The distinctiveness of Lesbian, Gay, Bisexual (LGB) persons affected by cancer treatment and impact on personhood: a participatory research study

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A thesis submitted in partial fulfilment of the requirements for the degree of Doctor of Philosophy QUEEN MARGARET UNIVERSITY

2021

98,892 words excluding references and appendix

“Tis a shame to human nature, such a head of hair as his;
In the good old time 'twas hanging for the colour that it is;
Though hanging isn't bad enough and flaying would be fair
For the nameless and abominable colour of his hair.”

Oh who is that young Sinner – 1896
(AE Housman – 1859-1936)

Abstract

Background

Delivering person-centred care is National Health Service policy within Scotland and advocated by the World Health Organisation. At present the needs and experiences of Lesbian, Gay and Bisexual (LGB) persons affected by cancer are not fully understood and they cannot be assured of healthcare delivered in a non-judgmental way.

Methods

This research is underpinned by person-centred philosophy with participatory research principles, using a devised Impact on Personhood Participatory Inquiry Framework (IPPIF). The researcher worked in-depth with nine LGB participants and their support persons exploring the impact of cancer treatment on aspects of personhood (i.e. long-term wellbeing and identity). The researcher worked with participants to co-create methods of exploration of how cancer treatment had impacted on them.

Findings

Participants' accounts revealed a broad range of issues that both corroborate and build on existing evidence. LGB persons in this research explored context specific disorienting dilemmas in their own care experience, focusing on coming to terms with their diagnosis, negative experiences of care, and coping with the effects of treatments. Participants reflected on the impact of their treatments on their own self which included attitudes towards being labelled, reconciling intersectionality, and coming to terms with their sexual orientation. Participants discussed the development of new relationships and building confidence in new roles after treatment.

Conclusions

LGB persons were found to have distinct care experiences and needs related to cancer across a variety of areas. The main findings of this research provide an evidence base for this assertion, and were used to develop a national practitioner guide with the participants and key stakeholders. The guide was aimed at raising awareness of the needs of LGB persons affected by cancer and improving the care experience.

Key words

Person-centred Care; LGB Cancer Experience; Radiotherapy Treatment; Participatory Research; Patient Experience

Acknowledgements

I would like to acknowledge all the help and support throughout my doctorate and the write up of my final thesis. I have come into contact with particularly kind people over the course of this five year journey, and have received encouragement from so many.

I would first like to offer my most sincere thanks to my supervisory team, Professor Jan Dewing and Professor Cathy Bulley. Their guidance and expertise have been so valuable and have found this experience to be truly transformational both in my learning and my practice, I will always be grateful for this.

I would particularly like to thank my colleagues and wider key stakeholders for their commitment to this work and their collaborations. In particular, Lesley Howells and Andrew Anderson at Maggie’s cancer centres, Rachel Harris, from the Society and College of Radiographers, and Dawn Doran at University of Central Lancashire. Their support during the course of my PhD has been instrumental in its success.

I would also like to thank my peers in the student international community of practice based in the Centre for Person-Centred Practice Research at Queen Margaret University. This inspiring learning community has meant so much over the last five years, and has really helped me to develop my thinking and overall research.

Most importantly, I must convey my sincere gratitude to all the participants who came forward to share their experiences of how cancer had impacted on their lives. Their contribution has been key to the success of this research.

In addition, I would like to thank my husband for his wise counsel and sympathetic ear. You are always there for me and keep me tethered to the ground. Finally, there are my friends and family, who are always excellent support and sounding board to discuss my perspectives, as well as providing me with happy distractions to rest my mind outside of my research.

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1. Introduction

Introduction

There have been a number of legislative reforms and advancements for Lesbian, Gay, and Bisexual (LGB) people within the UK over recent years, however they still cannot be assured that their healthcare can be delivered in non-judgemental ways or cater for their specific needs (Stonewall 2015). Limited research examining the experiences of LGB persons with cancer in the UK has been undertaken. This reveals that they have distinctive needs and experiences when accessing cancer services (Hill and Holborn 2016; Doran et al 2018; Fish and Williamson 2018, Fish et al 2019). These studies start to portray a picture of discriminatory attitudes within care. However, none of the research has focused on a holistic view of personhood or person-centeredness. Further, research to date has not specifically reviewed the effects of cancer treatment on personhood. The literature on person-centredness does not address sexual diversities and this needs attention. I believe that someone's sexual orientation should be taken into consideration regarding their own person-centred care in cancer. Ultimately, there is a need to ensure that cancer services are meeting the needs of all users including persons that identify as LGB. Therapeutic Radiographers such as myself are well placed as oncology-specific health professionals to research this. I have been drawn to this research area due to the lack of understanding within the literature of LGB persons' needs when it comes to cancer. Further, as a member of the LGB community myself, I have felt it important to design my research to aid in addressing these issues. I have combined my professional background and knowledge to address this research through the medium of person-centred emancipatory methods.

Background to the research

Delivering person-centred care is health policy within NHS Scotland and is supported by the WHO policy (The Scottish Government 2010, WHO 2015). It is increasingly seen as the gold standard in many western nations (McCormack 2015). In addition, The Society and College of Radiographers indicate that radiography professionals must endeavour to provide high quality, evidence based, compassionate care for those accessing radiography and radiotherapy services (SoR 2013). LGB people have had protective rights granted to them in recent years within the UK, and their lives have received more focused attention as society's attitudes have shifted towards addressing inequalities. Unfortunately, despite progress that has been made to date, LGB people still face difficulties within today's society with regards to accessing services (Stonewall 2015). Research undertaken by Hill and Holborn (2016) supports this claim, revealing that LGB persons have distinctive experiences and needs relating to cancer care, particularly when attempting to access specific psychosocial and psychosexual support. Only three published studies have been conducted in the UK examining LGB experiences of cancer care (Doran et al 2018; Fish and Williamson 2018, Fish et al 2019). These studies have started to portray a picture of some of the issues from an English perspective, with no known participants from Scotland and no exploration of the effects of cancer treatment on personhood. I believe that someone's background should not influence the level of care that they receive, or to be to their detriment. In my research I argue that LGB people's cancer experiences within Scotland are not fully understood. Further exploration is required to establish what the impact of cancer treatment is to determine LGB people's support needs. As Person-centred care is becoming more embedded within contemporary healthcare practice I feel that a person's sexual orientation should be taken into consideration as a core facet of their personhood, and thus given consideration when evaluating the support and care services they access.

Lesbian Gay Bisexual Cancer experience

Her Majesty's Treasury Department of Business (2015) estimates that 5–7% of the population in the UK is Lesbian, Gay or Bisexual, which equates to approximately 370,000 LGB persons living in Scotland. Macmillan (2015) also estimates that there are approximately 220,000 persons living with cancer in Scotland, and this will include approximately 15,400 persons that will identify as LGB. The needs of LGB people are starting to be more understood within Cancer services in the UK, with Macmillan and Cancer research UK acknowledging this in recently published reports (Macmillan 2013, Cancer Research UK 2015). There has been some progress with the introduction of LGB Cancer support groups in England and the formation of LGB advocacy groups and organisations such as the LGB alliance (Out with Prostate Cancer 2014; The Lesbian Gay Foundation 2015). The cultural context is, however, different in Scotland. It took until 1980 for homosexuality to be decriminalised for men, compared with 1967 in England and Wales. As a result this could have given rise to differences in wider acceptability of homosexuality within Scottish society, and potential differences in experiences of healthcare. As cancer tends to affect people who are older, with a peak age incidence of 70 to 74 years, many members of the LGB community will have lived for a significant proportion of their adult lives in Scotland at a time when homosexuality was not legal (Information Services Scotland 2019). As a result, this may contribute to persons being less vocal about their needs.

Previous UK-based studies in this area have reported a nuance of discrimination and raised levels of apprehension and anxiety experienced by LGB persons using oncology specialist services (Fish and Williamson 2018; Doran et al 2018). Fish and Williamson (2018) conceptualise this as an ‘awkward choreography around disclosure’ manifested through micro-aggressions and heteronormative care systems and practices, contributing to the nuance of discrimination. No UK study has recruited participants in Scotland, which raises a gap in the literature, due to the cultural specificity of experiences of LGB persons. In addition, these novel studies did not take a person-centred perspective which prioritises what matters to the person and mutual respect (McCormack et al 2010). Person-centred care is holistic in its approach, in that it tries to address the wider practical, emotional, financial, and social concerns of the person. Further valuable insights uncovered in this research result from explicitly exploring experiences from a person-centred perspective (Macmillan 2013). This is in line with international prioritisation of person-centred practice, now health care policy within Scotland (McCormack et al 2015). Therefore, the focus of my research has been to explore how the experiences of LGB persons affected by cancer treatment impact on personhood. As a result, my research increases awareness and understanding of LGB social issues and ensures that the views and experiences of persons who may not usually be listened to are represented.

Approach to the research

Using person-centred and critical theory as a foundation to my research, I used participatory inquiry (Heron and Reason 1997) to work with nine LGB people and explore their experiences of cancer treatment and establish how this has affected their personhood. As a consequence of this, I devised a theoretical framework to investigate the impact of health interventions on personhood. I have called this the Impact on Personhood Participatory Inquiry Framework (IPPIF). Through undertaking this research I wanted to establish how cancer treatment in health services impacted on the personhood of LGB people. The research participants reflected on their identity and what mattered most to them. This is key to adopting a person-centred approach (McCormack and McCance 2010). The participants then reflected on how their cancer treatment experiences impacted on aspects of their identity and personhood. This was facilitated through supporting the participants to select the co-creation methods that they felt were most appropriate for exploring their own journeys. To support the level of depth required for the reflective process, identity maps were created. Participants were supported through using methods such as art, drawing, timelines, sculpture, photography, artefacts, and collage as a means of exploration. These were used to facilitate reflection to establish their thoughts, perceptions and insights into their experiences (Deacon 2000). Using these methods assisted in focusing the participants on an exploration of their own stories and past experiences of care. Rather than relying on more conventional interviewing methods, this provided positive engagement that was more creative, dialogical and at times therapeutic experience.

The nine participants (with or without their key support persons) were invited to participate in the research on the basis that they had experienced cancer treatment within the past five years and identified as LGB. Persons were recruited through purposeful sampling via LGB community organisations and word of mouth. I met with participants at a venue that felt comfortable to them. On the first occasion I worked with the participants to create personhood identity maps. The creation process and content of the map enabled a more in-depth discussion, so then at a second meeting we were able to focus the discussion around their cancer treatment experiences. The discussion around treatment experience was recorded and then analysed against my analytical framework which is based on Jack Mezirow's (1923-2014) Transformational Learning Theory (Mezirow 1978). Following the sessions, transcripts and extracts were shared with participants to invite further contributions. The responses were themed under the four main categories of a content analysis framework. Participants were invited to participate in analysis by commenting on themes and any guidance formulated. Drawing on the themes and empirical evidence, we outlined ideas for best practice guidelines and for policy development. It was initially envisaged that a Scottish stakeholder event with professionals and some participants would be organised to share findings, and develop guidelines to inform on practice and education curricula for health professionals. However, due to the Covid-19 pandemic this event was not possible. Instead, participants were approached individually to contribute to formulation of a practitioner guide. Once agreed this was again shared with key stakeholders for additional feedback. The final version, now ratified, is ready for publication and dissemination to key stakeholders and education providers.

The inclusion of Transgender or Intersex persons in the research

It must be noted that I made a conscious decision not to target the recruitment of transgendered or intersex individuals who identify as heterosexual within this study. This research focused on enabling the participants to reflect on their identity, through questioning what their sexual orientation means to them, and how cancer impacted this from a minority perspective. Transgenderism is not a matter of one's sexual orientation but an issue pertaining to gender identity (Diamond 2002). Although from the literature it is known that the transgender cancer experience has been far from ideal and that many transgender persons have faced issues of discrimination when accessing care (Braun et al 2017), they also have specific medical needs related to gender reassignment and cancer, that require further understanding. It was not within the scope of this research to investigate this area. Those transgendered individuals that identified as being homosexual or bisexual, however, were welcome to participate within the research if they wished, as it was recognised that they would have a unique perspective of cancer treatment from a sexual orientation standpoint. I was approached by those in the transgender and intersex community to enquire about my research, although this didn't result in the successful recruitment of anyone from within these groups.

Why not queer?

At the onset of this research I recognised that there is an emergence of a more fluidic trend in today's Lesbian, Gay, Bisexual, Transgender (LGBT) communities. Many persons with an alternative sexual orientation may prefer to adopt other labels or prefer to remain without a label. 'Queer' for example, is a term that is adopted by those who view their sexual orientation as different from heterosexual. For those who feel they are queer, the terms 'lesbian gay and bisexual' are often seen to be too limited and occasionally linked with cultural connotations that people don't feel apply to them. Queer has long been considered a negative term, and it has been reclaimed by some of the LGBT community to describe themselves; however the term is not without controversy within the community given its history, and can still cause offence to many. Throughout this thesis the use of the term 'LGB' will be used to describe those with a homosexual or bisexual sexual orientation, and the wider, more inclusive term 'LGBT' will be used as a means of describing the wider community to which LGB people belong.

Philosophical underpinnings of the research

This research is underpinned by person-centred principles and I explore these further within my next chapters, particularly in chapter three when I address my views of personhood in detail. These principles influence my world view and the approaches that I have used to undertake this research. I define myself as a Critical Social Theorist drawing from Jürgen Habermas (1929 – current) and Jack Mezirow (1923 - 2014). I sought to encourage the participants to reflect on their experiences of cancer treatment, and my methods were selected to stimulate this rational discourse. I was drawn to undertaking my research in a person-centred way because person-centred research is about doing research with persons, not on persons (McCormack et al 2017). I have a commitment to work with persons to fully understand their issues and help focus on a solution or way to help contribute, and this is a significant underpinning aspect of the research I have undertaken.

My research lens or ontology is personal to me, and my approach is that of a relativist. As a relativist I deny full objectivity of the research, and this is influenced by my personal views. I have a commitment to, and belief in justice, democracy, communication, and rationality, and these inform my beliefs about what a person is and what personhood means. In summary, I feel a person is:

A unique entity that can make moral judgements that are influenced by life experiences, abstract and rational thought and potential for higher self-awareness and logic. They have the ability to learn and are capable of transformation.

I believe personhood is:

The status of being a person that is bestowed with certain rights to equality and liberty. As such, LGB persons have a unique and unifying perspective because of the way that society treats them, and in some instances due to a lack of equality and liberty, are denied the full recognition and potential of their own personhood.

I have focused my research from the epistemological stance that a person's understandings of knowledge are constructed socially, and the understanding of this knowledge can be changed. This drives my methodology which is focused on empowering persons, clarifying understanding and promoting communication. In this research I have therefore sought to collectively bring persons into spaces in which they can explore themselves and work with persons to establish what this means. These stances cumulate to form my paradigm of research, in which I am a Critical Social Theorist. In my research I feel it is important to enable those that are affected by the issues to contribute to creating both knowledge and solutions, rather than just merely studying participants to gain answers to questions.

Involving participants and stakeholders

In keeping with principles of community-based participatory research, I have been committed to ensuring that key stakeholders and potential participants were enabled to contribute to the design of the research process. I made contact with key stakeholders with an information sheet prepared to brief anyone who may wish to be involved informally in the development of the research and its methods, or lend support in raising awareness of the study. I established contact at the outset of the research with the Out with Prostate Cancer support group, Maggie's, the LGBT Cancer Alliance, Edinburgh LGB Health Centre and The LGBT and Cancer Staffordshire Project. This led to several informal contacts who identify as LGB and have cancer who provided informal feedback on the design of the research.

There was the opportunity for participants to participate as little or as much as they wished across the research process. For example, some participants engaged with the study at the start by providing insight into their experiences and stopped at that stage, whereas other participants then became more involved in the final development of national guidance. Participants were asked throughout the research if they were happy to continue by using ‘process consent’ (Dewing 2007). Areas for potential involvement were highlighted in the information provided when initial contact was made and throughout the rest of the research.

Relating this research to Therapeutic Radiography

The research fits within the Society and College of Radiographers (SoR) key research priorities (SoR 2017), in the area of Public and Patient Experience. This investigates Survivorship in Oncology by informing an understanding of how LGB persons adjust following their experience of cancer care. In the early stages of developing my PhD I was awarded a College of Radiographers Fellowship in order to support me to undertake the research (See appendix 1). The research achieved its aim of establishing UK national practitioner guidance focused on improving the experiences of LGB persons affected by cancer. The guide ensures that the participant’s voice is clear in demonstrating the importance of the recommendations, by providing targeted information and real-life accounts with the aim of improving patient choice and communication. The research adds to understanding of how LGB persons interact with cancer services, providing an evidence base to better develop cultural competence within the profession of Radiography and more broadly oncology services.

Conclusion

In this chapter I have provided an introduction to my research thesis to provide a context and rationale. I have introduced my approach of a participatory inquiry, used in what has been a five-year journey with the research participants. I would now like to invite the reader to progress into the rest of my thesis, starting with an indication of how my own beliefs and perspectives inform on my own understanding of personhood and the lens with which I approach this research. This will then progress through the subsequent chapters to demonstrate how I have worked with the participants in the research to develop an understanding of their experiences, and then formulate a practitioner guide to improve the care of future LGB persons affected by cancer.

2. My Ontology

Introduction

In this chapter I will critically discuss my chosen ontology and how this impacts on my research. My ontology forms a part of my larger research paradigm and serves as a set of guiding principles for how I addressed the research that I have undertaken. In addition, my ontology, which is personal to me, gives an indication of my thoughts and interpretive processes. I will present in this section the lens through which I view my research design and process by giving an indication of my assumptions, values, and beliefs as these influence my analysis of events and conclusions. Throughout this section I comment on what my own view of reality is, known in philosophy as metaphysics, and relate this to me and my area of research. I discuss the concepts of relativism and how they impact on my views and perceptions. I conclude that how I feel that through dialogue and reason perspectives of reality and morals can be changed for the purposes of emancipation and equality. My own views are fuelled by a sense of liberty and social responsibility to others and greatly influence my own view of reality. It is my social responsibility and ethical framework that I act for the betterment of others, and those discriminated against within society. In this chapter I explain my view that individuals interpret things differently and have differing moral values due to background, education, and the society in which they exist; this relativism can be used to explain how differing views of social justice and reality can be formed by the individual. Rather than just accepting a rather apathetic pure relativist point of view, I speculate that if a person were removed from these pressures, they would still have an inherent process of logic within their mind that would allow them to be able to organise their experiences, beliefs and understandings without having the influence of external views and opinions. I believe therefore that a person's emotions, views and long held assumptions of reality can change or be changed by discourse, logic, and argument. In this chapter I explain that through consensus, discussion, and thought, liberty can exist through allowing individuals the power of self-determination despite the constraints, adversity and discrimination that society and one's own background and way of life may introduce.

Perceptions of what's real

Hofweber (2011) discusses the theory of ontology and describes the field of study as addressing the nature of being or the kinds of things that have existence. To put this simply ontology addresses questions of whether something exists or not. Is something real or fake? Ontological questions can therefore be frequently phrased as dichotomies, such as whether something is determined or undetermined. An example of this within my research relates to the biological determinism or non-biological determinism of a person’s sexual orientation which is debated in a subsequent chapter. This section is written with the purpose of indicating my approach to the ontology of my research and is written as a narrative on how I have reflected and come to the realisation of my thinking and feelings. Throughout my research I have needed the capacity to recognise not only my own, but also other persons’ feelings, and to be able to recognise the differences or tensions between these in order to categorise them correctly, and to use these to guide the development of the inquiry.

To understand if something exists or not it is important to enable appreciation and understand of how the human mind perceives information. Persons can have differing views when it comes to interpreting and perceiving information and images (Wittengenstien 1967). At a superficial level a person’s mind interprets the images and uses their own experience and knowledge to assist the beholder in processing meaning (Chambers and Reisberg 1985). It is for this reason that the processing of information is subjective to the person’s experience, existing knowledge and beliefs. When applying this to my own research area and how it is influenced by my own experience as a gay man born in the 1980’s, I acknowledge that my perspective of LGB rights, equality and social justice is formed from a relatively recent advancement in LGB legal reform in England. Therefore, I have a differing perspective than older LGB persons affected by cancer in Scotland.

My research however relies on several understandings of being and not just the broad classification of images; it requires me to understand more about the mind of the person perceiving experiences and how they are rationalised within their thoughts. Once this understanding is established I then work with the persons affected by the issues to develop a consensus through all of their differing experiences and formulate recommendations and interventions for cancer centres. Relating this to my research in the area of sexual orientation, I know that sexual identity exists regardless of how I sense, perceive and interpret it because I and many others who are attracted to those of the same gender exist in today’s society. Further, persons with LGB identity have specific experiences of cancer care/therapy regardless of how I make judgements and come to conclusions about these. However, when I bring ‘me’ into the context, it is my sensing, perception and interpreting that brings objects into a personal relationship in which I always have a personal intentionality. It is for this reason I believe in “the self”, as “the self” defines the conditions of identity that make one subject of experience distinct from all others creating a true sense of individuals (Gertler 2015).

Metaphysics

Having started this chapter by explaining my view that persons perceive information differently, I am now going to discuss how I have arrived at my views on how these perceptions are formed and influenced through a metaphysical standpoint.

> *Metaphysics is the branch of philosophy that deals with the principles of things, including abstract concepts such as Being, knowing, identity, time, and space.*
>
> (Oxford Dictionaries 2010).

For the purpose of this chapter, I will focus on the concept of Being and how as persons we perceive Being. To understand perception and differing views on reality it is first important to appreciate how the mind works and processes stimuli. The notion of how the mind and brain works has been studied by many philosophers over time and there are many theories that have debated this. The concept of a free-thinking mind was famously addressed by Rene Descartes in his work *Discourse on the Method and Principles of Philosophy 1637.* Descartes believed in a single binding principle that thought exists, and that thought could not be separated from the person. He suggested that if you think you must exist, known as the maxim "I think, therefore I am". This theory is the foundation of Cartesian Dualism, that the body and mind are separate and different entities. This notion appeals to me because I prefer to believe that as a person, I am more than just a collection of biological processes as I have an inherent consciousness and self-awareness that I can use to conceptualise my existence. Through this conceptualisation I know that I am real and not a dream, and that my life isn’t predestined or determined. Although Cartesian dualism supports my beliefs of existence Descartes felt that that God governed the development of the free-thinking mind and this is where my more agnostic and scientific views depart from Descartes’ way of thinking (Descartes 1637). However, I note that many ideas of western philosophy such as spirituality have developed and have been encultured into a Cartesian reality and are widespread in the western post-modernist world. Intelligent design is also another example of acknowledging that as human beings we are capable of an independent existence and thought, but the world and what has been created, had a supreme being (Shanks 2004). It is for this reason, I have sought to develop my understanding further, and was attracted to more secular thinkers and theorists as I am more doubtful in my religious views.

Philosophers such as David Hume (1596 –1650) held a more secular and empiricist view because they felt that beliefs and values were ultimately traceable to experience and thus constructed the mind. Hume adopted the stance that the mind was ultimately a “bundle” of perceptions and these bundles of experiences then go on to formulate a person's world view and morals (Torchia 2007). This view however doesn't explain how distinct selves can have perceptions that stand in relation to similarity and causality with one another, for example perceptions of time and space. I believe that the mind must already possess a certain amount of unity or logic that cannot be generated or constituted by these relations alone. This inbuilt logic is a part of our distinctness of personhood and is something that cements in one's mind at an early stage of childhood development at a point where we become self-aware. I have a relativist view of most things; that I think that beliefs and morals can have subjective value influencing differences in perception and consideration, for example the views of right and wrong, but I still believe there is something that is overarching to assist the formation of one's views of reality. John Locke (1632 - 1704) believed that the mind was a plain sheet of paper, otherwise known as a 'tabula rasa', which remained blank until a person's experiences, sensations and reflections started to construct their understanding and knowledge (Uzgalis 2012). In contrast, Locke believed that a person was born with certain inbuilt faculties to make sense of process and perceive knowledge once acquired, developing Hume's view (Uzgalis 2012). Both Lock and Hume held humanistic beliefs by emphasising the value and agency of human beings, individually and collectively, and generally preferring to use critical thinking and evidence over acceptance of religious doctrine or superstition. Although I hold humanistic views by not accepting superstitious views and valuing the agency of humans, I also believe that a person is a district entity to a human being, and that ultimately within my research I adopt a more person-centred rather than humanistic approach. The distinction between person-centred rather than humanistic is discussed by Edvardsson and Innes (2010), and means that rather than merely just respecting the value of individuals who participate within my study, I sought the participants' active involvement. This was achieved by ensuring that the persons affected by the issues were involved in formulating solutions to the problems they had encountered. The research took into account their needs and beliefs and ultimately, I have depended on other persons' altruistic tendencies and need to help others as motivations to engage with my research.

Science explains acts of altruism through the 'selfish genes' suggesting that persons have an evolved characteristic to prevent self-annihilation. This allows for different perspectives and views to be characterised and acted upon without solely relying on a person's education, background annd culture. Kant (1724 – 1804) attempted to address this issue by suggesting that the human mind makes judgements from experience, but that there is also an underlying reason behind the ways that the mind perceives these events and contextualises them. Kant separated what he termed "a priori" and "a posteriori" judgments.

A priori judgments are solely based upon reason, and are independent of all sensory experience, and are universally applied (Kant 1787). A posteriori judgments, on the other hand, are grounded upon a person's experience and are confined to this (Kant 1787). Kant, whilst still maintaining a secular view, felt that perceptions were still subjective but the mind had an element of moral discourse. Kant believed that persons form views based on experience and moral standpoints and these in turn are informed and contextualised by the person's own mind (Kamerling 1997). For my research I also acknowledge that when considering such influences, I don't have cancer, I am a relatively young LGB person, and a white western professionalised male. Therefore, it would be an arrogant assumption that I alone could come up with needed recommendations for tackling discrimination without the involvement of LGB persons affected by cancer. I can only imagine persons' experiences and empathise while feeling strongly that I wish to empower those specifically marginalised by the issues to help address the barriers that have hindered them. I believe this to be important within my research as I develop a person-centred approach to addressing my research, but a blank sheet/slate approach doesn't adequately explain how persons formulate differing views within the same society. For this to happen there must be some universal logic and process of reflection to apply context and meaning to shared experiences as well as the ability to develop concepts and thoughts around things that have not actually happened to the individual.

Relativism and its limitations

Relativism has several facets but its main features relevant to my area of study are conceptual and moral relativism. Conceptual relativism as a metaphysical doctrine which is centred on not presenting the world as separate from a person's interpretation, and that it is not ready made (Baghramian and Carter 2015). Kant argued that thought in the human mind was not passive in its interpretation of its surrounding, but was actually active in shaping its own view on reality (Guyer and Wood 2000). A purer conceptual relativist adds that persons construct their own interpretation of the world due to differences in language or culture (Baghramian and Carter 2015). From a cultural perspective I find troubling that the core tenet of relativism is that all cultural values and perspectives are equal. I believe in a relativist view that explains the rise of differing cultural perspectives and values, but I do not feel that all these views are on an equal standing when you examine the effects of globalisation. Some persons views may contravene my own morality of social justice, freedom, civil rights and equality. For example, I understand why some cultures may believe and practice what I would define as extreme views, such as infanticide or female genital mutilation and feel that within these cultures this is relative, but I do not feel that these practices should be maintained and as such I depart from a pure relativist view. I acknowledge that I cast my own westernised views of what is right and wrong. However, I also advocate for democracy, education, and free will. I feel that these practices must be challenged to allow persons to come to the self-realisation of positive change.

Cultural relativism explains how in a globalised world there have evolved differing views and moral standards. Pure relativism therefore can frame and position inequality as there is an acceptance that differing views and standards are held by different groups but are not more valid or superior to one another (Kanarek 2013). I find myself asking: if all views are acceptable because they are relative from person-to-person and to the society that practices them, how with the rise of globalisation can this lead to a world that tries to address the problems of inequity and discrimination? Through inaction passive discrimination can occur and I find it therefore hard to rationalise that all views are equal. I do not see that all values are correct where they go against human rights. The treatment of LGB persons and attitudes towards this group of persons varies enormously from mild discrimination to more extreme examples of outright persecution. It is for this reason that I find relativism can give rise and justification to extreme views to which I cannot subscribe. Although I do not necessarily want to eliminate others' views I would rather change them through logical argument and discourse to reach a common understanding of the greater good.

Ultimately, I believe that things exist but are open to interpretation from the person-as-observer, and different observers can have many different perspectives. This relativist view of reality initially appealed to me as an overarching ontology, but when explored further can be concerning when addressing morality. My research is concerned with social justice, specifically with persons who have LGB identities receiving hospital-based therapy for cancer. Relativism in itself could be used to justify political oppression which is not my desired outcome. When establishing the views of LGB persons, relativism can be used to explain how differing LGB persons will have different views to each other formed by their individual experiences, cultures, and identities. The persons involved within my research have been strongly influenced by their experiences and some have encountered past discrimination, prejudice, changing of societal views, and the lack of acceptability of LGB persons in Scotland in general. Trying to establish why LGB persons think the way they do, has been key to establishing and understanding the nuances of discrimination. Influences on the views of these persons inevitably impact on their opinions, perceptions, and experiences of care. This represents a limitation of a pure relativist approach and has led me to develop my thinking further. Although I still believe that everyone can perceive things differently, I don’t feel that everyone’s view is necessary morally correct or in the interests of humanity or society. I think there must be an overarching sense of logic that can contextualise meaning and understanding of the nature of being or the kinds of things that have existence. These ideals are supported by philosophers including Friedrich Nietzsche (1844 – 1900) in developing philosophical views explaining that although particular perspectives hold truth and value, they are not necessarily all valid (Wicks 2011). I find that Nietzsche’s views articulate well with my own belief that relativism serves as a good diagnostic tool to explain why differing things happen and occur in differing societies and groups. However, they don’t provide a means of challenging morally repugnant issues for the greater good of society.

How my own beliefs and values impact on my reality

For my research I explore the experiences of LGB persons affected by cancer and to do this the participants and I were required to interpret relative and subjective views. Although cultural relativism is acceptable it has limitations and dangers. I find my myself asking how can I sanction and defend different views that are different to my own and morally repugnant to me. I feel a strong sense of social responsibility and this is informed by my own moral standards. I am aware that within my personhood I tend to be traditional, like structure, and have a strong sense of right and wrong. I embrace honesty, dedication and dignity, and as a health professional have always valued my ability to offer clear advice, help, and guidance to others. I have always taken pride in bringing persons together and have previous experience of being a LGBT community leader. In this role I worked hard to bring everyone together in celebration of diversity and offer a forum for those who may have felt threatened. One of the main challenges I recognise for myself is that not everyone follows the same path or contributes in the same way. As a facilitator of action, I must support the individual to bring ideas to the table, as representations of their true selves, as well as then recognising the power of a group. I feel it is important embrace all views especially those that are marginalised. I a have a great desire to help those in need and stand up for what is right and feel that this is a core element of my personality and PhD.

I, as an individual, have my own values and beliefs and I have been careful that my assumptions and beliefs do not detract from the views by participants in this research. Relativism is part of the Constructivist research paradigm, which is key to my focus on gathering the experiences of LGB persons affected by cancer within Scotland (Denzin and Lincoln 2012). Due to my intention of interpreting and collaborating with participants when addressing my research questions, I have undertaken a participatory research approach.

I am also very aware that the views of the participants may have had the potential to influence me. I acknowledge that I prefer not to engage in unconventional situations or a setting that sometimes makes me feel uncomfortable. I have taken care and not be judgmental as I have my own strong convictions about what is right, wrong, and socially acceptable. My research means that I may unveil sometimes uncomfortable truths about LGB persons and their experiences. I have reminded myself to be aware that there is more than one right way to get things done and act sensitively to those who hold differing views to my own. I took care to relax around those of differing backgrounds to my own. I sometimes find that I have difficulty expressing emotion publicly and throughout my research I am aware that some person’s experiences affect me. To a certain extent I am a hetero-normalised gay man who is in a monogamous relationship with hopes to have a family one day. This view may be different to that of other LGB persons as I am a product of the liberalised and current social and legal reform within the UK. I acknowledge however that I represent the first generation of young LGB persons to be able to enjoy these rights and freedoms. This has the effect of influencing how I view and interpret events and makes me appreciate the social freedoms that I have within society.

I have assumptions about life. Sometimes persons do not hold virtues that I hold dear and this is a challenge to reconcile. I ensure that I don’t judge others by my own standards and accept that there are different interpretations and views of life. Through the research I have found that I have become more tolerant and accepting of other views, even if I do not agree with them. I now have a better understanding of why persons hold these views, and I accept that there is a place within my world sphere for those that hold views that are not my own. Like many western professionalised people my research means a lot to me. My profession and conduct define a lot about the type of person that I am, and I take pride in my achievements. I measure my success in life through work and as such can be protective over its constituents. I have often felt that those who disagree with my views are not wrong, but that I need to present a more reasoned argument or justification to be able to convert others to my way of thinking. I feel a reasoned and logical argument can influence the way that persons view and interpret things. Through this process I also admit that when presented with new ideas and perspectives my views can also change and think of myself as progressive in this attitude. Therefore, I know I have the capacity to operate in an environment of debate and discourse and feel comfortable in this setting. I have sought to influence and be influenced by others in the pursuit of knowledge and believe in the goodness of humanity to ultimately address social stigma and victimisation.

Changing perspectives

Hardin and Higgins (1996) discuss that without social verification, experience is momentary, and often random, but when this is then acknowledged and shared by others, reality then comes into existence. This sharing of ideas and experiences greatly appeals to my sense of working. It could be viewed that the differing subjective elements of perception of care once shared and discussed as a group then become objective through the discourse. This is referred to as the subjective-objective reality (Guba and Lincoln 2005). I view it as central to my research that I have been able to facilitate and assist the persons who have been affected by these issues to work together to create guidance and solutions for cancer services. As these are based on their views and experiences, only the participants can judge whether the solutions we/they have come up with are sufficient. I have strong views about civil rights, emancipation and social justice and it is for this reason that I have adopted a stance of involving the participants throughout my study.

From these standpoints critical theory appealed to me as a means of engagement and discourse and is necessary to develop a logical argument to permit the change of views and perspectives. This form of research is advocated by critical theorists such as Jurgen Habermas (1929 – current) and is used in conjunction with participatory research (Baum et al 2006). Lindolf (2002) described modernist critical theory as focused on the systems and processes of authority and injustice, and supports the unrepresented to question oppressive actions. I have adopted an alternative way of conducting research which is based on encouraging reflection. I feel that I am right to enable persons affected by these issues, who have the perception of the care that they do, to be central to the process in establishing solutions and to help others in the same position. Researchers who have undertaken Critical Social Theory inquiries are typically focused on representing the views of the marginalised and those without power in hope of addressing social problems and developing understanding of the issues (Kidd and Krall 2005, Byrdon-Miller 1997).

Conclusion

Throughout this chapter I have discussed that relativism is an effective perspective to explain how different views are held by others at different points of time and in society. It is important to note that these views are not fixed, and I ultimately believe in the goodness of persons and their ability to be able to be agents of social change and that they can themselves change their own views. I believe in social justice and change and want to ensure the liberty of marginalised persons in society. These are my key guiding principles to my research and as such I feel that knowledge is socially constructed and is made up by both rational ideas and experience. Through discussion the subjective relative views of reality that we hold can be made objective and can therefore be a means of enacting social change. This is a foundation of Critical Social Theory. Through reflective discourse, new ideas and solutions to problems can be formulated. Having reviewed my assumptions, values and beliefs in this chapter I have articulated how I arrived at using Critical Social Theory to providing guiding principles throughout my research as I wish to understand the issues but then work to change things for the better.

3. Exploring Personhood

Introduction

I have felt it important to have a person-centred focus in my research because of my own values and world view. I have sought to support individuals who chose to participate in my research to address the research questions with their views and experiences as central to the process. Ultimately, I have established guidelines with the help of persons directly affected by the issues and have sought to improve person-centred cancer care for those identifying as Lesbian Gay and Bisexual (LGB).

Personhood is the way we tend to consider what it means to be a person. I feel personhood is two things: firstly, the status of being a person bestowed with certain rights to equality and liberty (Kitwood 1997). This is attributed to Kitwood’s views on person-centeredness and is one key principle in understanding person-centred practice (McCormack and McCance 2016). Secondly, I believe that personhood is also a measure of an individual’s humanness (McCormack and McCance 2010). In this chapter I will explore how I am coming to understand more about person-centredness through a philosophical consideration of the notion of person and personhood. Building on the great depth and rigour of thinking that has gone before, I aim to do this sufficiently for the purposes of my research. I aim to bring an original contribution to the person-centred healthcare practice field by considering person and personhood with a LGB focus.

Specifically, in this section I will address what makes LGB persons’ personhood distinct and how this contributes to the framework of my research and possibly to understanding persons and personhood more broadly. In order to be able to articulate these views I will first explore the more traditional definitions and ideas of personhood but argue that these are largely blind to any diversity factors such as sexuality, and that for the purposes of my research I need to also examine Queer Theory. I debate the differences between notions of there being a distinct LGB personhood, or if personhood is more universal umbrella term that can be applied to all LGB persons in a more non-distinct manner without erasing LGB persons’ cultural identity or struggles. I explore these concepts through use of a queer lens, arriving at my view that personhood is unique regardless of sexual orientation but society and culture impact on persons’ world views, and that with a realist view LGB persons are a distinctive group with a shared sense of belonging.

The evolution of Personhood since the Enlightenment and in Europe

It is important to understand what is meant by the term ‘person’ in order to fully appreciate what constitutes the person element of person-centred care. Me/I or The Self is a culmination of a person’s experiences, impacted on by their own thoughts, feelings, perceptions, and behaviours (Gertler 2015). I feel that these facets demonstrate that a person has a distinct consciousness from all others, and that as a result, consciousness is core to being a person. I also feel that because of individual consciousness, this enables a person to form a unique understanding of their surroundings and world. This formulates and makes a person distinct from other persons, allowing the development of true individuality and identity. In my research I recognise that certain persons are grouped and on occasion are marginalised, such as LGB persons affected by cancer.

Rene Decartes (1596 – 1650)

The concept of consciousness and the mind have been subject to debate and classification by many philosophers. “I think therefore I am” is perhaps the most widely known of the judgments of the philosopher Decartes, essentially meaning that to be able to doubt and contemplate your own existence, served as a justification of a presence of an independent mind and free thinking entity i.e. ‘the self’ (Russel and Gottleib 2009). Decartes held what has become known as the Cartesian view that the mind is separate and made from a different substance to the body. Sensation and the perception of reality was thought to be the source of being false and ultimately an illusion, and that the only reliable truths were in the existence of an abstract mind (Grosholz 1991). Philosophers such as those in the Scottish enlightenment attempt to explain what could constitute ‘the self’, with Hume (1711 – 1776) denying that humans have an actual conception of the self. Instead, what they actually experience and perceive as ‘the self’ equates only to a bundle of sensations and causally-connected perceptions (Torchia 2007).

John Locke (1632 -1704)

A more inclusive perspective offered by Locke (1689) in his essay concerning human understanding discusses the self as a conscious thinking thing. He makes allowance for differing interpretations of the substance of the self, by declaring that it matters not if the self is spiritual, material, simple, or compounded, but that consciousness extends to the feelings of pleasure and pain. Locke explained the gradual unfolding of a conscious mind, postulating that a person once borne into existence has an "empty" mind which is then shaped by experience, reflection and perception. Locke asserted that one’s experiences and education are major influences on persons’ perceptions of life. He takes into consideration the impact of an individual’s circumstances in defining who they are, adding the view that a person is someone who is created by their life experiences, culture and knowledge. I feel this is aligned with my own views and beliefs, and lends itself well to the Kantian perspective of a human mind being a blank slate that is influenced by differing experiences. It also highlights how individuals can create LGB culture by having distinct experiences, cultural facets and knowledge related to this minority grouping. Locke’s theories don’t explain how a person’s experiences are organised and contextualised and I prefer to think that a person has an inbuilt mechanism to be able to rationalise thoughts.

Immanuel Kant (1724 –1804)

Kant suggested that the human mind makes judgments from experience, but there is also an underlying reason as to how the mind perceives these events and then organises them. Whilst still maintaining a secular view, Kant felt that perceptions are still subjective but the mind has an element of moral discourse. Kant believed that persons form views based on experience and moral standpoints and these in turn are informed and contextualised by the person’s own mind (Kamerling 1997). These standpoints demonstrate how a person’s situation is heavily influenced by their experiences, history, culture and background. LGB persons have distinct experiences of all of these and this will heavily influence the way that they choose to engage with society, or how society reacts to them. Queer, as an umbrella term, is perhaps useful as an alternative means of describing the LGB community, as it represents those that think differently when compared with norms of gender, sex, and sexual desire (Jagose 1996). I will go on to discuss this further in chapter four of my thesis. Nelson (2009) discusses how Kant and his ethical theory are grounded in moral imperatives and the emphasis on humans having respect for one another; rather than having a value on an individual’s personhood, there is an intrinsic value for persons because they are humans. In contrast, there are several other approaches to the theory of personhood such as Empirical Functionalism, which defines human personhood as a set of functions or abilities and a hierarchy of attributes; such as self-awareness, the ability to have higher brain functions, and to be able to relate to others (Sullivan, 2003). Put simply, this is the view that a human is a sum of their parts. This has limitations including the denial of the designation of a person to those who don’t have all of the set functions and abilities. Through this I find that the value of personhood is therefore lost. For example, this could mean that someone with mental health issues or who is sleeping may not be able to be classified as a person and I do not accept this view.

Regarding the measure of humanness, Kant expresses that a person is a unique entity that is capable of making moral judgements that are influenced by life experiences, abstract and rational thought and higher self-awareness and logic (Kemerling 1997). I find this statement to be mostly aligned with my personal preferred way of thinking of personhood because it fits well with my own ontological and metaphysical beliefs. I feel that a person is a distinct entity with a unique self that has the ability to logically rationalise, change views, and acquire a higher level of knowledge beyond that of primal desires. However, given my research interests in exploring the experiences of LGB persons I am faced with a dilemma. Can I maintain the assertion that someone’s sexual orientation is a core aspect of their personhood or is it just that of primal desire? I also struggle to reconcile a distinctive LGB personhood specifically with Kant’s views.

I believe that a person cannot choose their sexual orientation and therefore it is an intrinsic aspect of who they are. However, the way society views sexual orientation and what this is understood to be changes through time, and reactions to homosexuality and other sexualities is very much driven by the views of society at that point. We now see an emergence of a more fluid perspective on sexual orientation, particularly amongst younger persons in the western world, and this is starting to become more acceptable with certain members of society as a more post-modern perspective is accepted. I will discuss this in more detail in the following chapter. Here, I am taking a realist view of this issue, so I acknowledge an emergence of LGB culture within the UK and sense of belonging for those that identify as being part of this community. I also see an emergence of values and beliefs that derive from this culture with common and shared history among its members. Therefore, these need to be taken into consideration when providing person-centred care and conducting research. As a result, what I understand as intrinsic to someone's personhood could in effect be performative, although the underlying desire is still there, and is no less important.

I maintain a view that LGB persons have a unique and unifying perspective because of the way that society treats them, in some instances denying the full recognition of their personhood. I will go on to explain later in the chapter that a Queer Theory perspective offers a solution by viewing a queer mind as distinct. My epistemological stance is that persons construct their own understanding and knowledge through experiencing and reflecting on events that happen to them (Bagnolli 2011). As social beings and relating this to society I believe that persons jointly construct understandings of the world, and these common understandings go on to form the basis for shared assumptions about reality. Therefore I feel that views of reality can be changed through critical discourse and democratic principles, demonstrating my ontological stance of relativism and my chosen research paradigm of Critical Social Theory (Habermas and McCarthy 1986).

Richard Dawkins (1941-present)

In naturalism a person appears to be nothing significant; there is nothing distinctive about human life other than the biological processes and it is the result of evolution (Dawkins 2006). I find this view can lead to the devaluing of human beings and, if following this view literally, doesn't recognise the distinction between a human being and a person. I find this troubling as naturalism could lead to a person no longer having an inherent dignity and worth. I feel strongly about moral values and if a person was just put down to the result of the randomness of biological processes, there could be no basis for law or morality. I understand that differing moral codes can develop in different cultures and relativism serves as a good explanation as to why this occurs, but my own views extend beyond the pure relativist views as I wish to change and adapt through advancement of education and knowledge societies' attitudes towards LGB persons. Postmodernism takes the naturalist view further and promotes the idea of illusory goals that are ultimately not worth pursuing (Zhao 1993). These views are far from my beliefs and I think that persons can work for the greater good of society and I do not share this rather apathetic view of existence. To contrast, a Judaeo-Christian world view promotes that man resembles his god, and that he is a morally significant being that is separate from the rest of the animal kingdom (Zimmerman 2015). My own personal views are heavily influenced by a Judaeo-Christian world view because of my upbringing and education, but I don't classify myself as religious. Ontological Personalism holds the belief that all human beings are human persons, so being a human automatically classifies you as a person (Sullivan2003). This view at first recognises the value of human life but has a limitation if we were able to produce artificial intelligence or discover new life that can hold personal characteristics. I would like to think that the classification of a person and all the rights and privileges that ensue with this designation would then extend to these new individuals by valuing their life and dignity.

Peter Singer (1946-present)

Singers views on personhood support the idea of non-species diversification models (Degrazia 2006). This is the view that a person can be seen as a distinct entity from a human being. The term 'human being' is a genetic classification for Homo-Sapiens and ultimately refers to the physical form; however, a person is something more than the mere constituents of their genetic make-up and biology. Many properties have been suggested as necessary to make someone a distinct person rather than just a human being, for example person's intellect, linguistics, moral reasoning, free thinking, and higher awareness (Russell 2014). Ultimately many members of the animal kingdom are capable of some but not all of these facets, for example the ability to make moral judgements, abstract thought and higher self-awareness through the concept of the mind are unique characteristics of persons. Tattersall (1998) defines the metaphysical underpinnings of theories of human nature common to personhood and the self by referring to a person as someone who lives in the world of their own making, created in their minds. Humanness is also discussed by Tattersall as a behavioural characteristic of how someone behaves rather than what they are by nature. The human nature encompasses what all human beings share, a pattern of living comprised of all these traits; for example, the biological, the emotional and the rational work in synergy to set human persons apart from other living things. In contrast, Ehrlich (2000) describes human nature as a single concept and the notion that persons possess a common set of rigid, genetically specified behaviours that are likely to be altered by life’s circumstances and that one’s better selves seem to be in conflict with one’s primal drives. My view is that those conflicts can easily be won and that a person is distinct with a unique self that has the ability to rationalise, change views, and acquire a higher level of knowledge than that of primal desires.

Self and identity

In the development of my understanding of what a person is, I have noted that the majority of the philosophers contemplate the concept of ‘the self’. The analysis on the societal or cultural level of the conception of a person, gives rise to the concept of ‘the self’, which is distinct to the concept of identity. The concept of the self and identity are pertinent to my research given the level of introspection that the participants have to undertake to understand how cancer has affected them. Self and identity are highly contingent upon culture, for example, what does it mean to be an LGB person? Or how does someone treat me differently because I am gay? Chartrand and Bargh (1999) describe 'identity' as a description for someone’s social 'face' and is how others perceives them. They go on to state that the ‘self’ is the person’s perceptions of 'who I am and what I am'. The self is a unique reflective consciousness and separates individuals from others (Edvardsson et al 2010). For the purposes of this research I have chosen to focus more on the notion of identity. This is because persons interact with others in society, and how a LGB person is perceived and interacts with society is a key aspect of the research I am undertaking. This research is focused on the participants’ care experiences and how these are influenced by who the person is and how they appear to others. As such identity is a more accessible and translatable means to enable the participant to think about how their care experiences have been impacted by their own ‘social face’. In addition, social identities are a way for persons to make sense of themselves and others, they fulfil important functions in societies, they can help to describe problems at hand and point to injustices suffered (Reinhardt 2020); in this case, the treatment of LGB persons.

Understanding sexual orientation

My understanding of what it is to be a lesbian, gay and bisexual person is informed by my experiences as a self-identifying gay man in the society and in the world in which I live, and how I experience the world and the evidence in the world that influences me. This includes the influence on me and my views by my westernised upbringing, education, and media. The definition of a lesbian and gay person, or homosexual, is a person who tends to direct sexual desire toward another of the same sex (Seidman 1996). For me, this raises the philosophical dilemma that if this is the full extent of being LGB, then it is not a core aspect of personhood as per the Kantian definition that I prefer. However, I wonder if there is something more to being a member of this group, for example does it influence rational and abstract thought? Although the definitions I have offered are relatively superficial and direct, there are complex and underlying concepts inferred within the language related to gender, sexual practices, and sexuality.

Attitudes of society towards homosexuality have varied over time and place, from instances where same sex activity has been accepted and encouraged, through seeing homosexuality as a sin, and thus the development of judicial mechanisms to persecute individuals that identify as LGB (Melvin 2016). Young unmarried woman in the 17th through 19th centuries, were encouraged to take female companions in which intimate relationships developed, this was deemed to be acceptable and fashionable at the time (Fadderman 1981). Termed "sentimental friends", or later ‘Boston marriages’. The were common in the U.S. and Europe, and seen as a rehearsal to married heterosexual life. Since there was not defined language in relation to lesbianism at the time, these relationships were seen to be homo-social. Legal discrimination against homosexual men developed in the 19th century, but there was a failure to acknowledge the existence of lesbianism. Lesbianism started to become more recognised by society and then marginalised in the 20th century (Melvin 2016).

Gender, sexual practices, and sexuality could be interpreted as physical manifestations of the body, and therefore I could connect these easily to a view of personhood. This would mean departing from examining the notion of personhood from a dualist perspective. Such philosophies are advocated by some philosophers such as Maurice Merleau-Ponty (1908-1961) for example. I feel that going down this line of thinking may lead me to the possibility that there is a stratification to a distinct lesbian personhood, gay personhood, and bisexual personhood. This is because of the differences in their corporeal form and how that would then impact on gender, sexual practices, and sexuality. I feel that there must be an underlying unifying aspect of personhood that links Lesbian, Gay and Bisexual persons. I want to believe that LGB personhood is distinct from others that fall under the umbrella of Queer. This would suggest that Queer is a primary characteristic of someone's personhood, because of a distinct LGB culture, derived through a shared sense of community and common space due to a common history and work to address discrimination (Adriaens and Block 2006). Culture, language, and interpretation of history are social constructions (Mallon 2013).Thus leaving this as the sole view of what LGB personhood constitutes is insufficient and has led me to examine what it is to be LGB from a Queer Theory perspective.

The question of how to classify a person's sexual orientation as either a personal or genetic characteristic is also a matter for debate and important to consider when working with persons who identify as LGB. Homosexual and bisexual characteristics occur in several other animal species where they are seen to engage in same-sex mating behaviours and parenting (Bagemihl and Megahan 1999). There is, however, only one species that practices homophobia, human beings. The Royal College of Psychiatrists (2015) concludes that a person's sexuality is not a choice and is developed from a combination of biological and environmental factors. I believe that our understanding of Homosexuality today is a social construction that has developed over time, and our current understanding is largely based on Victorian attitudes that rejected male same sex behaviours. Cultural responses to same-sex sexuality led to homosexual activity becoming exclusive and thus led to the creation of a homosexual identity (Adriaens and Block 2006). Theorists like Foucault (1926-1984) argue that sexualities are socially constructed concepts, which are then ascribed onto bodies. Foucault advocates the rejection of *sexual object choice* as fixed foundation for sexual behaviour, and this stands at odds with other philosophical views related to the formulations of queer or gay identity (Downing 2008). In recent years there have been attempts to classify sexuality as a biologically determined event for example, where a person is born gay or has gay genes. This has been seen by some as a great success of the gay-rights movement; however, it can be argued that it has also been a great loss for LGB acceptance. There have been many recent advancements in LGB rights within the UK and within Scotland, but more progress is needed to address issues of discrimination and wider acceptance.

Kahn (2016) believes that biological determinism can do substantial damage as it can marginalise members of the gay community, such as those that identify as bisexual and transgender. Kahn (2016) argues that biological determinism limits LGB persons and can lead to them misunderstanding their own identity and society. Biological determinism can be used to serve oppressive regimes and its recent emancipatory role is an interesting twist. For example, Nazi science was used to commit genocide and atrocities towards many minority groups, that were deemed to be ‘born that way’, classifying them as a genetically different race that could then be exterminated. It is unscientific to suggest that a gay human is any different genetically than a straight human and from that standpoint it could be argued that to be LGB is a personal characteristic. This does not mean that a person chooses to be gay, is raised gay, or could spontaneously change sexual orientation; but it is rather the society in which we live that classifies those that are attracted to the same gender as something that is different to mainstream. For example, Jang Yeong-jin, a North Korean defector, only realised that he was gay when he crossed the border and started to live in an open society in South Korea. Until that point in North Korea the very concept of homosexuality wasn’t acknowledged in society. It was only when Jang learnt of homosexuality’s existence that he realised what and who he was and that he had feelings in common with other persons in South Korea’s more free and open society (Kim 2016). The reality in today’s world is that persons who are attracted to those of the same or both genders exist, and that it is the society in which they live that makes the judgment. I feel that persons attracted to those of the same or both genders may have a unique perspective and views and therefore might feel marginalised and have certain healthcare needs that are not being addressed.

Intersectionality

When considering someone’s personhood and identity, it is important to note that there are many things that will make up who a person is. Due to the rise of globalisation and multi-culturalism there is now an increasing recognition of how different cultures and identities then intersect, and gives rise to the term intersectionality (Crenshaw 1997). All of the participants in my research came from different backgrounds and held different attitudes towards matters of sexual orientation, gender, religion, and race. Intersectionality is an important consideration, as the participants had several aspects of their identity that inform their world views, not just their sexual orientation. This adds weight to the philosophical underpinnings of this research, where the participants were encouraged to explore their own personhood, rather than solely reviewing how cancer impacted on their sexual orientation.

Persons as learners

I believe that persons are curious beings that learn though their experiences by reflecting on them and then achieving growth as these experiences are absorbed. Boud et al (2013) explains:

> *“Reflection is an important human activity in which persons recapture their experience, think about it, mull it over and evaluate it. It is this working with experience that is important in learning.”*

As persons progress through their lives and gain further experiences this starts to be assimilated in their identity and personhood. Events become part of who they are and I believe that when someone has a significant experience in their life it can influence their overall world view, challenged their assumptions and beliefs, which can be transformational. The notion of personhood and transformation highlights how were are evolving as persons we are ever evolving, and always in a state of becoming. The state of being is an indication of a person’s nature or behaviour (Natanasabapathy and Maathuis-Smith 2019). A state of Becoming is an indication of a person’s movement towards achieving transformational change in their being (Meek et al 2020). I feel that the way a person engages with therapy can affect them in different ways, including leading to transformation. As result I have sought to understand this process further by using Jack Mezriow’s (1923-2014) theory of perspective transformational learning theory to inform on the analysis of my research findings (Mezirow 1997).

Person-centredness

'Person-centredness' is a term that is widely used within the health and social care setting across the world, and is used to describe systems where the ‘patient’ is central to the care process (McCance et al 2011). Person-centred care as a term started to be used frequently from the 1990’s and is focused on relationships that are developed to influence a person’s care journey and has an emphasis on being holistic (Slater 2006). McCormack and McCance (2016) provide the following definition of person-centredness:

> *“Person-centredness is an approach to practice established through the formation and fostering of healthful relationships between all care providers, service users and others significant to them in their lives. It is underpinned by values of respect for persons (personhood), individual right to self determination, mutual respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development”.*
>
> (McCormack and McCance 2016)

A key aspect of my research is to ensure that the outputs of my work can go on and influence policy making and service delivery and in particular, support the lives of vulnerable persons and groups. In this research, I focus on those affected by cancer and belonging to the LGB community. My research has person-centredness at its core and is being undertaken within a larger research centre focused on this area in Queen Margaret University, Edinburgh. My research focuses on ‘humanising healthcare’ which ensures that the ‘person’ is central when developing new methodologies for person-centred research. My PhD draws on this approach, influencing my choice to undertake a participatory research design, keeping my participants at the centre. Ultimately, my aims are to enhance people’s experiences of care, wellbeing and flourishing, and to make a difference to people’s lives locally, nationally and internationally. McCormack and Titchen (2015) provide the following definition of human flourishing:

> *“Human flourishing occurs when we bound and frame naturally co-existing energies, when we embrace the known and yet to be known, when we embody contrasts and when we achieve stillness and harmony; when we flourish we give and receive loving kindness.”*
>
> (McCormack and Titchen, 2015).

This research ensures that LGB people can have a direct influence on development of support offered by cancer services. The output of this research will have a direct impact on patient care by enhancing the experiences of LGB people when accessing cancer services, informing the teaching and learning of future radiographers, and transferring learning beyond Radiography through its impact on cancer support services more broadly.

Summary discussion

Ultimately, I believe that persons are products of the society in which they live and are informed by experience and views. They are ever learning and capable of transforming their views and values. I prefer to think that if a person is a tabula rasa (blank sheet) one’s sexual desires and preferences are part of the fabric of the sheet rather than the writing materials on it. This said, in current society there is an impetus to classify persons into different groups, and LGB persons have a unique perspective on rights and discrimination and therefore have a shared common history and culture. Evidence suggests that there are a great many LGB persons that feel they have an LGB identity, a feeling of belonging to a group(s) or culture with shared history and goals of equality and recognition. Through this shared understanding a sense of belonging to a community is created and allows LGB persons to feel acceptance by others in the same position as themselves. This allows them to acknowledge their own feelings and beliefs in a likeminded community. The LGB community in the western world does, however, have intersectional problems with diversity and difference, for example with misogyny and biphobia, mainly through a lack of recognition. This lack of recognition had particularly been the case for those that identify as lesbian in the past and is currently an issue for those that identify as bisexual. The gay community has a lack of acceptance, and in some instances of biphobia, with persistent and mis-held doubts that bisexuality even exists (Welzer-Lang 2008). I have sought to ensure that my study is as inclusive as possible and welcomed the views of persons who are bisexual and have cancer. Furthermore, in current western society it is my view that sexuality informs a person's identity as this an expression of how we choose to procreate and express affection. I think that a person can use their free will to try and remove themselves from being identified by their sexual orientation, but this act also produces an identifying label of a-sexual or non-scene individuals. This represents a dilemma for these individuals because either a labelled sexuality can be embraced by a person who wishes to engage in the cultural facets that go along with it; or they can choose to opt out by not allowing their sexual orientation to define them. This act of removal, however, actually causes the act of being labelled through the construction of the very culture that they reject. My research sought to include those that try to remove themselves from LGB culture, rejection of influence of one's sexual practices as significant in influencing care is in itself an important viewpoint. Previous studies in this field have failed to find persons that identify as a-sexual, homo-romantic, or non-scene and their contribution are welcomed as equally valid in this study.

Conclusion

In summary, I feel a person is:

A unique entity that can make moral judgements that are influenced by life experiences, abstract and rational thought and potential for higher self-awareness and logic. They have the ability to learn and are capable of transformation.

I feel personhood is:

The status of being a person bestowed with certain rights to equality and liberty, and as such LGB persons have a unique and unifying perspective because of the way that society treats them, in some instances, denying full recognition of their personhood.

Throughout this chapter I have addressed the concept of LGB personhood and feel that I cannot argue that this is something that exists as a distinct entity; however, I do acknowledge that through a realist view there is a distinct LGB culture and a queer mind. There is a sense of community and common space due to a shared common history and work to address discrimination as well as being the general recipients of past and current persecution. LGB persons view gender, sexual practices, and sexuality differently to that of society’s more heteronormative perspectives. It is therefore necessary that additional support be provided though a commitment to person-centredness in health services towards LGB persons; this is to engender a sense of acceptance to ensure they can receive the best care available to them and their support persons.

4. Queer Theory

Introduction

I have been heavily influenced by Habermasian theories of discourse and communicative action and have sought ways to enable the participants to reflect on their own personhood using a participatory inquiry (Habermas 1987). Through this process the participants can reflect on their experiences and are awakened to how their cancer treatment has affected them. Rather than using a paradigm that seeks to solely understand what a person has had happen to them and how they feel, such as a more traditional phenomenological approach, my research focused on working with the participants to articulate and define the issues that they have faced and to consider them critically. Through this process I have worked with the participants to explore their personhood and due to my research being focused on recruiting LGB participants, the origins and foundations of sexual orientation and identity have inevitably arisen within my research. The main basis for my research is in person-centred principles and practice as well as my own views and beliefs of personhood. However, as a researcher that has chosen to do research with the LGBT community, matters of culture and identity arise readily and I am aware that there is a breadth of research related to Queer Theory that can inform my views and research in this area.

In this section I have sought to explore Queer Theory as a concept and position it within the context of my own research. Queer Theory has commonalities with my own research paradigm and blends well as a branch or offshoot from Critical Social Theory; this is because it is both a theory and has the potential for political action and change. Queer Theory is focused on developing an understanding of power structures and norms within society, and how these oppress those with a different or alternative sexuality (Dilly 1999). In this section, I will explore the origins of the concept of Queer Theory, drawing on areas that are pertinent to my own research, and discuss some of the key philosophers and thinkers within the field.

Queer Theory origins

Queer Theory originates from multiple critical perspectives such as feminism, gay and lesbian activism, civil rights movements, and is postmodern theory. It emerged in the early 1990’s and had its beginnings in the academic Critical Social Theorists sphere, although it has been heavily influenced by political and civil rights movements in its creation (Jagose 1996). Activism which focused around the lack of support and government interest in the AIDS’s epidemic in the 1980’s assisted in the rise of the field of research and its origins focused on developing an understanding of non-normative options of queer identities and groups that were marginalised within society (Barker 2016).

Queer Theory developed from the gender and sexuality fields of study, which in themselves arose from lesbian and gay studies and theories on feminism (Richardson 2004). It is a recent theory developed over the last 30 years, and as a post-modernist theory contests some of the set ideas and established modernism, such as identity categories, as well as moral binary classifications such as good and bad sexual orientations (Richardson 2004). Queer Theorists assert that there is no defined and fixed normal, only more changing norms that are the creation of society, and that persons will fit into these categories or not. Queer Theorists then focus on trying to disrupt binary classifications in the hope of addressing the inequalities that are created as a result of an imbalanced society (Sumara and Davies 1999). Queer Theory expands on Gay and Lesbian studies, which is restricted to the examination of natural and unnatural behaviours, by including any sexual activity or identity classified as ‘normal’ or deviant (Love 2015).

Queer as a label

Queer is a useful term for defining all sexual orientations and gender identities that are not heterosexual or cisgender, and its etymology arises from being strange, funny and peculiar (Whittington 2012). In the 19th century the term ‘Queer’ was increasingly used as a pejorative term for those who were engaged in same sex relationships or attraction (Whittington 2012). From the 1980’s civil rights activists started to reclaim the word queer as an alternative to those in mainstream LGBT communities, deliberately chosen to be radical and provocative (Love 2015). To date the term queer remains controversial in both LGBT and non-LGBT communities. Some LGBT persons and organisations do not like to use the word queer, even as an umbrella term, as they associate the word with radical political movements. It is felt by some in the LGBT community to be divisive across many areas including politics, class, age and gender; and is felt by some that this represents a more extreme, radical, and political movement of homonationalists, which many members of the LGBT community do not identify with, rejecting the label (Pretzen 2012).

As a result of the controversy over the word queer, there are political and social divisions within the LGBT community, especially along the lines of those that are involved in community activism. There are individuals within the community who feel that they are ‘normal’ and want to be treated as ordinary and equal members of society. This is a separate view to those who wish to separate themselves off, who want to confront what is considered ‘normal’ in society, and challenge what is considered to be acceptable (Monk 2012).

I have empathy with these views myself, and with other LGBT persons who disapprove of using the word queer as they consider it an offensive and pejorative term used by some heterosexuals. I do, however, understand that the word queer in this context isn’t used in a pejorative sense, but acknowledge that this is only through my own further research to further understand its meaning. Many LGBT persons may not know of this distinction and the term could be off-putting due to their lack of awareness of this debate and their previous experiences of marginalisation and homophobia.

I have found that some of the issues described around the use of the term “queer” have emerged within my own research and its creation. Firstly, I have been called queer in a pejorative sense and as a result I have negative memories and experiences of the term. I have found myself in a position where I have had to review my own values and beliefs and how these create my own personhood when developing the initial stages of my research. Queer is something that has probably fuelled my own early views on feeling that LGBT persons are marginalised and discriminated against in today’s society because I have been subject to this and therefore have an element of lived experience. This has then gone on to provide an initial personal interest in my research area, and it could be argued that negative experiences in my youth have fuelled motivations for investigating matters associated with the LGBT community. Because of that I find myself in an odd position where I am thankful for the label Queer.

As my research was devised and progressed, I engaged with a wide range of stakeholders, and I have come across those who are not in the LGBT community who also feel uncomfortable with the use of the term. In addition, I have also come across many of my LGBT peers and stakeholders who have previous negative associations with the term “queer” as they have not wanted to cause offence through its use. When taking all of this into consideration, when producing my recruitment materials, I made the decision to appeal to persons who identify as LGB to participate in my research. This term is well recognised and adopted by LGB organisations within the UK, although I will admit the term is becoming dated and too fixed for all persons with non-heterosexual orientations to identify with. Queer for example is a more inclusive term for those that may not feel right with either Lesbian or Gay labels but recognise that they differ from the norm in terms of their sex, sexuality origination or gender. Although I acknowledge and support a more inclusive approach, and felt tempted to use the term queer, this would also include persons who are not the subject of my PhD research, for example those that are transgender, that then also identity as heterosexual.

Heteronormativity

One of the key concepts in Queer Theory is the idea of "heteronormativity," which is defined as:

> *"The institutions, structures of understanding, and practical orientations that make heterosexuality seem not only coherent but privileged"*
>
> Berlant 2014, pp 33).

Heteronormativity is concept that is focused on the idea of a world where the normal, and promoted view of heterosexuality is privileged and preferred. This is then promoted within society through a vision of what institutions define as acceptable and normal such as marriage, rights to goods and services, and family structures (Ward and Schneider 2009). I have experienced examples of heteronormativity and many LGB persons living in the UK will have also. As a result of this I know the concept of heteronormativity exists and is present within our society along with the challenges that a person faces when having to correct this assumption. As an experienced health professional and a gay person, I can see how heteronormative assumptions are employed in day-to-day life, although a great many LGB persons can feel unease as a result of previous negative responses when correcting heteronormative views.

Acceptability of homosexuality

At the time of writing this chapter the worst mass shooting in modern American history has occurred and it now appears this was a hate crime against the gay community (Lussenhop 2016). These shocking acts serve to remind me that despite the progress that has been made in recent decades towards the acceptance of LGBT persons there is still significant progress to be made. Out of the tragedy it can be observed how a community of LGBT individuals across the globe are now united in grief and solidarity in response to this event, but it also demonstrates further aspects about how LGBT hate crimes can be distorted, side-lined and even erased. Owen Jones walked out of a Sky News live broadcast over the issues because the presenter of the programme refused to acknowledge that Omar

Mateen’s attack was homophobically motivated. Jones (2016) went on to write about his experience in the Guardian, explaining that it was a deliberate attack on a LGBT venue and as such was homophobia as well as terrorism. The New York Times failed to point out that a gay club in the LGBT community had been targeted and The Daily Mail didn’t put the attack on its front page. I find that these types of issues demonstrate nuances of discrimination within western society and a lack of acknowledgement of the LGBT community’s suffering. Furthermore, a safe place for a community to go was attacked, meaning that this attack also engenders a sense of fear within a community that would otherwise have classified a gay venue as a safe place to escape such persecutions.

Concept of Queer Theory

Queer Theory is focused on the debate of sexuality and gender, and whether one’s sexual orientation is inbuilt, natural or essential to a person (Barry et al 1999). An essentialist believes epistemologically that sexuality is core to being a person, for example essentialist feminists argue that those who are female have an inbuilt and natural predisposition to be caring and nurturing, rather than being aggressive and self-centred. Due to this belief that the nature of a person is inbuilt, it then follows that a person's sexual orientation is also essential to a person's personality (Blackburn 1996).

Queer Theory is an analytical framework that centres on the incongruities of sex, gender and desire (Jagose 1996). Queer Theory is predominantly divided into two main theories of essentialism or social constructionism. Essentialism in Queer Theory is the belief that one’s sexuality and gender are natural, inevitable, and biologically determined which has been the basis for much of the LGB community’s stance in advancing LGB rights and advocacy (DeLamater and Hyde 1998). Pickett (2015) discusses several limitations with the binary classifications of Lesbian and Gay identity and sexuality, and critiques heterosexism for its exclusion and marginalisation of those whose sexuality is different. As essentialist approach, however, also has the same effect. Those identifying as LGB who do not conform, such as sadomasochists and butch/feminine lesbians, arguably do not fit the ideal of an equally natural, inevitable, and biologically determined view. A second limitation is that placing such an emphasis upon gender leads to other valued aspects of identity potentially being marginalised, such as race, religion and ethnicity (Jagose 1996). Finally, essentialism doesn’t take into account the changes in attitudes towards sexuality from differing locations and times (Foucault et al 2001).

Social constructivism asserts that reality is produced and the meanings persons construct are the culmination of social congruence, through communicating and living within a society that defines and conveys what is natural (Beiver et al 1998). Critical Social Theorists, such as those that influence my research, believe that through discourse these views can be deconstructed and therefore changed and influenced by political and social powers. Extending from critical theorists' deconstructive narratives, queer theorists believe that there is no true self, and that a person exists as an object in a socially constructed world. Queer theorists such as Foucault and Butler believe that gender identity and sexual orientation are not intrinsic to a person, but both are largely performative due to a person's socially acquired understanding of what these concepts are in a socially constructed world. Thus, by analysing and deconstructing society's understanding of history and the creation of what we understand as sexual orientation and gender, this can then be reconstructed to remove binary views in which heterosexuality and heteronormativity thrive and oppress others (Butler 1988). Based on this and my own ontological and epistemological beliefs I feel I have an understanding of the queer theorists' view and can see how I am not an essentialist.

Taking the above into consideration, I surmise that Queer Theory as a concept is a global theory that extends to matters of alternative gender, sex and sexual orientation and gives rise to fluidity. From a philosophical standpoint, however this can be criticised, as "queer" does specify any particular sexual orientation or gender. Halperin (1995) argues that heterosexual people can easily identify as "queer," robbing LGB persons of the distinctiveness of what causes them to be marginalised. I do not believe this to be the case, however I acknowledge that I have also found that a queer theorist view makes it difficult to identify more specific persons within the queer community for the purposes of recruitment and selection within my own research. My research focused on specific LGB persons from within the queer community and I believe that the issues LGB persons face would be distinctive to issues faced by those that are transgender or gender queer. In the next section I explore more about Foucault's and Butler's theories as they have similar epistemological views about sexual orientation to myself, although I acknowledge that I am using a Critical Social Theory rather than Queer Theory for my research paradigm. There are distinctions between these, particularly around views of structuralism and modernism, versus and post-structuralism and post-modernism as larger theoretical concepts.

Micheal Foucault (1926-1984)

Micheal Foucault was a French poststructuralist and is known in the field of Queer Theory for his writing: *A History of Sexuality*, published in 1978. His work examining the construction of sexualities, although written nearly a decade before the concept of queer theory was defined, is generally seen by many as the initial progenitor for the development of the concept of Queer Theory (Spargo 1999). Foucault’s work on sexuality discusses how as a concept, sexual orientation can’t be defined, but focuses on how those in power, i.e. governments, and established knowledge structures within society, actually define what is understood to be normal and acceptable (Foucault 1978). Foucault felt that the topic of identity politics had flaws and that what is understood to be the ‘individual’ by society, is created as a result of the synergies and power between discourse and established knowledge. As a poststructuralist, Foucault believed that homosexuality had become medicalised in modern society and that scientists along with the medical establishment had dominated the discourse by defining and categorising sexuality as the creation of the homosexual person in the West (Foucault 1978).

In his works, Foucault analysed intersections of knowledge, power and sexuality, and he asserted that sexual acts had become medicalised, and in today’s society categories of sexuality had become constructed through speciation, belief in truth and reverse discourse (Callis 2009). Foucault felt that sexual practices in any form, other than those used for procreation, had become controlled by science, and sexual practices that were solely pleasurable had become stigmatised, creating what he terms the ‘sexual deviant’ (Foucault 1978). Foucault believed that once persons in society had accepted a label, they eventually would seek each other out and an alternative discourse thus emerges. Through this argument Foucault was able to demonstrate the marginalisation of the LGBT community. He terms this mechanism as the “reverse” discourse which makes possible the creation of self-identities. As a result, Foucault explains that in the mid-20th century:

> *“Homosexuality began to speak on its own behalf, to demand that its legitimacy or ‘naturality’ be acknowledged, often in the same vocabulary, using the same categories by which it was medically disqualified”*
>
> (Foucault, 1978 page 101).

As a result of the ‘reverse discourse’ LGB people were able to classify themselves when they came out, and there was then power in a newly established LGBT community. Taking Foucault’s views over time it can be understood why lesbianism was largely invisible in the early 20th century, only recently gaining more recognition. However, bisexuality and pansexualism are still largely invisible, and in some cases, individuals assume that these sexualities or labels are not legitimate or don't exist.

Judith Butler (1956-present)

Judith Butler is considered one of the foremost thinkers and influencers of Queer Theory. She is from the United States and is a gender theorist, philosopher and author (Duignan 2020). Her main works are: *Gender Trouble: Feminism and the Subversion of Identity (1990)* and *Bodies That Matter: On the Discursive Limits of Sex (1993) I*n both works she explores society's understanding and the convention of gender, developing her assertion that what is understood by gender is largely performative. Her work heavily influences many Feminist and Queer Theory scholars. Butler's argument in 'Gender Trouble' is that what is understood and categorised in terms of sexuality and gender is culturally constructed by society (Butler 2002). She asserts that what is understood as the masculine gender, and the desire of the male form, is actually constructed through repetition. She believes that society has created an imagine of what it believes is right in terms of gender, and that as such what is understood to be acceptable in terms of desire is largely a performative dramatisation of the body. Butler rejects the biological accounts of binary sex, and feels that the gendered, sexed, desiring person must be constructed, building on Foucault's theories and coining the term, 'regulative discourses'. These discourses then define what is natural and acceptable in terms of the possibilities of gender, sexual orientation and gender expression, and this is to the detriment of both heterosexuality and homosexuality (Butler 2002).

Butler is a sometimes controversial figure amongst other leading feminists and is critical of essentialist views of feminism (Butler 2002). Butler asserts that the feminist movement was wrong to define "women" as a distinctive group with common characteristics, and rejects binary views of gender. Butler is a proponent of the view that sexuality and gender are fluid when absent of social construct and power systems, and that as such the feminist movement should focus on removing the power systems that have created the entrapment of women.

Positioning Queer Theory within my own work

My own epistemological views are that knowledge is constructed by persons, and the world in which we live is independent of humanity. It is through a person's distinctive mind, culture, and social interaction that our understanding of the world is established and formed. As such

I understand that limitations of objectivism, as I believe it would be impossible for a person to be truly objective, as they are influenced by their understanding of the world which has been developed by the society in which they live. In the context of sexual orientation, I believe that this is also a construction rather than holding a more essentialist view and Foucault's and Butler's theories appeal to me. Overall I feel that sexual orientation is a construct of society, but that doesn't mean that I reject its existence or the problems and categorisations that are created as a result. However, I do feel that as a society we need to work within existing structures to improve and tackle injustices, and for this reason I adopt a more realist and modernist, rather than postmodernist, view of society, and as such Queer Theory has limitations when applying it to my own research.

Conclusion

As I researched the topic of Queer Theory, I was drawn to theorists such as Foucault and Butler and understand how the constructivist epistemological lens explains more fluid perspectives. I have noted from the literature that both philosophers would claim to be post-modernists, and for that reason I can see a small divergence between my own tendencies to rely on a more Habermasian modernist view of society as an essential aspect of my research paradigm. I presently contemplate whether society is at a stage where Queer Theory can be applied universally, as I don't feel that we are currently at the stage in which we are reaching a post-modernist culture. It seems to me, particularly today, that traditional norms are seem to be becoming more solidified and binary, and we are not yet at the stage where we can contemplate a post-structuralist and postmodernist world view.

5. My Theoretical Framework

Introduction

It is my intention in this chapter to demonstrate the theory behind my research paradigm. I do this to show how my research is designed, organised and how it can be understood within a theoretical perspective. A research paradigm is a way for researchers to be able to demonstrate the overall approach that they have undertaken to investigate and study a phenomenon (Guba 1990). It provides a clear view of how they view reality (ontology), how they believe that knowledge is constructed (epistemology), and how they have undertaken the research practically (methodology) (Guba and Lincoln 1994 pp 105-117). In this chapter I set-out and make explicit my research paradigm and how these individual components have been intrinsic to the research I have undertaken.

My application of ontology, epistemology and methodological principles are explored in more depth in other chapters. Throughout this chapter I intend to demonstrate how these come together to create a theoretical framework aligned with Critical Social Theory, which is a recognised research paradigm. Specifically, I will discuss how I draw influences from Critical Social Theorists such as Jürgen Habermas (1929 – current) and Jack Mezirow (1923 - 2014) to develop the foundations for my theoretical framework in my research and for my learning journey. I will critically discuss how key tenets of these philosophers' theories are apparent within my research and how they are aligned to my ontological assumptions and practices.

Critical Social Theory

Critical Social Theory is defined as:

> *"A form of self-reflective knowledge involving both practical understanding and theoretical explanation which aims to reduce entrapment in systems of domination or dependence",*
>
> (Dant 2004, page 1)

I argue that this is the case for potentially marginalised LGB persons affected by cancer. It is the primary reason why I have chosen it to be my paradigm and is part of the reason why I have chosen to research with a participatory research design (Dant 2004). In addition to my research being developed to support my view on social justice and democracy, I also feel that it is key to working in a person-centred way by focusing on what matters most to the participants in my study.

A critical theory is distinguished from traditional theory as it has an immediate practical purpose. For example, a theory is critical as it serves as a liberating influence and investigates to create a world which addresses a person’s needs through emancipation (Horkheimer and O’Connell 1975). Briefly, emancipation is means of freeing persons from oppression and restrictions present within society. In my research I felt it important to enable those that are affected by the issues to contribute to creating knowledge and solutions, rather than just merely studying participants to gain answers to questions. A critical theory provided the means to conduct a social inquiry to address domination and promote freedom (Bohman 2005). This is something I have reflected on and learnt to be reflexive about my research. Critical theory appealed to me as a means of engagement and discourse and is a necessary part of developing a logical argument to permit the change of views and perspectives. This form of research is advocated by critical theorists. I have chosen to draw on and be influenced by Habermas and Mezirow in conjunction with participatory action research (Baum 2006). Lindlof and Taylor (2002) describe modernist critical theory as being concerned with forms of authority and injustice. It focuses research on local manifestations, rather than broad generalisations. I adopted this alternative way of conducting research to encourage creative reflection. In critical theory the personified, cooperative aspects of qualitative research are required and align to my way of thinking and being. I feel that it is morally right to enable persons affected by these issues to be central to the process of establishing solutions and to help others in the same position. My research has sought to provide a space where participants can find and use their voice. I created some conditions for empowerment for LGB persons whose perspectives of care have been overlooked and not taken into consideration to date. This can be achieved through either inquiry or action orientated approaches to research. I felt it was more appropriate to follow an inquiry-based theme in my PhD. In my next section of this chapter, I will critically discuss what I mean by this and the unique features, similarities and differences between the two. I will discuss how I arrived at my choice of participatory inquiry as being the most appropriate recourse in my research.

Participatory research is generally focused around the enactment of research with those persons whose life world or experiences are under investigation (Bergold and Thomas, 2012). In my research I have aimed to investigate an otherwise under-researched area, because of my beliefs in social justice and democracy. I feel that those truly affected by the issues should also be included as co-contributors to the research process and not just studied. With the use of participatory methods both the participants and the researcher should benefit from the process, and thus demonstrate a convergence of the researcher’s sphere of interest and the participants’ lived experiences (McTaggart1991). It is therefore key in my way of researching in my PhD to ensure that the participants are aware of the benefits of their unique contribution. The results of our research have then been used to develop support and guidance not only for future LGB persons affected by cancer, but also the participants themselves. Despite participatory research being a relatively recent and novel way of researching within health science research, it advocates the possibility, the importance, and the worth of actively involving research participants in the production of knowledge. This is rather than the more traditional way of distancing researcher and participant. Participatory research does share some commonalities with more traditional methods of qualitative research methods and is equally rigorous in processes and findings (Bergold 2007). It is for this reason I have opted to choose participatory research to address my research questions as this is consistent with my overall research paradigm.

Habermas, communicative action, and the public sphere

Jurgen Habermas is a philosopher who advocates Critical Social Theory, participatory inquiry, and action research (Baynes 1991). I find that as I develop my thinking, many of my key methodological ideas align to many of his principles. For example, Habermas is influenced by philosophies of consciousness and logical conceptions that have foundations in Kantian ethics but then goes on to develop ideas associated with construction and communication paradigms (Outhwaite 2009). Habermas is a German philosopher with a strong association with the neo-Marxist Frankfurt school of Philosophy and spent most of his life's research developing theories around communicative rationality in law in policymaking. He is seen by many as a grandfather of Critical Social Theory; it is for this reason that many of his philosophical tenets influence my research. Habermas also considers that the benefits of rationality build a community through communication and researching in harmony (Wiggershaus 2004). This is another reason why I have found myself drawn to his research. I feel that this is a noble goal and it has been the ultimate achievement of my research to foster a sense of community amongst the participants and to create a shared understanding and knowledge. From an epistemological stance, I think that knowledge is a compilation of human-made constructions, such as our current understanding of sexuality and sexual orientation (Bagnoli 2011). I also feel that some forms of knowledge are valued more than others in society, for example patriarchy being more valued than feminism (O'Donnell et al 2004).That is why it is necessary to break down any power that could influence understanding and use democratic principles within ways of researching. I feel that it is key to engage participants in the ownership and creation of the knowledge that is gained through my research and within what Habermas terms the "Public Sphere". Habermas focused on achieving an 'ideal speech situation', so a group of persons could express their views about problems and then come to solutions through the use of rationality as a means of successful communication (Sanberg 2014). Like myself, Habermas feels that persons are able to reach consensus through speech, which translates into co-created knowledge (Powell 2014). Therefore, I am seeking to ensure that I establish a small community of persons who have lived through/live with cancer to agree a shared understanding of their experiences.

Theory of Communicative Action

One of Habermas's major works, *The Theory of Communicative Action* (Habermas 1984), discusses two of his main concepts, the Public Sphere and Life world. These are key to addressing issues that affect persons from all walks of life and can be seen to connect well with the principles of participatory inquiries and my research. The intentions of communicative action are to express and develop cultural knowledge and mutual understandings (Peters and Besley 2011). This is achieved through generating shared and common understanding of participants through discourse and argumentation. It ensures that arguments may be logical and maintain validity while they are rational, and based on reason (Williams 2016).

I conducted research with some of the LGB community to establish whether there was a shared experience of cancer treatment, and then progressed this to help those affected to achieve a level of social integration and solidarity. Habermas used his theories on communicative action to influence law and politics, where he suggested that these power structures were open to public discussion and suggestion through rationality and logic (Tugendhat 1985). Rienstra and Hook (2006) offer criticism of the theory of communicative action, as they argue that it is difficult to ensure that persons are capable of full rationality, and that it is hard to sure they are able to have a clear awareness of their own reasoning skills. It is for this reason that I wish to employ aspects of Mezirow's concept of transformative learning to enable this level of self-actualisation and realisation to occur.

Mezirow developed the theory of communicative action by arguing that participants' emotional and social conditions are important and should be taken into consideration (Illeris 2014). I felt it necessary to offer participants the chance to meet me in a safe space to engage through communicative actions. I believe that this way of addressing issues and enacting change aligns with my beliefs in social justice and democracy and can ultimately help the marginalised in society. These tenets also fit well with my ontological perspectives where I believe in the moral agency of persons and their ability to be agents of social change, and that they can in themselves change their own views. Further, I believe in the merits of social justice with democracy and wanted to ensure the liberty of marginalised LGB persons with cancer by upholding democratic principles within my research. Through discussion, the subjective relative views of experiences that the participants held became objective though shared discourse and understanding. Therefore, the participants used the theories of communicative action as a means of enacting change in care systems, and this related back to my theoretical framework of Critical Social Theory.

Having set out my position on the theory of communicative action and its relative strengths and weaknesses, I will now go on to consider further the main concepts of achieving this by using tenets advocated by Habermas, namely the Public Sphere and Life world.

Public Sphere

Habermas describes the Public Sphere as a body of ‘private persons’, who by being private are not associated with government or ruling organisations, who assemble to discuss matters of public concern or common interest (Baynes 2016). Habermas (1991) defined this as a “bourgeois public sphere” which is conceived as the sphere of private persons come together as a public. Susen (2011) discusses how the public and the private persons are linked and epitomised by the conditions of the social context, to the degree that private persons are represented by their performance of a public persona. In my research I have sought to develop my own public sphere of LGB persons and their key support givers by providing a small forum to encourage discourse about care experiences. To enable this, it was essential that the sphere/space was free of the pressures of instructions and permitted a group of private individuals to feel enabled and empowered to discuss the issues important to them. This is why I chose to recruit individuals directly from the LGB community, rather than through the care setting. My desire was to bring an otherwise possibly silenced minority together within a public sphere, so then they were encouraged to feel freer to express their views openly and not be influenced by the dominance of organisations or usual social constraints that may not allow LGB persons to express themselves openly. Of course, there are two challenges here; first, persons recruited may not have perceived themselves to be oppressed, whether or not it seems this way to an outsider; and second, I was mindful not to take on board the perceptions of an oppressor by regarding or even stereotyping persons in the LGB community in certain ways.

Habermas proposes that the public should be equipped with capacity to question the legitimacy of forms of power (Calhoon 1993). This is termed rational-critical debate and relates to the care systems providing treatment to the participants. Rational-critical discourse is designed so that everyone within the sphere is an equal participant and the supreme communication skill during debate is the power of argument (Calhoon 1993). The space allows for rational critical debate, where private individuals have come together to form their own public, and where their opinion is formed and expressed. Due to the marginalisation of LGB persons this may be in critical opposition to the oppressive systems that exist in society and the heteronormative care systems that are present within the National Health Service

(NHS) (Somerville and Bridger 2015). The key goal of this forum (as I saw it), was to encourage discourse about the issue concerned and to develop a common understanding of the problems and power systems that exist. It must be noted that there are several limitations of the rational critical debate and public sphere. Habermas indicates that in order for the public sphere to thrive there needs to be a removal of status. Despite my best efforts to reduce this, it is entirely possible that in a vulnerable state the participants still viewed me as the researcher and not co-participant.

The public sphere created for this research was not truly open and inclusive to everyone, and this represents a limitation of my research, but was necessary as it was hard to reach everyone through the recruitment process. It was limited by the scope of my study, as well as being subject to time and resource constraints. I regard one of the key indicators of success in my research to be the facilitation of meaningful discourse. Due to the experience of being cancer survivors, participants had varying abilities to communicate, relating to their condition disability and/or education. In my research I facilitated ways of developing a shared understanding despite differing person’s backgrounds and abilities. This is one reason behind my selection of both Habermas and Mezirow to influence my research. I will discuss this further in my methodological principles contained in chapter seven. With my professional experience, I am aware that as persons we cannot be emotionally stable enough to be entirely rational and therefore debate logically. Therefore I sought to address these issues by allowing non-verbal forms of communication through pictures, and objects of significance, to help the participants articulate how they feel. I am also aware that by selecting a group of private persons to address these issues it could be perceived by organisations and key stakeholders as a clique or closed discussion forum. This is why I ensured public awareness of my study and sought to draw on stakeholder input.

Life world

Habermas’s views of the life world are grounded in communication, consisting of socially and culturally created linguistic meanings, giving rise to a sociological rather than phenomenological concept (Habermas 1970). To Habermas, the life world is an environment of competences, practices, and attitudes represented in terms of a person’s cognitive horizon, and this is heavily influenced by the media, money and power. This also aligns with my epistemological stance. Once these external factors take hold the process of rational communication within the life world is decimated and the ability for coordinated action ceases.

The ‘life world’ is also described as:

> *“The world of communicative action and is organised through the intersubjective transmission of cultural and historical traditions”*
>
> (Baynes 1994)

To offer a context to these definitions in relation to my research, this could be described as the communication at play in LGB culture or the gay rights movement, which has been researched through lobbying and debate to enhance civil liberties and visibility in societies of LGB persons. This is a key aspect of my epistemological and ontological views. I feel that Queer will always be in existence as there will always be a power play between the normative majority and the non-normative minority, that can therefore be oppressed by organisations, governments and wider society. Examples can be seen in the attitude towards homosexuality from organised religion, such as the Catholic Church. Despite the power and viewpoint of the organisation there is usually an underclass or movement that exists that can be described as the “life world” existing separately from the oppressive system. This is in contrast to a Phenomenological perspective which is based on persons understanding of the world through their perceptions, and that the world is not independent of human consciousness. This is advocated by Frankfurt School philosophers, Edmund Husserl (1859 – 1938) and Martin Heidegger (1889 – 1976) (Smith 2016). My own ontological standpoint is that I believe that reality exists independently of human knowledge; a person’s understanding of reality is socially constructed and relative through the time and space that the person occupies (Wendt 1992). As a Critical Social Theorist I sought to foster a form of self-reflective knowledge in myself and the participants. This involved both the practical understanding and the theoretical explanation of events which extended beyond the phenomenological perspective, and aimed to reduce address imbalances of power and domination.

Using some of the most relevant of Habermas’ principles allows me to explain the purpose of communication as reaching common understanding with the participants. The notion of the Public Sphere allows the exploration and resolution of which issues are important to LGB persons through discourse. My research aimed to bring together LGB persons from a variety of backgrounds to discuss and reflect on their experiences. In order to have a productive and meaningful ‘public sphere’ and ‘life world’ within my research I had to uphold and follow certain principles.

"Safe space"

Participatory research offers an opportunity to create safe places where persons can go to discuss things using rationality and democracy away from judgement. Habermas refers to this process as “opening communicative space” (Habermas, 1996). This opening up of a safe space is usually necessary when addressing emancipatory issues as most avenues of communication have either been shut down, or don’t exist in the first place. Wicks and Reason (2009) state that:

> *“Opening of communicative space is a principal task of action researchers and reminds us that central to this task is a critical awareness of and attention to the obstacles that get in the way of dialogue.”*
>
> Wicks and Reason (2009)

In the case of LGB persons who are affected by cancer treatment, currently there are no safe spaces such as cancer support groups or forums that exist within Scotland for LGB persons specifically. My research sought out participants to discuss their experiences of care and explore how that was affected by their sexual orientation in the context of their personhood. This is a very deep explorative process. The participants were vulnerable during this, and it was therefore key to develop a safe space in which these explorations could be facilitated carefully. Participatory research has a great dependency on supporting the participants to discuss matters that are very personal to them (Lofman et al 2004). Within my research this may pose a challenge given the sensitivity of the subject area and the psychological issues that may exist in participants associated with a cancer diagnosis and treatment. Within the UK there is a propensity amongst the population to be grateful for the care that they receive, particularly if it is lifesaving. Participants may be reluctant, given my professional background and being a stranger, to discuss aspects of care that may be interpreted as negative. It is for this reason that fostering a space will be needed. It is also necessary to agree the subject areas that will be discussed and to assure participants of confidentiality within reporting of the results. I was aware that in order for this to happen participants needed to trust me (and I them). To enable this I decided to move away from the institutional setting of the university or clinical department and opted to go into the participants’ homes or other location that they felt to be safe.

In addition to ensuring the right setting for the safe space being formed, it is also important to note that the LGB persons recruited into my study may have a legitimate fear generally of being attacked for saying or doing something that society generally views as wrong (French et al 2015). It is therefore key to establish a sphere of trust when researching with participants regardless of the setting (Benhabib 1992). In my research I took steps to ensure that I was reflexive and these are explored in future chapters. I acknowledged my position as the researcher and a young LGB person and reflected on how this may have prevented persons from sharing experiences and expressing their views and opinions, especially when they appeared to contradict what I may think (Guijt and Shah 1998). To address these issues I researched with the participants to provide assurance that as a group it is acceptable to have a conflicting way of knowing. Accepting a diversity of views of knowing between participants and researcher is the essence of democracy acknowledging that persons don’t necessarily hold the same views (Thomas et al 2014).

Jack Mezirow and Transformational Learning

Having set out my position on the key ways in which Habermas helped me shape my research, I also discuss some other influences on my research. I feel that use of the public sphere, life world, communicative action and a safe space were all key to my theoretical framework. I also needed to appreciate that I needed to extend beyond just a Habermasian when supporting participants to reflect on their own personhood. In personhood chapter Three, I discuss my views of personhood and and explain my belief that persons are reflective learners who are in a continual state of becoming. It is for that reason that I drew on influence from Jack Mezirow. Mezirow was influenced by Habermas and founded the concept of transformative learning theory which he divided into three distinct categories: Instrumental, Communicative and Emancipatory (Collard and Law 1989). The emancipatory dimension, suggests that persons have the ability to transform, break free, and change their life; However, this requires the person to be aware of their current state of being, and thus an awareness of one's current life conditions, requiring reflection and an awareness of a person’s emotional state and wellbeing (Mezirow 1991). My research required the participants to undertake a level of self-examination and reflection to be able to define the problems that they had encountered as a result of their cancer treatment. This level of self-actualisation of the experiences that they had endured would be a transformative experience and is why I was drawn to Mezirow’s research. It was my hope that in addition to providing the conditions to enable the participants to gather and tackle the power or organisation and systems that marginalise them, they would also be able to learn something new about themselves and the experience would therefore, ideally be transformative.

Jack Mezirow describes Transformational Learning Theory as:

> *"An orientation which holds that the way learners interpret and reinterpret their sense experience is, central to making meaning and hence learning"*
>
> (Mezirow 1991, page 222).

The theory holds two types of learning, which are defined as instrumental and communicative. Instrumental learning is concerned with developing knowledge through problem solving of tasks and deducing relationships between cause and effect. Communicative learning is focused on how people express their needs, feelings, and perceptions (Mezirow 1994). Mezirow believes that problem solving is very similar to reflection, and that as such through a process of reflection, a person is able to understand their own self and identity more, especially when a sufficient dilemma results in a transformation (Mezirow 1991).

Transformative learning is where a person is able to change their world view, and increase their own capacity, through the expansion of their own consciousness (Taylor 1998). This appealed to me, as through my ontological stances and beliefs in personhood, I believe there to be a distinct self and identity. My methods encouraged the participants to map their own personhood, which for some of the participants was unconscious, and then afterwards we analysed together the effects that cancer treatment had on their identity maps. This process enabled the participants to make new meaning of their experiences, and also provide a context of the LGB person's perceptions of cancer care yet to be explored within the literature.

Developing a person's understanding and meaning of experience is a cornerstone of Mezirow's research and helps develop autonomous thinking. He suggests that a "disorienting dilemma" which would normally be stimulated by life crisis or major transition, such as cancer treatment and marginalisation in healthcare, is the starting point for transformative learning and reflective processes (Mezriow 1997). An aim of my research, was to develop a model for exploring LGB personhood, and this process is fundamentally rational and analytical and thus aligns with a theory of communicative action.

In summary, the core theoretical ideas or tenets that I drew on to shape the research are:

- Underpinning my research with person-centred and democratic processes
- Using theories of communicative action
- Developing a public sphere of participants
- Engaging with the participants in transformative learning about their experiences

- Operating on the assumption that persons are reflective learners
- Engaging in the life world of LGB persons in the study

At all times I provided as safe a space as possible to facilitate the research process and our shared learning.

Conclusion

In this chapter I have shown how my ontology and epistemological tenets aligned, making a coherent Critical Social Theory theoretical framework to shape this research and the development of new knowledge that emerged from it. As a consequence I chose to engage with a Critical Social Theorist's paradigm and draw influence from Habermas and Mezirow. I have argued through the use of communicative action that individuals can mutually deliberate and then arrive at solutions to problems and new shared understanding. This is dependent on the use of Habermas' public sphere as a safe space in which persons can gather and openly discuss and identify problems, and that through rational discourse persons can influence action. I have then also drawn on Mezirow's theory of transformative learning as a process of enabling the participants to understand the changes within their own self, belief systems, and lifestyle. Through these theories I aimed to research with the participants and my research has a practical purpose to improve the care and experience of LGB persons treated for cancer. In my next chapter I will go on to explore the current published literature base related to LGB persons' experiences of cancer treatment, and will explore any areas that align or contrast with to the person-centred principles and means of critical reflection that are outlined in my theoretical framework.

6. Literature review

Introduction

The literature review chapter in my PhD builds on the research undertaken previously from my master's degree, although I have found it necessary to go back and critique the literature once again as my perspective of the research in this field has evolved. My research is now underpinned more by theoretical principles of person-centeredness woven and integrated with my own ontological and epistemological views, contributing to a different theoretical lens to when I did my masters research. In this chapter I have explored the distinctiveness of the impact of cancer treatment on LGB persons, and updated the literature review undertaken for my MSc. Within the chapter I have first provided a discussion of key papers on person-centred research related to cancer more generally and the transformative experience of cancer survivors more broadly. The first part of this chapter takes the form of a narrative review of general approaches in person-centred care and what this can look like within an oncology setting. In the second part of the chapter I have then focused on the literature, identifying the distinctiveness of the LGB experience from that of the population at large through using a Boell and Cecez-Kecmanovic (2014) hermeneutic literature review process. This second part interrogates the literature to a greater degree as expected at doctoral level and builds on the work undertaken for my MSc using a different theoretical lens.

How the review has informed my research

This review has informed my research in two ways. Firstly it feeds into my method, particularly by generating ideas for recruitment, publicising the research findings, and working with minority persons in what is widely understood to be a hard to reach group. Secondly, it served as a means of feeding the wider evidence base into the final discussion and practitioner guidelines. When working with the participants it was important for me to have established a good level of background knowledge of the LGB cancer experience, even though this is a very narrowly researched field. As the research progressed I have found myself developing my understanding and insight of my topic area and this has made me more informed when working with my participants and other stakeholders. It has helped me to develop recruitment strategies, key contacts, to offer support to participants who encountered problems from their treatments, and in the end to formulate recommendations for practice. It was therefore necessary for me to be engaging with the literature throughout the entire research process, from forming my initial motivations to conducting my research and to making links with other researchers and potential key stakeholders in the field. The review continued in parallel with the inquiry and informed on my interpretation of the findings, as well as possible ways of addressing the findings through action. It was therefore hard to place within the Thesis final structure as there was a continual engagement with the literature throughout the research process. The reader should be mindful that this is in keeping with the methods of a Hermeneutic literature review.

In my person-centred care should exhibit examples of a more holistic approach to health care. I was therefore keen to see if these approaches had been employed by other studies, or if they had been found within the published evidence base from accounts of participants. Through employing a critical perspective of the literature I now present an overview of the experiences of LGB persons in receipt of cancer care in many western countries, and by demonstrating my own values, I am able to present a balanced narrative in the chapter whilst improving my own knowledge.

Defining Person-Centred Care

Generally, in order to deliver true person-centred care, professionals should work together with service users and those that are most important to them (Santana et al 2018). The Health Foundation (2016) also suggest that good person-centred care should work collaboratively with people to develop the knowledge skills and confidence they need to make informed decisions about their healthcare and how this is managed. Despite this, there appears to be a wide array of different uses and terminology of person-centred care and this makes searching for appropriate literature in this area a challenge (Dewing et al 2015).

Many health and social care providers will use the term ‘person-centred care’ to describe a situation where the individual in receipt of treatment or intervention is central to the process or practice of care delivery (McCormack et al 2011a). Alternative terminology is also used to describe similar visions of care and is used frequently and interchangeably with person-centred care, including patient-centred care, woman-centred care, relationship-centred care and client-centred care (McCormack et al 2011a).

Throughout my research I have been drawn to the McCormack and McCance (2016) definition of person-centeredness. They have worked to develop this through their own research by establishing a person-centred framework for clinical practice. Although the framework is international, it has informed local policy within Scotland and their definition of person-centred care has been central in developing the Scottish Government’s healthcare policy (NHS Scotland 2011). The Scottish Health Service national policy states that care should be safe, effective and person-centred as part of the NHS Scotland quality improvement programme (NHS Scotland 2015).

I was also drawn to McCormack and McCance's research work through attending practice development schools that have been devised to improve healthcare teams' workplace culture, learning culture, and the physical environment in person-centred ways (McCormack et al 2011b). The use of the practice development schools to improve teams includes the use of emancipatory methods to ensure that people are heard and that their values are taken into consideration when developing practice. As such, these methods and underlying philosophical frameworks appealed to me and my own values as a practitioner, educator and leader in my profession.

The term 'person-centredness' is not new, and is a concept that has its origins within humanist philosophy (Rogers 1980 and Heron 1992). McCormack and McCance (2016) offer the following international definition of person-centredness in clinical practice:

> *"Person-centredness is an approach to practice established through the formation and fostering of healthful relationships between all care providers, service users and others significant to them in their lives. It is underpinned by values of respect for persons (personhood), individual right to self-determination, mutual respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development".*
>
> (McCormack and McCance 2016)

The Person-centred Practice Framework originates from The Person-centred Nursing Framework (PCNF) where McCormack (2003) combined his conceptual framework examining person-centred practice with older persons, and Tanya McCance's (2003) framework which examines patient and nurse experience of care in nursing. The framework was comprised of the following four domains of practice:

- Prerequisites focus on the attributes of the nurse.
- The care environment focuses on the context in which care is delivered.
- Person-centred processes focus on delivering care through a range of activities.
- Expected outcome is the result of effective person-centred nursing.

Since the development of the framework, it has been updated to be multi-professional in its use (McCormack 2020) and the newer version of the framework McCormack (2016) can be seen in figure (6.1)

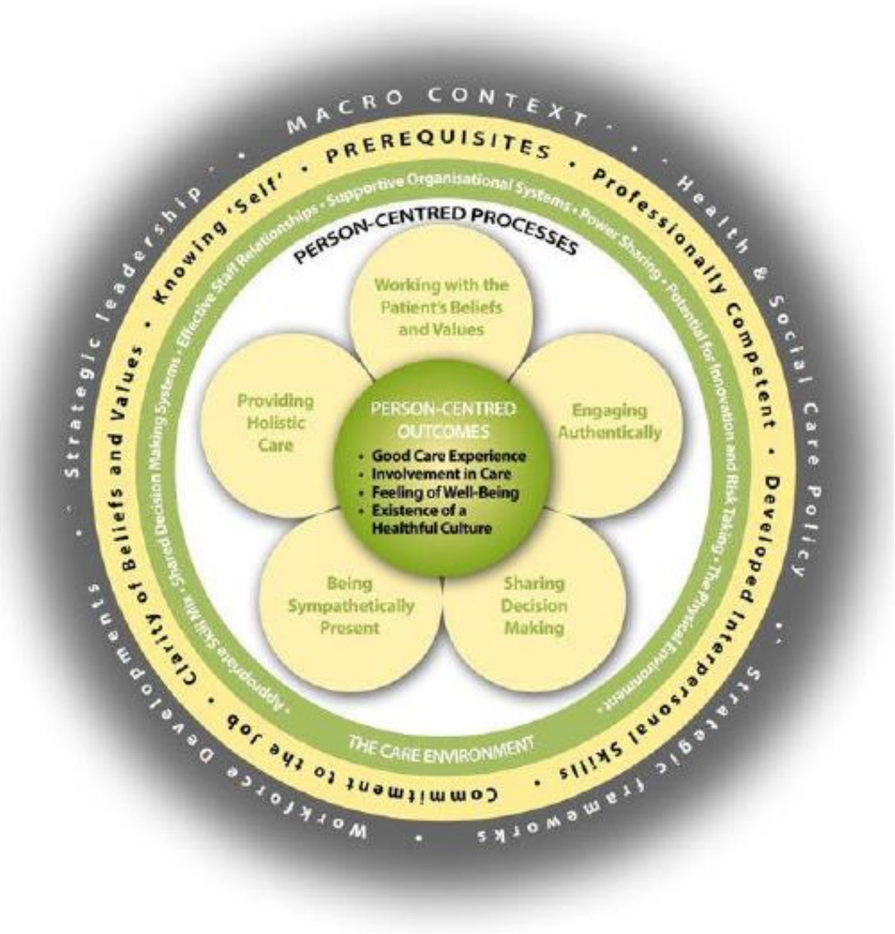


Figure 6.1 McCormack and McCance Person-centred Practice Framework 2016

(Shared with permission)

Narrative review – Person-centred care in cancer

For the purposes of exploring and identifying key research examining person-centeredness in cancer generally, and the transformational effects of cancer broadly, the first part of this chapter takes the form of a narrative review. A wide-ranging literature search was undertaken using key databases such as CINAHL, MEDLINE and Science Direct, using the terms patient-centred care, relationship-centred care, client-centred care, oncology, cancer, neoplasm, change, and transformation. The articles were then reviewed and content analysed to provide an overview of key research undertaken within these fields.

Articles included in the narrative review were then discussed against The McCormack and McCance Person-centred Practice Framework (2016). Specifically, working with the patient's values and beliefs, engaging authentically, shared decision making, being sympathetically present and providing holistic care; however it should be noted that these processes often operate in synergy and there can be overlaps, and as such the literature discussed has elements of crossover (McCance and McCormack 2016).

Patients' values and beliefs through authentic engagement

A central tenet to delivering person-centred care is working with people in a manner that recognises that they are distinctive human beings (Manley et al 2011). In practice, this means that it is necessary to understand that people accessing health services will be from a variety of backgrounds, and that each individual will in themselves have a distinct set of values and beliefs (Broderick and Coffey 2013). In order to be assured that health services are person-centred it is necessary for the health provider to make active steps to work with a person's distinct values and beliefs (Moody et al 2018).

In the first article included in this narrative review, I have chosen to draw attention to a piece of Australian research whereby Kaur et al (2018) undertook an evaluation of the communications skills of oncology nurses who work with patients from minority backgrounds. The authors developed the use of an Effective Cultural Communication in Oncology (ECCO) website as a means of improving the overall cultural competence of staff across the unit. The tool was not focused on supporting patients from a particular community, but rather developed oncology staff skills in working with people from different backgrounds from their own and enabling the staff to acknowledge their own cultural biases. The website consisted of four modules that took approximately two hours for team members to complete. Staff were then invited to complete a post intervention questionnaire within two weeks, and then again three months after accessing the training. Eight questions with Likert scale responses asked participants to assess their level of satisfaction with the intervention, which included: relevance, usefulness, and acceptability. One hundred and eight professionals completed the training, demonstrating wide uptake within the team, and the authors determined that the sample size necessary to evaluate statistical significance with sufficient power should be at least 35 completed post-intervention evaluations. Unfortunately only 54 people responded to the survey, 53 of whom were oncology nurses. As such the authors focused the evaluation on that staff group only, but it should be recognised that wider staff groups also participated in the training. Thirty-two percent of the oncology nurses had received some previous cultural training in the past, and demographics were recorded, revealing that all of the participants identified as female, with 75 percent being born in Australia.

Results revealed that perceptions of it being the responsibility of the health care team to adapt to the needs of persons from minority backgrounds increased significantly from baseline (mean = 22.3, SD = 3.6) to the second follow up (mean = 25.4, SD = 2.3, $X^2 = 8.75$, $P = 0.01$). In addition, participants reported a significant positive improvement in their ability to work with people with limited English language abilities with the score increasing significantly ($X^2 = 13.29$, $P < 0.001$) from 25.5 (SD = 2.3) to 27.9 (SD = 1.3) and 28.3 (SD = 1.4) as the first and second follow-up respectively. Limitations of the research include the fact that the intervention was taken up by a variety of professionals, but only one oncologist, and that the nurses were the only ones to provide full evaluations within the specified time scales for inclusion within the analysis. In addition, the evaluation was self-reported by the participants, rather than being independently evaluated. The authors also suggest that if a randomised controlled trial was undertaken then a better evaluation of the intervention could be undertaken. Despite these limitations, the published paper indicates an area of practice development that the oncology team attempted to undertake to improve service-wide change to support people accessing oncology from different and minority backgrounds.

A particularly thoughtful paper uncovered in this review, published by Canadian colleagues, demonstrates a commitment to developing an authentic connection between practitioners and patients, as advocated by McCormack and McCance (2016). Calisi et al (2016) obtained the views of staff members and patients in their oncology facility about what their understanding of person-centred care meant to them. Calisi et al (2016) conducted a qualitative inquiry with two distinct phases. The first phase one of the research invited staff, patients and visitors to write on large wall mounted pieces of paper to define what ‘person-centred care meant to them’. The second phase followed up with 120 paper-based questionnaires with open ended questions seeking further clarification of what is understood by the term person-centred care. Forty-four responses from a range of staff across the unit, and eight patient replies concluded that person-centred care is caring, compassionate, and empathetic. The staff asserted that the central focus of care should be the person and their focus should be catering to their individual needs. Limitations of the research include the small sample size, and the respondents may not have been representative of all the individuals that use the facility. As the research was conducted in one facility the findings may not be transferable to others. However the method of establishing what is important to patients in oncology is transferable to other facilities. This research demonstrates a commitment towards engaging users in their care by supporting them to define what person-centred care is. The outcomes have then supported staff within the facility to provide what is most important to people affected by cancer who are attending appointments without making assumptions about what people want. Furthermore, the barriers between the staff members and patients have also been broken down by engaging the wider team as well as the patients in addressing this question.

In another article considered in this review, Mills (2018) attempts to demonstrate the importance of working with patients’ values and beliefs when treating patients with oropharyngeal cancer. McCormack and McCance (2016) describe how it is necessary for the health provider to work with what people value in life, and how they make sense of their experience of healthcare. Mills (2018) provides an overview of how they attempted to do this by working on an individual basis with a variety of patients to establish what they valued most about the care they received. Mills (2018) presents an overview of a single case where they interviewed a 70 year old lady who had required surgery for head and neck cancer presenting on her tongue three years previously. The interview was undertaken thirty six months post treatment, and recall bias is noted as a potential limitation of this research. Although a sample size of one is small and hard to draw conclusions that are transferable, the main motivation for conducting the work one-to-one was to illustrate the importance of providing individualised care. The participant in the research provided an overview of their experience, highlighting that continuity of care should always be preserved for patients where possible, and this was the single most important aspect of treatment when addressing her values and beliefs. The researcher demonstrated the importance of working with peoples’ values and beliefs, but did not provide an indication of the analytical tools used to analyse the transcripts of the individual participant, nor was there any attempt to be able to discuss what was important to a wider range of patients. The demographics of the participants involved in the research focused on age and gender, but did not incorporate any aspects of religious beliefs, sexual orientation, or background. This article is useful as a case study to demonstrate the individual needs of someone that needed to be taken into consideration with their treatment, but it is hard to draw wider conclusions that can apply to more than one patient. However, the importance of being able to do this is questionable in person-centred research methods (Baraas et al 2017). This article was included in this narrative review to contrast with the article by Kaur et al (2018), and to highlight some of the issues with person-centred research in terms of their wider findings and impact, but demonstrates a commitment at a service level to work with individuals to establish what is important to them in their care.

Shared decision-making and sympathetic presence

Shared decision-making is a means of involving people in the key decisions of their care, as well as those that are most important to them (McCormack and McCance 2016). Bomhoff-Roordink et al (2018) developed a shared decision-making model around cancer treatment in the Netherlands, which involved wide stakeholder engagement, and was informed by the literature. The researchers interviewed a total of 76 key stakeholders, which included cancer patients, potential future patients, oncologists, nurses and researchers. The authors recognised that their healthcare system had the potential to be paternalistic, and as such were keen to seek opportunities to develop further shared decision-making in their oncology settings. Purposive sampling was used taking into account a mix of gender, age and education. However other characteristics such as sexual orientation and race were not recorded indicating a potential weakness or bias. Persons who were identified as being potential future patients were classed as those that were entirely cancer free and over the age of 30. In addition, the researchers specified that those identified as being potential future patients shouldn't have had anyone who was significant to them affected by cancer within the last six months. Interviews lasted approximately 30 to 60 minutes, with some patients opting to have a support person with them. Each interview was recorded and transcribed verbatim. Three coders analysed the transcripts of the various participant groups and coding was devised inductively.

The results of Bomhoff-Roordink et al (2018) indicated that oncologists should be placed in a role of determining possible treatments, highlighting the importance of the patient's opinions with regards to their treatment options, and attempts should be made to get to know patients' values using guides. The participants highlighted the importance of having the opportunity to be able to express thoughts and feelings, the time to consider various treatment options, and the ability to decide treatment decisions for themselves or delegate the decisions to the oncologist. This research demonstrates the expectations of both care providers and patients in the shared decision-making process within oncology. Unfortunately the research doesn't make explicit the selection process, and how individuals were contacted in order to be able to participate within the research.

McCormack and McCance (2016) describe being "sympathetically present" as where a practitioner responds actively to a patient's emotional and physical state in the moment. Controversially, they argue that empathy is undesirable within the healthcare setting, as this isn't transferable to others, and it is impossible to truly comprehend another person's experience. Sinclair et al (2017) conducted research to investigate the experiences and preferences of patients who have advanced cancer to inform in clinical practice. Specifically, the researchers examined staff and patient understandings of sympathy, empathy and compassion, and how these were connected. McCormack and McCance's (2016) framework calls on practitioners to employ the use of a sympathetic presence, and this isn't without controversy as many researchers and health professionals prefer to indicate that they convey empathy towards those in their care, and thus demonstrate a greater depth of compassion (Van der Merwe 2016). The inclusion of Sinclair et al's (2017) work in this review helps to provide a differing perspective to McCormack and McCance (2016) and explores how this has been used to assess oncology workforce and patients' perspectives and views.

Sinclair et al (2017) collected data through the use of semi-structured individual interviews. There were then independently analysed by the research team using grounded theory. There were a total of 53 participants within the research that were recruited from one large urban hospital in Canada. In order to reduce bias, interviews were conducted by a research nurse in private spaces within the hospital away from oncology, with each lasting approximately one hour. All interviews were then recorded and transcribed verbatim, analysed using grounded theory, through open, axial, and selective coding, to investigate the relationship between sympathy, empathy and compassion. The results indicated several themes, with those in receipt of care preferring compassion to empathy, and identifying overlapping themes with each concept. Interestingly, participants in the research identified that sympathy was very distinct from compassion and empathy, with sympathy being viewed to be a construct of largely pity and a lack of understanding. Participants felt that those who demonstrated empathy generated a greater connection to the person, rather than just engaging in someone else's suffering. Participants believed sympathy positioned healthcare professionals as outsiders, and empathy placed practitioners alongside those in receipt of care. This study highlights the importance of the use of language related to practitioners working alongside those that are in receipt of care. The authors highlight that empathy has possible issues, such as the potential to contribute to burnout of oncology staff.

Sinclair et al (2017) provided a breakdown of participants' demographics, showing that 72% were educated to a university level and so indicating that the participants may have a greater understanding of nuances within the constructs being investigated. In addition the vast majority of the participants within this research were women with partners, demonstrating some potential issues around the diversity of the sample. Religious views were captured indicating that half of the participants were spiritual or religious, providing further insight into the philosophical perspectives that some of the participants may have had around care giving behaviours; however ethnicity and sexual orientation were not captured as part of the participants' demographics.

Providing holistic care and transformation effects of cancer

McCormack and McCance (2016) state that providers should ensure that all treatment offered pays due diligence to the person as a whole, and that someone's care should take into account the physiology, psychology, and spiritual background of the individual. Rose and Yates (2013) conducted a case study of their team's perceptions of implementing a person-centred care model in their outpatient radiotherapy department in Australia. The model was used as a means of demonstrating the working practices of the department that were established to ensure that patients’ holistic needs were taken into account throughout their treatment pathways. However, little detail is provided on how this was applied within the clinic. The model of care is stated to have developed from the Delbanco et al (1993) person-centred practice framework, and the authors were keen to examine the factors that impacted on its evolution within the day-to-day setting of the unit and to establish if there was interest amongst the staff in developing a newer model. The research was intended to employ a case study design over a six-month period and then one year after the implementation of the person-centred model of nursing practice. Semi-structured interviews were conducted with 13 radiotherapy staff and managers. Three separate interview schedules were devised for different professional groups, which included nursing staff, radiation therapists, managers, oncologists and allied health professionals.

Rose and Yates (2013) carried out a content analysis to evaluate the interviews, which involves the researchers extracting visible and obvious components in interview data as well as interpretations of the textual data. Audio recordings were transcribed verbatim and the analysis identified several themes related to developing staff practice in the use person-centred models. Specifically the authors reported the need to challenge practices and overcome engrained profession-centric models within the clinic, as well as the need to further support the primary nursing team to engage in a multidisciplinary approach with a new design model. The data highlighted some gaps in continuity of patient care, with professionals not accepting full responsibility for the holistic care needs of patients. In particular radiation therapists commented about the lack of information that was provided to patients in advance for their radiotherapy, and this was attributed to time management problems that the nurses experienced. As a result, the research highlighted a lack of consistency of care between the different professional groups, particularly when relaying pertinent information about patients and what they need to take into consideration with regard to their care. Staff within the unit felt they provided good holistic care for patients overall, but there were missed opportunities to make sure that the needs of all patients were carried through the system. The research suggests that moving to a person-centred model of care offered potential advantages to patients, but there is very little information provided within the research in relation to the demographics of the participants within the case studies. Furthermore, there is little information provided about the dates and timing of when the new model of person-centred care was introduced within the oncology clinic, indicating that some members of staff may be more experienced with using it than others. Although Rose and Yates (2013) provide little detail about how their adopted model of care is used with patients directly, they did highlight some of the wider issues to be considered when trying to address holistic needs within care systems and procedures within the service as a whole.

Holistic needs assessments have been advocated for use within cancer services in the UK since 2013, and are seen as necessary to provide the opportunity for people to see how cancer affects their lives and establish any support needs they may have (National Health Service Improvement 2013). The tool devised in partnership with Macmillan enables both the care provider and the person with cancer to discuss the effects that diagnosis and treatment may have on their wellbeing, as well as taking into consideration the things that matter most to them (Macmillan Cancer Support 2012). The assessment tool should be conducted at the point of diagnosis but then also revaluated throughout the person’s cancer journey (Young et al 2015). This presents a challenge to ensure that the completed tool follows the person and that all professionals involved in the person’s care are able to access the tool’s findings. However, when used effectively the holistic needs assessment provides an excellent opportunity to take into consideration the various physiological, psychological and spiritual dimensions that could be affected by cancer to then provide better support.

Boyko (2018) provided details of how they conducted a narrative enquiry with six adult breast cancer survivors to examine the transformational effects of cancer on learning. The six women were asked to participate in the research to establish more information about the emotional and cognitive needs of a person affected by cancer. Data collection involved the use of methods such as semi-structured interviews and journal notes made by the researcher. Thematic analysis was undertaken of textual data transcribed from the interviews, and the use of arts-based artefacts, such as photos, were used as a means of supporting the participant to reflect. This article has been selected for use within this narrative review given that it uses a similar method to my own.

Results indicated that participation in the research was empowering to some degree to the participants, as it was important for them to be able to be understood by somebody who knew how cancer worked. This helped to validate their experiences and to support and help others who are affected by cancer that were involved in the research project. The researcher commented that the use of arts-based artefacts allowed a deeper exploration of what matters most to the participants. Key findings suggested that the participants’ emotional needs related to common experiences of frustration and uncertainty, shock and distress, fear of recurrence, and a sense of responsibility. Boyko (2018) reviewed the transformational aspects of learning that applied to these particular research participants and noted examples of experiential learning, observing that the participants became disoriented by the shock of diagnosis with an evolving feeling of how they viewed the situation. They found it beneficial to be involved in their own care, to be able to learn more information about managing the side-effects and process pain, fatigue and anxiety fully. All these capabilities required the time and space to reflect, with some participants remarking that they have grown in confidence.

Boyko’s (2018) research had several limitations, such as the potential for bias, as the authors conducted the interview questioning as well as taking observation notes and creating the transcripts without verification. The use of snowball sampling as a sole means of finding participants means that those recruited into the research had more potential to identify other people who had similar feelings and beliefs. I have taken this into consideration in my own research, which is discussed more in my methodology chapters. Snowball sampling is only one of several tools that are employed in sourcing participants. In addition, I have also felt that it is important to be able to establish what is important to the participants, rather than cast my own views on this, and have afforded the opportunity at several points throughout the research for people to comment on their own data and on the researcher’s overall findings. This reduces the overall bias that can be present within qualitative research and offers advantages of having a participatory design. It should also be noted that all the participants in Boyko (2018) research were white, English-speaking and heterosexual, indicating a lack of diversity within the sample.

Focusing on the transformation effects of cancer treatment in terms of learning about themselves and their own health, Boyko (2018) concludes that most people don’t have in-built experience or skills to take on the challenges of their own care for cancer. The diagnosis and treatment signifies a crisis and people will do the best they can to absorb this. With information and emotional support persons are able to make decisions regarding their care, although many will feel caught up with what is thought to be best. It is for this reason that continual dialogue is needed for the learning to be transformational and effective. Boyko (2018) focused on the information and support needs of cancer rather than the transformation effects cancer can have on relationships.

The existential changes that someone may experience as a result of cancer are explored by Uleland et al (2021). Their research was carried out with a group of 21 cancer survivors from Norway to examine how experiences of cancer effected their existence, seeking to move beyond the biological effects and examine this phenomenon in a holistic way. The research employed a phenomenological hermeneutic design, which involved in-depth interviews with participants with a variety of cancers which were treated 5-10 years ago. The participants were recruited from a local support group which provided support and counselling and guidance to those affected by cancer. The interviews aimed to ask participants about their lived experiences and the authors sought to introduce a different perspective on life for those involved. Semi-structured interviews were designed to encourage reflection on the interviewee's own life situation and how cancer had affected this. Follow-up questions were then used to establish what was most important for the participants' lives now. Each interview lasted approximately an hour and a half and was conducted in the cancer support group's building. Interviews were transcribed verbatim and the text was analysed by the interviewer for 'self-understanding', then the data were subject to a 'common sense' evaluation by the participants, and finally the theoretical interpretations were arrived at through applying a life world theoretical lens which was selected by the researcher. The participants outlined three areas in which they felt that their lives are changed the most: experiencing unfamiliar tiredness, experiencing not being fully oneself, and experiencing the feeling of being alone. Participants remarked that they found themselves in a challenging situation after they completed their initial treatments, where they became uncomfortable with themselves, and found it hard to accept their situations. The participants also remarked that they struggled with day-to-day encounters in their outside world, and most struggled with what they described as an unmanageable situation after being declared healthy. The researchers acknowledge the limitations of the work, such as the use of purposeful sampling through a local cancer support group. This meant that the participants may have been more accustomed to discussing the effects of treatment openly than cancer survivors generally. The researchers also acknowledge the various cancers and treatments that the participants had, and that these varied quite significantly. However, they note that the goals of the research were to establish the effects of cancer treatment and to go beyond the biomedical perspective. As such they feel that the research is applicable to people with all types of cancer.

Summary of Narrative review

Cancer is known to be a life-changing disease with significant impact on long-term quality of life (Ganz et al 2002). These implications can have long-lasting effects and can change the way people feel about themselves and others (Hawkins et al 2009, Barnard et al 2016). From the research discussed it is clear that person-centred care is starting to be evaluated within the oncology care setting, and there are some contemporary research studies examining the transformational effects of cancer. The literature uncovered in the narrative review is useful in demonstrating the positive and negative aspects of person-centred care, but fails to address sexual diversities, or deficiencies in care. The next area of the chapter then focuses on this specifically in the context of LGB persons.

Critique of Hill and Holborn (2016)

As part of demonstrating that I now have a different theoretical lens with which to view others' research, I have gone back to the original article that I published in 2016 whilst undertaking an MSc in Radiotherapy. Despite the original work being valuable in generating and fuelling my interest in this subject area, there are limitations that should be noted, and I have produced a short critique of the original publication. This is so that I can illustrate the changes made and differentiate the academic work streams more specifically by showing that I built on my master's level work and advanced it to doctoral level. In addition, I have developed my thinking within this field and wish to demonstrate the progression of my understanding of this topic.

The original article Hill and Holborn (2016) was published following a systematic review undertaken by the authors that was focused on establishing the experiences of cancer treatment for sexual minorities. Key databases were searched for peer-reviewed original articles published since 2005 uncovering a total of twenty five papers that were analysed and themed within the following areas: Experiences of care (n = 6), Coping and Wellbeing (n = 6), Emotional Support (n = 4), Body Image (n = 3), and Sexual Function (n = 6).There was a conscious decision in the original review to focus on the treatment and care aspects of cancer patients' pathways rather than diagnosis or screening, and this was maintained in the new review to provide a degree of focus and to assist in informing the PhD Research aims and objectives.

The Support Unit for Research Evidence (SURE 2013) critical appraisal tool was used to assess eligibility for inclusion within the review. However, in the final peer reviewed publication the articles arguably lacked specific detail about the appraisal undertaken of the individual articles that were included and there was a need to go back and re-appraise the literature selected as well as to make explicit study methodologies limitations and strengths. There was a rigorous search strategy encompassing both scientific and social science databases in the original article, and in order to conduct as wide a search and include as broad a range of results as possible, it was determined the same approach in the selection of databases should be maintained. The original article examined LGB people's cancer experiences ranging back to 2005. This presents a challenge when society's attitudes towards homosexuality are ever evolving and rapidly changing within western cultures, and so a more rigorous approach to continually engage with the literature was required throughout my PhD journey. This represented a significant change between the two reviews both in the search methods and the ongoing addition of recent literature and developments. A hermeneutic approach that advocated continual familiarity with the literature was adopted in the revised review for this reason and is discussed within the search strategy section of the literature review chapter.

Search terms were modified to include person-centred literature rather than examining the topic from a purely patient perspective. It is in this area where my thinking has developed the most since my MSc and I have now opted to develop my own practice as a healthcare professional to be less paternalistic and more enabling, seeing the people that use cancer services as ‘persons’ rather than ‘patients’. However, the revised literature search didn’t uncover any articles that were written using person-centred language in the context of LGB people in receipt of cancer care, further highlighting the novelty of this research.

One further challenge of reviewing literature within this field, which occurred in both reviews, was the plethora of different terminologies that are used to describe Lesbian Gay and Bisexual persons. At the time of the original review I opted for the term “sexual minority” to capture those articles that related to Lesbian, Gay and Bisexual people or those that do not wish to be labelled. However, as a PhD researcher I have reflected on this and have opted to refer to the study population as Lesbian, Gay and Bisexual (LGB). This also has limitations as discussed in my previous chapters on Queer Theory, although LGB is a classification that is recognised and used within the UK, and therefore I have updated my literature review to be reflective of this change in my own practice when reporting my findings.

In the original article, the authors make reference to worldwide literature, but having re-examined this phrase it is clear that this assertion is hard to maintain and that only articles that were published in or translated into English were included within the first review. Examining the demographics of the articles in the final publication, it is evident that all were published in the western world, and in particular North America and Australia. It was noted that there is a great variety in relation to the laws and social attitudes that affect LGB people across these countries and worldwide, and this served as further justification to go back and see; to explore where there had been any developments within the UK specifically related to LGB research in the field of cancer care. I was aware that several other researchers were active in this area within the UK, who were both due to publish results of their own work. This approach highlighted that there were as yet unpublished articles that were of key interest to me as a researcher working in the UK in a rapidly developing field. These articles were unable be included in the original review, and there were very few publications uncovered that originated from the UK and Ireland.

Both reviews have been successful in demonstrating contrasting experiences of LGB individuals undergoing cancer treatments with distinctive perspectives on how their care differed. The articles uncovered tended to focus on negative and discriminatory care experiences but were limited in that they didn’t fully address why this might be the case. The revised review within this thesis sought to have a more continual engagement with the literature, and a greater degree of critique that was wasn’t published in the original.

Systematic Review – LGB peoples experiences of cancer care

For the second part of the literature review, I have adopted a Hermeneutic process as described by Boell and Cecez-Kecmanovic (2014) as a method of moving between individual papers and the whole body of literature revealed in my search to then seek patterns in the findings. The hermeneutic approach to literature reviews differs from more traditional formal narrative or systematic reviews (e.g. Cochrane reviews). Traditional narrative or systematic literature reviews critique and summarise a body of literature about a thesis topic, but are more fixed in their approach, being very specific, and often missing late breaking work or articles that may not meet rigid inclusion criteria but are still pertinent to the field of study (Egger et al 2001). For the purposes of my research, I have deemed it necessary to have a more continual and iterative approach to gathering and appraising the literature. A Hermeneutic approach works well for this as my research is focused in a new and emerging field along with changing societal and social attitudes towards sexual orientation which can develop and evolve quickly.

In addressing the lens through which I view the literature uncovered in this review, it is important to note that I am influenced by the health care environment in my practice as well as my ontology and commitment to person-centred principles. As a practicing health care professional leader based in Scotland I am mindful of the implications that the literature uncovered in this review may have for practice and policy, as well as the potential to inform the practitioner guide derived from this research. In my PhD research I argue that one’s sexual orientation forms an integral part of one’s personhood and self-determination. As such, in order for healthcare staff to deliver person-centred health care priorities, there should be examples of staff employing a holistic approach to care that recognises the distinctiveness of LGB persons within the literature. As such the literature review findings will be discussed in the context of the Person-centred Practice Framework and my own views on person-centredness outlined in my previous chapters.

Aims

A Hermeneutic review encompassing the worldwide research literature base to evaluate, assess and obtain a perspective on LGB person's experiences of cancer care and approaches used by researchers and practitioners to establish this.

Objectives

The following objectives were established at the outset of this review and align to the overall objectives of my research:

1. Find out any distinct aspects of interactions, or care experiences of LGB persons with cancer.
2. Critically review the current evidence base relating to cancer treatment and care tailored for persons identifying as LGB.
3. Critically evaluate and discuss evidence uncovered through a person-centred lens and identify any examples of good or bad/poor practice

4. Critically evaluate the methodologies and approaches undertaken in the exploration of LGB cancer survivors experiences to inform my own methods and understanding.

Search Strategy

The Boell and Cecez-Kecmanovic (2014) Hermeneutic Framework was adopted for the second part of this review. The Hermeneutic Framework is described as iterative and focused on developing an understanding and meaning of the topic being investigated (Boell and Cecez-Kecmanovic 2014). Using the Hermeneutic Cycle, I conducted my review in two phases, the first focused on the acquisition and searching of the literature in the following seven step cycle:

- Searching,
- Sorting,
- Selecting,
- Acquiring,
- Reading,
- Identifying,
- Refining.

During the course of the search and acquisition phase, is was necessary also to engage with the literature through a second phase of analysis and interpretation of the articles uncovered. This could result in a return to further searches as described in phase one. The analysis and interpretation phase is broken down into the following constituent parts:

- Classifying and mapping,
- Critical assessment,
- Argument development.
- Research problems/questions.

The Hermeneutic approach is underpinned by a need to continually engage with the literature, and then to develop understanding and insights of the wider field through the gradual development of understanding by the researcher.

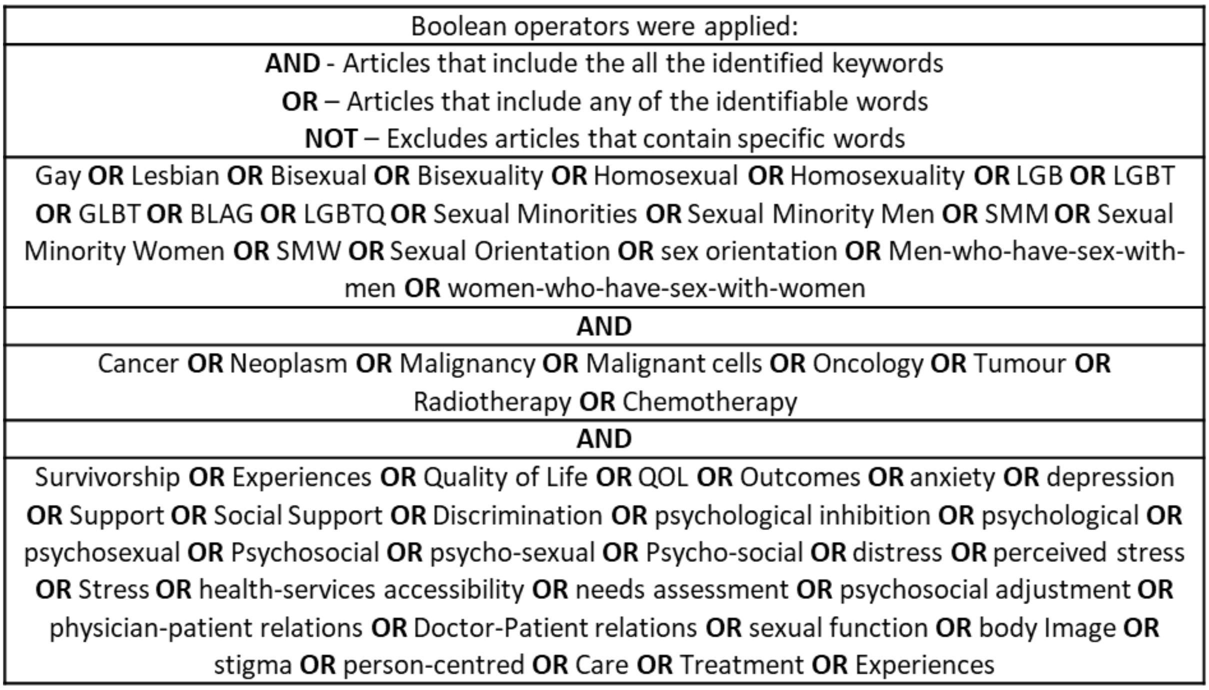
The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flowchart was used as a means of recording the numbers of articles uncovered through the search process as this is a widely accepted tool to report results of a literature review in research (Moher et al 2010). The final version of the PRISMA template is available within the appendix (see appendix two).

Several social and health science databases were searched to identify peer reviewed literature and assessment for inclusion within the review. These included:

- The Cochrane Library,
- Medline,
- Embase,
- CINAHL,
- AMED,
- Science Direct,
- ASSIA database.

I made the decision to search a large range of databases that included both medical and social science libraries. This was because I felt it was important not to restrict searches to solely medical databases as many of the research papers in this field may have related to social science concepts when examining how sexual minority cancer survivors behave and react.

Table 6.1 demonstrates the key search terms identified that related to LGB health and oncology.



Boolean operators were applied:
AND - Articles that include the all the identified keywords **OR** – Articles that include any of the identifiable words **NOT** – Excludes articles that contain specific words
Gay **OR** Lesbian **OR** Bisexual **OR** Bisexuality **OR** Homosexual **OR** Homosexuality **OR** LGB **OR** LGBT **OR** GLBT **OR** BLAG **OR** LGBTQ **OR** Sexual Minorities **OR** Sexual Minority Men **OR** SMM **OR** Sexual Minority Women **OR** SMW **OR** Sexual Orientation **OR** sex orientation **OR** Men-who-have-sex-with-men **OR** women-who-have-sex-with-women
AND
Cancer **OR** Neoplasm **OR** Malignancy **OR** Malignant cells **OR** Oncology **OR** Tumour **OR** Radiotherapy **OR** Chemotherapy
AND
Survivorship **OR** Experiences **OR** Quality of Life **OR** QOL **OR** Outcomes **OR** anxiety **OR** depression **OR** Support **OR** Social Support **OR** Discrimination **OR** psychological inhibition **OR** psychological **OR** psychosexual **OR** Psychosocial **OR** psycho-sexual **OR** Psycho-social **OR** distress **OR** perceived stress **OR** Stress **OR** health-services accessibility **OR** needs assessment **OR** psychosocial adjustment **OR** physician-patient relations **OR** Doctor-Patient relations **OR** sexual function **OR** body Image **OR** stigma **OR** person-centred **OR** Care **OR** Treatment **OR** Experiences

Table 6.1. Key search terms used in systematic review

There are numerous terms that can be used to classify an individual’s sexuality. As such, a dictionary and thesaurus of terms was used to establishment this list to ensure as many articles were returned as possible that could relate to Lesbian, Gay and Bisexual persons. In addition, some of the articles uncovered in this review focused on LGB, Transgender and Queer persons, and where this occurs, I have used the appropriate acronym to reflect the scope of the articles findings i.e. LGB, LGBT, LGBTQ.

Articles for Inclusion had to meet the following criteria:

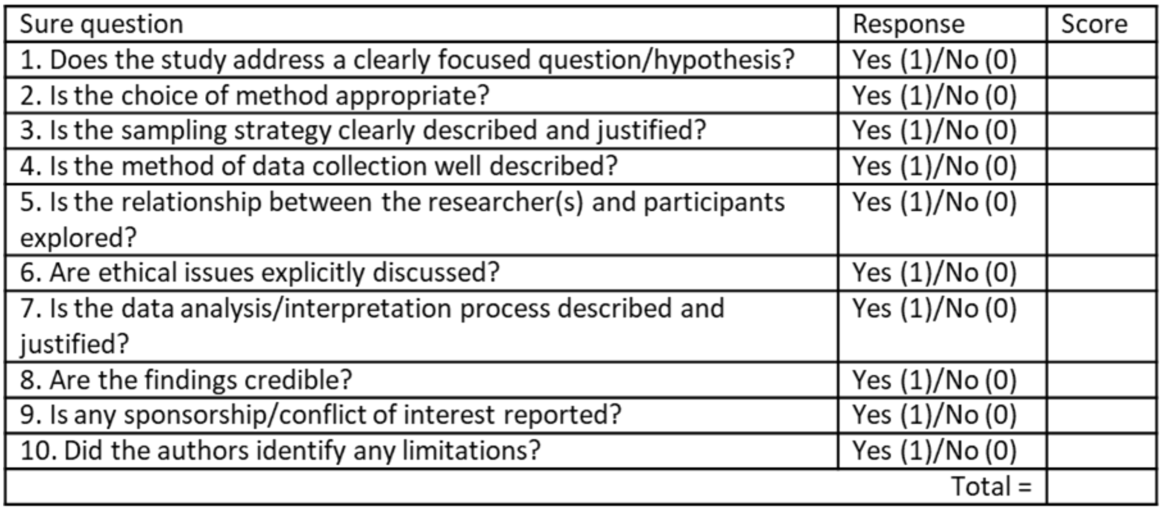
- English language only sources of literature, due to time limitations and insufficient resources to translate literature into English for review.
- Peer reviewed publications to ensure a sufficient degree of academic rigour and scrutiny had been applied to the sources prior to publication.
- Grey literature presenting primary studies that included otherwise unpublished research, or project reports, examining the experiences of care of LGB people affected by cancer treatment.

- Both qualitative and quantitative studies, although qualitative studies such as interviews and questionnaires were deemed especially important for inclusion when considering the experiences of care of LGB persons.
- A limit of papers that have been published within the last fifteen years at the time of the initial search (2019) was applied to increase the breadth of literature obtained from this small topic area.

Articles were automatically excluded from the study based on the following:

- Non-English language sources of literature due to resources available.
- Any paper over the age of 15 years from (2019). The change in LGB rights in Western Europe has been relatively quick and as such experiences over fifteen years may not represent a true picture of current LGB experiences of cancer.
- Papers related to targeting screening programmes, HPV vaccination and health awareness in the LGB community as these are quite different subject areas and not the primary focus of my research.
- Meta-Analysis, narrative articles or systematic reviews were deemed unsuitable for inclusion, as they may omit information about primary research that is pertinent for my review. However, other reviews found were hand searched for original source articles that may have been missed in my own searches in order to provide as large a sample collection as possible.

Articles were then critically appraised using The Support Unit for Research Evidence (SURE) critical appraisal tool. The SURE tool was deemed the most appropriate critical appraisal tool due to its ease of application to both qualitative and quantitative articles (Appendix three). Scoring of the literature was undertaken using the SURE tool, where a ‘yes’ in the questions indicated a score of ‘one’, and ‘no’ provided a score of ‘zero’. Articles were given a total score out of ten and used the scoring card demonstrated in figure 6.2.



Sure question	Response	Score
1. Does the study address a clearly focused question/hypothesis?	Yes (1)/No (0)	
2. Is the choice of method appropriate?	Yes (1)/No (0)	
3. Is the sampling strategy clearly described and justified?	Yes (1)/No (0)	
4. Is the method of data collection well described?	Yes (1)/No (0)	
5. Is the relationship between the researcher(s) and participants explored?	Yes (1)/No (0)	
6. Are ethical issues explicitly discussed?	Yes (1)/No (0)	
7. Is the data analysis/interpretation process described and justified?	Yes (1)/No (0)	
8. Are the findings credible?	Yes (1)/No (0)	
9. Is any sponsorship/conflict of interest reported?	Yes (1)/No (0)	
10. Did the authors identify any limitations?	Yes (1)/No (0)	
	Total =	

Figure 6.2 Score card used for critical appraisal of literature

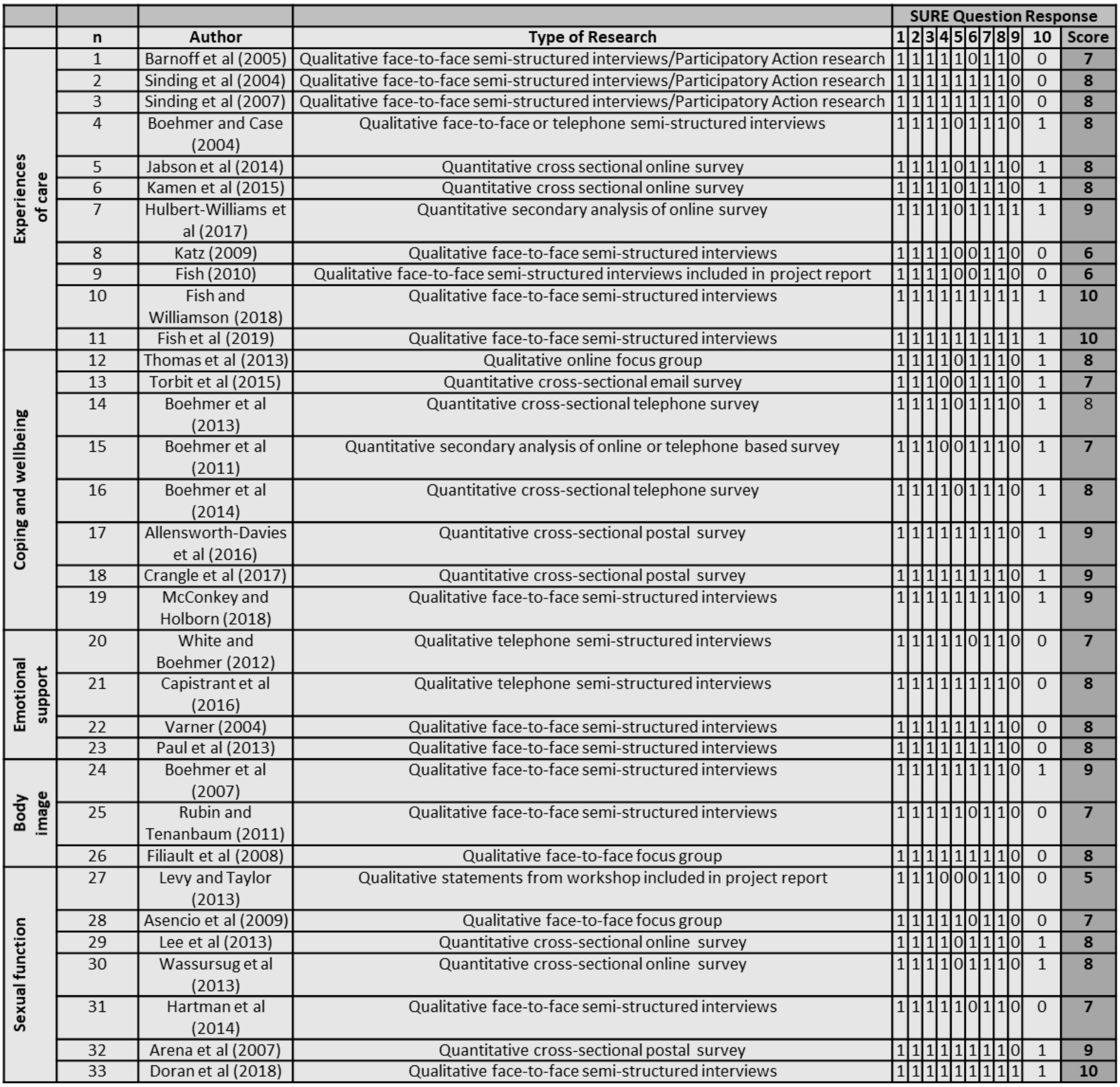
No minimum score for the SURE tool was established. After the appraisal of articles, literature was then analysed and coded by subject matter and then classified by the emerging themes as indicated in the hermeneutic process. Pearl growing of the literature was undertaken, whereby all research articles that met the inclusion criteria of the review had their reference and citation lists searched for other appropriate literature that met the inclusion criteria.

Grey literature meeting the selection criteria was also sought. To account for a potential publication bias, the authors of primary studies uncovered were then searched for using Google. Uncovered academic profiles and websites were then searched for any appropriate grey literature meeting this review’s inclusion criteria. In addition, searching was also undertaken for relevant materials on the Stonewall, Macmillan, UK Government, Queering Cancer, and Department of Health websites. The literature uncovered was then discussed in the context of my own theoretical lens and person-centred perspectives.

Results

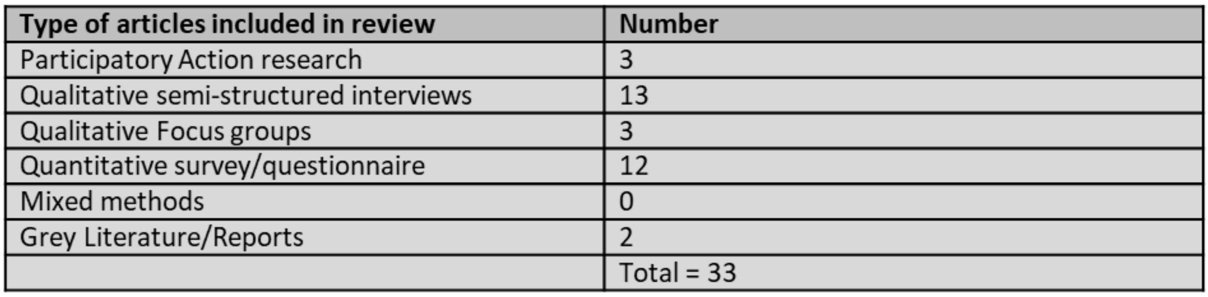
One-hundred-and-forty peer reviewed publications and *two* project reports from the grey literature were screened after the initial searches using the eligibility criteria above. This left *forty-four* articles to analyse using the SURE critical appraisal tool (Appendix three). Articles were then reviewed and *eleven* were rejected because they related to targeting health promotional programmes and cancer screening programs focused on LGB individuals, or were replicated studies and as such demonstrated duplicate results. *Thirty-one* peer reviewed studies and *two* project reports from the grey literature remained. The remaining total of *Thirty Three* articles were then analysed for this review (Appendix four).

The data extraction was carried out and revealed contrasting views and experiences of LGB individuals’ experiences of cancer care and this formed the body of the discussion of this chapter. The papers were categorised into the following emerging themes from the literature: Experiences of care (n=11), Coping and Wellbeing (n=8), Emotional Support (n=4), Body Image (n=3), and Sexual Function (n=6). The returned articles were a mixture of qualitative (n=21) and quantitative papers (n=12) with no mixed methods studies found. A full breakdown of each of the papers along with the SURE critical appraisal score are provided in table 6.2 and a summary of the literature type is provided in table 6.3. The themes then provided a structure for the discussion of LGB experiences of cancer care in this review. Themes were discussed more broadly against other literature and guidance within the fields of person-centred research and other evidence that relates to LGB research undertaken in other fields. I chose to include a broader discussion because the Hermeneutic model for reviews advocates moving between individual papers and the whole body of literature to seek patterns in the findings.



				SURE Question Response										
	n	**Author**	**Type of Research**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Score**
Experiences of care	1	Barnoff et al (2005)	Qualitative face-to-face semi-structured interviews/Participatory Action research	1	1	1	1	1	0	1	1	0	0	**7**
	2	Sinding et al (2004)	Qualitative face-to-face semi-structured interviews/Participatory Action research	1	1	1	1	1	1	1	1	0	0	**8**
	3	Sinding et al (2007)	Qualitative face-to-face semi-structured interviews/Participatory Action research	1	1	1	1	1	1	1	1	0	0	**8**
	4	Boehmer and Case (2004)	Qualitative face-to-face or telephone semi-structured interviews	1	1	1	1	0	1	1	1	0	1	**8**
	5	Jabson et al (2014)	Quantitative cross sectional online survey	1	1	1	1	0	1	1	1	0	1	**8**
	6	Kamen et al (2015)	Quantitative cross sectional online survey	1	1	1	1	0	1	1	1	0	1	**8**
	7	Hulbert-Williams et al (2017)	Quantitative secondary analysis of online survey	1	1	1	1	0	1	1	1	1	1	**9**
	8	Katz (2009)	Qualitative face-to-face semi-structured interviews	1	1	1	1	0	0	1	1	0	0	**6**
	9	Fish (2010)	Qualitative face-to-face semi-structured interviews included in project report	1	1	1	1	0	0	1	1	0	0	**6**
	10	Fish and Williamson (2018)	Qualitative face-to-face semi-structured interviews	1	1	1	1	1	1	1	1	1	1	**10**
	11	Fish et al (2019)	Qualitative face-to-face semi-structured interviews	1	1	1	1	1	1	1	1	1	1	**10**
Coping and wellbeing	12	Thomas et al (2013)	Qualitative online focus group	1	1	1	1	0	1	1	1	0	1	**8**
	13	Torbit et al (2015)	Quantitative cross-sectional email survey	1	1	1	0	0	1	1	1	0	1	**7**
	14	Boehmer et al (2013)	Quantitative cross-sectional telephone survey	1	1	1	1	0	1	1	1	0	1	8
	15	Boehmer et al (2011)	Quantitative secondary analysis of online or telephone based survey	1	1	1	0	0	1	1	1	0	1	**7**
	16	Boehmer et al (2014)	Quantitative cross-sectional telephone survey	1	1	1	1	0	1	1	1	0	1	**8**
	17	Allensworth-Davies et al (2016)	Quantitative cross-sectional postal survey	1	1	1	1	1	1	1	1	0	1	**9**
	18	Crangle et al (2017)	Quantitative cross-sectional postal survey	1	1	1	1	1	1	1	1	0	1	**9**
	19	McConkey and Holborn (2018)	Qualitative face-to-face semi-structured interviews	1	1	1	1	1	1	1	1	0	1	**9**
Emotional support	20	White and Boehmer (2012)	Qualitative telephone semi-structured interviews	1	1	1	1	1	0	1	1	0	0	**7**
	21	Capistrant et al (2016)	Qualitative telephone semi-structured interviews	1	1	1	1	1	1	1	1	0	0	**8**
	22	Varner (2004)	Qualitative face-to-face semi-structured interviews	1	1	1	1	1	1	1	1	0	0	**8**
	23	Paul et al (2013)	Qualitative face-to-face semi-structured interviews	1	1	1	1	1	1	1	1	0	0	**8**
Body image	24	Boehmer et al (2007)	Qualitative face-to-face semi-structured interviews	1	1	1	1	1	1	1	1	0	1	**9**
	25	Rubin and Tenanbaum (2011)	Qualitative face-to-face semi-structured interviews	1	1	1	1	1	0	1	1	0	0	**7**
	26	Filiault et al (2008)	Qualitative face-to-face focus group	1	1	1	1	1	1	1	1	0	0	**8**
Sexual function	27	Levy and Taylor (2013)	Qualitative statements from workshop included in project report	1	1	1	0	0	0	1	1	0	0	**5**
	28	Asencio et al (2009)	Qualitative face-to-face focus group	1	1	1	1	1	0	1	1	0	0	**7**
	29	Lee et al (2013)	Quantitative cross-sectional online survey	1	1	1	1	0	1	1	1	0	1	**8**
	30	Wassursug et al (2013)	Quantitative cross-sectional online survey	1	1	1	1	0	1	1	1	0	1	**8**
	31	Hartman et al (2014)	Qualitative face-to-face semi-structured interviews	1	1	1	1	1	0	1	1	0	0	**7**
	32	Arena et al (2007)	Quantitative cross-sectional postal survey	1	1	1	1	1	1	1	1	0	1	**9**
	33	Doran et al (2018)	Qualitative face-to-face semi-structured interviews	1	1	1	1	1	1	1	1	1	1	**10**

Table 6.2 Breakdown of the included literature types and SURE score



Type of articles included in review	Number
Participatory Action research	3
Qualitative semi-structured interviews	13
Qualitative Focus groups	3
Quantitative survey/questionnaire	12
Mixed methods	0
Grey Literature/Reports	2
	Total = 33

Table 6.3. Summary of type of articles included in review

Discussion

My review explored the LGB cancer experience across five broad areas that then provided a structure to the discussion section in this chapter. These areas were derived from the overarching themes of articles and were based on my initial review conducted for my MSc. Although my research is now focused on more person-centred principles, no articles that discussed issues of identity or personhood found within the literature review. As such the groupings arrived at for my MSc were still deemed appropriate means of categorisation, although the articles were looked at with a new lens related to my person-centred principles. In addition, new articles were also uncovered as part of this review and were categorised in the same manner to ensure parity. I discuss the themes critically to develop and inform understanding of the current LGB perspectives of healthcare and then determine any aspects of good or bad practice from which to learn.

My first theme is focused around **experiences of care**; this captures the views of LGB people in their day-to-day interactions with oncology staff and how they view the quality of their experiences and relationships with their care providers. The ideal experiences of care should not be distinctive from an LGB perspective, as each person should be treated as an individual. However, the literature revealed discriminatory aspects in the care of LGB persons as well as examples of where persons felt they could not be open and honest about who they are to healthcare professionals.

The area of **coping and wellbeing** also formulates a theme within this review and refers to how persons deal with problems or difficulties during their cancer journey. This includes emotional well-being, dealing with frustration and anger, mental health, and how cancer treatment has made the person feel. LGB persons should be able to feel safe and confident within healthcare systems, however the literature points to issues whereby LGB persons can feel isolated and without conventional means of support.

The need for **emotional support** is also discussed and is its own distinctive theme within this review. Research suggests that LGB persons are more likely to suffer with mental health issues and have poorer relationships with family origin and the communities in which they live. This means that LGB persons can have a lack of support when they undergo cancer treatment and diagnosis, consequently this leaves them in a position of low mental resilience and more likely to need formal support mechanisms rather than relying on general emotional support from family members.

The themes of **body image** and **sexual function** are closely related, but appear distinctive within the literature. Cancer and its treatments can change a person's body and how they feel about it and body concerns are common in persons affected by cancer. The changes to a person's body may be temporary or permanent and are seen by the person, or by others, as reminder of what has happened to them, such as hair loss or weight gain. There are articles uncovered in this review that discuss LGB person's attitudes towards illness and distinctive characteristics of the acceptance of illness within the LGB community.

Finally, the theme of **sexual function** is discussed distinctly and includes the mechanics of a sexual act. Sexual expression is distinct from this and includes acts of intimacy and mood such as holding hands, special looks, hugging, kissing, etc. Warmth, caring, and physical and emotional closeness are as necessary and rewarding as anything else in a person's relationship, but these matters of sexual expression are absent from the literature uncovered within this review. I explore this in more detail but tend to find the literature thus far focused more on the mechanisms of sexual acts of gay men affected by pelvic cancer such as prostate cancer, rather than the issues around intimacy and the impact on relationships.

The results of the literature can be found in appendix four, where I have provided a table of the literature included within the following discussion. The table is arranged by themes and it can be seen that most of the articles found in the review related to experiences of care or sexual function. I have provided details of the publication dates of the research uncovered as well an overview of the participants and findings of the articles. The themes formulate the basis for my discussion.

Experiences of Care

LGB persons' experiences of cancer care are discussed in eleven articles uncovered as part of this review (See Appendix four). The literature reveals examples of discriminatory attitudes from health care staff towards LGB people. The levels of discrimination experienced throughout the studies vary, but it is known that social stress levels can increase with even minor forms of discrimination, which in turn can impact on a person's overall mental health (Collingwood 2011). This is significant when coupled with the additional emotional stress that can be experienced by a person when undergoing cancer treatment and diagnosis.

Barnoff et al (2005) coordinated a Participatory Action Research (PAR) study that explored the experiences of twenty-six lesbian and bisexual women in Ontario who had treatment for various stages of breast and gynaecological cancer. As the research was action oriented, the researchers worked with the participants to establish what changes in services and support the participants felt were necessary. There were several recommendations devised by the group which aimed to support cancer care of lesbian women. These included the need for more opportunities to connect with other lesbian women with cancer, through the formation of a cancer support group for women and partners, and a need for more targeted information that reflected the inclusion of lesbian women within published resources. The study aimed to interview participants face-to-face for approximately an hour each, but nine interviews were carried out over the phone indicating some inconsistencies in the described methods. However, given the study's motivation to maximise participation of the persons affected by the issues in the design and conduct of the research, and the overall preference of the participants themselves, it is easy to see how a more flexible approach to facilitating participation evolved out of a PAR study. The researchers aimed to ensure a diverse sample of participants by selecting volunteers with varied backgrounds and cultural groups, although most were university educated (n=25). In addition, ethical considerations of the research and any approvals were not published within the article, indicating a potential weakness given the sensitivity of the issues the participants explored. Information regarding the procedures of consent were also not detailed within the published article, meaning that experiences could not be shared and learnt from for my own research. This research follows a similar approach to my own and has the added benefit of enabling the participants to have a stake in developing the research methods which can be very empowering. All interviews were described as semi-structured, audio-recorded and transcribed verbatim for analysis. Transcripts were coded by the researchers indicating some level of bias and there was little published information in the article about how the participants contributed to the formation of the final recommendations, or how they may have commented on the transcripts. The participants described instances of discrimination where they were not offered breast reconstructions due to a misbelief that lesbian women wouldn't want this, or having heterosexist assumptions made about them and their partners. Participants felt they were regularly placed in embarrassing situations where they would have to correct healthcare staff who assumed that they were heterosexual. The PAR group recommended that health care staff should attempt to offer gender neutral language in their consultations to prevent incidents of heterosexist behaviours occurring. The paper didn't make clear if a support group was formed as a result of the PAR findings, although it does demonstrate a good commitment from the community coming together to address a common concern, which is a core principle of PAR according to Hacker (2013).

Two further papers authored by Sinding et al (2004) and Sinding et al (2007) appeared to be produced from the same PAR study authored by Barnoff et al (2005), indicating a degree of replication of results. However, these other articles offered further insight into the participant's experiences. Sinding et al (2004) and Sinding et al (2007) provided additional accounts from participants who discussed heterosexist assumptive attitudes of healthcare practitioners in the cancer pathway. They also indicated the research did receive full ethical approval and consents suggesting a higher level of assurance about the trustworthiness of the data. There were clear examples in the data whereby healthcare professionals were felt to be withholding treatment options for breast reconstruction following surgery, due to a perceived belief that lesbian women wouldn't have wanted this. The articles aren't able to account for whether this actually occurred or whether it was just the participant's perceptions. However, from a person-centred perceptive, these findings do demonstrate misunderstandings in care due to the person's sexual orientation. This is a clear example of a person's belief systems not being fully considered and assumptions being made about their healthcare choices. Further examples of a lack of person-centred approach were also observed whereby genetics counsellors were not understanding towards lesbian women who were estranged and alienated from their family origins due to their sexual orientation. The participants worked with the researcher to provide recommendations suggesting that providers should make active attempts to be welcoming to LGB people, and be open to discussion issues that affect these groups in an accepting manner. The participants believed that equitable care couldn't be achieved currently, for them or their partners, without a more active approach from health providers to address historical failures towards the LGB community.

There have been attempts by some health providers to show visible symbols that they aspire to deliver inclusive healthcare, for example, within the UK the Lesbian and Gay Foundation (LGF 2015) awards 'pride in practice awards'. The awards are given to health providers who want to demonstrate their commitment to promoting LGBT equality and that they recognise LGBT people's needs in respect of their health. The Pride in Practice approach presents a possible solution to problems described by research by Sinding et al (2004), Sinding et al (2007) and Barnoff et al (2005) and is noteworthy of a potentially very good practice to assure LGB persons of the quality of services they access.

A further USA study included in this review by Boehmer and Case (2004) attempted to assess the attitudes of lesbian and bisexual breast cancer survivors regarding disclosure of their sexual orientation to the health providers. The researchers employed community based purposive sampling through use of internet posts and flyers targeted at health clinics to recruit 39 lesbian and bisexual women who had treatment for breast cancer. Snowball sampling was also employed to facilitate a greater exposure and recruitment to the research. By implication, there is a potential limitation of this recruitment strategy, in that it focused more on women who were more likely to be out, thus potentially more comfortable with disclosing their sexual orientation to their health providers. Demographics of the participants were recorded, demonstrating that 37 were white and well educated, with 28 of the participants holding either an undergraduate or post-graduate degree. As a consequence the research participants were not from a diverse background, and potentially those recruited were more equipped than many to challenge issues that arose in care. Twenty-seven of the participants were partnered, and one of the key findings of the research indicated that having a partner can help facilitate disclosure of sexual orientation, demonstrating an uneven inclusion of those who had support to disclose. Semi-structured interviews lasting 90 minutes were conducted in either the participant's homes, office locations or over the phone, with all being audio-recorded and transcribed verbatim. Interviews focused on the examination of the attitudes of the participants when revealing sexual orientation to health providers in a cancer setting. A software package to identity text related to medical interactions and disclosure was used to analyse the data. Most women in the research discussed how they made an active decision to disclose their sexual orientation to their healthcare providers, whereas eleven of the participants refused to during their entire cancer journey. The participants noted how they felt apprehension around disclosing their sexual orientation and that they had to initiate the process, rather than the health provider. This suggests a lack of trust between the health provider and those in receipt of care, and a lack of willingness to try and establish the clarity of the participant's values and beliefs which is a pre-requisite within the Person-Centred Practice Framework (McCormack and McCance 2016). Interestingly, the Lesbian women within the study that went on to disclose their sexuality, then reported that they were met with a largely positive response, where non-heterosexist language was used in consultations, and partners felt included in decision making. This indicates that when the initial anxieties can be put aside healthcare providers can be largely respectful of the participants needs and even refute their fears over disclosure. The study discussed details of the participants' demographics, indicating that they were mainly younger white women. This could indicate that these women might be more likely to self-disclose their sexual orientation over older women and those from other minority groups, and is supported by other evidence in the field (Rosario et al 2004).

Research around the disclosure of sexual orientation to care providers has been conducted in non-cancer settings, and is discussed by Krychmal and Kellogg (2010). They suggest that individuals often prefer their care provider to initiate discussions about their sexual orientation, suggesting that a lack of attempts to enquire can be a barrier to a good healthcare experience and a self-perceived feeling of discrimination. This points to a possible need to provide organisational systems that may facilitate disclosure in the cancer care setting. Providing some pre-requisites of person-centred care, by having a largely supportive response when someone discloses their sexual orientation, will enhance a person’s experience and confidence.

A methodologically contrasting study included in this review was conducted by Jabson and Bowen (2014) in the USA. The authors conducted a cross-sectional survey of 68 female breast cancer survivors, who identified as being sexual minority women. The survey was administered online, advertised through health venues and online social media platforms. Participants were asked to complete assessment of their quality of life and perceived levels of discrimination within care. The participants used the “The Quality of Life Cancer survivors survey” devised by Ferrell and Dow (1997), which comprised of 41 questions, with scaled Likert responses graded 0-10, with zero being ranked as the worst outcome and 10 being marked as the best outcome. The survey measured four areas related to quality of life, specifically, psychological, physical, social and spiritual wellbeing. Perceived discrimination was assessed using a modified question bank from a racial minority questionnaire devised by Thornton and Bogart (2005), where participants were asked to respond to questions using a 5 point Likert scale, with zero indicating a low level of perceived discrimination to the question stem, and five indicating the highest level of perceived discrimination. Statistical analysis pointed to a two-fold decrease in quality of life measures ($t=3.68$, $p<.001$) for participants that who perceived discrimination ($t=4.79$, $p<.001$) over the course of their care. The authors reported limitations of the survey indicating that the sample size was relatively small and thus hard to demonstrate statistical significance as well as having no baseline, or heterosexual control group for comparison. In addition, the sample was not diverse, being all white and predominantly well educated. There was also a potential selection bias towards those who had computer access and relevant skills to be able to respond to the survey. Despite this the survey adds some quantitative evidence of how perceived levels of discrimination can impact on quality of life. This adds further weight to the other literature and evidence included within this review, and highlights potential vulnerabilities within the LGB community when they progress through the difficulties associated with survivorship after their treatment. The paper would seem to suggest an early act of discrimination in one’s healthcare journey can then come back at a later stage and impact on overall quality of life. It is therefore vital that the importance of even minor acts of discrimination is not underestimated in terms of the long-term effects on someone’s wellbeing, and that the interpersonal skills of healthcare staff must incorporate an understanding of the diversity of and persons that access cancer services to prevent such acts of discrimination.

A cross-sectional study by Kamen et al (2015) used a self-reported online survey using descriptive and exploratory multivariate statistical approaches in analysis. Two-hundred and ninety-one LGBT persons who had a treatment for cancer were recruited. The respondents comprised of a diverse population with mixed cancers based in California, USA. Kamen et al (2015) reported that 89% of the participants were white and 50% identified as being gay, 36% lesbian, 7% bisexual, and 3% transgender. This represents a good cross section of the LGBT community, however the research doesn’t go on to explain the gender identity of those respondents and this could affect the figures. Questions were based on the Livestrong survey, which is a USA cancer survivorship survey, which focuses on measures of psychological distress (Backjord et al 2008). The survey was advertised in clinics that endorsed the use of the survey throughout the USA, indicating a possible selection bias of participants. Thirty-five dichotomous questions (yes or no) were asked related to the emotional concerns of the respondents. Most of the questionnaire respondents (79%) reported having to continually disclose their sexual orientation throughout the pathway and to several health providers. Participants felt that they had to bring up the topic of their orientation and identities themselves, and a third felt they had to correct care providers’ assumptions that they were heterosexual. Friends were the most common members of LGBT person’s support teams. The survey is limited as it relies on dichotomous answers, and as such does not establish the level of importance that could be applied to each of the questions for the participants. Kamen et al (2015) concludes that difficulties around the disclosure of sexual orientation and identity are important factors when examining self-reported health amongst LGBT people in care. The authors highlight the limitations of using an online survey, which include the need for people to have access to appropriate levels of IT equipment and skills to complete, and that more computer literate persons would be more likely to respond. They conclude that establishing a safe health environment free of judgement and facilitating disclosure are key to developing cancer services, and this articulates well with person-centred ways of working in respect of the care environment domain.

A further quantitative secondary analysis conducted by Hulbert-Williams (2017) examined the 2013 UK National Cancer Patient Experience Survey. The survey is not aimed specifically at LGB persons, but rather all cancer patients treated in the UK, and contains 70 multiple choice questions targeted at specific acts of care, and six multiple choice questions that focus on overall experience. Hulbert-Williams (2017) conducted a secondary analysis of the 68,737 individuals who responded, finding that 0.8% identified as LGB. They employed logistic regression analysis using Wald tests to explore the response differences between heterosexual and LGB respondents. Statistically significant differences were found between the two groups for 16 questions. LGB respondents were offered only a single treatment option ($p < .01$), wanted to be more involved in treatment decisions ($p < .01$), and had less contact with healthcare professionals ($p < .01$) than their heterosexual counterparts. In addition, LGB respondents felt as though their professionals talked about them as if they were not there ($p < .02$), and were less likely to have a family member or friend with them during consultations ($p < .01$). In terms of aftercare, LGB people were found to lack aftercare arrangements more often when compared with heterosexual people ($p < .02$). The results would indicate negative experiences and inequality for LGB persons within the UK when accessing cancer services. The comparison between heterosexual and LGB respondents demonstrated a strength over the Jabson and Bowen (2011) study conducted in the USA, as comparison could be drawn between heterosexual and homosexual respondents, rather than just having responses from LGB people. Hulbert-Williams (2017) also had a significantly larger sample size, and was therefore able to draw potentially more accurate and representative results. However, it must be noted that the 0.8% proportion of respondents in the survey indicating they identify as LGB, is significantly less than UK estimates where 5–7% of the population are LGB (Her Majesties Treasury Department of Business 2015). This may indicate a lack of LGB respondents, or a lack of disclosure of sexual orientation in the survey. Whilst offering excellent use of statistical modelling and a basis of comparison, the secondary analysis has limitations through its design. Specifically, these include the large disparity between LGB and heterosexual respondents, missing sexual orientation data for 6% of the survey responses, and grouping together LGB respondents as one homogenous group where there may be disparities between genders and bisexuals.

A further Canadian study (Katz 2009) explored the experiences of three sexual minority men, and four sexual minority women, with various types of cancer. This research contrasts with the larger quantitative research discussed previously, but offers more detail about the lived experience of the participants, through the use of face-to-face semi-structured interviews. Participants were recruited purposefully from one Canadian city, through the use of advertising and recruitment campaign and posters for the study through local cancer support networks and LGBT groups. Face-to-face in-depth interviews followed a semi-structured guide and were transcribed verbatim. Transcripts were then analysed and coded by the author for themes that were verified with the participants to aid in identifying their priorities relating to cancer treatment. The researcher does not report if the codes were independently verified, however they demonstrated good practice by going back to the participants for verification. The wider ethical considerations of the research and the consent process are not discussed within the article, presenting some potential weakness in the publication and selection bias. However, the study was deemed important for inclusion within this review as it presents a counterview of the LGB persons' experiences of care, the research contrasts others in that the participants didn't experience overt homophobia within their own cancer care experiences. This demonstrates variation in LGB person's care experiences within Canada and examples of healthcare staff getting things right. The research demonstrated that through good relationships between the participants and the healthcare provider, their holistic needs and sexual orientation were addressed in the care setting, and resulting in having a good overall care experience which contributed their overall wellbeing. However, the research goes on to inform on the further understanding of the complexity of needs of a person who is having cancer treatment and need for support. The participants placed great value on the central role of their partners in coping with cancer but identified gaps in the cancer care system specifically relating to support groups for LGB persons with cancer. The need for cancer support groups has been long understood. It is particularly important to facilitate social support beyond immediate friends and family enabling the venting of emotions that are experienced through the cancer treatment journey (Taylor et al 1986). The participants in Katz's (2009) research study point to a lack of tailored support groups for LGB persons indicating a care need that wasn't being met and the need to rely on friends and family for support. Participants also described some of their worries about the LGBT community's attitudes towards illness, where the gay participants were concerned about their peers' attitudes towards illness and feelings of stigma. In particular, there were concerns about how the deteriorating physical effects of cancer and treatment could be misread as a sign that the gay men involved in the research had AIDS.

A piece of grey literature included within this review, is a project report conducted by Fish (2010). The report documents the activities of the researcher and the National Cancer Action Team to explore the needs of lesbian and bisexual women affected by breast cancer within the UK. The results of a pilot study are presented in the report, whereby 13 breast cancer survivors and 4 partners of women who died of breast cancer, came forward to take part in semi-structured interviews lasting between one and 1.5 hours. Interviews were conducted Face-to-face in the participant's homes and audio recorded. Transcripts were created verbatim and analysed thematically. Unfortunately the report does not contain much information about the process of data analysis, or any procedures that were undertaken in order to be able to reduce researcher bias. However, the report did document that the project received full ethical approval and recruited participants via a flyer that was distributed through various networks. Like other studies conducted within the UK, information is provided about the participants' demographics, and interestingly all participants came from England. The findings of the research indicate negative experiences by the participants when engaging with Cancer services, particularly when interacting with doctors and nurses. Issues were also experienced by participants around the disclosure of their sexual orientation to healthcare staff.

Fish and Williamson's (2018) study represents one of only three published research papers from the UK. The research team recruited fifteen LGB cancer patients with a variety of different diagnoses, to discuss their experiences of the care they received. The data were collected through using in-depth semi-structured interviews which were conducted face-to-face at a location of the participants choosing. Interviews were recorded, transcribed verbatim, and analysed by the research project team. Full ethical approval was granted for the research and participants were sought through an intensive recruitment campaign, which included the use of social media, radio and flyers. Fifteen participants were recruited through cancer support groups and a key stakeholder project team was also established at the onset of the research. This supported the involvement of participants and other stakeholders in the research. Participants were recruited from outwith of the NHS and the use of purposive and snowball sampling was also used as a means of attracting more people. Transcripts were coded into three main themes, which were described by the authors as an 'awkward choreography around disclosure', 'making sense of sub-optimal care' and 'alienation from usual psychosocial cancer support'. The authors reported that participants found many dilemmas when accessing care, especially around the conditions of when to come out to health practitioners, as well as providing accounts of discriminatory attitudes from health practitioners. The authors used Meyers Minority Stress Theory (2003) as a lens to examine the participant's accounts. Micro-aggressions and heteronormative health practices resulted in perceived feelings of being discriminated against. The paper usefully closes with recommendations to develop inclusive and affirming care for LGB people affected by cancer, which includes the need for additional training for healthcare staff and explicit organisational commitment to LGB people. The article is well formed and includes details of the formulation of the research design, which had good accounts of community participation, as well as details of recruitment through social media platforms and generalised media. The paper discussed the great difficulty in recruitment, and does not state whether successful recruitment was achieved from all the areas of the UK, or just recruited locally from England.

However, the grey literature search uncovered a project report undertaken by Fish and Lockley (2015). This related to the same research that was later published by Fish and Williamson (2018), and provided more insight into the participants in the original research. None of the participants came from Scotland. This is a significant point as LGBT legislative reforms from within the UK have proceeded at different rates, as well as societal attitudes varying between communities in devolved nations, urban and rural communities. Fish and Williamson (2018) point to issues around the inability to mobilise fully person-centred care through a lack of processes for working with patients’ values and beliefs, providing holistic care, and staff having strong interpersonal skills to address some of the nuances around disclosure.

Fish et al (2019) conducted research investigating the nuanced understanding of disclosure of sexual orientation within oncology clinics. The researchers recruited 30 lesbian gay and bisexual people affected by various different types of cancer from across England. Participants were recruited through displaying research posters within five oncology departments in various parts of England, and through cancer charities, social media and radio. In-depth qualitative interviews were undertaken. Interviews lasted between one and two hours in a location of the participant’s choice, which was reported to be mainly their own homes. Interviews were recorded, transcribed verbatim and analysed thematically. Particular attention was paid towards meaning-making of participants’ views through employing an iterative process, where the research team independently coded the transcripts, then discussed recurring themes as a group and developed an overarching framework. Finally the data were reviewed using an analytical framework that used the lends of salutogenesis when interrogating the data (Jonas et al 2014), as a lens to interrogate the data. The participants discussed their experiences around the disclosure of their sexual orientation to the care providers. Findings revealed that authenticity of participants is a key driver for their needs and wants to disclose their sexual orientation, the use of partners as a resource and creating a safe-space to help facilitate disclosure, and that healing environments need to be developed and conducive to facilitating disclosure of sexual minority individuals. The research is novel in that it analyses some of the issues underpinning the reluctance of LGB people to disclose their sexual orientation in the healthcare setting. In addition, this research is one of four studies included in this review that recruited UK participants. Its findings can therefore be viewed as being closely aligned to my own research, in respect of the context of the UK LGB population and their cancer needs. Limitations include the lack of diversity of participants, particularly from black and Asian minority ethnic communities and bisexual women. In addition, as participants were recruited through Cancer support networks and the hospital setting, they were more likely to be out to their health providers, and potentially more confident discussing their sexual orientation with the researchers. The research also recruited predominantly partnered participants, rather than single LGB people, which could also influence the findings of the research when establishing methods to promote sexual orientation disclosure.

From the literature discussed in review there appear to be issues that arise from a lack of understanding and awareness from healthcare staff around LGB specific issues, in particular these misunderstanding are often manifested through heterosexist assumptions. Although not within the scope of this review, Reygan and D'Alton (2012) have devised a noteworthy approach in Ireland whereby training has been directed at oncology health professionals to address the types of issues described within the literature. This is a potentially successful programme that could be transferred to other areas as it aims to improve the use of terminology and make staff more knowledgeable about issues LGB people may face when accessing healthcare. The training is well evaluated and participants have reported feeling more confident when working with LGB patients.

There is a clear apprehension felt by LGB persons over the disclosure of their sexual orientation and this can impact on the cancer care journey. The Person-centred Practice Framework provides information on the pre-requisites required to achieve a person-centred healthcare environment. These are built on trust and facilitating human flourishing when employed correctly. The literature indicates how negative experiences have the consequence of compromising LGB persons' ability to receive truly person-centred care, and as such indicates missed opportunities to facilitate flourishing. An issue not explored in the literature to any great depth is how past experience can influence a person's lens of how they receive care, and if whether healthcare systems can provide a service that is able to transform LGB persons' attitudes towards service providers. After reviewing the literature in this area I am left wondering if whether someone who has suffered acts of discrimination because of their sexuality will have an inevitable apprehension when accessing healthcare, and how a truly person-centred model can alleviate these issues. Nevertheless, it appears clear that the questions of whether past experiences of discrimination influence a person-identity and world view remains unexplored within the literature uncovered in this review.

Coping and Wellbeing

The way in which cancer affects coping and wellbeing is discussed within several papers included in this review, and many are common regardless of sexuality. However, LGB persons generally tend to report poorer levels of health, and therefore may have additional support needs and their ability to manage with the effects of cancer treatment are discussed within the next section. Thomas et al (2013) conducted online focus groups over a period of four weeks, whereby participants were asked to discuss a range of concerns about their experiences following prostate cancer diagnosis. The research was conducted in Australia, and recruited a total of 10 participants that identified as being gay and one bisexual man. All participants were Australian and had a confirmed diagnosis within the last seven years. The rationale for using online focus groups was to encourage the participants to elicit a range of experiences that could be shared. They were recruited by word-of-mouth through gay and bisexual prostate cancer support groups, however the researcher doesn't provide any further details of how this was undertaken. The research conducted by Thomas et al (2013) examined matters of sexual expression, relationships, and identity. Considerable effort was made by the researcher to exclude bias when analysing transcripts of the focus groups, by ensuring that each of the transcripts was reviewed by three separate researchers and a coding system was devised in order to be able to identify emergent themes from the data. The researcher didn't specify whether or not the participants were able to talk through the online platform, or whether they typed their responses, indicating significant limitation in the reporting the research procedure in the publication. Participants discussed some of the impacts of the physical effects of cancer such as sexual changes, incontinence, and associated stigma of the effects following treatment. Following treatment participants felt isolated from the gay community, reporting that they felt like ‘damaged goods’ and worthless. The use of a stigma theory as a theoretical framework for this research was employed, to be able to analyse stress and psychological challenges of the social situations that a minority may face. The participants discussed how the effects impacted on their sense of identity and overall well-being causing the participants to re-evaluate their lives. The research indicates that the participants struggled to be able to cope and adjust following their treatments. The researchers noted potential selection bias as well as its limitations of employing a cross-sectional design, indicating that views will just be a snapshot of what the participants felt at that particular time. The data were gathered through online focus groups indicating this as a potentially advantageous method of engaging a hard to reach group. However, as the focus group worked on an anonymous platform, participants would have been unable to pick up social cues of others within the focus group and this may have impacted on the types of experiences they were willing to disclose. Thomas et al (2013) only rectruited men who had prostate cancer, which raises the question of whether some of the themes that were discussed could apply to persons who have a different diagnosis. Persons affected by prostate cancer are likely to be older men, from an epidemiological perspective, and older LGB people in the UK are more likely to live on their own (Stonewall 2010). When coupled with potential barriers to being able to engage with the LGB community, this could mean that a sexual minority person with cancer has less access to emotional support.

Torbit et al (2015) examined the fear of occurrence amongst gay and bisexual men affected by prostate cancer four years post diagnosis. Participants were purposively selected across Canada and the USA and the authors publicised the research through a variety of platforms, including electronic message boards, flyers, and engaging with local Cancer support groups for LGB people. Once recruited, participants were then sent via email the self-reported anonymous questionnaire. Ninety-two participants were sent information and invited to complete the questionnaire to assess function, symptoms and satisfaction with healthcare. Fear of recurrence for prostate cancer was investigated and analysed through a process known as bootstrapping. Bootstrapping involved continuous random sampling from the dataset to establish estimation of the indirect effects of a predictive and outcome variable. Fear of recurrence was assessed using a five point Likert scale ranging from ‘strongly agree’ to ‘strongly disagree’ to rate worries and beliefs about the possibility of a recurrence of the cancer. A confidence interval of 95% was calculated for the post estimate, and the study found that worse bowel function ($p<0.05$), hormone function ($p<0.01$), and sexual function ($p<0.01$) were statistically significantly associated with greater fear of recurrence. The authors discuss the limitations of the research indicating that there was a relatively small sample size for this particular analysis and design with bootstrapping. The authors also felt that the survey is cross-sectional in design and therefore captures opinions at that stage in time only, and that it relied on the self-reported fear of recurrence from the participants. The participants within the research were generally white and highly educated, and out. As such the participants may have had more positive physical and mental health outcomes compared with men who were not out, and represents a potential limitation of the research findings.

A number of other quantitative surveys have been uncovered in this review and indicate that sexual minority persons may have problems with coping and wellbeing when compared with their heterosexual counterparts. In the USA a study used the breast cancer module of the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire through thirty minute telephone based interviews with 161 lesbian and 19 bisexual women breast cancer survivors (Boehmer et al 2013). The participants were recruited from a larger study, which grouped both the lesbian and bisexual respondents together. The authors aimed to go back to their original sample to see if there were any differences between the bisexual and lesbian respondents. The authors used statistical t-tests and chi-square tests to examine differences between measures in the quality of life questionnaire against sexual minority factors. Measures took into account the demographics and levels of discrimination were given a score and categorised based as discrimination factors based on sexual and non-sexual orientation. The lesbian women were found to have better quality of life measures than bisexual women who were partnered with men. The mental health related quality of life in lesbian women was reported to be a median of 51.5, standard deviation = 9.5, versus median = 47.7, standard deviation = 10.2 for bisexual women. The authors found that the disclosure of sexual orientation was linked to less anxiety and depression on cancer survivors, although this was not statistically significant. The partner status and gender of partner had the greatest effect on anxiety and depression, with those bisexual women with male partners demonstrating worse quality of life than lesbians who were found to be more open about their sexual orientation with their families. Despite these findings, there are several limitations of the research which include a significant disparity in cohort sizes between lesbian and bisexual women recruited, and the overall small sample size limited the ability to gain statistically representative data. In addition, the survey was undertaken as a cross section, and no baseline data were establish to see of the lesbian women and bisexual women had a comparable base line score prior to treatment, therefore caution needs to be taken before drawing conclusions from the data.

Boehmer et al (2011) conducted a large-scale study examining cancer survivorship and sexual orientation. The authors pooled data from a California Health Interview survey from 2001, 2003, and 2005. Through using descriptive statistics and logarithmic regression, they analysed the self-reported health outcomes of men and women by sexual orientation with a 0.05 significance level. The California health interview represents one of the largest health surveys undertaken within the USA by undertaking a geographically stratified random digital dial sample of households. The survey had multiple response questions, and was administered over the telephone or internet depending on the participant’s preference. This resulted in one randomly selected adult for survey from each household being contacted. The authors reported that the survey had advantages, in that it was offered in multiple languages and thus enabled a more multicultural perspective to be captured within the survey. Demographics such as age, gender, salary, educational attainment, and employment are taken into consideration in the data, where the authors reported a good spread of persons from different groups. A total sample of 122,394 individuals, consisting of 51,259 men and 71,135 women responded to the survey. However it should be noted, that of the LGB respondents, most were highly educated and were predominantly white. In addition those over 70 years of age were not asked to disclose their sexual orientation, representing a significant limitation within this research given the typical age someone would have cancer. There was no significant difference in cancer prevalence by sexual orientation for women, but lesbian and bisexual participants were 2.0 and 2.3 times likely to report only poor or fair health when compared with their heterosexual counterparts. The authors warn about the generalisability of the sample across the USA, as the respondents are limited to California. Among men, significant differences in cancer prevalence were seen, with gay men having 1.9 times the odds of reporting a cancer diagnosis compared with heterosexual men. The results of the survey would indicate that Lesbian and Bisexual women may need more support as their health outcomes are worse than their heterosexual counterparts, and more targeted screening and health promotion may need to be targeted at gay men, given the increase in prevalence of cancer within this population.

Producing contrasting results, Boehmer et al (2014) conducted a further study comparing the coping strategies of 257 heterosexual women and 69 lesbian women with breast cancer. The authors used a Mini-MAC measure of coping, which was an abbreviated version of the Mental Adjustment to Cancer scale developed by Watson et al (1994), and a Benefit Finding Scale devised by Antoni et al (2001) to measure any positive perceptions of breast cancer. Using a thirty five minute telephone-based survey, a convenience sample of participants were recruited from a cancer registry and were asked to score their coping styles. These included a measure of fighting spirit, hopelessness, anxious preoccupation, fatalism and cognitive avoidance. The authors didn’t provide detail of the exact measures of the scale used, and how this differed from the full scoping model developed by Watson et al (1994), presenting a limitation of the publication. However, they did provide some limited information indicating that a higher score in the fighting spirit section, would demonstrate positive coping and higher scores, and higher scores in the remaining four sections would demonstrate negative coping. The scores were analysed using multiple regression models comparing sexual orientation and the various coping styles using chi-square and t-tests with a p value of greater or less than 0.1. Findings indicated that sexual minority breast cancer survivors had more benefit findings relating to their background, social and clinical support than their heterosexual counterparts. However benefit finding didn’t correlate with the coping styles assessed. The authors summarise that sexual minority women may be able to perceive more benefits after breast cancer than heterosexual women. The cross-sectional nature of the sample, and small sample size included in the analysis present further limitations of the paper.

Allensworth-Davis et al (2016) present the results of a cross-sectional survey they conducted within the USA. The survey examined self-esteem amongst gay men who were treated for prostate cancer within the last year. Recruitment was conducted through the use of LGBT publications and community newsletters from across the USA, whereby men over the age of 50 could come forwards and consent to the postal survey. Self-esteem was measured using a validated scale developed by Clark et al (2003), which included eight multiple choice questions relating to ‘feeling like a whole man’, ‘being weak and small’, ‘emotional rationality’, and ‘comparisons to other men’. Stigma was also assessed using The Macdonald and Anderson (1984) social stigma scale, offering scores from one (not at all) to five (very much). The respondents were predominantly white with only eight individuals identifying as being from a racial minority background, representing a limitation to the study and lack of participant diversity. In addition, 99 of the respondents had college level education, indicating that the survey was very focused towards white educated men. The authors used Spearman's rho and Kruskal-Wallis tests to calculate p-values and assess variables for correlations. One-hundred-eleven responses were deemed eligible for analysis. Findings suggested that men aged 50-74 years felt statistically significantly lower self-esteem than men over the age of 75 ($p = 0.002$). Eighteen percent reported an experience of severe stigma over the last month, and there was a strong correlation between those that experienced stigma and decreasing measurements of masculine self-esteem (spearman's rho =0.36 and $p=0.0002$). Men who told their doctor their sexual orientation were found to report self-esteem score fifteen points higher than those who didn't ($p=0.00001$). The authors conclude that health providers are well placed to recognise the signs of low self-esteem in men with prostate cancer, and that those who felt more comfortable disclosing their sexual orientation to their medical team were less likely to have lower levels of self-esteem. The research is limited by its cross sectional design, and by data collection taking place 12 months post treatment, as self-esteem may change over time. In addition, the respondents were self-selected meaning the generalisation of the findings may be difficult in relation to the gay population at large. Crangle et al (2017) examined the potential impact of being out to health providers for men treated for prostate cancer. The researchers recruited 92 gay and bisexual men to participate in a postal survey. The study was advertised through cancer support groups and LGBT community forums and online message groups and boards across the USA and Canada. Ten questions asked about the disclosure of sexual orientation using a seven point likert scale, one indicating 'definitely do not know about your sexual orientation, seven indicating 'definitely knowing about your sexual orientation and talking about it', against comfortableness with being out. Ten 'outness' questions used a seven point likert scale, with one signifying being 'very uncomfortable' and seven signifying being 'very comfortable' as the measure. In addition, illness intrusiveness was also assessed scaling from one 'not very much', to seven 'very much', assessing extent to which participants felt illness interfered with thirteen life domains. When participants felt less comfortable with being out there was a greater degree of anxiousness and illness intrusiveness ($p<0.001$). The findings of the research would suggest that if health providers are able to facilitate people being out they will report better healthcare outcomes and feel less anxious. The authors report that their research was limited by its cross-sectional design, and the predominantly early stage of the participants' diagnoses. The majority of participants were white and highly educated indicating that this is not a representative sample of all of the LGBT community affected by prostate cancer. The authors report that they missed capturing full demographic information regarding sexual orientation, indicating that they failed to distinguish whether if the participants were gay or bisexual, and this could also have also impacted on the results. In addition, due to the design of the research, exploration of what would help participants to disclosure sexual ordination to the health providers was not examined.

A study conducted by McConkey and Holborn (2018) in the Republic of Ireland examined the lived experiences of gay men affected by prostate cancer. Purposive sampling was used with a comprehensive strategy for raising awareness of the research in clinics, gay venues, and magazines. Chain sampling was also used to ensure that those included in the research could refer on other men to participate if they wished. Eight individuals participated in the research, each having had a variety of different treatments for prostate cancer within the last 12 years. All of the participants were above the age of 47 and had a maximum age of 66, suggesting a slightly lower than average age for prostate cancer. In-depth face-to-face interviews were used as a means of data collection in a neutral venue, and data were analysed using the Giorgi’s descriptive phenomenological method. All interviews were transcribed verbatim and analysed by the researcher. The researcher provides details of their attempts to ensure validity and trustworthiness, by providing insight into the reflexivity and verification methods of the data with both the researcher and supervisor in an attempt to reduce bias. The authors did not state if whether transcripts were passed back to participants for checking, as is common with qualitative phenomenological research (Moser and Korstjens 2018). Half the participants described a significant impact of treatment on their feelings of masculinity. The impact on gay identity was also discussed in detail, with participants feeling that a diagnosis of prostate cancer was a taboo subject within the gay community. Sexual dysfunction was also discussed by the participants, proving insight in the difficulties they faced and ability to cope post treatment with issues around urinary incontinence, lack of orgasm and ejaculation, and effects of erectile dysfunction. The authors acknowledge limitations of the research, suggesting that the men recruited into the research were predominantly white, well educated, and partnered. The authors felt that this was not necessarily representative of the larger gay community in Ireland.

When examining the literature relating to coping and overall wellbeing it is clear that there are stresses that LGB persons are exposed to. This phenomenon has been explored within more generalised data and is known as minority stress disorder. Minority stress is a condition whereby chronic levels of high stress are experienced by minority groups as a result of continued discrimination and stigma (Lehavot and Simoni 2011). The effects can be significant and symptoms can impact on wellbeing, including elevated blood pressure and anxiety disorders when experienced in the long-term (Meyer 1995, Miceli et al 2019). These factors may indicate that LGB persons may potentially be more vulnerable from a coping and wellbeing perspective when treated and diagnosed with cancer.

Emotional Support

Older LGB people are potentially more vulnerable to becoming isolated as they are more likely to live alone and not have children when compared with heterosexual persons (Yang 2017). Four studies included n this review discussed the importance of spousal or peer emotional support for sexual minority individuals (see appendix four). White and Boehmer (2012) undertook research examining perceptions of support from female partners of breast cancer survivors. The researchers recruited 15 partnered sexual minority women to participate in the research from a sample of 181 individuals from across the USA who participated in previous research conducted by Boehmer et al (2013). Thirteen white and two Hispanic women with a median age of 52 years, who were a mean of six years post diagnosis, were invited to undertake one to one semi-structured interviews over the telephone. The use of a telephone interview was deemed to be the most appropriate way to conduct this research, but is limited as visual aids and non-verbal cues couldn’t be taken into consideration. Interviews were conducted by one of two researchers with open ended questions designed to examine the impact of cancer on the sources, nature, and value of support. Interviews were recorded and transcribed verbatim for analysis. They lasted approximately 30 to 150 minutes in length, indicating the contents of the interviews varied significantly between the participants. Inductive and deductive codes were established and agreed between the authors, and quotations regarding support were reviewed to identify emerging themes from the data. Data collection was concluded when data saturation was reached in that no new or divergent themes emerged. Findings indicated that participants felt female partners were the singular source of most valued support, with continued concerns about their partner’s anxiety towards their illness, and a reliance on support with day-to-day activities. The dependency on support led to some participants feeling burdensome at the time of the interviews. Limitations are discussed within the article around the lack of diversity within the sample. The authors acknowledge that increased feelings of burden may be experienced by patients who are having continued treatment for their disease. The authors also state that they were unable to contact everyone within the original 181 sample of breast cancer survivors to see if they would like to participate as the contact information had become dated and changed. In addition, the research was limited by only examining the perceptions of support from same-sex partners, and didn’t capture the opinion of the partners themselves, or investigate support that may have been provided from close friends or family. The need for support is not unique to sexual minority individuals and similar studies examining heterosexual couples corroborate these findings (Gremore et al 2011), although sexual minority individuals in the UK are more likely to be single (Stonewall 2010).

Capistrant et al (2016) undertook research examining 30 gay bisexual men affected by prostate cancer and their sources of support during their treatments. Telephone-based interviews were conducted with the participants who were recruited through a national Cancer support group based in the USA. A sample of convenience was obtained through the support groups mailing and email networks. Participants were invited to come forward and consent to the research online, and had to have completed their treatments at least six months ago as well as residing in the USA. Interviews were transcribed verbatim with both inductive and deductive codes used to create the themes from the transcripts, which were based on the themes of the interviews which included instrumental, informational, and emotional sources of support. Participant demographics were captured with a mean age of 65, and 19 having had a radical prostatectomy. Six had radiotherapy and five received other treatments. Participants were between one and eleven years post treatment. Participants reported receiving help and support from a variety of sources, which included family, friends, partners, and carers. The authors reported that single men tended to want less support, commenting that they had turned down support and wanted to assert their independence more. The participants discussed the need to seek additional information and support from support groups, commenting that they wished to have more support groups that were aimed specifically at gay and bisexual men affected by prostate cancer and more locally based to their homes. The study had several strengths in that it was able to recruit a large sample of 30 participants, albeit not very diverse. The study is therefore larger than most of the qualitative studies included in this review. The authors did not report the stage of disease of the participants, indicating that might have included people who were receiving treatment for early stage cancer, and those with advanced prostate cancer who may have different support needs. In addition, relationship status was not captured, and this could signify a key area of support post diagnosis. The authors acknowledge that telephone interviews, whilst advantageous in recruiting a large range of participants from across the region, will have lacked the level of emotional depth of a face-to-face interview especially when establishing rapport with the participants. Capistrant et al’s (2016) research demonstrates distinct patterns of social support needs and providers however the participant’s social circumstances and relationships with family origin could be explored further.

It is known that many persons with cancer draw strength from religious or support groups in addition to their partners (Balboni 2013), however this is not widely discussed in the literature. In this review one study, conducted by Varner (2004), recruited a convenience sample of eight lesbian women diagnosed with cancer, to examine the experiences and effects of religion and spirituality. A sample of convenience was employed for this pilot study in a large city in the USA. The use of flyers posted in feminist bookshops, advertisements in newspapers, and word-of-mouth were used to be able to publicise the research. The participant's length of time since initial diagnosis ranged from 10 months to 3 years, and all the participants were aged from 41 to 55 years old. The recruited women were from a variety of religious backgrounds, including Methodism, Catholicism, Judaism, and Baptism. Six of the participants were in relationships, and two were single, having come out as recently as five years ago or as long as 20 years ago. One-to-one semi-structured tape recorded interviews were conducted with the participants, all were transcribed verbatim and analysed thematically. Interviews lasted 45 to 90 minutes with open ended questions such as "tell me about your journey with cancer", and "how has your spirituality and/or religion been affected during your journey with cancer". Data were analysed and coded openly line by line by the researcher. Distinct themes emerged, which revealed participants finding some degree of support through spirituality, although the definitions of what spirituality meant varied between the participants. The participants indicated that religion was something that they found to be a source of support; however no participant still worshiped formally within the religions from their upbringing. Varner (2004) appears to be unique, in that their research indicates LGB people can draw on support from religion during cancer treatment, and that healthcare professionals should include spiritual needs in needs assessments. Limitations of the research include the convenience method of sampling, which means that the views are not easily generalisable to the wider lesbian population. In addition the authors reported that one of the interviews had to conclude early as the participant became very distressed, and a tape recorder malfunctioned during an interview, cutting it short. Given that my research is to recruit Scottish participants, and I know in my own social network that there are members of the LGB community that are active within local churches and faith groups, I have found it surprising that aren't more examples of LGB persons finding support through religion in the literature. This could represent a missed area of exploration, and highlights possible limitations of research gravitating towards negative care experience rather than trying to establish LGB persons' holistic needs. Holistic needs are a key aspect of delivering person-centred care and therefore this area will need to be explored more within my own research.

Paul et at (2013) undertook a series of semi-structured interviews with sexual minority women affected by breast cancer. Thirteen participants were recruited from community-based organisations and underwent one-to-one interviews which were audio-recorded, transcribed verbatim, and analysed thematically. The participants ages ranged from 29 to 56 years and they were predominantly white, Jewish, and in long-term committed relationships.

The cancer stages of the participants were included in the publication and ranged from non-invasive breast cancer, to stage 3B, with a medium time of 17 months since treatment. The participants all identified as lesbian or bisexual and lived in New York City, and the recruitment strategy included newsletters and community boards in organisations serving lesbian and bisexual women. Interviews lasted approximately one hour, taking place in the university, and were facilitated by the researcher or one of three PhD students. The authors discuss how the original study focused on decision-making with regard to breast reconstruction, and that this secondary research was a result of a separate qualitative analysis of the original data. The initial coding was therefore modified into a set of key domains and themes, which were then applied the transcript data. Domains related to sources of support from organised groups, family, or partners. Participants emphasise the importance of Cancer support groups and resources that were tailored to lesbian and bisexual women affected by breast cancer. Partners and family members origin were typically the participant's primary source of support, with single women facing the greatest challenges in terms of lack of support. Participants discussed heteronormative care systems, and a lack of inclusion for same-sex partners. Limitations of the research included the lack of ethnic diversity of the participants, and the median age of the participants being less than the typical age of people affected by breast cancer. In addition, family and partner support may vary across time and place due to differing attitudes towards homosexuality and same-sex marriage.

Body image

This review found contrasting views on body image and sexual minority individuals appear to be affected in different ways. The literature uncovered in the review examined body Image as a multidimensional structure, with articles including reference to cognitive, behavioural and emotional components. For example, Boehmer et al (2007) also examines the decision-making process of sexual minority women affected by breast cancer when examining their options for reconstruction. The researchers recruited a total of 15 lesbian women who had received a mastectomy as part of breast cancer treatment, along with 12 support persons were most important to the participant. The researchers employed community-based purposive sampling to avoid the challenges of recruiting generally from lesbian populations, as this can be difficult when recruiting from hidden or vulnerable populations. However, they didn't record how they did this for example through a support group, or LGBTQ organisation. The research had a roughly equal split of women who had undertaken reconstruction (n=8) or declined reconstruction (n= 7) representing an equal balance of experience. Most of the participants had experienced a variety or combination of treatments for cancer such as radiotherapy, and chemotherapy. It wasn’t reported where the research was conducted, but fourteen of the women were white, with one identifying as African America, indicating that the sample was not very diverse. Participants were invited to participate in a semi-structured interview lasting thing on average 90 minutes. The interviews were conducted to investigate several broad domains throughout a patient journey including diagnosis, treatment course, decision-making, and sources of support. Then there was a review of the persons feeling of adjustment. When interviewing the participants key support person were consented separately, although their demographic information was not recorded. The audio recordings were transcribed verbatim and then analysed using grounded theory methods. The authors recorded themes emerging from the data that included all women entered into in terms of the decision-making process, such as women with smaller breasts feeling more comfortable in rejecting reconstruction, and larger breasted women struggling with the implications of mastectomy. Fears of being unbalanced and having to wear prosthetics also factored in decision making. The Importance of self-image was another issue that was identified by many of the participants when influencing who chose to undertake reconstruction or not. In the research it was found that body strength and physical functioning were more of an important consideration then aesthetic considerations in the women. This research provides an indication of the motivations and value systems of sexual minority women in relation to their body image and prioritising a sense of overall well-being including their strength, survival and physical function over their outward appearance. The researchers reported several limitations including the reliance on a small convenience sample. The authors also acknowledge that due to the retrospective nature of the research there is the potential for recall bias to occur.

Rubin and Tenanbaum (2011) recruited a total of 13 lesbian and bisexual women who in the last seven years had undergone a mastectomy as part of cancer treatment. The aim of the research was to address speculation that sexual minority women were less motivated to undergo a reconstruction. The participants were all aged from 29 to 56 years old and were recruited via a newsletter for a New York City based LGBT organisation. Hour-long interviews were conducted by the author (n=8) or by doctoral students whose is ethnicity matched the participants. Although an interview schedule was used, different interviewers may introduce an inter-researcher bias or inconsistency in the data collection. Recordings were transcribed verbatim and then subjected to a theoretical thematic analysis. The authors suggested that their ‘theoretical’ thematic analysis differed from a standard thematic analysis devised by Braun and Clark (2006), as the authors were focused on finding data that related to specifically to breast cancer. Participants were described as either white (n=12) or Latina, all educated to a minimum of college degree, and as such did not represent a very diverse sample of the population. Five were single, one was divorced and the remainder were in long-term partnerships/married, with 11 participants identifying as predominantly Lesbian. Participants were invited to discuss the decision-making behind their reconstructions. Finding suggested that the women who underwent a mastectomy faced similar anxieties and influences as heterosexual women reported within the literature. They expressed wanting to feel whole, and normal, and avoiding the use of prosthetics. Despite the participant's sexual orientation, issues around femininity and culture impacted on the women's cosmetic concerns. This research challenges the speculation that lesbian and bisexual women hold a different set of priorities when it comes to their decision making processes with reconstruction. This research had a number of limitations, for example the participants that were recruited had predominantly undergone reconstruction and this could influence the views then presented on behalf of all women that are offered reconstruction. The participants were also younger with medium age of 44.5 years compare to the median age of diagnosis of breast cancer within the United States. The authors stated that younger women are potentially more likely to access support resources, and that surgeons are more likely to discuss reconstruction with younger women, which is likely to have influenced the participants' decision-making. Finally, the study recruited from an LGBT specific support group for breast cancer, with the authors remarking that the participants may have had more support needs than women who didn't have to rely on these services. Participants described their identities from a political, sexual and gender perspective when discussing their motivations for reconstruction, and although revealing that sexual minority women have similar motivations as heterosexual women with regards to their reconstruction preferences, demonstrates a novel aspect of research by discussing the impact that body image can have on identity. When examining the Person-centred Practice Framework, these contrasting choices demonstrate that there cannot be a 'one size fits all' approach to providing persons with access to treatments.

Filiault et al (2008) conducted a study in Australian recruiting a total of two gay men affected by prostate cancer, with one of the participants having a partner present in interviews. Authors described the methodology as small focus group type interviews, although each of the participants were interviewed separately. Both authors conducted the interviews which followed a semi structured fashion design to explore questions around issues that related to relationship changes, sexual activities following treatment, and heteronormativity that may be experienced from healthcare staff. Participants particularly focused on some of the challenges around body changes during the course of their recovery from cancer treatment. One participant remarked in particular about the impact on the sense of self, body image, and their desires to other gay men towards himself, and when discussing the effects of scarring on his abdomen following a prostatectomy. This research is only presented as a pilot, so acknowledges the limitation of a very small sample size, however the views of two participants may not be representative of prostate cancer patients who identify as being gay at large. Furthermore, the demographics of the participants are not recorded within the research publication, nor did it indicate how long the participants had been together in their relationship. Despite these limitations, the study does discuss experiences that are similar to those found in other literature, but it should be noted that the authors asked targeted questions around these issues, rather than a more open exploration of gay men’s priorities. The research recruited through a local centre for gay men’s health, and cited that there may have been a reluctance to participate in people who had had negative experiences with care in the past. However this appears to be the position of the authors, and not the participants.

Sexual Function

A report released by Prostate Cancer UK and Stonewall summarises a day workshop in which key stakeholders including men affected by prostate cancer, researchers, and healthcare professionals were all brought together to explore the various issues that may be faced (Levy and Taylor 2013). The report was found in grey literature, and was deemed worthy for inclusion within this review given the paucity of the findings. Unfortunately the report does not contain information on exactly how many participants attended the workshop, nor was any information provided in relation to the data analysis. However the report is useful in the fact that it contains extracts from participants including those affected by prostate cancer. The report summarises a series of recommendations to support prostate cancer UK and their strategic priorities concerning support for gay bisexual men affected by this disease. The report concludes that there are some specific needs around the masculinity and sexuality of men affected by prostate cancer, information and support needs, and the need to have inclusive images and language within information that is created. The project also highlighted the need for support from other gay men and partners in the same position. The project includes a commitment to develop training materials for staff, and information targeted specifically towards bisexual men affected by prostate cancer. This should include personal stories, accounts and a commitment to involve those that are affected by cancer in developing any advice and support. This literature review corroborates these findings by uncovering a variety of sources that explore sexual function after cancer treatment, however, it must be noted that the effects of any cancer treatment to the pelvis area can result in physical impacts on sexual function, not to mention the more broader effects that can impact on a person’s mood and arousal after cancer treatment.

Asencio et al (2009) conducted research examining gay and bisexual men‘s knowledge of prostate cancer and its effects. The researchers conducted four focus groups in a small city in the USA, comprising a very diverse sample of thirty six gay and bisexual men. The potential strength of this study is that is encapsulated the views of minority populations within the LGB community. One of the focus groups was conducted in Spanish, another group was comprised of entirely African-American men, and the remaining focus groups had men of mixed ethnic background. Participants were invited to engage with the focus groups to investigate their knowledge of prostate cancer, its treatment effects, and their views about how erectile dysfunction and anal problems following treatment would affect same-sex relationships. Sessions notes and audio recordings were transcribed and analysed thematically by the researchers. Findings indicated that many of the men were unaware of their internal anatomy and lacked exact knowledge of where the prostate gland was, as well as being on unaware of the complications and potential impacts of prostate cancer treatment on sexual function. Many of the participants also commented that their ability to be able to have sexual intercourse was a fundamental aspect of who they were, indicating that a loss of sexual function would impact significantly on same-sex relationships. Seventeen of the men were not partnered, however details of whether they had a previous diagnosis of prostate cancer are not included in the publication. This represents a significant limitation of the research, as it opens up the possibility that the participants were only informed about prostate cancer and its effects by the researchers and not by a qualified oncologist. In addition, the mean age of the participants was 49.3 years old, which is significantly lower that than the average age of those affected by prostate cancer. Considering that the research is focused only on the sexual side-effects of prostate cancer treatment, the authors canvassed views of men who were younger and therefore more likely to be sexually active (Lewis et al 2004), rather than those who are older and more representative of men affected by prostate cancer.

Further research conducted in Canada by Lee et al (2013) undertook a pilot study examining the quality of life and sexual function of gay men affected by prostate cancer. Seven participants had a mean age of 58 and had been treated with surgery, while eight others had a mean age of 67 and had been treated with radiotherapy. The Canadian participants were recruited purposively through health clinics, radio and flyer advertising. To be eligible for inclusion men had to declare that they had sex with men, and that they had had surgery or radiotherapy for prostate cancer. No minimum or maximum time was needed to have elapsed from treatment to be included in the research. Demographics indicated this ranged this from 8.3 months to 184.3 months post treatment, representing a wide range that could influence results. Quality of life was assessed using a 50 item questionnaire, known as the

Expanded Prostate Cancer Index Composite (EPCI), and a questionnaire asking participants to score sexual function, ejaculation, desire, and sexual activity, known as the Male Sexual Health Questionnaire (MSHQ). Higher scores indicated better levels of satisfaction. Neither questionnaire catered for men who had sex with men specifically. They were sent to the participants through the post once they had consented to the research. The sample size meant that the results couldn't be formally statistical analysed, however potential differences were found in urinary and bowel domains of the EPIC and the ejaculation scores from the MHSQ. Participants from the radiotherapy group were able to maintain both insertive and receptive intercourse after treatment which was not the case with those who had surgery. However, given the limitations of the small sample size this conclusion not cannot be definitively drawn. In addition, as quality of life can change over time, the large variation in time post-treatment indicates another limitation of this research. Studies examining the effects of treatment in heterosexual men have found loss of sexual function to be a significant impact; however, gay men's sexual practices may be impacted on more by certain cancer treatments (Sanders et al 2006 and Knight et al 2009).

A larger international study by Wassursug et al (2013) conducted research to measure the outcomes and differences between heterosexual and non-heterosexual men treated for prostate cancer. The researchers recruited 460 self-identified heterosexual men and 96 gay and bisexual men to complete an online survey. The study was advertised to recruit from 17 different countries, (USA 63%, Australia 18%, Canada 9% and UK 6%), and took approximately 20 minutes to complete. The research was publicised through men's health services and inclusions in websites, Facebook, emailing lists, newsletters, and a combination of these. Ninety-four percent of participants received treatment for prostate cancer, with 61% having had this in the last three years. Treatments were broken down as: 44% open prostatectomy, 36% robotic prostatectomy, and 26% radiotherapy. All responses were anonymised, and participants were directed to complete the survey through links in the advertisements. Questions focused around sexual practices after treatment and were generated from standardised and validated questionnaires such as the Expanded Prostate Cancer Index Composite. Question responses had five point Likert categories, ranging from "almost all times" to "never or almost never". Logistic regression was used to identify and compare differences between the two groups. The authors reported that there was no significant difference in the ages of the participants or the side effects experienced in the two groups. However, the gay and bisexual men reported significantly higher rates of being bothered about their inability to ejaculate (P=0.04), suggesting that gay and bisexual men appear to be more distressed by this effect. The majority of respondents came from affluent countries with higher social economic status, meaning that they may not be representative of men with prostate cancer at large. In addition, the authors report that 31% of the respondents were less than 65 years of age, suggesting a less representative sample of men affected by prostate cancer. The authors also felt that older men may have different support needs and challenges that arise from a prostate cancer treatment than younger men. The gay and bisexual men recruited from other countries were also low in number, with most participating in the research from the USA. The research also relied on patient reported outcomes rather than independent measures and this may not be as reliable as data from medical notes.

Hartman et al (2014) undertook a longitudinal study examining sexual dysfunction post prostatectomy at 3 to 6 months, 12 to 15 months, and 12 to 24 months follow-up intervals. They employed the use of interviews with individuals who received surgery for prostate cancer and their partners from one centre in Canada. To be included in the research, all were initially between three and six months follow-up and had reported sexual dysfunction as a result of treatment. Semi-structured interviews were undertaken with the use of open-ended questions focused around sexual interest in functioning, the use of assistive devices, implications for intimacy, and satisfaction with supportive care. All were conducted face to face, and were recorded and transcribed verbatim for independent analysis. Transcripts were independent reviewed, and then scrutinised by the research team to cross validate. Phenomenological coding was undertaken inductively examining the unique lived experience of the participants, and care was taken to synthesise data without comprising the uniqueness of each of the participants. Three couples aged between 42 and 62 years of age were recruited to participate in the study. They were recruited purposefully from a cohort of 25 couples, and were asked to explore the effects of surgery on sexual function; however these three couples identified as being in a homosexual relationship, so were selected as the primary focus of the study. Participants discussed changes in sexual experience and accommodating these, which included changing of sexual role to being anally receptive during sex, and on occasion opening relationships to alternative partners. The authors reported the findings as novel, demonstrating that gay men explored openness of relationships, and changing of sexual roles which was something that they felt was not observed within heterosexuals. The article had several limitations which included a lack of comparison with heterosexual counterparts, and reveals a level of assumption regarding heterosexual relationships and accommodation practices around loss of sexual function. The authors report that the research was limited by the lack of diversity of participants, and lack of specificity with regards to the types of support received which can affect the level of sexual function post treatment. Nevertheless the article reported the needs of several gay couples relating to their sexual function post cancer treatment, and also proving some insight into their concerns around heteronormative care practices and lack of support.

Arena et al (2007) used a postal survey recruiting from across the USA, to ascertain the opinions of 78 women, of which 39 of whom were lesbian, about their sexual adjustments following breast cancer treatment. Participants in the two groups were matched by age, stage, time since diagnosis, and race. Questions were designed to focus on psychosexual adjustments following treatment and took approximately one hour to complete. Psychosexual adjustment was measured using self-ratings of attractiveness (e.g. how physically attractive do you feel you are?), with likert scales ranging from zero (not at all) to four (extremely). Sexual concern was measured using a Psychosocial Adjustment to Illness Scale, with each question having it’s own separate response options. Findings of the study indicate that heterosexual and lesbian women adjust post-treatment in different ways from a psychosexual perspective. Lesbian women reported lower levels of sexual concern when analysed using Cronbachs alpha (0.76 amongst lesbians and 0.91 amongst heterosexuals) and less investment in their appearance (0.84 amongst lesbians and 0.67 a no that heterosexuals). The authors reported several limitations to their research, which included a selection bias as the participants were recruited through a sample of convenience. In addition the pairing of heterosexual to lesbian participants was based on several characteristics; however educational status was not taken into consideration. The authors reported that the lesbian participants were more highly educated than their heterosexual counterparts; however both groups were more educated than the general population and predominantly white. The results, therefore, may not be representative of typical breast cancer survivors. The sample was also smaller than what would be desirable when exposing the data to statistical significant analysis, indicating that the results should be interpreted with a degree of caution.

Doran et al (2018) conducted a qualitative study examine the experiences of bisexual men affected by prostate cancer within the UK. In-depth interviews were carried out with 12 participants who had received a diagnosis of prostate cancer but who were not in the active phases of treatment. A comprehensive strategy was devised using snowball sampling and adverts aimed at the gay and bisexual men throughout England’s prostate cancer support groups. The research unfortunately didn’t recruit any participants from any of the devolved nations within the UK, indicating that only the experiences of men in England were captured as part of this research. The average age from initial diagnosis was 56 years old and the participants ranged from 1-16 years post treatment. Ten of the participants had ongoing cancer treatments such as surgery, radiotherapy and brachytherapy, and two participants were under active surveillance. The researcher also captured data on HIV status, indicating that two participants were positive for the virus. Semi-structured interviews with open questions were used following a phenomenological approach. Interviews were audio recorded, lasting between 64 and 164 minutes, and where transcribed verbatim. Data collection and analysis were undertaken simultaneously which involved the researcher identifying selected words and phrases in isolation and against the dataset as a whole. Four key themes emerged from the data which related to information needs, relationships with healthcare providers, the need for support networks, and sexual wellbeing. It was noted by the authors that sexual wellbeing affected every aspect to the participants lives and was a consistent thread throughout. Participants wanted candid discussions with health professionals about how treatment would affect their lives and sexual function, and that culturally relevant support for gay and bisexual men should be developed and available before and after treatment. Participants felt that their health practitioners had little understanding about their needs and about how their experiences were different because of their sexual orientation. In addition, heteronormative assumptions were also discussed as part of the care experience. Limitations of the research include the lack of participants from the devolved nations within the UK, the lack of diversity from Black and Asian minority ethnic men. Difficulties were also experienced by the researchers in recruiting participants into the research, leading to a need to simultaneously analyse the data, rather than reviewing the whole data set once collected had ceased.

Hermeneutic Interpretation and macro findings

The findings of this review have been thematically presented up to this point. Next, in accordance with the Hermeneutic process, I consider the whole literature base, to make interpretations of the review findings, which then feed-forward into my own research. As I engaged with the research, I uncovered further literature and the collective literature presented in this chapter informed my interpretation of the inquiry findings, as well as possible ways of addressing the findings through action, with the final aim of bringing this together when formulating the final guidance. This review feeds into my method, by providing further rationale of a person-centred and empowering approach to the research. It is clear from the literature that LGB persons can be underrepresented in studies and the review helped me to generate ideas for the approaches I undertook with recruitment, such as working with stakeholders in advance of the inquiry to establish trust and increase participation. It also made me more informed when engaging with my participants and helped me to support them when they found difficulties themselves, for example helping me to provide reassurance that they were not on their own when experiencing some of the issues they faced in the care environment and lack of LGB specific support. This approach can be seen through my chapters that include findings and discussion.

In this next section I will discuss the meaningful findings behind some of the research and how this informs the understanding of LGB persons' experiences of cancer care derived from the literature. Through doing this, it allows a better overview of some of the issues LGB persons face and some of the areas that need to be further explored within my own research. I have identified three main issues to include in the following synthesis.

Limited UK perspectives in the research

My literature review has uncovered a diverse picture of the LGB person's cancer experience across multiple countries. As I integrated these findings into my own research it was important to note the following key issues, i) the subject of the LGB person's cancer experience is a newly emerging research field, and ii) the pace of change of LGB persons' social acceptability and legal reforms vary considerably across the world. In terms of implications for my research, the literature presented limited perspectives of LGB persons. This has the effect of portraying the needs of LGB persons with cancer as being narrowly focused around patient and health practitioner interactions and its impact on sexual function. These needs are important and should not be disregarded, however the outcomes and priorities of LGB persons within the literature are flattened, even demonstrating a uni-dimensional portrayal of LGB persons in cancer research. This then gets transferred to practice as research is disseminated, enhancing the effect of a 'dumbed' down identity or personhood. The findings of this literature review may not be generalisable to a Scottish UK population and their experiences of cancer care which adds further rationale and justification for undertaking a person-centred inquiry to establish LGB person's needs.

Issues with identifying as LGB and being out

Research that aims to recruit LGB persons as a target population can sometimes struggle to find participants and this is for two main reasons. Firstly, some individuals struggle to identify with more traditional and binary terms such as being a lesbian, gay or bisexual person. Secondly, there are many LGB persons who are not out to their care providers or indeed in their day-to-day lives and wider society. This then makes engaging in LGB specific research potentially problematic for these individuals. These issues are raised and discussed within the literature gathered in this review, particularly within the studies conducted in the UK and Canada by Doran et al (2018), Fish and Williamson (2018) and Hartman et al (2014). Relating this to my own research, I was mindful of some of the issues I may have faced when trying to recruit from this population and representing the more fluid and non-out members of the LGBT community. I discuss this in more detail in chapter four. One of my principal aims was to ensure a diverse representation within my research that draws across the spectra of the LGB elements of the LGBT community. These members of the LGBT community have had less of a presence within most of the literature uncovered in this review. The phenomenon of not being out is explored within the literature and there are examples of research which recruited non-out participants conducted by Doran et al (2018) and Allensworth-Davies et al (2016). However, these research studies are in the minority when considered against the larger evidence base although they are relevant when establishing support and care needs. Allensworth-Davies et al (2016) suggests that not being out can impact on a person's wellbeing, especially when receiving treatment for prostate cancer. This finding raises the question of whether this issue could be faced by persons with other cancer disease types. LGB history and historical acts of discrimination may be a contributory factor as to why a LGB person may not wish to disclosure their sexual orientation (Shetty et al 2016). As such, this means that some LGB persons may not be out to their care providers, although some individuals may be out to some persons in their day to day lives or inner circles. This can be attributed to fear of rejection, harassment, violence, losing one's job, or other concerns. Given LGBT history over the past 50 years within the UK these fears are perhaps unsurprising attitudes for a person to hold. In my research it was therefore important to find methods that encouraged the participation of all LGB persons affected by cancer, including those that were not out and have types of cancer other than prostate, to ensure their voice is heard. These findings have directly influenced some of the key principles of my research such as providing safe and communicative spaces that enabled persons who feel vulnerable to come forwards and participate in the research.

Lack of person-centeredness demonstrated towards LGB persons

There are examples of LGBT persons with less positive experience of accessing a range of health services within Scotland, but it is unknown whether this translates into the cancer care setting. The Equality Network (2016) report in Scotland examined the experiences of LGB persons when accessing health care generally, indicating that one in five LGBT respondents experienced discrimination or poor treatment when accessing NHS Scotland's services. Other respondents raised concerns about healthcare staff not being adequately trained in understanding issues specific to LGBT persons such as same-sex partners being a next of kin. This would indicate that despite the current healthcare policy towards delivering person-centred care in Scotland there are examples of persons' core beliefs not being taken into consideration when delivering their healthcare. However, the limitation of this report is that it only indicates a snapshot of practice across healthcare in Scotland, and doesn't provide focus on the experience within a cancer care setting. It has therefore been the goal of this review to determine examples of care from across a variety of healthcare settings and encompass a world-wide perspective on LGB person’s cancer experiences. This assisted me in the development of approaches undertaken in my PhD research and informed the current evidence base in this field.

One of the key findings of this literature review is that there are clear acts of discrimination demonstrated towards members of the LGBT community when accessing healthcare in the cancer setting. There may be nuanced hints of homophobia from health care staff, for example, experienced as awkwardness between healthcare staff and participants, such as where there is an awkwardness or discomfort experienced in the care setting which is attributed to the person’s sexual orientation. Many discuss awkward situations around the disclosure of their sexual orientation which can be met with mixed positive, negative and sometimes extreme responses (Boehmer and Case 2004, Boehmer et al 2005, Kamen et al 2015, Fish and Williamson 2018). When considering this from a person-centred perspective, I am drawn to attempting to work out why a person may feel uncomfortable about disclosing their sexual orientation to healthcare provider. I feel this area could have more exploration within my own research to aid in informing and educating healthcare providers as well as documenting the occasions where cancer professionals get things right. Given the LGBT community’s history, it is perhaps unsurprising that the healthcare setting could be interpreted as a non-safe space, however this question is not fully addressed within the literature when examining the LGB cancer experience. Where acts of discrimination are more nuanced or result from misunderstanding, I think that if there were more focus on providing a more holistic style of care which is delivered in a non-judgemental fashion and modelled on mutual respect, there may be fewer awkward moments in the healthcare setting. Methods of how to facilitate the disclosure of sexual orientation are not fully explored within cancer literature, with the exception of Fish (2019). There is a lack of examples of when healthcare staff get things right. This presents a potential bias towards documenting negative care experience and ignoring what can be learnt and shared. Within the wider literature base, LGBT people describe experiences of healthcare providers that practice in judgemental ways, and it is important to learn from these experiences (Stonewall 2015 and Equality Network 2016). My research aims to make provision to explore this area by encouraging critical reflection amongst the participants, to establish when things have gone well and when things have gone badly. There are also opportunities for key stakeholders to engage in the formulation of guidance to feed forward for cancer professionals to use.

There is an apparent lack of literature that examines a broader view of LGB persons, or examining the effects of cancer treatment to establish support needs. For example, there were no examples of issues raised when it came to LGBT parenting perspectives, carer needs, or financial issues, and few examples of ongoing isolation and religious perspectives. These areas of personhood may be relevant to anyone who has had treatment for cancer and not just LGBT persons, but through the eyes of an LGB person could present a unique perspective that could contribute to their overall well-being. For example, not being able to work due to cancer treatment and being more likely to live on their own without social support could be compounded because of a person's sexual orientation. There are examples within the literature which explore LGB person's problems and needs when accessing cancer services in relation to physical sexual rehabilitation (Rosser et al 2018, Asencio et al 2009, Lee et al 2013), and further literature uncovering discriminatory acts of care (Jabson et al 2011 and Katz 2009). However, I feel that this demonstrates a limited depth of who LGB persons are. This doesn't detract from other researchers' key findings and the relevance of their research, indeed this has led to development of useful guidance and support for gay and bisexual men affected by prostate cancer so far in the UK (Levy and Taylor 2013, Ralph 2014). Little has been done, however, to develop tailored support for LGB sufferers of other cancers such as head and neck or breast cancer.

Based on the literature uncovered I believe it is necessary to have a more rounded view of LGB persons. This is to better inform the need for support and be more representative of the LGB cancer experience. It is necessary to ascertain what can be done to ensure that LGB persons can access general or sexual orientation specific support services and groups. The literature recognises that LGBT service users may feel isolated when using cancer support services and there are recommendations to ensure that activities and discussions are inclusive (Katz 2009, Paul et al 2013). Recommendations from Macmillan also suggest that there should be consideration of developing cancer support services specifically aimed at LGBT persons, such as a support groups due to some LGBT persons appreciating meeting other LGBT persons and carers with cancer (Macmillan 2019). There are also recommendations around creating LGBT inclusive literature and information when developing cancer support materials.

In addition to establishing experiences of care, I have felt it important to ensure I take note of good examples of research methods and the underlying theoretical basis that could be incorporated into my own PhD, and learn from others when trying to engage the LGBT community. When considering the body of research and the recruitment methods employed there are good examples used by the researchers in Canada and UK when attempting to facilitate shared decision making in the design of the research and suggest a more person-centred philosophical approach, although these studies are in the minority. In these studies, researchers can be seen to be building capacity and support from within the LGBT community, however most research in this review highlights a lack of person-centred care experienced by participants before they become involved in research. As a result, this represents a potentially empowering aspect of being able to participate in such research, and that suggests the involvement in such studies can be therapeutic and meaningful for the participants. Fish and Williamson (2018), Sinding et al (2004), Sinding et al (2007) and Barnoff et al (2005), demonstrated community based participatory approaches through the co-construction of research in partnerships between researchers and LGB persons affected by cancer, although the majority of this research was conducted in England and in Toronto, Canada. The participatory approach has potential benefits over more traditional forms of research as it ensures that it is culturally appropriate, is person-centred, enhances recruitment capacity, generates capacity and competence in the community, and increases the quality of outputs and outcomes. I feel there are many benefits to this approach when considering my own research design and approach to working with a marginalised and hard to reach community.

Limitations of this review

The vast majority of the articles included participants from mainly white middle class and well educated backgrounds. As a consequence they are not entirely representative of the wider LGBT community. In addition, literature searching was a challenge due to the diversity of classifications of sexual minority persons, resulting in the potential for missing published research. Very few of the uncovered studies consider intersectionality and there is poor inclusion of other characteristics such as disability and ethnicity. There are also many aspects that are important to most persons during cancer treatment and diagnosis that don’t feature as priorities within the published data, such as parenthood and carer responsibilities. The majority of the studies in this review that are quantitative in their paradigms do not have controls making it harder to draw conclusions and measure their impact across the whole LGB population. Finally, due to the varying degree of protective legislation and societal acceptance of LGB people worldwide, it is challenging to draw direct comparisons between some of the studies and their application to UK healthcare for LGB people.

Summary and Conclusions

The aim of this review was to undertake a Hermeneutic exercise that encompassed the worldwide research literature base to evaluate, assess and obtain a perspective on LGB persons’ experiences of cancer care, and this was achieved. The literature included has provided an overview of some of the needs and experiences of LGB persons affected by cancer. Many of these needs are similar to those of heterosexual populations, however there are examples of deficiencies in support, and LGB specific issues that have failed to be addressed. LGB persons have shown that support in some cases is entirely absent, and where occasionally present, may not be taken up because of previous past experiences of homophobia and lack of assurance of care. Evidence of negative care experiences has certainly been established in this review, however there is a mixed approach to how to address these with the confidence of LGB persons. The full picture of how cancer affects LGB people and their resultant support needs has yet to be addressed within the UK literature base, but there is an emerging picture warranting further investigation and research.

LGB people in the UK cannot be assured of healthcare delivered in non-judgmental ways, nor are their specific health needs addressed (Stonewall 2015). Some research has been undertaken to examine the needs of LGB persons with specific cancers and has been discussed in this review revealing that LGB persons have distinctive experiences and needs of cancer services (Hill and Holborn 2016; Doran et al 2018; Fish and Williamson 2018). These studies start to portray a picture of discriminatory attitudes within care towards some of the participants; however none of the research has focused on a holistic view of a person’s identity. Further, research to date has not specifically reviewed the effects of cancer treatment on personhood. The literature on person-centredness does not address sexual diversities and as such this needs attention. There is an emergence of a more person-centred approach with care in cancer, and my role as a cancer service manager is central in helping to drive this trend. I argue that persons’ sexual orientation should be considered in the context of personhood and be taken into consideration when planning services, treatment and care provision. Ultimately, there is a need to ensure that cancer services are meeting the needs of all users including persons that identify as LGB and up until now these needs have yet to be fully met.

7. Methodology

Part 1 - Methodological Principles

Introduction

Throughout this chapter I focus on the key methodological principles to my research. I begin by discussing what participatory inquiry is and in doing so demonstrate how I draw on the philosophical tenets set out in previous chapters. I discuss how my methodological principles integrate into my research paradigm of Critical Social Theory. I emphasise that facilitating critical reflection amongst participants is a key facet to my research. Further, in this chapter, I will set out the distinction between participatory action research (PAR) and participatory inquiry (PI) and demonstrate that my research falls into the latter. I discuss how I feel that to be person-centred in my research is something that is important to me and this ethos is a driving factor behind my selection of a participatory inquiry. I have therefore selected methodological principles that are focused on placing those that are involved in my research as central to the design, implementation, and analysis stages of the research.

I intend to show that individuals that share common perceptions and interests can come together in a safe space, arrive at an agreed, mutual understating through discourse and reflection, and then can seek to address issues of concern as a collective or group. In my research I define ‘a group’ of persons as ‘the researcher’, ‘the key participant affected by cancer’ and if available, their ‘key support person or persons’. This permits the participants, who may be less ready, have fewer capabilities in knowing and asserting their own needs, and potentially less able to seek information to address marginalisation to come together, better define their problems or needs, and then be able to feel empowered through a new understanding and learning of their experiences.

Defining Participatory Inquiry and Participatory Action Research

My research is an investigation into the effects of cancer treatment on LGB person’s identity as part of their overall personhood. I have opted for participatory inquiry and its associated key methodological principles. Participatory inquiry (PI) and Participatory action research (PAR) are closely related but are distinct methodological approaches. It is important for me to address the differences and commonalities and discuss critically why my research fits more within participatory rather than action orientated research to provide a rationale behind my selection.

Kurt Lewin (1890 – 1947), is described as a pioneer in developing action research (Alderman 1993). As a professor at Massachusetts Institute of Technology he published the seminal work '*Action Research and Minority Problems*', and defined action research as:

> '*A comparative research on the conditions and effects of various forms of social action and research leading to social action*' that uses '*a spiral of steps, each of which is composed of a circle of planning, action, and fact-finding about the result of the action*'
>
> (Lewin 1946 p34).

This process is referred to as the Lewinian spiral which places the onus on participation and action within communities (Dickens and Watkins 1999). PI is similar in many of its principles, and I go on to explain this further in the chapter, but PI is distinct as the primary goal is the inquiry into the co-defined problem rather than the resultant action. The participatory inquiry in my research is based on the work conducted by John Heron (1928), pioneer of co-operative inquiry. This was developed by Heron, based on his work in 1970 on the phenomenology of social encounter (Heron 1970), which has been applied by practitioners in many fields of professional and personal development. Heron and Reason (1997) define the tenets of co-operative inquiry. A group or community come together to be define matters that they need to investigate and how they wish to explore these (propositional knowing); they work together or separately within a common field or community where there is shared understanding of the context(practical knowing); this then results in the development of new understandings and appreciation of the area being investigated (experiential knowing); and as a group go on define and categorise representations of issues they encounter (presentational knowing) which results in a revision of the originating questions. PAR then takes the next step in the process to enable rather than encourage those involved to take action as part of the research process.

The participatory inquiry used in this research differs slightly from a cooperative inquiry as the participants work in smaller groups with myself to explore their experiences, rather than with each other in community cooperative. Further, I initiated the research process with my participants, so started the initial line of inquiry. Typically, in a cooperative inquiry a number of individuals in the same community would come together to address a common concern, but it was necessary for me to seek out and find those affected by cancer treatment in the first instance. Following this the participants worked with me to develop further understanding of their experiences and then formulate recommendations for practice through use of participatory rather than a cooperative method.

Sohng (1995) comments that PI and PAR are both collaborative and empowering processes because they bring isolated persons together that have common needs; this enables them to validate their experiences, engage in critical reflection, and develop understanding. My research will attempt to bring the knowledge and experiences of the researcher, in my case as derived from being a gay man and a Therapeutic Radiographer, upon which the participants can critically reflect with about their own experiences of cancer care and then examine the effects on personhood. This ‘enabled’ the participants to contextualise what might have previously felt like individual problems as broader issues in the deficiencies in cancer services to recognise their personhood. Reason and Bradbury (2001) suggest that the researchers need to be aware of how participants understand and discuss their own perspectives on life, endeavouring to find out more about the subject of the community. Ideally, the researcher would be an active member of the community with already established links and relationships. In this case as a gay man living in Scotland, I do have some awareness of the community and understand shared common language and culture, but I acknowledge that I am not a person that has been diagnosed with cancer. In addition, as a gay man I am relatively young compared with the average age of a person diagnosed with cancer and I am a man, so cannot understand what it means to be a sexual minority woman. In keeping with the principles of PI and PAR I ensured that I acknowledged these characteristics and limitations with the participants. My hope was to serve as an impetus for the participants to share further their experiences so then we could develop a more shared understanding.

The goal of PAR and PI is to ensure they both encourage collaborative researching between researcher and participant throughout the research process Chesler (1991). PAR and PI both have an emphasis on solving real problems and are used in an emancipatory context. This methodology fits well within my own personal beliefs and understandings of some of the issues LGB persons face and I can try to constructively address and influence some of these issues. Consequently, my research requires a high level of commitment and involvement from myself and the participants in ensuring a process that is holistic, flexible, and enhances shared ownership. Having presented four of the broad commonalties between PAR and PI, I will now progress the discussion by highlighting the distinctive aspects of PAR and will then provide more detail about my chosen key methodological principles of participatory inquiry.

Participatory action research

In this section I will start by discussing some of the key methodological principles of PAR by pointing out some of its distinctions with PI. I start with PAR in this chapter because I want to demonstrate its facets as I believe it to be an equally justifiable methodology as PI to addressing a social problem. However, a primary outcome of PAR is a subsequent act and therefore does not align with the aims of my research where I am seeking a deeper inquiry and understanding. I will move into my chosen methodological approach of PI and explore this in greater depth to demonstrate how my methodological principles align more with this approach and how I feel this was the more appropriate approach for my research. PAR is an approach to research which results in change for communities through working collaboratively with the participants and following reflection (Reason and Bradbury 2008). PAR also has a strong focus on trying to tackle issues of social injustice and understand entrapment systems in industrialised societies, through social analysis and critical questioning (Fay 1987). It has also been employed in attempting to address disadvantages attributed to gender and ethnicity as well as to social class. At first glance PAR would seem to fit well with my goals of the research process of trying to address some of the issues LGB persons may face when accessing cancer treatment services (Zuber-Skerritt, 1996).

PAR also aims to develop the capabilities and practices of the professional researchers, through the attainment of objectives and changing participants understandings of issues; this is done through the involvement of all parties in the planning, implementation, and evaluation of the research (Hacker 2013). The research approach is developed in partnership through discourse between the researcher and the participants (McNiff and Whitehead 2011). Whilst I acknowledge that persons affected by the issue investigated are usually in the best place to develop solutions, in my case LGB persons affected by cancer and possible discrimination, I have not involved the recruited participants in the initial design concept of my research due to access limitations to my research population. I did, however, engage stakeholders, of which many had previously had cancer, and were LGB offering the insight needed in the initial stages in the development of the methodology. In addition, PAR should also achieve practical results as well as generating new theory and knowledge. The problems that would be associated with using PAR in the instance of my research is that at this stage, LGB persons' experiences of cancer treatment have not yet been fully explored in context of their personhood within the local or national population. As such, I have felt it important to have a deeper inquiry into LGB personhood after cancer treatment to better understand the issues that they face. It is my feeling that more preliminary explorations establishing how cancer treatment affects LGB persons is needed prior to mobilising those affected in addressing the issues they face. When reviewing the literature, I felt there is a large number of unknowns in relation to this population and my research then sought to address a more holistic view of personhood that had yet to be explored in any other similar study. To pursue a PAR mode of research at this stage would have meant making an initial assumption about the participants needs.

Participatory Inquiry

Kemmis (2006) describes PI as a research method a group of person come together, to engage in a process, and then formulate a ‘local theory’ that has the potential to be actioned. Cornwall and Jewkes (2005) develop this argument by suggesting that participatory research emphasises the approach as being a "bottom-up" method, with a focus on defining perspectives and priorities of the participants involved in the research. Israel et al (2008) defines Community-Based Participatory Research (CBPR) as:

> “A partnership approach to research that equitably involves community members, organisational representatives, and researchers in all aspects of the research process and in which all partners contribute expertise and share decision making and ownership.”
>
> Israel et al (2008) page 47

It is for these reasons that I have been drawn to PI as my key methodological principle aligns well to my core belief that those individuals that have been affected by the issues should be central to the process in addressing a solution. This is a key aspect of my ontology, which is personal to me, and is the lens through which I view my research design and process.

I feel that those affected by the issues are best placed to address them, as it is their perspective that is largely being ignored, most important to them, and is key in defining the problem or research question; this is a key aspect of participatory research. From my ontological perspective, I feel that reality is defined by persons and is not fixed and is the reason that I believe in relativism (Baghramian et al 2015). I feel that through dialogue and reason perspectives of reality and morals can evolve and change over time and through education, discourse and emancipation. I believe that social reality as we understand it is biased through media, institutions and society and it is for this reason that I feel that views of reality can be influenced and changed through critical debate, discourse, and democracy (McCarthy 1992). These tenets are also foundational underpinnings of understanding social theory and explain that through critical debate, discourse, and democracy, social change can be enacted. My research will aim to bring together those affected by the issues to enable them to come to a common understanding to address issues that they face.

PI is initiated by the researcher or organisation and the participants work together in group process to study and change their understanding of their own realities (Whyte 1989). A PI, therefore is more appropriate for my PhD because I started the process of framing of the context of the research i.e. LGB persons experiences of cancer treatment in Scotland prior to participant involvement. In PI, the participants must be willing to participate throughout the whole research process, from defining the initial problem, selecting the methods of how this can be examined, analysis of the data, generating and presenting findings, and where appropriate taking action (Boga 2004 and Elden at al 1981). In my research, I worked with the participants to facilitate an exploration and mapping of their own personhood and then encouraged them to critically reflect on their cancer treatment journey, specifically focusing on its effect on personhood.

Heron and Reason (2006) describe a co-operative inquiry as a way of working with other persons who have common interests to the researcher, in order to enable a new understanding of life and to develop creative and new ways of examining things. I have chosen to blend Heron and Reason's Corporative inquiry into my research methodology and will discuss this in more detail in the next section of the chapter. However, I can see how this key principle in their ways of working aligns closely to my own and my desires to seek a shared understanding and develop new ways of looking at their experiences. Further, I also feel that my belief that good research is research that is conducted with persons rather than on persons, is also a key facet of how I have chosen to approach my research (Heron and Reason 2006).

Aims of Participatory inquiry

Having set out an overview of PI and PAR I will now develop this by discussing the main aims of PI and how these align to my core epistemological and ontological views. I have identified four main aims of PI that are present within my research such as enabling participants to serve as co-researchers, by sharing in the research process and data creation, breaking down the barriers and power play between participant and researcher, and equipping those that are affected by the issues with the skills necessary to be able to make meaning of their experiences and then go on to be able to influence change.

PI attempts to enable participants to be researchers themselves, and to support them to tackle and address issues and questions to subjects and problems that affect their day-to-day lives (Tandon 1988). I argue in chapters three and four, that there is a distinct LGB culture, as there is a sense of community and common space due to a shared common history and research to address discrimination as well as being the general recipients of past and current persecution (Adriaens and Block 2006). Through my research I have aimed to engender a sense of shared common understanding and empowerment within participants to address their experiences of cancer treatments.

PI seeks to break down the distinction between the researchers and the participants (Gaventa 1988). My core epistemological stance is that knowledge is socially constructed and there is no single truth and this is a key facet of constructivism and I therefore reject objectivism (Vrasidas 2000). I think that knowledge is a culmination of human defined constructions, such as our current understanding of sexuality and sexual orientation (Bagnoli 2011). Further, some forms of knowledge are more respected than others in society, for example patriarchy is more valued that feminism (O'Donnell et al 2004). I feel that when knowledge is created, the owners of this knowledge are best placed to determine if it is worthwhile, and is why I feel that it is key to engage participants in the ownership and creation of the knowledge that is gained through my research. As a result I also feel that knowledge and understanding should be co-created by participants and researchers (Titchen 2000).

In the process of PI, participants are placed in a position of being mobilised for action and learning more about themselves, as well as creating the knowledge of the phenomena under investigation (Gaventa 1988). PI aims to enable those that are marginalised to gather and develop skills through their own transformation and create leverage to address specific projects and day-to-day struggles (Fals-Borda 1987). I think that knowledge is both a product and expression of power rather than truth due to the fundamental aspects of a relativist view, all knowledge is ultimately subjective and constructed by society (Townley 1993). Knowledge is a compilation of human-made constructions and knowledge can therefore be changed though questioning and debate (Downing 2008; Hodson and Bencze 1998). I acknowledge that my views are different to others and can influence those around me. I am therefore as much a part of the research as the participants and can therefore be influenced by others' knowledge and views. PI differs from other forms of research. Traditional research tends to emphasise a distance between participant and researcher. PI, in contrast, advocates breakdown of the distance between participants and researcher. The process of PI research is an exploration of both parties who should be on an equal standing. Given the nature of PI as being quite different to other more traditional research methods I will now go on to discuss the strengths and limitations of this methodological approach.

Strengths of Participatory Inquiry

There are several strengths of PI over more traditional research methods and this is mainly due to its relevance to local community and aims of empowerment. Rather than just carrying out research on participants PI aims to place participants as central to the research process and thus adds a level of authenticity to the research as there is a sense of community ownership over the project (Minkler and Wallerstein 2011). PI builds local capacity and community skills as part of the research process and in turn develops the researcher's skills in areas of mediation, facilitation and development (Minkler et al 2003). It builds trust and bridges the barriers between organisations, in my case the university, my profession and the otherwise marginalised participants (Isreal et al 2001). The ultimate success of PI, as a research method, is that it permits the possibility to support social action and change and imparts in-depth knowledge of community context, needs, and assets to those that were previously unaware of the issues that concern the participants. PI aims to develop sustainable changes beyond the specific scope and context of the research, and then provides the community of participants to go on and challenge the various issues they may face (Pain and Francis 2003). By ensuring that the participants are central to the process, PI also ensures that there is a deeper level of interpretation of the results the study compared with other methods of inquiry; as such this means that the results are more meaningful and potent to those concerned or assisting others in developing future services. It turn it helps participants feel as though their voice and concerns are being heard and acted upon (Hacker 2013).

Goals of PAR	Goals of PI
Participation that results in action	Participation can serve as stimulus for action
Focus on trying to change and improve circumstances	Focus on improving and understanding circumstances
Working collaboratively with participants	Working collaboratively with participants
Incorporates reflection and iterative process	Incorporates reflection and iterative process
Reveals injustices and addresses disadvantage	Reveals injustices and establishes disadvantages
Improves capacity of all participants and develops co-researchers	Improves capacity of all participants and develops co-researchers
Co-creation of design, data, and analysis	Co-creation of design, data, and analysis
Context bound and used to develop action	Context bound and used to develop understanding
Focus on locally defined priorities and perspectives	Focus on locally defined priorities and perspectives
Process indicated by the researcher and problem further defined by participants	Process indicated by the researcher and problem further defined by participants
Breaks down distinction between researcher and participants	Breaks down distinction between researcher and participants

Table 7.1. Summary Table of goals of PAR and PI

Limitations and challenges for me

From my reading and reflection, I argue that there are four challenges relevant to me and this research. I am now going to consider each of these to ensure that I can demonstrate how I have attempted to address and acknowledge these to enable my research to be thoughtful and robust.

Limitation One: Forming trust

By following a PI time will be needed to form partnerships with participants and key stakeholders. This process started in the early stage of the research as I have found myself almost campaigning on these issues at conferences and through my professional networks (Tillerton and Smart 2008). The facts of this have been that I am starting to establish a reputation and develop links with others who are concerned about this field. I am aware that in order to release one person or groups from entrapment systems and marginalisation, can then lead to the development of others freedoms and powers being limited (Patton 1989) To prevent misuse of this I believe in using democracy and education, and that you can have a more fair and just society and therefore destabilise the “freedom and power” of the oppressors. This is also advocated as a key facet of participatory methods of research (Adelman 1993, Brydon-Miller et al 2003, Macaulay and Nutting 2006). I have strong views about civil rights, emancipation and social justice and therefore I am interested in Critical Social Theory as a means for driving forwards social change and understanding. I therefore built into my research process time to build and establish trust between myself and the participants in the research to ensure mutual respect and full contribution. In addition, when participants made contact with me, I would first speak to them informally about the research and my motivations for undertaking it, as well as my professional role in cancer services. This helped the participants see my perspective and enabled more of a rapport and trust to be built up between us.

Limitation Two: Rigour of the research

As with other forms of qualitative research the findings of PI may not be generalisable to other populations, but is more focused and concerned with how and why persons feel what they feel and seeking to emancipate and empower those that are marginalised, and thus my research may be less valued in certain academic environments (Hacker et al 2012). However, through the PI approach, the research has the added benefit of making it focused and it is important to judge it academically by the principles of rigour relevant to community based participatory research. Another aspect of my research that is transferable to other areas of research will be the theoretical framework created to explore LGB personhood, and this is one of the key outputs of my research that is academically recognisable within the field of social science research. It is key therefore that to ensure rigour when using a PI that there is critical assessment of the intended and unintended outcomes of the research and that the use of a relevant theoretical model is used (Lenny 2006), in this case the cooperative inquiry paradigm devised by Herron and reflective processes developed by Mezirow (Mezirow 1991, Heron and Reason 1997).

Limitation Three: Being flexible and open to new ideas

PI requires flexibility given to changes that may arise to the contextual factors under research. I have to be careful not to manage the process of the inquiry too rigidly. For example, I am aware that time frames that are required for reporting results of my findings, but these have occasionally differed to the priorities of the participants (Cornwall and Jewkes 1995). PI approaches can give rise to conflicts between partners on dissemination, strategies, decisions and a potential loss of control (DiGirolamo et al 2012). I accept that I have conflicting ways of knowing between the participants and this is also key to ensuring democracy and acknowledging the persons that don't hold my views (Thomas et al 2014). Through this notion I understand some forms of knowledge are valued more than others. I feel this is very much down to being in the "eye of the beholder" and through discourse logic must be created to demonstrate more solid views (O'Donnell et al 2004).

Limitation Four: Ethical considerations

Within the framework of participatory inquiry, it was clear that there would be ethical challenges that I would face as a researcher. The level of exploration of personhood required in the research depended on the participants being able to discuss sensitive matters related to their background in an intensive manner, and they were also members of a marginalised group. As such developing trust was an essential aspect of my working relationship with the participants and facilitating the research and inquiry process (Rath 2012). In enable trust to form through ensuring that I was honest and authentic in developing working relationships with the participants, and being empathetic towards their circumstances (Denith et al 2012). I was mindful during field work of the importance of showing my own emotional reactions; as research suggests that to withhold such reactions and remain silent about the occurrences, then could possibly contribute to the re-traumatisation of a research participant (Rath 2012, Denith et al 2012). Dewing (2007) discusses how a person-centred researcher should be open about the aims and goals of the research, and they must ensure that those significant to the person are given the opportunity to be involved in the consent process. I have done this by involving the significant other into the research and have been careful to ensure that both are happy to participate and they both feel that taking part in the research is of mutual benefit. The applied methods of how I undertook this will be described in the second part of this chapter.

In summary I adopted the use of a participatory inquiry because of the following reasons:

- PI ensures that my research is person-centred
- PI permits me to explore the values and personhood of the participants

- PI is not exploitive and focuses on building capacity
- PI enables me to facilitate questioning of services by participants
- PI allows focus on generating solutions to issues LGB persons undergoing cancer treatment may face

Principles of a community based participatory inquiry

Having discussed PI critically, I will now go on to demonstrate some of my developed thinking about four methodological principles that were key to maintaining the research process. In this next section, I go on to expand on the core tenets which are most pertinent to my research that flow from my ontological and epistemological tenets and views on personhood.

When I began, I assembled a list of the possible principles that seemed relevant to me and my research. These were:

- bringing together those affected by the issues,
- enabling persons to come to a common understanding,
- exploring how cancer treatment has affected identity and individual personhood,
- ensuring the research is context oriented to LGB persons,
- enabling the coming together of a diverse range of stakeholders and participants,
- fostering a greater sense of responsibility amongst the participants,
- fostering a sense of public will and community spirit amongst the participants,
- empowering participants if they choose, to go on to promote further change,
- developing capacity building and knowledge exchange within the research process,
- reconstructing the knowledge and process of understanding of LGB persons,
- embracing collaboration and partnership in stages of the research,
- developing partnership researching between community, stakeholders and university,
- having mutual respect and trust through transparency, communication, and shared decision making,
- opening up communicative spaces to support domination free discourse ,
- recognising that recruited persons may not be professional researchers,
- providing appropriate support to encourage participants to be able to speak up,
- developing co-learning and capacity building,
- working for the mutual benefit of all partners,
- ensuring that my research is person-centred,
- co-constructing knowledge together,

- ensuring that social determinants are considered within my research,
- engaging in transformative reflection,
- employing creative means to explore participants narratives.

The issue with this was I provided myself with a cumbersome list; it wasn't easy to identify what the core values and principles of my research were. I felt that I needed to refine this list to be able to present a more concise view of my thinking and research. Through a process of critical analysis and refection of each principle I was then able to merge these and reduced the list to four items. I argue these are sufficient and coherent enough to help me in my research and I will now go on to discuss each of these principles in turn.

Principle one: Respecting the scope of the research and the community

A community is defined as persons linked by social ties who share common perspectives and may share a geographical location (MacQueen et al 2001); in my case it is LGB persons who have received cancer treatment in Scotland. Guidance suggests that a participatory researcher, like myself, must be flexible in developing a context-specific framework that is sensitive to the needs and local knowledge generated from the participants, and must aims to address issues of their own concern (Reason and Rowan 1981). I am acutely aware as a researcher that my research is very context oriented, at the same time, I acknowledge that what I feel my priorities may be in relation to the development of cancer services for LGB persons may not be the priorities of the persons themselves. Although my research was context-oriented, it was open to create new shared understanding of the problems LGB persons may face as a key methodological principle. My own reflexivity needed to consider myself, and the effect of my personality or presence had on the views of the other co-researchers. I will discuss the ways I built this into my own reflexivity and methods, and this will be discussed in part two of this chapter.

In contrast to more traditional research methods, which can be undertaken in a variety of social conditions and settings, participatory research requires a democratic social and political context (Lenz 2012). In my research the social and political context are framed within western society and how that society then constructs and treats the notion of LGB personhood. I am aware because of my epistemological leaning of constructionism that a power dynamic can be involved in forming knowledge. I incorporated democratic principles within the public spheres that I created to enable consensus and shared understanding between participants. My desire was to not marginalise those that don't hold the views of the majority and ensure that all views were represented. The creators and owners of knowledge should be able to determine what is worthwhile through their own propositional power and therefore I was mindful to explore my research in a democratic fashion (Kemmis 2006).

PI focuses on the local issues and problems that can then have a significant effect of the multiple determinants of health (Hacker 2013). It is therefore key that I must recognise that social determinants were important factors to be considered in my research. This is not only relevant to health, but larger perspectives such as LGB community, recognising that external issues have much to do with study. This was the case in my research as participants were found to have poor relationships with family, lack of support generally and some have been victims of discrimination and crime as well as the issues under study.

In my research I draw on democratic values, recognising that this is a key aspect to fostering and respecting a community, as well as developing a greater sense of responsibility amongst the willing participants (Craig and Mayo 1999). The participants are the ones who have a stake and ownership in the knowledge that is created. They will also have an element of responsibility and accountability for it, bringing a feeling of obligation towards the research and other participants involved (Baga-Gupta 2007). In addition, I created a democratic environment cultivating good habits for both myself as the researcher and the participants (Doherty 2006). Ultimately the research created a sense of public will and community spirit amongst the participants, promoting the potential for further change as a consequence of being involved in the research process (Cargo and Mercer 2008). I believe that knowledge is both a product and expression of power rather than truth (Kilgore 2001), and I am aware that some of the participants may wish to exercise their democratic rights and principles during and after the study was completed.

I have facilitated a collaborative partnership in all stages of my research, by involving participants fairly within the study and taking into account any social inequalities (Wilson et al 2017). I did this by developing partnership researching between community, stakeholders and university. It was built on mutual respect and trust and as such transparency, communication, shared decision making, and appropriate allocation of resources was essential to achieving this (Jones and Wells 2012).

Wicks and Reason (2009) suggest that communicative spaces need to be opened in order to support domination free discourse throughout the research journey. Participation needed to be encouraged, and I recognised that recruited persons in the research were not professional researchers and appropriate support was offered to encourage participants to be able to speak up (McNiff 2013).

Principle Two: Engaging in partnerships and collaborative working

A key principle of a community-based PI is to enable the coming together of a diverse range of stakeholders and participants and as the research unfolds a variety of skills will be present within community (Hacker 2013). It was therefore key to focus on capacity building and knowledge exchange within the research process, through the exploration of individuals' identities additional skills and knowledge were uncovered and contributed to the capacity building of the community of participants, enriching the research process (Browne 2005).

In addition, the aim of my research was to reconstruct the knowledge and process of understanding and empowerment of LGB persons who in themselves are a marginalised group and whose views are seldom sought or heard. Normally, these groups have little opportunity to be able to voice their concerns and interests, or have them openly discussed (Borda 2001). Berg et al (2004) discuss how participatory research permits the enlightenment and awakening of common persons, and recruiting these hard to reach persons can be a great challenge. I employed snowball sampling via those who were already included, and took place step by step during the research process allowing the inclusion of more persons within the study.

In keeping with PI principles, I worked to develop co-learning and capacity building (Minkler 2000). I learnt from the community realities of the issues that they faced, and they then developed competence and familiarity in the use of reflection, data handling, feedback, and critical evaluation. All of this built mutual capacity and enriches understanding of the community issues. In my case, the impact of cancer treatment on LGB personhood. Responsibility was taken by myself as the researcher to ensure that all results were shared to all partners and those involved.

Principle Three: Shared understanding and new knowledge generation

In PI there should be mutual benefit for all involved, and this means that there needs to be a moderation of the knowledge that is gained versus the demands that are placed on the participants involved in the research (Israel et al 1998). Real world issues, such as discrimination and poor aspects of health, demand action, and I had to enable the participants to act if needed. This means that the knowledge and understanding of the issues needs to be fully understood in order to then better define the problems and issues. Through a Critical Social Theory paradigm and wanting to ensure that my research is person-centred I have identified several methodological principles that I feel are important within my study. For example, I felt it is key to carry out research and create data in collaboration with the participants and this is fundamental to my beliefs (Cornwall and Jukes

1995). My research explores with participants what they feel LGB personhood is and then how their cancer treatment affected this. It is through this process that we co-constructed knowledge together and is a fundamental basis to participatory research (O'Donnell 2004).

During the research process it was entirely possible that initial data collection may initiate new lines of inquiry that were not anticipated by myself and is a common aspect of PI (Walker 1993). This is why I sought to involve participants in question development, data collection, and analysis. The sessions were conducted and focused around participants' personal reflections on 'knowing self'. This included what LGB meant to them, and what they, as LGB persons, valued most in their lives. Georgakopoulou (2007) discusses narrative research as a means for identity analysis, and it was my goal to help the participants to discuss their own stories of cancer treatment and explore their own narratives. Creative methods were employed to support the participants to reflect on these areas, and to help articulate their thoughts for further critical reflection. The participants used 'creative mind mapping' to help structure and theme their thoughts about LGB terminology and personhood. Once completed, the participants and researcher established what is understood to be a foundation of what the participants view their LGB personhood was, then questions focused around how the participant's cancer treatment affected the themes. Through the exploration and reflection on the data the researcher co-created knowledge with participants. By creating the framework for discussion participants were involved to some degree in formulating the direction the sessions took.

Principle Four: Enable a transformational experience though reflection

Having set out my reasons for following a PI rather than PAR research design and the main principles, I will now discuss the other key methodological principles of my research that I feel were necessary to support my person-centred values and beliefs, Critical Social Theorist paradigm, and the participatory inquiry. I have chosen to draw on Mezirow's research on transformative learning to help participants review their own personal cancer treatment journeys through a critical reflective perspective. The intention of doing this was to enable participants to be able to follow a comprehensive process to interpret, confirm, and reformulate the understanding of their experience (Cranton 1994). This incorporated their specific values, state of being, attitudes, and emotional stances which led to a re-evaluation of their perspectives and experiences (Mezirow 1991). Mezirow believed that people who experienced a major life crisis or event had a "disorienting dilemma" in which they could learn and achieve transformational change, I believe that this can be applied to cancer treatment and lack of acknowledgement of LBG person's personhood (Mezirow 1997).

Throughout my research I asked the participants to consider their own personhood and critically reflect on their experiences. During this process the participant took the time to understand and be aware of themselves as a member of a modern multicultural society, which may not fully acknowledge, and in some cases deny, aspects of care and services due to their own sexual orientation. I asked the participants to reflect on and analyse their own personhood so then they developed the knowledge and skills to assess which aspects of their personhood was affected by cancer treatment. This was a challenging process for some of the participants and for the researcher; as a consequence, there was need to attempt to encourage a level of rationality and distance during the research process.

Using critical theory and person-centred methods, participants were asked to discuss what is important to them in their lives to provide a holistic assessment of need, and what their understanding of being LGB is. To facilitate this exploration, I felt it important to research with participants by co-creating the methods and findings, and to explore their experiences through a person-centred lens examining their healthcare from a holistic perspective. To learn about and understand the insights, state of mind, and life events of the participants, methods such as sculpting, photography and videography, art and drawing, role playing, writing exercises, metaphors, and timelines were all offered (Deacon 2000). The aim of employing these methods was to attempt to focus the participants on the exploration of their own narratives and past care experiences. I feel it was key to carry out research and create data in collaboration with participants and was fundamental to my beliefs and methodological principles (Cornwall and Jukes 1995). It is through this process that we co-constructed knowledge together and is in line with the fundamental processes of participatory research (O’Donnell 2004).

Developing shared and common understandings and helping participants to better articulate and share their experiences through a mixture of narrative and creative principles enabled the participants to tell their stories in a logical manner. Through the use of their self-created identity maps, critical questioning of experiences was facilitated, as the maps were used to frame a context to the discussion. The process is rooted in relying on these perspectives, which are rooted in hermeneutics and intersubjective processes. Through this I was able to consider the whole person in context, recognising the other, and showing further empathy (Estrella and Forinash 2007). Josselson (1995) refers to this process as “imagining of the real”. The research then becomes concerned with addressing distance rather than creating it, and developing understanding between researcher and participant of their independent selfhood and experiences, ensuring that what is most important to the participants was fully understood.

The development an Impact on Personhood Participatory Inquiry Framework (IPPIF)

The participatory inquiry used within this research is based on stages of Heron and Reason's cooperative inquiry framework (1997). A cooperative inquiry is a form of action research which is based on doing research with people rather than on people and is therefore aligned with the principles of person-centred research (McCormack et al 2017). Key to the inquiry is to ensure that all participants are actively involved in the decisions and processes related to the research, and they are, therefore, defined as co-researchers. The inquiry framework uses a cycle of four different stages in which the participants work together to define a problem that needs to be investigated and explored:

1) The initial reflection phase that determines the focus and means of addressing the inquiry
2) An action phase with the group which is focused on testing the agreed actions from stage one
3) A second action phase and whereby individuals are able to explore their findings in everyday life, leading to new insights that may deviate from the original ideas
4) Final reflection phase where the group comes back together to reflect on their experiences and any data that has been collected in the preceding stages of the inquiry.

During the course my research I developed The Impact on Personhood Participatory Inquiry Framework (IPPIF) in order to facilitate my inquiry. It demonstrates how groups and persons can gather to explore their own personhood and the impacts of cancer treatment on this. An early design of the framework is first depicted in figure 7.1 and represents my initial approach to the research prior to undertaking the field work. As I reflect back there were a number of assumptions that I made as a researcher that informed its original design and post fieldwork I felt it needed to be updated to better reflect how the framework was used practically. These are explained, after which the final framework is illustrated in Figure 7.2.

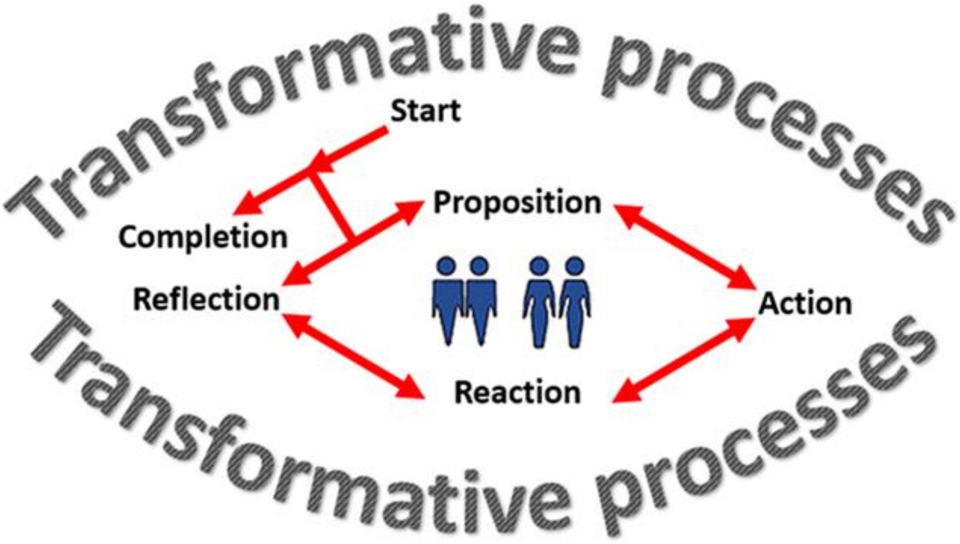


Figure 7.1

Initial design Impact on Personhood Participatory Inquiry Framework (IPPIF)

The IPPIF draws on the theories of Jurgen Habermas in the creation of safe spaces to promote free speech. When aligning the work to Habermasian theories I was able to work with the participants to form “counter publics" through the use of participatory inquiry sessions (Habermas 1984). These often happened within the participants homes, an area where they felt safe, and served as arenas where a vulnerable group could critically reflect and contextualise their experiences of the power dominant space. The ultimately aimed to enable participants to return to the public sphere more empowered to tackle their own oppression. In the context of my own research this was related to the experiences of cancer treatment and the underlying vulnerabilities the participants experienced because of their diagnosis and sexual orientation. The Safe spaces, therefore, represented an attempt to create counter publics for a marginalised group. These counter publics served two purposes. Firstly, to provide the opportunity for those involved to recuperate, reconvene, and create new strategies and develop understandings for resistance. Secondly, they serve to produce their own counter publics which assisted in making visible any issues or problems that the group have experienced that might otherwise be unheard (Waugh 2019). I used this approach to enable people to discuss their traumas, if they had experienced them, which relate to a cancer experience. This helped to explore unique and unifying experiences that may be common to many LGB people and therefore enabled me to make a case for distinctive personhood and identity. The use of a safe space was particularly important to the success of the research due to the imperative need to establish trust with the participants and the final development was informed by my field notes:

> *John's partner would occasionally challenge stances or opinions that he took. This was interesting as it forced John to clarify his position on aspects of our conversation and develop his thinking further on aspects of his identity. Both appeared to naturally have their conversation flow without much questioning from me, they seemed engrossed in the task at hand and seemed to enjoy it. I actively listened, nodded, and took notes as they both worked through the task. There was clearly mutual trust and respect between all.*
>
> (Personal field note extract, John, Session one)

In the final design of the framework (figure 7.2) the use of a safe space needed to be made explicit and is symbolised by a permeable perimeter line and orange background. This signifies the ability to enter and leave a safe space when needed. The colour orange is associated with many positive meanings such as joy, sunshine, enthusiasm, creativity, success, encouragement, change, determination, freedom, expression, and fascination (Bourn 2021). As such it seemed the most appropriate colour choice to symbolise the safe space required to work through the process of the inquiry with the participants.

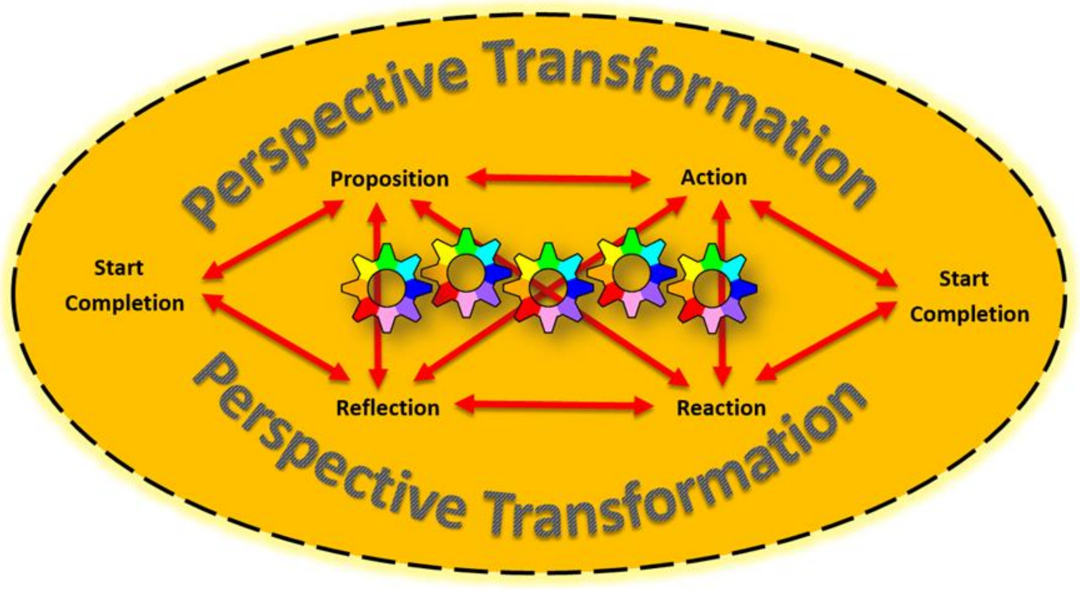


Figure 7.2
Final Impact on Personhood Participatory Inquiry Framework (IPPIF)

The IPPIF is also underpinned by Mezirow's theory of perspective transformation which argues that every individual has a particular view of the world and that this can change as a result of disorienting dilemmas (Christie et al 2015). The particular worldview may or may not be expressed well, although it is usually developed though assumptions of pragmatism that are manifested from the person's life experience and background (Mezirow 1997). Mezirow highlighted that persons often have difficulty in adjusting their worldviews because they are unconscious and constructed habits of the mind. This is why he felt that it takes a significant dilemma or crisis to generate the unearthing of a person's deeply formed perspectives and worldview (Mezirow 1997). This research has found that cancer treatment can act as a disorienting dilemma that changes a person's perspective and that this can then be transformational. Using the IPPIF enabled the participants to consider their own values, beliefs, feelings, and perspectives through their own lived experience of their cancer journeys. Fact, truth, evidence, opinion, argument, and proof were all used as elements of material for making sense and understanding of their experiences in an in-depth exploration of personhood as illustrated by the following field note:

> *We evaluated the session and Tate seemed very happy with what we have discussed. She even remarked that it seemed like she was talking to a counsellor and that I did a very good job listening to her. She said she felt very comfortable in talking about what she discussed and was happy to be able to help in my research. She explained that she would go away and reflect on the identity map that we had created, and possibly adapt further prior to the next session.*
>
> (Personal Field note extract, Tate, Session one)

The initial design of the framework includes reference to “transformational processes”, although in the final version of the IPPIF this was changed to “perspective transformation”. Through the process of the participatory inquiry, it became evident in the findings that the participant's perspectives seemed to continually change throughout their experiences, and it was only when these were reflected upon, accepted by the participant or culminated together, did they result in a transformation of the participant's world view and relationships with others around them. As such the framework was altered to include a greater reference to the initial perspective changes that can be seen as a precursor to full transformation.

The IPPIF is based on a participatory inquiry approach which is deemed to be a valid approach to this research as it enabled the persons involved to explore their experiences in a collaborative manner (Reason and Rowan 1981). Through generating critical subjectivity by enabling high quality, critical, self-aware, discriminating and informed judgements of the participants, validity is assured (Reason and Rowan 1981). Critical subjectivity involves the development of a person's ability to develop reflexivity and then review past experience with distance, which in turn enables transformational learning (Bateson 1972). This provides a theoretical basis for using an inquiry as a means of exploring health experience, and justify that this method as a valid tool. Further, due to the reflective nature of the sessions and mode of the inquiry, participants took time and moved onto other areas of discussion. Often they would come back to points they made earlier, or bring in new information towards the end of a session rather than at the start.

> *Tate seemed eager to engage creatively with this process. However, she wanted to go on work on the task more when I wasn't there. This was the first time that this has happened in my research as most participants were quite happy to work with me creatively and generate their identity map. I spoke to Tate about this, saying that we were to jointly create the identity map, however we arrived at compromise whereby we would come up with a draft using words, and then if after the session she wanted to go away and develop it creatively that would be perfectly fine.*
>
> Personal Field note extract – Session one – Tate

This is understandable given human nature, and the research was flexible enough to support this. However, I recognised that this might happen at the outset of the field work and modified my framework to reflect the non-linear exploration that the participants took during the research. I don't believe this is reflected in the Heron and Reason (1997) inquiry model and is a notable difference with my framework.

The initial design for the IPPIF recognised that participants may move from one topic to another or go back and make reference to previous stages on the inquiry process. This is why the arrows that symbolise the direction of the inquiry stages pass both forwards and backwards. In the field, the participants were not constrained to this level of linear working, as this was not person-centred or reflective of how persons think. As such the final design of the framework recognises that participants may jump between stages of the inquiry as they explore their own personhood and a more web-like structure indicated by the red arrows was incorporated to reflect this. Red as a colour generally represents courage and power, and is used to that effect in many settings, such as a VIP carpet or its use in national flags or banners (Bourn 2021). Given the central role of the participants in the research and its person-centred philosophy, I felt that their importance should be highlighted, even more after I conducted the field work, therefore red was deemed to be an appropriate colour to incorporate to symbolise this in both the initial and final design of the framework.

Within the inquiry sessions, emphasis was placed upon the participant's journey towards deepening their understanding of themselves and consequently the decisions they made throughout their care journeys. Using a creative approach to reflection can be a challenging experience (McCormack and McGowan et al 2014). The use of creativity within the sessions permitted a technique to give participants ‘hands on’ experience of reflection that provided them with a structure and produced a tangible product or evidence of reflection for future reference. Most importantly, it enabled the participant to see their situation objectively and discuss the personal meanings of images and the relationships between them (Williams 2000). In addition, the circumstances of the participants having to recount their experiences caused a significant amount of emotional labour so using a creative approach to teaching enabled them to process emotionally charged situations (Casey 2009). The framework asked the participants to create “identity maps”. However it should be noted that identity is merely a group of unique and recognisable characteristics that are held by no other person whereas the overall goal of this research was to explore each participant’s personhood. Personhood is the status of being a person and what it is like to be that person. Therefore the mechanism of reflection over the creation of the identity maps enabled an exploration of the participant’s personhood as they discussed what they valued most in their maps, and what it was like to go through the experience of cancer treatment as a LGB person. The IPPIF could be applied to other health interventions or other minority groups as a translational output of this research. After conducting my field work, I increasingly recognised that the participants were working hard to help me appreciate the extent of their experiences. The identity maps helped with this recognition, and each participant inputted into this process openly, which was challenging for some. As such the level of work required, reflections, and engagement with this wasn’t adequately encapsulated in the initial design of the framework, and simply had a picture of bringing people together. I decided therefore that I would change these symbols into cogs. For me cogs symbolise cooperation, unity, and determinism. They also represent procession, progress and power. The use of cogs therefore symbolises the minority group that are working together through the process of the inquiry to establish any injustice and reflect the empowering and emancipatory nature of participatory research.

During the final design of the IPPIF I decided to incorporate the use of the rainbow flag to denote that the focus of the inquiry was LGB persons (Sanders 2018). The colours of the rainbow flag were created to demonstrate the diversity of the LGBTQ (Lesbian Gay Bisexual Transgender and Queer) community and are often used as a means of demonstrating pride. Initially, I shied away from this as it advertised the framework overtly as a tool for the exploration of LGB personhood. Over the last five years I have worked with the LGB community and the participants to understand the struggles they have faced. As such I feel that there needs to be an element of LGB pride within the tool and I therefore decided to make this more explicit within the final version of the IPPIF. Over the course of the Covid-19 pandemic the flag has also been used to indicate support for the NHS, creating some unease within the LGBTQ community that the flag has been appropriated and its true meaning diluted (Wareham 2021). This is particularly controversial as members of a more dominant culture and society have taken a symbol from the minority LGBTQ community and repackaged and used the flag for their own purpose. This also served as an added motivating factor to ensure that the rainbow flag was being used within my research to make clear the distinctive elements of the minority LGB community.

Many of the participants engaged with the research differently to what was envisaged. Although most had a key support person, I had expected that this person would accompany the research participant throughout the inquiry session. Instead, most of the support persons came into the inquiry sessions for short amounts of time, or supported the participants in the time between the inquiry sessions. In many cases the participants in the research would remark and make notes between the sessions and these would come into the next session. On these occasions participants with their partners in the interim and thought of other areas about which to speak. It was important to ensure that this was captured within the final design of the framework and as a result this has been indicated by the differing start and end points stages of the inquiry.

Conclusion

I feel that by adhering to democratic principles I have achieved several important strengths that have improved the quality and legitimacy of my research; it ensured that a true representation of views within the participatory inquiry are present and it has been my duty not misrepresent them. Democracy helped to prevent a monopoly of authority during the research process; participatory research aims to break down the power dynamic between researcher and participant and it is important that participants were considered equals (Baum et al 2006). This notion also builds on the rule of equality, which is a core aspect of democratic principles, and has been important to instil within my research given its context.

My ultimate goal was to enable the participants to have control over the research agenda, the process and finally the actions. Most importantly, LGB persons recruited were the ones who then helped to analyse and reflect on the data created. This led to shared findings and conclusions and a mutually inclusive research process. Finally, with adhering to person-centred and democratic ways of working I feel I have been able to ensure that those from the community affected by the issues were best placed to contribute to the research process and outcomes of my PhD.

Part 2 - Applied Methods

Introduction

In the first part of this chapter, I have addressed my methodological principles for my research in order to put forth the philosophical assumptions underpinning my research (McGregor and Murname 2010). I have provided insight into four core methodological principles of my research and these are to respect the scope of the research and the community, engage in partnerships and collaborative working, seek shared understandings and new knowledge generation, and to enable a transformational experience though reflection.

The core research question of this research was;

How is LGB personhood impacted by the experience of cancer care/treatment? The aims and objectives of the research were;

- To explore with LGB persons with cancer, their experiences throughout the cancer care pathway,
- To find out with LGB persons any distinct aspects of their treatment and care,
- To work with LGB persons and their representatives and key stakeholders to develop a set of guidelines of best practice for cancer services and LGB persons,
- To contribute theoretically to knowledge on personhood/person-centredness.

It is key to my research that I employed a collaborative ethical and methodological approach to my research to address my question and aims so I therefore engaged the participants as co-researchers to address the objectives. I have developed the following Impact on Personhood Participatory Inquiry Framework (IPPIF) (See figure 7.3) that outlines the methodology, in this case based on a participatory inquiry, and I will go on to provide an explanation of how I have arrived at this and blended Mezirow's concepts of transformative processes in the following sections of the chapter.

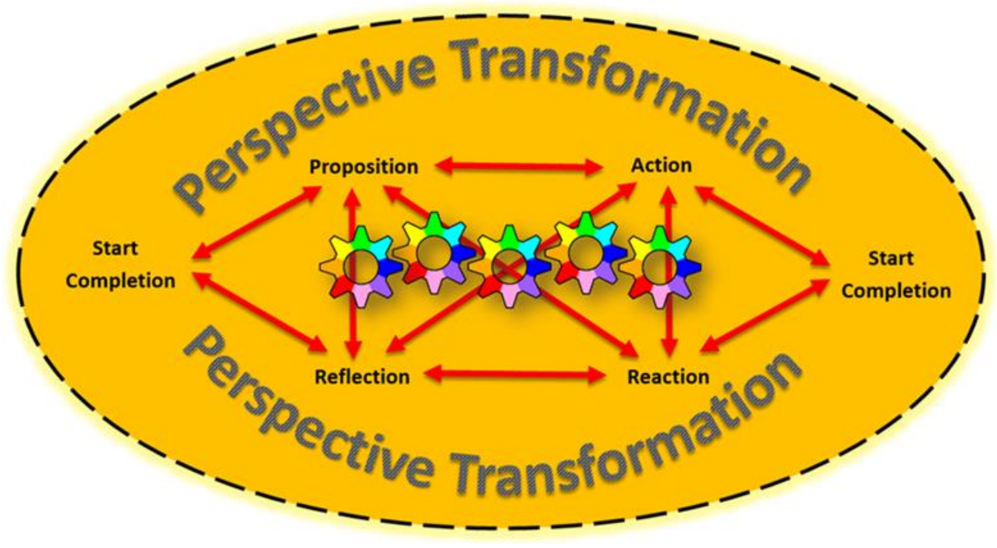


Figure 7.3. Impact on Personhood Participatory Inquiry Framework (IPPIF).

In this next part of the chapter, I intend to demonstrate my methods which are more practical, describing how my research has been carried out (Smith 2012). I will show the tools and methods that I used to carry out the research and how they have been driven by my methodological principles. The methods in this section detail the actions of my research, the practices that have been used to gather and analyse data. In addition, they answer how my research addressed the research aims and objectives and how they enabled participation by all the research participants (Cordeiro et al 2016).

Ethics and safety

My ethics

As I decided to use participatory inquiry as a means of pursuing my research questions there were several ethical principles that I felt are important to adhere to. I will now go on to discuss these three main ethical principles prior to addressing specific organisational ethical issues that were raised in the process of the research. My ethics are in keeping with the person-centred and philosophical tenets indicated in my earlier chapters, as well as my ontological values related to democratic participation.

Mutual respect and trust

Key to the research being successful was developing mutual respect and trust between the participants and the researcher. This included ensuring that ground rules were established, and ways of working were discussed at the start of the participatory sessions. This incorporated the diverse perspectives that were apparent between the participants and ensured that everyone involved had their voice heard when deciding how to proceed through the enquiry (University of Sheffield 2017). It was also key that all the participants were encouraged to act in a responsible manner with a commitment to being open to challenge and honest ways of working with, reviewing the analysis, and the reporting of the research. It was key to my research to have mutual respect between the participants, and I needed to ensure that all were able to voice their views and concerns as well as come to mutual agreement of how to resolve issues that arose in the research process. I was determined that my research was not going to be exploitive and my ethical and methodological principles served as my guiding compass throughout the process.

Equality and inclusion

I felt it important to encourage and enable persons from a range of backgrounds to be able to participate within the study. Limitations within previous studies in this field have included a very narrow perspective of LGB persons from a limited range of backgrounds. I made every effort to try and include representatives from different ethnic backgrounds, race, age, class education and gender within the research. As part of this process, I sought to ensure that venues and formats of the meetings and sessions were accessible to all that participated. Participants opted to negotiate a venue that they considered safe for both them and myself (Lofman 2004). Strategies were used to enable wider participation including the targeting of public organisations that represent minority groups within the LGB community, raising awareness of my study, and enabled members of those organisations to participate.

Democratic participation

I sought to ensure that I promoted democratic participation within the research. I did this by making sure that all participants contributed meaningfully to decision-making with a commitment to discussing the differences in status and power of the research participants by discussing ways of working and allowing participant’s the opportunities to raise questions and air concerns. I also made a concerted effort to communicate in accessible language that everyone involved in the sessions understood and focused on developing participants’ communication and expressive abilities (University of Durham 2012). I encouraged participants to speak up and incorporated creative ways of making sure that participants had the means of support to be able to articulate their experiences. The specific creative methods were negotiated with each of the participants, and these took on various forms, including but not exclusively the use of artistic materials drawing, flash cards, music and pictures.

Organisational ethics and governance

Researchers who wish to work with people to understand the effects of cancer treatment, traditionally recruit from within the NHS, and therefore need to obtain NHS Ethical approval. As sexual orientation monitoring is not currently captured in the UK as part of cancer registration, this presented a challenge that could not be overcome and made targeted recruitment impossible. Therefore the decision was made to recruit participants from outwith of the NHS and QMU ethical approval was sought

Prior to conducting the research there were six ethical issues identified that were then considered and addressed. Ethical approval was sought from the Queen Margaret University Ethics Committee (See appendix five). I will now discuss these ethical issues briefly and explain how they were taken into consideration in the study.

Role of researcher and Informed consent

I am aware that as the researcher I had a dual role as co-participant and the initiator of the research process. However, this might be considered as having an agenda of my own. To avoid this, I ensured that all participants were included in shared decision-making process in all phases of the research process and was a key principle to this research.

Participants were provided with information to enable them to take part, confidentiality, privacy and informed consent were assured (See appendix six). All participants needed to meet predetermined criteria (See appendix seven). In addition, they were given an information sheet prior to meeting and at least 48 hours to decide if they still wanted to participate. Further, any participants recruited were also given the name and contact details of an independent staff member within QMU to be able to discuss the study and ask questions. This provided additional assurance to participants and ensured that they were not being coerced in any way to participate. Participants were invited to sign a consent form if they wished to proceed (See appendix eight).

Contact sessions with the participants unfolded in a negotiated way, and as such it was impossible to exactly communicate to participants ahead of the meetings what they were going to experience and, hence, what they were consenting to (or for how long) (University of Sheffield 2017). Therefore, in addition to the initial consent form there was also time made available during the inquiry process for staged consent, in which research participants, after a period of dialogue and negotiation, agreed to a shared set of rules around participation. This was in keeping with the with the consent methodology known as ‘process consent, devised by Dewing (2007).

Inequalities within the group were addressed, as I provided opportunities for the participants to have their opinions heard as well as the chance to openly express any concerns. At all times participants were of the understanding that they could withdraw from the research at any stage.

Participant safety

Participants were informed that they could pause, reconvene or terminate any of the sessions. In addition, contact details for local cancer support and counselling services were able to be provided to participants should they have anything that arose in conversations as part of the research process that they wished to explore in more detail with a qualified counsellor.

Researcher safety

As most of the inquiry sessions took place in the participant’s home, or other location of their choosing, a lone working procedure was devised following a risk assessment. In line with promoting researcher safety, a process was created to provide contact between myself and my supervisors during the inquiry sessions. In addition, I also took into consideration my own emotional state of wellbeing during the study and ensured that I debriefed with my supervisory team and kept a personal diary to assist in reflecting on my experiences. I made sure that if I needed, I could also access additional support and guidance offered by QMU occupational health.

Data storage and handling

The ways in which the participants chose to feedback was negotiated with the participants, and in most cases took the form of providing copies of anonymised materials that related directly to the individual participant either electronically or through secure post. I then provided the opportunity for the participants to be able to comment on the materials either in written or verbal formats. All data was securely stored at QMU and anonymised to protect confidentiality and was kept in accordance with General Data Protection Regulations (GDPR) (European Parliament and Council of European Union 2016). Data was held either in secure lockable storage cabinets on QMU campus or in lockable carry cases when in transit. In addition, all electronic data such as data recordings were held on QMU cloud storage facilities, which are also encrypted using QMU login credentials. All raw data is planned to be destroyed 12 months after the study has been completed. In keeping with the methodological principles of my research, all data ownership and storage for during and after the research process was discussed and agreed with the participants in a consensual manner.

Out-puts and publication

It my desire to ensure that there are outputs of the research, and as such briefing publications and conference presentations may and have already been produced. I am aware that academic publication and productions may be a low priority for the other participants and they predominantly wanted to focus more on resolution of issues in care. It was therefore essential that I made sure I responded to the needs of the group through negotiation. I wanted to ensure that participants were empowered to develop the skills to build on the research if they wished. In that spirit I also afforded the opportunity for participants to serve as co-authors as I published or presented materials that relate to their experiences, although no participants have wanted to be co-authors to date. In the event that they didn’t wish to do this I ensure that I acknowledge the participants’ assistance where appropriate within the dissemination of the research.

Research Participants

Cancer Research UK information indicates that adults aged 50-74 account for over half (53%) of all new cancer cases, and older persons aged 75 years and older account for over a third (36%), with slightly more cases in men than women in both age groups (Cancer Research UK 2021). Someone who identifies as LGB and who was born in 1945 would now be in their seventies and more likely to develop cancer. Throughout their life they will have seen many experiences that may influence their world view, such as persecution and discrimination in society. It should be noted that legal reform and societies overall attitude and treatment of those that identity as LGB are not necessarily equal, and there is still progress to be made with homophobic hate crime still being a problem today. It was likely that any persons who choose to participate in my study would be of this 50-74 age group, and this was the case, as such the participants have a unique perspective of what it is to be LGB with cancer today.

The research sought to include LGB persons who had undergone primary treatment for cancer and their key support person, if there was one. Accessing the participants for this study posed a challenge as sexuality monitoring is not current practice at cancer registration. A comprehensive strategy for recruitment was devised drawing on my local and national networks. For example, I ensured awareness of the study through the use of social and online media. Targeted recruitment was focused at voluntary sector organisations working in the LGB communities, word of mouth, and LGB cancer support groups in the UK (See appendix nine). Publicity materials were designed, and distributed to Lesbian, Gay, Bisexual and Transgender (LGBT) groups, support agencies, individuals, Twitter feeds, and LGBT venues to ensure maximum possibilities for recruitment into the study (See appendix ten). I also sought access to place recruitment materials in local cancer charities that were already linked to QMU via student placements and these yielded results:

> *“I saw on twitter that you've got funding to research cancer experiences of LGBT+ folk in Scotland. Congratulations! This is an important study, and close to my heart as I underwent cancer treatment in 2013-14.”*
>
> Research participant

Facilitating Participation in the Research

Purposive sampling was used in order to gain access to participants who had direct experience of the phenomena being explored as advocated by Crotty (1998). In this case this involved LGB persons who had treatment for cancer in the UK and their key support person if there was one. The study was promoted through the following organisations and support groups email and contacts lists:

- Maggie’s Cancer centres
- CLAN cancer support
- Ayrshire LGBT

- Queen Margaret University's
- LGBT Health and Wellbeing Scotland
- The Equality Network Scotland
- Stonewall Scotland
- The Terence Higgins Trust
- Age concern

Over 50 organisations and individual support groups were approached, however the above list is the final list of organisations that actually agreed to publicise the research to its members. All other organisations failed to reply to communications and this was a challenging time particularly when originations and support groups failed to support my work as outlined in the below examples:

"Hi Gareth,

I do not think my group would be able to assist with your research as to the best of my knowledge the group does not have any gay/bisexual members, if I am missing the point of your communication please contact me again."

"Hi Gareth,

I have to let you know that we cannot be involved with your research as we only participate within the partnership we have agreed between (Anon) Scotland and (Anon) University."

Negative email responses

An intermediary was provided to act as a point of initial contact for potential participants to discuss the study. If participants then wished to proceed the intermediary placed them in contact with myself and then I consented them to enter. Throughout the research opportunities were made for participants to reaffirm their consent and the opportunity to discuss if they were not happy to proceed and wished to withdraw from the study in keeping with the key principles of participatory research and process consent.

A generic email was composed outlining the study with a request for Key charitable organisations and support groups to promote the study and permit recruitment from within the LGB community. With agreements from the organisation to promote the study, a poster was created for posting the details on their websites, forums or social media sites. Recruitment posters were also emailed or posted to those contacts who agreed. The publicity flyer was also produced and distributed at pride events in all five Scottish cities, as well as being placed in gay venues and information kiosks in all Maggie's centres within Scotland (See appendix ten). This approach was very useful as generated interest and awareness of my research and started to engage wider stakeholders early in the process of recruitment and advocacy:

“I spotted your leaflets in XXXXXX offices today. As well as working for the XXXXX, I also work for XXXXXX, hence the reason for me being there today. I wanted to contact you to say that I would be very interested in finding out more about your project…. As an employee of both XXXX and XXXX I am massively interested in the content of your research and am checking in to see if I can be of any assistance to you?

I look forward to hearing from you if and when you see fit.”

Positive Key stakeholder reply

“Thanks for getting in touch and for sharing your research and doctorate plans. XXXXXX has as promised passed your email onto me.

Whilst this is clearly an important issue, I’m unfortunately not aware of any study or LGBT-specific work currently being carried out around cancer care or support groups. Given the high prevalence of certain types of cancer within our communities, such as the increased risk of breast cancer for lesbian and bisexual women who have not had children or used oral contraceptives, there is certainly plenty of scope and value in looking at this whole area. And of course high prevalence rates are coupled with the generally poorer experience of health care of LGBT people, which would potentially support the development of specialist initiatives. Not something we have to my knowledge had requests for, but that is of course not to say the need is not there.

We would be happy to try to support you in finding participants for your doctorate. However as you have already correctly identified, the lack of sexual orientation monitoring is regrettably likely to make recruitment quite a challenge.

Do please keep in touch and let us know how we can support your work.”

Positive Key stakeholder reply

I was initially worried about not getting anyone to come forward to participate in the research as this took some time. I also noted the difficulties that other studies uncovered in my literature review had in finding LGB persons who were willing to come forward and discuss their experiences. In all, it took over a year to recruit and carry out the inquiry session, with participants coming forwards over a period of 18 months as knowledge of my research became increasingly known. Queen Margaret University were very supportive and aligned marketing support through their media and communications department with three local and national newspapers taking on press releases. The university also used their own website to sharing publicity about my research and then again shared this through their own social media sites.

Snowball sampling involving asking active participants if they knew of any other individuals, within their own circle of contacts, who would be interested in taking part in the study was carried out and is a recognised method of recruiting participants who are considered ‘hard to reach’ (Johnston and Sabin 2010). Participants were encouraged to pass on my contact details as well as the participant information sheet within their circle of contacts. Any interested parties could then contact me if they were interested. The aim of the research was to recruit approximately 10 LGB persons from across Scotland who had undergone cancer treatment and their key support person. It was agreed that the study would be closed to new participants in the event of recruiting more than 15 participants. Participants needed to meet the following inclusion and exclusion criteria:

Inclusion Criteria

- Persons who self-identified as LGB and are aged 18 or over
- LGB persons who live in the UK and have received treatment for cancer/been closely effected by cancer in the past 5 years*
- Persons who can sufficiently speak and understand English
- Persons who can participate in the sessions

*Please note that during the course of the research I was approached by two persons that had recently lost a same sex partner to cancer. They both asked if they could participant in my research as they felt they had experienced the cancer pathway from an LGB perspective in the last five years and wanted to share their experiences. Given my commitment toward person-centred principles this seemed entirely appropriate, and I sought an ethical exemption, which was granted, to enable these two participants to partake in the research.

In addition, the original research forms called for participants that had cancer treatment in the past five years. This could have been any form of cancer treatment, including, but not exclusively radiotherapy. Therefore in the final publication of the thesis this has been removed from the text for the avoidance of doubt.

Exclusion Criteria

- Persons under the age of 18
- Persons that identify as heterosexual
- Persons who cannot speak and understand English
- Persons who were currently undergoing, or about to undergo invasive treatments such as surgery, radiotherapy, brachytherapy and chemotherapy or had undergone treatment during the past three months.

Participants who had treatment needed to be in the follow-up stages of the cancer treatment pathway. In addition, key support persons who were also recruited had to be able to independently consent to the study and were able to sufficiently speak and understand English and be over the age of 18.

My research sought to involve, where possible, a participant's key support person. The reason for this was to allow a greater generation of materials and a richer flavor and representation of who the person was through the identity mapping process. According to my philosophical position on personhood (see chapter three) I argue that persons do not exist in isolation and that those close to them at a time of significant illness can also provide unique insight into the effects of cancer treatment on the key participant. I felt it important to enable the participant to have a key support person, if they wished, in the research process to assist in building mutual respect and trust. In these cases we all followed the process of the participatory inquiry together. It was also the case the support person would be able to help the participant recall events of their cancer treatment and its effects. If a participant's key support person chose not to participate or disengage with the study, I discussed this with the key participants and established if they felt that they would like to continue in the research.

I also chose to limit cancer treatment experiences to the past five years as from a medical standpoint practices employed in the management of disease may have been significantly different, in addition social progress and stigmatisation of LGB persons may have changed for some. In addition, it was my hope to be able to help participants reflect on their experiences, and treatment had impacted on personhood with the view of establishing a set of national guidelines. It was key that the participants could sufficiently recall events that contributed to the way they feel and served as another justification to limiting my study to include participants who have had treatment in the last five years.

Through the information and awareness campaign of the research, two participants approached me to if see they could take part in the research. These participants were spouses of LGB persons who had recently died from cancer and asked specifically if they could participate, see following example:

"I was talking with one of the staff at the Maggie's Centre today and he told me about your research and asked if I would be willing to be interviewed. My partner died of bowel cancer 18 months ago, and both she and I have had a lot of help from Maggie's over the years. If you wish to talk to me about this I would be happy to discuss it."

Tabitha, initial email

As such, I erred on the side of being person-centred rather than what the criteria said and made sure I obtained permission from QMU ethics committee to recruit these participants into the research. These two participants' insights into cancer treatment were equally valuable to the research as they had been through the full cancer pathway as an LGB person. I also felt that they had strong justification in saying that cancer had affected their own personhoods. These participants also challenged my own assumptions and initial misconceptions of who would be willing to come forwards to participate in the research.

Throughout the research I have participated in several national and international conference discussing aspects of my research. This also enabled me to have a platform with key stakeholders who then became aware of my research and very kindly agreed to publicise my research further. Some of these stakeholders started to campaign and raise awareness of my research and its importance within their own organisations, and several participants became aware of my research through word of mouth thanks to these key stakeholders.

The research sought to recruit participants who self-identified as LGB, however this presented certain challenges as members of this community don't always like to be identified in this way or have labels attached to them. Participants were recruited to the research via my local and national networks, in keeping with the principles of community based participatory research. Targeted recruitment using purposeful and snowball sampling was focused at voluntary sector organisations working with the LGB communities and cancer support groups in Scotland, in attempt to establish trust with the community being researched. The publicity materials were designed and distributed to LGB groups, support agencies, individuals, twitter feeds, and Scottish LGB venues to ensure maximum possibilities for recruitment into the study. In addition to this cancer support groups were also canvassed and some of the participants came from these, or other professional contacts. Some individuals didn't feel they met the inclusion criteria of my research, but still contacted me anyway.

"I don't identify with the gay scene I'm not the flag-waving yes and so I'm not sure that I am eligible to participate in your research"

Evan

"I've read and reread your criteria for your study. I am not sure I do meet the spec. I don't define myself as gay as such. I would define myself as 'European male' who happens to be gay. Fully integrated into society with not many gay friends."

John initial email exchange

Process of the Participatory inquiry

In the next section of the chapter, I intend to make clear how the methods were in keeping with my four methodological principles, how they addressed the four stages of Heron and Reason's (1997) "cooperative inquiry paradigm", and at each stage how I incorporated and blended transformative reflective processes advocated by Mezirow (1997) to allow me to address the aims of my research. I have developed Figure 7.4, Impact on Personhood Participatory Inquiry Framework (IPPIF) that outlines the methodological approach the inquiry I undertook. Underpinning my framework are an examination of the transformational effects of cancer. This is based on Mezirow's theories of perspective change and transformational learning. Using the Impact on Personhood Participatory Inquiry Framework, I explored with the participants any unique aspects of crisis or disorienting dilemmas related to their sexual orientations. This was conducted with the view that I could establish a further understanding of the impact of cancer on personhood and establish if there is any learning from LGB person's cancer treatment experiences to influence and develop guidelines for health care professionals. This is with the view that LGB persons may have additional support needs due to their background and state of being, and the care experience and diagnosis in some cases may cause disorienting dilemmas or crisis because of the person's sexual orientation.

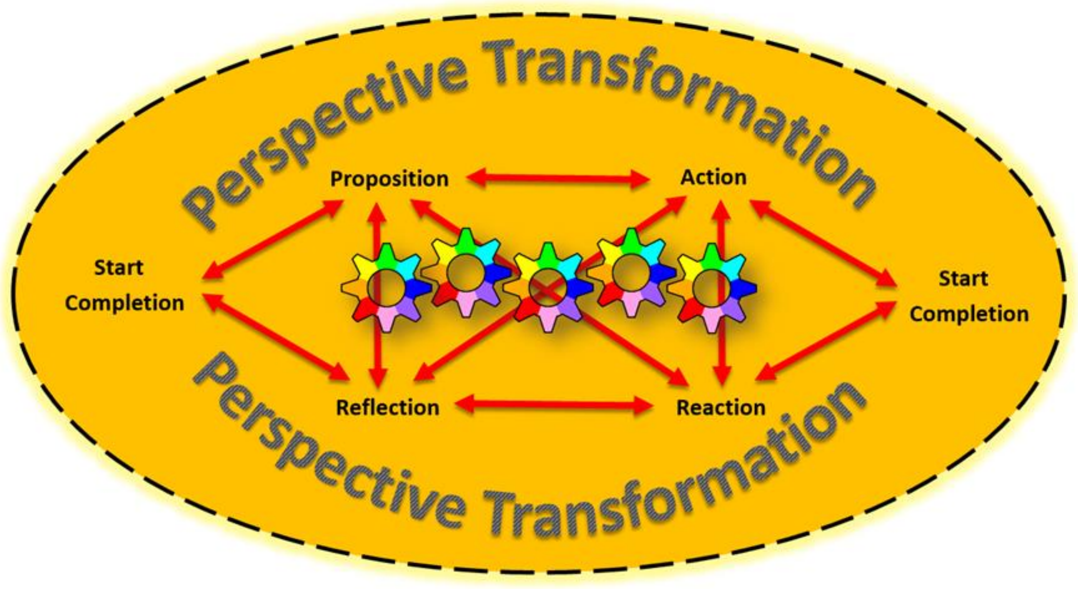


Figure 7.4.

Final Impact on Personhood Participatory Inquiry Framework

I have provided an explanation of the trajectory that the participants followed.

Stage one: Proposition

The first stage of the research was to work with participants to agree consensus/common understanding in area to be examined. In this case the focus of the research was to establish who they were as persons, and how their identity and personhood was affected by cancer treatment. Establishing consensus was a key stage in the research process and was required to be able to pay the appropriate respect and establishing the scope of the community of participants, as well as fostering a sense of shared understanding, this was in line with the key methodological principles of my research.

Stage Two: Action

The second stage of the research represents a level of practical knowing and its purpose is to engage in Co-creation of identity maps through agreed means of expression, for example, art, collage, dance, music photos, and/or personal artifacts. I was mindful that I couldn’t be too prescriptive as to the exact creative means of exploring LGB identity with the participants in the study. This was because it was a key principle to my research to engage in partnerships and collaborative working, and as such I needed to devise and agree the exact creative means to explore identity with each of the participants. The goal was to establish an identity map of the individual that has received cancer treatment and thus provide a framework to then discuss how treatment has impacted the various aspects of their personhood. After this, I supported the key participant to critically reflect about how cancer treatment affected the various aspects of their own personhood.

Stage Three: Reaction

Upon commencing stage three the group discussed the identity map refection process and their feelings about doing things, any assumptions that were challenged were raised, and any new areas that arose from the process also emerged. This stage connects strongly with my views of Critical Social Theory and facilities experiential knowing. I did not want to merely examine the experiences of LGB persons or just provide a forum to voice any grievances or deficiencies in services, but I hoped to challenge the assumptions of participants about the research process and undertake a much deeper exploration of the key participant’s personhood in the first two stages. It was only towards the end of the second stage did examination of the co-created framework occur, and this was to assess the impacts of cancer treatment on the person. It was hoped this would engage participants in addressing any concerns; they may have had with care and enabled them to disclose any issues they have had during their treatment journeys, but also facilitated a much deeper exploration allowing more perspectives of the effects of treatment to emerge.

Stage Four: Reflection

Finally, participants reflected on the process and agreed the findings/themes of the discussions. This helped the process of consensus building and helped identify if there were any other areas that the participants wished to explore. At this stage the participants were asked to review their experiences of the inquiry and see if they had been enabled to gain new perspectives on their experiences, or if they had learnt anything new about themselves. Participants were directed onwards if they wished to access additional support or engage in the process of developing the outputs of the research i.e. guidelines, evidence, additional support groups. One of the key principles in my research was to try to enable a reflective experience that would in some way contribute to transformation and therefore this final stage was key to the process.

Pilot of Inquiry

Through my research journey I have been a member of a community of practice for learning (SiCoP) within a research centre at Queen Margaret University. The membership consists of a core group of people who regularly 'think together' about research related problems. Members share a common interest in carrying out research where we humanise healthcare and formally meet twice a year, whilst working across geographical regions, disciplinary boundaries and formal reporting lines. Engaging in this community has been very important to me as it helped expose me to other philosophical perspectives and methodologies within my field of research. It also helped me develop as I have been able to gain challenging feedback, and then incorporating this learning into my research along my journey.

In the process of developing the IPPIF I piloted its use with fellow SiCoP members to gain further confidence in working with people to establish their perceptions, feelings, and life events as well as facilitating the creation of identity maps. I devised a workshop where ten volunteers assisted me in piloting the method. In the workshop it was not necessary for participants to discuss a cancer experience, but a healthcare experience in general. Methods such as writing, metaphors, sculpting, photography and videography, art and drawing and timelines were all open for participants to use. The aim of employing these methods was to help focus the pilot participants in the exploration of their own narratives and past care experiences, and engage them in a creative, dialogical and possibly therapeutic experience rather than simply interviewing them.

The pilot group had approximately twenty minutes to create an identity map, and a further ten to fifteen minutes to add in a health care experience and its impact on identity/personhood. Afterwards they were invited to divide into small groups for a 30 minute discussion to explore the following question:-

How did your healthcare experience influence your identity and personhood?

Participants were informed that experiences could be either positive or negative and participants need not share this with the rest of the group. They were dived into teams of three/four and just one or two volunteers within each group were invited to share their experience using the created tool. Participants in the pilot were advised to bring along anything that they felt would help in the process, and that their health care experiences and narratives would not be recorded. The aim of the pilot was to improve my competence and skill in using creative methods, and to test whether the stages of the IPPIF could translate into the real world. In the final stages of the pilot session I engaged the group in general discussion about the method and canvassed feedback on my facilitation skills. Participant were invited to evaluate their own personal experience of the workshop, by providing a line to a poem. These were then collated as a group to serve as a record of the discussion and capture how the pilot participants felt about the experience (see figure 7.5):

More aware of my identity you say,
My surprise was that this may have impacted on who I am.

sleeping
Like an iceberg – dormant frozen thoughts
Crystallised below the surface warmed, wakened
melted, salty tears.
Revealing

Exposure confirms comfort with self.
Exposing what matters when feeling vulnerable.
It may (or not) promote powerfulness and/or vulnerability.

Diving deep into still water,
riding the waves of exposure and vulnerability,
riders in the storm,
back to shore.
Inner strength rising up,
remembering my longing for belonging.

I am not a number,
my life is full of colour,
seeing support for peers is inspiring,
despite our different 'wiring'!

Figure 7.5 Co-created poem from SiCoP pilot workshop

Through engaging in the pilot I developed further confidence in the use of creative methods, and this provided me with further assurance about the IPPIF development and structure. The workshops also supported me in the development of personal qualities that have been key to developing effective relationships with research participants. Without those abilities it would have been impossible to gain their trust. I was able to develop my listening skills in someone else's company by ensuring that I gave them my full attention, with no distractions. It was necessary to ensure that participants felt supported and through building a therapeutic relationship with them and their key support persons through using active listening to develop mutual trust. It was important to ensure that the participants felt that their needs, problems and issues were recognised and understood by myself through sympathetic presence. By actively listening I not only accepted what the participants said but also encouraged them to keep talking.

Data Gathering and Analysis

The Face-to-face inquiry sessions with the participant and their key support person were audio-recorded and transcribed afterwards. The inquiry sessions were conducted to focus on participants' personal reflection on 'knowing self'. This included what LGB means to them, and what they, as LGB persons, valued most in their lives. Creative methods were employed to support the participants to reflect on these areas, and to help articulate their thoughts for further critical reflection. The participants used 'creative mind mapping' to help structure and theme their thoughts about LGB terminology and personhood. Once the participants and researcher established what was understood to be a foundation of what the participants viewed their LGB personhood was, questions then focused on how the participant's cancer treatment had affected the themes. Through the exploration and reflections, the research used participatory methods and co-created knowledge with the participants. This was facilitated by using critical theory and person-centered methods such as Heron and Reason's (1997) cooperative inquiry and Merzirow's (1997) models of transformative learning. Participants were asked to discuss what is important to them in their lives to provide a holistic assessment of need, and what their understanding of being LGB was. Questions were then put to the participants to ask how their cancer treatment has affected their co-created priorities and views of being LGB. Afterwards the sessions were transcribed, and other materials photographed, copies of the transcripts were then sent to the participants to check for accuracy and comment if they wished. I then used Mezirow's framework for perspective transformation as a means of an initial content analysis to identify issues and themes emerging from participants' experiences of, and feelings about, the care and treatment they had received for the cancer. Once the issues and themes were identified, agreed, and analysed, I was able to consider these against other existing evidence.

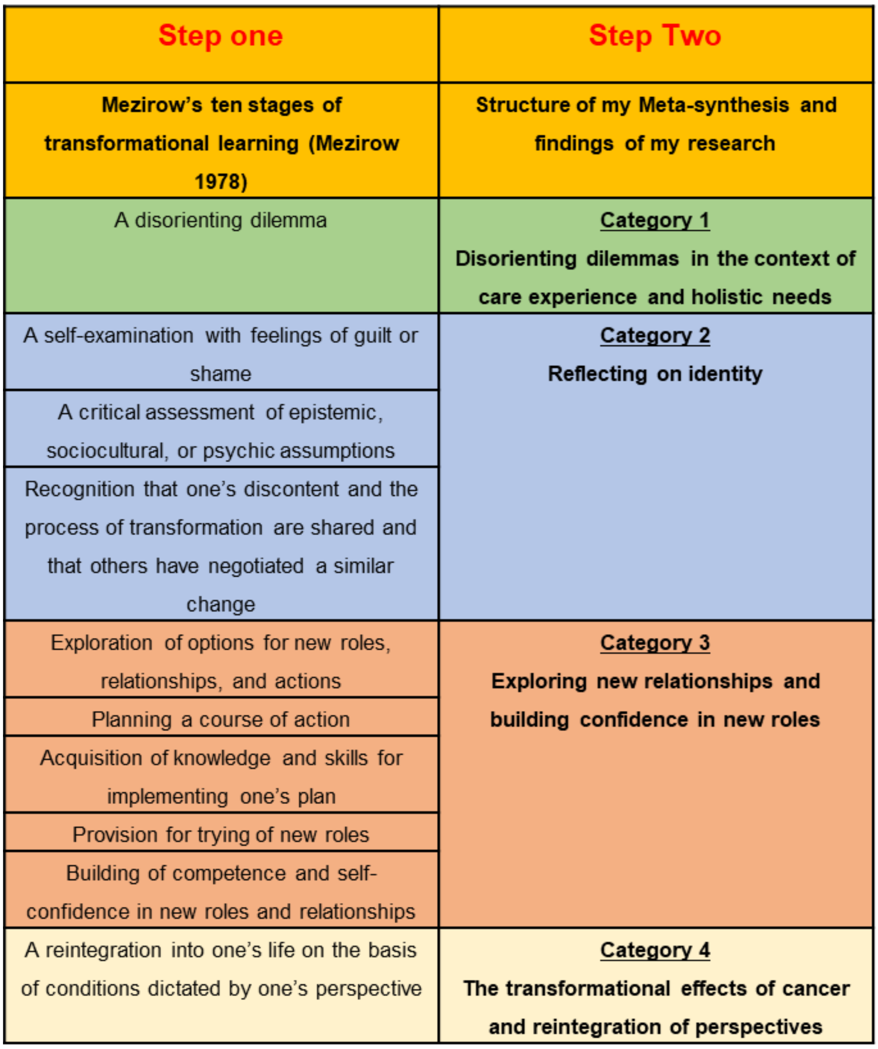
Approach to Analysis

A qualitative meta-synthesis is a process whereby researchers are compile and identify a research question that can be the applied across all qualitative data sets, it supports them to then select, appraise, summarise, and combine qualitative evidence to address the research question (Ezzy 2013). This process should use rigorous qualitative methods to synthesise existing qualitative studies to construct greater meaning through an interpretative process (Ezzy 2013). In this section, I will discuss my approach to my meta-synthesis and data extraction of my field work. I used a qualitative content analysis as a first step to categorise the data and then allowed themes to emerge inductively within these areas thought the interpretation of textual data using the systematic process of coding.

When first approaching this task, I was drawn to the literature as I was aware that several different methods are available for the synthesis of qualitative findings in research. The University of York (2009) published resources in this subject area and focussed specifically on qualitative research designs such as my own. Some of the methods involve converting qualitative findings into a quantitative form, for example certain types of content analysis, whereas others maintain the original qualitative form of data and evidence such as those employed in meta-ethnographic research (Sandelowski and Barroso, 2006). The choice of my own method has been influenced by several factors including my research question, aims and objectives, the numbers of my participator sessions, types of data for synthesis, and my knowledge and expertise in undertaking the review.

I reviewed various other options when considering the approach to the analysis of my data. The means of analysis had to fit within a critical paradigm and be cognisant of my theoretical framework and therefore heavily influenced my choice. In my research I have sought to further understand the effects of cancer treatment on someone's personhood and identity, believing that cancer is a transformational event. I was aware that I would be asking a lot of persons to reflect on things that they may not previously have reflected on, and that would draw on their ability to formulate a true sense of rationality. Therefore, I used Mezirow to help frame my interviews, and was consistent by using Mezirow’s framework to help analyse the resulting data.

Health science researchers commonly use content analysis as a means of interrogation and evaluation of data to study phenomenon (Schreier, 2014). Most have three distinct approaches which are described as either conventional, directed, or summative (Hsieh and Shannon, 2005). I followed the directed approach using the process described by Hsieh and Shannon (2005), whereby I read the textual data highlighting areas that on first impression related to predefined codes suggested through a theoretical model, in this case Mezirow’s perspective transformation (1978).



Step one	Step Two
Mezirow's ten stages of transformational learning (Mezirow 1978)	**Structure of my Meta-synthesis and findings of my research**
A disorienting dilemma	**Category 1** **Disorienting dilemmas in the context of care experience and holistic needs**
A self-examination with feelings of guilt or shame	**Category 2** **Reflecting on identity**
A critical assessment of epistemic, sociocultural, or psychic assumptions	
Recognition that one's discontent and the process of transformation are shared and that others have negotiated a similar change	
Exploration of options for new roles, relationships, and actions	**Category 3** **Exploring new relationships and building confidence in new roles**
Planning a course of action	
Acquisition of knowledge and skills for implementing one's plan	
Provision for trying of new roles	
Building of competence and self-confidence in new roles and relationships	
A reintegration into one's life on the basis of conditions dictated by one's perspective	**Category 4** **The transformational effects of cancer and reintegration of perspectives**

Table 7.2 Framework of categories used for initial content analysis of the data

(Based on Mezriow (1978) 10 phases of perspective transformation)

To assist in the analysis of the participatory sessions, I opted for an initial content analysis of my data aligned to a modified analytical framework I created, which was based on Mezriow's theory of transformational learning (see table 7.2). My analytical framework has four pre-defined themes/categories, as listed in the right hand column of the table, against which I categorised the data against. These four groups encompassed the ten phases of 'perspective transformation' described by Mezirow in his 1978 theory which are listed in the left hand column. The four categories I created are more open than Mezirow's original 10 steps, and this was done to take into account the differing experiences of the participants, recognising that each of the participants was at a different stage of their cancer journey and different points in processing their experiences and effects of cancer treatment (Elo and Kyngäs 2008; Mezirow 1978). By having the four overarching categories as a lens to review the data, it then made it possible to synthesise the datasets and progress to further inductive analysis.

I felt that Mezirow's ten stages of transformational learning needed to be adapted when applying this to my own research (left hand column figure 7.2). This is because Mezirow's framework was initially designed to examine transformational learning and not the transformation effects of disease, nor was it designed for practitioners to learn from and modify practice based on people's experiences of care. In addition, I wanted to offer the opportunity for the participants to comment and contribute to the analysis if they wished. Given the diversity of backgrounds of the participants I needed a boarder version that could be more easily explained and applied to each of the datasets/transcripts.

I adapted a version for the initial content analysis to ensure the research aims and objectives could be addressed and articulated, specifically when establishing distinct aspects of care throughout the pathway. Mezirow's ten step framework was devised to examine the processes of transformational learning; however it is very granular and specific to the context for it was initially created, and is typically used by those with more expert knowledge in pedagogy.

In order to make sure Mezirow's work was more practical when examining the transformational effects of cancer treatment, easier to interpret and explain to the participants, and to analyse the collective experiences of all nine participants, a more applied version was devised for the initial content analysis. The modified framework for this research was divided into four distinct categories (right hand column 7.2) that correspond to Mezirow's original theory. The content analysis categories for this research were designated as; 1) Disorienting dilemmas in the context of care experience and holistic needs, 2) Reflecting on identity, 3) Exploring new relationships and building confidence in new roles, 4) The transformational effects of cancer and reintegration of perspectives.

This approach is not without precedent, and other authors have also similarly grouped Mezirow's ten steps into the four simplified categories such as Nerstrum (2014). Nostrum simplified Mezirow's work into four overarching phases but this was focused around education and the transformation effects of learning. The four phases of Nostrum's work are (a) having experiences, (b) making assumptions, (c) challenging perspectives, and (d) experiencing transformative learning. I was eager to find a more applied tool for the purposes of this research context and so took a more realist view in the creation of an overarching framework, similar to that of Nerstrum (2014), but applied to my own research context.

The added benefit of this approach resulted was being able to establish the transformational effects of cancer on personhood, as well as providing data sets that were then exposed to an inductive analysis. By having the four overarching categories as a lens to review the data, it then made it possible to synthesise the datasets together to then subject to further inductive analysis. This then enabled me to derive themes related to LGB persons' experiences of the cancer pathway and to address the research aims and objectives. I have provided the following overview of each stage of the process to indicate how and when the analytical framework was used.

Overview of process

Step one of content analysis

See Table 7.2

1. I aggregated all transcripts of participatory sessions (two per participant), supplementary emails and communications following the sessions with participants, and field notes into nine data individual datasets.
2. I examined each participant's dataset and then coded any text relevant to the following 'perspective transformation' sections as a lens: 1. Disorienting dilemmas, 2. Self-examinations 3. Sense of alienation, 4. Relating discontent to others, 5. Explaining options of new behaviours, 6. Building confidence in new ways, 7. Planning courses of action, 8. Knowledge to implement plans, 9. Experimenting with new roles, 10. Reintegration of perspectives (Mezirow 1978)
3. I then extracted the coded data onto an overarching matrix with each of the ten phases used (See example appendix eleven)

Step two of content analysis

See Table 7.2

1. I moved on to then aggregate each of the individual datasets into a single dataset corresponding to the categories of the framework I created (right hand column of table 7.2).
2. These datasets were then reviewed inductively for themes i.e. all examples of dilemmas across all participants, all examples of self-examination across all participants, and so on.
3. Each of the four categories then had several key findings that could be critically discussed and analysed.

Inductive analysis

Once extracted, the data were then exposed to an inductive analysis to derive themes within each of the stages of the transformational learning theory. The final inductive approach were used for the following reasons:

1. To condense raw textual data within each of the stages of transformational theory into a succinct and concise format,
2. To indicate the links between the research questions, aims and objectives that can be derived from the data,
3. To develop an understanding of the order of experiences that are present in the data that can then be presented as findings of the research,
4. To enable presentation of key findings of this research study and to inform the creation of a guide for health professionals in the oncology setting.

The general inductive approach provided an easy to use systematic approach and clear set of procedures that produced reliable and valid findings (Thomas 2006). I have provided an example of how this was undertaken for one participant within appendix eleven.

Reflexivity and trustworthiness

Reflexivity is a means of dealing with knowledge construction systematically on the part of the researcher throughout the research process. As a researcher, I know that my background and position will have affected what I have chosen to investigate, the rationale for the research, the tools and methods that have been assessed as most appropriate to develop findings, and the means of conveying the conclusions (Malterud 2001). Throughout this journey my own perspectives or position can shape the research and there is a need for researcher to be open and transparent about how this occurs and to take measures to minimise this. As Malterud (2001) writes:

> *"Preconceptions are not the same as bias, unless the researcher fails to mention them"*
> (Malterud 2001 page 484)

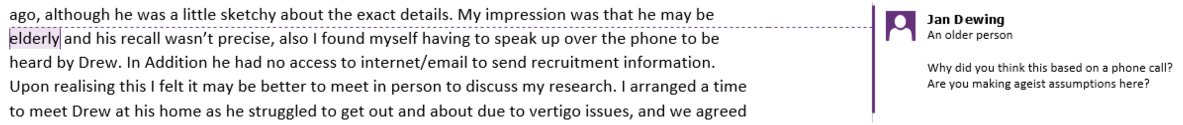
Up to now I have been very clear about my values and beliefs and how they have impacted on my research. In addition, I have also set out the ethical considerations for this research, which include my own ethics and principles, as not to distort what participants discussed with me. I understood that my position, perspective, beliefs and values have been potential influences on the research, especially as in qualitative research I am a 'human research instrument.'

The participants and I approached this research from different positions or perspectives, and therefore this resulted in the creation of different, although valid, understandings. This is why I have engaged through the process of the inquiry, to clarify understanding with the participants, and to ensure a mutual understanding of the research findings. I understand that some researchers will feel that different understandings between the researcher and participants can be seen as a problem, although in this study it was necessary to establish people’s values and beliefs, and provide a richer and more developed understanding of the issues that the participants faced.

I have designed the research to include multiple participants throughout the research process, from the design, to the creation of its outputs. I have fostered dialogue that has resulted in both agreed and differing understandings of LGB persons affected by cancer. This was done through developing a clarification of beliefs, values, perspectives and assumptions of each stakeholder. In order to ensure a trustworthy and reliable set of research data it was necessary to ensure inclusion of a wide range of participants from different backgrounds and experiences, and to ensure that the research was inclusive enough to draw from across the LGB community. Prior to the conducting the inquiry sessions, I ensured that I had already established contact with the participants several times, developing an initial rapport and gaining a level of trust. From my experience, this was very important in gaining perspectives from participants across different backgrounds. During recruitment I was mindful that if I didn’t get enough participants, there was danger of only hearing a limited range of views that could not be substantiated giving a potential for bias within the analysis towards individual agendas.

I started a reflexive journal and made regular entries throughout the research process. I found this to be of use and important when reviewing my progress with my supervisory team and exploring the data (Lincoln and Guba 1985). The structure of my field notes was based on what I did, felt, saw and heard, as per the practice observation and facilitation skills I had learnt in practice development school (Dewing et al 2014).

The notes were written up in journal following each of the participatory sessions and focused on thoughts and learning from each of the stages of the inquiry framework. These were then shared with my supervisory team during debriefing supervision sessions. The extract below shows comments made on my field notes to help focus our session and tackle assumptions or issues I had made during the field work:

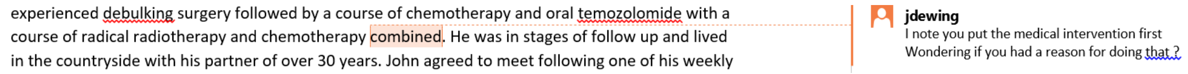


ago, although he was a little sketchy about the exact details. My impression was that he may be elderly and his recall wasn't precise, also I found myself having to speak up over the phone to be heard by Drew. In Addition he had no access to internet/email to send recruitment information. Upon realising this I felt it may be better to meet in person to discuss my research. I arranged a time to meet Drew at his home as he struggled to get out and about due to vertigo issues, and we agreed

Jan Dewing
An older person

Why did you think this based on a phone call?
Are you making ageist assumptions here?

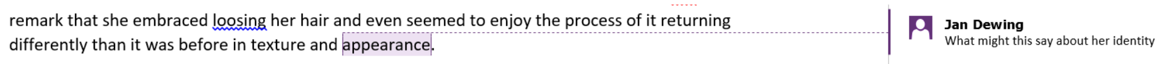
Field note debrief extract - Drew



experienced debulking surgery followed by a course of chemotherapy and oral temozolomide with a course of radical radiotherapy and chemotherapy combined. He was in stages of follow up and lived in the countryside with his partner of over 30 years. John agreed to meet following one of his weekly

jdewing
I note you put the medical intervention first
Wondering if you had a reason for doing that ?

Field note debrief extract – Michael



remark that she embraced loosing her hair and even seemed to enjoy the process of it returning differently than it was before in texture and appearance.

Jan Dewing
What might this say about her identity

Field note debrief extract - Sisi

In my diary entries I documented any decisions that I made regarding the application of the methodology as well as the rationale and underlying motives for any decisions I needed to make. In addition, I was also diligent in reflecting on my own values and beliefs as challenges occurred when conducting the research. The use of diary keeping was very private and cathartic at times and also helped me to ensure that my decisions were consistent with my research aims.

Debriefing was means of establishing credibility in this research. My supervision was very useful in providing the opportunity to debrief, identify any issues that I had, and identify any of my own preferences and biases that may be impacting on the research. As I move forward, I am also mindful that I outline any relevant views, personal beliefs, values in my publications and outputs.

Qualitative and participatory research methods have traditionally been criticised for lacking rigour and being impressionistic with biased results. I have made efforts to address these criticisms and applied a content analysis framework to provide structure and integrate reflexivity in the research when analysing the textual data.

8. Findings and meta-synthesis

Introduction

In this chapter I am going to present the main findings of my PhD research and critically discuss how I have been able to explore my research question in relation to my theoretical framework. From the onset of my PhD programme, I have sought to understand how the personhood of LGB people is impacted by the experience of cancer treatment. It is my assertion that cancer treatment presents a disorienting dilemma in which a person may achieve transformation and growth through the effects and impact of treatment. Using my field notes, data extraction tables, and participants' own accounts, I have synthesised my findings within with my research framework. As a reminder, the main aim of this participatory inquiry was to "research 'with' rather than 'on' people and as such the participants in the research were viewed as co-researchers.

To address my research aims I will present my findings chapter in four sections. These are aligned to my theoretical framework, which is based on Mezriow's ten stages of transformational learning theory and discussed in the previous chapter. The research findings are broken into four overarching categories that are derived from the initial directed content analysis of the raw data, these go on to form the structure of how the findings are presented in this chapter and are demonstrated below:

1. Disorienting dilemmas in the context of care experience and holistic needs,
2. Reflecting on identity,.
3. Exploring new relationships and building confidence in new roles,
4. The transformational effects of cancer and reintegration of perspectives.

This research managed to successfully recruit a total of nine participants who had treatment for cancer in Scotland at various stages of their disease. One participant relocated to England after they recovered from their cancer treatments, but the experiences they discuss are relate to the care their received in the Scotland. Each participant engaged in two inquiry sessions in which they were supported by myself and a key support person if they wished. During the course of the inquiry session's participants discussed what was important to them as an LGB person, and how cancer impacted on this.

Introducing the participants

The participants within the research all have a unique set of values, beliefs and past histories which informs on their world view and their own cancer experience. I have provided a short introduction to each of the participants (i.e. who is this person) to aid when referring to them throughout the thesis. I have included back ground information that relates to their job history, age, location, treatment details and their relationship status. Each of the participants are referred to through the use of a pseudonym, as well as key individuals such as support persons, family members, professionals in order to ensure their confidentially is maintained. I have also provided a copy of the participant's identity map which was blurred and agreed by each participant for publication in the final thesis.

Drew

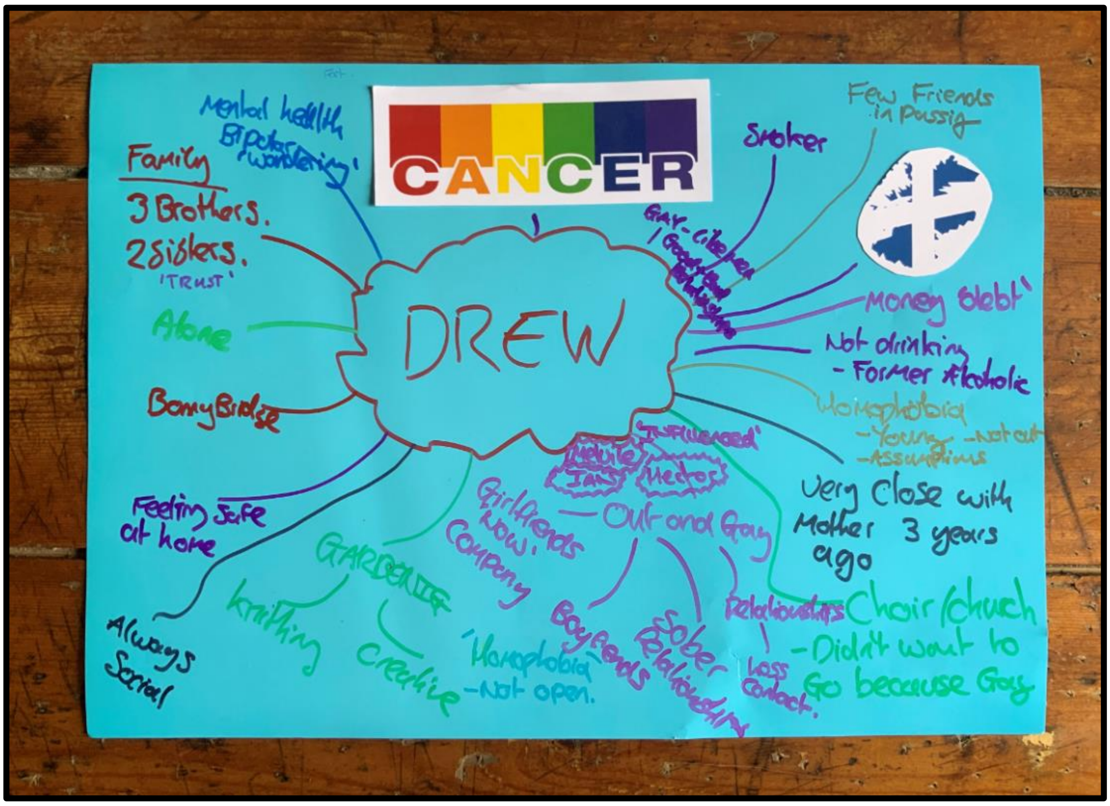


Figure 8.1. Drew identity map

Drew is a 67-year-old gay man, who has had previous radiotherapy and chemotherapy for anal cancer five years ago. During the course of his treatment he became unwell with depression and was forced to move from a larger city in Scotland to a smaller more rural area. He maintains contact with his family who provide him support, but has a complex relationship with them. He is lonely and relies on the support given to him through the local LGBT cancer support help lines.

John

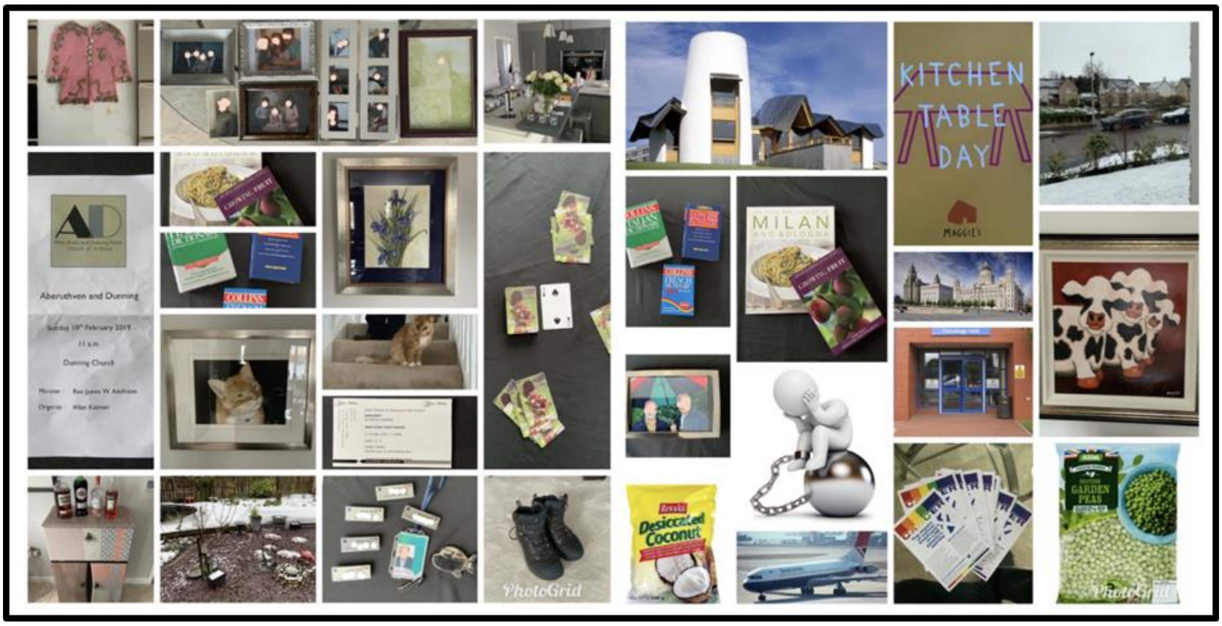


Figure 8.2. John identity map

John is a 67 year old gay man, who is a retired cabin crew member who now lives with his long-term partner of 30 years in a rural area of Scotland. Three years ago he had a diagnosis of high grade glioma and underwent debulking surgery, followed by chemotherapy and radiotherapy. He is an avid walker and has a broad social circle of friends with whom he enjoys going to the theatre, and hosting dinner parties. He enjoys gardening and participates in his local cancer support group at the Maggie’s centre.

Sisi

Figure 8.3. Sisi identity map

Sisi is a 55 year old lesbian woman who is a teacher and originates from Europe. She has lots of family back home and maintains regular contact with them through video calls and WhatsApp. She lives with her long term partner of over ten years in a large Scottish city, and provides a level of care to her mother-in-law. Sisi had a diagnosis of stage two uterine cancer and had surgery, followed up with chemotherapy and radiotherapy 18 months ago in her local Cancer Centre. She and her partner sing in an LGBT choir in Scotland, and she enjoys outdoor activities such as walking and hill climbing.

Lewis

Figure 8.4. Lewis identity map

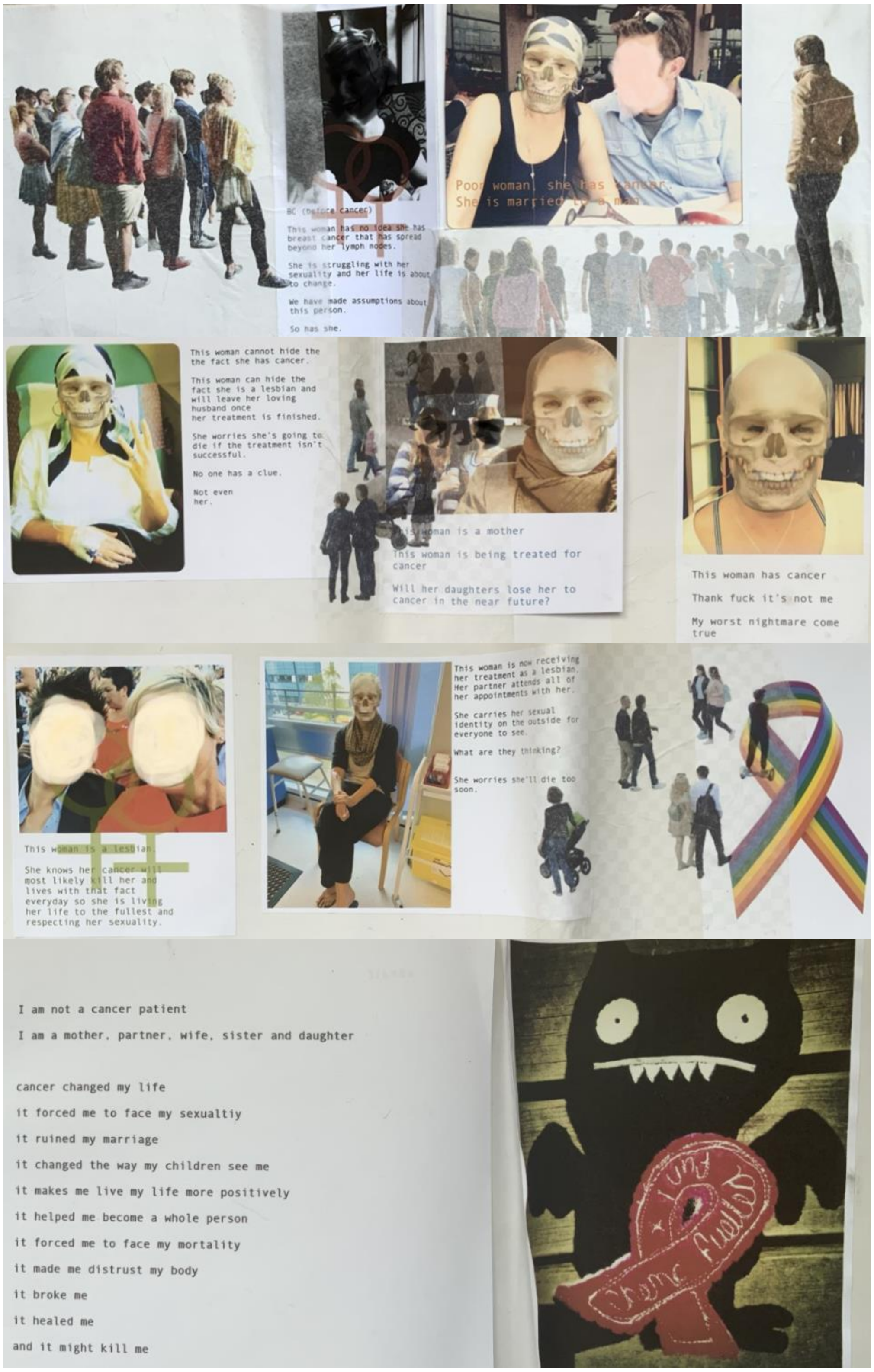
Lewis is a gay man who was born in Scotland in 1959 and into a strong evangelical Christian family. He lived in an island community and was married for 23 years and with three children from that marriage. He spent many years coming to terms with his sexuality and eventually separated in 2005 and was divorced in 2008. Shortly afterwards Lewis was diagnosed with bladder cancer and had surgery to remove this. Since then he has had a local recurrence but is now currently clear. He is now remarried living in the south-east of England with his new husband and is a qualified allied health professional.

Tabitha

Figure 8.5. Tabitha identity map

Tabitha is a 54 year old lesbian woman who lives in a large Scottish city and lost her wife to cancer three years ago. Tabitha contacted me through email as she had seen one of my leaflets within the Maggie's centre near to her home. The head of that Maggie's centre also spoke to Tabitha and indicated that I was still looking for participants in my research. Through a brief email exchange, I found out that Tabatha hadn't actually had cancer herself, but her partner had recently passed away from colorectal cancer. Tabatha was keen to participate in my research as she felt that she had been affected by cancer treatment and the associated pathways involved. When this occurred, I realise that Tabitha wouldn't actually meet the inclusion criteria set out for my research. Despite this, when looking at my principles, I decided that I should try to be as inclusive as possible with my research, and felt that Tabitha would be able to make a valued contribution as someone that experienced the entire cancer pathway as a key support person. I made changes to my research, and was granted an amendment to my ethical approval, and Tabitha was kind enough to participate.

Tate



BC (before cancer)

This woman has no idea she has breast cancer that has spread beyond her lymph nodes.

She is struggling with her sexuality and her life is about to change.

We have made assumptions about this person.

So has she.

Poor woman, she has cancer.
She is married to a man

This woman cannot hide the the fact she has cancer.

This woman can hide the fact she is a lesbian and will leave her loving husband once her treatment is finished.

She worries she's going to die if the treatment isn't successful.

No one has a clue.

Not even her.

This woman is a mother

This woman is being treated for cancer

Will her daughters lose her to cancer in the near future?

This woman has cancer

Thank fuck it's not me

My worst nightmare come true

This woman is a lesbian.

She knows her cancer will most likely kill her and lives with that fact everyday so she is living her life to the fullest and respecting her sexuality.

This woman is now receiving her treatment as a lesbian. Her partner attends all of her appointments with her.

She carries her sexual identity on the outside for everyone to see.

What are they thinking?

She worries she'll die too soon.

I am not a cancer patient

I am a mother, partner, wife, sister and daughter

cancer changed my life

it forced me to face my sexualtiy

it ruined my marriage

it changed the way my children see me

it makes me live my life more positively

it helped me become a whole person

it forced me to face my mortality

it made me distrust my body

it broke me

it healed me

and it might kill me

Figure 8.6. Tate identity map

Tate is a 45-year-old lesbian woman who lives in the suburbs of a large Scottish city. She is American by birth and three years ago had a diagnosis of advanced breast cancer. Her initial treatment was delivered in China, although she subsequently returned to Scotland and manages her treatment in a cancer centre near to her home. Tate has stage four breast cancer, and has regular treatments for managing this near to her home. Tate is a mother of two teenage children and is married, working as an artist. During the course of her treatment Tate came out to her husband and they chose to live separately. Tate remains married and maintains contact with her husband, and now has a new female partner whom she lives with.

Susy

Figure 8.7. Susy identity map

Susy is a 45-year-old lesbian woman and was diagnosed with intermediate stage breast cancer five years ago requiring chemotherapy and surgery for treatment. Just prior to her initial diagnosis she lost her partner and was therefore still in the process of grieving for her during the course of her treatment. Susy is in her follow-up stages post treatment, and had extensive surgery including a hysterectomy and mastectomy. Susy now has a new partner, but had experienced depression and had to access support for this during her cancer treatment as she dealt with her bereavement. Susy lives in a large Scottish city, and works for a higher education institution nearby.

Agnes

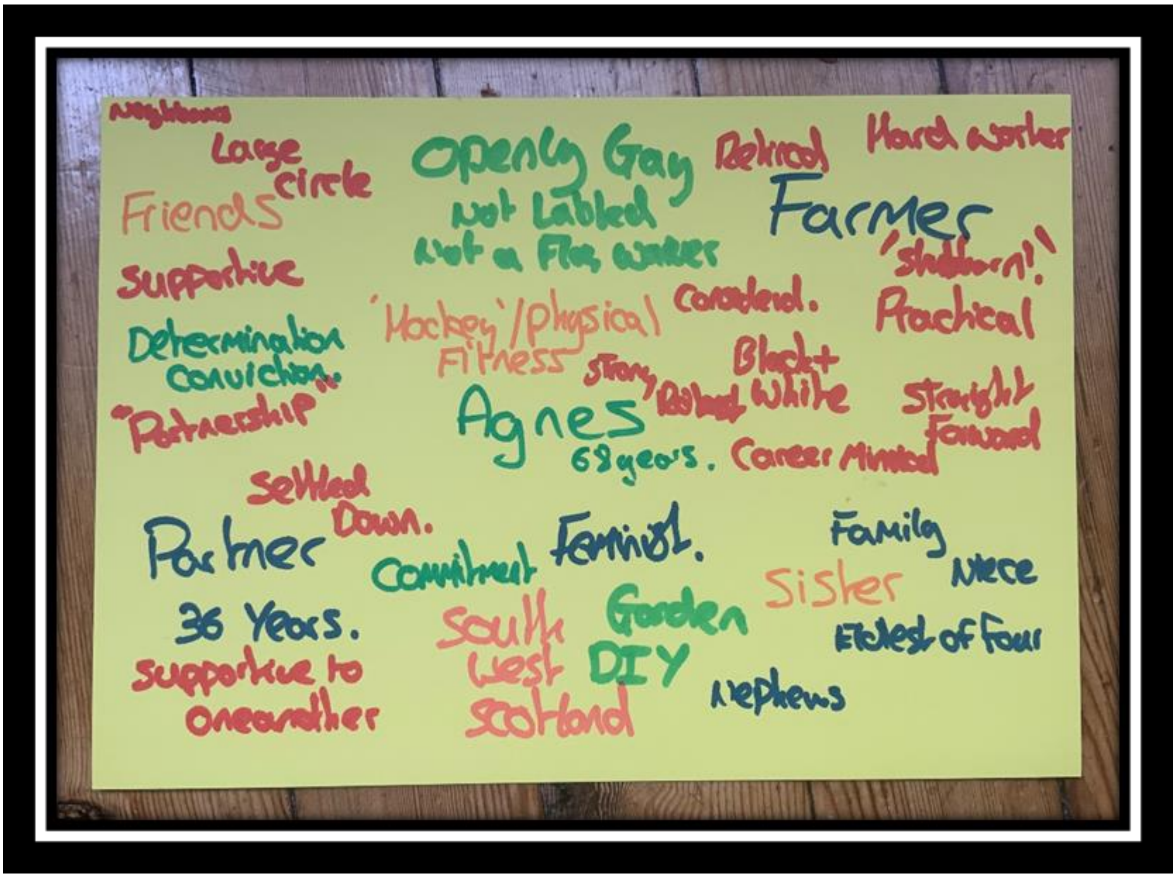


Figure 8.8. Agnes identity map

Agnes is a 68-year lesbian women who lives in the countryside of a farming area in Scotland. She is retired and a farmer by background, and originally is from the west coast. Agnes was diagnosed with advanced ovarian cancer, and has had several courses of chemotherapy treatment. She lives with her partner of 36 years and is a self-confessed straight talker. She has always been very physically active having several sporting and outdoor hobbies, and has a large circle of supportive friends. She has become involved with the activities of her local cancer support group and maintains strong links with her family who reside around Scotland.

Evan

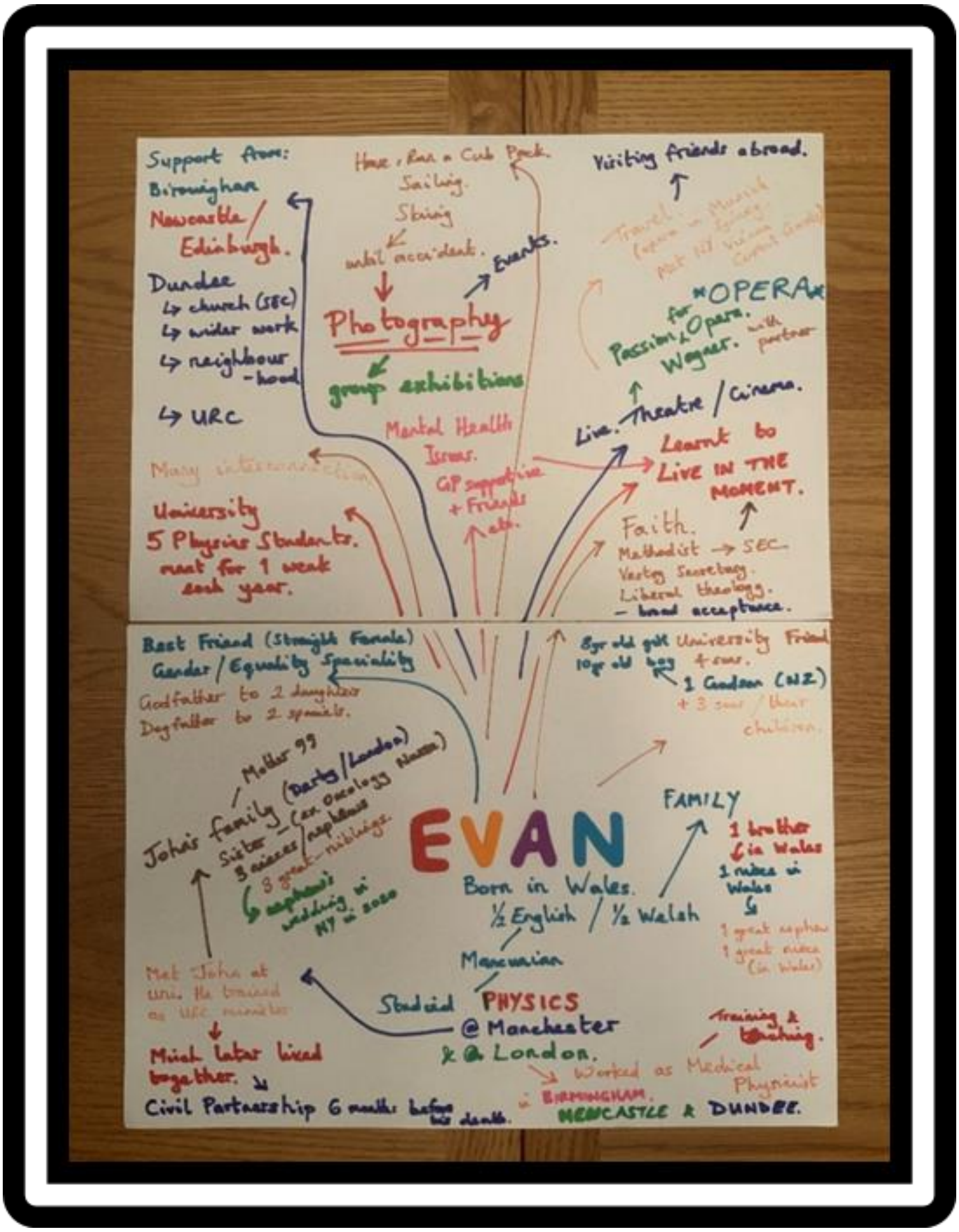


Figure 8.9. Evan identity map

Evan is 67 year old gay man and a retired medical scientist who lost his civil partner to cancer. At the time, Evan had just started his retirement and his partner's illness came on quite suddenly. Initially, Evan's partner's primary cancer was unknown, but it soon became clear that it was advanced. After a few weeks from diagnosis Evan's partner John passed away. John and Evan had lived together for many years, but had been very discrete about their relationship because John used to be a priest.

Overview of the findings

The below table 8.1 demonstrates the structure of the synthesis and findings of my own research plotted against the four overarching categories of my analytical framework (left hand column), and the inductive themes derived from the data (right hand column).

Initial content analysis structure of Meta-synthesis and findings	**Inductive themes derived from the findings**
Category 1 **Disorienting dilemmas in the context of care experience and holistic needs**	• Dilemmas of a cancer diagnosis • Coming to terms with the effects of cancer • Dilemmas of attending oncology apportionment and staff attitudes
Category 2 **Reflecting on identity**	• Coming to terms with ones sexual orientation • Reconciling religious beliefs, values and intersectionality • Attitudes of participants towards labels and being labelled
Category 3 **Exploring new relationships and building confidence in new roles**	• Exploring companionship and kinship • Family connections and expectations • Affirming experiences of care
Category 4 **The transformational effects of cancer and reintegration of perspectives**	• Perspective changes • Transformational changes

Table 8.1 Outline structure of analysis and synthesis

Based on table 8.1, in my first section of my discussion I will review the first category, disorienting dilemmas in the context of the care experience. These dilemmas represent the first of four key themes of my analytical framework. Persons, who have been in the receipt of carer treatment, will have experiences which generally do not fit with their pre-existing meaning structures, i.e. their core values, beliefs and self, causing disorienting dilemmas. In my research I have sought to explore with the participants experiences that are unique to them in the context of their sexual orientation and will be discussed in the first sections on the discussion chapter.

The next section of my findings chapter will discuss the important aspects of the second of the theory's themes, this is known as the reflecting on identity in the context of Being Lesbian, Bisexual or Gay with cancer. Category two demonstrates the critical reflection of the participants after experiencing their disorienting dilemmas. During this I demonstrate any self-examination with feelings of guilt or shame, and where participants have undertaken critical assessments of epistemic, sociocultural, or psychic assumptions.

The next chapter will discuss the third category of the analytical framework's themes, rational discourse. In this section I discuss accounts of the participants exploring new relationships and building confidence in new roles, it is also the section where I address the participants' positive accounts of health practice as there are good examples of affirming and enabling relationships between some of the participants and with their health providers.

The final chapter in the findings section of my thesis focuses on the fourth category which explores the transformational effects of cancer and reintegration of perspectives into the participants' lives and explores whether this has been achieved. I will discuss if participants have been able to acquire additional knowledge, and newfound competence and self-confidence in roles and relationships, as well as being able to reintegrate this knowledge into their life dictated by their unique perspective.

I present my findings in which I establish any distinct aspects of care the participants encountered in their cancer journey related to their sexual orientation and critically discuss my use of my theoretical framework as a means of analysis. This addresses my aims of establishing if there are any distinct aspects of care for LGB people affected by cancer and assists me in my aims of making a theoretical contribution to the concept of personhood.

Findings Category One

Disorienting dilemmas in the context of care experience and holistic needs

Introduction

Disorienting dilemmas represents the first of the four categories of my analytical framework. My focus in this next chapter is to review the participants' disorienting dilemmas in the context of care experience and highlight any missed opportunities in terms of their holistic needs.

I elaborate and illustrate how a disorienting dilemma, such as a life-event crisis like cancer, can stimulate in depth transformation. Mezirow's theory conceptualises how a person works through a crisis cognitively and accounts for how an individual's perceptive can change. For many, being informed that they have cancer will signify a significant crisis, as they usually don't have the habitual knowledge and problem solving abilities to enable them to navigate through the cognitive confusion this creates, such as how to think through and problem solve the many issues that may arise (Naaman 2008). The shock of the situation can mean that the information a person receives at that point is inadequate to fully prepare them for what is ahead, and doesn't support the person to fully understand situation or implications. In essence the person is often thrown in to a state of shock or panic and an unnatural way of being is then adopted (Naaman 2008). In my research, I identified three main dilemmas that can impact on an individual's identity and personhood and I have drawn on these areas to group the main priorities of my research participants. This forms the structure of this first chapter of my findings:

- Dilemmas of a cancer diagnosis,
- Coming to terms with the effects of cancer,
- Dilemmas of attending oncology appointments and staff attitudes.

In my experience as an oncology health professional, I am aware that for most persons being informed that they have cancer represents only one potential crisis in the journey ahead of them. After they move on from this initial crisis, they may have many other subsequent crisis throughout their care path. For example the person may be thrown into crisis by the presentation or symptom of their disease, treatment side effects, or even after the initial intensive treatment such as surgery, chemotherapy or radiotherapy, may then have a deep fear recurrence or complication. In this first section of my discussion, I will provide accounts (I.e. evidence) of when and how the participants have experienced disorientation through their cancer journeys related to their sexual orientations.

Cancer as an illness is correlated with a number of significant effects ranging from the physical to the psychological, with invariable social and finical implications for the individual and those close to them. The literature reviewing the LGB cancer experiences tends to focus more on interactions within care settings or physical sexual needs associated with effects of cancer treatment. In my research I worked with the participants to explore more deeply and reflect on their identities and personhood as part of the inquiry process. I was therefore able to gain more of a holistic view of the individual, as well as establishing more about their own values and what was important to them. Each of the participants' disorienting dilemmas occur at different points of their journeys, and had varying degrees of significance. As these dilemmas start to build over time, they start to reach a critical mass that then can influence either a change in their perspectives, or result in transformational effect on their own world views. The difference between perspective change and transformational change will be discussed later in my findings and discussion chapters, but it should be noted that Mezirow acknowledges that disorienting dilemmas can occur in a non-linear fashion and are presented in such a manner in my findings. During my sessions with the participants, I worked to establish what were the most important or significant dilemmas that they faced during the course of their own cancer journeys and this revealed a much broader set of priorities that is currently understood within the existing literature and evidence base.

Dilemmas of a cancer diagnosis

Coming out

Two of the participants, Tate and Lewis, found that one of the most challenging aspects of their cancer treatment was coming to terms with their own sexual orientations. Both Tate and Lewis were married to people of the opposite gender, with children; despite this, they had chosen to make the difficult decision to come out and revaluate their life priorities. This presented significant challenges and dilemmas, and in the next section of the chapter I will discuss in more detail how Tate and Lewis came to revaluate and assess their epistemological assumptions through this. Interestingly, in the research to date, I have found no other examples of accounts of LGB people with cancer having to deal with the challenges of coming out and endure cancer treatment side by side

*“Coming out, it’s funny. When I came out it was like you’re broken, almost like back in the f***ing 1930s, you’re broken. It was just so negative, my mother and my husband and my children were all like bullying me. Everyone was like you’re a Dyke, I hate you. It was just so negative…. These were the people I loved the most and thought they would be there for me”.*

“I don’t wanna identify as somebody who has cancer…. it’s something that I don’t wanna identify with, and to be honest if I could have stayed with my husband and not been a lesbian that would’ve been easier…. I don’t wanna associate that (cancer) with being a lesbian, but it is another thing that I’ve had to get through“

(Tate, Session 1)

Coming out is a very difficult process for many LGB people, it can be especially hard if those who are most close to the person coming out then reject or persecute the individual. In Tate’s and Lewis’ situations the families’ reactions were that of disgust and rejection and this was something they then had to experience as well as coming to terms with their diagnosis and treatment.

“My mum and dad are coming to see me, and I had to out myself only two months ago. Then told them a few months later I have split up with my wife, and then a few months on I was having to tell them I had cancer”

“I basically lost my full support network, because as a Christian, I am supposed to know that I am in the wrong. I had no one, except for talking to people on websites. I’ve come out of a marriage, and I am gay, and suddenly I am having to live as a gay man”

(Lewis, session 1)

Tate’s and Lewis’ experiences indicate a lack of support available for LGB people who come out in later life and having to deal with a cancer diagnosis at the same time. Whilst this finding may have been previously understood to be relatively uncommon in the literature, two of the nine participants in my research have undergone this life challenge recently. Therefore, it has been deemed as significant for inclusion within this research and indicates a possible support need. The support needs of LGBT people in such situations are largely unreported within the existing evidence base, and may indicate a sub-group of persons within the gay community that may have additional needs. In both cases, coming out represented a significant dilemma and life crisis at a time in which Tate and Lewis were very vulnerable. In terms of the theoretical framework of my research, coming out and the reaction to a cancer diagnosis would represent a significant crisis in which transformation was eventually achieved. In addition, a number of factors, such as past experiences of homophobia and rejections due to sexual orientation, length of time being out, confidence about altered identity may influence the way that a person interacts with health providers and the amount of support they have available.

Care commitments for children and older family and friends

Three of the participants, Sisi, Tate and Lewis, had caring responsibilities for children or older relatives. Cancer and its treatment are known to often disrupt family life and normal routines. As a result, care needs will typically feature as a significant issue of crisis or dilemma for most people that have a cancer diagnosis. However, within the literature there is very little reference to LGB people having caring responsibilities. I have been surprised to find this, as a gay man myself that knows many other LGB people who are in a position of caring for others, or indeed have children themselves. Sisi and her partner both took care of her mother-in-law who was elderly and had dementia as other family members had children and carer responsibilities themselves. This placed additional difficulties on their ability to manage during Sisi's treatment and was one of her main areas for discussion when talking about the impact that cancer treatment had on her life.

> *"I had painkillers, but they didn't really work for me, I was in pain quite a bit, my knees and my shoulders and sick and stuff. My wife said, "what do you wanna do", and I said, just go for a drive. So we spent loads of time just driving as I couldn't really walk anywhere. We just drove, and I thought, Jeez, how does she do that? You know, 'cos she kept it together. She had counselling at that time as well. And I thought how, how does she manage now with her Mum being so ill too? I Think this is not fair on her, you know"*
>
> (Sisi, session 1)

.

It is widely accepted that the LGBT community have had issues of portrayal within the media of having either sensationalised or stereotypical portrayals (Wolf and Kielwasser 2014, Dondoli 2020). When having a more person-centred and holistic views of the needs of the LGB persons in this research; the findings indicate that there may be a bias to portraying LGB people as two dimensional within the published literature. The literature tends to present studies related to loss of sexual function and negative experiences of care. In contrast my findings would seem to indicate that LGB people have a greater diversity of needs, particularly when considering carer responsibilities for older relatives or children, as well as coming to terms with sexual orientation in later life during cancer treatment and diagnosis. LGB families or those with carer responsibilities are largely absent from the current academic understanding of LGB cancer patients' needs, and there is a lack of diversity demonstrated in the research that has been undertaken to date. Tate also discussed her difficulties with her family, but despite this her responsibilities to her school age children were paramount. Tate also remarked on the difficulties that they may face with coming to terms with her own sexuality as well as her cancer diagnosis.

"My first thought was staying alive for my kids"

"For my kids it's been bad. You don't know what's worse, being a lesbian or having cancer, sadly. I don't want it to be, I want being a lesbian to be a great thing. I'm like a whole person now"

(Tate, Session 1)

Lewis expressed feelings of guilt and discussed how he felt that his family would have been better off without him when he first came out and had initial treatment for cancer. It is common for many people affected by cancer and coming out, to have feelings of self-blame for upsetting the people they love or worry that they have become burdensome in some way.

"I felt worthless because I was gay, I had cancer, and nobody really cared. I felt that my parents and family would be better off without me, and the kids would come to terms easier with a dead Dad rather than one who was gay and had cancer"

(Lewis, follow-up email)

Carers have a key role within society providing support for others, which in turn creates many social and economic benefits. There are a number of originations and services that have been set-up to support carers in Scotland, but, but these are not targeted towards the LGB community or the support needs of those facing cancer.

Coming to terms with the effects of cancer treatments

The physical effects of cancer treatment

The physical effects of cancer treatment can be difficult for a person to endure, and some of the participants remarked on the dilemmas that this caused for them and their feelings of how their own body changes had impacted on them and their quality of life. The late effects of pelvic cancer treatment are well documented and understood, and late pelvic radiation disease can have many late debilitating effects including effects on sexual intimacy (Arthur et al 2020, Incrocci 2017). Drew discussed some of the issues that he had as a single gay man affected by anal cancer. Having the long-term effects of his treatment means that this impacted on his ability to meet other men for physical relationships. He had several close friends with whom he would have sexual relationships with prior to his diagnosis and treatment, but he never wanted to cohabit with these people or exist in a monogamous relationship with them. As a result, his relationships were based on his ability to be able to physically perform sexually, and when this ended it meant that these relationships could no longer be sustained.

“My testicles just disappeared after treatment, and I was very tired. We couldn’t be physically intimate. I just stopped having sex with him a long time ago, and it was over.”

(Drew, session 1)

Drew tended to meet these men on the gay scene that was within travelling distance of his home. However due to his cancer treatment, this created problems for Drew as he wasn’t able to engage in physical intimacy due to his side effects, further due to his declining physical condition he wasn’t able to travel to the larger cities to go on the gay scene and meet other gay people.

“I always went to gay bars. Yes, I went to gay bars…. now I can’t”

(Drew, session 1)

This created a situation where Drew was effectively cut off from meeting gay men and engaging with his own community. In the area he lived he didn’t know any gay people and was deeply troubled by this. He had recovered from his illness and was now cancer free, but due to the long-term effects he was unable to travel far and had started to experience loneliness. One of the surprising elements of the conversation with Drew was that due to his desperation for companionship he was contemplating having physical relationships with members of the opposite sex as he couldn’t find any other gay men to have relationships with.

I'm just so lonely and think I am going to have get a girlfriend. I'm going to have to get a girlfriend because its company of some kind.

(Drew, session 1)

As Drew was so lonely and removed from other gay people, he was contemplating going back into the closet so then he could have company. In this case this represents a significant dilemma, and a possible indication of what it is like to live in a rural area and have no transport links to larger cities. Other participants also remarked on the need for physical intimacy and dating during cancer treatment, expressing apprehension about how their new partners would react to the physical side effects of treatment.

> *"When we got to the point of being intimate for the first time I think my girlfriend had no idea what to expect, she wasn't even clear at that point if I'd had a mastectomy"*
>
> (Susy session 1)

Agnes and Susy reflected on the side effects of their treatments and how it affected their appearance. The loss of hair can cause more than a change in a person's physical appearance. It can be an emotional challenge that affects a person's self-image and quality of life. Long hair can be considered as a symbol and indication of a person's femininity and gender expression. During my sessions, Agnes commented about the loss of her hair and to her this was a very matter of fact experience and didn't seem to affect about how she felt about her own image or outward appearance.

> *"And for the first couple of chemo's I thought, "Well, your hair will fall out", I thought "Alright." After the third once it went "dumpf!" hair everywhere, mostly out in the shower. I thought "Ah well, it's coming out, it was a known, upcoming side effect. A friend who has beaten breast cancer three years ago turned up one afternoon, and she'd brought wigs and fancy hats and all that. And I'm just not a wig person….*
>
> *Agnes' Partner: Agnes is the least self-conscious person I know. And from day one said "I'm not having a wig!"*
>
> (Agnes session 1)

This tells me, that despite the connection a person may have to their hair, everyone will then have different attitudes as to cope with its loss. In contrast to Agnes' experience, Susy commented about her use of wigs during chemotherapy and remarked how she decided to embrace the experience.

“So I knew I would get one wig on the NHS, and I went and I chose a wig that was called Miranda… I still call it Miranda, it was one of the ones I kept. Big long sort of glossy black one, which is still used for dressing-up purposes. It’s a cracking wig, and I was so pleased about it. I just loved the fact I could just go out and I loved that. And then I got a bit addicted to wigs”

(Susy, Session 2)

Although the experience of cancer treatment is not one that Susy would ever want to undergo voluntarily, it did give an unexpected opportunity to explore different identities in the context of dating and meeting new people. Susy decided to embrace the experience and depart from her usual norm and this allowed her to experiment with aspects of her persona that she wouldn’t usually permit to surface with people she had only just met.

Loss and changes in relationships

Cancer is known to have a significant impact on those in relationships, it can cause sadness, anger, anxiety and despair with both the person diagnosed and their long-term partners (Kirchhoff et al 2012).The effects are different for each partnership, with some facing the dilemmas from treatments that can strengthen relationships, to others finding that the strain on their relationship is too high. Most partnership will notice some degree of changes to their relationships, whether that is through changes in their roles and responsibilities, intimacy, parenting or the ability to future plan. Changes in relationship dynamics were experienced by John, Drew, and Evan who were in long term relationships. The effects of this took a significant period of adjustment as these changes were not only present in the relationship, but symbolised the extent of participants changing health status and physical abilities due to the effects of cancer treatments.

“It's been quite strange because I have moved from the carer to the cared”

(John, session 1)

Gay men with the diagnosis of AIDS have also been noted to have levels of psychological stress, combined with stigma, and potential issues of internalised homophobia (Wolcott et al 1986). Drew, who had always lived on his own, had several male friends that he had intimate physical relationships with. However, he talked of the issues he experienced due to the loss of his sexual function due to cancer treatment. This meant that those who he was most intimate with were no longer willing to associate with him and cut off all ties.

“Well, I wasn't able to have sex with them after treatment. And they just got fed up with the situation and they couldn’t stay. They were elsewhere…. one just came in one day and said, the relationship’s over.”

(Drew, session 1)

Despite the negative effects that cancer can have on relationships, it should also be appreciated that there were several examples of the participants forming new relationships as a result of their cancer journeys. Some relationships deepened and became stronger as a result of the illness. For example, Evan felt he was able to establish a deeper relationship with his partner’s family after his partner died of cancer.

“She and her husband came up to John's funeral. And I said ‘it's very good of you to come and attend’, and she said ‘well ***we are*** *family’”*

(Evan, session 1)

He also remarked about the great sources of support that his in-laws had been during the care of his dying partner, which they both didn’t expect. Both Evan and his partner, like many LGB people, lived far away from their family origins and were not close to their relatives prior to their cancer experience. However, in a time of great need for support, relationships started to grow.

“That's when he was really ill and I was wanting to keep busy, but his sister came over. Then his family came over and they all looked after me.”

(Evan, session 1)

Within the literature it is frequently noted that LGB people can have poor relationships with their family origin, indicating that there may be a need for additional support. Susy, Drew, Lewis, Tabitha, and Tate would corroborate this, however upon closer inspection through this inquiry, I suggest, this isn't necessarily universal and that despite challenges in someone's past due to their sexual orientation there are examples of where a cancer treatment journey can bring family closer together.

Dilemmas of attending oncology appointments and staff attitudes

Most people can feel a level of apprehension before going into the hospital setting for an appointment, but for people with cancer this feel can be amplified. Some people with cancer can find that they become anxious as they build up to attending for appointments for diagnostic tests or receiving test results, this has become known to many as “scanxiety”, but some people also experience fear as they prepare for routine cancer appointments. The contributing factors for this can be multifaceted but are influenced by someone's apprehension over how their healthcare interaction is going to play out. For LGB people, there may have been occasions of past homophobia or negative healthcare experiences of the cancer setting that may influence how they engage with cancer services. Participants in my research discussed their direct experiences of care during their cancer journey, and some gave accounts of disorienting dilemmas related to their interactions with staff.

During our sessions, Tate indicated that she had negative experiences from an Oncologist in China. Tate felt the Oncologist examined her inappropriately, and it is only after this experience she feels that the encounter was inappropriate and didn’t want to do anything about this now. However, she added repeatedly the treatment that she had received had been largely positive in Scotland, although she did indicate that at times she and her partner felt uncomfortable when attending clinics in the UK. She discussed that when she attended appointments she felt as though other people may be judging her and how this contributed to additional anxiety in the outpatient appointment setting.

> *“Not only am I waiting to find out if I have cancer or not, I’m also worrying about the people in the waiting area. Are they thinking that I’m weird…? I am thinking about that.… It’s like just another thing“*
>
> (Tate, Session 1)

Tate’s feelings on this matter revealed that at times she felt uncomfortable about what other people may be thinking. Given her experiences of past homophobia from those close to her, and her previous negative experiences of care in China, this is perhaps understandable. In addition, these feeling of discomfort and awkwardness are present within the literature and are recognised as having negative or detrimental effects on a person’s wellbeing (Igartua et al, 2009. Stones and Glazzard 2019). Participants within my research (who) also discussed receiving homophobic treatment from healthcare staff. For example, Lewis gave an account of an interaction with his GP shortly after coming out and his diagnosis of cancer.

> *"I was talking to my GP about my situation, and she said you know that it's wrong. She said you need to accept that you are in the wrong. She was a real demon in the church"*

(Lewis, session 1)

Lewis accounts provide insight into how healthcare staff are also members of the same community and local population to which LGB people also belong. As such attitudes within that community towards sexual orientation can also manifest themselves within the healthcare setting. All healthcare professionals must abide by codes of conduct to practice in a non-discriminatory manner; however, it can be observed through Lewis' experiences that this isn't always the case. This example illustrates well how a healthcare practitioner's beliefs can impact on the quality of care an LGB person receives.

One of the participants in my research, Tate, came out over the course of her treatment, and she discussed some of the differences between attending an oncology appointment when she was with her husband. She elaborated how she now feels when she attends with her same sex partner. Tate's former husband and her new partner both accompanied her to medical treatments and follow-up appointments. When exploring the feelings of anxiety that Tate experienced during outpatient appointments we discussed if there were any differences between how she used to feel attending appointments with her husband prior to coming out and now with her new same-sex partner.

> *"It's a thing…. I'm aware that I'm sitting with my partner… I am like aware of it. When I used to go to appointments with my husband it wasn't an issue, and I didn't have to think about it…. It makes me think, I wonder what they're thinking"*

(Tate, session 2)

Throughout my discussion with the participants there were examples of when healthcare staff sometimes misread situations or assumed that one of the participants was heterosexual. Heteronormativity when applied in a healthcare setting can give rise to misunderstandings, which on most occasions LGB people with less life threatening or debilitating disease may feel enabled to correct. However, in the case of the LGB people with cancer, who may have additional anxieties and vulnerabilities, these interactions can sometimes give rise to a poor healthcare experience and lack of understanding from staff. Tate's experiences reaffirm the findings of other UK researchers such as, Fish and Williamson (2018), and Doran et al (2018), whereby their participants also felt awkward when attending appointments with same sex partners. Susy described a situation where a nurse didn't appreciate that she had experienced the death of her partner just prior to her cancer diagnosis. Susy attempted to ensure that health care staff were aware of this by indicating on documentation that she was widowed. However, there appeared to be a lack of recognition that Susy, as a lesbian woman, could be a widow, and that this term (and experience) also applied to same sex relationships. This case demonstrates a real lack of awareness of some healthcare staff; Susy was understandably very bereaved by this situation, and was feeling vulnerable. As a result, Susy was not best equipped to challenge poor behaviour and lack of understanding from staff.

> *“She's doing the paperwork before they administer the first dose, and she says, ‘I'm sorry, I have to ask you this, and I think I know the answer anyway, but could you be pregnant?’ And I said, No, you know, being a lesbian... she looked very surprised, and went away. I thought OK, 'cos she hadn't seemed like anyone who might be homophobic, and then she came back, actually quite discreetly, managed to say ‘ooh, you know, your form says you were actually widowed, but then you said you were lesbian?‘ I then had to say, well actually, it was my civil partner that died, and I ticked the widowed box. That was horrible”*
>
> (Susy, session 1)

Following this, Susy described further experiences where the fact that she was widowed was not taken into consideration by healthcare staff. During further consultations, Susy described situations whereby staff made remarks that made her feel quite uncomfortable and angry at times. She described one situation where staff recommended her to try and go home and have a normal weekend prior to having interventional treatment scheduled the following week.

> *“I haven’t done a normal weekend since my partner died in September! There was this appalled silence, ‘cos on the one hand she, she’d just caused that by saying that ridiculously stupid thing. But then actually she claimed it back and she actually then got it right, and she said, “and what was your partner called?”*
>
> (Susy, session 1)

LGB people can often feel vulnerable about sharing openly information about them that relates to their sexual orientation. This is because many LGB people have had negative experiences about sharing or disclosing their sexual orientation, and over time, many LGB persons have hid their true identities when in public. During one of my sessions with Evan, he described that he and his partner used to be members of the church and as such couldn’t get married and were not used to expressing any mutual physical affection in public. This is a common occurrence for many LGB people, however Evan discussed how this situation proved problematic when caring for a loved one in the presence of healthcare staff. He described a situation of unease when his partner was dying of cancer and what it felt like to be in the presence of an oncology nurse.

> *“I don't express affection, physical affection with my partner, very much in public. The reason for that is that's quite loaded, I think to do with LGBT history and the social acceptability, and we get very good I think hiding who we are.”*
>
> (Evan, session 1)

Throughout my time with the participants, they were often keen to share how grateful they were with the care that they received, but there were accounts of when healthcare staff didn’t get the situation right for them. This wasn’t present throughout their healthcare journeys and most tried to make light of situations when misunderstandings occurred. Tate described a situation where pregnancy status needed to be obtained prior to a radiation exposure under Ionising Radiation (Medical Exposure) Regulations it is a requirement for radiographers to ascertain from anyone of childbearing age if there is any chance they could be pregnant due to the risks to the foetus.

> *“I’m forever asked if I could possibly be pregnant - every time I’m scanned, for example. Only once have I jokingly said that would be impossible as I’m a lesbian (as well as the fact I have had my ovaries removed!). The woman I was speaking to didn’t laugh or make any further comments. Anyway, I just answer, “No” now and accept the mildly annoying fact it will always happen.”*
>
> (Tate, follow up Email)

On this occasion, Tate joked and said no there was no chance that she could be pregnant and that she was a lesbian, the radiographer reacted very awkwardly and that there was a silence. The consequence now being, as with other people facing a similar situation, that at future appointments people like Tate may feel uncomfortable or awkward, contributing to the anxiety that may be felt in anticipation of an oncology appointment or scan. Susy went on to explain in her session that staff should be able to facilitate the disclosure of a person’s sexual orientation by staff not reacting in a surmised, shocked or negative manner.

“I would like to come out gracefully, just drop it into the conversation, but make it just seem the most natural thing in the world, so there's no awkwardness about it”

(Susy, Session 1)

When examining these experiences through a person-centred lens, it is clear that the service provider should be making attempts to treat people with dignity, compassion, and respect. In the findings of my research, I can see that despite wider organisational commitment, local practices create situations whereby individuals are made to feel uncomfortable due to their sexual orientation.

Findings Category Two

Reflecting on identity

Introduction

In this section of my discussion, I am going to move onto the second section of the analytical framework, reflecting on identity. The first key finding relates to the participant's joint exploration of their identity in the context of being an LGB person having cancer treatment and diagnosis. The goal of the participatory inquiry was to enable participants to explore their own identity through the use of reflective narratives, and this process was assisted through discussing personally created identity maps of personhood. This was achieved using a creative method acceptable to the participant e.g. using existing objects and artefacts, photograph of personal significance, using creative expression such as painting, music, craft, etc. The materials were then used as a trigger and basis for conversation, exploring its meaning in relation to a person who identifies as LGB. Through interaction with the identity map the participants reflected on important aspects of personhood. As each of the sessions were analysed and themed, four key areas arose in the discussions that relate to the impact of cancer on self:

- Coming to terms with one's sexual orientation
- Reconciling religious beliefs, values and intersectionality
- Attitudes of participants towards labels and being labelled

As the identity maps were individualised to each participant, each was structured around what was felt to be most important to them. During the sessions I encouraged participants to talk about key relationships, their lives, and their values and beliefs. This encouraged them to explore their own identity, with the aim of establishing a picture of the individual's personhood. Participants then reflected on how cancer had impacted on the different facets of their personhood. Each of the participants had several aspects of their identity encapsulated in our discussions, and one of the central themes was the participants' sexual orientation and how cancer had affected this. Sexual orientation held different value to the different participants, with some not viewing it as important, and others finding it central to some of the issues they face and how they interacted with the world. As such it was evident that being Lesbian, Bisexual or Gay with cancer is distinctive, and a core aspect of each participants' identity, although this varied in importance from person to person.

In this next section I provide accounts of my exchanges with the research participants. There were several accounts where they reflected on aspects of establishing their true identity, such as what being lesbian or gay meant to them. These uncovered stories of family reactions, previous experiences of homophobia and outright support. Whilst exploring their identity maps it became evident that Tate and Lewis had come out during their cancer journey to their families and friends, and in some cases the ordeal of a cancer diagnosis led to them feeling the need to establish a more authentic identity and not wanting to live in the closet. Lewis, Evan, and Michael, had strong and long held views about labels where Lewis and Evan indicating past experiences of homophobia and negative associations with terms such as queer. Further some participants didn't like to be associated with gay liberation and rights movements and demonstrated unease at being interpreted as being out, loud and proud. Participants reflected on the experiences of dating when having cancer and having to come out as having cancer to the gay. This inquiry has revealed that all the participants' sexuality featured in their lives as such confirms that this is an aspect of their identity. This gives rise to differing experiences of the participants, where they then interact in certain ways due to their sexual orientation with others, and this influences the way that others interact with them.

Coming to terms with one's sexual orientation

Coming out to friends and family is often a gradual process that takes place over many years for lesbians, gay men, and bisexual people, as they come to realise and accept their own sexual orientation and gender identity. I have said that sexual orientation is intrinsic to a person's identity, and several participants discussed how they came to terms with this over their lives, but Tate and Lewis came out around the time of their cancer diagnosis. The gradual acceptance of a ones sexual orientation varies from person to person and can take varying degrees of time/. Generally, acceptance is characterised by several stages that are dependent on the individuals own history, personality and the culture in which they live. According to Cass (1984), the acceptance of a person's sexual orientation includes six steps: confusion; comparison; tolerance of one's orientation; acceptance; pride; and finally, the synthesis of one's identity. Within my research one of the participants reflected on what it was like to come to terms with their sexual orientation after they were diagnosed and treated for cancer.

> *"With having a cancer, you know, I fell apart after the treatment. I think I had a nervous breakdown of some sort, and it was like I was on self-preservation almost. I don't know what it was; I just lost control that ability to suppress my sexuality. I just couldn't suppress it."*
>
> (Tate, Session 1)

Several factors are known to hinder the ability for someone to accept their sexual orientation and come out, and this can include the any previous homophobic remarks that have been made by colleagues, friends and family. These can add to a person feeling confused, scared, and the development of internalised homophobia. People can reject their homosexuality or bisexuality despite the damage that this can cause to their health . This may place LGB people in a more vulnerable position, less resilient to facing a life-threatening illness such as cancer.

"Before I allowed myself to become a lesbian, and now I have cancer, I have two things that I carry around with me in my head. You know, now I have cancer, and now the lesbian thing….. two things weighing me down, two things on me that I don't have before"

(Tate, Session 1)

It should be understood that a person does not choose their sexual orientation, rather people choose to accept it or not. In whatever form it is generally recognised that 'coming out' is a very challenging thing to do even in today's age and can be detrimental to a person's mental health and wellbeing (Alonzo and Buttitta, 2019. Cleland, 2019). Coming out as Gay, Lesbian or Bisexual at the same time as having to deal with the psychological effects of cancer, may include increased anxiety, distress, and depression. Participants in my research discussed the attitudes of family, friends, and colleagues towards their sexual orientation and some of their day to day struggles they encountered with a lack of acceptance of who they were and how they chose to live their lives.

"My parents didn't come to our civil partnership, my Mum didn't even make it up for (deceased civil partners') funeral"

(Susy, Session 1)

Many people struggle for years coming to terms with their sexual orientation, with participants in my research discussion seeking counselling and conversion therapies due to previous rejections they faced. The therapies aimed to change a person's sexual orientation or not to act on feelings of homosexuality. In the UK, The NHS and all large counselling bodies have issued a memorandum of understanding condemning LGB conversion therapies (Romero 2019), yet the practice continues and is accessible through other sources, such as privately or through religious groups.

“I had read books, Christian books, on both sides and this was like something that I had chosen. I was put under a lot of pressure from the church and those individuals and I did seek help from a Christian group. At the group the guy said it was ok to be gay, but you can’t act on those feelings”

(Lewis, Session 1)

As a consequence of coming out, two of the participants had to go through the process of their marriages breaking down as well as having children at home whilst adapting to the situation during treatments. There were many occasions during our discussions whereby participants expanded on what this felt like, rejection experiences and the need to come out. Despite the potential consequences and the difficulties this would cause, having a cancer diagnosis and treatment led the participants to reassess their own values, and assumptions, and go against many of the things they had grown to accept as normal or had learnt to live with.

“I got to 39 and I have prayed for so many years for this to go away and have tried not to be gay. Am I going to go through my world life to not know what it is like to love a man? To hold a man, to kiss a man you know all of that. So, I am not proud to admit it, but yeah, I did meet someone when I was 40 and things happened.”

(Lewis, Session 1)

The experience of cancer treatment caused some participants to re-evaluate their life priorities and took the very difficult steps to come out. Tate achieved an aspect of growth with respect to her sexual orientation and felt truer to her own identity.

“My sexuality has always been suppressed, then after the treatment, I was like… no life is too short. I can’t live like this”

(Tate, Session 1)

Negative reactions or reactions from family members or those most close to a person can lead to feelings of loneliness and isolation. Loneliness is recognised as being prevalent among the LGBT community and can be compounded with the feelings of isolation that coming out can create (Wilkens, 2015). Research indicates that social isolation can add to poor cognition resulting in a more rapid decline, depression, instability, and poor mental wellbeing (Tomaka et al 2006). Social isolation also contributes to accelerating the ageing process in older people (Hawkley and Cacioppo 2007). Moreover, people can lose the ability to form positive and satisfying relationships when they are socially isolated (Stokes 1985).

These feelings can contribute to a downward spiral where they can become more isolated and can be witnessed in the discussions I have had with my own participants.

> *"I felt worthless because I was gay, I had cancer and nobody really cared. I felt that my parents and family would be better off without me and the kids would come to terms easier with a dead Dad than one who was gay and had cancer"*
>
> (Lewis, Follow-up email)

Coming out can be a difficult experience for many LGB people and is recognised as a significant life event for a person when this first starts to occur. Over the course of LGB people's lifetimes they will continue to come out to people, but the individual starts to build resilience as well as a trusted network of support and belonging. Health providers should be mindful that people may not be out to their family or could be in the process of doing this through their cancer journey. In the initial stages of coming out this can be a lonely experience and significant event whilst a person tries to establish a true reflection of their own self. It therefore is important for health professionals to realise that those in receipt of their cancer care may be revaluating their own life priorities and then choosing to come out. Due to the emotions and psychological challenges that a cancer experience entails, health professionals should be mindful that LGB people may have additional support needs when also coming to terms with their own sexual orientation.

Reconciling religious beliefs and intersectionality

Homosexuality and religion have had a complex relationship that has varied over time within society. Most of the major religions present in the world today differ vastly in terms of their acceptance and teachings on homosexuality, with many religions having differing views across sub faith groups. The reaction towards homosexuality from a religious perspective can range from being extreme where a person is punished or excommunicated, or to where homosexuality is discouraged generally (Englander 2011, Small 2018, and Meyer 2016). Research has demonstrated that homophobic views can be expressed by individual belief systems as well as those that are involved in national faith leadership, and that those in positions of religious authority have argued that homosexuality is sinful which can be discouraged through counselling or prayer (Sue 2019, Dworkin and Yi 2003).

In my research, four participants called themselves religious and regular attendees of church. When exploring their identity maps some intersectional aspects arose in respect of incompatible beliefs. Lewis discussed how he was raised in a very religious community and talked about the difficulties in reconciling his beliefs, even suggesting that his community felt his cancer was a punishment.

“I hit some very low points in my cancer pathway, including considering suicide, and on more than one occasion, people telling me my cancer was a judgement from God and that it was because I had ‘CHOSEN’ to be gay.”

(Lewis, follow-up email)

Evan discussed the importance of religion to himself and his partner and talked about some of the challenges that arose when engaging in certain circles of his church. It is important to note that a church community and congregation is diverse in its membership and there are those that are accepting towards sexual orientation. Evan discussed how there can be occasions of duplicity in attitudes towards his homosexuality within these circles.

“Certainly through my church connections it slightly annoys me that people would say sometimes. “So I don't like homosexuals but you're alright, you know”

(Evan, session 1)

It should be noted that many within religious communities and faith groups can regard homosexuality as a positive thing, and that some dominations bless same sex marriages and are support of LGBT rights and legislative reform . Some of the participants talked about the importance of their religion and how they gained a great deal of support and acceptance through the religious communities they belong to.

“My church community has been very good. I go to my local church. So actually, it's probably the most LGBT friendly church”

(Tabitha, session 1)

Many persons of faith can also look to scripture for guidance on homosexuality, but the interpretation of this scripture is usually enshrined in tradition and authority figures. This gives rise to issues that are sometimes hard for people to reconcile and on occasion conflicts arose between members of the LGB community and the participants. This was particularly the case when Lewis came out and started to engage with more LGB people in the community at large. He described how many Gay men found it hard to accept that he was both strongly religious and gay, creating a situation whereby he was rejected to some degree by both the Christian community to which he belonged and the new gay community that he was attempting to integrate in.

"You know, why can't I be a Christian who believes that it's okay to be gay"

(Lewis, session 1)

Ultimately the church and religion encompass a very broad spectrum of views but many of the participants in this research commented about either the opportunities or difficulties that engaging with their own religion created for them. Evan's feelings on the matter were clearly expressed in his sessions, and he seemed to have come to terms with these tensions between acceptance of homosexuality and religions.

"I gather it very much depends as well on the congregation's views."

(Evan, Session 1)

Intersectionality was observed in my research, and participants discussed how different aspects of the social categorisations such as religion, sexual orientation and gender interconnected and overlapped. In certain situations, this gave rise to conflict, but each participant had found means of addressing or accepting these conflicts and would indicate that their religious identities were just as integral to their own values and beliefs as their sexual orientation.

Attitudes towards labels

Arguably, labels are a requirement for those in society to be able to differentiate between things. They can assist us being able to categorise complex things, and be able to create order in knowledge creation and common understanding. However labels can often influence people's common understanding of things, which can be impacted on by power and those with agendas. This relativist view aligns with my own ontological and epistemological views. Given my epistemological stance is that people construct their own understanding and knowledge of the world, through experiencing things and reflecting on those experiences, this is a core facet to constructivism and constructionism. Some individuals didn't feel they met the inclusion criteria of my research, but still contacted me anyway.

"I don't identify with the gay scene and I'm not a flag-waver, so I'm not sure that I am eligible to participate in your research"

(Evan, session 1)

Many criticise the terms LGB and LGBT as being too simplistic to classify someone's lived experiences of their gender identity or sexual orientation (Wagaman 2016). There are many examples and variation from across the world in terms sexual identities (Kinitz et al 2021). Many of these do not fit into the LGBT category easily, and some are even erased in the process, with many people that identity as LGBT feeling that they have been adsorbed or forced to conform to what is commonly understood by these terms and LGBT culture s (Eliason 1996). The participants reflected on the use of labels and most held views about what their preferred labels were, if any.

"The term LGB…T…Q, whatever, it just keeps getting longer and longer, as folk recognise there are more folk that don't fit the norm. As the description expands, it should be inclusive, it should bring people in, we all at some point or other have to go through the same"

(Agnes, Session 1)

Queer can be described as more inclusive term for those that may not feel right with a Lesbian, Bisexual and Gay label, but recognise that they differ from the norm in terms of their sex, sexuality origination or gender. Some of the participants felt that queer was an acceptable term to use when working with the LGB community as an alternative, but were keen to point out their dislike of being labelled.

"It's a shorter word but it's a happier word…. I don't think it carries, as far as we're concerned, any stigma.

We're just us. I don' think of myself as a label."

(Agnes and Partner, Session 1)

However, the use of the term queer is not uncontroversial with people and organisations in society at large. Some from the LGBT community object to the use of the term queer as an umbrella term because it can be associated with political ideology or used in an insulting way . Further there are strong connotations with the term being used in a derogatory sense and many members of the LGBT community, myself included, have an uneasy association with a term that has been used as an insult. It is for this reason I didn't adopt the term in my recruitment documentation. I have found that some of the issues described around the use of the term "queer" have emerged within my own research and its creation, and this has reaffirmed that it was the right thing to do.

"Queer, don't get that. Don't ever, ever, call me queer, to me that's such an insult. I don't get that word, I think it's appalling, it's one of these worse things you could ever call someone when I was a kid. Why would you want to own that?!"

(Lewis, Session 2)

Uneasiness around the use of labels was expressed by many of the participants. Possible explanations for this are that people generally form their own perceptions and stereotypes through previous interactions with society and media, resulting in an increased reliance on generalisations.

"I think it's possibly. Maybe the way ethnic minorities feel…. I just don't want to be singled out."

(John, Session 1)

. A stereotypes threat can sometimes occurs when minority persons who are aware of a negative stereotype about their own community, can then feel anxious and sometimes distressed when they see examples of the stereotype first hand, and anyone attempting to conduct health research with the LGB community should be aware of this. Identity categories such as LGBT are not open enough for people to develop their own sexual identities, and as such people can feel constrained (Hagai et al 2020). For example people who behave in certain ways, such as men who have sex with men, can be labelled as gay or bisexual, but may not necessarily identify with being members of LGBT group (Ojeda-Leitner and Lewis 2019).

My research findings highlight the importance of partnership working with the LGB community, and this is a key principle of community based participatory inquiry. To establish trust is key, and other researchers and health workers should be mindful that many LGB people have issues with labels and don't want to conform to any group. This presents a challenge when considering asking people to tick boxes related to their sexual orientation or gender identity and doesn't represent a person-centred approach.

Summary

During a person’s coming out they first must come to terms with realising they are LGB and having an acceptance that they are different to those around them. As a result, many LGB people hide their authentic selves from friends, family, and acquaintances before they come out, which is often an incredibly isolating experience for those who are late to coming out. People who undergo this will have had a significant aspect of their life in which their personhood could not be fully actualised and as such they are unable to fully flourish.

Findings Category Three

Exploring new relationships and building confidence in new roles

Introduction

In this third section of my meta synthesis, which corresponds to the third categories of my analytical framework, I will show the areas that the participants discussed relating to how they have started to build new relationships through their own journeys. This included examples of where they have built confidence in relation to being an LGB person affected by cancer, but also includes some of the difficulties they have experienced through having to wear this label also. In this section I will also focus on presenting accounts where the participants had positive health care experiences. In these areas it can be seen where the participants have felt empowered and could acknowledge their identity. Many of the participants formulated new relationships as a result of navigating the cancer experience, by meeting new people or professionals, and establishing new links with existing family and friends. Many of the experiences show areas in which the participants are trying new roles and building confidence; where this occurred, the outcome was not always positive but did enable a chance for them to establish new confidence and understanding. The main areas to arise within my research can be categorised into the following overarching areas:

- Exploring companionship and kinship
- Family connections and expectations
- Affirming experiences of care

Exploring companionship and kinship

Companionship can prevent social isolation, and is a fundamental human need to engender a sense of belonging; this can be provided in many forms from having a family members, friends or pet serving as a companion in life. (Berkman 1984). Having a trustworthy companion can help someone have honest conversation that can convey how they feel and what they are thinking. A companion in life can be very useful to support a person to deal with mental health problems, or cancer and can ensure that the person affected does not feel alone. Kinship can be described as a the connectivity between social relationships, and it is important to all those in society to have access to (Fortes 2018). A person's position with others establishes their relationship in society, prescribing their responsibilities towards other persons.

Dating whilst having cancer treatment can be a challenge for people; Susi and Lewis discussed the importance of being able to explore physical intimacy during this time. It is in a person's nature to require physical intimacy, which can be fulfilled by differing aspects of physical affection, such as handholding, cuddling, hugging and kissing. These behaviours are all important in a person's wellbeing, alongside the emotional understanding and capability that is required to sustain an intimate relationship. After cancer treatments, some of the participants discussed how they had a desire to find and build new physical relationships, although this presented difficulties in knowing what to expect from others in response to the physical effects of their treatment.

“I was sort of super-skinny, hollowed-out and had all kinds of scars…..There are definitely some people who just go "oh that's terrible" and then freak out and then run away.”

(Susy, Session 1)

My research explored with participants what it felt like for them to be LGB with cancer and to start dating on the gay scene. Lewis came out as gay prior to his cancer treatment, and once finished he was keen to start exploring this new side to himself that he was now accepting as part of his own self. During the initial encounters with other men over the internet, Lewis, described how certain men would expect him to engage in certain risk behaviours such as unprotected anal sex. Gay men engaging in increased sexual health risk behaviours has been observed in other research, however this was also seen within my own research findings.

“My life was like I have this cancer, and anyone I meet I thought I would say. Really interesting, on gay websites, and folk are like, I would only meet if you go bare and that kind of thing, but I would say, well I can't. Then someone would say oh, you’re a prude. Then you would be like, well no I’m not, I have bladder cancer and I can't risk any kind of infection.”

(Lewis, session 1)

Other examples were also found within my research where the effects of cancer treatment had damaged relationships due to the inability to be physically intimate. Drew discussed how he found it difficult to be able to have sex with his boyfriend at the time, and this led to their eventual separation.

> *"I had the radiotherapy and the chemotherapy.... it was at that point that he stops having sex with me. He said he had been seeing someone else and they were basically boyfriends, I don't know, it's rather upsetting for me to think about."*
>
> (Drew session 2)

Drew was then unable to establish new relationships with other gay men, as he was unable to travel to areas in which he could meet others on the gay scene in safety. He lived in a rural location and didn't know any other gay people. Attitudes about illness from LGB community towards a person with cancer were also discussed as part of the reflective sessions. Lewis remarked that he had encountered some surprising reactions from certain members of the gay dating scene. Having cancer didn't seem to affect the perception of Lewis by those he encountered who had HIV, and in this he found a level of acceptance.

> *"Guys with HIV were quite sympathetic, they were like well you have a long-term health condition, join the club."*
>
> (Lewis, session 2)

During the time that I worked with the participants it became evident that `some individuals had coped better than others. Of those that tended to be more equipped to deal with the challenges that a cancer diagnosis and treatment brought, most had large social networks. These included strong and positive relationships with family and those that engaged in social activities. Several participants who lived away from their family origin spoke of the importance of engaging in social activities aimed at LGB people, and those that had done this for years had an additional support network near to their homes. Sisi spoke of her work in an LGBT community choir in the city in which she lived.

> *"And, so, yeah, the choir is mega [emphatic] important, and in particular the section that we are singing, they're family. And they were really important when I was ill. They were my backbone... there's quite a lot of us, and we have been together for quite a long time now. We know each other so well and I don't know what I would do without. "*
>
> (Sisi, Session 1)

In contrast to Lewis and Drew, participants who were able to access sources of support lived in urban areas. For those that felt it was important they were able to connect with other LGB people. There were, however, seven participants that had good and supportive networks of friends that were found through engaging in other activities. Tabitha talked about the therapeutic aspects of Beekeeping and how having special connections during the challenging times of her wife's bereavement gave her a focus and something to engage in which she found very rewarding.

> *Each local area has its own, beekeeping association. Beekeepers are a real help, we talk about bees all the time. But actually, that's just a joy, because they become so fascinated. I'm just the same, you know, you share the, the same kind of stresses.*
>
> (Tabitha, Session 2)

In the cases whereby participants found connections with others, they seemed to be able to draw support from these networks. This is potentially very significant as many of the participants had poor relationships within their family origins, as in other research (Fish and Williamson 2018), and my findings demonstrate where LGB people can draw on additional support away from more traditional structures. Those participants who lived in more remote areas, or had difficulties in accessing or fitting into social groups, struggled to manage with the isolating aspects of cancer, and may indicate an additional support need amongst LGB people who live in rural areas. Drew was one such participant and he was feeling very lonely at the time of our inquiry sessions. I asked him if he attended his local church or cancer support centre to meet new people, but he didn't feel he fitted in.

> *"They are all right if you go to attend the groups, but not if you just go for a cup of coffee. They seem to be always wanting donations and things"*
>
> (Drew, Session 1)

The concept of psychological sense of community, generally referring to individuals' feelings of belonging to and being able to depend on a larger community, has been acknowledged to provide a level of psychological assurance to a person (Lin and Israel 2012). It is also a core facet to someone's personhood. In Tate's case, both prior to, and post coming out, there were few opportunities for her to establish a state of belonging, and this points to a potential need when assessing support for people in a similar position. Tate also expressed why having others lesbian women around at the time would have helped.

> *"I would use one… It's about having a better understanding of me, like I have more in common with them…. Because your sexuality is a big part of who you are and major part of your life, and a kinship almost. A kinship other than having breast cancer, you know?"*
>
> (Tate, Session 2)

Feeling isolated from her close family network as well as undergoing cancer treatment demonstrated a real lack of support for Tate's feelings of loneliness and isolation during this time. It is widely recognised the cancer treatment can be a lonely experience in itself and is widely reported within the literature (Tabrizi et al 2016, Fox et al 1994). With Tate's and Lewis circumstances there appeared to be a lack of LGB specific support available, and I asked Tate about how she felt about this.

"It is funny that there is nothing north of the border for gay people at Maggie's centres and stuff. I know Manchester and London are big cities and I get that, but so is Glasgow and this is odd. And I would use it"

(Tate, Session 1)

Family reactions and expectations

Several participants explained how they had difficult relationships with their family, and in many cases these relatives lived far away. There were many accounts from the participants where their close family members had a history of struggling to come to terms with their sexual orientation or accepting same sex partners. It is recognised that many LGB people can have poor relationships with their family origin as well as experiencing outright rejections (Carastathis et al 2017); Drew's experiences would seem to correlate with this:

"I've never had a great relationship with my sister, she is a lost soul, but she sent me an email that was just horrible. It attacked my sexuality and my partner, you know, it was talking about things like chicks with Dicks, go fuck yourself with a dildo, you know it was just ugly, ugly stuff. It was just right at the heart of my sexuality, who I am, it was just awful. So, I just can't go back to talking with her. It's sad"

(Tate, Session 1)

"I'm rather suspicious of them because I had an awful lot of trouble with my family."

(Drew, session 1)

Changing perspectives and attitudes towards a person's sexual orientation are often observed when LGB people come out to their families (Weheliye 2011). Wider societal attitudes towards sexual orientation still mean that being confronted with this news can be seen as negative (Watt and Elliot 2019). Sometimes it can take time for people to grow to accept people after their initial and shocked reaction, however Lewis wasn't able to access any LGB specific support for this trauma and is still coming to terms with the longer-term effects this has had on himself and family.

"I did go and see this guy, one thing he did was really good. During my counselling, I talked about my brother and several other people, and he helped me, he said your exercise for tonight is to write down a list of everything that these people have done to hurt you and what they've done. Then I went to see him the next day and he said, right this is your choice, you can either bury or burn those lists, he said whichever one you do it's a final act. Whatever you do it's a final act, you burn them or bury them. I chose burying them, and I went to a wood and buried them.

(Lewis, Session 1)

In addition, cancer is known to cause sadness, depression and anxiety and can have a lasting effect on those in long term partnerships or marriages (Serafini et al 2020). The effects of cancer will vary from couple to couple. Although for some couples, cancer and the challenges it creates, can strengthen their relationships, however in Tate's and Lewis cases their marriages broke down. Despite this, during Tate's treatment it was seen that some members of her family did start to accept Tate's sexuality where initially they found it hard.

"My husband didn't cope well, the girls now have friends who think it's cool. She thinks it's cool and she doesn't mind telling people. But before it was like, I hate you, you're a lesbian, I never wanna see you again. It was like that, so the changes are positive"

(Tate, Session 1)

Family attitudes towards a person's sexual orientations can be the cause of great rifts and in some cases disownment of individuals. This places the LGB person in greater isolation and potentially more vulnerable to psychological effects of cancer treatment. It would be hard for a person to attempt to build bridges and maintain contact with their families if they are unwilling to accept a person's sexual orientation and identity. However, at a time of great emotional need, a person may feel the need to re-establish old connections, or the need to draw on family contact despite the negative experiences that they have had. Tabitha talked about her connection with her father, and how difficult this was over the years and when having her civil partnership. This became more of a challenge when she then lost her wife to cancer.

> *“Whereas my sister fully embraced it and all of my cousins and were all, you know “Oh it’s a wedding.” And Mum and Dad you know, hoped it would all go off without any embarrassment. Dad in particular can’t bear any kind of embarrassment. So that’s a major thing. Let’s not have a scene. Please let’s not have a scene. Erm, one of the… So, you know, Dad can’t bear any distress.”*
>
> (Tabitha, Session 1)

Cancer professionals should be mindful of these complex relationships between LGB people and their family origins when in consultations and be sensitive if there any expectations that individuals should establish contact through the use of genetic screening and counselling services. In addition, my research has shown a much greater diversity of an LGB family, whereby participants such as Tate also have children and career responsibilities; this is not widely shown within the literature uncovered in my review.

> *“It’s almost like our families and partners have a second loss for them, it’s not my husband almost lost me and he could lose me, and he’s lost me already to a woman. My mum has lost her idea of my perfect life, she’s like what do I tell my friends now. I’m like I don’t give a shit what you tell your friends…. it’s made me feel that I don’t really respect my mum.”*
>
> (Tate, session 1)

During a person’s journey of coming out they first must come to terms with realising they are LGB and having an acceptance that they are different to those around them. As a result, many LGB people can feel the need to conceal their authentic selves from friends, family, and acquaintances before they come out, which leads to isolation and in some of the participants’ cases this was experienced right through their adulthoods. LGB people who come out in later life will therefore have a significant aspect of their life in which their personhood could not be fully actualised and as such they have been denied being able to flourish. When Tate finally felt the courage to come out her family reactions were extremely negative, and she described to me how that was.

> *“Coming out, it’s funny. When I came out it was like you’re broken, almost like back in the fucking 30’s, you’re broken. It was just so negative, my mother and my husband and my children were all like… It was like bullying. Everyone was like you’re a Dyke, I hate you. It was just so negative…. People I love the most and thought they would be there for me…”*
>
> (Tate, Session 1)

Coming out to families as an LGB person is often a pivotal event that can change the family system (Coleman 1982). Race, ethnicity, and immigration intersect with a family member's disclosure of sexuality and gender identity, and this can mean that LGB people sometimes feel a great sense of isolation when issues occur. The role of the family in coming out, can create issues related to the process of revelation or concealment of homosexuality (Pachankis and Goldfried 2004).

Positive experiences of the care setting

The World Health Organisation (2020) defines empowerment as:

> *“A process through which people gain greater control over decisions and actions affecting their health”*
>
> World Health Organisation (2020)

Empowerment should be seen as process that is essential for society to engage and support. As such empowering care should ensure that people are able to understand their role, have their community and cultural differences taken into account, and are provided with the abilities and support from the health-providers to engage in their own care. As part of developing its vision for delivering healthcare services, NHS Scotland has set out its position on achieving measurable goals and objectives. The current mission statement, Better Health, Better Care was based on the Institute of Medicine's six dimensions of quality (Tzelepis et al 2015). The first of the six dimensions is central to the approach and is listed as being Person-centred, this means that providing care should be responsive to individual personal preferences, values, and beliefs and ensuring that these guide clinical decision making.

Delivering person-centred care is seen as a key strategic priority for NHS Scotland as a vital part of achieving its vision for Health and Social Care, with a desire to work in partnership with the population who access its services. This is to be achieved by focusing on what really matters to people, the Institute of Medicine's six dimensions of quality indicate a commitment to mutually beneficial partnerships between patients, their families and those delivering healthcare services. Although my PhD research has found cases in which person-centred practices appear to have failed to materialise, I also accept that that I have found some good examples of person-centred care moments. The participants have found these to be empowering and felt it important to ensure that these were reflected in my PhD findings. These person-centred moments represent opportunities in which the participants have been able to be their true selves, and thus build confidence as a LGB person affected by cancer. It is therefore with this in mind, that it is more appropriate to discuss these experiences in the ‘building confidence in new relationships’ section of my synthesis to correspond to this area of my analytical framework.

There is a greater need for cultural competence, whereby professionals are seen to be being working with the health beliefs and practices of a given group. Staff members who are more aware of the needs of diverse population groups are more able to provide effective healthcare. Awareness of culture and terminology is essential in providing the best care to LGB people, and could be considered more when creating learning resources for professionals. Tate discussed some good examples of when oncology professionals seemed to get this right and were not necessarily out or identifying as LGB and still provided very good person-centred care by considering those that were important to her.

> *“The oncologist will answer her questions, she’ll look at her (partner), she’ll involve her in the conversation as if as if she was my husband, as a man. So that makes me at ease. It’s like okay you’re respecting the fact that I’m a lesbian, and this is my partner. And you’re involving her in the conversation like you should”*
>
> (Tate, session 1)

This heath interaction demonstrates a good example of shared decision-making. Person-centred care should support people to retain control over their healthcare, through supporting them to engage and make informed decisions, it should also foster partnership between families, health providers and social services (Isbell, 2019 and Vance 2019). Despite this there were missed opportunities during Tate’s healthcare journey to facilitate the disclosure of a person’s sexual orientation. This was made difficult due to the negative responses from health professionals when Tate made attempts to do this. It is important for LGB people to have assurance that their health professionals have a degree of cultural competence and not to express surprised, shocked, or negative attitudes when someone discloses their sexual ordination. In these situations, it is an important for health providers and professionals to use more gender neural language and have better recognition that they are working with a greater hidden diversity of people than they may realise or assume. Agnes also discussed how health providers made attempts to ensure that she knew her same sex partner would be welcome in consultations, by actively suggesting that her same sex partner should attend consultations.

“The very first one at the oncology Unit, I dropped you off, and was driving out when I got a phone call saying, “Oh you’ve to stay here too!”

(Agnes, session 1)

Tate and Lewis discussed the importance of having professionals that were openly lesbian or gay and therefore seemed to have an understanding of who they were. Despite some negative experiences in the care setting, Tate was full of praise for the support services that she accessed during the course of her cancer treatment whilst in Scotland.

“Speaking to a therapist, who is a lesbian, she just kind of got it more than a straight person would, which is probably fair to say that but you know.… I was really pleased and she was a lesbian actually, I felt like I just had it on my side when I really needed someone on my side, to not judge me. Especially when I was judged ever so harshly.”

(Tate, session 1)

“My doctor, he was gay as-well. He was good shoulder, you know, because he was kind of where I wanted to be. I didn’t fancy him or anything, I had got no one else, I had lost my network. No one else wanted to have anything to do with me.”

(Lewis, session 1)

Baker et al (2019), discuss how nearly 40% of participants in research they conducted had sought support from charities and other organisations though their cancer. The research indicates that people with cancer don’t receive all the information they need from sources such as the internet or healthcare professionals, and that cancer support services have a key role in providing such information. Susy felt the need to go to the private sector to find the additional support she needed with respect to her being a lesbian affected by cancer.

“ I said, look, I'm gonna go, I'm gonna pay for my own, I'm gonna find someone else.... can you recommend someone who is gonna be good at both bereavement and is gonna be OK with the LGBT thing?”

(Susy, Session 1)

This identified a gap where third-sector support groups can work in partnership with the NHS to fill this gap and areas in which they can seek to improve the inclusive aspects of the care they offer to LGB people affected by cancer. Both John and Tabitha discussed how they had sought additional support from charitable organisations and how this helped them.

Maggie's and church are kind of similar…. They give you the space, and the time to examine yourself from different perspectives… you know, especially on the mindfulness programme to recognise parallels between the old spiritual elements and the self. Absolutely.

(John, session 2)

"But she had such a shit time with the cancer, she had so much pain, it was just a nightmare. And I did this bereavement group at Maggie's, Maggie's were fantastic with Catherine all the way through. And with me too."

(Tabitha, Session 1)

My research has found many examples of when care providers have given the appropriate level of dignity and respect to LGB people affected by cancer. In the occasions where these interactions have been positive, it can be observed that the relationship is affirming to the person in receipt of care. However, the issue arises when this level of positive relationship between care provider and recipient is inconsistent, and is made worse by situations that a LGB person with cancer finds themselves in. This can be due to previous poor relationships with service providers, past homophobia in general, or apprehension and vulnerability as an underlying aspect of having cancer treatment and diagnosis.

Summary

Often relationships with others can teach people about the relationships they have with their own selves. Throughout this synthesis there are examples of the participants' exploration of options for new roles, and this is a significant aspect of Mezriow's framework for perspective transformational theory. All participants were able to account for instances where they had built and changed relationships, and what actions they took to support this. Healthful relationships (see chapter three) are key to human flourishing and having appropriate emotional support during challenging times and crisis is a benefit to having close relationships with others (McCormack and McCance 2016). Emotional support and emotional and informational support are significantly associated with peoples' health related quality of life and self-efficacy outcomes (Lee et al 2008, Strine et al 2008).

Findings Category Four

The transformational effects of cancer and reintegration of perspectives

Introduction

In this, the final section of the findings chapter, I am going to explore fourth category of my analytical framework, which is focused on the transformational effects of cancer. Perspective transformation has three dimensions: psychological which can manifest in changes in understanding of identity; convictional, which means that a person may form a revision of their belief systems; and behavioural changes that result in modifications in their own lifestyle (Mezriow 1978). Mezirow acknowledges that full transformation doesn't occur often, and when it does it is usually because of a life changing and significant dilemma that a person experiences. In my research I have sought to understand through the participants the effects of cancer treatment on their own personhood and have sought to establish if the impact of cancer was transformational.

Transformational learning is a significant event that only occasionally manifests through perspective transformation,. Mezirow believed that these transformations were triggered by a crisis or significant life event, or a culminations of several less dramatic events over a person's lifetime, such as those created by a teacher in an educational setting.

Individuals need to change their frames of reference and their minds through critical reflection of their own assumptions and beliefs, and make a deliberate point of planning new ways to implement and redefine their own world views. I have sought to facilitate this through the participatory inquiry sessions. Full transformation would occur when a complete change in the appearance or character of something or someone has been observed, and this would be especially so when a person has achieved a level of personal growth.

Cancer is arguably a significant life changing event and dilemma for many, however the ways in which an illness can trigger transformation in a person wasn't observed in all of the participants in this research. Agnes for example, felt very strongly that the whole experience of cancer treatment and diagnosis wasn't going to change them or the ways that people perceived them and was very important to her own beliefs. In order to achieve transformation, there first needs to be changes in the perspectives on a person's world view. Changing perspectives are, for many people, like changing the lens through which they view the world, or their own ontology. When people change how they view the world, they change how they feel about it.

Perspective changes

Research into the experiences of people affected by different diagnoses have generated similar views about struggling, fear, altered self-image, adjusted life, but also provide insight into people going about finding solutions, and hope. Studies have found that people perspectives strongly influence the way they act toward symptoms, triggers and how they integrate their illnesses in their lives (Scherman et al. 2002, Ho¨rnsten et al. 2004, Darr et al. 2008). Despite this some of the participants discussed how their treatment had changed their perspectives and the way they viewed things, although they didn't feel that their life had been transformed. Sisi discussed in her session her irritation at being labelled a cancer patient and the assumptions that this brought from wider people. She was very grateful for the support she received but didn't think of herself as special or needing preferential treatment.

"You know how people say to you, when you had cancer treatment, "you're so brave", and you think, no, I'm not brave, they are brave, 'cos, you know, I just got ill."

(Sisi, session 2)

Throughout our sessions Sisi was more concerned with the effects that the cancer treatment had on the ways that other people viewed her and the difficulties that this created for them. She had an extensive support network around her, and they came to her aid in times of crisis. Some of the participants gained further appreciation of the support groups around them and were keen to stress that because of these supportive relationships they were able to cope with the difficulties cancer treatment and diagnosis presented. Agnes seemed to cope very well with her journey and discussed how having other lesbian women in her closer friendship circle was very important to her. She acknowledged that she sees them in an affirming light, and that she draws great strength from being part of this group.

"It's just a good, supportive, strong group of women to deal with. You know, feminism and bra-burning never came into it, it was just women together and creating a strong situation to get stronger"

(Agnes, Session 2)

Despite seeing her friends and support group in a new light, there was very little indication that Agnes achieved a full level of transformation. She was keen to stress that she is the type of person that would just get on with things, and that with a close partner and friends she drew on strengths of this collective and dealt very well with the dilemma of cancer. Agnes seemed to have such strong support in place it seemed that her cancer diagnosis was of little consequence to her life and as such could be thought of as not being a crisis event in which to achieve full transformation.

Evan discussed how he felt after his Husband suddenly died from cancer. He described the difficulties in an initial adjustment to undertaking day-to-day activities in his home, but, when asked if he felt that cancer had impacted on who he was, indicated that he seemed to have adjusted to his partner’s loss reasonably well.

> *“It was more like how am I going to manage to cut the grass and I didn't cook. I didn't actually go for bereavement counseling, I asked for some bereavement counseling, which I got through the church, but I have to say that by the time you wait, I'd actually pulled the courage of getting it done. So I've actually realised I could do it on my own.”*
>
> (Evan, Session 2)

Evan discussed how he didn’t engage much with counselling through the bereavement process, and as such I wonder if there could be a role to play for therapy in enabling people to move on and achieve full transformation. Although Evan appears to have managed well in his day-to-day life, I found it unusual for him to speak in such frank terms about the practical sides of his spouse’s death. Evan was also adamant that his views on life and living had not altered since his partner’s death, and that he just needed to move forwards.

Tabitha also lost her long-term partner to cancer and discussed how it was difficult for her to move on; this was made especially difficult in her home. Despite this Tabitha talked about the memories of her wife and drew strength from this in day-to-day living. Tabitha spoke very fondly of her wife and despite the adjustments she made in her life I didn’t get the sense that she had been able to fully move on. Tabitha's perspectives on life had clearly changed, but there is still appeared to be some more time required before she was able to move forwards and achieve growth. Tabitha also eluded to the fact that the loss of her partner still caused her feelings of disorientation, indicating that she was still in a point of crisis.

> *“I don’t want to leave the house because it’s full of our memories. It’s been hard not being there. I had this really strong feeling of my wife as I sat there the day after the fire, had this really strong feeling of her saying “Look, this is your house, you need to make it yours.” So I have done quite a few changes but I’ve ordered this stained glass window as a sort of memorial to her. And that will be, so that will be a really big source of light in the house. So, I don’t know which way life is heading.”*
>
> (Tabitha, Session 2)

Drew also talked about how he struggled with making sense of where he ultimately ended up. He found himself very isolated and alone having beaten cancer but unable to go out or make new friends due to the effects of his treatment. During our sessions I asked Drew about his thoughts and if his mind-set had changed at all after his experience.

"So I don't know if it's changed our mind. Yes, it does trouble me sometimes all this mixed up, came to stuff in my head. Because I don't know what to think, yet."

"Because I don't have much to do with other people. I just keep myself to myself, and stay in the house."

(Drew, session 2)

Like Tabitha, Drew seemed to be still in a process of disorientation, and it may be that he was able to achieve a level of transformation to a point, but at the stage of participating in the research, he was struggling to make sense of the changes in perspective he saw at that point in time.

Transformational changes

Perspective transformation can be seen as an improvement of a person's capacity for decision making and empowerment. This is achieved through critical reflection and discourse of a person's assumptions and beliefs, offering them an expansions on the options and possibilities for them to make more choices (Tokiwa-Fuse 2000). The resulting choice may not necessarily be to change, but to have the increased self-awareness to support the stance that they have adopted through more clear reasoning. Some of the participants discussed their interactions with therapists and counsellors, and how they had managed to work through the difficulties and challenges that cancer awoke for them. In Susy's case she felt empowered to address previous issues that she had with her mother in relation to her being a lesbian. Susy had found this a significant challenge over many years and reflected on how her counsellor, who was also a lesbian, had really helped her achieve a complete change in her relationship with her mother and how she felt about this.

"So in the end, counselled by my therapist [laughs] I basically said I can talk to you once, maybe twice a week, but I cannot cope with this, and, and actually, you know, we had that conversation and she respected it. And that was quite, that was quite something actually"

(Susy, Session 2)

In addition, my research had two participants that came out around the time of their diagnosis and treatment. In Tate's case, she felt that she could no longer suppress her true identity and that she had an aspect of duality when it came to having a hidden cancer and sexuality that others that couldn’t see. In addition to recognising the commonalities her sexuality and cancer had, she reflected on how this made her feel.

> *“I don’t wanna think of cancer and my sexuality in negative ways, you know by having cancer it give me that strength that I needed to be true to myself. So it’s a good thing in my life in a way”*
>
> (Tate, Session 2)

Lewis talked about his relapse of his bladder cancer, and that although this was difficult he could see how things had changed and that he was much happier in a new, more authentic relationship with his new same sex partner.

> *“The second time it came back, I had my husband with me, and he was sat beside me and we talked about all the treatment options and stuff”*
>
> (Lewis, Session 2)

During the sessions, John discussed the positive effect his cancer treatment had on his own motivation to learn new things. Through this process John increased his own self-esteem and sense of self-efficacy, and as such resulted in an empowerment in relation to his own disease.

> *“Yeah, it was a voyage of discovery. Yeah. And I think if you get yourself into that state of mind, you forget. Almost. Now you could die, you think no, no I'm too busy, learning about stuff, learning about me.”*
>
> (John, session 2)

Mezriow advocated education as a means of enhancing a person’s ability to have self-determination, stating that

> *'The essence of adult education is to help learners construe experience in a way that allows them to understand more clearly the reasons for their problems and the action options open to them so that they can improve the quality of their decision making’*
>
> (Mezirow 1991)

Mezriow felt that adults should be autonomous thinkers, as he was influenced by humanism and democratic participation (Mezirow 1997). He saw that it was essential for people to have the capacity to support decisions in their own lives, and that if this could be better enabled through a crisis, human flourishing should ensue. Mezirow might see it as a bit of a failure or missed opportunity for someone to have cancer and not achieve transformational learning or at least perspective change.

Summary

Transformative learning is only achieved where there is a paradigm shift in someone's thoughts feeling, and behaviours. It is something that is irreversible and alters the worldview of the persons. It then changes the understanding that someone has of themselves, and their relationships with others, and the natural world. As a result, this will impact on someone's personhood as will change their values and perspectives of what they see and how they relate to the world around them. It shifts a person's interpretation and visions of class, race and gender; body awareness, enabling the possibilities for social justice and fulfilment. These are core aspects of a person's identity and as such cancer as a disease and its associated treatments have been seen in this research to impact on both the participants identity and personhood.

Extracted summary of key findings of the research

As I wrote this chapter, I felt a sense of catharsis, the participants in my research have gone through some truly scary experiences and I feel fortunate that they shared these with me. Despite the crisis and difficulties this created for them, most were able to articulate changes in their views or outlook on life. On some occasions this has been affirming, although some are still awaiting their moments of perspective change.

In this closing section I provide an overview of the key findings of the research that run across the four categories of my analytical framework. These are presented as the original new findings of this research that are not currently known, developing a further understanding of the existing knowledge base and published literature. These will be discussed further in the next chapter, although they are summarised below in overarching themes for clarity:

1. LGB persons coming out and coming to terms with their sexual orientation as well as dealing with a recent cancer diagnosis and treatment.
2. LGB persons having to prioritise their cancer treatments and deal with its effects around their existing care commitments for children and older family and friends.
3. LGB persons' attitudes towards labels, with particular sensitivity of not being labelled by care providers as all having the same needs, and the triggering aspects of using the term queer and more fluidic language to describe LGB persons with cancer.

4. LGB persons reconciling their religious beliefs and intersectionality as part of their own personhood, and how this interplays with the issues they experience during the crisis of cancer and their own faith needs.
5. Changes in perspective and the transformational effects of cancer on someone's personhood, which include fundamental revaluations of a person's belief system and the way that they perceive others around them.

In addition to the original new findings, this research has also found five other significant findings that add to existing knowledge base. These are also discussed in detail in the next chapter, however in summary the overarching themes of these are:

1. LGB person's dilemmas of attending oncology appointments and staff attitudes, which can be positive, but also included issues around the disclosure of sexual orientation, staff not understanding same sex partners can be next of kin, and the dilemmas around asking persons their pregnancy status.
2. LGB persons experiences of the physical effects of cancer treatment, demonstrating that this isn't just an issue for Gay and Bisexual men with prostate cancer. This research has demonstrated a greater diversity of cancer types and that lesbian women also have issues with the physical effects of cancer treatment.
3. LGB persons loss and changes in personal relationships, which includes further exploration of companionship and kinship when dating on the LGB scene and some of the LGB communities' attitudes towards cancer.
4. The changes observed in LGB persons' family connections and expectations, which are in addition to some of the changes that are known in the literature that can occur between cohabiting spouses; this expands on the complexities of the relationships LGB persons can have with their family origin.
5. Isolation that is indirectly caused by cancer treatment and the seclusion of LGB persons living in rural communities.

9. Discussion

Introduction

The principal aim of this research was to explore how LBG people's personhood was impacted by cancer treatment. The objectives were to explore their experiences throughout the cancer care pathway and to work with them, their key support persons, and other stakeholders to develop a set of guidelines for best practice for cancer services. The research aimed to influence education of radiography and other healthcare professionals through offering an evidence-base for the curriculum and to contribute theoretically to knowledge of personhood and person-centredness. My research has achieved its main aim by working with the participants, using a participatory inquiry, to establish what mattered most to them during their cancer experiences. Through the use of my theoretical framework, The Impact on Personhood Participatory Inquiry Framework, I have then been able to determine if the experiences the participants had were transformational, and I explored this using person-centred methods to enable the participants to articulate their own stories of care.

This chapter discusses the aims and objectives that were outlined in the initial design of the research, along with the existing published evidence and literature. In this next section of my thesis, I discuss the original new findings of the research that add to the understanding of LGB people's cancer experience and priorities. There is some degree of blending of issues that arise within each of the following sections, as many of the themes of my research are multidimensional, which is a fundamental consequence of conducting participatory research within diverse communities. In the final sections of the chapter I present the key recommendations and guidelines for practice, as well as outlining the limitations and strengths of this research.

Original new findings

This research has uncovered five key original findings which add to the understanding of the LGB person's cancer experience and their key priorities. In this next section they will be discussed in detail indicating the significance of the finding and how this adds to the evidence base, and how it addresses my research aims to understand LGB person's experiences of cancer care and the impact this has on personhood. As a reminder, the original findings of this research are focused in the following overarching themes:

1. LGB persons coming out and coming to terms with their sexual orientation, as well as dealing with a recent cancer diagnosis and treatment.

2. LGB persons having to prioritise their cancer treatments and deal with its effects around their existing care commitments for children and older family and friends.
3. LGB persons' attitudes towards labels, with particular sensitivity of not being labelled by care providers as all having the same needs, and the triggering aspects of using the term queer and more fluidic language to describe LGB persons with cancer.
4. LGB persons reconciling their religious beliefs and intersectionality as part of their own personhood, and how this interplays with the issues they experience during the crisis of cancer and their own faith needs.
5. Changes in perspective and the transformational effects of cancer on someone's personhood, which include fundamental revaluations of a person's belief system and the way that they perceive others around them.

Original finding one:

LGB persons coming out and coming to terms with their sexual orientation, as well as dealing with a recent cancer diagnosis and treatment.

Coming out, for many, is a process that is continual and repeating over the course of someone's life. An LGB person may have a continual requirement to come out as they encounter new experiences and settings here they are assumed to be heterosexual, such as meeting new professionals in the cancer setting. LGB people experience issues of homophobia within society, so coming out is a difficult thing to do, especially when so many LGB people have experienced negative reactions of discrimination and homophobia. In contrast, many of the participants in this research discussed their issues with not coming out, especially when trying to reconcile their religious beliefs with their sexual orientation. In the process of coming to terms with their sexual orientation, they experienced rejection and fear, which resulted in increased isolation by creating rifts and loss of contact or poor relationships with families and family. Both Lewis and Tate came out to around the time of their cancer diagnosis, and this presented a significant challenge to them on top of dealing with their cancer treatments. This is an original finding that has been uncovered in this research; it has not been discussed within any of the literature uncovered in the review, and represents a potential strength of the recruitment methods, whereby persons who were non-scene and recently out came forwards to participate in the research and discuss their unique perspective. This finding sheds light on some of the additional support issues that LGB persons affected by cancer may have, and in Tate's case reveals how the diagnosis of cancer served as a final motivation to come out.

It is important to consider the possible life stage and journey of a person who may be accessing cancer services in Scotland. Cancer Research UK information indicates that those aged 50-74 represent over half (53%) of new cancer registrations, and those over the age of 75 years make up over a third (36%) (Cancer Research UK 2021). There are more people in the general population that are aged 50-74 than over the age of 75, therefore the number registrations is higher in the 50-74s, but rate of incidence is higher in those aged 75 and over (Information Services Scotland 2019). Consider someone who identifies as LGB and who was born in 1945: they would now be in their seventies and likely to develop cancer. Throughout this time, they have seen many experiences that may influence their world view. Most of the participants in my research were above the age of 50 and had spent a significant portion of their lives living as Lesbian or Gay within Scotland; some of these people were 'out' and some were less open about their sexual orientation with others.

The nine participants were all within the 45-67 age range and as such they represent people living during a certain period of time where society's attitudes towards sexual orientation would be significantly worse than now. Their age is typical of most people who tend to be diagnosed with cancer, but it should be noted that this age range is context bound and isn't entirely representative of the lived experiences of the entire LGB community. Whilst appreciating that all experiences are unique, socially constructed and contextually bound, there is a need to consider how these findings translate to LGB populations as a whole. When reviewing UK LGBT history, it can be seen that legal reform to decriminalise homosexual acts happened in England and Wales in 1967, but this didn't occur in Scotland until 1980. This means that gay men in Scotland had to wait significantly longer to have the decimalisation of homosexuality where they lived. Meek (2011) suggests that there was a degree of cultural and institutions ambivalence present at the time that held up legal reforms applied to Scotland. As a result, homosexual activity was outlawed and there was a dominance of anti-LGB views in society, and lack of public support for reform. This had significant implications for the identity formation and attitudes among the LGB community in Scotland. Despite the eventual decriminalisation in 1980 of homosexual acts the struggle for acceptance of LGB people continued. The stigma of the AIDs epidemic in the 1980s did little to foster an understanding or acceptance of homosexuality within mainstream society. Phrases such as the "gay plague" were frequently used during this time period and added further reason to fear and mistrust the disclosing of one's sexual orientation at the time (Kozloski 2010). Section 28 of the Local Government Act 1988 prohibited schools and councils from portraying homosexuality in a positive light (Rayside and Rayside 1998), and The World Health Organisation did not declassify homosexuality as a mental illness from its ICD-10 until 1990 (Cochran et al. 2014). For those participants living at a time in which these events, and similar events in other countries, took place it is easy to see why they may have encountered issues when trying to be open about their true identities. This can have the effect of culminating in longer-term psychological issues where a person is not comfortable talking about who they are and feeling susceptible to discrimination from society at large.

In addition to exploring with Lewis and Tate about their experiences of coming out around the time of their diagnosis, this research also recruited four other participants that were not out during a significant proportion of their adult lives. This issue has not been explored within the published literature in the context of cancer experience, and the effects of doing so this appear to be significant. Coming out is recognised as a challenging time, and that doing alongside the early stages of cancer treatment can be a very difficult ordeal to endure. The participants in this research that came out around the time of their cancer diagnosis spoke of their difficulties that they had explaining their decision to their family members and close friends. As described in the research findings, participants provided accounts of their marriage breaking down and estrangement from family members and religious communities. This had the effect of making them less well-equipped when dealing with issues and challenges that cancer treatment brought and were not able to access more typical sources of support due to alienation from close family and friends. In addition to trying to build themselves up after the effects of cancer these participants were then trying to rebuild their lives. This is a novel finding of this research.

Original finding two:

LGB persons having to prioritise their cancer treatments and deal with its effects around their existing care commitments for children and older family and friends.

This research was successful in recruiting participants from more diverse backgrounds than other UK studies. From the literature, LGB parenting has not featured as an issue as far as LGB persons' support needs when being diagnosed with cancer. The whole family unit can be affected by cancer, and not just the person who is diagnosed with the disease (Huizinga et al 2011). Research suggests that children have an increased incidence of emotional and behavioural issues when a parent undergoes treatment for cancer (Compas et al 1999). Cancer can cause disruption in daily routine, shifting roles, financial burden, and the physical and emotional absence of parents which can add to emotional and behavioural issues (Osborne 2007, Korneluk and Lee 1998). These problems have not been reported within the literature base relating to LGB persons having families and how their experiences of cancer influenced this. Within the published literature base, LGB people with cancer are portrayed as having concerns mostly about the physical side effects of treatments, for example, Arena et al (2007), Boehmer et al (2014), Hartman et al (2014), and Wassersug et al (2013). However, three of the participants in this research reflected on the challenges that being an LGB parent with cancer entailed, and this was particularly evident with those that were having issues with relationships with their families due to their sexual orientation. The cancer diagnosis and treatment brought on feelings of guilt and shame in some of the participants and this clearly affected their health. Not only did they feel guilty for being LGB, but the situation brought feelings of disappointment to their families by coming out, and they were also having to navigate breaking the difficult news that they had cancer to those close to them. Again, the findings of this research suggests that there was a lack of wider support available in the situations the participants found themselves in. This was clearly influenced by the participants' sexual orientation and treatments, demonstrating a synergy between these two factors. This finding of the research is very relevant to care providers understanding the needs of some members of the LGB community who are faced with cancer, and they should be aware that the support needs of LGB persons may not always be around the physical effects of cancer treatment or how these treatments impact on sexual intimacy. Whilst the needs of gay and bisexual men affected by prostate cancer have been researched, and which highlighted legitimate concerns in the physical effects of cancer treatment (Hartman et al 2014 and Wassersug et al 2013), it should also be noted that there are also other potential support requirements that LGB people with other cancer types may have that relate to other aspects of their personhood and specific to the LGB community.

Original finding three:

LGB persons' attitudes towards labels, with particular sensitivity of not being labelled by care providers as all having the same needs, and the triggering aspects of using the term queer and more fluidic language to describe LGB persons with cancer.

Social constructionism advocates that what is understood as being homosexual and LGB is an invention of society, and through tracing back historically it can be seen that today's idea of homosexuality is a relatively recent concept (Meek 2015). With the rise of homosexuality in the modern era, a person can often feel as though they are placed into a specific category such as straight or LGB, even if the person does not act upon those inclinations (Pickett 2015). The social constructionist position, by theorists such as Foucault, is that there is no single natural sexuality and that our understanding of sexual orientation is developed through knowledge constructions in society. As a self-identifying gay man, I feel that what I understand as homosexuality exists as I acknowledge those feelings, but I do not believe that a person is raised or turned gay. I do feel, however, because of my epistemological stances, that the categorisation of a person's sexual orientation into a "box" is the work of society. In my research it became clear that each of my participants had differing views on their own sexual orientation and what this was understood to be. I explored with them what their own sexual orientation was and what this meant to them in terms of importance to their identity and how this was then impacted on by the cancer journey. For some of my participants their sexual orientation was a small part of who they were and dictated their sexual preferences in terms of who they chose to be intimate with, whereas other participants found that they became isolated from the LGB community due to their illness and that participation in my research led to a reconnection with something that they had lost. During the course of research recruitment I had met with participants that wanted to clarify if they were able to participate in my research, and some demonstrated uneasiness about being labelled as gay or lesbian. Unfortunately, the level of diversity and nuance within a label was hard for me to navigate but became necessary in terms of providing a clear definition of who the research was focused upon.

Butler (1990) proposes that binary definitions such as heterosexual and homosexual are understood through each other and that social power privileges heterosexuality over homosexuality. She theorises that gender and sexuality are also social constructions that can be challenged and reformed. From this perspective using binary definitions of LGB is perhaps unhelpful when applying this to personhood, as they are something that can change over time and be redefined. Queer is an inclusive umbrella term for those that are different from the defined heteronormative in society, and can also include those that feel marginalised (Giffney, 2004). As per the definition of queer, which is a group of persons that view and think about gender, sexual practices, and sexuality from a non-heteronormative perspective, I understood that the notion of a queer personhood may be a more appropriate term that LGB persons encompasses. This is because a queer personhood acknowledges that the queer person thinks differently to society's norms and conventions in respect of gender, sexual practices, and sexuality; it is a more inclusive and less discriminating term that permits the unifying concept of a queer lens or ontology in which those people that possess it are able to have rational and abstract thought to reject normativity. It is for this reason that the concept of queer will always exist as long as society bestows power in relation to gender, sexual practices, and sexuality i.e. homosexual and heterosexual.

Despite my own views of the term queer, and even though I felt it to be an inclusive term, I had to acknowledge that the attitudes of the participants in my research were different and that queer as a term has been used in a very pejorative manner to many of the participants in the past. This then drove the terminology used in recruitment materials, although some participants struggled to identify with the binary terms that I used. However, during the sessions, my research enabled the participants to explore what their sexuality and orientation meant to them and they were able to input into the overall understanding of this. Other researchers and health practitioners of LGB populations should have an understanding of some of the nuances regarding labels and the sensitivities that surround these. In the event that issues arise over labels, they can have a profound impact of how LGB people will engage with and perceive research and healthcare. Ultimately it has the potential to cause conflict and can therefore degrade trust.

Original finding four:

LGB persons reconciling their religious beliefs and intersectionality as part of their own personhood, and how this interplays with the issues they experience during the crisis of cancer and their own faith needs.

When reconciling religious beliefs, values and intersectionality Lesbian, Gay, and Bisexual individuals often experience internalised and/or externalised religious rejection due to their sexual orientation. This research recruited several participants that had strong feelings of connection to their religions, and in some cases, this brought great strength for them to draw on. However, the research also found participants who had been rejected from their religious communities on the basis of their sexual orientation. This novel finding emerging from this research develops further understanding of some of the issues that religious LGB people may have as they need to depend on their religion for guidance as well as balancing this with acceptance of their religious communities view of their sexuality. Some participants discussed that when they faced cancer, their faith was an important source of support. However, participants that were rejected from their faith communities, on account of the sexual orientation, were then brought into further crisis. In the literature review conducted for this PhD, only one study, conducted by Varner (2004) examined the role of religion and spirituality with lesbian women who had breast cancer. In Varner’s (2004) research, eight participants were interviewed with all of them finding support through spirituality, although what this was defined as differed between the participants.

For those that that have faith, coming out can be particularly challenging, if the faith community or teachings reject the notion of homosexuality. This can in itself cause a crisis and disorienting dilemma leading the person, in some cases, to question why they have developed their illness and if it could be a punishment and can affect the way in which the person comes to terms with their illness. Two of the participants in this research demonstrated that having a religious perspective helped them as they grappled with these issues and sought to keep their bearing through the mental and emotional turmoil that came with having cancer. However, Lewis was rejected from his religious community on the basis of him coming out as gay, and that his cancer was deemed to be punishment from God because of this. The literature uncovered in my review didn’t explore the negative impacts of religion on LGB persons that were affected by cancer, nor did the literature indicate that LGB persons sought religious support or counselling in respect of their diagnosis and treatment. Given that religion can be a huge source of support for persons in crisis, this is surprising to me, and indicates a novel finding of this research.

Original finding five:

Changes in perspective and the transformational effects of cancer on someone’s personhood, which includes the fundamental revaluations of a person’s belief system and the way that they perceive others around them.

This research has sought to make a theoretical contribution towards the field of personhood as one of the main aims of the research. I feel a person is a unique entity that is capable of making moral judgements that are influenced by life experiences, abstract and rational thought and higher self-awareness and logic. These are characteristics that are potentially transferable to other forms of life apart from human beings; and not all human beings, although their life is precious, are capable of acquiring these characteristics. I feel personhood is the status of being a person bestowed with certain rights to equality and liberty; as such LGB persons have a unique and unifying perspective because of the way that society treats them and, in some instances, denying the full recognition of their personhood. From the start of the research process, I decided to examine the transformational effects of cancer through a theoretical lens of a transformational learning theory analytical framework. This framework has been created with the view of analysing this research and was based on one of the key Critical Social Theorist from whom I draw influence, Mezriow. As an oncology health professional, I understand that an illness, like cancer, brings crisis to a person’s experience and can potentially confuse the structure of a person’s understanding of reality as well as disturbing their world view.

Mezriow’s Transformational Learning Theory is described as being

> *“Constructivist, an orientation which holds that the way learners interpret and reinterpret their sense experience is central to making meaning and hence learning”*
>
> (Mezirow 1991 page 3)

It is through this theory that I have developed an analytical framework for the research, and how I have examined the impact on personhood. Within the theory there are two different types of learning, referred to as instrumental and communicative. Instrumental learning is achieved through a person carrying out tasks and problem solving through cause and effects. Commutative learning is concerned with how persons express their emotions, thoughts and feelings. My research has focused on cancer being a transformation experience; through the journey of diagnosis and treatment a person's world view can be impacted by the experience and results in either a perspective change, or full transformation of a person's attitudes, relationships, thoughts, feelings or behaviours.

Mezirow's believes that adults do not apply old ways of understanding to new situations, but they evolve to develop new perspectives and understanding of events (Mezirow 1991). Taking cancer as a journey of discovery, I have theorised that a person would learn about themselves during their journeys as they find solutions to the problems that they have faced. Mezirow described this process of reflection and change as Perspective Transformation (Mezirow 1991).

> *"A defining condition of being human is that we have to understand the meaning of our experience. For some, any uncritically assimilated explanation by an authority figure will suffice. But in contemporary societies we must learn to make our own interpretations rather than act on the purposes, beliefs, judgments, and feelings of others. Facilitating such understandings is the cardinal goal of adult education. Transformative learning develops autonomous thinking"*
>
> Jack Mezirow (1995) page 5

A perspective transformation can lead to a deeper level of transformational learning is some but not all circumstances. To achieve a full level of transformation a disorienting dilemma needs to occur, usually through a major life event or crisis, or culmination of smaller events. This dilemma could be triggered by diagnosis of a threatening disease like cancer, which would trigger a process of reflection and contemplation resulting in transformation in their worldview or relationships.

Baumgartner (2001) attempted to identify signs of transformation experiences in life and found that where an individual goes through periods of heightened sensitivity, they provide conditions that lead to contemplation and a revaluations. My research has found that some of the participants have also undergone this, especially when it came to the building of new relationships. There were examples of participants reasserting themselves with care providers or other individuals that have caused previous difficulties in their lives, signalling transformation in their beliefs and their personal capacity to deal with difficult problems. Most participants talked about their cancer diagnosis with mixed emotions, as they would never want to have cancer. However, cancer as a life threatening illness caused a disorienting dilemma and enabled them to be able to reaffirm certain aspects of their personhood and belonging. It must be noted that not all of the participants in the research would claim to have been changed, or that their views and outlook have necessarily improved. From that standpoint transformation doesn’t necessarily translate to personal growth universally.

The participant’s history appears to be key in the development of their unique perspective and identity and are deep rooted in their past. This research found that participants had far-reaching experiences associated with their religion, community, family and friends that influence their world views and structures and these were explored through reflection on their identity maps. This research has found a mixed response regarding the transformational effects of cancer. From the data and the areas of importance indicated by the participants, it appears that John, Sisi, Lewis, Tabitha, Tate and Susy were able to access extensive support either from friends, family, or counselling, and appear to be able to achieve a greater sense of transformation and perspective change. They all had significant disorienting dilemmas that prompted them to revaluate aspects of their lives. It is seen in the data that the participants have all gone through a process of refining or elaborating their own meaning schemes, and in some cases transforming meaning perspectives. In those participants that have achieved a sense of transformation, they appear to have more resilience to get through the difficulties that cancer can bring, including significant changes in relationships. From the findings of this research, it is clear that those participants that achieved transformation came out better adjusted after treatment. On the other hand, some participants in this research (Agnes and Evan) appear to have so much support in place around them that they didn’t have a significantly disorienting dilemma when faced with cancer to result in any significant transformation or perspective changes in their world views or relationships. However, Drew has very little sources of support, and seems to get stuck in the situation and doesn’t appear to demonstrate transformation at this stage of the research. Recovery from the cancer involves a learning experience about one’s own personhood, which comprises of a critical assessment of values, beliefs, behaviours and relationships that are then reconstructed and rebuilt to achieve transformation. At the core of personhood is the concept of identity, which represents who we are, our values and beliefs. Cancer as an experience impacts and transforms people views of themselves and those around them. This is a novel finding of my research as currently there is no known published research that examines the effects of cancer against Mezirow’s theoretical framework of transformation.

Complementary findings

In addition to the original findings of this research, there have also been five complementary findings that have already been touched upon in the literature but have required further exploration and a deeper understanding. In this next section of the chapter, I go on to discuss these findings and how they complement the existing understanding, and address my research aims of understanding LGB persons’ experiences of cancer care and impacts on personhood. These are also discussed in detail in the next chapter. However, as a reminder, the complementary findings of this research are:

1. LGB persons’ dilemmas of attending oncology appointments and staff attitudes, which can be positive, but also included issues around the disclosure of sexual orientation, staff not understanding same sex partners can be next of kin, and the dilemmas around asking persons their pregnancy status.
2. LGB persons’ experiences of the physical effects of cancer treatment, demonstrating that this isn’t just an issue for Gay and Bisexual men with prostate cancer. This research has demonstrated a greater diversity of cancer types and that lesbian women also have issues with the physical effects of cancer treatment.
3. LGB persons’ loss and changes in personal relationships, which includes further exploration of companionship and kinship when dating on the LGB scene and some of the LGB community’s attitudes towards cancer.
4. The changes observed in LGB persons’ family connections and expectations, which are in addition to some of the changes that are known in the literature that can occur between cohabiting spouses; this expands on the complexities of the relationships LGB persons can have with their family origin.
5. Isolation that is indirectly caused by cancer treatment and the seclusion of LGB persons living in rural communities.

Complementary finding one:

LGB persons’ dilemmas of attending oncology appointments and staff attitudes, which can be positive, but also included issues around the disclosure of sexual orientation, staff not understanding same sex partners can be next of kin, and the dilemmas around asking persons their pregnancy status.

My research has found that some of the participants have not had an ideal experience of healthcare, and on occasions where they have divulged their sexual orientation this has been met with a mixed response from healthcare staff. It is also evident from my research that the attitudes towards homosexuality from the health worker can strongly influence their professional interactions with LGB patients. This is of concern as the health practitioner professional and regulatory bodies all have codes of conduct indicating that Health Professionals should not allow their own beliefs or views to impact on the care that they provide (Nursing and Midwifery Council 2018, Health and Care professions Council 2016, General Medical Council 2019). This was also found to be especially the case in close knit communities where Health Professionals may also know the person very well, as evidenced through Lewis's experience of discrimination from his wider religious community, of which the Health Professionals responsible for his care belonged.

The findings of this research indicate that some staff still have difficulties in accepting homosexual relationships, and that on occasion, they allow this to become an issue that then interferes with their ability to practice in a non-judgemental way. These experiences are disorienting, but the research has determined that LBG persons with cancer may have underlying vulnerabilities such as raised levels of anxiety or apprehension about outpatient appointments, as well as a lack of support and social isolation, meaning that the LGB recipient of care is less well-equipped to handle misunderstandings in the clinical setting. During the course of this inquiry, I have found that the participants had variation in relation to their satisfaction about their own cancer experiences. Most of the participants were able to provide accounts of both positive and negative aspects of care.

The main focus of my research was to establish the experiences of LGB persons affected by cancer within Scotland. As a result, my research increases awareness and understanding of LGB social problems and will ensure that the views and grievances of marginalised people are represented. From my literature review I have found that there is a lack of published evidence from within the UK examining the needs of LGB persons with cancer and as such the full extent of their needs has yet to be fully determined, especially within Scotland. Of the recent studies that have been conducted none have had Scottish LGB representation but have reported a nuance of discrimination and raised levels of apprehension and anxiety experienced by LGB persons using oncology specialist services (Fish and Williamson 2018) (Doran et al 2018). Fish and Williamson (2018) conceptualise an ‘awkward choreography around disclosure’ manifested through micro-aggressions and heteronormative care systems and practices. This contributes to the nuance of discrimination. My primary data collection has found some reasons why this might be the case, and that this process may not only initiate within the care setting but is actually influenced by a person’s past experiences. These underlying issues of previous homophobia and concerns can then manifest within the care setting when a disorienting trigger, such as a misunderstanding in care, occurs.

LGB persons' experiences of cancer are not fully understood in Scotland, and it is necessary to establish any deficiencies that might affect care. To that end, as there is a transition to more person-centered care in cancer I feel that a person's sexual orientation should be taken into consideration when reviewing the services and support that they access. Worldwide evidence demonstrated that LGB identity can influence or alter healthcare experiences as studies have found that sexual minority individuals sometimes experience discriminatory attitudes from oncology healthcare workers (Sinding et al 2004). There also appears to be a lack of recognition of the unique aspects of sexual activity undertaken by some gay men and how this can be influenced by cancer treatment (Thomas et al 2013), and a lack of LGB specific cancer support mechanisms and groups for dealing with emotional distress (Paul et al 2013).

Several of the participants in this research reported negative experiences within the care setting, and these tended to be during interactions with health practitioners that didn't know or understand how to appropriately respond when a person came out to them. There were instances where staff didn't understand that LGB people could have same sex partners, or be widowed, and that health professionals' negative reactions and apprehensions caused breakdowns in trust. Many legal reforms have taken place over the past two decades in relation to LGB equality but the problems of anti-LGB sentiment still exists within Scotland. Staff should be able to navigate a situation whereby a person comes out to them as LGB and not be met with a response of shock or not knowing what to do. This research has focused on developing guidelines for healthcare practitioners to raise awareness to mitigate against this type of approach being taken. Despite this, the root cause of the problem is that staff are not necessarily able to equip themselves to respond to people's responses that don't fit a 'script' that they have in their heads for certain questions. This reinforces previous research findings but from a different context (Fish and Williamson 2018, Fish and Lockley 2015). In my own profession it is necessary that a radiographer asks someone of childbearing capacity if there is any chance that they are pregnant. This is a challenging question for many to ask and answer, and sometimes can be responded to with a light-hearted or humorous response to diffuse the situation. The issue arises when the practitioner doesn't anticipate that someone could indicate their sexual orientation when this happens, and misunderstandings occur. Staff not being equipped to deal with the disclosure of someone's sexual orientation often don't realise that this is an uncomfortable process for the person concerned. From the findings of my research, I recommend that staff enable LGB persons to come out gracefully. When a situation like this is handled well, it can cause recipients of care to relax to a greater extent and goes a long way to addressing their apprehensions. If handled badly, these experiences stand out and then influence future interactions with other health care providers.

This research also explored with the participants their feelings of being unable to be themselves in the care setting, which included being able to hold hands with their partners or offer reassurance by expressing affection publicly. This was not necessarily because of a negative experience, but a negative experience can make this situation much worse. There are still issues with public displays of affection between LGBT people, and this contributes to fear and anxiety (Furlotte et al 2016). More than a third of LGBT people surveyed by Stonewall said they don't feel comfortable walking down the street while holding their partner's hand and this increases to three in five gay men (Stonewall UK 2020). Some of the participants within the research did discuss how staff were able to make them feel comfortable within the hospital setting, with examples of staff using gender neutral language and being inclusive of same sex partners and making inquiries if lone attendees at appointments had additional support at home. This is another finding that is addressed in the research recommendations.

There are good examples of care within my research, but despite this there are occasions where there were missed opportunities for health teams to make LGB people feel less anxious and able to be open about who they are. One of the key outputs of this research is guidance that practitioners can use to increase their own awareness and minimise cultural misunderstandings when working with LGB people. This guidance will be presented at the end of this discussion, as it is a key output of the research. However, based on the finding of the research there have been some good examples of when healthcare providers have got things right, and these are noted as important findings of this research that inform on the guidance produced. For example, the research findings have examples of care providers exercising shared decision-making, with those important to the LGB person in receipt of care, for example same sex partners in consultations. There were examples of staff who were open about their own sexual orientation as a means of building trust, and many other staff giving the appropriate level of dignity and respect though the acceptance of LGB people affected by cancer.

Lesbian, Gay and Bisexual people need access safe, supportive, and culturally accepting services. Some of the participants have discussed occasions where staff were welcoming towards them and were able to address their needs with sensitivity, and it is clear from the research findings that the participants were more likely to disclose their sexual orientation to staff when they felt safe and enabled to do so. Further training of healthcare staff in enabling care that is free from judgement and based on trusting relationships is key to ensure that improvement is practice can be enabled and delivered in a non-discriminatory manner (Henry et al 2013).

Complementary finding two:

LGB persons' experiences of the physical effects of cancer treatment impacting on intimacy, demonstrating that this isn't just an issue for Gay and Bisexual men with prostate cancer. This research has demonstrated a greater diversity of cancer types and that lesbian women also have issues with the physical intimacy effects of cancer treatment.

The findings of this research have found that LGB people with a variety of cancer types, for example breast cancer, anal cancer, and bladder cancer, have experienced physical side effects that impact on physical intimacy. Dealing with cancer and side effects of treatment may change the way a person thinks about sex (Levy and Taylor 2013). Cancer can change a person's sexual desire and function, and as such can put strain on relationships (Horden 2002, Manne et al 2010). The theme of sexual function is discussed within my literature review and includes the mechanics of a sexual act, presenting a limited perspective and understanding of issues LGB people may face in respect of physical intimacy. For example, Asencio et al (2009) conducted research in the USA, finding that men's' reactions to potential sexual problems arising from treatment are shaped by their sexual practices. The findings revealed those who usually engage in anally receptive sexual activity could manage the loss of erectile function more easily than those who valued being able to anally penetrate during intercourse.

Sexual expression, as a distinction, includes acts of intimacy and mood such holding hands, hugging, kissing, etc. Warmth, caring, and physical and emotional closeness are as necessary and rewarding as anything else in a person's relationship, but I have found that these matters of sexual expression are absent from the literature uncovered within the review. The literature thus far focused to a greater extent on the mechanisms of sexual acts of gay men affected by pelvic cancer such as prostate cancer, rather than the issues around intimacy and the impact on relationships. However, one piece of research by Hartman et al (2014), examined the experience of three gay couples managing sexual dysfunction following radical prostatectomy. Hartman et al's (2014) study found that participants opened their relationships to others as a means of accommodating sexual dysfunction in their partners.

This inquiry has found that Lesbian women also have difficulties related to sexual expression and physical intimacy, and this could be explored to a greater extent. The key finding of this research indicates that further research is needed in this area, but sexual expression rather than just function should be considered for LGB persons' needs in respect of the cancer literature, and that there needs to be additional resources for women and people affected by other cancer types such as breast and head and neck.

Complementary finding three:

LGB persons' loss and changes in personal relationships, which includes further exploration of companionship and kinship when dating on the LGB scene and some of the LGB community's attitudes towards cancer.

All the participants recruited in this research discussed changes in their personal relationships with family, friends, and those close to them. This builds further on the findings within the literature, that the physical effects of cancer treatment impacts on intimacy and spousal relationships (Asencio et al 2009 and Hartman et al 2014). The literature focuses more to the effects of prostate cancer, and on the impacts on relationships that the loss of sexual function has on intimacy. Cancer had a major effect on the inquiry's participants' marriages and other long-term partnerships, with experience sadness, anxiety, anger, or even hopelessness. However, for some of the partners of participants, such as those of Tabitha and Agnes, facing the challenges of cancer together strengthened their relationships. For others, the stress of cancer created new problems and worsened existing problems, including the re-evaluation of some of the participants' life priorities, such as Tate and Lewis, and ultimately ended their heterosexual relationships and enabled them to come out.

Some roles and relationship changed, for example, John talked about how he always considered himself a person who was normally in charge and served as the caregiver pre-cancer, and this gave rise to him having some trouble accepting a more dependent role after experiencing his treatment. This is discussed in some of the UK literature undertaken by Doran et al (2018) where the participants, affected by prostate cancer, discussed changes in relationship dynamics. This research provides more insight into this dynamic with participants discussing the impacts of cancer treatment on the responsibilities they felt they had within their relationships. Further, additional responsibilities at times led to feelings of frustration and resentment in the circumstances of both John and Evans case, as future plans in retirement and travelling were altered causing feelings of sadness within their relationships. These issues are not explored within the literature, and this research demonstrates some of the wider priorities of LGB people affected by cancer regarding changes in relationships beyond that of physical intimacy.

Participants who were non-partnered at the time of cancer treatment, such as Susy and Lewis, sought to develop new relationships and started to explore dating soon after their initial treatments. Both Lewis and Susy provided further insight into the experience of LGB dating whilst suffering the effects of cancer treatment. The literature uncovered in my review by Asencio et al (2009), discussed that their participants had difficulties when experiencing weight gain through hormone treatments, explaining the gay community's negative attitudes towards them and the pressures of being able to sexually perform in what they viewed as sexually charged community. Again, Asencio et al (2009), researched the effects of prostate cancer for Gay and Bisexual men, but this research has found that LGB people affected by other cancers, such as bladder, breast and anal cancer, also have issues when dating within the Gay community. Susy found that she had concerns over changes to her physical appearance due to a mastectomy, which aligns well with the findings by Asencio et al (2009). However Lewis discussed how men with HIV tended not to care that he had bladder cancer and reveals an interesting subsection of the gay community yet to be explored within the LGB cancer survivorship literature. This research did not fully explore the experiences of the attitudes of others within the gay scene towards the participants, as this was not the primary focus of this research; however, this finding indicates an area of possible additional research and develops the current understanding of the LGB community's attitudes towards cancer that was understood previously from the literature.

Complementary finding four:

The changes observed in LGB persons' family connections and expectations, which are in addition to some of the changes that are known in the literature that can occur between cohabiting spouses; this expands on the complexities of the relationships LGB persons can have with their family origin.

It is often the case that LGB people can have issues with their family origin due to their sexual orientation, but this isn't discussed in relation to cancer in great detail in the literature uncovered as part of this research (Almack et al 2015). More broadly, it is recognised that many LGB people can have poor relationships with their family origin as well as experiencing outright rejections (Carastathis et al 2017). Existing cancer literature also explores the change in dynamic between partners, however wider family relationships are rarely explored (Asencio et al 2009). Within the literature uncovered in review for this research, three published papers by Sinding et al (2004), Barnoff et al (2005) and Sinding et al (2007) examined the experiences of Lesbian women affected by breast cancer, commenting that there was an increased need for support due to the estrangement that some of the participants had from their own families. The published research appears to be produced from the same PAR study based in Ontario, Canada. This work concluded that the participants had a greater need to rely on support outwith of their families and demonstrated a potential additional need that Lesbian cancer suffers may have. Family is often the key source of support for someone who has cancer, and LGB persons who are estranged or have poor relationships with their families are not able to rely on this (Harris et al 2009, Kim et al 2009).

My research has found that many of the participants involved in the inquiry had poor relationships with their family origin, namely Susy, Lewis, Tate, Drew and Tabitha. This would appear to affirm what is understood within the literature. However due to the unique exploration of what family connections participants had, progressing to discuss how cancer impacted on these relationships, this research has been able to gain further insight into some of the difficulties LGB persons may face and the nature of the complexities of relationship breakdowns.

Some of the participants in this research were not fully estranged from their families, and after their diagnosis of cancer their relationship changed. Susy, Tabitha and Tate commented on how they felt that they had been able to gain further support through counselling to be able to tackle long standing issues with some family members. Tabitha and Susy discussed how their partners had not been accepted by their families and some of the difficulties of trying to maintain close relationships with their families despite the rejections or lack of recognition of their partners. Through aligned cancer support, the participants were then supported through this, and this had the effect of either improving or terminating poor longstanding relationships. Drew and Lewis discussed the ongoing need to engage with their family, but because of their diagnosis and treatment, this was made much harder as additional relatives started to try and establish and build links which then made them feel uncomfortable. As this started to raise original issues regarding the participants' sexual orientation, which is why they fell into disagreement with their family in the first place.

Not all of the participants had poor family connections and relationships. For example, Evan and John discussed how their relationships had improved with family and the experiences of cancer had actually brought them closer together. This research has found that LGB people's relationships with their family origin can be complex and that having cancer changes the status of these relationships. This is potentially very significant as many of the participants had poor relationships within their family origins, as observed in other research (Fish and Williamson 2018), and my findings demonstrate that LGB people may need to draw on additional support away from more traditional family structures and that difficulties with family relationships alter over the course of a cancer journey.

Complementary finding five:

Isolation that is indirectly caused by cancer treatment and the seclusion of LGB persons living in rural communities.

The participants from this research have come from diverse backgrounds, with ranging levels of support during their cancer journeys. The research was successful in finding participants from across the LGB community, with those that describe themselves as out and being comfortable with their sexual orientation and who they are, to those that were struggling to come to terms with their sexual orientation or dealing with their own families' or community's negative attitudes towards them. Despite the diversity of the participants and varying degrees of acceptance of their own sexual orientations, nearly all of them had experienced some degree of negative attitudes at some stage of their lives due to them being LGB. This research has found that the negative experiences a person has can then extend throughout their life, influencing the lens through which they perceive care, and make them potentially more susceptible to distress and harm when they encounter a disorienting dilemma along their own cancer journeys.

This study has provided evidence to support the idea that the LGB community have a distinct experience of services within Scotland, as well as varying social attitudes, and aligns well to a general understanding of LGB persons' experiences of living in Scotland (Stonewall UK, 2020). Generally, the reaction to social marginalisation can contribute to engendering a feeling of community amongst those who identify as LGB (Renschleret al 2010). This can give a sense of belonging and the creation of safe spaces to those that identify within these groupings, allowing them to be able to securely interact without the fear of marginalisation from society in places such as the gay scene and LGB community groups (Cronin and King 2012). This would also suggest that some LGB people feel the need to have safe spaces to be themselves and want to remain less visible in everyday society. This may derive from the history of legal reform in the UK.

It can be seen from the research findings that the effects of cancer treatment can increase the levels of isolation from the LGB community and scene, particularly with participants who live in rural areas such as Drew. Drew found it hard to sustain relationships with other LGB people as he was unable to access the gay scene due to the debilitating effects of his cancer treatment. In addition, there were occasions whereby Susy and Lewis discussed how they navigated dating after their cancer treatments, and where the knowledge that they had cancer brought negative attitudes from the gay community itself. This indicated that if someone's only source of social support and interaction was from the LGB community, being cut off or rejected from this community can mean that a person has no one else that they can turn to for support, leaving them very isolated.

What findings might mean for others

This project has sought to inform professional practice and patient care within Radiography and among other health care professionals involved in cancer care by establishing LGB persons’ cancer experience and adding to the evidence base. The output of the research then goes on to develop recommendations for a practitioner guide. There is potential for this research to inform national policy of the College of Radiographers when interacting with LGB people, as well as providing valuable information to other key stakeholders and organisations. In this next area of the discussion, I go on to explain the potential meaning of the findings of this research for Health practitioners, policy makers and other researchers, and show opportunities for learning.

Misunderstandings in care

Many of the difficulties experienced by the participants that are documented within the findings of this research tend to arise from misunderstandings between the LGB persons affected by cancer and the views or unconscious bias of health workers. The Health and Social Care Act (2008) makes clear that the intention to provide personalised care to all those that access the health service within Scotland. The legislation states that providers must ensure that they act to ensure that every individual receives person-centred care that takes into account their needs and preferences. Health policy makers should be aware that despite the act of legalisation, this has not been translated into practice on the ground in all cases. Clearly personalised and person-centred care has not been universally applied across the health service in Scotland as evidenced by the findings of this research. Providers must attempt to foster supportive relationship to work in partnership with those in need of care, and make all reasonable adjustments for them to make decisions related to their health and treatments that are informed and the extent in which they can manage their conditions themselves. This includes practitioners seeking opportunities to being open to those in receipt of care being from a LGB community and not permitting this to influence their practice or the quality of care they provide.

How does the research apply beyond Scotland?

Although my research has recruited participants that reside in Scotland there are many findings that are translational to other geographical areas, and as such the vulnerabilities of the LGB people encountered in this research should not be dismissed as a Scotland-only issue or an isolated case. It is apparent that within my own literature review of the published evidence from across several countries, including England and Wales, distinctive aspects of the cancer care journey related to sexual orientation. Therefore my research adds to the body of knowledge and informs understanding of this field. Further it is understood that LGB people can have a poorer cancer experience and overall support which is demonstrated in the UK national cancer patient experience survey (Department of Health 2013). My research helps to further the understanding of why this may be the case.

In addition, the research findings of this PhD also incorporate the findings from the literature to best inform on evidence-based practice. I have brought together findings from my primary data collection from the inquiry sessions and analysis with my 'secondary' research into the existing literature uncovered in the hermeneutic review. Therefore, the literature synthesis also adds to the existing research and topic.

Working with the LGB community for participatory research

Community-based participatory research is a systematic process that uses a community collective, to reflect and engage with stakeholders in an inquiry of equal partnership throughout all phases of the research with specific aims to educate, improving practice or bringing about social change with those involved (Isreal et al 1998, Green et al 1995). From the outset of my research, I decided that in order to secure the trust of the LGBT community and participants it was necessary to recruit to the research from outwith of the hospital setting and thus my work is community based. Whilst developing the research and working with the LGBT community to design the methods and recruit participants, there were challenges that arose over the course of my work that other researchers who are about to embark on a piece of community-based participatory inquiry can learn from.

Researchers studying sensitive topics, like a person’s sexual orientation or their cancer, need to understand that there might be a reluctance for people to disclose information about themselves. The subject matter may be sensitive, as the participant may feel that the questions are instructive and an invasion of privacy, and that it may have repercussions where this information could get back to others (Holtgraves 2004). My methods focused on establishing trust with participants, and this stage was key to the process of the cooperative inquiry. Initial contact was made with the participants, and email exchanges and informal meetings took place frequently to discuss the research prior to recruitment into the study. This was to ensure that participants could fully consent but also understood the terms that the exploration of their own personhood would cover. I provided details of how sensitive topics such as relationships, sexual practices, and membership in a stigmatised group would arise. There were potential participants that then chose not to participate in the study at all, which unfortunately reduced the overall number of participants in my research.

Participants' views of LGB safe spaces

The facets of the individual can work together in synergy with other persons and through the construction of social groups, culture and common understanding are developed. Through the common understanding and shared experience of LGB persons there are examples of distinct characteristics of culture such as art, history and language, as with any other minority group, giving rise to LGB culture. The development of homosexual language such as slang and Polari demonstrate how a marginalised underground of interacting communities construct different identities and produce particular speech styles as well as how individual identities are expressed (Baker 2001). These factors play a part in the development of an LGB community and as such there is a creation of a safe space and environment for LGB people to engage.

Communities have been created by lesbian and gay people due to their oppressed status (Ellis 2007). Within the UK these comprised of a wide range of venues and organised social activities, such as LGBT community centres, women's centres, and book shops. However, due to the mainstreaming of LGBT culture, these are starting to disappear (Ellis 2007) Mills (2006) discusses the emergence of a prominent discourse on queer history in the public sphere with the creation of LGBT History Month. This event is marked to celebrate the lives and achievements of LGBT people, but Mills argues that these events and a public acceptance of being out and proud can in itself create potential exclusions of those that choose not to be defined by their sexual orientation. Despite some LGB persons discomfort with being defined by their sexual orientation it is evident that LGB persons can be the subject of attack and hatred. As a community-based researcher, it was important that I understood how many of the participants had spent time in which they had kept their true selves hidden for fear of discrimination. Due to the methods employed at the start of the research this enabled participants who were not necessarily out and open about their sexual orientation to come forward and participate in the research. This research therefore has been able to achieve one of its primary aims by recruiting persons who wouldn't normally participate in this kind of research. This is a novel aspect of my research. In order to do this, great care was taken to assure participants' safety and discretion was key when protecting participants' identities.

Differing views of sexual orientation amongst LGB people

Any researchers and those people in practice who are about to embark on a programme of working with the LGB community should be aware of the mixed attitudes of participants towards labels and being labelled and the sensitivities surrounding this. In order to ensure that the research is robust it is necessary for the researcher to build trust with the participants and stakeholders. The new-found public acceptance of homosexuality appears evident within current UK society, but this new acceptable gay persona can also be contentious. For example, public recognition of gay people and their relationships is discussed by Joshi (2012) in a framework called "respectable queerness". Joshi (2012) theories that LGB peoples recognition in society has been contingent on them acquiring a respectable social identity, that is created through the premise of a public performance of respectability, and keeping LGB peoples queerness private. The challenges posed by such recognition include dissonance between a LGB person's public and private selves and fuels moralism and entrenches divisions between different queer constituencies. I feel that society has now come to a new dawn of LGB culture and needs to recognise and acknowledge the needs of this group in respect of health, justice and parenting as the LGB person that has previously had to exist behind closed doors becomes more visible within society. Unfortunately, many of the participants in this research are not at that point, and this is likely due to them being older LGB people with a long history of not being able to be openly gay in society. During the research many of the participants felt happy to meet in LGB venues for initial discussions about the research, and then later indicated that meeting in their homes would be preferable to other locations to participate in the inquiry. I was challenged on several occasions that despite this, participants didn't want to feel categorised into a box and that their values, beliefs and behaviours should be accepted for the diverse group of persons they are.

Strengths and limitations of the research

The Strengths and limitations are discussed in this next section as a means of making the validity of the research transparent for its context, and as a means of being able to represent the credibility level of the overall research and its findings and recommendations (Guba and Lincoln 1994).

It is understood that in qualitative research there is less emphasis on counting the number of people who think or behave in certain ways and there is more emphasis on explaining why people think and behave in those ways. My research, being participatory in nature, ensures that the issues and areas of exploration that matter most to the participants are reflected in the research findings. The research could be considered contemporary in its methods and design, and differs from more conventional approaches to qualitative research; however, it still remains rigorous in its approach. This represents a possible limitation of this research due to its accessibility and familiarity with the health science research community. Despite this, participatory research is a legitimate research methodology and there is growing evidence for its use (Jagosh et al 2012). This research has an advantage in that it has worked with the participants to establish what is most important to them and has been focused on attempting to find practical solutions to the issues they have faced during cancer treatment.

The research only managed to recruit a total of nine participants. This was below the target figure of ten to fifteen. Despite this, the research has recruited a similar number of participants to other research studies conducted within the field, and it should be noted that the LGB community is deemed to be a hard-to-reach group. It should also be noted that the research findings are also supported with the emerging picture of other research in the field and is supported by the current understanding of LGB persons experiences in society.

This research was very successful in recruiting participants who were non-scene and not out. As such their views add weight to this research, as these participants represent a voice that doesn’t presently feature in much of the published research to date in this field. In addition, the research study recruited participants with a diverse range of cancers not represented within UK literature and helps to form additional understanding from those affected by a larger range of cancers. However, this research did attempt to seek a greater diversity of LGB people, although it did not succeed in the aim of increasing participation from individuals from a non-white background or with a disability.

As a gay man and member of the LGB community there were occasions where I misunderstood some of these things and underappreciated the level of sensitivity around the topic of labels. Luckily due to the strong community engagement I had worked on in the initial stages of the research, this meant that there was a collective group of advocates for my research that encouraged participants to come forwards who I may have inadvertently alienated. An overall limitation of the research is that it relied on a binary classification of a person’s sexual orientation, and although this may be appropriate for older LGB people, there needs to be an ongoing recognition that terminology in respect of sexual orientation and a person’s feelings towards labels are in an ever-changing flux that is influenced by culture, background, and belief.

The Covid-19 pandemic has impacted on the final stages of this research, and it was originally envisaged that a key stakeholder workshop would be undertaken to help formulate the final conclusions of the research. This was going to take the form of national guidance and learning materials. It has been unfortunate that I have not been able to bring together the participants and key stakeholders at this final stage in a workshop setting. However an alternative strategy was formulated in keeping with the model of the participatory inquiry. Instead of having a stakeholder event, the decision was taken to produce a practitioner guide. This guide was then discussed one to one with each of the participants via MS teams, email and phone and then the feedback obtained was used to develop the guide prior to seeking stakeholder’s feedback (See appendix twelve). This has meant that those that matter most to this research, the participants, have been able to have a direct influence and input in the design of an output of the inquiry, and the stakeholders have had the opportunity to collaborate with ratifying the final version of this. The research has still been able to fulfil its aims in that respect and follows the stages of the participatory inquiry methodology. In addition, this research is inquiry focused, and not participatory action research as discussed in Chapter 7. Therefore, the exploratory nature of this PhD, aiming to determine the impact of cancer treatment on LBG personhood, has been achieved.

Theoretical and methodological contribution of the research

This research has been successful in developing a theoretical framework to assess the impact of a health care intervention for a marginalised group. In this section of my discussion chapter, I return to focus on the methodological and theoretical framework of the research. This addresses the research aim to contribute theoretically to the knowledge of personhood and person-centredness and has been achieved through the development of a theoretical model to explore people’s personhood. As I developed the framework over the course of my research, I have termed it the Impact on Personhood Participatory Inquiry Framework (IPPIF) (see figure 9.1). In the next section I demonstrate how I updated the methodological and theoretical model of the research based on my learning and findings.

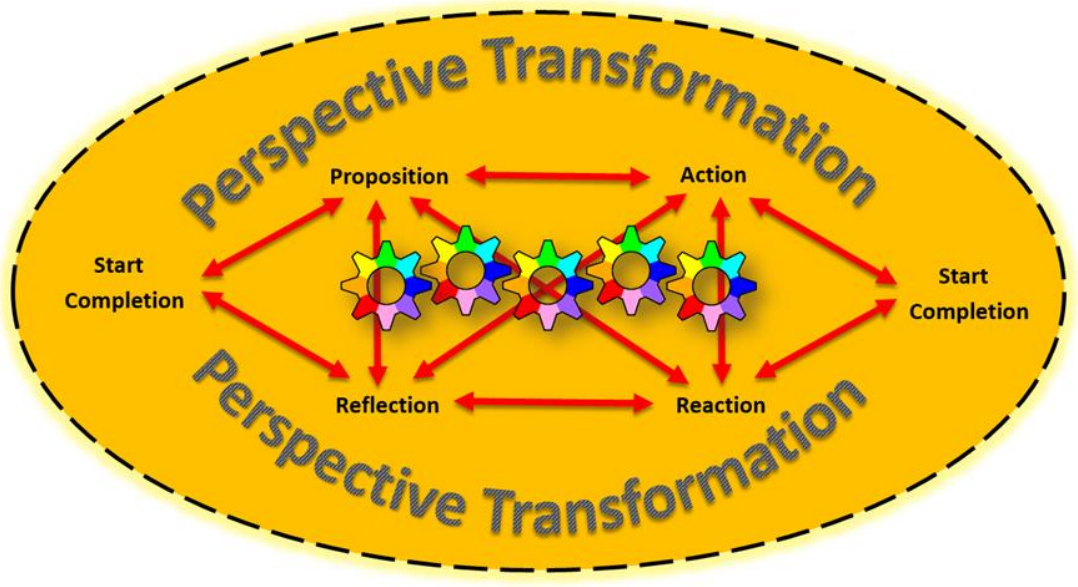


Figure 9.1

Impact on Personhood Participatory Inquiry Framework (IPPIF)

Based on the initial design of the inquiry, the process is then potentially open to being threatened by unaware projection and potential collusion of the support persons. This means that enabling the participants to have one-to-one sessions within the structure of the inquiry helped to minimise this and is a significant modification of the Heron and Reasons original participatory inquiry framework (Heron and Reason 1997). The topic matters in the inquiry are anxiety-provoking and are psychologically profound for the participants. The research then could permit anxieties into the topic we were supposed to be studying (Devereaux, 1967). In a more conventional PI, the participants can sometimes group and start to defend their anxieties, and prevent a full exploration of their experiences. My final theoretical framework permits the exploration of health care events and was able to counteract these defensive tendencies. A comprehensive set of procedures was developed to reduce threats to validity, by to acknowledging, engaging and exploring with the participants any anxieties they had through the use of ways of working and democratic participation advocated by Habermas (Habermas 1991). In addition, the traditional PI was modified in the final IPPIF to permit the movement and progression between action and reflection phases so that issues were discussed form different angles and revisited where needed and establishing norms whereby participants could challenge assumptions (Reason and Rowan 1981 and Heron 1988).

This research was successful in its aim of making a theoretical contribution to personhood and person-centeredness through developing the IPPIF to explore the participant's personhood and how this was impacted on by care. The framework was tested through the exploration of the research and yielded a diverse range of experiences of LGB cancer care. The findings were validated by the means of blending techniques to promote communication and rationality through the use of creative methods, and an investigatory mechanism to evaluate the impact of cancer treatment. The IPPIF is therefore transferable to other areas of research and presents a future direction of potential research.

Guidelines and recommendations

It was the initial intention to engage the participants in a stakeholder workshop to agree the final recommendations of this research. However this has not been possible due to the impact of the COVID-19 pandemic and associated restrictions. Synthesis of the findings of the literature review, primary data collection and analysis was carried out as detailed in the discussion chapter. Areas where findings suggested a need for change were highlighted to provide a basis for recommendations. As I was not able to hold a stakeholder workshop, I decided instead to develop a first draft practitioner guide from the findings, and then send this to the participants for feedback, which I used to revise the guidance (See appendix twelve).

It should be noted that the main aim of the inquiry was to explore how cancer treatment impacted on LGB people's personhood, and was not to produce a practitioner informed guide as part of the research process. This research was participatory inquiry (PI) focused on the effects of treatment, rather than participatory action research (PAR). The distinctions between these are outlined more in chapter seven. However, it was deemed appropriate and consistent to go back and seek the views of key stakeholders and participants involved in the earlier aspects of the inquiry, rather just devise the guidance without any feedback from those that had come to support the research. Further it was important to be assured that the participants, as people who were directly affected by the issues, were satisfied with any guidance created from this research and it was deemed fit for purpose in their eyes. This approach is consistent with person-centred principles and having respect for the community involved in the research.

Extracts of research transcripts were used to support the recommendations and provide the participants' voices to add weight to the guidance. Throughout the inquiry I also made note of any suggestions made by participants about what additional support they may have found useful, and areas of their own journeys which they found the most difficult. Appendix 12 demonstrates the initial guide devised by myself, and how this then changed following the feedback from the participants recruited to the research. Participants were invited to complete a feedback sheet which included 5 point likert scales, with responses ranging from 'very poor' to 'excellent', as well as free text responses, focusing on the information, recommendations, and resources contents within the guide. Participants were also given the opportunity to provide feedback over the phone, by email or by post, and were offered the choice to edit the text contained within the guide if they wished.

"This is really good and informative. It should at least make people listen or take pause for thought. I've added some comments and. me being me, they are a bit wordy. Happy to talk through them if you want. The one that keeps coming back to me is the relationship part. Having been in a hetero marriage and now in a gay one, it is different taking my now husband with me to an appointment than with my ex-wife. It's like there's another layer you have to get through before you walk into an appointment. You know there'll be a questioning look when your name is called and you stand up with another bloke. There was never that with my ex-wife."

(Lewis email feedback example)

"It seems ages since we met and I'm glad to see that you have carried on and now brought it to completion, congratulations. Looking at your recommendations they all seem extremely sensible and helpful and will steer services towards better practice going forward which is really good."

(Tabitha email feedback example)

All nine participants responded within three weeks using the questionnaire via email, indicating that the contents of the guide were good (n=6) or excellent (n=3). There were some suggestions regarding specific the wording of the draft text, and these were all incorporated in to the guide (see appendix 12). In addition, three participants explicitly stated that they were happy to have been involved in the research and were pleased to have seen the guidance created as a result.

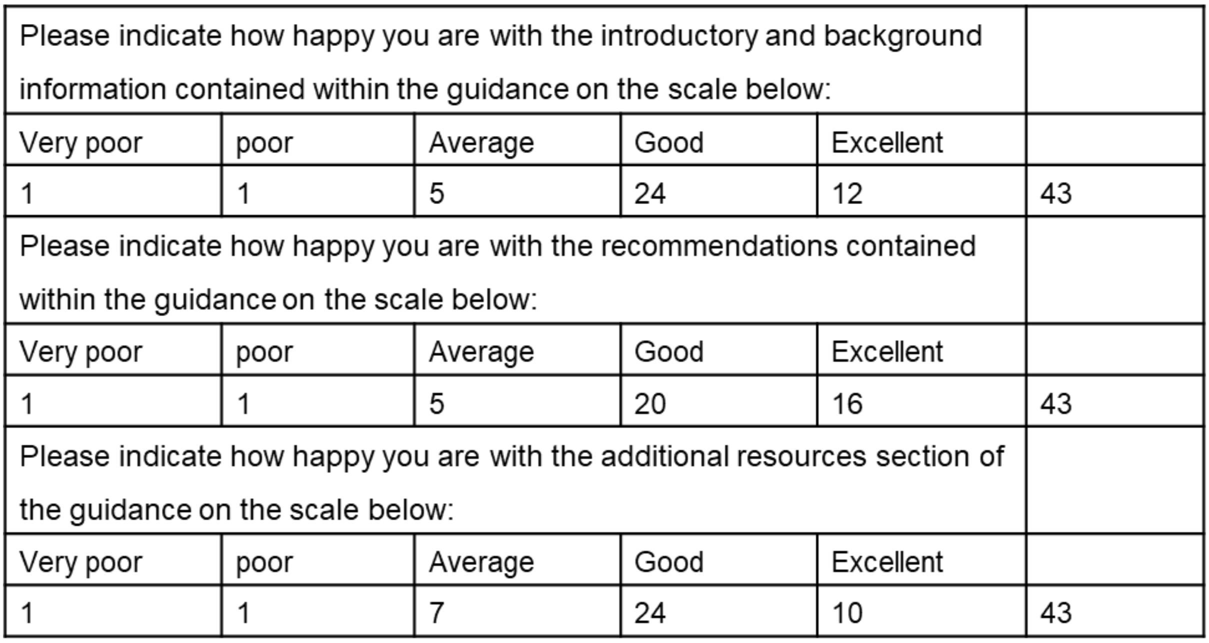
"Being part of your research helped me enormously. It was tough in a lot of ways but it opened up 'me' to myself and I'm thankful for that. The worms needed to get out of the can and I appreciate the way in which you did it."

(Lewis follow-up email)

After the research participants had agreed the final text, stakeholders were then invited to contribute. Feedback was used as a means of developing the final guidance and served as verification that key stakeholders and the participants involved in the research were content with the guide. Fifty-three individuals who had become known to myself throughout the course of the participatory inquiry were approached to see if they would be willing to provide feedback on the final practice recommendations. Those willing to participate completed the same eight open questions, which sought free text responses, and the same five-point Likert scales, as used with the research participants. Similarly, a draft of the final guide was also offered for stakeholders to make suggested modifications and corrections. Forty-three feedback replies were received from representatives and employees of the following organisations within eight weeks:

- Maggie's Cancer Centres
- MacMillan Cancer Support
- Prostate Cancer UK
- Out With Prostate Cancer Support Group (Manchester)
- Lesbian Gay Foundation Manchester
- Society of College of Radiographers professional officers
- Society and College of Radiographer's Council representatives
- LGBT cancer academics employed at universities in the UK and Canada
- Eighteen NHS employed oncology professionals from 8 different trusts and boards, which included therapeutic and diagnostic radiographers, health managers and policy makers, oncologists, specialist oncology nurses, counsellors and psychologists
- Four members of the public who had cancer and identified as Lesbian Gay or Bisexual, but were not in themselves participants in the research inquiry.
- LGBT Health Edinburgh
- The Equality Network Scotland
-

A summary of the frequency of Likert responses are contained in table 9.1



Please indicate how happy you are with the introductory and background information contained within the guidance on the scale below:					
Very poor	poor	Average	Good	Excellent	
1	1	5	24	12	43
Please indicate how happy you are with the recommendations contained within the guidance on the scale below:					
Very poor	poor	Average	Good	Excellent	
1	1	5	20	16	43
Please indicate how happy you are with the additional resources section of the guidance on the scale below:					
Very poor	poor	Average	Good	Excellent	
1	1	7	24	10	43

Table 9.1. Frequency of Likert responses for stakeholder feedback.

Appendix 13 demonstrates the final guidance that incorporated all key stakeholder feedback. Free-text suggestions focused on specific wording of areas of the document which were all incorporated, and resources to be used in the final guide. In addition, it was suggested that references could be incorporated in the information to support statements and these were added. Finally, further information was incorporated around use of LGBT staff support networks as a source of advice within NHS organisations, and use of rainbow badges as a means of identifying LGBT friendly staff. The revised guide was then returned to all of the participants for approval to ensure that it was still representative of their views. All research participants agreed that the guide contained in appendix thirteen was satisfactory and that they were happy with its contents. This final version is due to be sent to a graphics designer to improve the final product and will be ready for dissemination at the conclusion of this research.

Practitioner Guide recommendations

Recommendation 1: Practitioners should support disclosure of sexual orientation in a non-judgemental way.

"I would like to come out gracefully, just drop it into the conversation, but make it just seem the most natural thing in the world, so there's no awkwardness about it" - Susy

Practitioners need to be mindful of practicing in a heterosexist way and making assumptions about someone's sexual orientation. LGB people are more likely to come out to staff if they feel comfortable and safe to do so. Training for non-judgemental, relationship-based working is key. Asking questions about people's circumstances without the use of assumptions or gender can help LGB people to disclose rather than correct a practitioner.

Recommendation 2: Practitioners should always be cautious of asking scripted questions and reacting to people's responses in a negative or surprised way.

> *"I'm forever asked if I could possibly be pregnant - every time I'm scanned, for example. Only once have I jokingly said that would be impossible as I'm a lesbian (as well as the fact I have had my ovaries removed!). The woman I was speaking to didn't laugh or make any further comments. Anyway, I just answer, "No" now"* -Tate

Practitioners should be mindful about asking people questions that are presumptive and guided by what they anticipate someone may say, such as questions regarding pregnancy status. It is also important to be non-judgemental in reactions to responses that practitioners don't expect. Negative and surprised reactions from practitioners can undermine LGB people's confidence in your ability to provide non-judgemental care.

Recommendation 3: Practitioners should know where to signpost LGB people who need mental health support.

> *"I felt worthless because I was gay, I had cancer and nobody really cared. I felt that my parents and family would be better off without me and they as kids would come to terms easier with a dead Dad than one who was gay and had cancer."* - Lewis

LGB people can be signposted to local cancer support through Macmillan and Maggie's Centres. Both are committed to supporting all persons affected by cancer, no matter their sexual orientation.

Recommendation 4: Practitioners should be mindful of how LGB people may be feeling about appointments.

"I don't express affection, physical affection with my partner, very much in public. The reason for that is that's quite loaded with LGBT history and the social acceptability." - Evan

"Not only am I waiting to find out if I have cancer or not, I'm also worrying about the people in the waiting area are they thinking that I'm weird... I am thinking about that.… It's like just another thing." – Tate

Many LGB people don't feel comfortable showing physical affection in public or in front of people they don't know. This includes holding hands and expressing comfort when supporting someone that is close to them that is affected by cancer.

Recommendation 5: Practitioners must recognise that LGB people have next-of-kin with the same status as those of heterosexual people.

"She came back, actually quite discreetly, managed to say 'ooh, you know, your form says you were widowed, but then you said you were lesbian', and then I had to say, well actually, it was my civil partner that died, and I ticked the widowed box. That was horrible." - Susy

Some LGB people find that their doctor, nurse, radiographer, or other health professionals assume they are heterosexual or don't think beyond the label. Practitioners need to be mindful that LGB people have relationships with the same status as straight persons and that these relationships are just as meaningful.

Recommendation 6: Practitioners devising health information targeted at the LGB populations need to be cautious when using labels.

"Queer, don't get that. Don't ever, ever, call me queer, to me that's such an insult. I don't get that word, I think it's appalling, it's one of these worse things you could ever call someone when I was a kid. Why would you want to own that?!" - Lewis

Many LGB people have uncomfortable associations with specific labels, especially those that have been used in a derogatory sense, or as a means of previous discrimination or abuse. Opportunities should be sought to include representation of LGB people on patient information groups and when designing LGB literature.

Recommendation 7: Practitioners should be prepared to discuss the effects of cancer on physical intimacy.

“When we got to the point of being intimate for the first time, I mean, I think my girlfriend had no idea what to expect, she wasn't even clear at that point if I'd had a mastectomy.” - Susy

“After treatment I was very tired, we couldn’t be physically intimate. I just stopped having sex with him a long time ago, and it was over.” - Drew

LGB people may feel more unconformable about talking about the effects of cancer on physical intimacy. Practitioners should approach these conversations sympathetically and, where needed, seek additional support for themselves and the LGB persons. In addition, written advice and support should be created to be inclusive of people who engage in same sex activity. Further signposting to LGB specific advice and support is contained in the additional resources section of this document.

Additional recommendations

In addition to the practitioner guide I have also formulated the following recommendations from the findings of the research. These recommendations are focused for education institutions, health providers and support organisations, but unfortunately due to the impact of Covid-19 it was not possible to present these at a stakeholder workshop for further development.

Education providers

Recommendation 8: Pre-registration curricula developing learning materials that include LGB people perspectives of cancer treatment as part of case studies and learning resources.

Adoption of this recommendation will help to ensure that the future training of the cancer workforce will be inclusive of a variety of LGB persons’ perspectives and develop the overall cultural competence of pre-registrants. It is supported and aimed at addressing ‘complementary research finding one’ of this inquiry. Specifically by increasing awareness of the issues that LGB people face to trainee health professionals and should have the effect of improving practice and addressing LGB person’s dilemmas of attending oncology appointments and possible staff attitudes. This can give rise to issues around the disclosure of sexual orientation, staff not understanding same sex partners can be next of kin, and the dilemmas around asking persons their pregnancy status.

Recommendation 9: Universities should develop post-registration education learning materials related to LGB cancer for oncology health professionals

This recommendation will help to ensure that the existing cancer workforce are able to develop knowledge and skills of working with LGB persons affected by cancer and ensures they are able to support their needs. Take up of this recommendation should help to address the inquiry's 'complementary finding two', whereby LBG persons' experiences of the physical effects of cancer treatment can span across a greater diversity of cancer types than current guidance covers and that these also include the needs of lesbian women.

Care providers

Recommendation 10: Radiotherapy and Oncology departments should consider a LGBT diversity champion who can review information and support offered to patients to assess if this is inclusive

This recommendation is aimed at addressing 'original finding three' of this research. With members of the team championing best practice of the treatment of LGB people, this will address misunderstandings of labels. Care providers should be particular sensitivity of not labelling LGB people as all having the same needs, and the sensitivities and triggering aspects of using the term queer and more fluidic language to describe LGB persons with cancer.

Support organisations

Recommendation 11: LGB health organisations should consider providing support for LGB cancer sufferers

This recommendation may help to tackle some of the social isolations found within the findings of this research. LGB health organisations should work to combat loneliness and rural isolation for LGB people and work to address supplementary finding five of this research, which recognises the isolation that is indirectly caused by cancer treatment and the seclusion of LGB persons living in rural communities.

Recommendation 12: Cancer support groups should develop skills and resources to support people who may be coming out to other people in lives during their cancer treatment.

'Original finding one' of this research shed further light on LGB persons coming out and coming to terms with their sexual orientation as well as dealing with a recent cancer diagnosis and treatment. Cancer support organisations should be prepared to support individuals who are going through this process given the transformational effects cancer treatments have been observed to have within this inquiry's findings.

10. Conclusions

Despite legal reforms within Scotland over the past ten years general societal views and acceptance towards those that identify as LGB still remain problematic. Older LGB persons, who will be more likely to develop diseases such as cancer, will inevitably find being open about their sexuality the hardest due to rapid change in legal reform and social acceptability of homosexuality in recent times. In this research I have highlighted some of the underlying vulnerabilities of the participants providing insight into why they may have difficulties when reacting to disorienting dilemmas in care. When reviewing the data under the theoretical lens of perspective transformational theory it is clear that the participants have all experienced a significant life event, but not all have been able to achieve full transformation. This is either because they are not yet at a stage of successfully processing these events for this to have occurred, or that due to their support networks and own resilience they have not found the dilemma of cancer treatment to be significant enough to stimulate a change in their own world views. In this final chapter, I provide research dissemination and impact plans, possible future research priorities and my final conclusions of my thesis.

The people in this research

When I embarked on my PhD journey, there was an established trend in the literature whereby LGB people's needs were often seen to be focused on sexual advice relating the physical effects of cancer treatment. There were also clear examples of assumptions of what of others felt LGB people wanted regarding their care needs. There was a scarcity of research that incorporated real views and perspectives from LGB people with regards to what they needed to improve their own care. This felt wrong from my own experiences as a gay man and I believed that there was a lot more to learn from LGB people about their wider support needs when faced with the experiences and dilemmas of cancer. This, coupled with my commitment to person-centrednes, enabled me to work with the nine participants involved this research to establish what is most important to them.

The overall research question was to establish how cancer treatment impacted on the personhood of LGB people. The research was highly successful in this regard, as the participants demonstrated themselves to be a diverse group of persons with a variety of needs, aspirations and priorities. They were indeed *unique persons,* and this contrasted with the more one dimensional picture that is sometimes portrayed. The participants in this research indicated that they had many issues to face when going through cancer treatment. I was saddened to learn that some of the participants in my research had experienced rejections form their families and communities, and one person having endured gay conversion therapies, which are still legal today within the UK. This was all alongside having to work through the many other problems that cancer brings. They needed to be assured that healthcare could be delivered in non-judgemental way, and were let down on occasions. I am truly grateful to them for giving the time to this research to establish how cancer impacted on their identities.

These original contributions to the field highlight how people have felt the need to come out during the course of their treatment and prioritise their care around others close to them, including children and older relatives. There were examples of people having to reconcile their spiritual beliefs with previous rejection and homophobia from their past. The research has also indicated that care should be taken regarding the use of labels, especially given the desire of LGB people not to be singled out or insulted, and ultimately wanting to be respected by their care providers. Finally, for many of the participants in this study, cancer has been a difficult and challenging experience. However, through facing this crisis and dilemma, many have found this to be empowering through being enabled to transform their world views of others and themselves.

Plan for dissemination and impact

Before the research commenced, awareness of the study through the use of social and online media was used and targeted at voluntary sector organisations working in LGB communities and LGB cancer support groups in Scotland. Publicity materials were designed and distributed to LGB groups, support agencies, individuals, Twitter feeds, and Scottish LGB venues to ensure maximum possibilities for recruitment into the study and the dissemination of its findings. Now the study is complete, these organisations will be contacted again to share the research findings and recommendations.

During the research inquiry, participants, supporters and both LGB and cancer organisations were updated through plain English briefings, social media tweets, and press releases. At the conclusion of this inquiry, I now aim to present at the Annual Radiotherapy Conference and submit a publication to the Radiography Journal and International Practice Development Journal. I will also work with my local and national networks established throughout this research to promote the dissemination of research among non-academic audiences through the media and communications department at Queen Margaret University.

This research is being undertaken as part of a much larger multi-professional research and development programme in the Centre for Person-Centred Practice Research at QMU. A key aspect of the Centre is that it ensures that research impacts on the way healthcare services are delivered and in particular, on the lives of vulnerable persons and groups. This includes, amongst others, those affected by cancer and those who belong to the LGB community and as such this project aligns well with the Research Centre’s goals. My research draws on this approach, influencing my choice to undertake a participatory research design. As such it fits very well into the Research Centres agenda by ensuring that LGB people could have a direct influence on the development of support offered by cancer services. This will have a direct impact on patient care by enhancing the experiences of LGB people when accessing cancer services, informing the teaching and learning of future radiographers, and transferring learning beyond Radiography to cancer support services more broadly.

This project seeks to inform professional practice and patient care within Radiography and evidence will be collected to demonstrate the breadth and nature of its impact. There is potential to inform national policy with the College of Radiographers when interacting with LGB people and provide valuable information to other key stakeholders and organisations. Future impacts of this project should be evidenced across Scotland through strategic involvement of key stakeholders who are placed at the heart of policymaking and development of cancer services. I aim to build on this research at post-doctoral level and have provided the following table 10.1 as a summary of the dissemination of the findings of the research.

Issue	Stakeholder(s)	Activities that actively engage relevant stakeholders/publics	Timelines	Progress with stakeholder/public engagement and impact.
Literature review	Researchers, health care professionals, academics, policy makers	Presentation at BWOSC study day Oral abstract delivered at SCoR 2019 Oral abstract delivered at UKIO 2019 Publication in Imaging and oncology practice Publication in LGBTQ Health Journal	Completed Completed Completed Completed 12 -18 months	Several outputs have already been produced related to the literature within the field. A final publication will be produced and targeted towards LGBT health peer reviewed journals.
Methodology: Recruiting 'hard to reach' groups	Researchers, patients, health care professionals, academics, policy makers	Key stakeholder event Presentations at SICoP Invited speaker UKIO 2021 Publication in LGBTQ Health Journal Publication in IPDJ	Jan 2021 Ongoing June 2021 12 -18 months 12 -18 months	Key stakeholders links established with international researchers, CoR, third sector cancer support agencies, and wider researcher community through social media and existing professional links to UK cancer services. Several conference presentations have already been done related to research, and a national and international following has been established.
Findings: LGB peoples experiences of care	Researchers, patients, health care professionals, academics, policy makers	Key stakeholder event Publication of national guidance Presentation at SCoR 2022 Invited speaker UKIO 2021 Publication in LGBTQ Health Journal Publication in IPDJ Publication in Radiography Journal Abstract put forward to WCC 2022 Abstract put forward to UKIO 2022	Jan 2021 Feb 2021 Jan 2022 June 2021 12 -18 months 12 -18 months 12 -18 months TBA 2022 TBA 2022	Key stakeholders links established with international researchers, CoR, third sector cancer support agencies, and wider researcher community through social media and existing professional links to UK cancer services. Several conference presentations have already been done related to research, and a national and international following has been established.
Output: Theoretical contribution to personhood literature base	Researchers, patients, health care professionals, academics, policy makers	Key stakeholder event Presentations at SICoP Publication in IPDJ	Jan 2021 Ongoing 12 -18 months	Key journals will be targeted post acceptance of the final thesis and I will continue to engaged with SICoP during my tenure of membership

Table 10.1 plan for dissemination of the research findings.

Future directions of the research

This research has uncovered a variety of issues that LGB people face when treated for cancer. Whilst there has already been some excellent research that has been conducted in this field it has been sparse, and this research helps to build and inform greater understanding of the dilemmas that LGB people face through their cancer journeys. The literature review of this project found that research in the UK focused mainly on care experiences, and in particular gay and bisexual men's experiences of prostate cancer and their associated health needs. Whilst this is very useful for the support of these persons, the research inquiry has shown that lesbian women affected by breast cancer and men affected by anal cancer also have similar issues with relationships and intimacy, and they also value access to tailored LGB specific support and information. Therefore, this finding should be considered an area of potential further research, support and policy development. This will ensure that a broader range of LGB people with differing cancers can access support.

My PhD project has shown that having carer responsibilities and children influences the choices and decision making of LGB people regarding their cancer journeys and has touched on some of the issues this entails. A great deal of my research findings have focused on the participants' relationships with others but due to the breadth of issues this can entail, it would be appropriate to conduct research examining the effects of cancer treatments on family, spousal, and carer relationships specifically. This would assist in further understanding the impacts of cancer on the family, with LGB people being recognised in this group, and assist in developing further support.

In addition, there are other minority groups and community-based populations that may also have additional needs when it comes to cancer. The IPPIF that was developed over the course of this research could be employed with other minority or hard to reach groups to establish their health needs and experiences. The IPPIF could easily be used to support people with other underlying conditions or circumstances such as people with physically disability, who are homelessness, or transgender persons. In addition to exploring health needs the IPPIF would also prove flexible enough to look at the impacts of other disorientating dilemmas such as the impact of AIDS or other life changing illnesses. Further research could also be conducted in this area and represents an area of post-doctoral work that I may be able to investigate further.

Final words

This PhD thesis adds to the body of knowledge concerning the Lesbian, Gay and Bisexual Cancer experience and has achieved its aim by examining the impacts of cancer on personhood. It has found that as for most other persons, LGB people have an array of priorities when it comes to the support they need throughout their cancer journeys. I have contributed theoretically to knowledge of personhood and person-centredness, through the development of the IPPIF. I have worked with participants from varied backgrounds and with different diagnoses to develop the current understanding of LGB persons’ distinct priorities. The participant’s voice in this research is significant, and the people who have participated have been able to provide insight that enabled the development of agreed guidance that is available for practitioners to use.

I have explored with LGB persons with cancer their experiences throughout the cancer care pathway. I have worked with LGB people, their support persons and key stakeholders to develop guidelines for best practice for cancer services and LGB people, which can then influence education of radiography professionals through developing an evidence-base for the curriculum. This has established that LGB persons and their personhood can be impacted upon by the experience of cancer treatment though changing their own perspectives, and ultimately offering a transformational experience that has changed participants’ world views and key relationships.

The ultimate outcome of this research has been to develop understanding and evidence that people are diverse and there is no ‘one size fits all’. The key to working with people in a person-centred fashion is being able to explore the things that matter to the individual in a sympathetic manner, offer enabling healthcare, and thus promote human flourishing. A person’s sexual orientation can impact on their own flourishing, especially when health practitioners are unable to adequately address someone’s needs or practice in a non-discriminatory fashion. The research has uncovered distinctive dilemmas for LGB people when faced with cancer, and the outputs of the research have been formulated to support practitioners to address this.

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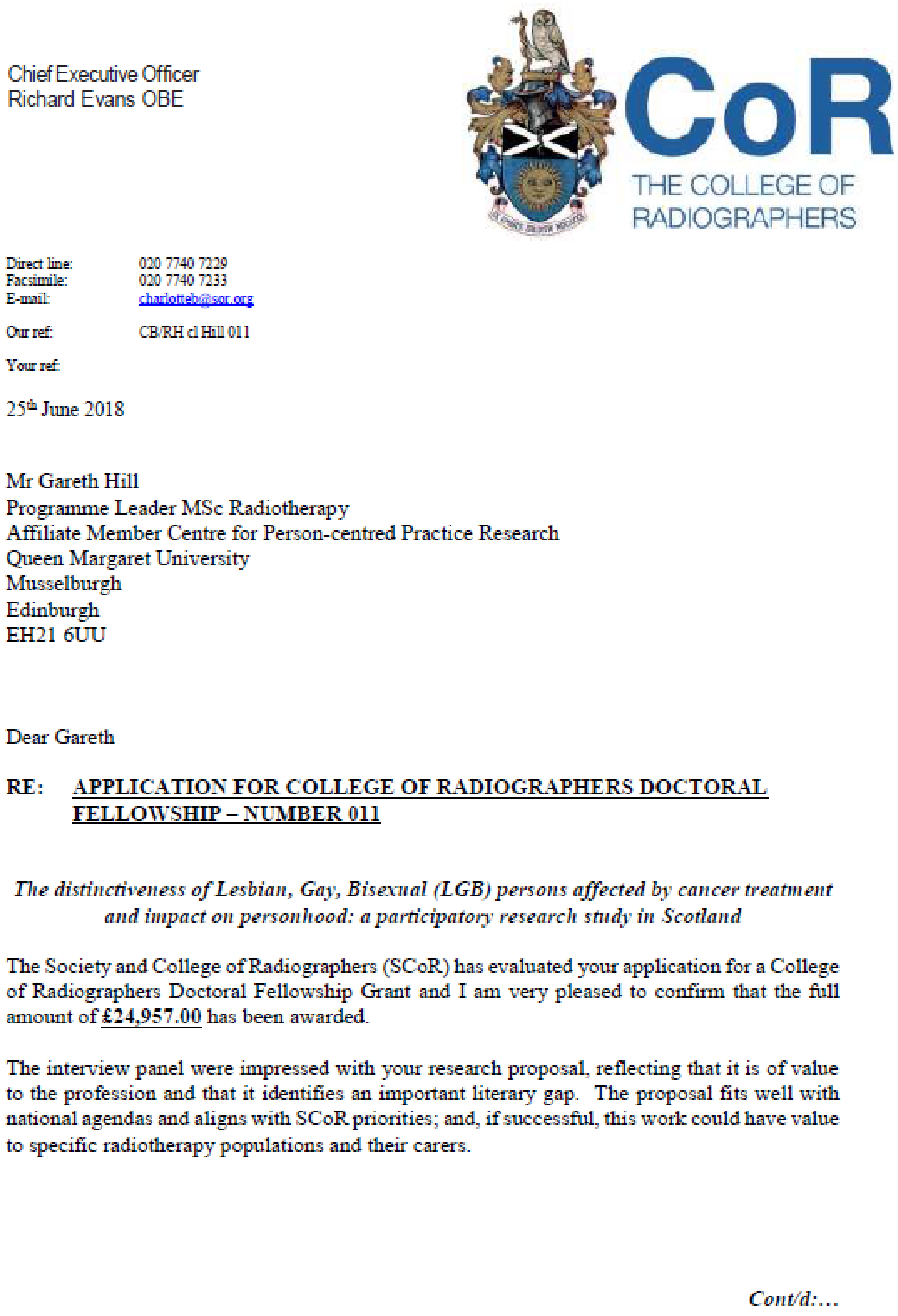
Appendix 1 – College of Radiographers Doctoral Fellowship



Chief Executive Officer
Richard Evans OBE

CoR
THE COLLEGE OF
RADIOGRAPHERS

Direct line: 020 7740 7229
Facsimile: 020 7740 7233
E-mail: charlotteb@sor.org

Our ref: CB/RH cl Hill 011

Your ref:

25th June 2018

Mr Gareth Hill
Programme Leader MSc Radiotherapy
Affiliate Member Centre for Person-centred Practice Research
Queen Margaret University
Musselburgh
Edinburgh
EH21 6UU

Dear Gareth

RE: <u>APPLICATION FOR COLLEGE OF RADIOGRAPHERS DOCTORAL FELLOWSHIP – NUMBER 011</u>

The distinctiveness of Lesbian, Gay, Bisexual (LGB) persons affected by cancer treatment and impact on personhood: a participatory research study in Scotland

The Society and College of Radiographers (SCoR) has evaluated your application for a College of Radiographers Doctoral Fellowship Grant and I am very pleased to confirm that the full amount of **£24,957.00** has been awarded.

The interview panel were impressed with your research proposal, reflecting that it is of value to the profession and that it identifies an important literary gap. The proposal fits well with national agendas and aligns with SCoR priorities; and, if successful, this work could have value to specific radiotherapy populations and their carers.

Cont/d:…

The panel were particularly impressed as:

- The overall design of the study is suitable and the qualitative methodology correct for this type of research; any queries regarding this were sufficiently answered during your interview;
- You clearly answered all queries regarding budget during your interview and satisfied the panel's concerns on this subject;
- Service user involvement appears to be adequate at a research level, however it might be valuable to have service users on some form of management group for the project as a whole;
- Your dissemination strategy is sound, but the panel would encourage you to consider the use of social media for disseminating outcomes once at the end of your research. It is also noted that you have much more dissemination in mind, beyond the scope of this funding application which is admirable;
- There is good evidence that appropriate mechanisms are in place in the host institution to support your research, with suitably experienced, named supervisors appearing on your application form, suggesting these people will have some level of involvement/responsibility for the work. The work also sits within the ambitions of the host institution and the training environment appears to be acceptable.

The expected outcomes of the work were discussed at length and it was agreed that the research will likely inform the development of national guidelines, rather than produce them within the PhD itself. It is felt that this aim may be a little ambitious, and the panel question whether this could be softened, such that 'evidence will be generated to help develop guidelines'?

Under section 8 of your application, further aims are indicated along with the two initial aims set out earlier in the document (section 6). The panel suggest that you take on board comments about the aims and make a further revision of the document deleting the initial two aims from section 6 and simply keeping all aims in section 8, in a modified format.

Additionally, the title of the study appears to be reasonable, however, as the work unfolds it could perhaps be revisited and amended as necessary.

Regarding ethical approval, for which an application has been submitted, the panel pose the following questions for your consideration:

- Have the correct levels of ethical approval been identified for the work proposed?
- Is ethical approval likely to be achieved within the timeframe suggested?
- Are there ethical issues that may stop the project being approved?
- Has the team considered and attended to all the relevant ethical issues including how they intend to approach and recruit participants etc.?

Cont/d:...

Finally, the panel would like to commend you on an absolutely excellent presentation and a particularly brilliant answer to their question "why do a PhD"?

The above recommendations do not affect the funding decision. Prior to the release of the funds we request that you please carefully read and return a signed copy of the Terms and Conditions document.
As you kindly informed us, and as per the details on your original application, funds will be released to The Centre for Person-centred Practice Research (CPcPR).

The College will expect an interim report by the end of November 2019 and a final report when you complete your thesis.

The aim of these grants is to support higher levels of research activity, therefore, your work is important to our organisation and the profession. As such, your final report is for publication on the SCoR research webpages and there is an expectation of final work submission to *Radiography* and presentation at the Annual Radiotherapy Conference or a similar event.

Very well done Gareth. I wish you every success with your Doctoral research and look forward to receiving your outcomes.

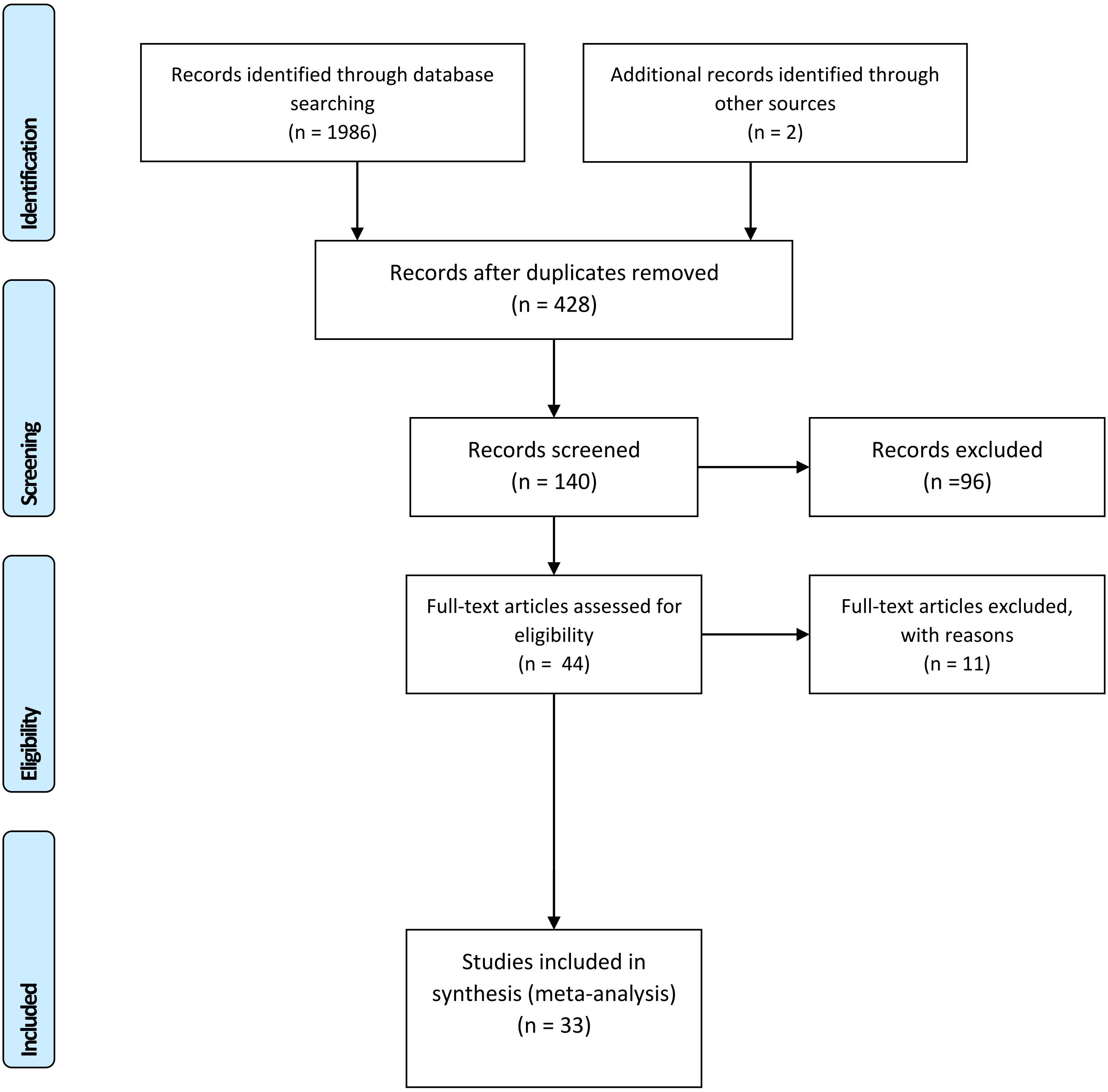
Yours sincerely

Charlotte Beardmore

CHARLOTTE BEARDMORE, FCR, MBA (Open), DCR (R), DCR (T), BSc (Hons) CM, DMS
Director of Professional Policy

Appendix 2 – PRISMA chart of the literature review

PRISMA 2009 Flow Diagram

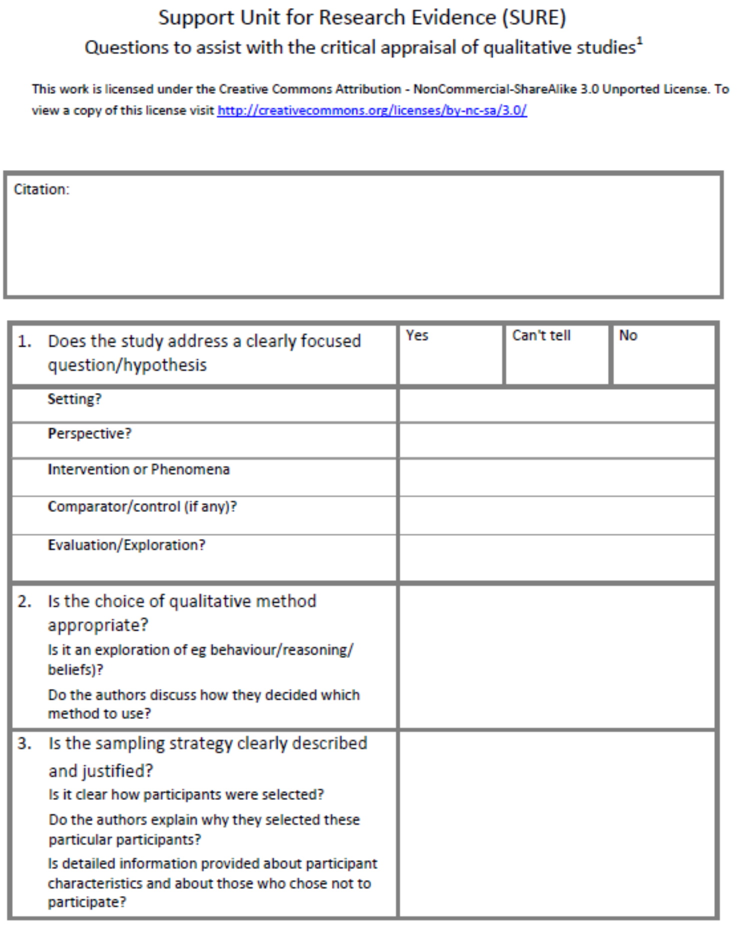


From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *P*referred *R*eporting *I*tems for *S*ystematic Reviews and *M*eta-*A*nalyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit www.prisma-statement.org.

Appendix 3 - The Support Unit for Research Evidence (SURE 2013) critical appraisal tool

Adapted and updated from the former Health Evidence Bulletins Wales (HEBW) checklist with reference to the NICE Public Health Methods Manual (2012) and previous versions of the Critical Appraisal Skills Programme (CASP) checklists, makes the SURE (2013) tool an up-to-date and rigorous method of appraising the eligibility of the studies uncovered in this review. The SURE (2013) tool also has safeguards to screen for bias and this was deemed to be particularly important when reviewing articles for this study as many aspects of current sexual minority research has been undertaken by LGB support organisations rather than independent bodies, as such these may have a political agenda to influence sexual minority provisions within health services and care was taken to ensure that these did not influence the outcome of this review.

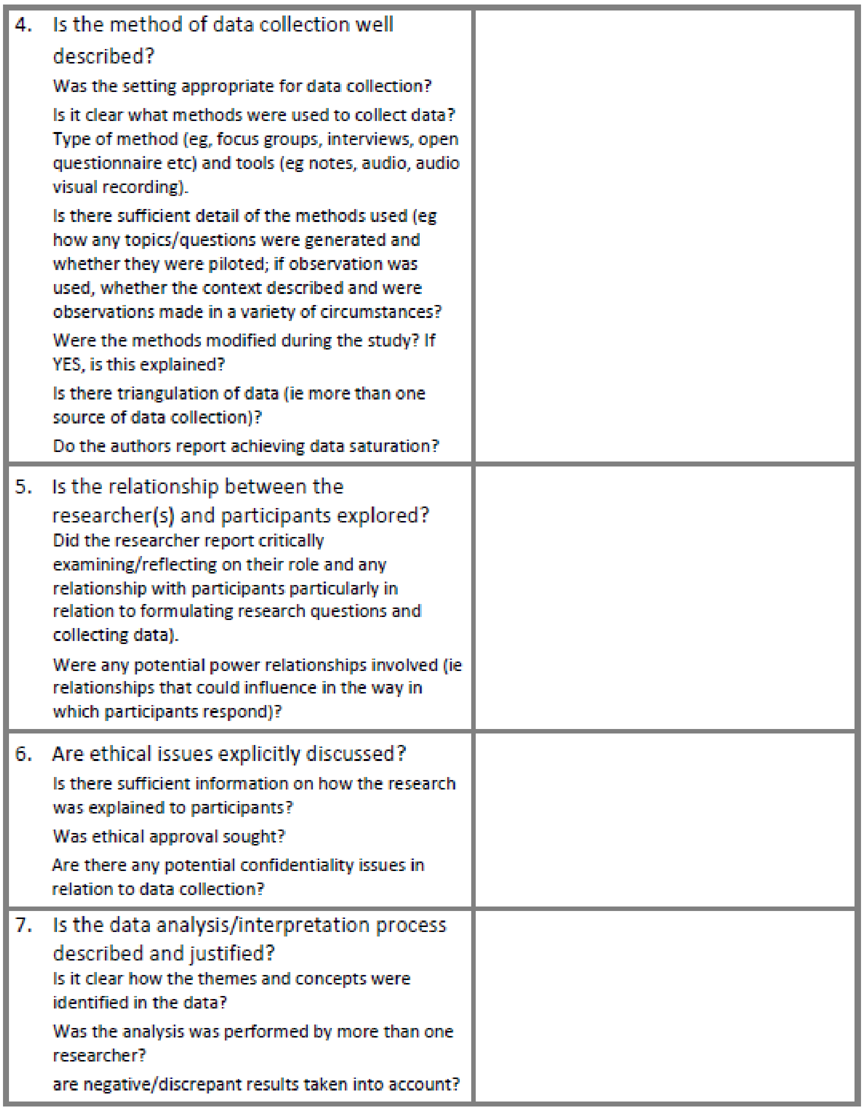


Support Unit for Research Evidence (SURE)
Questions to assist with the critical appraisal of qualitative studies[1]

Citation:

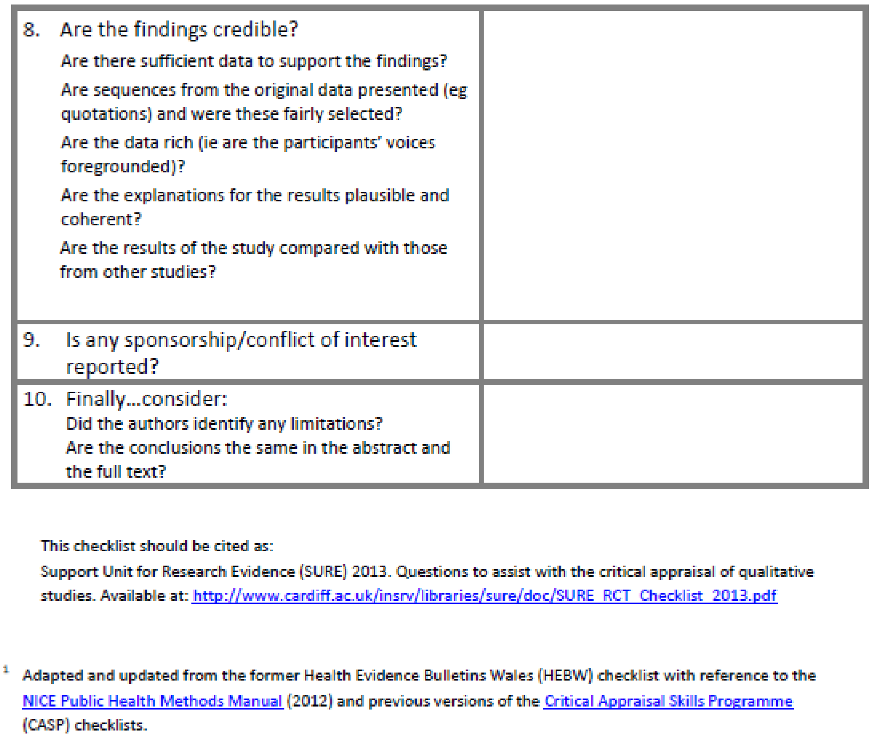
1. Does the study address a clearly focused question/hypothesis	Yes	Can't tell	No
Setting?			
Perspective?			
Intervention or Phenomena			
Comparator/control (if any)?			
Evaluation/Exploration?			
2. Is the choice of qualitative method appropriate? Is it an exploration of eg behaviour/reasoning/ beliefs)? Do the authors discuss how they decided which method to use?			
3. Is the sampling strategy clearly described and justified? Is it clear how participants were selected? Do the authors explain why they selected these particular participants? Is detailed information provided about participant characteristics and about those who chose not to participate?			

Appendix 3 (continued) - The Support Unit for Research Evidence (SURE 2013) critical appraisal tool



4. **Is the method of data collection well described?** Was the setting appropriate for data collection? Is it clear what methods were used to collect data? Type of method (eg, focus groups, interviews, open questionnaire etc) and tools (eg notes, audio, audio visual recording). Is there sufficient detail of the methods used (eg how any topics/questions were generated and whether they were piloted; if observation was used, whether the context described and were observations made in a variety of circumstances? Were the methods modified during the study? If YES, is this explained? Is there triangulation of data (ie more than one source of data collection)? Do the authors report achieving data saturation?	
5. **Is the relationship between the researcher(s) and participants explored?** Did the researcher report critically examining/reflecting on their role and any relationship with participants particularly in relation to formulating research questions and collecting data). Were any potential power relationships involved (ie relationships that could influence in the way in which participants respond)?	
6. **Are ethical issues explicitly discussed?** Is there sufficient information on how the research was explained to participants? Was ethical approval sought? Are there any potential confidentiality issues in relation to data collection?	
7. **Is the data analysis/interpretation process described and justified?** Is it clear how the themes and concepts were identified in the data? Was the analysis was performed by more than one researcher? are negative/discrepant results taken into account?	

Appendix 3 (continued) - The Support Unit for Research Evidence (SURE 2013) critical appraisal tool



8. Are the findings credible? Are there sufficient data to support the findings? Are sequences from the original data presented (eg quotations) and were these fairly selected? Are the data rich (ie are the participants' voices foregrounded)? Are the explanations for the results plausible and coherent? Are the results of the study compared with those from other studies?	
9. Is any sponsorship/conflict of interest reported?	
10. Finally...consider: Did the authors identify any limitations? Are the conclusions the same in the abstract and the full text?	

This checklist should be cited as:
Support Unit for Research Evidence (SURE) 2013. Questions to assist with the critical appraisal of qualitative studies. Available at: http://www.cardiff.ac.uk/insrv/libraries/sure/doc/SURE_RCT_Checklist_2013.pdf

[1] Adapted and updated from the former Health Evidence Bulletins Wales (HEBW) checklist with reference to the NICE Public Health Methods Manual (2012) and previous versions of the Critical Appraisal Skills Programme (CASP) checklists.

Appendix 4 - List of included studies in the literature review

				SURE Question Response															
	n	**Author**	**Type of Research**	**1.**	**2.**	**3.**	**4.**	**5.**	**6.**	**7.**	**8.**	**9.**	**10.**	**Score**	**Country**	**Aims**	**Methodology**	**Cohort**	**Key findings**
Experiences of care	1	Barnoff et al (2005)	Qualitative face-to-face semi-structured interviews/Participatory Action research	1	1	1	1	1	0	1	1	0	0	**7**	Canada	Research focused on "heterosexism" and strategies to counter it in a health care context.	LESBIAN WOMEN were interviewed face-to-face about their experiences of cancer diagnosis, treatment, health care and social support, and their feelings and perceptions about shifts in identity, body, sexuality and relationships	26 LESBIAN WOMEN with Breast or gynaecological cancer	Findings revealed a need to transform the ways in which cancer support services are currently provided in order to make them welcoming to LESBIAN WOMEN. Respondents to the interviews had poor experiences of health care, suffered discrimination and found a heterosexist approach to care
	2	Sinding et al (2004)	Qualitative face-to-face semi-structured interviews/Participatory Action research	1	1	1	1	1	1	1	1	0	0	**8**	Canada	This qualitative study examines "what is lesbian" about lesbians' experiences of cancer and cancer care.	26 LESBIAN WOMEN interviewed about their experiences of cancer diagnosis, treatment, and support, and their feelings and perceptions about shifts in identity, body, sexuality, and relationships.	26 LESBIAN WOMEN with various cancer	A minority of participants were targeted, denied standard care, or had aspects of their identity and social context relevant to cancer care dismissed. The majority commented on the lack of attention to lesbian realities in psychosocial support. Heterosexism appears to prompt strategic efforts to avoid homophobia and also appears to foster gratitude for equitable care.

	3	Sinding et al (2007)	Qualitative face-to-face semi-structured interviews/Participatory Action research	1	1	1	1	1	1	1	1	0	0	**8**	Canada	A study examining the Canadian lesbians' experiences with breast or gynaecological cancer and their care.	Semi-structured face-to-face and telephone interview of themes related to participants' experiences of treatment, cancer care, and support.	26 LESBIAN WOMEN with either breast or gynaecological cancer	Findings reveal the complex and contradictory ways that the lesbian community unfolds in the lives of LESBIAN WOMEN with cancer. Most participants experienced robust and competent community support; participants also reported instances of isolation and 4disconnection linked to fear of cancer, homophobia in the broader community, and patterns of exclusion within lesbian communities.
	4	Boehmer and Case (2004)	Qualitative face-to-face or telephone semi-structured interviews	1	1	1	1	0	1	1	1	0	1	**8**	USA	The study was undertaken to describe the disclosure of sexual orientation among LESBIAN WOMEN with breast carcinoma.	Individual semi-structured interviews were conducted with a sample of LESBIAN WOMEN with a diagnosis of breast carcinoma.	39 LESBIAN WOMEN with breast carcinoma	Sexual minority patient-provider relationships were marked by apprehension, and providers did not inquire about sexual orientation. The majority of women actively disclosed their sexual orientation, whereas 11 women passively refused disclosure.

	5	Jabson et al (2014)	Quantitative cross sectional online survey	1	1	1	1	0	1	1	1	0	1	**8**	USA	Cross sectional study examining LESBIAN WOMEN perceptions of discrimination as one of the multiple facets of the breast cancer survivorship process.	Sixty-eight purposefully sampled sexual minority breast cancer survivors completed assessments of quality of life, perceived discrimination, social support and stress via an online survey	68 LESBIAN WOMEN breast cancer survivors	Statistical analyses pointed towards perceived discrimination and social support as important indicators for predicting LESBIAN WOMEN's quality of life.

	6	Kamen et al (2015)	Quantitative cross sectional online survey	1	1	1	1	0	1	1	1	0	1	**8**	USA	Investigating the factors related to diagnosis, identity disclosure, and social support among lesbian, gay, bisexual, and transgender (LGBT) patients with cancer, and to explore associations between these factors and self-rated health.	Participants completed a researcher-designed online survey assessing experiences of cancer diagnosis among LGBT patients at a single time point.	291 LGBT patients (89% Caucasian; 50% gay, 36% lesbian, 7% bisexual, 3% transgender) with mixed cancers	9% of participants reported disclosing their identities to more than one cancer care provider. Participants most commonly introduced the topic of LGBT identity themselves, sometimes as a way to correct heterosexual assumptions (34%). Friends were the most common members of LGBT patients' support teams (79%). Disclosure and support factors were consistently associated with better self-rated health.

	7	Hulbert-Williams et al (2017)	Quantitative secondary analysis of online survey	1	1	1	1	0	1	1	1	1	1	**9**	UK	The cancer care experiences of gay, lesbian and bisexual patients: A secondary analysis of data from the UK Cancer Patient Experience Survey	a quantitative secondary analysis of the 2013 UK National Cancer Patient Experience Survey which contains 70 questions on specific aspects of care, and six on overall care experiences.	68,737 individuals responded, of whom 0.8% identified as lesbian, gay or bisexual	Significant differences were found for 16 questions relating to: (1) a lack of patient-centred care and involvement in decision-making, (2) a need for health professional training and revision of information resources to negate the effects of heteronormativity and (3) evidence of substantial social isolation through cancer. These findings suggest a pattern of inequality, with less positive cancer experiences reported by lesbian, gay and (especially) bisexual respondents. Poor patient–professional communication and heteronormativity in the healthcare setting potentially explain many of the differences found. Social isolation is problematic for this group and warrants further exploration.
	8	Katz (2009)	Qualitative face-to-face semi-structured interviews	1	1	1	1	0	0	1	1	0	0	**6**	Canada	A study to investigate the cancer experience of GAY MEN and LESBIAN WOMEN.	In-depth, face-to-face interviews were conducted with a semi-structured interview guide.	3 GAY MEN and 4 LESBIAN WOMEN with various cancer.	Overt homophobia or discrimination within the cancer care system was not experienced by this study's participants. Participants valued the central role of their partners in coping with cancer. Some gaps in the cancer care system relating to support groups were identified.
	9	Fish (2010)	Qualitative face-to-face semi-structured interviews included in project report	1	1	1	1	0	0	1	1	0	0	**6**	UK (Eng)	Explore the needs of lesbian and bisexual women affected by breast cancer within the UK.	Semi-structured interviews lasting between one and 1.5 hours. Interviews were conducted Face-to-face in the participant's homes and audio recorded	13 breast cancer survivors and 4 partners of women who died of breast cancer	The findings of the research indicate negative experiences by the participants when engaging with Cancer services, particularly when interacting with doctors and nurses. Issues were also experienced by participants around the disclosure of their sexual orientation to healthcare staff.

	10	Fish and Williamson (2018)	Qualitative face-to-face semi-structured interviews	1	1	1	1	1	1	1	1	1	1	**10**	UK (Eng)	Exploring lesbian, gay and bisexual patients' accounts of their experiences of cancer care.	Semi-structured interviews lasting between 1 and 2 h took place in a location of participants' choice, between July and December 2014. The interviews were digitally recorded and tran- scribed verbatim.	Fifteen LGB people	Themes relating to dilemmas and difficulties experienced by participants around disclosing their sexuality, negative experiences of care from some healthcare professionals with a focus on heteronormativity, institutional heterosexism and micro-aggressions and accounts of post-treatment support in both clinical and community contexts and how well these resources met the psychosocial needs of the participants.
	11	Fish et al (2019)	Qualitative face-to-face semi-structured interviews	1	1	1	1	1	1	1	1	1	1	**10**	UK (Eng)	investigating the nuanced understanding of disclosure of sexual orientation within oncology clinics	In-depth qualitative interviews were undertaken. Interviews lasted between one and two hours in a location of the participant's choice	30 lesbian gay and bisexual people affected by various different types of cancer	The participants discussed their experiences around the disclosure of their sexual orientation to the care providers. Findings revealed that authenticity of participants is a key driver for their needs and wants to disclose their sexual orientation, the use of partners as a resource and creating a safe-space to help facilitate disclosure, and that healing environments need to be developed and conducive to facilitating disclosure of sexual minority individuals.
Coping and wellbeing	12	Thomas et al (2013)	Qualitative online focus group	1	1	1	1	0	1	1	1	0	1	**8**	Australia	A study examining the experiences of GAY MEN diagnosed with prostate cancer	An online focus group was conducted over a 4-week period with participants responding to a range of discussion questions concerning their experiences following a prostate cancer diagnosis.	10 GAY MEN prostate cancer survivors.	Some participants gained a positive perspective and adopted a sense of empowerment, some spoke about emotional responses to a diagnosis of prostate cancer, accessing help and support, the impact of incontinence, the impact of sexual changes on identity, a re-evaluation of life, changed sexual relationships, the need to find the most suitable healthcare professionals and identification of current needs to improve quality of care.

	13	Torbit et al (2015)	Quantitative cross-sectional email survey	1	1	1	0	0	1	1	1	0	1	**7**	Canada	A study to determine the relationship between greater physical symptoms and worse fear of recurrence (FOR) among GAY MEN prostate cancer survivors.	Self-report questionnaires that assessed symptom function, self-efficacy for prostate cancer symptoms, satisfaction with healthcare, and fear of recurrence	92 GAY MEN with prostate cancers	The study found that worse bowel function, hormone function, and sexual function were significantly associated with greater FOR.
	14	Boehmer et al (2013)	Quantitative cross-sectional telephone survey	1	1	1	1	0	1	1	1	0	1	8	USA	A study to determine differences between LESBIAN WOMEN breast cancer survivors to examine whether sexual minority–specific issues contribute to survivors' adjustment.	A 35-minute telephone interview using the breast cancer module of the EORTC Quality of Life Questionnaire.	180 LESBIAN WOMEN breast cancer survivor	Sexual minority–specific factors contributed toward explaining lesbian and bisexual survivors' anxiety and depression but did not contribute toward explaining survivors' physical and mental health.

	15	Boehmer et al (2011)	Quantitative secondary analysis of online or telephone based survey	1	1	1	0	0	1	1	1	0	1	**7**	USA	Study explores prevalence of cancer survivorship by sexual orientation and cancer survivors' self-reported health.	Analysis of pooled data from California Health Interview survey from 2001, 2003, and 2005. Examining the cancer Prevalence and self reported health of LESBIAN WOMEN and GAY MEN	Sample size of 122,394 individuals Consisting of 51,259 men and 71,135 women.	No significant differences in cancer prevalence by sexual orientation, but lesbian and bisexual female cancer survivors had 2.0 and 2.3 the odds of reporting fair or poor health compared with heterosexual female cancer survivors. Among men, significant differences in cancer prevalence, with gay men having 1.9 the odds of reporting a cancer diagnosis compared with heterosexual men.
	16	Boehmer et al (2014)	Quantitative cross-sectional telephone survey	1	1	1	1	0	1	1	1	0	1	**8**	USA	Study comparing coping strategies of heterosexual and LESBIAN WOMEN with breast cancer.	Heterosexual and LESBIAN WOMEN with breast cancer recruited from a cancer registry had telephone based questionnaires to assess coping.	257 heterosexual and 69 LESBIAN WOMEN with breast cancer	While survivors with a sexual minority orientation had more adaptive coping than heterosexual survivors, these differences in coping did not relate to benefit Finding.
	17	Allensworth-Davies et al (2016)	Quantitative cross-sectional postal survey	1	1	1	1	1	1	1	1	0	1	**9**	USA	The health effects of masculine self-esteem following treatment for localized prostate cancer among gay men.	A national cross-sectional survey of gay prostate cancer survivors was conducted in 2010–2011.	111 GAY MEN with prostate cancer	Men aged 50–64 years and men aged 65–74 years reported lower masculine self-esteem scores than men aged 75 years or older. Lower scores were also reported by men who reported recent severe stigma. Men who reported feeling comfortable revealing their sexual orientation to their doctor reported higher masculine self-esteem scores than men who were not

	18	Crangle et al (2017)	Quantitative cross-sectional postal survey	1	1	1	1	1	1	1	1	0	1	**9**	USA and Canada	The effects of attachment and outness on illness adjustment among gay men with prostate cancer.	Self-report questionnaires assessed demographic and medical variables, attachment, outness level and comfort, and illness intrusiveness.	92 GAY MEN with prostate cancer	Results suggested significant associations between anxious attachment, outness comfort, and illness intrusiveness. Less comfort with outness significantly mediated the association between greater anxious attachment and more illness intrusiveness. Avoidant attachment was not significantly associated with illness intrusiveness.
	19	McConkey and Holborn (2018)	Qualitative face-to-face semi-structured interviews	1	1	1	1	1	1	1	1	0	1	**9**	Ireland	Exploring the lived experience of gay men with prostate cancer: A phenomenological study.	In-depth interviews were recorded and transcribed verbatim from a purposive sample of eight gay men treated for prostate cancer in Ireland. A qualitative methodological approach employing Giorgi's descriptive phenomenological method was used to collect and analyse data.	8 GAY MEN	While the sample was geographically diverse with men representing the four provinces of Ireland, a recent survey indicated that between 14% and 23% of the gay population in Ireland are foreign born (O'Donnell et al., 2016), yet all of the men recruited into this study were Irish, Caucasian, predominantly well-educated, most were partnered, and their HIV status was not disclosed, and therefore may be unrepresentative of the wider gay community.

Emotional support	20	White and Boehmer (2012)	Qualitative telephone semi-structured interviews	1	1	1	1	1	0	1	1	0	0	**7**	USA	The aim of this study was to investigate the social support experiences of long-term breast cancer survivors who have female partners.	One-on-one interviews were conducted by telephone. Interviews were semi-structured through the use of an interview guide. A purposive convenience sample of partnered LESBIAN WOMEN (LESBIAN WOMEN) (e.g., women with female partners) diagnosed with nonmetastatic breast cancer from 2000–2005.	15 partnered LESBIAN WOMEN (LESBIAN WOMEN) with Breast cancer	Six salient themes describe LESBIAN WOMEN survivors' perceptions of support: (a) female partners are the singular source of survivors' most valuable support; partners support survivors by (b) discussing survivors' health and distress, which survivors associate with (c) perceived partner distress, and (d) managing the home and caretaking, which survivors associate with (e) perceived partner burden; and partners support survivors by (f) sharing in a life beyond cancer
	21	Capistrant et al (2016)	Qualitative telephone semi-structured interviews	1	1	1	1	1	1	1	1	0	0	**8**	USA	Study examining the caregiving and social support for gay and bisexual men with prostate cancer.	This study used qualitative data from in-depth, semi-structured, one-on-one telephone interviews recruited from a national support group	30 GAY MEN with prostate cancer	Participants reported help from friends, family (parents, siblings), ex-partners, and paid caregivers. Men in relationships reported varying levels of reliance on their partners for support, in part due to relationship dynamics and living arrangements. Single men showed a theme of independence. After diagnosis, many men reported seeking informational and emotional support from prostate cancer support groups; most expressed wanting more support groups specifically for GAY MEN.

	22	Varner (2004)	Qualitative face-to-face semi-structured interviews	1	1	1	1	1	1	1	1	0	0	**8**	USA	Experiences and effects of spirituality and religion among lesbians diagnosed with cancer	A convenience sample of LESBIAN WOMEN diagnosed with cancer responded to advertisements for the study. Each woman was interviewed, and interview transcripts were analysed thematically.	8 self-identified LESBIAN WOMEN	Results indicated that all participants found support in spirituality, though definitions of this term varied. Five women found religion supportive, but not one participant still worshipped in the tradition in which she was raised. The participants' identification as lesbian affected their relationships with all sources of support, including spirituality and religion.
	23	Paul et al (2013)	Qualitative face-to-face semi-structured interviews	1	1	1	1	1	1	1	1	0	0	**8**	USA	A study examining support needs and resources of LESBIAN WOMEN (LESBIAN WOMEN) breast cancer patients.	Semi-structured interviews were conducted with LESBIAN WOMEN, who were recruited from community-based organisations and had undergone mastectomy for treatment of breast cancer. Interviews explored support needs and resources.	13 LESBIAN WOMEN breast cancer survivors.	Participants emphasised the value of cancer support groups and resources tailored to LESBIAN WOMEN while stating that other dimensions of identity or experience, particularly age and cancer stage, were also important. Participants noted the dearth of social support resources for same-sex partners. Family of origin and partners were typically participants' primary sources of tangible and emotional support. Single women faced the greatest challenges in terms of support needs and resources. Former partners were often key sources of support.

Body image	24	Boehmer et al (2007)	Qualitative face-to-face semi-structured interviews	1	1	1	1	1	1	1	1	0	1	**9**	USA	Study exploring issues LESBIAN WOMEN considered when making decisions on reconstructive surgery after breast cancer.	Individual semi-structured interviews with LESBIAN WOMEN who had been treated with mastectomy and 12 “support persons”.	15 LESBIAN WOMEN breast cancer survivors and 12 support persons	Women who chose reconstruction experienced difficulties and regrets, whereas women without reconstruction adjusted well after time. Partners of LESBIAN WOMEN matched the level of satisfaction with reconstructive choice achieved by the women themselves.
	25	Rubin and Tenanbaum (2011)	Qualitative face-to-face semi-structured interviews	1	1	1	1	1	0	1	1	0	0	**7**	USA	Research exploring LESBIAN WOMEN’s experience of mastectomy and decision making about reconstruction	Individual In-person qualitative interviews exploring decisions to have, or not have, breast reconstruction.	13 LESBIAN WOMEN with breast cancer, (purposely selected patients who had not taken up reconstruction)	Findings suggest that sexual identity is not the only influence on women’s decisions for or against breast reconstruction. Participants described sexual, gender, and political identities and orientations as influences on their decision making, for most participants, experiences with physicians who encouraged reconstruction and concerns about stigmatisation of illness in romantic, professional, and social contexts were also central to decision making.

	26	Filiault et al (2008)	Qualitative face-to-face focus group	1	1	1	1	1	1	1	1	0	0	**8**	Australia	A study investigating the difficulties encountered by GAY MEN with prostate cancer.	In-depth, face-to-face interviews were conducted with a semi-structured interview guide	2 GAY MEN prostate cancer survivors with one long term romantic partner	Major themes expressed included concerns related to relationship changes and strains, altered sexual function and associated implications for a gay identity, and the perception of heteronormative attitudes in the health care system.
Sexual function	27	Levy and Taylor (2013)	Qualitative statements from workshop included in project report	1	1	1	0	0	0	1	1	0	0	**5**	UK	Workshop in which key stakeholders including men affected by prostate cancer, researchers, and healthcare professionals exploring the various issues in pathway	Report contains extracts from participants including those affected by prostate cancer	report does not contain information on exactly how many participants attended the workshop	Specific needs around the masculinity and sexuality of men affected by prostate cancer, information and support needs, and the need to have inclusive images and language within information that is created. The project includes a commitment to develop training materials for staff, and information targeted specifically towards bisexual men affected by prostate cancer.

	28	Asencio et al (2009)	Qualitative face-to-face focus group	1	1	1	1	1	0	1	1	0	0	**7**	USA	A study examining the knowledge and experiment of GAY MEN diagnosed with prostate cancer	five focus groups with a total of 36 participant	36 GAY MEN prostate cancer survivors	The data suggest that gay men have little to no understanding of their prostate and the range of sexual challenges associated with prostate cancer and its treatment. In addition, gay men's reactions to potential sexual problems arising from treatment are shaped by their sexual practices, sexual roles, and beliefs about gay relationships and the gay community
	29	Lee et al (2013)	Quantitative cross-sectional online survey	1	1	1	1	0	1	1	1	0	1	**8**	Canada	Research to post-treatment QoL in PCa patients who are GAY MEN, and to investigate the utility of current QoL assessment tool	Each participant completed a Male Sexual Health Questionnaire (MSHQ), and a questionnaire focused on insertive and receptive roles of anal intercourse.	7 GAY MEN treated with surgery and 8 treated with radiation	While the two validated assessment tools suggested similar QoL scores including sexual function for both surgical and radiation groups, post-treatment sexual function related to anal intercourse may be better in the radiation group, as compared to the surgical group. Larger studies in PCa patients from MSM community are warranted to verify these data
	30	Wassursug et al (2013)	Quantitative cross-sectional online survey	1	1	1	1	0	1	1	1	0	1	**8**	International	A study comparing diagnostic and treatment outcomes of heterosexual and GAY MEN.	An anonymous online survey assessing how "bothered" patients were about certain treatment related side effects after prostatectomy	466 heterosexual and 96 GAY MEN	Finding indicated that both groups of men were generally similar, GAY MEN might experience more intensive screening for disease, as indicated by lower Gleason scores at diagnosis. GAY MEN appear more distressed by loss of ejaculation after prostatectomy.

	31	Hartman et al (2014)	Qualitative face-to-face semi-structured interviews	1	1	1	1	1	0	1	1	0	0	**7**	Canada	Study examining the experience of three gay couples managing sexual dysfunction as a result of radical prostatectomy	Patient, partner, and couple face-to-face semi-structured interviews were conducted to explore the effect of sexual dysfunction at three stages: 3–6 months, 12–15 months, and 21–24 months after radical prostatectomy	3 GAY MEN couples with a history of prostatectomy	This study revealed that GAY MEN can engage in novel accommodation practices, such as opening their relationship to alternate sexual partners, and that GAY MEN have specific roles in their sexual relationships which uniquely compromised their sexual functioning and satisfaction.
	32	Arena et al (2007)	Quantitative cross-sectional postal survey	1	1	1	1	1	1	1	1	0	1	**9**	USA	To ascertain any differences between heterosexual and LESBIAN WOMEN with breast cancer	This study compared the experiences of though a questionnaire completed at home and returned by post.	78 women 50:50 heterosexual and lesbian. All with breast cancer.	Compared to the heterosexual women, lesbians reported less thought avoidance, lower levels of sexual concern, less concern about their appearance, and less disruption in sexual activity, but also substantially lower perceptions of benefit from having had cancer.
	33	Doran et al (2018)	Qualitative face-to-face semi-structured interviews	1	1	1	1	1	1	1	1	1	1	**10**	UK	A qualitative study of gay men's experiences of healthcare provision in the UK.	In-depth interviews were conducted with gay men who had been diagnosed with prostate cancer. A phenomenological approach was used to collect and analyse data.	12 GAY MEN men	Participants wanted, and expected, candid discussions with healthcare professionals, about how prostate cancer could affect their lives, sexual function, and how to access culturally relevant support before and after treatment. Participants perceived that their healthcare team had little knowledge about their needs, and if, or how, their experience differed due to their sexual orientation. Information provided was perceived as being misplaced or informed by heteronormative assumptions.

Appendix 5 - QMU Ethics application form

Queen Margaret University
EDINBURGH

For Office Use Only

Ref. Number	
Assigned Reviewers	
Outcome	☑ Granted ☐ Amendments ☐ Rejected

APPLICATION FOR ETHICAL APPROVAL FOR A RESEARCH PROJECT

This is an application form for ethical approval to undertake a piece of research. Ethical approval must be gained for any piece of research to be undertaken by any student or member of staff of QMU. Approval must also be gained by any external researcher who wishes to use Queen Margaret students or staff as participants in their research.

Please note, before any requests for volunteers can be distributed, through the moderator service, or externally, this form MUST be submitted (completed, with signatures) to the Secretary to the Research Ethics Panel (ResearchEthics@qmu.ac.uk).

You should read QMU's chapter on "Research Ethics: Regulations, Procedures, and Guidelines" before completing the form. This is available at: http://www.qmu.ac.uk/quality/rs/default.htm

The person who completes this form (the applicant) will normally be the Principal Investigator (in the case of staff research) or the student (in the case of student research). In other cases of collaborative research, e.g. an undergraduate group project, one member should be given responsibility for applying for ethical approval. For class exercises involving research, the module coordinator should complete the application and secure approval.

The completed form **should be typed** rather than handwritten. **Electronic signatures** should be used and the form should be **submitted electronically**.

Checklist: Documents enclosed with application:
Please note that any application with missing relevant documentation will be returned to the applicant.

Enclosed (please tick)	Not applicable (please tick)	Document name
☑	☐	**Research protocol or proposal**
☑	☐	**Participant Information Sheet(s) (PIS)**
☑	☐	**Participant consent form(s)**
☑	☐	**Copies of recruitment advertisement material**
☐	☑	**Sample questionnaires (please detail below)**
☐	☑	**Interview schedules or topic guides**
☐	☑	**Letter(s) of support from any external organisations involved in the research**
☐	☑	**If interacting with potentially vulnerable groups, please provide the following information for checks by authorised personnel:** **PVG[1] Membership No:** **Disclosure Number (unique to each certificate):** **Date of issue:**
☑	☐	**Risk assessment documentation**
☐	☐	**Any other documentation (please detail below)**

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[1] Protecting Vulnerable Groups – This membership scheme was introduced by the Scottish Government to improve disclosure arrangements for people who work with vulnerable groups. When you provide us with the certificate identification number for your PVG status, only authorised countersignatories for this scheme within the university will have access to your PVG records. The Research Ethics Panel and assigned reviewers will not have access or knowledge of your PVG records. Please be aware that if you are barred from working with the research population in your research application, and the PVG countersignatories have been made aware of your application, processes for Fitness to Practice will be triggered within the university.

Section A: Applicant details

A1. Researcher's name:

Gareth Robert Hill

a. Post:

PhD Candidate, Centre for Person-centred Research Practice

b. Qualifications:

BSc (Hons) Radiotherapy and Oncology
MSc Radiotherapy and Oncology
Fellow Higher Education Academy

c. Contact email: GHill1@qmu.ac.uk

A2. Category of researcher (please tick and enter title of programme of study as appropriate):

☐	QMU undergraduate student Title of programme:
☐	QMU postgraduate student – taught degree Title of programme:
☑	QMU postgraduate student – research degree
☑	QMU staff member – research degree
☐	QMU staff member – other research
☐	Other (please specify) Details:

A3. School:

Health Sciences

A4. Division:

Nursing

A5. Subject area:

Centre for Person-centred Research Practice

A6. Name of Supervisor or Director of Studies (if applicable):

Professor Jan Dewing

A7. Names and affiliations of all other researchers who will be working on the project:

First name	*Last name*	*Position*	*Affiliation*	*Role on project*
Cathy	Bulley	Associate member centre for person-centred research practice	Supervisor	Supervisor

Section B: Research details

B1. Title of study: The distinctiveness of Lesbian, Gay, Bisexual (LGB) persons affected by cancer treatment and impact on personhood: a participatory research study in Scotland

B2. Expected start date:

September 2018

B3. Expected end date:

May 2020

B4. Protocol or proposal version:

LGBPH_20182505_VERSION_1.0

B5. Protocol date:

25TH May 2018

B6. Details of any grants/funding/financial support for the project from within/outside QMU:

This project has been fully economically costed in accordance with QMU procedure with the view of releasing myself from full-time employment to carry out the research. A grant bid has been submitted to the College of Radiographers to award funding for this project. The outcome of this funding application is expected at the end of June 2018.

B7. Do you plan at any stage of the project to undertake research involving adults lacking capacity to consent for themselves?
☐ Yes ☑ No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. If you answered yes, please refer to the online training module by University of Leicester and University of Bristol on 'Adults lacking capacity to consent for research' for further information:
https://connect.le.ac.uk/alctoolkit/
Your research may require approval by an authorised Research Ethics Committee (e.g. NHS Research Ethics Committee).If in doubt, please contact QMU Research Ethics Panel for further advice (ResearchEthics@qmu.ac.uk).

B8. Do you plan to include any participants who are children?
☐ Yes ☑ No

Answer Yes if you plan to recruit participants aged under 16. Please also ensure that question F6 is answered.

B9. Do you plan at any stage of the project to work with human tissue samples (or other human biological samples) and data?
☐ Yes ☑ No

If you answered Yes to question B9, please also ensure that Section G is completed. To obtain a copy of Section G, please email ResearchEthics@qmu.ac.uk.

Section C: Overview of the research

C1. Summary of the study.
Please provide a brief summary of the research (maximum 300 words) ***using language easily understood by lay reviewers and members of the public.*** *Please note that this summary may be published in the public domain.*

Drawing on critical, person-centred theories, I will use participatory inquiry (Heron and Reason 1997) to explore in-depth, with up to twelve participants, their experiences of cancer treatment in Scotland. I particularly want to establish how cancer treatment in health care services, especially radiotherapy, impacts on personhood for LGB persons. Participants will be asked to share insights into who they are and what matters to them, as these notions are core to personhood (McCormack et al 2010). Participants will reflect on how their experiences of cancer treatment have affected aspects of their personhood. To facilitate this person-centred exploration, participants will co-create the methods we use to explore their experiences and examine their healthcare. To gain insight into the perceptions, feelings, and life events of participants, we will create identity maps. Methods such as writing exercises, metaphors, sculpting, photography and videography, art and drawing and timelines will be offered (Deacon 2000). The aim of employing these methods is to help focus participants in the exploration of their own narratives and past care experiences, and engage them in a creative, dialogical and possibly therapeutic experience rather than simply interviewing them.

The project will address the following aims and outcomes:

Aims

1. Explore with LGB persons with cancer, their experiences throughout the cancer care pathway.
2. Work with LGB people, their support persons and key stakeholders to develop guidelines for best practice for cancer services and LGB people
3. Influence education of radiography professionals through developing an evidence-based curriculum
4. Contribute theoretically to knowledge of personhood/person-centredness.

Objectives

1. Find out with LGB people, any distinct aspects of their treatment and care.
2. Contribute to the evidence base of cancer treatment and care for persons identifying as LGB.
3. Develop a best practice guideline for hospital-based oncology services and LGB people.
4. Embed the research findings within professional education
5. Make a theoretical contribution to person-centred practice research, specifically personhood in the context of LGB persons

C2. Summary of main issues.

Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them. Not all studies will raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by other review bodies (as appropriate to the issue).Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.

Researchers who explore the experiences of individuals who have experienced cancer often request ethical approval to recruit within the NHS. However, as sexual orientation is not a demographic that is routinely captured and monitored across the NHS at present, and none of the study participants will be in receipt of active treatments, a decision has been made to employ alternative strategies in order to identify and recruit potential participants. As such only QMU ethical approval is to be sought as participants will be recruited outwith the NHS.

I have identified ten ethical and five managerial issues and these are summarised below.

Ethical issues

Mutual respect and trust

Key to this research is developing mutual respect and trust between the participants and the researcher. This will include ensuring that ground rules are established and ways of working are discussed at the start of the participatory sessions. The participants will be encouraged to behave in a responsible manner with a commitment to being open to challenge and honest ways of working with reviewing the analysis and the reporting of the research.

Equality and inclusion

I will make every effort to include representatives from different ethnic backgrounds, race, age, class education and gender within the research. As part of this process I will also seek to ensure that venues and formats of the meetings and sessions are accessible to all that used to participate, in this case the participant can opt to negotiate a venue that is considered to be safe for both them and myself. Strategies to enable wider participation will include the targeting of public organisations that represent minority groups within the LGB community to raise awareness of my study and to enable members of those organisations to participate.

Democratic participation

I will promote democratic participation within the research. I will do this by making sure that all participants can contribute meaningfully to decision-making by discussing ways of working and allowing participant's the opportunities to raise questions and air concerns. I will also to communicate in accessible language that everyone involved in the groups can understand, and focus on developing participants' communication and expressive abilities.

Physical threat or abuse, being in a comprising situation

As it is likely that most of the inquiry sessions will be conducted either at the participant's home or somewhere located near to them for ease of access, a risk assessment will be completed. A ‘buddy’ system will also put in place to ensure that there is regular contact between myself and a member of the supervision team prior to, and following each inquiry session. In addition I will also carry a mobile phone, ensuring my location and activities are known to QMU in advance of the sessions as well as maintaining contact with my supervisory team during the inquiry sessions.

Participant safety

A “distress” protocol will also implemented to the participants so they have the right to pause, reconvene or terminate any of the sessions. In addition, contact details for local cancer support and counselling services will be provided to participants should they have anything that arises in conversations as part of the research process that they would wish to explore in more detail with a qualified counsellor. I am a qualified oncology health care professional who is trained and has experience in talking with people about cancer and how this affects them. At all times I will abide by professional codes of conduct stipulated by the Society and College of Radiographers as well as the Health and Care Professions Council to ensure the safety of the participants.

Psychological harm for participants

To minimise the risk of causing psychological harm I will ensure that contact details of local cancer support and LGBT services are provided to participants in case they wish to discuss any matters that arise as a result of the research. Full contact details of the participants local Maggie’s Centre, Macmillan Support and Information Centre will be provided in addition to the Macmillan Cancer Support Hotline. All of the above services offer free practical, emotional and social support to people with cancer and their families and friends and are offered freely to anyone affected by any type of cancer.

Psychological harm for researcher

To reduce the risk of causing psychological to myself from potentially distressing conversation topics I will ensure that I debrief with the supervisory team, complete a reflective diary, and ensure that if necessary that I use the occupational health and psychological support mechanisms available through QMU.

Participant disclosing a very bad care experience

There is a chance that a participant may disclose a very bad experience where a healthcare professional or organisation may have severely breached codes of conduct. At this stage I will ensure that in addition to the support materials offered to the participant I will make sure they are aware of the local NHS board or Cancer Networks complaints procedures. In addition, details of the HCPC, NMC, or GMC can also be made available to a participant.

Participant not wanting to disclose identity and/or sexual orientation

As a researcher investigating a problem from people who identify by a specific characteristic I am mindful that people may become concerned about their sexual orientation becoming known to others or being disclosed. Compete confidentially for participants is assured and all data will be anonymised and have the use of pseudonyms. In addition, I will ensure that abide by professional codes of conduct stipulated by the Society and College of Radiographers as well as the Health and Care Professions Council in relation to respecting participants’ confidentially during the research and beyond.

Intrusion, inconvenience or changes to lifestyle

Participation in the research is entirely voluntary and should participants wish to withdraw at any time this will be permitted. It is anticipated that a total of two inquiry sessions with participants and support person will be required and information about the timing of these will be provided to all participants and support persons in the information sheet and when consent is taken. In addition verbal consent and establishing ways of working will also be established at the start of each contact session to ensure that all participants are still happy to proceed.

Managerial issues

Research Administrator recruitment may be not be timely.

In the event of successful funding award, finalising the research agreement will be prioritised and administrative processes relating to the approval and advertisement of related research posts will be expedited through the Centre for Person-centred Practice Research at QMU and HR. Advertisements relating to these posts will be disseminated widely through the research team networks.

It is possible that participants may find it difficult to attend face-to-face sessions, particularly those with demanding work or other roles.

In order to optimise face-to-face sessions: we will plan well ahead with administrative support from the research administrator; costs are included in the grant application to reduce the impact, including for the time of support persons. The researcher will be flexible about session times. To mitigate for inability to attend face-to-face: the team will book the video-conferencing suite at QMU and discuss different ways of attending remotely if necessary. Technological support will be available and planned ahead for those at a distance.

Difficulties recruiting participants nationally

The recruitment plan for Edinburgh and Glasgow is well developed and supported through local contacts. The national recruitment plan will be developed in an ongoing way. During the stage of grant development networking has been prioritised, which will continue and be supported through the wider network of the supervisory team. Further networking will take place while searching for grey literature and contacting relevant organisations and services. While this can be seen as a risk as it is iterative, it also enables the ongoing development of the impact strategy and recruitment of people to participate in the Stakeholder Workshop or receive updates afterwards.

Difficulty recruiting people to the Stakeholder Workshop with roles that would facilitate impact of project outcomes

Networking and promotion of the project through different routes including social media will be a specific work stream in the project design and management. This will form an agenda item at a regular meetings with the employed research administrator to ensure that activities are coordinated and strategic. As the project develops, a specific strategic plan will be developed for who to invite to the Stakeholder Workshop, to include people who can impact on policy, practice and research in Scotland and across the UK.

C3. What is the principal research question/objective/aim?
Please put this in language comprehensible to a lay person.

Research Question

How is LGB personhood impacted by the experience of cancer treatment?

Aims

1. Explore with LGB persons with cancer, their experiences throughout the cancer care pathway.
2. Work with LGB people, their support persons and key stakeholders to develop guidelines for best practice for cancer services and LGB people.
3. Influence education of radiography professionals through developing an evidence-based cubiculum.
4. Contribute theoretically to knowledge of personhood/person-centredness.

C4. What are the secondary research questions/objectives/aims if applicable?
Please put this in language comprehensible to a lay person.

Objectives

1. Find out with LGB people, any distinct aspects of their treatment and care.
2. Contribute to the evidence base of cancer treatment and care for persons identifying as LGB.
3. Develop a best practice guideline for hospital based oncology services and LGB people.
4. Embed the research findings within professional education.
5. Make a theoretical contribution to person-centred practice research specifically personhood in the context of LGB persons.

C5. What is the academic/scientific justification for the research?
Please put this in language comprehensible to a lay person.

Despite recent legal reforms and advancements in UK society, the LGB community still cannot be assured of healthcare delivered in non-judgmental ways, nor that it fully addresses their specific health needs (Stonewall 2015). Some research has been undertaken to examine the needs of LGB persons with specific cancers, revealing that LGB persons have distinctive experiences and needs of cancer services (Hill and Holborn 2016; Doran and Beaver 2015; Fish and Williamson 2016). These studies start to portray a picture of discriminatory attitudes within care; however none of the research has focused on a holistic view of a person’s identity. Further, research to date has not specifically reviewed the effects of cancer treatment on personhood. The literature on person-centredness does not address sexual diversities and this needs attention. As there is a general trend towards more person-centred care in cancer, I argue peoples’ sexual orientation should be considered in the context of personhood and be taken into consideration when planning services, treatment and care provision. Ultimately, there is a need to ensure that cancer services are meeting the needs of all users including persons that identify as LGB and Therapeutic Radiographers are well placed, as oncology-specific health professionals, to research this.

Section D: Design and Methodology

D1. Research procedures to be used: *please tick all that apply*.

Tick if applicable	
☐	Questionnaires (*please attach copies of all questionnaires to be used*)
☐	Interviews (*please attach summary of topics or interview schedule to be explored*)
☐	Focus groups (*please attach summary of topics or interview schedule to be explored / copies of materials to be used*)
☐	Experimental / Laboratory techniques (*please include full details under question D2*)
☐	Use of email / internet as a means of data collection (*please include full details under question D2*)
☐	Use of materials that are subject to copyright (*please include full details under question D2 and confirm that the materials have been / will be purchased for your use*)
☐	Use of biomedical procedures to obtain human tissues (or other biological materials) (*please include full details under question D2 and Section G. Also include subject area risk assessment forms, where appropriate)*
☑	Other technique / procedure (*please include full details under question D2*)

D2. Please summarise your design and methodology.
It should be clear exactly what will happen to the research participant for research involving human participants. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol.

Up to twelve participants (with key support persons where appropriate) will be invited to participate on the basis that they have had cancer treatment within the past five years and identify as LGB. Persons will be recruited through purposeful sampling via LGB community organisations and word of mouth. I will meet with participants at a venue that feels comfortable and where we can carry out the method in privacy. This is likely to be in participant's own homes or a known support centre.

On the first occasion we will create personhood identify maps. The creation process and content of the map will enable more in-depth discussion at a second meeting of cancer treatment experiences and the impact on identity and personhood. The discussion around treatment experience will be recorded and then analysed. Following the session, transcripts will be shared with participants to invite further contributions, and responses themed. Participants will be invited to participate in analysis by commenting on themes and any other contribution they wish to make; recognising this might differ from person to person. Drawing on the collated themes and existing empirical evidence, we will outline ideas for best practice guidelines and for policy development. A Scottish stakeholder event with professionals and some participants will consider and contribute to the guidelines. The guidelines will aim to influence practice, policy and education across Scotland.

D3. Does your research include the use of people as participants?
☑ Yes ☐ No

Answer No *if your project involves secondary analysis of collected data.*
If you answered Yes to question D3*, please ensure that Section F is completed.*

D4. Does your research include the experimental use of live animals?
☐ Yes ☑ No

If you answered Yes to question D4*, please note that the university is not insured to experiment on live animals. Please attach the insurance coverage certificate to this application for review. Please check and ensure that appropriate university insurance is in place to cover the work. If in doubt, please contact Karen Sinclair (Head of Finance, ksinclair@qmu.ac.uk) on insurance coverage.*

D5. Does your research involve experimenting on plant or animal matter, or inorganic matter?
☐ Yes ☑ No

If you answered Yes to question D5*, please check and ensure that appropriate university insurance is in place to cover the work. If in doubt, please contact Karen Sinclair (Head of Finance, ksinclair@qmu.ac.uk) on insurance coverage. Please attach the insurance coverage certificate to this application for review.*

D6. Does your research include the analysis of documents, or of material in non-print media, other than those which are freely available for public access?
☐ Yes ☑ No

If you answered 'Yes' to Question D6, give a description of the material you intend to use. *Describe its ownership, your rights of access to it, the permissions required to access it and any ways in which personal identities might be revealed or personal information might be disclosed. Describe any measures you will take to safeguard the anonymity of sources, where this is relevant:*

Not applicable

D7. Will any restriction be placed on the publication of results?
☐ Yes ☑ No

If you answered 'Yes' to question D7, give details and provide a reasoned justification for the restrictions. (See Research Ethics Guidelines Section 2, paragraph 7)

Not applicable

D8. Who will have access to participants' personal data during the study?
Where access is by individuals outside the research team or direct care team (health research), please justify and say whether consent will be sought.

Gareth Hill

Jan Dewing

Cathy Bulley

Research administrator employed by QMU (centre for Person-centred Practice Research)

D9. How long will personal or personally identifiable data be stored or accessed after the study has ended?
Please note this question only relates to retention of personal or personally identifiable data.

☐ Less than 3 months
☐ 3 – 6 months
☑ 6 - 12 months
☐ 12 months – 3 years
☐ Over 3 years

It is recommended that data containing personal details that would lead to the identification of participants should be destroyed ***as soon as possible****. Examples of personally identifiable data include participants' email addresses, NHS/CHI numbers, expressions of interest etc., BUT NOT consent forms. Personally identifiable data should be stored separate from the anonymised data to prevent linkage. If potential participants have provided you with their contact details, this information should only be retained until they have consented or refused to participate in the research. However, if a participant noted that they would like to receive a summary of the research, it would be appropriate to retain their contact details until this summary has been sent out.*
See the following for advice on data handling:
http://www.lancaster.ac.uk/shm/study/doctoral_study/dclinpsy/onlinehandbook/ethics_and_data_storage_advice/

D10. For how long will you store research data generated by the study? *State if the data will be stored for an infinite time period.*

Years:7

Months:0

More information: Anonymised data will only be stored long term, 7 years, after the study has been completed. Any identifiable data and recordings will be deleted 12 months after the study has been completed. Study completion is defined as the submission of the thesis.

D11. Please give details of the *short term (duration of project)* and *long term (after project completion)* arrangements for storage of research data after the study has ended. (See Research Ethics Guidelines has Section 1, paragraph 2.4.1)

Short term storage of research data on any of the following:
☑ Manual files (includes paper or film)
☐ Home or other personal computers
☑ University computers/server
☐ Laptop computers
☐ Hard drive storage
☐ USB storage devices
☐ Other portable storage (e.g. CDs, DVDs etc.)
☐ Cloud/online storage (please provide name and server location of cloud storage below)
☑ Others (please state):

Say where data will be stored, who will have access and the arrangements to ensure security (for example, encryption used). Explain how and when data will be destroyed (if applicable).

Data will be held either in secure lockable storage cabinets on QMU campus or in lockable carry cases when in transit from data gathering during field work. All electronic data such as data recordings and transcripts will be held on QMU IT servers, which are encrypted using QMU login credentials. During the field work an audio dictaphone and digital camera will be used to record conversations and identity maps created by participants. The audio recorded and camera will be stored in in the lockable carry case in transit and uploaded to QMU's IT servers within 24 hrs. No data will be stored on recording devices outwith this period. Hard copy data such as consent forms and eligibility criteria forms will be stored in the same manner.

All indefinable data will be destroyed 12 months after the study has been completed. In addition, all data ownership and storage both during the research process and after the project has reached its conclusion will be discussed and agreed by the participants in a consensual manner in keeping with the methodological principles of my research.

Only the Gareth Hill, Jan Dewing, Cathy Bulley and the research administrator employed by QMU will have access to the data in the short term.

Long term storage of research data on any of the following:
☐ Manual files (includes paper or film)
☐ Home or other personal computers
☑ University computers/server
☐ Laptop computers
☐ Hard drive storage
☐ USB storage devices
☐ Other portable storage (e.g. CDs, DVDs etc.)
☐ Cloud/online storage (please provide name and server location of cloud storage below)
☐ eData – QMU open access data repository
☐ Others (please state):

Say where data will be stored, who will have access and the arrangements to ensure security (for example, encryption used). Explain how and when data will be destroyed (if applicable).

After the project has completed all hard copy and personally indefinable data, such as consent and eligibility forms will be destroyed. All data recordings and images will also be deleted.

In the long term there is a possibility that anonymised data may be examined or analysed and will be kept for a period of seven years on the university computer/server. Anonymised data will be achieved securing within the Centre-for Person-centred Practice Research data archive. Professor Jan Dewing will be the custodian of this data which will only be accessible by her.

Will the data be stored:

☑ In fully anonymised form? (link to participant broken)

☐ In linked anonymised form? *(linked to data but participant not identifiable to researchers)*
If Yes, say who will have access to the code and personal information about the participant:

☐ In a form in which the participant could be identifiable to researchers?
If Yes, please justify.

D12. Who will have control of and act as the custodian for the data generated by the study?

Professor Jan Dewing

D13. Will the research participants receive any payments, reimbursements of expenses or any other benefits or incentives for taking part in this research?
☐ Yes ☑ No

If Yes, please give details.

D14. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?

This question is concerned with "in pocket" financial payments or additional benefits to be provided direct to researchers personally, over and above the costs of conducting the research.

☐ Yes ☑ No

If Yes, please give details.

Section E: Risks and benefits

E1. Give details of all procedure(s) or intervention(s) that will be received by participants as part of the research protocol?
These include seeking consent, interviews, observations and use of questionnaires.

Please complete the columns for each procedure/intervention as follows:

1. Total number of procedures/interventions to be received by each participant as part of protocol.
2. Average time taken per procedure/intervention (minutes, hours or days)
3. Details of who will conduct the procedure/intervention, and where will it take place.

Procedure or intervention	*1*	*2*	*3*
Telephone Call for initial inquiry for the study	1	30 mins	Myself/researcher – QMU/Phone
Telephone Call for confirmation of face-to-face session	1	15 mins	Myself/researcher – QMU/Phone
1st face to face session to include consent	1	1 hrs 30 mins	Myself/researcher -Participants home or other location
2nd face to face session to include consent	1	1 hrs mins	Myself/researcher - Participants home or other location
Participants invited to comment on own transcript and themes (optional)	1	1 hrs	Myself/researcher - Virtually
Participants invited to comment anonymised themes and recommendations (optional)	1	1 hrs	Myself/researcher - Virtually
Participants invited to stakeholder workshop (optional)	1	2hrs	Myself/researcher - QMU or partner organisation
E			

E2. How long do you expect each participant to be in the study in total?
Duration of participation should be calculated from when participants give informed consent until their last contact with the research team.

In keeping with participatory research principles participants can remain in contact with the research team as long as they wish whilst the overall research is being conducted, analysed, written up and disseminated. It is anticipated that for participants who wishing to take part in the stakeholder workshop the maximum time they would be involved in the project would be 12 to 18 months. Although should participants not want to be involved in the research after the point of data gathering their contact with the project would only be for the face-to-face sessions and the option there after to comment on their transcripts.

E3. What are the potential risks and burdens for research participants and how will you minimise them?

For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.

Where the research only involves the use of data, consideration should still be given to the risks for participants associated with any breach of confidence or failure to maintain data security.

Participation in the research is entirely voluntary and should participants wish to withdraw at any time this will be permitted. It is anticipated that a total of two inquiry sessions with participants and support person will be required and information about the timing of these will be provided to all participants and support persons in the information sheet and when consent is taken. In addition verbal consent and establishing ways of working will also be discussed at the start of each contact session to ensure that all participants are still happy to proceed.

A "distress" protocol will also implemented to the participants so that they have the right to pause, reconvene or terminate any of the sessions. In addition contact details for local cancer support and counselling services will be provided to participants should they have anything that arises in conversations as part of the research process that they would wish to explore in more detail with a qualified counsellor. I am a qualified oncology health care professional who is trained and has experience talking with people about cancer and how this affects them. At all times I will abide by professional codes of conduct stipulated by the Society and College of Radiographers as well as the Health and Care Professions Council to ensure the safety of the participants.

To minimise the risk of causing psychological harm I will ensure that contact details of local cancer support and LGBT services are provided to participants in case they wish to discuss any matters that arise as a result of the research. Full contact details of the participants local Maggie's Centre, Macmillan Support and Information Centre will be provided in addition to the Macmillan Cancer Support Hotline. All of the above services are designed to offer free practical, emotional and social support to people with cancer and their families and friends and are offered freely to anyone affected by any type of cancer.

There is a chance that a participant may disclose a very bad experience where a healthcare professional or organisation may have severely breached codes of conduct. At this stage I will ensure that in addition to the support materials offered to the participant I will make sure they are aware of the local NHS board or Cancer Networks complaints procedures. In addition details of the HCPC, NMC, or GMC can also be made available to a participant.

E4. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?

☐ Yes ☑ No ☐ Not applicable

If Yes, please give details of procedures in place to deal with these issues:

Not applicable

E5. What is the potential for benefit to research participants?

You should state here any potential benefits to be gained by the research participant through taking part in the research either now or in future. However, do not over-emphasise the benefits. In some cases there may be no apparent benefit.

There may or may not be a direct benefit to participants talking part in the research study. However it is hoped that taking part in the research, it may serve as a useful learning process to help integrate the effects of cancer treatment into the participants' identity and life. Taking part may result in information that helps others in the future, and therefore participants may wish to join the study for this reason i.e giving something back.

E6. Will the researcher be at risk of sustaining either physical or psychological harm as a result of the research? *Please delete as appropriate.*

☑ Yes ☐ No

If you answered 'Yes' to the question E6, please give details of potential risks and the precautions which will be taken to protect the researcher.

To reduce the risk of causing psychological to myself from potentially distressing conversation topics I will ensure that I debrief with the supervisory team, complete a reflective diary, and ensure that if necessary that I use the occupational health and psychological support mechanisms available through QMU.

Section F: Research Involving Human Participants

You should only complete this section if you have indicated above that your research will involve human participants.

F1. Please indicate the total number of participants you intend to recruit for this study from each participant group:

Participant Group	Please state total number
QMU students	
QMU staff	
Members of the public from outside QMU	Maximum 12
NHS patients	
NHS employees	
Children (under 16 years of age)	
People in custody	
People with communication or learning difficulties	
People with mental health issues	
People engaged in illegal activities (eg. illegal drug use)	
Other (please specify):	

* *Please declare in Question F8 where the participant group may necessitate the need for standard or enhanced disclosure check*

F2. How was this participant number decided upon? *If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation. If another method of determining participant numbers was used, please provide sufficient details for the method and justify the decision.*

A target recruitment sample size of up to 12 participants has been deemed appropriate and feasible for this type of study. Given the nature of in-depth data gathering and analysis 12 was been deemed achievable within the study timeframe. In addition 12 participants are deemed to be a realistic number considering the target population demographics and compares with other comparable studies in the field.

F3. Please state the inclusion and exclusion criteria to be used. (See Research Ethics Guidelines Section 1, paragraph 2.4)

The research participants in this study are LGB persons who have undergone primary treatment for cancer and will need to meet the following criteria. Note: Key support person (if available) are invited to be present although they are not the focus of the research. Support persons are included because they can have a view on the impacts of cancer treatment. However, I am not specifically seeking to explore their personhood.

Inclusion Criteria

- People who self-identify as LGB and are aged 18 or over
- LGB people who live in Scotland and have received treatment for cancer, including radiotherapy, in the past 5 years
- People who are able to sufficiently speak and understand English
- People who can participate in the sessions

Exclusion Criteria

- People under the age of 18
- People that identify as heterosexual
- People who cannot speak and understand English sufficiently
- People who are currently undergoing or about to undergo invasive treatments such as surgery, radiotherapy, brachytherapy and chemotherapy or have undergone treatment during the past three months.

F4. Will you obtain informed consent from or on behalf of research participants?
☑ Yes ☐ No

F5. Please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). *If you plan to include any participants who are children, please describe the arrangements for seeking informed consent from a person with responsibility and/or from children able to give consent for themselves.*

Participants will be provided with full information to enable them to take part; confidentiality, privacy and informed consent will be assured. Potential participants will be provided with an information sheet prior to arranging a face-to-face meeting and given at least 48 hours to decide if they want to participate. They will be given the name and contact details of an independent staff member within QMU to be able to discuss the study. Individual consent forms will be sent to participants for completion at the start of the first face-to-face session. At the start of each face-to-face session verbal consent will also be revisited and taken to ensure that all participants are happy to proceed. Key support persons will also be contacted independently and sent the information sheet and given the opportunity to have an informal discussion, but will not need to consent for the study.

In addition to the formal process outlined a commitment to process consent will also be adopted. Process consent is an approach where the researcher focuses on an ongoing consensual process that involves the participants in mutual decision making and ensures that the participants are kept informed at all stages of the research process and is in keeping with principles of person-centred research (McCormack et al 2017). During each stage of the face-to-face sessions where I provide information to the participants or qualify any instructions I will make sure that I ask if participants are happy to continue. Ways of working will also be established at the start of each face-to-face session emphasising that participants can also withdraw or refuse to answer questions if they feel uncomfortable or unsure of what is being asked of them.

If you are not obtaining consent, please explain why not.

Not applicable

F6. (Children) If you intend to provide children under 16 with information about the research and seek their consent or agreement/assent, please outline how this process will vary according to their age and level of understanding. *Copies of written information sheet(s) for parents and children, consent/assent form(s) and any other explanatory material should be enclosed with the application.*
For further information on providing information and obtaining consent/assent from children, please refer to this online information for best practice: *http://www.hra-decisiontools.org.uk/consent/principles-children.html*

Not applicable

F7. Will the research involve participant deception?
☐ Yes ☑ No

If you answered Yes to Question F7, please justify the use of deception. Also describe what procedures will be implemented to safeguard the dignity, safety and welfare of the participants during the research and after it has ended.

Not applicable

F8. Ethical principles incorporated into the study (*please tick as applicable*):

Ethical principles
Will participants be offered a written explanation of the research? ☑ Yes ☐ No ☐ Not applicable
Will participants be offered an oral explanation of the research? ☑ Yes ☐ No ☐ Not applicable
Will participants sign a consent form? ☑ Yes ☐ No ☐ Not applicable
Will oral consent be obtained from participants? ☑ Yes ☐ No ☐ Not applicable
Will participants be offered the opportunity to decline to take part? ☑ Yes ☐ No ☐ Not applicable
Will participants be informed that participation is voluntary? ☑ Yes ☐ No ☐ Not applicable
Will participants be offered the opportunity to withdraw at any stage without giving a reason? ☑ Yes ☐ No ☐ Not applicable
Will independent expert advice be available if required? ☑ Yes ☐ No ☐ Not applicable
Will participants be informed that there may be no benefit to them in taking part? ☐ Yes ☐ No ☑ Not applicable
Will participants be guaranteed confidentiality? ☑ Yes ☐ No ☐ Not applicable
Will participants be guaranteed anonymity? ☑ Yes ☐ No ☐ Not applicable

Will the participant group necessitate a standard or enhanced disclosure check of the researcher?
☐ Yes ☑ No ☐ Not applicable

Will the provisions of the Data Protection Act be met?
☑ Yes ☐ No ☐ Not applicable

Has safe data storage been secured?
☑ Yes ☐ No ☐ Not applicable

Will the researcher(s) be free to publish the findings of the research?
☑ Yes ☐ No ☐ Not applicable

If the research involves deception, will procedures be in place during and after the research to safeguard the dignity, safety and welfare of the participants?
☐ Yes ☐ No ☑ Not applicable

If the research involves questionnaires, will the participants be informed that they may omit items they do not wish to answer?
☐ Yes ☐ No ☑ Not applicable

If the research involves interviews, will the participants be informed that they do not have to answer questions, and do not have to give an explanation for this?
☑ Yes ☐ No ☐ Not applicable

Will participants be offered any payment or reward, beyond reimbursement of out-of-pocket expenses?
☐ Yes ☑ No ☐ Not applicable

Section G is a reserved section of the form for applications involving Human Tissues. Please email ResearchEthics@qmu.ac.uk if you require a copy of Section G.

Section H: Risk Assessment

Queen Margaret University
EDINBURGH

Reference:	**LGBPH_20180525_VERSION_1.0**

School / Division:	Health Sciences - Nursing	**Location:**	Scotland	**Date**	25/5/18
Assessed by:	Gareth Hill	**Job Title:**	PhD Candidate	**Signature**	
Activity / Task:	Field work	**Total Number exposed to risk**	1	**Review Date**	25/5/19

		People at risk					**Likelihood**				**Severity**						
		Employees and students	**Members of public/visitors**	**Contractors**	**Young people**	**Mothers: new or expectant**	**Improbable**	**Remote**	**Possible**	**Probable**	**No injury**	**Minor**	**Major**	**Fatal**	**Total risk**	**Existing control measures**	**Adequate controls?**
1.	**Researcher being under physical threat or abuse, or being in a compromising situation**	x	x				x						x		3	As it is likely that most of the inquiry sessions will be conducted either at the participant's home or somewhere located near to them for ease of access, a risk assessment will be completed. A 'buddy' system will also put in place to ensure that there is regular contact between myself and a member of the supervision team prior to, and following each inquiry session. In addition I will also carry a mobile phone, ensuring my location and activities are	

																known to QMU in advance of the sessions as well as maintaining contact with my supervisory team during the inquiry sessions.	
2.	**Risk of Participants feeling vulnerable/unsafe**		x						x			x			6	A "distress" protocol will also implemented to the participants so then they have the right to pause, reconvene or terminate any of the sessions. In addition contact details for local cancer support and counselling services will be provided to participants should they have anything that arises in conversations as part of the research process that they would wish to explore in more detail with a qualified counsellor. In addition I am also a qualified oncology health care professional who is trained and has experience talking with people about cancer and how this affects them. At all times I will abide by professional codes of conduct stipulated by the Society and College of Radiographers as well as the Health and Care Professions Council to ensure the safety of the participants.	
3.	**Risk of *Psychological harm for participants***		x					x				x			4	To minimise the risk of causing psychological harm I will ensure that contact details of local cancer support and LGBT services are provided to participants in case they wish to discuss any matters that arise as a result of the research. Full contact details of	

																the participants local Maggie's Centre, Macmillan Support and Information Centre will be provided in addition to the Macmillan Cancer Support hotline. All of the above services offer free practical, emotional and social support to people with cancer and their families and friends and are offered freely to anyone affected by any type of cancer.	
4.	***Risk of Psychological harm for researcher***		x					x				x			4	To reduce the risk of causing psychological to myself from potentially distressing conversation topics I will ensure that I debrief with the supervisory team, complete a reflective diary, and ensure that if necessary that I use the occupational health and psychological support mechanisms available through QMU.	
5.	***Participant disclosing a very bad care experience***		x				x						x		3	There is a chance that a participant may disclose a very bad experience where a healthcare professional or organisation may have severely breached codes of conduct. At this stage I will ensure that in addition to the support materials offered to the participant I will make sure they are aware of the local NHS board or Cancer Networks complaints procedures. In addition details of the HCPC, NMC, or GMC can also be made available to	

															a participant.	
6.	**Risk of Data loss or theft**	x	x				x						x		3	The audio recorded and camera will be stored in in the lockable carry case in transit and uploaded to QMU's IT servers within 24 hrs. it is unlikely that the Dictaphone would be stolen in transit, but will not be left out of sight of the researcher when out of the locked carry case. No data will be stored on recording devices outwith this period. All identifiable data will be destroyed 12 months after the study has been completed (completion of thesis). All anonymised data will be stored for seven years.	
						Risk value (RV)	**1**	**2**	**3**	**4**	**1**	**2**	**3**	**4**		

Total risk = Likelihood (RV) x Severity (RV) *Total risk of 1 – 4 = 'L', low risk* *Total risk of 6 – 9 = 'M', medium risk* *Total risk of 12 – 16 = 'H', high risk*

Queen Margaret University
EDINBURGH

Reference:	

Remedial action required

Ref no.	**Action required**	**Target date**	**Action by:**	**Date completed**
1.				

2.				
3.				
4.				
5.				

Section I: Declarations by applicant

I1. Having completed all the relevant items of this form and, if appropriate, having attached the Information Sheet and Consent Form plus any other relevant documentation as indicated below, complete the statement below.

- I have read Queen Margaret University's document on "Research Ethics: Regulations, Procedures, and Guidelines".
- The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.

- *In my view* this research is:

Please tick	*See Research Ethics Guidelines Section 6*
☑	Non-invasive
☐	Minor invasive using an established procedure at QMU
☐	Minor invasive using a NEW procedure at QMU
☐	Major invasive

- I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.

I2. Access to application for training purposes (please tick as appropriate):
☑ I would be content for members of Research Ethics Committees to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed.

Name *(if you have an electronic signature please include it here)*

Date 25/5/18

I3. **If you are a student**, show the completed form to your supervisor/Director of Studies and ask them to sign the statement below. If you are a member of staff, sign the statement below yourself.

- I am the supervisor/Director of Studies for this research.

- *<u>In my view</u>* this research is:

Please tick	*See Research Ethics Guidelines Section 6*
☑	*Non-invasive*
☐	*Minor invasive using an established procedure at QMU*
☐	*Minor invasive using a NEW procedure at QMU*
☐	*Major invasive*

- I have read this application and I approve it.

Name *(if you have an electronic signature please include it here)*

Jan Dewing

____

Date _____25/5/18____________

I4. For all applicants, send the completed form to your Head of Division or Head of Research Centre or, if you are an external researcher, submit the completed form to the Secretary to the QMU Research Ethics Panel (ResearchEthics@qmu.ac.uk). **You should not proceed with any aspect of your research which involves the use of participants, or the use of data which is not in the public domain, until you have been granted Ethical Approval.**

For completion by
The Head of Division/Subject Area/Group, OR
Division/Subject Area/Group Research Ethics Committee:

Either

☐ I refer this application back to the applicant for the following reason(s):

Name *(if you have an electronic signature please include it here)*

______________________________________ (Head of Division/ Subject Area/ Group)

Date ______________

Please return the form to the applicant.

Or

Please tick **one** of the alternatives below:

☐ I refer this application to the QMU Research Ethics Panel.

☐ I find this application acceptable and an application for Ethical Approval should now be submitted to a relevant external committee.

☑ I grant Ethical Approval for this research.

Name *(if you have an electronic signature please include it here)*

Professor Brendan McCormack, Head of the Divisions of Nursing, Occupational Therapy and Arts Therapies

BMcCormack

(Head of Division/ Subject Area/ Group)

Date 29/05/2018

Please email one copy of this form to the applicant and one copy to the Secretary to the Research Ethics Panel (ResearchEthics@qmu.ac.uk).

Date application returned: ____________________

Title of the project

The distinctiveness of Lesbian, Gay, Bisexual (LGB) persons affected by cancer treatment and impact on personhood: a participatory research study in Scotland

Abstract/Summary of research

Delivering person-centred care is NHS policy within Scotland and advocated by the WHO (McCormack et al 2015; WHO, 2015). At present the needs and experiences of Lesbian Gay and Bisexual (LGB) persons affected by cancer are not fully understood and they cannot be assured of healthcare delivered in a non-judgmental way (Stonewall 2015; Hill and Holborn 2016).

This research will work in-depth with up to twelve LGB participants to explore impacts of cancer treatment on personhood (i.e. long-term wellbeing and identity). It is underpinned by person-centred philosophy with participatory research principles (from co-operative inquiry). The researcher will work with participants to co-create methods of exploration and findings.

This research is innovative to my profession of Therapeutic Radiography because it employs person-centred methods and philosophy in its design, and seeks to develop a new understanding of how cancer treatment has affected LGB persons identity. It is envisaged that the research will aid in the establishment national guidelines with the help of people directly affected and stakeholders in healthcare and inform educational curricula of radiography and healthcare professionals nationally and internationally.

Background/Rationale of the project

Person-centred care is becoming the norm in terms of policy directing the planning and provision of healthcare in many Western countries (McCormack 2015, The Scottish Government 2010); and is supported by WHO policy (WHO 2015). In addition, The Society and College of Radiographers in stipulate that radiographers must provide the best compassionate care for patients based on current evidence (SoR 2013).The lives and health of LGB people have in recent times gained increased attention as societal attitudes change and recognition of likely inequalities grows. Despite recent legal reform and advancements in UK society, the LGB community still cannot be assured that their healthcare needs are fully recognised and met and that treatment and care are delivered in non-judgmental ways (Stonewall 2015). Recent research undertaken by Hill and Holborn (2016) supports this claim. A recent review of the worldwide literature revealed that LGB people have distinctive experiences and needs relating to cancer care, particularly when attempting to access specific psychosocial and psychosexual support. Although attitudes towards homosexuality differ vastly throughout the world, only two studies have been conducted in the UK examining LGB experiences of cancer care (Doran and Beaver 2015; Fish and Williamson 2018). These studies have started to portray a picture of some issues from an English perspective, with no participants from Scotland. Neither study explored the effects of cancer treatment experience on LGB personhood. Further, literature on person-centeredness in general, does not address sexual diversities, which warrants attention.

Research for my Master's degree, my profession, and subsequent publications have fuelled my interest in i) what the experiences of LGB persons are when they and their support givers are in hospital settings for cancer treatments and ii) what the longer term impact is on personhood, including identity. I have a longstanding interest in social justice and equality issues; as an oncology healthcare professional, and as a person who identifies as a homosexual, I believe that persons should have access to the same level and continuity of care regardless of social background, race, or sexuality or other 'special characteristics'. I argue that currently, the experiences of LGB persons in Scotland in relation to cancer are not fully understood and it is necessary to establish any deficiencies that might affect care/treatment. As there is also a general trend towards more person-centred care in cancer services, I argue that person's sexual orientation should be considered as core to personhood and be given consideration when reviewing the services, care and support that they use.

Literature search strategy (optional)

The Literature search strategy for the research follows the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) methodology. PRISMA is a widely recognised evidence-based set of items for reporting in systematic reviews and meta-analyses for academic journals and as such was deemed an appropriate methodology for this study, ensuring the transparent and complete reporting of the results (Moher et al 2009). The search strategy included the initial identification of peer review articles following a broad-ranging literature search carried out on several health and social science databases. These included The Cochrane Library, Medline, Embase, CINAHL, AMED, Science Direct and ASSIA databases. Key terms were identified that related to LGB health and oncology, then Boolean operators were applied (see below).

Gay OR Lesbian OR Bisexual OR Bisexuality OR Homosexual OR Homosexuality OR LGB OR LGBT OR GLBT OR BLAG OR LGBTQ OR Sexual Minorities OR Sexual Minority Men OR SMM OR Sexual Minority Women OR SMW OR Sexual Orientation OR sex orientation OR Men-who-have-sex-with-men OR women-who-have-sex-with-women AND Cancer OR Neoplasm OR Malignancy OR Malignant cells OR Oncology OR Tumour OR Radiotherapy OR Chemotherapy AND Survivorship OR Experiences OR Quality of Life OR QOL OR Outcomes OR anxiety OR depression OR Support OR Social Support OR Discrimination OR psychological inhibition OR psychological OR psychosexual OR Psychosocial OR psycho-sexual OR Psycho-social OR distress OR perceived stress OR Stress OR health-services accessibility OR needs assessment OR psychosocial adjustment OR physician-patient relations OR Doctor-Patient relations OR sexual Function OR body Image OR stigma

Articles were reviewed and selected on the basis of complying with inclusion and exclusion criteria:

- English language only sources of literature were selected as there was no means of translating other languages.
- Peer reviewed only publications were included to ensure the academic rigour required of this review.

- Articles had to be published within the last ten years to ensure that only current or recent experiences of sexual minority care were taken into account.
- Papers related to targeting screening programmes, HPV vaccination and health awareness in the LGB community were excluded as were not the primary focus of this review.
- Other Meta-Analysis or systematic Cochrane reviews were excluded from this study, but hand searching of reference within these articles was carried out to identify other potential primary studies for inclusion.

Articles were then subject to critical appraisal and scoring to assess their eligibility to be included within the study. The Support Unit for Research Evidence (SURE 2013) critical appraisal tool was determined to be the most appropriate tool to use in the evaluation of the articles given that the studies for review were qualitative in nature. Once suitable articles were appraised they were then analysed and coded by subject matter to classify emergent themes within the literature, these themes are then appraised in this paper.

Two-hundred-and-Thirty articles from a variety of publications were uncovered as part of this review. Fig. 1 indicates the number of included articles in the review from the hits identified from the database searches.

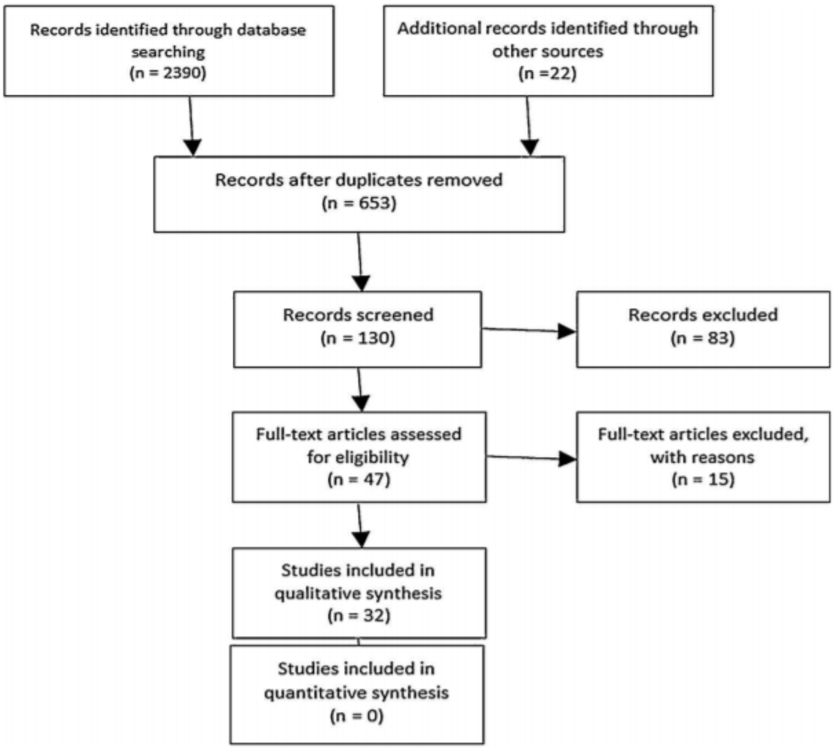


Fig. 1. PRISMA flow diagram.

One-Hundred-and-Thirty were deemed worthy of analysis and were screened using eligibility criteria leaving Forty-seven research articles to analyse. The articles were then reviewed and fifteen were rejected because they related to targeting health promotional programmes and cancer screening programs focused on LGB individuals. Thirty-two studies remained and were then analysed for this paper using the SURE critical appraisal tool. Twenty-five articles were selected for inclusion. No minimum score for the SURE tool was established, but seven articles were rejected as they were replicated studies and such demonstrated duplicate results. The data extraction was carried out and revealed contrasting views and experiences of LGB individuals' experience of cancer care and this formed the body of the discussion of this paper. The papers were categorised into the emerging themes from the literature: Experiences of care (n = 6), Coping and Wellbeing (n = 6), Emotional Support (n = 4), Body Image (n = 3), and Sexual Function (n = 6), the groupings then formulated a structure to the discussion of LGB experiences of cancer care for this review. Studies methodologies were a combination of online and postal surveys (n = 8), face-to-face or telephone based semi structured interviews (n-15), or focus groups (n = 2). Of the articles uncovered, all were found to be qualitative in nature and provided an overview of the experiences of sexual minority individuals, or carers or partners who had come into contact with an LGB person that had undergone treatment for cancer.

Aims/objectives

Research question:

How is LGB personhood impacted by the experience of cancer treatment?

Aims

1. Explore with LGB persons with cancer, their experiences throughout the cancer care pathway.
2. Work with LGB people, their support persons and key stakeholders to develop guidelines for best practice for cancer services and LGB people
3. Influence education of radiography professionals through developing an evidence-based curriculum
4. Contribute theoretically to knowledge of personhood/person-centredness.

Objectives

1. Find out with LGB people, any distinct aspects of their treatment and care.
2. Contribute to the evidence base of cancer treatment and care for persons identifying as LGB.
3. Develop a best practice guideline for hospital-based oncology services and LGB people.
4. Embed the research findings within professional education
5. Make a theoretical contribution to person-centred practice research, specifically personhood in the context of LGB persons

Methodology

Study design

The study will follow the stages of a participatory inquiry underpinned by values derived from person-centred research and Critical Social Theory. The research will explore with participants the effects of cancer treatment on personhood and therefore focus on possible or actual points of transformation as a result of healthcare experiences. My theoretical framework is illustrated in Figure 2, and is adapted by me from the cooperative inquiry paradigm devised by Heron and reflective processes developed by Mezirow (Mezirow 1991, Heron and Reason 1997). The framework proposes that cooperative inquiry can offer participants an opportunity to 'process' and learn (further) from their experiences of cancer treatment and reflect on how the learning has been or can be absorbed into personhood.

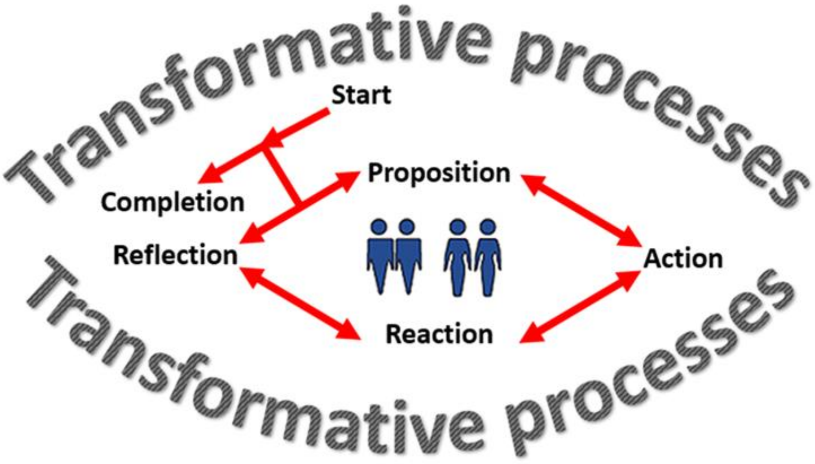


Figure 2. Theoretical framework to the research (version1 2017-18).

Research population/sampling frame

The research participants in this study are LGB persons who have undergone primary treatment for cancer and will need to meet the following criteria. Note: Key support person (if available) are invited to be present although they are not the focus of the research. Support persons are included because they can have a view on the impacts of cancer treatment. However, I am not specifically seeking to explore their personhood.

Inclusion Criteria

- People who self-identify as LGB and are aged 18 or over
- LGB people who live in Scotland and have received treatment for cancer, including radiotherapy, in the past 5 years
- People who are able to sufficiently speak and understand English
- People who can participate in the sessions

Exclusion Criteria

- People under the age of 18
- People that identify as heterosexual
- People who cannot speak and understand English sufficiently
- People who are currently undergoing or about to undergo invasive treatments such as surgery, radiotherapy, brachytherapy and chemotherapy or have undergone treatment during the past three months.

Participants should be in the follow-up stages of the cancer treatment pathway (see figure 3).

Figure 3. Participants for the research will be recruited from the areas on the pathway highlighted in red. Adapted from Baker and Scwartz (2005).

Recruitment

Participants will be recruited via my local and national networks. Targeted recruitment using purposeful and snowball sampling will be focused on voluntary sector organisations working in the LGB communities and LGB cancer support groups in Scotland. Publicity materials and an introductory email will be designed and distributed to LGB groups, support agencies, individuals, twitter feeds, and Scottish LGB venues to ensure maximum possibilities for recruitment into the study (See appendix A). This means that an independent person will make the initial approach rather than the researcher. A contact number and email address will be established at QMU for potential participants to contact and obtain further details of the study. All recruited participants will also be asked if they know of anyone within their own networks that may be interested in participating in the study and if they do should make contact with myself through the QMU contact email address and phone number.

Sep-by-step recruitment process

Once the study is open, potential participants will be able to establish contact through the contact details provided on promotional materials (See appendix B). Those that request further information will be sent a reply thanking them for their interest requesting if they would like a copy of the information sheet to be sent through the post or email (See appendix C). I will also explain within the email or letter that if they decided they would like to take part in the study, I will need to clarify on the telephone whether they were eligible to participate (See appendix D). In particular I will need to assess participants circumstances (i.e. if they were undergoing active treatment) if they decided they would like to take part.

After 48 hours of them receiving the information, participants will be asked to contact me to arrange a time to speak over the telephone. During this phone call an eligibility checklist will be completed by myself and a verbal description of the study, a consent form will then be sent out, and date agreed for the face-to-face sessions (See appendix E). This phone call will also serve as an opportunity for me to introduce myself to the participant in a friendly and informal way to help establish initial contact and trust, as well as address any concerns or questions the participants may have. At this stage I will ask the participants if they have a support person that would be willing to participate in the sessions. The support person is primarily there for the participant and their support needs. However if they wish to participant in the activity and conversation within the session that will be encouraged. Please note that support persons will not be expected to provide data for the study and are not the focus of the research, therefore consent will not be required from the support person. Participants will be asked to pass on my contact details to the support person to arrange informal conversation over the phone to ensure they understand their purposes and role within the research.

If all participants are happy to proceed they will be asked to sign the consent form at the start of the arranged session. A mutually convenient time and location will be arranged for an face-to-face sessions to take place with the participant. As the locations will require me to travel to other parts of Scotland, I will check that I can contact participants once again, the day prior to the interview, to ensure that our meeting arrangements will still be in place. This phone call will also offer a further opportunity to build rapport with the participants.

Once I meet the participants further introductions and informal conversation will occur, and then discussion will naturally turn to the purpose of my visit. At this point, formalities surrounding consent will be discussed and I will ask participants how they would like to work together through the face-to-face sessions and discuss the process of the research.

Consent

Participants will be provided with full information to enable them to take part; confidentiality, privacy and informed consent will be assured. Potential participants will be provided with an information sheet prior to arranging a face-to-face meeting and given at least 48 hours to decide if they want to participate. They will be given the name and contact details of an independent staff member within QMU to be able to discuss the study. Individual consent forms will be sent to participants for completion at the start of the first face-to-face session. At the start of each face-to-face session verbal consent will also be revisited and taken to ensure that all participants are happy to proceed. Key support persons will also be contacted independently and sent the information sheet and given the opportunity to have an informal discussion, but will not need to consent for the study.

In addition to the formal process outlined a commitment to process consent will also be adopted. Process consent is an approach where the researcher focuses on an ongoing consensual process that involves the participants in mutual decision making and ensures that the participants are kept informed at all stages of the research process and is in keeping with principles of person-centred research (McCormack et al 2017). During each stage of the face-to-face sessions where I provide information to the participants or qualify any instructions I will make sure that I ask if participants are happy to continue. Ways of working will also be established at the start of each face-to-face session emphasising that participants can also withdraw or refuse to answer questions if they feel uncomfortable or unsure of what is being asked of them.

Withdrawal

In keeping with a person-centred philosophy I will ensure that I respect any signals of distress, stress or unwillingness to continue to participate in research (McCormack et al 2017). Consent for participation will therefore continue throughout the research process and will respect the autonomy of the participants. Any participant will be free to leave the research study at any time. When withdrawing from the study, the participant will be asked to let the research team know that they wish to withdraw. A participant may wish to provide the research team with the reason for leaving the study, but is not required to provide their reason.

Withdrawing participants will still be given the same information about local cancer support groups and contact details should they wish to access these support services. Contact details will also be provided to the participant for if there are any questions or concerns that arise after completing or withdrawing from the research. At the time of withdrawal participants will be asked to let the research team or myself know if they will allow the already collected information and used in the data analysis. If the participant does not wish for their information to be stored or examined within the analyses this can be destroyed. I will keep a field log of all major decisions including any withdrawals.

Study procedures

Face-to-face inquiry sessions with the participant and their key support person, if available, will take place in an agreed venue. Prior to each session, participants will be sent information setting out how the sessions are constructed and the sorts of activities that I hope to engage them in. The first meeting will focus on personhood and identity with participants asked to construct their personhood mapping (See appendix F). This will be achieved using a creative method that is acceptable to the participant e.g. using existing objects and artefacts, photograph of personal significance, using creative expression such as painting, music, craft, etc. The materials will then be used as a trigger and basis for conversation exploring its meaning in relation to self as a person who identifies as LGB. The conversation will be transformed during the interaction into an identity map that the participants feel reflects important aspects of personhood.

The second meeting will use a process of critical reflection to focus on how experiences of cancer treatment have impacted on participants' personhood (See appendix F). In the sessions I will draw on the 10 steps of Mezirow's (1997) transformative learning model to assist us. Questions will focus on the personhood map, using this to trigger critical reflections on how different aspects of their being have been impacted on, positively or negatively, through experiences of cancer care. Participants will use the 'creative map' to help structure and theme their thoughts about any impacts on personhood. A third session can be organised if required. Probing questions will also be used to explore matters raised in more depth (See appendix F).

The sessions require one-to-one negotiation with participants about how best to record them. This could make use of digital recording, video, photography, use of creative products and flow charts, or a combination. Participants will be offered copies of any record or recording made. Next, individual participants will be offered an opportunity to take part in the thematic analysis of their inquiry session. Again, I will draw on the 10 steps of Mezirows (1997) transformative learning model to assist us in theming and to gain a new perspective on the participants' experience.

The next step will be a participatory synthesis of the combined themes from different participants. It is anticipated that this will be done at a distance through the use of private social media or other web-based technology. Figure 4 demonstrates the likely trajectory of the research and participant's pathway.

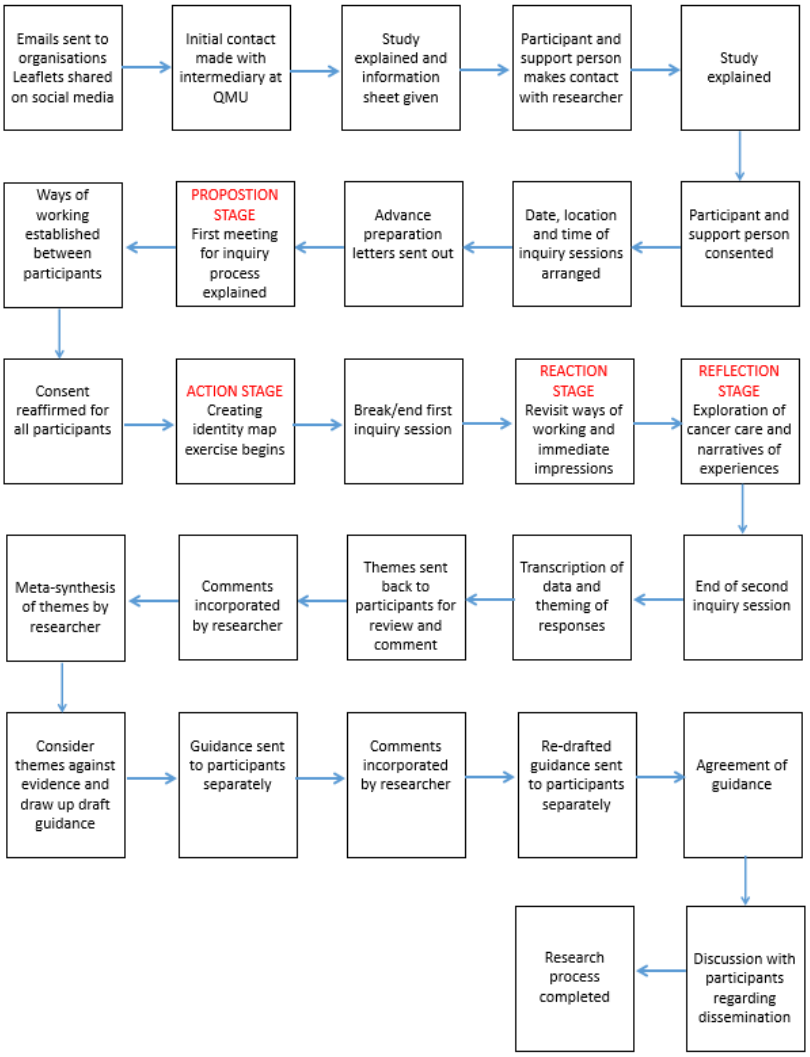


Figure 4. Likely stages of the research process.

Some participants will then be invited to share the draft findings in a stakeholder workshop to assist in the formulation of professional guidance. Stakeholders such as Macmillan, Maggie's cancer charity, local cancer centres, Stonewall, and The Society and College of Radiographers will be invited to take part in a half day event at QMU or a suitable venue in Edinburgh that will focus on ratifying and agreeing the final set of guidance. Research participants will be able to attend if they wish. Funding for the stakeholder aspect of the research will be met by the Centre for Person-centred Practice Research.

A consensus agreement from within the group will be established at the start of the inquiry session on how to record the session and group rules. It is anticipated that the draft guidance will be a key output from this workshop.

It is key that throughout the research process that I as the initiator of the research and the other participants continue to be committed to the methodological principles of engaging in partnership and collaborative working. This will be achieved by continually reflecting on each stage of the inquiry process to ensure that all participants are at ease with the research and providing opportunities to seek shared understandings and new knowledge generation that is key to the research process. I will use reflection techniques and my research supervision to facilitate this. I will audio-record my reflections in supervision so I can access them again at later dates. At all times, participants will understand that they can withdraw from the research should they wish. It is my goal that participants have the opportunity to develop an enhanced understanding of their own transformational experience of cancer treatment by engaging in the research.

Data management

Participants will be involved should they wish, in reading and commenting on their own session transcripts, observational notes, identity maps, and will be encouraged to provide feedback in various ways. The ways in which the participants choose to feedback will need to be negotiated with the participants. I will then provide the opportunity for the participants to be able to comment on the materials either in written or verbal formats.

All data will be securely stored at QMU and anonymised to protect confidentiality and will be kept in accordance with The General Data Protection Regulation (GDPR) (EU) 2016/679. Each transcript will have a pseudonym applied to ensure that confidentiality is maintained. In addition if there is any identifiable information contained within photographs of identity maps these will be blurred to further maintain confidentiality. Data will be held either in secure lockable storage cabinets on QMU campus or in lockable carry cases when in transit. In addition all electronic data such as data recordings and transcripts will be held on QMU IT servers, which are also encrypted using QMU login credentials. During the field work an audio Dictaphone and digital cameral will be used to record conversations and identity maps created by participants. The audio recorded and camera will be stored in in the lockable carry case in transit and uploaded to QMU’s IT servers within 24 hrs. No data will be sorted on recording devices outwith of this period. All data will be destroyed 12 months after the study has been completed. In addition, all data ownership and storage both during the research process and after the project has reached its conclusion will be discussed and agreed by the participants in a consensual manner in keeping with the methodological principles of my research.

Analysis

Face-to-face inquiry sessions with the participant and their key support person will be audio-recorded and transcribed. After the sessions are transcribed and other materials photographed, copies of the transcripts will then be sent to the participants to check for accuracy and comment. The researcher will then use Mezirows (1997) framework for transformative processes as a means of analysis to identify issues and themes emerging from participants’ experiences of, and feelings about, the care and treatment they had received for the cancer. Mezirows (1997) transformative process are divided into ten sections and will be used to assist me in theming the information discussed in the sessions to gain a new perspective of the participants experiences. The stages of the analytical framework are as follows:-

1. A disorienting dilemma
2. Self-examination
3. A critical assessment of epistemic, sociocultural, or psychic assumptions
4. Recognition of a connection between one's discontent and the process of
5. Exploration of options for new roles, relationships, and actions
6. Planning a course of action
7. Acquisition of knowledge and skills for implementing one's plan
8. Provisional trying of new roles
9. Building of competence and self-confidence in new roles and relationships
10. A reintegration into one's life on the basis of conditions dictated by one's new

Participants will be invited to comment on the themes and analysis should they wish to become involved as a key principle of participatory research (Hacker 2013). Once themes are agreed with each participant data will then be fully anonymised and undergo meta-synthesis to establish key themes across the research using the same transformative framework advocated by Mezirow. Once the issues and themes are identified, agreed, and analysed, I will be able to consider these against other existing evidence.

Findings of the research will be shared with key stakeholders and previous participants who will be invited to a workshop. The workshop will examine the research evidence and will devise a set of national guidelines for the treatment of LGB persons. Participants who have been involved in the research can choose to voluntarily participate only if they wish and are not required to attend the workshop as part of the research. In addition, if they wish they will also be sent a copy of draft guidance for further comments either electronically, telephone or by post.

Ethical considerations

Researchers who explore the experiences of individuals who have experienced cancer often request ethical approval to recruit within the NHS. However, as sexual orientation is not a demographic that is routinely captured and monitored across the NHS at present, and non of the study participants will be in receipt of active treatments, a decision has been made to employ alternative strategies in order to identify and recruit potential participants. As such only QMU ethical approval is to be sought as participants will be recruited outwith the NHS.

Mutual respect and trust

Key to this research is developing mutual respect and trust between the participants and the researcher. This will include ensuring that ground rules are established and ways of working are discussed at the start of the participatory sessions. The participant's will be encouraged to behave in a responsible manner with a commitment to being open to challenge and honest ways of working with reviewing the analysis and the reporting of the research.

Equality and inclusion

I will make every effort to try and include representatives from different ethnic backgrounds, race, age, class education and gender within the research. As part of this process I will also seek to ensure that venues and formats of the meetings and sessions are accessible to all that used to participate, in this case the participant can opt to negotiate a venue that is considered to be safe for both them and myself. Strategies to enable wider participation will include the targeting of public organisations that represent minority groups within the LGB community to raise awareness of my study and to enable members of those organisations to participate.

Democratic participation

I will seek to ensure that I promote democratic participation within the research. I will do this by making sure that all participants can contribute meaningfully to decision-making by discussing ways of working and allowing participant's the opportunities to raise questions and air concerns,. I will also to communicate in accessible language that everyone involved in the groups can understand, and focus on developing participant's communication and expressive abilities.

Physical threat or abuse, being in a comprising situation

As it is likely that most of the inquiry sessions will be conducted either at the participant's home or somewhere located near to them for ease of access, a risk assessment will be completed. A 'buddy' system will also put in place to ensure that there is regular contact between myself and a member of the supervision team prior to, and following each inquiry session. In addition I will also carry a mobile phone, ensuring my location and activities are known to QMU in advance of the sessions as well as maintaining contact with my supervisory team during the inquiry sessions.

Participant safety

A "distress" protocol will also implemented to the participants so then they have the right to pause, reconvene or terminate any of the sessions. In addition contact details for local cancer support and counselling services will be provided to participants should they have anything that arises in conversations as part of the research process that they would wish to explore in more detail with a qualified counsellor. In addition I am also a qualified oncology health care professional who has is trained and experiences with talking with people about cancer and how this affects them. At all times I will abide by professional codes of conduct stipulated by the society and college of radiographers as well as the Health and Care Professions Council to ensure the safety of the participants.

Psychological harm for participants

To minimise the risk of causing psychological harm I will ensure that contact details of local cancer support and LGBT services are provided to participants in case they wish to discuss any matters that arise as a result of the research. Full contact details of the participants local Maggie's centre, Macmillan support and information centre will be provided in addition to the Macmillan cancer support hotline. All of the above services are designed to be able to offer free practical, emotional and social support to people with cancer and their families and friends and is offered freely to anyone affected by any type of cancer.

Psychological harm for researcher

To reduce the risk of causing psychological to myself from potentially distressing conversation topics I will ensure that I debrief with the supervisory team, complete a reflective diary, and ensure that if necessary that I use the occupational health and psychological support mechanisms available through QMU.

Participant disclosing a very bad care experience

There is a chance that a participant may disclose a very bad experience where a healthcare professional or organisation may have severely breached codes of conduct. At this stage I will ensure that in addition to the support materials offered to the participant I will make sure they are aware of the local NHS board or Cancer Networks complaints procedures is made available. In addition details of the HCPC, NMC, or GMC can also be made available to a participant.

Intrusion, inconvenience or changes to lifestyle

Participation in the research is entirely voluntary and should participants wish to withdraw at any time this will be permitted. It is anticipated that a total of two inquiry sessions with participants and support person will be required and information about the timing of these will be provided to all participants and support persons in the information sheet and when consent is taken. In addition verbal consent and establishing ways of working will also be established the start of each contact session to ensure that all participants are still happy to proceed.

Resources and costs

This project has been fully economically costed in accordance with QMU procedure with the view of releasing myself from full-time employment to carry out the research. A grant bid has been submitted to the College of Radiographers to award funding for this project. The following costings and timelines have been provided on the basis that this grant is successful.

Research expenses (directly incurred costs)	
Details	
Salary	
Salary for costs for PI x 2 days per month for 18 months	**£9915**
Salary for Research Administrator, 2 days per week for 18 months	**£13032**
Dissemination	
Annual Radiotherapy Conference	**£650**
Subtotal	**£22877**
Other costs *(e.g. travel, essential equipment)*	
Details	
Digital Recorder	**£100**
Stationery: creative materials	**£250**
Mobile phone for researcher (lone working): borrowed from QMU; 50 for pay as you go	**£50**
Travel and Subsistence for Inquiry sessions	**£880**
Travel and Subsistence for SoR annual Radiotherapy Conference	**£80**
Subtotal	**£1360**
Budget summary	
Salary	**£22947**
Expenses	**£1280**
Dissemination – conference attendance	**£730**
Total	**£24957**

Justification of Budget

Salary

£9915 - Salary for costs of PI, for 2 days per month for 18 months – Salary costs will ensure the release of time to be able to conduct the field work for the inquiry sessions.

£13032 - Research Administrator, 2 days per week for 18 months – To provide administrative support for the research that would be significantly less expensive than the PI salary for the same amount of time. The RA will be the point of contact for participants, handle the scheduling of visits, raising awareness of the study through social media and stakeholder contacts through sending out pre-prepared materials, carry out transcription of the inquiry sessions, procure inquiry session materials, etc. The RA would not be responsible for the formulation of guidance, creation of recruitment materials, carrying out analysis or conducting the fieldwork.

Dissemination

£650 - Annual Radiotherapy Conference – conference aimed at bringing together therapeutic radiographers from across a range of service areas for learning, networking and sharing of best practice. This conference will be ideal to disseminate my finding to my profession.

Other costs (e.g. travel, essential equipment)

£100 - Digital Recorder – Cost of a digital recorder of sufficient quality to record the inquiry sessions.

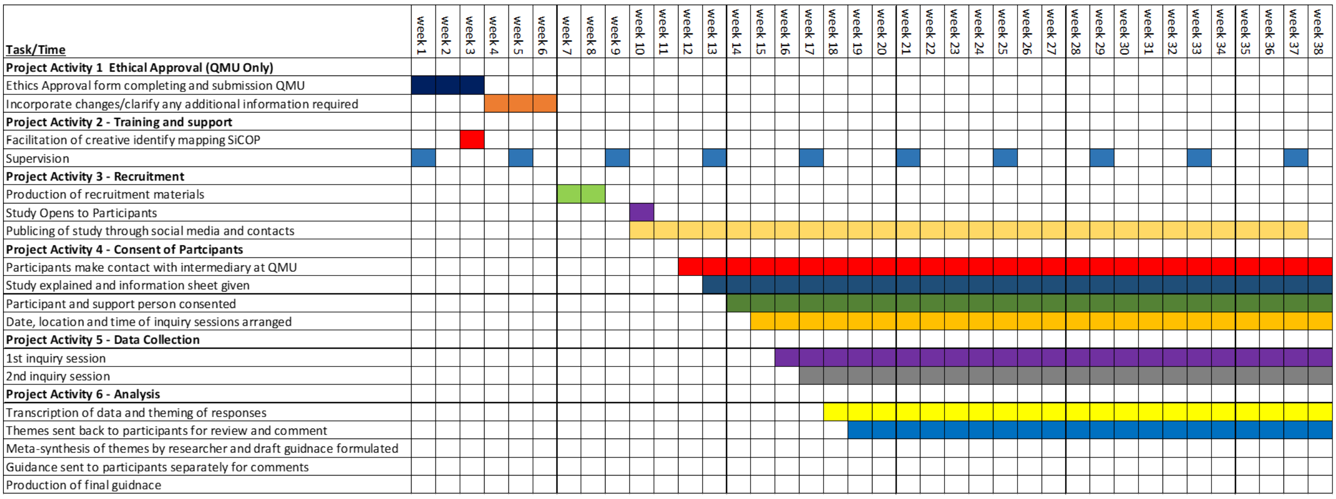
£250 - Stationary: creative materials - Due to the creative work required by participants, art materials will need to be purchased to facilitate the mind mapping process.

£50 - Mobile phone for researcher (lone working): borrowed from QMU; £50 for pay as you go

£880 -Travel and Subsistence for Inquiry sessions – n=24. Car mileage: for 1 person, 24 trips, est 100 miles/trip @40p/mile

£80 - Travel and Subsistence for SoR annual Radiotherapy Conference – cost of second class rail fare to annual radiotherapy conference in Newcastle.

Project time plan



Task/Time	week 1	week 2	week 3	week 4	week 5	week 6	week 7	week 8	week 9	week 10	week 11	week 12	week 13	week 14	week 15	week 16	week 17	week 18	week 19	week 20	week 21	week 22	week 23	week 24	week 25	week 26	week 27	week 28	week 29	week 30	week 31	week 32	week 33	week 34	week 35	week 36	week 37	week 38
Project Activity 1 Ethical Approval (QMU Only)																																						
Ethics Approval form completing and submission QMU	🟦	🟦	🟦																																			
Incorporate changes/clarify any additional information required				🟧	🟧	🟧																																
Project Activity 2 - Training and support																																						
Facilitation of creative identify mapping SiCOP			🟥																																			
Supervision	🟦				🟦				🟦				🟦				🟦				🟦				🟦				🟦				🟦				🟦	
Project Activity 3 - Recruitment																																						
Production of recruitment materials							🟩	🟩																														
Study Opens to Participants										🟪																												
Publicing of study through social media and contacts										🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	
Project Activity 4 - Consent of Partcipants																																						
Participants make contact with intermediary at QMU												🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥
Study explained and information sheet given													🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦
Participant and support person consented														🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩
Date, location and time of inquiry sessions arranged															🟧	🟧	🟧	🟧	🟧	🟧	🟧	🟧	🟧	🟧	🟧	🟧	🟧	🟧	🟧	🟧	🟧	🟧	🟧	🟧	🟧	🟧	🟧	🟧
Project Activity 5 - Data Collection																																						
1st inquiry session																🟪	🟪	🟪	🟪	🟪	🟪	🟪	🟪	🟪	🟪	🟪	🟪	🟪	🟪	🟪	🟪	🟪	🟪	🟪	🟪	🟪	🟪	🟪
2nd inquiry session																	⬛	⬛	⬛	⬛	⬛	⬛	⬛	⬛	⬛	⬛	⬛	⬛	⬛	⬛	⬛	⬛	⬛	⬛	⬛	⬛	⬛	⬛
Project Activity 6 - Analysis																																						
Transcription of data and theming of responses																		🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨
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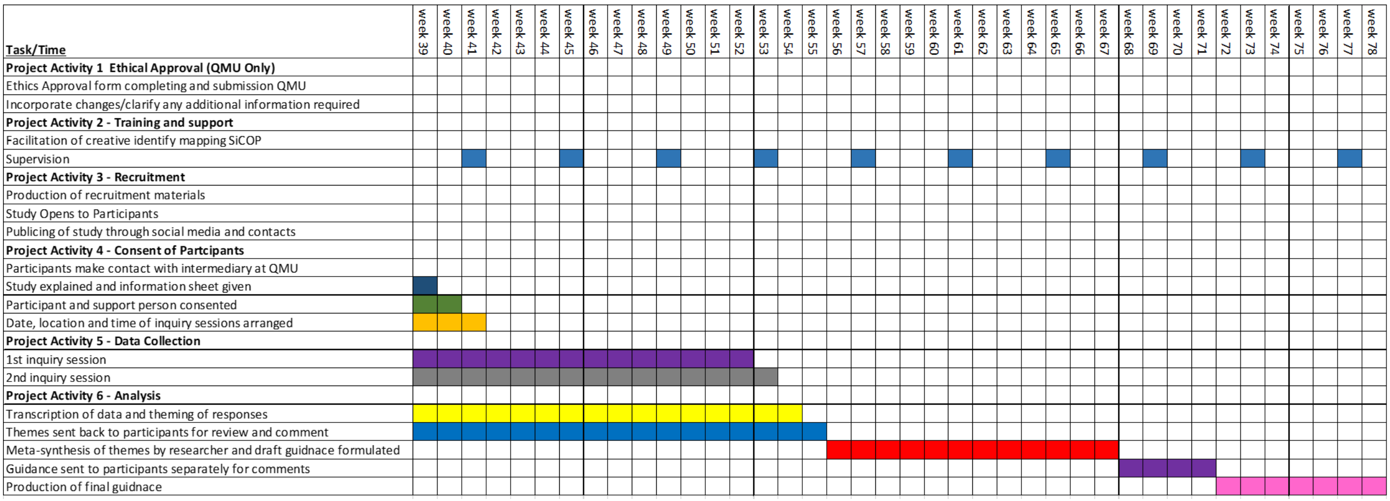

Task/Time	week 39	week 40	week 41	week 42	week 43	week 44	week 45	week 46	week 47	week 48	week 49	week 50	week 51	week 52	week 53	week 54	week 55	week 56	week 57	week 58	week 59	week 60	week 61	week 62	week 63	week 64	week 65	week 66	week 67	week 68	week 69	week 70	week 71	week 72	week 73	week 74	week 75	week 76	week 77	week 78
Project Activity 1 Ethical Approval (QMU Only)																																								
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Project Activity 3 - Recruitment																																								
Production of recruitment materials																																								
Study Opens to Participants																																								
Publicing of study through social media and contacts																																								
Project Activity 4 - Consent of Partcipants																																								
Participants make contact with intermediary at QMU																																								
Study explained and information sheet given	🟦																																							
Participant and support person consented	🟩	🟩																																						
Date, location and time of inquiry sessions arranged	🟧	🟧	🟧																																					
Project Activity 5 - Data Collection																																								
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Project Activity 6 - Analysis																																								
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Guidance sent to participants separately for comments																														🟪	🟪	🟪	🟪							
Production of final guidnace																																		🟪	🟪	🟪	🟪	🟪	🟪	🟪

Dissemination

Prior to the research commencing, awareness of the study through the use of social and online media will be needed and will be targeted at voluntary sector organisations working in LGB communities and LGB cancer support groups in Scotland. Publicity materials will be designed and distributed to LGB groups, support agencies, individuals, twitter feeds, and Scottish LGB venues to ensure maximum possibilities for recruitment into the study.

During the research project, participants, supporters and other LGB and cancer organisations will be updated through plain English briefings, social media tweets, and press releases.

At the end of the research we aim to present at the Annual Radiotherapy Conference and submit a publication to the Radiography Journal and another International Journal. We will also work with our local and national networks established throughout this study to promote the dissemination of research among non-academic audiences, including the stakeholder workshop.

Appendices

Appendix A - Example introductory email to organisations and support groups and LGB organisations in Scotland to promote the study

Appendix B – Promotional materials

Appendix C – Information Sheet

Appendix D – Eligibility criteria question form

Appendix E – Consent form

Appendix F - Face to face sessions topic guide

Appendix G - Example probing questions

Protocol version number

LGBPH_20180525_version1.0

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QMU ETHICS APPLICATION - Appendix A - Example introductory email to organisations and support groups and LGB organisations in Scotland to promote the study

Dear **INSERT CONTACT NAME**

My name is Gareth Hill and I am a Registered Therapeutic Radiographer and PhD research candidate at the Queen Margaret University, based within the Centre for Person-Centred Research within the School of Health of Health Sciences. I found your details on **ORGINASATION NAMES** website and wondered whether your **support group/organisation** would be able to help promote a piece of research that I am currently working on for my PhD?

Title of Research: The distinctiveness of Lesbian, Gay, Bisexual (LGB) persons affected by cancer treatment and impact on personhood: a participatory research study in Scotland.

I am conducting research examining the experiences of Lesbian, Gay and Bisexual people following treatment for cancer and am aiming to explore in-depth, with up to twelve people, their experiences of cancer treatment in Scotland. I particularly want to establish how cancer treatment in health care services impacts on identity for LGB persons. Participants will be asked to reflect on how their experiences of cancer treatment have affected aspects of their own identity (personhood) through the creation identity maps and discussing their experience.

The lives and health of Lesbian Gay and Bisexual (LGB) people have in recent times become more of a focus of attention as societal attitudes evolve. However, despite recent legal reform across the UK countries and NHS policy in Scotland focusing on the delivering of person-centred care, LGB people still cannot be fully assured that their healthcare is delivered in non-judgmental way, or that it fully addresses their specific health needs. Further, the needs and experiences of LGB persons affected by cancer are not fully understood. Therefore, the focus of this research is to participate with LGB persons and supporters to explore the effects cancer treatment has on 'personhood' (i.e. identity and rights) will address the following aims and objectives:-

Aims

1. Explore with LGB persons with cancer, their experiences throughout the cancer care pathway.
2. Work with LGB people, their support persons and key stakeholders to develop guidelines for best practice for cancer services and LGB people.
3. Influence education of radiography professionals through developing an evidence-based cubiculum.
4. Contribute theoretically to knowledge of personhood/person-centredness.

Objectives

1. Find out with LGB people, any distinct aspects of their treatment and care.
2. Contribute to the evidence base of cancer treatment and care for persons identifying as LGB.
3. Develop a best practice guideline for hospital based oncology services and LGB people.
4. Embed the research findings within professional education.
5. Make a theoretical contribution to person-centred practice research specifically personhood in the context of LGB persons.

If you are able to help in any way I would be most grateful. The study has received ethical clearance from the University Ethics Committee and I can send you an A5 promotion poster (by email or by post) which outlines the study and provides my contact details for anyone who may be interested in taking part. Following completion of this research, I will also be willing to share my research findings with you in a format that would suit your needs; if this is something you would be of interest.

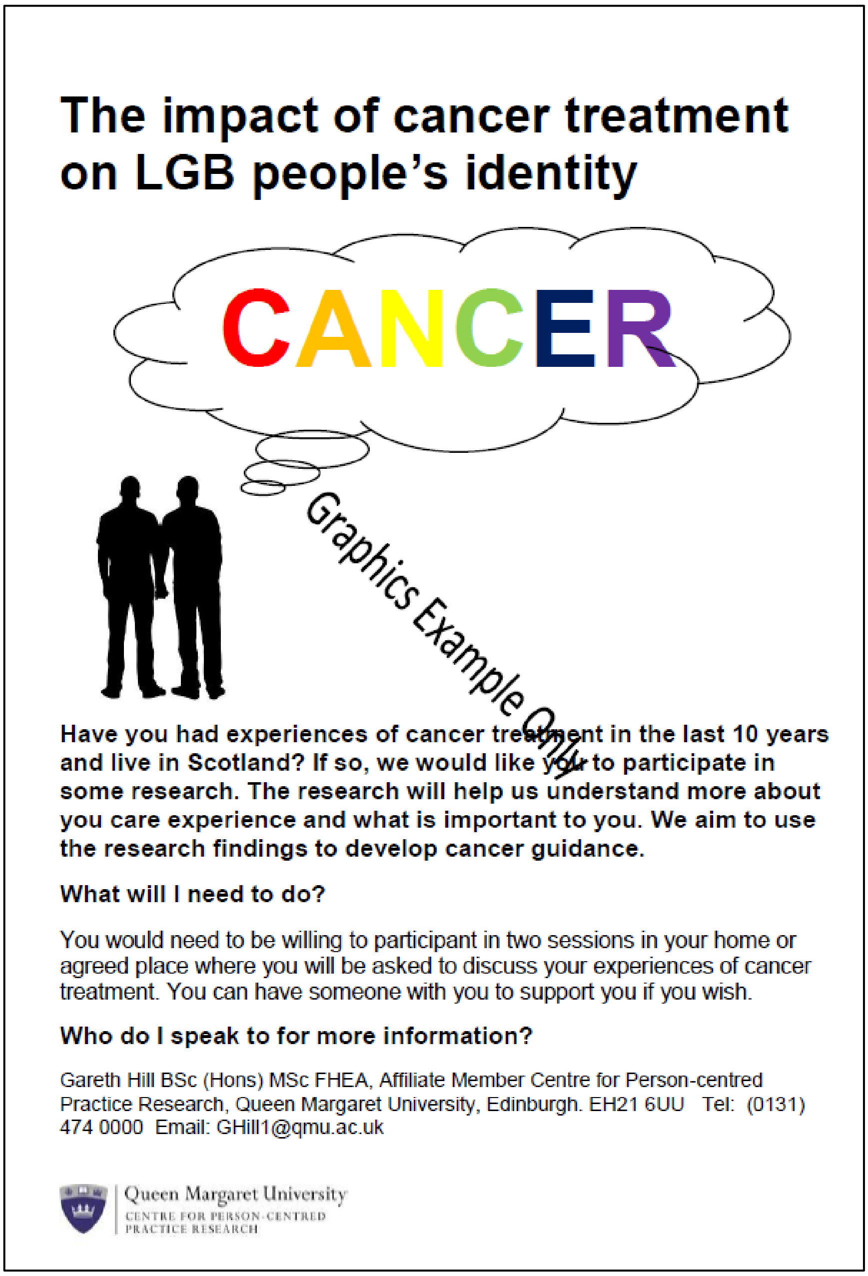
I look forward to hearing from you,

Kind regards,

Gareth Hill

PhD Research Student
Centre for Person-Centred Research Practice
School of Health Sciences
Queen Margaret University, Edinburgh
Musselburgh
East Lothian EH21 6UU
0131 474 0000

QMU ETHICS APPLICATION Appendix B – Promotional materials



The impact of cancer treatment on LGB people’s identity

CANCER

Have you had experiences of cancer treatment in the last 10 years and live in Scotland? If so, we would like you to participate in some research. The research will help us understand more about you care experience and what is important to you. We aim to use the research findings to develop cancer guidance.

What will I need to do?

You would need to be willing to participant in two sessions in your home or agreed place where you will be asked to discuss your experiences of cancer treatment. You can have someone with you to support you if you wish.

Who do I speak to for more information?

Gareth Hill BSc (Hons) MSc FHEA, Affiliate Member Centre for Person-centred Practice Research, Queen Margaret University, Edinburgh. EH21 6UU Tel: (0131) 474 0000 Email: GHill1@qmu.ac.uk

Queen Margaret University
CENTRE FOR PERSON-CENTRED PRACTICE RESEARCH

*****Please note that graphic design may be changed, but the text on the document will remain the same*****

QMU ETHICS APPLICATION Appendix C – Information Sheet

Queen Margaret University
EDINBURGH

Information Sheet for Potential Participants

My name is Gareth Hill and I am a Registered Therapeutic Radiographer and a PhD research candidate from Centre for Person-centred Research Practice at Queen Margaret University in Edinburgh. As part of my course, I am undertaking a research project. The title of my project is: The distinctiveness of Lesbian, Gay, Bisexual (LGB) persons affected by cancer treatment and impact on personhood: a participatory research study in Scotland.

This study will in looking into how cancer treatment in health care services impact on the identity of Lesbian, Gay and Bisexual people.

Participants will be asked to share their thoughts on who they are and what matters to them and after this is established, participants will reflect on how their experiences of cancer treatment have affected aspects of their identity.

The findings of the project will be useful because it aims to work with LGB people, to find out if there are any distinct aspects of their treatment and care and to see how this has impacted on the sense of identity or personhood. With this information the research will then go on to shape a best practice guideline for hospital based cancer services and LGB people, as well as inform on education of future healthcare students.

This research is being funded by The Society and College of Radiographers

*****subject to successful grant award remove if needed*****

I am looking for volunteers to participate in the project who meet the following criteria:

- People who self-identify as LGB and are aged 18 or over
- LGB people who live in Scotland and have received treatment for cancer, including radiotherapy, in the past 5 years
- People who are able to sufficiently speak and understand English
- People who can participate in two sessions each lasting approximately one hour

People who are currently undergoing or about to undergo treatments such as surgery, radiotherapy, brachytherapy and chemotherapy or have undergone treatment during the past three months will not be able to participate. This is because you will likely have hospital appointments to keep as well as potential side effects to manage and we don't want you to be overly inconvenienced by taking part in this study.

If you agree to participate in the study, you will be asked to participate in two face-to-face sessions to explore your experiences of cancer treatment. I will come to your home or another location of your choosing at a time that is convenient to you and each session will last approximately 2 hours. You are also encouraged to have a key support person that knows you well during the sessions to help support you and assist in the discussion of your experiences.

In the first session, we will create an identity map (about you) with the help of a key person that supports you. This is a resource that will help you share your perceptions, feelings and thoughts about key life events and help us to talk together.

I am open to using a range of methods such as writing, metaphors, sculpting, photography and videography and art; and you should feel free to use what would be most useful to you. The aim of employing this way of working to help focus past care experiences in an engaging and creative way. However, if you are not used to creative methods, please do not worry or exclude yourself from the research.

In the second session we will meet again for about an hour and we will explore how your cancer experience influenced or influences your identity and personhood.

Your experiences may either be positive or negative and you don't need to share anything or answer any questions you are uncomfortable with. You are welcome to use anything that you feel would help you in this process. In the final stages of the second session I will invite you to have some general discussion about your experience of the identity mapping and our discussions and any feedback you could offer me.

There is a risk that some people may become upset during one or either of the sessions. If this happens, you or your support person can pause, have a break, or stop the session at any time. You will also be made aware of contact details for your local cancer support services if you would like to talk in more depth about any of the experiences that we explore. The whole process should take no longer than 2 hours per session with comfort breaks as you need them. You are free to withdraw from the study at any stage and you do not have to give a reason.

The sessions will be audio-recorded to help me revisit what you have said and create a transcript of our discussions. These transcripts will then be themed and analysed to see if there is anything that can be learnt from your experiences and how these compare to other research and current guidance. I would also like to take a picture of your identity map but will make sure you cannot be identified in any way. Your anonymised results will then be joined up with other peoples experiences and examined further. You be offered the opportunity to feedback on the transcripts and the themes if you wish.

After the research has been completed I will host a stakeholder workshop to discuss the key findings of the research. There will be representation form key cancer charities and LGB organisations that will look at the work and devise a set of national guidelines to help future LGB people affected by cancer and if you wish you can also participate, but this isn't a requirement of you participating in the study.

All data will be anonymised as much as possible, but you may be identifiable from tape recordings of your voice. Also, any photographs that may be taken of your created identity maps may reveal personal details about you. Anything used that may be identifiable can be blurred. Your name will be replaced with a pseudo name and it will not be possible for you to be identified in any reporting of the data gathered.

The anonymised results will be published in my thesis and in a journal or presented at a conference and the study finding will also be used to develop a workshop with key professional from LGB organisations and cancer services to develop best a set of best practice guidelines.

If you would like to contact an independent person, who knows about this project but is not involved in it, you are welcome to contact Debbie Baldie. Her contact details are given below.

If you have read and understood this information sheet, any questions you had have been answered, and you would like to be a participant in the study, please now see the consent form.

Contact details of the researcher

Name of researcher: Gareth Hill

Address:
PhD Research Student, Centre for Person-Centred Research Practice Division, School of Health Sciences

Queen Margaret University, Edinburgh

Queen Margaret University Drive

Musselburgh

East Lothian EH21 6UU

Email / Telephone: GHill1@qmu.ac.uk / 0131 474 0000

Contact details of the independent adviser

Name of adviser: Dr Debbie Baldie

Address: Head of Division of Nursing, Nursing Division, School Health Sciences
Queen Margaret University, Edinburgh
Queen Margaret University Drive
Musselburgh
East Lothian EH21 6UU

Email / Telephone: DBaldie@qmu.ac.uk / 0131 474 0000

QMU ETHICS APPLICATION Appendix D – Eligibility criteria question form

Queen Margaret University
EDINBURGH

Eligibility criteria checklist

To be completed by the research team prior to consenting participants

Pseudo Name:

Date Completed:

The distinctiveness of Lesbian, Gay, Bisexual (LGB) persons affected by cancer treatment and impact on personhood: a participatory research study in Scotland

All participants must meet eligibility criteria based on the inclusion/exclusion criteria as detailed in the ethics section of the research protocol.

Section 1

Do you self-identify as Lesbian, Gay or Bisexual (LGB) and are aged 18 or over?
Yes/No

Do you who live in Scotland and have received treatment for cancer, including radiotherapy, in the past 5 years?

Yes/No

Are you able to sufficiently speak and understand English?

Yes/No

Are you able to participate in two face-to-face sessions lasting approximately 1 hour?

Yes/No

Are currently undergoing or about to undergo invasive treatments such as surgery, radiotherapy, brachytherapy and chemotherapy or have undergone treatment during the past three months?
Yes/No

Does the potential participant meet the eligibility criteria? If so, continue to the next section
Yes/No

Section 2

Are you happy to provide some contact details so I can post or email an information about the research to you?

Yes/No

Name:

Email address:

Postal address:

Are you happy for me to contact you after 48 hours after receiving the information?

Yes/No

How would you prefer me to contact you? (please tick) Telephone/Email/text/post

Telephone Number:

Best time to call:

QMU ETHICS APPLICATION Appendix E – Consent form

Queen Margaret University
EDINBURGH

Consent Form

Pseudo Name:

“The distinctiveness of Lesbian, Gay, Bisexual (LGB) persons affected by cancer treatment and impact on personhood: a participatory research study in Scotland”

I have read and understood the information sheet and this consent form. I have had an opportunity to ask questions about my participation.

I understand that I am under no obligation to take part in this study.

I understand that I have the right to withdraw from this study at any stage without giving any reason.

I agree to participate in this study.

Name of participant: _______________________________________

Signature of participant: _______________________________________

Signature of researcher:_______________________________________

Date: ___________________

Contact details of the researcher

Name of researcher: Gareth Hill

Address:
PhD Research Student, Nursing Division, School of Health Science
Queen Margaret University, Edinburgh
Queen Margaret University Drive
Musselburgh
East Lothian EH21 6UU

Email / Telephone: GHill1@qmu.ac.uk/ 0131 474 0000

QMU ETHICS APPLICATION Appendix F - Face to face sessions topic guide

Summary of topics being discussed over the two inquiry sessions

Initial questions/topics

Session 1

- Guidance for developing an identity map will be used. This has been piloted in 2 sessions to date.
- Can you show me/us what your identity means to you
- How has your identity developed over your lifetime?
- What matters most to you about your identity now?
- Has it changed (much) over your lifetime?
- Can you add what being LGB means to you?

Session 2

- How has cancer treatment affected your identity/your LGB identity?
- (positives and less positives)
- How have you felt about this?
- What does it mean to you to feel this?
- How would you prefer it to be different in any way?
- If you had to go through it again how might your identity be (further) effected?
- What needed to happen to prevent a reduction or loss of identity?

QMU ETHICS APPLICATION Appendix G - Example probing questions

Example of follow-up Probes: Rubin and Rubin (2005)

Type of Probe	**Purpose**	**Example**
Continuation Probes	To encourage the participant to continue talking about the present subject	“Mmm hmm. So…” “Then what?” “And…?”
Elaboration Probes	Encourage the participant for more detail or explanation of a particular concept	“Such as?” “Could you give me an example?” “Can you tell me more about that?”
Attention Probes	These let the participant know they are being listened to carefully which encourages elaboration.	“Ok, I understand” “That is interesting”
Clarification Probes	Asks the participant to explain something that the researcher does not follow or understand	“Could you run that by me again?” “Could you explain that to me again in a bit more detail?”
Steering Probes	To get back onto a topic that has gone off track	“Sorry I distracted you with that question, you were talking about… “So you were saying earlier that… let’s explore that…”
Sequence Probes	To explore causation or when event sequences are blurred	“Could you tell me what happened step by step?” “When did this happen?”
Evidence Probes	Asks what a person knows and how they came to their conclusions	“Could you give me an example?” “Are there specific instances when this happened?”
Slant Probes	Help the researcher to determine the lens through which people see and interpret their worlds	“How did you feel about (the incident / topic)?” Describe how that felt

Appendix 6 - Participant Information Sheet

Queen Margaret University
EDINBURGH

Information Sheet for Potential Participants

My name is Gareth Hill and I am a Registered Therapeutic Radiographer and a PhD research candidate from Centre for Person-centred Research Practice at Queen Margaret University in Edinburgh. As part of my course, I am undertaking a research project. The title of my project is: The distinctiveness of Lesbian, Gay, Bisexual (LGB) persons affected by cancer treatment and impact on personhood: a participatory research study in Scotland.

This study will look into how cancer treatment in health care services impact on the identity of Lesbian, Gay and Bisexual people.

Participants will be asked to share their thoughts on who they are and what matters to them and after this is established, participants will reflect on how their experiences of cancer treatment have affected aspects of their identity.

The findings of the project will be useful because it aims to work with LGB people, to find out if there are any distinct aspects of their treatment and care and to see how this has impacted on their sense of identity or personhood. With this information the research will then go on to shape a best practice guideline for hospital based cancer services and LGB people, as well as inform on education of future healthcare students.

This research is being funded by The Society and College of Radiographers

I am looking for volunteers to participate in the project who meet the following criteria:

- People who self-identify as LGB and are aged 18 or over
- LGB people who live in Scotland and have received treatment for cancer, including radiotherapy, in the past 10 years
- People who are able to sufficiently speak and understand English
- People who can participate in two sessions, each lasting approximately one to two hours

People who are currently undergoing or about to undergo treatments such as surgery, radiotherapy, brachytherapy and chemotherapy or have undergone treatment during the past three months will not be able to participate. This is because you are likely to have hospital appointments to keep as well as potential side effects to manage and we don’t want you to be overly inconvenienced by taking part in this study.

If you agree to participate in the study, I will ask you to participate in two face-to-face sessions to explore your experiences of cancer treatment. I will come to your home or another location of your choosing at a time that is convenient to you and each session will last approximately 2 hours. I will encourage you to have a key support person who knows you well with you during the sessions to help support you and assist in the discussion of your experiences.

In the first session, we will create an identity map (about you) with the help of a key person that supports you. This is a resource that will help you share your perceptions, feelings and thoughts about key life events and help us to talk together.

I am open to using a range of methods such as writing, metaphors, sculpting, photography and videography and art; and you should feel free to use what would be most useful to you. This is to help us focus on past care experiences in an engaging and creative way. However, if you are not used to creative methods, please do not worry or let that stop you taking part.

In the second session we will meet again for about an hour and we will explore how your cancer experience influenced or influences your identity and personhood.

Your experiences may either be positive or negative and you don’t need to share anything or answer any questions you are uncomfortable with. You are welcome to use anything that you feel would help you in this process. In the final stages of the second session I will suggest general discussion about your experience of the identity mapping and our discussions and invite any feedback you could offer me.

There is a risk that some people may become upset during a session. If this happens, you or your support person can pause, have a break, or stop the session at any time. You will also be given contact details for your local cancer support services if you would like to talk in more depth about any of the experiences that we explore. The whole process should take no longer than 2 hours per session with comfort breaks as you need them. You are free to withdraw from the study at any stage and you do not have to give a reason.

The sessions will be audio-recorded to help me revisit what you have said and create a transcript of our discussions. These transcripts will then be themed and analysed to see if there is anything that can be learnt from your experiences and how these compare to other research and current guidance. I would also like to take a picture of your identity map but will make sure you cannot be identified in any way. Your anonymised results will then be joined up with other people’s experiences and examined further. You will be offered the opportunity to feedback on the transcripts and the themes if you wish.

After the research has been completed I will host a stakeholder workshop to discuss the key findings of the research. There will be representation from key cancer charities and LGB organisations that will look at the work and devise a set of national guidelines to help future LGB people affected by cancer. If you want to you can also participate, but this isn’t a requirement of you participating in the study.

All data will be anonymised as much as possible, but you may be identifiable from tape recordings of your voice. These recordings will be deleted as soon as possible. Also, any photographs that may be taken of your created identity maps may reveal personal details about you. Anything used that may be identifiable will be blurred. We will use a different name so that it will not be possible for you to be identified in any reporting of the data gathered. All your data will be destroyed seven years and the study has ended.

The anonymised results will be published in my thesis and in a journal or presented at a conference. The study findings will also be used to develop a workshop with key professional from LGB organisations and cancer services to develop best a set of best practice guidelines.

If you would like to contact an independent person, who knows about this project but is not involved in it, you are welcome to contact Debbie Baldie. Her contact details are given below.

If you have read and understood this information sheet, any questions you had have been answered, and you would like to be a participant in the study, please now see the consent form.

Contact details of the researcher

Name of researcher: Gareth Hill
Address: PhD Research Student, Centre for Person-Centred Research
Practice Division, School of Health Sciences
Queen Margaret University, Edinburgh
Queen Margaret University Drive
Musselburgh
East Lothian EH21 6UU

Email / Telephone: GHill1@qmu.ac.uk / 0131 474 0000

Contact details of the independent adviser

Name of adviser: Dr Debbie Baldie

Address: Lecturer of Nursing, Nursing Division, School Health Sciences
Queen Margaret University, Edinburgh
Queen Margaret University Drive
Musselburgh
East Lothian EH21 6UU

Email / Telephone: DBaldie@qmu.ac.uk / 0131 474 0000

Appendix 7 - Eligibility criteria question form

Queen Margaret University
EDINBURGH

Eligibility criteria checklist

To be completed by the research team prior to consenting participants

Pseudo Name:

Date Completed:

The distinctiveness of Lesbian, Gay, Bisexual (LGB) persons affected by cancer treatment and impact on personhood: a participatory research study in Scotland

All participants must meet eligibility criteria based on the inclusion/exclusion criteria as detailed in the ethics section of the research protocol.

Section 1

Do you self-identify as Lesbian, Gay or Bisexual (LGB) and are aged 18 or over?
Yes/No

Do you who live in Scotland and have you received treatment for cancer, including radiotherapy, in the past 10 years?

Yes
/No

Are you able to sufficiently speak and understand English?

Yes/No

Are you able to participate in two face-to-face sessions lasting approximately 1-2 hours?

Yes/No

Are you currently undergoing or about to undergo invasive treatments such as surgery, radiotherapy, brachytherapy and chemotherapy or have undergone treatment during the past three months? Yes/No

Does the potential participant meet the eligibility criteria? If so, continue to the next section
Yes/No

Section 2

Are you happy to provide some contact details so I can post or email an information about the research to you?

Yes/No

Name:

Email address:

Postal address:

Are you happy for me to contact you after 48 hours after receiving the information?

Yes/No

How would you prefer me to contact you? (please tick) Telephone/Email/text/post

Telephone Number:

Best time to call:

Appendix 8 - Consent form

Queen Margaret University
EDINBURGH

Consent Form

Pseudo Name:

“The distinctiveness of Lesbian, Gay, Bisexual (LGB) persons affected by cancer treatment and impact on personhood: a participatory research study in Scotland”

I have read and understood the information sheet and this consent form. I have had an opportunity to ask questions about my participation.

I understand that I am under no obligation to take part in this study.

I understand that I have the right to withdraw from this study at any stage without giving any reason.

I understand that QMU will retain copies of my contact details to arrange face-to-face sessions, send back a copy of my session transcript for comment, and invite me to the stakeholder workshop.

I understand that all my personally indefinable data will be destroyed 12 months after the completion of the whole study, and that anonymised data will be retained for seven years for potential analysis but will be destroyed seven years after the completion of the research.

I agree to participate in this study.

Name of participant: ______________________________________

Signature of participant: ______________________________________

Signature of researcher: ______________________________________

Date: __________________

Contact details of the researcher

Name of researcher: Gareth Hill

Address: PhD Research Student, Nursing Division, School of Health Science
Queen Margaret University, Edinburgh
Queen Margaret University Drive
Musselburgh
East Lothian EH21 6UU
Email / Telephone: GHill1@qmu.ac.uk/ 0131 4

Appendix 9 – Recruitment letters

Queen Margaret University
EDINBURGH

LGB persons affected by cancer treatment and impact on personhood:

A participatory research study in Scotland

This sheet has been prepared to brief anyone who may wish to be involved informally in the development of the above study and its methods, or lend support in the raising awareness of the study in accordance with principles of community based participatory research. It is not a recruitment sheet and there is no requirement of those who have any informal discussions or contact with the research team to participate in the study.

The lives and health of LGB people have in recent times become more of a focus of attention as societal attitudes have changed. However, despite the recent legal reform and much advancement that has been made in UK society, the LGB community still cannot be fully assured that their healthcare is delivered in non-judgmental way, nor does it fully addresses their specific health needs. Delivering person-centred care is currently NHS policy within Scotland, but at present the needs and experiences of Lesbian Gay and Bisexual (LGB) persons affected by cancer are not fully understood. The focus of this research is to work with LGB persons and their support persons to explore the impact cancer treatment has on personhood. Participatory methods will be used to explore with the participants experiences of cancer treatment within Scotland. The overall aim of the research, at this point, is to establish a set of national guidelines with the help of people directly affected, that will be used to develop and improve person-centred cancer care in Scotland for persons identifying as LGB.

Research Question

1. How is LGB personhood impacted on by the experience of cancer care/treatment?

Aims

1. Explore with LGB persons with cancer, their experiences of being in the cancer care pathway and what this means for personhood.
2. To find out with LGB people any distinct needs.
3. To work with LGB people and their representatives and key stakeholders to develop and refine a set of best practice guidelines for cancer services and LGB people.
4. To contribute theoretically to knowledge on personhood/person-centredness.

Intended Outcomes

1. A conceptual model of LGB personhood.
2. A contribution to the evidence base on cancer treatment and care for persons identifying as LGB through a best practice guideline for hospital based oncology services and LGB people.
3. A theoretical contribution to person-centred practice research specifically personhood in the context of LGB human beings.

Contact details

Gareth Hill BSc (Hons) MSc FHEA
Affiliate Member Centre for Person-centred Practice Research
Queen Margaret University
Edinburgh
EH21 6UU
(0131) 474 0000 GHill1@qmu.ac.uk

Appendix 9 Continued – Recruitment letters

Gareth Hill BSc (Hons) MSc FHEA
Affiliate Member Centre for Person-centred Practice Research
Queen Margaret University
Edinburgh
EH21 6UU

(0131) 474 0000
GHill1@qmu.ac.uk

Dear Sir/Madam,

My name is Gareth Hill and I am a Registered Therapeutic Radiographer and PhD research candidate at the Queen Margaret University, based within the Centre for Person-Centred Research within the School of Health of Health Sciences. I wondered whether you would be able to help promote a piece of research that I am currently working on for my PhD by displaying the enclosed leaflet in your information library.

Title of Research: The distinctiveness of Lesbian, Gay, Bisexual (LGB) persons affected by cancer treatment and impact on personhood: a participatory research study in Scotland.

I am conducting research examining the experiences of Lesbian, Gay and Bisexual people following treatment for cancer and am aiming to explore in-depth, with up to twelve people, their experiences of cancer treatment in Scotland. I particularly want to establish how cancer treatment in health care services impacts on identity for LGB persons. Participants will be asked to reflect on how their experiences of cancer treatment have affected aspects of their own identity (personhood) through the creation identity maps and discussing their experience.
The lives and health of Lesbian Gay and Bisexual (LGB) people have in recent times become more of a focus of attention as societal attitudes evolve. However, despite recent legal reform across the UK countries and NHS policy in Scotland focusing on the delivering of person-centred care, LGB people still cannot be fully assured that their healthcare is delivered in non-judgmental way, or that it fully addresses their specific health needs. Further, the needs and experiences of LGB persons affected by cancer are not fully understood. Therefore, the focus of this research is to participate with LGB persons and supporters to explore the effects cancer treatment has on 'personhood' (i.e. identity and rights) will address the following aims and objectives:-

Aims

5. Explore with LGB persons with cancer, their experiences throughout the cancer care pathway.
6. Work with LGB people, their support persons and key stakeholders to develop guidelines for best practice for cancer services and LGB people.
7. Influence education of radiography professionals through developing an evidence-based cubiculum.
8. Contribute theoretically to knowledge of personhood/person-centredness.

Objectives

6. Find out with LGB people, any distinct aspects of their treatment and care.
7. Contribute to the evidence base of cancer treatment and care for persons identifying as LGB.

8. Develop a best practice guideline for hospital based oncology services and LGB people.
9. Embed the research findings within professional education.
10. Make a theoretical contribution to person-centred practice research specifically personhood in the context of LGB persons.

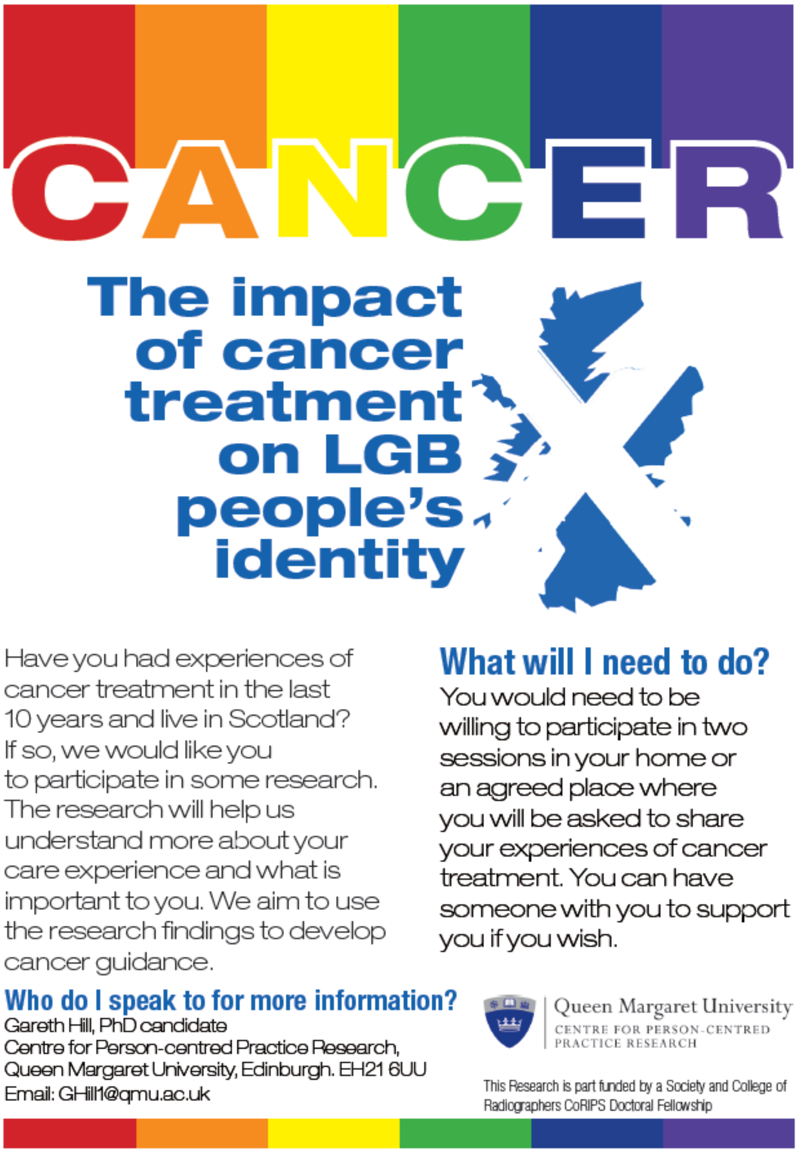
If you are able to help in any way I would be most grateful as I am keen to get participants from across Scotland. The study has received ethical clearance from the University Ethics Committee and the enclosed A5 promotion posters outline the study, providing my contact details for anyone who may be interested in taking part. Following completion of this research, I will also be willing to share my research findings with you in a format that would suit your needs; if this is something you would be of interest.

I look forward to hearing from you,

Yours Sincerely,

Gareth Hill

Appendix 10 - Publicity flyer



CANCER

The impact of cancer treatment on LGB people's identity

Have you had experiences of cancer treatment in the last 10 years and live in Scotland? If so, we would like you to participate in some research. The research will help us understand more about your care experience and what is important to you. We aim to use the research findings to develop cancer guidance.

What will I need to do?

You would need to be willing to participate in two sessions in your home or an agreed place where you will be asked to share your experiences of cancer treatment. You can have someone with you to support you if you wish.

Who do I speak to for more information?

Gareth Hill, PhD candidate
Centre for Person-centred Practice Research,
Queen Margaret University, Edinburgh. EH21 6UU
Email: GHill1@qmu.ac.uk

Queen Margaret University
CENTRE FOR PERSON-CENTRED PRACTICE RESEARCH

This Research is part funded by a Society and College of Radiographers CoRIPS Doctoral Fellowship

Appendix 11 - Example data extraction table - Lewis

Lewis was born in Scotland in 1959 and into a strong evangelical Christian family. He lived in an island community and was married for 23years and with 3 children from that marriage. He spend many years coming to terms with his sexuality and eventually separated in 2005 and was divorced in 2008. Shortly afterwards Lewis diagnosed with bladder cancer and had surgery to remove this. Since then he has had a local recurrence but is now currently clear. He is now remarried living in the south-east of England with his new husband and is a qualified allied health professional.

Disorienting dilemma

On care needs:

“During that time I split up with my wife. I went to my GP, and told her that I was struggling a bit as I was going through a separation…. I was having a lot of stress with that, and a lot of hassle with work. What I wanted was some counselling, when I split up with my wife, she told everyone that I was Gay, and that was the reason why she was having an affair, and it was because I was gay and I had no one to talk to” – session one 11 minutes, 1 seconds

On sexuality:

“I was going to counselling, and I was gay, and effectively we were trying to stay together and maintain our marriage” session two, six minutes, 45 seconds.

“There was definitely, definitely, homophobia against me. There were people that stopped talking to me in the hospital, there were people who treated me totally differently when I came out as gay, the cancer added to that, so I felt weak because I am gay and weak because I have cancer” 1 hour 33 minutes, 20 seconds, session

On receipt of care:

“I was talking to my GP about my situation, and she said you know that it’s wrong, she said you need to accept that you are in the wrong. She was a real demon in the church” Session 2, 12 minutes, 30 seconds

On diagnosis:

“My mum and dad are coming to see me, and I had to out myself only two months ago, then told then a few months later I have split up with my wife, and then a few months on I was having to tell them I had cancer” Session 2. 23 minutes, 3 seconds.

On coming out:

“I basically lost my full support network, erm because as a Christian, I am supposed to know that I am in the wrong. I had no one expect for talking to people on websites. Ive come out of a marriage, and I am gay, and suddenly I am having to live as a gay man” – session 1 – 11 minutes and 45 seconds.

Self -examination of assumptions

On religious beliefs:

“I hit some very low points in my cancer pathway, including considering suicide, and on more than one occasion, people telling me my cancer was a judgement from God and that it was because I had ‘CHOSEN’ to be gay.” – email exchange

“You know, why can't I be a Christian who believes that it's okay to be gay” session 1.

The Divine Weaver

My life is but a weaving
between my Lord and me;
I cannot choose the colours
he worketh steadily.

Oftentimes he weaveth sorrow
and I, in foolish pride,
forget he seeth the upper
and I the underside.

Not till the loom is silent
and the shuttles cease to fly,
shall God unroll the canvas
and explain the reason why.

The dark threads are as needful
in the Weaver's skilful hand
as the threads of gold and silver
in the pattern he has planned.

On sexual orientation

“I never believed that anyone liked me, I always believed that if they knew the truth they would reject me, and they would hate me. Part of the counselling that I had lead me to believe that I had a deep hatred of myself and didn’t love myself” session 1 17 minutes, 15 seconds

Critical reflection on assumptions

On sexuality

“I got to 39 and I have prayed for so many years for this to go away and have tried not to be gay, am I going to go through my world life to not know what it is like to love a man, to hold a man, to kiss a man you know all of that. So I am not proud to admit it, but yeah, I did meet someone when I was 40 and things happened.” – session 1. 15 minutes

On religious beliefs

“I was as a Christian at that time, I didn’t act on anything. I started looking back on my life, I don’t know if it was a midlife crisis, but I started looking back, and asking if I had done things differently would I have ended up where I am now’ – sessions 1 16 minutes, 14 seconds.

On own attitudes

“I was very anti-gay, because If I showed any sympathy, then people would suspect. Erm, when I first told my mum and dad and they said I was abhorrent to them, and when I married they sent me a really horrible letter.” 1 hrs 6 minutes, 15 seconds, session 2.

Recognition of dissatisfaction

On care experience:

‘Not once did anyone discuss my sexuality or the effect any treatment could have on my love life - that was ignored’ – email exchange

On relationships:

“During that time, I was becoming the gossip of the island. My wife told me to leave, I didn’t leave my wife, I was told to leave.” Second session 41 minutes, 15 seconds

On being confronted about his sexuality:

“He got a mission, and his mission was, he grabbed me by the army and said that’s what gods told me to tell you, because I have the gift of prophecy and he’s told me to tell you that your cancer is a punishment from god. I felt so angry, I could cry…. This was in the public library in the high street” 42 minutes, 20 seconds, session 2.

On labelling:

“Queer, don’t get that. Don’t ever ever call me queer, to me that’s such an insult. I don’t get that work, I think it’s appalling, its on of these worse things you could every call someone when I was a kid. Why would you want to own that?!”. 1hr 41 minutes, 20 seconds, session 2

Exploration of alternatives

On coming to terms with sexuality

“I felt worthless because I was gay, I had cancer and nobody really cared. I felt that my parents and family would be better off without me and they as kids would come to terms easier with a dead Dad than one who was gay and had cancer” – follow-up email

I did things without her knowing, and I never confessed them to her, but after about a year I had my first experience. I told her that I was gay, she was great at that time and was really supportive. Then, when we moved up to the island, she fell in with this woman’s group through church, and then she was like it’s a choice” session 1. 19 minutes 45 seconds

On counselling

“I had read books, Christian books, on both sides and this was like something that I had chosen. I was put under a lot of pressure from the church and those individuals and I did seek help from a Christian group. At the group the guy said it was ok to be gay, but you cant act on those feelings” session one 21 minutes and 20 seconds

Plan for action

On coming to terms with sexuality

“I told her my plan was to take all the tablets, drink the whisky then when things became fuzzy, I would let the handbrake off and let the car roll over the cliff onto the rocks below. If the fall and drugs didn’t kill me then the sea would carry me off. No-one would know and I’d not be found.” – follow-up email

Acquisition of new knowledge

On counselling and coming to terms:

“I did go and see this guy, one thing he did was really good. During my counselling, I talked about my brother and several other people, and he helped me, he said your exercise for to get is to write down a list of everything that these people have done to hurt you and what they’ve done. Then I went to see him the next day and he said, right this is your choice, you can either bury or burn those lists, he said whichever one you do it’s a final act. Whatever you do it’s a final act, you burn them or bury them. I chose burying them, and I went to a wood and buried them” – session 2 – four minutes and 45 seconds

Experimentation with roles;

On establishing new relationships/dating:

“My life was like I have this cancer, and anyone I meet I thought I would say. Really interesting, on gay websites, and fold are like, I would only meet if you go bare and that kind of thing, but I would say, well I cant. Then someone would say oh, you’re prude. Then you would be like, well no I’m not, I have bladder cancer and I cant risk any kind of infection.” 57 minutes 12 second, session 2.

“Guys with HIV were quite sympathetic, they were like well you have a long term health condition, join the club.” 58 minutes, 2 seconds, session 2.

“I was seeing someone, and he wanted something more, and this was in my up and down year. I needed to go in for another operation, and I got this dear John letter, and he was like I cant cope. We got on like a house on fire, and I wasn’t looking for anything as I was just out of my marriage, erm he was thinking he wanted more than that, and he couldn’t cope with my cancer. I have mixed feelings about that, but I did understand.” 1 hr and 15 seconds. Session 2

Building of competence and self-confidence in new roles and relationships;

On sexuality:

“I had spent my whole life praying, that god would take it away from me I am not camp….I didn’t conform to what my own step typical image of a gay man was, and I still feel I don’t. I have to tell people I am gay, they just don’t realise” – Session 1. 13minutes, 13 seconds.

On care providers:

“My doctor, he was gay as-well. He was good shoulder, you know, because he was kind of where I wanted to be. I didn’t fancy him or anything, I had got no one else, I had lost my network. No one else wanted to have anything to do with me.” Session 2. 13 minutes, 53 seconds

Reintegration of new perspectives into one’s life

On coming out:

“There was a hospital Chaplin that came into the ward…. I told him I’ve just been diagnosed with cancer, and I came out to him. And I said people are going to say that this is me being punished, and this judgement. He looked at me and said, I know a lot of gay people and you are you. That was really good, and I held on to that. I felt despite all these people thinking that I had changed, I felt I was who I had always been” 34 minutes, 46 seconds, session 2.

On diagnosis:

“Looking back, it was strange, I felt guilty because I had cancer. I did feel quite guilty.” 36 minutes, 21 seconds. session 2

On new husband:

“The second time it came back, I had my husband with me, and he was sat beside me and we talked about all the treatment options and stuff.” 1 hr 10 minutes, second session

On life after treatment:

New partner and remarried, out to family.


Jeff & Matt

Appendix 12 – Stakeholder feedback initial Draft Guidance Pack

Gareth Hill BSc (Hons) MSc FHEA
Affiliate Member Centre for Person-centred Practice Research
Queen Margaret University
Edinburgh
EH21 6UU

(0131) 474 0000
GHill1@qmu.ac.uk

Dear Sir/Madam,

My name is Gareth Hill and I am a Registered Therapeutic Radiographer and PhD research candidate at the Queen Margaret University, based within the Centre for Person-Centred Research within the School of Health of Health Sciences. I have previously been in contact with you as I have developed and conducted my PhD research.

Title of Research: The distinctiveness of Lesbian, Gay, Bisexual (LGB) persons affected by cancer treatment and impact on personhood: a participatory research study in Scotland.

Over the course of the research I have worked with Lesbian, Gay and Bisexual people following treatment for cancer and explored in-depth with nine participants, their experiences of cancer treatment in Scotland.

I particularly wanted to establish how cancer treatment in health care services impacted on identity for LGB persons. Participants were asked to reflect on how their experiences of cancer treatment have affected aspects of their own identity (personhood) through creating identity maps and discussing their experiences. Findings of the research showed that participants had mixed experiences - some had very positive accounts of care, and others had negative experiences.

Based on people's experiences, I have developed the attached practitioner guide as an output of the research. Participants wanted the research to produce something that informs practice and improves the care of future LGB people affected by cancer. I would be most grateful if you would be able to offer some feedback on the attached draft guide. I have marked in boxes areas where wording cannot be changed, but would welcome your views on the contents of the draft guide, and whether you feel these are appropriate.

Once the contents are finalised the practitioner guide will be shared with a graphic art designer who will improve the aesthetic appearance, but I am particularly keen at this stage to gain your feedback on the contents of the document. I have included a feedback form for you to use if you wish and your responses will be only used to inform the contents of this guide. Your responses and feedback will not be reproduced and will be kept confidential. I am happy to arrange a phone call or video call if you would prefer to provide verbal feedback.

I look forward to hearing from you,

Yours Sincerely,

Gareth Hill
GHill1@qmu.ac.uk

CANCER

Support Lesbian, Gay and Bisexual people with cancer
A Practitioner Guide

This guide has been produced as an output of research undertaken at Queen Margaret University, Edinburgh, exploring the experiences of Lesbian, Gay and Bisexual people affected by cancer. The lives and health of LGB people have in recent times become more of a focus of attention as societal attitudes have changed. However, despite the recent legal reform and much advancement that has been made in UK society, LGB communities still cannot be fully assured that their specific health needs are being addressed and that healthcare is delivered in non-judgmental ways.

This research was part-funded by the College of Radiographers as part of its commitment to conduct research for the betterment of patients and carers who undergo cancer care. This research recruited nine participants from across Scotland with a range of experiences and enabled them to have a voice that informs practice. In keeping with the principles of the research the guidance has been devised in collaboration with the participants and their individual voices are present in the recommendations. Many of the participants had very positive experiences of the services they accessed and this has been taken into account when creating the following recommendations:

Recommendation 1: Practitioners should support disclosure of sexual orientation in a non-judgemental way.

> *"I would like to come out gracefully, just drop it into the conversation, but make it just seem the most natural thing in the world, so there's no awkwardness about it"* - Susy

Practitioners need to be mindful of practicing in a heterosexist way and making assumptions about someone's sexual orientation. LGB people are more likely to come out to staff if they feel comfortable and safe to do so. Training for non-judgemental, relationship-based working is key. Asking questions about people's circumstances without the use of assumptions or gender can help LGB people to disclose rather than correct a practitioner.

Recommendation 2: Practitioners should always be cautious of asking scripted questions and reacting to people's responses in a negative or surprised way.

> *"I'm forever asked if I could possibly be pregnant - every time I'm scanned, for example. Only once have I jokingly said that would be impossible as I'm a lesbian (as well as the fact I have had my ovaries removed!). The woman I was speaking to didn't laugh or make any further comments. Anyway, I just answer, "No" now"* -Tate

Practitioners should be mindful about asking people questions that are presumptive and guided by what they anticipate someone may say, such as questions regarding pregnancy status. It is also important to be non-judgemental in reactions to responses that practitioners don't expect. Negative and surprised reactions from can undermine LGB people's confidence in your ability to provide non-judgemental care.

Recommendation 3: Practitioners should know where to signpost LGB people who need mental health support.

> *"I felt worthless because I was gay, I had cancer and nobody really cared. I felt that my parents and family would be better off without me and they as kids would come to terms easier with a dead Dad than one who was gay and had cancer"* - Lewis

LGB people can be signposted to local cancer support through Macmillan and Maggie's Centres. Both are committed to supporting all persons affected by cancer, no matter what their sexual orientation is.

Recommendation 4: Practitioners should be mindful of how LGB people may be feeling about appointments.

> *"I don't express affection, physical affection with my partner, very much in public. The reason for that is that's quite loaded I think to do with LGBT history and the social acceptability*" - Evan
>
> *"Not only am I waiting to find out if I have cancer or not, I'm also worrying about the people in the waiting area are they thinking that I'm weird... I am thinking about that.… It's like just another thing"* – Tate

Many LGB people don't feel comfortable showing physical affection in public or in front of people they don't know. This includes hand-holding and comfort they may express when supporting someone that is close to them that is affected by cancer.

Recommendation 5: Practitioners must recognise that LGB people have next-of-kin with the same status as those of heterosexual people.

> *"She came back, actually quite discreetly, managed to say 'ooh, you know, your form says you were widowed, but then you said you were lesbian', and then I had to say, well actually, it was my civil partner that died, and I ticked the widowed box. That was horrible"* - Susy

Some LGB people find that their doctor, nurse, radiographer, or other health professionals assume they are heterosexual and/or don't think beyond the label. Practitioners need to be mindful that LGB people have relationships with the same status as straight persons and that these relationships are just as meaningful.

Recommendation 6: Practitioners devising health information targeted at the LGB populations need to be cautious when using labels.

> *"Queer, don't get that. Don't ever, ever, call me queer, to me that's such an insult. I don't get that word, I think it's appalling, it's one of these worse things you could ever call someone when I was a kid. Why would you want to own that?!"* - Lewis

Many LGB people have uncomfortable associations with specific labels, especially those that have been used in a derogatory sense, or as a means of previous discrimination or abuse. Opportunities should be sought to include representation of LGB people on patient information groups and when designing LGB literature.

Recommendation 7: Practitioners should be prepared to discuss the effects of cancer on physical intimacy.

> *"When we got to the point of being intimate for the first time, I mean, I think my girlfriend had no idea what to expect, she wasn't even clear at that point if I'd had a mastectomy"* - Susy
>
> *"After treatment, and I was very tired, we couldn't be physically intimate. I just stopped having sex with him a long time ago, and it was over"* - Drew

LGB people may feel more unconformable about talking about the effects of cancer on physical intimacy. Practitioners should approach these conversations sympathetically and, where needed, seek additional support for themselves and the LGB person. In addition, written advice and support should be created to be inclusive of people who engage in same sex activity. Further sign posting to LGB specific advice and support is contained in the additional resources section of this document.

Research Details

This research worked in-depth with LGB participants and their support persons, exploring impacts of cancer treatment on personhood (i.e. long-term wellbeing and identity). It is underpinned by person-centred philosophy with participatory research principles (from participatory inquiry). I worked with participants to co-create methods of exploring people's experiences and the research findings. This research is innovative in Therapeutic Radiography because it employed person-centred methods and philosophy in its design, and sought to develop a new understanding of how cancer treatment has affected LGB persons' identities.

Nine participants were recruited into the research and explored how cancer treatment had impacted on them. Participants' accounts revealed a broad range of issues that both corroborate and build on the existing evidence base. LGB people in this research explored dilemmas in the context of their own care experience and holistic needs, and these form the basis of the accounts of care provided in this guidance.

The study received ethical clearance from the University Ethics Committee. Frrom the outset we sought to work with people directly affected and stakeholders in healthcare to establish a set of practitioner guidelines that would develop and improve person-centred cancer care for persons identifying as LGB. The principal investigator in the research is Gareth Hill, a Registered Therapeutic Radiographer and PhD research candidate at Queen Margaret University, based within the Centre for Person-centred Practice Research within the School of Health Sciences.

Gareth Hill BSc (Hons) MSc FHEA
Affiliate Member Centre for Person-centred Practice Research
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Additonal resources

www.queeringcancer.ca Queering Cancer provides online resources of information and stories aimed at supporting LGBTQ2+ community with cancer.

www.prostatecanceruk.org Prosate Cancer UK provide a wealth of inromation designed to support gay and bisexual people with prostate cancer.

www.outwithprostatecancer.org.ukOut with Prostate Cancer prostate cancer support group is based in Manchester, however can offer online support to persons across the UK and overseas.

Macmillan's "*Supporting LGBT people affected by cancer"* provides guidance on facilitating the disclosure of sexual orientation as well as other more general support.

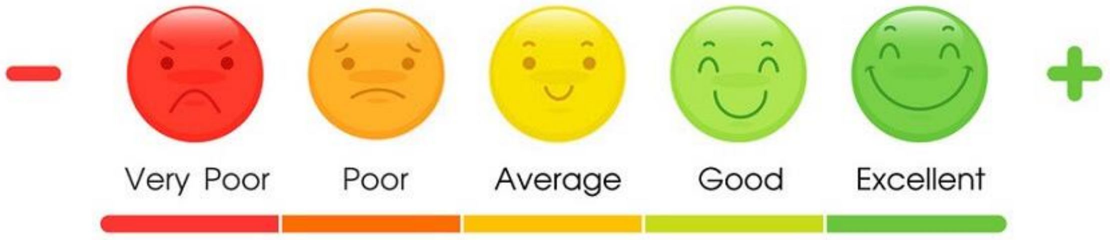
Queen Margaret University
EDINBURGH

Practitioner Guide - Feedback sheet

1. How best would you describe your connection with this research - please tick all that apply

- A person who has received treatment for cancer ....
- A person who has supported someone with cancer ....
- A representative from an organisation/key stakeholder with interests in this research (please specify) ....
- Other (please specify) ....

2. Please indicate how happy you are with the introductory and background information contained within the guidance on the scale below:



3. Please indicate any changes that you think could/should be incorporated in the introductory and background information?

4. Please indicate how happy you are with the recommendations contained within the guidance on the scale below:

5. Please indicate any changes you think could / should be incorporated in the recommendations?

6. Please indicate how happy you are with the additional resources section of the guidance on the scale below:

7. Please indicate any changes that you think could / should be incorporated in the additional resources?

8. Please provide any further feedback or comments that you feel would be useful to developing this guidance:

Appendix 13 – Final Guidance agreed with stakeholder and participants

Please note the version will be sent to a graphics art designer prior to final publication

Support Lesbian, Gay and Bisexual people with cancer
A Practitioner Guide

This guide has been produced as an output of research undertaken at Queen Margaret University, Edinburgh, exploring the experiences of Lesbian, Gay and Bisexual people affected by cancer. The lives and health of LGB people have in recent times become more of a focus of attention as societal attitudes have changed. However, despite the recent legal reform and much advancement that has been made in UK society, LGB communities still cannot be fully assured that their specific health needs are being addressed and that healthcare is delivered in non-judgmental ways[1,2,3].

This research was part-funded by the College of Radiographers as part of its commitment to conduct research for the betterment of patients and carers who undergo cancer care. This research recruited nine participants from across Scotland with a range of experiences and enabled them to have a voice that informs practice. In keeping with the principles of the research the guidance has been devised in collaboration with the participants and their individual voices are present in the recommendations. Many of the participants had very positive experiences of the services they accessed and this has been taken into account when creating the following recommendations:

Recommendation 1: Practitioners should support disclosure of sexual orientation in a non-judgemental way.

> *“I would like to come out gracefully, just drop it into the conversation, but make it just seem the most natural thing in the world, so there's no awkwardness about it”* - Susy

Practitioners need to be mindful of practising in a heteronormative way and making assumptions about someone’s sexual orientation. LGB people are more likely to come out to staff if they feel comfortable and safe to do so. Education for non-judgemental, relationship-based working is key. Asking questions about people’s circumstances without the use of assumptions or gender can help LGB people to disclose rather than correct a practitioner. Staff should be need to recognise the diversity of the people they meet, and should use open and neutral conversations such, “Do you have a partner?” or “Have you someone at home that looks after you?” In addition, relevant healthcare documentation should include options such as civil partnerships.

Recommendation 2: Practitioners should always be cautious of asking leading questions and reacting to people’s responses in a negative or surprised way.

"I'm forever asked if I could possibly be pregnant - every time I'm scanned, for example. Only once have I jokingly said that would be impossible as I'm a lesbian (as well as the fact I have had my ovaries removed!). The woman I was speaking to didn't laugh or make any further comments. Anyway, I just answer, "No" now" -Tate

Practitioners should be mindful about asking people questions that are presumptive and guided by what they anticipate someone may say, such as questions regarding pregnancy status. It is recognised that staff will have to ask people about their pregnancy status for example under their responsibilities outlined in the Ionising Radiation, (Medical Exposure) Regulations. However, it is also important to be non-judgemental in reactions to responses that practitioners don't expect. Negative and surprised reactions from can undermine LGB people's confidence in your ability to provide non-judgemental care. Having knowledge of clinical facts in advance of discussions where possible, and using neutral professional responses is important to prevent misunderstandings in care.

Recommendation 3: Practitioners should know where to signpost LGB people who need mental health support.

"I felt worthless because I was gay, I had cancer and nobody really cared. I felt that my parents and family would be better off without me and they as kids would come to terms easier with a dead Dad than one who was gay and had cancer" - Lewis

LGB people can be signposted to local cancer support through Macmillan and Maggie's Centres. Both are committed to supporting all persons affected by cancer, no matter what their sexual orientation is. In addition, most large NHS Trusts and Boards have Equality and Diversity Champions and LGBTQ+ forums that can also signpost to more specialist support.

Recommendation 4: Practitioners should be mindful of how LGB people may be feeling about appointments and the health care environment.

"I don't express affection, physical affection with my partner, very much in public. The reason for that is that's quite loaded I think to do with LGBT history and the social acceptability" - Evan

"Not only am I waiting to find out if I have cancer or not, I'm also worrying about the people in the waiting area are they thinking that I'm weird... I am thinking about that.… It's like just another thing" – Tate

Many LGB people don't feel comfortable showing physical affection in public or in front of people they don't know. This includes hand-holding and comfort they may express when supporting someone that is close to them that is affected by cancer. Departments are encouraged the use of posters and encourage teams to wear Rainbow NHS badges to promote diversity and inclusion, and foster an environment that reaches out and endorses peoples individuality and identity.

Recommendation 5: Practitioners must recognise that LGB people have next-of-kin with the same status as those of heterosexual people.

"She came back, actually quite discreetly, managed to say 'ooh, you know, your form says you were widowed, but then you said you were lesbian', and then I had to say, well actually, it was my civil partner that died, and I ticked the widowed box. That was horrible" - Susy

Some LGB people find that their doctor, nurse, radiographer, or other health professionals assume they are heterosexual and/or don't think beyond the label. Practitioners need to be mindful that LGB people have relationships with the same status as straight persons and that these relationships are just as meaningful and legally equitable.

Recommendation 6: Practitioners devising health information targeted at the LGB populations need to be cautious when using labels.

> *"Queer, don't get that. Don't ever, ever, call me queer, to me that's such an insult. I don't get that word, I think it's appalling, it's one of these worse things you could ever call someone when I was a kid. Why would you want to own that?!"* - Lewis

Many LGB people have uncomfortable associations with specific labels, especially those that have been used in a derogatory sense, or as a means of previous discrimination or abuse. Opportunities should be sought to include representation of LGB people on patient information groups and when designing LGB literature. In addition, Equality and Diversity Champions and LGBTQ+ forums can assist in feeding back when developing information.

Recommendation 7: Practitioners should be prepared to discuss the effects of cancer on physical intimacy.

> *"When we got to the point of being intimate for the first time, I mean, I think my girlfriend had no idea what to expect, she wasn't even clear at that point if I'd had a mastectomy"* - Susy
>
> *"After treatment I was very tired, we couldn't be physically intimate. I just stopped having sex with him a long time ago, and it was over"* - Drew

LGB people may feel more unconformable about talking about the effects of cancer on physical intimacy. Practitioners should approach these conversations sympathetically and, where needed, seek additional support for themselves and the LGB person. In addition, written advice and support should be created to be inclusive of people who engage in same sex activity. Further sign posting to LGB specific advice and support is contained in the additional resources section of this document.

Research Details

This research worked in-depth with LGB participants and their support persons, exploring impacts of cancer treatment on personhood (i.e. long-term wellbeing and identity). It is underpinned by person-centred philosophy with participatory research principles (from participatory inquiry)[4]. I worked with participants to co-create methods of exploring people's experiences and the research findings. This research is innovative in Therapeutic Radiography because it employed person-centred methods and philosophy in its design, and sought to develop a new understanding of how cancer treatment has affected LGB persons' identities.

Nine participants were recruited into the research and explored how cancer treatment had impacted on them. Participants' accounts revealed a broad range of issues that both corroborate and build on the existing evidence base. LGB people in this research explored dilemmas in the context of their own care experience and holistic needs, and these form the basis of the accounts of care provided in this guidance.

It must be noted that this research did not recruitment of transgendered or Intersex individuals who. It is known that the transgender cancer experience has been far from ideal and that many transgender persons have faced issues of discrimination when accessing care[5], they also have specific medical needs related to gender reassignment and cancer[6], that requires further understanding and was not within the exact scope of this research to investigate this area.

The study received ethical clearance from the University Ethics Committee. Frrom the outset we sought to work with people directly affected and stakeholders in healthcare to establish a set of practitioner guidelines that would develop and improve person-centred cancer care for persons identifying as LGB. The principal investigator in the research is Gareth Hill, a Registered

Therapeutic Radiographer and PhD research candidate at Queen Margaret University, based within the Centre for Person-centred Practice Research within the School of Health Sciences.

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Additonal resources

- Prosate Cancer UK provide a wealth of inromation designed to support gay and bisexual people with prostate cancer: www.prostatecanceruk.org
- Out with Prostate Cancer prostate cancer support group is based in Manchester, however can offer online support to persons across the UK and overseas. www.outwithprostatecancer.org.uk
- Live Through This is a patient-led support group for those who have felt on the outside of the usual support options. www.maggies.org/about-us/news/online-lgbtqi-support-in-partnership-with-live-through-this/
- The Gay and Lesbian Medical Association, Cancer in Our Lives. www.glma.org
- Queering Cancer provides online resources of information and stories aimed at supporting LGBTQ2+ community with cancer. www.queeringcancer.ca
- Centre for disease control Lesbian, Gay, Bisexual and Transgender Health www.cdc.gov/lgbthealth
- Simms/Mann-UCLA Integrative Oncology Program www.simmsmanncenter.ucla.edu
- CancerCare's LGBT Program www.cancercare.org/get_help/special_progs/lgbt.php
- The National Coalition for LGBT Health www.lgbthealth.net/
- LGBT Foundation www.lgbt.foundation
- Macmillan's "*Supporting LGBT people affected by cancer"* provides guidance on facilitating the disclosure of sexual orientation as well as other more general support. www.dmu.ac.uk/documents/research-documents/health-and-life-sciences/msrc/supporting-lgbt-people-with-cancer.pdf

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3. Stonewall UK. 2020. LGBT in Britain - Hate Crime and Discrimination. [online].[viewed 26th February 2021]. Available at: https://www.stonewall.org.uk/lgbt-britain-hate-crime-and-discrimination. [Accessed 19 October 2020].
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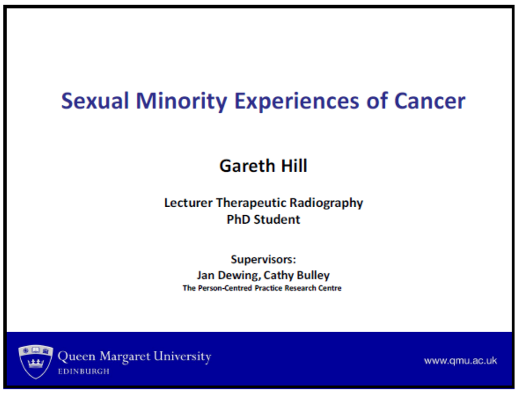
6. Ingham, M.D., Lee, R.J., MacDermed, D. and Olumi, A.F., 2018, December. Prostate cancer in transgender women. In *Urologic Oncology: Seminars and Original Investigations* (Vol. 36, No. 12, pp. 518-525). Elsevier.

Appendix 14 – Publications and Presentations related to the research

Annual radiotherapy Conference invited speaker– Society and College of Radiographer – January 2017



Sexual Minority Experiences of Cancer

Gareth Hill

Lecturer Therapeutic Radiography
PhD Student

Supervisors:
Jan Dewing, Cathy Bulley
The Person-Centred Practice Research Centre

Queen Margaret University
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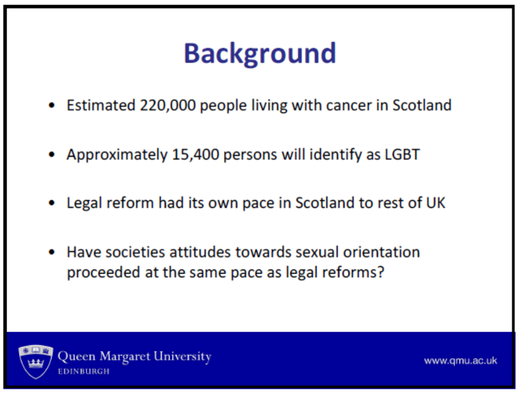
www.qmu.ac.uk



Background

- Estimated 220,000 people living with cancer in Scotland
- Approximately 15,400 persons will identify as LGBT
- Legal reform had its own pace in Scotland to rest of UK
- Have societies attitudes towards sexual orientation proceeded at the same pace as legal reforms?

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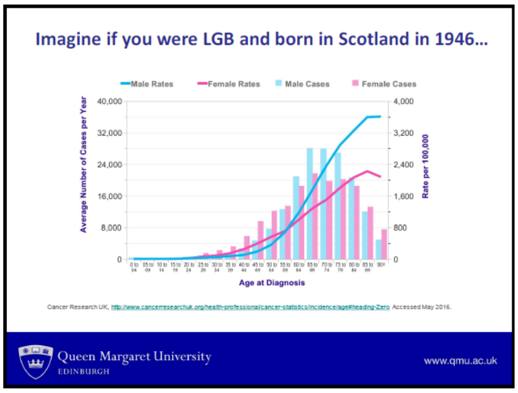

Imagine if you were LGB and born in Scotland in 1946…

Cancer Research UK, http://www.cancerresearchuk.org/health-professional/cancer-statistics/incidence/age#heading-Zero Accessed May 2016.

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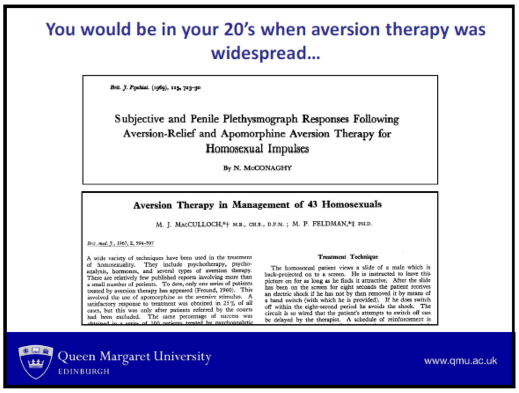

You would be in your 20's when aversion therapy was widespread…

Brit. J. Psychiat. (1969), 115, 723–30

Subjective and Penile Plethysmograph Responses Following Aversion-Relief and Apomorphine Aversion Therapy for Homosexual Impulses

By N. McCONAGHY

Aversion Therapy in Management of 43 Homosexuals

M. J. MACCULLOCH,*† M.B., CH.B., D.P.M.; M. P. FELDMAN,*‡ PH.D.

Brit. med. J., 1967, 2, 594–597

A wide variety of techniques have been used in the treatment of homosexuality. They include psychotherapy, psychoanalysis, hormones, and several types of aversion therapy. There are relatively few published reports involving more than a small number of patients. To date, only one series of patients treated by aversion therapy has appeared (Freund, 1960). This involved the use of apomorphine as the aversive stimulus. A satisfactory response to treatment was obtained in 25% of all cases, but this was only after patients referred by the courts had been excluded. The same percentage of success was

Treatment Technique

The homosexual patient views a slide of a male which is back-projected on to a screen. He is instructed to leave this picture on for as long as he finds it attractive. After the slide has been on the screen for eight seconds the patient receives an electric shock if he has not by then removed it by means of a hand switch (with which he is provided). If he does switch off within the eight-second period he avoids the shock. The circuit is so wired that the patient's attempts to switch off can be delayed by the therapist. A schedule of reinforcement is

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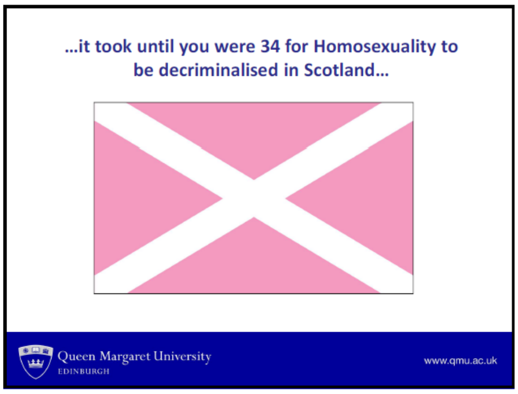

…it took until you were 34 for Homosexuality to be decriminalised in Scotland…

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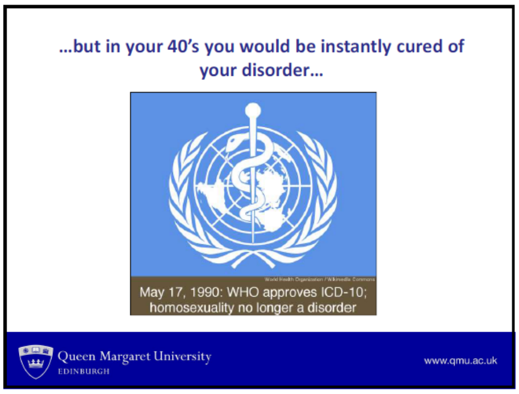

…but in your 40's you would be instantly cured of your disorder…

World Health Organization / Wikimedia Commons

May 17, 1990: WHO approves ICD-10; homosexuality no longer a disorder

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You would have to wait until you were 60 before it was illegal to be denied goods and services for being gay…

The Equality Act,
making equality real

You would be 68 before you could legally marry your partner…

…and now at the age of 70 you have cancer

Emerging area of research…

Journal of Cancer Policy 6 (2015) 11–22

Contents lists available at ScienceDirect

Journal of Cancer Policy

journal homepage: www.elsevier.com/locate/jcpo

Review

Sexual minority experiences of cancer care: A systematic review

Gareth Hill[a,*], Catherine Holborn[b]

[a] Queen Margaret University, Musselburgh, Edinburgh, EH21 6UU, United Kingdom
[b] Sheffield Hallam University, Faculty of Health and Wellbeing, Sheffield S102BP, United Kingdom

Wold wide view of LGB experiences of care categorised into several themes:

- Experiences of care
- Coping and Wellbeing
- Emotional Support
- Body Image
- Sexual Function

Emerging area of research…

European Journal of Cancer Care

Original Article

Exploring lesbian, gay and bisexual patients' accounts of their experiences of cancer care in the UK

J. FISH, PhD, PROFESSOR, Social Work and Health Inequalities, Centre for LGBTQ Research, De Montfort University, Leicester, & I. WILLIAMSON, PhD, PRINCIPAL LECTURER, Health Psychology, De Montfort University, Leicester, UK

FISH J. & WILLIAMSON I. (2016) *European Journal of Cancer Care*
Exploring lesbian, gay and bisexual patients' accounts of their experiences of cancer care in the UK

What do we know about Scotland?

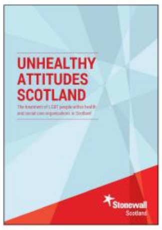
1 in 9 women felt that their partner was welcome during a consultation

Half have had negative experiences in the health sector in the last year

A third of men in have had a negative experience related to their sexual orientation

More than a third of men are not out to their healthcare professionals.

What do we know about Scotland?



Very Little in terms of cancer care

LGB persons have poor health care experience

Feel that needs are not being met

Fell reluctant to disclose sexual orientation with staff

Staff attitudes are sometimes less than progressive

Heteronormative Care

One in five felt that during the last year there was no opportunity to discuss sexual orientation, and they had sometimes had to stop mid-procedure to correct assumptions.

> ***"I was about to have an x-ray in hospital. The nurses and radiographer asked the routine question of whether there was any chance I could be pregnant, to which I replied in the negative. Without giving me the chance to explain further, they asked if I had a partner with whom I was sexually active, which I confirmed. They started to lecture me about the importance of being sure I was not pregnant before being x-rayed, telling me that there was no way I could possibly be sure I was not pregnant if I was having sex without contraceptives. I was not given a chance to speak at any length during this tirade and eventually had to shout "I AM A LESBIAN" (in front of the entire casualty ward) to get them to stop telling me off and give me the x-ray."***

Tabitha, 25

My PhD Research

Try to establish answers to the following research questions in a Scottish context:-

- Establish *if and how* LGB persons and their partners experience a nuance of discrimination when experiencing cancer care related to their sexuality
- Establish the reasons *why* LGB persons and their partners with cancer may experience a nuance of discrimination in an oncology hospital setting
- Establish *how* these issues can be addressed and ensure the confidence of persons in the LGB community

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How to go about this…

- Qualitative research design with strong focus on person centredness
- Explore with LGB persons with cancer, their experiences of hospital treatment and care
- To find out from LGB people the reasons for any differences (or discrimination) in their treatment and care
- To work with LGB people, their representatives, and key stakeholders to develop and test a set of principles of best practice and/or national guidance

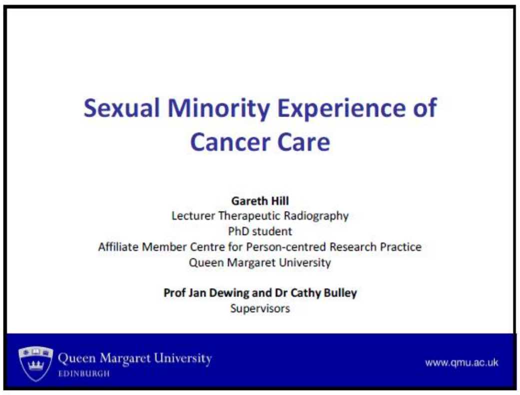
---

Recruitment Challenges

- Comprehensive strategy will be devised drawing on my local and national networks
- Awareness of the study the use of social and online media will be needed
- Targeted recruitment will be focused at voluntary sector organisations working in the LGB communities and LGB cancer support groups.
- Publicity materials will be designed, and distributed to LGBT groups, support agencies, individuals, twitter feeds, and Scottish LGBT venues to ensure maximum possibilities for recruitment into the study.

Thank you

Beatson Bootcamp study day – invited speaker – Glasgow May 2017



Sexual Minority Experience of Cancer Care

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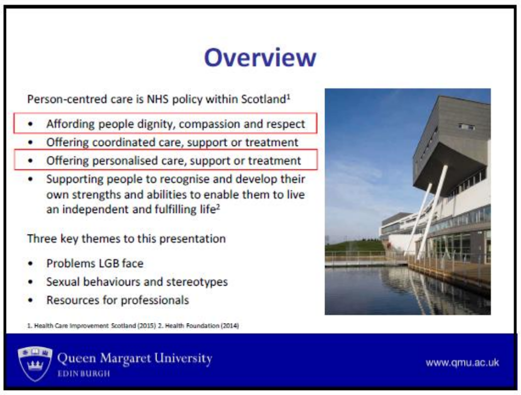

Overview

Person-centred care is NHS policy within Scotland[1]

- Affording people dignity, compassion and respect
- Offering coordinated care, support or treatment
- Offering personalised care, support or treatment
- Supporting people to recognise and develop their own strengths and abilities to enable them to live an independent and fulfilling life[2]

Three key themes to this presentation

- Problems LGB face
- Sexual behaviours and stereotypes
- Resources for professionals

1. Health Care Improvement Scotland (2015) 2. Health Foundation (2014)

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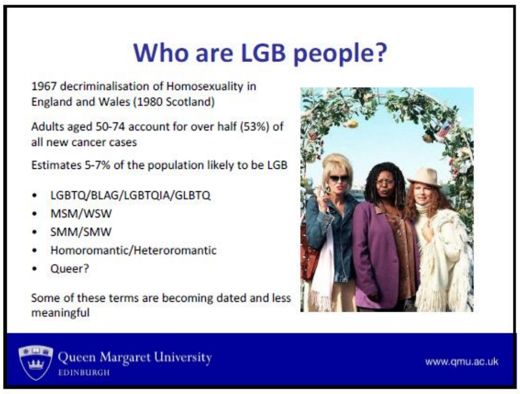

Who are LGB people?

1967 decriminalisation of Homosexuality in England and Wales (1980 Scotland)

Adults aged 50-74 account for over half (53%) of all new cancer cases

Estimates 5-7% of the population likely to be LGB

- LGBTQ/BLAG/LGBTQIA/GLBTQ
- MSM/WSW
- SMM/SMW
- Homoromantic/Heteroromantic
- Queer?

Some of these terms are becoming dated and less meaningful

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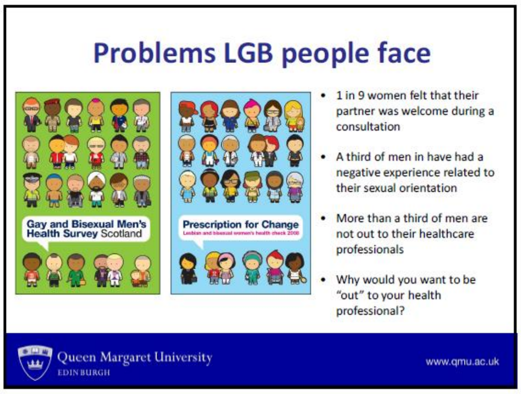

Problems LGB people face

- 1 in 9 women felt that their partner was welcome during a consultation
- A third of men in have had a negative experience related to their sexual orientation
- More than a third of men are not out to their healthcare professionals
- Why would you want to be "out" to your health professional?

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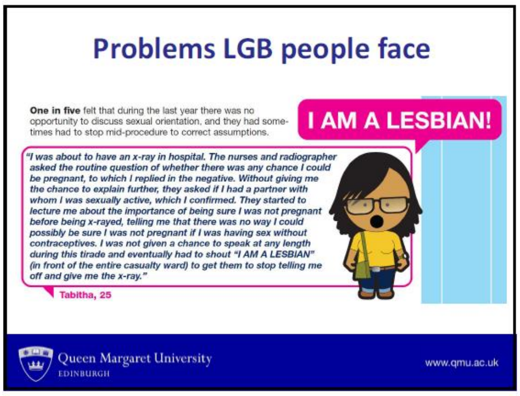

Problems LGB people face

One in five felt that during the last year there was no opportunity to discuss sexual orientation, and they had sometimes had to stop mid-procedure to correct assumptions.

"I was about to have an x-ray in hospital. The nurses and radiographer asked the routine question of whether there was any chance I could be pregnant, to which I replied in the negative. Without giving me the chance to explain further, they asked if I had a partner with whom I was sexually active, which I confirmed. They started to lecture me about the importance of being sure I was not pregnant before being x-rayed, telling me that there was no way I could possibly be sure I was not pregnant if I was having sex without contraceptives. I was not given a chance to speak at any length during this tirade and eventually had to shout "I AM A LESBIAN" (in front of the entire casualty ward) to get them to stop telling me off and give me the x-ray."

Tabitha, 25

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Problems LGB people face

- One out of five LGBT respondents experienced discrimination or less good treatment in Scotland's healthcare services
- Examples of staff not understanding that a same-sex partner can be a next of kin
- Concern about health professionals not being adequately trained to understand LGB issues

"There is a lack of recognition of the need for LGBT-focused healthcare and social support, organisations and departments need to recognise that some of their patients/clients will be LGBT, whether they're open about it or not."
Lesbian woman, 45-54, Edinburgh

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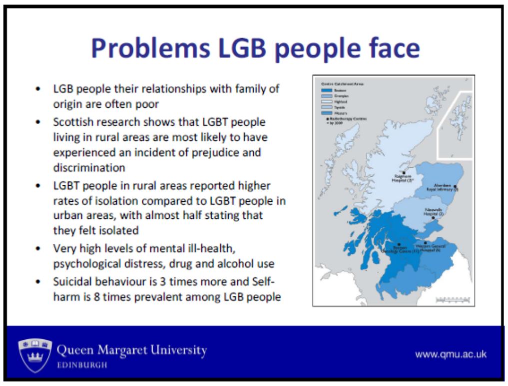
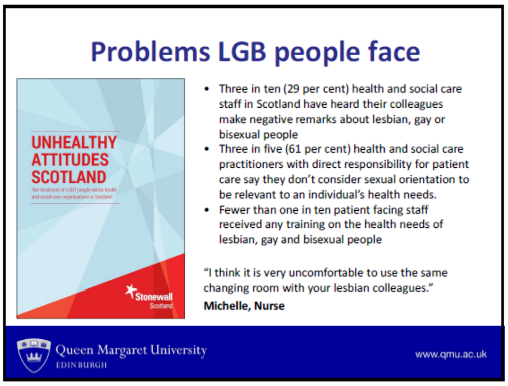


Problems LGB people face

- LGB people their relationships with family of origin are often poor
- Scottish research shows that LGBT people living in rural areas are most likely to have experienced an incident of prejudice and discrimination
- LGBT people in rural areas reported higher rates of isolation compared to LGBT people in urban areas, with almost half stating that they felt isolated
- Very high levels of mental ill-health, psychological distress, drug and alcohol use
- Suicidal behaviour is 3 times more and Self-harm is 8 times prevalent among LGB people

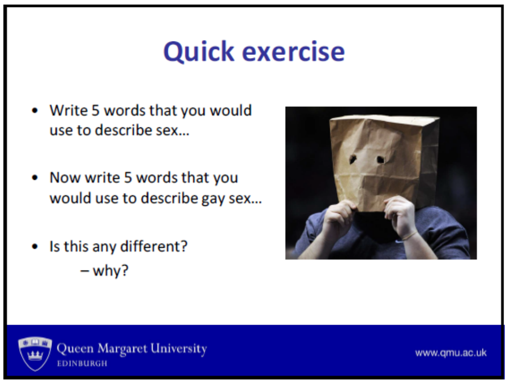


Problems LGB people face

UNHEALTHY
ATTITUDES
SCOTLAND
The treatment of LGBT people within health and social care organisations in Scotland
Stonewall
Scotland

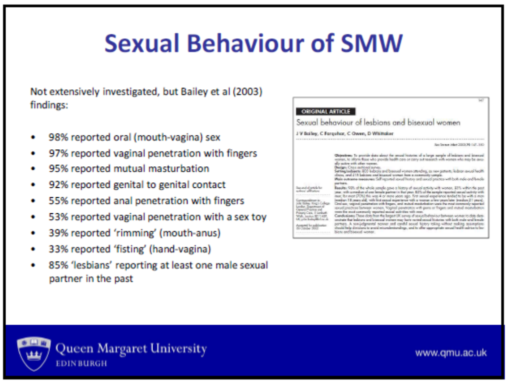
- Three in ten (29 per cent) health and social care staff in Scotland have heard their colleagues make negative remarks about lesbian, gay or bisexual people
- Three in five (61 per cent) health and social care practitioners with direct responsibility for patient care say they don't consider sexual orientation to be relevant to an individual's health needs.
- Fewer than one in ten patient facing staff received any training on the health needs of lesbian, gay and bisexual people

"I think it is very uncomfortable to use the same changing room with your lesbian colleagues."
Michelle, Nurse



Quick exercise

- Write 5 words that you would use to describe sex…
- Now write 5 words that you would use to describe gay sex…
- Is this any different?
  - – why?

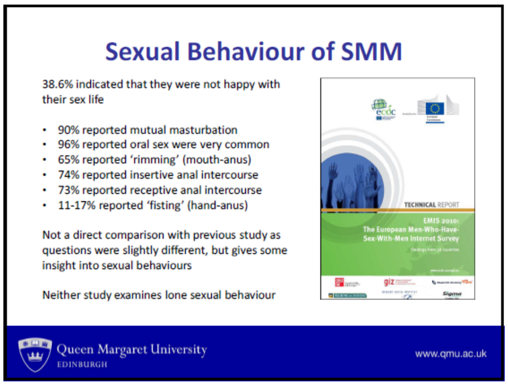


Sexual Behaviour of SMW

Not extensively investigated, but Bailey et al (2003) findings:

- 98% reported oral (mouth-vagina) sex
- 97% reported vaginal penetration with fingers
- 95% reported mutual masturbation
- 92% reported genital to genital contact
- 55% reported anal penetration with fingers
- 53% reported vaginal penetration with a sex toy
- 39% reported 'rimming' (mouth-anus)
- 33% reported 'fisting' (hand-vagina)
- 85% 'lesbians' reporting at least one male sexual partner in the past

ORIGINAL ARTICLE
Sexual behaviour of lesbians and bisexual women
J V Bailey, C Farquhar, C Owen, D Whittaker



Sexual Behaviour of SMM

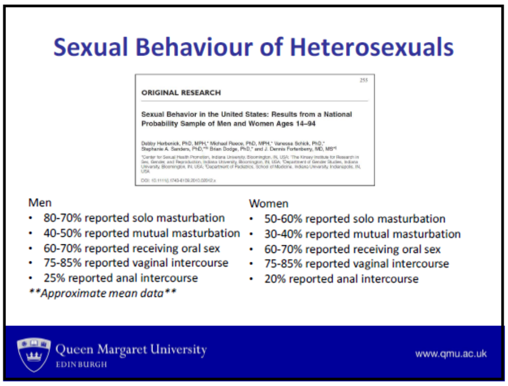
38.6% indicated that they were not happy with their sex life

- 90% reported mutual masturbation
- 96% reported oral sex were very common
- 65% reported 'rimming' (mouth-anus)
- 74% reported insertive anal intercourse
- 73% reported receptive anal intercourse
- 11-17% reported 'fisting' (hand-anus)

Not a direct comparison with previous study as questions were slightly different, but gives some insight into sexual behaviours

Neither study examines lone sexual behaviour

TECHNICAL REPORT
EMIS 2010:
The European Men-Who-Have-Sex-With-Men Internet Survey



Sexual Behaviour of Heterosexuals

ORIGINAL RESEARCH
Sexual Behavior in the United States: Results from a National Probability Sample of Men and Women Ages 14–94

Men
- 80-70% reported solo masturbation
- 40-50% reported mutual masturbation
- 60-70% reported receiving oral sex
- 75-85% reported vaginal intercourse
- 25% reported anal intercourse

****Approximate mean data*****

Women
- 50-60% reported solo masturbation
- 30-40% reported mutual masturbation
- 60-70% reported receiving oral sex
- 75-85% reported vaginal intercourse
- 20% reported anal intercourse

Stereotypes

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Not everyone fits in…

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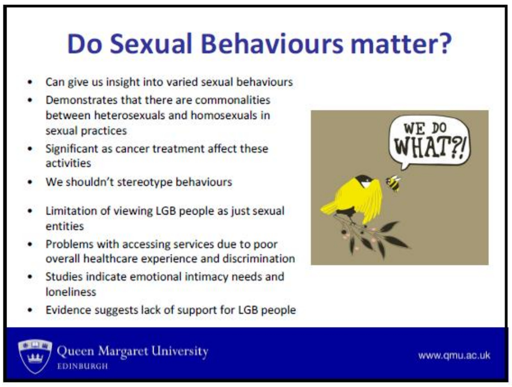

Do Sexual Behaviours matter?

- Can give us insight into varied sexual behaviours
- Demonstrates that there are commonalities between heterosexuals and homosexuals in sexual practices
- Significant as cancer treatment affect these activities
- We shouldn't stereotype behaviours
- Limitation of viewing LGB people as just sexual entities
- Problems with accessing services due to poor overall healthcare experience and discrimination
- Studies indicate emotional intimacy needs and loneliness
- Evidence suggests lack of support for LGB people

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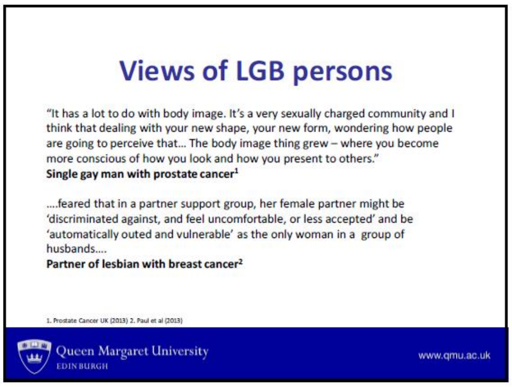

Views of LGB persons

"It has a lot to do with body image. It's a very sexually charged community and I think that dealing with your new shape, your new form, wondering how people are going to perceive that… The body image thing grew – where you become more conscious of how you look and how you present to others."
Single gay man with prostate cancer[1]

….feared that in a partner support group, her female partner might be 'discriminated against, and feel uncomfortable, or less accepted' and be 'automatically outed and vulnerable' as the only woman in a group of husbands….
Partner of lesbian with breast cancer[2]

1. Prostate Cancer UK (2013) 2. Paul et al (2013)

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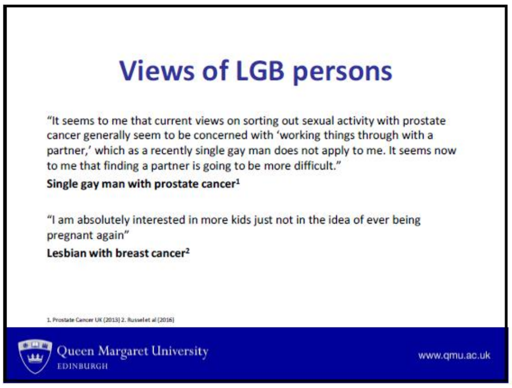

Views of LGB persons

"It seems to me that current views on sorting out sexual activity with prostate cancer generally seem to be concerned with 'working things through with a partner,' which as a recently single gay man does not apply to me. It seems now to me that finding a partner is going to be more difficult."
Single gay man with prostate cancer[1]

"I am absolutely interested in more kids just not in the idea of ever being pregnant again"
Lesbian with breast cancer[2]

1. Prostate Cancer UK (2013) 2. Russel et al (2016)

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Specific Resources

Case examples of practice are intended to support professionals to personalise care for LGBT people with cancer

Useful for staff as provides guidance on the following:-

- Involving partners and carers
- Coming out to health professionals
- Access to support
- Access to information

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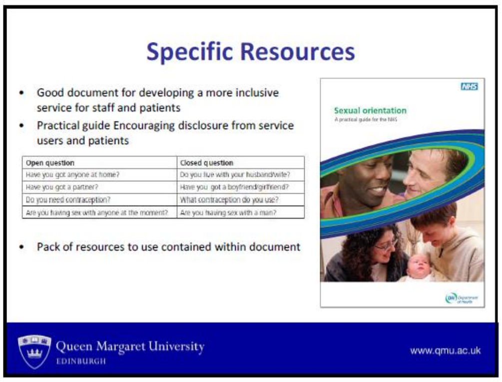

Specific Resources

- Good document for developing a more inclusive service for staff and patients
- Practical guide Encouraging disclosure from service users and patients

Open question	Closed question
Have you got anyone at home?	Do you live with your husband/wife?
Have you got a partner?	Have you got a boyfriend/girlfriend?
Do you need contraception?	What contraception do you use?
Are you having sex with anyone at the moment?	Are you having sex with a man?

- Pack of resources to use contained within document

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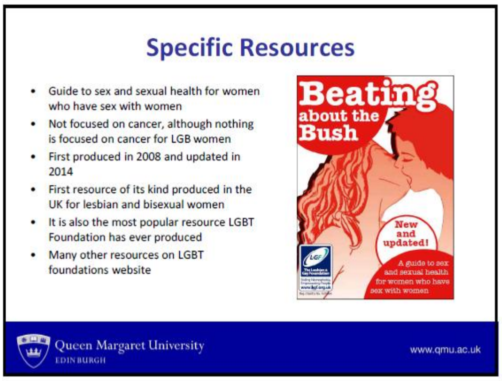

Specific Resources

- Guide to sex and sexual health for women who have sex with women
- Not focused on cancer, although nothing is focused on cancer for LGB women
- First produced in 2008 and updated in 2014
- First resource of its kind produced in the UK for lesbian and bisexual women
- It is also the most popular resource LGBT Foundation has ever produced
- Many other resources on LGBT foundations website

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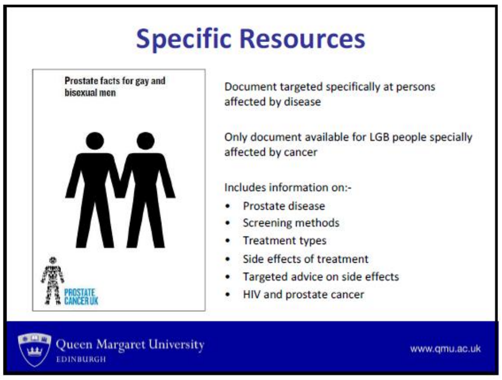

Specific Resources

Document targeted specifically at persons affected by disease

Only document available for LGB people specially affected by cancer

Includes information on:-
- Prostate disease
- Screening methods
- Treatment types
- Side effects of treatment
- Targeted advice on side effects
- HIV and prostate cancer

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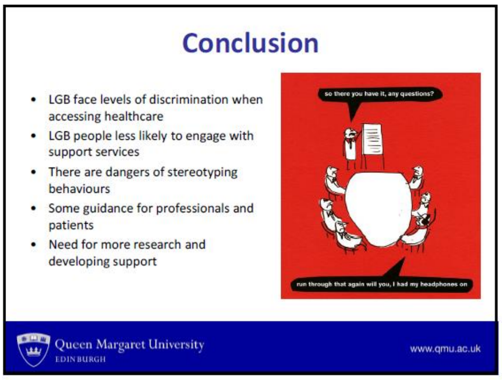

Conclusion

- LGB face levels of discrimination when accessing healthcare
- LGB people less likely to engage with support services
- There are dangers of stereotyping behaviours
- Some guidance for professionals and patients
- Need for more research and developing support

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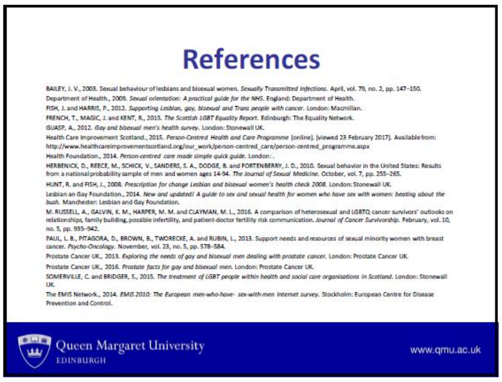

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FRENCH, T., MAGIC, J. and KENT, R., 2015. *The Scottish LGBT Equality Report.* Edinburgh: The Equality Network.

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Health Foundation., 2014. *Person-centred care made simple quick guide.* London: .

HERBENICK, D., REECE, M., SCHICK, V., SANDERS, S. A., DODGE, B. and FORTENBERRY, J. D., 2010. Sexual behavior in the United States: Results from a national probability sample of men and women ages 14-94. *The Journal of Sexual Medicine.* October, vol. 7, pp. 255–265.

HUNT, R. and FISH, J., 2008. *Prescription for change Lesbian and bisexual women's health check 2008.* London: Stonewall UK.

Lesbian an Gay Foundation., 2014. *New and updated! A guide to sex and sexual health for women who have sex with women: beating about the bush.* Manchester: Lesbian and Gay Foundation.

M. RUSSELL, A., GALVIN, K. M., HARPER, M. M. and CLAYMAN, M. L., 2016. A comparison of heterosexual and LGBTQ cancer survivors' outlooks on relationships, family building, possible infertility, and patient-doctor fertility risk communication. *Journal of Cancer Survivorship.* February, vol. 10, no. 5, pp. 935–942.

PAUL, L. B., PITAGORA, D., BROWN, B., TWORECKE, A. and RUBIN, L., 2013. Support needs and resources of sexual minority women with breast cancer. *Psycho-Oncology.* November, vol. 23, no. 5, pp. 578–584.

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SOMERVILLE, C. and BRIDGER, S., 2015. *The treatment of LGBT people within health and social care organisations in Scotland.* London: Stonewall UK.

The EMIS Network., 2014. *EMIS 2010: The European men-who-have- sex-with-men Internet survey.* Stockholm: European Centre for Disease Prevention and Control.

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Thank you

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UKIO
UK Imaging & Oncology
CONGRESS 2019

Personalise & Humanise
10-12 JUNE 2019 ACC LIVERPOOL

DISCLOSURE

- No relevant financial relationships exist

UKIO

The British Institute of Radiology
The College of Radiographers and
The Institute of Physics & Engineering in Medicine

Doctoral Den

Gareth Hill
PhD Candidate – CoR Doctoral Fellowship recipient

Affiliate Member Centre for Person-centred Research Practice
Queen Margaret University

Prof Jan Dewing and Dr Cathy Bulley
Supervisors

Queen Margaret University
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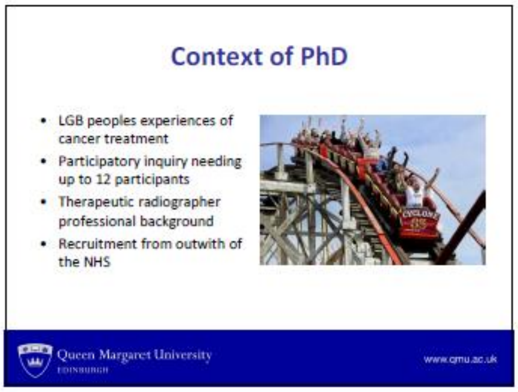

Context of PhD

- LGB peoples experiences of cancer treatment
- Participatory inquiry needing up to 12 participants
- Therapeutic radiographer professional background
- Recruitment from outwith of the NHS

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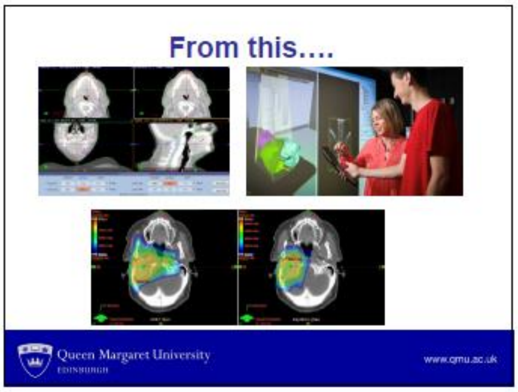

From this….

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To this…

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Quality supervision

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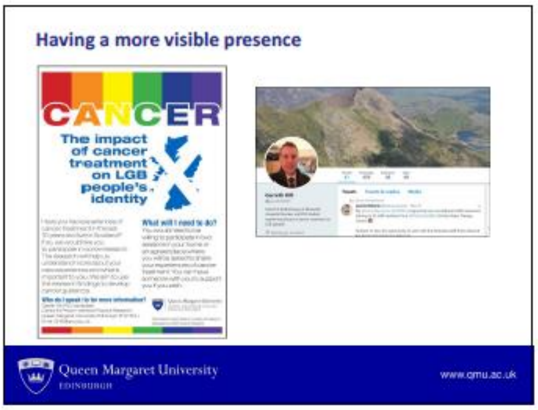
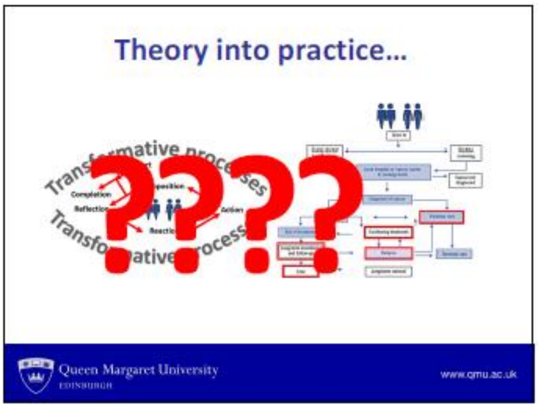
Resilience and support



Having a more visible presence

Challenging topics…



Theory into practice…

PhD – Persistence, hardwork and determination

"Hi Gareth,
I do not think my group would be able to assist with your research as to the best of my knowledge the group does not have any gay/bisexual members, if I am missing the point of your communication please contact me again."

"Hi Gareth,
I have to let you know that we cannot be involved with your research as we only participate within the partnership we have agreed between (Anon) Scotland and (Anon) University."

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Challenging my own assumptions…

DISCLOSURE

- No relevant financial relationships exist

The distinctiveness of LGB persons affected by cancer treatment and impact on personhood: a participatory research study in Scotland

Gareth Hill
PhD Candidate
Affiliate Member Centre for Person-centred Research Practice
Queen Margaret University

Prof Jan Dewing and Dr Cathy Bulley
Supervisors

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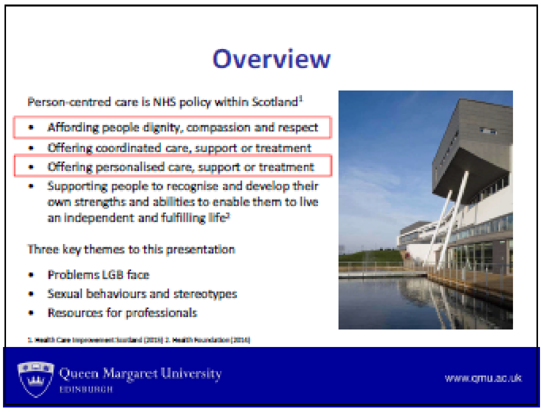

Overview

Person-centred care is NHS policy within Scotland[1]

- Affording people dignity, compassion and respect
- Offering coordinated care, support or treatment
- Offering personalised care, support or treatment
- Supporting people to recognise and develop their own strengths and abilities to enable them to live an independent and fulfilling life[2]

Three key themes to this presentation

- Problems LGB face
- Sexual behaviours and stereotypes
- Resources for professionals

1. Health Care Improvement Scotland (2016) 2. Health Foundation (2016)

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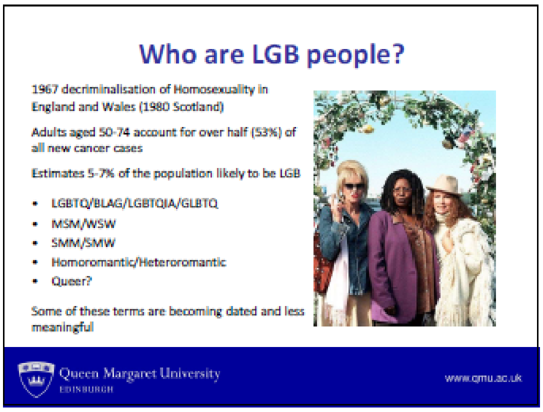

Who are LGB people?

1967 decriminalisation of Homosexuality in England and Wales (1980 Scotland)

Adults aged 50-74 account for over half (53%) of all new cancer cases

Estimates 5-7% of the population likely to be LGB

- LGBTQ/BLAG/LGBTQIA/GLBTQ
- MSM/WSW
- SMM/SMW
- Homoromantic/Heteroromantic
- Queer?

Some of these terms are becoming dated and less meaningful

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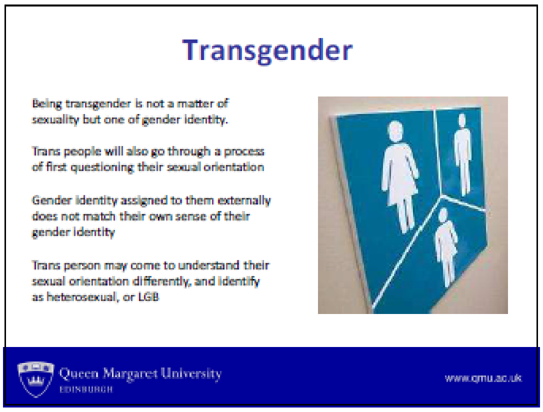

Transgender

Being transgender is not a matter of sexuality but one of gender identity.

Trans people will also go through a process of first questioning their sexual orientation

Gender identity assigned to them externally does not match their own sense of their gender identity

Trans person may come to understand their sexual orientation differently, and identify as heterosexual, or LGB

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Progressive Legislative reforms

1967 - Sex between two men over 21 is decriminalised in England and Wales
1980 - Decriminalisation in Scotland
1982 - Decriminalisation in Northern Ireland
1994 - The age of consent for two male partners is lowered to 18
2000 - The ban on gay and bisexual people serving in the armed forces is lifted
2002 - Same-sex couples are given equal rights when it comes to adoption
2003 - Gross indecency is removed as an offence
2004 - A law allowing civil partnerships is passed
2007 - Discrimination on the basis of sexual orientation is banned
2010 - Gender reassignment is added as a protected characteristic in equality legislation
2014 - Gay marriage becomes legal in England, Wales and Scotland

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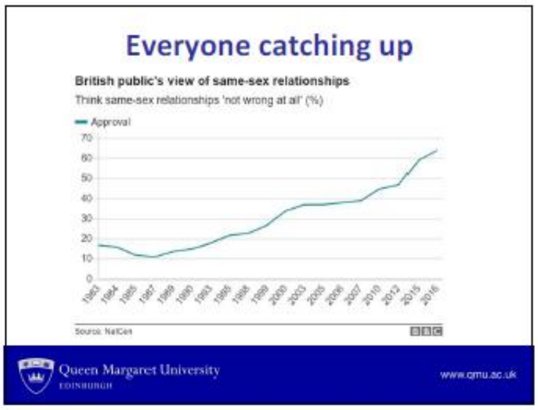

Everyone catching up

British public's view of same-sex relationships

Think same-sex relationships 'not wrong at all' (%)

Source: NatCen

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Problems LGB people face

- One out of five LGBT respondents experienced discrimination or less good treatment in Scotland's healthcare services
- Examples of staff not understanding that a same-sex partner can be a next of kin
- Concern about health professionals not being adequately trained to understand LGB issues

"There is a lack of recognition of the need for LGBT-focused healthcare and social support, organisations and departments need to recognise that some of their patients/clients will be LGBT, whether they're open about it or not."

Lesbian woman, 45-54, Edinburgh

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Problems LGB people face

- Three in ten (29 per cent) health and social care staff in Scotland have heard their colleagues make negative remarks about lesbian, gay or bisexual people
- Three in five (61 per cent) health and social care practitioners with direct responsibility for patient care say they don't consider sexual orientation to be relevant to an individual's health needs.
- Fewer than one in ten patient facing staff received any training on the health needs of lesbian, gay and bisexual people

"I think it is very uncomfortable to use the same changing room with your lesbian colleagues."

Michelle, Nurse

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Emerging area of research…

ORIGINAL ARTICLE

"It's not just about prostate cancer, it's about being a gay man": A qualitative study of gay men's experiences of healthcare provision in the UK

- Specific information needs
- Relationship with care providers
- Lack of Support Networks
- Changes in Relationships

European Journal of Cancer Care

Original Article

Exploring lesbian, gay and bisexual patients' accounts of their experiences of cancer care in the UK

- Issues around disclosure
- Making sense of poor care
- Alienation from support

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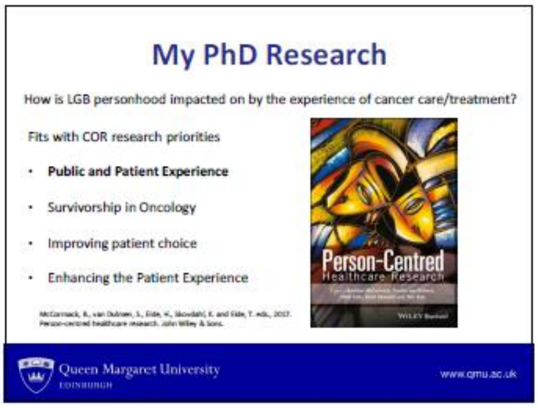

My PhD Research

How is LGB personhood impacted on by the experience of cancer care/treatment?

Fits with COR research priorities

- **Public and Patient Experience**
- Survivorship in Oncology
- Improving patient choice
- Enhancing the Patient Experience

McCormack, B., van Dulmen, S., Eide, H., Skovdahl, K. and Eide, T. eds., 2017. Person-centred healthcare research. John Wiley & Sons.

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Goals of Community based participatory research

- Research *with* rather than *on* people
- Emphasis on partnership working
- Requirement to engage fully with community
- Help participants feel as though their voice and concerns are being heard and acted upon
- Build trust and mutual understanding with community

Hacker, K., 2013. *Community-based participatory research*. Sage publications.
Heron, J. and Reason, P., 2006. The practice of co-operative inquiry: Research 'with' rather than 'on' people. *Handbook of action research*, *2*, pp.144-154.

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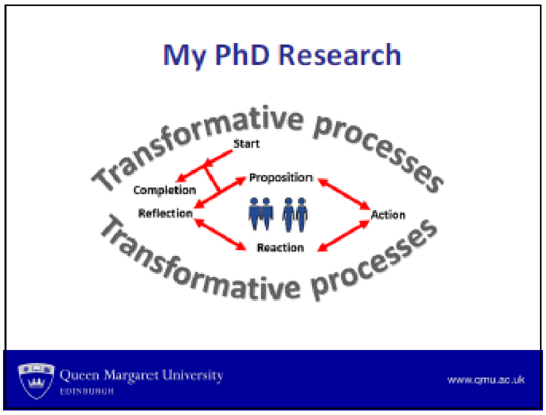

My PhD Research

Transformative processes

Start

Proposition

Action

Reaction

Reflection

Completion

Transformative processes

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Progress so far…

CANCER

The impact of cancer treatment on LGB people's identity

What will I need to do?

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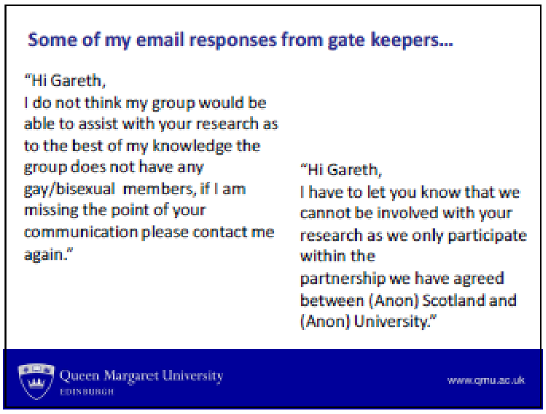

Some of my email responses from gate keepers…

"Hi Gareth,
I do not think my group would be able to assist with your research as to the best of my knowledge the group does not have any gay/bisexual members, if I am missing the point of your communication please contact me again."

"Hi Gareth,
I have to let you know that we cannot be involved with your research as we only participate within the partnership we have agreed between (Anon) Scotland and (Anon) University."

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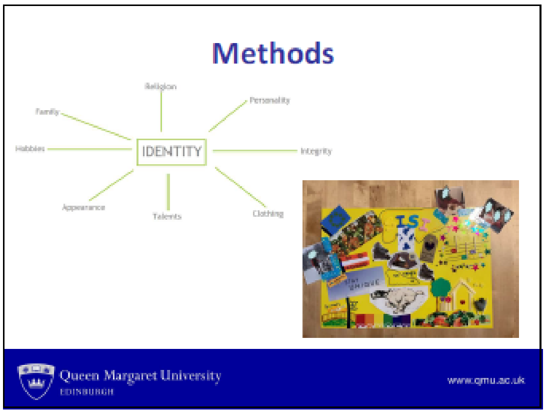

Methods

IDENTITY

Religion

Personality

Integrity

Clothing

Talents

Appearance

Hobbies

Family

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What my participants are saying…

- Participant relationships with family of origin sometimes poor
- Participants in rural areas discuss high rates of isolation
- Most have suffered mental ill-health, psychological distress, drug or alcohol use
- Participants often trying to make sense of homophobia in care
- Good examples of when people get things right
- Some issues from acceptance from within gay community
- Mixed views about support services

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Where Next…

- Building up a trusting relationship with participants
- Continuation of recruitment of more people
- Just about to start data collection with participants
- Stakeholder workshop with willing participants

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Peer review publication

Journal of Cancer Policy 6 (2015) 11–22

Contents lists available at ScienceDirect

Journal of Cancer Policy

journal homepage: www.elsevier.com/locate/jcpo

Review

Sexual minority experiences of cancer care: A systematic review

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[b] Sheffield Hallam University, Faculty of Health and Wellbeing,, Sheffield S102BP, United Kingdom

ARTICLE INFO

Article history:
Received 15 July 2015
Accepted 21 August 2015
Available online 28 August 2015

Key words:
Sexuality
Cancer
Minority groups
Health services needs
Target population

ABSTRACT

There is a lack of published evidence from within the UK examining the needs of LGB cancer patients. A full systematic review of the worldwide literature was carried out with the aim to ascertain the experiences of sexual minority cancer patients and identify specific needs required.

Key databases were searched with a variety of terms relating to the sexual minority cancer experience. Suitable literature was reviewed and references within all articles were search to ensure as inclusive a review as possible. Articles were subject to critical appraisal and scoring using The Support Unit for Research Evidence (SURE 2013) critical appraisal tools to assess eligibility for inclusion within the review. Twenty-five articles were selected for inclusion and were analysed. The papers were categorised into the emerging themes from the literature: Experiences of care ($n = 6$), Coping and Wellbeing ($n = 6$), Emotional Support ($n = 4$), Body Image ($n = 3$), and Sexual Function ($n = 6$). The data extraction revealed contrasting views and experiences of LGB individuals' experience of cancer care. Lesbian and gay individuals have different perspectives of cancer care and needs from heterosexuals. Discriminatory attitudes were found to be present in many studies as well as inequalities and gaps within care and support.

There is evidence that supports the development of sexual minority specific cancer support groups. Further research of sexual minorities affected by cancer in the UK should be carried out to increase the evidence base and better identify the needs in this cultural group.

Contents

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http://dx.doi.org/10.1016/j.jcpo.2015.08.005
2213-5383/

1. Introduction

Her Majesties Treasury Department estimates that 5–7% of the population in the UK are lesbian, gay or bisexual, which equates to approximately 3.6 million people [1]. Based on Cancer Research UK (2014) figures approximately one third of these individuals will develop cancer at some point in their lives [2]. Reports released by Macmillan (2013) and Cancer Research UK (2008) discuss the increased need of Lesbian Gay and Bisexual (LGB) individuals affected by cancer to have specialised support services [3,4]. Progress has started to be made with the recent introduction of gay cancer support groups in the UK and the formation of organisations such as the LGB cancer alliance [5,6]. There is however a lack of published evidence from within the UK examining the needs of LGB cancer patients and as such the full extent of their needs has yet to be fully determined. Therefore, the aim of this paper is to carry out a full systematic review of the worldwide literature to ascertain the experiences of sexual minority cancer patients and identify any specific needs required.

2. Objectives

This project sought to carry out a thematic analysis encompassing the worldwide literature base to evaluate and assess if the development of specialised sexual minority cancer support services is required, and to obtain a perspective of sexual minority experiences of cancer care.

For the purpose of this article the term sexual minority will be used as it encompasses all those that identify as having a sexual orientation whereby they engage in sexual activity with those that are of the same sex.

The following objectives were established for this review.

1. To determine the psychological and emotional needs of sexual minority individuals affected by cancer.
2. To determine the factors that could influence the quality of life of sexual minority individuals affected by cancer.
3. To determine if there is an evidence base behind developing sexual minority specific cancer support services.
4. To critically evaluate the evidence uncovered in the review and assess its merit to influence services.

3. Methodology

This review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) methodology to increase the rigour of the work. PRISMA is a widely recognised evidence-based set of items for reporting in systematic reviews and meta-analyses for academic journals and as such was deemed an appropriate methodology for this study, ensuring the transparent and complete reporting of the results [7].

The search strategy included the initial identification of peer review articles following a broad-ranging literature search carried out on several health and social science databases. These included The Cochrane Library, Medline, Embase, CINAHL, AMED, Science Direct and ASSIA databases. Key terms were identified that related to LGB health and oncology, then Boolean operators were applied (Table 1). Articles were reviewed and selected on the basis of complying with inclusion and exclusion criteria:-

Table 1
List of search terms used.

Gay OR Lesbian OR Bisexual OR Bisexuality OR Homosexual OR Homosexuality OR LGB OR LGBT OR GLBT OR BLAG OR LGBTQ OR Sexual Minorities OR Sexual Minority Men OR SMM OR Sexual Minority Women OR SMW OR Sexual Orientation OR sex orientation OR Men-who-have-sex-with-men OR women-who-have-sex-with-women
AND
Cancer OR Neoplasm OR Malignancy OR Malignant cells OR Oncology OR Tumour OR Radiotherapy OR Chemotherapy
AND
Survivorship OR Experiences OR Quality of Life OR QOL OR Outcomes OR anxiety OR depression OR Support OR Social Support OR Discrimination OR psychological inhibition OR psychological OR psychosexual OR Psychosocial OR psycho-sexual OR Psycho-social OR distress OR perceived stress OR Stress OR health-services accessibility OR needs assessment OR psychosocial adjustment OR physician-patient relations OR Doctor-Patient relations OR sexual Function OR body Image OR stigma

- English language only sources of literature were selected as there was no means of translating other languages.
- Peer reviewed only publications were included to ensure the academic rigour required of this review.
- Articles had to be published within the last ten years to ensure that only current or recent experiences of sexual minority care were taken into account.
- Papers related to targeting screening programmes, HPV vaccination and health awareness in the LGB community were excluded as were not the primary focus of this review.
- Other Meta-Analysis or systematic Cochrane reviews were excluded from this study, but hand searching of reference within these articles was carried out to identify other potential primary studies for inclusion.

Articles were then subject to critical appraisal and scoring to assess their eligibility to be included within the study. The Support Unit for Research Evidence (SURE 2013) critical appraisal tool was determined to be the most appropriate tool to use in the evaluation of the articles given that the studies for review were qualitative in nature [8]. Once suitable articles were appraised they were then analysed and coded by subject matter to classify emergent themes within the literature, these themes are then appraised in this paper.

4. Results

Two-hundred-and-Thirty articles from a variety of publications were uncovered as part of this review. Fig. 1 indicates the number of included articles in the review from the hits identified from the database searches. One-Hundred-and-Thirty were deemed worthy of analysis and were screened using eligibility criteria leaving Forty-seven research articles to analyse. The articles were then reviewed and fifteen were rejected because they related to targeting health promotional programmes and cancer screening programs focused on LGB individuals. Thirty-two studies remained and were then analysed for this paper using the SURE critical appraisal tool. Twenty-five articles were selected for inclusion (Table 2). No minimum score for the SURE tool was established, but seven articles were rejected as they were replicated studies and such demonstrated duplicate results.

The data extraction was carried out and revealed contrasting views and experiences of LGB individuals' experience of cancer care and this formed the body of the discussion of this paper. The papers were categorised into the emerging themes from the literature: Experiences of care ($n = 6$), Coping and Wellbeing ($n = 6$), Emotional Support ($n = 4$), Body Image ($n = 3$), and Sexual Function ($n = 6$), the groupings then formulated a structure to the discussion of LGB experiences of cancer care for this review.

Studies methodologies were a combination of online and postal surveys ($n = 8$), face-to-face or telephone based semi structured interviews (n-15), or focus groups ($n = 2$). Of the articles uncovered, all were found to be qualitative in nature and provided an

Table 2
Summary results table of included studies.

Citation	Authors	County	Purpose/aims	Methodology	Cohort size	Key findings	Coded theme
[10]	Barnoff et al.	Canada	Research focused on "heterosexism" and strategies to counter it in a health care context.	SMW were interviewed face-to-face about their experiences of cancer diagnosis, treatment, health care and social support, and their feelings and perceptions about shifts in identity, body, sexuality and relationships	26 SMW with Breast or gynaecological cancer	Findings revealed a need to transform the ways in which cancer support services are currently provided in order to make them welcoming to SMW. Respondents to the interviews had poor experiences of health care, suffered discrimination and found a heterosexist approach to care	Experiences of care
[12]	Sinding et al.	Canada	This qualitative study examines "what is lesbian" about lesbians' experiences of cancer and cancer care.	26 SMW interviewed about their experiences of cancer diagnosis, treatment, and support, and their feelings and perceptions about shifts in identity, body, sexuality, and relationships.	26 SMW with cancer	A minority of participants were targeted, denied standard care, or had aspects of their identity and social context relevant to cancer care dismissed. The majority commented on the lack of attention to lesbian realities in psychosocial support. Heterosexism appears to prompt strategic efforts to avoid homophobia and also appears to foster gratitude for equitable care.	Experiences of care
[13]	Sinding et al.	Canada	A study examining the Canadian lesbians' experiences with breast or gynaecological cancer and their care.	Semi-structured face-to-face and telephone interview of themes related to participants' experiences of treatment, cancer care, and support.	26 SMW with either breast or gynaecological cancer	Findings reveal the complex and contradictory ways that the lesbian community unfolds in the lives of SMW with cancer. Most participants experienced robust and competent community support; participants also reported instances of isolation and disconnection linked to fear of cancer, homophobia in the broader community, and patterns of exclusion within lesbian communities.	Experiences of care
[15]	Boehmer and Case	USA	The study was undertaken to describe the disclosure of sexual orientation among SMW with breast carcinoma.	Individual semi-structured interviews were conducted with a sample of SMW with a diagnosis of breast carcinoma.	39 SMW with breast carcinoma	Sexual minority patient-provider relationships were marked by apprehension, and providers did not inquire about sexual orientation. The majority of women actively disclosed their sexual orientation, whereas 11 women passively refused disclosure.	Experience of care
[20]	Jabson et al.	USA	Cross sectional study examining SMW perceptions of discrimination as one of the multiple facets of the breast cancer survivorship process.	Sixty-eight purposefully sampled sexual minority breast cancer survivors completed assessments of quality of life, perceived discrimination, social support and stress via an online survey	68 SMW breast cancer survivors	Statistical analyses pointed towards perceived discrimination and social support as important indicators for predicting SMW's quality of life.	Experience of care
[22]	Katz	Canada	A study to investigate the cancer experience of SMM and SMW.	In-depth, face-to-face interviews were conducted with a semi-structured interview guide.	3 SMM and 4 SMW with various cancer.	Overt homophobia or discrimination within the cancer care system was not experienced by this study's participants. Participants valued the central role of their partners in coping with cancer. Some gaps in the cancer care system relating to support groups were identified.	Experiences of care/emotional support/body image

Table 2 (*Continued*)

Citation	Authors	County	Purpose/aims	Methodology	Cohort size	Key findings	Coded theme
[24]	Thomas et al.	Australia	A study examining the experiences of SMM diagnosed with prostate cancer	An online focus group was conducted over a 4-week period with participants responding to a range of discussion questions concerning their experiences following a prostate cancer diagnosis.	10 SMM prostate cancer survivors.	Some participants gained a positive perspective and adopted a sense of empowerment, some spoke about emotional responses to a diagnosis of prostate cancer, accessing help and support, the impact of incontinence, the impact of sexual changes on identity, a re-evaluation of life, changed sexual relationships, the need to find the most suitable healthcare professionals and identification of current needs to improve quality of care.	Coping and wellbeing
[36]	Rubin and Tenenbaum	USA	Research exploring SMW's experience of mastectomy and decision making about reconstruction	Individual In-person qualitative interviews exploring decisions to have, or not have, breast reconstruction.	13 SMW with breast cancer, (purposely selected patients who had not taken up reconstruction)	Findings suggest that sexual identity is not the only influence on women's decisions for or against breast reconstruction. participants described sexual, gender, and political identities and orientations as influences on their decision making, for most participants, experiences with physicians who encouraged reconstruction and concerns about stigmatisation of illness in romantic, professional, and social contexts were also central to decision making.	Body image
[26]	Torbit et al.	Canada	A study to determine the relationship between greater physical symptoms and worse fear of recurrence (FOR) among SMM prostate cancer survivors.	Self-report questionnaires that assessed symptom function, self-efficacy for prostate cancer symptoms, satisfaction with healthcare, and fear of recurrence	92 SMM with various cancers	The study found that worse bowel function, hormone function, and sexual function were significantly associated with greater FOR.	Coping and wellbeing
[27]	Boehmer et al.	USA	Study explores prevalence of cancer survivorship by sexual orientation and cancer survivors' self-reported health.	Analysis of pooled data from California Health Interview survey from 2001, 2003, and 2005. Examining the cancer Prevalence and self reported health of SMW and SMM	Sample size of 122,394 individuals Consisting of 51,259 men and 71,135 women.	No significant differences in cancer prevalence by sexual orientation, but lesbian and bisexual female cancer survivors had 2.0 and 2.3 the odds of reporting fair or poor health compared with heterosexual female cancer survivors. Among men, significant differences in cancer prevalence, with gay men having 1.9 the odds of reporting a cancer diagnosis compared with heterosexual men.	Coping and wellbeing
[28]	Boehmer et al.	USA	Study comparing coping strategies of heterosexual and SMW with breast cancer.	Heterosexual and SMW with breast cancer recruited from a cancer registry had telephone based questionnaires to assess coping.	257 heterosexual and 69 SMW with breast cancer	While survivors with a sexual minority orientation had more adaptive coping than heterosexual survivors, these differences in coping did not relate to benefit Finding.	Coping and wellbeing

Table 2 (*Continued*)

Citation	Authors	County	Purpose/aims	Methodology	Cohort size	Key findings	Coded theme
[29]	Boehmer et al.	USA	A study to identify the factors associated with adjustment to breast cancer among SMW with breast cancer and their support person (SP).	A cross-sectional study, SMW with breast cancer and their support provider were asked to self-report social support, distress, and coping, using standardised measures.	Women without SP (n=7) Women with SP (n=23)	Disclosure of sexual orientation, less helpless-hopeless coping, and support provider perception of high fighting spirit were related to lower patient distress. Lower support provider distress was related to more patient disclosure of sexual orientation, a larger social network, and an underestimation of fatalistic patient coping. An overestimation of patients' anxious preoccupation coping was linked to higher support provider distress.	Emotional support
[30]	White and Boehmer	USA	The aim of this study was to investigate the social support experiences of long-term breast cancer survivors who have female partners.	One-on-one interviews were conducted by telephone. Interviews were semi-structured through the use of an interview guide. A purposive convenience sample of partnered SMW (SMW) (e.g., women with female partners) diagnosed with nonmetastatic breast cancer from 2000 to 2005.	15 partnered SMW (SMW) with Breast cancer	Six salient themes describe SMW survivors' perceptions of support: (a) female partners are the singular source of survivors' most valuable support; partners support survivors by (b) discussing survivors' health and distress, which survivors associate with (c) perceived partner distress, and (d) managing the home and caretaking, which survivors associate with (e) perceived partner burden; and partners support survivors by (f) sharing in a life beyond cancer	Emotional support
[33]	Varner	USA	Experiences and effects of spirituality and religion among lesbians diagnosed with cancer	A convenience sample of SMW diagnosed with cancer responded to advertisements for the study. Each woman was interviewed, and interview transcripts were analysed thematically.	8 self-identified SMW	Results indicated that all participants found support in spirituality, though definitions of this term varied. Five women found religion supportive, but not one participant still worshipped in the tradition in which she was raised. The participants' identification as lesbian affected their relationships with all sources of support, including spirituality and religion.	Emotional support
[34]	Laurie et al.	USA	A study examining support needs and resources of SMW (SMW) breast cancer patients.	Semi-structured interviews were conducted with SMW, who were recruited from community-based organisations and had undergone mastectomy for treatment of breast cancer. Interviews explored support needs and resources.	13 SMW breast cancer survivors.	Participants emphasised the value of cancer support groups and resources tailored to SMW while stating that other dimensions of identity or experience, particularly age and cancer stage, were also important. Participants noted the dearth of social support resources for same-sex partners. Family of origin and partners were typically participants' primary sources of tangible and emotional support. Single women faced the greatest challenges in terms of support needs and resources. Former partners were often key sources of support.	Emotional support

Table 2 (*Continued*)

Citation	Authors	County	Purpose/aims	Methodology	Cohort size	Key findings	Coded theme
[35]	Boehmer et al.	USA	Study exploring issues SMW considered when making decisions on reconstructive surgery after breast cancer.	Individual semi-structured interviews with SMW who had been treated with mastectomy and 12 "support persons".	15 SMW breast cancer survivors and 12 support persons	Women who chose reconstruction experienced difficulties and regrets, whereas women without reconstruction adjusted well after time. Partners of SMW matched the level of satisfaction with reconstructive choice achieved by the women themselves.	Body image
[37]	Filiault et al.	Australia	A study investigating the difficulties encountered by SMM with prostate cancer.	In-depth, face-to-face interviews were conducted with a semi-structured interview guide	2 SMM prostate cancer survivors with one long term romantic partner	Major themes expressed included concerns related to relationship changes and strains, altered sexual function and associated implications for a gay identity, and the perception of heteronormative attitudes in the health care system.	Body image
[40]	Asencio et al.	USA	A study examining the knowledge and experiment of SMM diagnosed with prostate cancer	five focus groups with a total of 36 participant	36 SMM prostate cancer survivors	The data suggest that gay men have little to no understanding of their prostate and the range of sexual challenges associated with prostate cancer and its treatment. In addition, gay men's reactions to potential sexual problems arising from treatment are shaped by their sexual practices, sexual roles, and beliefs about gay relationships and the gay community	Sexual function
[41]	Lee et al.	Canada	Research to post-treatment QoL in PCa patients who are SMM, and to investigate the utility of current QoL assessment tool	Each participant completed a Male Sexual Health Questionnaire (MSHQ), and a questionnaire focused on insertive and receptive roles of anal intercourse.	7 SMM treated with surgery and 8 treated with radiation	While the two validated assessment tools suggested similar QoL scores including sexual function for both surgical and radiation groups, post-treatment sexual function related to anal intercourse may be better in the radiation group, as compared to the surgical group. Larger studies in PCa patients from MSM community are warranted to verify these data	Sexual function
[45]	Wassersug et al.	International	A study comparing diagnostic and treatment outcomes of heterosexual and SMM.	An anonymous online survey assessing how "bothered" patients were about certain treatment related side effects after prostatectomy	466 heterosexual and 96 SMM	Finding indicated that both groups of men were generally similar, SMM might experience more intensive screening for disease, as indicated by lower Gleason scores at diagnosis. SMM appear more distressed by loss of ejaculation after prostatectomy.	Sexual function
[46]	Hartman et al.	Canada	Study examining the experience of three gay couples managing sexual dysfunction as a result of radical prostatectomy	Patient, partner, and couple face-to-face semi-structured interviews were conducted to explore the effect of sexual dysfunction at three stages: 3–6 months, 12–15 months, and 21–24 months after radical prostatectomy	3 SMM couples with a history of prostatectomy	This study revealed that SMM can engage in novel accommodation practices, such as opening their relationship to alternate sexual partners, and that SMM have specific roles in their sexual relationships which uniquely compromised their sexual functioning and satisfaction.	Sexual function

Table 2 (*Continued*)

Citation	Authors	County	Purpose/aims	Methodology	Cohort size	Key findings	Coded theme
[47]	Boehmer et al.	USA	Study examining sexual difficulties after cancer in sexual minority women (SMW).	Telephone survey with a sample of convenience comparing SMW either and without breast cancer to undertake sexual function test.	85 SMW with breast cancer 85 controls without cancer.	Cases and controls did not differ in sexual dysfunction or level sexual functioning. However, SMW after cancer treatment had lower sexual frequency, desire and ability to reach orgasm, and scored higher on pain compared to controls.	Sexual function
[52]	Arena et al.	USA	To ascertain any differences between heterosexual and SMW with breast cancer	This study compared the experiences of though a questionnaire completed at home and returned by post.	78 women 50:50 heterosexual and lesbian. All with breast cancer.	Compared to the heterosexual women, lesbians reported less thought avoidance, lower levels of sexual concern, less concern about their appearance, and less disruption in sexual activity, but also substantially lower perceptions of benefit from having had cancer.	Sexual function
[53]	Boehmer et al.	USA	A study to determine differences between SMW breast cancer survivors to examine whether sexual minority–specific issues contribute to survivors' adjustment.	A 35-minute telephone interview using the breast cancer module of the EORTC Quality of Life Questionnaire.	180 SMW breast cancer survivor	Sexual minority–specific factors contributed toward explaining lesbian and bisexual survivors' anxiety and depression but did not contribute toward explaining survivors' physical and mental health.	Coping and wellbeing
[54]	Jabson et al.	USA	A study exploring similarities and differences between SMW and heterosexual breast cancer survivors quality of life.	Participants were required to complete an Online surveys regarding quality of life.	204 breast cancer survivors (143 heterosexual and 61 SMW)	Quality of life scores were similar between heterosexual and lesbian breast cancer survivors	Coping and wellbeing

overview of the experiences of sexual minority individuals, or carers or partners who had come into contact with an LGB person that had undergone treatment for cancer.

5. Discussion

5.1. Experiences of Care

The articles uncovered as part of this review reveal that sexual minority individuals sometimes experience discriminatory attitudes from oncology health care workers [10,12,13,15,21,22]. The levels of discrimination experiences throughout the studies reviewed varies, but further studies conducted in the UK demonstrate that individuals who feel discriminated against experience social stressors, which in turn can increase their risk of experiencing mental health problems [9].

A Canadian study found in this review recruited a cohort of twenty-six Sexual Minority Women (SMW) from Ontario to discuss their experiences of care after treatment for breast or gynaecological cancer [10]. The study aimed to interview participants face-to-face, but nine interviews were carried out over the phone indicating inconsistencies and possible limitations. The interviews were semi-structured in design and revealed that the majority of participants had poor experiences of health care. The majority of SMW interviewed had suffered aspects of discrimination based on their sexuality by not being offered breast reconstructions based on the belief that lesbians had less of a desire to take up this treatment. All participants experienced a "heterosexist" approach to care within the hospital setting, for example one participant was presumed to be heterosexual in consultations leading to a need for the women to have to correct this assumption and feel embarrassed. The study concluded that the SMW recruited had a desire for gender neutral consultations to avoid heterosexist attitudes and the need for the creation of specialist support groups whereby lesbian or bisexual women could be provided with opportunities to explore their experiences and their feelings in a more comfortable setting. Participants all came from the same geographical area and this may indicate isolated heterosexist discriminatory attitudes in one particular care provider. The study followed a Participatory Action Research (PAR) methodology [11], allowing the collaboration of those affected by the issue being studied to help collate the findings and as such indicated a potential to introduce bias in the study's findings.

Two further papers uncovered in this review were produced from the same PAR cohort of 26 SMW in Ontario, Canada [12,13]. The articles reiterated the views of the previous study but offered more information with additional extracts from the interview transcripts discussing heterosexist assumptive attitudes of health care practitioners [12]. Participants were asked by health care providers to discuss treatment interventions such as breast reconstruction with their assumed husbands, and examples were given of genetic counsellors not being understanding towards an individual's inability to contact relatives who were estranged as a result of their families attitudes towards their sexuality [12]. The SMW desired

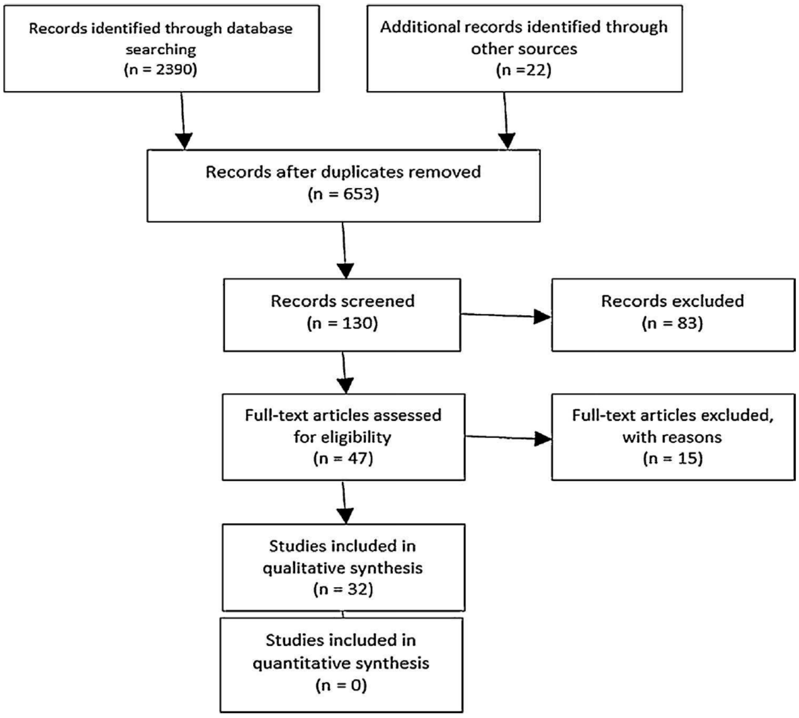

Fig. 1. PRISMA flow diagram.

to have their care provider explain that they were welcoming and open to discussing sexual minority issues [13]. It was felt that due to the perceived historical failure of health professionals to respect lesbians or grant legitimacy to lesbian relationships, lesbians with cancer sometimes did not expect that they or their partners would be offered equitable care. In the UK The Lesbian and Gay Foundation (LGF) have launched the "Pride in Practice" campaign to address issues similar to those raised by the Ontario studies. Healthcare providers can apply for "Pride in Practice Awards" to demonstrate their commitment providing inclusive services and recognise the specific needs of lesbian, gay and bisexual people[14].

The Ontario PAR team's work revealed relevant findings about a lack awareness of sexual minority issues regarding estrangement from family members and a lack of support services for SMW affected by cancer. However, the studies were all conducted by the same project group with motivations to campaign and change services in the area indicating a strong potential for bias.

A USA study used semi-structured interviews examining the attitudes of 39 SMW with breast cancer when disclosing their sexual orientation to their health providers [15]. The study discussed how the participants were mainly younger white women, who might be more likely to self-disclose as opposed to older women from ethnic minority groups. The majority of women actively disclosed their sexual orientation, whereas eleven women passively refused. Findings indicated that prior to disclosure sexual minority patient-provider relationships were marked by apprehension, and providers did not tend to enquire about sexual orientation. Lesbians within the study that went on to disclose their sexuality were met with a largely positive response. Whilst deemed to be helpful, research suggested that patients who wanted to talk about their sexual orientation often preferred their health provider to initiate these conversations [16], concluding that disclosure of sexual orientation can be a barrier to positive patient experiences and the existence of self-perceived feeling of discrimination amongst the participants. There are several reasons why an individual may not want to disclose their sexual orientation. The Sexual Offences Act 1967 decriminalised homosexuality [17], but it wasn't until the UK government passed the Equality Act in 2010 that it became unlawful for public services, including the NHS, to discriminate against protected characteristics such as sexual orientation [18]. This combined with society's negative attitudes towards homosexuality throughout the 20th Century as well as the AIDS epidemic in the 1980s could explain why LGB individuals of an older generation might be reluctant to disclose their sexuality [19]. In the UK sexual minority cancer patients will be demographically older and will have lived at time when homosexuality was illegal [20].

A cross sectional study in the USA examined SMW perceptions of discrimination as one of the multiple facets of the breast cancer survivorship process [21]. Sixty-eight purposefully sampled sexual minority breast cancer survivors completed assessments of quality of life and perceived discrimination via an online survey. Statistical analyses pointed towards perceived discrimination and social support as important indicators for predicting SMWs' quality of life. This study, although valuable in its conclusions, had several limitations. For example ethnic minority groups are underrepresented, and the survey was carried out online resulting in only computer literate participants and a lack of a comparison with heterosexuals. Although not statistically significant this paper draws attention to the fact that if an individual perceives aspects of discrimination within their care, it has the potential to impact on their overall quality of life.

Another Canadian study investigated the experiences of three Sexual Minority Men (SMM) and four SMW with various types of cancer [22]. In-depth, face-to-face interviews were conducted with a semi-structured interview. The study was deemed important for inclusion within this review to offer a balanced perspective, overt homophobia or discrimination within the cancer care system were not experienced by this study's participants. Participants valued the central role of their partners in coping with cancer but there were gaps in the cancer care system relating to support groups identified such as, Participants in this study discussed worries about the perceived reaction by their gay peers towards their health, and their concerns of being associated with having AIDS, revealing an insight into the gay community's attitude towards illness.

The majority of acts of minor discrimination found in this review appear to arise due a lack of awareness amongst staff of using gender neutral language when discussing partners and heterosexist assumptions. A novel approach of raising awareness of sexual minority patients has been trialled in Ireland, offering a training programme directed at oncology professionals [23]. Participants offered the training found that they became more familiar with LGB-related language and terminology, more knowledgeable of LGB health issues, and more confident in providing care to LGB patients. Training programmes and raising awareness of LGB cancer patients could address misunderstandings in care that have been revealed in this review.

5.2. Coping and wellbeing

The ways in which LGB individuals are affected by cancer and how they cope were discussed within several papers, indicating many sexual minority attitudes are common with heterosexual cancer survivors, but sexual minorities may report poorer health [24,26–28,53,54].

An Australian study examined the experiences of ten SMM diagnosed with prostate cancer, the results indicated that some participants adopted a sense of empowerment regarding their cancer journey whilst others felt isolated as a result of their treatments [24]. The data was gathered through online focus groups. Participants felt isolated after diagnosis and the majority of men within the study were single stating that the existence of a support group may have assisted them to connect with others going through the same experiences. One participant described themselves as 'damaged goods' in the eyes of the gay community so no longer felt they were able to enjoy the lifestyle that they had had prior to their treatments. No specific tool was used to assess quality of life after treatment but participants discussed their feelings of isolation from the rest of the gay community, feeling closer to friends, and being empowered to provide advice to those that they knew who were going through similar experiences. Sexual minority individuals in the UK over the age of 55 are more likely to live alone, when coupled with feelings of isolation from the gay community; this could signify a potential lack of emotional support for LGB persons with cancer [25].

A Canadian study examined SMM Fear of Reoccurrence (FOR) and noted that there was a relationship between (FOR) and the initial physical presenting symptoms of their cancer [26]. Ninety-two SMM with various cancer types completed self-report questionnaires that assessed symptom function, self-efficacy for prostate cancer symptoms, and FOR. The study found that worse bowel function, hormone function, and sexual function were significantly associated with greater FOR. The study didn't compare FOR with heterosexual individuals and as such might not be a sexual minority-only issue, but did highlight SMM fear and psychological wellbeing.

In the USA a study used the breast cancer module of the EORTC Quality of Life Questionnaire through telephone interviews with 180 SMW breast cancer survivors [53] Sexual minority specific factors such as discrimination in health, contributed toward survivors' anxiety and depression. The study befitted from having a large cohort of participants, but failed to have a control or comparison of non-breast cancer SMW or heterosexuals. Levels of stress between heterosexuals and SMW have been compared in one study uncovered in this review. A further USA study compared 68 SMW and 143 heterosexual women levels of stress, and found that minority breast cancer survivors had higher perceived stress compared to heterosexual breast cancer survivors, had an uneven balance of participants and may influence the quality of the findings [54]. An analysis of pooled data from a USA California Health Interview survey from 2001, 2003, and 2005 examined and the self-reported health of sexual minority individuals were compared with heterosexuals [27]. The study concluded that of the 51,259 men and 71,135 women analysed there were no significant differences in cancer prevalence by sexual orientation, but lesbian and bisexual female cancer survivors had between 2.0 and 2.3 times the chances of reporting fair or poor health compared with heterosexual female cancer survivors. Among men there were significant differences in cancer prevalence, with gay men having 1.9 times the odds of reporting a cancer diagnosis compared with heterosexual men. This study provided a context when comparing sexual minority experiences of cancer with the rest of the heterosexual population and was large enough to conclude that sexual minority individuals report poorer health after cancer diagnosis. Another study in the USA compared the coping strategies of 257 heterosexuals and 69 SMW with breast cancer using telephone-based questionnaires recruited from a cancer registry, finding that survivors with a sexual minority orientation had more adaptive coping strategies and were less fatalistic than heterosexual survivors [28].

5.3. Emotional support

Four studies uncovered in this review discussed the importance of spousal or peer emotional support for sexual minority individuals [22,29,33,34]. A USA cross-sectional study compared 7 single SMW with breast cancer and 23 SMW with partners finding women without partners to be more fatalistic, whereas SMW with partners were more resilient and had lower levels of distress [29]. The study used questionnaires and interviews to determine the extent of support, but had a disproportionate number of single women within the study to serve as a comparison. The social support experiences of long-term SMW breast cancer survivors were investigated in another study through one-on-one interviews by telephone [30]. Fifteen partnered SMW with breast cancer described female partners as being the source valuable support by discussing survivors' health and distress. The central role of partners in coping with cancer was investigated in another small study using interviews with 7 SMM and SMW [22]. The evidence suggested that having a supportive person, partner or otherwise, is significant when preventing sexual minority mental health problems after cancer diagnosis. Unfortunately none of the above studies compared levels of mental wellbeing and support with heterosexuals and should not be assumed to be a sexual minority-only area for concern. All the above studies were small but corroborated each other's findings that a support person is key to providing guidance through the cancer journey. The need for support is not unique to sexual minority individuals and similar studies examining heterosexual couples corroborate these findings [31], but sexual minority individuals are more likely to be single [25].

Many cancer patients draw strength from religious or support groups in addition to their partners [32]. A study in the USA explored the effects of spirituality and religion among lesbians diagnosed with cancer [33]. A sample of eight SMW diagnosed with cancer were interviewed and all participants found support in spirituality, though definitions of this term varied. Five women found religion supportive, but no participant still worshipped in the tradition in which they were raised. The participants' identification as lesbian affected their relationships with all sources of support, including spirituality and religion. Another study examined the support needs and resources of 13 SMW breast cancer patients [34]. Semi-structured interviews were conducted with SMW, who were recruited from community-based organisations and had undergone mastectomy for treatment of breast cancer. Participants emphasised the value of cancer support groups and resources tailored to SMW while stating that other dimensions of identity or experience, particularly age and cancer stage, were also important. Single women faced the greatest challenges in terms of support needs and resources, and former partners were often key sources of support for these individuals. Both of these studies were small scale, but highlighted the importance and usefulness of support for SMW affected by cancer from religious and support groups targeted at sexual minorities.

5.4. Body image

This review found contrasting views on body image and sexual minority individuals appear to be affected by this in different ways [35–37]. One study uncovered examined 15 SMW and their partners who had either received or declined reconstructive surgery after mastectomy [35]. Individual semi-structured interviews were undertaken suggesting that women who chose reconstruction experienced difficulties and regrets, whereas women without reconstruction adjusted well after time. Partners of the SMW matched the level of satisfaction with reconstructive choice achieved by the women themselves. The study concludes that SMW place less emphasis on external appearance compared with heterosexual women. A contrasting study conducted with 13 SMW with breast cancer who had deliberately not taken up breast reconstruction suggests that sexual identity is not the only influence on women's decisions for or against breast reconstruction [36]. Participants described sexual, gender, and political identities and orientations as influences on their decision making. For most participants, experiences with physicians who encouraged reconstruction and concerns about stigmatisation of illness in romantic, professional, and social contexts were also central to the decision making process. Both studies have limitations and were carried out retrospectively which may introduce a recall bias for the participants.

An Australian study examined the effects of prostate cancer in three SMM using in-depth face-to-face interviews [37]. The study uncovered several themes. Some participants discussed the effects of body changes and the negative attitudes of the gay community. Relationship changes and strains were also observed as a result of surgical scars and weight gain. The significance of body image and physical appearance in relation to quality of life were also discussed in another study that used face-to-face interviews with men who had various cancers [22]. Three other men were recruited who were all partnered at the time of diagnosis. Of these, one separated from their partner due to appearance issues and it was raised by several participants that the gay community's sexualised attitude towards appearance was a large factor in how participants viewed themselves. Homosexual attitudes towards appearance are documented in several other studies and appear to be a greater factor for wellbeing than in heterosexual men [38].

5.5. Sexual function

A report released by Prostate Cancer UK and Stonewall UK discussed the possible needs of gay and bisexual men after prostate cancer treatment [39]. The report discussed how gay and bisexual men may be more vulnerable to the side-effects of pelvic cancer treatments than straight men. This study corroborated these findings uncovering a variety of sources exploring the sexual function of SMM after cancer treatment.

Within the USA a cohort of 36 SMM who had a diagnosis of prostate cancer were placed in a study using focus groups [40]. The participants were asked to discuss their knowledge of their side effects and revealed that the gay men in this study had little understanding of their prostate and the range of sexual challenges associated with prostate cancer and its treatment. The study found that the men's reactions to potential sexual problems arising from treatment are shaped by their sexual practices. For example if the individual was usually anally receptive during sexual intercourse they could more easily accommodate the associated loss of erectile function, but those who valued being able to anally penetrate during intercourse suffered from being unable to do so. All the participants were concerned about the gay community's reaction to their physical appearance when gaining weight due to hormone treatments and the pressure of being unable to perform sexually in a sexually charged community. Further studies conducted in Canada revealed similar findings where 15 SMM were given sexual health questionnaires after treatment for prostate cancer with prostatectomy or external beam radiotherapy finding that post-treatment sexual function related to anal intercourse may be better in the radiation groups compared to the surgical group [41]. The study did not indicate the point at which the former patients were given the questionnaire and this could impact on the reliability of this study as prostate cancer-associated problems can become worse over time due to delayed side-effects [42]. Both of these studies were small and as such their findings lack the corroboration of other SMM experiences or a lack of comparison with heterosexual men. Studies conducted with heterosexual men indicate that loss of sexual function can be equally problematic but SMM sexual practices may be specifically impacted on by cancer treatments [43,44]. A larger international study comparing diagnostic and treatment outcomes of heterosexuals and SMM was carried out using an online survey to assess how "bothered" patients were about certain treatment related side-effects after prostatectomy, looking at 466 heterosexuals and 96 SMM. Both groups of men were generally similar, but the SMM appeared more distressed by loss of ejaculation after prostatectomy [45].

A Canadian study examining the experience of three gay couples managing sexual dysfunction as a result of radical prostatectomy conducted patient, partner, and couple face-to-face semi-structured interviews to explore the effect of sexual dysfunction at three stages: 3–6 months, 12–15 months, and 21–24 months after radical prostatectomy [46]. This study found that participants engaged in novel accommodation practices when their sexual function changed, such as opening their relationship to alternate sexual partners, and corroborated the findings of other studies in this review that SMM have specific roles in their sexual relationships which uniquely compromised their sexual functioning and satisfaction. Unfortunately the study did not use any sexual assessment tool to aid in quantifying the level of dysfunction at the different intervals and as such limits the study.

This review found two studies related to sexual function in SMW in the USA [47,52]. One, a telephone survey approached SMW either with or without breast cancer to undertake sexual function tests, the other used of a postal questionnaires. Both studies demonstrated good practice as used equal numbers of SMW and heterosexuals to compare, 85 SMW compared with 85 heterosexuals and 39 SMW compared with 39 heterosexuals respectively, although the sampling was purposeful and were not randomised. Cases and controls did not differ in sexual dysfunction or level sexual functioning. However, SMW after cancer treatment had lower sexual frequency, desire and ability to reach orgasm, and scored higher on pain compared to controls [47], whereas the other study found lower levels of sexual concern and less disruption in sexual activity. The studies have different findings but indicate that sexual function after cancer treatment is not a male-only issue and has yet to be explored in any of the other studies uncovered as part of the SMW cancer experience.

5.6. *Limitations*

There is a breadth of terminology in use to identity people as being homosexual and this presented a challenge when searching for studies that include those that are lesbian, gay, bisexual, or those that do wish not to be labelled [48]. Several articles uncovered in this review studied the same population of sexual minority individuals who were predominantly white and middle class, therefore several of the studies had potential to have repeated participant bias and were not wholly inclusive of all sexual minority views [49]. The majority of the studies in this review do not have controls and lack quantitative data making it harder to draw conclusions and measure their impact [50]. Differing laws and attitudes towards homosexuality vary worldwide making it difficult to draw caparisons between studies and should be noted when considering their application to UK populations [51].

6. Summary and conclusions

This review succeeded in establishing its objectives; the literature uncovered indicated that the psychological and emotional needs of sexual minorities are largely similar to that of heterosexual cancer patients by wanting to have support from a variety of sources such as family members, partners and support groups to maintain psychological health and wellbeing, but sexual minority individuals may not have access to these mechanisms of support in all cases. The evidence revealed that sexual minorities are affected physically by cancer like heterosexuals through weight gain, body changes and image, as well as sexual function, but sexual minorities appear to have differing social attitudes to one another and different sexual practices meaning that the physical effects of cancer have specific consequences on LGB populations. Given these conclusions there is an evidence base to warrant the exploration of sexual minority specific advice and services, but exact extent and needs of support required within the UK is yet to be established. This review has uncovered evidence of a range of acts of discrimination in healthcare towards sexual minorities overseas; differing attitudes towards homosexuality and dissimilarities in rights legislation from country to country denote that the UK population of sexual minority cancer survivors may have a different perspective or needs of current cancer services in the NHS. It is the conclusion of this review that sexual minority cancer patients needs have to be investigated and researched further within the UK to better formulate management and treatment policies.

Conflic of interests

No conflicting interests to declare.

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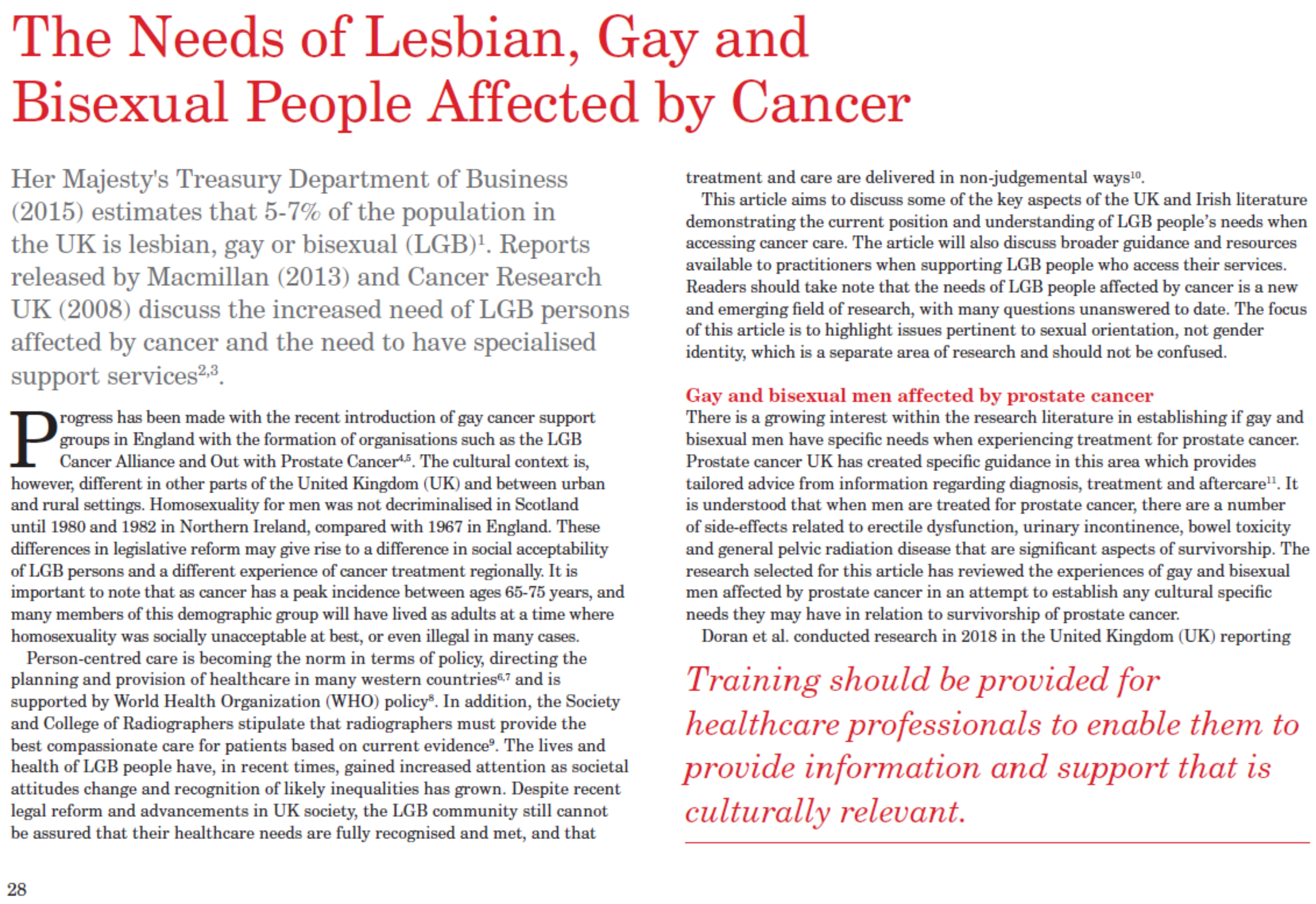

The Needs of Lesbian, Gay and Bisexual People Affected by Cancer

Her Majesty's Treasury Department of Business (2015) estimates that 5-7% of the population in the UK is lesbian, gay or bisexual (LGB)[1]. Reports released by Macmillan (2013) and Cancer Research UK (2008) discuss the increased need of LGB persons affected by cancer and the need to have specialised support services[2,3].

Progress has been made with the recent introduction of gay cancer support groups in England with the formation of organisations such as the LGB Cancer Alliance and Out with Prostate Cancer[4,5]. The cultural context is, however, different in other parts of the United Kingdom (UK) and between urban and rural settings. Homosexuality for men was not decriminalised in Scotland until 1980 and 1982 in Northern Ireland, compared with 1967 in England. These differences in legislative reform may give rise to a difference in social acceptability of LGB persons and a different experience of cancer treatment regionally. It is important to note that as cancer has a peak incidence between ages 65-75 years, and many members of this demographic group will have lived as adults at a time where homosexuality was socially unacceptable at best, or even illegal in many cases.

Person-centred care is becoming the norm in terms of policy, directing the planning and provision of healthcare in many western countries[6,7] and is supported by World Health Organization (WHO) policy[8]. In addition, the Society and College of Radiographers stipulate that radiographers must provide the best compassionate care for patients based on current evidence[9]. The lives and health of LGB people have, in recent times, gained increased attention as societal attitudes change and recognition of likely inequalities has grown. Despite recent legal reform and advancements in UK society, the LGB community still cannot be assured that their healthcare needs are fully recognised and met, and that treatment and care are delivered in non-judgemental ways[10].

This article aims to discuss some of the key aspects of the UK and Irish literature demonstrating the current position and understanding of LGB people's needs when accessing cancer care. The article will also discuss broader guidance and resources available to practitioners when supporting LGB people who access their services. Readers should take note that the needs of LGB people affected by cancer is a new and emerging field of research, with many questions unanswered to date. The focus of this article is to highlight issues pertinent to sexual orientation, not gender identity, which is a separate area of research and should not be confused.

Gay and bisexual men affected by prostate cancer

There is a growing interest within the research literature in establishing if gay and bisexual men have specific needs when experiencing treatment for prostate cancer. Prostate cancer UK has created specific guidance in this area which provides tailored advice from information regarding diagnosis, treatment and aftercare[11]. It is understood that when men are treated for prostate cancer, there are a number of side-effects related to erectile dysfunction, urinary incontinence, bowel toxicity and general pelvic radiation disease that are significant aspects of survivorship. The research selected for this article has reviewed the experiences of gay and bisexual men affected by prostate cancer in an attempt to establish any cultural specific needs they may have in relation to survivorship of prostate cancer.

Doran et al. conducted research in 2018 in the United Kingdom (UK) reporting

Training should be provided for healthcare professionals to enable them to provide information and support that is culturally relevant.

on the needs of gay men with prostate cancer, and their experiences of healthcare provision. In-depth interviews were conducted with 12 gay men who had been diagnosed with prostate cancer employing a phenomenological approach to collect and analyse the data[12]. Findings indicated that the participants wanted, and expected, candid discussions with healthcare professionals, about how prostate cancer could affect their lives, sexual function, and how to access relevant support aimed at gay and bisexual men before and after treatment. This included aspects of engaging in anal sexual practices which were relevant to the participants being included in the research. Participants perceived that their healthcare team had little knowledge about their needs in this regard, and if, or how, their experience differed due to their sexual orientation. This was compounded as the participants felt information that was provided was perceived as being misplaced or informed by heteronormative assumptions, i.e. assuming the men were straight and married.

Doran et al. suggest that consideration should be given to requesting sexual orientation when recording patient information if patients are willing to disclose this[12]. This knowledge would be helpful for practitioners to have in order to be able to deliver more tailored and specific information, avoiding potential heteronormative assumptions, although care must be taken not to assume that all gay or bisexual men engage in particular sexual practices, and that recording of sexual orientation can only serve as a tool to open up discussions about more tailored and person-centred support. In addition, sexual orientation monitoring isn't current practice within the UK at cancer registration, and it may be unacceptable for certain LGB people to answer such questions given the history and social acceptability of homosexuality. Doran et al. conclude that training should be provided for healthcare professionals to enable them to provide information and support that is culturally relevant at all stages of the consultation[12].

McConkey and Holborn conducted further research in 2018 through the use of in-depth interviews with a sample of eight men affected by prostate cancer from the Republic of Ireland[13]. Interviews were recorded and transcribed verbatim following a qualitative methodological approach employing Giorgi's descriptive phenomenological method and analysis. Key aspects emerged, representing the essence of the participants lived experience, including the experience of the healthcare service. When accessing healthcare, issues were found with participants disclosing their sexual orientation and openness of communication with the healthcare team, and highlighted that many LGB people feel the need to come out when accessing healthcare but felt unable to do so. Participants within the McConkey and Holborn study found sources of support and means of coping which came from their partners, family and friends, cancer support groups[13].

However, there is evidence that suggests that LGB people who are older are more likely to live alone and have problems with their family of origin than their heterosexual counterparts, and this may indicate a lack of support for LGB people facing cancer treatment and diagnosis[14].

McConkey and Holborn concluded that gay men with prostate cancer have unmet information and supportive care needs throughout their prostate cancer journey, especially related to the impact of sexual dysfunction and associated rehabilitation, and that this was seen to have a negative impact on their quality of life[13]. Like Doran et al., the research found issues associated with heteronormativity, and that minority stress and stigma were found to influence how gay men interact with the health service, and how they perceive the delivery of care[12]. McConkey and Holborn advocated that healthcare education providers should update prostate cancer education programmes accordingly, and it is not known if this has been taken up widely by education providers of pre-registration curriculum[13]. However, it is known that some post-registration education related to prostate cancer in the UK for radiographers does include some of the diverse needs of gay and bisexual men affected by prostate cancer, and thus demonstrates progress in this area.

Broader needs of LGB people affected by cancer

Despite the recent work that has been conducted examining the experiences of gay and bisexual men, there is little other research conducted within the British Isles that focuses on LGB patients of other disease site groupings, i.e. breast cancer, and there has been no research that has looked at lesbian women's perspectives of care specifically. There is however, some research that has focused on the experiences of care of LGB cancer patients more generally, that have been made up of people who have various forms of cancer and are of different sexualities[15]. This research is pertinent as many of the issues faced by gay and bisexual men with prostate cancer could also be faced by LGB people with other forms of cancer and treatment.

Fish and Williamson present an analysis of the accounts of fifteen British LGB cancer patients, who were diagnosed with different forms of the disease[15]. Data were collected through in-depth individual interviews and analysed using thematic analysis indicating three emerging themes that are discussed within the published paper. The paper includes an examination of what is conceptualised as the 'awkward choreography around disclosure', which is discussed.

Issues faced by gay and bisexual men with prostate cancer could also be faced by LGB people with other forms of cancer and treatment.

Additionally, the opportunities and dilemmas for LGB people to disclose their sexual orientation when in receipt of cancer care is also discussed. Disclosure of sexual orientation can be a daunting task for people, especially if they have had negative responses when coming out in the past. Previous negative experiences in this regard can then present a challenge when having to correct healthcare practitioners' assumptions in clinic or consultations. These dilemmas can lead to awkwardness, particularly if the reaction of healthcare staff is one of silence or negativity after a person has disclosed their sexual orientation. Fish and Williamson describe respondents in their research being left 'making sense of sub-optimal care' which included instances of overt discrimination but more frequently manifested through what was perceived as micro-aggressions, and heteronormative systems and practices from healthcare staff towards LGB cancer patients[15]. The authors also explored participants' accounts of what they describe as 'alienation from usual psychosocial cancer support', whereby they felt unwelcome in heteronormative support spaces.

Fish and Williamson employed Meyer's Stress Theory[16] as a lens to interrogate the data they gathered, and explore the ways in which actual or anticipated prejudice affected their participants' experiences of treatment and support. Minority stress is a condition where chronically high levels of stress can be faced by members of stigmatised minority groups, such as the LGBTQ community. It may be caused by a number of factors, including poor social support and low socioeconomic status, although it is well understood that the causes of minority stress are interpersonal prejudice and discrimination that are felt by the minority community. Having observed signs of minority stress with their participants, Fish and Williamson close their paper with recommendations to enhance LGB affirmative cancer care, which includes recommendations for enhanced training of healthcare professionals and explicit articulation of institutional commitment to LGB equality[15].

Practical guidance for practitioners

A few seminal articles related to the experiences and care needs of LGB people have been published within the peer reviewed literature, however readers should note that there are aspects of the grey literature, documentation from Prostate Cancer UK, and other articles from other UK researchers that are due to be published imminently in these areas.

Prostate Cancer UK has created a resource that can be made available for gay and bisexual men for prostate cancer and can assist by providing culturally targeted guidance that can help with information about side effects from diagnosis to treatment[11,17].

Gay men with prostate cancer have unmet information and supportive care needs throughout their prostate cancer journey.

LGB people want their partners' and carers' involvement to be welcomed and valued by cancer professionals.

Information contained in the guide is comprehensive and tailored to gay and bisexual men, for example advice is written in language that is specific to needs of those who are engaging in anal receptive sexual activities. In addition, information is also provided about how men affected by prostate cancer can broach the topic of their sexual orientation with healthcare professionals responsible for their care. The limitation of the materials however, is that they have been created to be specifically focused towards gay and bisexual men with prostate cancer, and there are no known other disease site specific resources for LGB persons affected by other cancers known to be published in the UK, i.e. breast cancer. Other cancer support groups and organisations should give consideration to providing LGB inclusive support information related to other site-specific disease, for example gynaecological cancers.

Fish and Lockely have published guidance to healthcare professionals to assist in increasing awareness of LGB issues associated with cancer and provide advice on how professionals can facilitate the disclosure of a person's sexual orientation[18]. The guidance demonstrates that LGB people appreciate it when assumptions are not made about them, their sexual orientation, relationships, living arrangements or support network, and that they value professionals initiating conversations about these important areas of their life. Although not cancer related, specific guidance related to sexual orientation and NHS workers has been produced, which provides specific examples of how professionals can help to facilitate disclosure of a person's sexual orientation in clinic by using gender neutral terms, e.g. partner, and not using language that makes assumptions about the person, e.g. Mrs[19].

The guidance from Fish and Lockely also indicates that LGB people want their partners' and carers' involvement to be welcomed and valued by cancer professionals, and opportunities for this should be sought where possible[18]. When this doesn't happen, it can lead to LGB people feeling that their partners and carers are ignored or disregarded, resulting in negative care experiences. Professionals may want to consider developing materials aimed at the LGB communities, possibly through working with local LGB organisations and demonstrating these on their websites and publicity materials.

Conclusion

LGB people face challenges when accessing cancer care within the UK. These challenges range from discriminatory attitudes from healthcare staff, to a lack of support tailored for LGB people to ensure their needs are being met.

This article provides some background to the research conducted in the area and demonstrates that there is a growing evidence base that LGB people's needs are not being fully assured. The reader should take note that this is a new and emerging field, and that publication of research is currently ongoing as well as the developing understanding of LGBT issues related to healthcare. This article can only serve as a starting point, but provides an indication of some of the resources that can be employed in current clinical practice to foster a more person-centred approach to healthcare delivery.

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