CANCER, SEX AND INTIMACY: THE EXPERIENCES OF GAY, BISEXUAL AND QUEER MEN

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A thesis submitted in partial fulfilment of the requirements of the
University of East London for the degree of Professional Doctorate
in Clinical Psychology

May 2022

Word count: 28,090

AKNOWLEDGMENTS

To all the participants who kindly gave up their time to speak with me about such a personal and intimate topic, thank you for your generosity and for being so open and honest in your accounts. This thesis could never have come to fruition without you and I feel so privileged to have been able to meet and speak with you all.

A huge thank you to my supervisor, Dr Ken Gannon, for all your guidance and words of wisdom throughout this whole process. I have been so grateful for your calming, supportive and containing presence.

To my wonderful friends and family, thank you for the countless check-ins, words of encouragement, and the very much needed distractions. You have kept me grounded and kept the motivation going whenever it dwindled.

A special thank you to Cara for being an unwavering source of support through all the recent ups and downs. Thank you for listening to me, encouraging me, and for reeling off our motivational mantras. Your friendship has kept me going when the challenges felt vast and I cannot thank you enough for that.

ABSTRACT

Background: Cancer and its treatments can significantly impact on a person’s sexuality and intimacy, resulting in considerable changes to sexual function, relationships, and self-concept. People from sexual minorities often have to contend with these changes whilst navigating healthcare settings which are centred around heteronormative principles and practices, resulting in difficulties receiving relevant support and advice. Research in this area has typically focused on the impact of sexual and reproductive cancers and little is known about how sexual minority men experience sexuality and intimacy across cancer types.

Method: A qualitative methodology was adopted to explore how gay, bisexual and queer (GBQ) men experience sexuality and intimacy in the context of cancer. Six men who had been diagnosed with a range of cancer types (prostate, bowel and multiple myeloma) took part in semi-structured interviews. Data was analysed using reflexive thematic analysis from a critical realist perspective.

Results: Three overarching themes were identified. ‘Navigating altered sexuality and relationships’ explored how participants experienced changes and challenges in their sexual and intimate relationships. ‘Undergoing changes in the self’ described the impact on the participants’ identity and psychological wellbeing. ‘Seeking community and support’ captured the importance of support, information and advice from peers and healthcare professionals.

Conclusions and Implications: The findings indicate that regardless of cancer type, sexuality and intimacy are disrupted, subsequently affecting relationships, self-concept and psychological wellbeing. Support groups, peer mentoring, and open conversations about sex with healthcare professionals are needed to support GBQ men in navigating and overcoming sexual changes. Increased awareness and an appreciation of people with cancer as sexual beings is needed to normalise conversations about cancer and sex.

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1. INTRODUCTION

1.1. Cancer

1.1.1. Cancer Terminology

Cancer is a disease caused by abnormal cells dividing in an uncontrolled way (Cancer Research UK, 2022b). Cancer can start in any location in the body and spread to other tissues and organs, a process known as metastasis. Metastases are the primary cause of death from cancer (World Health Organization, 2022).

For the purpose of this study, a broader definition of cancer will be used. Cancer is more than a disease; it can be considered a 'life narrative' consisting of many chapters, filled with decisions, wins, losses, and considerable pain and grief (Kreitler, 2019). Cancer is not a singular event but rather "a sequence of events linked with one another, which begins with the first signs of the disease, continues with treatments, hospitalisations, convalescence, and remission, and ends, possibly, with recurrence or death" (Guex, 1994, p. 58). This more holistic definition of cancer allows for a broader understanding of how cancer impacts the lives of sexual minorities.

1.1.2. Prevalence And Policy

Around 375,000 new cases of cancer are diagnosed in the United Kingdom (UK) each year (Cancer Research UK, 2022c). The incident rate of all cancers combined has steadily risen annually and in the last ten years alone, has risen by nearly 4%. Furthermore, the cancer survival rate in the UK has doubled in the last 40 years; now more than half of people diagnosed with cancer will live for ten years or more (Cancer Research UK, 2022e), though this figure hides considerable variation between cancer types. Whilst in part attributable to advances in medical oncology, increased survival rates are linked to a rise in public health initiatives, better screening programs leading to earlier detection, improved diagnostics, and the UK's ageing population (Macmillan, 2013a). In 2021, Macmillan reported that three million people were living with cancer in the UK (Macmillan, 2021b). This number is expected to grow by approximately one million every decade, with 5.3 million people predicted to be living with cancer by 2040 (Maddams et al., 2012).

The vast number of people living with and beyond cancer has caused discourses around cancer to shift towards survivorship. Whilst the notion of survivorship has been criticised for obscuring individual differences and implying trauma (Bell & Ristovski-Slijepcevic, 2013), it also gives hope. Organisations such as Macmillan have been particularly influential in promoting more hopeful narratives which challenge negative stereotypes and societal beliefs about cancer (Macmillan, 2013a). There has also been more interest in academia, such as with the establishment of the Journal of Cancer Survivorship in 2007, and increased funding for public health initiatives and research.

The impact of cancer does not always end when treatment finishes, and so with more people in need of treatment and more people living with the long-term side-effects of cancer and its treatment, there are cost implications for the National Health Service (NHS) and the wider economy (Laudicella et al., 2016). This generates concern about the additional strain placed on the already resource-stretched NHS. Although many people will return to pre-diagnostic levels of health and wellbeing once treatment ends, one in four people will face long-term physical and psychosocial consequences (Macmillan, 2013a). As a result, psychological wellbeing and quality of life in survivorship are now recognised as key health priorities. The *NHS Long Term Plan* (NHS, 2019) sets out ambitious goals to not only improve survival rates and earlier diagnosis, but to also enhance quality of life and reduce inequalities in cancer care. Building on the strategy outlined in *Achieving World-Class Cancer Outcomes* (Independent Cancer Taskforce, 2015), recovery packages were introduced as a way of meeting the physical and psychosocial needs of each patient. This essential intervention reflects a person-centred approach to care, by providing holistic assessments and care planning for any presenting needs and difficulties (NHS England, 2016).

1.1.3. The Impact Of Cancer

Each person's experience of cancer is different and will be determined by the type of cancer they have been diagnosed with and their unique set of personal and social circumstances. Nevertheless, regardless of the cancer type, people are likely to experience significant physical and psychosocial side-effects, disruptions to quality of life, altered relationships, and existential issues (Goerling & Mehnert-Theuerkauf, 2018). The impact can be felt at any point of the cancer journey and not only by people diagnosed with cancer (PWC), but also by family members, friends, carers, and intimate partners (Hodges et al., 2005).

1.1.3.1. *Psychological impact:*

Despite more hopeful narratives around survivorship, cancer is still perceived as a death sentence by many (Falvo & Holland, 2017). Whilst this belief is stigmatising, it is potentially warranted given the 166,000 cancer deaths in the UK each year (Cancer Research UK, 2022d). Beliefs and attitudes towards cancer are shaped by societal, cultural and community discourse. Some cultural beliefs see cancer as ‘contagious’ or that a diagnosis is a ‘punishment from God’ (Lord et al., 2012). These misunderstandings or general lack of knowledge can add to the psychological distress of PWC and those in their social network.

Receiving a cancer diagnosis and undergoing treatment understandably prompts a wide range of emotional responses such as shock, anxiety, fear, sadness and anger (Cordova et al., 2017). Anxiety and depression are more common among cancer patients compared to the general population (Pitman et al., 2018; Walker et al., 2013), with psychological distress found in 52% of patients (Mehnert et al., 2018). Some people may also experience aspects of their cancer journey as traumatic (Abbey et al., 2015). Cancer survivors face lingering fears of recurrence which is considered one of the most distressing consequences (Simard et al., 2010). Psychological distress has been found to adversely affect treatment, recovery outcomes and quality of life (Zhu et al., 2017). Increased vulnerability has been identified in those who previously accessed psychiatric services, where a cancer diagnosis was associated with greater risk of mortality (Klaassen et al., 2019).

Brennan’s (2001) social-cognitive transition model of adjustment can be used to understand some of the psychological processes that occur for PWC. People have ‘mental models’ of the world which allow them to predict and navigate their lives as a coherent narrative. The shock of cancer disrupts these mental models, resulting in a period of fundamental adjustment whereby the individual, and those in their social network, learn from and adapt to the multiplicity of changes that cancer brings. The emotional distress observed in cancer patients can therefore be seen as appropriate given the demands of cancer; people need time for their mental models to adjust to new information and develop coherency. Factors can disrupt this adjustment process, such as sociodemographic factors (e.g., income), cancer-related factors (e.g., fatigue, cancer stage, physical function) and psychosocial factors (e.g., optimism, trait anxiety, social support, coping strategies) which can result in PWC struggling to adjust, resulting in more long-term psychological difficulties (Brandão et al., 2017).

Qualitative interviews and multidimensional quality of life questionnaires have created a more nuanced picture of cancer, by suggesting that in addition to adverse physical and psychosocial effects, positive life changes can occur (Ferrell et al., 1995; Zebrack & Cella, 2005). This phenomenon is referred to as post-traumatic growth (Tedeschi & Calhoun, 1995), whereby following a traumatic or stressful event, people can also experience improved changes to their life philosophy, relationships and self-concept.

1.1.3.2. *Physical impact:*

Symptoms of cancer will vary with each cancer type, however people commonly report pain, fever, weakness, weight loss, and disturbed sleeping and eating habits (Kirkova et al., 2006). Treatment for cancer is often invasive and can involve a combination of surgery, chemotherapy, radiotherapy, hormone therapy and immunotherapy. Each intervention produces its own set of short and long-term side-effects, including hair loss, nausea, soreness, dizziness, poor concentration, sexual dysfunction, infertility, and gastrointestinal problems (Gegechkori et al., 2017; Kreitler, 2019; Tipton, 2015); the list is seemingly endless. Often side-effects have to be treated themselves, usually with drugs, producing additional side-effects. One of the most commonly reported symptoms is fatigue which often continues once treatment is complete, significantly impacting on quality of life due to reduced ability to function, socialise and work (Al Maqbali et al., 2021).

Given the extensiveness and intensity of physical symptoms and side-effects, it is unsurprising that people experience altered body image as a result of cancer. PWC often report feeling ‘betrayed’ by their bodies (Kreitler, 2019). They may feel a sense of distrust towards their body and feel insecure engaging in activities they once enjoyed (Lehmann et al., 2015). Surgical scaring, loss of an organ such as a breast, or other bodily changes such as weight loss, can also serve as constant reminders of the cancer (Kreitler, 2019).

1.1.3.3. *Social impact:*

Considering the wide-reaching impact of cancer on people’s lives, it is unsurprising that people feel stigmatised and isolated from their usual social networks (Wells & Kelly, 2008). Cancer survivors are 1.4 times more likely to be unemployed compared to the general population (de Boer et al., 2009), with barriers such as poor physical and mental health preventing people from working (Macmillan, 2013b). PWC also often feel misunderstood in their experiences (Adams et al., 2017, 2018) and as such, may be reluctant to share details with others, instead preferring to deal with the consequences privately (Davison et al., 2000). This is particularly true if they perceive aspects of their illness to be embarrassing. PWC may seek a trustworthy person to confide in, either through their existing support networks or cancer-specific groups. If this is not possible, patients can be left with feelings of isolation and loneliness which adversely impact physical and mental health outcomes (Friedman et al., 2006; Kroenke et al., 2006). Isolation has been reliably identified as a risk factor for cancer mortality, especially among men living alone (Kraav et al., 2021; Moore et al., 2018).

Literature on help-seeking behaviour in non-cancer-specific populations shows that men have low levels of help-seeking behaviour for both health and psychological problems (Galdas et al., 2005; Yousaf et al., 2015) and are less likely than women to seek support for health and psychological issues (Galdas et al., 2005; Liddon et al., 2018; van Osch et al., 2007). Ettridge et al.’s (2018) qualitative study found that most of the 20 men in their sample living with prostate cancer (PCa) did not seek or receive support due to embarrassment and anticipated awkwardness, a desire to be autonomous, and not wanting to burden others. This indicates that men in particular may need active encouragement through their cancer journey to seek support and address physical and psychosocial needs.

It is important to note that the COVID-19 pandemic significantly exacerbated the isolating and distressing impact of cancer. During this time, PWC reported elevated anxiety due to delayed diagnoses, disrupted treatment and being labelled as ‘vulnerable’ by the UK Government (Swainston et al., 2020). The imposed lockdowns, limits on social mixing, and a ban on visitors in hospital added a further layer of loneliness to a group of people already struggling with isolation (Garutti et al., 2020; Hartman et al., 2020; Sannes et al., 2020).

1.2. Cancer and Sexuality

1.2.1. Sexuality Terminology

In accordance with The World Health Organization (WHO), this study will define sexuality as:

> “A central aspect of being human throughout life [that] encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships.” (WHO, 2006, p. 5)

Sexuality is far more than the act of having sex, but rather consists of a complex amalgamation of psychological, emotional and social factors. It is a fundamental aspect of quality of life for many people, with one large cohort study indicating that 62% of men and 43% of women reported sexual health and sexual satisfaction to be integral to quality of life (Flynn et al., 2016). There is no definite age limit determining the end of a healthy sex life, however societal constructs and ageist stereotypes perceive older adults as ageing out of sexuality and becoming asexual (Ayalon & Tesch-Römer, 2018). Sexual expression may indeed change over the lifespan but sexuality remains an important aspect of quality of life for many older adults (Srinivasan et al., 2019).

1.2.2. Impact Of Cancer On Sexuality And Intimacy

Research on cancer and sexuality has historically focused on cancers that affect sexual or reproductive organs (e.g., breast, gynaecological, prostate and testicular cancers). Literature reviews on sexuality post-breast and gynaecological cancer treatment indicate that women can face long-term negative effects on fertility, arousal, orgasm, vaginal lubrication, and sexual pleasure (Cleary & Hegarty, 2011; Gilbert et al., 2010b). These effects, as well as altered body image, can lead to decreased feelings of femininity and attractiveness, lower sexual self-esteem, increased sexual dissatisfaction and less frequent sexual activity (Cleary & Hegarty, 2011; Gilbert et al., 2010b). Research on the impact of prostate and testicular cancer indicate that men also experience a variety of negative effects, including difficulties with ejaculation, erectile dysfunction, orgasm, urinary incontinence, fertility, and low libido (Gurevich et al., 2004; Incrocci, 2006; Stanford et al., 2000). These effects are associated with feelings of embarrassment and anxiety, resulting in an impaired sense of masculinity and self-worth (Bokhour et al., 2001), due to compromised sexual performance being perceived as ‘less manly’.

More recently, research has demonstrated that the impact on sexuality is not limited to cancers of ‘sexual’ sites, with studies indicating that 60% of people diagnosed with a range of cancer types report long-term sexual problems (Beckjord et al., 2014; Goldfarb et al., 2013; Schover et al., 2014). The prevalence varies with cancer site and treatment type, but people diagnosed with cancers such as leukaemia, multiple myeloma, bowel and liver cancers report similar negative side-effects, including problems with erectile function, arousal, desire, body image, fertility, sexual confidence and pleasure (Gilbert, Ussher, & Perz, 2013; Ussher et al., 2012). Sexual impairments in these cancers stem from treatment damaging physiological systems required for a healthy sexual response (Schover, 2019). Due to the impact of treatment on fertility, techniques such as cryopreservation of sperm and eggs offer hope to PWC and partners who wish to have children in the future. However, research suggests that many cancer patients are not informed about potential changes to sexual function and fertility, meaning that fertility preservation interventions remain underused in industrialised countries (Schover et al., 2014). Specific interventions will also have their own unique impact on sexuality, such as having a colostomy which can result in changed body image, fear and anxiety during sexual intercourse, decreased sexual desire and avoidance of sex (Vural et al., 2016). Psychosocial factors, including the stress, fatigue and disruption to normal life that cancer brings, also contribute to sexual problems. The symbiotic nature of psychological distress and sexual difficulties means that problems become embedded and perpetuate one another in a vicious cycle of sexual and emotional distress (Dunn et al., 1999; Van Minnen & Kampman, 2000), with sexual distress exerting a negative impact on overall wellbeing and quality of life (Santos-Iglesias et al., 2018).

There is a growing recognition of partners needs in this area, with studies finding that partners of PWC report a decrease in their own libido, fears of initiating sex, and feeling unwanted or unattractive due to cessation of sex (Hawkins et al., 2009; Sanders et al., 2006; Ussher et al., 2012). Partners who assume a caring role report difficulty positioning their loved one as a sexual being, and instead find themselves repositioning them as a child or an “asexual sick patient” (Gilbert et al., 2010a, p. 1006), thus impairing arousal and desire to initiate sexual activity.

The effect of cancer has ramifications beyond sexual function, with PWC and their partners also reporting diminished intimacy. When sexual activity stops in the context of cancer, often so do other forms of intimacy, such as affectionate touching (Ussher et al., 2012), due to the belief that these moments of closeness will lead to sex, which is either not possible or does not feel appropriate at that time. This creates tension in relationships, with PWC and their partners left feeling rejected, angry and upset, and couples feeling emotionally distanced from one another (Hawkins et al., 2009). These problems can have devastating impacts on relationships, particularly if couples are unable to communicate their needs effectively, and can result in couples failing to renegotiate their sexual and intimate relationship. Feeling underconfident talking about sexuality and not wanting to upset their partner or make the PWC feel guilty for not being able to perform sexually, are key factors in preventing renegotiation from occurring (Gilbert, Ussher, & Perz, 2013).

Broader social constructions of sexuality can help provide a framework to understand further why many heterosexual couples struggle to renegotiate sexuality in the context of cancer. Historically, understandings of sex have been bound by the ‘heterosexual matrix’ (Butler, 1993), whereby traditional male and female gender roles are performed through normative sexual practices, described as the “coital imperative” (Jackson, 1984, p. 44). The coital imperative is the notion that only penetration of the vagina by a penis (coitus) constitutes ‘real sex’. Failure to perform coitus has, in the past, been considered dysfunctional and other sexual practices have been dismissed (Few, 1997), linked to the often religious belief that the sole purpose of sex is reproduction. This narrow and dated understanding of sex may explain why frequency of sexual activity decreases and sometimes stops when penetrative sexual intercourse is no longer possible.

Despite these difficulties, many PWC and their partners report that sexuality is still important to them and still see themselves as sexual beings with a desire to have sex and be intimate. Some people (particulalry women) report being able to sexually reinvent themselves post-cancer and express greater sexual confidence, more positive self-image, and feel more emotionally evolved as a result (Gilbert, Ussher, & Perz, 2013). Assumptions, however, are made about cancer patients; they are often viewed through a neutered lens, with a ‘sanitised’ version of a cancer survivor being promoted by global cancer charities (Goh, 2021). Society does not expect cancer patients to be empowered sexual beings with fantasies and desires, an experience which is often shared with disabled people (Tepper, 2000).

Evidence suggests that sexuality and intimacy are important sources of support and coping throughout people’s cancer journeys (Ussher, Perz, Gilbert, Wong, & Hobbs, 2013). Some people report improved relationships as a result, with better communication, enhanced mutual understanding, and more intimate and emotionally close bonds. Many PWC and their partners are able to have satisfying and meaningful sexual relationships, particularly when provided with support and advice (Gilbert et al., 2010a; Gilbert, Ussher, & Perz, 2013; Ussher et al., 2012; Ussher, Perz, Gilbert, Wong, & Hobbs, 2013). Being less bound by the coital imperative and moving away from a phallocentic way of having sex appears to be instrumental to this, with people exploring alternative sexual practices such as oral sex, mutual masturbation, massage, and encorporating sex toys. Effective and open communication was deemed an important factor in enabling sexuality and intimacy to remain in relationships.

1.2.3. Support For Sexual Difficulties

In line with NHS guidance on recovery packages, rehabilitation, clinical support and wellbeing events should be offered to those experiencing "specific issues relevant to the individual's type of cancer, for example, body image and sexual function" (NHS England, 2016, p. 11). Whilst promising, this implies that support may be limited to people diagnosed with sexual cancers, where the impact on sexual function may be more obvious. A study of 659 Australian cancer survivors suggests this may be the case, with 48% of people with sexual cancers reporting that they had discussions of sexuality with a healthcare professional (HCP), compared to only 32% of people with non-sexual cancers (Gilbert et al., 2016). In general, only 26% of cancer survivors reported receiving support for their sexual difficulties (Beckjord et al., 2014). It is therefore unsurprising that patients ranked sexual problems at their top unmet need (Schover et al., 2014).

Macmillan's (2019) booklet *Cancer and Your Sex Life* provides guidance on seeking support for sexual difficulties, however it appears to place the onus on the PWC to raise such issues with their medical team. Given societal stigma around talking about sex, which can be particularly felt by individuals from minoritised groups where beliefs and attitudes towards sex may differ from the dominant norm (e.g., Meston et al., 1998), it may be difficult for patients to raise this with HCPs. Some positive accounts have been reported by PWC whereby HCPs were understanding, respectful and knowledgeable advising on sexuality in the context of cancer (Gilbert et al., 2016). However, many negative accounts have also been reported; PWC felt the doctors and nurses lacked relevant information and provided unsatisfying advice, and at times, felt their concerns were trivialised in relation to 'legitimate' medical concerns, with some doctors saying they were more concerned with the patient's survival than their sexual function (Gilbert et al., 2016; Hordern & Street, 2007).

HCPs have acknowledged that discussing sexual function in the context of cancer is their responsibility, however it is not routinely discussed (Krouwel et al., 2015). Barriers to this include insufficient training and feeling ill-equipped to provide advice, not having a motive to initiate discussions, and feeling uncomfortable discussing intimate details (Krouwel et al., 2015; Moore et al., 2013). HCPs are even more reluctant to give advice about sexuality to non-heterosexual patients (Tamargo et al., 2017) or those from minoritised cultures and nationalities (Wray et al., 2014). Some HCPs' advice may be confined within the heterosexual matrix and only provide information about vaginal intercourse, refraining from advising on alternative sexual practices (Ussher, Perz, Gilbert, Wong, Mason, et al., 2013). This contrasts with PWC reporting a desire for support with a range of sexual issues, including feeling attractive, having safe sex during and after cancer treatment, and coping with sexual dysfunction (Flynn et al., 2016; Reese et al., 2017). Men report more of a desire to have these discussions with HCPs than women (Gilbert et al., 2016).

When required, specialist, psychosexual support is available on the NHS, but it is under-resourced. A minority of NHS oncology teams have sexual rehabilitation pathways embedded within their service or HCPs who have had some psychosexual training. Otherwise, patients can be referred to their local sexual health service, if available, whilst others may be forced to seek private support. Support includes behavioural or biomedical interventions to overcome sexual difficulties (e.g., penile pumps or injections for erectile dysfunction) and advice around adjusting sexual expression. Psychological interventions drawing on models such as cognitive behavioural therapy (CBT) and emotionally-focused couples therapy, can be implemented to explore issues of desire, orgasm, sexual avoidance and relationship difficulties (Grayer, 2016; Hummel et al., 2018). It is important that PWC and their partners are provided with support since successful sexual rehabilitation post-cancer not only improves sexual function and satisfaction, but is also related to enhanced quality of life and reduced low mood (El-Jawahri et al., 2018; Flynn et al., 2016; Hummel et al., 2018).

1.3. Cancer and Sexual Minorities

1.3.1. Sexual Minority Labels[1]

There is no absolute way to label this group of people, since each person's journey with their sexual orientation (SO) is unique, and labels will hold different meanings to each person. This study will use the terms people tend to use to label themselves, such as gay, bisexual and queer (GBQ). Lack of robust data collection and variation in individual willingness to openly identify as lesbian, gay, bisexual, transgender, queer and/or any other sexual or gender identity label (LGBTQ+) means that precise numbers are unknown. Positioning LGBTQ+ people as being a minority may therefore be unfitting, however, in order to be consistent, the term 'sexual minorities' will also be used as it makes a distinction between sexual and gender minorities which both fall under the LGBTQ+ umbrella term. References to the LGBTQ+ community will still be made when referring to the population more broadly.

1.3.2. Cancer Risk Factors

Despite major advances in cancer care, less attention has been given to diminishing the burden in the LGBTQ+ population (Margolies & Brown, 2018). Sexual minorities were declared a disparity population in 2016 by the National Institutes of Health, yet research exploring their specific cancer needs is still limited (Waters et al., 2021). Some evidence suggests that sexual minorities are exposed to greater cancer risk factors than heterosexual people, with increased rates of smoking tobacco (Roberts et al., 2017; Shahab et al., 2017) and greater drug and alcohol misuse (Mitchell et al., 2009). These lifestyle choices increase the risk of preventable cancers (Macmillan, 2021a). However, a large UK study of self-reported cancer incidence found that cancer site distribution did not significantly vary between sexual minorities and heterosexual populations, except for HPV and HIV related cancers (Saunders et al., 2017).

Further understanding of cancer risk factors can be sought from drawing on minority stress theory which suggests that sexual minorities are at greater risk for health problems than heterosexual people, due to facing greater exposure to

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[1] A more detailed explanation of labels used in this study can be found in Appendix A.

social stressors related to prejudice and discrimination (Conron et al., 2010; Meyer, 2003). Social stressors can range from microaggressions, to being physically attacked, to the cognitive burden associated with negotiating coming out (Meyer, 2003; Meyer et al., 2008). Stress is known to adversely impact on health (e.g., Thoits, 2010) and increase the likelihood of unhealthy coping mechanisms such as smoking (Kassel et al., 2003). Many sexual minority PWC therefore experience the distress of cancer compounded by pre-existing stress associated with being part of a minoritised group.

Sexual minorities are also less likely to engage in cancer screening programs due to fear of prejudice and are more likely to present at services with more advanced illness (Williams et al., 2013). The lack of routinely collected data on SO within the NHS means that robust information about sexual minorities living with cancer does not exist. This perpetuates the risk of not meeting the needs of this population by keeping them hidden, meaning that services risk providing inadequate care and being commissioned ineffectively (Public Health England, 2014).

1.3.3. Experiences With Cancer Care

The National Cancer Patient Experience Survey repeatedly finds that sexual minority patients in the UK report more dissatisfaction with their overall cancer care compared to their heterosexual counterparts (Picker, 2020). Studies from both the UK and internationally suggest that sexual minority PWC experience and fear homophobia and discrimination when accessing cancer care (Hayman et al., 2013; Hill & Holborn, 2015). Many sexual minority patients find it stressful deciding whether to come out to the many HCPs involved in their care, due to worrying about the reaction they will receive and whether this will negatively impact on their care (Stonewall, 2018). Around 55% of sexual minority PWC have experienced assumptions about their gender identity and/or SO in the NHS (Hudson-Sharp & Metcalf, 2016), with this reported to be one of the most frustrating microaggressions (Macmillan, 2014). Sexual minority PWC are less likely to be given written information about their cancer type and when they are, the language and imagery in the materials tend to assume heterosexuality (Margolies, 2014). A systematic review indicated that HCPs also lacked knowledge of LGBTQ+ specific issues, further resulting in inadequate information and advice (Webster & Drury-Smith, 2021).

Sexual minorities are more likely to be single, less likely to have children and may be alienated from their biological family (Almack et al., 2010; Barrett et al., 2015), resulting in many sexual minority individuals forming their own networks of ‘chosen family’. Older GBQ men with cancer are particularly likely to be single and live alone, compared to LBQ women and heterosexual people (Levy & Taylor, 2013; Macmillan, 2014). Limited support may exacerbate cancer-related isolation, resulting in a greater dependence on NHS services and existing relationships. Cancer support groups, which are usually a meaningful source of support for PWC, may not always feel accessible to sexual minorities who report experiencing hetero-sexism when attending mainstream groups, and feel uncomfortable coming out to their peers and bringing their partners (Brown & McElroy, 2018; Capistrant et al., 2016; Carr, 2018).

All these factors make it extremely difficult for the person to be seen and treated as a whole person and can lead to feelings of anxiety, invisibility, isolation and frustration along the cancer care pathway (Lisy et al., 2018). Sexual minority individuals are already at risk of poorer mental health compared to heterosexual people due to their experiences of discrimination and marginalisation. Rates of anxiety and depression are 1.5 times higher in the LGBTQ+ population than the general population (Stonewall, 2018). Sexual minority PWC facing the additional psychological burden of cancer can further put patients at risk, especially if their needs are not adequately met by services. Indeed, one study indicated that sexual minority PWC are more likely to experience depression and trauma symptoms compared to the general population (Kamen et al., 2015), however the association between SO, mental health and cancer requires further research attention (Boehmer et al., 2012).

Consideration also needs to be paid to the additional barriers for patients who identify with multiple intersecting identities (Burnham et al., 2008), and who may as a result experience not just homophobia, but additional discrimination such as sexism, racism and ageism (Kamen et al., 2019).

1.4. Cancer, Sexuality and Sexual Minorities

Most research to date exploring the impact of cancer on sexuality has neglected the experiences of sexual minorities, with studies predominately using heterosexual and partnered samples. It is important to explore this topic in a range of populations where sexuality may have different meanings. Evidence suggests non-heterosexual relationships may differ from heterosexual ones in several domains that are relevant to research on cancer and sexuality, such as communication, connectedness and conflict resolution (Green et al., 1996; Kurdek, 2003). There also tends to be differences in sexual expression between heterosexual and LGBTQ+ couples, with oral and anal sex most frequently practiced between men who have sex with men (Lee et al., 2015; Wassersug et al., 2017). Non-heterosexual couples are less bound by the coital imperative and as a result may be more able to renegotiate sexuality post-cancer due to already having a broader appreciation of what constitutes sexual activity. On account of differences in sexual expression, comparative studies of heterosexual and sexual minority populations do not capture the nuanced effects of cancer and sexuality and so research specifically looking at their experiences is warranted.

Whilst the experiences of all sexual minority individuals are equally valid, this study will focus specifically on understanding GBQ men's experiences. Due to socially constructed narratives around female and male sexuality and gender differences in how sexuality is impacted in the context of cancer, focusing exclusively on GBQ men will allow for a more homogenous sample and comprehensive exploration of their experiences.

1.5. Scoping Review

1.5.1. Search Strategy

A scoping review was conducted to summarise existing literature exploring sexuality and intimacy for GBQ men diagnosed with cancer. Search terms 'cancer' and 'neoplasm' were combined with words and phrases reflecting the population and constructs of interest (i.e., sexuality, intimacy, gay, bisexual, queer). For a full summary of search terms see Appendix B. The following databases were searched: PsychInfo, CINAHL, Academic Search Complete, and PubMed.

1.5.1.1. *Inclusion criteria:*

Articles published in the English language, from any location, describing research of any methodology that explored the impact of cancer on sexuality in broad terms (i.e., not just limited to physiological sexual function, but examined sexuality, intimacy, relationships and sexual identity, in order to capture a more holistic understanding of the impact of cancer). Literature was required to substantially discuss the impact specifically for cis-gender, non-heterosexual males over the age of 18.

1.5.1.2. *Exclusion criteria:*

Papers not written in the English language, where the focus was purely on physiological sexual function, and where the sample was with children or young people. Book chapters, editorials and reviews which did not contribute additional information were also excluded.

1.5.2. Search Results

Appendix C depicts a PRISMA flow diagram outlining the process of conducting initial searches and manually reviewing titles, abstracts then full texts according to the inclusion and exclusion criteria. One paper was unable to be retrieved for full text screening and so was excluded. Four additional records were identified through searching websites and organisations for grey literature and reviewing the reference lists of relevant publications. One further paper was identified during a final search across databases of key terms in combination with common cancers (e.g., lung, bowel) to identify studies that may have been missed.

The search process resulted in a total of 19 papers (see Appendix D for a summary). Five of the papers used quantitative methodologies, 11 used qualitative methodologies, one used mixed-methods, and two were reviews. All papers were in the context of PCa, except for two studies (rectal cancer, Li, 2009; anal cancer, Mauro et al., 2021). One study’s sample (Gilbert, Ussher, Perz, et al., 2013) represented a cross section of cancer types and SOs but it was excluded due to failing to explicitly outline the needs of GBQ men. The sample in Macmillan’s (2015) study consisted of people diagnosed with a range of cancers, however the section on sexual function appears to only mention PCa and it is unclear whether the quotes are from men diagnosed with other cancers and so is summarised alongside the other PCa papers.

1.5.3. Prostate Cancer

There has been an increase in research in recent years investigating the specific needs of GBQ men following PCa diagnosis and treatment. The findings from 17 studies are summarised below and provide a comprehensive overview of the impact of PCa on sexuality and intimacy.

1.5.3.1. *Sexual function:*

All 17 studies outlined the impact PCa and its treatment has on sexual function. Effects included loss of libido, erectile dysfunction, urinary and bowel incontinence, anal irritation and pain, changes in size and appearance of penis, changed orgasms, and loss of ejaculation (Danemalm et al., 2019; Doran, 2015; Filiault et al., 2008; Hart et al., 2014; Hartman et al., 2014; Hoyt et al., 2020; Lee et al., 2015; Macmillan, 2015; Matheson et al., 2017; McConkey & Holborn, 2018; Rosser et al., 2016, 2020; Thomas et al., 2013; Ussher et al., 2016; Ussher, Perz, et al., 2017; Ussher, Rose, et al., 2017; Wassersug et al., 2013).

Many men reported mourning the loss of ejaculation, which was felt to be an integral part of their identity as a GBQ man and an important sign of sexual gratification within the GBQ community (Doran, 2015; Lee et al., 2015; Rosser et al., 2016; Ussher, Perz, et al., 2017). Two studies found that GBQ men reported greater concern about loss of ejaculation compared to their heterosexual counterparts (Hart et al., 2014; Wassersug et al., 2013). Hart et al.’s (2014) quantitative study of 92 GBQ men found that they had worse urinary and bowel function than heterosexual men with PCa from other published studies, but better sexual function. These findings were replicated by Rosser (2020) and Ussher (2016). Wassersug (2013) conversely found no difference in urinary incontinence or erectile function between GBQ and heterosexual men.

Changed orgasms were noted in many studies, but experiences were not always negative, with some men reporting more intense and full-bodied orgasms, with some comparing this feeling to what they imagine women experience when they climax (Danemalm et al., 2019; Rosser et al., 2016). Loss of libido also had a positive impact for some men, allowing them to connect with more subtle, sensual feelings and become more in touch with their emotions (Doran, 2015).

1.5.3.2. *Sexual practices:*

A profound and often permanent impact on sexual practices was reported due to sexual difficulties and the loss of the prostate as a sexual organ (Danemalm et al., 2019; Filiault et al., 2008; McConkey & Holborn, 2018; Rosser et al., 2016; Ussher, Perz, et al., 2017). A reduction in the frequency of sexual intercourse and masturbation was reported, with men saying a great deal of enjoyment and pleasure had disappeared from sex and instead had been replaced with concerns about sexual performance (Danemalm et al., 2019; Hart et al., 2014; Ussher, Perz, et al., 2017). Some men reported avoiding sex completely (Hartman et al., 2014; Hoyt et al., 2020; Lee et al., 2015; Rosser et al., 2016; Ussher, Rose, et al., 2017).

‘Opening up’ monogamous relationships was experienced as a positive way of managing some of the strain placed on relationships (Doran, 2015; Hartman et al., 2014; Hoyt et al., 2020; Matheson et al., 2017). Some men attended commercial sex venues as a way of exercising ‘healthy’ sexuality, seeing this as analogous to going to the gym to stay fit (Ussher, Rose et al., 2017). Men reported that adaptions and adjustments to sexual practices helped mitigate some of the challenges they experienced, such as moving away from phallocentric sex towards oral sex, mutual masturbation, nipple play, and using sex toys (Hoyt et al., 2020; Lee et al., 2015; Matheson et al., 2017; Rosser et al., 2016; Thomas et al., 2013). Men reported attempting to maintain sexual function by using biomedical interventions that target erectile dysfunction, with varying degrees of success (Lee et al., 2015; Ussher, Rose, et al., 2017).

1.5.3.3. *Sexual roles:*

Some men were forced into sexual role changes. Partners who usually assumed the penetrative role (known as ‘top’ in the LGBTQ+ community) had to become the receptive partner (known as ‘bottom’), or vice versa (Doran, 2015; Lee et al., 2015; Macmillan, 2015; Rosser et al., 2016, 2020; Thomas et al., 2013; Ussher, Perz, et al., 2017). Difficulties being a top were associated with not having a firm enough erection for penetrative anal intercourse or not being able to sustain an erection for long enough. Anal irritation and pain made it difficult to be the receptive partner. For some, the switching of roles was not possible due to deeply engrained ties with identity or simply not enjoying the alternative position (Doran, 2015; McConkey & Holborn, 2018; Rosser et al., 2016; Ussher et al., 2016).

1.5.3.4. *Relationships:*

PCa treatment considerably impacted on GBQ men’s ability to seek and maintain new and current sexual relationships (Danemalm et al., 2019; Doran, 2015; Filiault et al., 2008; Hart et al., 2014; Hartman et al., 2014; Hoyt et al., 2020; Lee et al., 2015; Ussher, Perz, et al., 2017). Sexual problems created strain within relationships, resulting in sadness, frustration and guilt for both the person with PCa and their partner (Doran, 2015; Filiault et al., 2008; Hart et al., 2014; McConkey & Holborn, 2018; Ussher, Perz, et al., 2017). Changes to body image and bodily function prevented some men from seeking new relationships, for fear of rejection and concerns about not being able to satisfy potential partners (Danemalm et al., 2019; Filiault et al., 2008; Hoyt et al., 2020; Lee et al., 2015; Thomas et al., 2013). Men from two studies reported feeling like ‘damaged goods’ and shared that erectile dysfunction and loss of ejaculation were undesirable in the GBQ community (Hoyt et al., 2020; Thomas et al., 2013; Ussher, Rose, et al., 2017). The new lack of spontaneity with sex was commonly reported as a barrier, particularly when assistive aids such as medication or penile devices were required (Danemalm et al., 2019; Doran, 2015; Hartman et al., 2014; Hoyt et al., 2020; Lee et al., 2015; Macmillan, 2015; Rosser et al., 2016; Thomas et al., 2013).

Men with supportive partners reported being less affected by the sexual side-effects of PCa. Good communication, finding compromise, and having understanding partners were listed as factors that enabled couples to cope (Lee et al., 2015; Rosser et al., 2016; Ussher, Perz, et al., 2017). For some men, this resulted in greater intimacy and emotional closeness, and an ability to renegotiate sexual practices in a satisfying way (Danemalm et al., 2019; Ussher, Perz, et al., 2017; Ussher, Rose, et al., 2017). Participants from Hartman et al.'s (2014) study reported placing an increased importance on verbal and nonverbal intimacy, such as talking about their feelings or engaging in non-sexual touching, as a way of facilitating connectedness and easing some of the detachment associated with decreased sexual activity.

1.5.3.5. *Emotional impact:*

For some GBQ PCa survivors, treatment had a profound impact on mental health and emotional wellbeing, with five studies reporting direct correlations between treatment side-effects and increased anxiety and depression symptoms (Hoyt et al., 2020; Lee et al., 2015; Rosser et al., 2016; Ussher, Perz, et al., 2017). Hart et al. (2014) and Rosser (2020) also reported worse mental health outcomes for GBQ men compared to heterosexual PCa survivors in other published studies. Isolation and loneliness were reported by two studies (Doran, 2015; Lee et al., 2015); cessation of employment and not knowing other GBQ men with PCa contributed to these feelings. Men reported feeling a sense of 'inferiority' (Matheson et al., 2017) and 'incompetence' (Ussher, Perz, et al., 2017) compared to other GBQ men due to their sexual problems, resulting in emotional distress.

1.5.3.6. *Identity:*

For some participants, sexual problems made them feel like less of a man, whilst others felt their masculinity was multifaceted and not solely defined by sexual function (Doran, 2015; McConkey & Holborn, 2018; Thomas et al., 2013). Narratives around natural sexual decline and ageing helped some men make sense of their experiences, whilst others resisted this narrative (Danemalm et al., 2019; Hartman et al., 2014; McConkey & Holborn, 2018; Rosser et al., 2016; Ussher, Perz, et al., 2017; Ussher, Rose, et al., 2017). Some men saw their bodies as being 'disabled' and drew comparisons between erection dysfunction and feeling like an amputee (Danemalm et al., 2019). One's identity as a GBQ man within the GBQ community was also impacted, for example, losing hair was seen as problematic when identifying as belonging to the gay subculture known as ‘bears’ (Doran, 2015). Loss of libido or role as a top or bottom also impacted on sexual identity (Filiault et al., 2008; Hoyt et al., 2020; Matheson et al., 2017; Rosser et al., 2020; Ussher, Perz, et al., 2017; Ussher, Rose, et al., 2017).

1.5.3.7. *Healthcare system:*

Assumptions of heterosexuality resulted in difficulties receiving tailored advice and appropriate treatment for GBQ men (Filiault et al., 2008; Macmillan, 2015; Matheson et al., 2017; Thomas et al., 2013; Ussher, Perz, et al., 2017). Participants reported a desire for information about the sexual impact of PCa but recalled a lack of resources tailored to GBQ men. Some participants who attempted to discuss sexual concerns with their medical team, reported that HCPs were uncomfortable discussing sex and seemed to lack knowledge about the specific issues facing GBQ men (Filiault et al., 2008; Hoyt et al., 2020; Lee et al., 2015; McConkey & Holborn, 2018; Ussher, Perz, et al., 2017). Some men felt their concerns were not taken seriously which contributed to them feeling marginalised and reinforced feelings of shame about their sexuality (Hoyt et al., 2020).

Many GBQ men found it distressing having to weigh up the risk of disclosing their SO to the many HCPs involved in their care (Macmillan, 2015). Fear of discrimination and the possibility of this negatively impacting on their care meant some avoided disclosure, resulting in psychological distress (Doran, 2015; Filiault et al., 2008; Hoyt et al., 2020; Lee et al., 2015; McConkey & Holborn, 2018; Thomas et al., 2013). Macmillan’s (2015) study reported rare cases where professionals had laughed at GBQ men’s SO and held stereotypical views about them. GBQ men who were able to have open conversations about the sexual side-effects of PCa treatment with HCPs, reported positive experiences and less distress when met with empathetic, professional and knowledgeable HCPs (Doran, 2015; Hoyt et al., 2020; McConkey & Holborn, 2018).

Given these experiences, it is unsurprising that GBQ men were more dissatisfied with their PCa care compared to heterosexual survivors (Hart et al., 2014; Ussher et al., 2016). For example, Hartman et al. (2014) and Macmillan (2015) found that men had regrets about having a prostatectomy and felt that the lack of timely and relevant information and discussions about the implications of sexual side-effects specifically for GBQ men, meant they undertook treatment without fully understanding the consequences.

1.5.3.8. *Support:*

Being older and single were associated with lower levels of support (Hoyt et al., 2020; McConkey & Holborn, 2018; Rosser et al., 2016). Men who were partnered reported fewer psychosocial impacts of PCa compared to unpartnered men; partners appeared to provide a source of information and emotional support (McConkey & Holborn, 2018). Some men reported not wanting to burden their loved ones with their difficulties or felt they did not have people in their network who would understand their experiences and so chose to suffer alone (Doran, 2015; McConkey & Holborn, 2018). Sex, for some men, had been a way of connecting and making friends, and so with a loss of sex, came a loss of their place within the GBQ community (Hoyt et al., 2020; Lee et al., 2015).

Men yearned for a sense of community but felt out of place in mainstream (heterosexual) groups and often did not return after the first session (Doran, 2015). Many studies reported on the need for specific GBQ support groups, so that issues of sex and relationships could be discussed freely without fear of judgement (Lee et al., 2015; Macmillan, 2015; Thomas et al., 2013). Participants expressed wanting advice from other GBQ men about sexual practices and wanted to talk with others who understood the language, history and context of being a GBQ man with PCa (Doran, 2015; Lee et al., 2015; McConkey & Holborn, 2018).

1.5.3.9. *HIV and prostate cancer:*

GBQ PCa survivors living with concurrent HIV experienced the compounding stigma of both diagnoses and reported feeling cautious about disclosing this information to new partners (Doran, 2015). For some older men, receiving a PCa diagnosis brought back distressing memories of being diagnosed with HIV during the 1980s AIDS epidemic (Doran, 2015). Two studies reported on how there seemed to be a lack of community support for GBQ men with PCa compared to those affected by HIV (Hoyt et al., 2020; McConkey & Holborn, 2018).

1.5.3.10. *Critical evaluation:*

PCa is the most common male cancer in the UK, with 52,300 new cases diagnosed each year (Cancer Research UK, 2022a). Given the high incidence rate and the direct role the prostate has in urological and sexual function, it is understandable that PCa has been the focus of research on the sexuality of GBQ men. The small but growing body of peer-reviewed research provides vital information about the experiences of a group that has historically been overlooked in research and underserved by services. Qualitative studies focused on patients' experiences and personal conceptualisations of the impact of PCa have brought rich, nuanced findings which go beyond a physiological understanding of sexual function to encompass the impact on sexual practices, relationships and identity.

Quantitative measures have value in contributing to understanding the needs of PCa survivors, particularly when validated measures such as the Expanded Prostate Cancer Index Composite (EPIC) were used. However, the EPIC was constructed for use with heterosexual samples, so may not be application to other populations. Studies comparing heterosexual and non-heterosexual groups provide valuable information, however appropriate, population-based comparators are required in order to fully assess the landscape of challenges facing GBQ men (Griggs et al., 2017).

All of the samples consisted predominantly of white, educated and 'out' participants. Men tended to be recruited from LGBTQ+ organisations, meaning that those who were not openly out or who did not identify as belonging to the LGBTQ+ community may have been excluded. Many of participants were also exclusively in relationships with other men and identified as gay, disregarding those who identified as bisexual, queer or who were not in relationships. These sample biases limit the representativeness of findings.

1.5.4. Anal Cancer

Mauro et al.'s (2021) study is the first to address sexual difficulties in GBQ men with anal cancer, providing a unique contribution to the literature. The quantitative, Brazilian study of 19 GBQ men treated for anal cancer, found that quality of life and sexual function worsened during and after treatment for anal cancer, but improved within a year post-treatment. Impact on sexual function was associated with the emotional experiences of cancer and impact on overall quality of life, rather than anatomical changes.

Whilst an important start in understanding this minority population, findings are limited in providing a relatively narrow understanding of sexuality in a small sample. Measured via a brief sexual inventory, considerably more is still to be learnt about the sexual impact of anal cancer. A more comprehensive battery of questionnaires and qualitative methodologies could be employed to investigate further.

1.5.5. Rectal Cancer[2]

Li's (2009) literature review summarises what limited knowledge there is about the impact of rectal cancer on sexuality. The review of 55 articles explores sexual concerns after rectal cancer surgery and the construction of a colostomy, specifically looking at the influence of gender, SO, and Asian heritage. The review suggests that GBQ men living with colostomies may be at higher risk of inadequate sexual counselling following surgery compared to their heterosexual counterparts. Sexual expression for GBQ men who engage in receptive anal intercourse may be altered if surgery included the removal of the rectum or closure of the anus. The presence of a colostomy may significantly influence perceptions of body image, which is seen as being of particularly importance to the GBQ community.

These findings are limited, based on studies that are more than two decades old. Conclusions appear to be an amalgamation of findings from previous research rather than drawn from studies directly investigating the experiences

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[2] Rectal cancer is a type of bowel cancer that starts in the rectum.

of GBQ men with rectal cancer. Further research is needed to examine and understand the specific impact of rectal cancer in this minority population.

1.5.6. Summary And Conclusions

The review identified that GBQ men have clear needs regarding sexuality in the context of cancer. The growing body of literature on GBQ PCa survivors indicates that sexual function is impaired as a result of treatment and has wide-reaching effects on sexual expression, relationships and identity. The lack of specific support and advice from HCPs and other networks further contributes to difficulties and results in many GBQ men feeling isolated and lacking appropriate information. Evidence suggests that GBQ men experience unique issues when in a sexual relationship with another man that their heterosexual counterparts may not experience, owing to differences in sexual expression, social support networks and relationships with medical professionals. Renegotiation of sexual practices may be possible by adjusting roles during sex, expanding the repertoire of sexual activities, or through redefining the boundaries of relationships. Supportive partners and social networks, and knowledgeable and understanding healthcare teams were deemed vital in ensuring patients coped with the impact on sexuality.

The limited literature exploring the impact of other cancer types on sexuality indicates that difficulties are not limited to PCa, with GBQ men with anal and rectal cancer experiencing poorer sexual function, worsened quality of life, and inadequate support. However, the full extent of their experiences is not known. Sexuality across cancer types has been explored in heterosexual samples, however non-heterosexual samples have so far been overlooked. As evidenced in the literature, GBQ men are at risk of experiencing additional challenges along their cancer journey, such as discrimination and homophobia, and difficulties accessing relevant information and support. If GBQ men with PCa are struggling with aspects of their cancer care and treatment, then it can be assumed that there is a multitude of other GBQ men diagnosed with other cancers who are finding it equally (or potentially more) challenging obtaining appropriate treatment, information and support.

The evidence is also limited with regards to socioeconomic, ethnic and racial diversity which limits the representativeness of findings cross-culturally. Greater attention should be paid to intersectionality to understand how experiences of cancer and sexuality are influenced by other demographics such as race and culture. Furthermore, the majority of the studies in the scoping review were conducted in countries other than the UK, such as Ireland, Sweden, Australia, Canada, and the USA, whereby different cultural values and healthcare systems will impact the way sexuality and cancer are experienced. Of the studies that did take place within the UK, most were quantitative or mixed-methods studies which combined findings with international research, or adopted ‘light touch’ qualitative methodologies. Doran’s (2015) qualitative study based in the UK yields interesting insights from a UK perspective, although focuses on the impact of PCa cancer generally, rather than focusing specifically on sexuality and intimacy. Therefore, in-depth qualitative research on cancer and sexuality within a UK context is warranted.

1.6. Rationale and Aims of the Current Study

Research exploring sexuality and intimacy in the context of cancer for GBQ men within the UK is scarce. Due to sexuality being an important aspect of quality of life, it is important that all PWC are supported to achieve the level of sexuality and intimacy in their lives that they desire. Greater understanding of how GBQ cancer survivors from a diverse range of backgrounds experience sexuality and intimacy is therefore needed, including an exploration of what has helped them endure any difficulties, and what they feel is missing in terms of support. In the last decade, patients’ accounts of their experiences have become more respected in research; qualitative methodology is therefore well-suited to this sort of research.

To ensure good quality cancer care, healthcare settings must be inclusive environments to facilitate disclosure and staff must be knowledgeable about the needs of sexual minorities. HCPs report feeling ill-equipped to deal with LGBTQ+ specific issues. Berner et al.’s (2020) study indicated that 84% of 258 UK oncologists reported feeling comfortable treating LGBTQ+ patients, yet only 8% felt they were knowledgeable about their specific healthcare needs. Being provided with appropriate information contributes to lessening distress and empowers couples to discuss sexuality and work through any problems (Gilbert et al., 2016). Therefore, further research is needed to enrich understanding of GBQ men’s experiences, to inform clinical practice and ensure high quality cancer care is provided to all patients, regardless of SO.

The aim of this study is to make novel contributions to the literature through hearing male GBQ cancer survivors’ descriptions of their experiences of sexuality and intimacy. Findings from the study will aim to influence approaches for supporting GBQ men living with and beyond cancer.

1.6.1. Research Questions

A qualitative design will be employed that aims to answer the following research questions through interviews with GBQ men diagnosed with cancer:

1. How do GBQ men experience sexuality and intimacy in the context of cancer?
2. How do GBQ men experience healthcare settings with regards to advice, treatment and support around sexuality and intimacy in the context of cancer?

2. METHODS

This chapter outlines the study's epistemological position and design, followed by reflections on my position in relation to the research. Ethical considerations, the research procedure, and approach to data analysis are then described.

2.1. Epistemology

Researchers must consider their epistemological position before conducting any sort of exploration of knowledge, in order to contextualise the foundations upon which the knowledge is sought (Willig, 2021). This study adopts a critical realist position. Born out of Roy Bhaskar's critiques of positivism and constructivism (Bhaskar, 1975), critical realism posits that our observations of the world can come close to reality but are always fallible due to socially constructed, contextual and subjective accounts of reality. Obtaining data through research methods reveals something important about what exists in the world, but these observations are not a direct reflection of reality itself.

In healthcare, positivist approaches to knowledge production are widespread, basing research on the assumption that it is possible to 'know' reality through using sophisticated instruments to study phenomena. This is evidenced by the hierarchy of evidence, whereby randomised control trials are considered superior at yielding 'scientific truths', based on the epistemological assumption that it is possible, through 'objective' science, to establish fundamental truths (Clark et al., 2007). However, this approach neglects the important role of context (Sturgiss & Clark, 2020). Patients and their diseases do not exist in isolation; instead they are situated in complex networks across healthcare systems and personal communities, influenced by the actions of many individuals in their social world, as well as the wider social, cultural and historical context (Byrne, 2005).

By adopting a critical realist stance, I recognise the materiality of the body but understand that *accounts* of the body are mediated by social contexts and subjective narratives (Bhaskar, 1989). I acknowledge that cancer is a disease that has a ‘real’ impact on the mind and body but that the *meaning* of cancer is unique to each person. Social constructs of gender identity and SO interacting with strongly determined cultural beliefs about sexuality, also provide further context to people’s accounts of their experiences and my interpretations as the researcher. A truly objective understanding of GBQ men’s sexuality and intimacy post-cancer may therefore never be achieved, but attempts to discover something of the truth can be meaningfully made, nonetheless.

2.2. Design

A qualitative design was chosen to explore the experiences of GBQ men through the use of semi-structured interviews. Qualitative methodologies are appropriate when a particular area has been relatively under-researched (Kimble, 1984). This design allowed me to be exploratory in my approach, by being open to unexpected insights and important details about the participants’ circumstances (Wilkinson et al., 2004). It also allowed me to hold a wider appreciation of sexuality and SO in mind, by being mindful of historical and cultural contexts. A qualitative approach also offers a voice to marginalised groups (Willig, 2021), which is particularly relevant given that research in this area has historically overlooked the experiences of sexual minorities.

Thematic analysis (TA) was chosen as the analytic approach due to not being aligned with any particular epistemological position. TA is therefore compatible with the study’s critical realist stance (Braun & Clarke, 2006) as it acknowledges that people make meaning of their experiences, influenced by broader social contexts, and that their accounts are limited in what they tell us about reality. TA describes and analyses data, producing detailed accounts of the phenomenon of interest. This is particularly beneficial when exploring under-researched areas as it provides a foundation of knowledge upon which further research can build (Braun & Clarke, 2006). Reflexive TA was adopted as the particular approach (Braun et al., 2019) which “emphasises the importance of the researcher’s subjectivity as analytic *resource*, and their reflective engagement with theory, data and interpretation” (Braun & Clarke, 2021, p. 330).

The analysis adopted a predominantly inductive approach to identifying patterns within data (Braun & Clarke, 2006), meaning that themes were identified in a data-driven manner, fitting with the exploratory aims and critical realist stance. However, TA is not passive and data is also not coded in a theoretical vacuum, but rather influenced by the researcher's assumptions which are theoretically, philosophically and contextually informed (Braun & Clarke, 2021). Furthermore, it is important to consider relevant literature so as to avoid repeating previous research and contribute to expanding knowledge in the area (Joffe, 2011). Therefore, a deductive approach (Braun & Clarke, 2006) was also adopted whereby the analysis was informed by existing theories and research. A combined semantic and latent approach to identifying themes was also used, recognising that themes are explicitly and directly observed in data, yet their development requires a level of interpretation (Braun & Clarke, 2006). Dual inductive-deductive and semantic-latent approaches have been found to produce high-quality qualitative research (Joffe, 2011).

2.3. Reflexivity

To make explicit the constructed nature of research outcomes, researchers should reflect on how their "experiences, values and positions of privilege" influenced their approach (Harrison et al., 2001, p. 325). I used reflective journaling (see Appendix E for an extract) throughout the research process to facilitate self-reflection.

I reflected on my clinical experience as a trainee clinical psychologist. Having worked in an NHS cancer service, I witnessed the wide-reaching impact cancer can have on relationships and sexuality, yet noticed that these topics were rarely discussed within teams and with clients. Having also worked in an NHS sexual health service, I noticed the positive impact that addressing psychosexual difficulties can have on psychological wellbeing and quality of life. I therefore had a professional interest in both these areas which ostensibly motivated me to conduct this study.

I considered how my identity as a relatively young, white British, middle-class female may have impacted on the interview process when speaking with men who differed from me across multiple demographics. I wondered how the types of questions I asked and the stories participants shared were influenced by our different intersecting identities. I considered how my liberal feminist political views and critical psychology stance, shaped by training at the University of East London (UEL) which emphasises the social context of distress, further influenced our interactions.

I also reflected upon my identity as a queer woman. I ‘came out’ during the period of conducing this study and was interested in how my shifting identity may have impacted on how I related to the participants. I was mindful of the complex and constantly fluctuating boundaries of ‘insider’ and ‘outsider’ status when conducting research (Sherif, 2001) and was aware that despite potential similarities in being categorised as a ‘sexual minority’, there was a plethora of other differences between myself and the participants. I chose not to disclose my SO as I felt this would detract from the focus of our interactions but hoped my responses and comments made my sexual identity more explicit.

2.4. Ethics

Ethical approval was sought (Appendix F) and granted (Appendix G) by UEL’s School of Psychology Ethics Committee. Subsequently, an ethical amendment was submitted (Appendix H) and granted (Appendix I) which expanded the inclusion criteria to include men who had been diagnosed with any cancer type, not just bowel cancer as had been intended initially. This was done to increase the likelihood of hearing from as many people as possible within a marginalised group. Previous studies (e.g., Gilbert et al., 2013; Ussher et al., 2012) provide a rationale for grouping cancers together when investigating the impact of cancer on sexuality and intimacy. An application to change the study’s title was also approved (Appendix J).

2.4.1. Informed Consent

Potential participants were provided with an information sheet (Appendix K) outlining the study’s purpose and design. The right to withdraw was clearly explained, as well as how data would be used and protected. Multiple opportunities were provided for participants to ask questions about the research process. All participants were required to sign a consent form (Appendix L) before taking part and verbal consent was obtained immediately before commencing interviews.

2.4.2. Potential Distress

I was aware of the potential distress participants may experience as a result of discussing sensitive topics related to cancer and sexuality (Alty & Rodham, 1998). In an attempt to manage this, time was taken to build a rapport with the participants to ensure they felt as comfortable as possible during the interview. I carefully considered the interview structure and chose to start with general questions related to health and wellbeing, before discussing relationships, intimacy and, lastly, sexuality. I hoped this graded approach would reduce any potential harm, allowing participants to relax into the process and feel more comfortable when discussing intimate matters. I was alert to signs of distress and made sure to go at the pace of the interviewee. I also reminded participants of their right to withdraw and that they did not have to answer all of my questions. As a trainee clinical psychologist, I am experienced in dealing with emotional content and felt confident recognising and managing distress.

2.4.3. Debrief

A debrief was offered at the end of each interview, allowing participants the opportunity to reflect on the research experience and raise any concerns or questions. A debrief form (Appendix M) was emailed to them after the interview outlining cancer, relationship and LGBTQ+ organisations where they could seek further support, if required.

2.4.4. Confidentiality And Anonymity

Personal information and content from the interviews were kept confidential, transcripts were anonymised, and a data management plan was followed ensuring the secure and ethical storage of information. Please see Appendix N for more detail about the plan and how confidentiality and anonymity were adhered to.

2.5. Research Procedure

2.5.1. Recruitment

A combination of purposive and snowball sampling techniques were used to maximise recruitment of GBQ men who had been diagnosed with cancer. I contacted several cancer and LGBTQ+ organisations and charities who shared the study advertisement (Appendix O) with support groups and posted it on social media platforms (Facebook, Instagram and Twitter). The study advertisement was also published on research websites and physical leaflets were left in an LGBTQ+ community centre in London. After each interview, I asked participants to pass on the study advertisement to anyone they thought might be eligible. These recruitment approaches are well established in qualitative research (Carter & Little, 2007), particularly when targeting marginalised groups such as GBQ men (Patton, 2002).

2.5.2. Inclusion Criteria

The inclusion criteria were:

- ≥18 years old
- Identify as a gay, bisexual or queer man, or any other label that fit within the category of 'man who loves/is attracted to/has sex with men'
- Been diagnosed with any cancer type
- Be in remission and have completed any treatments at least six months prior to the interview

2.5.3. Sample Demographics

As summarised in Table 1[3], six GBQ men were recruited. Three participants had been diagnosed with PCa, two with bowel cancer, and one with multiple myeloma. The average age at diagnosis was 49 which is younger than expected. In the UK, more than a third of new cancer diagnoses are in people aged over 75 and rates peak in 85-89 year olds (Cancer Research UK, 2021), though there is considerable variation between cancer types. The younger sample may be a result of recruiting via social media and other online channels;

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[3] Pseudonyms, age ranges and broad ethnicity categories have been used to preserve anonymity.

whilst the generation gap is narrowing, people aged over 75 are less likely to use the internet that younger people (Office for National Statistics, 2021). Older men may also be further past treatment or be less sexually active, so may be less motivated to take part in a study exploring sexuality (Wassersug et al., 2013).

Jay was married to a man and Zayn was in a relationship with a man when they were diagnosed with cancer, but these relationships subsequently broke down as a result of the strain cancer placed on their relationships. Peter and Callum remained married to men throughout their cancer journey and beyond. Arthur had recently divorced his wife and entered into a long-term partnership with a man soon after he was diagnosed with PCa. Lee remained singled throughout his cancer journey.

Table 1

Sample Demographics

Name	Ethnicity	Age at interview	Age at diagnosis	Cancer type	Cancer treatment	Sexual orientation	Relationship status at interview
Jay	Asian British	41-55	41-55	Bowel	Chemotherapy, radiotherapy	Queer	Single
Zayn	Any other mixed background	26-40	26-40	Bowel	Surgery	Gay	Single
Peter	Any other white background	56-70	56-70	Prostate	Surgery	Gay	Married
Arthur	White British	71-85	56-70	Prostate	Hormone therapy, radiotherapy	Gay	Long-term partnership
Callum	White Irish	41-55	26-40	Multiple Myeloma	Chemotherapy, radiotherapy, surgery	Gay	Married
Lee	White British	56-70	56-70	Prostate	Surgery	Gay	Single

2.5.4. Sample Size

The recruitment process resulted in a relatively small sample. Difficulties with recruitment may be related to the reluctance of GBQ men to participate in health-related research given they can suffer negative experiences when navigating a heteronormative (and sometimes homophobic) healthcare system. Indeed, previous research has noted that older gay men are difficult to recruit, labelling them an ‘invisible population’ (Blando, 2001). Cancer adds an additional layer to this invisibility, further confounding recruitment efforts (Filiault et al., 2008).

Although a larger sample size is preferred in qualitative research to increase chances of achieving data saturation, a minimum of six interviews is deemed enough (Guest et al., 2006). Since qualitative research focuses on rich and complex accounts rather than breadth of information, a small sample size is sufficient (Patton, 2002). Studies have proposed the utility of conducting small-sample qualitative research when conducting interviews with sub-populations of gay men (Filiault & Drummond, 2008). Therefore, the small sample in this study does not diminish the significance of participants’ experiences or the value of their perspectives when exploring the place of GBQ men within contemporary, Westernised healthcare (Filiault et al., 2008). Finally, as this is the first known study of this kind in the UK, a large number of men was not required. Rather the intent was to give initial accounts from GBQ men about sexuality across cancer types from a UK perspective.

2.5.5. Data Collection

Six people emailed to express an interest in the study and after having read the information sheet, consented to participate. Participants were then required to complete consent and demographic forms whereby they could also opt in to receive a £10 Amazon voucher as a token of gratitude for their involvement. A mutually agreed time was then arranged for the interview, all of which took place over Microsoft Teams.

Prior to commencing the interview, I reiterated information about consent, confidentiality and the right to withdraw, and participants were given the opportunity to ask questions. A candid approach to discussing sexuality was taken in order to reduce embarrassment (Bellamy et al., 2011), by making it clear the interview would cover issues of sexuality. I briefly assessed the participants’ level of comfort with discussing such issues and whether there was anything I could do to make the process more comfortable (e.g., using particular language). Consent to audio record the interview via Microsoft Teams was obtained before starting the semi-structured interviews.

The interviews lasted between 47 minutes and 1 hour 17 minutes. Interviews were guided by the interview schedule (Appendix P), however questions were followed flexibly so that participants' responses shaped the format. The interviews concluded with a debrief and finally, I made field notes and added to my reflective journal.

2.5.6. Transcription

Transcripts of the audio recordings were automatically generated by Microsoft Teams. I listened back to each recording to check accuracy and to insert punctuation according to the transcription key (Appendix Q). Names were replaced with pseudonyms and all other identifying information was removed. The transcripts were checked again for anonymity and accuracy by re-listening to the recordings (Gibbs, 2007).

2.6. Data Analysis

Braun and Clarke's (2006, 2021) six phases of analysis were followed and are outlined below. The phases were not followed rigidly, but rather analysis was a recursive process, moving between the different stages until a coherent report was produced (Braun & Clarke, 2021).

2.6.1. Data Familiarisation

The process of familiarisation began when collecting and transcribing the data. To immerse myself further, I read and re-read the entire data set to become familiar with the breadth and depth of content. I then 'actively' read each transcript by writing in the margins potential codes and patterns I was starting to notice (see Appendix R for an example). I also re-read my reflective journal and field notes.

2.6.2. Data Coding

Next, I systematically reviewed the transcripts to identify initial codes. Codes are “the most basic segment, or element, of raw data or information that can be assessed in a meaningful way” (Boyatzis, 1998, p. 63). I approached the data from both inductive-deductive and semantic-latent positions and with the research questions in mind. Context was retained around data items to preserve meaning (Bryman, 2001) and some data was coded in multiple ways to capture conflicting narratives. NVivo 12 software was used to generate a list of codes (see Appendix S) and organise the data.

2.6.3. Generating Initial Themes

A flexible approach was taken to identify initial themes from the codes by looking at all possible relationships between codes and patterns. In addition to using NVivo 12, I used ‘mind maps’ to support this iterative process. This resulted in a provisional thematic map (Appendix T) of initial themes.

2.6.4. Developing And Reviewing Themes

I then read the collated extracts for each initial theme to ascertain whether the data fit. This led me to combine, refine, separate and discard themes and data items, resulting in updated themes with corresponding coded data extracts (Appendix U shows an intermediate thematic map). Following this, I re-read the transcripts to check if the updated themes fit with the entire data set, allowing for further refinement and the coding of additional data that had previously been missed. Developing themes can be an infinite process (Braun & Clarke, 2006), so I stopped when refinement ceased to produce substantial changes (Appendix V shows the final thematic map).

2.6.5. Defining Themes

To define the themes, I considered their ‘essence’, using data extracts to form clear and succinct accounts of what each theme comprised. I held the research questions in mind when considering how the themes and sub-themes related to one another, so that the analysis represented a coherent ‘story’.

2.6.6. Producing The Report

The report outlined in the next chapter contains vivid quotes to convey a compelling account of the data. For the quotes, the researcher is referred to as ‘Hannah’ and the participants are referred to by their pseudonym. The type of cancer they were diagnosed with is also included to highlight the differing experiences between cancer types.

3. RESULTS

This chapter outlines the results of the data analysis. The context to analysis is provided, followed by an overview of the themes and subthemes. Each theme is then discussed in detail, illustrated with quotes from the data.

3.1. Contextualising the Analysis

As described in Chapter 1, cancer has a wide-reaching impact on many aspects of life, not just sexuality and intimacy. This was evident in the interviews as participants spoke about some of the wider challenges of being diagnosed with cancer, such as the stress of going through treatment or the fact that cancer led them to re-evaluate what was important in their lives. Many of the participants were also contending with other stressful life events, such as work or their partner's own health issues. In addition to this, all participants described changes to sexuality and intimacy as a result of cancer, to varying degrees. In two cases, the impact on sexuality was a key contributor to both relationships ending. For one person, cancer highlighted pre-existing tensions and brought greater distance between the couple. For two of the men, the impact on sexuality seemed lessened by good support networks, and for the final person, the sexual impact was significant but successful treatment resulted in little change to their sex life.

3.1.1. Cultural Differences

One of the participants, Zayn, identified as south Asian and was a practicing Muslim. He spoke often about specific cultural and religious issues and how they compounded his experiences of cancer and sexuality. Such experiences are described throughout the results since I felt the importance of cultural differences and intersectionality should permeate the different points raised in analysis rather than be reduced to a single subtheme.

3.2. Summary of Themes and Subthemes

The TA produced three themes and seven subthemes which are summarised in Table 1 and Appendix V.

Table 1

Summary of Themes and Subthemes

Theme	Subtheme
Navigating altered sexuality and relationships	"My ability to engage in sex was limited": Encountering sexual changes and challenges
	"We found ways around it": Overcoming obstacles
Undergoing changes in the self	"I felt different, changed, damaged”: Identity and sense of self
	"It affected me mentally": Emotional and psychological wellbeing
Seeking community and support	“A lonely journey”: Isolation and coping alone
	"The beauty of peer support": Supporting each other through shared experiences
	"The doctors and nurses": Sexual support from healthcare professionals

3.3. Theme 1: Navigating Altered Sexuality and Relationships

The first theme outlines the ways in which cancer disrupted the men’s sexual function and sex lives. Some men were able to overcome these obstacles in various ways, whereas for others, the difficulties were more challenging to navigate and resulted in increased tension and relationship breakdown.

3.3.1. "My Ability To Engage In Sex Was Limited": Encountering Sexual Changes And Challenges

All men, regardless of cancer type, reported sexual changes including: difficulties achieving or sustaining an erection, difficulties reaching orgasm, experiencing changes in the way orgasms felt, loss of ejaculate, and decreased libido.

Not having a firm enough erection was “problematic” (Arthur) for men who identified as a top, whereas was less of a concern for those who identified as a bottom. Lee, who identified as a bottom, spoke about how he missed having erections from a “visual point of view” rather than for his own satisfaction, due to the outward display of attraction a firm erection conveyed. The importance of erections and ejaculation symbolising pleasure and attraction was noted by others. For Callum, ejaculating simultaneously with his husband had been something integral to their sex life and missed this shared intimacy without it, a sentiment that Lee shared.

> Lee (prostate): I had to have my seminal glands removed as part of the surgery and as a quite horny bloke I do kind of miss that. You know I do. There is something about ejaculation which was nice.

Some of the men reported changed orgasms, however these were not always experienced negatively. For Peter, the lack of an erection allowed space for him to become more curious about the internal sensations of orgasm, making comparisons to what he imagined women feel.

> Peter (prostate): I've tried to be aware of what is the experience of arousal and um orgasm, and just that whole trajectory, once you get onto that road. And what does that feel like inside? So some of that not being so much focused on what the external that I'm, that I'm hard and that there's an erection. And that it's a certain size and whatever or solidness. But more of the internal, the warmth that's inside, the energy. And the only way that I've been able to kind of at least somewhat crassly put my head around it or articulate it, is there have been times where I've had

> orgasm, and I equate it for what a woman might experience because there is not that external manifestation of the arousal.

All of the men reported decreased libido, often linked to the many cancer symptoms and treatment side-effects they reported: nausea, fatigue, pain, difficulties with sleep, urinary incontinence, weight gain, gynaecomastia, gastrointestinal issues, reduced mobility, ‘brain fog’ and scarring. These side-effects resulted in the men feeling differently about their bodies which subsequently impacted on their desire to engage in sex. Some also reported feeling unattractive and undesirable to their partners as a result.

> Hannah: I'm wondering how you, whether you, whether [cancer] impacted on how you saw yourself or your body image or how you felt in yourself?
> Arthur (prostate): Not the cancer as such, it was the side-effects. I'm quite a pragmatic person, as I mentioned earlier, so the cancer itself didn't impact me. But the fact that I was beginning to put on a little bit of weight and obviously I had the tiredness associated with the radiotherapy as well. I had a bit of a gastrointestinal upset so I wasn't feeling fantastic. And actually when I met my partner, as well, so yeah, he saw me at probably, not at my worst, I mean, not at my best.
> Hannah: Yeah, so it sounds like the side-effects weren't making you feel particularly, I don't know, sexy or attractive?
> Arthur: Yeah, exactly, exactly.

For Zayn, who had a temporary colostomy fitted as part of treatment (which he refers to as “the bag”), these feelings of unattractiveness were particularly stark. He felt “filthy and dirty” and worried how the bag would fare during sex, resulting in decreased desire and avoidance of sex.

> Zayn (bowel): But with [the bag] it just felt as though [poo] was going to, it was just gonna flow out basically. I was just so worried about the involuntary response that it just felt easier to stay away just in case, so that I didn't have that and then I'd have to almost feel really embarrassed and then I'd probably definitely need a shower, or at least to wash that

> entire area. It just, yeah, I think the feeling of being filthy and dirty just really made me feel physically sick, really.

Decreased libido was also linked to psychological factors. Jay was experiencing pain and noted that anxiety about the pain made it worse, resulting in even lower desire. Callum experienced difficulties with orgasm as medication and fatigue made it difficult to focus during sex. This may have impacted on how his partner also experienced sex, possibly impacting on the couple's sense of connectedness and resulting in mutual disengagement towards sex.

> Callum (myeloma): Um but you know, and of course part of the challenge with the medications are because you're fatigued um your ability to focus on the present and the moment is actually quite challenging, so you sometimes find it, what I would say is you find yourself wandering off and away from the actual, the, the, the psychological and the physical engagement of the sexual activity and you have to try and bring yourself back.

Practicalities such as different sleeping arrangements and reduced mobility posed additional challenges. All these factors outlined above resulted in less frequent sexual activity, including masturbation, and in two cases, a complete cessation of sex.

3.3.2. "We Found Ways Around It": Overcoming Obstacles

Some of the men were able to overcome the sexual and relational obstacles that cancer created. For others, this was more difficult, resulting in challenges becoming more pervasive and negatively impacting the relationship.

A key factor that helped half the participants manage the impact of cancer was the fact that anal sex was already less important than alternative sexual practices (e.g., mutual masturbation, oral sex, using toys). Anal sex was already infrequent pre-cancer due to it feeling "mechanical" (Arthur), taking a lot of "preparation if you want to be clean and tidy" (Callum), or just finding it not as pleasurable as other sexual practices. For Lee, it was always "a bit of a fantasy the hard sex, the fucking" and had always tended to focus on alternative sexual practices. This meant that cancer did not particularly disrupt their sex lives and made the renegotiation of sexual practices easier.

> Callum (myeloma): We weren't having much anal sex up to that point anyway, because um, I think, uh, so I would be a top and [my husband] would be, be a bottom. And um he actually quite enjoys other aspects of, of physical sex that are not anal, if that makes sense. So whether that's playing with toys or fingering or different things like that. That's kind of more sensitive and more interesting to him in in that sense. (...) I would have more of a fixation on anal sex than he would, but we, we both really enjoy the way that we have sex if that makes sense. So it actually wasn't a big change for us practically.

Arthur implied that having cancer allowed him to pause and reflect on what he really enjoyed sexually. Taking the pressure off performing penetrative anal sex meant he learnt to concentrate on alternative sexual practices that he found “much more enjoyable”.

When challenges did present for these men, they spoke about “working through” (Arthur) issues and finding “practical ways around these things” (Callum) to renegotiate a degree of sexuality that was satisfying for both partners. Open and upfront communication and supportive, understanding partners seemed crucial in enabling this to occur. Being open helped set realistic expectations about sexual performance and helped explain that their lack of erection, orgasm or ejaculation was not due to their lack of attraction for the other person. This seemed to help maintain connectedness and mutual understanding that prevented partners feeling rejected.

> Peter (prostate): I'm very upfront about it. I do let people know, I let people know whether I've taken a medication like Viagra to help me along. Um I've, yeah, I just, I try to be forthcoming about it so that there's some realistic set of expectations for them, you know, especially if I'm feeling aroused and I'm attracted, that okay, my attraction and my arousal is going to look different then for you, then you know if you're not a prostate cancer survivor or you don't have just general erectile function

> issues, you know which guys have. Yeah, it's different from prostate cancer. So... And most appreciate that.

Peter shared that being with partners who understood his sexual function and who enjoyed his body post-cancer had been very “healing” and helped him feel accepted as a “whole person”.

In contrast, difficulties with communication seemed integral to relationships breaking down. Jay shared that “we couldn’t talk like we normally do, it’s just difficult, and the communication wasn’t there that we had” which limited opportunities to discuss and work through intimate challenges. Zayn felt his partner did not understand why the bag made him feel so “dirty”. Due to having different relationships to cleanliness, Zayn felt the cultural differences between himself and his white British boyfriend became more apparent and more of an issue. This resulted in Zayn avoiding talking to his partner which he felt “drew a wedge” between them.

> Zayn (bowel): I suppose it didn't help being in a mixed kind of relationship with somebody who's white because it was very much like 'Oh yeah, we should talk about [our problems] la la la' and I was just very much kind of like you just don't get the whole relationship that I have with cleanliness.

Five of the men spoke about sex still being an important part of their lives during and post-cancer, but that it had become less of a priority. For Jay, his psychological wellbeing had become more important, whereas for Lee, it was having a life that was fulfilling in other ways (e.g., friends, career). For others, other forms of non-sexual intimacy such as emotional closeness and cuddling had become more important.

> Peter (prostate): [I’ve been] wanting and desiring more a deeper sense of connection to someone. And if it takes place through a sexual encounter or experience, and where that's fulfilling for both, then that's all the better. But I find that there's more, there's a deeper hunger for that sense of connection and intimacy. (...) If I'm finding that I have other forms of

> intimacy in my life, the sexual part takes a different, plays a different role, has a different sense of priority.

In some cases, having to navigate cancer and sexual changes “drew us closer together” (Callum). In others, it resulted in greater emotional distance and less intimacy. Zayn worried about hugging or kissing in case his partner accidently touched the bag and he ended up “having an involuntary poo”, which resulted in him pushing his partner away.

> Zayn (bowel): So I was very much like don't touch that area at all and I think it was just really hard for him because he just was like he wanted to comfort me. But I just didn't want to I suppose you know, I didn't want to be touched, I didn't want to be felt. (...) Um and every time his hand automatically kind of, you know, by accident at night, I used to have to kind of slowly move it away so that it was, you know, not in that area. Um it just felt as though I was, I suppose pushing him away.

Jay also avoided intimacy because he was in pain and did not want small intimate moments to progress to sex, yet did not feel able to communicate this to his husband. This resulted in emotional and physical distance which ultimately led to the relationship ending.

> Hannah: And what, if you don't mind me asking, what was kind of the, the reason why [your husband] left?
> Jay (bowel): Um he just didn't think. Well, because I think he just thought there's nothing there in our relationship. He just felt that because we couldn't have sex then that's, really what, I think what we wanted, then that was it. There's nothing really there, 'cause physically it was clear, but we just felt that... his body language and his behaviour said it all. And yeah, that was it.

This highlights an important point made by Callum, that for many people, sex is a vital part of a relationship, and that without it, relationships can breakdown.

> Callum (myeloma): I think I'm also, [my husband] and I, I think, recognised that sex is really important in terms of psychologically, uhm, uhm, being glued together. If you stop having sex it will then you, ultimately I think there's a, there's a, something that breaks in the psychology.

For Peter, a barrier to overcoming obstacles was that cancer and the impact on sexuality exacerbated pre-existing tensions and “waning attraction” in his relationship. Peter felt well supported emotionally by his husband, but sexually, cancer had created more distance. One way of managing this was through ‘opening up’ their relationship, which also allowed Peter to receive support for sexual difficulties.

> Peter (prostate): I'm married to a man but I have also sought some additional support for [my sexual difficulties], through some friends that I know that I can be kind of sexually intimate with. And they have actually been a real help too, kind of, some of this additional perspective for me. (...) [My friend], he's a fellow married man. Interestingly enough, he's a sex therapist. He's having issues in his own relationship and he's extremely supportive of where I find myself, and it's not so much an issue and then, what I can share with him, um, is a nice addition to the support that I get from my husband on this.

3.4. Theme 2: Undergoing Changes in the Self

The second theme captures how cancer and its impact on sexuality and intimacy affected the men’s identity and psychological wellbeing.

3.4.1. "I Felt Different, Changed, Damaged”: Altered Identity And Sense Of Self

Many of the participants spoke about masculinity, their comments seeming to reflect particular framings of masculinity that indicate impaired sexual function is an assault on manhood. Lee characterising himself as a “horny bloke” (p. 48) and his comment below indicates that for him, masculinity was tied to virility and sexual performance. For Lee and Peter, their masculinity felt so impacted that they made comparisons to feeling like a woman, and in Peter’s case “asexualised”.

> Lee (prostate): But as the months went on and I couldn't, I couldn't get an erection and even getting orgasm was difficult. This began to make me feel that my sexuality as a man was dissipated and did begin to mentally bother me. It definitely did. (...) I think the only comparison I can give is, as I say, probably if I was a woman, it, it was absolutely that. It's just not feeling properly masculine anymore. That my masculinity had somehow been invaded.

> Peter (prostate): I was beginning to feel asexualised. The way I would describe it would be, I guess, to my mind it was like, uh, a woman who had to have full breast removal and, and initially, just being delighted to be cancer free and then later on going, you know what? I don't feel quite complete.

Peter’s comment here interestingly contrasts with his response about orgasm above (p. 48), implying that difficulties with sexual function were managed by ‘turning inwards’ and focusing on different ways of experiencing pleasure. He felt he had developed as a “sexual being” as a result.

Arthur’s framing of masculinity was more nuanced and went beyond sexual function.

> Arthur (prostate): I'm not defined by whether I can get an erection or things like that. I'm defined by the complex nature of who I am. Yeah, not having an erection, does it make me not a man? No I don't think so.

Zayn’s sense of self extrapolated beyond not feeling like a “real man” to feeling inhuman, describing himself as “this extra thing” and “a dog” because of the visible, external nature of defecating via the colostomy.

Identities around disability and illness were also questioned. Zayn did identify with feeling disabled and could not understand why his partner still wanted to be with him, reflecting that he did not feel “worthy” of a relationship. Callum’s false starts in the quote below seem to draw a distinction between ‘technical’ definitions of disability and how he characterised himself, suggesting a resistance to the label.

> Callum (myeloma): I felt um felt different, changed, you know, damaged, I suppose. Uhm, I never use the word disabled. I mean, I think I'm prob-, I'm tech-, but I think that was an interesting conversation I kind of had with myself, you know, am I disabled? Should I apply for a blue badge, you know? And, and all that type of stuff. (...) The point I'm trying to, I suppose make is that I decided that I wasn't disabled and I would never label myself as disabled.

As evidenced in the quotes, some participants used quite negative labels to describe themselves (e.g., filthy, damaged). This appeared to become more pronounced when interacting with partners and friends. The men spoke about being treated differently (as though they were a “wounded, damaged individual”, Callum) which led them to transcribe these negative labels onto themselves. Zayn felt that he was being touched differently by his partner and was concerned that opening up to him would further impact the way his partner saw him.

> Zayn (bowel): It didn't feel the same either, the whole kind of touch sensation didn't feel the same, it just felt as though, um, you know somebody was touching me out of pity rather than out of love and, um, you know the whole kind of, I suppose, the feeling just didn't feel so great. (...) I thought well, if I talk to you about it, you won't see me as a real person anymore. You're kind of almost see me as a victim. I'd almost been devalued kind of in your eyes. Um, I'm not you know, I'm not worth the amount that kind of almost you got me for beforehand. I now have just, you know, I've got less value.

It appears Zayn felt positioned as a “victim” rather than a ‘lover’, most likely because of the negative self-concept that developed from having the bag, but also perhaps due to his partner’s treatment of him. However, he did not feel able to talk to his partner about this. Callum, conversely, was able to tell his partner to “stop wrapping me up in cotton wool” as he felt this was contributing to him feeling “damaged”.

The concept of ageing helped many of the men process or adjust to changes in their body. Peter felt that maturation had contributed to him seeking different qualities in relationships (i.e., intimacy over sex) whereas Lee felt that being older and having a life that was meaningful in other ways meant he was content with a sex life that consisted mostly of masturbation.

> Lee (prostate): But you know to be honest I'm also, I mean, it sounds a bit sad, but I'm also very happy with a degree of masturbation so you know, I mean, if I was, if I was in my twenties or thirties now I would possibly be concerned about [erectile difficulties]. But with the life I have and the happiness level I have, I'm not concerned about it.

For the younger participants, having cancer at a young age made the impact harder to process. Zayn felt it would have been easier to manage if he and his partner had been in their seventies “when you’ve built up that love”.

3.4.2. "It Affected Me Mentally": Emotional And Psychological Wellbeing

The following emotions were described by the men when undergoing sexual changes: sadness, shame, loss, grief, anger, frustration and anxiety. For Peter, it was an “emotionally and mentally” challenging life adjustment coming to terms with a changed body.

> Peter (prostate): The fact that there was not an outward physical, visible manifestation of what an erection looks like, or what arousal looks like, that has been something that I've had to grieve. And I mean, I don't want to make it sound like I'm ruled by my dick, but at the same time, there was a real loss there, or there has been a real loss. I function differently than before. And it's taken me some time to really kind of sort that through.

Lee felt “cheated” by the loss of sexual function. After two years of struggling with erections post-proctectomy, his mental health was starting to be impacted so he opted for surgery for a penile implant. He reported feeling very satisfied with this as a result and no longer had any concerns about his sexual function or emotional wellbeing.

Some participants reported positive personal and emotional growth. Surprisingly, Zayn who felt so “deformed” as a result of having the bag, reflected that “it’s really made me the person I am today, so that can only be a good thing” and felt he had learnt about himself from having a changed relationship to his body. Arthur’s response below indicates how some side-effects of hormone suppression can also be experienced in a positive manner. He implied that being in a loving relationship where he could fully embrace his sexuality had also contributed to that.

> Arthur (prostate): Yeah, um, I certainly became a little bit more emotional when I was on the androgen deprivation therapy. Um and actually it was the bit I liked which is bizarre. And it's continued, I don't know if it's a long-term side-effect or maybe it's just I'm a more relaxed person because I'm, you know, with someone I love. Um but yeah, I cry very easily at movies, all sorts of stupid things. And it's a side of me, because, you know, originally a scientist, I tended to be a little bit clinical before, and I mean, I think it's a positive aspect actually.

A profound impact on mental health was experienced by some. The loss of sex in the relationship and subsequent breakup had a “devastating impact” on Jay’s life, resulting in a long period of depression.

> Hannah: Do you want to say a bit more about in what ways you were struggling with your mental health?
> Jay (bowel): I was uh I couldn't think and focus clearly, and I just couldn't do anymore living um normal tasks 'cause I was just dwelling on my thoughts with him when we were together and life just became like a dream. I couldn't concentrate, I couldn't look after myself, I neglected myself, I didn't bother eating and, but it's just been a really tough journey.

Zayn also reported living with long-term depression and OCD-type behaviours as a result of his experiences with cancer, which lasted long after the bag was removed.

In terms of psychological support, Jay accessed therapy via his GP and Zayn attended wellbeing and recovery events via his hospital. Callum shared that he declined psychological therapy offered to him by his hospital after he was diagnosed. He felt the referral came “too early” and did not think it would be helpful reflecting on recent events, but shared during the interview that in retrospect, he feels he would have benefited from talking to someone.

A number of coping strategies were shared which enabled the men to manage some of the emotional and psychological distress. These included taking each day at a time, exercise, yoga and meditation.

> Peter (prostate): One of the ways that I've tried to take care of myself emotionally to try to go through this is being very mindful of the spiritual, the inner life. So occasionally I practice yoga. I might sit in meditation. Um, I'm very hooked into beauty when I'm out in nature. I try to exercise. That type of self-care has helped a lot with dealing with emotional content.

For three of the men, they felt their own individual coping style had helped them cope. They felt they were “pragmatic” (Arthur) and proactive people, not the type to “wallow” (Peter), and would rather try and resolve issues through thinking about solutions in a “very contained, practical way” (Callum).

3.5. Theme 3: Seeking Community and Support

The final theme refers to the importance of community and support. It describes feelings of loneliness and the fact that some men preferred to cope alone. It outlines how sharing experiences with other GBQ men with cancer was incredibly beneficial and describes interactions with HCPs and hopes for further support.

3.5.1. “A Lonely Journey”: Isolation And Coping Alone

Nearly all participants spoke about feeling alone when managing the impact of cancer on sexuality and intimacy. Jay “just thought it was me” who was struggling to be intimate with his partner. Participants felt they did not have anyone they could talk to about their experiences who they felt would understand. This was particularly true for the younger participants who did not know anyone else who had cancer. For Zayn, this combined with his community’s cultural beliefs towards cancer, exacerbated loneliness.

> Zayn (bowel): UM but yeah, I just think that I wasn't able to really talk about [cancer] and I think some of it is obviously that in my culture we don't talk that much about stuff like that. And of course you don't really know anybody like that either. You know, we don't go out actively meeting people that have got cancer, so it's one of those where you know, with a lot of kind of illness or sickness, we just think well even being almost in their presence, first of all we may catch it, and secondly, it's kind of that whole well if we're close enough or something kind of happens, we could get contracted with it.

Zayn added that he withdrew from the gay community due to feeling negatively about his body.

> Zayn (bowel): The gay community is very, very quiet about all of these things [referring to cancer] because it's all, it all impacts on appearances and the way that we look and how kind of sexual we feel. So obviously if we don't feel that great or feel that sexual, then we don't usually go out or do anything. And I suppose I stopped really going out.

Jay also socially withdrew due to the depression he was experiencing, further exacerbating his mental health difficulties.

> Jay (bowel): I came to an all-time low and I was sad and lonely, isolated, not wanted. And had neglected my friends, didn't want to talk, just wanted to be on my own.

Other participants shared this sentiment of wanting to be on their own. Callum felt being alone helped him stay focused on recovery rather than having to have conversations about illness, explaining that “it was a lonely journey, but it was a journey that I chose to be lonely on”. Zayn also felt that he could more effectively focus on recovery without his partner, which contributed to pushing him away. However, this resulted in loneliness which then contributed to feelings of depression as it seems he had no other support in place.

> Hannah: And do you feel that the depression started, sort of coincided with the impact of bowel cancer?
> Zayn (bowel): Yeah, yeah. I mean, I think it was just kind of very much the loneliness, the isolation, um, you know, and then having to deal with a partner as well on top. It, it wasn't really fair to him um you know, but I just felt so unlovable that it was just like well, now I've got to kind of almost push this person away and keep people away. (...) Um, just so I think for my own, my own kind of protection, and for me to really deal with it myself, really, which is what I needed to do.

Callum linked the idea of coping alone to being stereotypically male.

> Callum (myeloma): All of your questions really are kind of leading to why, as a man, did you kind of deal with it in the way that you, you did, and I'm giving you the stereotypical way in which most men do, which is they don't talk with very many people about it, they suffer in silence or, or they deal with it in silence. And that's exactly what I did. (...) Um, but I did bury it and you know um.. contained it and stuff like that. (...) But that's just me and I, but I think it's also most men, isn't it really? And how we, how we deal with stuff.

In some cases, having a good support network helped alleviate some of these feelings of isolation, however it was still felt that the topic of conversation had to be monitored somewhat among friends.

> Peter (prostate): I thought it was gonna be a bit more of an isolating experience and a bit more lonely and I have not experienced that. My network of friends, my family, obviously there are topics that I don't bring up with different people, but I have very much felt supported and I did not go through this alone.

Arthur commented on the fact that gay men (and in particular older gay men) are more likely to feel isolated and alone due to having different support networks, something that he had witnessed when attending support groups. He reflected that for him, having children from his previous marriage helped mitigated loneliness.

3.5.2. "The Beauty Of Peer Support": Supporting Each Other Through Shared Experiences

The importance of sharing experiences with other GBQ men with cancer was highlighted. The three men diagnosed with PCa described the benefits of receiving advice from other PCa survivors, not just HCPs. This helped reduce feelings of isolation and helped them feel more supported and informed during their cancer journey.

> Peter (prostate): I had these three different men that all were prostate cancer survivors, that I met through circles here in [my city] that provided me with an unbelievable amount of support and perspective and opportunity to kind of talk and share and kind of make sense out of all this.

> Arthur (prostate): There's no doubt talking to someone else who's really been through it, who has got similar issues to you, is invaluable. Yes, a nurse can understand. Yes, the doctor can understand but they can't really because they're not in exactly the same position as you.

Specific support groups for GBQ men with PCa were spoken of very highly, particularly in terms of receiving advice around sexuality and treatment options.

> Arthur (prostate): So I went away to think about [treatment options], did some research and found out about the [support] group. I'm not particularly into, you know, those kind of support groups. That's just not the way I work, but I found out about it, so I went along to the meeting. I found it incredibly useful because I was able to talk openly to other men who'd had either type of treatment, and yeah, had real detailed discussions about the side-effects because as a gay man looking for another relationship, the possibility of impotence the day after the surgery, was just not an option for me.

It appears that the type of cancer makes a difference to available support. Zayn expressed a desire for a shared community and wondered whether that could be an outcome of the study.

> Zayn (bowel): It would have been nice to have, out of through this [study] specifically, that there couldn't be an emergent type of community now that everything is going online, actually connecting with other people in the same type of situation, the same type of kind of problems that we've had and, you know, who knows, you know, I suppose you meet people that are similar to yourself. You've both shared the same type of journey um, with cancer and obviously also being, um, homosexual or bisexual or transsexual or any of the other labels um that people are given and just kind of, I suppose, knowing that you're not really truly on your own.

Some of the men had attended or considered attending mainstream support groups, however felt they were too heteronormative to be of real use. Zayn reflected that he could have “blended in” as heterosexual during these groups but felt there was not much point as he would not “be able to ask any of the real intimacy type questions” for which he was seeking support for. Arthur also shared that men typically attended the groups with their wives and did not openly discuss sex.

The mainstream groups also felt too white for Zayn who expressed a desire for culturally specific support groups. Arthur also recognised the importance of having groups for other marginalised communities, including Asian subcultures, as he acknowledged that different cultures talk about sex in different ways.

> Zayn (bowel): I didn't really look online [for support groups] because I think the problem is that when you look for these kind of groups, they're all white type groups, and there's nothing for, you know, south Asian people really. Um and then when you're talking about stuff, you know, some of the stuff that I've said to you about feeling filthy and dirty, a lot of people seem to be okay with that, whereas for me I just thought no, I need like a bunch of Muslims who are all kind of, you know, super hygienic, like myself, to talk about and to say okay how can I make myself feel clean again without having to rub bleach into me or something.

Geographical location was deemed another barrier to receiving specific support, with people living outside of London believing they would have been able to meet others in similar situations had they lived in the capital. Zayn recognised that belonging to part of a “niche group” (i.e., gay, Muslim, with a diagnosis of bowel cancer) posed a barrier to accessing such support and shared he felt “more alone” when looking for groups in his local area.

All the PCa participants spoke about giving back to other GBQ PCa survivors. They expressed wanting others to feel supported and have access to relevant information and advice. Arthur had done this through making a website for a PCa charity to signpost GBQ men to specific resources and had enrolled in a peer mentoring scheme. They all commented that this act of giving back helped them emotionally too.

> Peter (prostate): Hopefully the, some of the emotion around the giving back, the wanting to be able to be there for other gay men who are going through this, is where I have channelled some of that sadness and, you know, maybe a little bit of depression, a lot of the bargaining. Um and the acceptance of saying I have something that I can offer to others through their process and their journey.

3.5.3. "The Doctors And Nurses": Sexual Support From Healthcare Professionals

Support from HCPs around sexuality appeared to predominantly depend on cancer type. For the PCa patients, discussions of sex took place and sexual function was considered as part of the treatment plan. Peter and Lee stressed the importance of nerve sparing prostatectomies with their surgeons to help them achieve a degree of potency post-surgery, whist Arthur discussed and changed his hormone treatment several times to find one that had the least sexual side-effects.

For the other participants, discussions of sex were limited. Jay reported that he understood from HCPs that the cancer treatment would affect his sex drive and his sex life since the cancer was “bowel related” but discussions failed to go beyond this surface level conversation. Discussions of sex did not take place for Zayn and Callum, leaving them feeling as though they lacked knowledge about how to navigate sex in the context of cancer and its treatment.

> Zayn (bowel): I just didn't know what, I didn't kind of know what to expect. You know there wasn't, they don't give you a speech after you've had the bag removed and they go 'oh yeah, this is what you can and can't do', that you know, the subject of sex just doesn't really appear on that.

Both Callum and Zayn felt these conversations did not take place because of where the cancer was located.

> Hannah: [I’m wondering] whether it came up, any conversations about sex and intimacy with health care professionals.
> Callum (myeloma): No, there was not. There was never any discussions around um around that. I, as I said, I think it was because of the type of cancer that I had. Um it, you know, had I been a female and it had been ovarian cancer or you know, prostate cancer or bowel cancer or whatever, I'd imagine that probably would have been part of the treatment that, you know, discussions and algorithms, but there wasn't. There wasn't, um, any discussion as far as I can kind of, um, recollect.

When sex had been discussed, the participants reported positive experiences. The HCPs were described as understanding, compassionate and helpful. The participants felt most at ease when HCPs were matter of fact.

> Arthur (prostate): [The advanced nurse practitioners] were very pragmatic. They'd seen it all before. It was no big deal to them. You know, they were there to help you. And also the fact that I could, I could talk very technically about [sex] um made me feel very comfortable about it.

Comfort with disclosure of SO to HCPs appeared to be related to individual comfort with own ‘outness’ rather than individual HCP factors, however friendly and encouraging HCPs were easier to come out to than “macho” (Arthur) ones. When the men were open about their SO in healthcare settings, they were, on the whole, met with positive responses and supportive professionals. Only one explicitly negative experience with a HCP was reported.

> Arthur (prostate): Just as an aside, during one of the discussions with the medical follow-up clinic at the [hospital], I mentioned to the doctor who was a, is a junior doctor, I don't know what he was, SPR probably, that I was having, you know, I wasn't having a full erection and I said and I'm gay and as you probably know you need a strong erection. He was a little bit uncomfortable, and he was in his 30s, a little bit uncomfortable and said well you probably know more about it than me and moved off the subject. So that was the only negative type thing I've ever had at the [hospital].

Some of the men spoke about the societal assumption that PWC are not sexually active: “If you've got the big C, you don't picture somebody with cancer having sex” (Callum*)*. They felt this was a barrier to broaching the topic of sex as they felt HCPs might judge them for still having sexual desires.

> Zayn (bowel): I suppose in a lot of ways, you know, I think there's almost an unwritten rule with when you're unwell that people don't expect you to be having that kind of activity [referring to sex]. Um, and I think, you

> know, if you were to then mention it, I think it becomes, you end up with, I think, a few doctors and maybe nurses kind of feeling a bit of, you know, feeling a bit of shame or kind of think 'Oh God you know, this person is still quite active whilst they're on all of this'. I don't, I think just as a general rule of thumb, people don't really think about it or talk about it, because when you think about cancer, who's having sex when they've got cancer?

Assumptions of asexuality were exacerbated when cancer intersected with race.

> Zayn (bowel): I think the thing is, is that when you're quite visibly somebody of colour, [sex] isn't really spoken about anyway. And I think people think that you know that, it’s strange, I don't, I don't think people think we even have sex at all, so it's one of those things where you just [healthcare professionals] don't really broach the subject at all.

The participants felt that HCPs should broach the topic of sex first and that they should be more open to discussing sexuality so as to provide support and hope.

> Jay (bowel): I think [healthcare professionals] should be more open about sex. And they must have more work done on their end so they can, are able to put the patient more at peace of mind in opening up about what's happening and feel they've got a life at the end of the tunnel.

The participants also expressed a desire for HCPs to have more understanding of LGBTQ+ specific issues, with Jay suggesting they should “have more training” on the particular sexual practices and needs of GBQ men. Arthur expressed how helpful it had been to find sexuality resources online for GBQ PCa survivors and felt that this sort of information should be readily accessible in healthcare settings. The participants stated that they would have liked “hints and tips” (Jay) about navigating sexuality in the context of cancer, specifically for GBQ men, potentially in the form of leaflets. Arthur felt this information should be “available discreetly” but easily, such as online. The men felt this information would have helped them feel more prepared for the sexual changes and more able to manage any disruptions.

> Jay (bowel): If they'd have given me some leaflets or some leaflet information beforehand, or you know, I could be more prepared for it and put me more at peace of mind knowing that these are the changes that were like, that were coming to affect my life. And, you know, I know they might not be able to support me, but you know the other, when I got to see him in the meeting, in the consultation sorry, but at least they can give me something, at least I've got some hope with it, but I didn't get that much support with that I don't think.

None of the men diagnosed with non-sexual cancers received support for sexual difficulties, perhaps because the impact was less obvious or sex was not discussed openly enough for it to be suggested. Peter, Arthur and Lee all received psychosexual support, likely due to the direct and long-lasting impact on sexual function, through either having the prostate removed or being on hormone therapy. Lee had a penile implant which he found “extremely satisfying”, Arthur tried medications and a penile pump which he did not find helpful and so had resigned himself to “learning to live with [sexual difficulties]”. Peter was left feeling moderately satisfied relying on a combination of medication, penile pump and injections.

4. DISCUSSION

The final chapter summarises the findings and discusses the themes in relation to the research questions. A critical review and discussion of the study's strengths and limitations are provided. Recommendations, implications and suggestions for future research are described, followed by a reflexive account and concluding comments.

4.1. Summary Of Findings

The study aimed to explore how GBQ men experience sexuality and intimacy in the context of cancer and learn how they experienced healthcare settings with regards to advice, treatment and support for sexual difficulties. The findings indicate that, regardless of cancer type, cancer disrupts the sexuality of GBQ men, impairing sexual function and reducing libido. Some participants were able to overcome these obstacles through open communication with their partners, being upfront about sexual issues, and setting realistic expectations about sexual function. Having a varied sex life that was less dominated by anal sex and more focused on alternative sexual practices appeared to lessen the disruption of cancer on their sex lives and made renegotiation of sexual practices easier. At times, this process brought couples closer together, with some reporting greater intimacy and emotional closeness. For others, sexual changes were more difficult to navigate, due to pre-existing tension in relationships or difficulties with partner communication and understanding. This made it more difficult to work through issues, at times resulting in relationship breakdown.

Changes to sexuality and intimacy resulted in participants undergoing changes in the self. Some participants felt their sense of masculinity had been impacted by difficulties achieving erection and orgasm. Identities of disability were considered and at times negative labels such as “deformed” and “dirty” were self-ascribed. The concept of ageing helped some participants make sense and adjust to changes in their sexuality. Participants also reported an impact on their emotional and psychological wellbeing. Grief and loss around sexual function were reported as the participants adjusted to their changed bodies. At times, positive emotional growth was reported. The impact on mental health was pronounced for some, with cancer and the subsequent impact on sexuality and relationships leading to more long-term psychological difficulties.

Support appeared to be key in helping the men navigate cancer, sexuality and intimacy. The participants described feeling isolated and lonely in their experiences, sometimes preferring to cope alone rather than being around others they felt they could not confide in. The importance of a support network of other GBQ men with cancer was reported, particularly so that issues of sexuality could be openly discussed. Discussions of sexuality with HCPs were felt to be an important part of treatment, regardless of cancer type, whereas detailed discussions only occurred for the PCa patients. A desire for open conversations about sex with HCPs and support and advice specifically tailored to GBQ men was expressed.

4.2. How Do GBQ Men Experience Sexuality And Intimacy In The Context Of Cancer?

4.2.1. Sexual Changes And Challenges

All participants, regardless of cancer type, reported an impact on sexual function, including difficulties achieving or sustaining an erection, difficulties reaching or changed experiences with orgasm, loss of ejaculation and decreased libido. This is consistent with literature on sexuality across cancer types (Gilbert et al., 2013; Gurevich et al., 2004; Incrocci, 2006; Stanford et al., 2000; Ussher et al., 2012). Concern about erectile function depended on sexual roles assumed during sex, with tops reporting greater concern than bottoms due to needing a firm erection for penetrative anal sex.

Participants commented on the loss of erection and ejaculation as an outward display of attraction. This is reflective of studies in the scoping review (Doran, 2015; Lee et al., 2015; Rosser et al., 2016; Ussher, Perz, et al., 2017) which found that GBQ men diagnosed with PCa mourned the loss of ejaculation, yet these findings provide more depth by demonstrating that it is erections as well as ejaculation which is mourned, and not only for men with PCa but for other cancers such as multiple myeloma too. The participants also spoke about changed orgasms, with some reporting sexual growth from experiencing pleasure in a new and different way, consistent with previous studies (Danemalm et al., 2019; Rosser et al., 2016).

Decreased libido was reported by participants, associated with feeling physically unwell from cancer symptoms and treatment side-effects, often resulting in changed relationships to their body and feeling less attractive. This is understandable given the extensiveness of physical symptoms and the impact on body image, as demonstrated in the literature (Kreitler, 2019). Changed body image and feeling unattractive was particularly stark for the participant who had a temporary colostomy, which supports research with heterosexual couples (Vural et al., 2016). These findings demonstrate similar issues for GBQ men and supports hypotheses suggested by Li (2009) that the presence of a colostomy would alter body image which is seen as an importance aspect of the GBQ community, which appeared evident by the participant avoiding interactions with the GBQ community. Participants also described psychological factors such as the anticipation of pain, and practical factors such as reduced mobility, as additional barriers to engaging in sex, also consistent with studies finding that sexuality is linked to psychosocial factors (Dunn et al., 1999). All of these factors resulted in less frequent sex, consistent with GBQ PCa research (Danemalm et al., 2019; Hart et al., 2014; Ussher, Perz, et al., 2017).

4.2.2. Overcoming Obstacles

Some of the participants were able to navigate the changes and challenges that cancer created in their sexual and intimate relationships, whereas others found them more difficult to overcome. Factors that appeared integral to overcoming obstacles were strong, open communication in the relationship and understanding partners. This is reflective of GBQ PCa research highlighting that supportive partners, good communication and finding compromise reduced the impact of sexual side-effects of cancer (Lee et al., 2015; Rosser et al., 2016; Ussher, Perz, et al., 2017).

Participants who expressed enjoying sexual practices not confined to anal sex before the cancer diagnosis noticed less disruptions in their sex lives. This may be linked to GBQ men being less bound by the 'heterosexual matrix' (Butler, 1993) and the coital imperative (Jackson, 1984), in that sex is defined by a broader range of practices than just penetrative intercourse (though at least some erectile function seemed to be important in order to signal sexual attraction and desire as mentioned above). Resistance of the coital imperative has been noted to be the primary strategy through which couples (both heterosexual and non-heterosexual) renegotiate sexuality and intimacy, breaking the narrow heteronormative boundaries through which sex has historically been viewed (Ussher et al., 2013).

For some participants, sex became less of a priority compared to other areas of their lives, with emotional closeness becoming more important for some. Participants reported closer relationships with enhanced intimacy as a result, consistent with previous heterosexual literature (Gilbert et al., 2010, 2013; Ussher et al., 2012, 2013) and research with GBQ PCa survivors (Danemalm et al., 2019; Ussher, Perz, et al., 2017; Ussher, Rose, et al., 2017).

Conversely, factors associated with relationship tension and breakdown included difficulties communicating with partners, feeling as though partners did not understand, and increased emotional and physical distance in the relationship. Fears around sexual performance led to avoidance of sex, contributing to some participants "pushing away" their partners and avoiding intimacy too. These findings reflect research with heterosexual couples which suggests that when sexual activity stops in the context of cancer, so do other forms of intimacy (Ussher et al., 2012). This can create tension in the relationship particularly if communication is difficult and creates distance, having devastating consequences of relationships ending (Hawkins et al., 2009), as was the case for some participants in this study.

'Opening up' the relationship in order to cope with some of the tension was felt a helpful and resourceful way of overcoming obstacles for one PCa participant, which has been reported by other GBQ men with PCa (Doran, 2015; Hartman et al., 2014; Hoyt et al., 2020; Matheson et al., 2017). Changes in sexual roles were spoken about by the participants but in less of a negative way compared to how other GBQ men with PCa have described (Doran, 2015; McConkey & Holborn, 2018; Rosser et al., 2016; Ussher et al., 2016). For some of the participants in this study, changes in sexual roles meant the pressure was taken off anal sex and they learnt to enjoy other sexual practices.

4.2.3. Identity And Sense Of Self

A consequence of altered sexuality and intimacy were changes in the participants' identity and sense of self. Participants reported feeling as though their masculinity had been depleted by impaired sexual function. This framing of masculinity is consistent with the concept of hegemonic masculinity whereby erectile function is perceived as fundamental to manhood (Potts, 2000), and reflects research with other cancer survivors (Gannon et al., 2010; Thomas et al., 2013). The findings also reflect previous literature that for some, masculinity is more multifaceted and consequently less impacted by sexual difficulties, due to participants having a broader sense of what constitutes their masculinity (Doran, 2015; McConkey & Holborn, 2018).

Comparisons to women were made multiple times: impaired sexual function made the participants feel emasculated and more like a woman, having their prostate removed was compared to a woman having a breast removed, and changed orgasms were compared to what they imagine women experience during sexual climax. Using metaphorical language to make sense of changed sexual function is common among men with cancer and the general public, with one study finding that when sexual difficulties in the context of cancer were spoken about, the language of emasculation was used which often faulted the subject, implied a dysfunction and powerlessness, and often shamed the PWC for their sexual difficulties (Cushman et al., 2010). This is consistent with elements of hegemonic masculinity which characterises men as being physically robust, strong and in control of their bodies (Lee & Owens, 2002). The findings here indicate some negative comparisons with women, but also some more neutral and at times positive curiosity about their changed bodies.

However, shameful and critical descriptive labels were in some cases self-ascribed by the participants, reflecting findings from other GBQ PCa studies whereby negative labels such as ‘inferior’ were used (Matheson et al., 2017). Identities of disability and illness were also questioned and individual factors seemed to determine whether the participants attributed these labels to themselves or not. This finding is supported by Magasi et al. (2022) who found that only 50% of their 30 participants identified as being a person with a disability despite all participants experiencing significant restrictions in their lives due to cancer. People felt the label did not fit with how capable and competent they felt and had strong emotional aversions to the negative connotations of the word ‘disabled’.

Some participants’ responses implied that they felt positioned as a “victim” rather than a ‘lover’, however it is unclear whether this was due to their own negative self-concepts that had developed or due to their partner’s reactions, or potentially a combination of both. Partners who assume caring roles have reported finding it difficult to continue seeing their lover as a sexual being, instead repositioning them as ‘asexual’ or a ‘patient’ (Gilbert et al., 2010). The findings in this study indicate that this can come from within the PWC too.

In line with previous research identified in the scoping review (Danemalm et al., 2019; Hartman et al., 2014; McConkey & Holborn, 2018; Rosser et al., 2016; Ussher, Perz, et al., 2017; Ussher, Rose, et al., 2017), participants felt the concept of ageing helped them process and accept sexual changes. The study expands on these findings by highlighting that being younger and diagnosed with cancer made the sexual and relational changes more difficult to process, due to the belief that it was too soon in the relationship to be going through such challenging circumstances. This is supported by studies finding that young PCa patients report greater concern about the sexual side-effects of PCa treatment than older PCa patients (Van Dam et al., 2016).

4.2.4. Emotional And Psychological Wellbeing

In line with the social-cognitive model of adjustment (Brennan, 2001), the participants described expected and understandable emotional responses to sexual and relational changes, such as anxiety, grief and frustration. Adjustment was interrupted when it coincided with managing other stressors such as relationship breakdown or impaired body image. In these cases, more long-term and distressing mental health difficulties developed, such as depression and OCD-like behaviours. It is worth noting that the two participants reporting such difficulties appeared to have the least support from social networks and HCPs. These experiences fit with existing literature examining psychological adjustment in women after breast cancer, in that factors such as perceived social support and body image predicted the development of depression and anxiety symptoms and psychological distress (Brandão et al., 2017).

The impact on mental health was potentially compounded by the pre-existing stress of being part of a sexual minority, as outlined by minority stress theory (Conron et al., 2010; Meyer, 2003) and the higher rates of anxiety and depression reported in the LGBTQ+ population (Stonewall, 2018). Of note, the PCa participants in this sample did not describe mental health difficulties, which contrasts with findings from Australian studies where men with PCa reported elevated rates of anxiety and depression symptoms (Thomas et al., 2013; Ussher et al., 2016; Ussher, Perz, et al., 2017). This may reflect cultural differences between Australia and the UK in talking about mental health, or differences in service provision and support. The PCa participants in this sample appeared to be well supported which may have contributed to reduced mental health needs, fitting with research indicating that greater social support resulted in improvements in anxiety and depression for cancer patients (Gonzalez-Saenz de Tejada et al., 2017).

Post-traumatic growth (Tedeschi & Calhoun, 1995) was reported in some cases, with participants feeling as though they had learnt from challenging circumstances and developed as people. For some, hormone treatment resulted in personal emotional growth which was experienced as a surprising yet pleasant side-effect. This is interesting given some men (often heterosexual) report being disturbed by heightened emotionality, seeing it as an attack on stereotypically masculine qualities of emotional control (Darabos & Hoyt, 2017). These findings are supported by Doran (2015) whereby loss of libido allowed GBQ men diagnosed with PCa to connect with more subtle, sensual feelings in their bodies and became more in touch with their emotions as a result. The findings in the current study build on this by indicating that treatment side-effects as well as loss of libido may be ways of achieving more emotional vulnerability.

Participants reported coping strategies focused on self-care and exercise which have been found to be effective at managing the emotional toll and physical side-effects of cancer (Johnston et al., 2009; Kidd et al., 2008; Segal et al., 2017). Other coping strategies such as adopting a pragmatic, proactive, solution-focused approach were also reported by the participants. This aligns with research exploring traditional masculine coping styles, which indicates that men value traits of self-reliance and autonomy when coping with mental health difficulties (Spendelow, 2015).

4.2.5. Isolation And Support Networks

Consistent with previous research with heterosexual samples (Adams et al., 2017, 2018; Wells & Kelly, 2008) and GBQ PCa samples (Doran, 2015; Lee et al., 2015), participants reported loneliness on their cancer journey. This was particularly true for the younger participants who did not know anyone else their age who had been diagnosed with cancer. Many of the participants expressed preferring to be alone than seek help from others. This is supported by literature which suggests some PWC prefer to cope privately due to feeling misunderstood in their experiences (Adams et al., 2018; Davison et al., 2000). GBQ men with PCa have also reported preferring to cope alone so as not to burden others (Doran, 2015; McConkey & Holborn, 2018). This fits with findings that men have been found to be more reluctant than women to engage in help-seeking behaviours (Ettridge et al., 2018) and subsequently conceal or ignore negative emotions (Oliffe, Kelly, et al., 2010) and do not seek formal help (Oliffe, Robertson, et al., 2010). However, for some of the participants in this study, this resulted in increased isolation and loneliness and negatively impacted on their mental health, findings which other studies have reported (Friedman et al., 2006; Kroenke et al., 2006).

Some participants withdrew from their usual social networks, such as the GBQ community due to feeling unattractive, or from friends due to mental health difficulties making it hard to socialise. Other GBQ men with PCa have reported similar behaviours, such as losing their place within the GBQ community due to feeling less attractive (Doran, 2015), and other research suggesting that reduced levels of social support were a consequence of men who experienced depression (Pettit et al., 2011). Support networks such as friends, having children from a previous marriage, and empathetic partners helped mitigate feelings of loneliness and helped participants feel more able to cope. Good support networks have consistently been found to be key to managing the impact of cancer (Bloom, 2008).

The finding that GBQ men experienced barriers when accessing mainstream cancer support groups is consistent with previous literature (Brown & McElroy, 2018; Capistrant et al., 2016; Carr, 2018; Doran, 2015). Support groups specifically for GBQ men were only availble to men diagnosed with PCa. The bowel cancer and multiple myeloma participants expressing a desire for such groups and a yearning to connect with other GBQ men, and for this support to be accessible nationally, not just in London. The peer support accessed by the PCa participants appeared very beneficial, helping participants feel less alone, give back to others in need, and access appropriate, relevant advice that went beyond what HCPs could offer. This helped participants feel more informed and supported along their cancer journey, consistent with reports from other GBQ men with PCa (Doran, 2015; Hoyt et al., 2020). This was particularly relevant for support around sexuality and relationships, discussions of which could occur freely in these groups. These findings demonstrate that the desire for specific GBQ groups is common across cancer types, not just PCa.

4.2.6. Cultural Issues

Despite discussing cultural issues throughout the results, I believe it is important to revisit this topic as a standalone issue. Whilst only reported by one participant of south Asian and Muslim background, their experiences and struggles were significant due to the interplay between cancer, sexuality, and cultural and religious beliefs, specifically views concerning cleanliness making it very difficult having a colostomy. This is supported by a systematic review which demonstrated that quality of life is impacted in Muslim patients with ostomies, with participants reporting reduced psychological wellbeing, social exclusion and sexual difficulties, leading to breakdown of marital relations and decreased religious practices (Iqbal et al., 2016). The study concluded that

Muslims requiring ostomies must receive adequate counselling from HCPs, faith leaders and hospital chaplaincy.

This participant experienced these issues compounded by sexual minority status making their difficulties even more “niche”. Obtaining specific support was even more challenging, resulting in greater feelings of isolation and feeling misunderstood. This is consistent with literature which suggests patients with multiple intersecting identities will face additional barriers along the cancer care pathway (Kamen et al., 2019), and that people from the non-dominant culture will face difficulties getting support for sexual difficulties (Wray et al., 2014). A desire for culturally and sexually relevant support groups, information and discussions with HCPs were expressed. It is important to note that this is just one person’s experience and relates to one cultural subgroup; it can be assumed that people belonging to other cultural groups will experience their own set of specific needs.

4.3. How Do GBQ Men Experienced Healthcare Settings With Regards To Advice, Treatment And Support Around Sexuality And Intimacy In The Context Of Cancer?

A main determinant in the quality of sexual support from HCPs appeared to be cancer type, with PCa patients having more open discussions about sexuality than non-sexual cancers. This supports findings from Australian studies that discussions of sexuality with HCPs and psychosexual support are less likely to occur with non-sexual cancers than sexual cancers (Beckjord et al., 2014; Gilbert et al., 2016).

For the PCa participants, discussions with HCPs were helpful and mostly focused on maintaining a level of potency post-treatment. Interactions with HCPs were positive, with staff reported to be knowledgeable, compassionate and pragmatic, helping participants feel at ease. Psychosexual support on the NHS was offered to and accepted by two of the PCa participants; the other PCa participant received psychosexual support and, whilst unclear, it seems they accessed this privately. For the non-sexual cancers, discussions with HCPs were limited or did not occur, leaving participants feeling unsure how to navigate sex in the context of cancer. This is consistent with literature suggesting HCPs do not routinely discuss sexuality with their patients even though they recognise it to be their responsibility (Krouwel et al., 2015). The findings also support Li's (2009) hypotheses that GBQ men living with colostomies are at risk of inadequate sexual counselling. The participants spoke about assumptions that they were not sexually active which posed a barrier to them broaching the topic with a HCP. This fits with unhelpful societal assumptions that cancer patients are not sexual beings (Goh, 2021). There was a consensus that HCPs should be the ones to broach the topic of sex first.

Most of the participants felt able to come out to at least one member of their healthcare team. This seemed to depend on individual comfort with own 'outness', however a friendly HCP helped make it easier to disclose. It is positive that participants were met with understanding HCPs and that only one negative interaction was mentioned. This contrasts with studies suggesting it can be difficult for patients to come out to HCPs (Stonewall, 2018) and that patients experience and fear homophobia and discrimination when interacting with the NHS (Hayman et al., 2013; Hill & Holborn, 2015). The small sample and the fact that most of the participants lived in large cities where atittudes towards LGBTQ+ individuals tend to be more accepting, may have also contributed to the lack of negative experinces reported. In recent years, there has also been a spike in interest in improving the healthcare needs of 'hard to reach' groups, including sexual minorities, and a move towards striving for equitable access to health and social care. Macmillan and principal LGBTQ+ charity Stonewall have produced many publications on LGBTQ+ health, providing vital information about the experiences of sexual minority patients and gaps in services. It may be that this increased awareness of LGBTQ+ issues has contributed to more positive experiences within the healthcare system.

Whilst the PCa participants had access to specific LGBTQ+ information about cancer and sexuality, they reported having to search for it themselves. All participants expressed a desire for this information to be more readily available. The participants shared they would have appreciated "hints and tips" about navigating sexuality and intimacy in the context of cancer, specifically for GBQ men, potentially in leaflet form and online so that it could be processed at home in their own time and available discreetly. This confirms previous research suggesting sexual minority PWC are less likely to receive specific information (Margolies, 2014; Picker, 2020), and builds on GBQ PCa research that all GBQ cancer patients, not just PCa, would like specific information about the sexual impact of cancer that is tailored to GBQ men.

4.4. Critical Review

This study will be evaluated in relation to the concept of trustworthiness (Lincoln & Guba, 1985) with reference to Nowell et al.'s (2017) four criteria developed specifically for TA: credibility, transferability, dependability and confirmability. A discussion of the study's strengths and limitations is also provided.

4.4.1. Credibility

Credibility refers to the congruence between participants' accounts of their experiences and the researcher's analysis and representation of them (Tobin & Begley, 2004) and that through reading the findings, the participants' experiences are recognised (Lincoln & Guba, 1985). In this study, credibility was established through prolonged engagement with the data, facilitated by conducting and transcribing the interviews and further data familiarisation processes. Data collection triangulation was not appropriate in this study, due to wanting to hear directly from a marginalised group of people rather than other sources. However, perhaps hearing directly from HCPs about their experiences of supporting GBQ men with sexuality across cancer types may have provided helpful insights to the support currently offered by the NHS. Only one data set was considered, however the study is situated within the context of existing theory and research documented in previous chapters, my consumption and understanding of which likely influenced the research process. Research triangulation did not occur since I was the only researcher, however peer debriefing was implemented so that external checks could be made on the research process (Nowell et al., 2017). Separate discussions with my research supervisor and a fellow trainee clinical psychologist took place throughout the research process to ensure resemblance between the data, analysis and report. Themes and subthemes were also repeatedly checked and refined against the raw data to ensure they accurately reflected the participants' accounts.

4.4.2. Transferability

Transferability refers to the generalisability of findings to other settings. Qualitative research concerns only ‘case-to-case’ transferability since there is no single correct or ‘true’ interpretation of accounts (Tobin & Begley, 2004). The findings are specific to the individuals who took part in the study, due to being located within specific temporal, geographical and cultural contexts. However, since rich, detailed descriptions of the themes are provided in the results section evidenced with raw quotes from the data, a degree of transferability is possible, the level of which can be judged by those others who wish to transfer the findings to their own setting (Lincoln & Guba, 1985).

4.4.3. Dependability

Dependability can be achieved through describing the research process in a “logical, traceable, and clearly documented” way (Tobin & Begley, 2004, p. 392). An audit trail (Koch, 1994) of decisions and choices made is provided in previous chapters, outlining why and how research decisions were made, such as the rationale for choosing this particular population and the epistemological position. Detailed descriptions of the research procedure and approach to analysis are provided in the methods section and evidenced by documents in the appendices. Field notes and a reflective journal were kept throughout the research process, documenting the development of themes and personal reflections. Using NVivo 12 software supported me in documenting, relating and cross referencing the raw data throughout theme development. All data, meeting notes, iterations of theme development, and reflections have been retrained and stored in clearly organised electronic folders. Supervision also helped ensure Braun & Clarke’s (2006) TA procedure was adhered to.

4.4.4. Confirmability

Confirmability refers to the researcher demonstrating how conclusions were reached, by clearly showing how interpretations and findings were derived from the data (Tobin & Begley, 2004). Confirmability is established through following the processes of credibility, transferability and dependability outlined above (Lincoln & Guba, 1985). Reasons for theoretical, methodological and analytical choices have been provided throughout the entire study, alerting the reader to how and why decision were made (Koch, 1994), indicating that the study has achieved a satisfactory level of trustworthiness.

4.4.5. Strengths And Limitations

Adopting a qualitative approach allowed for a detailed exploration of GBQ men's experiences of sexuality and intimacy in the context of cancer. The TA produced a rich, nuanced account of the data, capturing the diverse perspectives of participants, highlighting similarities and differences across cancer types and generated unanticipated insights (Braun & Clarke, 2006). The findings are particularly pertinent given the scarcity of existing literature examining this topic from a UK perspective. Given the life-expectancy for PWC has increased and consequently more PWC are engaging in sexual and intimate relationships, the lack of literature and knowledge of sexuality across a range of cancers poses a barrier to men receiving appropriate care. As discussed, men can be reticent to seek help and discuss emotional and sexual difficulties, due to masculinity norms and assumptions around cancer and sexuality, so it is vital that their voices are heard through research. The contributions of this study therefore are paramount in providing honest accounts of GBQ men's experiences, reducing stigma and misconceptions around cancer and sexuality, and highlighting what can be done differently along the cancer care pathway. Despite the relevance of these findings, there is a risk they will remain detached from the "context of real-world action and interaction" (Yardley, 2000, p. 224). It is hoped that dissemination and discussion of the study within healthcare settings will extend the findings from explaining existing problems to creating new solutions and bringing about real-world improvements in cancer care for sexual minorities.

A sample size of six participants is deemed acceptable according to Guest et al. (2006), however could be viewed as being relatively small. The fairly stringent inclusion criteria, the reluctance of LGBTQ+ individuals to participate in health-related research, principally adopting online recruitment methods, and the sensitive nature of the research topic all posed potential barriers to recruiting a larger sample. The recruitment criteria were initially expanded from people diagnosed with just bowel cancer to include all cancer types, which to some extent benefited recruitment efforts. However, this resulted in the sample becoming more heterogeneous. The themes were generated from grouped participant data which did highlight some differences between cancer types, however more nuanced differences may have been missed. Future research that draws on larger samples or that focus specifically on one cancer type (e.g., bowel cancer) would likely result in findings that expand on the current study.

Whilst there was some variation in the sample across demographics such as age, culture, and SO, this was constrained by the small sample, further limiting the generalisability of results to all GBQ men diagnosed with cancer. The sample mostly identified as gay, and whilst efforts were made to recruit men across a spectrum of sexual identities and through using inclusive language and inclusion criteria, GBQ men were not completely represented. Furthermore, only one cultural subgroup was represented in the sample. Greater representation of minoritised communities is important to understand the particular needs and challenges that intersections of cancer, sexuality, religion and culture can bring. Despite this, the findings of the current study are still important to other GBQ with cancer, their partners and the wider network of people that support them by providing an insight into their unique experiences of sexuality and intimacy.

Individual interviews were conducted due to the sensitive nature of the research topic which yielded interesting results. However, barriers such as embarrassment, shame or stigma may have prevented some participants from being completely open, despite attempts being made to help the participants feel as comfortable as possible. Interviews with partners and focus groups with other GBQ men with cancer could have been adopted and may have resulted in additional or different ideas being generated through sharing perspectives and experiences. This may have helped create a richer picture of GBQ men's experiences of cancer and sexuality.

Cohesion to the study's epistemological position was promoted by explicit stating and consciously applying the critical realist stance (Holloway & Todres, 2003). When analysing participants' accounts, I considered how the men were making sense of their experiences whilst also acknowledging their lived realities. A level of interpretation may however have been missed by adopting this approach. An alternative stance such as social constructionism may have allowed for a greater exploration of language and of wider societal discourses of cancer and sexuality. This may have been particularly interesting when considering asexual assumptions towards cancer patients and constructions of masculinity. A less individualised account with a greater focus on how experiences were constructed in relation to broader narratives may have been revealed as a result.

Finally, the study design and development would have benefited from direct input from GBQ men diagnosed with cancer themselves. Whilst attempts were made to recruit men with lived experience to co-produce aspects of the study, it was not possible due to recruitment difficulties. Input from the people who this study aims to serve would have likely increased the relevance of findings and may have resulted in ideas about how to overcome recruitment barriers. A more participatory methodology could be followed with future research, for instance, Participatory Action Research (Kagan & Burton, 2000).

4.5. Implications And Recommendations

The findings are relevant to PWC and individuals in their social network such as friends, family and partners, as well as professionals working across cancer, sexual health and therapeutic services. Implications and recommendations across clinical practice, policy and research levels are discussed below.

4.5.1. Implications For Clinical Practice

4.5.1.1. *Support within the healthcare system:*

The findings indicate that all cancer patients would benefit from conversations about sexuality and intimacy with HCPs. More training should be provided to HCPs to enable them to overcome some of the barriers they face when discussing sexuality (Filiault et al., 2008; Hoyt et al., 2020; Krouwel et al., 2015; Lee et al., 2015; McConkey & Holborn, 2018; Moore et al., 2013). Training on sexuality and GBQ men's needs across cancer types, not just PCa, would help provide HCPs with the skills, knowledge and confidence to address these issues with GBQ men. UK oncologists are in support of this, with many agreeing that LGBTQ+ healthcare needs should be a mandatory part of medical training

(Berner et al., 2020). Positively, there is evidence of this taking place, with organisations such as the LGBT Foundation developing teaching materials in conjunction with medical schools and research producing recommendations for oncology services (e.g., Berner et al., 2021; Webster & Drury-Smith, 2021). However, few training programs have collected data to evaluate whether training is effective in reducing disparities in cancer care (Alpert et al., 2020).

The findings suggest that conversations about sexuality should be initiated by HCPs so as not to strengthen asexual narratives and that staff should adopt a frank, pragmatic, yet understanding and compassionate approach. Cathcart-Rake et al.’s (2020) paper supports this, providing advice to oncologists for discussing sexuality with sexual minority patients, including gauging the patient’s willingness to discuss sexual matters, initiating discussions early on and repeatedly throughout the cancer pathway, becoming comfortable discussing sex, and using plain, direct language. Patients should also be provided with practical information about the potential changes to sexuality and relationships to help patients feel prepared and to normalise any changes and challenges. Information should specifically relate to GBQ men and be available in leaflet form and online for people to access at their own convenience. Not every patient will require psychosexual or psychotherapeutic interventions, but creating an atmosphere in the healthcare setting that is open to conversations about sex, regardless of SO, could help normalise patients’ experiences, empower them to communicate their sexual concerns, affirm them as sexual beings, reduce feelings of isolation and shame, and support the renegotiation of sexuality post-cancer.

It is positive that only one negative interaction was reported by participants when they disclosed their SO to HCPs. Services need to continue being safe places for disclosure as sharing SO during cancer treatment is associated with greater care satisfaction and enhanced well-being (Durso & Meyer, 2013; Kamen et al., 2015). Inclusive discussions of sexuality should take place across multidisciplinary teams, so that firstly, a holistic approach to care-planning which includes sex and relationships is adopted thus promoting a fuller quality of life for PWC, and secondly, so that professionals are consistently holding LGBTQ+ healthcare needs in mind.

Lastly, HCPs need to feel comfortable having conversations about sexuality with all patients, regardless of SO, age, race, and relationship type (e.g., non-monogamous). This intersectional approach to sexuality will better enable all patients to feel supported and less ostracised in their experiences. Cultural humility and cultural curiosity (Mosher et al., 2017) approaches are needed so that HCPs can better understand the influence of systemic oppression on the health of people with multiple, intersecting, stigmatised identities (Feagin & Bennefield, 2014; Turan et al., 2019). These approaches have proved effective in improving HCP knowledge of sexual minority's needs (Feagin & Bennefield, 2014), with patients reporting more satisfaction with care, trust in professional and improved access to healthcare (Clifford et al., 2015; Lie et al., 2011; Majumdar et al., 2004).

4.5.1.2. *Therapeutic interventions:*

Whilst some psychological distress is expected and understandable, referrals for psychological support could enhance coping and prevent more long-term difficulties developing. Therapeutic interventions for PWC are effective at promoting psychological wellbeing, improving quality of life and positive self-image (Barrera & Spiegel, 2014; Henoch & Danielson, 2009; Jassim et al., 2015; Nnate et al., 2021). Given participants reported coping strategies such as exercise and yoga, exercise-based interventions could be offered which have been found to exert positive effects on masculinity, body image and identity in PCa survivors (Langelier et al., 2019). Value and strengths-based interventions, such as Acceptance and Commitment Therapy (Hayes et al., 1999) and Narrative Therapy (White & Epston, 1990), may also support the men in coping with the emotional impact of cancer, empowering them to connect with their lives outside of cancer. Given some of the men also reported the importance of taking each day at a time and meditation, mindfulness-based therapy could be appropriate, which is effective in helping patients manage feelings of loss, uncertainty and mental health difficulties (Carlson, 2016). These psychological therapies could be beneficial in mitigating the negative self-image labels that developed, the long-term impact on mental health, and instead scaffold individuals towards achieving post-traumatic growth which could positively influence current and future sexual and intimate relationships.

Therapists should adopt a flexible approach to offering support, respecting that time alone may sometimes be preferrable to therapeutic approaches. Holding this in mind, therapists could gently encourage men to seek and feel comfortable participating in psychological support. Of course, each individual is different and will have different preferences in therapeutic style, however a scoping review (Seidler et al., 2018) suggested normalisation, self-disclosure, adapting language, using metaphors, and adopting a collaborative, transparent, and goal-focused approach to therapy can help engage men in psychological support. In line with some of the participants expressing a more pragmatic individual coping style, action-orientated and solution-focused interventions may be preferred.

Therapeutic interventions could also provide support with the sexual and relational impact of cancer. Interventions such as CBT and emotionally-focused couples therapy can help with desire, orgasm, sexual avoidance and relationship difficulties (Grayer, 2016; Hummel et al., 2018). Additionally, compassion focused therapy has been found to be effective in managing shame, self-criticism and sexual difficulties (Vosper et al., 2021), which could be particularly relevant given the negative self-image and shame that was spoken about by participants. Evidence also suggests men with PCa benefit from acknowledging and grieving the loss of sexual function (Walker et al., 2013).

Support should not only be offered to PWC but also to their partners, either via joint couples sessions or their own individual therapeutic support. Given the importance of communication and partner understanding in overcoming sexual changes, therapists should facilitate open communication and mutual understanding in relationships. Couples-based interventions have been found to contribute to emotional support and dyadic coping with cancer (Baik & Adams, 2011) and improve the effectiveness of sex therapy, resulting in improved sexual satisfaction (Johnson et al., 2018). Furthermore, an appreciation of the wider social and systemic context should be considered when working with PWC and their partners, drawing on Bronfenbrenner’s (1979) ecological systems framework, to recognise that people and their problems exist in interconnected, complex systems.

Psychologists are skilled in having difficult, emotive and sensitive conversations and are well placed to support GBQ PWC and their partners with issues of sexuality. However, studies indicate that psychologists can feel reluctant discussing sexuality in therapy, due to attitudes towards sex and a lack of training (Miller & Byers, 2008; Reissing & Giulio, 2010). A survey of 23 UK clinical psychology training courses indicated that only 57% of courses dedicated more than two hours of teaching about working with LGB clients (Shaw et al., 2008). Furthermore, continuing professional development courses in the UK are inconsistent and lacking in specificity about sexuality (Anderson, 2012). This is unlikely to result in clinical psychologists feeling adept in supporting sexual minority clients. Further training is needed to ensure the psychological workforce feels confident supporting GBQ clients with their sexuality, as psychologists who are self-confident and who receive training and supervision regarding sexuality have been found to deal with sexual topics more often (Træen & Schaller, 2013).

4.5.1.3. *Peer support:*

Another key recommendation is for GBQ PWC to have access to specific and relevant support, ideally via support groups and peer mentoring. At present, some specific GBQ support groups exist for men diagnosed with PCa and I am aware of two London-based LGBTQ+ cancer support groups, however the participants did not appear to know about these. Working collaboratively with cancer charities and NHS services may facilitate the provision and awareness of such groups, however GBQ PWC must be at the centre of determining what support is helpful by privileging their expertise and ideas (Afuape & Hughes, 2015). Harnessing the collective knowledge and power of GBQ men through community approaches (Holland, 1991) would result in more appropriate spaces for GBQ PWC, mitigating some of the negative impacts of cancer in general, not just sexuality and intimacy. Intersecting identities should also be respected and valued, so that every PWC has access to support that is relevant to their unique needs. At the very least, mainstream cancer support groups should be well facilitated in order for different identities and experiences to be spoken about respectfully and helpfully. Peer support should also be available online, such as via video links or via telephone, so as to be inclusive of geographical location and ability.

4.5.2. Wider Implications

More awareness of the impact of cancer on sexuality is needed within the healthcare system and general public, in order to continue seeing PWC as sexual beings, regardless of cancer type and SO. Public campaigns such as *Sex with Cancer* (www.sexwithcancer.com) provide a vital platform for people to ask questions and learn about sex in the context of cancer, including hosting an online sex shop with products designed specifically for PWC and their lovers. These campaigns are essential in creating awareness, breaking down stigma and challenging dominant narratives about who is 'worthy' of sex and love (Pangman & Seguire, 2000). Psychologists and other health professionals can also fulfil an important role in challenging societal discourses, through supporting new, varied stories to emerge through collective narrative practices (Denborough, 2008). Community psychology approaches which place PWC as central to the development of such narratives are key. Psychologists can work collaboratively with local communities such as LGBTQ+ community centres and places of worship to explore ways of creating awareness and sharing knowledge. Spreading awareness through creative means such as media, podcasts, and events may also be impactful, some of which is already happening (e.g., *Not Your Grandma's Cancer Show* produced by Shine Cancer Support frequently discuss sexual and queer topics).

Health and care policies such as National Institute for Health and Care Excellence (NICE) guidelines should be updated to recommend that HCPs discuss sexuality across all cancer types, not just sexual cancers as currently stands (e.g., prostate cancer; NICE, 2019). Furthermore, services should be encouraged to collect data on SO. Whilst this suggestion has been criticised (Morabia, 2017), it enables the surveillance, delivery and evaluation of services, ultimately supporting services to improve and address disparities in cancer care (Schabath et al., 2017), as well as enabling HCPs to explore and understand the unique needs of their patients. The NHS also needs more psychosexual pathways embedded within cancer services, or at the very least, more HCPs who are psychosexually trained.

4.5.3. Future Research

Future research should be conducted with larger samples of GBQ men across a broader range of cancer types and demographics. This would contribute to a more nuanced and detailed understanding of sexuality and intimacy in this population and further highlight how sexual support from HCPs differed according to cancer type. Research that included HCPs would also be interesting, to gain additional perspectives on the barriers to support GBQ PWC with their sexuality. More intersectional research that includes people from a range of ethnic, cultural and religious groups is also warranted to explore and understand how cancer and sexuality intersects with these important aspects of people’s lives and how multiple axes of oppression influence cancer outcomes.

Existing research involving heterosexual partners of PWC provides important perspectives on navigating sexuality and intimacy in the context of cancer, however this perspective is limited in LGBTQ+ populations. Additional research with partners of GBQ PWC would highlight their experiences of navigating sexuality and intimacy when their loved one has cancer and provide a space for them to share any specific challenges they face and ideas about how services can best support them. Joint interviews could also provide a more comprehensive understanding of the challenges couples face and how they navigate obstacles together. Whilst mentioned briefly by two participants, it would also be interesting to learn more about individuals who were navigating dating and the potential barriers they face when initiating new sexual relationships.

This study focused exclusively on the experiences of cis-men. It would be equally important to explore sexuality and intimacy for sexual minority women diagnosed with cancer, as well as transgender, genderqueer and non-binary individuals. A critical gap exists in studies focused on gender diverse people, generally in the field of cancer research, but especially in sexuality and intimacy (Pratt-Chapman et al., 2021). Similarly to male cancers, sexuality research in female populations needs to go beyond breast and gynaecological cancers to include all cancer types. It would be important to include women and gender diverse people in the designing and conducting of studies in order to make the research more relevant and accessible for these groups facing high levels of marginalisation and oppression.

4.6. Reflexive Account

Having worked in a sexual health service helped me feel fairly confident approaching the interviews. I was curious about how forthcoming the participants were when discussing their sex lives, with some providing very detailed accounts and others appearing more awkward, reverting to using euphemisms to imply sexual struggles. I was mindful of the fact that discussing sexuality is often a sensitive topic and that in the context of this research, the men faced additional barriers due to the stigma an health condition adds to sex. Limiting the interviews to approximately one hour meant I did not have the luxury of taking the conversations as slowly as I would have liked; I would have preferred a slower pace, taking longer to build a stronger rapport and help the person gradually open up. However, I hoped that adopting a non-judgemental, curious, sometimes playful and sometimes frank approach helped the men open up as much as possible in a short period of time. I wonder whether having had multiple or longer interviews, richer, more detailed discussions of sexual function may have emerged. I also noticed when writing up the thesis that the topic of fertility was missing from the interviews and wondered whether this would have emerged had I conduced longer interviews. It is interesting that none of the participants mentioned fertility nor that I thought to include it in the interview schedule. I wonder whether unconscious assumptions about SO and family planning options prevented me from asking about this topic.

I also reflected upon my contrasting identity as a female without cancer and whether the participants perceived me to be heterosexual even though my identity was shifting from ‘questioning’ to ‘queer’ throughout the research process. These aspects of myself and the fact that I was talking to members of the opposite sex who had been ‘out’ for many years would have influenced how I approached the interviews, the questions I asked about sexual practices and the language I used. I imagine my approach and their perceptions of me likely influenced their responses too.

At times I felt conflicted between having to maintain my role as a researcher without being drawn into a therapist role. There were times when participants were speaking about particularly painful experiences, such as concerns about cancer reoccurrence or having to share bad news with family members, where I wanted to adopt a more therapeutic stance and discuss these experiences further despite them not being so relevant to the research question. I used my skills as a therapist to offer empathetic and containing comments, yet was mindful of not offering too many reflections or interpretations as I did not want to influence the participants' responses too much. I flexibly used the interview schedule as an anchor to keep the conversations focused on the research topics as much as possible. Some of the participants spoke about finding the interview process a positive experience, allowing them time and space to reflect on issues they had not previously considered, which implies that perhaps the interviews were somewhat therapeutic nevertheless.

I also tried to be aware of how my experiences of working in cancer and sexual health services influenced the analytic process, as well as my own personal values and beliefs. I am passionate about sexuality being an important aspect of quality of life for many people, including those diagnosed with cancer, and was conscious of not letting these views shape the analysis. I adopted a curious stance to analysis and interpretation, noticing the varied narratives that emerged from the data, and respected the language the participants used to describe and label their experiences, in line with the critical realist approach.

4.7. Concluding Comments

In conclusion, I hope that the dissemination of this study will positively impact GBQ men with cancer, their partners, and the professionals that support them, by contributing knowledge and awareness to the field of cancer and sexuality. Although disruptions to sexuality and intimacy may occur in the context of cancer, it is evident that with access to good psychosocial support, there is the possibility for high levels of psychological wellbeing and fulfilling sexual and intimate relationships for GBQ men.

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6. APPENDICES

6.1. Appendix A: Sexual Minorities Labels

It is important to note that sexual minorities are not a homogenous group, but rather comprised of individuals who identify across multiple demographic factors, of which sexual orientation is just one (Williams et al., 2013). There is no absolute way to label this group of people, since each person's journey with their sexual orientation is unique, and labels will hold different meanings to each person. One qualitative study found that young gay men's choice of sexual orientation labels depended on sexual, romantic and intellectual factors (Savin-Williams et al., 2017). This study will use terms people tend to use to label their own sexual orientation, such as gay, bisexual and queer (GBQ). Issues of erasing people's heterogenous experiences arise when using acronyms but will be retained in this study for the purpose of brevity.

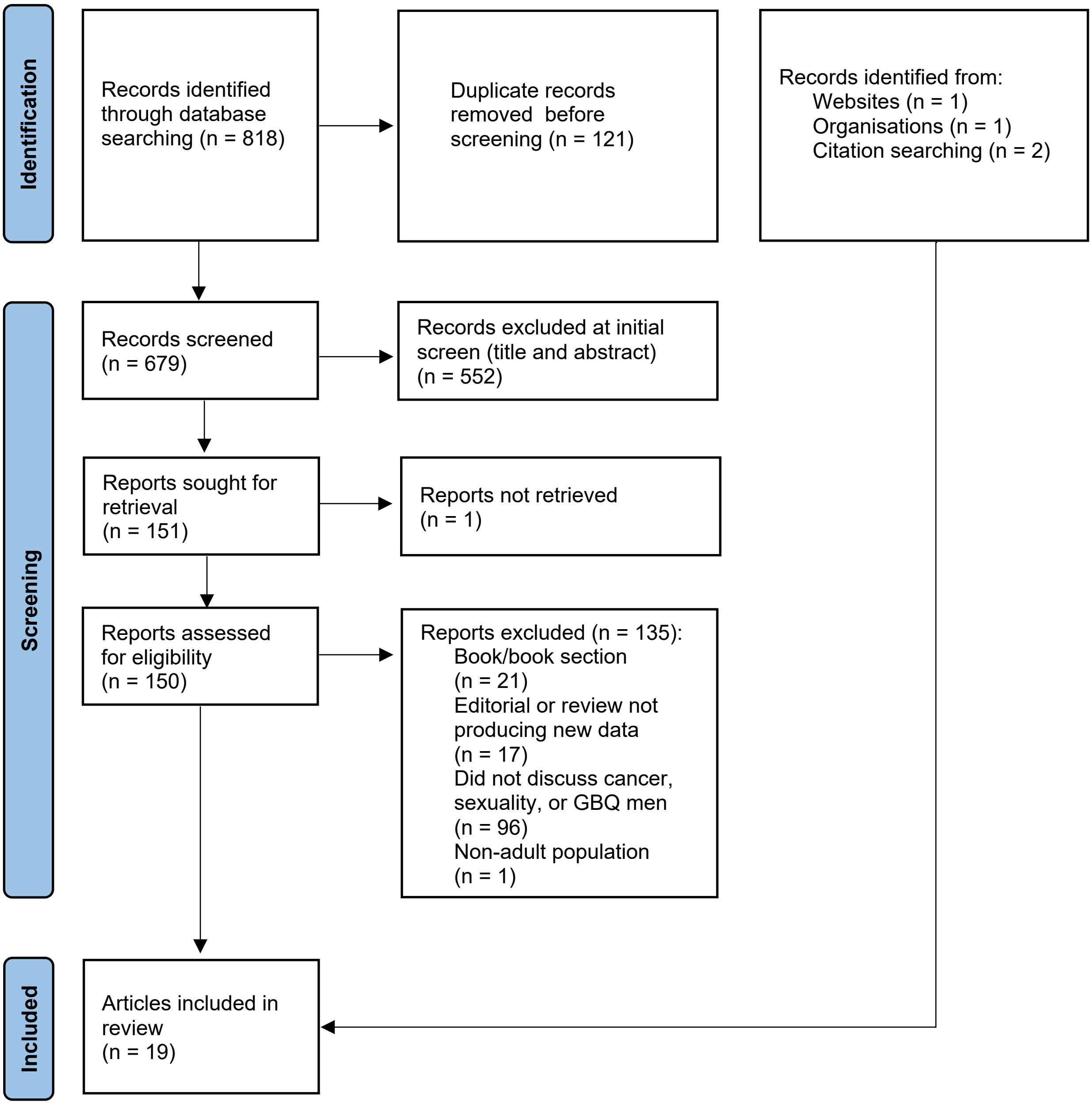
Population data estimates that 2.7% of the UK population over the age of 16 identify as lesbian, gay or bisexual (LGB); a further 0.7% identify as 'Other' which may capture identities such as 'pansexual', 'queer' or those questioning their sexual orientation (Office for National Statistics, 2021) . The number of people identifying as LGB has steadily risen each year, particularly among young adults. A recent survey of 1,127 British adults found that although 86% of people identified as heterosexual, only 74% said they were exclusively attracted to the opposite sex (Ipsos MORI, 2020). Breaking this down into generational groups, only 54% of Generation Z (aged 18-24) and 66% of Millennials (aged 25-40) said they were exclusively attracted to the opposite sex, compared to 81% of Baby Boomers (aged 55-75). These findings indicate that ONS data is likely an underestimate. Lack of robust data collection and variation in individual willingness to openly identify as lesbian, gay, bisexual, transgender, queer and/or any other sexual or gender identity label (LGBTQ+) means that precise numbers are unknown. Positioning LGBTQ+ people as being a minority may therefore be unfitting, however, in order to be consistent, the term 'sexual minorities' will be used in this study. References to the LGBTQ+ community, as it is commonly known, will also be made.

Lastly, whilst the LGBTQ+ acronym includes people who identify as transgender, the focus of this study is on the experiences of cis-gendered GBQ men. Transgender, gender diverse and non-binary individuals face exceptional challenges with regards to health, including cancer care, which requires specific attention in research (Pratt-Chapman et al., 2021).

6.2. Appendix B: Scoping Review Search Terms

DE Neoplasms, MH Neoplasms, “Neoplasms”[MeSH], DE Cancer, Sex*, Sexual*, Intima*, Gay, Homosexual*, “Homosexuality, Male”[MeSH], "Men Who Have Sex With Men", MSM, Bisexual*, Queer, LGBT*, GBQ, “Sexual Minorit*”, “Sexual and Gender Minorities”[MeSH]

6.3. Appendix C: PRISMA Flow Diagram



Note: Figure adapted from Page et al. (2021)

6.4. Appendix D: Summary of Scoping Review Papers

Authors	Country	Design	Sample	Conclusions
Danemalm et al (2019)	Sweden	Qualitative: Semi-structured interviews (30-90 minutes); thematic analysis	11 gay men aged 58-81 treated for prostate cancer. 3 single, 8 partnered. Time since treatment 0.5-15 years.	Participants reported physical changes (e.g., loss of ejaculate, erectile dysfunction, weaker orgasms), reflections on identity regarding age and disability, and relationship changes.
Doran (2015)	UK	Qualitative thesis: Semi-structured interviews (64-164 minutes); interpretive phenomenological analysis	12 gay men aged 49-82 who had received a diagnosis of prostate cancer. Time from diagnosis 1-16 years. Two participants had positive HIV status.	First UK study exploring experiences and identifying unmet needs of gay men with prostate cancer. Themes identified were about changed identity and physical body, ageing, altered relationships, and a need for community.
Filault et al. (2008)	Australia	Qualitative: A small semi-structured focus group and one semi-structured interview; thematic analysis	Two gay men with prostate cancer and one partner of a gay man with prostate cancer	Identified themes related to relationship changes and strains, altered sexual function and implications on gay identity, and experiences

				of a heteronormative health care system.
Hart et al. (2014)	USA and Canada	Quantitative: Standardised questionnaires on quality of life, sexual function, and experiences of living with cancer. Also measures of self-efficacy for prostate cancer management, illness intrusiveness, and disclosure of sexual orientation.	92 gay men diagnosed with prostate cancer in the last four years. Mean age was 57.8 years, most in partnered relationships.	Gay men reported significantly worse quality of life, mental health function, fear of reoccurrence, and were less satisfied with care compared to published prostate cancer samples of heterosexual men. However, reported higher sexual function scores in comparison to the validation cohort.
Hartman et al. (2014)	Canada	Qualitative: Semi-structured interviews; interpretive phenomenological analysis	Three gay couples (aged 40-62) following one partner’s radical prostatectomy due to prostate cancer	Superordinate themes identified related to acknowledging, accommodating and accepting sexual and relational changes.
Hoyt et al. (2020)	USA	Qualitative: Semi-structured focus groups (2-3 hours); conventional content analysis	11 gay prostate cancer survivors aged 43-84	Major challenges reported were minority stress, intimacy/sexuality concerns, impact of life outlook, healthcare experiences,

				social support and the gay community, and intersectional identities.
Lee et al. (2015)	Canada	Qualitative: Semi-structured interviews (45-60 minutes); qualitative analysis	16 MSM treated for prostate cancer aged 58-71	Themes included sexual dysfunction, challenges to intimate relationships, and lack of cancer and psychosocial support. Greater sexual dysfunction was related to lower sexual quality of life and relationship confidence.
Li (2009)	USA	Literature review: Searched electronic databases using key words such as ‘colostomy’ and ‘sexuality’	Identified 55 papers referring to colostomy and sexuality. Summarises principle factors affecting sexuality among patients with a colostomy following treatment for rectal cancer, including gender, sexual orientation, partners, and Asian culture.	Reported that GBQ men living with ostomies at higher risk of inadequate counselling about sexuality following surgery than heterosexual counterparts, altered sexual expression for GBQ men if surgery on rectum or anus, and impact of ostomy on body image.
Macmillan (2015)	UK	Qualitative: Participants set a	Sample (n=45) consisted of 9 gay,	Gives voice to participants,

		series of online research and engagement tasks. Responses to tasks were recorded ‘openly’ for other participants to comment on, or ‘privately’ for only the researchers to view. Responses descriptively summarised.	8 lesbian, 3 bisexual, and one transgender participants, aged 18-65. Participants were diagnosed with a variety of cancers including breast, prostate, bowel, malignant melanoma, non-Hodgkin lymphoma, head and neck, lung, and cervical. The sample also consisted of 24 healthcare professionals, diversity specialists and academics.	allowing them to define and discuss issues in their own terms. Participants discuss emotional and psychological needs, physical needs (including sexuality), practical needs, and underlying heteronormative assumptions and perceptions in the healthcare system.
Matheson et al. (2017)	UK	Systematic metasynthesis of qualitative studies	Of the 35 papers analysed, 11 related to the experiences of gay men with prostate cancer	Synthesis of studies indicated that gay men with prostate cancer report lower quality of life, more concern over sexual problems, lower self-esteem, worse physical and mental health, and poorer experiences of cancer care, compared to heterosexual counterparts.

Mauro et al. (2021)	Brazil	Quantitative: Validated questionnaires on quality of life and sexual function. Survival rates and cancer symptoms also evaluated.	19 MSM treated with radical chemoradiation for anal cancer. Median age 59.3 years. 15 of the participants were living with HIV.	Quality of life and sexual function worsened during and after treatment but improved within a year post-treatment. Impact on sexual function was associated with emotional experiences of the cancer and impact on overall quality of life, rather than anatomical changes. People living with HIV did not report any additional concern.
McConkey & Holborn (2018)	Ireland	Qualitative: In-depth interviews (24-111 minutes); descriptive phenomenological analysis	8 gay men treated for prostate cancer (aged 49-66). Time since treatment ranged 3-10 years	Theme major themes emerged that covered the experience of the cancer journey from diagnosis to treatment, sexual impact of treatment, experiences of the healthcare service, and sources of support, including lack of gay community resources.

Rosser et al. (2020)	USA and Canada	Quantitative: Online survey, validated and tailored questionnaires on sexual and urinary function	193 gay and bisexual men with prostate cancer. Majority of participants were white, non-Hispanic, well-educated, in 60s, living in the US, gay-identified, HIV-negative, and "out"	GBM reported worse urinary and hormonal function and worse hormonal concern, but better sexual function and concern than published norms for heterosexual prostate cancer survivors. Two thirds of participants reported sexual function post-treatment as fair to poor, with difficulties related to erections, orgasm, and urination during sex. GBM reported worse mental health and better physical health than published norms.
Rosser et al. (2016)	USA	Qualitative: Semi-structured interviews (60-90 minutes); thematic analysis and grounded theory approaches	19 gay and bisexual men who had undergone radical prostatectomies, aged 48-72.	Themes included changes to sexual function and sexual activity. Participants reported loss of sexual confidence, altered sex-role identity, and

				adaptations in relationships.
Thomas et al. (2013)	Australia	Qualitative: Online asynchronous focus group held over four weeks, discussed impact of living with prostate cancer	10 gay and bisexual men who had been diagnosed with prostate cancer in the last 7 years. Aged 47-70.	All participants reported a significant impact on their lives, including emotional distress about diagnosis, impact of sexual changes on identity and sexual relationships, and challenges accessing appropriate support.
Ussher et al. (2016)	Australia	Quantitative: Wide range of validation questionnaires related to health-related quality of life and sexual function.	Prostate cancer survivors (124 GBM, 225 heterosexual men). GBM were significantly younger, less likely to be partnered, and more likely to have casual sex, compared to heterosexual participants.	Compared to heterosexual men, GBM reported significantly lower HRQOL, masculine self-esteem, and satisfaction with treatment, and higher psychological and cancer related distress, ejaculatory concerns, and higher sexual function and sexual confidence.

Ussher, Perz et al. (2017a)	Australia, New Zealand, UK, USA	Mixed-methods: cross-sectional, online survey and individual semi-structured interviews (approximately 1 hour); descriptive statistics and thematic analysis	124 GBM with prostate cancer and 21 male partners completed survey. Subset of 46 survivors and 7 partners interviewed.	Participants reported sexual problems (e.g., erectile dysfunction, loss of libido, pain, lack of ejaculation), emotional distress, feelings of sexual disqualification, impact on gay identity, and feelings of exclusion from gay community. Some able to renegotiate sexual practices and reconcile sexual changes.
Ussher, Rose et al. (2017b)	Australia	Qualitative: Semi-structure interviews (approximately 1 hour); material-discursive analysis	46 GB men with prostate cancer, aged 45-78.	Themes emerged related to a desire to maintain sexual activity in order to stay connected to the gay community and defer a sense of ageing. Some men able to view the decline in sexual activity as a natural part of ageing process and renegotiate sexual practices.
Wassersug et al. (2013)	International: Primarily	Quantitative: Online survey about	556 men from 17 countries with a	No significant difference

	USA, Australia, Canada, and UK	physical health, sexual function, and emotional wellbeing, pre- and post-treatment; groups compared using logistic regressions	diagnosis of prostate cancer (460 heterosexual, 96 MSM)	between heterosexual men and MSM for urinary incontinence and sexual dysfunction, however, MSM more concerned by inability to ejaculate than heterosexual peers.

6.5. Appendix E: Reflective Journal Extracts

Reflections On Interview 1

- Perhaps a more challenging first interview – feel like participant found it quite difficult, not very forthcoming with information, feel like I had to give quite a lot of prompts, difficult to hear at times due to bad connection
- He became a bit upset when talking about relationship breakdown. Think he found it quite difficult at times. I found it difficult not slipping into therapy mode but hope I gave space and time and was empathic to their struggles
- Some embarrassment/awkwardness when talking about sexual difficulties – was difficult to get detail e.g. about erectile dysfunction, rapid ejaculation, he used euphemisms, pushed a bit to get more detail but was respectful of boundaries
- Feel I could be a bit more mindful about the language that I used e.g. think I said at one point “your inability to have sex”, upon reflection this feels quite blaming, feel I could use more normalising language. Also think there was some confusion between sexuality and SO – I was using sexuality to refer to sex life and think he thought I meant I was referring to his queer identity. Make sure I use really clear language going forwards e.g. sex life, sexual function
- Areas to expand on in future interviews that I don’t think we covered in great detail – intimacy/non-sexual touching/emotional closeness/alternative sexual practices
- Missed a key bit when he said about sexual difficulties ‘being bowel related’ - would have liked to explore what he meant by that further i.e. how did the bowel cancer and treatment impact on anal sex and sexual practices such as top/bottom identities and alternative sexual practices?

Reflections On Interview 2

- A really rich interview with a strong narrative of how cancer and its treatment impacted on sexuality, body image, identity, relationships etc.

- Feel I could have explored further the effects on masculinity – could have asked: What does being a man mean to you? What aspects of your manhood were missing?
- Could have also asked more about being gay and connecting with gay culture/community. E.g. you mentioned that appearance is important in the gay community, could you say a bit more about that?
- Debrief – explicitly signposted to Live Through This as expressed wanting community with other gay men with cancer, can connect virtually with this organisation
- Lack of support and feeling alone appeared key factor in his struggles
- Could have asked more explicit details about particular sexual acts and positioning i.e. top/bottom and about erectile function – did him being a gay men and me being a women get in the way of me feeling comfortable to ask?
- Balance between researcher/therapist role – was alerted to perhaps some trauma or OCD symptoms following bag removal. Wanted to explore further and signpost to further support, but instead directed to the resources on debrief form
- Specific influence of cultural and religious beliefs towards cancer, being gay, and attitudes towards hygiene.
- Feel like I wasn't as present as I could have been during this interview as had other personal circumstances going on that were making me feel a bit distracted. Feel like I could have provided more empathy and validation towards his difficulties, sounded like he'd had an incredibly tough time

Reflections During Data Familiarisation

Noting patterns emerging around the following topics:

- Community is key
- Intersectionality – harder getting support as a gay man from a minoritised community
- Pain and feeling unattractive getting in the way of sexual desire
- Impact on sexual function - erection, orgasm – seem to be the main ones
- Men preferring to be alone than discuss issues with other people

- Loss of sex led to broken connections & relationship
- Comparisons to women made a number of times about several different things
- HCP – preference for them to be business-like and professional
- Lots of impacts on identity and sense of self - broken, masculinity, ageing
- Feels like there are three main areas across three different levels, drawing on Bronfenbrenner's ecological systems theory: self, dyadic/romantic relationships, wider community

6.6. Appendix F: Ethics Application Form

UNIVERSITY OF EAST LONDON
School of Psychology

APPLICATION FOR RESEARCH ETHICS APPROVAL FOR RESEARCH INVOLVING HUMAN PARTICIPANTS
(Updated October 2019)

FOR BSc RESEARCH
FOR MSc/MA RESEARCH
FOR PROFESSIONAL DOCTORATE RESEARCH IN CLINICAL, COUNSELLING & EDUCATIONAL PSYCHOLOGY

1.Completing the application

1.1 Before completing this application please familiarise yourself with the British Psychological Society's Code of Ethics and Conduct (2018) and the UEL Code of Practice for Research Ethics (2015-16). Please tick to confirm that you have read and understood these ☑ es:

1.2 Email your supervisor the completed application and all attachments as ONE WORD DOCUMENT. Your supervisor will then look over your application.

1.3 When your application demonstrates sound ethical protocol, your supervisor will submit it for review. By submitting the application, the supervisor is confirming that they have reviewed all parts of this application, and consider it of sufficient quality for submission to the SREC committee for review. It is the responsibility of students to check that the supervisor has checked the application and sent it for review.

1.4 Your supervisor will let you know the outcome of your application. Recruitment and data collection must NOT commence until your ethics application has been approved, along with other research ethics approvals that may be necessary (see section 8).

1.5 Please tick to confirm that the following appendices have been completed. Note: templates for these are included at the end of the form.

- The participant invitation letter ☑
- The participant consent form ☑
- The participant debrief letter ☑

1.6 The following attachments should be included if appropriate. In each case, please tick to either confirm that you have included the relevant attachment, or confirm that it is not required for this application.

- A participant advert, i.e., any text (e.g., email) or document (e.g., poster) designed to recruit potential participants.
  Included ☑ or

  Not required (because no participation adverts will be used) ☐

- A general risk assessment form for research conducted off campus (see section 6).
  Included ☐ or

  Not required (because the research takes place solely on campus or online) ☑

- A country-specific risk assessment form for research conducted abroad (see section 6).
  Included ☐ or

  Not required (because the researcher will be based solely in the UK) ☑

- A Disclosure and Barring Service (DBS) certificate (see section 7).
  Included ☐ or

  Not required (because the research does not involve children aged 16 or under or vulnerable adults) ☑

- Ethical clearance or permission from an external organisation (see section 8).
  Included ☑ or

  Not required (because no external organisations are involved in the research) ☐

- Original and/or pre-existing questionnaire(s) and test(s) you intend to use.
  Included ☑ or

Not required (because you are not using pre-existing questionnaires or tests) ☐

- Interview questions for qualitative studies.
  Included ☑ or

  Not required (because you are not conducting qualitative interviews) ☐

- Visual material(s) you intend showing participants.
  Included ☐ or

  Not required (because you are not using any visual materials) ☑

2.Your details

2.1. Your name: Hannah Ward

2.2. Your supervisor’s name: Dr Kenneth Gannon

2.3.Title of your programme: Professional Doctorate in Clinical Psychology

2.4.UEL assignment submission date (stating both the initial date and the resit date):

May 2022. There is no resit date for this assignment.

3.Your research

Please give as much detail as necessary for a reviewer to be able to fully understand the nature and details of your proposed research.

3.1. The title of your study:

The impact of bowel cancer on sexuality and intimacy: The experiences of sexual minorities.

Bowel cancer and its treatment can significantly impact on a person’s sexuality and intimacy, resulting in considerable changes to sexual function, relationships, and self-esteem. People from sexual minorities often have to contend with these changes whilst navigating healthcare settings which are centred around heteronormative principles and practices, resulting in difficulties receiving relevant support and advice. The proposed study aims to use qualitative research to explore, describe and interpret how men who have sex with men experience their sexuality and intimacy in the context of bowel cancer. Themes from the study can be used to inform healthcare professionals about the ways sexual minority men navigate their sexual and intimate relationships post-cancer, to ensure the advice they provide is relevant and meeting the needs of this population.

3.2.Your research question:

1. How do men who have sex with men experience their sexuality and intimacy in the context of bowel cancer?
2. What has been helpful or unhelpful in navigating any changes in their sexuality and intimacy?

3.3.Design of the research:

The study will adopt a qualitative methodology to allow for the exploration, description and interpretation of participants' experiences of sexuality and intimacy throughout their cancer journey. Data will be collected by means of individual, semi-structured interviews and will be analysed by employing Thematic Analysis.

3.4.Participants:

Participants will be over the age of 18 years old and self-identify as a man who has sex with men. They will have had a diagnosis of bowel cancer and be in remission. They must have completed any treatments at least six months prior to interview. The study will exclude participants who have a permanent ostomy as a result of their bowel cancer treatment; it will include participants who had temporary ostomies or no ostomies as part of their treatment.

Twelve to 15 participants will be recruited, as this number of interviews should be sufficient to achieve data saturation (Guest et al., 2006).

3.5.Recruitment:

Participants will be recruited by posting advertisements for the study in various online forums and emailed to research networks. The study will be advertised in the following places:

[redacted]

3.6.Measures, materials or equipment:

The proposed study will require access to:

- Password-protected computer
- Mobile phone
- Audio-recording equipment

- Transcription equipment

3.7.Data collection:

Semi-structured interviews will be conducted with participants, either by video call (via Microsoft Teams) or telephone. Telephone interviews will be offered so as not to exclude people who do not have the technology to connect by video call or those who prefer to talk over the phone. Interviews will be audio recorded and transcribed verbatim into transcripts. Interviews conducted by video call will be audio recorded by Microsoft Teams within the application. Interviews conducted via telephone will be audio recorded using a password protected Dictaphone.

3.8.Data analysis:

Thematic analysis will be used to identify, analyse and highlight patterns and themes in the transcripts. The researcher will use NVivo software to aid the analysis process. The analysis will result in themes and subthemes summarising the experiences of sexual minority men.

4.Confidentiality and security

It is vital that data are handled carefully, particularly the details about participants. For information in this area, please see the UEL guidance on data protection, and also the UK government guide to data protection regulations.

4.1. Will participants data be gathered anonymously?

Due to data being collected via semi-structed interview, it will not be possible to gather data anonymously.

4.2. If not (e.g., in qualitative interviews), what steps will you take to ensure their anonymity in the subsequent steps (e.g., data analysis and dissemination)?

To protect anonymity, names and identifying information will be removed or altered when the audio recordings are typed into transcripts by the researcher. Short quotes will be taken from the transcript and used in the thesis write-up and dissemination of findings via publications, presentations or reports. However, the researcher will ensure that participants are unidentifiable by the quotes by deleting or changing identifying features. Some broad demographic information (such as age and ethnicity) may appear in the thesis and works based on it, but there will not be sufficient information to allow identification of participants.

4.3. How will you ensure participants details will be kept confidential?

Information about the participants and content from the interviews will be kept confidential. Personal data and consent forms will only be accessible to the researcher. Personal data will include the participant’s name, age, gender, ethnicity, sexual orientation, contact details (telephone and email address) and details of health conditions and treatment. Participants may also provide their home address and national insurance number if they wish to be given an Amazon voucher following their participation in the research. The researcher will only collect data that is absolutely necessary and will not link any data with names of participants. Personal data will be securely stored separately from the transcripts. Only the researcher will listen to the audio recordings of the interviews when typing them into transcripts. The researcher's supervisor and the examiner who will assess the thesis may request to read the transcripts.

4.4. How will the data be securely stored?

Personal data, audio recordings, consent forms and transcripts will be securely stored on the researcher's personal UEL OneDrive for Business account which only the researcher will have access to. All data will be stored in separate electronic folders. Transcripts will be backed up on the researcher's UEL H:Drive.

4.5. Who will have access to the data?

Only the researcher will have access to personal data and the audio recordings. The researcher, their supervisors, and the thesis examiner will have access to the transcripts.

4.6. How long will data be retained for?

Personal data and audio recordings will be deleted from the researcher's OneDrive once the thesis has been examined and passed. The transcripts and consent forms will be transferred to the Director of Studies' OneDrive account and stored as a computer file for three years, after which it will be destroyed. Transcripts on the researcher's own OneDrive and H:Drive will be deleted once they have been successfully transferred.

5.Informing participants

Please confirm that your information letter includes the following details:

5.1. Your research title: ☑

5.2.Your research question: ☑

5.3.The purpose of the research: ☑

5.4.The exact nature of their participation. This includes location, duration, and the tasks etc. involved ☑

5.5.That participation is strictly voluntary: ☑

5.6.What are the potential risks to taking part: ☑

5.7.What are the potential advantages to taking part: ☑

5.8. Their right to withdraw participation (i.e., to withdraw involvement at any point, no questions asked): ☑

5.9. Their right to withdraw data (usually within a three-week window from the time of their participation): ☑

5.10. How long their data will be retained for: ☑

5.11. How their information will be kept confidential: ☑

5.12. How their data will be securely stored: ☑

5.13. What will happen to the results/analysis: ☑

5.14. Your UEL contact details: ☑

5.15. The UEL contact details of your supervisor: ☑

Please also confirm whether:

5.16. Are you engaging in deception? If so, what will participants be told about the nature of the research, and how will you inform them about its real nature.

No, the research does not involve deception.

5.17. Will the data be gathered anonymously? If NO what steps will be taken to ensure confidentiality and protect the identity of participants?

No, the data is not being gathered anonymously.

To protect anonymity, names and identifying information will be removed or altered when the audio recordings are typed into transcripts by the researcher. Short quotes will be taken from the transcript and used in the thesis write-up and dissemination of findings via publications, however the researcher will ensure that participants are unidentifiable by the quotes by deleting or changing identifying features. Some broad demographic information (such as age and ethnicity) may appear in the thesis and works based on it, but there will not be sufficient information to allow identification of participants.

Information about the participants and content from the interviews will be kept confidential. Personal data and consent forms will only be accessible to the researcher. Personal data will include the participant's age, gender, ethnicity, sexual orientation, contact details (telephone and email address) and details of health conditions and treatment. Participants may also provide their home address and national insurance number if they wish to be given an Amazon voucher following their participation in the research. The researcher will only collect data that is absolutely necessary and will not link any data with names of participants. Personal data will be securely stored separately from the transcripts. Only the researcher will listen to the audio recordings of the interviews when typing them into transcripts. The researcher's supervisor and the examiner who will assess the thesis may request to read the transcripts.

5.18. Will participants be paid or reimbursed? If so, this must be in the form of redeemable vouchers, not cash. If yes, why is it necessary and how much will it be worth?

Participants will not be paid for their time but will be offered a £10 Amazon voucher as a token of appreciation. The vouchers will be sought from the School of Psychology and the relevant procedures will be followed when issuing the vouchers. Participants will be informed via the participant information sheet of the procedure of receiving the voucher and can provide their home address and national insurance number on the demographics form if they wish to receive one. It is felt that offering this incentive will encourage more people to participate in the research which is important when recruiting from a hard to reach population.

6.Risk Assessment

Please note: If you have serious concerns about the safety of a participant, or others, during the course of your research please see your supervisor as soon as possible. If there is any unexpected occurrence while you are collecting your data (e.g. a participant or the researcher injures themselves), please report this to your supervisor as soon as possible.

6.1. Are there any potential physical or psychological risks to participants related to taking part? If so, what are these, and how can they be minimised?

There are no known physical risks. Participants may become distressed during the interviews due to discussing sensitive topics related to sexuality, intimacy and cancer. Time will be taken to build a rapport with the participants to ensure they feel as comfortable as possible during the interview. The researcher will start this rapport building from the point of recruitment and ensure there is space at the beginning of the interview for ice breaker questions. During the interviews, the researcher will allow adequate time for participants to respond to questions and will go at the pace of the interviewee, allowing time for breaks if needed. The researcher will remind participants they have the right to withdraw at any time without consequence. They will be fully debriefed, provided with a debrief form and signposted to further support if necessary. As a trainee clinical psychologist, the researcher is experienced in dealing with emotional content and confident in recognising and managing distress.

6.2. Are there any potential physical or psychological risks to you as a researcher? If so, what are these, and how can they be minimised?

There are no known physical risks. The researcher may become distressed during interviews due to hearing participants disclose sensitive information related to cancer. If felt it was needed, the researcher would debrief with their research supervisor and discuss the emotional impact of the interview. The researcher will ensure they engage in self-care and allow time and space for reflection and recuperation between interviews. Participants will also be offering up to an hour of their time to talk about potentially challenging topics and so it is felt their involvement should be compensated in some way.

6.3.Have appropriate support services been identified in the debrief letter? If so, what are these, and why are they relevant?

Yes, the support services cover a range of areas that are relevant to the research.

- Cancer – Macmillan Cancer Support Specialists
- Mental health – Samaritans, Mind
- Relationships – Relate
- Sexual minorities – Switchboard LGBT+ Helpline

6.4.Does the research take place outside the UEL campus? If so, where?

No, interviews will take place by video call (Microsoft Teams) or telephone.

If so, a 'general risk assessment form' must be completed. This is included below as appendix D. Note: if the research is on campus, or is online only (e.g., a Qualtrix survey), then a risk assessme is not needed, and this appendix can be deleted. If a general risk assessm m is required for this research, please tick to confirm that this has been completed:

n/a

6.5.Does the research take place outside the UK? If so, where?

No, the research will take place in the UK.

If so, in addition to the 'general risk assessment form', a 'country-specific risk assessment form' must be also completed (available in the Ethics folder in the Psychology Noticeboard), and included as an appendix. [Please note: a country-specific risk assessment form is not needed if the research is online only (e.g., a Qualtrix survey), regardless of the location of the researcher or the participants.] If a 'country-specific risk assessment form' *is* needed, please tick to confirm that this has been included:

n/a

However, please also note:

- For assistance in completing the risk assessment, please use the AIG Travel Guard website to ascertain risk levels. Click on 'sign in' and then 'register here' using policy # 0015865161. Please also consult the Foreign Office travel advice website for further guidance.

- For *on campus* students, once the ethics application has been approved by a reviewer, all risk assessments for research abroad must then be signed by the Head of School (who may escalate it up to the Vice Chancellor).
- For *distance learning* students conducting research abroad in the country where they currently reside, a risk assessment must be also carried out. To minimise risk, it is recommended that such students only conduct data collection on-line. If the project is deemed low risk, then it is not necessary for the risk assessments to be signed by the Head of School. However, if not deemed low risk, it must be signed by the Head of School (or potentially the Vice Chancellor).
- Undergraduate and M-level students are not explicitly prohibited from conducting research abroad. However, it is discouraged because of the inexperience of the students and the time constraints they have to complete their degree.

7.Disclosure and Barring Service (DBS) certificates

7.1. Does your research involve working with children (aged 16 or under) or vulnerable adults (*see below for definition)?

No, it does not involve working with children or vulnerable adults.

7.2.If so, you will need a current DBS certificate (i.e., not older than six months), and to include this as an appendix. Please tick to confirm that you have included this: n/a

Alternatively, if necessary for reasons of confidentiality, you may email a copy directly to the Chair of the School Research Ethics Committee. Please tick if you have done this instead: n/a

Also alternatively, if you have an Enhanced DBS clearance (one you pay a monthly fee to maintain) then the number of your Enhanced DBS clearance will suffice. Please tick if you have included this instead: n/a

7.3.If participants are under 16, you need 2 separate information letters, consent form, and debrief form (one for the participant, and one for their parent/guardian). Please tick to confirm that you have included these: n/a

7.4.If participants are under 16, their information letters consent form, and debrief form need to be written in age-appropriate language. Please tick to confirm that you have done this n/a

* You are required to have DBS clearance if your participant group involves (1) children and young people who are 16 years of age or under, and (2) 'vulnerable' people aged 16 and over with psychiatric illnesses, people who receive domestic care, elderly people (particularly those in nursing homes), people in palliative care, and people living in institutions and sheltered accommodation, and people who have been involved in the criminal justice system, for example. Vulnerable people are understood to be persons who are not necessarily able to freely consent to participating in your research, or who may find it difficult to withhold consent. If in doubt about the extent of the vulnerability of your intended participant group, speak to your supervisor. Methods that maximise the understanding and ability of vulnerable people to give consent should be used whenever possible. For more information about ethical research involving children click here.

8.Other permissions

8.1. Is HRA approval (through IRAS) for research involving the NHS required? Note: HRA/IRAS approval is required for research that involves patients or Service Users of the NHS, their relatives or carers as well as those in receipt of services provided under contract to the NHS.

No. If yes, please note:

- You DO NOT need to apply to the School of Psychology for ethical clearance if ethical approval is sought via HRA/IRAS (please see further details here).
- However, the school *strongly discourages* BSc and MSc/MA students from designing research that requires HRA approval for research involving the NHS, as this can be a very demanding and lengthy process.
- If you work for an NHS Trust and plan to recruit colleagues from the Trust, permission from an appropriate manager at the Trust must be sought, and HRA approval will probably be needed (and hence is likewise strongly discouraged). If the manager happens to not require HRA approval, their written letter of approval must be included as an appendix.
- IRAS approval is not required for NHS staff even if they are recruited via the NHS (UEL ethical approval is acceptable). However, an application will still need to be submitted to the HRA in order to obtain R&D approval. This is in addition to a separate approval via the R&D department of the NHS Trust involved in the research.
- IRAS approval is not required for research involving NHS employees when data collection will take place off NHS premises, and when NHS employees are not recruited directly through NHS lines of communication. This means that NHS staff can participate in research without HRA approval when a student recruits via their own social or professional networks or through a professional body like the BPS, for example.

8.2. Will the research involve NHS employees who will not be directly recruited through the NHS, and where data from NHS employees will not be collected on NHS premises?

No.

8.3. If you work for an NHS Trust and plan to recruit colleagues from the Trust, will permission from an appropriate member of staff at the Trust be sought, and will HRA be sought, and a copy of this permission (e.g., an email from the Trust) attached to this application?

N/A

8.4. Does the research involve other organisations (e.g. a school, charity, workplace, local authority, care home etc.)? If so, please give their details here.

Yes, the following organisation require permission to advertise the study via their online communities, research networks or social media pages:

[redacted]

Furthermore, written permission is needed from such organisations if they are helping you with recruitment and/or data collection, if you are collecting data on their premises, or if you are using any material owned by the institution/organisation. If that is the case, please tick here to confirm that you have included this written permission as an appendix:

☑

In addition, before the research commences, once your ethics application has been approved, please ensure that you provide the organisation with a copy of the final, approved ethics application. Please then prepare a version of the consent form for the organisation themselves to sign. You can adapt it by replacing words such as ‘my’ or ‘I’ with ‘our organisation,’ or with the title of the organisation. This organisational consent form must be signed before the research can commence.

Finally, please note that even if the organisation has their own ethics committee and review process, a School of Psychology SREC application and approval is still required. Ethics approval from SREC can be gained before approval from another research ethics committee is obtained. However, recruitment and data collection are NOT to commence until your research has been approved by the School and other ethics committee/s as may be necessary.

9. Declarations

Declaration by student: I confirm that I have discussed the ethics and feasibility of this research proposal with my supervisor.

Student's name (typed name acts as a signature): Hannah Ward

Student's number: 1945541 Date: 21/3/2021

As a supervisor, by submitting this application, I confirm that I have reviewed all parts of this application, and I consider it of sufficient quality for submission to the SREC committee.

6.7. Appendix G: Evidence of Ethical Approval

School of Psychology Research Ethics Committee

NOTICE OF ETHICS REVIEW DECISION

For research involving human participants
BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

REVIEWER: Lorna Farquharson

SUPERVISOR: Kenneth Gannon

STUDENT: Hannah Ward

Course: Prof Doc in Clinical Psychology

Research Title: The impact of bowel cancer on sexuality and intimacy: The experiences of sexual minorities.

DECISION OPTIONS:

1. **APPROVED:** Ethics approval for the above named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.

2. **APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES** (see Minor Amendments box below)**:** In this circumstance, re-submission of an ethics application is not required but the student must confirm with their supervisor that all minor amendments have been made before the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.

3. **NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED** (see Major Amendments box below)**:** In this circumstance, a revised ethics application must be submitted and approved before any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.

DECISION ON THE ABOVE-NAMED PROPOSED RESEARCH STUDY
(Please indicate the decision according to one of the 3 options above)

1. Approved

Minor amendments required *(for reviewer)*:

Major amendments required *(for reviewer):*

Confirmation of making the above minor amendments *(for students)*:

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data.

Student's name *(Typed name to act as signature):*
Student number:

Date:

(Please submit a copy of this decision letter to your supervisor with this box completed, if minor amendments to your ethics application are required)

ASSESSMENT OF RISK TO RESEACHER *(for reviewer)*

Has an adequate risk assessment been offered in the application form?

YES / NO

Please request resubmission with an adequate risk assessment

If the proposed research could expose the researcher to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:

☐ HIGH

Please do not approve a high risk application and refer to the Chair of Ethics. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not approved on this basis. If unsure please refer to the Chair of Ethics.

☐ MEDIUM (Please approve but with appropriate recommendations)

☒ LOW

Reviewer comments in relation to researcher risk (if any).

Reviewer *(Typed name to act as signature)*: Lorna Farquharson

Date: 26.05.2021

This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee

RESEARCHER PLEASE NOTE:

For the researcher and participants involved in the above named study to be covered by UEL's Insurance, prior ethics approval from the School of Psychology (acting on behalf of the UEL Research Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

For a copy of UELs Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard

6.8. Appendix H: Amended Ethics Application Form

UNIVERSITY OF EAST LONDON
School of Psychology

APPLICATION FOR RESEARCH ETHICS APPROVAL FOR RESEARCH INVOLVING HUMAN PARTICIPANTS
(Updated October 2019)

FOR BSc RESEARCH
FOR MSc/MA RESEARCH
FOR PROFESSIONAL DOCTORATE RESEARCH IN CLINICAL, COUNSELLING & EDUCATIONAL PSYCHOLOGY

1.Completing the application

1.1 Before completing this application please familiarise yourself with the British Psychological Society's Code of Ethics and Conduct (2018) and the UEL Code of Practice for Research Ethics (2015-16). Please tick to confirm that you have read and understood these ☑ es:

1.2 Email your supervisor the completed application and all attachments as ONE WORD DOCUMENT. Your supervisor will then look over your application.

1.3 When your application demonstrates sound ethical protocol, your supervisor will submit it for review. By submitting the application, the supervisor is confirming that they have reviewed all parts of this application, and consider it of sufficient quality for submission to the SREC committee for review. It is the responsibility of students to check that the supervisor has checked the application and sent it for review.

1.4 Your supervisor will let you know the outcome of your application. Recruitment and data collection must NOT commence until your ethics application has been approved, along with other research ethics approvals that may be necessary (see section 8).

1.5 Please tick to confirm that the following appendices have been completed. Note: templates for these are included at the end of the form.

- The participant invitation letter ☑
- The participant consent form ☑

- The participant debrief letter ☑

1.6 The following attachments should be included if appropriate. In each case, please tick to either confirm that you have included the relevant attachment, or confirm that it is not required for this application.

- A participant advert, i.e., any text (e.g., email) or document (e.g., poster) designed to recruit potential participants.

  Included ☑ or

  Not required (because no participation adverts will be used) ☐

- A general risk assessment form for research conducted off campus (see section 6).

  Included ☐ or

  Not required (because the research takes place solely on campus or online) ☑

- A country-specific risk assessment form for research conducted abroad (see section 6).

  Included ☐ or

  Not required (because the researcher will be based solely in the UK) ☑

- A Disclosure and Barring Service (DBS) certificate (see section 7).

  Included ☐ or

  Not required (because the research does not involve children aged 16 or under or vulnerable adults) ☑

- Ethical clearance or permission from an external organisation (see section 8).

  Included ☑ or

  Not required (because no external organisations are involved in the research) ☐

- Original and/or pre-existing questionnaire(s) and test(s) you intend to use.

  Included ☑ or

  Not required (because you are not using pre-existing questionnaires or tests) ☐

- Interview questions for qualitative studies.

  Included ☑ or

  Not required (because you are not conducting qualitative interviews) ☐

- Visual material(s) you intend showing participants.

  Included ☐ or

  Not required (because you are not using any visual materials) ☑

2.Your details

2.1. Your name: Hannah Ward

2.2. Your supervisor's name: Dr Kenneth Gannon

2.3. Title of your programme: Professional Doctorate in Clinical Psychology

2.5. UEL assignment submission date (stating both the initial date and the resit date):

May 2022. There is no resit date for this assignment.

3.Your research

Please give as much detail as necessary for a reviewer to be able to fully understand the nature and details of your proposed research.

3.1. The title of your study:

Cancer, sex and intimacy: The experiences of gay, bisexual and queer men.

Cancer and its treatment can significantly impact on a person's sexuality and intimacy, resulting in considerable changes to sexual function, relationships, and self-esteem. People from sexual minorities often have to contend with these changes whilst navigating healthcare settings which are centred around heteronormative principles and practices, resulting in difficulties receiving relevant support and advice. The proposed study aims to use qualitative research to explore, describe and interpret how men who have sex with men experience their sexuality and intimacy in the context of cancer. Themes from the study can be used to inform healthcare professionals about the ways sexual minority men navigate their sexual and intimate relationships post-cancer, to ensure the advice they provide is relevant and meeting the needs of this population.

3.2. Your research question:

3. How do men who have sex with men experience their sexuality and intimacy in the context of cancer?
4. What has been helpful or unhelpful in navigating any changes in their sexuality and intimacy?

3.3.Design of the research:

The study will adopt a qualitative methodology to allow for the exploration, description and interpretation of participants' experiences of sexuality and intimacy throughout their cancer journey. Data will be collected by means of individual, semi-structured interviews and will be analysed by employing Thematic Analysis.

3.4.Participants:

Participants will be over the age of 18 years old and identify as a man who has sex with men. They will have had a diagnosis of any cancer type and be in remission. They must have completed any treatments at least six months prior to interview.

Twelve to 15 participants will be recruited, as this number of interviews should be sufficient to achieve data saturation (Guest et al., 2006).

3.5.Recruitment:

Participants will be recruited by posting advertisements for the study in various online forums and emailed to research networks. The study will be advertised in the following places:

[redacted]

3.6.Measures, materials or equipment:

The proposed study will require access to:

- Password-protected computer
- Mobile phone
- Audio-recording equipment
- Transcription equipment

3.7.Data collection:

Semi-structured interviews will be conducted with participants, either by video call (via Microsoft Teams) or telephone. Telephone interviews will be offered so as not to exclude people who do not have the technology to connect by video call or those who prefer to talk over the phone. Interviews will be audio recorded and transcribed verbatim into transcripts. Interviews conducted by video call will be audio recorded by Microsoft Teams within the application. Interviews conducted via telephone will be audio recorded using a password protected Dictaphone.

3.8.Data analysis:

Thematic analysis will be used to identify, analyse and highlight patterns and themes in the transcripts. The researcher will use NVivo software to aid the analysis process. The analysis will result in themes and subthemes summarising the experiences of sexual minority men.

4.Confidentiality and security

It is vital that data are handled carefully, particularly the details about participants. For information in this area, please see the UEL guidance on data protection, and also the UK government guide to data protection regulations.

4.1. Will participants data be gathered anonymously?

Due to data being collected via semi-structed interview, it will not be possible to gather data anonymously.

4.2. If not (e.g., in qualitative interviews), what steps will you take to ensure their anonymity in the subsequent steps (e.g., data analysis and dissemination)?

To protect anonymity, names and identifying information will be removed or altered when the audio recordings are typed into transcripts by the researcher. Short quotes will be taken from the transcript and used in the thesis write-up and dissemination of findings via publications, presentations or reports. However, the researcher will ensure that participants are unidentifiable by the quotes by deleting or changing identifying features. Some broad demographic information (such as age and ethnicity) may appear in the thesis and works based on it, but there will not be sufficient information to allow identification of participants.

4.3. How will you ensure participants details will be kept confidential?

Information about the participants and content from the interviews will be kept confidential. Personal data and consent forms will only be accessible to the researcher. Personal data will include the participant's name, age, gender, ethnicity, sexual orientation, contact details (telephone and email address) and details of health conditions and treatment. Participants may also provide their home address and national insurance number if they wish to be given an Amazon voucher following their participation in the research. The researcher will only collect data that is absolutely necessary and will not link any data with names of participants. Personal data will be securely stored separately from the transcripts. Only the researcher will listen to the audio recordings of the interviews when typing them into transcripts. The researcher’s supervisor and the examiner who will assess the thesis may request to read the transcripts.

4.4. How will the data be securely stored?

Personal data, audio recordings, consent forms and transcripts will be securely stored on the researcher’s personal UEL OneDrive for Business account which only the researcher will have access to. All data will be stored in separate electronic folders. Transcripts will be backed up on the researcher’s UEL H:Drive.

4.5. Who will have access to the data?

Only the researcher will have access to personal data and the audio recordings. The researcher, their supervisors, and the thesis examiner will have access to the transcripts.

4.6. How long will data be retained for?

Personal data and audio recordings will be deleted from the researcher’s OneDrive once the thesis has been examined and passed. The transcripts and consent forms will be transferred to the Director of Studies’ OneDrive account and stored as a computer file for three years, after which it will be destroyed. Transcripts on the researcher’s own OneDrive and H:Drive will be deleted once they have been successfully transferred.

5.Informing participants

Please confirm that your information letter includes the following details:

5.1. Your research title: ☑

5.2.Your research question: ☑

5.3.The purpose of the research: ☑

5.4.The exact nature of their participation. This includes location, duration, and the tasks etc. invo ☑

5.5.That participation is strictly voluntary: ☑

5.6.What are the potential risks to taking part: ☑

5.7.What are the potential advantages to taking part: ☑

5.8.Their right to withdraw participation (i.e., to withdraw involvement at any point, no questions asked ☑

5.9.Their right to withdraw data (usually within a three-week window from the time of their participation ☑

5.10. How long their data will be retained ☑

5.11. How their information will be kept confident ☑

5.12. How their data will be securely stored: ☑

5.13. What will happen to the results/analy ☑

5.14. Your UEL contact details: ☑

5.15. The UEL contact details of your super ☑:

Please also confirm whether:

5.16. Are you engaging in deception? If so, what will participants be told about the nature of the research, and how will you inform them about its real nature.

No, the research does not involve deception.

5.17. Will the data be gathered anonymously? If NO what steps will be taken to ensure confidentiality and protect the identity of participants?

No, the data is not being gathered anonymously.

To protect anonymity, names and identifying information will be removed or altered when the audio recordings are typed into transcripts by the researcher. Short quotes will be taken from the transcript and used in the thesis write-up and dissemination of findings via publications, however the researcher will ensure that participants are unidentifiable by the quotes by deleting or changing identifying features. Some broad demographic information (such as age and ethnicity) may appear in the thesis and works based on it, but there will not be sufficient information to allow identification of participants.

Information about the participants and content from the interviews will be kept confidential. Personal data and consent forms will only be accessible to the researcher. Personal data will include the participant’s age, gender, ethnicity, sexual orientation, contact details (telephone and email address) and details of health conditions and treatment. Participants may also provide their home address and national insurance number if they wish to be given an Amazon voucher following their participation in the research. The researcher will only collect data that is absolutely necessary and will not link any data with names of participants. Personal data will be securely stored separately from the transcripts. Only the researcher will listen to the audio recordings of the interviews when typing them into transcripts. The researcher’s supervisor and the examiner who will assess the thesis may request to read the transcripts.

5.18. Will participants be paid or reimbursed? If so, this must be in the form of redeemable vouchers, not cash. If yes, why is it necessary and how much will it be worth?

Participants will not be paid for their time but will be offered a £10 Amazon voucher as a token of appreciation. The vouchers will be sought from the School of Psychology and the relevant procedures will be followed when issuing the vouchers. Participants will be informed via the participant information sheet of the procedure of receiving the voucher and can provide their home address and national insurance number on the demographics form if they wish to receive one. It is felt that offering this incentive will encourage more people to participate in the research which is important when recruiting from a hard to reach population.

6.Risk Assessment

Please note: If you have serious concerns about the safety of a participant, or others, during the course of your research please see your supervisor as soon as possible. If there is any unexpected occurrence while you are collecting your data (e.g. a participant or the researcher injures themselves), please report this to your supervisor as soon as possible.

6.1. Are there any potential physical or psychological risks to participants related to taking part? If so, what are these, and how can they be minimised?

There are no known physical risks. Participants may become distressed during the interviews due to discussing sensitive topics related to sexuality, intimacy and cancer. Time will be taken to build a rapport with the participants to ensure they feel as comfortable as possible during the interview. The researcher will start this rapport building from the point of recruitment and ensure there is space at the beginning of the interview for ice breaker questions. During the interviews, the researcher will allow adequate time for participants to respond to questions and will go at the pace of the interviewee, allowing time for breaks if needed. The researcher will remind participants they have the right to withdraw at any time without consequence. They will be fully debriefed, provided with a debrief form and signposted to further support if necessary. As a trainee clinical psychologist, the researcher is experienced in dealing with emotional content and confident in recognising and managing distress.

6.2.Are there any potential physical or psychological risks to you as a researcher? If so, what are these, and how can they be minimised?

There are no known physical risks. The researcher may become distressed during interviews due to hearing participants disclose sensitive information related to cancer. If felt it was needed, the researcher would debrief with their research supervisor and discuss the emotional impact of the interview. The researcher will ensure they engage in self-care and allow time and space for reflection and recuperation between interviews. Participants will also be offering up to an hour of their time to talk about potentially challenging topics and so it is felt their involvement should be compensated in some way.

6.3.Have appropriate support services been identified in the debrief letter? If so, what are these, and why are they relevant?

Yes, the support services cover a range of areas that are relevant to the research.

- Cancer – Macmillan Cancer Support Specialists
- Mental health – Samaritans, Mind
- Relationships – Relate
- Sexual minorities – Switchboard LGBT+ Helpline
- Cancer support for LGBT+ individuals – Live Through This
- Website with resources specifically about sex with cancer – Sex with Cancer

6.4.Does the research take place outside the UEL campus? If so, where?

No, interviews will take place by video call (Microsoft Teams) or telephone.

If so, a 'general risk assessment form' must be completed. This is included below as appendix D. Note: if the research is on campus, or is online only (e.g., a Qualtrix survey), then a risk assessment form is not needed, and this appendix can be deleted. If a general risk assessment form is required for this research, please tick to confirm that this has been ted:

n/a

6.5.Does the research take place outside the UK? If so, where?

No, the research will take place in the UK.

If so, in addition to the 'general risk assessment form', a 'country-specific risk assessment form' must be also completed (available in the Ethics folder in the Psychology Noticeboard), and included as an appendix. [Please note: a country-specific risk assessment form is not needed if the research is online only (e.g., a Qualtrix survey), regardless of the location of the researcher or the participants.] If a 'country-specific risk assessment form' *is* needed, please tick to confirm that this has been in

n/a

However, please also note:

- For assistance in completing the risk assessment, please use the AIG Travel Guard website to ascertain risk levels. Click on 'sign in' and then 'register here' using policy # 0015865161. Please also consult the Foreign Office travel advice website for further guidance.

- For *on campus* students, once the ethics application has been approved by a reviewer, all risk assessments for research abroad must then be signed by the Head of School (who may escalate it up to the Vice Chancellor).
- For *distance learning* students conducting research abroad in the country where they currently reside, a risk assessment must be also carried out. To minimise risk, it is recommended that such students only conduct data collection on-line. If the project is deemed low risk, then it is not necessary for the risk assessments to be signed by the Head of School. However, if not deemed low risk, it must be signed by the Head of School (or potentially the Vice Chancellor).
- Undergraduate and M-level students are not explicitly prohibited from conducting research abroad. However, it is discouraged because of the inexperience of the students and the time constraints they have to complete their degree.

7.Disclosure and Barring Service (DBS) certificates

7.1. Does your research involve working with children (aged 16 or under) or vulnerable adults (*see below for definition)?

No, it does not involve working with children or vulnerable adults.

7.2.If so, you will need a current DBS certificate (i.e., not older than six months), and to include this as an appendix. Please tick to confirm that you have included this: n/a

Alternatively, if necessary for reasons of confidentiality, you may email a copy directly to the Chair of the School Research Ethics Committee. Please tick if you have done this instead: n/a

Also alternatively, if you have an Enhanced DBS clearance (one you pay a monthly fee to maintain) then the number of your Enhanced DBS clearance will suffice. Please tick if you have included this instead: n/a

7.3.If participants are under 16, you need 2 separate information letters, consent form, and debrief form (one for the participant, and one for their parent/guardian). Please tick to confirm that you have included these: n/a

7.4.If participants are under 16, their information letters consent form, and debrief form need to be written in age-appropriate language. Please tick to confirm that you have done this n/a

* You are required to have DBS clearance if your participant group involves (1) children and young people who are 16 years of age or under, and (2) 'vulnerable' people aged 16 and over with psychiatric illnesses, people who receive domestic care, elderly people (particularly those in nursing homes), people in palliative care, and people living in institutions and sheltered accommodation, and people who have been involved in the criminal justice system, for example. Vulnerable people are understood to be persons who are not necessarily able to freely consent to participating in your research, or who may find it difficult to withhold consent. If in doubt about the extent of the vulnerability of your intended participant group, speak to your supervisor. Methods that maximise the understanding and ability of vulnerable people to give consent should be used whenever possible. For more information about ethical research involving children click here.

8.Other permissions

8.1. Is HRA approval (through IRAS) for research involving the NHS required? Note: HRA/IRAS approval is required for research that involves patients or Service Users of the NHS, their relatives or carers as well as those in receipt of services provided under contract to the NHS.

No. If yes, please note:

- You DO NOT need to apply to the School of Psychology for ethical clearance if ethical approval is sought via HRA/IRAS (please see further details here).
- However, the school *strongly discourages* BSc and MSc/MA students from designing research that requires HRA approval for research involving the NHS, as this can be a very demanding and lengthy process.
- If you work for an NHS Trust and plan to recruit colleagues from the Trust, permission from an appropriate manager at the Trust must be sought, and HRA approval will probably be needed (and hence is likewise strongly discouraged). If the manager happens to not require HRA approval, their written letter of approval must be included as an appendix.
- IRAS approval is not required for NHS staff even if they are recruited via the NHS (UEL ethical approval is acceptable). However, an application will still need to be submitted to the HRA in order to obtain R&D approval. This is in addition to a separate approval via the R&D department of the NHS Trust involved in the research.
- IRAS approval is not required for research involving NHS employees when data collection will take place off NHS premises, and when NHS employees are not recruited directly through NHS lines of communication. This means that NHS staff can participate in research without HRA approval when a student recruits via their own social or professional networks or through a professional body like the BPS, for example.

8.2. Will the research involve NHS employees who will not be directly recruited through the NHS, and where data from NHS employees will not be collected on NHS premises?

No.

8.3. If you work for an NHS Trust and plan to recruit colleagues from the Trust, will permission from an appropriate member of staff at the Trust be sought, and will HRA be sought, and a copy of this permission (e.g., an email from the Trust) attached to this application?

N/A

8.4. Does the research involve other organisations (e.g. a school, charity, workplace, local authority, care home etc.)? If so, please give their details here.

Yes, the following organisation require permission to advertise the study via their online communities, research networks or social media pages:

[redacted]

Furthermore, written permission is needed from such organisations if they are helping you with recruitment and/or data collection, if you are collecting data on their premises, or if you are using any material owned by the institution/organisation. If that is the case, please tick here to confirm that you have included this written permission as an appendix:

☑

In addition, before the research commences, once your ethics application has been approved, please ensure that you provide the organisation with a copy of the final, approved ethics application. Please then prepare a version of the consent form for the organisation themselves to sign. You can adapt it by replacing words such as ‘my’ or ‘I’ with ‘our organisation,’ or with the title of the organisation. This organisational consent form must be signed before the research can commence.

Finally, please note that even if the organisation has their own ethics committee and review process, a School of Psychology SREC application and approval is still required. Ethics approval from SREC can be gained before approval from another research ethics committee is obtained. However, recruitment and data collection are NOT to commence until your research has been approved by the School and other ethics committee/s as may be necessary.

9.Declarations

Declaration by student: I confirm that I have discussed the ethics and feasibility of this research proposal with my supervisor.

Student's name (typed name acts as a signature): Hannah Ward

Student's number: 1945541 Date: 21/10/2021

As a supervisor, by submitting this application, I confirm that I have reviewed all parts of this application, and I consider it of sufficient quality for submission to the SREC committee.

6.9. Appendix I: Ethics Amendment Approved

UNIVERSITY OF EAST LONDON
School of Psychology

REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION

FOR BSc, MSc/MA & TAUGHT PROFESSIONAL DOCTORATE STUDENTS

Please complete this form if you are requesting approval for proposed amendment(s) to an ethics application that has been approved by the School of Psychology.

Note that approval must be given for significant change to research procedure that impacts on ethical protocol. If you are not sure about whether your proposed amendment warrants approval consult your supervisor or contact Dr Trishna Patel (Deputy Research Director/Chair of School Research Ethics Committee).

HOW TO COMPLETE & SUBMIT THE REQUEST

1. Complete the request form electronically and accurately.
2. Type your name in the 'student's signature' section (page 2).
3. When submitting this request form, ensure that all necessary documents are attached (see below).
4. Using your UEL email address, email the completed request form along with associated documents to: Dr Trishna Patel at t.patel@uel.ac.uk
5. Your request form will be returned to you via your UEL email address with reviewer's response box completed. This will normally be within five days. Keep a copy of the approval to submit with your project/dissertation/thesis.
6. Recruitment and data collection are **not** to commence until your proposed amendment has been approved.

REQUIRED DOCUMENTS

1. A copy of your previously approved ethics application with proposed amendments(s) added as tracked changes.
2. Copies of updated documents that may relate to your proposed amendment(s). For example an updated recruitment notice, updated participant information letter, updated consent form etc.
3. A copy of the approval of your initial ethics application.

Name of applicant: Hannah Ward
Programme of study: Professional Doctorate in Clinical Psychology
Title of research: The impact of bowel cancer on sexuality and intimacy: The experiences of sexual minorities.
Name of supervisor: Kenneth Gannon

Briefly outline the nature of your proposed amendment(s) and associated rationale(s) in the boxes below

Proposed amendment	Rationale
Expand the inclusion criteria to include all cancers, not just bowel cancer.	Recruiting from a relatively specific group of people (sexual minority men who have had bowel cancer) has been difficult due to low numbers expressing an interest in participating in the study. Expanding the inclusion criteria to include men who have had all types of cancer would not only help improve recruitment rates, but would also increase the chances of hearing from this marginalised group of people that are so often overlooked in cancer research. Studies carried out by Ussher and colleagues provide a rationale for grouping cancers together when investigating the impact of cancer on sex and intimate relationships.
Change title to 'Cancer, sex and intimacy: The experiences of gay, bisexual and queer men'	Reflects the current study better than the old title which was bowel cancer specific.

Please tick	YES	NO
Is your supervisor aware of your proposed amendment(s) and agree to them?	x	

Student's signature (please type your name): Hannah Ward

Date: 28.10.21

TO BE COMPLETED BY REVIEWER		
Amendment(s) approved	YES	

Comments

You will need to complete the change to title request form and submit for approval separately.

Reviewer: Trishna Patel
Date: 29/10/2021

6.10. Appendix J: Request to Change Study Title Approved

University of East London Psychology

REQUEST FOR TITLE CHANGE TO AN ETHICS APPLICATION

FOR BSc, MSc/MA & TAUGHT PROFESSIONAL DOCTORATE STUDENTS

Please complete this form if you are requesting approval for proposed title change to an ethics application that has been approved by the School of Psychology.

By applying for a change of title request you confirm that in doing so the process by which you have collected your data/conducted your research has not changed or deviated from your original ethics approval. If either of these have changed then you are required to complete an Ethics Amendments Form.

HOW TO COMPLETE & SUBMIT THE REQUEST

Complete the request form electronically and accurately.
Type your name in the 'student's signature' section (page 2).
Using your UEL email address, email the completed request form along with associated documents to: Psychology.Ethics@uel.ac.uk
Your request form will be returned to you via your UEL email address with reviewer's response box completed. This will normally be within five days. Keep a copy of the approval to submit with your project/dissertation/thesis.

REQUIRED DOCUMENTS

A copy of the approval of your initial ethics application.
Name of applicant: Hannah Ward
Programme of study: Professional Doctorate in Clinical Psychology
Name of supervisor: Kenneth Gannon

Briefly outline the nature of your proposed title change in the boxes below

Proposed amendment	Rationale
Old Title: The impact of bowel cancer on sexuality and intimacy: The experiences of sexual minorities.	The focus of the study has slightly changed to include all cancers, not just bowel cancer. Also focusing specifically on the experiences of men. Ethics amendment for the change has been submitted and approved.
New Title: Cancer, sex and intimacy: The experiences of gay, bisexual and queer men.	

Please tick	YES	NO
Is your supervisor aware of your proposed amendment(s) and agree to them?	X	
Does your change of title impact the process of how you collected your data/conducted your research?	X – ethics amendment approved	

Student's signature (please type your name): Hannah Ward

Date: 2/11/21

TO BE COMPLETED BY REVIEWER		
Title changes approved	YES	

Reviewer: Glen Rooney

Date: 02/11/2021

6.11. Appendix K: Participant Information Sheet

PARTICIPANT INFORMATION SHEET
11/11/21 – Version 2

You are being invited to participate in a research study. Before you agree it is important that you understand what your participation would involve. Please take time to read the following information carefully.

Who am I?

My name is Hannah Ward. I am a postgraduate student in the School of Psychology at the University of East London (UEL) and I am studying for a Professional Doctorate in Clinical Psychology. As part of my studies I am conducting the research you are being invited to participate in. The research will be written up to form part of my academic thesis.

What is the research?

Cancer, sex and intimacy: The experiences of gay, bisexual and queer men.

I am conducting research to explore how men who love/attracted to/have sex with men experience sex and intimacy in the context of cancer. I am interested in finding out in what ways cancer has impacted on sexuality and/or intimacy and learning about factors that have helped or got in the way of navigating any changes.

Cancer and its treatment can significantly impact on a person's sexuality and intimacy, resulting in changes to sexual function, relationships, and self-esteem. People from sexual minorities often have to manage these changes whilst navigating healthcare settings which are centred around heteronormative principles and practices, resulting in difficulties receiving relevant support and advice. This research can be used to inform healthcare professionals about the ways men who have sex with men navigate sex and intimacy post-cancer, to ensure the advice they provide is relevant and meeting the needs of their patients.

My research has been approved by the School of Psychology Research Ethics Committee. This means that the Committee's evaluation of this ethics application has been guided by the standards of research ethics set by the British Psychological Society.

Why have you been asked to participate?

You have been invited to participate in my research as someone who fits the kind of people I am looking for to help me explore my research topic. I am looking to involve men over the age of 18 years old who identify as a man who loves/is attracted to/has sex with men. They must have received a diagnosis of any cancer type, be in remission and have completed any treatment at least six months prior to taking part in the research.

I emphasise that I am not looking for 'experts' on the topic I am studying. You will not be judged or personally analysed in any way, and you will be treated with respect.

Participation in the research is voluntary. You are quite free to decide whether or not to participate and should not feel coerced.

What will your participation involve?

If you agree to participate, you will be asked to take part in an interview with me, the researcher. The interview will take up to one hour and can be over Microsoft Teams video call or telephone. The questions asked during the interview will be about your experiences of having cancer and the impact it has had on your sex life and intimacy. Due to the nature of the interviews, it is likely we will speak about your health, relationships, sex life and sexual orientation, as well as the emotional impact of living with cancer. The interview should be like having an informal chat and you will be free to share as much or as little about your experiences as you feel comfortable. Please note that the interview will be audio recorded either directly by Microsoft Teams, or on a password protected Dictaphone if the interview is by telephone.

I will not be able to pay you for participating in my research, however, I will offer you a £10 Amazon voucher as a token of appreciation for your participation. HMRC regulations require that recipients must provide details of their name, address and National Insurance Number. If you wish to receive a voucher, please tick the relevant box on the consent form to indicate that you agree with this requirement, and provide your details on the demographics form.

Your taking part will be safe and confidential

Your privacy and safety will be respected at all times. There are no risks involved in taking part in the study, however, it is possible you may find aspects of the interview upsetting if drawing on emotional or difficult experiences. If you do become upset, then you can pause, take a break, or stop your participation without consequence. You do not have to answer all of the questions that I ask. We can discuss the emotional impact of the interview and I will share information about services that can offer further support.

One advantage of taking part in the study is that you will be contributing to better understanding the experiences of a group of people who have, so far, been mostly overlooked in cancer research. By more fully understanding the experiences of men who have sex with men, healthcare professionals will be able to provide better care and more appropriate support to their patients. Participants also often enjoy taking part in research interviews as they find it a liberating experience and a chance to tell their story in a safe and confidential space.

All your personal information and the content from the interview will be kept confidential. You will not be identified on any written material resulting from the data collected or in the write-up of the research.

What will happen to the information that you provide?

Only I will listen to the audio recording of the interview and will type it into a transcript. Any identifying information, such as names or places, will be removed or changed in the transcript. I will analyse the transcripts and write up the findings to form part of my academic thesis and publications in academic journals. Anonymised extracts of interviews will be used in the thesis, presentations, reports, publications and any other ways in which the findings will be disseminated. Any identifying information will be removed or changed to ensure you remain anonymous. Some broad demographic information may appear in the thesis (such as age and ethnicity) but it will not be sufficient information to allow the identification of individual participants. A copy of the thesis will be publicly accessible on UEL's Institutional Repository (ROAR).

Your personal contact details, the audio recording, consent form and transcript will be securely stored on the researcher's personal UEL OneDrive for Business account. Only I will have access to your personal contact details, the audio recording and consent form. The transcript may be read by my research supervisor at UEL, Kenneth Gannon, and the examiner who will assess the thesis. No one else will have access to the transcript.

Your personal contact details, the audio recording and consent form will be deleted following examination of the thesis (around June 2022). The transcript will be stored as a computer file for three years on my supervisor's personal UEL OneDrive for Business account, as it may be used for further publications. It will be deleted after three years.

What if you want to withdraw?

You are free to withdraw from the research study at any time without explanation, disadvantage or consequence. Separately, you may also request to withdraw your data even after you have participated, provided that this request is made within 3 weeks of the data being collected (after which point the data analysis will begin, and withdrawal will not be possible).

Contact Details

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

Hannah Ward
Email: u1945541@uel.ac.uk

If you have any questions or concerns about how the research has been conducted please contact the research supervisor, Kenneth Gannon. School of Psychology, University of East London, Water Lane, London E15 4LZ,
Email: k.n.gannon@uel.ac.uk

or

Chair of the School of Psychology Research Ethics Sub-committee: Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ.
(Email: t.patel@uel.ac.uk)

6.12. Appendix L: Consent Form

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

11/11/21 – Version 2

Cancer, sex and intimacy: The experiences of gay, bisexual and queer men.

Please read the statements below and tick the box if you consent to each statement.

I confirm that I have read the information sheet dated 11/11/21 (Version 2) for the above study and that I have been given a copy to keep. ☐

I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

I understand that my participation in the study is voluntary and that I may withdraw at any time, without providing a reason for doing so. ☐

I understand that if I withdraw from the study, my data will not be used. ☐

I understand that I have <u>three weeks</u> from the date of the interview to withdraw my data from the study. ☐

I understand that the interview will be recorded using Microsoft Teams, if the interview takes place by video call, or recorded using a password protected Dictaphone, if the interview takes place by telephone. ☐

I understand that my interview data will be transcribed from the recording and anonymised to protect my identity. ☐

I understand that my personal information and data, including audio recordings from the research will be securely stored and remain strictly confidential. Only the research team will have access to this information, to which I give my permission. ☐

It has been explained to me what will happen to the data once the research has been completed. ☐

I understand that short, anonymised quotes from my interview may be used in the thesis and that these will not personally identify me. ☐

I understand that the thesis will be publicly accessible in the University of East London's Institutional Repository (ROAR). ☐

I understand that short, anonymised quotes from my interview may be used in mater such as conference presentations, reports, articles in professional and academic journ resulting from the study and that these will not personally identify me. ☐

I would like to receive a summary of the research findings once the study has been completed and am willing to provide contact details for this to be sent to. ☐

A £10 Amazon voucher is offered as a token of appreciation for your participation in the study. HMRC regulations require that recipients of vouchers must provide details of their name, address and National Insurance Number. By ticking here, I indicate that I have been informed of this requirement, I wish to receive a voucher and I am happy to provide my details. ☐

I agree to take part in the above study. ☐

Participant's Name (BLOCK CAPITALS)

………………………………………………………………………………………….

Participant's Signature

…………………………………………………………………………………………..

Researcher’s Name (BLOCK CAPITALS)

…………………………………………………………………………………………..

Researcher’s Signature

……………………………………………………………………………………………

Date: ……………………..…….

6.13. Appendix M: Debrief Form

PARTICIPANT DEBRIEF LETTER
11/11/21 – Version 2

Thank you for participating in my research study *Cancer, sex and intimacy: The experiences of gay, bisexual and queer men*. This letter offers information that may be relevant in light of you having now taken part.

What will happen to the information that you have provided?

The following steps will be taken to ensure the confidentiality and integrity of the data you have provided.

Only I will listen to the audio recording of the interview and will type it into a transcript. Any identifying information, such as names or places, will be removed or changed in the transcript. I will analyse the transcripts and write up the findings to form part of my academic thesis and publications in academic journals. Anonymised extracts of interviews will be used in the thesis, presentations, reports, publications and any other ways in which the findings of the research will be disseminated. All identifying information will be removed or changed to ensure you remain anonymous. Some broad demographic information (such as age and ethnicity) may appear in the thesis and works disseminating the findings, but it will not be sufficient information to allow the identification of individual participants. A copy of the thesis will be publicly accessible on UEL’s Institutional Repository (ROAR).

Your personal contact details, the audio recording, consent form and transcript will be securely stored on the researcher’s personal UEL OneDrive for Business account. Only I will have access to your personal contact details, the audio recording and consent form. The transcript may be read by my research supervisor at UEL, Kenneth Gannon, and the examiner who will assess the thesis. No one else will have access to the transcript.

Your personal contact details, the audio recording and consent form will be deleted following examination of the thesis (around June 2022). The transcript will be stored as a computer file for three years on my supervisor's person UEL OneDrive for Business account, as it may be used for further publications. It will be deleted after three years.

What if you have been adversely affected by taking part?

It is not anticipated that you will have been adversely affected by taking part in the research, and all reasonable steps have been taken to minimise potential harm. Nevertheless, it is still possible that your participation – or its after-effects – may have been challenging, distressing or uncomfortable in some way. If you have been affected in any of those ways you may find the following resources/services helpful in relation to obtaining information and support:

- Macmillan Cancer Support Specialists
  Support for people living with cancer and their loved ones.
  Phone: 0808 808 00 00 (7 days a week, 8am to 8pm)
  Website: www.macmillan.org.uk

- Samaritans
  Emotional support for people in distress or struggling to cope.
  Phone: 116 123 (24-hours)
  Website: www.samaritans.org.uk

- Mind
  Support and advice for people with mental health problems.
  Phone: 0300 123 3393 (Monday to Friday, 9am to 6pm)
  Website: www.mind.org.uk

- Relate
  Relationship advice and support.
  Phone: 0300 0030396 (Monday to Friday, 8am to 6pm)
  Website: www.relate.org.uk
  Also offer WebChat with a counsellor

- Switchboard LGBT+ Helpline
  Safe space to discuss issues related to sexuality, gender identity and emotional wellbeing.
  Phone: 0300 330 0630 (7 days a week, 10am to 10pm)
  Website: switchboard.lgbt

- Live Through This
  Cancer support and advocacy charity for the queer community.
  Website: www.livethroughthis.co.uk

- Sex with Cancer

An inclusive website with information, resources and an online shop for people living with and beyond cancer.
Website: www.sexwithcancer.com

You are also very welcome to contact me or my supervisor if you have specific questions or concerns.

Contact Details

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

Hannah Ward
Email: u1945541@uel.ac.uk

If you have any questions or concerns about how the research has been conducted please contact the research supervisor, Kenneth Gannon. School of Psychology, University of East London, Water Lane, London E15 4LZ,
Email: k.n.gannon@uel.ac.uk

or

Chair of the School of Psychology Research Ethics Sub-committee: Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ.
(Email: t.patel@uel.ac.uk)

6.14. Appendix N: Data Management Plan

UEL Data Management Plan: Full

For review and feedback please send to: researchdata@uel.ac.uk

If you are bidding for funding from an external body, complete the Data Management Plan required by the funder (if specified).

Research data is defined as information or material captured or created during the course of research, and which underpins, tests, or validates the content of the final research output. The nature of it can vary greatly according to discipline. It is often empirical or statistical, but also includes material such as drafts, prototypes, and multimedia objects that underpin creative or 'non-traditional' outputs. Research data is often digital, but includes a wide range of paper-based and other physical objects.

Administrative Data	
PI/Researcher	Hannah Ward
PI/Researcher ID (e.g. ORCiD)	1945541
PI/Researcher email	u1945541@uel.ac.uk
Research Title	The impact of bowel cancer on sexuality and intimacy: The experiences of sexual minorities.
Project ID	N/A
Research Duration	12 months, proposed start date April 2020
Research Description	Bowel cancer and its treatment can significantly impact a person's sexuality and intimacy, resulting in considerable changes to sexual function, relationships, and self-esteem. People from sexual minorities often have to contend with these changes whilst navigating healthcare settings which are centred around heteronormative principles and practices, resulting in difficulties

	receiving relevant support and advice. The proposed study aims to use qualitative research to explore the following questions: - How do sexual minority adults experience their sexual and intimate relationships following the onset of bowel cancer? - What has been helpful or unhelpful in navigating any changes in their sexual and intimate relationships? Themes from the study can be used to inform healthcare professionals about the ways sexual minority adults navigate their sexual and intimate relationships post-cancer, to ensure the advice they provide is relevant and meeting the needs of this population.
Funder	N/A – part of the professional doctorate
Grant Reference Number (Post-award)	N/A
Date of first version (of DMP)	07.02.2021
Date of last update (of DMP)	26.02.2021
Related Policies	UEL's Research Data Management Policy
Does this research follow on from previous research? If so, provide details	N/A
Data Collection	
What data will you collect or create?	Recordings in .mp3 format Transcripts in Word format Demographic data in Excel format
How will the data be collected or created?	Interviews by video call will be audio-recorded directly by MS Teams. Telephone interviews will be recorded on a password protected Dictaphone. Audio recordings of interviews will be transcribed on a laptop into a Word document. Between 12 and 15 participants will be interviewed by the researcher either by video call or telephone. Interviews will last up to one hour

	and be semi-structured. All interviews will be audio-recorded and transcribed by the researcher. Data will be anonymised at the point of transcription. Each participant will be given a participant number (in interview chronological order) and all identifiable information (e.g. names, locations, identifiable scenarios) anonymised in the transcripts. Personal data will be collected on a electronic demographics forms (age, gender, ethnicity, sexual orientation, and details of health conditions and treatment), consent forms (names) and prior to the interview (email address and/or telephone number for purposes of arranging the interview, via the researcher's UEL email address). The demographic and consent forms will be electronic Word documents emailed to participants using the researcher's UEL email address. The participants will be required to email back the completed forms. Personal data from the forms will be transferred into an Excel spreadsheet. No further data will be created in the process of analysing the transcripts
Documentation and Metadata	
What documentation and metadata will accompany the data?	Participant information sheets, consent forms, demographics forms, list of guide interview questions and debrief sheets. To help organise the data, a Word document will be used to outline the electronic folder structure and detail what is kept in each folder. Each participant will be attributed a participant number, in chronological interview order. Transcription files will be named according to the participant number e.g. "Participant 1". Each audio file will be named as followed: 'Participant initials: Date of interview'.
Ethics and Intellectual Property	

How will you manage any ethical issues?	Informed written consent will be obtained for all participants before commencing interviews. Participants will be advised of their right to withdraw from the research study at any time without having to give a reason. This will be made clear to participants on the information sheets and consent forms. Participants may also request to withdraw their data even after they have participated, provided that this request is made within 3 weeks of the data being collected (after which point the data analysis will begin, and withdrawal will not be possible). Participants may become distressed during the interviews due to discussing sensitive topics related to sexuality, intimacy and cancer. Time will be taken to build a rapport with the participants to ensure they feel as comfortable as possible during the interview. The researcher will allow adequate time for participants to respond to questions and will go at the pace of the interviewee, allowing time for breaks if needed. The researcher will remind participants they have the right to withdraw at any time without consequence. They will be fully debriefed, provided with a debrief form and signposted to further support if necessary. As a trainee clinical psychologist, the researcher is experienced in dealing with emotional content and confident in recognising and managing distress. Transcription will be undertaken only by the researcher to protect confidentiality of participants. Participants will be anonymised during transcription to protect confidentiality. Agreement will be made that no names will be used or any other identifiable information including locations and identifiable scenarios will be removed or substituted. When necessary, pseudonyms and generic descriptors will be used consistently to alter identifying information. Demographic data, audio recordings and transcripts will all be kept in a separate folders. Only the researcher will have access to the audio recordings and demographic data and it will be deleted once the thesis has been examined and passed. This minisises the risk of re-identification of participants as no one else will have access to identifying data. Furthermore, no list will be kept

	of participant numbers linked to personal identifying information.
How will you manage copyright and Intellectual Property Rights issues?	N/A
Storage and Backup	
How will the data be stored and backed up during the research?	All data will be saved on the researcher's personal UEL OneDrive for Business account. This is only accessible to the researcher and protected with a password only known to the researcher. Transcripts will be backed up on the researcher's UEL H:Drive. Demographic data, audio recordings, consent forms and transcripts will all be kept in separate folders on OneDrive. Demographics forms emailed back to the researcher's UEL email address will be destroyed once the personal data has been transferred to an Excel file and saved onto OneDrive. Consent forms emailed back to the researcher's UEL email address will be saved directly onto OneDrive in a separate folder from the other data. MS Teams recordings of the interviews will be stored by default on the MS Stream Library. These will be downloaded onto the researcher's personal laptop and uploaded to OneDrive. Once successfully transferred to OneDrive, audio recordings will be deleted from the personal laptop. The laptop is a password protected Mac with a password only known to the researcher; the iCloud syncing option will be turned off. If the interview takes place by telephone, it will be recorded using the researcher's password protected Dictaphone. After the interview, these audio recordings will be transferred directly onto OneDrive. Once successfully ransfered to OneDrive, audio recordings will be deleted from the Dictaphone.

	No list will be kept of participant numbers linked to personal identifying information.
How will you manage access and security?	Only the researcher will transcribe all interviews (removing identifiable information in the process) and only the researcher, supervisor and examiners will have access to the transcripts. Anonymised transcripts will be shared with the research supervisor via UEL OneDrive for Business. File names will be participant numbers e.g. Participant 1. Recordings from the Dictaphone and from MS Teams will be uploaded onto the researcher's OneDrive immediately after the interview has ended. Recordings will be deleted from the Dictaphone and the researcher's personal laptop. Audio files will be saved in a separate folder on the researcher's OneDrive and titled as follows: 'Participant initials: Date of interview'.
Data Sharing	
How will you share the data?	Extracts of transcripts will be provided in the final research and any subsequent publications. Identifiable information will not be included in these extracts. Anonymised transcripts will not be deposited via the UEL repository. This is because, whilst the thesis and subsequent publications will use excerpts from the transcripts, allowing access to full transcripts poses a greater risk of participants being identified. Furthermore, as the project is relatively small-scale, it is unlikely the data the transcripts provide will be of particular use to other researchers.
Are any restrictions on data sharing required?	N/A
Selection and Preservation	

Which data are of long-term value and should be retained, shared, and/or preserved?	Personal data, audio recordings and electronic copies of consent forms will be kept until the thesis has been examined and passed. They will then be erased from the researcher’s OneDrive. Once the thesis has been examined and passed, transcripts will be transferred to the Director of Studies (DoS) who will store them on their OneDrive for three years. The transcript copies on the researcher’s OneDrive and H:Drive will be deleted.
What is the long-term preservation plan for the data?	As above.
Responsibilities and Resources	
Who will be responsible for data management?	Hannah Ward
What resources will you require to deliver your plan?	N/A
Review	
	Review plan after feedback from Ethics and regularly thereafter [PJ] Send back any amendments to researchdata@uel.ac.uk
Date: 26/02/2021	Reviewer name: Penny Jackson Research Data Management Officer

6.15. Appendix O: Study Advertisement

PARTICIPATE IN RESEARCH

University of East London

Are you a man who loves/is attracted to/has sex with men?

Have you ever been diagnosed with cancer?

If so, we would like to hear from you!

We know that cancer and its treatment can significantly impact on a person's sexuality, resulting in changes to sexual function, intimate relationships, and self-esteem. People from sexual minorities often have to cope with these changes whilst navigating heteronormative healthcare settings. This study aims to explore how men who love/are attracted to/have sex with men experience sexuality and intimacy in the context of cancer and explore how healthcare settings can better meet their needs.

WHAT WOULD TAKING PART INVOLVE?

Taking part involves a one-to-one interview with Hannah, the researcher, either by video or telephone call, lasting up to 1 hour. You will be asked about your experiences of having cancer and the impact it has had on your sex life and intimate relationships. It is a chance for you to share your experiences in a confidential and non-judgemental space. All information will be kept anonymous.

WHO CAN TAKE PART?

To take part you must:

- Be over the age of 18
- Identify as a man who loves/is attracted to/has sex with men
- Have been diagnosed with any cancer type
- Be in remission and completed any treatment six months ago

Receive a £10 Amazon voucher for taking part!

INTERESTED?

Please email Hannah Ward at u1945541@uel.ac.uk to find out more

This study forms part of my Doctorate in Clinical Psychology. Ethical approval has been granted by the University of East London School of Psychology Research and Ethics Committee

6.16. Appendix P: Interview Schedule

Introduction

- Introduce self and outline the interview plan.
- Check in about discussing sexuality.
- Review consent, confidentiality and the right to withdraw.
- Build rapport by asking ice breaker questions e.g. where are you calling from today? If you weren't here today what would you usually be doing?
- Any questions before we start?

Interview topics

- Cancer journey
    - Tell me a bit about your cancer journey, such as when you received your diagnosis and any treatment you received.
    - How did cancer impact on you generally/physically/emotionally?
- Relationship status
    - Tell me a bit about your current relationship status.
    - Is this different to when you were diagnosed?
- Changes to intimacy e.g. closeness, non-sexual touching, emotional support
    - What has intimacy been like throughout your cancer journey?
    - Have you noticed any changes to intimacy? (Positive? Negative?)
    - How did you feel about those changes? What did they mean to you?
- Changes to sexuality e.g. sexual function, sex life
    - What has sexuality been like throughout your cancer journey?
    - Have you noticed any changes to sexuality? (Positive? Negative?)
    - How did you feel about those changes? What did they mean to you?
- Impact on identity e.g. masculinity, ageing, sexual orientation
- Navigating changes in sexuality and intimacy
    - How did you manage any changes in sexuality and intimacy?
    - How did your partner respond to changes? Did you feel able to communicate with them?
    - Did you turn anywhere for help or advice during that time? (E.g. friends, family, professionals)
    - Were you able to re-negotiate sexuality and intimacy in any way?

- Support from healthcare professionals
    - Tell me about your experiences of discussing sexuality and intimacy with healthcare professionals.
        - Anything helpful/unhelpful?
        - Barriers?
    - What would you have liked done differently?
    - Did you feel able to disclose your sexual orientation?
        - [If so] What helped you feel able to disclose? How was it received? What impact did that have on you?
        - [If not] What got in the way? How did that feel? What would have helped?

Prompts

- Can you say a bit more about that? Can you think of an example? Tell me what you mean by that. How did you feel about that? How did you manage that? What helped? What didn't help? How did you make sense of that?

Debrief

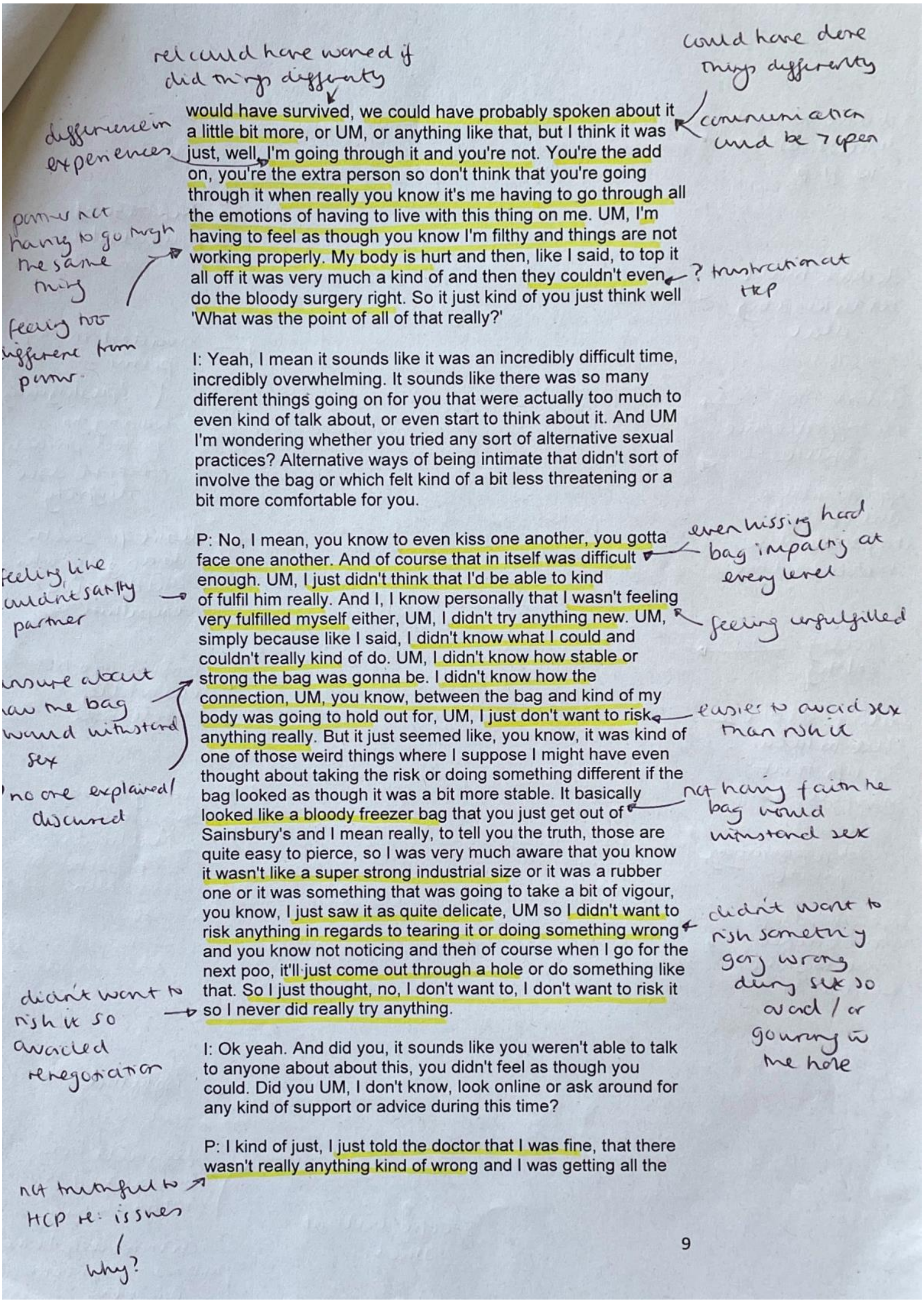
- Is there anything you think I haven't asked or that you want to tell me?
- What was it like talking about those experiences? How are you feeling now?
- Do you have any questions for me?
- Provide debrief form with contact details and let them know they can contact me with any questions or comments.

6.17. Appendix Q: Transcription Key

This transcription key is adapted from Parker (2005):

..	Indicates short pause in speech
...	Indicates long pause in speech
[unclear]	Indicates speech was unclear
[ ]	Indicates when a comment has been added by the researcher e.g. [participant laughs] or information replaced to perverse anonymity e.g. [the hospital]
= =	Indicates overlapping speech
< >	Indicates interruption
-	Indicates unfinished word
(...)	Indicates irrelevant speech has been removed from quote

6.18. Appendix R: Example of Annotated Transcript



rel could have worked if did things differently

could have done things differently

communication could be > open

difference in experiences

would have survived, we could have probably spoken about it a little bit more, or UM, or anything like that, but I think it was just, well, I'm going through it and you're not. You're the add on, you're the extra person so don't think that you're going through it when really you know it's me having to go through all the emotions of having to live with this thing on me. UM, I'm having to feel as though you know I'm filthy and things are not working properly. My body is hurt and then, like I said, to top it all off it was very much a kind of and then they couldn't even do the bloody surgery right. So it just kind of you just think well 'What was the point of all of that really?'

partner not having to go through the same thing

feeling too ifferent from partner.

? frustration at HCP

I: Yeah, I mean it sounds like it was an incredibly difficult time, incredibly overwhelming. It sounds like there was so many different things going on for you that were actually too much to even kind of talk about, or even start to think about it. And UM I'm wondering whether you tried any sort of alternative sexual practices? Alternative ways of being intimate that didn't sort of involve the bag or which felt kind of a bit less threatening or a bit more comfortable for you.

P: No, I mean, you know to even kiss one another, you gotta face one another. And of course that in itself was difficult enough. UM, I just didn't think that I'd be able to kind of fulfil him really. And I, I know personally that I wasn't feeling very fulfilled myself either, UM, I didn't try anything new. UM, simply because like I said, I didn't know what I could and couldn't really kind of do. UM, I didn't know how stable or strong the bag was gonna be. I didn't know how the connection, UM, you know, between the bag and kind of my body was going to hold out for, UM, I just don't want to risk anything really. But it just seemed like, you know, it was kind of one of those weird things where I suppose I might have even thought about taking the risk or doing something different if the bag looked as though it was a bit more stable. It basically looked like a bloody freezer bag that you just get out of Sainsbury's and I mean really, to tell you the truth, those are quite easy to pierce, so I was very much aware that you know it wasn't like a super strong industrial size or it was a rubber one or it was something that was going to take a bit of vigour, you know, I just saw it as quite delicate, UM so I didn't want to risk anything in regards to tearing it or doing something wrong and you know not noticing and then of course when I go for the next poo, it'll just come out through a hole or do something like that. So I just thought, no, I don't want to, I don't want to risk it so I never did really try anything.

even kissing hard bag impacting at every level

eeling like couldn't satisfy partner

feeling unfulfilled

nsure about ow the bag would withstand sex

no one explained/ discussed

easier to avoid sex than risk it

not having faith the bag would withstand sex

didn't want to risk something going wrong during sex so avoid / or going in the hole

didn't want to risk it so avoided renegotiation

I: Ok yeah. And did you, it sounds like you weren't able to talk to anyone about about this, you didn't feel as though you could. Did you UM, I don't know, look online or ask around for any kind of support or advice during this time?

P: I kind of just, I just told the doctor that I was fine, that there wasn't really anything kind of wrong and I was getting all the

not truthful to HCP re: issues / why?

9

6.19. Appendix S: List of Initial Codes

Number	**Initial code**
1	Adjustment
2	Advice from other (GBQ) cancer survivors
3	Ageing - changed relationship to sex
4	Ageing - desire for connection
5	Ageing - natural decline in sexuality
6	Ageing - unnatural because young
7	Alone
8	Alternative sexual practices
9	Anal sex less important
10	Anticipated sexual changes
11	Anxious
12	Appearance important to GBQ community
13	Ashamed around partner
14	Asexual assumption
15	Attempted sex
16	Attraction waned
17	Avoided sex
18	Body image
19	Cancer changed relationship
20	Cancer changed relationship to sex
21	Cancer ended relationship
22	Cancer hidden
23	Cared for by partner
24	Cessation of sex
25	Unfair
26	Closer together
27	Communication - difficult with partner
28	Communication - upfront with partners
29	Community important - not as lonely
30	Community support - others in similar situation
31	Comparison to others
32	Comparison to women
33	Connection
34	Coping - focus on present moment
35	Coping - pragmatic
36	Coping - proactive
37	Coping - wanted to deal with it alone
38	Coping - exercise

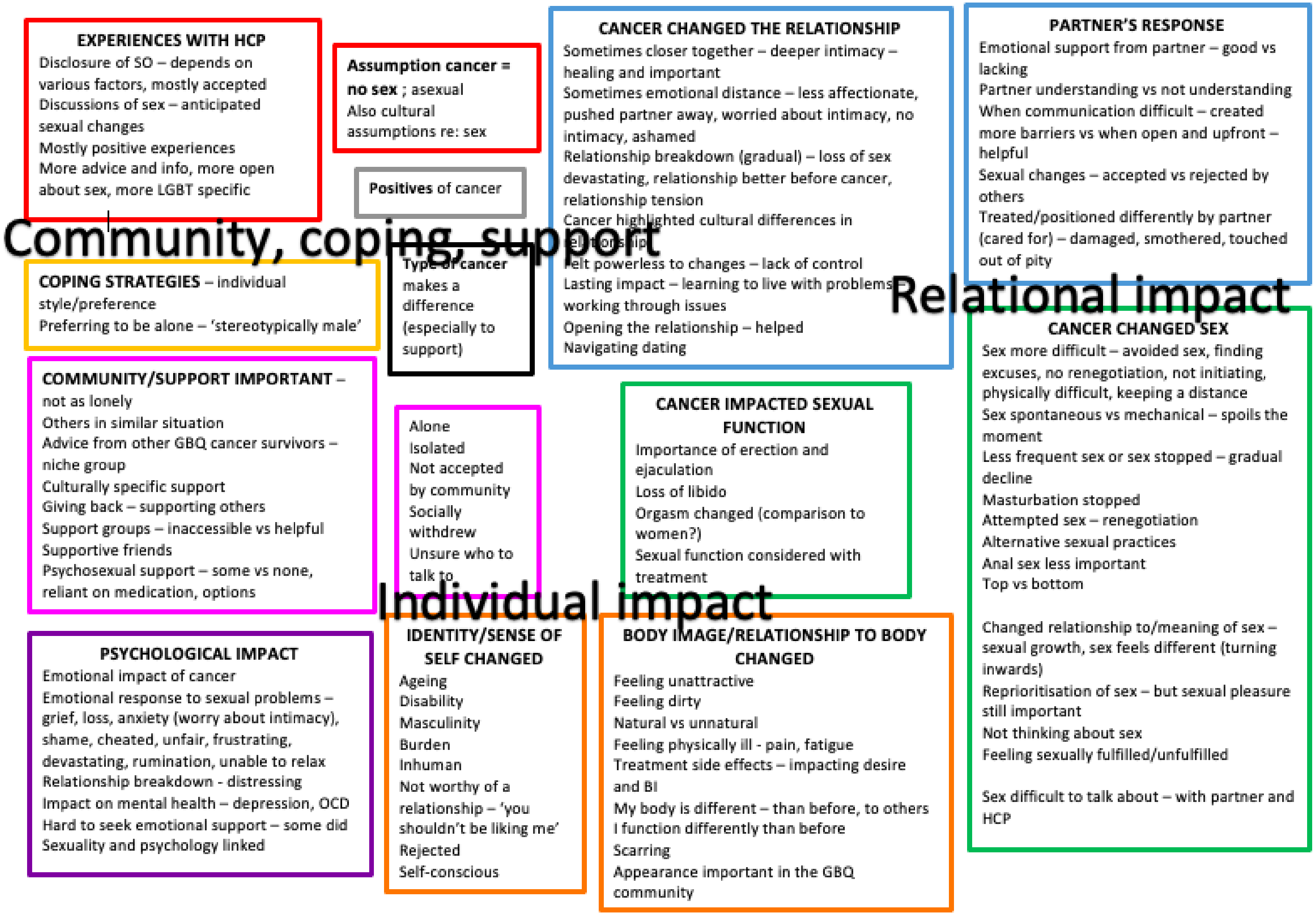
39	Coping - self-care
40	Cultural assumptions
41	Cultural differences
42	Culturally specific support
43	Dating
44	Dating - doesn't feel possible
45	Deeper intimacy
46	Did not seek psychosexual support
47	Didn't engage with GBQ community
48	Direct impact of cancer
49	Dirty
50	Disability
51	Disclosure of SO - depends on level of outness
52	Disclosure of SO - difficult
53	Disclosure of SO - embarassed
54	Disclosure of SO - inconsistent staff
55	Emotional distance
56	Emotional impact of cancer
57	Emotional support from partner - good
58	Emotional support from partner - lacking
59	Feeling powerless to relationship changes
60	Finding excuses not to have sex
61	Frustrating
62	Function differently than before
63	GBQ community - quiet about cancer
64	Giving back - supporting others
65	Gradual breakdown in relationship
66	Gradual decline in sex
67	Grief
68	Hard to seek emotional support
69	HCP - did not discuss sex
70	HCP - discussed sex
71	HCP - negative interactions
72	HCP - no advice given
73	HCP - provided information
74	HCP - surface level conversations
75	HCP - positive interactions
76	HCP could have more understanding of LGBT issues
77	HCP should discuss sex

78	HCP should give advice
79	Hiding SO
80	HIV
81	I'm a burden
82	Illness
83	Impact on mental health
84	Impact on sexual function
85	Importance of erection and ejaculation
86	Inhuman
87	Interview process - difficult talking about issues
88	Interview process - positive talking about issues
89	Intimacy healing and important
90	Isolated
91	Lack of control
92	Lasting impact
93	Leaflets
94	Learning to live with problems
95	Less affectionate
96	Less sex
97	Location (geographical)
98	Loss of libido
99	Loss of sex - devastating
100	Masculinity
101	Masturbation - stopped
102	Mental health support
103	More information needed
104	Natural fluctuations
105	Natural vs unnatural
106	Niche group
107	No renegotiation
108	Not accepted by community
109	Not initiating sex
110	Not thinking about sex
111	Not worthy of a relationship
112	Open relationship
113	Open relationship - helped with loneliness
114	Open relationship - source of support
115	Orgasm - changed
116	Other stressful life stuff

117	Pain - barrier to sex
118	Partner - didn't understand
119	Partner - understanding
120	Positives of cancer
121	Previous relationship
122	Private matter
123	Privileged position
124	Processing breakup
125	Psychosexual treatment or support
126	Pushed partner away
127	Realistic expectations
128	Rejected
129	Relationship better before cancer
130	Relationship breakdown - distressing
131	Relationship breakdown - not able to have sex
132	Relationship ended
133	Relationship tension
134	Relationship to body
135	Reliant on medication
136	Renegotiation
137	Reprioritising of sex
138	Rumination
139	Scarring
140	Self-conscious
141	Sense of self
142	Sex = connection
143	Sex = loving bond
144	Sex difficult
145	Sex difficult - had to keep a distance
146	Sex difficult to talk about
147	Sex spontaneous vs mechanical
148	Sexual changes - accepted by others
149	Sexual changes - distressing
150	Sexual function considered before treatment
151	Sexual growth
152	Sexual pleasure important
153	Sexuality and psychology linked
154	Sexually fulfilled
155	Sexually unfulfilled

156	Shame
157	Single but not due to cancer
158	Sleep impacted
159	Smothered
160	SO accepted
161	SO dismissed
162	Socially withdrew
163	Specific LGBT resources
164	Spoils the moment
165	Support groups - avoided
166	Support groups - helpful
167	Support groups - inaccessible
168	Support groups - mentioned
169	Support important
170	Supportive friends
171	Top vs bottom
172	Touched out of pity
173	Treated or positioned differently - damaged
174	Treatment - satisfied with outcomes
175	Treatment - unsatisfied
176	Treatment options
177	Treatment side effects - fatigue, nausea, tingling, freezing
178	Treatment side effects - limited mobility
179	Treatment side effects - pain
180	Treatment side effects - urinary control
181	Treatment tough
182	Turning inwards
183	Type of cancer makes a difference
184	Unable to relax
185	Unattractive
186	Uncertainty
187	Understanding HCP helped with disclosure of SO
188	Unsure who to talk to
189	Wanting to feel prepared
190	Worked through issues
191	Worried about intimate touch
192	You shouldn't be liking me

6.20. Appendix T: Generating Initial Themes



Community, coping, support

EXPERIENCES WITH HCP
Disclosure of SO – depends on various factors, mostly accepted
Discussions of sex – anticipated sexual changes
Mostly positive experiences
More advice and info, more open about sex, more LGBT specific

Assumption cancer = no sex ; asexual
Also cultural assumptions re: sex

Positives of cancer

COPING STRATEGIES – individual style/preference
Preferring to be alone – 'stereotypically male'

Type of cancer makes a difference (especially to support)

COMMUNITY/SUPPORT IMPORTANT – not as lonely
Others in similar situation
Advice from other GBQ cancer survivors – niche group
Culturally specific support
Giving back – supporting others
Support groups – inaccessible vs helpful
Supportive friends
Psychosexual support – some vs none, reliant on medication, options

Alone
Isolated
Not accepted by community
Socially withdrew
Unsure who to talk to

Individual impact

PSYCHOLOGICAL IMPACT
Emotional impact of cancer
Emotional response to sexual problems – grief, loss, anxiety (worry about intimacy), shame, cheated, unfair, frustrating, devastating, rumination, unable to relax
Relationship breakdown - distressing
Impact on mental health – depression, OCD
Hard to seek emotional support – some did
Sexuality and psychology linked

IDENTITY/SENSE OF SELF CHANGED
Ageing
Disability
Masculinity
Burden
Inhuman
Not worthy of a relationship – 'you shouldn't be liking me'
Rejected
Self-conscious

BODY IMAGE/RELATIONSHIP TO BODY CHANGED
Feeling unattractive
Feeling dirty
Natural vs unnatural
Feeling physically ill - pain, fatigue
Treatment side effects – impacting desire and BI
My body is different – than before, to others
I function differently than before
Scarring
Appearance important in the GBQ community

CANCER IMPACTED SEXUAL FUNCTION
Importance of erection and ejaculation
Loss of libido
Orgasm changed (comparison to women?)
Sexual function considered with treatment

CANCER CHANGED THE RELATIONSHIP
Sometimes closer together – deeper intimacy – healing and important
Sometimes emotional distance – less affectionate, pushed partner away, worried about intimacy, no intimacy, ashamed
Relationship breakdown (gradual) – loss of sex devastating, relationship better before cancer, relationship tension
Cancer highlighted cultural differences in relationship
Felt powerless to changes – lack of control
Lasting impact – learning to live with problems, working through issues
Opening the relationship – helped
Navigating dating

PARTNER'S RESPONSE
Emotional support from partner – good vs lacking
Partner understanding vs not understanding
When communication difficult – created more barriers vs when open and upfront – helpful
Sexual changes – accepted vs rejected by others
Treated/positioned differently by partner (cared for) – damaged, smothered, touched out of pity

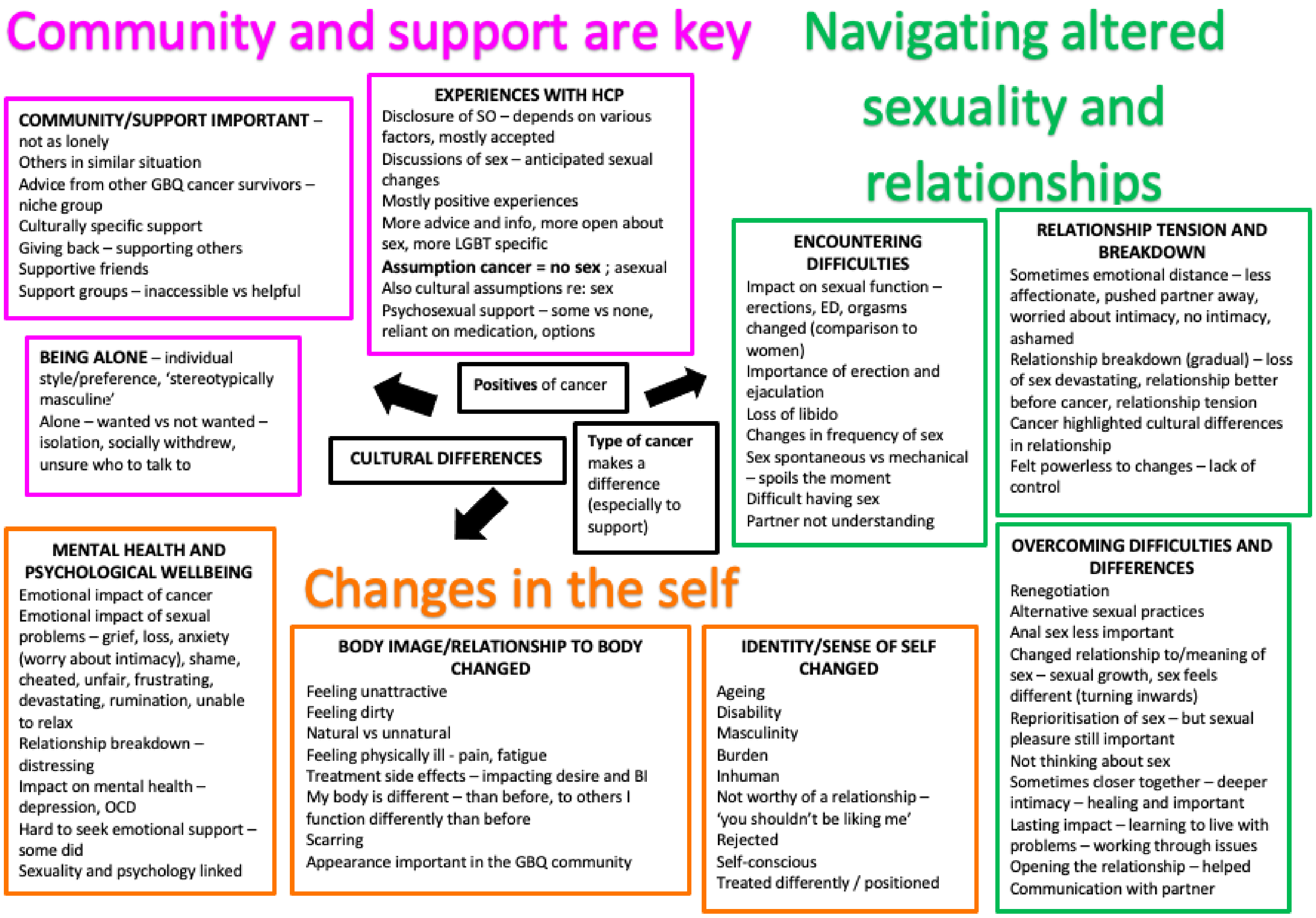
Relational impact

CANCER CHANGED SEX
Sex more difficult – avoided sex, finding excuses, no renegotiation, not initiating, physically difficult, keeping a distance
Sex spontaneous vs mechanical – spoils the moment
Less frequent sex or sex stopped – gradual decline
Masturbation stopped
Attempted sex – renegotiation
Alternative sexual practices
Anal sex less important
Top vs bottom

Changed relationship to/meaning of sex – sexual growth, sex feels different (turning inwards)
Reprioritisation of sex – but sexual pleasure still important
Not thinking about sex
Feeling sexually fulfilled/unfulfilled

Sex difficult to talk about – with partner and HCP

6.21. Appendix U: Intermediate Thematic Map



Community and support are key

COMMUNITY/SUPPORT IMPORTANT –
not as lonely
Others in similar situation
Advice from other GBQ cancer survivors – niche group
Culturally specific support
Giving back – supporting others
Supportive friends
Support groups – inaccessible vs helpful

EXPERIENCES WITH HCP
Disclosure of SO – depends on various factors, mostly accepted
Discussions of sex – anticipated sexual changes
Mostly positive experiences
More advice and info, more open about sex, more LGBT specific
Assumption cancer = no sex ; asexual
Also cultural assumptions re: sex
Psychosexual support – some vs none, reliant on medication, options

BEING ALONE – individual style/preference, 'stereotypically masculine'
Alone – wanted vs not wanted – isolation, socially withdrew, unsure who to talk to

Positives of cancer

CULTURAL DIFFERENCES

Type of cancer makes a difference (especially to support)

Navigating altered sexuality and relationships

ENCOUNTERING DIFFICULTIES
Impact on sexual function – erections, ED, orgasms changed (comparison to women)
Importance of erection and ejaculation
Loss of libido
Changes in frequency of sex
Sex spontaneous vs mechanical – spoils the moment
Difficult having sex
Partner not understanding

RELATIONSHIP TENSION AND BREAKDOWN
Sometimes emotional distance – less affectionate, pushed partner away, worried about intimacy, no intimacy, ashamed
Relationship breakdown (gradual) – loss of sex devastating, relationship better before cancer, relationship tension
Cancer highlighted cultural differences in relationship
Felt powerless to changes – lack of control

OVERCOMING DIFFICULTIES AND DIFFERENCES
Renegotiation
Alternative sexual practices
Anal sex less important
Changed relationship to/meaning of sex – sexual growth, sex feels different (turning inwards)
Reprioritisation of sex – but sexual pleasure still important
Not thinking about sex
Sometimes closer together – deeper intimacy – healing and important
Lasting impact – learning to live with problems – working through issues
Opening the relationship – helped
Communication with partner

Changes in the self

MENTAL HEALTH AND PSYCHOLOGICAL WELLBEING
Emotional impact of cancer
Emotional impact of sexual problems – grief, loss, anxiety (worry about intimacy), shame, cheated, unfair, frustrating, devastating, rumination, unable to relax
Relationship breakdown – distressing
Impact on mental health – depression, OCD
Hard to seek emotional support – some did
Sexuality and psychology linked

BODY IMAGE/RELATIONSHIP TO BODY CHANGED
Feeling unattractive
Feeling dirty
Natural vs unnatural
Feeling physically ill - pain, fatigue
Treatment side effects – impacting desire and BI
My body is different – than before, to others I function differently than before
Scarring
Appearance important in the GBQ community

IDENTITY/SENSE OF SELF CHANGED
Ageing
Disability
Masculinity
Burden
Inhuman
Not worthy of a relationship – 'you shouldn't be liking me'
Rejected
Self-conscious
Treated differently / positioned

6.22. Appendix V: Final Thematic Map

Navigating altered sexuality and relationships

"My ability to engage in sex was limited": Encountering sexual changes and challenges

Impact on sexual function – erections, ejaculation, importance/ symbolism of erection & ejaculation
Orgasms changed (comparison to women) – sexual growth
Loss of libido – treatment side effects, feeling unattractive, impact on BI
Sex and psychology linked
Practical factors
All these factors leading to less frequent sexual activity

"We found ways around it": Overcoming obstacles

Renegotiation – anal sex less important, alternative sexual practices
Working through issues – open communication and supportive, accepting partners
Contrast – partner not understanding (highlighted cultural differences), difficulties with communication – relationship tension and breakdown
Reprioritisation of sex – intimacy more important
Sometimes closer together – deeper intimacy – healing and important
Contrast – worried about intimacy, pushed partner away, less affectionate, emotional distance
Exacerbated pre-existing tension – open rel helped

Undergoing changes in the self

"I felt different, changed, damaged": Identity and sense of self

Masculinity
Inhuman
Disability and illness
Treated/positioned differently
Not worthy of a relationship – 'you shouldn't be liking me'
Ageing

"It affected me mentally": Emotional and psychological wellbeing

Emotional impact of sexual changes – grief, loss, anxiety, anger, frustration, unfair, shame
Positives of cancer – emotional growth
Impact on mental health, devastating impact – depression, OCD
Coping strategies
Psychological support

Seeking community and support

"A lonely journey": Isolation and coping alone

Isolation, alone, socially withdrew
Unsure who to talk to
Different cultural beliefs and values barrier to feeling connected
Preferring to cope alone
Support networks
Sex is a private matter

"The beauty of peer support": Supporting each other through shared experiences

Importance of advice from other GBQ cancer survivors
Helped with isolation & discussing sex
Desire for shared community and support
Support groups – type of cancer makes a difference – benefits when specific, barriers when mainstream, heteronormative, culturally inaccessible
Geographical location barrier to specific support
Giving back and supporting others

"The doctors and nurses": Sexual support from healthcare professionals

Discussions of sex – depends on cancer type, yes vs no
Mostly positive experiences with HCP
Disclosure of SO – depends on various factors, mostly accepted by HCP
Barriers to discussing sex – assumed asexual, cultural assumptions
What needs improving – HCP should bring up sex, more LGBT specific, more culturally specific, advice/hints/tips, leaflets
Psychosexual support – some vs none