychosocial Impact of Prostate Cancer on Gay Men: A Review of Current Literature. *Psycho-Oncology*. 22(Suppl.1):26

### **Oral and Poster Presentations**

Doran, D; Beaver, K; Williamson, S; Wright, K. (2014) "It's not just about prostate cancer, it's about being a gay man": How can phenomenology help to uncover the experiences of gay men with prostate cancer? Oral session presented at: 20<sup>th</sup> Qualitative Health Research Conference, British Columbia, Canada

Invited Speaker: A Gay and Bisexual Man's Introduction to Male Cancers - Resource Launch Event. The Lesbian and Gay Foundation, Manchester - August 15th 2014

Doran, D; Beaver, K; Williamson, S; Wright, K. (September, 2013). Looking beyond the surface: Learning from in-depth interviews with gay men about their experiences of prostate cancer. Oral session presented at: Changing Attitudes to Cancer Conference, University of Central Lancashire, Preston.

Doran, D; Beaver, K; Williamson, S; Wright, K. (May, 2013). An exploration of the psychosocial impact of prostate cancer on gay men: A review of current literature. Poster session presented at: Health Research with Real Impact conference, University of Central Lancashire, Preston.

Doran, D; Beaver, K; Williamson, S; Wright, K. (January, 2013). An exploration of the psychosocial impact of prostate cancer on gay men: A review of current literature. Poster session presented at: British Psycho-Oncology Society (BPOS) Conference, Southampton.

Doran, D; Beaver, K; Williamson, S; Wright, K. (July, 2012). Prostate Cancer and Gay Men: Uncovering Hidden Voices. Oral session presented at: Graduate Research School Annual Research Conference. Preston.

### **Miscellaneous**

Doran, D. PhD Student spotlight: Gay Men with Prostate Cancer. Published in British Psycho-Oncology Society Newsletter Issue 2 (2012).