Queering the sick room.
A queer feminist narrative inquiry into the lived experiences of lesbians with cancer

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Abstract

Introduction

Queering the sick room has brought together ten lesbian women's stories of living with cancer and offers new insight into the experiences of being lesbian and having cancer within the United Kingdom. The study participants first discussed their life since coming out as lesbian and then their lesbian life with cancer.

Method

Queering the sick room is a queer feminist inquiry that employs Queer Phenomenology (Ahmed 2006) to construct narrative accounts of experiences of being lesbian and of having cancer. A convenient and purposeful sample of ten women were recruited. Focused, conversational interviews were audio recorded and transcribed verbatim. Reflexive thematic analysis was undertaken to construct the narratives included. Three overarching narratives were constructed: Living a lesbian life, living a lesbian life with cancer, and queering the sick room.

Results

The narratives presented as living a lesbian life show the multiplicity of experience, there is no one experience that captures the "lesbian experience", but there are some commonly shared moments, fear of reactions from others, homophobia both internally felt and externally experienced. Significantly the recognition of self for these women was a truly empowering moment, that enabled them to begin to live as their authentic selves. An important factor for all the women was time, particularly in relation to coming out. The political mood of the time, for these women, dictated not only their feelings of safety but also their personal activism. The lived experience of being lesbian and having cancer included eight themes; constructed cancer hierarchies, being diagnosed, why have I got cancer, cancer and my [lesbian] body, treatment, coping, support, and environment. This narrative exploration adds a clear indication of the impact of cancer on their lives as the participants navigate the cancer journey. It highlights that heterosexism, homophobia and assumption-saturated care persists, despite the rhetoric that things are better.

Conclusion

Queering the Sick Room presents a new way of thinking about orientation and disorientation, and it asks us to consider how a space can be queered by who occupies that space. When we are not orientated, we are disorientated, but moments of disorientation are vital. They are embodied experiences that destabilise but also allow restabilising, an opportunity for re-orientation. Queering the sick room examines the experiences of queer bodies disorientating and being disorientated by normative spaces.

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Glossary of terms

LGBTQIA+	Lesbian, Gay, Bisexual, Trans, Queer/Questioning, Intersex, Asexual + (all other minority sexuality and gender identities) identifying people
Lesbian	A person who identifies as a woman who is sexually attracted to other women
Bisexual	A person who is sexually attracted to both men and women, recognising a gender binary
Queer	A person who identifies as a member of a minority sexuality community and/or someone who's gender is different to the gender assigned to them at birth
Trans	A person whose gender identity is different to the gender assigned to them at birth
Cis	A person whose gender identity matches the gender assigned to them at birth
BrCa2	A hereditary gene mutation that increases the risk of a person developing cancer. Linked to breast, ovarian, pancreatic, and prostate cancer.

Abbreviations

AYA	Adolescent and Young Adult
Br	Breast
Ca	Cancer
CNS	Clinical Nurse Specialist
CT	Chemotherapy
D	Daughter
IH	Internalised Homophobia
LB	Lesbian and Bisexual
LGBT	Lesbian, Gay, Bisexual, Trans
LGBTQIA+	Lesbian, Gay, Bisexual, Trans, Queer/Questioning, Intersex, Asexual + (all other sexual and gender identities)
Mast	Mastectomy
MOAB	Monoclonal antibody
NB	Non-Binary Person
NCPES	National Cancer Patient Experience Survey
NCRAS	National Cancer Registration and Analysis Service
NDRS	National Disease Registration Service
NHS	National Health Service
ONS	Office of National Statistics
P	Partner
PI	Principle Investigator
PTSD	Post-Traumatic Stress Disorder
RT	Radiotherapy
SMM	Sexual Minority Man/ Men
SMW	Sexual Minority Woman/ Women
SOGI	Sexual Orientation, Gender Identity
T	Town
TBI	Total body irradiation
WLE	Wide local excision

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Dedication

I dedicate this work to my beautiful darling wife who has been alongside me every step of the way, encouraging and supporting me throughout, and to my three fur babies who have been my constant companions, thank you.

Always and forever

Px

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I would like to thank the 10 women who graciously gave up their time and stories for this work. I hope I have done you justice in this interpretation of your journey.

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To my family, and above all Mum and Dad for never doubting in me, I miss you both so much. I hope this makes you proud, wherever you are.

Lastly, to my amazing wife. You are my everything. Thank you! I love you.

Declaration

I declare that:

- The work presented in this thesis is my own and embodies the results of my research during my period of registration.
- I have read and followed the University's Academic Integrity Policy and that the thesis does not breach copyright or other intellectual property rights of a third party. Where necessary I have gained permission to reproduce copyright materials.
- Any material which has been previously presented and accepted for the award of an academic qualification at this University or elsewhere is clearly identified in the thesis.
- Where work is the product of collaboration the extent of the collaboration has been indicated.
- All names of people and places have been changed to provide anonymity and confidentiality.

Signature Date 31/5/23

Chapter 1: Introduction

Rolling eyes = feminist pedagogy.

Raised eyebrows = lesbian feminist pedagogy

(Ahmed 2019 pg. 309)

Weeks (2017) highlights that in every civilisation throughout time, culture has been concerned with the regulation, organisation and ordering of sexuality and gender, and for the last two hundred years has piqued the interest of scientific inquiry and political debate yet there is still a paucity of research that focuses on the health care needs of the queer community and their lived experiences of illness (Griggs 2017). Queering the sick room aims to assist in overcoming this inequality by providing insight into the lived experiences of ten lesbian women diagnosed with cancer. Queering the sick room is a queer feminist inquiry that employs Queer Phenomenology (Ahmed 2006) to construct narrative accounts of experiences of being lesbian and of having cancer.

In the 2021 UK Government census, sexual orientation and gender identity questions were asked for the first time, responses were voluntary but 92.5% of the population over 16 years old answered the question. 3.2% of the population (1.5 million people) identified as lesbian, gay, or bisexual, and a further 0.3% selecting "other" for sexual orientation. Additionally, 0.5% of the population declared their gender identity did not match their assigned gender at birth. LGBTQIA+ communities favoured residing in large metropolitan areas such as London, Manchester, Liverpool, and Brighton, with London having the largest overall LGB population by percentage (4.3%) and Brighton and Hove with the largest population by local authority (ONS 2023). This means for the first time we have a detailed picture of the LGBTQIA+ community in the UK. However, we do not yet have a clear picture of the health status of this community or how they are affected by illness.

Individuals identifying as Lesbian, Gay, Bisexual, or Trans (LGBT) are not a homogenous group, but vary in socioeconomic characteristics; the degree to which being LGBT is central to self- identification and to what extent we engage in LGBT culture. Terms and labels, such as lesbian or transgender, also need to be applied with care as they may not reflect a person's self-identification (Williams et al 2012, Meyer 2001). Indeed, Marques et al (2013) and Diamond (2008) point to the fluidity of female sexuality and the inherent difficulties in attempting to define a person against a predetermined label.

Experiences of stigma and discrimination are well documented within the LGBTQIA+ literature, but are experienced in different ways. Overt discrimination includes violence, homophobia, and poor care, whereas more pervasive discrimination may include inadequate attention to health concerns, heterosexism, and lack of awareness or 'culturally sensitive' care (Power et al 2022, Wakefield 2021, Webster 2021, Sherrif et al 2018, Hulbert-Williams et al 2017, Meyer 2001). Smith and Turrell (2017) concluded that the healthcare experiences of the LGT community include persistent heteronormativity, micro aggressions, homophobia and transphobia.

Systemic barriers to providing inclusive care include: lack of inclusivity in intake forms and lack of recognition of LGBTQIA+ health care needs in health care education (Ussher et al 2022, Wakefield 2021, Sherriff et al 2019, Smith and Turell 2017). Additionally, Mule (2009) highlights that heterosexism is manifest throughout social policy documentation and McNair (2003) talks to the negative provider attitudes visible in health care. Meyer (2001) further suggests that although homophobia or heterosexism may not be deliberate it appears in policy subversively by defining LGBT issues as marginal, exotic, and difficult to study or by suggesting LGBT issues are too political or sensitive for study.

Lesbian's health differs in key ways to heterosexual women regarding behaviour, risk and experiences of health care; yet the construct of women's health is based on a heteronormative discourse and assumptions of marriage and children, and where lesbian and bisexual women are seen as a homogenous group (McDermott, Nelson and Weeks 2021, Fish and Anthony 2005, Lewis et al 2006, Fish 2008, Mule et al 2009, Fish and Bewley 2010). Winnow (1992) highlighted that lesbians were always the 'other' in equality movements; the other within the women's movement and the other within gay liberation, and Marinucci (2010) argues, the other within Queer theorising, all resulting in scarce attention being paid to their experiences.

Several papers have called for the LGBTQIA+ community to not be seen as a homogenous group and for studies to focus on the individual experiences of each (Berner and Meads 2022, McDermot, Nelson and Weeks 2021, IoM 2011 and Solarz 1999). McDermot, Nelson and Weeks (2021), and Mule et al (2009) further argue that there must be recognition of the unique and specific health issues affecting LGBT individuals and that employing anti-oppressive, critical, intersectional analysis will enable this to occur. Women identifying as lesbian are a distinct group with diverse needs that should be investigated independently to ensure their experiences are captured. Additionally, it should not be taken for granted that a study focusing on lesbians can capture the voices and experiences of all lesbians, indeed heterogeneity within a group must be recognised and celebrated (McDonald et al 2003).

In adopting a queer feminist stance, this study avoids the reductionist approach that perpetuates the binaries endemic within much health care research (man/woman, straight/lesbian). A convenient and purposeful sample of ten women were recruited to participate in focused, conversational interviews to describe their lived experience of being lesbian with cancer. A poststructuralist position was adopted, and a narrative methodology employed. Reflexive thematic analysis was undertaken to construct the narratives. Three overarching narratives were constructed: Living a lesbian life, living a lesbian life with cancer and queering the sick room.

Queering the Sick Room presents a new way of thinking about orientation and disorientation, and it asks us to consider how a space can be queered by who occupies that space. When we are not orientated, we are disorientated, but moments of disorientation are vital. They are embodied experiences that destabilise but also allow restabilising, an opportunity for re-orientation. Queering the sick room examines the experiences of queer bodies disorientating and being disorientated by normative spaces.

Structure of the thesis

This thesis details the research study that was undertaken in fulfilment of the award of PhD.

The thesis is structured into thirteen chapters:

- Chapter one places the thesis within the context of healthcare in the UK.
- Chapter two introduces the key theory underpinning the thesis, Queer Phenomenology
- Chapter three offers a very personal and reflexive account telling my story of being adjacent to cancer and why this thesis is such a personal undertaking.
- Chapter four provides an overview of the literature exploring LGBT health drawing out lesbian specific detail where it is applicable to do so.
- Chapter five is a narrative literature review of the published studies examining lesbian cancer.
- Chapter six defines the post structuralist theoretical, ontological, and epistemological position of the study and includes a brief analysis of queer feminism.
- Chapter seven discusses narrative methodology, in particular life narratives and small stories.
- Chapter eight details the methods used to conduct this study, including a discussion on the ethics of feminist research.
- Chapter nine presents the results of the study under the three narrative themes: living a lesbian life, living a lesbian life with cancer, and queering the sick room.
- Chapter ten answers the final research question and offers a discussion of the findings in relation to this.
- Chapter 11 discusses the limitations of the study.
- Chapter 12 discusses the implications for practice.
- Chapter 13 concludes the thesis.

Chapter 2: Notes on a Queer Phenomenology

Sara Ahmed's (2006) germinal work Queer Phenomenology asks how do we orientate to the world, and what does it mean to be orientated? She tells us that if we know where we are in a place and at a time then we are orientated, we can find our bearings, we can navigate our world. But when we experience disorientation, we are unable to make sense of the world around us. To say we are orientated also means we can turn towards objects, we can recognise and use those objects with intention and purpose. As we see these objects, we are orientated to them. She uses the example of Husserl's writing table to illustrate this. When we see a table, we know what its purpose is. Its purpose may be varied, and it may change given the task we wish to undertake but we will know that this is a table, and this is how we can use it; a writing table to write at, a dining table to eat at, or a sewing table to sew at. One table may achieve all these tasks but when we want to write the table becomes a writing table, when we want to sew, it is a sewing table. There is an orientation that is purposeful and recognisable. Furthermore, she suggests that when we are orientated, we might not even comprehend we are, for example when was the last time you sat down at the dining table and purposely thought to yourself, this is a dining table, and I must eat at a dining table? Rather you are probably more likely to have sat at the table and undertaken the action without even giving it a second thought. Familiarity is given, and orientation is not about just finding our way, or purpose, but it also becomes about what feels familiar, what is given, what am I already orientated towards.

Examining tables, however, is not her main purpose, her purpose within this text is to ask two key questions of sexuality, what does it mean for sexuality to be "lived as orientated" and does the "What" or "Who" we are orientated towards make a difference. She further argues that to be orientated is to focus our energy on the who and what we direct our attention to and consider how we inhabit and comprehend our world. Her queer phenomenological project is to redirect this energy towards different, deviant, or deviated objects; objects that are not close at hand, distant, unfamiliar, or become unfamiliar. How might we queer a table or see a queer table? Observing a table from the other side or bottom-up perspective, to turn the table and work on the underside. These orientations queer, or make strange, the object; they offer a queer perspective.

> "I start here because phenomenology makes "orientation" central in the very argument that consciousness is always directed "toward" an object, and gives its emphasis on the lived experience of inhabiting a body…phenomenology can offer a resource for queer studies insofar as it emphasises the importance of lived experience, the intentionality of

> consciousness, the significance of nearness or what is ready-to-hand, and the role of repeated and habitual actions in shaping bodies and worlds" (Ahmed 2006 pg 2)

Queer phenomenology also considers the temporality of objects and orientations. Ahmed questions phenomenology that just considers objects as ahistorical, without the context of time and space, as just simply being there. How did the object arrive "an arrival that is at once the way in which objects are binding and how they assume social form" (pg41). Objects are transplanted from somewhere to here, they are never just here, so she asks what came before, what is/was before in a spatial sense?

Drawing on Merleau-Ponty (1968 cited by Ahmed 2006) Ahmed contends that in order for an object to have action, the object needs to be near enough to be seen "I see it only if it is within the radius of my action" (Merleau-Ponty 1968:7), but also the action brings the object, what is within the scope of your actions and the radius of your body.

> "So, you can only write on the writing table if the table is within reach, but the reachability of the table might be an effect of what you already do for a living. It exists for you insofar as it is near. In other words, the nearness of certain objects is an effect of the work the body does, and the work the body does is what makes certain objects near." (Ahmed 2006 pg. 52)

Together they construct their joint purpose, neither is the same without the other, they are different. Their orientation is changed. A table without a someone to write at it is not a writing table, the writer constructs the writing table. Bodies and objects take form by being orientated toward each other, as an orientation that is experienced as the inhabitation or sharing of space.

Repetition over time creates a sense of normativity; we see or do it often therefore it becomes normal, unseen, muscle memory. The normative creates a bodily horizon, a space for action, which places some objects in reach but not others. When thinking of the normative straight body, the body appears "in line" with others, they are aligned. We do not see them. But when someone is not performing to the normative expectations, when a body becomes misaligned, they become visible.

> *"*Think of tracing paper: when the lines on the tracing paper are aligned with the lines of the paper that has been traced, then the lines on the tracing paper disappear: you can simply see one set of lines. If lines are traces of other lines, then this alignment depends on straightening devices that keep things in line, in part by "holding" things in place. Lines disappear through such processes of alignment, so that when even one thing comes "out of line" with another thing, the "general effect" is "wonky" or even "queer". (Ahmed 2006 pg. 66)

Again, we return to the table, but this time the restaurant dining table on Valentine's day. Table after table you see one man one woman, aligned, sitting opposite each other, so familiar it goes unseen, one couple melding into another. Then the line falls out of step, two women sitting opposite each other, attention is immediately drawn to this misalignment, a momentary pause; what does this mean, how do we make sense of this? There is a queering of the moment, a queering of the space and object.

The phrase "orientation" relates to spatiality: directing how one is placed in relation to objects. But in relation to sexuality this directional metaphor has superseded others used prior to the 1970s: inclination, deviant, pervert, invert, taste, tendency, bent, drive. The idea of sexual orientation relates only to the homosexual body, homosexuality is an orientation, heterosexuality is the neutral, you are orientated away from the neutral, you are defined by being out of alignment or "deviated" from the neutral. Sexual orientation is therefore created through the production of "the homosexual".

A queer orientation, however, is not simply being directed towards the same sex, but occurs whenever the straight line is not followed, when the tracing line fails to stay aligned with the original/ neutral line. Any orientation not in line with the neutral is therefore queer, or anti-normative.

> "Here the "direction" of instinct or desire toward "the same sex" is an "aberration." An aberration can refer to "the act of wandering from the usual way or normal course," or even to a "deviation from truth and moral rectitude." (Ahmed 2006 pg.70)

Ahmed suggests that queer desires can be defined by the subject going off the straight line to reach objects of desire. To move off the line is to move toward "one's own sex" and to turn away from the straight line or "the other sex". And yet turning towards one's own sex is read as threatening to put one's sex into question. Ahmed using Ellis's (1975: 94) work considers why. Through the performance of "congenital masculinity" queer women can bring queer desire back "in line", back to normal: if the queer woman is really a man, then she is following the straight line when she is orientated to what she is not; the feminine woman. This type of argument acts as a straightening device, to put back into line that which is off-line, conflating the line with what is right, good, or normal. In other words, to be "in line" is to direct one's desires towards marriage and reproduction.

When we are not orientated, we are disorientated, but moments of disorientation are vital. They are embodied experiences that destabilise but also allow restabilising, maybe in a different pattern, an opportunity for re-orientation. Disorientation is unsettling and can threaten to destabilise our feeling of stability and our confidence that the metaphorical ground beneath us, our foundations, can support us as we navigate our lives. This feeling of destabilising, of being shattered, might endure to become a crisis. Or it might pass if the ground returns to stability or as we return to the stable ground. Our body might orientate if we can reach out and hold onto something, or someone, to steady ourselves. But if we reach out and there is nothing to hold, then we might be lost, undone, thrown off our balance. In this disorientation there is a search to find a place where comfort and security can return. A queer person experiencing disorientation in a straight space may search for a queer space and when they find that queer space, they become orientated (again). Failure to find the queer space may lead to crisis.

> The point is not whether we experience disorientation (for we will, and we do), but how such experiences can impact on the orientation of bodies and spaces, which is after all about how the things are "directed" and how they are shaped by the lines they follow. The point is what we do with such moments of disorientation, as well as what such moments can do – whether they can offer us the hope of new directions, and whether new directions are reasons enough for hope." (Ahmed 2006 pg. 158)

Disorientation can be a violent feeling, or a feeling affected by violence. Disorientation can result in violence being enacted upon a body. Bodies that do not conform to the line are vulnerable in their visibility, they may be stopped from progressing, held back, pushed aside, ignored, "I can see you therefore I choose not to see you". The effect of being out of place creates disorientation in others. It is at this time and in this space that the sick queer body can queer the sick room. The sick room is the space in which a person can be sick, cared for, consulted about sickness, but when the body in the room does not follow the line, when the body can be seen as deviant from the line, it queers the space, it disorientates it, it challenges the normative. Queering the sick room aims to examine the experiences of queer bodies disorientating and being disorientated by normative spaces. Ahmed (2006) is asking how bodies are gendered, sexualised, and raced by how they extend into space? It is with these questions in mind that queering the sick room is a queer phenomenological project.

Chapter 3: Being adjacent to cancer

Cancer has been my life, from my very earliest memories to the present day sitting at my desk trying my hardest to construct a PhD thesis, cancer seeps into every moment, every nook and cranny, every conversation. It has become an obsession, a passion, and a nightmare, one I wish I could escape but simultaneously one that I crave contact with. Yet I have never had cancer, I have never had to endure months of life altering treatments, painful conversations, and ultimately the end of my life. But so many people I have loved, have, and it's through being next to them on their journeys that my life with cancer has become what it is today. A love hate relationship.

I have lost someone to cancer every decade of my life. When I was 10 my aunt died, in my teens I lost my nan and grandad, in my twenties it was the turn of my 24-year-old cousin to die from leukaemia. In my thirties I lost my Dad. My forties, started with my cousin Marie, she was 42 years old, then Uncle Phil, Aunty Pam, Aunty Diane and finishing a year ago with Mum! Every single person diagnosed with cancer, bar one, has died! So, this for me, is a heavy history of being adjacent to cancer.

I have also had my own cancer scares. During the time I have been undertaking my PhD I have had referrals for two week wait investigations for both colorectal and bladder cancer in addition to annual mammograms because of our BrCa 2 family history. Thankfully, none have come back positive for cancer, yet! But I live in constant expectation. It feels like I have led my life waiting for the inevitable and because of this I have chosen a life that doesn't hold back from enjoyment and living for the moment. So, this is one of the benefits of the sword of Damocles hanging over my head, don't wait for tomorrow as it may not come, I don't wait for retirement as I am not likely to see much of it, if any. Pessimistic and positive at the same time. It is an odd place to exist.

These experiences have also led me to focus my professional life on cancer too. The impact of it being so present at a young age was a desire to look after those affected by the disease, to study it and ultimately through my MSc and this PhD learn more about the experiences of those living with and beyond it. Public health campaigns aim at raising awareness of cancer; however, cancer has never been something we don't talk about in my family. We have never been able to avoid talking about it. It is always there, someone is always being treated for it, attending follow ups, living beyond it or, more normally, is no longer with us because they have died from it. But we do not talk about the impact that cancer has had on us emotionally, after the fact. All conversations are based in an historic narrative; do you remember when, or a pragmatic narrative, who's doing what to support. We talk about cancer as if it were a member of the family. We come together as a family because of cancer. It is our USP! We are a BrCa 2 family!

BrCa2 is one of the ever-growing numbers of hereditary cancer gene mutations, and is linked to several cancers including breast, ovarian, prostate, and pancreatic cancer, all of which have affected my family. But it doesn't stop there. My family also have a history of heavy smoking (you could ask yourself though what working class, baby boomer/ gen X family doesn't have a strong history of smoking?) So, alongside the hereditary cancers there are also many smoking related cancer deaths, including my Mum and Dad.

I don't write the chapter to make you feel sorry for me or pity me, but to give you some insight as to why I am seemingly obsessed with this disease and why it is the driving force behind my professional and personal life.

My story begins as a young child playing in my aunts' front room with my cousins, and one of my cousins (now a hairdresser) cutting off my long hair and us taking my uncles angel fish for a walk! However, for me, the prevailing image entwined with all these stories is my aunt in the corner of her living room in her hospital bed, living with the ravages of breast cancer. My auntie Maureen, my Mum's oldest sister, was diagnosed with breast cancer when she was 32 years old. She had four young children, the oldest had just reached 12 when she was diagnosed. What followed was 4 years of constant pain, ongoing treatments, mastectomies, oophorectomy, radiation therapy, chemotherapy and eventually death at the age of 36. I sat watching all this from the floor of her living room (chairs were for the adults). Her sisters and mother caring for her every day in her own home, nurses coming and going at all hours, doctors talking quietly in corners to my uncle, Mum, and other aunties. No one really speaking about what was going on. Instead, my cousins and I just continued to play and watch. Then early one morning in June there was a loud knock on the door (we didn't have a phone then). Mum had spent the night at home, a rarity as she was normally at auntie Maureen's. Hushed voices carried up the stairs and then Mum was gone again. We woke later that morning and Dad called us into their room he told us we didn't need to get ready for school as we weren't going today, Mum was back home and sitting on the bed quietly crying, "your auntie Maureen died this morning". That's when I first knew cancer, that's the first time it came and shocked my world, I was 10 years old. It was 1983.

Eighteen months later, "come on girls we have to go and see your grandad in hospital, he's had his operation". Six months later he was dead from prostate cancer. That was 1985. Six months later, "come on girls we need to go and see Nan, she's back from the hospital". This was the one that ripped me to the core, completely decimated me, my beloved nan had cancer and it was taking her quickly. I had spent my life with my nan, she was the one I went to, she was my best friend. I spent hours with her just being together. Mum was always off caring for sick relatives, Dad was always working to make ends meet, Nan was the one who was there after school, at the weekend, whenever I needed her. But now she was dying too. This was not fair; how could we go through this again, three people in just short of 2 years. My Mum was at the end of the line, first she had lost her oldest and closest sister, then her beloved Dad and now her mum. The family began to fall apart, arguments, blame, resentment, who was in charge, who was making decisions, who should look after Mum! It took a long time but slowly rifts healed and the family came back together. Life carried on, families reformed, my uncle got remarried. Us "kids" left school and started to live our own adult lives; it seemed the spectre of cancer had, at last, left us alone.

It was during this period of my life that I started to realise I was gay. It was the mid 1980's, the height of the AIDS crisis and a moral panic about gay people, led by the conservative government and right-wing press. Margaret Thatcher, the then Prime Minster, was on a family values crusade and Section 28 was becoming law. Just being suspected of being different at school led to bullying and vilification. There was no way I was going to tell anyone my dark little secret, so I hid it. I buried it deep down and I ate my feelings. The bigger I became the less interested anyone was in me as a potential love interest, so I was safe. I was the happy fat girl, everyone's best friend. As McPhail and Bombak (2015) highlight fatness is akin to asexuality and undesirability, and for me this provided cover, a safety net.

But I still felt the impact of cancer, I still felt that it was asking something of me. It is a bit of a cliché, I know, but I wanted to give back and I wanted to be helpful. I had never thought about being a nurse when I was at school, my mind was preoccupied with being a police officer, but alas I was not tall enough for that career path, plus I really wanted a job where I was liked for what I did! I needed to think of a career, one that was achievable and not pie in the sky, so no more dreaming about being a helicopter pilot in the RAF or a graphic designer (especially as my artistic abilities stretch to stick men and cartoon dog faces).

Well, to cut a long story short I blew my A levels, leaving at the end of the first year. Mum told me I could leave school, but I had to get a job! Now what was I going to do? Then my grandad's second wife (an important distinction from a step-gran; a role she never wanted and never took on), told me there was an opening at the local hospital for a nursing auxiliary. I had never considered nursing; I didn't even know a nurse. But I went along for the interview and to my shock, I got it. I was now a fully-fledged nursing auxiliary, and I was 17 years old. This is where I fell in love with nursing. From the day I started I knew exactly what I wanted to be, I was going to be a registered nurse and I was going to look after people with cancer. I was going to give back, I was going to be like those nurses I had seen care for my auntie, my grandad, and my nan. Five years later, 1995, and after three years training, I had just qualified, and I was now working as a staff nurse in oncology, I had succeeded, I was looking after people with cancer and people told me how proud they were of me!

But then the spectre of cancer returned to my family. My favourite cousin, Mike was diagnosed with chronic myeloid leukaemia, and he needed a bone marrow transplant if he was going to survive. This time though I knew the statistics and the pathology, I knew what lay ahead for Mike and for the family. It was so different, the family turned to me for information and Mike turned to me for support. Long hours watching him struggle as his body turned against him followed. Mike died three weeks later of sepsis from a failed bone marrow transplant.

Life carried on though, cousins got married, had children, built their lives in the shadows of cancer. At this time no one knew about the genetic mutation we carried. There was suspicion and often talk of what if; but as no one had active cancer there was no one to test. Everyone had died before testing was truly available. Then my mum's youngest sister was diagnosed with ovarian cancer at 49. The pattern was clear to see in the genealogical tree, three first degree relatives all diagnosed at a young age with an aggressive form of their cancer. But Pam didn't want to be tested. She didn't want to be the person that brought that to the family. That didn't happen until my cousin Karen was diagnosed with breast cancer at 46 and she wanted to know! What followed was a rift in the family between those that wanted to be tested and others who felt this was irrelevant or would bring cancer on through worry; "what was the point of finding this out, would it make any difference, why do you want to know? Just deal with it if it happens" were all said to me and others. At the same time my other cousin was diagnosed with pancreatic cancer at 42 years old, so the links to BrCa2 were even more obvious, but the arguments continued.

It is a hugely complex process to go through genetic screening, first someone with cancer must be tested and the cancer they have identified as having the genetic mutation. This then tells the geneticist that your family is a carrier, so the testing is then opened to the wider family on the affected side, in my case the maternal line. However, before you can be tested you must know whether your parent carries the mutation, so parents go first, and then you wait! When it comes back that your parent is a carrier then it's your turn. There's counselling to take you through the implications of the results, both positive and negative. Then there's the long wait to find out if you do indeed carry it. It's a 50-50 chance that you will have inherited the trait and each sibling carries that same individual 50-50 chance. In my family about half of the cousins came back as positive, but I was lucky, I was negative!

This story of being adjacent to cancer finishes with the production of this PhD, three years after it was meant to come to an end, and it finishes with the story that has hit me the hardest and almost derailed this whole project. It is the hardest thing I have had to recover from, and its impact made completing this thesis more difficult and it is only working through grief in therapy that has made completing this possible.

My mum had been diagnosed with bladder cancer three years into this supposed five-year project and as I was her primary carer following my dad's death three years earlier, most of the caring responsibility fell onto my shoulders. Endless hospital visits, investigations, operations, and chemotherapy appointments followed for 6 years. Cancer for many is a long-term condition, continuing for years as the disease slowly and progressively impacts on the functioning of the body and the psyche. In late 2019 she fractured her hip and could no longer manage living on her own so we made the decision that she should come and live with us, then four months later the covid 19 pandemic hit the UK. The significance of telling this is the dramatic effect it had on this study. I was no longer able to spend the time and energy required to complete the study so I had to interrupt, this then in turn resulted in not being able to return the analysis results to the participants as had been planned, which for me affects the trustworthiness of the final results, from the feminist co-construction approach I had advocated for (the impact of this is discussed later in the thesis).

I had attempted to return to the study following my mum's death in 2021 but dealing daily with thoughts of cancer and the experiences of people affected by the illness that has decimated my family, I found I was paralysed in both thought and action; being triggered by what my participants and the literature was revealing to me. But, thankfully, therapy and the support of my family and friends helped me return to the work and conclude this study presenting the stories of the 10 lesbian women who graciously shared their experiences being lesbian and living with cancer.

It seems to be also important here to briefly outline my academic journey, to begin to judge my positionality within this thesis. As I mentioned earlier, I left school before completing my A levels but with enough GCSEs to be able to undertake a Diploma in Nursing. My course was one of the very early Project 2000 courses where nursing education within the UK had moved into the higher education setting away from a more traditional apprenticeship/ training model in local hospitals. I was the archetypal first person in my family to enter higher education. This ignited my passion for learning and my drive to obtain more knowledge, particularly in relation to cancer and how it manifests within the body. Following completion of my initial training I undertook my bachelor's degree and specialist training in oncology, all this set again within a scientific, positivist paradigm. I craved the scientific knowledge of pathology and pharmacology but also felt there was something missing. I wanted to know more about the experiences people had when they entered my world of nursing and oncology. This drew me initially towards a more phenomenological methodology, however the idea of a single truth that could be discovered was also problematic for me. Finally, through this doctoral work I was able to delve into the world of post structuralism and postmodernism and finally I found a place that made sense to me, where I could begin to reconcile my thoughts about the nature of truth. So, from a positivist biomedical model of knowledge construction, I hope to emerge from this thesis with a developing poststructuralist view of the world, where truth does not exist outside of discourse.

I am a lesbian woman who has lived adjacent to cancer my whole life. I currently teach cancer care both undergraduate and postgraduate levels. I have spent nearly 30 years working in oncology either within practice or education. I hold a master's degree in advanced cancer nursing practice, and I have undertaken research examining the lived experiences of people living with cancer. As a result of my own lived experience of being lesbian I have a passion for disrupting power, challenging inequalities, and promoting social justice within nursing practice. This thesis is bringing together these passions. In queering the sick room, I am asking, from my adjacent position, how lesbian women construct their lived experiences of having cancer and of being lesbian in the hope that this will centre their experiences and provide healthcare practitioners with the push they need to develop person centred approaches to care that reflect the needs of these and other lesbian women. But I also want to be as up front and honest with my readers as I can be in my positionality within this study. I am present throughout this study; my voice can be heard throughout as I am interpreting the stories shared with me from this adjacent position. Queering the sick room is a very personal thesis and represents a story that is not finished, but a momentary reflective stop on this lifelong journey as researcher, educator, nurse, and lesbian, adjacent to cancer.

Chapter 4: Lesbian, Gay, Bisexual and Trans Health

Introduction

This chapter examines health issues discussed within the Lesbian, Gay, Bisexual, and Trans literature, but where possible and appropriate, draws out lesbian specific concerns for further consideration. Individuals identifying as Lesbian, Gay, Bisexual, or Trans (LGBT) are not a homogenous group, varying in socioeconomic characteristics; the degree to which being LGBT is central to self- identification and to what extent we engage in LGBT culture. Terms and labels, such as lesbian or transgender, also need to be applied with care as they may not reflect a person's self-identification (Williams et al 2012, Meyer 2001). Indeed, Marques et al (2013) and Diamond (2008) point to the fluidity of female sexuality and the inherent difficulties in attempting to define a person against a predetermined label.

The experience of stigma and discrimination is common across the LGBT spectrum but may be experienced in different ways. Overt discrimination includes violence, homophobia, and poor care, whereas more pervasive discrimination may include inadequate attention to health concerns, heterosexism, and lack of awareness or 'culturally sensitive' care (Power et al 2022, Wakefield 2021, Webster 2021, Sherrif et al 2018, Hulbert-Williams et al 2017, Meyer 2001). Smith and Turrell (2017) concluded that the healthcare experiences of the LGT community include persistent heteronormativity, micro aggressions, homophobia, and transphobia.

Systemic barriers to providing inclusive care have been reported in several studies, including lack of inclusivity in intake forms and lack of recognition of LGBTQIA+ health care needs in health care education (Ussher et al 2022, Wakefield 2021, Sherriff et al 2019, Smith and Turell 2017). Additionally, Mule (2009) highlights that heterosexism is manifest throughout social policy documentation and McNair (2003) talks to the negative provider attitudes visible in health care. Meyer (2001) further suggests that although homophobia or heterosexism may not be deliberate it appears in policy subversively by defining LGBT issues as marginal, exotic, and difficult to study or by suggesting LGBT issues are too political or sensitive for study. McDermott, Nelson, and Weeks (2021) go further and in their scoping review of the politics of LGBT+ health inequalities, state:

> "This thin evidence base is partly due to national policy discussions of LGBT+ health inequality that are framed within a depoliticised 'it's getting better' narrative, and an unwillingness to adequately acknowledge the unjust social and economic relations that produce LGBT+ health inequality. In addition, LGBT+ health inequality is depoliticised by existing public health explanatory theories, models and frameworks that exclude sexual orientation and gender diversity as dimensions of power that interlock with those of socio-economic, race and ethnicity." (McDermott, Nelson, and Weeks 2021 pg2)

Lesbian's face even more barriers to equitable healthcare. Lesbian's health differs in key ways to heterosexual women regarding behaviour, risk, and experiences of health care; yet the construct of women's health is based on a heteronormative discourse and assumptions of marriage and children, and where lesbian and bisexual women are seen as a homogenous group (Fish and Bewley 2010, Mule et al 2009, Fish 2008, Lewis 2006, Fish and Anthony 2005). Historically, Winnow (1992) highlighted that lesbians are always the 'other' in equality movements; the other within the women's movement and the other within gay liberation, resulting in scarce attention being paid to their experiences. Fish (2009) more recently contends that lesbian experiences of sexism and heterosexism are quantitatively different to the experiences of heterosexual women which has led to inequalities in lesbian health and lack of focus on qualitative issues and experiences. Fish and Bewley (2010) confirmed a lack of knowledge and embarrassment over lesbian and bisexual issues amongst health care professionals, whilst Sherrif et al (2018) and Bjorkman and Malterud (2009) demonstrated heterosexuality was taken for granted, with prejudiced care and inaccurate information provided. Further, women may feel compelled to reveal their sexuality to ensure they receive appropriate care as unless lesbian and bisexual women come out to their health care providers their distinct needs are invisible (Ussher et al 2022, Fish and Bewley 2010).

Prior to 1990 lesbians were undetectable within health care research (Roberts 2001) and lesbian populations remain an under-represented minority in health care research today (McDermott, Nelson and Weeks 2021, McDonald et al 2003). Stevens (1992) argued that male dominated science paid little attention to women's health issues, including those of lesbians, on which health care professionals can base their care. This is still the case today with continued calls being made for more focused evidence on which to base health care practice. Bjorkman and Malterud's 2009 study of lesbian women's experiences of health care within a Norwegian context and Hunt and Fish's (2008) UK study both highlight that prejudice and heterosexism are still experienced by women seeking care and support (see also Jowett and Peel 2009 and Almack et al 2010). Stevens (1992) highlighted hostility, fear, heterosexism, and homophobia experienced by lesbians seeking health care; and from more recent evidence there appears to be only minor changes in these attitudes 30 years later (Ussher et al 2022, Webster 2021, Bryson et al 2018, Sherrif et al 2018, Hulbert-Wilson et al 2017).

In 2017 the UK National Health Service introduced sexual orientation monitoring which required all health and social care providers to record a person's sexual orientation at every face-to-face interaction where this information does not already exist (NHS England 2017). The National Disease Registration Service (NDRS) introduced a sexual orientation question set in 2018 which became mandatory for all diseases in 2020, however reporting has been severely delayed because of the

Covid-19 pandemic (Berner and Meads 2022). The National Cancer Patient Experience Survey (NCPES) commenced in 2015 but only began collecting sexual orientation data in 2018 (NCPES 2021). Further, despite the requirement to record orientation at all health and social care interactions (NHS 2017), currently data is not collected on incidence, morbidity or mortality based on sexual orientation within the National Cancer Registration and Analysis Service (NCRAS) project.

Mule et al (2009) argue that the focus on a public health model has resulted in LGBT populations being excluded from health policy as the methodology used within public health research does not allow minority issues to come to the fore and leads to a disease-based focus:

> "...despite the health effects of prejudice and discrimination on LGBT populations and the impact of intersections with and among other determinants of health, these populations are ignored in conventional population health models. As a result, they are overlooked when developing health policy" (Mule et al 2009 pg. 6)

Mule (2009) continues that there must be recognition of the unique and specific health issues affecting LGBT individuals and that employing anti-oppressive, critical, intersectional analysis will enable this to occur. This all leads to the need for lesbian women to be seen as a distinct group with diverse needs that should be investigated independently to ensure the true experience is captured. Additionally, it should not be taken for granted that a study focusing on lesbians can capture the voices and experiences of all lesbians, indeed heterogeneity within a group must be recognised and celebrated (McDonald et al 2003). However, the turn in recent years, particularly within cancer care research, has been towards studies focusing on an inclusive LGBTQIA+ community experience, potentially obscuring the unique needs of each group within this community (Berner and Meads 2022).

Health Inequalities

Following the HIV and AIDS crisis in the 1980s and 1990s LGBT health became synonymous with sex and sexual health, which has resulted in wider LGBT health not receiving the attention it requires (Jowlett and Peel 2009). There appears, however, to be key health issues that are commonly experienced in LGBT identified groups, including, mental health illness, smoking and misuse of alcohol and drugs, though there is no consensus in other areas such as obesity. Bowen and Boehmer (2007) for example, found higher rates of smoking, increased obesity, and alcohol consumption within lesbian and bisexual women in the US, whereas Hunt and Fish (2008) and Meads et al (2007) concurred with smoking and alcohol consumption but did not find higher rates of obesity in the United Kingdom (UK), drawing attention to the unreliability of direct comparisons across cultures (Berner and Meads 2022).

In a public health focused study King and Nazareth (2006) examined the health of LGB identified individuals across 13 family practices in London. Of the 1307 participants 13% identified as LGB, which could be considered as representative. Within this cohort gay men were more likely to experience mental health issues, bisexual women were more likely to misuse alcohol, and LB women and B men were more likely to smoke, concluding that an awareness of a person's sexual orientation can help health care practitioners focus health promotion advice. There was no attempt, however, within this study to understand why certain behaviours were more prevalent within the LGBT community, without which any health promotion work could fail to address underlying needs.

In a large National survey, on behalf of Stonewall, Hunt, and Fish (2008) examined lesbian and bisexual women's health in the UK. 6178 women participated, 81% of which identified as lesbian, 82% white British and 14% had a disability. They found higher levels of smoking, drinking, and substance use, domestic violence rates and mental health issues. Experiences of discrimination within health care practices, including homophobia and heterosexism, were highlighted. Hunt and Fish (2008) concluded that there was a need for health care professionals to develop greater understanding of lesbian health needs, avoid assumptions about sexuality and develop explicit, inclusive, and visible policies and information.

In a further analysis Fish and Bewley (2010) considered these results within a human rights paradigm, finding there were improving attitudes amongst health care professionals, but heteronormativity led to lesbian invisibility. They concluded that in order to provide inclusive and responsive services, minority groups need to be enabled to participate in health care policy and delivery decision making, there needs to be more inclusive information and literature to inform and empower LB women about their health and health professional education programmes should address the needs of this group more explicitly, a position supported in numerous reports, for example Margolies and Scout (2013), Williams et al (2012) and Makadon (2006).

This is an improving situation with many cancer patient charities providing LGBT affirming patient information (for example Macmillan Cancer Support, and Marie Curie) and professional organisations offering resources to support the development of culturally safe care (e.g., UK Oncology Nursing Society and British Medical Association). However, the impact on national policy making is yet to be seen.

Illness Experience

There is very little evidence that helps build understanding of the experience of illness from a non-heterosexual perspective. In one attempt to redress this Jowlett and Peel (2009) undertook a qualitative online study to explore how sexual identity was significant. There were 363 respondents, coming from eight countries, 190 of which had a chronic illness. There were 52 different conditions including: arthritis, diabetes, mental illness, cardiovascular disease, and cancer. Four themes emerged from the analysis [1] ableism within the LGBT community [2] isolation from the community [3] heteronormativity within sources of support and information and [4] homophobia from health care professionals (2009 pg. 460). The LGBT community mirrored the ableism of the general community e.g., body perfection. They found evidence that the only illnesses the LGBT community responded to were those seen as uniquely affecting the community, for example HIV and AIDS and breast cancer. Furthermore, access issues were even more pronounced in LGBT venues, than in assumed heterosexual ones, increasing the isolation experienced. Jowlett and Peel (2009) found there was a lack of LGBT focused formal support groups, disease focused groups worked within heteronormative assumptions and LGBT people were largely invisible within written information; issues which are also apparent in Fish's (2010) study on women with breast cancer. Although not common within the data respondents described homophobic responses from health care professionals. Additionally, there were also experiences that referred to the fear that hearing such stories induced, which resulted in respondents choosing not to disclose their sexuality and therefore not receive LGBT focused support. This raises interesting questions as to the power and impact of negative experience stories. It further highlights issues within a minority stress framework, where the fear of encountering homophobic reactions may prevent disclosure. Jowett and Peel (2009) conclude that what unites LGBT people living with chronic illness is not their "epidemiological similarities" but their common experiences of oppression, invisibility, and isolation.

Older LGB

With the growing aging population there has been an increasing interest in the impact of aging on the LGB population. Hoy-Ellis and Fredriksen-Goldsen (2016) highlighted that older LGB adults are more likely to conceal their sexual orientation than younger LGB individuals and this concealment may increase the likelihood of depression and minority stress is indirectly associated with long term health conditions and depression. Wallace et al (2011) highlighted higher rates of serious chronic physical and mental health conditions and higher use of mental health services than in comparable heterosexual populations. Lesbian and bisexual older women also report delays in getting care. In a study of 2439 self-identified older lesbian, gay and bisexual people Fredriksen-Goldsen et al (2012) found that a lifetime of victimisation, financial concerns, obesity and reduced physical activity accounted for poor general health, disability, and depression among their study group. Lesbian and bisexual women were less likely to have routine check-ups and more likely to be obese than gay or bisexual men however GB men had higher rates of smoking, excess drinking, lifetime victimization, internalized stigma, less social support and smaller social networks than LB women.

In a further study analysing 7 years of data from a US state-wide, random dialled, health survey Fredriksen-Goldsen et al (2013) extrapolated data examining health disparities in older LGBT participants (over 50 years). They noted lesbians were younger, more educated and had higher rates of employment than heterosexual women; were less likely to be married but likely to be partnered. Interestingly the numbers who had children or were living alone was comparable to heterosexual women, but they were more likely to have a disability and have poor mental health but not poor physical health. Again, lesbians had greater obesity levels and were at higher odds for cardiovascular disease; there was a greater incidence of drinking and smoking; lower mammogram uptake and more HIV testing than heterosexual women. Unfortunately, however, the survey designed did not gather any further cancer specific data, which is a missed opportunity; and despite the high total number of female participants (n=58, 319) only 1.03% (n=562) identified as lesbian and 0.54% (n=291) as bisexual women. Although these results reached statistical significance, comparing 1.5% to the other 98.5% raises questions of clinical applicability (Malterud et al 2009).

Smith and Wright's (2021) systematic review of the experiences and perceptions of older LGBTQI+ people receiving home care services found that fear of discrimination or experienced homophobia were common, leading to study participants hiding their sexuality, resulting in anxiety and emotional stress. Study participants also spoke of removing LGBT identifying objects from their homes to conceal their identities to reduce the risk of discrimination and of care workers delegitimising their LGBTQI+ relationships. Protective strategies employed included being open about their sexuality with the expectation that care workers who displayed homophobic attitudes would not be sent to care for them and looking for outward signifiers of inclusion such as rainbow flags and inclusive advertising materials.

In the UK senior members of the community have lived through the decriminalisation of homosexuality, its removal from mental illness categorisation, gay liberation protests and the HIV and AIDS crisis, to a time of apparent equality and growing societal acceptance (Almack et al 2015, Almack et al 2010). However older LGB individuals are more likely to be single; socially isolated and have no one to call in an emergency (Almack et al 2010, Williams et al 2012). Newcomb (2010) identified a correlation between internalized homophobia and mental health illness in older LGBT people and Mule et al (2009) highlighted that many older LGB individual face coercion to return to the 'closet', particularly those in care settings such as nursing homes.

As a result, the US Institute of Medicine (2011) and Public Health UK (Williams et al 2012) identifies older LGB adults as an at-risk group that is underrepresented in both research and policy. They further argue that services should be cognisant of the lived experiences of this group and ensure that there are opportunities to share and express their experiences.

Mental health

One aspect of LGBT health that has received research attention is mental health and illness. Although there is no evidence of homosexuality being a psychiatric disorder (King et al 2008) and was removed from classifications of mental illness since the 1970's, this attitude still prevails (Volpp 2010 in Adams et al 2013). LGBT identified people experience higher rates of mental health illness including substance abuse, mood and anxiety disorders and suicide attempts (Newcomb and Mustanski 2010, King et al 2008, McNair 2003, Meyer 2003). Lesbians are at particular risk of substance dependence and depression (Adams et al 2013), whilst gay men are at increased risk of suicide attempts (Newcomb and Mustanski 2010), although it is not known whether they have a higher rate of suicide mortality (Meyer 2003). These increased risks are attributed to minority stress, internalised homophobia, and repeated exposure to a wide range of psychosocial stressors including bullying and homophobic attitudes (Hoy-Ellis and Fredriksen-Goldsen 2016, Adams et al 2013, Newcomb and Mustanski 2010, Meyer 2003).

Ramirez and Galupo (2019) in one of the first studies to examine the intersection of race and LGB identity on mental wellbeing and multiple minority stress found that LGB people of colour (POC) perceived distal and proximal minority stressors accurately predicted their rates of depression and anxiety, mirroring previous findings in predominantly white participant studies. The impact of vicarious trauma on self-reports of depression and anxiety was also evident in the sample. LGB-POC reported higher rates of distress when violence was perpetrated against other members of their community, hearing of another person's ill-treatment had comparable effects on mental health to experiencing the trauma first-hand.

One mediator of minority stress and psychological distress appears to be locus of control (LoC). Carter et al (2014) examined the relationship between LoC and minority stress in 165 LGB identified participants, finding that an internal locus of control moderated the relationship between workplace prejudice and psychological distress but not for internalised heterosexism and distress. They concluded that an internal LoC may act as an important resiliency factor.

Both the concepts of internalised homophobia and minority stress have been criticised. The tools used to measure internalised homophobia, for example, were designed to detect this in gay men and are based on a single point of oppression (homophobia), but they have been applied to all members of the LGBT spectrum without due consideration, leading to accusations of invalid and unreliable findings, for example lesbians have at least two stigmatisations: being female and lesbian (Newcomb and Mustanski 2010). Minority stress has been criticised for describing members of minority groups as passive victims of oppression rather than active participants in society (Meyer 2003). It is also worth considering that the minority stress model is based on US society where the experiences of prejudice and racial discrimination are different to those experienced in Europe.

A significant review of the literature on minority stress published by Diamond and Alley in 2022 highlighted that 20 years of research on minority stress had yielded inconclusive and mixed results. Rather they posit that the "Generalised Unsafety Theory of Stress" (Borsschot et al 2018 cited by Diamond and Alley 2022) offers a more comprehensive understanding of the impact of multiple forms of marginalisation that SOGI minority groups experience, including racism, ageism and ableism. Within this theory social safety refers to stable social connections that offer protection and belonging and that the absence of these impacts negatively on wellbeing

> "The absence of social safety is just as health-consequential for stigmatized individuals as the presence of minority stress, because the chronic threat-vigilance fostered by insufficient safety has negative long-term effects on cognitive, emotional, and immunological functioning, even when exposure to minority stress is low." (Diamond and Alley 2022 pg. 1)

They conclude that if social safety is a core human need, then it is of relevance to health care and interventions to increase this are paramount. However, this needs to be authentic as inauthentic use of affirming care may erode rather than increase feelings of safety.

Kwon argues that it is not sufficient to just understand factors that lead to suffering but to also understand factors that lead to flourishing and fulfilment. There is an individual future focus, one of hope, optimism, and flourishing (Kwon 2013). Meyer (2003) suggests that there is a growing call for researchers to move away from viewing minority groups as victims of prejudice but towards seeing them as "resilient actors" (pg. 23) who interact effectively in all aspects of society. However he goes on to caution that this may be problematic, as resilience and the concept of the resilient actor shifts the focus from society to the individual, who can then be viewed as having failed to cope and failed to be resilient, rather than seeing society as having failed; it's not society's attitudes that are at fault but the individual's failure to adapt to society and overcome prejudice (Meyer 2003). Williams et al (2012) go on to highlight that it is not clear what role resilience plays in LGBT health yet, nor is it clear what role strategies devised by the LGBT community play in protecting individuals. Despite this a resilience framework may offer a more positive approach to examining the lived experience of LGB individuals and move us away from seeing minority groups as victims of societal oppression, but rather as active participants in life (Kwon 2013).

End of Life Care

There is a lack of data on LGBT views of End-of-life Care (EoLC) (Bristowe et al 2018, Dixon et al 2015, Harding et al 2012). So little is known about the experiences of LGBT people facing this that the End-of-life Care Strategy for England concluded that LGBT people are the most likely to experience inequality and discrimination (Department of Health 2008).

Studies have identified key areas of concern for LGBT people within end-of-life care. Historically, families offered very little support to LGB relatives and their partners (Brotman et al 2003). Fear of stigmatisation, discrimination or hostility acted as a barrier to accessing services (Bristowe et al 2018, Marie Curie 2016, Almack et al 2010). Clinicians often made assumptions about relationships and family structure or discriminated based on sexual orientation resulting in many patients to access services late or not at all due to fear of discrimination and unsafe care (Bristowe et al 2018, Marie Curie 2016).

Positive findings indicate past and present partners, friends and support groups entered caring relationships together as part of a ‘family of choice’ (Marie Curie 2016). Conversely, study participants spoke of disenfranchisement, when one or both members of a couple were not open about their relationship; partners being redefined/labelled as a ‘friend’ and excluded from important decisions like funeral arrangements by family and care workers. Participants further highlighted family of choice being excluded from care settings, care decision making, a lack of compassionate leave for partners, partners not being recognised in their bereavement and increased pressure on informal carers due to estrangement from their birth family (Bristowe et al 2018, Marie Curie 2016, Almack et al 2010).

For older members of the LGBTQIA+ community, care is provided against the backdrop of UK LGBT history including criminalisation, hospitalisation, oppression, and homophobia. Health care professionals need to be cognisant of these experiences of older LGBT individuals particularly, where being open and ‘out’ was not safe. HCPs must further seek to ensure care is inclusive and ‘families of choice’ are recognised will hopefully go some way to reduce fear and anxiety (Bristowe et al 2018, Marie Curie 2016, Almack et al 2010).

LGBTQIA+ and cancer

Internationally, sexual orientation is not consistently recorded in cancer registries which results in a lack of LGBT cancer surveillance data (Berner and Meads 2022, Berner et al 2020, Quinn et al 2015a, Bowen and Boehmer 2007). Although contested, evidence is thought to suggest that lesbians are at higher risk of breast cancer than heterosexual women, primarily due to pregnancy related factors (Dibble et al 2004 and 2002, Cochran, 2001, Solarz, 1999). However, systematic reviews of breast cancer incidence and prevalence in lesbian and bisexual women have found no published data on breast cancer incidence in this population and unreliable prevalence estimates (Quinn et al 2015a, Meads and Moore 2013). Further, Quinn et al (2015a) highlight that although many lesbian and bisexual women may have an increased prevalence of breast cancer risk factors it remains unclear as to whether this translates into an increased risk of breast cancer.

In areas where there is a high density of sexual minority populations there is high lung cancer incidence and mortality in sexual minority men but not in sexual minority women (Boehmer et al 2012). In a Danish study Frisch et al (2003) analysed the cancer risk in people registered in homosexual partnerships to the general population. They found that women in homosexual partnerships had a cancer risk comparable to those of Danish women in general. For men there was a twofold increased risk for cancer, almost entirely due to the numbers of HIV and AIDS related cancers. However, when HIV and AIDS related cancers and anal cancers were removed from the analysis, risk fell to a level comparable to the general male population. In a US study Boehmer et al (2011) highlighted a difference in the rate of cervical and uterine cancer in heterosexual, bisexual and lesbian women with bisexual women having higher rates of cervical cancer and lesbians being diagnosed more frequently with uterine cancer. In line with the Danish study, Makadon (2006) found gay men were twice as likely to be diagnosed with cancer as their heterosexual counterparts. As a result, there are calls for anal dysplasia screening programmes to reduce the incidence of anal carcinoma as clinical trials have demonstrated the efficacy of the Human Papilloma Virus (HPV) vaccination programme in preventing HPV associated cancers in both men and women (Guiliano et al 2012, Makadon 2006). Following a lengthy campaign for equal access, the UK now offers the HPV vaccine to both boys and girls born after September 2006, however, there is still no inclusive national screening programme for HPV infection, with men deemed at high risk advised to request a test at sexual health clinics (NHS 2022). What this evidence does however show us is there is yet sufficient information available on the true risks and incidents of many cancers within the LGBT population despite many calls for such information to be collected in national and international cancer registries (Quinn et al 2015a).

Disclosure of sexual identity during health care interactions is a high risk undertaking but thought to bring benefits to LGBTQIA+ individuals, including appropriate and focused information, treatment advice and increased levels of comfort and satisfaction with care (Fish et al 2019, Smith and Turell 2017). Most research on disclosure has been conducted within a primary care setting (Mosack et al 2013) however, Fish et al (2019) suggest that cancer care environments differ greatly to primary care setting where long term relationships can be created, and trust built over multiple interactions. Conversely, oncology consultations are often hierarchical, with the oncologist leading the interaction and the patient receiving a life-threatening diagnosis, neither circumstance being conducive to disclosure. In their study Fish et al (2019) found that sexual orientation disclosure is relevant and fundamental to authenticity but only when this is received positively by health care professionals. Participants felt constrained and unable to seek physical reassurance or comfort for fear of negative reactions from others. Symbols of inclusion, such as rainbow flag pins were welcome but there were no incidences of system wide approaches to inclusivity visible to participants within the study. They concluded that creating conditions that signal inclusive and culturally safe care enables the disclosure of sexual identity and enhances the possibility of greater health care experiences for LGB patients. These findings support an earlier study by Quinn et al (2015b) where clinical settings displaying equality signs and using inclusive/ gender neutral language on forms were perceived as safer by LGBTQ patients seeking cancer care. However, Webster and Drury-Smith (2021) suggest that this is not sufficient on its own, services need to go further by ensuring neutral and inclusive language is used in all interactions to maximise safety and minimise heteronormative assumptions.

Gordon et al (2019) undertook a systematic review of 12 studies comparing the mental health of sexual minority and heterosexual cancer survivors. They concluded that sexual minority men may experience greater impacts on their mental health than heterosexual men, particularly those with prostate cancer. This was primarily linked to chronic and specific stressors; prejudice, discrimination and anticipated rejection and marginalisation, resulting in higher anxiety, distress, and depression impacting negatively on quality of life. There was, however, no difference in mental wellbeing between sexual minority and heterosexual women. Indeed, sexual minority women were more likely to access mental well-being services and take medications to help alleviate mental distress than sexual minority men. Nonetheless, these results need to be read with caution as there was heterogeneity and uncertain reliability and validity of the tools used to measure the impact on mental health. Conversely, Boehmer et al (2022), in a secondary data analysis of over one hundred thousand heterosexual and sexual minority cancer survivors, found mental health outcomes vary in relation to sexual orientation, race and ethnicity, with White, Black, and Hispanic sexual minority men and women having a 2 to 3 times higher odds of depression and poor mental health than heterosexual cancer survivors. Power et al (2022) in an interview study of 430 LGBTQI cancer patients and 132 partners and carers found that despite chronic and cumulative minority stress patients and their carers were not passive recipients of discriminatory and exclusionary care, but rather demonstrated agency and resistance to inequity. Heteronormativity, hostility, and the legacy of minority stress impacted negatively on the cancer experience but social, family and companion animal support buffered against this.

There are distinct barriers to accessing and receiving quality cancer care, with multiple inequalities existing including a lack of appropriate care, inappropriate outing by staff and heterosexist assumptions about people's lives (Berner and Meads 2022, Boehmer 2018, Bryson et al 2018). Focusing on the experiences of LGBT people diagnosed with cancer Margolies and Scout (2013) reported on an online survey completed by 311 respondents. They found a lack of supportive care, and both homophobic and transphobic experiences. Only 5% of respondents received information on LGBT specific support groups and only 43% received information on any form of cancer support. In common with previous studies there was conflict associated with coming out to health care providers for fear of substandard care, and in some cases substandard care was experienced, for example, physicians refusing to accept patients onto their caseloads. Furthermore, respondents highlighted wanting to talk about issues such as lifestyle, fertility, and sex. However, they were not given opportunities to do so, mirroring Perz et al (2013) findings. One aspect raised by lesbians within this study was the 'Pink Ribbon' effect where breast cancer has been "over-feminised" to the degree that some women feel pressured into decisions about reconstruction and excluded from the support available. This is also discussed by Jain (2007) who debates the cultural importance of breast cancer and associated gender conforming expectations which serve to alienate gender diverse people.

Bryson et al (2020), in a unique study examining LGBTQ/T2 patients experiences of breast and gynaecological cancer as they operated as "women's cancers" at the intersection of minority gender and sexual identities, interviewed 81 participants. They found that there was a strong relationship between cultural safety and experiences of SOGI participants, especially relating to disclosure, which increased when racial oppression was also experienced. Health care professionals were tangibly uncomfortable when in the presence of LGBTQ/T2 patients and when caring for folk who did not identify as women with a "woman's cancer" they made no attempt to understand their needs, experiences or treatment and care decisions. The results of this were an increased burden on the person with cancer to navigate the complexities cancer treatment and survival whilst managing inequitable and discriminatory health care.

The impact of this need to navigate care is also highlighted in Jabson and Kamen (2016) in a comparison study with heterosexual cancer survivors where they found sexual minority cancer survivors had a lower satisfaction with cancer care even when controlled for demographic and clinical variables. Further, a secondary analysis of the UK National Cancer Patient Experience Survey (NCPES) also concluded that sexual minority cancer patients have a less positive experience of cancer services than heterosexual patients, particularly in relation to lack of patient centred care and involvement in decision making, heteronormativity and lack of culturally competent care (Hulbert-Williams et al 2017).

One of the key areas for improvement in cancer care is health care professional education and training in LGBT cancer experiences, culturally competent or sensitive care and cultural humility (Ussher et al 2022, Berner and Meads 2022, Berner et al 2021, Webster and Drury-Smith 2021, Boehmer 2018). Quinn et al (2020) highlighted that many oncologists are uncomfortable caring for sex or gender minority patients due to a lack of knowledge, are unsure how information on sexual and gender diversity is important to cancer care, or how to meaningfully engage the LGBT community in their care. Sutter et al (2021) analysed oncologists experiences of caring for LGBTQ patients with cancer and found positive experiences and personal growth when caring for LGB patients but there was a lack of experience in caring for Trans patients and a paucity of educational opportunities. Many study participants stated they provided the same care to all patients, regardless of sexual or gender identity. Ussher et al (2022) labels this as egalitarian care, which has a negative impact on the SOGI diverse patient, including risk of disclosure, feeling unsafe and fearful of discrimination or invisibility. In a UK study Stonewall (2016) reported that 72% of patient facing staff had never received training on the healthcare needs of LGBT people and 57% of respondents did not feel that sexual orientation was relevant to healthcare. However, Ussher et al (2022) found that reflective and inclusive health care practitioners offered proactive, affirmative, and supportive cancer care, where LGBTQI patients felt safe and respected, willing to disclose their sexual orientation or gender identity and were satisfied with their care. It is therefore essential that all health care professionals undergo instruction on offering inclusive, person centred, and culturally humble care.

Discussion

Many studies have combined LGBT people into one homogenous group; however, the groups within this collective umbrella term are diverse and have their own health care needs. Furthermore, even in areas of high LGBT population density (such as Brighton, London, Manchester, New York, or San Francisco) we are still a minority and are often hidden from mainstream gaze, therefore any study that attempts to show a statistical pattern or identify statistically significant variations needs to be extremely large in order for a sufficient number of voices to come through. Even when studies show statistically significant findings these are often so weakly powered that the clinical implications are meaningless (Malterud et al 2009). Qualitative studies that attempt to be inclusive of all sexualities struggle to recruit sufficient number of LGBT identified individuals for the differences in experience to show; therefore, it is imperative that research methods be developed that can better examine the needs of small groups (Mollon 2012) and studies should focus on distinct groups in order to show the specific realities of living as an LGBT identified individual (Berner and Meads 2022, IOM 2011).

Currently LGBT research is, for the most part, driven by the biomedical model and conducted within a positivist-empiricist paradigm, particularly in the USA (Wolitski et al 2008 cited by Jowett and Peel 2009, Fish 2009). Fish (2009) and Jowlett and Peel (2009) emphasis, the need for more qualitative approaches to LGBT research as there is little understanding as to how sexual identity may be relevant to the experience of a range of illnesses. Berner and Meads (2022) and Malterud et al (2009) argue that we do not know the extent to which research carried out in North America can be applied to the UK or Europe; therefore, questions of representativity must be considered. Furthermore, the wrong strategy or question can lead to interpretations that add unintentional burdens to the marginalised group. Malterud (2009) further stress that complete transparency must be evident in research methodologies, research questions, defining the term lesbian and the identification and recruitment of a study population, to improve quality and usefulness of any research output. Berner and Meads (2022) in their extensive review of LGBT cancer in the UK strongly advocate for research that is UK specific, co-designed and co-produced studies that focus on specific groups within the LBBTQIA+ community to fully understand the multiple aspects of this experience.

Conclusion

Despite over 25 years of literature asking questions and examining LGBTQIA+ health issues it is currently impossible to draw any firm conclusions from the literature. Most studies highlight that there is still no standard definition of what constitutes a non-heterosexual population, and whether this is possible or desirable is questionable. Waiting for a specific definition adds to the myriad of reasons given for not investing in LGBT health research. Furthermore, for every study that highlights a health-related concern, such as obesity or smoking, or identifies a higher prevalence of risk, e.g. breast cancer, there is another that disputes this. One of the key reasons for the paucity of answers is a lack of longitudinal, total population based, random, sampling studies, however these are expensive and at a time of austerity may struggle to find funding. Additionally, there is a lack of understanding of qualitative experiences of lesbians living in a society where there is apparent growing acceptance of “alternative” lifestyles. This chapter has, however, attempted to shed light on some key concerns that are ripe for further investigation but most importantly it has hopefully demonstrated that there is a need for greater qualitative research with defined groups within the LGBTQIA+ family to begin to understand the impact of living with and adapting to health challenges.

Chapter 5: Lesbians and Cancer: A Literature review

Introduction

As discussed previously lesbian specific health care faces many barriers to equity. Prior to 1990 lesbians were undetectable within health care research (Roberts 2001) and the lesbian population remains an invisible minority in health care today (Fish and Bewley 2010). Lesbian's health differs in keyways to heterosexual women regarding behaviour, risk and experiences of health care; yet the construct of women's health is based on a heteronormative discourse and assumptions of marriage and children, and where lesbian and bisexual women are seen as a homogenous group (McDermott, Nelson and Weeks 2021, Fish and Anthony 2005, Lewis et al 2006, Fish 2008, Mule et al 2009, Fish and Bewley 2010). Winnow (1992) highlighted that lesbians were always the 'other' in equality movements; the other within the women's movement and the other within gay liberation, and Marinucci (2010) argues, the other within Queer theorising, all resulting in scarce attention being paid to their experiences.

Additionally, Fish (2009a), contends that lesbian experiences of sexism and heterosexism are quantitatively different to the experiences of heterosexual women which has led to inequalities in lesbian health and a lack of focus on qualitative issues and experiences. Lesbians have highlighted their experiences of hostility, fear, heterosexism, and homophobia when seeking care (Desai et al 2021, Brown and McElroy 2018 a and b, Legere and MacDonnell 2016, Almack et al 2010, Bjorkman and Malterud 2009, Jowett and Peel 2009, Hunt and Fish 2008, Stevens 1992) and amongst health care professionals there is a lack of knowledge and embarrassment over lesbian and bisexual issues (Bjorkman and Malterud 2009, Fish and Bewley 2010). Lesbians therefore face a paradox when accessing health care services; disclosure of their sexual minority status places them at risk of homophobia and poor care, alternatively, not disclosing their sexuality potentially leads to heterosexism and care that is not responsive to their individual needs (Fish 2010, Sinding et al 2004). Furthermore, lesbians with cancer face making this choice at every interaction with a new health care professional (HCP), at a time when they are confronting life changing health decisions (Fish 2010). It is not however clear at this time how this burden is felt and managed by individuals or whether life experiences play a significant role in managing this.

Berner and Meads (2022), McDermot, Nelson and Weeks (2021), IoM (2011) and Solarz (1999) have made calls for LGBTQ communities not to be considered as homogenous but instead to be invited to participate in studies as distinct groups to ensure that their unique perspectives are given clear and unambiguous attention. McDermot, Nelson and Weeks (2021), and Mule et al (2009) further argue that there must be recognition of the unique and specific health issues affecting LGBT individuals and that employing anti-oppressive, critical, intersectional analysis will enable this to occur. Women identifying as lesbian are a distinct group with diverse needs that should be investigated independently to ensure their experiences are captured. Additionally, it should not be taken for granted that a study focusing on lesbians can capture the voices and experiences of all lesbians, indeed heterogeneity within a group must be recognised and celebrated (McDonald et al 2003) and in taking a queer feminist stance, the avoidance of a reductionist approach, that potentially perpetuates the binaries endemic within much health care research (man/woman, straight/lesbian), is paramount. Therefore, a narrative review of existing literature was undertaken to examine the scope of published knowledge about lesbian's experiences of cancer, to identify gaps and unanswered questions in the research, and to develop a research study that aims to provide new insights into this lived experience.

Method

A narrative review provides an important insight into a particular topic (Jahan et al 2016) and aims to summarise and critique the most salient and recent published literature (Onwuegbuzie and Frels 2016). Narrative reviews can include both qualitative and quantitative research studies as well as grey literature and systematic reviews. Narrative reviews are currently the most common type of published medical literature and offer a contemporary review of key areas of interest (Baethge, Goldbeck-Wood and Mertens 2019).

A literature search was undertaken using ASSIA, BioMed Central, British Nursing Index, Cumulative Index of Nursing and Allied Health Literature (CINAHL), JSTOR, Medline, Oxford Journals, Project Muse, PsychInfo, Pubmed Central, Sage, Science Direct and Wiley Online databases. Key words used in the search were Lesbian, sexual minority woman/women, homosexual*, female, cancer, neoplasm. The initial search resulted in 3057 articles.

Repeat citations were discarded and abstracts were screened for relevance using the following inclusion criteria; peer reviewed journals, primary research, systematic literature reviews, cancer screening, treatment, incidence, risk, experience; quality of life; psychosocial issues, survivorship; lesbian, bisexual, sexual minority women participants; comparative homosexual and heterosexual female studies and published in English. The following were excluded; opinion pieces, non-peer reviewed journals, LGBT focused, not cancer specific, not published in English. A hand search of reference lists was carried out to identify missing literature. Grey literature was accessed via the online search engine Google. No publication date limit was applied to the search as all relevant papers were considered important to the review.

Table 1: Literature search strategy

Databases searched	ASSIA, BioMed Central, British Nursing Index, Cumulative Index of Nursing and Allied Health Literature (CINAHL), JSTOR, Medline, Oxford Journals, Project Muse, PsychInfo, Pubmed Central, Sage, Science Direct and Wiley Online
Key words included	Lesbian, sexual minority woman/women, homosexual*, female, cancer, neoplasm
Inclusion criteria	Peer reviewed journals, primary research, systematic literature reviews, cancer screening, treatment, incidence, risk, experience; quality of life; psychosocial issues, survivorship; lesbian, bisexual, sexual minority women participants; comparative homosexual and heterosexual female studies and published in English
Exclusion criteria	Opinion pieces, non-peer reviewed journals, LGBT focused, not cancer specific, not published in English

The original literature review was undertaken in 2014 and resulted in 45 studies. The search was updated in 2022 and a further 13 studies, published from 2014 – 2022, were identified and included in the review. The total number of studies included in this narrative review was 58.

Table 2: literature search results

Initial results: 3057			
Remaining after screening against inclusion and exclusion criteria 58			
Quantitative studies 37	Qualitative studies 14	Mixed methods 6	Systematic reviews 1

Most studies were quantitative and cross-sectional design. Secondary analysis of samples drawn from larger studies was a common approach to identifying appropriate participants. Within the 14 qualitative studies, convenience sampling and snow balling were the most common forms of selection and recruitment of participants. In more recent studies social media played an important role in reaching this historically hard to reach group. Most studies focused on breast cancer, with a few including reproductive cancers (Appendix 1 for a summary of studies reviewed).

The problems with defining “lesbian”.

Within a positivist biomedical discourse there is a desire to explicitly define the population under study however there is no agreement on a definition of who a lesbian is. Many studies refer to the US Institute of Medicines 1999 report of Lesbian Health

> “The term has been used to describe women who have sex with women, either exclusively or in addition to sex with men (i.e., behaviour); women who self-identify as lesbian (i.e., identity); and women whose sexual preference is for women (i.e., desire or attraction)” (Solarz, 1999 page 22)

What this does not acknowledge is that the term lesbian is a socially constructed label that is dependent on time and place (Rupp 2009, Jennings 2007). For this literature review the terminology used by the individual studies will be used. Table one outlines the definitions used in the various studies examining lesbians and cancer, however, it is also apparent that many studies do not define their population (for example Fish 2010, Darwin and Campbell 2009, McGregor et al 2001, Lauver et al 1999, Matthews 1998) highlighting the arbitrariness and restrictiveness of such activity:

Table 3: Definitions of lesbian within empirical studies

Definition of lesbian	Sexual minority women (SMW)
“Primary emotional and sexual relationships were with women” (Sinding et al 2004, 2005) “Primarily attracted to and engaging in sexual activity with women over the previous 12 months” (Matthews et al 2004) “Any woman who partners with another woman” (Burnett et al 1999) “self-identified lesbians, women who identify as having a sexual orientation other than heterosexual and or partner with other women in romantic and spousal relationships” (Jabson et al 2011) “a lesbian may be defined as a woman who reports herself to be a lesbian, engages in sexual behaviour with a woman, or has enduring emotional, romantic, or sexual attraction to other women” (Zaritsky and Dibble 2010)	“Women who partner with women or identify as lesbian or bisexual” (Boehmer 2004) “self-reported partnering with women and those with a lesbian or bisexual identity…defined our population using two of three dimensions (identity and behaviour but not desire) of sexual orientation” (Boehmer et al 2005a, b) “Stating lesbian or bisexual identity”- inc. Women who Partner with Women (WPW) to be inclusive (Boehmer et al 2007) “Reporting a lesbian or bisexual self-identity or reporting a preference for having a female partner” (Boehmer et al 2013a, b, c) “Women who have sex with women” (Cochran et al 2001)

Cancer risk, the perception of risk and cancer incidence.

Based on extrapolation and self-reporting studies from the US, it appears that lesbians are at greater risk of breast and ovarian cancer, primarily due to a reduced accumulation of pregnancy acquired protective factors, “lifestyle” choices, such as screening uptake, and obesity (Brown et al 2015, Meads 2013, Dibble et al 2002a and 2004, Cochran et al 2001, Solarz 1999, Roberts et al 1998). A consequence of this is a prejudicial belief that “being a lesbian” puts you at risk of cancer, rather than the coexistence of life choices and risk factors such as nulliparity, which are not unique to lesbians, that increase the risk of these cancers. Conversely, other risk factors, such as age of first menarche and age of menopause, are no different in lesbian and heterosexual populations (Roberts et al, 1998; Dibble et al, 2004) and it is still unclear whether this concentration of risk factors results in detectably higher incidence rates of breast cancer (Cochran and Mays, 2012).

Following a systematic literature review Meads and Moore (2013) concluded that there remained uncertainty as to whether there is a higher rate of breast cancer in lesbian and bisexual women and the only realistic way of determining this with certainty was to collect sexual orientation data in routine statistics and cancer registries, something that has only been in place in the UK since 2020, and as highlighted earlier has been severely impacted by Covid-19 (Berner and Meads 2022). In an Australian longitudinal study Brown et al (2015) examining risk factors and diagnosis of cancer found that SMW did not have a significantly higher diagnosis rate than exclusively heterosexual women, but they did have higher rates of risk factors, including smoking and alcohol intake. Brown et al (2015) assert that, despite not currently having higher incidences of cancer, the increase in risk factors could lead to higher rates of diagnosis as the women in this study age. However, of the 10 451 women participating in this study only 2% (251) identified as SMW, notably lower than the estimated 3.4% of Australian women who describe themselves as non-heterosexual (Wilson and Shalley 2018).

The risk of mortality has also been examined. Cochran and Mays (2012) extrapolated the risk of breast cancer mortality among women cohabiting with same sex partners from the 1997-2003 US National Health Interview Survey. The findings indicated that women in same sex couples had a 3.2 times greater age adjusted hazard for fatal breast cancer but no difference in the overall (all causes) risk of mortality. However, these data must be interpreted with caution as the parent study did not directly ask for sexual orientation, the follow up time was only 7 years and the percentage of presumed homosexual women was very small (0.5%).

In the UK the National Lesbians and Health Care Survey (Fish and Anthony, 2005) examined the perception of risk for breast and cervical cancer in 1066 respondents; the majority believed their risk of breast cancer was the same as heterosexual women, with only 19% believing it was higher and half the respondents believing their risk of cervical cancer was lower than heterosexual women. Polek and Hardie (2010) examined lesbian's knowledge of Human Papilloma Virus (HPV) and cervical cancer risk finding, of the 96 women who took part, 30% did not know or did not believe that HPV could be spread via female-to-female sexual contact and a further 29% did not identify HPV as a cancer risk factor. Significantly, women who had shared their sexual orientation status with health care professionals (73%) were less likely to know about the risks, raising questions regarding health care professionals as gatekeepers to health information and education. Conversely, Tracy et al (2013) found that women who had disclosed their SM status to their primary care physician or gynaecologist had greater odds of routine screening than those who did not and Bowen, Powers and Greenlee (2006) found that a risk counselling programme for SMW resulted in reduced perceived risk, anxiety and fears about breast cancer and there was increased uptake of screening and breast self-examination, demonstrating that targeted health education can have a beneficial impact on the perception of illness risk and the uptake of screening.

Although evidence for an increased risk for breast and gynaecological cancer appears to be available this is not the case for other cancers. For example, the prevalence of smoking increases the risk for several cancers, including lung, head and neck and renal cancer. Obesity increases the risk of colorectal cancer; and alcohol use increases the risk of gastro-intestinal cancer, yet no data exists for these common and deadly diseases, even though health studies have indicated that lesbians smoke and drink more and within the US have higher rates of obesity (Hutchcraft et al 2021). Furthermore, the focus on lifestyle choices as being causative within these studies firmly places the blame for cancer occurrence with the individual and does not reflect the social reality in which many women find themselves, for example in low paid jobs, relative poverty, and poor housing, all potentially contributing to an increased cancer incidence. There is also a dearth of evidence examining reasons why key risk factors such as obesity and smoking behaviours occur within the lesbian population, as already identified there is an increase in mental health illness and experiences of prejudice which may lead to individuals adopting coping mechanisms that are consequently detrimental to physical health.

Cancer screening

Screening programmes for cancer and their impact vary by country and socioeconomic factors. In a US national study of health-related behaviours and cancer screening Roberts and Sorensen (1999) found that lesbians had similar health behaviours to the general US population in several areas and in others had better. In the UK Fish and Anthony (2005) found that 55% of lesbians attended for regular Pap smears, 80% of those eligible had attended for a mammogram (higher than the UK average) but only 13% said they regularly undertook breast self-examination, compared to 41% of women in a general study (Umeh and Rogan-Gibson, 2001). Fish and Wilkinson (2003a and b) in a study examining lesbian's beliefs and practice of breast self-examination (BSE) showed that most respondents did not regularly practice BSE, however, those that did had experienced breast problems, were aware of their risk of breast cancer, had established a routine or had prior knowledge of BSE.

Barriers to obtaining mammograms and factors that would overcome these are like those expressed by presumed heterosexual groups including: system factors, life demands, fear, and lack of motivation, cost, and in addition; poor past experiences, homophobia, racism, and mistrust of the medical profession. Reasons for undergoing the examination include perceived high risk; and facilitators included encouragement from health care providers and the creation of safe spaces (Lauver et al, 1999, Burnett et al 1999). However, in studies where the high-risk factor is not present the level of adherence is not replicated (Hart and Bowen 2009).

Significant variables for adherence to cervical screening recommendations are heterosexuality, history of an abnormal Pap smear, an annual medical visit; awareness of risk and physician recommendation (Tracy et al 2013, Ben-Natan and Adir 2009, Fish 2009, Matthews et al 2004). However, Darwin and Campbell, (2009) found that lesbian and bisexual women rejected the notion that Pap testing was more important for heterosexual women and screening was a normative behaviour rather than a choice.

Furthermore, lesbians are more likely to report a perceived sexuality bias in the health care provider and fear of discrimination as key barriers to screening (Tracy et al 2013, Fish 2009, Matthews et al 2004). Greene et al (2019) identified intersecting structural and personal factors impacted on the uptake of cervical screening, including health insurance status, childhood physical abuse, early drinking and internalised homonegativity. Additionally, women who reported attending for cervical screening were younger, feminine presenting and more likely to report more than one male sexual partner or greater than 28 lifetime sexual partners.

It appears from this evidence that there is confusion over the risk factors associated with cancers and a lack of interventions aimed at addressing this. Although in the UK there has been a concerted effort to target lesbian and bisexual women with health information and screening advice, particularly in relation to cervical cancer (NHS Cervical Screening Programme 2009) the impact of this is still unclear. Additionally, perceived or actual homonegativity and heterosexism are consistently identified as barriers to SMW attending cancer screening interventions.

Treatment decisions and outcomes

Currently no significant differences by orientation regarding breast cancer treatment choices have been found (Dibble and Roberts 2002, Matthews 1998). There was some disparity in the experiences of side effects from chemotherapy with Dibble and Roberts (2002) suggesting they were worse for lesbian respondents, however, Boehmer et al (2013a) were unable to confirm these findings despite interviewing women at a similar time point in the cancer journey. These findings raise questions about trust in relationships between lesbians and their health care providers during treatment, particularly nurses as they are the primary care giver in this setting. However, no attempt was made within either study to evaluate the 'inclusiveness' of the care settings, which could have shed light on the willingness of participants to discuss treatment related issues with professional care staff.

Boehmer et al (2007) explored SMW considerations when making decisions about reconstructive surgery finding that not being defined by having breasts was closely aligned to SM status and they noted SMW's otherness to mainstream values, for some reconstruction was seen as a straight woman's choice. Views supported within critiques of the heteronormativity of breast cancer (see Bryson and Joynt 2013, Jain 2007, and Lorde 1997). In a more recent study Brown and McElroy (2018b) explored the choice of 16 US women to have bilateral mastectomy without reconstruction. They discovered that, at the intersection of gender and sexuality, bilateral mastectomy for gender queer identified folk offered a sense of gender clarity even within the challenges of breast cancer treatment. Further, the participants in the study disclosed that being open about sexual orientation and gender identity helped health care professionals to understand treatment choices and they were more likely to receive the care they required. However, they still experienced negative reactions, a lack of understanding about choices, gender policing and heterosexist assumptions. Despite a growing number of studies focusing on treatment outcomes and choices for SMW there remains insufficient evidence to draw any conclusions about whether or how sexual identity impacts on these.

Coping with cancer; quality of life and mental health outcomes

Studies have attempted to show that being a sexual minority woman with breast cancer puts you at greater risk of psychological trauma; however, this hypothesis is not supported by the evidence, rather inconsistent and contradictory findings persist. McGregor et al (2001) for example, examined the impact of internalised homophobia (IH) on women diagnosed with early breast cancer concluding that lower self-esteem leads to IH by way of elevated distress, however, except for screening; they fail to link their findings to cancer. Fobair et al (2001) found no difference in mood and ability to deal with conflict, lesbians experienced less body image and sexual activity disturbances and felt more support from partners, who rated highly on giving love and support as well as practical assistance. In Boehmer et al (2005a) lesbians were more likely to perceive greater levels of social support and coping and had lower levels of distress. Interestingly, however, lesbians in support groups expressed significantly more cognitive avoidance coping and distress. Jabson et al (2011) could not identify a significant relationship between sexual orientation and quality of life in breast cancer survivors, proposing that participants may have developed resilience due to chronic minority stress, which in turn facilitated coping with breast cancer. Boehmer et al (2012) was also not able to confirm that SMW breast cancer survivors had lower quality of life compared to heterosexual women, however they did note that there was a significant association between SMW experiences of discrimination and worse physical health, a novel finding of this study. Conversely, Schefter et al (2021) concluded that although there was no difference in overall quality of life and distress; lesbian, gay and bisexual gynaecological cancer survivors had poorer emotional health than heterosexual women, particularly depression, anxiety, and post-traumatic stress disorder (PTSD). Arena et al (2006) and Boehmer et al (2012a) compared the rates of anxiety and depression between heterosexual and SMW survivors finding no difference between them. In a further study Boehmer et al (2013 a, c) attempted to determine the differences between lesbian and bisexual survivors' adjustment finding sexual identity had no significant relationship with physical or mental health. They did however confirm McGregor's (2001) finding that internalised homophobia led to greater distress among lesbians, and, supporting their earlier work, found partnered survivors fared better compared to single women (Boehmer et al 2005b).

When specifically looking at the mental health outcomes for adolescent and young adult (AYA) female sexual minority cancer survivors Desai et al (2021) found a high prevalence of anxiety and depression. AYA survivors had significantly higher odds of anxiety when compared to their heterosexual counterparts, reduced social support and higher, but not statistically significant, rates of depression. Desai et al (2021) consider that the heteronormative frameworks, in which cancer services are designed and operated, lead to AYA feeling isolated and invisible and that health care services need to design strategies to ensure this group are fully supported in their cancer journey.

Fobair et al (2002) evaluated a 12-week supportive-expressive group therapy intervention finding a significant improvement over base line in mood, distress and coping. Body Image (BI), sexuality or attitudes to health care professionals remained unchanged which may be due to lesbians rating BI and sexuality higher to begin with, however this is not supported by later studies (Sinding et al, 2004). Fobair suggested that this intervention may help women cope with the stigma of being a lesbian with cancer; however, no test for perceived stigma was carried out.

These studies have assumed that being a sexual minority woman with breast cancer would automatically result in increased mental health problems, however, they have not first tried to develop an understanding of the meaning of cancer for their participants. Interestingly resilience appears to play a part in coping with cancer and this resiliency appears to come from coping with social attitudes to homosexuality, a key finding of Kamen et al (2021) where resilience, as measured by the Resilience Scale 14 (Wagnild 2009), significantly mitigated against distress from discrimination. Additionally, Desai et al (2021) observed that surviving cancer may contribute to feelings of resilience, protecting against poor mental health outcomes in AYA cancer survivors. Previous literature has indicated that effective coping and emotional adjustment may build resilience and resilience is bidirectional in relation to social support, with SMW reporting reduced reactivity to discrimination when they perceive high levels of social support (Kamen et al 2017). But this has not been fully explored within the LGBTQ cancer literature and offers an opportunity for greater exploration: does resilience that develops in the face of any adversity consequently assist with coping in later traumatic life events; for example, does resilience developed in response from homophobia assist with cancer resilience and does cancer resilience assist with homophobia?

In a study examining spirituality and religiosity among lesbian women diagnosed with cancer (Varner 2004), participants spoke of constructing unique definitions and practices of spirituality and religion to help them through their cancer experience. Their definitions of spirituality were closer to feminist theorists than patriarchal and traditional views and their spirituality was rooted in their lesbian community and culture, with “gay friendly” congregations. The participants had all left the religious tradition in which they were raised, and they were not willing to belong to any religious organisation where they felt judged. All had begun their religious journey prior to cancer and for all bar one of the 8 participants their increased interest in spirituality continued past their cancer treatment. This study was undertaken in one location within one city in Maryland USA, so is not generalisable to the wider lesbian community, however this is currently the only study specifically addressing the spiritual and religious coping mechanisms used by lesbian women with cancer, so is worthy of note.

Data suggests that SMW do need additional and specific health quality of life and wellbeing resources to manage the impact of structural inequalities, heterosexism, homophobia, coping with long term minority stress, internalised homophobia and building on resilience strategies that may already be in place (Desai et al 2021, Hutchcraft et al 2021, Schefter et al 2021, Kamen et al 2017).

The impact of disclosure of sexual minority status on wellbeing

One of the most spoken about concerns highlighted across several studies was the dilemma of disclosing their sexual minority status to health care professionals and risking negative outcomes on their care following this decision (Brown and McElroy 2016 a and b, Legere and McDonnell 2016). Sexual minority women undertake preparatory work early in healthcare relationships to gauge whether the care environment is safe to disclose their status; the absence of a response to disclosure or a negative reaction is perceived as ignorant or discriminatory (Sinding et al 2004, Boehmer and Case 2004, Matthews et al 2002, Matthews 1998). Health care providers who also identify as lesbian, with good medical reputations, are sort after (Sinding et al 2004, Boehmer and Case 2004, Matthews et al 2002, Matthews 1998) but SMW are generally less concerned about the gender of their oncologist, preferring competence and success over compassion and empathy (Matthews et al 2002). Failure to ask about sexual orientation and relying instead on the client to disclose this information led to heteronormative assumptions and heterosexist approaches to care (Brown and McElroy 2018a, Legere and McDonnell 2016, Boehmer and Case 2004). In some cases, sexual orientation was only addressed when discussing pregnancy and reproductive health care (Legere and McDonnell 2016). SMW disclosed to correct heteronormative assumptions, but this often led to care being affected (Brown and McElroy 2018a and b).

In early studies women who were ‘out’ in their general life were more likely to be ‘out’ with their HCPs, with lesbians being significantly more likely to disclose their sexual orientation than bisexual women, especially if they were in a relationship (Boehmer et al 2005a, Boehmer and Case 2004). Openness about sexual orientation was associated with lower levels of anxiety and avoided inappropriate questions (Boehmer et al 2013a, c, Fish 2010). However, Boehmer et al (2012) found that SMW were more likely to experience gender-based discrimination than their heterosexual counterparts and for the participants in Kaman et al (2021) outness was associated with increased levels of psychological distress. This increase in distress could be related to the current political and social challenges facing SMW in socio-economically privileged countries, where LGBTQIA+ rights are being openly challenged or reversed, particularly in the UK and USA, potentially leading to an increased level of distress prior to a cancer diagnosis.

Matthews (2002) found lesbians were less satisfied with the care they received from HCPs and Sinding et al (2004) reported that lesbian identity and social context was ignored or dismissed within health care and there was a lack of lesbian positive psychosocial support. Barnoff et al (2005) highlighted the importance of information sources focused on lesbian realities, access to lesbian service providers and support and wellness groups to address this inequality. Fish (2010) in a UK study described situations where participants faced heterosexism from HCPs which resulted in discomfort and on occasion conflict and a lack of continuity in care, where seeing a different doctor at each appointment meant having to ‘come out’ to a new HCP at each consultation. It is evident that health care professionals have significant power to affect the wellbeing of patients, however it is not clear to what degree this impact is felt.

Cancer support

The concept and act of social support is discussed in multiple papers and primarily focuses on three contexts: intimate partner relationships and support, family and community support and professionally organised support. Within these three contexts the type of support offered varies in the level of comfort and safety it provides sexual minority women with cancer, with experiences ranging from well received emotional and physical support from partners, families, and communities to lack of awareness, homophobia and heterosexism/ centrism being a common manifestation within professional support settings.

The support offered by intimate partners was the most referenced positive support experience and negative perceptions of partners was rarely expressed (White and Boehmer 2012, Boehmer et al 2005a, Fobair 2001). White and Boehmer (2012) found female partners were continuingly responsive to their partners needs and did not withdraw from cancer related discussions, but they had ongoing stress and burden which needed to be recognised. Study participants cited their concern for their partners wellbeing and the burdens put on them as carers. Boehmer et al (2005b) found that the woman with breast cancer's emotional wellbeing was dependent on their primary support provider (most often their intimate partner), whereas the primary support providers' emotional wellbeing was dependent on their connections with their wider community. They also found that when well supported and less isolated the primary support providers distress was eased. Further, Barnoff et al (2005) found participants expressed the desire to connect with other lesbians with cancer and they wanted their partners and children to have the same opportunities for support as heterosexual couples. However, there were barriers to participation in support groups for both the person with cancer and their partners due to a lack of perceived acceptance, an overemphasis on breasts as an object of male sexual desire and being a lone woman in partner support groups (Paul et al 2014, Fish 2010, Matthews 1998). Participants in Brown and McElroy (2018a) expressed a need for their partners to receive recognition and ongoing support but that this was often not forthcoming, there was a dearth of organised support groups for LGBTQIA+ people and both women with cancer and their partners did not feel welcome or able to trust support groups that were not LGBT focused due to heterocentrism. However, when other LGBT people were visibly members of support groups the level of trust grew, and support was increased. The recognition of partners by health care professionals and the acceptance of same sex relationships created a more trusting relationship for SMW with cancer and resulted in a less difficult treatment experience (Brown and McElroy 2018a).

Despite evidence suggesting that same sex partners offer greater support to their partner when going though breast cancer (White and Boehmer 2012) a negative impact of breast cancer on intimate relationships was highlighted by Paul et al (2014), where there were often changes in relationships following a breast cancer diagnosis leading to disruption or dissolving of partnerships. Brown and McElroy (2018a and b) found that although for some women the impact of breast cancer surgery had been positive on their relationships, particularly through a renewed gender expression, most participants reported a negative impact on intimacy, related to hormonal medications. In a case control study of 85 matched cases Boehmer et al (2014) found that partnership status was not significantly associated with sexual disfunction, whereas menopausal status was, a more common occurrence in breast cancer survivors due to hormone therapy. Additionally, cases had reduced frequency of sexual intimacy, reduced desire, a reduced ability to reach orgasm and increased pain. However, unlike Paul et al (2014) findings partnership status was not put at risk because of cancer related sexual disfunction.

The role of the wider lesbian community is less clear. Barnoff et al (2005) highlights “the lesbian advantage” (pg. 66) where women were especially empathetic, participants felt understood and the support provided was especially competent and well organised which some related back to the experience of caring for gay male friends with HIV. They also discussed a lesbian community organising around the person with cancer and that in an urban setting a diagnosis of cancer resulted in a community response. However, the opposite of this, when a community response was not forthcoming, was isolation and disconnection. Additionally, women also discussed tensions with their families of origin due to their orientation and a reliance on their family of choice for support (Matthews 1998, Paul et al 2014). Some women spoke of a support network that was good at logistics but lacked empathy, there was a fear associated with cancer within the community and a personal fear of forming new relationships all of which happened against a homophobic and heterosexist backdrop. Furthermore, contrary to other studies women here spoke about how other lesbians identified their breasts as a sexual object and that values often expressed did not always merge with practice. Lastly there was a sense that within lesbian culture certain manifestation of cancer were empowering, for example, alopecia affirming a butch identity some women could not have otherwise expressed, reflecting Jain (2007).

Support from survivor organisations and health care professionals was the main area for criticism within studies, where support was not inclusive of the needs expressed by SMW, was expressly exclusionary or heteronormative in the assumptions made about participants. This dearth of professional support made navigating their cancer experience more difficult and increased distress (Desai et al 2021, Brown and McElroy 2018a, Legere and MacDonnell 2016, White and Boehmer 2012). Interestingly in Legere and MacDonnell (2016) although participants did not specify issues within the health care environment that would make them uncomfortable, they did speak about experiences of heterosexism and biphobia and heteronormativity, which contributed to an unwelcoming care environment, highlighting an incongruence between expectation and lived experience of inclusive health care environments. One area of growing support was the online community, these groups enabled breast cancer survivors to connect with other LGBT survivors and reduce the feeling of isolation (Brown and McElroy 2018a). Further research in this area would be warranted.

In Boehmer and White (2012) an important discussion arose. Sexual minority women discussed breast cancer as a woman's issue not a lesbian one, where breast cancer was aligned to being a woman and not their sexual identity. However, once they had established the primacy of being a woman, they discussed how they managed their sexual identity in the context of breast cancer. Some participants highlighted living as a SMW in a hetero-normative society had given them confidence to ensure their status did not become an issue. Whilst others suggested they were better off than heterosexual women as physical appearance was less important to them and their female partners, they were protected from social expectations, e.g., hair loss and weight gain and had partners who could empathise. The rejection of breast cancer as a SMW's issue may explain the apparent reluctance of women to participate in these studies. Nevertheless, the placing of being a woman ahead of being lesbian also needs to be considered from a queer feminist perspective when analysing the implications of these findings. The issues of gender and sexuality have been seen as oppositional in terms of theoretical discourse, however according to Lykke (2010) and Butler (1997) gender, sex and sexuality are so entwined with one another that it will result in analytical and political reductionism if they are separated. This entwinement therefore leaves space for a queer feminist interpretation of cancer.

Discussion

These papers have shed some light on a complex area of adaptation and coping with a personally and socially challenging illness. It is evident that heterosexism and homophobia are experienced by people accessing health care services, despite many countries having non-discriminatory policies in place. Furthermore, there is an overwhelming, and persistent, view within the biomedical literature that being non-heterosexual puts you not only at greater risk of developing cancer, but, also of mal-adaption to this (Bryson and Stacey 2013), rather than recognising a more complex interplay between bio-psycho-socio-political factors. Despite many theorists highlighting this more complex reality this has not yet translated into research outputs (Bryson 2007, Stacey 1997, Lorde 1997).

Of the 58 papers reviewed 50 focused on cancers labelled "women's" cancers, i.e. breast and gynaecological cancer[1]. Five focused on screening, risk factor identification and health behaviour[2], and only 3 of 58 studies examined the experiences of lesbian or bisexual women with a variety of cancer diagnoses[3]. Most studies being focused on breast cancer is reflective of this being the most commonly diagnosed cancer in women globally (International Agency for Research on Cancer 2023) but whether the findings from these studies can be extrapolated and applied to any cancer situation is unclear, for example cancers where there is a propensity for self or external blame and stigmatisation, e.g., smoking or alcohol related cancers.

There was also a wide diversity in the inclusion criteria for studies with later studies referring to their participants as sexual minority women rather than lesbian and or bisexual. This may be an attempt to be more inclusive and include other sexual identities that are non-heterosexual, for example, pansexuality, yet this is not made clear in the papers. Fifteen of the reviewed papers were comparing sexual minority women to heterosexual women to extrapolate risk factors or behaviour differences, however there were inconsistent findings across the sample and no clear results were identified. Additionally, whenever comparisons are made across sexualities the number of women included that identify as a sexual minority is often very small and when secondary analysis of larger cohort studies is undertaken this rarely goes above 3% of the total sample. Although it could be argued that this is representative of the estimated SM population, with 3.2% of the UK and Australian populations identifying as LGB (ONS 2021, Wilson and Shalley 2018), this figure is far higher in the US at 7.2% (Gallup 2022) where most of these studies were undertaken. The overall impact of cancer risk factors on sexual minority women and cancer incidence remains unclear and this will likely remain the case until consistent and reliable data from cancer registries can be obtained (Berner and Meads 2022).

As is often the case in studies focusing women's cancers the participants in most of the reviewed studies were white, cisgendered, middle class and college/university graduates. Berner and Meads (2022) highlight the urgent need for future studies to develop intersectional approaches so differences within and across experiences can be fully explored and key inequalities, such as gender, socioeconomic and race, can be brought to the fore. Queering the sick room applied just such a

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[1] Schefter et al 2021, Greene et al 2019, Brown and McElroy 2018 a, b, Kamen et al 2017, Legere and MacDonnell 2016, Boehmer et al 2014, Paul et al 2014, Meads and Moore 2013, Tracy et al 2013, Boehmer et al 2013a, Boehmer et al 2013b, Boehmer et al 2013c, Boehmer et al 2013 d, White and Boehmer 2012, Boehmer et al 2012a, Boehmer and White 2012b, Boehmer et al 2012b, Boehmer et al 2012c, Cochran and Mays 2012, Jabson et al 2011, Boehmer et al 2011, Tracy et al 2010, Polek and Hardie 2010, Fish 2010, Hart and Bowen 2009, Darwin and Campbell 2009, Ben-Natan and Adir 2009, Boehmer et al 2007, Sinding et al 2006, Bowen et al 2006, Fish and Anthony 2005, Boehmer et al 2005b, Boehmer et al 2005a, Barnoff et al 2005, Sinding et al 2004, Boehmer 2004, Dibble et al 2004, Matthews et al 2004, Fish and Wilkinson 2003b, Fish and Wilkinson 2003a, Dibble and Roberts 2002, Dibble et al 2002, Fobair et al 2002, McGregor et al 2001, Fobair et al 2001, Lauver et al 1999, Burnett et al 1999.

[2] Brown et al 2015, Hutchcraft et al 2021, Dibble and Roberts 2003, Cochran et al 2001, Roberts and Sorensen 1999.

[3] Desai et al 2021, Varner 2004, Matthews 1998.

framework to identify and explore intersecting inequalities that exist within the participants experiences of being lesbian and having cancer.

Conclusion

What is clear from this literature review is that there remain vast unanswered questions about the experiences of lesbians with cancer, but specifically cancers other than those of the breast and reproductive organs. Currently LGBTQ research is, for the most part, driven by the biomedical model and conducted within a positivist-empiricist paradigm (Wolitski et al 2008 cited by Jowett and Peel 2009, Fish 2009). Jowlett and Peel (2009) emphasise the need for more qualitative research as there is little understanding as to how sexual identity may be relevant to the experience of illness. Berner and Meads (2022) and Malterud et al (2009) argues that we do not know the extent to which research carried out in North America can be applied to the UK or Europe. Further the wrong strategy or question can lead to interpretations that add unintentional burdens to marginalised groups, and complete transparency must be evident in research to improve quality and usefulness.

Although there is an abundance of qualitative literature examining cancer experiences Mathieson and Stam (1995 cited by Bryson and Stacey 2013) argue that what is missing from these phenomenological accounts is a simultaneous analysis of how the social and medical worlds are organised around this experience. In other words, there is yet to be an exploration of cancer lived experiences from the perspective of lesbian lived experiences. Queering the Sick Room attempts to redress this imbalance through the application of a queer feminist perspective, and what Butler (1993) calls critically queer attention, to the lived experiences of being lesbian with cancer. It is hoped that this approach will not only produce a unique interpretation of the experience of being lesbian with cancer but also offer health care providers valuable insight into the real-life experiences of these women so that they can plan and deliver cancer care that is holistic, empathetic, inclusive, non-discriminatory and fit for purpose.

Chapter 6: Philosophical frameworks

Poststructuralism

> “There is no self that is prior to the convergence or who maintains “integrity” prior to its entrance into this conflicted cultural field. There is only a taking up of the tools where they lie, where the very “taking up” is enabled by the tool lying there” (Butler 1990 pg. 199)

Poststructuralism gives name to a paradigm, and group of theories that question and challenge knowledge about the relationships between humans and our perceptions of the world, and the practice of making and reproducing these meanings. It challenges the way we understand reality and rejects objectivity and the notion of absolute truth and a single reality. Our perceptions of phenomena are a matter of perspective. Poststructuralism turns to discourse as the primary site for analysis reflecting its deep scepticism of the realist social sciences that make claims to describing real worlds, existing independently of the researchers’ observations and their subjects. (Holmes and Gagnon 2018, Frost and Elichaoff 2014, Gannon and Davies 2014, Belsey 2002). In contrast to postmodernism, poststructuralism questions the individualism of the humanist approaches and in this is the antithesis of a global capitalist, neoliberal world view (Gannon and Davies 2014).

The purpose of feminist poststructuralism is to challenge the notion of “essentialism” and the description of women as an immutable identity category. Instead, it prioritises the social construction of lived realities and seeks to expose the violence that occurs when power interests, for example heteropatriarchy, have their constructions upheld and perpetuated. It provides ways of scrutinising dominant heteropatriarchal constructions of realities that arise from and serve dominant heterosexual, male, power interests. Poststructuralism sees knowledge as unstable and informed by the social and material world (Frost and Elichaoff 2014). Therefore, the aim of poststructuralism is to determine how power affects knowledge production that is ultimately organised into norms (Holmes and Gagnon 2018). For feminist researchers, and for this project specifically, this gives primary attention to the exploration of power, in particular heteropatriarchy, and its role in creating the structures of oppression experienced by the lesbian women who shared their stories with me.

It is impossible to produce more than a partial story of women’s lives, this study rejects the possibility of the objective collection of facts but instead insists that knowledge is rooted in the culture, values, and interests of particular groups. This thesis abandons binary frameworks to fluid conceptualisations of women’s experiences where there are multiple truths existing within different discourses, none of which are privileged. The aim of feminism, therefore, within this frame is to present alternative accounts, to question and challenge the status quo (Letherby 2003, Olesen 2005).

Lather (2007) highlights that, in contrast to constructionist, realist and emancipatory paradigms located before the deconstructive break, post-structural theory works to trouble “all major epistemological, ontological, and methodological concepts” (Lather, 2007, p. 164). Further, grand narratives, from before the break excluded alternate ways of seeing the world, privileging accounts from existing power structures, and upheld an erroneously straight version of history. Within the deconstructivist paradigm reality is unknowable and truths are socially constructed systems of signs. Discourse is inseparable from its subject and is “contingent and vulnerable” (Lather 2006). Kitzinger (1987) argues that social constructionism does not affirm any single theory about people, gender or sexuality but instead proposes to treat constructs “as generated from situated and constitutive social practices” (Kitzinger 1987 pg. 188). Butler (1990) and Lykke (2010) assert that feminist researchers must consider the current meaning and political situatedness of “women” rather than take this as an *a priori* given, reflecting consciously on the exclusions, reductionisms, normativities, and power differentials that are (re)produced when using the category “women” or “lesbian”. Poststructuralists resist essentialism, determinism, and naturalism (Williams 2005), questioning the structuralist project of knowledge production and its hierarchies; resisting attempts to identify essential attributes, or the essence of a phenomenon, person, or thing. Further disputing the hypothesis that knowledge can create an accurate representation of a reality that is just sitting and waiting to be discovered. This does not mean to imply the total rejection of science, but the rejection of dominant discourse that claims to have a greater understanding of the phenomenon being studied (Holmes and Gagnon 2018). At the centre of feminist poststructuralism is the certainty that there are better ways to theorise gender than those contingent on patriarchal or essentialist claims (Frost and Elichaoff 2014).

Belsey (2002) contends that within the poststructuralist project language, and its symbolic equivalents, is the most crucial determinant within our social affairs, our thoughts, and our beliefs about who and what we are. Communication does not remain static over time regardless of human intervention. We can choose to intercede in language with a view to altering meaning, the norms and values our culture takes as given, however “poststructuralists affirm, consciousness is not the origin of the language we speak and the images we recognise, so much as the product of the meanings we learn and reproduce” (Belsey 2002 pg.5).

Gannon and Davies (2014) put forward five principles of feminist poststructuralism. Firstly, objectivity must be carefully rethought. An account is always situated, it is always an account from somewhere, from someone and from some time. There is always a purpose, and it is always with an audience in mind. Accounts are therefore always partial and always particular. Secondly, attention must be paid to the mode of writing, the ways in which views of the world are presented. There needs to be simultaneous "weaving and un-weaving" (pg. 2) of our thoughts and practices, what we say and do, when we make claims to be feminist in our research. Thirdly, positions of power are understood as maintained in discourse, power is complex and unstable; agency, resistance and emancipation are contingent and limited. Fourthly, attention must be paid to binary categories and their capacity to limit what can be imagined as possible.

> "These binary categories—such as man/woman and good/evil—are implicated in dividing and constraining the world in ways that may be violent in their effects, positioning those categorized as belonging in subordinate categories, for example, as inferior. The discursive naturalising and normalising of the categories makes their membership, along with their characteristics, appear to be inevitable." (Gannon and Davies 2014 pg 4)

They further point out the deconstructive project is not about destruction, and despite many emancipatory theorists believing that poststructuralist theorists have destroyed many categories including man and woman, rendering them unusable in emancipatory work, Butler (2004) proposes that questioning terms does not mean debunking them but enables them to be used in different, revitalised, ways.

> "In a double move that is characteristic of deconstructive writing, post-structuralist feminists continue to use particular categories, such as woman or feminist, but work to destabilize some of the categories' certainties. We can put them "sous rature" or "under erasure," following Derrida (1976), perhaps using a textual reminder—woman, feminist—to stand as a reminder that we both need the concept and are wary of some of its dangers." (Gannon and Davies 2014 pg. 5)

In their last principal Gannon and Davies (2014) argue for a deep scepticism towards any assumption of truth or knowledge which are taken for granted. Through deconstruction of thoughts and ideas we can make discourse and discursive practices visible and therefore open to scrutiny and question; rendering them less able to create normative frameworks or be considered as self-evident truths. Where critical feminists confront power structures and practices, poststructuralist feminists aim to shift the foundations on which they sit so that what was thought of as normal and natural, becomes unimaginable and inconceivable. Furthermore, within post-structural feminist research "liberation" is made problematic because we can never exist outside of discourse. Agency is fundamentally "conditioned by the positions made available to the acting, agentic subject; and subjectivity is always also subjection to the available ways of being." (Gannon and Davies 2014 pg.9)

Belsey (2002) turning to thoughts on culture suggests that there are no ideas outside of language, and nothing motivating language that is external to culture. “Culture consists of the meanings its subjects produce and reproduce.” (Belsey 2002 pg. 26) and when we attempt to understand or make sense of it, we are only taking up another position within culture, taking up space culture supplies, or is persuaded to supply.

> “The issue here is not what exists, but what we can accurately say exists … post structuralists don’t (normally) doubt that there is a world: their anxiety concerns what we can claim to know about it with any certainty… Truth and knowledge exist at the level of the signifier. In other words, truth is a matter of what we can say (or write or indicate in diagrams or chemical symbols). If we lay claim to the truth, whether we conceive of this as objective or subjective, we are drawing on the big Other to do so. We are defining what we believe, that is to say in terms drawn from out there, however much we seem to feel it in here… To that extent what we believe is no longer purely personal, but a conviction that culture permits (even if that same culture also deplores it). How many of the beliefs we experience as subjective are in practice culturally inculcated?” (Belsey 2002 pg. 71-72)

Importantly there are no correct research methods that will produce reality outside of the research texts as reality does not pre-exist the constitutive and discursive work. For feminist researchers this is an important insight as it makes obvious the cultural, discursive, historical, and social systems through which current oppressive or dominant realities are maintained (Gannon and Davies 2014).

A frequent criticism of poststructuralist theory is that it deprives us of agency and the power to choose for ourselves or to act in our lives. According to Belsey (2002) this is binary thinking:

> “if the subject is an effect of meaning, if we are not the free, unconstrained origin of our own beliefs and values, so the story goes, we must be no better than artificial intelligences, programmed outside ourselves to act according to patterns determined elsewhere.”

However, according to Foucault, deconstruction does not result in a lack of agency. Through multiple works on resistance, he claims that meanings are not unalterable. Power is mobile, flexible, and transferable, and resistance to power is always possible, as power is always power over something or someone who can disobey (Foucault 1980). There is always choice and responsibility (Belsey 2002 pg. 89). Frost and Eilchaoff (2014) add that the criticism of relativism is valid, but that the focus on multiple voices adds to the understanding of the complexity of the human experience and enables those that would otherwise be marginalised to be included. Feminist poststructuralism focuses on this as a strength to develop multifaceted representations of experience preventing manipulation to fit one, so called, truth.

> “Construction is not opposed to agency: it is the necessary scene of agency, the very terms in which agency is articulated and becomes culturally intelligible. The critical task for feminism is not to establish a point of view outside constructed identities; that conceit is the construction of an epistemological model that would disavow its own cultural location and, hence, promote itself as a global subject, a position that deploys precisely the imperialist strategies that feminism ought to criticise” (Butler 1990 pg. 201)

Using Queer Phenomenology

Sara Ahmed's (2006) Queer Phenomenology was used as a philosophical framework for the proposed study.

> "A queer phenomenology would involve an orientation toward queer, a way of inhabiting the world by giving support to those whose lives and loves make them appear oblique, strange, and out of place." (2006 pg. 179)

Drawing on Foucault, Sedgwick, Butler and de Lauretis and using the phenomenological philosophies of Husserl, Heiddegger and Merleau-Ponty, Ahmed (2006) offers a queer interpretation of objects of study. Taking sexuality as the object of investigation she suggests that when one 'becomes' lesbian it takes work to re-orientate ourselves to this 'being' as it is not the expected or 'normal' family/social orientation. We have queered the normal, veering from the straight line.

> "To move ones sexual orientation from straight to lesbian, for example, requires re-inhabiting one’s body, given that one’s body no longer extends the space or even skin of the social" (Ahmed 2006, page 101)

Queering the sick room will examine whether cancer also queers the body if cancer requires a person to re-inhabit their body from the family/social orientation (health, reproduction, and productivity). In this queering process one becomes disorientated and loses the ground beneath your feet (pg. 160). Therefore, in the context of an established queer (lesbian) orientation, what is the impact of cancer, when health (the ground) is the expected future and cancer takes this expectation away?

Queer feminism

Queer can function as a synonym for lesbian and gay, an umbrella term or shorthand for LGBTQ but more importantly Queer recognises the social construction of prescribed identity and loosely describes a varied, often contradictory set of interdisciplinary approaches to “desire, subjectivity, identity, relationality, ethics and norms” (Giffney and O’Rourke 2009 pg 2).

Queer feminism challenges the heterocentric tendencies of mainstream feminism (Lykke 2010). Further, Marinucci (2010 pg. 105) postulates that queer feminism is;

> “the application of queer notions of gender, sex and sexuality to the subject matter of feminist theory, and the simultaneous application of feminist notions of gender, sex and sexuality to the subject matter or queer theory.”

Queer feminism seeks to make the connections between queer theory and feminism more explicit by providing a queer orientation to feminist theory and a feminist orientation to queer theory. In doing so a synergistic relationship is created where the outcome is greater than the sum of its parts. Furthermore, she argues, the emphasis queer feminism places on sexuality can help alleviate the biases within feminist theory towards lesbian women, gay men, bisexual people, and transgender people.

Lykke (2010) argues that to queer feminism gender, sex and sexuality are so entwined with each other that it will result in analytical and political reductionism if they are divorced. Instead, the intersections between them should be deconstructed and reflected upon. Butler (1997) contends that Gender Studies cannot ignore biological sex or sexuality and in the same way Lesbian and Gay Studies cannot ignore gender and sexed embodiment as to do so would result in both becoming reductionist and they would subsequently cut themselves off from important insights into the gendered and sexed dimensions of sexual practices and identities (Lykke 2010).

In a postmodern era, identities can be assembled, disassembled, reshaped, accepted, and contested (Holstein and Gubrium 2000) and queer theory’s critique of binary thinking leads to the subsequent denial of the reality of categories of gender. However, through Derrida, Marinucci (2010) suggests that although meaning cannot be permanently fixed, it can and should be negotiated. Furthermore, through the deployment of “strategic essentialism” (Spivak 1996) Marinucci (op. cit.) argues that groups with shared goals and interests can momentarily show themselves publicly as essentially the same, whilst, simultaneously engaging in ongoing and less public debate. It is through these strategies that I am able to deploy the identity labels ‘lesbian’ and ‘woman’ within a queer feminist paradigm.

Much qualitative research is argued to be inductive in nature, where theoretical understanding arises from an unfettered examination of personal experiences, imaginings, and thoughts of the world. However, both Letherby (2003) and Elliott (2005) argue against the possibility of truly inductive research, instead believing that all work is theoretically grounded and subject to the influence of politics. Therefore, researchers must acknowledge an “intellectual and personal presence” (Letherby 2003 pg. 67), furthermore, as feminism takes, as its starting place, the perspective that gender is a prime organiser of social life it cannot be argued that theory arises from the research (Kelly 1994 cited by Letherby 2003). The same is also true within queer discourse where sexuality is the point of privilege and is therefore the key analytical tool. This study therefore sits in an inductive/deductive continuum in offering a queer feminist analysis.

Chapter 7: Narrative Methodology

The social world is constantly evolving, and it is through the interpretation of the production of that social world that meaning can be achieved (Elliott 2005). Gubrium and Holstein (2000) contend that an understanding, of the way people take part in the construct of their lives, can be achieved by asking 'how' questions. Narrative researchers are interested in specific aspects of people's lives and how they communicate meaning though language, how stories are embedded in the exchanges between the researcher and participant and how they make sense of their experiences in relation to culturally and historically significant discourses (Chase 2005). Narratives are reflective of reality but also challenge taken for granted, beliefs, assumptions, and assertions (Frazer 2004). Letherby (2003) argues that a specific feminist method does not exist, but rather the way any method is used makes it feminist and it is the adoption of a feminist methodological position that is an essential part of our intellectual, political, and social practice. Narrative techniques offer the opportunity for a participatory approach to research, for power relationships to be examined and challenged and provide an avenue through which the social experiences of women can be heard (Letherby 2003).

> "Narrative research is a multilevel, interdisciplinary field and any attempt to simplify its complexity would not do justice to the richness of approaches, theoretical understandings and unexpected findings that it has to offer" (Squire, Andrews and Tamboukou 2013 pg. 13)

Narratives are an essential means of human sense making. It is widely considered that we are living in the "age of narrative" however the truth is thought to be more complex than this statement would suggest (Goodson 2017, Squire, Andrews and Tomboukou 2013). Goodson (2017) suggests that although it is true that narratives and stories are commonly encountered, their scale, scope, and aspirations have dramatically altered, asserting that there is a new era of life narratives and small-scale narratives. Squire (2008) further suggests that in the last two decades narrative research has an increasingly high profile, where it appears all social researchers are 'doing' narrative research. Narratives are at the centre of subjectivity and delve into the many ways our subjective perceptions and accounts relate to our understanding and action (Goodson 2017). Narrative is remarkably diverse in the way it is valued in popular culture and social research; culturally offering insight into good, or less-good forms of biographical patterns, social structures, and social representations and within a social research frame 'narrative' refers to hugely diverse theoretical positions, topics of study, methods of investigation and approaches to analysis (Squire 2008). Further, narrative offers no rules as to the correct materials to gather, the ideal modes of investigation or the best ways to study stories, analyse and interpret findings (Squire 2013). But in doing this work Squire (2008) asserts we can see diverse and oftentimes contradictory layers of meaning, enabling us to bring them into useful dialogue with each other and understand more about individual and social change. Narrative enables the investigation of how stories are structured and the ways in which they work, and how some narratives are silenced, contested, or accepted.

> “Stories often seem to function in narrative research as forms of politics, broadcasting ‘voices’ that are excluded from or neglected within dominant political structures and processes – as indeed stories have often done in recent western history, for instance in the writing and reading of 19th century accounts of working-class life, slavery, and women’s experiences. The study of narrative seems to promise change, ‘forcing’ the social sciences to develop new theories and new methods and new ways of talking about self and society’ (Denzin, 2004: xiii cited by Squire 2008 pg. 8)

Squire, Andrews and Tamboukou (2013) suggest that we should treat narratives as modes of resistance to existing structures of power. Andrews (2017) further suggests that politically centred narrative work can bring unique layers of meaning, whilst simultaneously demanding a daunting level of reflexivity, combined with dynamic temporal and moral positions, from the researcher; ultimately making possible new examination and insight.

Plummer (2017) adds that how a story is fashioned and how it affects the world politically, ethically, and culturally depends on many events, in particular:

> “when it is being told (time), where is it being told (space and place), who is being told (audience), why it is being told (motivation) and what is being told (contents).” (Plummer 2017 pg281).

Different stories will be told in different times and places, to different people for different purposes, but with the unmistakable force of narrative power; the capacity of story tellers to influence, control and regulate the stories of self and others. In interpreting these stories, Plummer (2017) goes on to suggest that the essential concept of ‘narrative empathy’ is core; being able to climb into the skin of another and see the world though their eyes. Listening to the stories of others and engaging in dialogue in conjunction with compassion for the other are central to building empathy.

Goodson (2017) cautions that, within a Western context, dominant interest groups control the narratives that are told: in this age of fake news, they can reposition narratives and truth to suit a given political agenda; separating what people are presented as truth from validated, empirical evidence within a historical context. The importance placed on contextual background is both intellectually and politically significant as narratives are capable of being misdirected and misused. The many potential dangers of misusing narrative data arise from their uncoupling from their social and historical contexts. Therefore, narratives are at their most trustworthy when they are fully located in their time and place; "stories of action within theories of context" (Goodson 2017 pg. 4, Plummer 2017).

As narrative researchers, embedded within the research process, we present stories from our ontological, epistemological, and political standpoints. If we do not clearly articulate our own positionalities when doing this, and attempt to present narratives as universal truths, it is hard for the reader to discern where this narrative interpretation fits into their scheme of knowledge creation or subjective story telling. It is therefore imperative for narrative researchers to be open and transparent in the retelling of stories and to show what positions they are representing, so dissenting voices can be heard. My interest in narrative comes from my background as a nurse to understand how lives, and in particular lives with illness, are experienced as lived. What does it mean to someone to live with illness, what stories do they tell of this life, what sense do they make of their life through these stories? Caine, Clandinin and Lessard (2022) suggest that, due to its relational nature, this interest in lived experience might position narrative as in opposition or contrast to theory, however they do not agree, seeing theory as interrelated with practice and therefore not in opposition. This thesis is grounded in a post structuralist paradigm and using queer phenomenology as its theoretical lens (Ahmed 2006), both of which fit comfortably alongside a narrative methodology.

Experience is the central position of narrative work. Any inquiry into how we experience the world emphasises not just one person's experiences, but experiences located within social, historical, linguistic, political, familial, and other settings. It is in thinking through experience that we can begin to understand the stories told by people, about people in relation (Squire, Andrews and Tamboukou 2013).

> "In this view of experience, there is always a sense that life is in the midst, that experience is always evolving, and that experience builds upon experience. Experience, then is something always in the making, being shaped and reshaped over time, as new situations are encountered. Experience is neither fixed nor certain… Experience understood narratively is always in the midst and it is shaped in the making and remaking, in the recollecting of what is past, but also in what continues to live on in future moments." (Squire, Andrews and Tamboukou 2013 pg. 20)

Knowledge in narrative is always in context, either immediate within relationships, or larger, shaped by social and cultural times and locations. Who everyone is and is becoming, is produced by, and expressed through gender, privilege, geography, and relationships and is integral to how we make sense of knowledge. This concept of knowledge is at the centre of narrative inquiry, of thinking narratively about phenomena and the intricate ways in which time and place help shape an individual's knowledge (Caine, Clandinin and Lessard 2022).

Connelly and Clandinin (1988) define knowledge within narrative inquiry, labelled "personal practical knowledge", as

> "a particular way of reconstructing the past and the intentions for the future to deal with the exigencies of present situation … a narrative, curricular understanding of the person is an understanding that is flexible and fluid, and that therefore recognises that people say and do different things in different circumstances and, conversely, that different circumstances bring forward different aspects of their experience to bear on the situation" (Connelly and Clandinin 1988 p25-6)

Goodson (2017) contends, however, that the "personal" as prioritised in some western contexts is a specific account of being a person, an individualistic version which is unrecognisable to much of the globe. The impact of which are narrative accounts presented in terms of "isolation, estrangement and loneliness … as autonomy, independence and self-reliance" (Goodson 2017 pg. 17). Andrews (1991) suggests that ignoring social context, deprives us and our partners of meaning and understanding, saying,

> "it would seem apparent that the context in which human lives are lived is central to the core of meaning in those lives… Researchers should not, therefore, feel at liberty to discuss or analyse how individuals perceive meaning in their lives and in the world around them, while ignoring the content and context of that meaning." (Andrews 1991 p13)

A personal life story is at high risk of becoming an individualising device if divorced from context, ignoring, and obscuring collective circumstances and historical context. Narrative life stories offer greater insight when placed in specific historical circumstances and cultural conditions which should be brought into our methodological grasp (Goodson 2017).

The narratives collected within this thesis all occur in a very specific social and historical context. The interview conversations all took place in the southeast of the UK in the mid 2010's during the middle section of the current conservative government, under the leadership of David Cameron, then Theresa May. Marriage equality had recently been legalised in 2014 and there was a general sense of things getting better. Some of my participants spoke about their excitement about getting married or converting their civil partnerships to marriage. The first adverts to feature same sex couples were appearing on TV and lesbian or gay couples were a regular part of mainstream shows. Visibility of LGBT people seemed to be at an all-time high and there appeared to be growing support for LGBT people within the general population. Towards the latter end of data collection, politically there was a definite shift to the right, the country was preparing for and going through Brexit with an upswelling of right-wing rhetoric towards people seeking asylum, immigration to the UK and "protecting our boarders" and a rising negativity towards the UKs participation in the European Convention on Human Rights which protected many of the rights fought for by LGBT people. Historical context was also central to the construction of these narratives, in particular the legacy of Section 28 of the Local Government Act (1988), the prohibition of the intentional promotion of homosexuality in local authorities. The analysis of the stories shared occurred during a particularly tumultuous time for LGBT rights, in particular the rights of trans people which are being eroded at an alarming rate. All of these and other political, social, and cultural factors were visible and impactful on the narratives that were shared and subsequently on the interpretation of them.

According to Caine, Clandinin and Lessard (2022) narrative research is the study of the way we as humans experience our world, it is both phenomenon and method, it both provides structure to experiences and to the way we can study experiences. People live storied lives and tell stories of their lives; as narrative researchers it is our role to collect, describe, and tell these stories in relational narrative. Embodiment is a particularly useful tool in the articulation of how stories and experiences are told though and with bodies and bodies in relation. Ahmed and Stacey (2001) stress the need for narrative inquiry to continuously focus on the relationship between touch and the sociality of embodiment: one is always touched by other beings, not all of which will be human.

> "Embodiment is a social process that draws attention to how we embody stories and experiences. Our emotional expressions reflect our experiences and are seen as embodiments (Neumann 1997, Sarbin 2001). Often these embodiments provide us with insights into experiences that cannot be expressed verbally, or are carried in our bodies over generations." (Caine, Clandinin and Lessard 2022 pg. 43)

Ideas of embodiment that seemingly have been with us for many years are often rooted in indigenous teachings and thought, and the writings of women of colour such as Audre Lorde, Maya Angelou, bell hooks, and Toni Morrison were influential in articulating the interconnected ways that embodiment shapes narrative inquiry. Lorde, notably in both Sister Outsider (1984) and The Cancer Journals (1980), emphasizes and demonstrates the profound influence of the body in mediating knowledge and what feelings and senses teach us about our lives (Caine, Clandinin and Lessard 2022).

A narrative is also a journey through time that is told by a storyteller, who tells a listener what happens on the way. Yet, story tellers do not merely 'tell' a simple story; they also explain and reflect on the story rationalising behaviours, linking past and present thinking and actions (Freshwater and Holloway 2015). Additionally, the story must be special, it must be worthy of telling, and it is never just the imparting of a sequence of events. There is a dramatic or critical moment, unusual, unplanned for happenings or behaviours, insights, and epiphany moments such as the diagnosis of an illness within a life. The idea of lives as created over time rather than fixed and frozen is foundational to narrative research. Experience is always occurring 'in the midst' of life. It is always ongoing, never complete, always a work in progress (Caine, Clandinin and Lessard 2022).

> "We speak of this notion of temporality within experience as showing the making of a life over time, as a process of being "not yet" as Greene suggested. It is impossible to think narratively if one is thinking of each life as somehow fixed and frozen or as somehow finished and complete… Lives are always nested within social, cultural, and institutional narratives within which each individuals' experiences are shaped, expressed and enacted." (Caine, Clandinin and Lessard 2022 pg. 61)

Within narrative work it is essential to distinguish between historical truth and narrative truth. Historical temporality refers to the exploration of time as it corresponds to noted events and the search for patterns and understanding. Conversely, narrative temporality is understood within the margins of lives as they are being lived, within personal and social contexts, unfolding and enfolding "in the midst" of lives being composed. Temporality is present in both but the starting point for understanding the unfolding time is different (Caine, Clandinin and Lessard 2022). Narrative is occupied with the telling stories in the midst of living, where lives are never finished but are presented as a work in progress, an unfinished story always in the making, working against the sense of an ending but occurring within a social and historical context.

In contrast to many qualitative methodologies narrative inquiry offers no automatic start and finishing points, no distinct method, no instructions on the studying stories and no overall rules of investigation (Squire 2013). Squire (2013) highlights two key approaches to narrative inquiry. Firstly, event centred inquiry as described by Labov (1997). Labov's work focused on the objective accounts of specific events that people have witnessed or lived though, akin to a verbal movie of a specific event. Labov posited that shared emotional evaluations of events will be made within language communities and that personal event narratives claim privileged places in all forms of communication as it embeds itself in the speaker's biography in ways that other forms of speech do not (Labov, 1997).

However, Squire (2013) argues that the focus on event narratives neglects three important elements of narrative inquiry:

1. Talk that is not about events but that is nevertheless significant for the narrator's story of who they are.
2. Representation itself. The uncertain, changeable nature of written, spoken, and visual symbol systems means that stories are distanced from the happenings they described, have many meanings and are never the same when told twice.
3. Interactions between storyteller and listener, researcher, and research participant, in the co-construction of stories (Squire 2013 pg.47)

In contrast to event centred narrative inquiry Squire advocates for an experience centred approach.

> "this work rests on the phenomenological assumption that experience can, through stories, become part of consciousness. It also takes a hermeneutic approach to analysing stories, aiming at full interpretation, and understanding rather than, as in Labov's case, structural analysis...the dominant conceptual framework within which current social-science narrative research operates. It is perhaps most often and widely related, across disciplines, to the work of Paul Ricoeur (1984)," (Squire 2013 pg. 48)

Squire's experience-centred approach assumes four core characteristics of narratives. Firstly, that narratives are sequential and meaningful. Secondly, that narratives are definitively human. Thirdly, that they 're-present' experience, they re-form it; as well as mirror it and lastly, narratives display transformation or change.

Squire (2013) also advocates for the move to small story narrative, as posited by Goodson (2017). This focus on 'small stories' prioritises socially oriented over individually oriented narratives, giving focus to the 'social' in its 'microsocial' as well as in its wider, cultural variants. Unlike Labov's event centred research, experience centred narrative research presumes the shared 'personal narrative' includes all significant stories of a given personal experience. Such stories may include event narratives, but they are wider, and more flexible about time and personal experience, incorporating changing views and growth, and may be characterised by themes rather than structure. Experience-centred narratives might address life-turning points, such as a realisation about sexuality or they might address more specific triggers, such as living through a trauma and its lifelong consequences. There is inherent flexibility that enables participants to take their narrative to places that are important to them. Narratives represent personal changes that go beyond formal resolution, addressing the theme rather than the causes. Therefore, this approach fits the aims and objectives of this study. The intention is to present life stories that focus on two major narratives in the participants lives, that of being gay and of living with cancer. This approach offers the opportunity for participants to consider their whole life in relation to the focus of inquiry, to consider time and place in general as well as in relation to key events, to think sequentially or to jump across timespans to focus on themes that they deem as important to their lived experience.

Reflexivity within narrative research

Feminist reflexivity refers to showing an awareness of the identity of the researcher within the research process, to critically examine and reflect on the nature of research, the role of the researcher in conducting and reporting empirical work and understanding how their social background, location and assumptions influence their research practice (Hesse-Biber 2012, Elliott 2005).

> "Feminist researchers are continually and cyclically interrogating their locations as both researcher and as feminist. They engage the boundaries of their multiple identities and multiple research aims through conscientious reflection. This engagement with their identities and roles impacts the earliest stages of research design. Much of feminist research design is marked by an openness to the shifting contexts and fluid intentions of the research questions." (Hesse-Biber and Leckenby 2004 p. 211)

Key considerations include being reflexive about the project, working in partnership with participants on how to communicate the results of the research, and within this recognising the hidden and/or unrecognised elements in the researcher's background (Olesen 2005). Feminist qualitative research is particularly concerned with how participant's voices are heard, with what authority and in what form, as, despite attempts to jointly shape accounts with participants, the researcher, as author of the final account, remains in the more powerful position (Olesen 2005). Furthermore, through the production of a reflexive diary an analytical lens can be turned on these concerns to ensure that their impact is considered in the analysis and reporting of the study. Elliott (2005) suggests the application of reflexivity at each stage of the project, for example reflexivity within data collection, asks the researcher to consider ethical issues such as detached objectivity verses a more reciprocal relationship. Discussing issues such as coming out or receiving a cancer diagnosis may prompt participants to ask about the researcher's experiences of being lesbian or cancer. Discussing personal history may promote a more natural conversation however it must also be recognised that a shared identity does not guarantee increased access or insight.

I have attempted to be reflexive throughout every stage of this thesis. As I have mentioned I am present in all areas, from sharing my life as adjacent to cancer, through the analysis of the participants lived experience and the bringing together of ideas in the discussion and conclusion, I hope this visibility embeds a degree of trustworthiness within the work.

Chapter 8: Method

Queering the sick room is a queer feminist inquiry that employs queer phenomenology (Ahmed 2006) to construct narrative accounts of experiences of being lesbian and of having cancer. A convenient and purposeful sample of 10 women were recruited via community networks, snowballing and cancer care providers. Ethical approval was granted by the NHS Health Research Authority and local approvals were granted via NHS Research and Development centres. Reflexive thematic analysis was undertaken (Squire 2013). The social world is constantly evolving, and it is through the interpretation of the production of that social world that meaning can be achieved (Elliott 2005). Narrative researchers are interested in specific aspects of people's lives and how they communicate meaning through language, how stories are embedded in the exchanges between the researcher and participant and how they make sense of their experiences in relation to culturally and historically significant discourses (Chase 2005). Narratives are reflective of reality but also challenge taken for granted beliefs, assumptions, and assertions (Frazer 2004). Narrative techniques offer the opportunity for a participatory approach to research, for power relationships to be examined and challenged and provide an avenue through which the social experiences of women can be heard (Letherby 2003). This chapter describes the processes that were undertaken in the completion of this narrative study.

Research aim and questions

The aim of this study is to deconstruct heteropatriarchal-normative cancer experience narratives by examining these through a queer feminist lens. Through the prisms of gender, sex and sexuality this study's objective was to explore how lesbian cancer narratives are constructed and performed within a social world by asking:

1. How do women[4], identifying as lesbian, who have received a cancer diagnosis, construct their 'lesbian' narratives?
2. How do women, identifying as lesbian, who have received a cancer diagnosis, construct their 'cancer' narratives?
3. How do discourses of gender, sex and sexuality help interpret the intersections of cancer and lesbian identity?
4. How does a queer feminist epistemology help deconstruct the prevailing cancer narrative?

Ethics

There are many ways of interpreting the stories we are told, but this is always through a listener and the listeners assumptions, experiences and lived reality. When we attempt to interpret narrative

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[4] For this study women are defined as any person (transgender or cisgender) who self-identify as women

stories, it is incumbent upon us, alongside staying close to the narrators' intentions and words, to also name the assumptions that lead us to choose to tell the stories we do, what we decide to put in the spotlight, and why we chose certain stories over others. Ethically, there needs to be honesty and transparency in every element of the research process and Doucet and Mauthner (2002) posit that the most effective way of achieving this is through reflexivity. Research studies, involving human participants, must make every effort to address all inherent ethical issues. However, within a feminist paradigm, this is greater than the procedural undertaking of being granted institutional permissions to undertake the inquiry. There are moral deliberations, power dynamics, choices, and accountability to be considered throughout the entire research process (Edwards and Mauthner 2012). Code (1995 cited in Doucet and Mauthner 2002) emphasises our ethical responsibility to those from whom and for who knowledge is produced, often what is the ethically correct action to take may not be obvious in any given situation, but something must be done or decided. Therefore, feminist researchers are never finished thinking ethically or making ethical decisions.

The act of writing narratives freezes lives in a specific time and place, fixing attitudes, beliefs, and values, without allowing for change or growth in the future (Sikes 2017), within any construction of narratives acknowledging this is of paramount importance. They are temporal; time and place dependant, therefore ethically it is not possible to place a truth claim on these narratives outside of exactly what they represent on that given day. Just because this was what was said on the day of the interview does not mean this will be the view or belief of that person the next day, as the ancient Greek philosopher Heraclitus asserted, you can never step in the same river twice (Heraclitus 2003) or to quote my mechanic dad "it's just like an MOT, only good on the day it was done". Therefore, as replicability is not achievable it is vitally important that researchers be as transparent as is reasonably possible about their epistemological and ontological positions, and theoretical and personal assumptions, showing clearly how they reached their conclusions. Furthermore, as all stories are told through an interpretational lens writers need to be as clear as they can be about the lenses they use to create authenticity and demonstrate ethical practice (Sikes 2017). Clandinin et al (2017) assert that any observation is always interpreted though the observers' lived experiences, beliefs, attitudes, and values. The relationship between researcher and participant is always incomplete and partial in its understanding. As the researcher is actively constructing narrative stories for the purpose of addressing their research questions the researcher is always present in the research whether they explicitly acknowledged this or not (Sikes 2017). Consideration, therefore, needs to be given to the biases of the researcher, implicit and explicit, drawing attention to what is happening within this construction and how both narrator and researcher are changed in the process of narrating and interpreting their stories.

Reflexivity is often framed as a methodological approach where the researcher decides how much to share about themselves within the research process, however Doucet and Mauthner (2002) are concerned with the broader relevance to issues of honesty, transparency, and accountability particularly within data analysis where the power and privilege of the researcher are most pronounced and where the ethics of actions and choices are acutely relevant due to the relative invisibility of interpretive processes. They suggest that researchers struggle to reconcile dominant political or theoretical ideas with contrasting accounts and emergent concepts and there is not a uniform ethical relationship with all participants, with some accounts being heard with greater commitment and connection than others.

> "As qualitative researchers confronted with differing ways of interpreting a story, it is not just staying close to the research participants or subjects that merits recognition as an ethical issue, but the naming of assumptions that lead us to read and tell stories that we do… A robust conception of reflexivity means giving greater attention to the interplay between our multiple social locations and how these intersect with the particularities of our personal biographies *at the time* of analysing data" (Doucet and Mauthner 2002 pg 9 emphasis in original)

Throughout Queering the Sick Room, I have attempted to clearly articulate my positionality within a queer feminist, poststructuralist paradigm. I have made clear my thoughts that there can be no claim to truth that extends beyond the boundaries of this work and that I am fully present in both its conception and materialisation. Although I do not live with cancer my articulation of the narratives shared with me, comes from my position of being adjacent to cancer. As conceived within the opening chapter of this work, my life has been one of close personal and professional association with cancer and of being lesbian. So, I present these stories to the reader acknowledging these facts. These stories are told though my interpretation and analysis. They are therefore both flawed and incomplete. However, Hill-Collins (2009) considers this from black feminist perspective and in particular, the ethics of caring, where truth emerges through connected knowing; a connection that sees individual personalities as adding to and enriching a group's understanding. She describes the ethics of caring as having three interrelated components; individual uniqueness, appropriateness of emotion in dialogue and the capacity to develop empathy. These must be observable and articulated clearly within any claim to knowledge, and whilst the speaker must have validity, it is the group that appraises these knowledge claims for authenticity.

Feminist ethical praxis critiques traditional, positivist, masculinist and Eurocentric knowledge making (Hill-Collins 2009) and is further concerned with the primacy of lived experience. Particularly through dialogue, managing conflict, disagreement, and ambivalence rather than attempting to eliminate these (Edwards and Mauthner 2012). A collaborative approach to feminist research should avoid the decentring of other voices to centre the “expert” voice. Further, Young (1997) asserts that power dynamics must be considered as there can be no symmetry between the self and others, it is not possible to step into the shoes of others nor should it be desirable as each has differing needs and priorities. Therefore, the power imbalance between researcher and participant must be acknowledged within any project (Doucet and Mauthner 2002).

Downs (2017) outlines four principles for ethical feminist praxis:

1. There is a responsibility to the participants not to reinscribe them into the prevailing representations.
2. Feminist researchers should be cognisant of the macro political context in which their work is carried out and have awareness of historical moments.
3. They must account explicitly for differences, speak directly to, and make usefully problematic “like me” statements.
4. Offer transparency around the micro political process of research in which everything is entwined, particularly within the research interview, as Bhavnani (1993) highlights the micro politics of research are no clearer than within the interview, where you are brought face to face with participants and dominant/subordinate power relations become ever more apparent.

In addressing feminist research praxis three approaches to ethics were in operation throughout Queering the Sick Room. Firstly, situational ethics (Downs 2017). Constant vigilance sits at the heart of situational ethics in practice and duty. It is infinite and relentless, fluid, and dynamic. It is not a fixed ethics, nor should it be mitigated. Rather, qualitative research involving other people, as well as the researcher, is an active process that is shaped and reshaped and that shapes and reshapes itself during its execution. A situational ethics needs to be responsive to changing situations as and when they occur during the study. Therefore, discussions about the ethical underpinnings of this study are not just confined to this chapter but are interlaced throughout this thesis, in particular when thinking through methodological issues such as authenticity and rapport within conversational interviews and in particular the choices of what to present in order to answer the research questions.

Secondly, relational ethics. Ellis (2017) contends relational ethics become paramount when the researcher acts from heart and mind and acknowledges interpersonal bonds. Relational ethics also includes mindful self-reflection about researcher role, motives, and feelings particularly when research is motivated by a personal agenda and topics that have a deeply personal resonance.

Clandinin (2017) further asserts the deeply relational work of narrative research draws attention to how the inquirer and the participant are both changed by living within the telling of the narrative. In this way both enquirer and participant are at the heart of the narrative inquiry, and we need therefore, to honour the relational ethics of narrative research.

As a result of my mother's illness and subsequent death, I took a three-and-a-half-year interruption to my PhD beginning right after data collection had been completed. I had all ten interview transcriptions returned from the participants but none of the analysis completed and none had received their planned four-page summary. This process had been key to me ensuring the lesbian cancer narratives I had constructed from their interviews represented their lived experience. Additionally, I had stated in the PIS that this was their final opportunity to withdraw their participation. The root of the ethical concerns for me was the impact of the passage of time to the authenticity of the narratives. However, I returned to the ethical concept earlier articulated, that narratives are both contextual and time bound, they were authentic representations of the participants experiences at the time they were shared with me, and therefore maintained integrity if I articulated within the thesis that time had passed and significant historic events had taken place, reflecting their temporality and historicity.

Additionally, given the time that had passed since I had last contacted them, I was concerned that I did not know the circumstances these women were now living in, whether they were well or had died from their cancer, or whether they had moved from the address they provided me; meaning I could potentially be returning confidential information with reduced certainty it would be received by the intended recipient. As a result of these concerns, I carried out a risk assessment and made the decision not to return the summary. Ethically, I justified this decision though the work of Letherby (2003) who acknowledges the impossibility of full representation but that some representation is better than none. Some representation had been achieved when each participant received a copy of their interview transcript and was asked, on reflection, to add or take away from their narratives as they saw fit. This decision was then communicated to the ethics committee and research and development teams for approval, which was granted. This however does impact on the feminist authenticity of this study due to its compromised participant participation, a key tenant of feminist research.

Lastly, procedural ethics which describes the ethical review process of seeking permission from independent review boards and ethics committees, ensuring protection from harm, informed consent, privacy, confidentiality, and anonymity. The researcher is required to make assumptions about situations and challenges and anticipate and or mitigate against these possibilities. This process is not about demonstrating ethical wisdom but more about adherence to protocol and therefore may offer a false sense of security if taken alone (Downs 2017). However, when undertaken in partnership with situational and relational ethics it provides a more robust safety net. The following documents the procedural ethical practices underpinning this thesis.

NHS Ethics approval, NHS Research and Development Approval and Liability

Ethical approval was granted by the NHS Health Research Authority on the 5th May 2015. (Appendix 2)

- REC reference 15/WM/0141

Research and development approval (R&D) was granted by each participating trust:

- R&D Ref 2015/NURSING/02

Access was granted to NHS trusts by clinical directors, and Directors of Nursing who provided oversight and sponsorship for each health care trust involved in the study. An honorary contract was issued to me from each NHS trust providing permission to work within the hospital setting for the purposes of this research study. Study sponsorship and liability insurance was obtained via the University. In addition, further liability insurance was provided as part of my professional union subscription. Contact information was provided within the participant information should a study participant or participating site require further information or have concerns about the conduct of the study.

Consent

Potential participants who expressed an interest in the study via their CNS were contacted by me within one week of receiving their contact details to answer any questions and where appropriate arrange the interview. The study information pack, containing the informed consent form and Participant Information Sheet (PIS), was reviewed at the interview meeting where two copies of the consent form were signed. The participant kept one copy of the consent form and the second was held in accordance with General Data Protection Regulation (GDPR) (ICO 2022) and United Kingdom Data Protection Act (2018), in a participant information file in a locked cabinet in a locked office at the University.

Potential participants who contacted me directly were sent a study information pack in hard copy by post. Participants were contacted within one[5] week of anticipated receipt to ascertain whether they would like to be involved in the study. At this time an appointment for the interview was arranged.

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[5] One week allows for 1st class postal delivery of the study information and consent form.

The informed consent form and PIS was reviewed at the interview meeting. Two copies of the consent form were signed with the participant retaining a copy and the second held at the University.

No study participants required materials in other formats or extra time, but arrangements were in place should this need arise, including:

a. Specialist expert advice would be sought should a participant with special communication needs or learning disabilities wish to participate in the study.
b. Potential participants with a disability would be provided with information in a format reflecting their individual needs, for example in Braille or an audio file.
c. Study information would be translated into other forms, including Welsh, at the time required.
d. Participants requesting extra time to decide on their involvement in the study would be given up to two months. At this point I would contact them, via their preferred method of communication, to determine if they wished to be involved in the study. This would be the final contact made.
e. If the potential participant decided later to become involved in the study, they would be able to contact me directly to discuss this option.

Only participants with capacity to provide informed consent were included in the study. Capacity to give informed consent was assessed by me at the time of the interview using the Mental Capacity Act (2005) two stage functional test:

Stage one: Is there an impairment of, or disturbance in, the functioning of the person's mind or brain (it does not matter if this is permanent or temporary).

Stage two: If so, does the impairment or disturbance make the person unable to make the decision? The person will be unable to make the decision if after all appropriate help and support to make the decision has been given to them (principle 2) they cannot do the following things.

1. Understand the information relevant to that decision, including understanding the likely consequences of making, or not making the decision.
2. Retain that information.
3. Use or weigh that information as part of the process of making the decision.
4. Communicate their decision (whether by talking, using sign language or any other means).

(Office of the Public Guardian 2009 page 19)

If a participant lost capacity during the study data collected prior to loss of capacity was to be retained and used within the study. The PIS details this and participants were asked to indicate their consent for this on the study consent form.

Further potential consent options were available to all participants and were detailed within the PIS:

1. Should a participant choose, up to the point of receiving the summary copy of their interview analysis, not to participate further they were able to withdraw from the study without prejudice and all material relating to their case destroyed.
2. If a participant wished for no further involvement in the study following their interview but for their interview to be included in the analysis arrangements were made to not send the interview transcript or summary to them. No participant asked for this option following their interview.
3. It was possible that during the study participants may become too unwell to continue or may die of their disease prior to its completion. Where I to be made aware of this the participant's interview transcript would remain as part of the study data unless there is a specific request to remove this directly from the participant prior to their decline or death. However, I was not made aware of any participants dying during the study.

Confidentiality

Confidentiality was maintained throughout the research process.

All data were handled in accordance with the United Kingdom GDPR (ICO 2022) and Data Protection Act (2018) which requires that data be anonymised as soon as it is practical to do so. Any personal contact data was stored on a password protected spreadsheet that only I had access to. Participant's real names were only known to me. All data was again stored on the University's password protected system to maintain an optimal level of security. The Department of Health NHS Confidentiality Code of Practice (2003) was adhered to. Additionally, as a registered nurse, I am professionally bound by the Nursing and Midwifery Council, The Code. Professional standards of practice and behaviour for nurses, midwives, and nursing associates (2018) and as such have a professional responsibility to preserve safety and maintain confidentiality.

To ensure confidentiality (NMC 2018) participants real names and place names have been removed. Each participant was invited to choose a pseudonym for themselves at the beginning of the interview process. Only two participants chose to do this, the remaining eight participants did not want to select a pseudonym, preferring to use their real name, however, this would breach research ethics and my Code of Conduct as a registered nurse. Therefore, I made the decision to allocate pseudonyms to my participants. Given (2016) suggests that pseudonyms help humanise participants within studies and to readers and aids in the narrative writing style of this thesis. Additionally, all other names of people and places referred to by the participant have been removed and referred to by descriptors for example:

- Partner: P
- Daughter: D1, D2 …
- Hospital: H1, H2 …
- Ward W1, W2 …
- Brother in law: BiL
- Nurse: N1, N2 …

All research data was stored in accordance with university regulations:

1. Manual identifiable participant information files, including demographic information and copies of their life history grid, were held in a locked filing cabinet to which only the Principal Investigator had key access.
2. The filing cabinet was in a locked office.
3. Electronic files were stored in a password protected file on a password protected secure university server.
4. Personal electronic data was stored in a password protected file on a password protected university server.
5. The key to the interview transcripts and pseudonyms was stored electronically in a password protected spreadsheet, on the password protected university server in a separate password protected file to the main study file.
6. Electronic audio files of recorded interviews were stored on the password protected university server.
7. Transcribed interviews were anonymised and securely stored in a locked filing cabinet and on the password protected university server.
8. Personal data was only be accessed by the principal Investigator during the study.
9. Interview transcripts were anonymised and only contained the pseudonym or initial of the participant.
10. Anonymised interview data was analysed by me at the university or at my home.

Long term data management:

1. Personal data will be stored for no more than 12 months from the end of the study.
2. Electronic data will be stored under password protection on the University secure server for 5 years following completion of the study in accordance with the Canterbury Christ Church Research Ethics and Governance Advisory Note (2013).
3. The principal investigator is the only person with password and key access to all data (electronic and manual).

Although I am a registered nurse I was not working within the clinical environment and therefore only a minimal risk of a coercion of potential participants existed. Clinical nurse specialists were only involved in providing study information and took no further part in recruitment to avoid any negative impact on the therapeutic relationship they had created with their patient.

During the interview participants may have discussed where a health care professional had done something of serious professional concern or revealed a breach of a professional code. Participants were informed during the consent procedure that if they were to mention an issue of serious professional concern then I had a professional responsibility to address this with the service under discussion. However, the individual participant's identity would not be released to the service. Thankfully, this did not occur during any interviews.

Furthermore, if a participant highlighted a safeguarding issue, then, in line with my professional accountability and responsibility, this would be reported via the appropriate channels. Again, the participants were informed of this during the consent procedure. No safeguarding issues were raised during any of the 10 interviews.

Risks, burdens, and benefits

One aim of the study is to provide health care professionals with information on how to provide person centred and culturally safe care, therefore the participants may benefit if the findings from the study are implemented within their local health care service. In addition to publication, it is my intention to present these findings to the participating trusts so they can consider how to implement the findings locally. This study's findings will offer an opportunity to help the wider LGBTQIA+ community through sharing these experiences as widely as possible.

One of the benefits participants may have experienced was my ability to signpost them towards additional information and support due to my experience working in cancer care. Ethically there is a very fine line drawn between researcher and practitioner relationships. I was very aware of how easy it would have been for me to step into “nurse” mode and attempt to help these women solve some problems. I was particularly aware of stopping myself from offering advice during our interview conversation as I wanted to avoid any influence over the stories they were raising. However, I was fully aware of my role as a professional nurse who has expertise in this area of practice, and that it would be unethical not to provide guidance and help. I therefore made the decision that following the interviews conclusion, when the recordings had been completed, any concerns they had I would offer some professional advice. This only happened on one occasion when a participant raised an issue about lack of libido and stated that they didn’t know what they could do about this. When the interview was completed, we discussed possible self-help interventions she could try and where to seek professional help. She stated that she was grateful for this as she had not felt able to discuss this with her consultant or GP. On returning home I reflected on this and considered whether I had stepped over that line. There are no easy answers to this, but I am convinced that undertaking reflective practice after the fact and planning for this eventuality I engaged in prior to the interviews offered some reassurance that I would be able to maintain a balance between my two identities as professional nurse and ethical researcher.

There was the potential that the recall of painful memories and emotional experiences related to their lesbian identity and/or their cancer experience may have caused distress to the participants. I had again prepared for this potential outcome by ensuring I had the contact details of their CNS and cancer and LGBTQIA+ support networks. On concluding each interview, I checked in with participants as to their wellbeing, offering to provide them with the contact details I had should they need them. I also asked whether they would be seeing anyone that day that would be able to offer support. Finally, I offered a debrief following the conclusion of the interview to ensure there were no lingering thoughts or feelings they wanted to discuss. All participants were happy with the way the interview had gone and stated that they did not require any further support or contact details. One participant expressed how valuable they had found the conversation as they had been able to discuss things they had not thought about for a long time

> Debbie:
>
> It’s completely unreal. I mean you sitting here having a conversation with me, bizarre. But it’s really nice. And thank you for doing the research because I’ve you know, it’s enabled me to sort of reflect on things that I hadn’t thought about for many years. So that’s been quite nice. So thank you.

Participants may not have disclosed their sexual orientation to their General Practitioner (GP) or other health care professional involved in their care and they may feel that to disclose this would put them at risk of discrimination or poor care. Therefore, the participant's GP, and other health care professionals, were not informed of their participation in this study.

Complaints, insurance, and indemnity

The participant information sheet detailed how a participant could make a complaint about the study. In the first instance the participant was invited to discuss their concerns with me as the principal investigator. If this failed to resolve their concerns or they wished to go straight to a formal complaint participants had the contact details of the PhD supervisor on their Participant Information Sheet. Finally, if these still failed to resolve the concerns raised and a participant remained unsatisfied the PIS had the contact details for the Faculty of Health and Wellbeing's Director of Research.

A clinical nurse specialist at one participating trust contacted me six months into the studies recruitment phase as a consultant had raised concerns about the study poster being on display in the waiting room. I was able to provide evidence of ethical and R&D approval alongside the Medical Director and Nurse Directors permission to undertake the study within that location and to advertise for participants. This satisfied the CNS that all relevant permissions had been granted and she would report this back to the consultant, I heard nothing further from them. Although I am not able to offer an underlying reason for why this poster triggered concerns it seems interesting that a poster advertising a study for lesbian women would do so. No concerns or complaints were raised about the study. Insurance and Indemnity was provided by Canterbury Christ Church University.

Peer review

Peer review of the research proposal and protocol was undertaken to improve the research methodology, ensure the proposal and protocol met the stated aims of the study, check for lay understanding, challenge theoretical assumptions made by the researcher and to build trustworthiness within the study (Chenail 2008). This was undertaken at three levels, the first as a formal process prior to ethical approval submission and the second and third as an informal process via in person conversation and email communication:

1. The study proposal and protocol were peer reviewed by a member of the health faculty who was not involved in the study. Following feedback recruitment strategies were clarified.
2. In depth review was undertaken by a senior academic at another higher education institution active within feminist and health research. Theoretical guidance and concept development, i.e., is there "a" universal lesbian experience, was incorporated into the methodology chapter.

This was incredibly valuable as it enabled me to question the assumptions, I had made, about lived experience, and further embrace the concepts of subjectivity and performativity developed by Butler (1990) in Gender Trouble.

3. To ensure research materials were applicable and acceptable to participants' health services user review was undertaken by two peer reviewers (Slattery et al 2020), both identifying as lesbian/ gay women with long term health conditions other than cancer (this decision was made so as not to remove two potential participants from the possible recruitment pool). Both women were known to me and were part of my local community networks. They agreed to undertake this role voluntarily. Clarification was added to the participant information and consent form following their review.

Pilot interviews

Two pilot interviews were conducted with lesbian women with long term health conditions, other than cancer, to test the interview schedule, life history grid and recording devices. No adjustments to the study protocol were required following this. The pilot interviews served multiple purposes. Firstly, they offered the opportunity to test the tools developed for the study; interview schedule and life history grid, and secondly it provided an opportunity to develop my skills in using conversational interviewing. Prior to undertaking this study, I had carried out two other interview-based studies and attended training on qualitative interview technique. However, this was mainly within a descriptive phenomenological paradigm, where I had aimed to "bracket" external influences over the interview process. Within this queer, feminist, narrative study this was neither appropriate nor desirable. My aim was to achieve an informal and reciprocal approach to the interview. The pilot interview recordings enabled me to listen to my questioning techniques and reflect on my communication style, identifying negative behaviours such as blocking or over speaking and building on more positive strategies such as rapport building, sociability and reciprocity, key to the conversational interview technique (Roulston 2008).

Access and Recruitment

The study was designed to use the National Health Service (NHS) cancer services and in particular Cancer Clinical Nurse Specialist's (CNS) as a primary path for recruiting participants. CNSs acted as gatekeepers for the study and provided study information to any interested patients. CNSs form a unique and long-term relationship with cancer patients that continues after the initial treatment phase has been completed. Due to the ongoing nature of this relationship, they were, potentially, in a position to be knowledgeable about a patient's sexuality and could therefore introduce the study in a safe manner. CNSs were asked to advertise the study within their support groups and clinic waiting areas and offer study and researcher contact information to any potential participant expressing interest. The following guided this role for the CNS:

1. CNSs will only act to refer potential participants to the researcher. They will not undertake any study recruitment activities.
2. Recruitment to the study will be undertaken by the principal researcher.
3. If potential participants agree, CNS's, acting as gatekeepers, will provide the researcher with the participants contact details so that initial telephone or email contact can be made. Alternatively, the potential participant may choose to contact the principal researcher directly for further information.

Forty-six information packs were sent to 4 separate hospital sites, across two NHS trusts. This included CNS introduction letters (appendix 3), guidance on sending encrypted emails (appendix 4), consent form (appendix 5), participant information leaflets (appendix 6), posters to advertise the study, and study flyers (appendix 7). Seven further information packs were sent to individuals contacting the PI directly or given to study participants to pass on to interested parties.

Table 4: Study information distribution

Site	Packs
1	1-10
2	11-20
3	21-30
4	31-46
Networks	47-51
Snowball recruitment	52-53

The use of gatekeepers does bring with it difficulties, for example, as discussed in the literature review segment of this thesis, not all health care professionals feel comfortable discussing matters of sexuality with patients. Additionally, potential participants may choose not to disclose their sexuality to their health care professionals for fear of homophobia or poor care. Therefore, secondary recruitment strategies were employed. Posters advertising the study were displayed in cancer treatment centres so that potential participants could self-refer using the study contact details Tel: 01227 782104 or email p.kuzbit46@canterbury.ac.uk. LGBTQ and cancer support groups, charities, community networks and community events were contacted and provided with information about the study and the principal researcher presented the proposed study at research or LGBTQIA+ events. Social media was used to reach out to the wider LGBTQIA+ community and advertise the study beyond the local population and to ensure women who are not currently receiving active treatment could also participate in the study. A Facebook page was established to advertise the study (https://www.facebook.com/LCV2015) and a personal Twitter account was used to contact LGBT charities, including Opening Doors, a national LGBT charity supporting people over 50, who retweeted the study contact details. Publications, including Diva magazine, were contacted via twitter with a request to re-tweet information about the study, which Diva magazine kindly did. One person contacted the PI following this retweet but sadly they did not meet the inclusion criteria as they had been a child when they were diagnosed. Two further potential participants reached out via social media but again neither met the study inclusion criteria, one's cancer treatment had completed more than 10 years ago and the second identified as bisexual. No further contacts were established through social media.

Previous studies have suggested that accessing the lesbian population may be difficult through standard recruitment strategies, therefore snowballing technique was used. Snowballing is particularly useful for contacting hidden or hard to reach populations as it relies on pre-existing communication channels, however there is a high risk of selection bias as participants may share common views, experiences, and political affiliations (Morgan 2008, Atkinson and Flint 2001). Following their interview all participants were provided with study information packs to pass on to any contacts who may be interested in taking part in the study. No potential participants were contacted without their expressed permission, two participants contacted me following receiving an information pack and consented to take part in the study.

By using multiple recruitment strategies selection bias can be avoided as much as possible and a diverse population of lesbian women could be reached. Participants were from a variety of physical locations and socioeconomic backgrounds, however, in other areas the group did present as a particularly homogenised participant group, all bar one person identified as white, all were cisgendered and six had breast cancer.

Table 5: Recruitment methods

Recruitment method	Contacts	Participants
Social media	3	0
Community contact	4	4
CNS	3	3
Study advertising poster	1	1
Snowballing	3	2

Participant inclusion criteria

The target population were adult women (18 years and older), who self-identify as lesbian or gay, living in Great Britain who had been diagnosed with cancer within the last 10 years. Women who identified as other queer sexualities e.g., bisexuality or pansexuality were not included as they have unique narratives that should be given distinct attention (Berner and Meads 2022).

The decision to include trans and cis women was made to ensure all people identifying as women had an opportunity to participate. Here, post-structuralism, rather than biological determinism, was given primacy, additionally enabling the intersections of gender and sexuality to be explored within the interviews. All women can talk to their experience of being a woman diagnosed with cancer at the point of diagnosis, in treatment and beyond. The intersection of transphobia and homophobia was also an important consideration for this study and warranted the opportunity for analysis. Sadly, however, no participants identified as trans women, therefore this study can only offer insight into the lived experiences of these 10 cisgendered lesbian women.

When discussing cancer, it is common practice to talk in terms of years of disease-free survival, this criteria changes with each cancer diagnosis but is commonly placed between 2-10 years, after which a person can reasonably be thought of as having been cured of their disease (although the use of the word cure is contentious with many physicians preferring to continue to use the phrase ‘remission’). This study is interested in exploring the experience of women with cancer or who were within the standard surveillance timeframe rather than those who have been deemed “medically cured”, therefore women with a disease-free survival of less than 10 years or who were diagnosed more than

10 years ago but are still receiving care related to their cancer were included. Further, as highlighted in the literature review most studies focused on breast and reproductive cancers and little attention was given to women with other cancer diagnoses. Therefore, the decision to include all cancers was made to try and offer a narrative of cancer where gender identity was not a defining feature of the disease but rather of the person with the disease. Of the 10 women who participated six had received a diagnosis of breast cancer, one of acute myeloid leukaemia, one of lung cancer, one of endometrial cancer and finally one participant had colorectal cancer. Three participants cancer diagnoses therefore sat outside the conceptual frame of "women's cancers". This is not a large number but does offer a small number of different voices to the cancer narratives most often collected from lesbian women.

For practical reasons the decision was made to only include English speaking participants as I am not able to speak a second language. This is a recognised limitation of the study. Important intersectional narratives may have been lost because of this decision and future research should aim to include non-English speaking lesbian women receiving cancer treatments in the UK to provide as full a picture of this experience as possible.

Inclusion criteria for this study was:

Women (cisgender or transgender), who self-identify as lesbian (or gay) and:

a. 18 years and older
b. Live in the Great Britain
c. Been diagnosed with a solid tumour or haematological malignancy. Their cancer will have been diagnosed within the last 10 years or they are currently receiving cancer care for a cancer diagnosed more than 10 years ago.
d. English speaking.
e. Able to provide informed consent at the outset of the study.

Exclusion criteria were:

a. Any person not meeting the inclusion criteria cited above.
b. Bisexual identified women will not be included as they have unique narratives that should be given distinct attention.
c. Women under the age of 18.
d. Men (cisgender or transgender).
e. Women diagnosed with non-malignant tumours or non-malignant haematological conditions.

f. Women whose cancer was diagnosed more than 10 years ago and are not currently receiving cancer care for this.

g. Non-English-speaking women will not be included as they have unique narratives and cultural experiences that are beyond the scope of the current study and require distinct attention.

h. Any person who is unable to provide informed consent at the outset of the study.

Table 6: Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Women	Men
Over 18 years old	Under 18 years old
Self-identify as lesbian (or gay)	Do not identify as lesbian (or gay)
Any solid tumour malignancy or haematological malignancy	Non malignant tumours or non-malignant haematological condition
Cancer diagnosis within the last 10 years or are currently receiving care for a cancer diagnosed more than 10 years ago	Cancer diagnosed more than 10 years ago and are not currently receiving care for it
English speaking	Non-English speaking
Able to provide informed consent at the outset of the study	Unable to provide informed consent at the outset of the study

Lone Working

I visited participants at a venue of their choosing to undertake the research interviews and therefore, a key concern was personal safety. A risk assessment was undertaken to ascertain the level of risk involved and to mitigate against this, a lone working protocol was established. I provided a colleague with details of my travel itinerary, expected time of arrival and departure, and a sealed envelope with details of my destination. Once I arrived at the destination, I contacted my colleague and again when leaving. Once I had confirmed my safe return the colleague shredded the unopened envelope. I chose a colleague who was bound by the same professional code of conduct stipulating confidentiality requirements, to safeguard my participants anonymity. I further instructed my colleague that should they not hear from me within one hour of the expected departure time they should attempt to contact me on three occasions within two hours, via mobile phone. If they were still unable to establish contact, they were to escalate this to my line manager who will follow appropriate procedures. Only when deemed necessary would the sealed envelope be opened. This procedure was never instigated, however having this safeguard in place offered a degree of reassurance.

Making contact

Following recruitment and once a participant had, in principle, agreed to be involved in the study an appointment was arranged for the interview to take place at a mutually convenient time and place. As the principal investigator, on all but one occasion, I travelled to the participants and met them in their own homes. On one occasion the participant came to my home. She was a member of my personal community network and felt more comfortable coming to me than having the discussion in her own home. On two occasions the participants partner was in the house at the time of the interview but stayed in a separate area of the house for most of the conversation. However, the two participants did ask their partners to join the interviews and offer their experiences in support of the discussion, particularly in relation to formal and informal support. This offered a different perspective to the discussion at the time and added valued data. Additionally, the partners prompted their loved one to be more open about key issues they had faced, again adding another dimension to the conversation that might otherwise not have been reached.

Data collection

To address the research questions 10 in-depth, focused, narrative, conversational, interviews were conducted focusing on the participant's life history. Each interview was recorded using two recording devises, firstly a handheld linear recorder direct to SD card and secondly on a password protected Dictaphone telephone application. Once the interviews had been completed the audio file was uploaded to the secure university server and deleted from the recording devices. Two devises were used to ensure the integrity of the recording. The importance of this became apparent during interview three when the linear recorder stopped working. Were it not for the Dictaphone application, there would not have been a record of the conversation. Handwritten notes were also taken during and after the interview to help me keep track of conversations and points that might need elaborating.

At the interview meeting the consent form and PIS was reviewed and I answered any questions. Interviews were commenced directly following the signing of the consent form. All interviews lasted between 2 and 3 ½ hours. Although this may seem a very long period to ask a participant to talk, this was directed by them; all were keen to continue sharing their stories and wanted to make sure they had addressed all the questions I had to the fullest. It was an immense privilege to be able to share this time with these women and their generosity was greatly appreciated.

An interview guide provided a general framework for the interview and an opening statement. An initial question focused on asking the participants to share stories of significance to them and then prompts for greater detail (appendix 8). A life history grid (appendix 9) was completed with the participant at the beginning of the interview and then, based on this history, participants were invited to share stories that were significant to them. Elliot (2013) contends that life history grids can help participants focus on specific times and places whilst navigating a very wide, possibly whole of life, time frame. In the interviews the life history grid acted as a starting point for the conversation and assisted participants to recall stories they wanted to share. Firstly, focusing on their experiences of being lesbian, from first realising they were lesbian, coming out, living as lesbian, and navigating their social reality. Secondly, their cancer narrative, participants were asked to share stories they felt were significant or important to them about their cancer journey and what it meant to have cancer, from first recognising there may be a health concern to their current situation. Participants were encouraged to speak openly and in their own way rather than following a predetermined, fixed, interview format. This approach has the benefit of shifting the power within the interview, and, although this will never be equal, the disparity can be lessened (Riessman 2008).

Breaks during the interviews were offered as I was very aware of the fatigue that people with cancer can experience both during and after treatment, however, everyone was happy to carry on with the conversation until they had exhausted their stories and felt that they had told me everything they felt was relevant to their experiences. When the two partners were present, they brought refreshments to us, again this added to the conversational style of the interview as a natural break in the interview occurred, this engendered a more relaxed atmosphere, and developing rapport. Additionally, one participant and her partner invited me to stay for lunch following the interview. I felt it was important to join them as it helped in the rapport building when I initially arrived.

The interviews were transcribed verbatim to assist in the narrative analysis process. The first two interviews were transcribed by me personally however, due to the time each interview took to transcribe the subsequent eight were transcribed by a colleague who had previously undertaken research transcription work. They signed a confidentiality agreement (Appendix 10). All files were sent using the password protected university email system and the transcriber deleted all files once each transcription had been completed. Participants were informed of this at their interview.

Participants received a copy of their interview transcript and were invited to add any details that they felt were missing or to redact any areas they wished to remove. I asked that they did not correct the interview for grammar and syntax as the way the story was told was as important as the content. However, one participant, a teacher, felt uncomfortable with this and corrected her transcript, adding an apology note for doing so at the end. One participant added a note expressing how they felt they had benefitted from the experience as it had been the first time that she had examined the relationship with her father since his death a year earlier. This speaks to the often-cited therapeutic nature of qualitative interviews, however this was not the aim of the conversation. Additionally, two other participants stated during the interview that it was useful to talk about their experiences. Finally, one participant redacted a portion of their interview transcript as on reflection they felt this area was too personal and could potentially cause harm to their relationship. This section was therefore removed from analysis.

As discussed in the ethics chapter, it had been the aim to return a four-page summary of the narrative analysis to each participant, however due to the extended time between interviews and analysis this was an unethical step and permission to change this was granted by the ethical review board and the local R&D departments.

Conversational Interviewing; a conversation with a purpose

Interviews offer an opportunity to gain unique insights into people's complex lives (Kim 2019). The central tenant of qualitative interviewing is that knowledge can be constructed through structured encounters organised around experiences (DeVault and Gross 2014). The narrative interview is a collaborative endeavour that aims to generate detailed accounts of peoples lived experiences; where the interviewer and participant jointly construct the narrative. This participatory model is viewed as non-hierarchical and non-manipulative; the researcher gives of themselves, answers questions, and engages in conversation with the participant to construct the narrative. Goodson and Sikes (2017) suggest that personal dynamics are key to developing a trusting and positive relationship within narrative interviewing. They recommend that researchers consider not only the language they use within the conversation, but also to share their own experiences, consider the clothes they wear, the interests they profess and how they generally present themselves. I made sure that I was authentic to myself in my dress, language, and the stories I shared about my life. I shared moments of recognition about my sexuality and created moments of connection to build rapport.

Paula
When we look back, we're always like oh yeah that makes sense. For me it was Cagney and Lacey

Kate
Oh yeah, I used to like that yeah, yeah, yeah. I always used to love Annie Lennox and she was a big gay icon really

Conversational interviewing is a particular approach that encourages participants to talk about the topics under investigation but in an informal way, researchers foreground sociability, reciprocity and symmetry in turn taking as seen in everyday conversation. Conversational interviewing strives to create a friendly and informal atmosphere. Further conversational interviewing attempts to create an environment where interviewees feel able to participate in extended discussions in a less formal or hierarchical environment than would be found in a structured research interview (Given 2008). Within the interviews, questions were framed using every day conversational language as these are most likely to succeed in eliciting stories that relate to their real-life experiences. I took on the role of topic initiator, question poser and clarification seeker within the conversation and I focused on active listening and facilitated the participant's storytelling using open ended and probing questions. Given (2008) highlights that conversational interviewing is subject to criticism, especially for being simplistic and naïve and open to manipulation, however all analysis is open to manipulation and through interventions such as reflexivity, and confirmability I can reduce the impact of this.

Narrative stories provide a sense of temporality, a "symbolic representation of time" (Horsdal 2017 pg. 260), unfolding in and over time, with beginnings and endings. The aim of the narrative interviewer is to offer opportunities for participants to explore these pieces of time. Additionally, In-depth, narrative interviewing is a particularly valuable tool for feminist research as it enables researchers to gain insight into the personal world of marginalised participants (Hesse-Biber 2014). As a feminist researcher, I am inherently interested in listening to the subjugated knowledge of women's lives as it is often hidden and unarticulated. Within Queering the sick room my main objective is to bring to the centre voices that have been underrepresented or unheard. In-depth interviewing can facilitate this as it aims to explore the lived experiences of women and examine their subjective understandings (Hesse-Biber 2014).

Horsdal (2017) asserts that the researcher must remain cognisant that interviewees are not new friends, and that within this frame we should accept the narrative participants are offering without prejudice, treating it as a gift. Feminist researchers should spend time assuring their participants that their experiences and interpretations of life are heard and appreciated as they narrate them. Taking these steps, according to Horsdal, may go some way to help reduce the power imbalance between researcher and participant. Taking this advice, I spent time before the recording commenced talking to my participants about the value I placed on their time and the stories they would be sharing with me. I am very aware of the power dynamic within the interview situation and mindful of the dangers of speaking for people rather than attempting to decentre myself and offering my space for their voices to be centred. Though my reflexive practice I have constantly returned to the concept of meaning making and placing these conversations within a socially, culturally, and historically specific context. Within the interview I monitored myself in my questions and ensured I wasn't taking over the conversation or offering my experiences in place of listening intently to my participants stories.

Analysis

This study employed reflexive thematic narrative analysis (Braun and Clarke 2021, Kim 2016, Squire 2013). Reisman (2008) contends that all narrative inquiry is concerned with content, with what was said, but in thematic narrative analysis this is the sole focus. It is the most common approach to narrative analysis and is often used by novice narrative researchers, as in my case. I have not previously undertaken narrative research so this jump into methodology felt the most authentic to me. Narrative thematic analysis incorporates both inductive and deductive analysis, theory being as integral to interpretation as interpretations coming directly from the words spoken. Any use of theory, additionally, needs to be made explicit from the outset so assumptions and interpretive leaps can be traced and illuminated (Braun and Clarke 2021, Kim 2016). This again sets this method apart from grounded theory for example (Braun and Clarke 2021, Reisman 2008). Braun and Clarke further assert that the most important consideration is that all elements fit the projects' purpose and are aligned; theoretical assumptions, research questions and methods and the overall design is coherent.

There is no single approach to narrative analysis and many researchers combine different narrative-analytic approaches. Again, the most important aspect is transparency in the approach and reflexivity in decisions made about the presentation and interpretation of narratives as they emerge from the data (Esin, Fathi and Squire 2014). Squire (2013) suggests the simplest approach to analysis is to begin by describing the interviews thematically, and then to develop and test theories that provide explanations and interpretations of the stories by going back and forth between the stories themselves and the generalisations and theorisations that are being constructed in what she calls the "classic hermeneutic circle" (Squire 2013 pg. 57). This should be undertaken both inductively and deductively, bottom up and top down. Narrative thematic analysis distinguishes itself from other thematic approaches in that it pays close attention to the sequencing and progression of themes within interviews, their transformation and closure, giving primacy to the narrative aspects of the themes. There are multiple valid interpretations that can emmerge from narrative thematic analysis, no one more accurate than the next. There are multiple narrative truths and multiple valid interpretations (Squire 2013). As previously stated, the purpose of this thesis is not to generate one essential truth but to offer multiple experiences that together can offer insight into a shared lived experience.

Polkinghorne's (1995) paradigmatic mode of analysis uses our thinking ability to organise experience whilst attending to general features and common categories and characteristics, classifying features into categories, and fitting individual features into larger patterns of experience. According to Polkinghorne (1995), paradigmatic thought "produces cognitive networks of concepts that allow people to construct experiences as familiar by emphasizing the common elements that appear over and over" (p. 10). The paradigmatic mode of narrative analysis establishes that findings are arranged around descriptions of themes that appear across assembled stories. Clandinin and Connelly (2000) also note, "An inquirer composing a research text looks for the patterns, narrative threads, tensions, and themes either within or across an individual's experience and in the social setting" (p. 132).

In summary Polkinghorne's analysis of narratives:

- describes the categories of particular themes while paying attention to relationships among categories;
- uncovers the commonalities that exist across the multiple sources of data; and
- aims to produce general knowledge from a set of evidence or particulars found in a collection of stories, hence underplays the unique aspects of each story (Kim 2016 pg.16).

Each individual interview audio file was listened to multiple times to fully embrace the essence of the stories the participants were sharing with me, and to consider the way the conversation progressed, the ease at which stories were imparted and for any uncomfortable moments, moments of hesitancy or loss. Listening was undertaken in concert with the research notes I had jotted down during the conversation. I listened for a chronology of experiences, particularly in relation to coming out and in telling their cancer journey. I then read and reread the full interview transcripts, reading through each participants life story in relation to the research questions multiple times, considering the text through a queer feminist prism, particularly queer phenomenology, queer orientation, and queer embodiment. Following the multiple readings and re-readings I was able to write a description of each participant in relation to the stories shared with me. It is important to remember that stories are always partial, and constructed for a purpose, therefore any attempt to claim that I heard everything about this lived experience from each participant cannot be made. The narratives offered here are always contextual and relative.

Once I had completed all ten interviews, I was able to return to each participants transcript and audio file and consider the experiences expressed across interviews. This allowed me to identify similar stories and experiences and to consider time and place; for example, stories of diagnosis, treatment, and follow up. NVIVO 12, was used to help manage the large amount of information and to assist in the development of themes within and across interviews. Looking for both shared experience and unique stories; points of sameness, difference, and divergence. These were organised into a traditional thematic schema, through merging codes and developing overarching narrative themes.

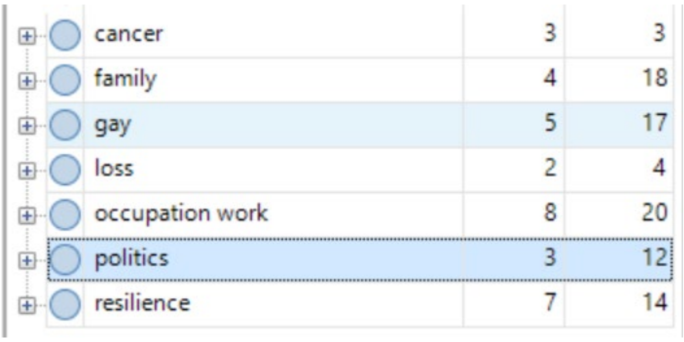
The first review created 521 individual codes. These were then merged into 49 major categories from which the final seven major narrative themes emerged.

Codes:

- first coding resulted in 521 individual codes.

Merging codes

- Condensing nodes where there is overlap e.g.:
  - Questioning ethnicity and questioning racism became questioning racism.
  - Growing up in a different country was integrated into the family cluster as the discussions here were primarily moving with family from the US to the UK
- Collapsed into 7 major initial thematic categories.



cancer	3	3
family	4	18
gay	5	17
loss	2	4
occupation work	8	20
politics	3	12
resilience	7	14

Renaming categories to reflect narrative interpretation:

1. Living a lesbian life
   - Coming out
   - Lesbian relationships; dyke drama and perfect partnerships
   - Family strife
   - Heterosexism and homophobia
2. Living a lesbian life with cancer
   - Constructed cancer hierarchies
   - Being diagnosed
   - Why have I got cancer
   - Cancer and my (lesbian) body
   - Surviving treatment
   - I just get on with it; coping with cancer
   - I couldn't have done it without her
   - The cancer environment
3. Queering the sick room

Once these themes were identified, each interview was re-examined to look for emerging interpretive narratives, did the themes generated appear in the stories told, had the interpretation moved too far away from the original text or was there congruence between the interview and the interpretation? Stories were constructed from comparing interpretations to the raw conversation, looking for unsafe interpretive leaps, inconsistency in interpretation, and seeking out contrary cases. Data analysis is a time consuming and absorbing process where total emersion in the data is the aim. Each interview provided an extremely large amount of data to work with and weaving in and out of stories looking for key narratives took place over nearly two years. It is important to again return to the time frame of this study and the situatedness of the findings. I cannot make claims that these narratives present an understanding of what a lesbian woman with cancer might experience in 2023 as there have been many social, political, and cultural shifts over this time, for example the UK, since 2015, has fallen from 1st to 17th place since on the ILGA rainbow map (ILGA 2023) which ranks countries equality standards, legal and policy support for LGBTQIA+ rights. However, what they do represent is how these women experienced their lives at the time of the interviews and the impact being lesbian and having cancer had on them. All research is ultimately from a given time and place and interpreted as such.

Trustworthiness

Credibility

Post-structural narrative approaches are less concerned with bias and validity and more with voice and text, or issues of representation, which are achieved, in part, through strong reflexivity and it is though this reflexive process that issues of trustworthiness can be addressed (Caine, Clandinin and Lessard 2022, Hesse-Biber 2014, Olesen 2005, Chase 2005). Although accountability for the construction of the narrative lies with the researcher credibility and believability is achieved by the storyteller. Narratives are socially situated and are therefore constructed for a particular audience and have a particular purpose, they do not seek to be a factual report of events but rather act as one articulation, told from a distinct perspective that seeks to persuade others to see events in a similar way (Chase 2005, Riessman 2008). Denzin (2000 cited by Riessman 2005) further asserts that narratives do not establish or reflect the truth of an experience, but create the events they reflect on, they are reflections *on*-not-*of* the known world.

Letherby (2003) holds that researchers cannot be emotionally detached from their work but that the subjective element of research should be acknowledged and welcomed, however, the rejection of objectiveness does not mean rejection of critical, rigorous, and accurate interpretation. Therefore, detailed records of decisions related to the study were kept in a research diary and email conversations for an audit trail to be constructed. Furthermore, although the participatory nature of narrative research aims to reduce the power imbalance inherent within research this cannot be completely eliminated therefore, researchers must be cognisant of, and through reflexivity, acknowledge the role of intellectual privilege (Letherby 2003, Chase 2005). In addition, to address these and other issues of credibility a reflexive diary was kept that documented and analysed my situated-ness within the study.

Transferability

Narrative researchers, writing as situated and positioned authors, reject the idea that the presented narratives must be generalizable as the range of narrative possibilities is limitless. Further, any narrative is significant as it gives insight into what is imaginable and understandable within a given social context; gives voice to marginalised, silenced lives, and is firmly rooted in a particular time and place (Caine, Clandinin and Lessard 2022, Goodson 2017, Squire, Andrews and Tomboukou 2013, Chase 2005, Richardson 1990 cited by Elliott 2005). Rather, transferability comes from the detailed documentation of the research context, epistemological and methodological assumptions central to the study, and well-constructed narratives, enabling similarities across social contexts, marginalised or silenced lives to be ascertained by the reader and findings considered in analogous social contexts.

Dependability

A research diary and decision-making log was maintained throughout the study as it is important that the context within which the narrative is constructed and the changes to the setting in which the research was undertaken is transparent in order to be considered by the reader (Riessman 2008).

Confirmability

Caine, Clandinin and Lessard (2022) and Riessman (2008) refer to the importance of analysing points of convergence and divergence between narratives in increasing trustworthiness. Furthermore, the persuasiveness of the research is increased when researchers include supportive evidence from participant’s accounts, negative cases and alternative interpretations. Therefore, a purposeful search for contradiction and negative cases within the analysis process was undertaken and presented within the findings.

Conclusion

DeVault and Gross (2014) argue that internal critiques of feminism, particularly queer theory, and poststructuralism, have deconstructed the concept of “woman” as “the” unifying and foundational subject of feminist work. Women are diversely positioned in history, culture, and class; genders are multiple; gender is a product of discourse. Feminists researching gender and sexuality and their intersections with race, class, sexuality, ability etc. must therefore resist the reliance on any categorical identity. We need to be fully aware of the differences that exist amongst women and be careful to ensure that when we offer to present women’s voices, we are not claiming a universal voice or to be speaking on behalf of some women only (e.g., white, straight, able-bodied, middle-class women). We need to speak to the “historically specific differences and similarities between women in diverse and asymmetrical relations” to create “alternative histories, identities, and possibilities for alliances” (Kaplan, 1994, pg. 139 cited by DeVault and Gross 2014).

Chapter 9: Results

This chapter details the results of the reflexive thematic narrative analysis undertaken. Firstly, I will introduce each participant in synopsis so that the reader can develop a sense of each individual and their life story as they chose to present it to me. Secondly the thematic analysis will be presented. Here, stories will be brought together to illustrate each narrative, how each woman experienced moments in time from their social, cultural, and political perspective. I will attempt to offer minimal interpretive explanation here as my intention is to provide a sense of the lived reality of these participants. However, I fully recognise that everything I have included represents a choice I have made, choosing stories and extracts from transcripts that I feel illustrate the point in discussion and any interpretation offered is through my personal ontological and epistemic perspectives, and my historical, cultural, and social positions explained previously in the thesis (Mauthner and Doucet 2003). I offer this statement as part of a reflexive acceptance of the situatedness of the study results in attempting to address the research questions:

1) How do women, identifying as lesbian, who have received a cancer diagnosis, construct their ‘lesbian’ narratives?
2) How do women, identifying as lesbian, who have received a cancer diagnosis, construct their ‘cancer’ narratives?
3) How do discourses of gender, sex and sexuality help interpret the intersections of cancer and lesbian identity?
4) How does a queer feminist epistemology help deconstruct the prevailing cancer narrative?

Participants

Kate

I met Kate at my house. She had asked that we meet there as she was not comfortable doing the interview in her own home. Although not very well known to me Kate was part of my community network and was familiar with my home, so I did not feel any concerns with agreeing to this. In fact, I felt it made for a very comfortable interaction on both our parts, there was already an easy rapport between us, so this was not something we needed to build. At first, I felt there may be an ethical concern that this was someone I knew personally and would maintain a relationship with following the interview, so when we discussed her participation prior to the interview, I raised this with her to ensure she was comfortable participating under those conditions.

When I met Kate for her interview, she was 44 years old and a year post treatment for acute myeloid leukaemia. She had undergone intensive chemotherapy, radiotherapy, and a stem cell transplant to irradicate her disease. She was currently in remission and beginning the road back to physical fitness. Kate had been an out lesbian since she was in her mid-twenties and was living with her long-term partner of over 10 years. She had dated men during her teenage years and early 20's but had been exclusively partnered with women since 26. Kate was not currently working and on long term sick leave from her job as a registered nurse.

Gail

Gail was a 55-year-old therapy assistant who had been diagnosed with breast cancer 18 months before our meeting. She had been treated with a wide local excision (WLE) more commonly known as a lumpectomy, which had been followed by chemotherapy and radiotherapy and she was currently taking the hormone suppression therapy tamoxifen. She was living with her partner of 13 years and their three cats. This was a key bonding moment for us and a point of rapport building as we shared a love of cats. Several minutes at the beginning of the interview were spent talking about our pets.

Gail was previously married to a man and had two daughters with him. Gail and her partner had five daughters between them one of which was also a lesbian. Gail had come out later in her life even though she had known she was not straight at a young age but felt societal pressure to get married and have children. We met at her house in the middle of winter. Gail was told about my study by a work colleague of hers who was also known to me.

Mei

Mei was 55 years old and the only participant in the study who did not identify as White British being of mixed Chinese American and White British heritage. This was an important aspect of her life story as she grew up in both the UK and USA but had resided in the UK since undertaking her nurse training in the 1980's. Mei had been diagnosed with breast cancer 9 years previously and had undergone a unilateral mastectomy without reconstruction and 5 years of tamoxifen treatment. She lived with her wife, and they were both retired from their careers as nurses. Mei had been aware of her sexuality from late teenage years and had exclusively dated and been partnered with women.

We met in her home and her wife was present in the house during the interview, although she spent most of this in a different area of the house. At one point she came and offered refreshments and then Mei drew her into the conversation about their "getting together" story. We spent over four hours together that day as they had invited me to stay for lunch after the interview. Rapport built easily in the conversation as we had a shared professional history and had both worked at the same hospital, although our times there did not overlap. Additionally, Mei had been introduced to the study by another member of my community network, so we were able to build an initial rapport though this shared connection.

Tracy

Tracy was introduced to the study by a work colleague of mine who belonged to a research group with me. She had been diagnosed with endometrial cancer when she was 46 years old and had undergone a hysterectomy. Tracy worked for a non-clinical hospital department whose office was right next door to the chemotherapy treatment centre, which became a significant location for Tracy as she told her story. Tracy lived with her wife who she had been with for 14 years and they had converted their civil partnership to marriage one year before we met. Tracy had been an out lesbian since she was a teenager and had told her parents just before she left for university. Tracy told me she would struggle with the conversational nature of the interview as she was not accustomed to talking freely about herself, preferring to answer direct questions. This meant I had to adjust my approach slightly and used a more direct questioning approach at times, although once we had stated the conversation Tracy was able to speak at length about the different aspects of her life.

Judy

Judy, 57, was one of only three participants who were made aware of the study by their nurse specialist. I contacted her following her CNS informing me she was interested in hearing more about the study. Judy had been diagnosed with lung cancer three years before our meeting and following extensive surgery and chemotherapy was now being actively treated with a novel immunotherapy. She was due to receive her third course of treatment the day after our meeting. Judy and I again bonded over our shared love of cats and spent the first few minutes discussing the quirks of each of our "fur babies". Judy had known she was a lesbian for all her adult life, coming out at age 21, but had kept this secret and was not out in her personal or professional life. She did have a lesbian social group, but these were very separate from her family and work life. It was only since her lung cancer diagnosis that she had begun sharing her life with more people and had moved in with her long-term partner. Judy held various jobs, including being a police officer, but had most recently worked for a car manufacturing company until she retired 2 years before our meeting.

Carolyn

Carolyn was the second participant to be referred to me by their CNS. She had been diagnosed with bowel cancer 10 months before our meeting at the age of 46 and was currently waiting to be admitted for a second surgical procedure. She had undergone emergency surgery at diagnosis and then chemotherapy and radiotherapy. The day before we met, she had just received positive scan results showing she would be able to have the anticipated second surgery. Carolyn was on long term sick leave from her role as a police community support officer. We met at her house that she shared with her wife, again bonding over cats.

She came out when she went to university but did not share this with her parents or family until she returned from a year travelling after university. Much of her adult life she had kept her sexuality private from work colleagues as she felt they would not be accepting, but since working for the police she felt able to be fully open about her relationship and sexuality, finding them to be an inclusive and supportive organisation.

Sabrina

Sabrina, 52, was diagnosed with breast cancer just two months before we met. She had undergone a WLE, was commenced on tamoxifen and was about to commence radiotherapy, so this was all very new to her. She had just returned to work as a case manager but was wondering if she had done this too quickly. Sabrina was the only participant who contacted me directly after seeing a poster advertising the study within the treatment centre waiting area. She stated she was very happy to see something for lesbians in the local area as she had not seen anything previously.

Sabrina had a long history of being active within the lesbian community and had participated in numerous social justice campaigns, including those opposing Section 28 (LGA 1988). We met on a beautiful summer’s day in the garden of her home she shared with her partner of 30 years. Sabrina and her partner had met whilst she was at university when she was 22 years old and had been together ever since. They were planning to marry that summer.

Samantha

I met Samantha when she was 45 years old, a year after her diagnosis and treatment for breast cancer. She had undergone a mastectomy with reconstruction, chemotherapy, radiotherapy and was currently taking tamoxifen. We met in the home she shared with her wife, who was present in the house for the interview but remained (mostly) at a distance whilst we were having our conversation. Samantha, at one point asked for a cup of tea and her partner then joined the conversation for a short period of time, encouraging Samantha to be more open about key aspects of her experiences, particularly in relation to her mental health journey. We began our conversation in the garden, but Samantha felt exposed and overheard by her neighbours so asked if we could move indoors. Once inside she appeared to relax and be more open to the conversation. I felt that Samantha was unsure about the interview at first and what I would be asking her, but as we commenced the conversation, she was very forthcoming with her stories about her cancer and her life as a lesbian. Of the ten women in the study Samantha was the youngest to recognise she was gay, realising she was different to others at the age of five and then that she was gay as a young teenager. She kept this secret until she was 17 when she came out to her mother.

Mary

Mary and I met in her home following another participant bringing the study to her attention. Mary was the oldest of the ten women in the study at 58 years old and she was the only single person, having split from her partner following her breast cancer diagnosis and treatment eight years previously. Mary had two children with a previous male partner and considered herself as a late starter coming out at 35 but has been living as a lesbian for over 20 years. Mary was a carpenter and musician and has been active within the LGBTQIA+ community. When we met, she was working for a not-for-profit social enterprise advocating for women in male dominated professions, particularly construction. It was whilst doing this job that she had been diagnosed with cancer when it was discovered during a routine health screening for private health insurance.

Melissa

Melissa was the youngest of the ten women at 43 years old, the youngest to be diagnosed with cancer and the newest to come out as a lesbian just fifteen months before we met. She was going through a tumultuous time with her divorce from her husband due to complete within weeks and having just resigned from her job with immediate effect as a teaching assistant in a pupil referral unit. All this occurring at the same time as being diagnosed with ductal carcinoma in situ and undergoing a unilateral mastectomy and failed reconstruction and then finding out her mother had also been diagnosed with breast cancer. We met in her shared accommodation late in winter, a place she had moved to after separating from her husband. Melissa was living there alone but seeing two women. Rapport was easy to build with Melissa, she was vivacious, outgoing, and easily shared her stories with me.

Table 7: Demographic information

No	Participant pseudonym	Age	Self-expressed sexuality	Self-expressed gender identity	Disability	Ethnicity	Relationship status	Cancer diagnosis	Treatments	Occupation
1	Kate	44	Gay	Female	No	WB	Cohabiting	AML	CT, TBI and SCT	Registered Nurse
2	Gail	55	Gay	Female	No	WB	Cohabiting	Breast	WLE, CT, RT, Tamoxifen	Therapy Assistant
3	Mei	57	Gay	Female	No	Other	Married	Breast	Mastectomy, tamoxifen	Midwife (retired)
4	Tracy	50	Lesbian	Female	No	WB	Married	Endometrial	Surgery	Clinical Auditor
5	Judy	57	Gay	Woman	No	WB	Cohabiting	Lung	Surgery, CT, MOAB	Car manufacturing (retired)
6	Carolyn	47	Gay/ lesbian	Woman	Yes/ no	WB	Married	Bowel	Surgery, CT, RT	Police Community Support Officer
7	Sabrina	52	Lesbian	Woman	No	WB	Civil Partnership	Breast	WLE, RT, Tamoxifen	Occupational Therapist/ Case manager
8	Samantha	45	Gay	Woman	No	WB	Married	Breast	Mastectomy, CT, RT, Tamoxifen	Advertising
9	Mary	58	Lesbian	Female	Yes	Irish	Single	Breast	Mastectomy	CEO – NFP
10	Melissa	43	Gay	Woman	No	WB	It’s complicated	Breast	Mastectomy	Teaching Assistant

Living a lesbian life

How do women, identifying as lesbian, who have received a cancer diagnosis, construct their 'lesbian' narratives?

The overwhelming sense from the women's stories is a very relaxed attitude towards their sexuality. This is not a thing, it is just who they are, they are gay get over it. There is a real feeling of history and a journey to get to this point, but most of the participants are comfortable with their identity as a gay woman, even if they have only recently come out, as was the case for Melissa.

Coming out

For some of the women coming out presented a choice as to whether to live as a lesbian or to adopt the expected heterosexual life. Sabrina spent some time in the interview discussing how, for her, sexuality and sexual identity presented a choice. She spoke about the expectation that she would be straight and that she could have chosen to live a heterosexual life, however even during the conversation with me she was debating, with herself, whether this was actually a choice she could have made and lived with. Reminiscent of Adrianne Riches (1980) compulsory heterosexuality argument, Sabrina goes on to explain that she would not have wanted to be heterosexual, particularly with the expectations of what a heterosexual relationship should be and how people should act within them. This also demonstrates Sabrina's lived experience with feminist thinking and lesbian activism of the 1970's and 80's rather than a theoretical or academic position.

> "Being a lesbian, because a lesbian in my mind I think, it was a choice. Although is it a choice or is it not? It's one of those. But I could've lived a heterosexual life. I could have. But I don't know if I could have… But no, I wouldn't want to be, I wouldn't want to be honestly. It's confirmed… I mean I couldn't imagine anything worse than being lumped in with that kind of lifestyle of men and woman and that, and the way everything is arranged in a way, and it's sold to you in a particular way how things should be. I think by being who we are, we very much choose." (Sabrina, interview 7)

This leads to questions of where does the choice lay? Is it with choosing your identity at a core level, i.e. who you truly are, or as Sabrina is implying in this statement, who you choose to show the world you are? This is a situation many women in this study faced when it came to "coming out", to both them and the world around them. When is the right time to come out, am I being forced to come out, can it wait longer, how do I tell people, can I continue to live a lie, live in secret?

Labelling sexuality

Like many of the biomedical texts examined in the literature review there was no agreement on which label accurately described each participants sexuality. How to define themselves offered the participants in the study food for thought. Many easily expressed the phrase “gay” to refer to themselves, others quantified this by adding woman to the descriptor “gay-woman” or joining together “gay-lesbian”. Interestingly, only three participants readily used the label lesbian, two of whom had been involved in the lesbian and gay rights movement, during the 1980’s in London and the third had been an active part of the LGBT community whilst at university in Manchester. The women referring to themselves as gay were overwhelmingly from smaller towns where there was not an identifiable or large LGBTQIA+ community, potentially reflecting the sociocultural-political nature of labels and claims to politically associated identities. Gay; a user-friendly term, lesbian; a political history!

> “Gay I suppose. I don’t really think about it too much to be honest.” (Gail, interview 2, small south costal town)
>
> “Gay, gay” (Mei, interview 3, home counties town)
>
> “I’m lesbian” (Tracy, interview 4, Manchester)
>
> “As a lesbian” (Mary, interview 9, London)

Mary and Melissa were the only two participants to use the phrase “dyke” when referring to themselves and other lesbian women in their social group.

> “I had a very close friend actually who was diagnosed the same time as me, also a dyke”, “having said that I’ve got a really good friend, my mountain climbing friend, who’s also a dyke,”, “when I told one of my friends who’s very butch dyke,” (Mary interview 3).

And highlighting when it was used against her as a homophobic slur.

> “You know “are you a dyke?” you know and then getting into all kinds of things outside of that.” (Mary, interview 3)

In the case of Judy, who had not been out to her family and work colleagues she struggled with defining her sexuality:

> “I just say I’m gay. Just you know, yeah…Yes, I just, I don’t know if I see myself as gay or whether I just see myself as me really. I don’t.” (Judy, interview 5)

For some orientation and identity was created through partnership. Being with a woman means you are orientated to women and therefore you are given the label gay woman or lesbian, but it is not an identity you claim for yourself, it is in relation to another. Gail explored this in relation to how her partner referred to her own sexuality.

> "I mean she's never, she was married. I don't think. And I don't think she considers herself to be lesbian. No she has the view that it is the person you fall in love with. Obviously, she says "I am a lesbian because I'm with you" and that's you know. But it's more fluid I suppose you know, it's the person you're with and the person you fall for. It doesn't matter whether they are male or female. It's the person you fall for." (Gail, interview 2)

All the participants stated they were women, but some became confused with this question and instead spoke of their sexual identity. It would be interesting to see whether this would be the same if the interviews were repeated now following the dramatic increase in the anti-trans rhetoric across popular media, and the pronouncements and expressions of gender, particularly pronouns, becoming a more widely recognised phenomenon.

Realising I was gay.

These stories focus on the participants realising that they were gay and how this impacted on their life. Realisation came at varying points in their life, for some, like Tracy, it was very early, and it was always a known factor about themselves,

> "I don't know really. I just knew. It was just who I was attracted to I suppose. I just knew once I left primary school and went to secondary school there was never a doubt in my mind I just knew then yeah." (Tracy, interview 4)

For Kate it was a gradual realisation during her twenties, when she began feeling attraction towards women. Whereas for others like Melissa, it was a gradual realisation over an extended period and through several heterosexual relationships. Gail, however, tells of knowing about her sexuality for a long time but not being able to start exploring this aspect of themselves until they were much older.

For Carolyn, like Tracy, the journey to realisation might be considered a more recognisable narrative, but unlike Tracy, Carolyn dated boys during school, primarily to mask her sexuality from herself and those around her, particularly her parents.

> "Ever since you're aware of something. I think from the age of 12 probably. But I went through a long time of denying it to myself. I dabbled in boys but realise now I was just kidding myself. I don't think I even had a boyfriend until I was about, at 6th form college, 16/17. I then came out to myself and then I was still at 6th form college and playing cricket, they had a girls, ladies

> cricket team. I was really into my sport, loved my sport. In fact, I put more time and energy into sport than work. The head commented on the report (laugh). There was a girl called S on the cricket team and she sussed me out because I held the door open for her.
>
> **Oh right**.
>
> Yeah, luckily. So, she was my first girlfriend and it just went on from there really. But I was completely secretive at home, completely in the closet at home for years really. I was quite a moody teenager. Most teenagers are though.
>
> **Yes I was going to say that sounds normal.**
>
> Yes, so I had a happy childhood, but I had this big secret. I was quite terrified of how it would affect everyone. So, getting away from home I felt free and was able to live my own life a bit." (Carolyn, interview 6)

Carolyn's story also resonates with Mei's experiences even though they were on different continents. Mei speaks of coming to terms with her sexuality in high school in the USA and during her nurse training in the UK. There is a familiar story of knowing very early about their sexuality but dating boys as this was the expectation.

> "I knew really that I was gay really when I was at high school. When I was about sort of 15. And I had this massive crush on a girl a year older than me. So that's when I first realised. And then life takes over doesn't it. You grow up. You go off to college or whatever path your life takes. And in my nurse training I initially went out with blokes and then towards the end of my final year of training I developed this huge crush on one of the sisters, the junior sister on the private ward at W. So, Karen and I, and I remember chasing her. Oh, it's terrible. And Karen and I got together, and we were together for 5 years." (Mei, interview 3)

Melissa's journey towards partnering with a woman was rooted in a lifetime of childhood abuse and trauma, sexual assault, and coercive relationships. Melissa and her sister were victims of violence within the home. On turning 16 she left home and moved in with a "biker" who subsequently married her sister. She continued to form relationships with men to rebel against her mothers wishes and continued to experience violence and coercion within these relationships:

> "Yeah, as for growing up, kind of went through men like there was not tomorrow. I got married at 18 to a 36-year-old. I should never have done it. I only did it to piss my mum off because she said I couldn't. It lasted all of about 18 months. Yeah, and then just different relationships one of which was with a violent alcoholic. It took me 4 years to get away from him. He put me

> in hospital god knows how many times. Yeah, it was a pretty messed up time. Eventually managed to get away and met what would then become my second husband. Married him in 1998 when I was five and a half months pregnant."

During her marriage she was raped by a "friend" and then blackmailed into not revealing this. This, she states was the turning point for her in recognising that she may always have been gay but had never acted on it due to social stigma and internalised homophobia.

> "Basically, kind of the last five years or so of the marriage I wasn't happy. I think I've known deep down all my life that I'm gay but never did anything about it because of the stigma that was involved in it, I think more than anything. And I think looking back on it now, that's probably why every relationship broke down. And I think what became the turning point was three and a half years ago I was raped by someone I classed as a friend. And that basically signalled the end of my marriage and the end of me ever wanting to be with a bloke again really. My ex-husband still doesn't know. Because I don't know why. I think it was part of the shame of it happening and there is no way that, basically he blackmailed me and said like, you know. Because we'd had a friendship but it was becoming more than that so there was a lot of sexting involved and things like that. And he basically said that if you say anything I'm going to show your husband all these messages and everything and that will be it. And at the time I didn't want to risk the marriage. As much as I knew I wasn't happy in it I didn't want to do that. So I didn't say anything to anyone but it ate away at me… But I think that was probably the turning point that made me realise that actually this isn't the life I want. This isn't who I am. And all through my marriage I couldn't be who I wanted to be. Couldn't be who I was. When I'm out with friends I'm quite bubbly and outgoing and I wouldn't say I'm centre of attention but I'm fun to be around. And yet at home I as completely different. I was the meek, mild housewife. As soon as he walked in the door dinner was on the table, housework was always done. He didn't like that side of me. He didn't like the outgoing side of me, so I reigned it in. And I'd done it right from the beginning but never actually realised until later on in the marriage that that is exactly what I was doing and how controlling that was. And then once I'd start realising that there is other little things that then start popping up like you know having to ask his permission to go out and things like that."

Then she entered her first same gender relationship and it changed everything for her, offering a freedom to be herself that she had never experienced before.

> "And then I met Partner1. That changed my life. She started working at our place and there

> was an instant friendship there. It was an instant connection that I couldn't even to this day, I can't explain. We just started off as friends, literally just started off as friends, going for a fag together in the mornings and putting the world to rights and all that sort of stuff. Within about a month or so, bearing in mind I hadn't actually been with a woman up to that point, we started sleeping together… I was so scared that first time. So scared. That changed my whole perspective on everything really. I suddenly felt where I should be. I suddenly felt right, and this is who I am. And I could be myself. I didn't have to pretend anymore. I didn't have to you know, just try and fit in for the sake of fitting in." (Melissa, interview 10)

Melissa's story particularly pushes back against the misogynistic, heteropatriarchal claim that women only enter same gender relationships to avoid trauma and that they just need to "find the right man". Melissa knew she was gay prior to her entering a gay relationship but was prevented from doing so by the social and political stigmatisation of lesbian relationships when she was growing up and into her early adult years. The trauma did not trigger her to "become gay", being gay was always already part of her, being a survivor of gender-based violence provided an opportunity to re-evaluate what was important to her and explore a different type of relationship that she was already psychologically open to.

For Gail, her narrative again spoke to the impact of social condemnation about homosexuality, feeling she had to hide who she was and take on the expected female role in society; to get married and have children.

> "I think I was coming up for 40 and I think I realised that actually this isn't what I want. There is more to being a fulfilled person than this. But having said that I mean I'd known him since I was 10. We'd been together since I was 17 and I would say that I, you know I am a lesbian. I've always known that I was gay from as long as I can remember being a little girl you know, having crushes on different women but I did fall in love with my husband. I can't make sense of that… Well, I just always knew I was different, and I didn't know at the time when I was growing up. I didn't know any lesbians or gay men or anything really. And as I got older the only gay women you did see were very, very butch that looked like men. And that didn't make sense to me either, because I didn't want to be a man and I didn't fancy somebody that looked like a man. I fancied girls. So that was a bit confusing. And I just buried it I suppose all the way through…Yes and for the secret not coming out I suppose. Because I'd gone into you know I'd got married and had children. Well, I was pregnant before I go married. It kind of just unfolded around me if that makes sense.

> **Was there a kind of sense for you that to get married was kind of the thing that was to be done?**
>
> Yes. Yes, that's right. But I mean I can't say there was a great deal of pressure on me from anybody other than the pressure I put on myself I guess." (Gail, interview 2)

Dating men

For some of the participants their journey towards recognition involved ending relationships with men, sometimes in very painful ways. Kate explains that her partner at the time was very supportive of her exploring her sexuality but eventually she felt she had to end the relationship as they wanted very different things from their lives.

> "And I said look I think I need to go explore the world, so I didn't know if I was bisexual then. So, I went out and saw lots of women, bisexual women, lesbian women and throughout that time we then split up, me and Steve split up. Because he was trying to support me, he said "look I'll still be here if you wanna go off and do whatever, I'll still be here for you". Which was so sweet, and I did love him, but I wasn't in love with him. And it didn't feel right, and I didn't want to hold him back and I knew he wanted children, and I didn't at that time." (Kate, interview 1)

Gail also makes it clear in the interview that despite knowing she was gay from a young age she did fall in love with her husband and that caused her some confusion.

> "I did fall in love with my husband. I can't make sense of that." (Gail, interview 2)

Judy's experiences were ones of dating "mates" but having no physical connection.

> "I had lots of boyfriends but never got physical with any of them and had lads that wanted to marry me because I guess I was like one of the lads, good fun. I just saw them as really good mates. You know I didn't really see them as boyfriends and all this funny business that goes on." (Judy, interview 5)

Mei spoke of dating men to hide her sexuality. At the time she was in the army and being gay was not permitted so having a smoke screen prevented her from being discharged from the service.

> "And in those days, you could be kicked out of the army, so I used to go out with blokes then periodically purely as a smoke screen. Not because I'd thought "oh I think I'm going to be a bisexual. I think I fancy trying that for a few years now. Self-preservation really. Because it's just so boring isn't it with a bloke. A twiddle here. "Was that good for you?" "Yes, okay thank

> you". So, it was purely for a smoke screen point of view and obviously some people that were very, that I was very close to knew but I could count that on less than one hand." (Mei, interview 3)

Carolyn and Samantha had dated boys during secondary school but once they went to university, they were more able to explore same gender relationships and never returned to dating men.

> "I dabbled in boys but quickly accepted I was just kidding myself. I don't think I even had a boyfriend until I was about, at 6th form college, 16/17." (Carolyn, interview 6)

Time to come out.

It is well documented that coming out is never a single event, but something that people in the LGBTQIA+ community navigate daily, making decisions that affect their interactions at both a macro and micro level. However, the trope of the "coming out" narrative normally refers to the first time a person tells those closest to them that they are lesbian. The following are the experiences of "coming out" that the women in this study shared.

The women in this study present a variety of narratives in their coming out stories all of which are well recognised within the literature. Several of the participants came out later in life after being married and having children, their journey was often led by a need to conform to the socially acceptable norm of marrying young, having children and being a good wife and mother, this did not involve them exploring their own sexuality and making choices to partner with a woman.

> "it was just automatically assumed that you would grow up and get married to a bloke. And I think that, it wasn't like something that was conscious there, I think it was always that kind of, not worry about how people would react but more of a case of it's not who they know me as." (Melissa, interview 10)

These stories were told against the background of knowing they were gay or acknowledging a difference within them about their sexual desires. Lack of fulfilment in their heterosexual relationships was forefront in the telling of these stories. Then discovering their true sense of self when they began to form relationships with other women and groups of women, some of which identified as gay or lesbian, opening an opportunity to explore and examine these, until now, unexamined desires. Gail for example found that through her membership of a women's football team she was able to socialise with gay women and begin to question her sexuality and her relationship with her husband. She tells of how she always knew she was gay but that it was expected that she would marry and have children. She recounts that during her marriage she would often develop strong female friendships but then sabotage them when she felt they were becoming too intense, protecting herself and masking her sexuality.

> "And what I have, what I know I've done is through the years I've got friendly with people, with girls I got close to and my feelings have become more than they should and obviously they are in relationships or whatever. So what I've done is then I've then been very cold and cut them out. And I think I've been quite horrible to some people over the years because I've not been able to say to them "actually I've got feelings for you and this isn't right. I shouldn't have feelings for you" and you know. And so it's easier just to say "ok". You be horrible to them and then they walk away from you don't they." (Gail, interview 2)

Her relationship with her husband transitioned into more of a friendship rather than a partnership and they drifted apart. At this time, she sought out the company of other women and in particular gay women. It was here that she first explored her sexuality having several brief relationships with women, some of which were problematic and challenging. But as Gail told it, it was an opportunity for her to come out as lesbian.

> "Well, that happened because I had a fling with one of the other girls on the football team. One that was quite a bit younger than me and barking mad really, she was. But it was a way of because I remember sitting down with a couple. Because there was quite a few of the girls in the football team that were gay, and I remember all this had gone on and like I say I'd gone off the rails a bit. I was going out and getting drunk and different bits and pieces. And I'd split up with this girl that I'd had the fling with, and we were sat round, funnily enough round at [P]'s with another two couples that were together, gay couples. And they said something to me about "what did you think you were doing?" So, I said, "it was just um" It was a way of coming out really I suppose. It was an easy way of coming out". And because they all knew what she, what this girl was like. They said, "oh god, you could've put out an advert in the paper". You didn't have to put yourself through that." (Gail, interview 2)

Melissa speaks in a similar way about her coming out, of starting a relationship with a woman that then led to disclosure to her family.

> "So, I only came out 15 months ago. Well, it wasn't kind of a full on "hey I'm gay!" It was more of a case of everyone at work knew that I was seeing [P]. My closest friends knew but other than that I didn't really broadcast it. I didn't tell my mum until just before Christmas because she had been diagnosed with cancer the week before I did. My oldest sister is gay, and I know how my mum reacted to that so I thought the longer I can keep it quiet the better and knowing

> how mine and my mum relationship has been. It's been very on, off throughout the years and gone many years without talking sometimes. I didn't really want to go and have that conversation with her. The rest of my family have been absolutely brilliant. My nan and grandad were just like, whatever, you are who you are kind of thing. None of them were shocked because I have always been a tom boy anyway. I think they have always seen it wasn't really who I really am to be with blokes and what not. So yeah, none of them were particularly shocked and when I did tell my ex-husband I said "oh just to let you know I am in a relationship with a woman" and he was like "oh I am not surprised." So yeah, my mum when I did eventually tell her I'm like "just to let you know that I'm in a relationship with a woman" and she's like "oh right". She didn't really do much by text she didn't say much by text but when I actually saw her it was like going through the Spanish inquisition. I got the, you know, "have you been gay all your life?" and "when did you know? When did you, what suddenly made you come out? Was that the reason for the end of the marriage?" and all that stuff. These aren't questions that are easy to answer because although I think deep down, I have known that I'm gay probably most of my life, because I have never acted on it, it's hard for me to tell when that realisation actually started to manifest. Because it must have been there before I started seeing [P] and quite strongly otherwise I wouldn't have gone down that route. But yeah I don't know, I don't really know, because although I find certain women attractive, I find certain men attractive so for me it was always kind of just a normal thing and it wasn't until I started getting into a lesbian relationship that I started to look at how I perceived things and the differences between them and it's almost like I've suddenly got a gaydar now" (Melissa, interview 10)

There are several key narratives appearing in Melissa's story that show the complexity of navigating a coming out journey. Here Melissa speaks of her mother's questions that lead her to question whether she has always been gay and why she is only just acting on this. This period of self-reflection acts as a solidifying moment for Melissa. Here we also see the relation of gender expression to assumptions of sexuality that are made by loved ones, particularly the role of the "tom boy".

For Mei a significant coming out story for her was when she shared with her now wife that she was gay, in response to her wife attempting to set her up with her brother.

> "We were going somewhere, and A was in the car with me. And she was going on about, and her brother's home on leave and "I must come round and meet Paul. He's ever such a nice man you know, and you'd really love him". And in the end, I had to pull over into a layby and say "now A" I switched the car off "now we need to have a little talk. There is something you

> need to know. I'm gay. So I'm just telling you this because" along the lines of "you are desperately trying to get me off with your brother and it ain't gonna happen" sort of thing. She went "oh, well that explains a lot then" And I said "sorry" She said "because I've been having these really strange feelings. I feel very unsettled, and I have got a crush on you and that explains why" She had obviously been picking up on my vibes that I didn't even know I was sending out" (Mei, interview 3)

Mary spoke of some of the difficulties coming out and choosing who to tell, firstly, in relation to her work as a music teacher and the potentially homophobic reactions that some parents may have had towards her. Secondly, in relation to her partners' reaction and the impact that may have had on her custody of her children. Although other participants were parents no one came out when their children were young. Mary's daughters were 3 and 6 when she split with her partner in the 1980's at the height of widespread anti-gay propaganda, Section 28 (LGA 1988), and the HIV and AIDS crisis. There was a real and present fear that she could have lost custody if her sexuality was ever made public.

> "Yeah, that's right. It was just a kind of natural thing really. I mean they'd be people I wouldn't talk to about it because it was none of their business particularly. So, there might be people at work. Lots of them knew but then they'd be others who I didn't have that kind of relationship with that I wouldn't talk to about it. I was also teaching, doing some music teaching. So, kids coming here and doing piano lessons mainly and I did feel a bit funny about how people would feel about you know. Because when you're straight everything is normal, you're just so normal. Everything's just taken as you're a normal person. So, but when you're lesbian you're strange and perverse and different and how people would feel about their kids coming here and you know. Would they be safe and all that? I was worried also about their dad trying to take the kids away and that. Because things were different then. It could've happened. It could've happened if he'd been more together. So, I did feel quite I suppose insecure in that way.

Not everyone got to choose when to come out. Mei recounts a story of the reaction of some nursing student colleagues to the revelation about her sexuality, referring to "when it came out", therefore not being a choice, she makes.

> "And I remember when it came out that I was gay and there were a couple that I had thought were friends in the group and this was probably, this was in my final year. So, we'd gone through hell and back all of us together. So, the couple that I thought were really good friends

> were absolutely horrified and the one person who I was friendly with who I thought, there were two, two that were friends. We'd go out drinking, but I wasn't as close to them. One was an Irish catholic and one wasn't. Susan and Breda. Susan was the catholic, the good catholic girl. But she wasn't. They turned round to these other two, who were talking about me behind my back and were absolutely horrified that I was a lesbian and that was it, they didn't want to have anything else to do with me and Breda and Susan rounded on them and said "how dare you treat her differently now you find out that she's not into men after all. She's the same person. She hasn't grown a second head over night. You're the ones that have got the problem, not her. And she thought you were her friends. Well, that's just disgusting that you can just do that to her" And it was through them that these two then changed their whole opinion and thought "yes, we were in the wrong. No, she hasn't grown a second head. No, she isn't suddenly treating us differently and trying to hop into bed with us or whatever" Because I think that's what the fear is. "Oh god. You're a lesbian. Oh, I'm not safe anymore". (Mei, interview 3)

This story also speaks to the well-rehearsed fear that all lesbians are predatory and sexually desire all women. This fear is grounded in the historic homophobic trope that lesbian women are trying to be men and as all men desire sex, lesbian women will prey on and coerce straight women into having sex with them, therefore straight women are not safe in the presence of lesbian women. This was an experience that Mei had to contend with repeated times in her life, even within her professional life, where she was not only forced to come out but also to defend herself from homophobia.

> "Because I think that's what the fear is. "Oh god. You're a lesbian. Oh, I'm not safe anymore" And I have actually had somebody sort of and it was a work colleague years ago who wasn't a particularly well liked member of staff anyway and she and I always, because she was lazy, workshy, would palm off what she could to everybody else so she had minimal to do. And she and I were always having set-tos because she was quite nasty to members of staff as well. So, I'd pull her up. And she took it on herself to tell a new member of staff once that they oughtn't to find themselves shut in the storeroom with me because of course "she is that way inclined, and you might not safe". And then Heidi this new member of staff went "are you a lesbian?" And I went "I prefer the word gay but yeah" "oh" I said, "is that a problem." "Absolutely not. But Sandra has just warned me" So I said, "Sandra can I have a word?" So, we had a word and I said "I don't know what your problem is. The only thing that I can imagine is that one of the problem other than I work and you don't is that I haven't made a pass at you. But rest assured if that is what your problem is with me you best get over it because I'm never going to make

> a pass at you" sort of thing. And I said that once or twice in my working life to people "Why are you being so obnoxious because of my lifestyle choice? You are not in any danger. I'm not going to make a pass at you because you're not my type or" (Mei, interview 3)

Both these experiences also include examples of people pushing back against homophobia and acting in allyship with the lesbian person, in the first example, other colleagues took it upon themselves to stop the continuation of the homophobic conversation, calling out the discrimination; and in the second example there was a move away from colluding with the homophobic person and distancing themselves from those views. Both of which offered Mei a sense of safety and belonging. These types of experiences are commonplace for LGBTQIA+ people and it is one of the key narratives within the study where I experienced resonance with the participant, being aware of homophobic conversations that targeted me, engendering a sense of "not being safe". The difference for me is that I was not out at the time and there was the added complication of someone discovering my secret.

For the participants who came out earlier in their life the significant narratives were in relation to telling family and their subsequent reactions, mostly positive and supportive, or as in Kate's experience offering a narrative of "already knowing", that this was not a revelation to them and that due to gender expressions as a younger child they had suspected this.

> "It was a gradual process. Yeah, and when I did, I didn't know how to tell my dad. Um, I had a sister and I told her when I was very drunk, and she went "Oh! That's alright, I always knew you were and la-de-da-de-da". And I think she was initially quite shocked um, but she said, "oh you're still my K K" and everything else but I think when she actually had time to think about it she was a little bit undecided about how she felt but she's fine now, she's absolutely fine now. My mum when I told her she was like "oh well I always thought you was from the age of 11 because I was a tom boy", but you know they put you in little boxes don't they parents. Well, you must have been gay if you was a tom boy I think, I didn't know I was gay at 11, I don't know what makes her think that but anyway that's what she said to me. And my dad. My dad really never spoken about it. He's never said "when did you think you were gay" he's never asked me specific questions about my life he just accepts that I'm with a girl." (Kate, interview 1)

For Carolyn she chose to write a letter to her parents to come out after much deliberation.

> "So I think I also wrote them a letter. Someone had encouraged me to do that. So, it was a tough time for them. Mum wasn't surprised. She's sussed out when I was with S. She sussed that out but sort of implied she hoped it was a phase. Dad who's a proper English gentleman

> and doesn't do. Mum's a nurse and talked about anything and he doesn't talk like that or can't deal with this sort of, anything embarrassing. So, I tell him that I've got a girlfriend and he said "right, but are you going to do your teacher training" (laughs)
>
> **Excellent. A bit of pragmatism going on there**
>
> Get rid of that, I can't cope.
>
> **Yeah we won't talk about emotions or anything.**
>
> So although I was out to them I was still, probably still quite secretive because Mum was quite upset. But now they're absolutely amazing. They absolutely adore P. And it was just that initial rickety bit of everyone getting used to it. And then there's that sort of that, they were of what Town and what their friends would think. But yeah, as you know things have moved on so much and now if we're both of us are with Mum and Dad in Town and Mum's a Quaker and we both sometimes go along to the meetings and Mum will proudly introduce P almost for a reaction, Carolyn's wife. So rocky sort of coming out period but absolutely amazing how everyone is." (Carolyn, interview 6)

Sabrina's coming out story reveals multiple examples of heteronormativity and homophobia. Sabrina was in her early twenties, finishing her degree and already in a relationship with her now wife when she made the decision to tell her family she was a lesbian. Her parents had already met her partner but had thought of her as "just a friend" and she had been invited to multiple family events and holidays. One holiday stood out for Sabrina as an example of her father's inability to see two women in a sexual relationship whilst also guarding against any situation that could lead to two men being in one, highlighting the invisibility of women and in particular, lesbians.

> "I know I went sailing and I'm not sure if it was in '87 or '88. And P came along as well. So, it's possibly, it must have been '87. So P and I went to Greece together and then we came back and then we must have gone on holiday and we sailed on the boat with my dad. He had no idea. I'd forgotten about that. And then in Turkey. And then he, we left him in Izmir or somewhere and got on the bus and I remember him saying to P "thank you for looking after S". And I remember getting on the bus and saying to P "little does he know what's going on". And then that's it, I mean there were all sorts of really crazy things that. Because we were on a boat that it was a 6 berth boat and these two boys or young men, one of them was called FN, and his friend and they were living in Italy but they were from the States, and FN was a friend of my father's good mate who, they worked together and he'd come out with his friend to stay in the boat and my dad, we were already on the boat before they arrived and my dad

> was saying “oh well two boys they are going to have separate bunks but you two girls you can have the same bunk. That will be all right” So it was just, um. I mean in way I just felt awful that I was so deceitful but then on the other hand what else, what do you?”

Like Kate, Sabrina told her brother first and like Kate’s sister, he professed to already know based on a previous conversation they’d had about the rights of women.

> “Anyway so, but when I did tell my brother eventually I told him and he said he knew anyway and I said “what do you mean?” and he said that conversation that I’d had with him when I was having my 21st birthday which wasn’t anything remotely to do with, I was talking about the ability or the right of a woman to choose who they wanted to love, I think that’s what the conversation was about and their sexuality. But I wasn’t necessarily referring to myself. But he thought that it meant me. So, he thought from then.” (Sabrina, interview 7)

Feeling that she could no longer keep her relationship with P secrete Sabrina decided to tell her mother she was a lesbian and in a relationship with the person they had known as her friend. Taking her mother out to lunch to break the news the conversation quickly affirmed heteronormative assumptions that any news that needed to be broken was about pregnancy. But then the conversation turned to protecting her father from the news and continuing to maintain the pretence and secrecy that had been troubling Sabrina. Sabrina’s mother feared that her husband would not be accepting of Sabrina and would break relations with her. Indeed, when her father did find out there was family conflict lasting for over 20 years with Sabrina being blamed for an escalation in her mother’s pre-existing mental illness. A guilt that Sabrina carried with her all her adult life.

> “Um. Oh, I don’t know now. It’s a long time ago. But when I came out, I decided I’d been living a secret life for too long and it was becoming too complicated. I just didn’t feel comfortable, so I thought I’d tell my mum. And she thought I was going to say that I was pregnant, and I think I took her out for a meal and then she said don’t tell my dad. And I said no I’ll tell him. I couldn’t have her having to sort of deal with the secret. And so, then that started a good 20 odd years of real problems. Within the family. And my father just refused to accept me. Well, he was OK for me to go home but he wouldn’t accept P, my partner. And so, it was just awful really. And then my mother, through her life, she’d been very ill with manic depression, what they called then. And then I was told it was bipolar affective disorder. She’d always thought she just had depression but all through, I mean I was hospitalised with her when she was very ill. So all my life I remember that. And so yeah, I got blamed by aunt because of coming out

> that I caused one of mother’s episodes, so to speak, now if you call it an episode. So yeah, thinking about it, it was not that straight forward…
>
> There was no way after I’d told my dad about P that was it. She wasn’t allowed anywhere near the house or to any family events or anything like that. And I was always like, well to everybody in the family, if you’re going to invite me you have to invite P as well. And it put them in a difficult position because then they had to make their minds up as to whether then, you know, did they want me to come and did they want me and P or would they prefer my dad. Because my dad wouldn’t go if, or there would be a problem.” (Sabrina, interview 7).

The key dissenting narrative was Judy. She never officially came out until she was diagnosed with cancer, when she introduced her partner as such during a consultation. During her life she had never told co-workers or straight friends she was lesbian although she never tried to conceal it either. She maintained lesbian relationships and had a lesbian social network but had never officially lived with a partner until her cancer diagnosis. She never spoken openly to her family about her sexuality, although she suspected her parents were aware, and kept it an open secret that was maintained throughout their lives.

> “Dad very “you bloody poofs” Mum just go along with it. So, it was never ever discussed while they were alive. We never discussed it at all so. I’m sure they knew but I didn’t like to rub it in their face. And I don’t like it being rubbed in anyone’s face to be honest. We’re just who we are aren’t we. I didn’t really know, we’re not anybody but just somebody…
>
> But I don’t think I ever really come clean about it. I never came clean about it at work. People just accepted me for who I was. People knew that I’d. I never really felt the need to tell anybody. And I didn’t need them to tell me they were straight, or they were gay. So, I never, I thought well you take me for me. If you want to ask, then ask but I never offered. They all kind of knew that I did those things with girls, and they used to say “you lot get up to all sorts” you know “you have a good time”. So I think people saw me as, as long as I’m having a nice time. Because I’m cheeky. I’m mouthy and you know I enjoy male company. I’m not er, I don’t want a boyfriend, but I enjoy a male company. I still play darts with the men on a Wednesday. They know I’m gay, but you wouldn’t think that they, you know, they’ll still grab me and you know. And I don’t. I’m just me. I don’t like to put it in anybody’s face.” (Judy, interview 5)

As with all other aspects of each woman’s lives in this study, the coming out stories I have presented here are as unique as the women are. However, time seems to be a key factor. For those coming out in the eighties and nineties there was greater fear and rejection, reflecting the political climate, and for some like Sabrina it triggered years of conflict within the family. Whereas, for those who came out later in their life and more recently, the journey reflects a more accepting narrative and one of not being surprised. To quote Gail "At one point it was almost trendy to be a lesbian."

Exploring sexuality

All the participants told stories of exploring their sexuality when they first questioned their orientation or came out. This often involved one-night stands or relationships that they now question and consider problematic. They were questioning their attraction and seeing if the new identity fit them. As well as liberation there is also a sense of pushing boundaries, pushing back against expectations, not wanting to conform to the heterosexual narrative they had been told was the correct way.

> "I was a bit of a mess when I split up from my husband and I had several flings with different people" (Gail, interview 2)

> "I had crushes on all the wrong people. And that is how I was in my younger years. If anyone was basically gay, then even if it was probably the wrong person for me I'd end up with them… Massive dyke drama." "And they let me in [to the club] and then I got picked up by this woman called L who it turns out she was pretty much married to another L and they were both prison officers but she claimed she wasn't very happy at that time. So, we had a bit of one-night stand. So yeah, ticked that box. And that was probably and definitely my first dabble into the gay community." (Carolyn, interview 6)

> "I was working in a bookstore, which I used to have a Saturday job in. And there was a member, two members of staff that were gay, a male and a female. I didn't really come out to them either even though they were there, you know, it was like deep seated within me. And then as a sort of work outing, we went to a club, a gay club. And kind of on the way to the gay club I told everybody that I might be. And then I sort of met someone there, although it was more of an opportunity to actually just be with a female rather than me actually really like her, So I was, yeah, but yeah that was my first adult experience. We stayed together I think maybe about a year but that was only because what happened was I was like, this is fun and free and sort of thing like that" (Samantha, interview 8)

> "my sexuality was sort of changing, I started liking women. I kept fanaticising about women the whole time so I was like I'm not sure what I'm doing here. Um, obviously we had set up a house and everything, we were together for a long time… So anyway, I was off exploring the world, the bisexual world and the gay world and um I sort of hitched up with this girl and me and Steve had split and it went from there really. And then I've been in about 1,2,3,4 four

different gay relationships now. Um and now, I had a split, I was on my own for about 3 years after some unsuccessful relationships (laughs) and then I met P and I've been with P for 10 years." (Kate, interview 1)

"And then I suppose the very first, I don't even know to be honest. There was one woman when I was in France doing my course. I was teaching English as Foreign Language. I was kind of helping in schools. I remember this woman and I thought she was amazing. Nothing ever happened but I did remember thinking that I wanted to be near her, I wanted to be close to her. So maybe that was my first sort of realisation that perhaps I was attracted to women sexually." (Sabrina, interview 7)

"Well, I felt like I didn't. I felt like I wanted to try it out. I wanted to experiment. And I kind of waited until we separated to do that, yeah… I worked with lots of lesbians who thought it was wonderful and I was teaching carpentry and some of my class were kind of "yeah go M" you know… As a lesbian I've decided "actually sexually I'm not interested in men anymore. I say goodbye to that little box you're trying to put me in there. So, I'm going to create my own space here where I feel comfortable" (Mary, interview 9)

Lesbian relationships; dyke drama and perfect partnerships

At the time of our conversation Melissa was in the throes of her first lesbian relationships, a tumultuous and complicated situation. She was dating two women, one of which she professed to be the love of her life and the other was the breakup relationship, but also the person she had gone to following her cancer surgery. The emotional roller coaster Melissa was riding was clearly visible in our conversation and spoke to the intensity of lesbian relationships often portrayed in fiction in particular, a definite dyke drama as she called it. But within this story is the total affirmation of her identity as a lesbian. Confirmation of everything she had ever considered about her sexuality.

> "It's all ever wanted. I've never experienced feelings like this before ever. It makes you wonder if you ever have actually been in love before. And it's not just the lust side of it. It's everything. Just being with her and watching telly. I'd never felt so content in my life just doing nothing. It's an amazing feeling. It's bloody scary, bloody scary. But it is the most amazing, and words, you can't put it into words. There aren't words to describe it. It's all consuming, totally. And I doubt I'll ever feel like this about anyone else again. As far as I'm concerned why waste it. And she feels the same so fingers crossed… To be honest I didn't question it. It was just. I was so scared that first time. So scared. That changed my whole perspective on everything really. I suddenly felt where I should be. I suddenly felt right, and this is who I am. And I could be myself. I didn't have to pretend anymore. I didn't have to you know, just try and fit in for the sake of fitting in. And once I realised that it was kind of like whoa, ok. So that was about 15 months ago. Then we split up and it completely destroyed me because I'd fallen in love, big time, fallen in love. Like to the point where I'd never experienced feelings like this. And everyone sort of says to me "oh well it's your first woman. It's always going to be the special one" But it was more than that. It was so much more than that. In that time that we split up she got engaged. I met somebody else through Plenty of Fish and started a relationship even though my heart wasn't in it and really shouldn't have done. Because I knew it was just for the sake of doing it. She lived up in Essex so I was spending every weekend up there and being down here during the week. And then out of the blue, I mean we were still messaging and friends, and obviously we worked together so it.
>
> **So, you saw each other regularly?**
>
> Yeah, which didn't help. Out of the blue I got a message on a Sunday evening saying "when are you home?" Just that. And I'm like "well probably not till late. Why what's wrong? Shes like "message me when I get in" So I messaged her when I got home and I was like "what's up?" and she's like "oh nothing. I'm just obsessing over you at the moment. Just can't get you

> out of my head. I need to see you" and like it had taken me, I had a breakdown when we split up. Literally had a breakdown. I fell apart, totally, and utterly fell apart and swore blind that I would never feel like that again. I never wanted to love with that intensity again if that's how it made you feel. And I'm like "oh right ok" Mixed emotions going on. It's like "I've come this far but I'm still in love with her"." (Melissa, interview 10)

When I left Melissa that day she was considering her future with both women, trying to work out who was the right person for her and what her next move needed to be. She was living through an incredibly emotionally challenging period on top of dealing with a very recent cancer diagnosis and a failed treatment. Her emotional wellbeing was being tested to the extreme and we had just spoken about some of the darkest moments in her life. Leaving her felt like I was leaving someone in crisis but also someone who had created a support network of friends and family around her that she was actively drawing on. I was aware that she was in contact with her nurse specialist and counsellor, so felt safe in leaving her, but this was the closest I came, during the study, to questioning my nursing role in supporting someone's wellbeing and my role as a researcher wanting to explore lived experience. An ethical question that still troubles me today as I am writing this thesis, the very real prospect of causing harm or at least adding to distress. The only answer I can offer myself is that I felt I had offered support during the conversation, I had listened attentively to her story, and I had ensured she was supported at the end of the interaction. I recognised that Melissa had the capacity to stop the interview and as an agentic person could make decisions for herself to carry on or withdraw from our conversation and she chose very clearly to carry on.

More commonly within the conversations participants spoke about the differences between lesbian and heterosexual relationships and highlighting the benefits of being in a relationship with another woman, in particular sharing domestic labour or the constant emotional support.

> "there's a very balanced relationship. You know, we do what we want to do, and it just so happens that. But you know the better person does the job rather than it falling to the person who's not so good whereas it's so unequal, well you know, generally in a heterosexual, it can be, you know the women are doing all the shopping, all the cleaning, all the cooking, all of that as well as working full-time… And they talk about their husbands in really disparaging ways and I just can't imagine how awful that must be, that you're in that, you know that relationship where you know, it's hard work. And then all that time that they spend at work talking about their husbands as well, sometimes I feel a bit left that I kind of think "oh I've got nothing to offer" but then I actually don't really want to part of that because it's so negative. It's not fun, It's miserable listening to their banter. And it's very sexualised banter as well

which is awful. I can’t stand it sometimes. And I just think it is so unkind. So you know I don’t want to part of that. No way.” (Sabrina, interview 7)

“She totally gets me. And if I’m having a bad day I don’t need to say it, she knows. She knows me so well and I know her well. But, she’s been my absolute rock and when she’s been through this and she’s been by my side it’s made us even stronger.” (Carolyn, interview 6)

“Yeah she has been a rock really. She’s been, she supported me emotionally and also physically so would always be there. So a lot of the time she’d, I’d be doing something that I shouldn’t be doing and it was like still doing the washing up or something and she could tell that I actually shouldn’t be doing it because I’m just clearly too tired. And it would be like “go and sit down and I’ll do it” So yeah just taking the brunt of, just looking after me, so emotionally and physically. Emotionally very, very a lot. Yeah. She’s amazing.” (Samantha, interview 8)

Family strife

There are various stories of family within the participants interviews, most containing some degree of conflict and move to recognition of identity and a fragile sense of "acceptance", an acceptance offered by family members that is based on a required move rather than an open embracing of difference, being seen to do the right thing. This is often manifest in the relationship between the family of birth and the participant's relationship. For example, for Sabrina this was manifest in her father not accepting her partner being present at family events, and family having to choose between inviting Sabrina and her partner or her father. However, this changed for Sabrina after the death of her mother and she talks of coming to understand this as a manifestation of the relationship between her parents rather than as a specifically homophobic views.

> "But at the same time then things got a lot easier once my mother died. So, then I kind of put things into perspective and thought that a lot of the issues weren't anything to do with me and my sexuality. It was more to do with my mum and my dad and how they clashed over different things and how they understood things. So that was one way of looking at it. And the other way of looking at it was since, after my mother died, my father no longer had anybody to do battle with so therefore he was able to accept things. I don't know." (Sabrina, interview 7)

For those participants who were partnered with or married to men prior to coming out as lesbian separation or divorce was part of their narrative and the impact this had on their children and wider family. For Gail this was very evident in our conversation.

> "He won't have anything to do with me. If either of the girls get married, I don't know what would happen because he won't have anything to do with me. Because we split up and then he kept begging me to go back and then we did get back together and then I, after about 6 months I said "no this isn't right. We can't make this work" So he was very bitter because he'd wasted another 6 months. That was how he saw it. He was very angry. I mean I have seen him. We've had to see each other over the house and the divorce and things like that. And he did tell the girls to wish me well when I got the breast cancer diagnosis. I think we probably should have remained friends. We should never have got married really. But no I did love him. I was in love with him." (Gail, interview 2)

The reaction of their children was also a concern; before coming out how would they react and after how would their relationships be affected? For Gail particularly her children's reactions to her coming out later in life was not what she expected, although they were accepting of gay people, when this was close to home and affected them personally the acceptance took longer to appear,

> “We did have a few problems when I first got together with P. D2 kicked off a little bit and [PD1] who is [P]’s oldest daughter, whose ages are similar, and they were the teenage girls. They were quite angry. I remember [PD1] saying to P that she, what was it? That she, [P] said to her “I didn’t think you had a problem with gay people” She said, “I don’t but I didn’t expect my mother to be one” or something you know” (Gail, interview 2)

Carolyn was her wife’s first lesbian relationship which started when she was married to the father of her children. They were aware of the impact this could have on the relationship with the children, both due to the divorce and to their mother coming out as lesbian. To support this transition and give the children time to adjust they took many years building trust between Carolyn and the children and delaying milestones in their relationship, not to cause upset and conflict.

> “I knew she wasn’t that happy in her marriage. So everyone thinks it was me, thinks I’m the big bad wolf, converted her. And then we had, because at the time, [son] was 14/15, living at home and there is an older daughter, [d] and they were both living at home with P. P had to sort her marriage out. I got out of my relationship with [ex P] and so we were seeing each other. It was basically an affair. And then once she’d moved out from, left her husband and I’d left [ex P], I was still absolutely adamant that kids come first and so I have my own flat, then she bought here, got divorced. But it wasn’t until [son] went off to university first, went to Southampton. P was basically, then we’d have date nights, would be Thursday nights. What they usually say about lesbians. What does a lesbian bring to the second date? A removals van. We had to put the brakes on. So, we’d meet when we could, and she usually spent Sundays with me at the flat. I got that. Then [son], I have nothing to do with [son] at all, he knew and understandably couldn’t deal with it because Mum’s always been with a man. And I get that totally. So basically, i didn’t see [son] at all and he got into uni. And then when he got into uni I was living here with P during term time then packed back off to my flat when he came back for holidays. And P, so that carried on for his 4 years at uni. Then obviously we got to the time when he graduated. P said to him I think about the February before he was due to graduate, she met up with him and said “look, Carolyn’s going to sell her flat and move in. This is how it is.” And he’s never ever once stayed with his dad. He’s just always been here. And then of course I was really dreading it. I was a bit anxious because I wanted it to work. But I just never ever took it personally. It was the situation rather than me. So, after he graduated, 2014 we had the situation where he was living here finally, we were all here under one roof.” (Carolyn, interview 6)

Heterosexism and Homophobia

A common experience across the participants was heterosexism, often occurring when in contact with service providers or work colleagues making assumptions about home lives and partnership status. This leads to a decision as to whether to correct the assumption made or let it pass. This is often mitigated by the importance and nature of the relationships, be they short term one off interactions which would not be corrected or longer term or frequent interactions that would be. Often this left the women in the study feeling angry that people had made these heterosexist assumptions and unseen in their lesbian identity.

Gail frames this as not wanting to embarrass the person who has made this assumption, but also points out that she has not experience overt homophobia or heterosexism so sees it is a genuine statement rather than done to cause harm.

> "But anybody else I don't, normally it doesn't come up. And very often they'll say, "What about your husband?" and I just say "oh well he's" and I tell then what P does but I don't enlighten them that actually it is not a man, it's a woman. Because I just don't think it is worth the, worth embarrassing them possibly really. I think I don't know, maybe I'm. Perhaps I'm a bit naïve in the fact because everybody has been so positive with us and everybody has accepted us or the people that matter have accepted us, I've not seen a negativity with people and obviously there are people that have been given such a hard time. But it hasn't happened to me" (Gail, interview 2)

Carolyn spoke about it as a learning moment for the person she was speaking to, correcting his assumption straight away and receiving an apology.

> "I had a conversation the other day putting P on my car insurance, and he assumed it was a husband. So hopefully he'll have learnt from that comment. He apologised and hopefully next time he won't assume anything when dealing with customers." (Carolyn, interview 6)

Sabrina also speaks of correcting people's assumption but feeling guilty for doing so. His niceness being a trigger for this guilt. But then she goes on within our conversation to question this guilt, causing a degree of cognitive dissonance for her in that moment.

> "Yeah, they are, the people who need to know, know and I put people right if they are making assumptions. I remember this one guy who was, he just assumed, and I thought "why would you assume that I am in a heterosexual, why would you assume that I've got a husband?" And he said "well". I don't know he had even thought, and I said "well, I'm not" and then that was the end of the conversation. He didn't know what to say after that. And then I felt really guilty

> because I'd kind of put him in a difficult position and then I thought afterwards "well actually you know" I mean he's a nice guy, he's a lovely guy. But the very fact that he'd not even bothered to find out was you know. And yet I sit and listen to everybody and listen. I am just that kind of person. I do listen and take and absorb and I'm interested in people but I also, you know, he could've, he's in the same job as me so therefore he could have been interested. But maybe he'd never spent any, but I know he's spent as much time with me as I have with him, so you know." (Sabrina, interview 7)

Samantha talks to the presumption of heterosexuality and to be recognised this presumption needed to be challenged.

> "And even back then people just didn't presume. They were, you were presumed straight unless you said otherwise." (Samantha interview 8)

Mary, coming from a unique position of being a leader in a male dominated profession, spoke about the difficulties women face within the construction industry where assumptions are made about sexuality from the opposite direction, and that all women working within this sector must be lesbian, making the astute observation that women are sexualised by their very presence in such a masculine framed work environment.

> "Yes, it can be. I've read a lot of studies around women in construction as you can imagine, from all over the world. And one quite recently published, "Gender and Sexuality in the Construction Industry" about how women are often assumed to be gay, you know, whether they are or not. And that can be difficult for both gay and straight women because you know, straight women would be like "actually that's not me but equally I don't want you to think I'm available in any way" It's all about, I think it's about being, because women are such a minority you're sexualised by your very presence." (Mary interview 9)

Homophobia was always looming in the background, in subtle and not so subtle speech acts, and in behaviours. However, there was the temptation to minimise this or to claim to be unaffected by such behaviour. Gail for instance was quick to dismiss the acts of teenagers in a public place, but focused on the homophobia expressed by a family member when her gay stepdaughter and her partner were discussing starting a family. This potentially speaks to the location of the act (home), and who is perpetrating it, family. Strangers can be dismissed as incidental, and as low risk of causing harm. Whereas when it is carried out by a family member, who should offer safety and support, the act is inherently harmful. Here she also refers to the thought that people talk behind your back, therefore homophobia exists and is perpetrated against you, it may not be directly enacted but there is collusion with others in claiming the unnaturalness of such relationship, a constant feeling of not being seen as authentic and natural.

> "I don't know. I can't say that we've had any problems really. No, I mean a couple of times walking down the town. When we first got together there was a couple of kids you know calling "oh look at them" but apart from that, not had any problems really… And I do think it is probably more men I think suffer with the stigma of it. She keeps using the word 'unnatural'. And I just think that's very. And of course, it's winding [PD3] up… I suppose because we hadn't had any, well not that I'm aware of, any homophobic comments. I'm sure people do talk behind your back because you know because that is the nature of people isn't it, but you know." (Gail, interview 2)

Unknowingness was also expressed by Kate several times in her interview. Her returning to this sense of unknowingness and questioning its origin suggests she felt unsafe and unsure of people's intentions, particularly in relation to vulnerability.

> "There were some people um, I heard apparently from Malcom, this gay man that there were some nurses on a ward that said oh yeah, those two are lesbians, absolutely disgusting but they never ever said anything to my face…
>
> "they're all fine but they don't know what was being said behind closed doors do you, and I don't think much was said really, I don't know.
>
> I don't know they just got to know us but at H they were just slightly more distant from you, um, I don't think that was being, I don't think that was about being gay I don't think it was because I've had other people that I've known go up there and they say the same thing but at the time it does make you think, well maybe it's because we're gay" (Kate, interview 1)

Tracy recounts an experience from a work colleague and remembers this as the only overt act of homophobia in her recall, and, like Carolyn, locates her sense of safety in her choice of workspaces and the protections public sector work affords her as a member of LGBTQIA+ community.

> "I can think of one incident years and years and years ago. I was doing voluntary work at actually a psychiatric hospital up in Manchester, and one of the volunteers, I got friendly with this woman and she came back to the house and we were just sitting chatting and stuff and then I had a couple of newspapers. It was actually the old News of the World, and they were framed. And one of them was um, do you remember the Police Chief from Manchester. James Anderson his name was.

> **No**
>
> He was horrible, really, really, homophobic, horrible man. Anyway the News of the World was " God's (?) Cop Girl is Gay" or "is a Gay" it actually says. Which is really because I had these things framed and she saw them and she said "oh why have you got those framed?" and I said "well I'm gay" and she virtually ran out of the house. And then I'd lent her a video. I can't remember what it was, probably something like Victoria Wood or something. And I came home one day and it was through the letterbox. She's just shoved it through the letterbox. She never did volunteering again at the hospital. Very strange. But that's the only, really the only thing I can ever think about. I've never had any. I mean I've always worked in the Public Sector like Councils and then the NHS so you are kind of protected at work anyway aren't you?" (Tracy, interview 4)
>
> "Well it's considered any homophobia, we deal with it obviously, it's a hate crime. It's under the hate crime heading. And then within the workplace, part of the training is sexism, homophobia. I'm not saying it doesn't exist because of course it does amongst the old school coppers of course. But they will be hauled up for it and you know that. And because you're dealing with it as a hate crime, professionally everyone is expected to be gay friendly." (Carolyn, interview 6)

However, for both Carolyn and Tracy, this finding may indicate a degree of privilege as white, middle class, cisgendered women, and this sense of safety in the workplace may not be felt by all members of the queer community, particularly trans people of colour. However, the findings of this study cannot speak to these intersections as all the participants identified as white and cisgendered, this though is a key limitation of the study.

Carolyn goes on to highlight the momentary sense of disorientation that people experience when encountering the unexpected, here she laughs about the experience of booking into a hotel as a lesbian couple and the reactions of reception staff.

> "And the worst you ever got was maybe a slight eye bulge. Just that, the best way to describe it. But no one batted an eyelid. You know what you get when you book into a hotel don't you, [giggles]. So that wasn't an issue." (Carolyn, interview 6)

This is the key factor of queering the sick room, the momentary pause that occurs to enable a person to re-orientate themselves to the picture in front of them, this readjustment is a fleeting moment, but one that is noticed by the queer person. This is seen as an indication that they are not the expected, they are unexpected, they are unusual, they are not normal. The response that followings either enables safety to return or trigger protective mechanisms.

Two participants, Melissa and Mei spoke about pushing back against prejudice, calling it out and being prepared to defend themselves from physical or emotional violence

> "Well I don't understand why people would treat you differently anyway. Just because your sexual preference is something different to some people, why would that mean that you get treated any differently? It's a mystery to me that just because you tell someone you're gay that automatically gives them the right to think whatever they may think. It's almost as if you don't meet their standards with some people. I don't' give a shit. I just get on with it… I've never felt that I've had to be defensive about it except for once when I was in a Weatherspoon's and there was some drunken prick in there. He was obviously homophobic, very obviously homophobic. But it's never been a conscious." (Melissa, interview 10)

> "Because I'll say "well excuse me. So in a heterosexual couple then, is he going to look at every woman and go 'phwar that's a nice bit of skirt'. No not all of them, some of them do but not all of them do. And the women in those relationships could be the same" you know "oh"" (Mei, interview 3)

Two further participants, Carolyn and Samantha spoke of the internalised homophobia they had experienced.

> "They are actually very liberal people or I think they are. But no I genuinely believe I have some homophobia instilled in me, the culture I grew up in, like at that time you were just sort of conditioned that it wasn't the right thing." (Carolyn interview 6)

For Samantha this had a significant impact on her mental wellness throughout her adult life, for which she had received extensive mental health care

> "I was just a bit further back. And I was already, suffered through my life with a bit of depression as a child you know and stuff because I was holding on to all these gay emotions and things… I had really given myself an incredibly hard time throughout my whole life. And then this was I think just a little… So yeah that mental health issue but that I do believe that all stemmed from being very very fragile actually about being gay and feeling that everyone would hate or feeling, just feeling not good about myself… Even though I had a long term partner at the time and then I'd moved to sort of Town for a while and it didn't feel

> comfortable enough to. And even back then people just didn’t presume.” (Samantha, interview 8)

This led to expectations of homophobia particularly in new settings or groups that were mixed

> “Then when I got put in that group I suddenly realised “oh my god , these are all straight, possibly married” you know they’re very different kind of people, but from different walks of life but very different. Like a Nigerian mother who I would never ever speak to normally, because there would be no reason unless they were in my advertising job, in which case they would already be accepting and then there were these 2 who’d actually been friends for many, many years and they got diagnosed within a couple of months from each other. So they were older ladies but from a very different walk of life. It was sort of like “oh my god I don’t, obviously I’m here to be open and talk about the help but I feel very strange like I actually have to come out to these people”. And so, I kind of again worried a little bit because how that was going to go because we’re supposed to be in a safe environment, you get given the talk that everyone respects each other and nobody talks over each other and nobody gives anyone advice and you talk about your own experiences, you don’t give advice. So there were all these ground rules that were set before you even start the meeting. So I went home to K and said “I don’t know. I feel very uncomfortable. I don’t know how it’s going to go because I feel like I’m going to be judged” and then I think it was, yeah it must have been the second one it just happened to be brought up in conversation and this is the way that I tend to do it anyway whilst having a conversation. I, my wife and then it’s done. And actually nobody even expression changed and I was like “Ok” there was no worry… I thought these people may be some of those people. But they weren’t luckily… I think it was because I had this group of this unknown group of people that came from different walks of life that you know, I was presuming that these ladies lived on a council estate and that they, because it was just the way they spoke and the way that they dressed or hailed from Exmouth market or something that kind of person that I was putting upon them, that I presumed they were. And so they in my experience those are the kind of people that actually give abuse back or non-acceptance rather than abuse because there would be no abuse in that environment. But quite frankly they were just like, fine, nothing, you know.” (Samantha, interview 8)

Conclusion

The narratives presented here as living a lesbian life show the multiplicity of experience, there is no one experience that captures the “lesbian experience”, but there are some commonly shared moments, fear of reactions from others, homophobia both internally felt and externally experienced, Significantly the recognition of self for these women was a truly empowering moment, that enabled them to begin to live as their authentic selves. An important factor for all the women was time, particularly in relation to coming out. The political mood of the time, for these women, dictated not only their feelings of safety but also their personal activism, particularly for Tracy, Carolyn and Mary, who were at both a time and a location where protesting against the anti LGBTQIA+ machinations of the government was an essential part of the everyday experience. However, for those participants like Melissa and Samantha, surviving within compulsory education, internalised homophobia and suppression of their sexuality was their everyday experience.

Living a lesbian life with cancer

The Journey with cancer: how do women, who identify as lesbian, construct their cancer narratives? The stories told within this section detail the journey and lived reality for these ten women of being diagnosed, living with cancer, and navigating cancer services. They take us on a chronological journey from first suspecting they had cancer, to the diagnosis and subsequent treatments. Then an exploration of how cancer and its treatments impact the body, and the experience of navigating the material reality of having cancer each day. Participants then speak about the informal and formal support mechanisms in place to support them and the effectiveness of this. Finally, they describe navigating the care setting and interactions with health care professionals.

Constructed Cancer hierarchies.

This narrative discusses how cancer is spoken about in terms of good and bad cancers, which cancer is the worst, or which is the best to be diagnosed with and how some women should consider themselves lucky that is it only this cancer. Here there are also clear messages given to the women as to how they should behave and recover from their cancers based on the internally constructed and externally validated hierarchy.

Internalised hierarchies

Melissa refers to her cancer as “lucky” as it was only Ductal Carcinoma In Situ (DCIS), even though she has undergone mastectomy and faces many years of follow-up, but her cancer was not considered to be as serious as invasive cancer, often labelled a pre-cancerous condition by the medical profession, so can be pre-fixed with “only”.

> “Luckily it was only DCIS” (Melissa, interview 10)

Tracy in a similar vein speaks of her endometrial cancer as less worrying than breast cancer and if you are going to get cancer this is a “good one” to get. She bases this on the diagnosis often occurring at an early stage in the diseases progress and therefore often only requiring surgical intervention, albeit major surgery, in contrast to other cancers (particularly breast cancer for Tracy) that require protracted diagnostic and treatment journeys.

> “So, I always say if you have to have cancer have that one as a woman in a way because a) you don’t have periods anymore which is brilliant and b) I didn’t have to have any other treatment. Because my close friend who was also a lesbian… she had breast cancer… And she had radiotherapy, chemotherapy and it’s just full on isn’t it. It’s way worse than what I had if you know what I mean. It’s different.” (Tracy, interview 4)

This came into sharp relief for Tracy when she was faced with the possibility of being diagnosed with breast cancer following a recall from her screening mammogram.

> "It was far worse, far worse than the endometrial cancer. It was absolutely awful. It was such a stupid system. And I understand it… Well, I think it's the post treatment I think for me. I didn't mind, well I didn't mind, I didn't want it but the idea of surgery to cure something is fine. It's almost like a mechanical thing isn't it. But I did not want to go through. Also, I didn't want it again. I didn't want another cancer. I really did not because you know. No, I don't want to go through that again really but I didn't want to go through treatment. I didn't want to go through what I'd seen my friend go through so… I don't want to go for the breast screening but. It's funny isn't it because I wouldn't mind like say stool sample or something like that, but I don't, breast cancer is the one I really don't want to have. Isn't that silly? You pick the cancer you really don't want. But I probably wouldn't want bowel cancer or anything else either but hey. I suppose having seen how it affected my friend and how rough it was. And it lasts for ages. She was feeling rubbish for about 2 years even after treatment finished. It's not to be taken lightly is it so it bothers me more."

Running tangentially to the idea of a cancer hierarchy is that of cancer in a hierarchy of other diseases, for Sabrina she particularly highlighted cancer in comparison to mental health illness.

> "What am I getting in a big stew about when I work with people who have schizophrenia, or get a diagnosis of schizophrenia. That to me is far more of a difficult diagnosis to deal with and manage with." (Sabrina, interview 7)

Externalised hierarchical narratives

Mei speaks candidly about how her colleagues were hugely sympathetic towards a colleague who had to have chemotherapy and radiotherapy for her cancer, whereas Mei was forced into a position of having to justify why she had not yet returned to work having "only had" a mastectomy.

> "But you know we had another colleague at work at the same time who had breast cancer and she had a lumpectomy and breast reduction. She chose for the breast reduction and then she went through chemo, and she had radiotherapy as well. And when I got back to work it was "oh poor" I can't even remember the girl's name "poor Jackie". She's going through the mill and back. She's really having a rough time. You're all right. You didn't have any problems, did you? You've come out of it really lightly!" And I'd look at them and it was D and her sidekicks there and I said "yes, I got off really lightly. I only had to have Tamoxifen. As you know I didn't have chemo and radiotherapy. But she's still got two boobs. I've only got one" … And that is something that I found very hurtful because they were always "poor Jackie" and "no, you just come back when you're ready" And yet I'd had all this pressure to come back." (Mei, interview 3)

Samantha spoke about her family's reaction to her physical weakness and compared this to other family members who had seemed more able during this time.

> "The family were like "oh so" like my brother-in-law "So, but my friend was up and doing like working and "and I'm like "I can't go round to that family event, I can't go out" and I went "because I can't even stand up off the sofa without actually having help". You know and it's like a non-understanding of the different types of cancer have different treatments, have different responses. People think if they have a friend that had some prostate cancer or something and then actually everyone's that chemo would be absolutely fine." (Samantha, interview 8)

Melissa speaks about how returning to work on a phased return was a fight as she was not thought to have really suffered because of her cancer and its treatments, impacting on her wellbeing and feelings of support.

> "Maybe it's a degree of that because the other individual had an awful lot of support and I had to fight to come back on a graduated you know getting back up to full-time hours. I had to fight to get the admins day whereas J was given it all on a plate. Because their perception was that I hadn't really suffered at all." (Melissa, interview 10)

Although for Tracy despite her internal conversations about cancer hierarchies this was never reinforced by those around her

> "No, I've never had anyone you know "it's only". I might say that, but other people wouldn't. I'm always honest with people you know. It wasn't a walk in the park. It was quite tough, physically it's tough, mentally it's tough. But just for me personally I would have hated anything with treatment, so I don't the mind surgery. If you I'm going to have it just take it out and then let me get on with things. But no, no one's ever played it down" (Tracy, interview 4)

For those women whose cancers were deemed as more serious from the beginning this narrative did not appear in their conversation with me, it was fully accepted that their situation was of significant seriousness not to be questioned.

Being diagnosed

Here the women speak of their journey towards their diagnosis, this includes narratives of missed diagnosis and prolonged investigations.

What lead me here?

Judy had just lost her mother and had for the first time moved in with her partner when her cancer was diagnosed. She had been experiencing a protracted chest infection and multiple antibiotic courses to treat this with no change in her condition. For her being diagnosed with something as life changing as lung cancer did not come as a surprise in one way as she states, she never gets little things, they are always huge. Her narrative here towards diagnosis is a familiar story in lung cancer, multiple trips to the GP and multiple courses of antibiotics which reduce the acute symptoms, but a low-grade persistent cough remains.

> "So we then, I mean I was living at home, just carrying on. It was the best thing to have happened. And then in was in the November, was it November? I got this bloody cough and that's when it all kicked off. I don't know if it was like relief because they said because when they found the tumour it was quite big and it was near the main [points to chest]
>
> **Bronchus?**
>
> Yeah thing, whatever. They didn't think they could operate. But they thought it had been there a long time. But you just wonder what triggers you know just a cough that wouldn't clear up, because it was fortunately, I'm not really a sickly person. So, I get a cold very rarely. And then if I get something then suddenly, I get something you know. They thought it was I'd got asthma and they gave me a pump and that didn't do any good. When back again and then, went back three times. They eventually sent me for an x-ray and that's when it showed up. But they gave me some antibiotics and it was at the time when antibiotics weren't really being given out. Anyway, he gave me these tablets, yeah lovely, just the job. So, when I went back for the results and he said, I said "how can I be? Because I'm fine, I feel fine" and anyway just by fluke really, I had a ...very strange but just this cough wouldn't clear up. And then it cleared up. So, if I hadn't had a cough, it could have been, I don't know" (Judy, interview 5)

For Tracy, she had been admitted for a hysterectomy to help resolve a long-standing gynaecological problem. On waking from the anaesthetic under the impression the surgery had gone as planned she was informed the operation could not go ahead as they had "found something" unexpected when they went in and that it was most likely cancer. In a state of surrealness and dazed from the anaesthetic she then had to deal with earth shattering news that would change her life.

> "And then yeah, I was in the um, coming round from the anaesthetic and the registrar, the reg. said to me "oh we couldn't do the operation. We think you might have" Or no and she said, "we couldn't do the operation because we found something" And then she wandered off. And then Mr [Consultant] I think that was his name, he came in and he said, "yeah I think we found cancer" OK. But I was kind of like "huh" because I literally had just come round." (Tracy, interview 4)

Here there was no regard paid to the breaking bad news guidelines or to the awareness that Tracy may have had about this conversation following anaesthetic.

Family members, particularly partners, were often involved in encouraging the participants to seek medical advice when they first discovered an issue, this is referred to as "nagging" by some of the participants. Although many of them left it some weeks prior to seeking out this help.

> "I started off with a lump that was just here. And it was quite tender to touch if I kind of pushed on it but didn't really think much of it…Five weeks later I'm getting nagged to go to the doctors." (Melissa, interview 10)

> "I found the lump on January, no not January, November the 12th because it was [PD3]'s birthday. And I went to the doctors. Luckily my daughter, my youngest daughter worked in our doctor's surgery so she got me an appointment and I went because I think I might have bottled it a bit if I hadn't have jumped on it straightaway. Do you know what I mean? So, she got me the appointment and the doctor was very good." (Gail, interview 2)

> "Well, I was a bit naughty really because I felt this lump and I said to P "have you felt this lump before?" She went "no". It's only a small lump so she examined me, and she said, "no you haven't had that before." And we were going to go away camping down in Cornwall. So, I felt this lump and I said, and she said, "you need to go to the doctor" and I said, "No I'm just going to leave it a couple of weeks". "No go to the doctor" I said, "ok I'll leave it a week" And then I went to work, came back and she said, "I've made you an appointment at the doctor's" So I went to the doctors. The doctor said "oh no. it might be a cycle type thing. Come back to me in a month" This was a female doctor in the old practice. "Come back to me in a month" which I can kind of see the sense there even though I'd had a hysterectomy. I still had one ovary left so it could have been a cyclical thing. And so, we did that. Meantime we went off camping. A was beside herself with worry and I'm like "it's probably just a lump. It's not going to be anything." "Well promise you'll go to the doctor's" I said "yes, yes. I'll go the doctor's if it's still there when we finish" So I went off to the doctor's because it was still there. She then said,

> "oh ok let's get you referred to the hospital" And then it just happened very quickly. I think it took about 6 weeks' maybe, maybe 7 from start to finish." (Mei, interview 3)

Mary had started a new, dream job and with this came a private health care package which expected her to undergo a mammogram at the beginning of the policy and it was during this procedure that the tumour in her breast was discovered.

> "When I started the job, I was just coming up to 50. And they had, there was a private health care package with it. Now I've never had that before or since so for that 2-year period while I was working with them, I had you know I was signed up to BUPA. So, when I first started, they gave me a health check including a mammogram and that was when the cancer was identified. So, within 6 months of having started that job, it was less than that actually, it was 3 or 4 months, I was diagnosed, and I was having to take time off for my operation. I was in quite a state with it." (Mary, interview 9)

Tests and waiting

For many of the participants their road towards being diagnosed with cancer included multiple tests, investigations, biopsies, and long waits for news, increasing anxiety and discomfort. However, explanations about the test findings offered confirmation of what they were facing.

> "It probably was a long 3 weeks to be honest, waiting for the thingy. But I also was pretty certain he would not have said to me "we've found a cancer" And when I went, I asked him to show me it actually when I went to get the results of the biopsy thing because he had photos and everything. And I said, "can I see?" and he showed me it. And I said "how did you know? And he said, "well it's got its own blood supply" So he showed me." (Tracy, interview 4)

> "I had a biopsy and I saw the consultant. It wasn't Mr [C]. I think he was off sick at the time. I saw the, his registrar. And he said he felt sure that they could remove it and you know get it." (Gail, interview 2)

> "I then had to go for a breathing test, and I found that quite stressful really because you're frightened, and you want to do the best you can, and you can't because it's not happening. And then I had to have one of these things where it down put a tube up and then they take a biopsy. God, bloody hell, that was horrendous." (Judy, interview 5)

> "They did a repeat mammogram and then they put a wire in. Did they put a wire in? No that was. I'm terrible. I can never remember things, but I know they wanted to make absolutely sure that the biopsy that they are removing, the biopsy that they did, they wanted to make

> sure that it was what they were seeing on the screen. So, they redid the mammogram. That's it. So, I saw the radiologist and then she said, "no I want to do a biopsy on this because it looks like this" and so then I went in and had the mammogram again. So, I don't think I had a second mammogram. I literally, because of what, that's it. Because she could see, because she'd done it 3 years before, she could actually see that what she was seeing was different to the adenoma. And so, she said that's what she didn't like. So therefore that, I then went and had a biopsy and the x-ray people team you know positioned me and squashed me and then took it, you know it was like a staple gun, and removed it and then they went and did a mammogram of me again to double check. Did they do it twice? I can't remember now. Did a mammogram, then I had the biopsy." (Sabrina, interview 7)

Tracy and Kate were faced with a dilemma whilst waiting for results. Both had access to the system that would have allowed them to find their test results prior to their consultations with their doctors. However, both women decided to take the opposite actions, Kate looked up her blood results and Tracy decided to wait.

> "they all disappeared and I was like, where've they all gone and my antibiotics had finished so I got up, turned the drip off, walked up to the desk and I thought, well I'm going to have a quick look at my bloods, I know I shouldn't have done but I wanted to look at my bloods to see what they showed and um, I looked at the bloods and they're all bright red, they're all highlighted. And bright red means they're all abnormal" (Kate, interview 1)

> "Then they discharged me, and he said, "you know we've taken a biopsy and you'll get the results" It was three weeks. That was the worst thing having to wait three weeks. The worst thing was I knew I could look it up. I could have asked a colleague. I didn't actually have access, one of my colleagues did. And then was quite difficult thinking "I could actually get that information. Because he was on holiday, that's why it took so long. He had a 2-week holiday, so it took. So that was the worst of it and then obviously you're just waiting, reading everything which you shouldn't be reading. And they say, "Don't google it" "Too late", you know. But I went to work. I didn't have any time off. I mean I went back that next you know the week I had booked off because there was no point. I hadn't had anything done. I didn't need time off. And yes, you just had to wait three weeks basically." (Tracy, interview 4)

The reasons for this may be varied and may in part be due to the length of time involved in these situations, Kate was acutely unwell and had instant access to help and support, whereas Tracy would not be seeing her consultant for some weeks and was not physically unwell at this time. Tracy also highlights in this segment that the waiting was a particularly difficult time and found herself seeking out information to manage this anxiety.

I don't think it's anything but

A common narrative is the warning shot across the bow where health care professionals will pre-empt the breaking of bad news by placing the thought into the persons head prior to the actual definitive conversation. This is evident in some of the participants stories and particularly for Melissa. Here the sentence "I don't think it's anything but …" leads her to contemplate that it could be something and she is then supposedly more prepared to receive the actual bad news when it is finally broken. In all these examples it seems that this strategy was successful as all the women felt that they had been prepared to hear the news or saw the subsequent diagnosis as a foregone conclusion, giving them time to prepare for this eventuality.

> "I went and the doctor said, "I don't think it's anything, but we need to send you to get it checked within two weeks", "Right Ok" Didn't really think anything of it. Got my appointment through. Went in and saw, can't even remember her name, a lady who flipped my boob around a bit and felt the lump and said, "I don't think it's anything, but we'll need to mammogram you". Went and had my boob squashed, bloody hurts where they found something. Not to do with this lump. Basically, they found a calcified deposits in the breast and they said that sometimes they turn out to be cancerous, sometimes they're not. "But we need to do biopsies" and I'm like "right" … When they told me I had cancer I think I was kind of prepared for it because they had already told me they'd found something. And as much as you never want to hear those words it didn't shock me as much as I thought it would." (Melissa interview 10)

> "So, I kind of knew he'd know. He wouldn't have said to me "oh I think we've found a cancer" if it wasn't. You know he is a well-respected doctor there. He wouldn't have said that… I also. I was certain it was cancer because he would not. He would have. Because I phoned to ask about the results, and he would have phoned me if it had been fine. I knew he would have done. So, I did know. And so when he told me I wasn't particularly shocked… And then bless her the nurse came out with me afterwards and said, "are you OK?" And I said, "yes I'm fine" You know I kind of expected it and it's fine. But of course, I was upset." (Tracy, interview 4)

> "She said that she would like to tell me that it was nothing to worry about, but she thought it was something to worry about and that over the next few months would be a very worrying

> time and she was going to refer me straight to the, I don't think you get referred to the Oncologist but there is a two-week referral isn't there." (Gail, interview 2)

The event

The common thought and published guidance on breaking bad news stipulates that a person receiving bad news should be accompanied by someone close to them to offer support and to help them recall what was discussed, as once bad news is broken most people shut down emotionally and are unable to recollect any further information. However, for Tracy this was not what she wanted for herself. She did not want someone with her, she wanted to hear the news on her own so she could ask her own questions and focus on her own needs rather than worry about supporting her wife and extended family. This was such an abnormal presentation of a patient in the oncology clinic that when faced with this situation the health care professionals (HCP) questioned her understanding of her situation and expressed relief when Tracy made it known she was fully aware of her cancer diagnosis.

> "And then I went into the office to see him, and he was like "oh ok so" I went on my own again. Everybody wanted to come with me. Bless them they did. But I just, it's just easier for me to concentrate and listen to what they're saying and take it in myself without having to worry about anyone else or anyone asking their questions because I want to ask mine. I had a list this time. And the nurse who was out then saw me on my own and she was so. Because when I went in they said "so what do you know" And I said "well I know I've got cancer" And they went "oh thank god. Because you're on own we didn't know that you knew."" (Tracy, interview 4)

Why this relief was felt is unclear, was this the HCP looking for an easy life at this point, and not having to offer emotional labour would be one way of achieving this? Did Tracy appearing on her own challenged this, or did it come from a place of care and compassion in that they knew they were going to be discussing particularly challenging topics and that without someone to support Tracy she would find it difficult to fully comprehend the impact? This could have been the case both consciously and unconsciously. The presence of another offered both support for Tracy and eased the emotional labour for the health care professional. Interestingly after Tracy told me of their relief that she was aware of her diagnosis she did not discuss further the HCP's interactions as to whether she was supported at home. It was just an expression of relief. If this HCP had been concerned for her welfare a further examination of the support available would have given some reassurance. In not doing this it is more likely that it was a reduction in emotional labour that was desired!

Judy explains how she was on her own when she unexpectedly received her diagnosis from her GP and the numbness that followed this.

> "I didn't feel anything. Got in the car and she said, "how did get on?" I said, "they think I've got cancer" She went quiet, I'm quiet and I said, "don't say anything, just drive, just go home". So, we've never really, really discussed it. And I said, "well until we know we don't, we can't talk about it" And then of course it plays up here then. I felt dreadful. It was like I'm OK, but it was like a button, and I was saying I just went gradually downhill." (Judy interview 5)

Reactions

Most of the participants explain the impact their cancer diagnosis had on them and for most this was unsurprisingly and predominantly a feeling of devastation and shock.

> "I'd got the diagnosis and I was waiting to go into hospital to have the lump removed; obviously there was a couple of weeks there and I was quite fragile mentally." (Gail, interview 2)

> "He said to me "it's cancer, lung cancer" So I kind of looked at him and thought "really?" (Judy, interview 5)

> "We were up in Cheshire. And I started getting blood. So, I didn't tell P because we were on holiday. So, I just thought, "Right, got to go the doctor's when we get back" Changed from there to S and it all went from there very quickly. I was passing blood. And then an appointment at hospital with a surgeon and he examined me and just said, "I don't even need to do a biopsy. I know straight away." He told us 14th September and it was utterly devastating. Just, your world falls apart." (Carolyn, interview 6)

> "Yeah, it was a bolt out of the blue yes. Neither of my parents have had cancer although my mother has skin cancers but that's you know through being out in the sun without any sun cream. We're quite fair skinned, Irish complexion, but on my mother's side both of her parents died of cancer and my mother's sister had ovarian cancer and died young. So, I'm the first and only I'm very pleased to say to have cancer in our family. So, my immediate family, my siblings. I'm the oldest. So, it was a bolt out of the blue. Especially as I've always been the healthiest. I've been the one who runs and who cycles and swims and climbs mountains and that kind of thing. So, it was a bolt out of the blue" (Mary, interview 9)

For Tracy, the thought of having an "oncology nurse" brought reality screaming home to her.

> "I thought "I don't want an Oncology nurse. I don't want to have cancer" But anyway that was a bit of shock." (Tracy, interview 4)

Melissa had just come out as lesbian and was enjoying exploring her newfound sexuality and living as her authentic self. So, finding out she had cancer completely obliterated this exciting and joyful time.

> “So, the cancer side of it came as massive, massive shock. I started off with a lump that was just here. And it was quite tender to touch if I kind of pushed on it but didn’t really think much of it. Yeah. It was kind of more of a kick in the teeth because I’d just come to realise who I was, and I was living the life that I was happy with. I was eventually who I really was. And then to have that happen was like “what the hell have I done to deserve this?” But it is what it is. You’ve just got to get on with it. It’s not like you can just put it off and ignore it.” (Melissa, interview 10)

This sense of shock was for some of the participants exacerbated by the fact that until they were diagnosed, they had not had any suspicion that they were unwell. Melissa explains how she felt well other than having a lump in her breast, there was no indication for her that she had a life changing and potentially life ending disease “raging” through her breast. She emphasised the lack of comprehension she felt, how could such a deadly disease be present in her body for so long, yet she knew nothing about it and could have done nothing to change the situation she suddenly was facing. Carolyn also highlighted the lack of symptoms at the early stages of the disease meaning she had no idea about the presence of her colorectal cancer, it was only when her disease had become advanced and she developed bleeding from the tumour that she was able to seek medical assistance, which subsequently failed to recognise this symptom as an indicator of a life-threatening disease. The vagueness of some cancer symptoms often leads to a missed diagnosis or misdiagnosis when people seek initial help from primary care physicians. So called cancer red flags are ignored when they do not coexist with other commonly presenting symptoms, for example with Carolyn weight loss.

However, for Kate her diagnosis came after a prolonged period of ill health, so the diagnosis was in some way a relief to know that there was actually something wrong with her.

> “I think it’s because I’m a very positive person anyway and I just wanted to feel well again, and I just knew something was wrong and I was just so exhausted as well I just took it all… I felt like a hypochondriac” (Kate, interview 1)

Carolyn also experienced this sense of relief, though it was tinged with sadness and angst, and did not negate from the overwhelming impact of the cancer diagnosis.

> “it’s not so much me; a little bit of me was relieved because I’d been feeling so tired it was “OK we’re here now. I know what’s going on.” But that cancer word, I’m getting quite

> emotional now, it’s just scary… We’d just got married. I’m the happiest I’ve ever been.” (Carolyn, interview 6)

Following her diagnosis Judy was reluctant to share the news with anyone as she did not want to have to face what she referred to as “war stories”, conversations with other people where they shared stories of people, they knew who had cancer.

> “And I didn’t want to tell anybody because I hadn’t got anything to tell them, And I didn’t want to start any war stories or you know, when people say, “oh my uncle had this” or “my aunt had that”,” (Judy, interview 5)

For Sabrina there is a sense of disbelief and despite having read the histology report and seen the mammogram films she is still questioning the actual diagnosis, from her words it is almost as if she cannot believe this is happening until she sees the actual cancer in its physical form …

> “I’ve not even, I mean they’ve shown me on the screen things. But I haven’t seen, I’ve seen the histology report which says things, but you know, do I really believe it? There’s a bit of me like that.” (Sabrina, interview 7)

Misdiagnosed?

Kate, Tracy, Carolyn and Samantha all experienced situations that led them to question the competency of health care professionals when seeking help for changes to their bodies, Carolyn particularly highlights the lack of person centredness in the doctor’s approach to her care.

> “I went to the doctor who made me feel awful actually. He was completely dismissive, no patience. And he should have looked and seen that this is someone who doesn’t go to the doctors very often. Anyway, he was useless, and I felt embarrassed that I went to the doctors” (Carolyn, interview 6)

Samantha tells a story of over 6 years of worry about lumps she had found in her breasts that subsequently were found to be concealing two cancerous tumours. As a result of this is she is sceptical about the service she received and questions whether she was misdiagnosed all those years ago. Her attention is focused on the dismissive way she was treated by the ultra-sonographer within the clinic who rejected her concerns and feels that this should be further investigated.

> “Well, we, a year, it will be 6 years ago now, I went for a breast examination, and I was by myself actually and they didn’t, this, because I had found some lumps. And they said it was fine, they didn’t biopsy, but they said, I don’t know I was a bit confused. In fact, P probably tells the story better than me because I’m still confused what went on. And so, I came home

> all very confused and not very happy with the fact that they had gone “oh they’re lumps but they’re whatever lumps” and then “just don’t worry about them” And so she made me have, made them see me again. And we saw the head person I think it was, because there was a younger, the first time, there was someone who was quite inexperienced at doing scans doing the scans, so I didn’t feel confident that they were. And there is that point where you get, if what the surgeon feels, the initial consultant and what the scan shows then you’re recalled. And I think that’s what happened although P tells me slightly different that she made me go again. But I believe I got that letter and it said actually you need to come back in again because there was a discrepancy. And then we saw the head ultrasound person and the ultrasound person again didn’t biopsy so basically poo-pooed us and said, “what are you doing back here?” basically. “it’s fine although the fibrous sort of tissue stuff and they are never going to turn into cancer. They are going to grow. The only reason we’d have them removed is just for cosmetic purposes” and she was so dismissive that I was like “Oh OK, OK, sure” Then over the 5 years they kind of grew 2 lumps to what’s called the auxiliary, right. And I felt these lumps growing, week in, week out, kind of thing. And now we do we need to investigate this further now I’m all well to actually get the original scans to show my now surgeon because either one of two things happened and I’m unclear still. Either those lumps masked the cancer that was growing underneath so I actually couldn’t feel it because of the 2 lumps that I’d always felt were always there or in actual fact they were misdiagnosed at the time. I’m inconclusive on that and I will find out at one point what happened. “(Samantha, interview 8)

Tracy highlights that it was only through her own persistence that she was eventually diagnosed with endometrial cancer after her symptoms had ascribed to fibroids, a commonly occurring benign condition.

> “It was behind one of the fibroids. And the fact there were fibroids in there meant that obviously 2+2=4. That’s what it must be. So, I mean fair enough I don’t blame anyone for not diagnosing it but I’m glad that I pursued it and didn’t just put up with that because it hadn’t gone through the womb lining at all” (Tracy interview 4)

Tracy also highlights a story of a close friend who had been dismissed by a doctor as one of the “worried well” when she presented with recurrent breast lumps following a benign biopsy result. Tracy tells of how her friend had to be persistent and insistent that they investigate her further, resulting in her being diagnosed with an aggressive form of breast cancer.

> “The doctor thought she was a “worried well” you know, and they weren’t convinced. But she pushed and pushed and pushed. Thankfully she’s really strong and quite persistent. And eventually they tested it and soon as they tested it, they went ballistic really because it was big, and it was growing very fast” (B int 4)

Why have I got cancer?

Everyone wants to know why cancer appears in some bodies and not others. Self-preservation triggering the onslaught of questions at least according to Tracy.

> “They all want to know why. Everyone wants to know why. If you get something everyone wants to know why because they want to know whether they can get it as well don’t they. “What did you do wrong?” (B int 4)

Both Tracy and Sabrina explain how there is an inevitable search for the cause, a quest to know if it was something they did, something that could have been prevented, something that could have been stopped by changing something about their lives. And this discourse is linked in some way to lesbian identity. During our conversation Sabrina begins to piece together various statements that were made and conclusions she had drawn about the cause of her cancer. The known discourse surrounding not having children being her starting point and then relating this situation to who was more likely to be child free; lesbians and nuns, she wasn’t a nun so therefore it must be because she was a lesbian.

> “It was also like “Oh god” as well. Yeah, lesbians are probably going to be the most affected because it’s more likely to be lesbians, women with no children, who are affected or nuns. I’m not a nun.” (Sabrina, interview 7)

No one explicitly said this to her, but she could read between the lines and see the implications of what was being spoken about. But through her working out she concluded that this was not an accurate conclusion as she was aware of many women with children, lesbian and straight who had been diagnosed with cancer. Questioning, although there may be a statistical variation between parous and nulliparous women, lived experience disputes this, probability verses certainty, and can life be lived in probability.

> “And that is, that is true. Not lesbian necessarily but it’s… I just, just kind of the incidence of women without children is what is the. I mean. When I actually got the diagnosis, I suppose the diagnosis, I was told that it was cancer. And I remember saying to the radiologist, I said “well, I’m just really unlucky. But statistically I’m in a high, I’m in a group which has got more

> likelihood of having cancer, breast cancer" And she said "yes" But it wasn't related in any way to the fact that I was a lesbian, it was just you know, without children and being 50 and oh what was the other one? No children, being 50. Not taking contraception. But also starting my period early. So that's what I said, and she said "yes" But she didn't sort of relate it to being a lesbian at all. She didn't mention that. But yes, I can see why, its shorthand isn't it. Well therefore that's that group. But it's rubbish. Because all my friends who actually have had breast cancer apart from F1 have all had children." (Sabrina, interview 7)

Judy spoke openly about believing that her lung cancer was her fault, being that she was an ex-smoker. This is a common feeling amongst people diagnosed with lung cancer and public health rhetoric has long existed reinforcing this belief, statistics about the percentage of lung cancers directly caused by smoking are readily cited and the latest health campaign by Cancer Research UK (CRUK) places smoking as the number one lifestyle cause of cancer (CRUK 2023). Whilst none of these facts are in dispute, the effect this has on the individual with cancer is profound. Not only are they contending with their impending death but also the internalised shame of the perception that they caused their illness. They should have known better; they could have and should have prevented this from happening.

> "It was just, own fault, I was a smoker. But at that stage I'd given up. Not that that makes any difference. About three or four years. So that bit was my own fault." (Judy, interview 5)

Sabrina linked her vulnerability to future cancers to an internal state of vulnerability, using her professional background to examine this.

> "I kind of think in what now, now that I'm vulnerable you know, is there a chance that I might get it in the other breast as well so, but I might not. But I just have to be optimistic but realistic that actually now that I've been touched, anointed so to speak, whichever way you want to look at it, it's, I'm vulnerable. And that might just be because of my training because I've been working in early intervention in psychosis and there is the stress/vulnerability model and I just might be a vulnerable you know, whatever I am, maybe more vulnerable to developing cancer as opposed to, it could be arthritis or whatever, age-related condition that might happen." (Sabrina, interview 7)

Over and over Tracy spoke of there being nothing she could have done to prevent her cancer, that is other than having children. Her thoughts went backwards and forwards over this point, nothing she could have done, having children might have prevented it, but there was nothing she could have done. The thought of children elicited a forceful "Christ no!" exclamation, for her having children was something she could not have done, even if it had meant preventing her cancer? Christ No! this was not an option for her, there was nothing she could have done. Because of this she held no guilt about her cancer, no self-blame. This firmly held belief could be read as an act of defiance against the childless lesbian to blame narrative.

> “I wanted to know why. And they reckoned it was because I’d never had children, so I’d never had, my periods had never been interrupted and I’d never taken birth control or anything so my hormones had never been and that’s what they thought. Because I said was it something I’d done? You always worry about that you know, lifestyle choices and no, there was nothing I could have done about it apart from had a child. But Christ no! No, no, no. If I ever got something because I like a drink or something and that gave me cancer, then I’d probably blame myself but not for that one. No not at all. I’m actually quite relieved you know. Could I have caused this by you know if I’d smoked years ago or drinking or whatever and any kind of lifestyle? And he said no, there was nothing, there was no link to it whatsoever. So, no I never felt guilty about it… I don’t think there is anything either of us could have avoided doing so no I don’t know, never felt guilty about it” (B int 4)

Cancer and my [lesbian] body

Cancer and my lesbian body discusses how the participants spoke about different aspects of their bodies in relation to their cancer, both the effects of the cancer itself, the treatments and the expectations of dress and presentation as the ideal cancer patient. Cancer was never viewed as a positive situation but there were positive stories arising from having cancer.

Samantha spoke of the imperative to look right: to fit, to be appropriate for the space they were occupying but of how the thought of dressing up to go to the clinic was too much when she was feeling so sick despite her wife doing so and feeling the need to "dress up". For Samantha and her wife this imperative was driven by the fact that it was a private health care clinic and you had to look the part.

> "Like P would always dress up to go to the [clinic] to see the oncologist. She'd put her work clothes on. You know whereas I would just be wearing comfortable clothes and I felt so poorly that the idea of trying to make something look more attractive and actually putting wigs on to go to chemotherapy when it was you know, I just couldn't do it." (Samantha, interview 8)

Melissa and Tracy spoke of the causal and impersonal manipulation of their bodies by health care professionals.

> "can't even remember her name, a lady who flipped my boob around a bit and felt the lump" (Melissa, interview 10)

> "I went for my 6 monthly thinking "oh it's brilliant. I'll never have to have a smear again" Well how thick am I? I think within about 2 minutes of being in there and bloody hell. Poking around down there again so I had to have that." (Tracy, interview 4)

My body's failing me!

Mary felt a huge sense of betrayal by body, that it had let her down. She was an exceptionally fit person before her cancer diagnosis, running, cycling and mountain climbing. Yet she had still developed breast cancer. She had done all the right things, but it did not protect her. Subsequently her treatments have had a long-term impact on her body and resulted in debilitating conditions that severely limit her lifestyle and sense of wellness. But she has forged a sense of resiliency and calmness through meditation that enables her to cope with this changing way of being.

> "Especially as I've always been the healthiest. I've been the one who runs and who cycles and swims and climbs mountains and that kind of thing. So, it was a bolt out of the blue. Well that as I was saying it felt like a betrayal of my body. So that has been really hard to cope with… So anyway, I've also you know, I've had more than 2 years of ill health. I've got osteoporosis as well partly as a result of the breast cancer. Apparently, it's connected. And that's the really

> bad fall to my leg. But previous to that I broke my wrist really badly. So, I've also got a lot of metal work in there. I had a big operation on that. So, the wrist broke like that, and leg broke like this. So, I've been, I've had quite a lot to deal with physically you know in the last I suppose last two and a half years. I mean I started with the leg and actually I started after breast cancer doing some meditation which has just really helped to calm me down and just accept this is how things are. There is no right or wrong. There is no fighting it. It's just how things are. The mobility has been really difficult, but I suppose the way I'm doing is I'm working on it." (Mary, interview 9)

Tracy had experienced years of heavy bleeding and discomfort so having a hysterectomy was in some ways a solution to a long-standing physical problem that had been impacting on her day-to-day life. So having the surgery was not unwelcome, she had also never wanted children or to be the person that carried children so losing her uterus was not a loss of womanhood for her. She viewed her excessive bleeding as her body not cooperating with her, causing her problems, discomfort, inconvenience, and pain so having a hysterectomy was a positive move. However, finding out she had an underlying cancer was a massive shock. She had attended for an ablation, a procedure that would release her from the burden of heavy and prolonged bleeding, she was in no way expecting them to tell her she had cancer, this was not even on her radar. Then they found cancer, she was not the right age for this cancer, this only happened to older women.

> "I'd had really heavy periods like just continuous bleeding for about 18 months. And I didn't even think about it… It was virtually all the time… And as I say I was really glad to get rid of the bleeding and that problem so that was actually quite a positive thing for me in a lot of ways. And I've never wanted children. I never wanted to give birth so that didn't concern me either. I mean it is a bit of a wake-up call isn't it. It's like ok that choice is now gone. It's completely gone but it wasn't a huge thing for me like I can imagine it would be for a lot of other people. It just didn't particularly bother me that much. And I'd so many problems really. It was good to get rid of it to be honest. Just take it out. I had to put up with towels because it was so heavy and tampons all the time and constantly having to have stuff and worrying about who to um, you know going on holiday and all that kind of stuff. It was just such a pain; it was such a massive pain that like I say I'm glad I didn't put up with it."

To reconstruct or not to reconstruct, that is the question.

For Mary a key aspect of her lesbian cancer experience was being able to reflect on her relationship with her breasts, how she felt about them and the prospect of them not being there. After being diagnosed she spent time talking to a butch lesbian friend who expressed her ambivalence to her breasts and that she would welcome a mastectomy. Mary felt hearing this different point of view helped her reflect on her own situation and her own relationship with her body.

> "Interestingly when I told one of my friends who's a very butch dyke, that I had breast cancer she said "you know I've always had an ambivalent relationship with my breasts. I can see that being really positive having a mastectomy" and I thought "oh" you know that's a different point of view actually. A different way of seeing things." (Mary, interview 9)

Mary went on to express how she felt that lesbian women's experiences of mastectomy were different to that of heterosexual women as their concerns are different. However, despite these feelings she does go on to say that she grieved for the loss of her breast and that she missed it.

> "And also, breasts are important for women for heterosexual women in particular it is considered to be part of our identity in a strange, very strange way. Even though, especially as the person I am, I wouldn't say as a lesbian, but as the person I am my breasts are a very weeny part of how I identify… So, the whole thing about what's expected of you as a woman when you have a breast cancer diagnosis in particular it doesn't apply particularly to me. It's going and I feel strong that I can say actually what you're saying applies to those other women maybe, those heterosexual women might well love to have reconstruction or really want to wear a prosthesis all the time or whatever. But you know they're going about you know; you won't be able to wear underwired bras to start with. I was like, I've never worn one in my life. So, for me then it can be a bit of a joke. It's like "ok yeah. I know where you're coming from. You're talking about those women. But actually me, I'm just a little bit different" and yes, I'm used to just being a bit different. I don't know. I'd have to think about that. Interestingly none of the lesbians I know who have had breast cancer have had reconstruction. So you know, that's kind of about us and you know how we feel about our bodies and what's important." Mary, interview 9)

She went on to consider the drive to conform to heteropatriarchal norms of female body presentation and how this didn't fit in with the picture she had for herself. Having a prosthetic was a constant reminder of what was missing, and Mary felt it was dishonest to wear a prosthesis, she wanted to embrace her new normal, but she felt this would not be acceptable within the workplace where the expectation of professionalism superseded the desire to be authentic to herself.

> "I think at first, I think around the whole body image thing, you know, would it be dishonest to wear a prosthesis? Am I then pretending I'm something I'm not? So, I kind of had to get over that and just see it as it's only a prosthesis after all… Well, it was the whole thing about

> not wanting to be, I suppose being self-conscious I suppose, not wanting to be at work really. So, I only ever wore it at work because I used to joke about, the minute I'd get out I'd kind of whip off the whole bra… So, then it became just something that I wore at work but very specifically it would go the minute I left." (Mary interview 9)

But having a bilateral mastectomy was also not an option for her, this would not have reflected an accurate gender expression for her, she wanted to feel authentic in her body, whatever her body looked like.

> "I suppose for me, you know, I've had breast cancer. I've had a breast removed. I've got a scar. OK. I've had a badly broken leg. I've got a lot of metal in there. I've got scars. This is part of who I am. It's part of my history. And yes, there are times when, maybe I'll want to cover it up and make myself look more symmetrical. And there are times I won't. But actually, I want to feel in my body how my body is with its history. So, I wouldn't go for a bilateral one because I'm keeping this. This one's fine. This is staying and this is part of who I am. I've got one good breast. Neither am I going to cover up for my leg with my scars and my bolts and everything. This is how it is. There's a scar there… Yes so it's about being real for myself. So, if I start pretending I'm something I'm not to me you know, what's? That's going to be really confusing. It's going to be a bit schizophrenic really. I'd rather just live in who I am you know, accept other things, I'm sure." (Mary, interview 9)

The push for reconstruction is a significant moment for Mary in the story of her lesbian cancer embodiment and reflects heteropatriarchy and the control of women's bodily expression. Her experience was one of pressure to undergo an unwanted surgical procedure for her to conform to prescribed gender norms. There was considerable and unwavering coercion throughout her cancer journey from diagnosis to the end of follow up for her to relent and have reconstruction, despite her continuous refusal to have the procedure.

> "There is one thing that I found difficult was that everyone going on about reconstruction all the time. Now I was absolutely adamant that I didn't want it. And I didn't want any more intervention. The more I read about it, the more I didn't like it. It was all this you know, if you take tissue from your back and the people, I've spoken to it hadn't really worked. It's not permanent anyway. If you put a prosthesis in it, it only lasts up to 10 years or something, then you've got to have another operation. It's just operation after operation. But it was constantly pushed at me every single consultation. We can still do reconstruction. You could have it all done at the same time and all this. But also, I felt and whether it's being a lesbian, being a

> feminist, being true to myself, somehow to plant something in there instead didn't feel right you know. But it was constantly pushed at me every single consultation… It was usually the breast care nurses. Yes, but also the consultants… So, I was going to the hospital regularly for 5 years and so right up until my very last consultation "we could still give you reconstruction" … That took a bit of coming to terms with but also just having to be firm. When you're actually feeling very vulnerable as well about "no I don't want reconstruction. I just want the minimum intervention. I want to feel my full strength again. I want to feel my body as it is. I don't want operation after operation. I want the fastest recovery possible from this". (Mary interview 9)

At one point the pressure to conform became too much and she almost acquiesced, but found an inner strength based on her own view of femininity and the female body to be able to again refuse this intervention.

> "There was a point when I almost considered it. They were talking about it so much. It was pushed so much. And I know where they are coming from. It's kind of, we want to out you back together again. We want to make you look. And also, breasts are important for women for heterosexual women in particular it is considered to be part of our identity in a strange, very strange way. Even though, especially as the person I am, I wouldn't say as a lesbian, but as the person I am my breasts are a very weeny part of how I identify". (Mary, interview 9)

This constant pushing for her to have a reconstruction was reinforcing the narrative that without two breasts women look wrong, abnormal and that it was only with reconstruction of the lost breast that the correct female body shape could be regained.

> "Yes, it was. It was quite hard. It was a bit like saying "you really don't look right. We could make you look right. You don't look right but we can make you look right" You know" (Mary interview 9)

To a lesser extent this same policing of body shape was experienced by Mei who tells of health care professionals being shocked at her refusal to have a reconstruction, when she decided, like Mary not to have another foreign body placed in her.

> "And they looked at me and went "oh! Well, you could have had reconstruction" And I said "and have another foreign body put into my" because I would have had to have had an implant at the time…So of course they said "well you would have to have an implant" Well I'm just getting rid of one, three foreign bodies in the one boob. Why do I want to stick something else there?... I'm just minus a boob… It's like I've never had that boob. That's how my head's adjusted to missing that" (Mei, interview 3)

Of the two women in the study who underwent reconstruction of the breast both experienced postsurgical complications and failure of the implant. For Melissa the decision to have reconstruction was made as she feared missing something after the surgery

> “I initially went in to have the first op, my thought was “I can’t go in with a boob and come out without one” because that would just mess my head up too much. So that was my main focus is look, give me something back.” (Melissa, interview 10)

However, following the surgery, she describes not being able to look at her body or the wound as she was not ready to deal with the reality of the reconstruction.

> “it took me a long time to look in the mirror and see it properly. Because when I got out the bath there was a mirror directly opposite and I used to turn my back and do it that way because I wasn’t ready to face what it looked like. And when I eventually did, she was like “see it’s not that bad. It’s cool” (Melissa, interview 10)

The breakdown of the reconstruction resulted in Melissa being admitted to hospital for emergency surgery to remove the implant. Experiencing considerable distress and discomfort from the breakdown pushed her to consider a different body presentation and to be completely flat.

> “I’d got to the point where I don’t care if it’s completely flat. I just need this gone because I can’t deal with looking at this. So, I went in for the second op and he put like a expander implant in which has got a 100ml of fluid which is what I’ve had since that day and I don’t want it done anymore. If anything, I’d have it taken out. I find it quite uncomfortable. I hate the jiggling sensation of water in there. It’s horrible. And now I’ve got to the point where as much as I hate it because it’s not a boob, I haven’t got a nipple, and I know things can be done about that and I’ve got a massive scar that goes across it.” (Melissa, interview 10)

Samantha explains that she hasn’t bonded with her new breast, feeling like a foreign object, and experiencing a bodily disassociation, a numbness. Although she is going to require corrective surgery her thoughts haven’t moved towards removal, maintaining the breast is still the major goal.

> “There is however, the mastectomy, um the reconstruction didn’t go as well I wanted it to and there is a possibility of, I have been to see the plastic surgeon since for a check-up and there is a possibility of early next year… It’s hardened a little bit and it remains a little bit too high sitting because of the scar tissue that was underneath. It didn’t place properly. So, it was called a capsulectomy or something, where they cut the scar tissue and actually just release it from being held because it is really very held by this muscle. With a mastectomy they cut the chest

> muscle up and slip it underneath. So that's because I haven't bonded with that breast at all. It's just not part of me. I kind of ignore it. And then every now and again because I don't have a sensation in it, if I knock it, it's a very weird sensation now, it's like a deep muscle sensation but nothing on the skin surface. Because sometimes I'd be like pushing into things, leaning over something, and wondering why I'm not going forwards further and realise I'm actually in contact with the laundry rack or something." (Samantha, interview 8)

Body Image

The impact on the body was profound for most of the participants and powerful adjectives were used when describing their new bodily reality including lopsided and asymmetrical. Thoughts turned to covering and camouflaging with baggy clothes and prosthetics.

Melissa discussed her lifelong struggle with self-esteem and body image, since coming out as lesbian she had begun working on these issues with her partner through positive reinforcement and championing bodily autonomy, the antithesis of Melissa's previous relationships with men that had been dominated by physical and psychological trauma. The diagnosis of cancer and being told she needed a mastectomy unravelled all the work she had accomplished and caused a breakdown in her body image again.

> "I'd started to actually work through them with the help of P. You know she's been amazing. And no matter how I feel she's like "you're beautiful, don't believe" And I just laugh at her, even now I laugh at her. But it had started to have that effect where I didn't feel so bad about myself, and I didn't hate the way I looked so much… I had lost a lot of weight but still wasn't particularly pleased with the way I am but had started to work through it and started to feel a bit better about it. And then to get told that you're going to lose your boob which is part of you, massive part of your femininity, whether you are gay or not that's, it is who you are, you're a woman. And to be in a new relationship and to have that happen it's a case of "well I'm going to look fucking hideous. How is anyone going to want to look at me" So that all started all that off again." (Melissa, interview 10)

The reconstruction helped to re-establish a bodily norm for her but the failure of this was a second challenging time. Being able to wear a prosthetic, especially in public, offered a sense of camouflage, and she hoped she could avoid being noticed, but she never felt confident in this. At home she didn't feel she had to wear the prosthetic as her partner was more accepting of her.

> "When I'm at home, or when I'm with P or whatever I'm quite happy not to wear a bra but I won't not, I won't go out without one because I've got the sponge implant in there and to me

> it is really noticeable. It's not. I wear baggy clothes but to me it is. And I feel like people are looking at me, even though they're not. And I know it's all in my head. It's that trying to get past that is really hard, really hard. And I know it's still early days.
> The mastectomy side has never bothered her, ever. Because I used to voice my fears to her and say you know "I'm going to look like fucking Frankenstein" And she's like "you're my Amazonian warrior and you've got the battle scars to prove it" (Melissa interview 10)

Mary experienced similar desires to reduce the outward physical difference her mastectomy created particularly when in the workplace. For her this was linked to professionalism and wanting to maintain focus on her purpose in the workplace; to advocate for women. For Mary the prosthetic enabled her to achieve this goal.

> "I've got is one of those little prosthesis that you wear in a nice little soft bra. So, I wear that for work now and I feel much more comfortable, just not wearing anything. So, I've found my own way of being with it. At first it felt weird wearing it but then I thought if I don't wear it, then it almost feels like a statement when I'm at work and actually as I suppose I've said before when I'm at work I like to be a professional person. I'm dealing with you around these work issues. I don't want you looking at me thinking "has she only got one breast?" I don't want that… I'm very small breasted anyway so I never used to wear a bra, I never bothered. But it's like ok so, but I feel a bit self-conscious about the fact that I only have one breast now… Well, it was the whole thing about not wanting to be, I suppose being self-conscious I suppose, not wanting to be at work really. So, I only ever wore it at work" (Mary, interview 9)

There is a sense that Mary feels she is betraying her feminist roots in making this decision as confronting heteropatriarchal views would sit more comfortably with her previous political activism, but for Mary the importance of the role and the benefits of her not being at the centre of the discussions outweighed the desire to challenge body policing.

Having a partner who is comfortable with the changes to their body helped the participants adapt to their new normal, having a partner who was comfortable and even complimentary about their body shape seemed to be a core element, but that isn't to say the journey to that acceptance of themselves wasn't difficult and did not contain moments of self-loathing and psychological pain.

> "At the end of the day I've got my life, I'm cancer free and I've got someone who loves me for, and she doesn't care about that, you know... So, for me now it's a case of just getting on with it really." (Melissa, interview 10)

> "I don't have an image problem. It's like I've never had that boob. That's how my head's

> adjusted to missing that. Yes, I could have reconstruction now if I wanted to but what's the point? P love me as I am and I'll make a joke about it" (Mei, interview 3)

> "Psychologically having the bag was difficult. P's been brilliant, absolutely brilliant about it. It doesn't bother her at all so that helped me cope. I've got an ego. I'm quite proud of the fact that I'm fit and healthy and to suddenly have this was quite a big change for me. But because of P I got through that… We just laugh about the noises it makes. We've just got to see the funny side. So really thanks to her acceptance and on a normal day when you're feeling well it's a bit like anyone; you know what to avoid, food wise. So, I can sort of manage it.." (Carolyn interview 6)

In direct opposition to the stories of developing a negative body image, Mei spoke about not being impacted by her mastectomy and embraced her new body normality, using humour to put others at ease and reassure them.

> "I don't have an image problem. It's like I've never had that boob. That's how my head's adjusted to missing that. Yes, I could have reconstruction now if I wanted to but what's the point? P loves me as I am and I'll make a joke about it and say "oh well you know there is pros and cons with having a prosthetic. One of the major bonuses is if you drop something behind a sofa or the bookshelf you can just whip your prosthetic out and gives you another couple of inches you reach" Because I've got a warped sense of humour and people go… So she's me whip my little foam fibre filled one, the lightweight one, she's seen me whip that out and pop it on top of my head. "Don't you ever call me a tit head again" To the point where one of the members at the dinner party, he had to get up and leave because he was almost choking. We were round at my mate's… We were at D and M's house and it was D's dad and mum there as well. It was her dad who we always sling you know "you miserable old git" T would go "yeah I am. Oh bloody hell if I'd known you were coming I wouldn't have come" "well we wouldn't have come either" You know we would just have that banter. And it's all just jokey and that, I'd put that on my head. And he's just taken a mouthful of food and he had to get up and go into the kitchen. "You almost killed me girl" "Well there you go. That will teach you" And I've been walking past the mirror on a couple of occasions, and I've gone "(intake of breath)" and P would go "what, what?" and I'd go "Jesus when did that tit fall off then? When did that happen?" "oh I don't know darling you must have been born like it" "Oh god, I'm deformed" We just have this, you know. Because I have got a pretty warped sense of humour. But yeah it does you know. So, things like that I don't have a problem with my body image. Because who sees it?" (Mei, interview 3)

Disability: navigating a new normal

Only Carolyn felt that she had any form of disability because of her cancer, and this was primarily due to her stoma and using the disabled toilet, clearly referencing the hidden disability stigma. But she was adamant that she wanted to take control of her life. She did not see herself as a person with a disability, but the possession of a key to the disabled toilets gave her this identity. She felt a tension when out in public by her lack of an outwardly obvious "disabled" body and she was always prepared to respond to challenges she may encounter when using disabled facilities.

> "I'm ready to say something if there is a queue because I'm aware. We went to the T the other day and I used the disabled loo and I'm always ready to say something. I'm aware I don't look disabled, but no one's challenged me yet. So maybe I look worse than I think. I'm conscious that I'm not in a wheelchair." (Carolyn, interview 6)

The stoma had a profound impact on her daily life.

> "Yes, basically from the start you just carry a kit around with you. I've always got a spare kit. And then the days when you've got diarrhoea you probably haven't been well enough to go anywhere so I've been pretty much house bound… It's when with the chemo, the side effects, diarrhoea and then you have to change it 5 times a day, just the practical side of it more than anything now. So, if I have to do it you know, it's for life, so be it. I'll cope. But I don't like going to quiet films anymore. Just silly things like that" (Carolyn, interview 6)

Carolyn also spoke about wanting to return to her job, but questioned how she could do this with a changed body and the physical nature of the role. There were options for adapted protective equipment, but her main concern was a question of how do you control something that you have very little control over. Her stoma could act at any time and managing this in a job where you do not know what you will be doing at any one time is problematic. So, for Carolyn, not only was the cancer threatening her very existence, but it was also changing her professional future, taking away a career she loved. Her life is changing all around her and she has no control over this, she cannot even control when and where her bowels work, something most of us take for granted. She now uses disabled facilities, giving her a new identity she did not ask for or does not recognise for herself – the disabled toilet makes her disabled – the stoma disables her not the cancer – but the cancer gave her the stoma – so the cancer disabled her!

> "I'm a bit worried about work because of this stoma, I have to wear a stab vest and it literally the bottom of that would be right on top so that will have to be looked at. I have been told that you can get a protective cover, a sort of band. So, there will be a way around that

> hopefully… But it is the days like today when I'm well and it's behaving that aren't difficult. So, with work going back to the front line could be interesting. But I'll do it." (Carolyn, interview 6)

For Judy when navigating her new normal she questioned how to best manage the practicalities of living with the results of cancer treatment particularly the difficulties managing social interactions with a limited voice.

> "And I just you know, even now I'd be like, like Sunday we were all out. Me and P are in the front and there are 3 of them in the back. And I said "P, I can't shout loud enough for them" because they are all arguing and um. But it was quite difficult. I found trying to change or do a few things on the phone was hopeless. I'd ordered some stuff from Next and anyway I couldn't get it to work. And then they said ring and I thought right, telly off, everything. And I still have a bit of a problem, psychological problem. But I couldn't say the number 8 and it was like (mutters) and they'd go "pardon?" And I thought "no I'm just going to leave this" And then people would say to me "It's getting so much better" "oh is it" you know. So that was confidence for me then to because they give you exercises and like anything you forget about. And the only one I really stuck to is singing in the shower. And you really don't want to hear that." (Judy, interview 5)

Hair

Two key narratives stand out about hair loss, anticipation, and actuality. Stories of hair loss are well documented in the cancer literature, with the focus on gender expression. The stories presented here reflect this.

The anticipation of hair loss includes emotional and physical planning, humour, and shaving.

> "I said "I'm not wearing a wig" I said "with my luck they'll be a strong gust of wind and it'll take off rolling down the road. Now I'm chasing after a bloody wig, and someone thinks I'm chasing a small animal. I will wear bandanas, Thank you very much. So, I got that all sorted in my head. I was going to have a head shaving party. And if my hair starts falling out, if we have a head shaving party the first that comes out, we'll have the party, booze, food, and we'll have a laugh and then we will sit down, and D will shave my hair. And then everybody's there together." Because otherwise I think that's a huge barrier because people don't know what to say. So, I thought no it's very important that they're there, that our friends that are important to us needed to be there to see the hair coming off. So, there weren't any barriers." (Mei, interview 3)

When the planning failed the impact of hair loss was deeply felt.

> "That was the other thing that shocked me as well because I, when you have your preparation for it she said "you will lose your hair" and I said "will it happen straightaway or what" So she said "oh no probably about 2nd or 3rd go in" And of course it started coming just after I'd had the 1st lot you know. And it just come in clumps. So, I just shaved it and that was it done and just wore hats and scarves." (Gail, interview 2)

> "So then when this happened, and it came out and I'd had one course and I noticed it was like that. I was in the garden, and I had a bit of a wobble. As much as I thought it was OK, I actually didn't like it. Well, what do I do? I didn't know it would affect me like that. And then my eyebrows and my eye lashes and everything else." (Judy, interview 5)

Wigs were not viewed favourably and were either dismissed with humour or by highlighting their impracticality or uncomfortable nature. Cold capping was also deemed as ineffective and mostly avoided. The women in the study chose to wear scarves and caps to cover their heads or to present bald, pushing back against gendered expectations.

Samantha described her traumatic experience with cold capping, one that started out positively, despite resulting in some hair loss, but quickly transitioned into an overwhelming and traumatic experience. Samantha shared feeling out of control and panicked during this event; as the situation could not be immediately rectified safely, she had to endure the sensations overwhelming her for some time heightening her distress and loss of control.

> "I did try the cold cap the first time. It's as they say it is. It's not very pleasant. It's like "ok I'm ready for this" and it was the first chemo experience too, so it was all very new and exciting … So, the time it had got through to the third week I'd just started, just very, very slightly started to come out. So, I was like OK, so I tried the second cold cap. But the second cold cap went so badly wrong. For some reason I felt so sick doing it. It's an unusual reaction and it doesn't happen very often that I was like "you have to get this off me now because I am going to be sick" … And then this big heavy, heavy hat thing got put on me and I was already feeling a bit, because some of the things as they are going through me it's making me feel a little but like headachy. And I leant forward and my whole head dropped. It was like being on a boat because I wasn't in control of my head and it made me feel so, so sick, you know that whole when the heat rises and it's like "I need some air. I need some air" Because with the cold cap you wrap up, like a blanket on, heated blanket, scarf on, because it's actually quite freezing. And I'm like "take these things off me. I need air" So they were preparing the anti-nausea and

> then I sit on my head. I couldn't take it off straight away because they had switched the machine off because they have to let it defrost. Because it freezes all the hair. So after about 15/20 minutes they could take it off and then I didn't do it again because it was so horrendous." (Samantha, interview 8)

And despite thinking they would be unaffected by hair loss participants talked about being shocked at how they were feeling when they were confronted with the situation

> "I didn't think it would affect me. I think that's. Because I just say "oh well so be it. If that's the worst it's going to do, then so be it" But when it actually happened, I thought "I don't think I like this" and I looked such a prat in a hat. I was like a bloody beanie hat that I had then I bought some bandanas and that was even worse still. So, I would go out bald in the end." (Judy, interview 5)

Following her negative experience with cold capping Samantha goes on to describe how she took back control by deciding when she would actually be seen as bald. This moment was actively shared with her wife, a moment of connection between the couple:

> "I then said to P, "P I think it's time. I think it's time" …There was no balding, no nothing. It was just because my hair was so thick that losing 40% of it just looked like everyone else still. And she grabbed a little bit here and she goes "no it's still" and that's when a great big chunk came out…it was like OK, so that's that done. Oh yes that has to be, happen. So, P, she shaved my hair. it's funny because I did buy a wig. And I wore that wig twice. And it was just so uncomfortable, and I felt that I was wearing a wig even though it was quite good. And because it was winter, I basically wore little beanies and woolly hats. And it was kind of acceptable these days because some people wear woolly hats inside, you know in pubs and stuff, you just see it around and people just wear it the whole time." (Samantha interview 8)

Sex and intimacy

It is well recognised that the presence of a stoma can have a negative impact on intimacy and sexual activity amongst couples however, Carolyn's partners acceptance of the stoma and talking about it in positive terms helped this couple navigate this distressing time. Focusing instead on what the stoma represents to them, a chance at life.

> "P being so brilliant about it and completely unfazed by the look of it. Sort of saying "it's actually really pretty" She was brilliant., her reaction helped me a lot. Because a huge part of our relationship was the intimate side of it so that really bothered me, but she couldn't be more supportive and unbothered… And ok if it's a bag for life, fine, I've at least now got my

> life. I'll deal with it." (Carolyn, interview 6)

However, this wasn't the case for Mary and her partner at the time. Contrary to general perceptions that lesbians are less worried about body aesthetics, Mary's partner struggled with the loss of her breast, and this had an impact on Mary's thoughts about seeking another relationship.

> "I think she missed the breast as well. Also, she did say that the kind of body shape thing made a difference as well, that she found that difficult. Now she wouldn't say that that's why we split up, but she absolutely wouldn't. But things did change you know in terms of our relationship and in terms of how she felt about me..." (Mary, interview 9)

> "actually, I am very aware you know, now being single and considering maybe if I did get into another relationship I am aware of being single breasted and that being perhaps a bit weird. So, I don't know how I would face that really going into another relationship." (Mary, interview 9)

For Mei, treatment for her breast cancer had eliminated her libido, affecting her intimate partnership with her wife. Mei's wife joined in during this discussion, emphasising the importance to them as a couple about the loss of this vital aspect of their relationship, whilst also supporting Mei come to terms with something she had no control over. There is within this conversation a real sense of inescapability.

> "I've got absolutely no sex drive.
>
> *Completely switched off. But whether it does that for every woman or not I don't know. [P]*
>
> And then you see is it the Tamoxifen or is it now because of my age, you know the menopause. It's just shoving me straight into menopause, isn't it? So, you won't be embarrassed, P was hoping when I came off the Tamoxifen and I still have one ovary that might be spitting a little bit of hormones out that I might go "oh hello Mei. Do you think you might be able to satisfy my nymphomaniac tendencies?
>
> *Self-confessed one [P]*
>
> Yes, you are a self-confessed nympho
>
> When we change the names, you can call her nympho. That is P, it's not a bone of contention.
>
> *It's not a problem, I'm not making a big deal out of it. It's just um [P]*

I'll just go "all right then, clamber on" "Oh that's just put me right off now. I was only joking" and we'll have a laugh. But I have absolutely no sex drive at all which is

But then what it does do is make you think of what [P]

And then I feel guilty.

But then there is more to life isn't there? Everybody even heterosexual couples get to a stage in their lives where it's too much bother. And you just have to look at the richness of togetherness as opposed to. And you know and the mind [P]

You see in my head I've now become like ex H, the second husband where he was like a big brother and there was you know, once you've gone past trying to have children because he wasn't into sex at all, and now I feel I've come into like a sister.

This isn't something we have a big argument about because life is too short. [P]

We don't and we've just come to terms with it." (Mei, interview 3)

Surviving treatment

The number and types of treatments the participants underwent were varied in all ways; length of time they were undergoing treatment, number of different treatments, perceived complexity, perceived impact physically, psychologically, and emotionally, perceived intensity. But a common theme among the participants was how they spoke about how others judged their cancer therapy; citing being told stories of other relatives and friends experiences as a way to judge how unwell they we going to be or how unwell they "should" be. The participants found this particularly unhelpful and at times found it to be a negative, controlling mechanism by their relatives, friends, colleagues, enforcing norms within the cancer sick role, this is how it should be for you, this is how you should behave whilst you are having treatment and how you should recover once your treatment has completed.

When asked about the treatments they were expecting or had received this led to a long list of surgeries, drugs, radiotherapy, that rolled off the tongue reminding me of nurses who had been working in a cancer care setting for many years. These women had become experts in their cancer.

> "Right to date I've had 4 rounds of. Oh, first of all an operation to put a stoma in. Then 4 rounds of chemo. Then 5 weeks of radiotherapy with chemo. And we are at the point now, hooray, it's shrunk enough the tumour and the next thing is, it's going to be removed on the 10th" (Carolyn, interview 6).

Alternatives

Alternatives or complementary therapy was researched by some participants or was bought to their attention by friends and relatives. This seemed to be accepted and for some of the women this became part of their daily lives. Nutritional supplementation, changing from animal-based products to plant-based foods, using teas and tinctures to reduce anxiety or aid sleep. Partners were often engaged in this activity, shopping for items, preparing foods, giving them something tangible and practical to focus on at a time when there was very little they could do to help.

> "I kind of figured that well they give people which is essentially an anti-anxiety medication that seems to be the pharmacological way of treating hot flushes so therefore if I drink things like camomile tea and Valerian before bed and things like that then perhaps… I introduce those calming things to see if it helps." (Samantha interview 8)

For Sabrina it seemed to be the one aspect of her life that she could take control of and be doing something to fight against her cancer

> I remember going to visit her as well and she was telling me what she was eating you know and stuff like that. So in the first 2 weeks after the operation, I was like hardly eating this and hardly eating that and D was looking after me and buying this and buying that. And then F1 came down and she's made this fantastic cake and I said, "but it's got butter in it" And she said "I know but you've got to have some" you know "you can't have a cake without butter". So, then I was thinking "oh right, if she's doing that, therefore she's not that you know, that precious about it. And then I've read this book that this friend told me about which was really interesting, and this woman had had, Jean Plante? Have you Professor Jean Plante?
>
> **Yes I know the name. I don't think I've read the book.**
>
> "Beat cancer" and stuff. So, she's had breast cancer 4 times so the only way she's managed to manage it is by eating virtually a vegan diet. And she did lots of research in China where the incidence is much lower of breast cancer and other cancers anyway. So, it's all to do with proteins. So, I was reading all about that. And so, yes, I was like. But then I spoke to the surgeon, and he said just eat healthily" So I suppose again I do, I've always thought about eating healthily since I was at University and I probably don't eat that healthily but you know, I like the idea politically of eating organic foods and things that aren't tainted with chemicals and things like that but I don't always do it."

When participants began cancer treatments, they were told to stop their complementary therapy, stating that it was contra-indicated with their prescribed therapy despite there being scant evidence available on these interactions; what their impact might be, the consequences or outcomes of taking various remedies. A blanket "no" exists to safeguard, but raises the question who is this safeguarding, the patient, or the healthcare system?

> "We got quite a lot of expensive supplements. And then when we got to chemo, I gave them a list of everything we were on. They did a blanket "no" to the lot. But you just have to respect that. I'm back on them now." (Carolyn interview 6)

Chemotherapy

Chemotherapy had a major impact on the wellbeing of all the participants who received it. The overwhelming narrative here is one of living through hell, a total wipe out; physically, emotionally, and psychologically. Participants spoke of the nightmare of enduring side effects from fatigue, alopecia, nausea, and vomiting. There were admissions to hospital for the treatment of sepsis. Participants spoke of feeling wretched and it being harder to recover each time they had a treatment, the illusion of a week off treatment was instead experienced as a time when all their energy was exhausted, they were “clobbered”, “depressed” and “lost track of the bad days” there were so many of them. There were many visits to accident and emergency centres or back to the chemotherapy units for advice, support, and management of the uncontrollable side effects.

> “I was so anxious beforehand. I was almost crying, well I would be crying the day before, the lead-up as I realised that chemo was coming around again. That was a like a massive breakdown and crying and saying “I don’t want to do it. I don’t want to do it… You see sometimes that’ll I break down into tears particularly before chemo. As I was saying I don’t want to go and I didn’t feel strong ever, I didn’t, and a lot of time I would be in almost denial that it was even happening. It was terrible, really terrible.” (Samantha, interview 8)

Carolyn specifically spoke of the trauma of having a colostomy caused when she experienced severe diarrhoea and the lack of control that ensured.

> “I ended up in A&E. but it wasn’t, it was literally just side effects. And with a bag that was no fun. That was probably the toughest time.” (Carolyn, interview 6)

Chemotherapy was seen as an essential treatment for their cancer though, providing hope when the disease was aggressive, or as a safety net, preventing the recurrence of the cancer, weeks, months, or years in the future. This was something to be endured, to be got through as safely as possible.

> “They said that the cancer was quite an aggressive cancer and although they they’d got it all and it hadn’t gone into the lymph nodes they thought that I should have a course of chemotherapy just to be on the safe side. Side effects yeah it is horrible. It’s not a nice thing to go through. No, it makes you feel wretched is the word I would use, real wretched. And the further on you get, I don’t know if this is true for everybody but certainly for me it was, each time took you longer to recover, to sort of start feeling” (Gail, interview 2)

Carolyn spoke of the shock the chemotherapy consultation induced, this was for her when reality hit home, how sick she really was.

> “Chemo, I just got on with it. I think me being me I put on a bit of a brave face. I just couldn’t believe I had that appointment where the nurse just talks you through everything and I just sat there thinking, I don’t believe this. D1 was with us too. So just the support has been phenomenal for me, and we’ve always been honest with people up until, the surgeon telling us, an operation is not definite. We will talk about it. D1 was there too, and I just sat there thinking “I don’t believe I’m in this appointment hearing about chemo” It was the shock still. That’s when I felt my ill-est and probably the most depressed was during the chemo.”

Nausea and vomiting were graphically described in visceral and emotional terms, sights and smells triggering bouts of vomiting or a constant battle with nausea only controlled by the constant monitoring of the clock and the well-timed administration of anti-emetic drugs, living anti-nausea drug to anti-nausea drug. Well-meaning care packages of toiletries had to be abandoned or rejected as the strong-smelling perfumes would trigger another session of vomiting.

> "Just through nausea, really, really bad and they just through everything at me. The first round I couldn't basically move from horizontal position for 12 hours and then I needed assistance getting up for a few days after that. Ironically, I was never actually sick because I did have the anti-nausea. I just lived anti-nausea to anti-nausea. I couldn't eat anything until I'd actually had the anti-nausea tablet because I just felt so sick, so sensitive to smell that there was a ban on any cleaning, perfume, anything because I'd be lying in bed and then the flat, the bathroom is actually quite close to the bedroom. But I smell particular shower gel that K was using. I was like "you can't use that shower gel" because it was just so nauseous… There's a million bunches of flowers that I got and someone, bless them, actually got a whole load of Molton Brown bath products instead of flowers. But my god, that stuff is so heavily scented that I cannot even stand to you know. And the whole because also ironically the [clinic] had Molton Brown in their bathrooms and I could not even use the hand wash, I had to use the aseptic wipes because of the whole smell was just so strong." (Samantha, interview 8)

Judy experienced a constant struggle with an unending list of complications, symptoms and side effects and fluctuating coping, one day she was able to carry on but others she was just overwhelmed and physically exhausted.

> "Some days I couldn't even clean my teeth. I couldn't get my head off the pillow. It was just awful; you know that bit." (Judy interview 5)

Decisions

There is a common rhetoric in health care that decisions about treatment are shared and are made in partnership between the patient and the doctor. However, this partnership decision making was not observed in any of the narratives, rather the conversations highlighted doctors informing the participants of what was "best for them" and the participant readily agreeing with the doctor's decision, despite this not necessarily being what they wanted for themselves. They spoke in terms of the doctors being the experts and knowing best even when this did not turn out to be the case.

In Mei's situation she wanted a mastectomy and was convinced this was the best option for her but was persuaded to have a lumpectomy by the surgeon. It was only after the multidisciplinary team insisted on undertaking an MRI scan and further problematic areas were discovered that the treatment plan was amended to a mastectomy. However, she did not see this as worrying, instead provided justification for his treatment decisions.

> “So, then my surgeon told me that on the results appointment he said “oh it’s unstable so really, I’m really delighted. I was wrong pushing for the lumpectomy” I said, “well you weren’t really wrong, but you didn’t know these other 2 areas existed” So he said “yes I’m delighted, I’m pleased that the team have said that they wanted you to go for this MRI because otherwise you would have been back to me within a year with these two other areas.” (Mei interview 3)

But for Mei this change involved a psychological readjustment back to the idea of losing her breast. This demonstrates the continued, and pervasive relinquishing of control over our bodies to the medical profession, and uncertainty as to what partnership in care actually means, or if it is even possible. There was no example given of patients being given a choice in treatment options, everything was presented from a paternalistic “this is what must happen, I know what is best for you” position, and decision making was readily surrendered by the participants.

> “And obviously we discussed it. Well, there was no discussion. I said, “if that’s what you think I’ve got to have then then I’ll have it” you know.” (Gail, interview 2)

> “Then my surgeon said which really threw me, he said, “we’ll do a lumpectomy” And I thought I really don’t want a lumpectomy. I said, “oh you wouldn’t consider a mastectomy” he said, “no because it is only a very small lump” I said, “oh ok”” (Mei, interview 3)

> “Basically, she says that “OK I will tell you what I think we need to do for you and if you disagree then we’ll argue about it. But basically, your whole breast needs coming off because not only will the 2 lumps that were there, that were cancerous and the whole of the right breast is pre-cancerous.” So that came off. But it is just about trusting, and I trusted her implicitly. I also trusted my oncologist implicitly.” (Samantha, interview 8)

Of all the treatment journeys Kate’s was probably the most intense. She was diagnosed in a critical condition and needed immediate and prolonged lifesaving treatment, this meant opportunities for discussion and decision-making were not available. Decisions had to be made without delay. But this created fear and uncertainty for both Kate and her partner.

> Um, I think it was about five weeks and obviously had all the chemotherapy um, loads of blood tests and all the chemotherapy and then they had to decide what the plan of treatment was because I had this horrible mutant gene, they said um, Dr1 I was under initially, he came in

> the room and he said “right we’re going to test your sister, sibling and if she’s a match then you’re going to have a full transplant. He said, “we can’t muck around with this”, he said [pause] “you need it”. P was absolutely mortified because you know I was, there were other people that I’d sort of befriended on the ward that was diagnosed and they weren’t gonna have the full-blown transplant. They were just going to have chemotherapy and she thought at the time “why, why are you going to have the full treatment, she’s got the worse form” and the doctors said “you have got a nasty gene and if we don’t get rid of it you will die” basically. And so, she was like absolutely pooping herself and why am I the only one going to have all this treatment, they’re only having chemotherapy you know what’s going on? So, she was really scared which is understandable. But it turned out to be the only thing that saved my life, because the other people who didn’t have the full transplant, they’ve all died.” (Kate, interview 1)

Later, during her recovery Kate began questioning decisions that had been made and why she had not been offered certain interventions, and it was at this point that the scale of her situation hit home.

> “They never really sat down no and discussed the consequences of us. Because one thing I said to P, I said “when I was first diagnosed” I said “I was never offered any egg harvesting” and she, I said “coz I don’t know why” I said “ coz they assume I’m gay and I’m not going to have children and I haven’t had children up until now” and she said “there wasn’t time for you to have that” she said “they needed to treat you now” I said “oh right coz I couldn’t remember all the details and she said “no I think they would have done” but she said “ you didn’t have time, they had to blitz you with chemo straight away. I said, “right ok”” (Kate, interview 1)

I just get on with it, coping with cancer.

Most of the stories in this section focus on actions and behaviours – what the participants did as a result of what they were thinking and feeling, rather than an in-depth exploration of their thoughts at the time, potentially because it was easier to describe what happened rather than risk triggering emotional reactions.

Resilience

There was a range of emotional reactions expressed at the diagnosis and ongoing burden of treatment, again this is well documented in other cancer literature on the crisis of diagnosis for example. However, what is interesting here is the role that their identity as lesbian women played in their different responses, each participant was asked whether they felt that their identity as a gay or lesbian woman had influenced their reaction to their cancer and all felt that this was probably significant to them. That dealing with society's reactions to them being gay had created a sense of resilience in them that they were then able to draw on when diagnosed with cancer, an inner strength.

> "Probably. Yes, I guess it probably did. I hadn't thought about it but I guess it did." (Gail, interview 2)

> "I am just me. I am gay and that is part of me and it's a very big part of me and the person I am. But whether that makes me more sort of stoic or whether that's just me, so you know what I mean? It's difficult to um. I am quite good at dealing with things so when there is a crisis or anything I do just, I'm quite clear headed and just get on with it. I'm not overly emotional. I don't cry, I just get on with it. If this is what it is, then I'm going to have to deal with it. And whether that is stuff because I've had to deal with things. Probably the way I dealt with it, probably being, going to those things on my own it was very much the way I'd known I was gay at the age of 11 and you just keep it to yourself. For those 7 years I didn't tell anyone. I hadn't spoken to anyone about it and I suspect that is part of my personality now which meant that I wanted to go to those meetings on my own because I couldn't deal with anyone else falling apart or even asking questions which is so mean because they've got their own questions but this is my time. I don't want to deal with your questions because they might not be my questions. So, I think that's probably quite a personality trait that came from those 7 years when I wasn't. So, I do tend to deal with things on my own. And I also think that I don't think I'll ever go and see a therapist or anything because I can't believe anybody would know better that I would. I'll sort it out myself. So, what would be the point?" (Tracy, interview 4)

> "And there are sort of parallels there. I can't remember the phrase I used to use. But I'm sure having grown up gay I think you probably do get more of an inner strength because you're

facing, you're dealing with something that society back then didn't really accept. Possibly am I a bit stronger because of that… Possibly I've got a bit of an extra inner strength. I don't know… I definitely think you're right. And dealing with adversity, maybe having dealt with it before." (Carolyn, interview 6)

"So I think that's how, yes so maybe because of being a lesbian, but I think it started before that. It started from when I was, you know, my mother, perhaps. So being, that knowing how to deal with it is, but maybe now with the cancer diagnosis… But I suppose I would have dealt with it and I would have got on with it. And that's what you have to do in the end, at the end of the day, just get on with it… But yes, I can understand. I'm living outside of society so being, you know, having cancer is outside of the you know. I can understand that. And so, I may be a bit more resilient in one sense." (Sabrina, interview 7)

"I think that, yeah my experience even though I would feel that I am sensitive emotionally I would think depressed and you know very upset especially coming out. And of course in my, as in coming out of the cancer the other side and also different points during my life but because I have learnt to deal with that and learnt to recognise these things in myself then I actually do seek help because I don't want to go where I went before when I was admitted kind of thing. And just tracking back why I had those mental health issues in the first place was because I felt that it was because of the whole strain that I put on myself being a young gay child growing up. So yeah I mean I don't know, because I only know how I've dealt with it myself." (Samantha, interview 8)

"Yes because I think the thing about being a lesbian we are different. I've got two girls. Bringing up girls, you know they're funnelled into pink, pink, pink, all this. You know this is how girls should be. This is especially how heterosexual women should be. So then when you identify as a lesbian you can throw it all out. So, you can start again. For instance, being able to resist the whole reconstruction thing and being able to think "actually how do I feel about my body?" Because I've already, yeah as you say, as a lesbian I've decided "actually sexually I'm not interested in men anymore. I say goodbye to that little box you're trying to put me in there. So I'm going to create my own space here where I feel comfortable" So the whole thing about what's expected of you as a woman when you have a breast cancer diagnosis in particular it doesn't apply particularly to me. It's going and I feel strong that I can say actually what you're saying applies to those other women maybe, those heterosexual women might well love to have reconstruction or really want to wear a prosthesis all the time or whatever...

> You're talking about those women. But actually me, I'm just a little bit different" and yes, I'm used to just being a bit different." (Mary, interview 9)

Feelings

Cancer diagnoses and treatments leave people emotionally vulnerable. Carolyn talks about the reality of cancer and chemotherapy hitting her whilst she was sitting in the pre-chemotherapy assessment meeting. Shock and depression being the overwhelming emotional response.

> "Just emotionally shattering… I said, "look I'm likely to burst into tears if anyone says anything so we can just let them know that i don't want to talk". So, there was an elephant in the room…
>
> I just sat there thinking "I don't believe I'm in this appointment hearing about chemo" It was the shock still. That's when I felt my ill-est and probably the most depressed was during the chemo. I definitely felt depressed. It's not the best time of year anyway the winter. I think we're all a bit like that aren't we." (Carolyn, interview 6)

Judy speaks of the fear she encountered whilst waiting to hear about the effectiveness of a new trial drug she was taking. Failure of her cancer to respond to the drug would mean progression of her disease. This is an ongoing fear that is faced at every scan result appointment, will this be the time you tell me its not working any more.

> "I was so scared. I said "I'm just so scared" … because I'd been on the trial drug, they were scanning me every 6 weeks. Which is great to monitor it, but it doesn't do you any good to think if something's happening… It's 6 of 1 and half a dozen of the other. So, she's saying to me "are you all right" "I'm bricking it" (Judy, interview 5)

Judy, Carolyn and Gail talk about how seeing adverts on TV for cancer research was triggering for them emotionally. Partly the Marley and me effect, where watching a sad movie provides cover to release otherwise hidden emotions, but here it is more of an overwhelming catalyst that they have little control over. And these need to be avoided to maintain that sense of control and "togetherness", the stoic front as Tracy phrased it.

> "you know that advert? The MacMillan? Where the guy is stood. Have you seen it? Where he is stood on the beach lonely. And that sums up really a little bit of how you feel a little bit of how you feel and you know you've got. I don't know how people get through it that are on their own. That was the one thing that kind of struck me." (Gail, interview 2)
>
> "But suddenly something will catch you unawares, you'll see something on telly" (Carolyn, interview 6)

> "Of course, like you see all these people who've been dying and what's that all about? You know, short illness with cancer. I'm like this. I don't want to hear it. Or every bloody advert. If it wasn't for those adverts and people donating, I wouldn't be getting any kind of treatment like I am which I am so grateful for. But sometimes I just think dealing with cancer on your own and I'm thinking I don't want to hear. Do you know what I mean? It almost seems like you've had a bereavement. There is always a bloody funeral on the telly isn't there. It always just seems a bit more raw. And sometimes when I'm you know, when it's all tickety boo boo but just sometimes I think get it over, go." (Judy, interview 5)

Quiet times also acted as catalysts for an emotional reaction, a time and space for reflection and realisation.

> "I mean I have very quiet times, not because I'm low but just because I over-analyse things a lot and that's my problem. I really do over-analyse things. I really need to learn how to stop doing that." (Melissa, interview 10)

> "Because I'm someone, I'm a bit more bury my head in the sand… Because that's me. I just get on… And then I will in my own time and at my own pace I will occasionally dip in." (R int 6)

> "So, I came home and told P and phoned Mum and Dad and everything and then went to the zoo. I went to the zoo, wandered around, looking at the gorillas and things because you have to take it out. And then after while I cried, I think once, the whole time. That was when I first got the diagnosis, that night. But that was only for about 10 minutes and then it was fine." (Tracy, interview 4)

One day at a time

Judy gave the clearest example of someone who really did not want to know the detailed information about her cancer and her prognosis.

> "I think the more I know up here, the more games you can play with nothing you know anything about. You know you convince yourself all sorts. That's the way I think anyway. So, when I go in for check-ups and all that I just say "Ok or not?" "no" "ok what are we doing then? Don't tell me why it's not" So anyway I don't know, I try to remain, I want to be as positive as I can about it. I don't want to waste good time and energy on something that I don't know about. And even if I did why do I want to shit myself up even knowing more about it. Some people want to know the ins and outs. I really, really don't. I think it keeps my head

> right. It keeps me feeling I hope stronger whether it is or not. But that's how it works for me. So that's how I look at it. But of course, I won't look on the internet. If any letters come P opens them and says "oh you've just got to be here" or wherever. I'm not in denial but I just that's the way I deal with it. So that sort of side of it and P and I have never really discussed it and I just say to her you know I'll be all right when I've had a check-up. Sometimes and I get in the shower and the bottom lip goes. She says "look you'll be fine" "you've said that. That will do for me" And if it's not then we'll deal with that when it happens" (Judy, interview 5)

She talks about the impact of hearing news about her scans and not wanting to confront the interpretations, only wanting to know enough information to understand what would be happening next in her treatment schedule. She asks the question but then retreats before the answer can be given.

> "Because as I say again thinking about what I could have or haven't got that it could turn. P only yesterday I said to her "I have the" I think the scans coming on the 12th and I think the idea really is, is what this is all doing now, is it will flare up, anything that's being laying there dormant that we've stopped. So, I said to her "now is it a good thing or bad thing for it to flare up?" and she said "well" I said "I didn't ask that, no fine" I mean there is, never had it, didn't realise it, been and gone. They've invited me to this, not an open day, but a day at the Hilton, where Dr X and other lung cancer sufferers would be there and what have you and it was a lunch which I thought was fantastic to ask me but then on the other hand I thought am I going to get information overload here which I don't want." (Judy, interview 5)

For Carolyn goal setting, small and large was an essential part of her coping mechanism during her treatment so she could feel as though she was achieving something, these goals ranged from small daily achievements, for example sending an email, to bigger lifetime goals to celebrate the end of her cancer journey.

> "It's not always possible but having a goal or being positive just got to try and do it. And I've had, when I'm well enough, I set myself little goals. I've learnt how to knit, which everyone finds hilarious. Even if I can manage 5 rows a day, I've achieved something that day. Even if I've sent one email or done a bit of weeding in the garden, it's trying to have a goal each day, so you're not feeling absolutely useless or just cook tea if you're well enough, so P doesn't have to do that after a hellish day at work. Or make a phone call. Just tiny things. So, I think because of my personality I'm naturally quite a positive person and that's got me through… And then another goal is Beating Bowel Cancer have a sponsored walk along the Thames every

> year. I'm aiming for 2017 to do it. That's my goal and P wants to do it as well and about 3 friends have said "count us in" So that's the goal." (Carolyn, interview 6)

This was shared by Mary who climbed Cotopaxi after completing her cancer treatment as vindication and proof that she was back to her pre cancer self.

> "Well that as I was saying it felt like a betrayal of my body. So that has been really hard to cope with. However, having said that I've got a really good friend, my mountain climbing friend, who's also a dyke, who worked for MacMillan at the time and 3 years later we climbed Cotopaxi which is the highest live volcano in the world in Ecuador for breast cancer, for cancer, for MacMillan basically. So, we did that as a sponsored thing. And that was a kind of a vindication. It was like "I'm back in the world now. I've recovered. I know I haven't been given the all clear but I'm back to strength and I'm able to do these kind of challenges" (Mary, interview 9)

For Samantha and Melissa, the key to coping with their cancer was emotional labour, knowing when to seek help and putting the work into it, receiving positive reinforcement also aided in this work.

> "I think that, yeah my experience even though I would feel that I am sensitive emotionally I would think depressed and you know very upset especially coming out. And of course, in my, as in coming out of the cancer the other side and also different points during my life but because I have learnt to deal with that and learnt to recognise these things in myself then I actually do seek help because I don't want to go where I went before when I was admitted kind of thing… Work on these emotions that I'm feeling because they do keep popping up every now and again and actually being very upset. So yeah, I mean I don't know, because I only know how I've dealt with it myself. And P and everyone saying I've been so strong. So strong." (Samantha interview 8)

> "I've gone through of a bit of counselling… Because as far as I'm concerned that's part of my recovery process. That's part of helping me deal with everyday things that come up that affect me to do with this… I've just done 3 months of counselling with her." (Melissa, interview 10)

For Tracy and Mei however, pragmatism was a key coping strategy, getting on with it and being self-sufficient.

> "So that is the sort of person I am. I will just get on with it. And I never think "oh why me?" Because you can't say that. If it's not you it's some then it's some other poor bugger, isn't it? So I would rather deal with it." (Mei, interview 3)

Its over

Participants spoke of how coming to the end of treatment was a watershed moment, an emotionally cathartic moment and time allowed a chance to regroup, recover and reflect on what they'd endured.

> "Everyone was saying that during chemo even though I felt terrible I was doing quite well and got on with it during surgery, everything, got on with it, everything was fine. When it all ended, I basically broke down just had just crying all the time I just. And I'm only just beginning to get over that now. If we'd have had this interview 2 weeks ago, 3 weeks ago I'd be crying now." (Samantha, interview 8)

I couldn’t have got through it without her.

My rock

> “So, it’s just being there as a support whether it’s a work colleague or a friend or a family member, is just to make sure that you are always that you’re there in whatever capacity. Whether just sit and listen or I think that’s the most important thing.” (Mei, interview 3)

The participants in this study expressed overwhelming appreciation for the support they have received during their cancer treatments, particularly from their partners and friends. Carolyn reinforced the thought that in times of crisis you learn who your support network is.

> “So out of an absolute utter crisis there has also been lots of good and you really get to know who your friends are.” (Carolyn, interview 6)

For those in a relationship their partner was their primary supporter. Kate’s partner even going so far as to take five months off work to be with her at every moment of her treatment.

> “I know, you just sort of plod on, get on with it and I know I’m going to get out the other end and um, yeah obviously P stayed up there with me all the time. She stayed, um, in the hotel down the road … So, she came in every day and how long did she stay, well she stayed there for the duration… Um, its, it’s really hard, but she really looks after me. She’s a massive support to me, without her I couldn’t have got through this I know that. She’s been there 100%. P was by my side and off work for five months helping me get through this” (Kate, interview 1)

Others also spoke about how they would have not got through their experience without the support of their partner, and their partners going above and beyond, providing the exact type of support they needed.

> “because of C I got through that… I couldn’t have got through it without her. She’s been my rock. And the days I can’t face cooking or anything, she’s really looked after me. And not over mothered. I sort of bristle” (Carolyn, interview 6)

> “But she’s allowed me to read and go off on a complete extreme view if I wanted to. And she’s supported it and I mean she has literally gone. I remember one day she’d gone out and she’d bought almond milk and soya milk and coconut milk and coconut water, and I had all of those because I decided I wasn’t going to have any dairy products at all. So, you know, just things like that which not everybody would be that supportive.” (Sabrina, interview 7)

> “I think P being there really and my girls really got us through it really. It’s really important to have… I just thought if I hadn’t got P and the girls” (Gail, interview 2)

Partners acted as gatekeepers and protecting the participants when dealing with the world was just too much.

> “So, P sort of put a stop to people doing that and then actually they would just text her to say you’ve got to leave Samantha alone because it was just too emotional for me.” (Samantha, interview 8)

Or maintained a high level of positivity, not letting them slip into negative thoughts.

> “She didn’t really say a lot. She just kept, she wouldn’t talk about anything really. No, she did talk that’s wrong. What she wouldn’t talk, wouldn’t have any negativity. We’re positive. We’re going to get through this. We are going to get this sorted. There is no question of anything else happening. This is it. We’re getting through this. It is just a blip. We’ll get through it.” (Gail, interview 2)

It was not always so positive though and Mary did not receive the support from her partner that she thought she might. Mary’s partner had just lost a sibling when Mary was diagnosed, and the impact of this continued grief was that she was not able to be there for Mary and withdrew from the relationship emotionally and physically.

> “The partner I was with at the time. So, she had just the year before her twin sister had died and so she had motor neurone disease. So, she had a very traumatic time and she found me being diagnosed with breast cancer it was like “what are you doing to me? come on” So she found it very difficult, my diagnosis and very threatening and so it was quite difficult with us then.
>
> “I found it very difficult to tell her. I remember it really well. I was in Harley Street. I went to Regents Park, which is really close by, and I just went and sat down in the café and called her up from there because I knew that she would just be devastated and just find it really difficult to cope with. Which she did. So, she was very ambivalent about the whole thing. So, she came sometimes to hospital appointments but generally not. And I found it not very supportive actually having her there because I was worried about how she was, because she had a huge emotional reaction to everything that was being said. And actually, I found it easier to kind of cope with on my own in a way.

> “There was definitely some anger and some resentment around you know my diagnosis. I think you know; she’s been through the most awful trauma, and it almost felt like I was trying to steal the show or something in some way. And she just couldn’t handle it. It was just the wrong time for her. So, we split up about 4 years ago now and I haven’t been in a relationship since.” (Mary, interview 9)

Alongside worrying about their own situation, the women in the study also expressed concerns about how their partners coping with the situation and the stress they were experiencing. Some partners were accessing formal support and others were in roles that enabled them to gain support. However, as Samantha highlighted, participating in support groups brought very specific challenges as a same sex couple.

> “I’ve put her through a lot lately with my illness.” (Carolyn, interview 6)

> “She’s been amazing. She doesn’t really express herself very much. So, she’s, but you know, she’s always been extremely stressed, but I wouldn’t have known it. She wouldn’t have shown it to me. I don’t think, or maybe I’m just unable to read how stressed she is because she doesn’t show it. Or maybe I’m insensitive. I don’t know. But she is quite something, quite special in sort of organising and you know keeping things going and yeah. But we’ve been all right. We’ve just kind of got through it really. I mean you can’t really do anything about it I suppose.” (Sabrina, interview 7)

> “She was on a counselling course, so she was getting sort of co-counselling from doing that, so I think that helped quite a lot. Family, friends, talk to people. You know I was encouraging her to go and talk to others about it and stuff. But yes so, she was doing that, she’s a qualified counsellor. As you can see, we are quite different even though we are close. So, she believes all that nonsense and I don’t.” (Tracy, interview 4)

> “P, she found that being gay and supporting me with breast cancer she, when she went to one of the help meetings because she was struggling at the end of my therapy… she was worried about reoccurrence. And she went to one of the meetings and she felt very out of place because she was the only gay woman there supporting someone with breast cancer. So, the people with breast cancer, there were men there and other people with woman there who were supporting other kinds of cancers. And also, maybe people that were also terminal to, it was an odd thing where people had reoccurred on different things. So, she almost came away from her meeting more worried than when she went in because there was no one she could connect with being lesbian and being supporting. And so that’s an area that I think is lacking,

> same sex kind of support groups.” (Samantha, interview 8)

For Samantha and her partner, being able to access an LGBTQIA+ support group would have helped them express the concerns that were relevant to them.

Mums and others

Within this study all the participants were still in contact with their birth families, and none had experienced a complete breakdown in relationships because of coming out as a lesbian. There were varying degrees of closeness across family groups but during their cancer experience mums were a particularly welcome source of support for most of the participants in the study, and in some instances the cancer diagnosis provided an opportunity to strengthen relationships. Often parents or siblings would accompany the participants to key appointments and treatments when the partner couldn’t, acting as a substitute, taking back the role they had relinquished when their child became an adult.

> “My mum came, and my mum and dad came for me every day. Well, they did come every day to look after me and make sure I’d got food and everything because obviously I was really weak and pathetic. My mum and dad were brilliant, they were there all the time. P was brilliant but she had to go to work. And my mum said to her “you carry on”. They can look after me. So, they were round every day for pretty much the whole time I was off. So, they were excellent actually. They were all really good, really nice, looking after me.” (Tracy, interview 4)

> “that’s been another positive. Mum has left Dad to his own devices and been up here once a month to stay with us for a week for her own reassurance as well. And I think we’ve got to know each other. So that’s been a real positive.” (Carolyn, interview 6)

> “My sister is just wonderful. She’s superb. We’ve really close and she’s always been brilliant actually. My girls are fantastic as well, so they are now in the 20s, the pair of them, So we have a very jokey, I’m still their mum but you know quite adult relationship now. I’ve got a very supportive family overall actually so I’m really lucky in that way and quite caring” (Mary, interview 9)

An aspect already well documented in the LGBTQIA+ cancer literature is the role friends or families of choice play, and this study was no different. All the participants spoke fondly of the support friends provided, linking this to lesbian identity. Support included providing transportation to appointments, keeping company, cooking, and cleaning, as well as offering psychological support and encouragement.

> “as lesbians we support each other. I’ve got great friends. I’ve got fabulous friends.” (Mary, interview 9)

> “I was going to have a head shaving party. P hates parties. She’s just not, I’m a party animal. So she said “god why does everything have to revolve around a party with you?” And I said “Because darling, these are our friends” and I said “well because we don’t know what’s going to happen and you’ll need them. You’ll need their support more than I will because I’ve got you, but you might want to go away and talk to them without me hearing. You know you might want to be strong for me, but you want to really inside cry. So, we need our friends.” (Mei, interview 3)

> “We’ve got lovely friends. We are very, very lucky. There are shed loads to be honest. I mean more than, more than enough. But we are very blessed with really good friends. Which I think has helped as well because they’ve all been so supportive as well. None of us are in one another pockets. We’ll give a bit of space. We’ll either see one another every week for about three weeks or we won’t see anybody for a couple of months. But they have been so supportive as in you know P would want to go out or you know we’ll come and babysit Judy or come over. It’s been really, really fantastic. They are just if anything that needs doing, your garden needs doing. They’ve been fantastic. And I think it’s really helped; you know their support.” (Judy, interview 5)

> “when I was ill two of my good friends came down from London, more three, four. So they came down to see me so yeah… I mean everybody’s been just so lovely. I tell you. I can’t really say how wonderful everybody’s been. It’s just been, you know you were asking about community. All my friends are there, you know. Even though they are not just around the corner they are just there, they are there… And then when I went to have my operation, F1, who is a good friend of ours, she drove us to the hospital, so I had P and F1. So that was nice. And then F1 was with P whilst I had my operation and then F1 drove us back. So that was nice. And when we got back here, F2 was here and F3 was here and F4 and F5, they are the 2 friends, they were here too. So that was really, I had a welcome home. So, it was really nice. Then yesterday I got a text from someone and just “how are you getting on” and you know, it’s just out of the blue and it’s kind of nice. So it’s been really nice” (Sabrina, interview 7)

Practical support was particularly appreciated, especially when it took some of the burden off the partner.

> "then she ran out of holiday basically and had put up for a schedule on icloud and invited our friends to put down a day. Because it was about a 1 o'clock start so basically some people could go to work and have half a day. So, it was like a chemo buddy system so their job was to meet me at chemo but it was much better if actually they came with me. One of the friends would actually travel with me because I was so anxious beforehand. I was almost crying, well I would be crying the day before, the lead-up as I realised that chemo was coming around again. That was a like a massive breakdown and crying and saying "I don't want to do it. I don't want to do it" And the friends would sit with me throughout the whole, between 4-6 hours." (Samantha, interview 8)

> "one of K's friends, work colleague, when she found out and her response was very incredible because people want to give you and buy gifts and stuff when they find out. She said "right, I'm going to drop round some food. When are you in?" and she made little portion of Thai curry. Obviously, what she was making for her family dinner or whatever and then gave us a portion for the 2 of us. Like cauliflower cheese and there was something else like a potato dauphinoise just little things and brought them round in little plastic containers, like takeaway ones and said "there you go, that's for when. Just pop them in the freezer" and just to ease the load off K to make eating easier. And it was, that was like the best thing that anybody could have done or even yeah, I think there needs to be some education about, for all illnesses, what to do to help. To come round and offer to go to maybe Sainsbury's for someone or yeah, I think that would really help. Because you do struggle on by yourself as P taking the brunt of the load and doing everything and just that simple help cleaning or simple help, anything. Because people are too proud to ask. Because everyone says "anything you need" but just bringing something" (Samantha, interview 8)

The participants also made it clear that it was all about the right kind of support, people being able to read just what was needed at any given time. Judy considered if the roles were reversed that she would not be as good as her partner as she would want to over protect her and not give her the freedom she would desire. She compares this to her partner knowing that she did not want to be coddled and needed space, but also that she did need practical help and support at times.

> "See if it was the other way round, I'd get on P's nerves. I'd be overly protective or whatever you know. Where she is not very good at playing nurse, but she knows when to come and say "do you want a cup of coffee?" or "do you want a cup of tea?" or "can I get you anything?" Because I'm not a very good patient. I just like to be left on my own if you like but I like to

> know you're in the background… because I think if you nurse me, you are just making it worse, do you know what I mean?" (Judy, interview 5)

But when this went wrong the impact was overburdening or caused distress. It became too much.

> "Although, it's weird I think a couple of times and she wouldn't know this, but because she's been so upset at times I think "Oh for god's sake, it's me" You know "at least you're not in pain or you haven't got a bag" But that's pretty selfish of me but no she's been absolutely amazing." (Carolyn, interview 6)
>
> "We've got one friend who over fusses and that does my head in so I'm very grateful that C is not like that. Because I'm functioning." (Carolyn, interview 6)
>
> "When I was diagnosed, before I was diagnosed because my immediate boss has had cancer. She had cancer of the stomach or somewhere around that area, 10 years ago. But that turned her into an expert all of a sudden even though it was a different type of cancer, and everybody deals with things differently. But she was forcing her opinions on me basically" (Melissa, interview 10)
>
> "I think at one point, it's an odd thing, when you kind of go into hospital and stuff everyone goes around and then sends a million bunches of flowers and it's like oh my god, not another bunch of flowers. And then all these people around and then everybody texting every single day going "how are you? How are you?" When I kind of didn't even know how I was doing myself, it was really upsetting… To be there having a bad day especially after the surgery to not be able to lift my arm enough to get a glass you know, suddenly this arm was useless. And people asking me how I am and I'm at home by myself, it just became so traumatic." (Samantha interview 8)
>
> "When I was diagnosed she was kind "you've got to stay positive because negativity breeds cancer" And I'm like "what fucking bollocks is that" I'm sorry but how can an emotion breed a disease or you know. It's just crap. And the amount of people that have said that to me. I just want to knock them out." (Melissa interview 10)

When participants asked for time or a different type of support this was not always responded to positively

> "I think my family took that to heart that they basically decided not to contact me at all. And I kind of was like well you know some sort of support would be nice…I should have been being nurtured by them… When I said that I'd bought a wig to my dad's wife she was like "why

> would you do that? I thought that" you know it was like a real big not understanding of what was going to happen and I think that they just didn't understand. They just had no appreciation of how bad it was." (Samantha interview 8)

Support is something that is hugely appreciated during cancer, but it needs to be the right sort of support. Negotiation with the person with cancer, offering practical support, cooking, cleaning, transport, taking the burden off others, and asking specifically what they need is key to this, rather than making assumptions or just waiting to be asked.

Support groups

Some participants had sought support from outside friends and family using social media networks, but this was hedged with a sense of caution and a need to protect themselves from the negativity and misinformation of the internet.

> "But that was a bad time because then you read everything and of course people that put stuff on the internet, they are always the people with negative stories aren't they. So, something like Hyster-Sisters is really good." (Tracy, interview 4)

Whilst others did not feel that this was a useful tool for them or found it difficult to access

> "I don't tend to kind of go into forums and stuff online and all that. The job I do is just so all-encompassing I don't really have time for all that really. So I haven't sought it out." (Mary, interview 9)

> "I didn't reach out to any services during my treatment because it just seemed quite difficult to access." (Samantha, interview 8)

Formal support groups, particularly those focused on a specific cancer, were not universally well received. Mei, particularly had a negative response to them, thinking of them as only an opportunity to focus on the negative. She considers this view a remnant of her time as a midwife and the experiences she had of working professionally with midwifery and neonatal support groups.

> "See I don't like support groups. And so, I, there was a support group, but I thought "no". Because I know what they're like. I've been to support groups in the past like through midwifery or through the neonatal side of things where you are there, it is supposed to be patient led but you are there as a member of staff to give support or whatever. And it turns into a "woe is me" I thought "I've had breast cancer. It's been got rid of. I don't need to listen to people saying 'ooh, oh my god. I brush my hair and a clump of hair fell out' and 'I'm really not coping with being disfigured'" because some people do labour it, don't they? It's human

> nature. Some people cope, some don't. And I thought I didn't need to be in that environment where sometimes some people I am sure go when they are feeling quite chipper and chirpy and then they come out and they don't feel so chipper and chirpy because Mildred two seats down was really "why me? Why me? Why me?" So I thought "no, no"" (Mei, interview 3)

However, Mei did find her support group and one she really benefited from, a breast cancer choir.

> "I belong to a breast cancer choir that has been going well we started in 2013 in September. So that keeps me busy because I'm the chairperson of that so. So it's been very good." (Mei, interview 3)

Like all cancer support groups, membership of a group that is dependent on the diagnosis of a life-threatening disease can bring participants closer to facing their own mortality, but again Mei dealt with this in a pragmatic way.

> "Unfortunately, in the choir, last year and the year before we lost 2 of the members to, they had secondaries. Or they had a re-occurrence of the breast cancer followed by secondaries. But that's the nature of the beast and that's what I point out to some of the choir members who get really upset. I said, "well one, we are coming into that age group anyway." Most of us are in our late 40s, early 50s, there are a couple who are in their 70s and 80s. So that automatically counts against you. And then I said, "and then we've all had breast cancer, so you are going to have to get your head around that because it's going to happen". (Mei, interview 3)

But for other participants this closeness to mortality was something they did not want to engage with

> "But you know I didn't want to, I was quite happy to be supportive of people not very well, but I didn't want to be in the middle of people not being very well and hearing why they're not very well, no." (Judy, interview 5)

> "Ironically a few years ago I had friends of mine going through bowel cancer and they pretty much started a stoma group in T and ironically got me to go and speak about my Police job. With my diagnosis I had them on at me to join the group and I just couldn't. I didn't feel I needed it. So, I've never joined that group" (Carolyn, interview 6)

Samantha, however embraced the concept to the support group and of hearing and learning from other people's experiences. She was also the only participant to talk about being gay in a support group and the fear this provoked in having to come out to a group of strangers.

> “I got a leaflet through from the breast surgeon the breast care nurse at [hospital] and so “ok that sounds good” And I also went to a few things at the [clinic] like moving on and going back to work lectures and stuff. So, I really got myself out there to help because I recognised that I needed help emotionally and I needed to see people that had gone through the same, if similar, experiences and needed to hear their stories as well. Then when I got put in that group I suddenly realised “oh my god, these are all straight, possibly married” you know they’re very different kind of people, but from different walks of life but very different… It was sort of like “oh my god I don’t, obviously I’m here to be open and talk about the help but I feel very strange like I actually have to come out to these people”. And so, I kind of again worried a little bit because how that was going to go because we’re supposed to be in a safe environment… So, I went home to P and said “I don’t know. I feel very uncomfortable. I don’t know how it’s going to go because I feel like I’m going to be judged” and then I think it was, yeah it must have been the second one it just happened to be brought up in conversation and this is the way that I tend to do it anyway whilst having a conversation. I, my wife and then it’s done. And actually, nobody even expression changed, and I was like “Ok” there was no worry. There was a worry for no reason.” (Samantha, interview 8)

Samantha went on to say that she felt her presence within the group could have been a learning experience for the other members of the group and challenge any discriminatory views they may hold.

> “I mean it’s not that, I mean like me, my experience when I went to the H thing, it was just like “oh my goodness, I have to come out to these people” But that was fine because it all was fine, and it was actually a learning experience for them and helps on their homophobic journey.

Samantha was the only participant who had spoken about a previous history of being treated in mental health services and this exposure to talking therapy may have helped her feel more comfortable within the group setting.

Sadly, Samantha’s wife did not have a positive experience when she accessed the support group for partners of people with breast cancer. Feeling isolated and unable to connect with other members as she was the only gay person present. They felt that an LGBTQIA+ support group would have been able to provide more affirming and focused support.

> “There is one thing that with P, she found that being gay and supporting me with breast cancer she, when she went to one of the help meetings because she was struggling at the end of my therapy… And she went to one of the meetings and she felt very out of place because she was

the only gay woman there supporting someone with breast cancer… So, she almost came away from her meeting more worried than when she went in because there was no one she could connect with being lesbian and being supporting. And so that’s an area that I think is lacking, same sex kind of support groups for… Whereas when P, I think it was more about her trying to connect with somebody and she couldn’t connect with any of the people so therefore she didn’t feel, she didn’t feel helped. She is very happy to go into, she’s got a lot of straight friends and stuff so it’s not like she would need to be in a, you know, I need to be supported by lesbians, around women and stuff. It was just the fact that she couldn’t connect.” (Samantha, interview 8)

The Cancer Environment

This theme is about what happens in the cancer environment, in the hospital, in the waiting areas, in the treatment room. How are the participants treated, does the environment make queer people feel welcome or isolated, what can be done, what is done to queer the space? What is the reality of being treated for cancer?

Choices of hospital, where do you want your treatment, which is the good hospital, which doctor should I see for my surgery, are they good or should I go elsewhere, insider information "brothers wife knows as she's a doctor"; should I go private or stay in the NHS, all this is work, this is cancer labour. This wasn't necessarily a choice that could be made but participants did their due diligence about the places they were going to be treated and whether they had a good reputation for treating cancer, no one spoke about whether these spaces were LGBTQIA+ friendly, this wasn't even a consideration, something that wasn't contemplated. When there isn't a "choice" then why look for something, you have no control over.

> "But for onc-gynae or anything like that absolutely they wouldn't hesitate to. There are two onc-gynae specialists. One of the few places that actually have onc-gyne specialists. So that was very good. So, I knew I was in good hands and I knew that was fine." (Tracy, interview 4)
>
> "And because we live between T1 and T2 they gave me the choice of where I had the chemo. The operation's been at H1. So I've been going to H2 for chemo" (Carolyn, interview 6)

Two participants had the option to use private healthcare for their cancer treatment. One chose to go private and the other NHS. These choices demonstrate the differences between private and NHS care provision particularly in relation to the care environment, the buildings, the bricks, and mortar, but also the sense of "care" that people experienced. For Samantha the NHS was the very epitome of everything that was wrong in healthcare, her previous experiences had all been negative, from her long-term exposure to mental health services to the distress she experienced with her earlier cancer scare and this had resulted in her not trusting the NHS. When the opportunity to attend a private clinic arose, she jumped at it even though she would have to contribute financially to some aspects of her care. This was even more meaningful for her when she discovered the surgeon was a woman. For Samantha the aesthetics of the building and the comfort of the clinic made a traumatic experience slightly more bearable, she spoke of being told about the nice Georgian building and fresh cut flowers that would greet her when she attended for treatment.

> "P knows somebody that suffered breast cancer, it would be now 11 years ago, and she was seen privately and said "ok you need to go and see my surgeon for at least a second opinion"

> And because as a person you trust, the health professional that's with you at the time. And I don't even know why I thought that I might ever stay with the NHS when I had the option to actually go fully private…
>
> She said "cancel the NHS scans, we do better scans" because they do CT PET which is the more expensive and full body scan. So I had all those scans the next week and the week after I had surgery, which is just this timescale which is so incredibly quick. She is a woman too, the surgeon, a woman…
>
> She goes, she said, "it's going to be terrible, but when you walk into the lovely Georgian building and they have a lovely display of flowers there, it just makes it just" She said "it somehow makes it just a little bit better" I can kind of see that but it was terrible, really terrible. I can't even fathom how it would be to walk into a hospital, and have it done when I felt that bad, actually having it done in what's considered to be a lovely environment with my own cubicle and my own guest chair, just sitting with my own TV my guest was there and basically catering, who just gave my guest cake and sandwiches and stuff… Like I said we are still terrible that I can't even fathom how it would have been to be in other system." (Samantha, interview 8)

Whereas Mary rejected the private sector in favour of the (as she described) horrid, bleak and drab NHS environment as for her it was about the trust she had in the people providing her care and offering comfort and reassurance. For Mary the cold and clinical Victorian hospital environment associated with the NHS provided a degree of solace, it was as is expected, this is what an NHS hospital is meant to be like, money spent on care not aesthetics. For Mary part of this decision was driven by her politics, in rejecting private health care she was maintaining her lesbian activism and socialist politics.

> "So off to Harley Street. So off I went you know. I don't like it. I just don't like it. You go in these big houses. The consultant is in basically a living room with armchairs and everything. He's got this huge antique desk. I just remember it. And it's kind of yeah you know, going "yes well we've found some cancer cells" It's a bit like that. That's what I felt. I mean I'm sure it's not what. Ever so cheery and you know "we'll get the nurse to sort you out. And we can do this procedure and that procedure, and we can book you into this hospital and reconstruction." I thought "I don't trust you."
>
> **Really?**
>
> Yes. But I had the biopsies with them and that was a horrible procedure. I thought "oh god, these private nurses" Actually they made a total mess of it. I passed out the first time. The

> pain was just excruciating. And the second time I managed to get through without passing out. And I just thought “I don’t trust you. I don’t trust you. I want to take all this to NHS” So I did. So, I went to my doctor. I said “I’ve had this diagnosis. I want a second opinion from the NHS” They just looked at the mammogram and the biopsy results and they said, “yes actually, yes it’s cancer and we make the same recommendation.” At that point I dumped the private. I could’ve gone off to a private clinic and had it all removed there. So, I went to [hospital] which had been recommended to me. And I just thought I love our NHS. It’s not about the money. So, I’d immediately been given costings from BUPA. You know “this is how much it is going to cost. You make this contribution” you know £50 or whatever it was. “and we’ll pay all the rest. And at a certain point it will run out and you will need to” you know, and I just thought you know I don’t like it. It’s not me and so I went to the poor old, stretched NHS. So, I was sitting around in the clinic for hours waiting to be seen and all the rest of it. But actually, I was seen pretty quickly. So, in terms of, once I’d got the diagnosis, in terms of getting my operation and everything, that all happened very quickly. So, I went to [hospital], horrid old Victorian ward. It was pretty grim, but I really trusted the consultant. He was lovely and I thought it’s not about money. He cares about me. He cares about my welfare in a way that the guy really didn’t. So that was that. So that was the private and the NHS.” (Mary, interview 9)

Safe spaces

A particularly poignant story was when Sabrina spoke about seeing the study poster in the clinic as she felt recognised and that there was something happening locally for people like her, something she had not seen since moving from London. This is particularly significant as she works in the NHS so would see other LGBTQIA+ inclusive symbols and the fact that she hadn’t, indicated a significant disparity.

> “It was really nice to see the rainbow flag on your poster because I was thinking “oh, even in (county) there is some kind of lesbian something going on” because really you don’t see anything. So that was quite nice. That’s another reason that I wanted to be part of it because I was thinking I’m not part of anything in H1. I’ll be part of the Cancer Lesbian Research.” (Sabrina interview 7)

Gail, on the other hand, mentioned not seeing any LGBTQIA+ information but also highlighted that she had not seen anything specifically heterosexual either, this may be a result of heteronormativity and that seeing “straight people” is so commonplace that it actually goes unseen?

> “No there wasn’t really. But then I don’t know that there was anything heterosexual if that makes sense…It would be quite nice, but I can’t say that I did but then I probably really didn’t take any notice. I’m not very good of taking any notice of my surroundings” (J int 2)

The importance of seeing indicators of lesbian and gay safe spaces in the health care setting is growing in recognition with many service users expressing a wish to see this, from posters to patient information, indeed the NHS Rainbow flag initiative is growing yearly as not only a signifier of individual health care practitioners being safe for LGBTQIA+ people but also of organisational commitment to inclusivity.

The pressures staff work under were evident in many of the stories told including clinics running late or closing due to lack of staff. Sabrina tells of her frustration at the lack of information given when they were waiting for long periods of time, she felt that even the basics of an apology for lateness were not offered, instead she tells of a nurse offering her a cup of tea whilst she was waiting and explaining that she was getting one for her and the doctor. This increased her frustration as she felt that rather than getting a cup of tea they could carry on with the clinic.

Community

Communal waiting areas offer a sense of camaraderie and support for people waiting for their treatment and the participants in this study were no different. This varied however from silent acknowledgement as to why people were there to reconnection with people who were inpatients at the same time. Participants spoke of others in the waiting room knowing what they were going through and a simple acknowledgement or saying “take care” as they left offered support and shared understanding.

> “But at the other end of the spectrum it’s your community that get’s what you’re going through. And I missed that at the end of radiotherapy. You’re going in every day… And that’s not difficult going in for 5 weeks but she just got it right. And staff they say things like “take care”. They just know what to say. And just she was always smiley. And you’d sit in the waiting room, and you’d have a chat with people because you are all going through the same thing albeit in very different ways. So, part of me felt a bit bereft when I lost that community who got it although I was glad to finish radiotherapy.” (Carolyn, interview 6)

Proximity

Carolyn also explained how seeing other people within the treatment centre brought the reality of cancer home to her, bursting her bubble of relative normalcy.

> “And then with the chemo, again I had to, I’m in a little bubble at home but you’re going to H2 and you see some seriously ill patients there , I found that a bit difficult as well. Because you do see some very, very ill looking people. I’m sure I wasn’t looking great but” (Carolyn, interview 6)

For one participant proximity of space caused difficulties for her during her treatment and recovery phase. Tracy’s job kept her in close proximity to the oncology centre in her local hospital and on a daily basis she was confronted with the realities of cancer treatments and the harshness of these on the body and wellbeing. Seeing the outward representation of cancer therapy, alopecia, greying skin, sunken tired eyes became a particularly hard reality for her to deal with. This needs to be thought of in juxtaposition to the standard narrative of the patient looking in the mirror and thinking “cancer patient”, for Tracy, she did not need to look in the mirror, there was no hiding for her, she was faced with this reality every day when she left the relative safety of her office space. A mirror can be avoided, people can be avoided, work can be avoided, but in reality, and with a desire to return to the normality of daily living none of these things can be avoided, for Tracy the reality of cancer and sickness was everywhere she turned.

> “But then I did use to work next to the Oncology ward in [hospital] so I’d see it all day long. And you’d see people with bags and no hair and you know a drip thing. See them all the time. I used to think about it a lot… So it does make you think about, well if you’ve got any sense it makes you think about your mortality anyway.” (Tracy, interview 4)

Staff

When speaking about the health care staff that had cared for them participants used positive phrases and adjectives including: “the girls in oncology”, wonderful, warm, nice, huggable, amazing, friends rather than doctors, faultless, thoroughly looked after, chatty, friendly, connected, knew who was who; long term relationship with nurses, lovely, “take care”. Experiences were generally seen as genuine, affirming and inclusive.

> “had a wonderful breast care nurse who was really great and really encouraging my partner at the time and who saw us both and spoke to us both equally… He (NHS consultant) was lovely, and I thought it’s not about money. He cares about me. He cares about my welfare in a way that the guy really didn’t. So that was that.” (Mary, interview 9)

> “I saw her for the next three years because I was going back which was nice.” (Tracy, interview 4)

> “no one batted an eyelid you know I would always say who C was.” (Carolyn, interview 6)

> “it’s funny because as I was going through that system because they were professionals I didn’t feel that that was ever going to be an issue, especially when P came along with me and she was introduced as my wife and there was never any, nothing, yeah it was just fully accepted.” (Samantha interview 8)

However not everyone had positive experiences with the health care professionals responsible for their care, including patronising nurses, assumptions about sexuality, heterosexism, and homophobia.

> “The breast care nurse was a bit patronising… She was pleasant enough but just a bit … Just a bit well patronising really like “there, there, there”. But like I say she was very nice, but it was kind of almost too, a bit too sickly sweet. Does that make sense?” (Gail, interview 2)

Tracy experienced heterosexism and assumptions about her need for contraception, as a woman who is sexually active you must need contraception to avoid getting pregnant!

> “It was in my notes because I’d never taken birth control and I got sick of them asking me “why aren’t you on the Pill?” so I said.” (Tracy, interview 4)

Gail and Sabrina faced questioning looks about the connection to and relationship with the person accompanying her to appointments, was this her sister, her friend, how did this relationship make sense in a heteropatriarchal framework?

> “She felt that they were looking at us wondering what the connection, you know “are they partners?” “Why isn’t her husband with her?” (Gail, interview 2)

> “And it wasn’t that, it was more the fact that she’d come out and she’d looked to try and work out who was the patient. And I thought “I’m sorry, that’s not good enough either. If you want to know you just ask or there was just so much of that” (Sabrina, interview 7)

And then when introducing her partner, Sabrina noted the momentary readjustment that the professional needed to make to the new, unexpected information, the “double take” and the profuse apology.

> “P and I were sitting there waiting, the nurse sort of came out and was trying to work out, obviously I don’t know whether she knew I was in a same sex relationship or not, but she as trying to work out who the patient was. And I thought they are so used to seeing husband and wife so that, you know, I just thought “hang on”… And it wasn’t that, it was more the fact that she’d come out and she’d looked to try and work out who was the patient. And I thought “I’m sorry, that’s not good enough either. If you want to know you just ask or there was just so much of that… I suppose what I thought at the time was that she’s wondering who’s the

> patient so therefore she’s not thought about the fact that we could be in a same sex relationship” (Sabrina, interview 7)

Carolyn talked about the subtleness of the eye bulge, the moment of disbelief and readjustment that needs to take place again when unexpected information is imparted.

> “maybe the odd eye bulge” (Carolyn, interview 6)

Whereas Mary experienced a far more impactful moment of readjustment that did not end in a positive outcome

> “So I really remember filling out one form and it had come down to the sexuality and all that and the nurse said “married?” and she’d ticked the box. And I was like “no, lesbian” And she was like, I could see the horror in her face because we’d been chatting in a very friendly way, I’d been talking about my kids, she’d been talking about hers, we’d been talking about silly things, the way you do as one woman to another. And she was like Oh my god, I’m looking at a lesbian” it was like that. “Oh my god, I’m this close to a lesbian” That is what I felt. And she wouldn’t talk to me after that. She just couldn’t. I could see.” (Mary, interview 9)

For Mei there was overt homophobia, a nurse specialist refusing to care for her because she was gay!

> “I said “how did you, oh, is that how you ended up with then. She didn’t like the look of us?” And she said “no it wasn’t that she didn’t like the look of you, she didn’t want to look after you because you were gay”” (Mei, interview 3)

For Mary the implications of refusing to have a mastectomy were that she was not conforming to the expected behaviour of a woman with breast cancer, of course you would want a reconstruction, surely you want to look whole again, not “lopsided”!

> “now there is one thing that I found difficult was that everyone going on about reconstruction all the time. Now I was absolutely adamant that I didn’t want it. And I didn’t want any more intervention…But it was constantly pushed at me every single consultation. “We can still do reconstruction. You could have it all done at the same time” But also I felt and whether it’s being a lesbian, being a feminist, being true to myself, somehow to plant something in there instead didn’t feel right you know… When you’re actually feeling very vulnerable as well about “no I don’t want reconstruction. I just want the minimum intervention. I want to feel my full strength again. I want to feel my body as it is. I don’t want operation after operation. I want the fastest recovery possible from this”. And there was a point when I almost considered it. They were talking about it so much. It was pushed so much… Even though, especially as the

> person I am, I wouldn't say as a lesbian, but as the person I am my breasts are a very weeny part of how I identify. " (Mei, interview 3)

Finally, and perhaps the most subtle of all was the homophobia on display with Kate and her partner when she was admitted to the ward following her diagnosis of leukaemia. She had asked if her partner could stay with her as she was frightened and extremely unwell, and despite hospital policy allowing for this to happen the senior nurse on the shift refused. Whether the intention of the nurse was to be discriminatory we do not know but the impact on Kate was that she was a problem because she was gay.

> "But the thing that actually really hurt us both was obviously by this time it was in the evening and I wanted P to stay. The sister on the ward said no, no one can stay. We're not allowed people to stay unless you're dying. And I said no I want P to stay, I said she's my partner. She said I'm really sorry, she said but I don't allow it… I said " I don't want preferential treatment" I said "but I need P to stay with me tonight and P needs to stay with me tonight, she needs to know I'm alright. Obviously, she's very scared, I'm scared can she stay please" I said "because the sisters not letting her, it's their policy." I didn't want to feel like I got preferential treatment because I'm a nurse, I just needed P there… And I wouldn't normally ask, but yeah, and I didn't know how they viewed us really. I think well, coz obviously they come in and say who's your, you know who's your partner, are you married and I said "no", "have you got a partner", and I said "yes its P" and they're like "oh alright, ok" and they're all fine but they don't know what was being said behind closed doors do you, and I don't think much was said really, I don't know." (Kate, interview 1)

Whether directly related to this experience or not, when Kate went to London for her stem cell transplant her partner rarely referred to herself as such and was fearful of homophobic care, having a profound destabilising effect on both Kate and her partners feelings of safety, was this happening because they were gay.

> "P was a little bit shy about being my partner. Because a lot of the nurses that looked after me were black and Christian, P's a Christian. I think she felt a little bit awkward about saying that she was my partner, even though they knew sometimes I would, I would hear her saying she was… She would be a bit shy sometimes about saying she was my partner, it depends who was asking… At H2 they were just slightly more distant from you, um, I don't think that was being, I don't think that was about being gay I don't think it was because I've had other people that I've known go up there and they say the same thing but at the time it does make you

> think, well maybe it’s because we’re gay. They were being a bit, bit nasty and she was like. Oh maybe because we’re gay”

Conclusion

This chapter has examined the lived experience of being lesbian and having cancer and eight themes help tell the story, constructed cancer hierarchies, being diagnosed, why have I got cancer, cancer and my [lesbian] body, treatment, coping, support, and environment. Many of the conversations detailed here show a narrative very close to those already published in the literature. But what this chapter does add is a clear indication of the impact of cancer on their lives as they navigate the cancer journey. It also highlights that heterosexism, homophobia and assumption saturated care persist, despite the rhetoric that things are better now. Although the instances of overt homophobia were thankfully few, the underlying and subversive homophobia and heterosexism is clearly present for example not stopping to consider that people are anything other than straight or only thinking in terms of a standardised picture of female body presentation. The chronological journey constructed here shows key moments and significant experiences that result from being diagnosed with cancer. It is important to also remember that these are only fragments of experiences, the full extent of the lived experience cannot be included here as it is infinite in its detail. What I can offer here is just an extract of place and time that was shared with me, within the confines of a constructed and unnatural situation, that of the research interview. However much we try to make these interactions as equal as possible, there is always an agenda and the participants were fully aware of this, they knew the topic I wanted to examine with them and therefore provided me with this, they constructed a story they thought I wanted to hear.

In the next chapter these experiences will be examined through a queer phenomenological lens to demonstrate how moments of reflection and readjustment can offer a queer perspective that can begin to queer the sick room.

Queering the sick room

In this chapter I will attempt to describe a new way of thinking about health care spaces through the queer bodies that may occupy them. How a queer body queers a space. Firstly, I will consider the normative sick room from the perspective of the nurse, a space that is occupied for a purpose. Then I will present this from the perspective of a patient entering a sick room and how the orientation of the space can change when an unexpected body occupies an unfamiliar space. Then I will move to the perspective of the health care professional and how seeing a queer body in a "seen as straight" space causes disorientation and queers space and time. Readjusting to queer bodies queering straight spaces.

I am defining a sick room as any room a sick person may occupy at a given time for a given purpose. This might be the outpatient's clinic room where bad news might be broken, or the hospital ward where a patient may be recovering from surgery, a GP practice where a person may be receiving nursing interventions such as a Pap smear. The sick room is a space that is used for the purpose of delivering "care", where a health care professional and a patient encounter each other. Healthcare is overwhelmingly straight and healthcare spaces are heteronormative, structures are in place that act as straightening devices, forms that don't allow for you to indicate your partnership status, assumptions made about who is accompanying you, assumptions made about your sexuality and your need for contraception or pregnancy testing.

> *"When we are orientated, we might not even notice that we are orientated: we might not even think "to think" about this point." (Ahmed 2006 pg. 5)*

As a nurse inhabiting a sick room you become orientated to a room in a certain way. This is your sick room. You enter knowing that you have power, you are the holder of knowledge, you have gifts to give, care, drugs, comfort, cure. This is your domain; you have control of what happens in this room. You know where things are, how things work, who should and should not be in that room, and you do all this from the position of "nurse". You enter a sick room knowing that you are in charge, you hold the key.

> *"The work of inhabitance involves orientation devices; ways of extending bodies into spaces that create new folds, or new contours of what we could call lovable or inhabitable space. If orientation is about making the strange familiar through the extension of bodies into space, then disorientation occurs when that extension fails. Or we could say that some spaces extend certain bodies and simply do not leave room for others" (Ahmed 2006 p11)*

When however, the nurse becomes the patient, this changes, especially if you are not in your own sick room. You no longer hold a position of power; you no longer hold the key or have the answers. You don't know where things are, or who can come into the room. You try to hold on to the things you do know, drip rate calculations, blood transfusion procedures, but all the time doubting, is this right, should I be saying this.

> *"At the same time our intimacy with rooms, even dark ones, can allow us to navigate our way. We might reach out and feel a wall. That we know how a wall feels, or even what it does (that it marks, as it were, the edge of the room) makes the dark room already familiar. We might walk slowly, touching the wall, following it until we reach a door. We know then what to do and which way to turn " (Ahmed 2006 pg 7)*

Kate when first entering the sick room, felt a familiarity. She felt at home. She knew the space, purpose, relationship to her. She knew what would happen, what needed to happen. She entered orientated as a nurse, a sick nurse, but a nurse nevertheless. When her partners presence was denied in that space it became queered. It changed shape, purpose, orientation. It was no longer a comfortable space, a safe space, a space whose intention she was aware of. It became a space to question, to fight for and against. In fighting for her partner's presence, she queered the space. The queer queered the straight space.

When a queer woman enters the sick room their very presence changes the room, it disorientates the space. Questions about "who is this with you", denying comfort from a partner "the policy doesn't allow it". Questioning if a heterosexual couple would be denied allowed this privilege/ right, this comfort? Would it even be questioned? Would a straight couple even have to ask? "I don't want preferential treatment but…" but why is this preferential treatment? All these questions left Kate struggling for answers and for safety, her presence in the space was out of alignment. She was out of alignment in a place she had previously been aligned to. The only difference now was that she was a sick queer body in a straight space, not a nurse in a nursing place. She had disorientated the space and she was disorientated by the space.

> *"When we experience disorientation, we might notice orientation as something we do not have… It is in this mode of disorientation that one might begin to wonder: what does it mean to be orientated?" (Ahmed 2006 pg 5)*

The feeling of disorientation followed Kate to her second hospital where again her presence created misalignment of spaces. Interactions were seen through a queer orientation, constantly on alert. The intention of the nurse is unknown but the impact on Kate and her partner is destabilising, creating uncertainty and a lack of safety, and crisis looms.

> "Mandy has to go and get the stuff and one day they just wouldn't let her in. she's like "can I just go and get my yogurts from the" "NO! No! No!" they were being a bit, bit nasty and she was like. Oh maybe because we're gay.
>
> I remember up in H2 really wasn't about being gay but we would sit there and they would come in with this bag of blood and they were about to stick it up and there would only be like check my number didn't even do that some of the time.
>
> When I was first diagnosed I was never offered any egg harvesting... I don't know why… coz they assume I'm gay and I'm not going to have children and I haven't had children up until now"

The feeling of disorientation does not need to be as emotionally violent as Kate experienced. But it can nonetheless feel as destabilising and unsafe.

> "It was sort of like "oh my god I don't, obviously I'm here to be open and talk about the help but I feel very strange like I actually have to come out to these people". And so, I kind of again worried a little bit because how that was going to go because we're supposed to be in a safe environment… So, I went home to K and said "I don't know. I feel very uncomfortable. I don't know how it's going to go because I feel like I'm going to be judged" (Samantha, interview 8)

The presence of two bodies that do not fit the expected couple, the queer dyad, two women, which one is the patient, what is the relationship between these two women, how do I handle this situation, what assumptions am I making, do I act on these assumptions or how do I find out the truth of this situation? These are all questions passing through the mind of the health care professional the split second they see two women together in the waiting room; are they sisters, are they friends, or are they something else? In that micro-moment the space is queered, it is turned on its head, the orientation of the room is changed; it is queered. The unexpected has done its job. It has changed what is about to happen in this space. Two bodies together challenging the [hetero]normativity of the space. This was the experience for Sabrina and her partner waiting in the waiting room.

> "P and I were sitting there waiting, the nurse sort of came out and was trying to work out, obviously I don't know whether she knew I was in a same sex relationship or not, but she as trying to work out who the patient was. And I thought **they are so used to seeing husband and wife** so that, you know, I just thought "hang on" … And it wasn't that, it was more the fact

> that she'd come out and she'd looked to try and work out who was the patient. And I thought "I'm sorry, that's not good enough either. If you want to know you just ask or **there was just so much of that…** I suppose what I thought at the time was that she's wondering who's the patient so therefore she's not thought about the fact that we could be in a same sex relationship" (Sabrina, interview 7)

Ahmed (2006) explains that the lesbian body does not extend the shape of this world, as a world organised around the form of the heterosexual couple. Bodies that don't reflect this back are out of place and are to be questioned.

> "She felt that they were **looking at us wondering what the connection**, you know "are they partners?" "Why isn't her husband with her?" (Gail, interview 2)

At the point of disorientation "this is not what I was expecting", a momentary visible reaction occurs, a slight eye bulge, a raised eye brow, a double take. Then an urgent realignment of thought, a reassessment, what is it I am seeing, how do I make sense of this unexpected situation. The queer person notices this disorientation and reorientation and waits for the outcome, is this going to be a crisis moment, am I going to face discrimination, heterosexism, or inclusion. Preparation is underway for all eventualities. Will the ground under our feet be stable or will we be rocked by an earthquake, a subsidence, a loss of stability. They sit with bated breath whilst the health care professional makes up their mind.

> *"Such a feeling of shattering, or of being shattered, might persist, and become a crisis. Or the feeling itself might pass as the ground returns or as we return to the ground. The body might be reorientated if the hand that reaches out finds something to steady an action. Or the other hand might reach out and find nothing and might grasp instead the indeterminacy of air. The body in losing its support might then be lost, undone, thrown."(Ahmed 2006 pg 157)*

Nothing can be done at this moment until the double take/eye bulge settles and the health care professional decides on their next action. Disorientation becomes reorientation but what are we reorientating into, what does this new queer space look like. How can we make sense of this newly queered sick room?

For some the moment of crisis passes and the world reorientates to a safe space, to an inclusive queer space.

> "And no one batted an eyelid you know I would always say who C was. And the **worst you ever got was maybe a slight eye bulge**. Just that, the best way to describe it. But no one

> batted an eyelid. You know what you get when you book into a hotel don't you, it's like [giggles]." (Carolyn, interview 6)

But for others the crisis looms large, and the "care" becomes unsafe.

> "I said "how did you, oh, is that how you ended up with us then. She didn't like the look of us?" And she said "**no it wasn't that she didn't like the look of you, she didn't want to look after you because you were gay**" (Mei, interview 3)

> "And she was like Oh my god, I'm looking at a lesbian" it was like that. "Oh my god, I'm this close to a lesbian" That is what I felt. And she wouldn't talk to me after that. She just couldn't." (Mary interview 9)

> "now there is one thing that I found difficult was that everyone going on about reconstruction all the time. Now I was absolutely adamant that I didn't want it. And I didn't want any more intervention…But it was constantly pushed at me every single consultation. When you're actually feeling very vulnerable as well about "no I don't want reconstruction… And there was a point when I almost considered it. They were talking about it so much. It was pushed so much." (Mary, interview 9)

The power is with the health care professional to decide whether this interaction is going to be safe or unsafe. There is nothing the patient can do at this moment, they are powerless. But they can see this process occurring they know that something will happen that will either take the ground from under their feet or create a soft and comforting landing.

> *"Orientation involves aligning our body and space: we only know which way to turn once we know which way we are facing. If we are in a strange room, one whose contours are not part of our memory map, then the situation is not so easy. We can reach out, but what we feel does not necessarily allow us to know which way we are facing; a lack of knowledge that involves an uncertainty about which way to turn." (Ahmed 2006 pg. 7)*

But what does all this mean for the nurse and other health care professionals. When we become aware of our disorientation, we can see it and then work against it. When we recognise that we have "eye bulged" or double taken, then we can reflect on this and ask ourselves "why did I do this", challenge the assumptions underpinning our care. In doing this reflection we can begin to see difference as always already there. We can begin to see the queer sick room and embrace it. That way when we meet a queer person or couple we are not disorientated, our ground does not "wobble", it stays firm and we can proceed in our offer of care. But we can also see the nurse who cannot move beyond the disorientation, and we can support them in unpacking their prejudices and working on becoming inclusive and person centred. Recognising and truly seeing the queered sick room is vital for inclusive person-centred care.

Chapter 10: How do discourses of gender, sex and sexuality help interpret the intersections of cancer and lesbian identity?

Queering the sick room has brought together ten lesbian women's stories of living with and beyond cancer and offers new insight into the experiences of being lesbian and having cancer within the United Kingdom. The study participants first discussed their life since coming out as lesbian and then their life as a lesbian with cancer. Interviews were conducted face to face and were held over an 18-month period in the mid 2010's.

Participants used a variety of descriptors for themselves from lesbian, gay and dyke, using lesbian and gay interchangeably throughout our conversations. The participants in this study came from a variety of socio-economic backgrounds and professions, including nursing and advertising. All were in the southeast of England, with one at the time living in a major metropolitan area. Nine were married or in a partnership. One participant was currently single, her relationship ended after their cancer treatment had completed. The time since diagnosis was a few weeks to 9 years, affording the opportunity to discuss cancer experiences across a wide timeline. Six of the women had been diagnosed with breast cancer, one with endometrial cancer, one with colorectal cancer, one with lung cancer and finally one participant had acute myeloid leukaemia (AML). The inclusion of a variety of cancer diagnoses enabled differing experiences to be captured. This contrasts with most other published studies examining lesbian women's experiences of cancer that have tended to focus on breast or reproductive cancers only.

Each of the participants had a very different story in relation to living as a gay woman or coming out. Although no definitive and generalisable statements can be made a key determinant within this study appears to be where the participants were at the time the Local Government Act came into force in 1988. All participants in the study are within 15 years of age of each other, the oldest being 58 and the youngest 43. However, there was a key division between being in secondary school in the mid 1980's or having already left the compulsory education sector. The participants that had left school and gone to university prior to Section 28 appear to have been more open about their sexuality more able to explore this aspect of their life, free from the oversight of parents, family and teachers and more active within local LGBT politics, particularly Sabrina and Tracy. Whereas those participants who were within compulsory education during the mid-1980's appeared less free to express their sexuality openly. Particularly Gail, Carolyn, Samantha, and Melissa who all stated they were unable to come out or talk freely about their sexuality at this age even though they were aware they were gay, because of increased stigma and hostility towards the gay community. Indeed, Gail also framed this within the heteropatriarchal assumptions of marriage and children and a lack of out lesbian role models that looked like her. Weeks (2018) highlights that although major breakthroughs were being made in the 1970's for gay liberation, the 1980's saw a resurgence of violence and hate towards the LGBT community. This was not a safe time to be a young school age lesbian! For others in the study the realisation they were lesbian did not happen until they were in their twenties. Kate realised she was attracted to women in her mid-twenties and spoke of wanting to fully explore her sexuality. Mary had partnered with a man and had two children with him when after living alongside a lesbian community she became aware of her attraction to women. These stories are all indicative of the complexity of women's sexuality as documented by Diamond (2008) in her comprehensive examination of female sexual fluidity who argues that women's sexuality is not rigid but fluid and responsive, often changing as women move through different parts of their lives which was certainly true for several women in this study, including Gail, Melissa and Mary who had all fallen in love with men, married and had children.

Cancer risk

The biomedical cancer literature argues that there is an increased risk of developing cancer for lesbian women, based on an accumulation of lifestyle factors including nulliparity, obesity and smoking. However, this has not been confirmed in definitive studies. Yet within the study most of the participants wanted to know the cause of their cancer, Sabrina for example jokingly, spoke about lesbians and nuns being at high risk. Tracy spoke about being childless as a key determinant in endometrial cancer but refused to link this to her lesbian sexuality, one did not cause the other; you could be straight and not have children and you could be lesbian have lots of children, the issue for her was being child free and this is something that she fully accepted as the idea of having children was never on her radar. When discussing causes Judy was very pragmatic about her lung cancer having been caused by smoking, but she did not link this to being lesbian and lesbians having higher rates of smoking behaviour, this was just incidental. Interestingly, although not measured as part of the study, none of the women who participated were overweight. Again, this cannot be generalised, but it is interesting to note as the general perception within many medical studies is that there is a higher rate of obesity in lesbian women (Hutchcraft et al 2021).

Cancer screening was an activity that the participants routinely engaged in, and no one expressed concerns or fears about participating in screening. Two of the participants breast cancers had been diagnosed as part of a routine health screening. None of the participants had cervical cancer so this topic never arose in discussions. For all the other participants their cancers were diagnosed following investigation for symptoms of ill health. Again no one expressed that they had been reluctant to seek help for fear of homophobic or discriminatory care, all readily sought out medical attention when they needed it. This is contrary to previous large scale study findings where lesbians were more likely to report a perceived sexuality bias in the health care provider and fear of discrimination as key barriers to screening (Tracy et al 2013, Fish 2009, Matthews et al 2004).

However, one of the key areas of concern raised in the study was the lack of attention health care professionals paid to the women when they attended with symptoms they were concerned about. Tracy spoke about years of going back and forth to the doctor with period related symptoms and it was only as a last resort that she was admitted for the procedure that led to her cancer diagnosis, had she not been persistent about her situation, the cancer may have gone undiagnosed for several more years. Judy spoke of having to return to her GP several times with an unrelenting cough that antibiotics had no effect on. Carolyn's bowel symptoms had been brushed aside as irritable bowel syndrome by a succession of medics, and Samantha's concerns about the lumps in her breasts had been dismissed as benign and nothing to worry about by radiographers and doctors. Kate's persistent infections were treated with antibiotic after antibiotic. Although it is true that many cancer symptoms are non-descript in the early stages, it seems that the women in this study experienced delays in their diagnosis and dismissive health care.

The growing rhetoric of the worried well is particularly focused on women and women's health issues and gives permission for the medical profession to ignore women who attend at surgery regularly with either repeated health concerns or several diverse health issues. Women as worriers, there is nothing wrong with them they are just spending too much time on the internet/ watching TV/ reading magazines/ talking to each other. Women put up with health issues for fear of the response they will receive from the medical profession, dismissal, fat shaming. This then delays them seeking health care interventions that could lead to the early diagnosis of life-threatening conditions. Health care professionals are constantly pushing for people to present to their doctors so they can be diagnosed earlier and therefore treated more successfully but when they do present, they are faced with a barrage of accusations or unconscious bias that then impacts on the success of that interaction. Women are in a lose, lose situation and health care professionals do not seem to recognise or care about their inconsistencies.

Treatment choices

Similar to the finding of previous empirical studies as well as theoretical papers (Brown and McElroy 2018b, Boehmer et al 2007 Lorde 1997, Jain 2007, Bryson and Joynt 2013) the women in Queering the Sick Room shared opinions about reconstructive surgery and that they did not require reconstruction to define their womanhood. This supports the finding that not being defined by having breasts is closely aligned to lesbian sexual identity, however contrary to Boehmer et al (2007) participants did not consider reconstruction as just a straight woman's choice. Indeed, for Melissa the need to have an immediate reconstruction was key to her coping with the diagnosis.

There are no other studies that have considered treatment choices for cancers other than reproductive cancer therefore it is not possible to compare findings here with previous studies. It is worth noting here that there was significant policing of women's body presentation post-surgical intervention, particularly in relation to reconstruction. Mary in particular details her ongoing battle with the breast cancer nurses and surgeons in her refusal to have reconstruction. For five years she had to maintain her steadfast belief that she did not want this intervention. Mary's fight reminiscent of Audre Lorde's powerful push back against heteropatriarchy during her cancer treatment.

> "I refuse to have my scars hidden or trivialised behind lambs wool or silicone gel. I refuse to be reduced in my own eyes or in the eyes of others from warrior to mere victim, simply because it might render me a fraction more acceptable or less dangerous … I refuse to hide my body simply because it might make a woman-phobic world more comfortable" (Lorde 1980 [1997] pg61)

This was a particularly salient example of queering the sick room. Where Mary did not fit the expected norm, it caused disorientation for the health care professionals, but rather than embracing this and working with Mary to provide gender and sexuality affirming care, they forced their heteropatriarchal agenda on her. Albeit probably from a well-meaning perspective, the impact of this was nevertheless coercive and violent.

Coping with cancer, mental health, and quality of life.

As with previous studies the hypothesis that being a sexual minority woman with cancer puts you at higher risk of psychological trauma was not supported in Queering the Sick Room. Indeed, many of the participants spoke of the resilience being both queer and having cancer afforded them. There was a clear link between dealing with minority stresses and developing coping strategies that they could then draw on when facing the diagnosis of cancer, obviously within this very small qualitative study no definitive conclusions can be drawn but further exploration of this question would benefit from future large-scale studies.

However, the impact of the cancer diagnosis was felt by all the participants, the diagnosis was shocking and feeling low or "depressed" as Carolyn referred to it, was a common reaction. Nevertheless, according to the study participants this never exceeded their expected level of emotional reaction to life altering news, no one spoke of needing additional psychological support beyond talking to nurse specialists or cancer counsellors. Treatment often resulted in feelings of vulnerability, often associated with side effects including nausea and vomiting, these were seen as reactionary and passed with the passing of the side effects. Again, it is not possible to expand on these findings beyond the remit of this study as no formal tools were used to measure emotional wellbeing or distress, however their stated lived experience does not concur with earlier studies (for example Schefter et al 2021) that problematise lesbian identity and cancer associated psychological wellbeing.

Disclosure of sexual minority status

The participants of Queering the Sick Room generally reported that disclosing their sexual minority status had not had a detrimental impact on their care, instead they spoke positively about the support that both they and their partner had received, and all participants had been open about their sexuality throughout their cancer treatment. Interestingly though all recognised moments of disorientation when they came out, moments of readjustment of expectations by the HCP. However, they chose not to define this as discriminatory care, but rather a momentary sense making of an unexpected situation. This is a positive finding and may demonstrate a move forward for inclusive health care in the UK. They did however note that they did not receive any information or support that was focused on their sexuality, for example information about sexual health and intimacy. Two experiences though stand out as exceptions, firstly was Mei's experience of being told that a nurse specialist had refused to care for her because she was gay. Thankfully this revelation was made several years after she had completed her treatment so there was no direct negative impact on her wellbeing. Nevertheless, this raises serious issues about nurses not being challenged for holding overt homophobic views and failing to abide by their professional code of conduct, which does not allow any nurse to refuse to care for a patient based on any defining characteristic. Secondly, as discussed earlier for Kate who appeared to fall victim to a nurse's bias towards her and her partner.

Unlike the US, UK health care does not allow patients to choose their surgeon or oncologist, but participants did talk about seeking out information about their doctors, but this was in relation to their medical standing, not whether they were inclusive of LGBTQIA+ patients. This did not seem to be part of any decision making or discussion about what to expect. This is a very different finding to the studies from the US that have shown this is a key determination for many women when seeking healthcare (Sinding et al 2004, Boehmer and Case 2004, Matthews et al 2002, Matthews 1998). This also highlights the different models of healthcare provision between the UK and US, supporting Berner and Meads (2022) assertion that you cannot automatically apply findings across healthcare systems.

Sabrina highlighted the importance of seeing LGBTQIA+ affirming literature within the clinical environment, sadly though it is evident from the study participants that this was not transitioning widely into practice areas and there was very little outward indication that this was a safe space for them, nor were there specific indicators that LGBT healthcare needs were recognised, such as the progressive pride flag or rainbow pins. This does however need to be considered in terms of when the interviews took place and the Inclusive NHS project had only just started. It also needs to be considered in light of what is meant by a signifier, as Gail pointed out she did not remember seeing any specific heterosexual information either. This speaks to queer phenomenology and the pervasive nature of heteronormativity and heterosexism that when things are in line we no longer see them, we do not see the posters advertising support that use a “thought to be” heterosexual couple as their models, this is just everyday life and we do not see the everyday, we only recognise the “not every day”. So when Sabrina saw my poster advertising this study she was drawn to the “not every day” nature of it, the unusualness, the rarity of seeing something focused on LGBT health in a healthcare setting. LGBT health literature has indicated the importance to LGBT people of seeing signs that indicate this is a safe environment for them. This would include posters with same sex couples on them, rainbow flags or staff wearing indicators of LGBT identity or allyship (Stonewall 2016, Marie Curie 2016). For Sabrina seeing the Lesbian Cancer Voices poster indicated to her that there was something happening that was specifically focusing on her needs, and it was this that gave the encouragement to participate in the study.

Support

As with other studies (White and Boehmer 2012, Boehmer et al 2005a, Fobair 2001) Queering the Sick Room demonstrates the positive support lesbians receive from their partners and their families of choice. Significantly in this study the participants also spoke positively about the support family provided them throughout their cancer journey. For those in relationships their partner was their primary support, but parents and siblings often stepped in when partners had to return to work. Partners also acted as gatekeepers, preventing unwanted visits, or planning visitation when participants would be feeling most up to receiving guests. Friends/ families of choice offered significant levels of both emotional and practical support, being alongside and supporting at times of significant emotional burden, such as diagnosis, organising travel arrangements, cooking, cleaning.

Support groups were not widely used by the women in this study, but those that did use them spoke of concerns that reflected the findings of previous studies by Brown and McElroy (2018a) Paul et al (2014), Fish (2010) and Matthews (1998). Often, they were the only LGBT person in the group and this lead to fears about coming out or being discriminated against, or for their partners being the only woman or gay person in the group and not being able to talk about issues that affected them specifically.

Body

As found by Brown and McElroy (2018a and b) intimacy was one area of life that was negatively impacted. Mei spoke at length about the impact breast cancer treatment had on her libido. Significantly none of the participants had received any advice that was focused on their specific needs as lesbian women, an area that needs to be addressed. All treatments for cancer, whether they be medication, radiotherapy or surgery cause significant changes to sexual wellbeing and focusing interventions on the specific needs of the patient is a core aspect of person-centred care, although it is well known that sex and sexuality are not assessed particularly well in nursing practice.

Another important discussion within Queering the Sick Room is the empowerment women gained from refusing to conform to heteronormative body ideals and existing as a unilaterally breasted woman. These are similar to the findings of Brown and McElroy (2018b) and their study with women who choose bilateral mastectomy without reconstruction and Jain's (2007 and 2013) treatise on being a "flat topper" and baldness as new expressions of gender that cancer permits. Jain argues that this may be the first time a person has had the opening to affirm the gender closest to their authentic self, and cancer treatment provides opportunity, space, and permission to do this, when they would otherwise have been unable to do so. However, as mentioned previously the women in this study align more closely with Audre Lorde (1980) and, not wanting to have foreign objects inserted into their bodies.

> "At times I miss my right breast, the actuality of it, its presence, with a great and poignant sense of loss. But in the same way, and just as infrequently, as I sometimes miss being 32, at the same time knowing that I have gained from the very loss I now mourn." (Lorde 1980/ 1997, pg. 79)

Chapter 11: Limitations

There are several limitations to this study, most notably the small numbers of participants limits any claims to articulating lived experience, even though the aim of this study has never been to generalise the findings, this study is only representative of the ten women who participated and shared their stories. They must be read in, and interpreted through, their historical, social, cultural, and political context.

Methodologically a key limitation is that the participants did not have an opportunity to read the analysis of their interview. This was a key component of the participatory feminist methodology I was aiming to achieve. However ethically, it was unsafe to do this as a significant time had passed since we had spoken, and I was not able to know their health status or location.

Additionally, as a singly produced and authored research project there is a high probability of bias or misinterpretation within the results. It is hoped that the research diary and reflexive work have minimise this, but as with all single authored work this is a key consideration for the reader.

As discussed previously in the thesis, due to my personal situation there was a long gap between the interview being undertaken and the analysis of these. There have been significant changes within the UK for LGBT people, particularly our trans brothers and sisters who are facing a barrage of hate. Therefore, this work has to be considered in the context of recent history rather than fully contemporary. We have survived a global pandemic and the NHS is in a hugely turbulent phase, whether the findings of this study still resonate with other lesbian women seeking cancer care is not known, but what they do is reflect the experiences of the ten women who kindly gave up their time to have a conversation with me.

Lastly due to the word constraints of this thesis, there are several narrative threads that have not been fully examined or presented in this thesis. It is my intention to return to these missing threads and continue to analyse them in the context of queering the sick room. What I have presented here are the significant stories that spoke to me. I have been open in my reflexive statements that these findings will come through my interpretive lens and decisions I make. I hope I have honestly presented the key stories the participants shared with me to the best of my ability.

Chapter 12: Implications for practice

Queering the sick room offers new knowledge to health care professionals on the experiences of women who are lesbian and have cancer. These are voices that have not yet been heard within the UK healthcare context and as such offer an opportunity to explore their lived realities. Health care practice can benefit from taking time to actively engage with these stories and consider how they may relate to the care they provide. Key re-orientating interventions individual health care practitioners can take forward include:

1. Unlearn their biases by engaging in education about the people affected by their care.
2. Be a champion and ally in the workplace, starting by ensuring there are visible signs of inclusivity within all care environments.
3. Reflect on the care they offer and asking whether the care they provide patients is person centred and focused on their individual needs, for example sexual health information.
4. Reflect on whether they are basing their care on heteronormative or patriarchal assumptions about body presentation. Queer orientation requires people to look for the unseen, to see with new eyes, queer feminist eyes.
5. Reflect on whether they dismiss people’s concerns based on inaccurate health care tropes such as the “worried well” that overwhelmingly negatively impact women.

Organisationally, services need to ensure their provision is inclusive, that health care professionals are afforded the opportunity to engage in meaningful education and training that can help disrupt unconscious and conscious bias. Ahmed (2021) talks about the non-performativity of Equality, Diversity, and Inclusion (EDI) policy and training, and that its purpose is not to challenge or change behaviour but exists so organisations can tick a box to say they are doing EDI training. Whether it works is irrelevant to the organisation and importantly we know that most EDI training does not work, particularly online half hour self-directed training packages! So, what is needed is engagement with real and reflective learning, that challenges and supports people to develop understanding and learn tools of inclusivity.

Structurally, nurses and other health care professionals need to be empowered to call out poor practice. One of the key stories in this thesis is Mei being told that a senior nurse refused to care for her because she was gay. However, what was not discussed here was why a nurse was allowed to continue practicing and left unchallenged when the nursing Code of Conduct (NMC 2018) clearly prohibits discrimination. Why do nurses feel disempowered to call out or call-in poor practice or to raise concerns with senior managers?

A key outcome of this PhD has been the introduction of nursing modules focused on social justice throughout the nursing provision within my School. For the last five years I have led modules which aim to consider and debate the concepts of social justice and ethics in relation to nursing, and in association develop an understanding of how privilege and bias operates within the health care system. It also aims to prepare students to be health activists. Using intersectionality and social models of health and disability, its provide students with the opportunity to examine critical concepts in understanding health and wellbeing within broader socio/cultural/political frameworks. It asks students to critique the dominant biomedical approach to health, disability and illness and in doing so enhances their ability to work in person centred, anti-oppressive ways. They further examine health care ethics and law as they relate to contemporary nursing practice. A research project currently in development will evaluate the impact of these modules.

Chapter 13: Conclusion: Queering the sick room.

Queering this sick room is a narrative study that details the lived experiences of ten lesbian women diagnosed with cancer. The sick room is the space in which a person can be sick, cared for, consulted about sickness, but when the body in the room does not follow the expected line, when the body can be seen as deviant from the line, it queers the space, it disorientates it, it challenges the normative. Queering the sick room has examined the experiences of queer bodies disorientating and being disorientated by normative spaces. Using Queer Phenomenology (Ahmed 2006) the study has shown how bodies are gendered, and sexualised, by how they extend into space.

Three narrative lines developed from the analysis to answer the research questions. The first narrative, living a lesbian life starts with the coming out stories of the women in this study, these stories are well told in existing literature and the women here reflect those narrative tropes. They spoke candidly about how they came to realise they were gay and how this turned their world upside down, how it disorientated them and their families. They then spoke about their partners and relationships, their experiences of drama, comfort and excitement. Lastly they shared personal stories of experiences of discrimination, heterosexism and homophobia and how they had managed a world that does not fully accept their sexuality (yet).

The second narrative thread focuses on their journey with cancer. Here they offer a chronological narrative from first thinking they may have cancer to being diagnosed and then treated. They explain the impact the cancer had and still has on their body, the limitations it has left them with and the long-term health consequences. Overwhelmingly they spoke of the love and support they had received by their loved ones. But there were also experiences of care that were compromised by discrimination and bias.

The final narrative explains queering the sick room

The sick room is a space that is used for the purpose of delivering “care”, where a health care professional and a patient encounter each other. Healthcare is overwhelmingly straight spaces and heteronormative, structures are in place that act as straightening devices, forms that don’t allow for you to indicate your partnership status, assumptions are made about who is accompanying you, assumptions are made about your sexuality and your need for contraception or a pregnancy testing.

When a queer woman enters the sick room their very presence changes the room, it disorientates the space. The presence of two bodies that do not fit the expected couple, the queer dyad, two women; which one is the patient, what is the relationship between these two women, how do I handle this situation, what assumptions am I making, do I act on these assumptions or how do I find out the truth of this situation? These are all questions passing through the mind of the health care professional the split second they see two women together in the waiting room; are they sisters, are they friends, or are they something else? In that micro-moment the space is queered, it is turned on its head, the orientation of the room is changed; it is queered. The unexpected has done its job. It has changed what is about to happen in this space. Two bodies together challenging the straightness, the [hetero]normativity of the space. The power is with the health care professional to decide whether this interaction is going to be safe or unsafe. There is nothing the patient can do at this moment, they are powerless. But they can see this process occurring they know that something will happen that will either take the ground from under their feet or create a soft and comforting landing.

But what does all this mean for the nurse and other health care professionals. When we become aware of our disorientation, we can begin to see it and then work against it. When we recognise that we have “eye bulged” or double taken, then we can reflect on this and ask ourselves, why we did this, challenge the assumptions underpinning our care. In doing this reflection we can begin to see difference as always already there. We can begin to see the queer sick room and embrace it. That way when we meet a queer person or couple we are not disorientated, our ground does not “wobble”, it stays firm, and we can proceed in our offer of care. But we can also see the nurse who cannot move beyond the disorientation, and we can support them in unpacking their prejudices and working on becoming inclusive and person centred. Recognising and truly seeing the queered sick room is vital for inclusive person-centred care.

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Appendix 1 Literature review matrix

By publication date:

	Author[s] Date	Country	Title	Aims	Methodology/ method	Population/ sample	Results	Conclusions	Comments
1	Matthews, A.K (1998)	USA	Lesbians and cancer support; Clinical issues for cancer patients.	Discussing the clinical issues addressed in support group meetings	Unclear – qualitative	24 members of 3 support groups [3-12 members in each av 5]; 20-68 yrs [42] 79% Cauc 20% AA, 57% in relationship; Br Ca 58%, 74% initial diagnosis, 23% recurrent disease- group notes used for data 7 1:1 SS interviews	1. Disclosure of sexual orientation; women with fewer resources were more hesitant to disclose 2. Emotional support; tension with family of origin. Reliance on family of choice 3. Inclusion of partners in treatment 4. Use of supportive services (inc AA experiences) 5. Interactions with HCP inc use of alt therapies, and communication	Embedded in the more universal concerns were attitudes and experiences not normally experienced by heterosexual women	LESBIAN Methodologically unsound- this looks like a study that has drawn key issues from a support group and then discussed these in interviews with 7 women chosen, no explanation of choice. No breakdown of diagnoses given. No ethical approval mentioned. It is good that it included AA participants as this is rare in other studies. Are some of these issues unique to the US re refusal of treatment/substandard treatment and inclusion of partner

									No definition of lesbian
2	Roberts S., Sorensen L (1999)	USA national	Health Related Behaviours and Cancer Screening of Lesbians: Results from the Boston Lesbian Health Project	Presenting data on lesbian health related and cancer screening behaviours	National survey Boston Lesbian Health Project = 17 page health questionnaire Undertaken between 88-89	Snowballing/ community National sample 1633 women 50 states 17-55+ majority 25-44 Only 1.3% AA	1. 1/5 smoked- fewer than in general US population or women 2. 61% had Pap smear within 2 yrs of the study (comp to general pop) 3. 9.6% never had a PS 4. 44% always or sometimes did BSE / over 50% rarely or never 5. 58%>40 and 79% >50 have had a mammogram (higher than gen pop) 6. Greater use of alcohol	In several areas the survey reports very similar health behaviours to Americans in general. In some areas this pop had better health behaviours eg exercise and diet, seat belt wearing	Cannot tell if this is representative of the lesbian population from the sampling technique used Old!
3	Burnett C., Steakley C., Slack R., Roth J., Lerman C., (1999)	USA	Patterns of **Breast Cancer** Screening among Lesbians at Increased Risk for Breast Cancer	Characterize the perceptions of susceptibility to breast cancer and describe factors that influence adherence to BC screening in a sample of L with a first degree	Quantitative Cross sectional Structured telephone interviews Measures: Behavioural model for	139 self identified lesbians with 1st degree relative with breast cancer- No history of cancer 35-75 yrs [43]	1. 84% adherence to Mam 2. 88% Clinical BE 3. 79% nulliparous 4. Women with a high degree of worry re getting BC were more likely to adhere 5. There was a low BSE rate (34%) but adherent to CBE and Mam	Lesbians are more similar than dissimilar to other groups of women with the same risk factors and demographic when looking at mammogram	Self selection for participation and data Predominantly young partnered white and college educated Small sample size

				relative with breast cancer	health services use ACS guidelines for screening adherence	Community/ convenience sample		adherence (pg 50)	
4	Lauver, D. R., Karon, S. L., Egan, J., Jacobson, M., Nugent, J., Settersten, L. and Shaw, V., (1999)	USA Midwest	'Understanding lesbians' mammography utilization'	To identify barriers to obtaining mammography, reasons for obtaining mammograms and factors that would help lesbians obtain mammograms	Telephone interviews Open ended questions	107 lesbians 51-80 yrs [55] Self defining as lesbian Convenience/ snowball 2 samples 1: lesbians who had obtained a mammogram in the previous year (68), 2 (39) had not had a mam in previous year (s2 recruited as part of a bigger study)	1. 59% S1 had benign breast disease 2. 34% S2 BBD 3. Barriers inc; system factors, life demands, fear, lack of motivation, cost, scheduling, poor past experience, homophobia racism mistrust of medical community 4. Reasons; perceived high risk 5. Encouragement from HCP, create open safe spaces, outreach 6. Social support facilitates uptake	Barriers and facilitators similar to general samples of women	No definition of lesbian given- relies on self definition Majority white in both samples (97% and 92%) Only researcher side of interview was tape recorded Superficial telephone survey – no depth of analysis
5	Cochran, S. D., Mays, V. M., Bowen, D., Gage, S.,	USA	'Cancer-related risk indicators and preventive screening	Are lesbians at increased risk for certain cancers as a result of	Meta analysis Prevalence estimates of	11876 (LB) 18-75	1. Greater prev of obesity, alcohol use and nulliparity, increase smoking,	LB women differ from het women in patterns of	Women who have sex with women

	Bybee, D., Roberts, S. J., Godstein, R. S., Robison, A., Rankow, E. J. and White, J., (2001)		behaviours among lesbians and bisexual women	accumulation of behavioural risk factors and difficulties in accessing health care	behaviour risks, cancer screening behaviours and self reported breast cancer histories from 7 independent surveys were compared to national estimates for women 1987-1996		less birth control, less, health insurance, gynae exams, mammograms 2. Those with health insurance more likely to access screening 3. No difference in self reported incidence of BC from gen pop	health risk, they are also at greater risk of chronic disease associated with smoking and obesity	
6	Fobair, P., O'Hanlan, K., Koopman, C., Classen, C., Dimiceli, S., Drooker, N., Warner, D., Davids, H. R., Loulan, J., Wallsten, D., Goffinet, D., Morrow, G. and Spiegel, D., (2001)	USA CA for L	'Comparison of lesbian and heterosexual women's response to newly diagnosed **breast cancer'**	Hypothesized that lesbians would report higher mood disturbance less BI and sexual activity problems; show more expressiveness and cohesiveness and less conflict with partners; find social support from partners and friends; report	Descriptive multi centre trial Report on 2 separate trials multi centre Het and single centre L (greater bay area of Cal) Measures: POMS; IES; BISS; SAQ; FRI	29 L 246 H College education Community/ convenience sampling	1. No difference in mood between two groups 2. Lesbians experienced less body image disturbance but difference in sexual issues 3. Not confirmed that L would have greater ability to express feelings or show more cohesiveness in relationships, no difference between L and H in dealing with conflict	Two pictures of social support; lesbian partners rated significantly higher in providing love and care, being willing to listen and practical help than H spouses. However L friends more likely to give	Only 29 lesbians compared to 246 Het so how comparable is this? Newly diagnosed women- how would this change over time? Recurrent or metastatic cancer excluded and history of major mental illness

				poorer perception of Med Care than heterosexual W	SNSA; CARES; PRSP; CECS; Mini MAC		4. Lesbians felt more support from partners and friends but felt friends and partners were more critical of them 5. L had poorer perception of medical care and partner involvement 6. No diff in communication with physician and control over treatment 7. Lesbians more likely to express anger and less fighting spirit but less fatalism too	advice and be critical. H more likely ot have a spouse who made demands but had relatives close by to help Predictions re BI, SS and MC supported. No diff in M, SA and RI	Lesbians further from treatment than H women due to issues with recruitment No definition of L
7	McGregor, B. A., Carver, C. S., Antoni, M. H., Weiss, S., Yount, S. E. and Ironson, G., (2001)	USA	'Distress and Internalized Homophobia Among Lesbian Women Treated for Early Stage **Breast Cancer'**	Positive feelings about oneself as homosexual would relate to better mental health. Higher rates of disclosure would relate to better emotional wellbeing. Self esteem and perceived social support might mediate between	Quantitative multiple tools used including CES-Depression, ISEL, self esteem scale, IH Questionnaire, SODQ	57 Lesbian Convenience sample, National recruitment. 31-71 yrs [49.11]. 53 white, 2AA, 2Hisp	1. Older lesbians reported less disclosure and increased IH 2. IH significant predictor of distress 3. Self esteem sign predictor of distress 4. Disclosure does not relate to lower distress 5. IH weakly associated with SE but not significant 6. SE and social support partial predictors of distress and IH	Low self esteem leads to IH by way of elevated distress "Psychological adjustment appears to be best among those who have accepted and integrated their sexuality and are committed to a gay or	Internalized homophobia: "holding a negative attitude about homosexuality and applying it to onself" pg 1 No definition of lesbian $25 for participation How can the measure of distress today compare to that at

				internalized homophobia (HI) and emotional wellbeing. Does IH relate to poorer health care practices in L involving external providers or self providers			7. IH related to lower levels of frequ of Pap and gynae exams 8. No correlation between distress and extent of disclosure of SO	lesbian identity" p7	time of diagnosis 24 yrs in one case The breast cancer seems incidental here
8	Fobair P., Koopman C., Dimiceli S., O'Hanlan K., Butler L., Classen C., Drooker N., Davids H.R., Loulan J., Wallsten D., Spiegel D., (2002)	USA CA	Psychosocial Intervention for Lesbians with **Primary Breast Cancer**	Examining the effects of supportive-expressive group therapy intervention. Hypothesised improvement in mood, psychological distress, coping, BI, interpersonal relationships, sexuality, social support, attitudes towards HCPs, impact of illness, pain and sleep	Interventional study Testing at baseline 3,6,12 months 12 week SE intervention Measures: POMS, HADS, IES, MAC, BISS, SESES, FRI, SNSR, CARES, PRPS, Impact of illness, sleep, pain	20 lesbians diagnosed in last 12/12 (taken from initial survey) mean 47yrs 3 unavailable for final testing but results included on curve	1. There were significant improvements in all primary outcome measures 2. Social support on the instrumental and informational variables declined over time 3. Family relations improved, reduction in pain, increased sleep 4. No change in BI and sexuality or attitudes to HCPs	Lesbians with breast cancer experience improvements in QoL following group therapy -	Group leaders all lesbian – They highlight the no change in BI and S could be due to lesbians having better BI and S in the beginning- not as affected but this isn't supported by the Sinding findings fully Make interesting comment about hope it will help with coping with stigma of being a lesbian with breast cancer but they do not test to see if the

									participants felt stigmatised
	Matthews, A. Peterman, A. Delaney, P., Menard, L. and Brandenburg, D., (2002)	USA	A Qualitative Exploration of the Experiences of Lesbian and Heterosexual Patients With **Breast Cancer**	To explore similarities and differences between lesbian and heterosexual survivors of breast cancer regarding cancer experience	Comparative study lesbian and heterosexual women Questionnaire and Qualitative focus groups thematic analysis used for focus group analysis	Urban community based health care centre. Convenience sample 13 lesbians and 28 heterosexual women diagnosed within the last 5 years. 7 focus groups, 4 hetero and 3 L. 66% white European. 85% lesbians reported being "out" 46% revealed sexuality to physician. 86% early stage Br Ca 15% had recurrence. Av time since	1. Lesbians higher stress, lower satisfaction with care and emotional support from HCPs 2. Het women reported greater satisfaction with medical interactions 3. Attitudes about medical decision making- no difference 4. Preferences for providers – both preferred female physician for routine care but did not care re oncologist, thought large cities and hospitals would offer better care 5. Patient provider relationship- sought skilled professionals, valued competence and success over compassion and empathy! 6. Disclosure of orientation- unique to lesbians – most disclosed to the HCPs	There are many similarities in the experiences of lesbian and heterosexual women. Important differences include less focus on breast reconstruction by lesbians, perceived lack of support/ acceptance over emphasis on breasts as an object of male sexual desire	LESBIAN AND HETEROSEXUAL COMPARRISON What about suburban or rural women's experiences Data taken from a larger study Small number of lesbians involved- not comparable Interesting issue re compassion verses competence are they mutually exclusive? Most studies talk of perceived acceptance, how can we judge actual acceptance – are we placing barriers up ourselves or do they exist in reality This study is mostly about the interactions

						diagnosis 3.2 yrs	they saw regularly but not to those they saw infrequently 7. Barriers to participation in support groups due to lack of perceived acceptance and breasts as sexual objects		with health care and not about the experience of living with cancer – how the cancer impacts on the person
9	Dibble, S. L., Roberts, S. A., Robertson, P. A. and Paul, S. M., (2002)	USA (CA)	'Risk factors for **ovarian cancer**: lesbian and heterosexual women'	To compare the distribution of risk factors in lesbian and heterosexual women	Secondary analysis of retrospective medical review	1019 women; 586 H, 433 L; 35-75 [42.9]. most lacked insurance, most were below poverty line. Fewer AA in lesbian group	1. H women had more pregnancies, children, miscarriage, abortion and pill use 2. L had >BMI 3. H > current smoking, no diff with history 4. Both groups were overweight according to BMI	Pregnancy related variables place lesbians at higher risk of ovarian cancer. No difference with other variables eg age of menarche, menopause, HRT use	LESBIAN AND HETEROSEXUAL COMPARRISON Clinic set in a low income area – more ethnic minorities included in sample but still a low rate of AA in L sample – what are the actual numbers of AA lesbians – do we know this at all? Lots of missing data, form not designed for this studies purpose, no questions about fertility drug use

10	Dibble S., Roberts S. (2002)	USA (CA)	'A comparison of **breast cancer** diagnosis and treatment between lesbian and heterosexual women'	To explore differences and similarities in the diagnosis and treatment of L and H women with Br Ca	Observational study; Nested survey. Respondents to another survey exploring differences in risk factors	Large convenience sample. Paired sample with het. friend or sister 83 returns (77% RR) 30 H and 50L (3B not inc), 41-78 [55.4] yrs Self-designed questionnaire	1. No sig difference by orientation how lump found – lesbians slightly more likely to find it through BSE 2. No difference in type of surgery, reconstruction or LND 3. No difference in RT or CT 4. Lesbians reported more side effect from CT 5. Lesbians more likely to be told on the phone (not sig)	There are few differences in the experiences of diagnosis and treatment Attitudes of oncology nurses to lesbians is unknown and may influence the expression and management of CT side effects	LESBIAN AND HETEROSEXUAL COMPARRISON Conversations between L and their chemo nurse – are they the same as for H? Nurse's attitudes towards lesbian patients is unknown. Is there something significant in the experience of side effects- is there something inherent with being a lesbian, do we express more, are H women more stoical, could it be down to interaction with HCP- nurse/pt relationships
11	Dibble S., Roberts S., (2003)	USA	Improving cancer screening among lesbians over 50: results of a pilot study	To explore the impact of 2x1hr lesbians specific educational interventions by a lesbian physician on cancer	Pre and post test interventional study on cancer screening	36 lesbians only 22 completed (55%) 50-81yrs/ 86% white	1. Breast Ca: all had at least one mammogram however 27% (6) hadn't maintained screening, 1/3 of these got one post 2. Gynae: all had had a pelvic exam but 18%	Does not give insight into why screening not maintained , some allusion to pain and HCP not organising	Interesting that they declared the physician as lesbian If 6.2% of US pop is L then roughly equates to 41K lesbians

				screening behaviours	Education programme on cancer risk and screening for Lesbians run by out lesbian researcher/ HCP	Convenience/ community sample	(4) not maintained screening recomm. 1 post test did 3. Colo: 55% up to date. 10 had no recent screening but only one got post intervention!	Does suggest that a focused intervention programme may increase uptake and adherence in lesbians older than 50	diagnosed with cancer each year Lack of faith in research and maintenance of anonymity raised – interesting considering this was conducted in the SF area – supposedly safe! No follow up to see why screening practices were low
12	Fish, J. and Wilkinson, S., (2003a)	UK	Explaining lesbians' practice of breast self-examination: Results from a UK survey of lesbian health	To explore the reasons for lesbians practicing BSE	Drawn from larger study on lesbian health survey, using qualitative comments and quantitative data provided to extrapolate, content analysis	137 lesbians (13% of 1066) **Breast cancer**	Reasons for BSE: experiences of problems (25%), awareness of risk (25%), established routine (24%); knowledge about BSE (14%); other (12%)	Fear of breast cancer did not feature heavily (contrary to US studies)	LESBIAN Drawn from larger study so not focused questioning,

13	Fish, J. and Wilkinson, S., (2003b)	UK	Understanding lesbians' healthcare behaviour: the case of breast self-examination'	Focus on lesbians who report never practicing BSE	Drawn from larger study on lesbian health survey, using qualitative comments and quantitative data provided to extrapolate, content analysis	218 lesbians (20% of 1066) **Breast cancer**	Reasons for not doing BSE: 34% don't know how, what to look for; 21% never got into the habit, thought about it, couldn't be bothered; 12% frightened they'd find something; 11% don't think they are at risk, too young, no family history; 7% uncomfortable with their body/embarrassed; 7% partner does it; 8% other inc. doubts about efficacy or dr does it	Sheds light on key reasons for low uptake of BSE in this population and gives focus to health promotion materials esp risk factors (frightening to me)	LESBIAN AA In other (US) studies of this type fear of finding something is normally more common as are issues re body image and embarrassment Why are so few lesbians aware of the breast cancer risk/ is this the case in the female population in general?
14	Varner A.	USA	Spirituality and religion among lesbian women diagnosed with cancer	Explorative study experiences and effects of spirituality and religion among lesbians diagnosed with cancer	Qualitative interview study	Convenience sample 8 women self-identified as lesbian Various cancers	1. Definition of spirituality closer to feminist writing that patriarchal 2. All participants had left the tradition they were raised in and prior to cancer diagnosis 3. Definition of spirituality – relational 4. Spirituality has increased since cancer diagnosis	Women found spirituality supportive during their cancer journey but all were participating in different religions from the one they had been raised in and they sort LGBT affirming	Self-selected participants, may only have the voices of people who were still finding support in religion No comparator group and other evidence shows religion causing harm

							5. Spiritual support found from within lesbian culture 6. Found anti LGBT lit in surgeons office	organisations/ churches	
15	Matthews, A. K., Brandenburg, D. L., Johnson, T. P. and Hughes, T. L., (2004)	USA	Correlates of underutilization of gynecological cancer screening among lesbian and heterosexual women	Examine cervical cancer risk factors, screening patterns and predictors of adherence in demographically similar groups of lesbians and heterosexual women	Comparative study Heterosexual and Lesbian women Quantitative multi-site survey on women's health conducted between 1994-1996	550 Lesbian and 279 heterosexual 33 bisexual women; 20-86 [43] yrs; 74% white, 66% in a relationship **Gynecological cancer**	7. Lesbians more likely to report a perceived bias based on sexual orientation in HCP's 8. Lesbians had more sexual partners and commenced sexual activity younger than H women 9. 86% lesbians reported never using safer sex devices, 13% L history of STD 10. More H women had abnormal Pap smear result (not sig 31 comp 25%) 11. No significant difference in cervical cancer, gynae cancer or HIV infection 12. L slightly less likely to adhere to Pap program	Significant independent predictors of adherence are heterosexuality, history of abnormal pap smear and annual medical visit.	LESBIAN AND HETEROSEXUAL COMPARRISON Cervical cancer Survey is pre HPV vaccine Adherence levels to Pap smear are different in the UK (check data) Limited definition of lesbian – sexually active with women in the last 12 months! Self-reporting study, convenience sample
16	Dibble, S. L., Roberts, S. A.	USA (CA)	'Comparing **breast cancer** risk between lesbians and their	Explore the similarities and differences between lesbians	Survey	(648) 324 pairs of Self-identified as	1. Lesbians had a significantly higher 5 year and lifetime risk over their sisters of	Lesbians are at higher risk of breast cancer due to	LESBIAN AND HETEROSEXUAL COMPARRISON

	and Nussey, B., (2004)		heterosexual sisters'	and their heterosexual sisters in the established risks for breast cancer	cross sectional design- matched pairs Gail breast cancer risk model	lesbians and their sisters Mean age L49.7 H 48.9	developing Br Ca due to all pregnancy related variables and high level of breast biopsies reported but it is not the 2-3 times increase reported elsewhere 2. Lesbians also reported higher rates of past smoking, BMI, higher alcohol consumption, waist to hip ratio. However exercised more often possibly negating other high risk activities	pregnancy related factors.	It seems that most tools identified are designed for an assumed heterosexual population – have any tools been designed to look specifically at lesbians? Few women of colour included
17	Boehmer, U. and Case, P., (2004)	USA	'Physicians don't ask, sometimes patients tell'	Describe the disclosure of sexual orientation among SMW with **breast carcinoma**	Qualitative, drawing on GT; in-depth interviews, CCA. No mention of saturation in data	39 women self identified as L/B, study made a concerted effort to recruit BME participants as disclosure less in group (Cochran), no restriction for stage or time since diagnosis	1. Women who were generally out were more likely to be out with HCP's 2. 11 did not disclose but none actively concealed- just weren't asked! Fear of homophobia, single or thought sexual orientation was private – key reasons given 3. 28 revealed: pts initiated explicit disclosure, no HCPs enquired. Perceived	100% of providers failed to enquire about sexual orientation	SEXUAL MINORITY WOMEN Lesbians want to be cared for by lesbians! How many providers are "out" How would this stack up in the UK where there isn't as great an option to choose

							safety of environment and preparatory work – reasons for. 4. Providers with good medical rep and lesbian in high demand 5. Disclosure strategies included manipulation of forms (adding partner to married) and active self disclosure 6. Done early to assess the need to change provider 7. Absence of response or lack or positive reaction seen as inability to deal/ignorance/discrimination 8. 13 had >1 lesbian provider		provider and change provider Why are researchers only interested in breast cancer – what is it about this disease that draws them; incidence, money, power, fear? What puts them off studying other groups, am I missing something? Are they harder to find, get to talk, access etc?
18	Sinding, C. Barnoff, L. Grassau P., (2004)	Canada	Homophobia and Heterosexism in Cancer Care: The Experiences of Lesbians	To examine what is lesbian about lesbians' experiences of cancer and cancer care	Participatory action research (PAR) Qualitative semi structured	26 Lesbian women with **breast, cervical and ovarian cancer**. Community/	1. Heterosexism: lesbian identity and social context ignored or dismissed 2. Heterosexism: lack of lesbian-positive psychosocial support 3. Lesbian positive care in a context of	Homophobia and heterosexism shape the experience Women discussed	LESBIAN Breast and gynea only Included one Bisexual, Initial interviews did not glean any lesbian

					interviews and focus group	convenience sample; 36-72 [50] yrs; 17 partnered 9 single; diagnosis >3 yrs: 13 <3 yrs 13	homophobia and heterosexism; screening for homophobia; gratitude/readiness to fight for equitable care	feeling gratitude for equitable care	specific data, only when revisited in the focus groups were themes expanded and explored from a lesbian perspective. Did not consider the nature of lesbianism and cancer, focused on services
19	Barnoff, L., Sinding, C. and Grassau, P., (2005)	Canada	Listening to the Voices of Lesbians Diagnosed with Cancer; Recommendations for change in cancer support services	To focus on heterosexism and strategies to counter it in psychosocial support services for Lesbians with cancer	Participatory action research (PAR) Qualitative semi structured interviews and focus group	26 Lesbian women with **breast, cervical and ovarian cancer**. Community/ convenience sample; 36-72 [50] yrs; 17 partnered 9 single; diagnosis >3 yrs: 13 <3 yrs 13	1. Connection with other lesbians 2. Partners and children to have connections 3. Information resources reflecting lesbian realities 4. Lesbian service providers 5. Support/wellness groups	Participants expressed the desire to connect with other lesbians diagnosed with cancer and they wanted their partners and children to have the same opportunities	LESBIAN Breast and gynae How important is the visibility of LGB identified H&SC professionals to L with cancer? Intersection of cancer and poverty
20	Boehmer, U., Linde, R. and	USA	'Sexual minority women's coping and psychological adjustment after a	Factors that influence SMW coping responses	Cross sectional Mixed methods;	64 SMW – targeted community	1. 78% “out” to providers 2. Lesbians significantly more likely to	Only sexual orientation group was related to	SEXUAL MINORITY WOMEN

	Freund, K. M., (2005a)		diagnosis of **breast cancer'**	and adjustment to breast cancer	qualitative SS interviews and quantitative questionnaire Min mental adjustment to cancer scale (MAC) and Profile of mood states (POMS)	sampling and snowballing Direct attempts to recruit BME: 5 non white (3 Latina, 2 AA) White, highly educated employed with health insurance. 26-73 [50.5] Mean of 4 years post diag	disclose to HCPs than B or PWW combined 3. Women who were open about SM status and those who disclosed to BC HCP perceived greater social support levels 4. Disclosure related to being in a relationship 5. Women in support groups reported significantly more cognitive avoidance coping and distress 6. Women in this study experienced low levels of distress	coping and lower distress (L) - disclosure did not relate to coping or lower distress – suggests future studies should look at clearly defined sexual orientation groups	Fobair also used POMS BME more likely to say they PWW rather than LB How much of a factor does the nature of NHS have on experience? Do women feel a pressure to disclose if they want a partner involved in their care? What does this finding re support groups actually mean?
21	Boehmer, U., Freund, K. M. and Linde, R., (2005b)	USA	'Support providers of sexual minority women with **breast cancer**: Who they are and how they impact the breast cancer experience'	To identify factors associated with adjustment to breast cancer among SMW with BrCa and their support person	Mixed cross sectional. Qualitative interviews with SMW and then partner Quantitative POMS and Mini MAC and Medical Outcomes Study (MOS) –	30 SMW and 24 partners WWBC 37-73 [50.8] P 37-70 [49.5] Once women had undertaken main study they were asked to	ers were female; 79% in a ne WWBC av 17 yrs of sexual minority status of distress of WWNC and P ress od support network then P ut not WWBC)	"the emotional wellbeing of women with breast cancer is dependent on the support provider, whereas support providers emotional wellbeing depends on	SEXUAL MINORITY WOMEN Partner as main support is mirrored in studies of het WWBC

					social support assessment	identify their main cancer support person who was then contacted to arrange an interview		their own connections to others. The support providers distress is eased if the WWBC they are supporting are less isolated”	
22	Fish J., Anthony D., (2005)	UK	UK National Lesbians and Health Care Survey	Is there a correlation between risk perceptions, experiences of health care and health seeking behaviour	Non-probability survey focusing on cancer screening and risk perception for cervical and breast cancer	1006 respondents (from 3627- 29% response rate) 20-70+ 87% 21-50 B to UK census South Asian below UK census levels	1. 55% attended pap smear regularly (more likely not to attend than general female pop). 16% never been tested/12 % of those eligible 15% had an abnormal 2. 21% never done BSE, no correlation with age (BSE 13%L but 41% for het in previous study p39) 3. 20% had breast problems, 4. 80% of those eligible had attended mammogram (more likely to attend than het). 5. 51% L thought lower risk of CC, 43% same risk – risk perception	Underscore need for proactive culturally competent health care and creation of systemic institutional change to improve care	S Asian may be to do with lack of L networks for this ethnic minority group/ could also be to do with level of homophobia?

							not correlated with regular attendance 6. BC 76% same risk, 19% higher risk, 3% lower 7. 44% had bad experience of PS, 46% good attendance and good experience correlated. L less likely to report good experience		
23	Bowen D., Powers D., Greenlee H., (2006)	USA	Effects of **breast cancer** risk counselling for sexual minority women	Evaluate the effects of RCT risk counselling on SMW and examine demograophic and cultural predictors of responses to counselling	RCT of breast cancer counselling randomised between counselling condition or delayed counselling control condition. Baseline, 6 and 24 month FU Group counselling; 4x2 hr weekly	150 SMW 81 control group 69 intervention 92% FU rate at 6 months another 4 lost at 24 Community/ convenience sample	1. @24 months intervention group significant higher screening rate (up12%) 2. BSE@6 months int. Group sig higher rate (up17%) 3. Significant predictor of screening mammography was cultural identity and outness 4. Sig predictor of BSE – outness	SMW overestimate their risk of breast cancer Counselling delivered in a SMW supportive environment is beneficial	Made the SMW status of researchers counsellors etc clear Used self defining labels to measure SM status Can't say what the impact of the SMW focus is- might be the same in a women only counselling etc

					session with 5-8 women				
24	Sinding, C., Grassau, P. and Barnoff, L., (2006)	Canada	Community Support, Community Values: The Experiences of Lesbians Diagnosed with Cancer',	increase understanding of Canadian lesbians' experiences with cancer and cancer care, and to suggest directions for change such that lesbians with cancer might be better supported by service providers and lesbian communities	Participatory action research (PAR) Qualitative semi structured interviews and focus group Focus on the lesbian community and support	26 Lesbian women with **breast, cervical and ovarian cancer**. Community/ convenience sample; 36-72 [50] yrs; 17 partnered 9 single; diagnosis >3 yrs: 13 <3 yrs 13	1. The lesbian advantage in support; perception of other women >empathy. Support esp competent and well orgnaised (from HIV experience). “lesbian chart” (but doesn’t work outside urban areas)! womans point of view- well understood as a woman 2. isolation and disconnection; some good at logistics but not empathy. Some in community has problems with cancer “fear” . shared experience of body 3. fear re forming new relationships happens against the heterosexist and homophobic backdrop. 4. Lesbian culture, values and norms; hair- loss seen as both empowering –	“While 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. As well, while lesbian norms and values appeared to buffer the negative effects of treatment-	LESBIAN How does a woman’s point of view (re support) equate to an non gender specific cancer? Interesting finding re the lesbian identity and breasts and hair-dissonance

							butch dyke and disempowering – passing. Breasts – not an issue in lesbian culture but some found it to be hugely problematic. Values and practice do not always comfortably merge	related physical changes, such norms also manifested as prescriptions for lesbians with cancer. Findings affirmed the value of creating networks among lesbians with cancer within a context of increased accessibility to mainstream cancer services.	
25	Boehmer, U., Linde, R. and Freund, K. M., (2007)	USA	'Breast reconstruction following mastectomy for **breast cancer**: The decisions of sexual minority women'	Explore which issues SMW considered when making decisions on reconstructive surgery and to understand the influences and perspectives of these women's most important support person	Qualitative 1:1 SS interviews drawing on GT.CCA Retrospective Hypoth: SMW consider different	15 SMW 8-reconstruction 7 no reconstruction and 12 support persons Community based sampling 41-61 / 40-63	1. Notion of not being defined by having breasts closely aligned to SM status 2. Noted their "otherness" – their values and BI to mainstream society 3. Smaller breasted women most comfortable rejecting reconstruction	Partners shared in decision making and played an important role in supporting the decision made. WWBC had great confidence that their partner would love	SEXUAL MINORITY WOMEN No definition of body image explored, recall bias, no assumptions re prevalence of beliefs re BI in SM population Doesn't really comply to GT norms

					dimensions of BI	Months since diag 31.9 NRec 17.4 WRec	4. Larger felt unbalanced and had heavy prosthesis 5. Body strength and function more important than aesthetics 6. Reconstruction “straight woman’s choice” 7. Passive partner= recon 8. No partner= recon 9. Contrary to women who chose recon the women who didn’t had no regrets	them regardless of their physical appearance	
26	Ben-Natan M., Adir O., (2009)	Israel	Screening for cervical cancer among Israeli lesbian women	Explore factors influencing lesbian women to undergo pap smear tests	Quantitative correlational using HBM	108 lesbian women from Tel Aviv 18-41	1. Only 22.2% had undergone PS 2. 30.8% intended to undergo PS 3. Older women more compliant with the test 4. Factors influencing intention inc: perceived susceptibility or benefits and general health motivation	Very low rate of uptake in comparison to other studies	No definition of lesbian Younger age group
27	Darwin, Z. and	UK	Understandings of Cervical Screening in Sexual Minority Women: A Q-	Explore the diversity of meanings that British SMW have	Q-methodology	34 SMW	1. Rejected the hypothesis that cervical screening was more important		SEXUAL MINORITY WOMEN

	Campbell, C., (2009)		Methodological Study	about cervical screening		**Cervical cancer**	for heterosexual women 2. No participants identified HPV 3. Screening seen as normative behavior rather than health choice 4. Good for me/ oppression not given a choice		Participants were young (all below 41) No definition of LB Only 34 returned out of 76, was this due to methodology or fear or lack of interest? q-set limited by omission of HPV items
28	Hart S., Bowen D., (2009)	USA	Sexual Orientation and intentions to obtain breast cancer screening	Longitudinal study to explore predictors of intention to undertake breast screening between LB and Het women	Quantitative questionnaire based study	150 LB and 400 H women. Sample taken from 2 larger studies on breast cancer risk counselling. Baseline taken at diagnosis and follow up at 6 months Mostly white middle income, employed	1. LB women significantly less likely to believe they would get breast cancer some day 2. LB less afraid of getting BrCa 3. Experiences of HC impact on screening uptake	LB women more likely to hold negative beliefs about BC screening and report lower perceived risk which influences screening choices. Interventions should be aimed at risk counselling for specific groups and improving relations	Original studies 1996-97 No definition of LB

						participants from LB		between user and provider.	
29	Fish, J. (2010)	UK	Coming Out About Breast Cancer: Lesbian and Bisexual Women.	Provide new data on L&B women's experience of living with breast cancer and of treatment support and care	Pilot study, Qualitative interviews 1:1	17 LB women, 13 with **breast cancer**, 4 partners. Convenience sample ; 28-70 (no mean given) no clear indication of number of years since diagnosis for all participants, no ethnic breakdown, no indication whether the partners of B women are male or female (if male could affect how services perceive them)	1. Lack of support/ reminded of "otherness" 2. Coming out 3. Non engagement with the patient 4. Heterosexism in cancer services/ screening for	Some women felt excluded from/ unable to access existing support groups	SEXUAL MINORITY WOMEN Breast cancer only No definition of L/B Are the experiences of lesbian and bisexual women the same? Study does not distinguish How do LB women use existing support networks (urban/suburban/rural) What is LB about the cancer experience still remains unanswered

30	Polek C., Hardie T., (2010)	USA Del	Lesbian Women and Knowledge about Human Papilloma virus	Association between HPV knowledge to age, education, openness	Descriptive correlational survey Convenience sample	96 women self identified 1 US state	1. 30% did not know or did not believe that HPV could be spread by F2F sexual contact 2. 30% did not id HPV as a cancer risk	Lack of HPV knowledge is prevalent in the population	Small study Limited sample
31	Tracy K., Lydercker A., Ireland L., (2010)	USA	Barriers to cervical cancer screening among lesbians	Evaluate practices and barriers to CS amongst lesbians	Cross sectional, on line, survey	225 self-identified lesbians 18-68 yrs White, mid income, employed	1. Routine screeners older, white and college grads 2. Non routine screeners more likely to delay seeking HC due to discrimination fears , were less likely to disclose orientation, were less knowledgeable about guidelines for CS 3. No difference in perceived seriousness and susceptibility	Significant minority of lesbians do not screen regularly for cervical cancer	Lesbian only- excluded Bi women Self-identification through forced choice (list of options LBH no QG) 28% had no insurance
32	Zaritsky E., Dibble S., (2010)	USA	Risk Factors for reproductive and breast cancers among older lesbians	Do older lesbians have more Br and Gynae risk factors comp to Het sisters?		370 lesbian and het sister pairs aged >40 and analysed subset >50 (42 pairs) Community/ convenience sample	1. Comp to sisters L had more education, fewer pregnancies, less total months pregnant, fewer months breast feeding 2. Lesbians had higher BMI, exercised fewer times 3. No difference in smoking and alcohol	Older lesbians may have greater risk factors for some but not all reproductive cancers comp to het sisters esp breast, ovarian and	White well educated and insured respondents

							4. L did BSE less than sisters	endometrial but NOT cervical	
33	Boehmer, U., Clark, M. A., Timm, A., Glickman, M. and Sullivan, M., (2011)	USA	'Comparing Sexual Minority Cancer Survivors Recruited Through a Cancer Registry to Convenience Methods of Recruitment	Assesses the representative-ness of SM BC survivors who were recruited into a convenience sample compared with a population based registry sample	Comparison of outcomes and results to assess representative-ness	Convenience = 112 [55.1 yrs] Registry 69 [55.9 yrs] **Breast cancer**	1. SM WWBC who volunteered shared many of the characteristics of the registry sample 2. Comparable representational quality	When linked to eligibility criteria thoughtful convenient recruitment provides good representational quality convenience samples	SEXUAL MINORITY WOMEN Methological study not really on cancer Still a lack of BME overall was non significant and comparable in the two groups [Con 86.6% and reg 94.2%] but slightly better in registry group
34	Jabson, J., M., Donatelle, R., J. and Bowen, D., J., (2011)	USA	'Relationship Between Sexual Orientation and Quality of Life in Female **Breast Cancer** Survivors'	Hypothesized that QoL would be lower in self identified lesbian breast cancer survivors	Cross sectional on line survey Measures: QoL in Cancer Survivors	204 BC survivors; 61 SIL and 143 H Convenience sampling 30-79 yrs; SIL av 56 H54 No AA in either sample!	1. H more likely to be partnered or married 2. SIL completed more years of education 3. Unable to id a significant relationship between SO and QoL 4. Plausible that survivors have developed heightened resilience stemming from exposure for chronic minority stress and this resilience	QoL scores similar in both H and SIL	SIL determined by measuring sexual orientation identity Small SIL sample included B excluded based on Inst of Med recommendations Not clear how long since cancer diagnosis This is a survivorship paper- if heterosexism

							facilitates coping with BC		is present in the journey does this paper imply it doesn't matter as its all good in the end. Issues include people who have experienced issues may be less willing to take part and also may have not survived!-healthy volunteer effect
35	Cochran S., Mays V., (2012)	USA	Risk of Breast Cancer Mortality among women cohabiting with same sex partners: findings from the national health interview survey 1997-2003	Investigate possible sexual orientation related differences in risk for fatal breast cancer	National health survey linked to mortality statistics	Married and cohabiting female participants 18-80yrs 693 –female partner	1. 0.5% of women cohabiting were with a woman 2. Women in same sex couples compared with women in different sex relationships had a greater age adjusted risk for fatal breast cancer but did not differ in overall risk of mortality	Sexual orientation is tentatively differentially linked to fatal breast cancer	The main study (National health interview survey) does not specifically ask for respondents to state sexual orientation-extrapolated based on responses of gender of cohabiting partner Mortality follow up only 7 yrs
36	Boehmer U., Timm A., Ozonoff A., Potter J., (2012)	USA	Explanatory factors of sexual function in sexual minority women breast cancer survivors	Identification of explanatory factors of sexual function among SMW with breast cancer in	Quantitative FSFI adapted to SMW, plus data collection using	85 SMW/ 85 control	1. Controls rated sexual attractiveness significantly higher 2. Mental wellbeing associated with	Findings indicate that, contrary to previous studies, long term SMWBCS	Same cohort 2013 paper Self-identification as SMW

				comparison to SMW without cancer	conceptual framework re predictors of sexual function		improved sexual function 3. A&D impacted negatively 4. Sexual attractiveness and urogenital symptoms explained 44% of variability 5. Treatment did not have a sig impact on sexual function	do not differ significantly from matched controls in respect of comorbidity, anxiety , depression and mental/physical wellbeing	
37	Boehmer, U., Glickman, M. and Winter, M., (2012)	USA	'Anxiety and Depression in **Breast Cancer** Survivors of Different Sexual Orientations'	To compare anxiety and depression by sexual orientation in long term breast cancer survivors – testing SMW have greater levels of anxiety and depression	Telephone survey and HADS Cross sectional	257 heterosexual 181 SMW (69 derived from cancer registry 112 convenience/ community recruitment	1. Similar proportion of H and SMW had A&D 2. SMW with discrimination experiences reported greater levels of distress 3. Younger age, low income and lower education increased psychological morbidity 4. Married SMW have reduced anxiety whereas married Het women have increased anxiety. Marriage protects from depression in both groups 5. Sexual minority group with radiation increased depression	Findings consistent with previous studies (Fobair 2001 and Arena 2006) lesbians do not differ from het women with respect to depression and self reported distress	LESBIAN AND HETEROSEXUAL COMPARRISON Minority stress paradigm Based hypothesis on data that shows SM are more likely to need MH services Did they assess for participants previous use of MH services? What happens long term Sample may be biased towards those with

							6. Stg 3 RT and mood stabilizing drugs increase depression in SMW 7. SMW use more antidepressive and mood stabilizing drugs compared to het survivors		better psychological health due to nature of sampling. If you are experiencing severe A&D you are unlikely to take part in a telephone survey about A&D! Is HADS the best tool for assessing A&D in a survivorship group
38	Boehmer, U. and White, J. L., (2012)	USA	'Sexual Minority Status and Long-Term **Breast Cancer** Survivorship'	Explore long term cancer survivor SMW perceptions of the relationship between their SM orientation and their survivorship experiences	Qualitative 1:1 SS interviews open ended questions. Modification of the guide after several interviews as not eliciting detailed responses	22 SMW, 43-69 yrs [54.6]; 19 W 2 Latina and 1 AA 15 partnered Mean 6yrs post diagnosis	1. *“Breast cancer is a womens issue not a lesbian issue”*; primacy of being a woman. Only after aligning with this statement did many women go on to explore how their SM status impacted on their survivorship experience. Women here marriage, raising children, universal acceptance by family of origin and hets in general 2. *I can manage my identity in the context of breast cancer.* Highlighted being	Themes consistent with minimizing discrimination and maximizing personal control Perceptions of breast cancer as a women’s issue and the general rejection of SM status salience may explain limited participation in other studies.	Additional study to the 2010 and 2011 BC studies above No qualitative methodology detailed. Coding undertaken by authors but no detail on how these were derived

							visible or out as SMW for many years. Reached a level of confidence and assurance in their interactions to ensure SM status was a non issue. Living in a hetero-normative society taught skills 3. *Better off than heterosexual women.* Physical appearance less important to self and women partners; protected from social expectations eg mastectomy, hair loss, weight gain. Women partners could empathize.	Relationships with HCPs in the long term participant non-issue- relationships mirror those found in other general HC settings No one highlighted SMW increase risk of BC so could talk to lack of information/ awareness – again may explain reluctance to participate in studies	
38	Boehmer U., Glickman M., Milton J., Winter M. (2012)	USA	Health related quality of life in breast cancer survivors of different sexual orientations	Study examines the physical and mental quality of life and its association with sexual orientation for long term	Telephone survey SF-112 – QoL looks at	Convenience sample recruited from cancer registry 438 participants	1. Expectation that smw have lower QoL was not confirmed 2. Almost non of the SMW survivors opted for reconstruction	Expectation that SMW would have worse QoL than heterosexual conterparts not found – on the	Another study showing that expectations of poorer outcomes for SMW not substantiated in studies

				breast cancer survivors	physical and mental QoL	257 heterosexual 181 sexual minority women	*3.* No significant difference in fair to poor health *4.* More experiences of discrimination associated with worse physical health *5.* Only age was a variable – indicating older women had better mental health *6.* Smw in lower or middle income groups had poorer physical health	contrary het women and smw presented similarly with scores close to US population mean Significant association between experiences of discrimination and worse physical health	
40	White, J., L. and Boehmer, U., (2012)	USA	'Long-Term **Breast Cancer** Survivors' Perceptions of Support From Female Partners: An Exploratory Study'	Describe the social support experience of LT BrCa survivors from partners	"lived experience" In-depth 1:1 interviews semi structured telephone Open ended questions Analysis began during collection	15 SMW partnered non met Br Ca taken from parent studies who agreed to further contact Mean 6 yrs post diag and 52 yrs relationships 7-33 yrs 13 white/ 2 lat	1. Partner singular source of most valued support 2. Discussing survivors health and distress 3. Perceived partner distress 4. Managing home and caretaking 5. Perceived partner burden 6. Sharing life beyond cancer	Female partners are responsive to survivors needs at time of diagnosis as well as many years after the cancer. Partners also ongoing stress and burden. Survivors did not report partner withdrawal from cancer	Most studies seem to be looking at non-metastatic breast cancer Parent study: Boehmer et al 2011 and 2010 Although lived experience stated no mention of the use of theoretical framework like phenom. Telephone based- how do you judge B Lang

								related discussions	Not mentioned whether any women split after BC diag, most respondents were young – where is the older SMW? How is this not just about being in a relationship
41	Boehmer, U., Glickman, M., Winter, M. and Clark, M. A., (2013)	USA	'Lesbian and Bisexual Women's Adjustment After a **Breast Cancer** Diagnosis'	Determine the differences between lesbian and bisexual survivors adjustment post Br Ca – do SM specific issues contribute to adjustment?	Quantitative survey: Cross sect. EORTC QLQ Br23, Trust in Physician Scale, Interpersonal support eval list, Mini MAC, discrimination measure, Outness inventory, LGB Identity scale	180 women, 161 L/ 19 B; 56 yrs 35 minute telephone survey Cancer registry/ community	3. Sexual identity had no significant relationship with physical or mental health 4. Difficult processes (defined by SMF and LGB Id scale) was a significant contributor towards depression scores 5. Link between internalized homophobia and greater distress among L with br ca supports McGregor 6. Female partnered survivors did better comp to un-partnered survivors, partnered to male had worse MH	Confirms minority distress model – issues of disclosure and neg perceptions of SMI linked to adverse MH outcomes Disclosure = less anxiety Perceiving the development of SI as difficult= greater depression	Using minority stress model Small (non comparable) number of B women Authors suggest future studies should look at un-partnered women-partner relationship variables US Institute of Medicine suggests L and B should be studied separately to Id differences

							7. Openness about SO in daily life associated with lower anxiety		
42	Boehmer U., Glickman M., Winter M., Clark M. (2013)	USA	'Breast cancer survivors of different sexual orientations: which factors explain survivors' quality of life and adjustment?'	Using sexual orientation as the independent factor: ascertain the QOL, anxiety, depression levels among SMW and HSW breast cancer survivors	Quantitative	SMW 181/ HSW 257	1. SMW reported more discrimination experiences, attendance at support groups and seeking MH counselling 2. SMW showed better coping and less cognitive avoidance coping 3. Sexual orientation contributed towards physical QOL outcomes indirectly related to health insurance status and partnership status 4. Sexual orientation positively impacted on mental QOL re hormone therapy, social support, and fatalism coping, but negatively for counselling. 5. Living with a partner was associated with more anxiety but relationships were stronger for SMW.	SMW strength is their use of cancer support groups and MH counselling More research needed on the increase in anxiety among SMW living with a partner	Consider role of counselling and support groups given other findings- were these groups LGBT specific or cancer specific support groups?

							6. Being older, having a BMI outside the healthy range, more social support, positive body image and better future perspective assoc. with less anxiety		
43	Boehmer U., Glickman M., Winter M., Clark M. (2013)	USA	Long term breast cancer survivors' symptoms and morbidity: differences by sexual orientation?	To examine differences by sexual orientation in symptoms and morbidity including arm morbidity, systemic therapy effects, hypertension and comorbidities	Quantitative telephone survey	SMW 181/ HSW 257	1. Prevalence of ¾ outcomes did not differ by sexual orientation (only BP higher in HSW) 2. Sexual orientation associated with arm morbidity and systemic side effects not with high blood pressure and comorbidities with SMW having fewer issues but this increased with time 3. Mastectomy, CT, HT and RT associated with arm symptoms in SMW	SMW respond more negatively to certain cancer therapies but this study did not support Dibbles findings re greater CT side effects	Same sample as previous study
44	Boehmer U., Ozonoff A., Timm A., Winter M.,	USA	'After breast cancer: sexual functioning of sexual minority survivors'	To test the hypothesis that SMW with Br Ca have poorer sexual function	Retrospective convenient case controlled comparative	85 smw/85 control	4. No difference in sexual dysfunction or overall level of sexual functioning between case or control status	Partner status is not a significant predictor of sexual function- contrary to	See also 2013 study reports Some conclusions just seem so obvious!

	Potter J. (2014)			than SMW without Br Ca	study with SMW Br Ca survivors and SMW without cancer	Completed active treatment Partner status matched	5. Cases had lower sexual frequency, lower desire and ability to reach orgasm 6. Higher levels of pain in cases 7. Partnership status not significant for sexual dysfunction 8. Menopause status had significant negative impact on sexual frequency and function, but not satisfaction, for both groups	findings in het studies. Sexual orientation should be ascertained when offering support re sexual problems	Tool used designed for het women – made some adjustments but really need a tool specific for SMW See also 2012 study
45	Tracy JK., Schluterman N., Greenberg D., (2013)	USA All 50 states and DC included	Understanding cervical cancer screening among lesbians: a national survey	Examine cervical screening behaviours in a national sample of lesbians	On line quantitative survey Frequency of pap smear, history of C ca, knowledge of C Ca risk factors, perceived susceptibility, seriousness, perceived discrimination,	4422 women randomly selected from the LGB speciality panel – tracked by Harris International Response rate 35% - 1307 women – 301 excluded-	7. 62% routine screeners 8. Lack of referral or lack of dr most common reason for not undertaking screening 9. Disclosure of SM status led to greater screening uptake 10. Routine screeners perceived more benefits and less barriers as well as higher susceptibility to C Ca	There is a potentially elevated risk of C Ca for some lesbians due to a lack of routine screening	Harris interactive was paid for their role, study funded by NIH

					disclosure of SM status	incomplete data 1006; 21-70 yrs			
46	Meads C., Moore D. (2013)	UK	Breast cancer in lesbians and bisexual women: systematic review of incidence, prevalence and risk studies	Investigate evidence on whether there is higher rates of breast cancer in LB women	Systematic review 16 papers after scrutiny		1. All studies small and had methodological issues 2. Incidence modelling suggested higher rate 3. Risk modelling 3 higher, 1 lower for LBW 4. Risk factor 6 higher and one no diff	Insufficient information to draw conclusions Need to collect SO in routine stats/ cancer registry to get true findings	Issues with documenting the review process as they do not clearly state in the narrative the final number of articles included – have to work this out from PRISMA
47	Paul L., Pitagora D., Brown B., Tworecke A., Rubin L. (2014)	USA NYC	Support Needs and resources of sexual minority women with breast cancer	Aim to better understand the support needs of SMW with breast cancer	Qualitative semi structured interviews	13 women 29-56 yrs Lesbian, white middle income 92% white, 62% Jewish Received mastectomy Primary study aimed at looking at reconstruction	9. Lack of LGBT awareness in gen support groups – decreased comfort level 10. Being in a support group for LGBT cancer pts took precedence over stage specific support 11. positive experiences with SMW support groups 12. lack of support groups for partners or family	Importance of recognising the intersections of multiple identities required within cancer care to ensure care for the whole person is achieved	Self-identification as LGBQ ? assumptions being made about the female caring role- seems to be implying that women will naturally take on a caring position Some contradictory findings to the Canadian study re support

						choices, secondary analysis for support conducted	13. changes in relationships, dissolved or disrupted 14. variation in support received from partners 15. single, middle aged or older reported least support 16. former partners, siblings offered support 17. multiple stressors included isolation from ethnic community due to L status and isolation from L community due to cancer status		
48	Boehmer U., Ozonoff A., Timm A., Winter M., Potter J. (2014)	USA	After breast cancer: sexual functioning of sexual minority survivors	Compare sexual functioning after cancer for smw – is this different to smw without cancer	Case control study comparing SMW with cancer (case) and smw without cancer (control) Convenience sampling	85 cases post breast cancer treatment 85 controls smw without cancer Age and partner status matched	1. found no difference in sexual dysfunction between case and control groups 2. cases had reduced sexual frequency 3. cases had reduced desire and ability to reach orgasm 4. cases had increased pain 5. more cases were menopausal (ca treatment induced)	Case-ness and menopause had significant negative association with sexual frequency Partnership status was not a significant predictor of	Study relied on survey data, but would this be the same in qual investigation? Self report study – could influence answers Tool used designed for het women

					Anonymous survey data		6. partnership status was not significant for risk of dysfunction	sexual function in smw Inconsistent evidence that SMW post br ca differ significantly in sexual function to smw without cancer	Could not totally control for HRT esp low dose vaginal oestrogen
49	Brown R., McNair R., Szalacha L., Livingstone P., Hughes T. (2015)	Australia	Cancer risk factors, diagnosis and sexual identity in the Australian longitudinal study of women's health	Compare exclusively het to SMW; cancer diagnosis, treatment and related risk factors among Aus women, middle aged,	Secondary survey from longitudinal health survey – women born 1946-1951	10,451 in total survey Only 2% smw in survey = 251 and of this 117 were "mainly het"	1. smw did not have sig higher cancer diagnosis than het women 2. smw more likely to not have mammogram or pap smear 3. smw higher rate of high risk drinking, and smoking behaviour 4. increased rate of depression in smw 5. increased history of being in violent relationships	Analysis of cancer risk factors and cancer diagnosis, risk factors did not predict cancer, nor did sm status	Interesting inclusion of mainly het in the SMW definition – not normally seen Although they do not find a difference in the rates they hold on to the hypothesis that increased number of risk factors will lead to increased cancers esp as the group age into old age Not original study – secondary survey data Mainly het data may sway findings

50	Legere L., MacDonnell J. (2016)	Canada	Meaningful support for lesbian and bisexual women navigating reproductive cancer care in Canada: an exploratory study	Exploration of interactions between smw with repro cancers and HC providers and how they may create barriers to meaningful support	Feminist/inter sectional lens used Purposeful convenient sampling Self-identification Reproductive cancers Completed treatment. Not recruited from treatment centres as they did not want to add burden during tx	6 LB women with cancer 20's-60's Breast, cervical and ovarian cancers 1 HCP (het)	1. gender normativity shaped care 2. het assumptions 3. meaningful support characterised by quality physical care (not psych or social) 4. did not go to nurses for support – perceived as too busy 5. interactions with HCP positive 6. no one asked about So and fear disclosure would lead to negative care 7. heterosexism evident when focusing on gendered elements of care eg pregnancy risks	Understanding of gender norms influenced women's perceptions of supportive and inclusive care inc. disclosure of SO	Interesting as this group did not perceive care as negative but also avoided being out to HCPs in case of substandard care – mixed age group. Different to other studies esp Bryson – cancers margins
51	Kamen V., Jabson J., Mustian K.,	USA	Minority stress, psychosocial resources and psychological distress among	Assess the association of MS and psych resource factors with depression	Cross sectional self report study	201 SMW 86% lesbian 14% Bi	1. age was the only demo neg ass with depression, all others positively ass 2. college ed positively ass with anxiety	Factors assoc with SM status eg minority stress may be assoc with	Interesting how none of the studies that use sexual minority breast cancer survivors include gay men

	Boehmer U. (2017)		sexual minority breast cancer survivors	and anxiety symptoms	Sample taken from larger study Participants drawn from AOW online recruitment tool 35 minute telephone interview Measured minority stress factors, psych resources – resilience scale supp eval list, and psych distress HADS	28-74 YO 88% non Hispanic white 66% partnered	3. no sig difference between L&B women 4. minority stress marginally associated with increased rates of psych distress 5. resilience could mediate relationship. 6. Discrimination and negative ID were sig and positively ass with distress 7. Resilience and social support neg ass on distress 8. Outness had positive assoc.	higher rates of psych distress among SM Br Ca survivors "Resilience significantly mediated the relationship between discrimination and psych distress but not social support" (p9) Greater resilience could foster less frequent anticipation of discrimination. Outness, contrary to other studies, was associated with greater distress within this study.	survivors of breast cancer – the assumption is always made this will just be women and cis women at that. No mention of trans or NB folk as part of the sample In write up it is women that are the focus

								Few differences between L&B – similar to other studies	
52	Brown T., McElroy J. (2018a)	USA	Unmet support needs of sexual and gender minority breast cancer survivors	Sources of stress and support experienced by SGM	Cross sectional Mixed method Purposeful and referral sampling SM platforms used, email invitations Web based survey – open and closed qs Questions designed for the study specifically plus breast impact of ttreatment scale	89 enrolled – 21 excluded for incomplete data Final no 68 SOGI breast cancer survivors 18-75 91% white	1. 16% queer id'd and sig younger and more likely to report BiLM without recon and more likely to think that disclosure affected care, also more likely to use LGBT supp groups 2. 83.8% disclosed SOGI to at least one HCP 3. Did not disclose in response to provider question or intake forms 4. Disclosure affected care 5. ½ of 85% who disclosed did so to correct het assumptions 6. More likely to use LGBT support than cancer supp 7. Reported current level of social support below average 8. No access to LGBT supp groups	Did not find a difference btn queer identified and non queer id'd parts in terms of disclosure Had similar levels of distress to presumed het study parts in other Br Ca studies Overwhelmingly felt sex lives had been negatively affected Report unmet needs for themselves and partners from social support	Self selected survivors Not face to face – cannot ask for expansion web based approach helped gain wider participant group – no geographical restrictions – what about access to internet

							9. When other LGB women in support groups, support improved 10. Non LGBT supp groups – heterocentric and unwelcoming – not able to trust 11. Br ca treatment traumatic and emotionally damaging 12. AI’s and EBs have massive impact on sexual intimacy	Study confirms finding from other studies of SGM Br Ca survivors	
53	Brown T., McElroy J. (2018b)	USA	Sexual and gender minority breast cancer patients choosing bilateral mastectomy without reconstruction: “I now have a body that fits me”	Explore exp of SGM BC survivors who chose not to have recon and prosthesis: healthcare experiences, social support systems, cancer survival experiences	Cross sectional Purposeful and referral sampling SM platforms used, email invitations Questions designed for the study specifically	68 SOGI diverse folk included 37.5% gender queer or trans people 91% white 57% married/ partnered/ cohab	1. Queer identified people are more likely to report having bilat mast without recon 2. 25% indicated they had “gone flat” – and were sig more likely to disclose SOGI 3. FT’s believed SOGI mattered to get support needed 4. Sense of gender clarity with BiLM 5. Disclosure often helped HCP understand treatment choice	SGM BC survivors who chose BiLM without recon were generally pleased with their treatment choice – better reflected their gender id thank recon would have SOGI factors can be an important factor when	Includes gender queer/ trans participants Subset of Brown and McElroy 2018a Uses phrase flat toppers to define group – do the participants identify with this or claim the name for themselves? What about unilateral and no reconstruction

							6. Frustration at gendered and het assumptions made by support groups eg LG facebook 7. Gender bias took form of seemingly benign assumption about surgical options or blatant and offensive gender bias	making treatment choices and interactions with care providers	
54	Greene M., Hughes T., Hanlon A., Huang L., Sommers M., Meghani S. (2019)	USA	Predicting cervical cancer screening among sexual minority women using classification and regression tree analysis	Identify subgroups of SMW that are more and less likely to be screened for cervical cancer	Cross sectional study from Chicago Health and Life Experiences of Women study wave 3 Self report of cervical screening within the previous year Over 21	691 women 485 lesbian 157 Bi 49 other	1. Women who reported pap smear were younger more likely to be unemployed 2. Self reported femininity and homonegativity 3. More likely to report at least one male partner 4. >28 sexual partners predicts PS testing	“Findings demonstrate intersecting components of individual and structural factors impact on screening” p158	Secondary data analysis of primary study – not designed to test this specific research question Self selected

55	Desai M., Gold R., Jones C., Din H., Dietz A., Shliakhtsitsava K., Martinez M., Vaida F., Su H., (2021)	USA	Mental health outcomes in adolescent and young adult female cancer survivors of a sexual minority	Compare depression and anxiety symptoms between AYA female cancer survivors who id as SM and het	Cross sectional Secondary analysis of WINDOW study Contacted via mail telephone or email – directions to online survey Online questionnaire	1025 AYA – only 64 SMW (6.2%) 75% white 64.1% married or cohab 15-40 Self reported SM (LB) Prefer not to answer excluded Presence of one ovary	1. Higher rate of unemployment in SMW 2. No diff in marital status, education or income 3. Equal levels of perceived stress 4. SM sig less social support 5. Higher clinical depression on SMW – not stat sig 6. Sig higher GAD score in SMW – twice odds	High levels of A&D across sample SM identification among AYA female cancer survivors was associated with higher levels of anxiety bit not depression	No option for other sexualities may have excluded ,many younger people who might identify as queer etc rather than lesbian and bi – does not reflect what other studies say about SOGI in young people (see Brown & McElroy for eg) Not trans inclusive as needed to have at least one ovary Small percentage of SMW in total pop
56	Hutchcraft M., Teferra A., Montemorano L., Patterson J. (2021)	USA	Differences in health related quality of life and health behaviours among lesbian, bisexual and heterosexual women surviving cancer from the 2013-2018 national	Assess differences in HRQoL and health behaviours in heterosexual, lesbian and bisexual cancer survivors		10830 het 141 lesbian 95 bisexual	1. Lesbians . fair to poor self rated health a) >COPD b) >Heart disease 2. Bi higher severe psych distress a) Heart dis b) Food insecurity 3. Lesbian women high rates of current and former smoking	LBW cancer survivors report poor HRQoL nd health behaviours that may contribute to higher morbidity and mortality – but study not	Again no inclusion of gender diversity v. few LB participants psych distress does not mirror other studies

			health interview survey				4. Bi women lower rates of mammography than het women 5. Lesbians did not have disparities in psych distress – ? unique protective factors like social support, resilience and coping (not seen in other studies)	designed to show this Need to id LBW pts requiring physical and mental health promotion, smoking cessation etc to improve HRQoL	
57	Schefter A., Thomaier L., Jewett P., Brown K., Stenzel A., Blaes A., Teoh D., Vogel R. (2021)	USA	Cross-sectional study of psychosocial well-being among lesbian, gay, bisexual and heterosexual gynaecologic cancer survivors	Assess psychosocial health among SM Gynae cancer survivors Comp GLB and het	Cross sectional study GOLD study FACT – G Distress therm Depression and anx – PHQ-8, GAD-7 PTSD – PTSDC Self report sexual orientation then LGB	401 completed surveys (92.6% RR) All cisgender bar one Trans person 22 LGB (5.5%) = (3.5LG, 2.0% B)	1. Rates of clinical relevant depression and anxiety and PTSD sig more common in LGB comp to het 2. No sig difference in QoL or distress 3. People with depression symptoms at time of study had previously been diagnosed with A or D – sim rates between H and LGB	Findings suggest LGB survivors are at higher risk of poor emotional health following G cancer diagnosis esp AD and PTSD – may therefore need additional and specific support and resources	V small

					grouped together(!)				

Appendix 2 Health Research Authority Ethics approval

NHS
Health Research Authority
NRES Committee West Midlands - Edgbaston
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Telephone: 0115 8839 440

05 May 2015

Miss Paula Kuzbit

Canterbury Christ Church University

North Holmes Road

Canterbury

CT1 1QU

Dear Miss Kuzbit,

Study title:	**A queer feminist narrative inquiry into the lived experience of being lesbian with cancer**
REC reference:	**15/WM/0141**
Protocol number:	**NA**
IRAS project ID:	**165782**

Thank you for your letter of 01 May 2015, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager, Rebecca Morledge, NRESCommittee.WestMidlands-Edgbaston@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [LCV Advertising Flyer localised]	1	20 February 2015
Copies of advertisement materials for research participants [LCV Advertising flyer]	1	20 February 2015
Copies of advertisement materials for research participants [LCV Poster localised]	1	20 February 2015
Copies of advertisement materials for research participants [LCV poster]	1	20 February 2015
Covering letter on headed paper [LCV Ethics submission covering letter]	1	13 March 2015
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [CCCU Indemnity insurance]	1	31 March 2015
Interview schedules or topic guides for participants [LCV Interview schedule]	3	20 February 2015

IRAS Checklist XML [Checklist_01052015]		01 May 2015
Letter from sponsor [P Kuzbit Sponsorship Letter]	1	31 March 2015
Letters of invitation to participant [LCV Participant invitation]	1	27 February 2015
Letters of invitation to participant [Invitation letter localised]	1	27 February 2015
Other [Prof Jan Burns CV]		
Other [Paula Kuzbit PhD Proposal]	2	27 February 2015
Participant consent form [LCV consent form]	2	19 December 2014
Participant consent form [LCV consent form localised]	2	19 December 2014
Participant information sheet (PIS) [LCV PIS]	version 6	01 May 2015
Participant information sheet (PIS) [LCV PIS version 6 track changes]	Version 6	01 May 2015
Participant information sheet (PIS) [PIS localised version]	version 6	01 May 2015
Participant information sheet (PIS) [LCV PIS localised clean]	version 6	01 May 2015
REC Application Form [REC_Form_01042015]		01 April 2015
Referee's report or other scientific critique report [LCV peer review]	1	09 February 2015
Research protocol or project proposal [LCV Protocol V3]	Version 4	01 May 2015
Summary CV for Chief Investigator (CI) [P Kuzbit CV]	1	12 December 2014
Summary CV for supervisor (student research) [Toni Wright CV]		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

15/WM/0141 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely,

pp

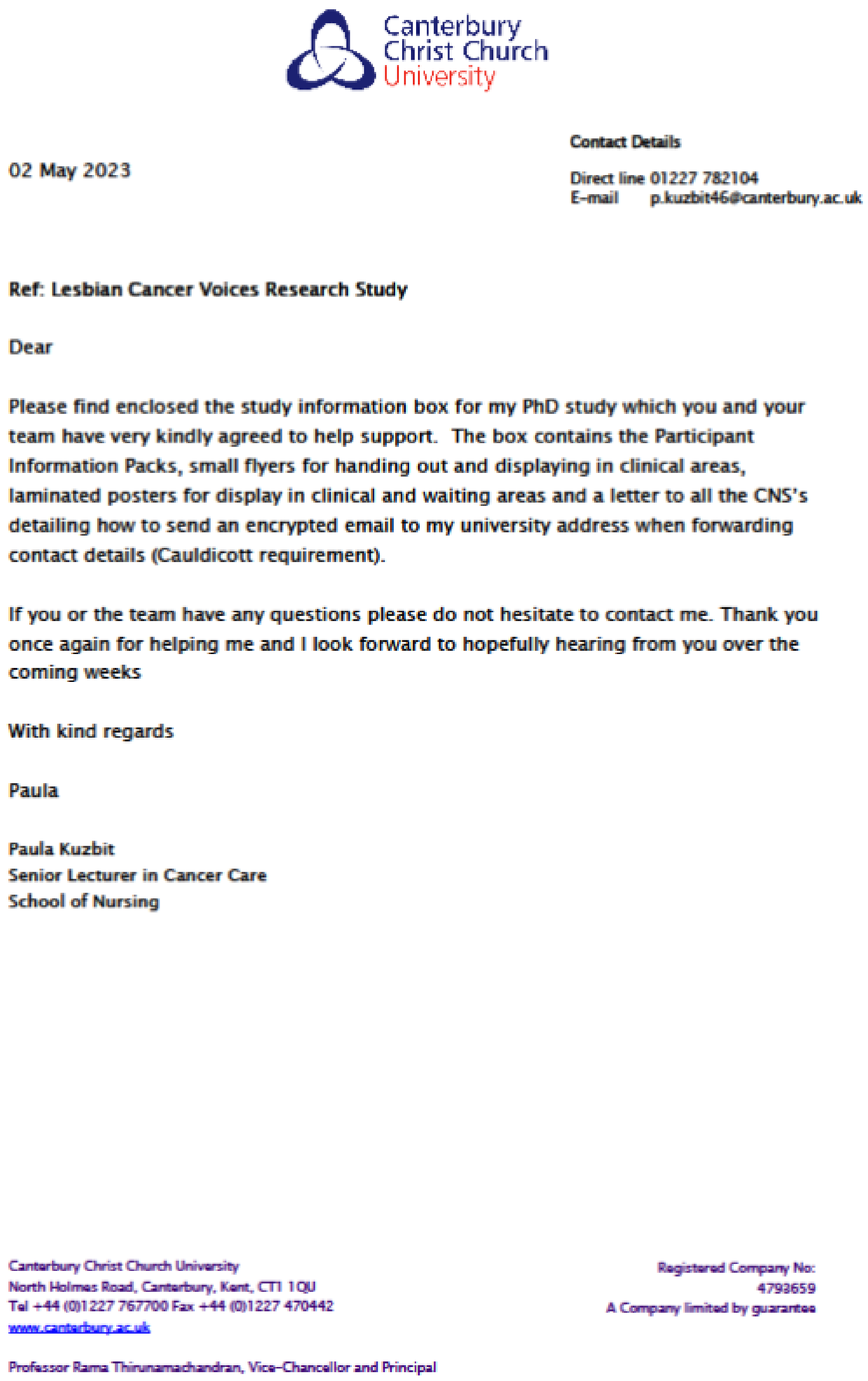
Mr Paul Hamilton Chair

Email:NRESCommittee.WestMidlands-Edgbaston@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: *Dr Toni Wright*

Appendix 3 CNS information letter



Canterbury
Christ Church
University

Contact Details

Direct line 01227 782104
E-mail p.kuzbit46@canterbury.ac.uk

02 May 2023

Ref: Lesbian Cancer Voices Research Study

Dear

Please find enclosed the study information box for my PhD study which you and your team have very kindly agreed to help support. The box contains the Participant Information Packs, small flyers for handing out and displaying in clinical areas, laminated posters for display in clinical and waiting areas and a letter to all the CNS's detailing how to send an encrypted email to my university address when forwarding contact details (Cauldicott requirement).

If you or the team have any questions please do not hesitate to contact me. Thank you once again for helping me and I look forward to hopefully hearing from you over the coming weeks

With kind regards

Paula

Paula Kuzbit
Senior Lecturer in Cancer Care
School of Nursing

Canterbury Christ Church University
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Tel +44 (0)1227 767700 Fax +44 (0)1227 470442
www.canterbury.ac.uk

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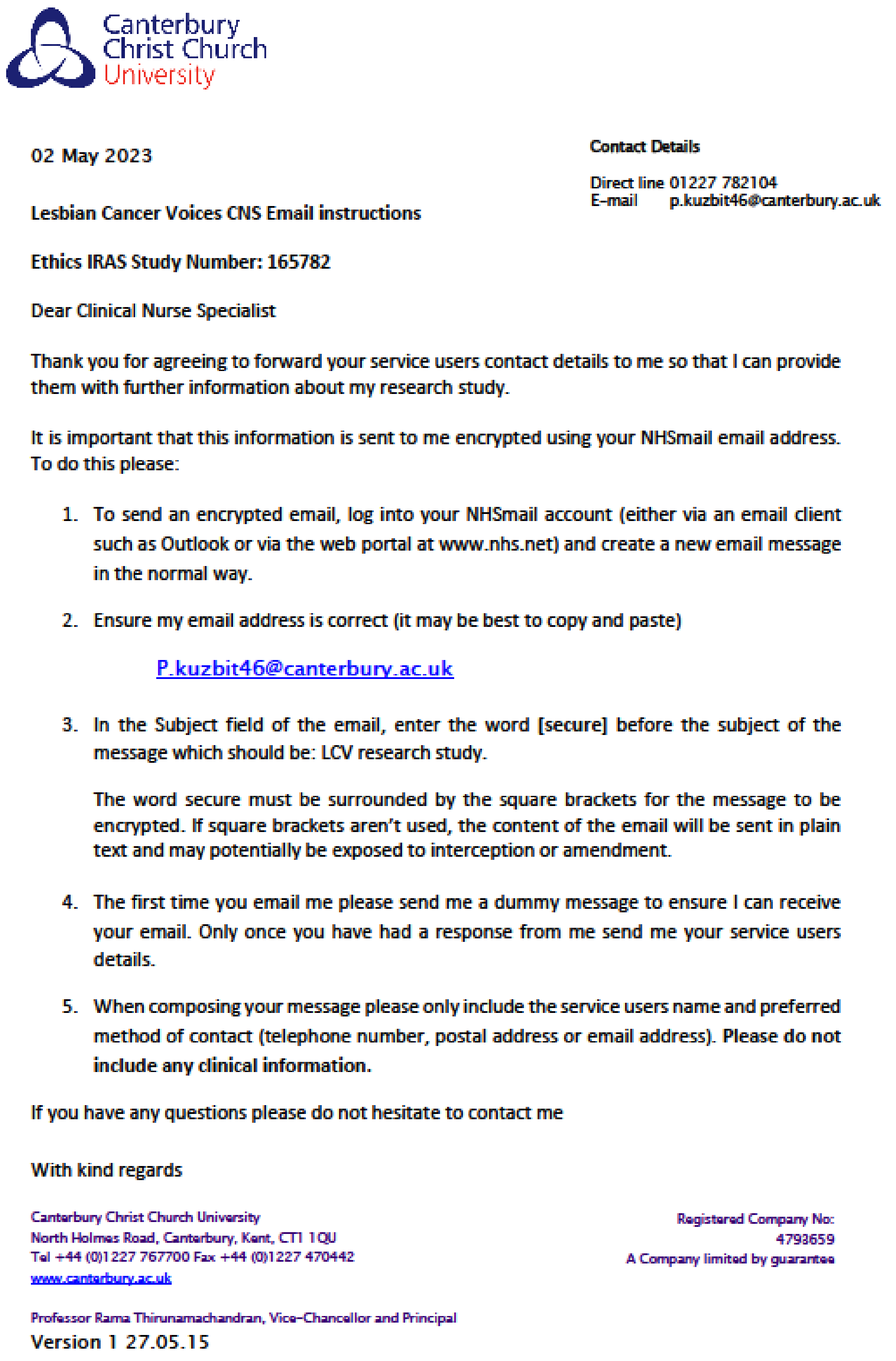
4793659
A Company limited by guarantee

Professor Rama Thirunamachandran, Vice-Chancellor and Principal

Appendix 4 CNS encrypted email instructions



Canterbury
Christ Church
University

Contact Details

Direct line 01227 782104
E-mail p.kuzbit46@canterbury.ac.uk

02 May 2023

Lesbian Cancer Voices CNS Email instructions

Ethics IRAS Study Number: 165782

Dear Clinical Nurse Specialist

Thank you for agreeing to forward your service users contact details to me so that I can provide them with further information about my research study.

It is important that this information is sent to me encrypted using your NHSmail email address. To do this please:

1. To send an encrypted email, log into your NHSmail account (either via an email client such as Outlook or via the web portal at www.nhs.net) and create a new email message in the normal way.
2. Ensure my email address is correct (it may be best to copy and paste)

   P.kuzbit46@canterbury.ac.uk

3. In the Subject field of the email, enter the word [secure] before the subject of the message which should be: LCV research study.

   The word secure must be surrounded by the square brackets for the message to be encrypted. If square brackets aren't used, the content of the email will be sent in plain text and may potentially be exposed to interception or amendment.

4. The first time you email me please send me a dummy message to ensure I can receive your email. Only once you have had a response from me send me your service users details.
5. When composing your message please only include the service users name and preferred method of contact (telephone number, postal address or email address). **Please do not include any clinical information.**

If you have any questions please do not hesitate to contact me

With kind regards

Canterbury Christ Church University
North Holmes Road, Canterbury, Kent, CT1 1QU
Tel +44 (0)1227 767700 Fax +44 (0)1227 470442
www.canterbury.ac.uk

Registered Company No:
4793659
A Company limited by guarantee

Professor Rama Thirunamachandran, Vice-Chancellor and Principal

Version 1 27.05.15

Appendix 5 Consent form

Contact Details

Direct line 01227 782104

E-mail p.kuzbit46@canterbury.ac.uk

22 October 2023

Centre Number:

Study Number: IRAS165782

Participant Identification for this study:

CONSENT FORM

Title of Project: Lesbian Cancer Voices

Name of Researcher: Paula Kuzbit

Please initial box

1. I confirm that I have read the participant information sheet dated.................... (version............) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw up until the final analysis, without giving any reason, without my medical care or legal rights being affected. ☐

3. If I lose my capacity to make decisions for myself during my involvement in the study I agree to my interview being included. ☐

4. I agree for the results of this study to be published. ☐

5. I agree to take part in the above study. ☐

____________________	____________________	____________________
Name of Participant	Date	Signature
____________________	____________________	____________________
Name of Person taking consent	Date	Signature

Appendix 6 Participant Information sheet

Lesbian Cancer Voices

Participant Information Sheet

Study Title

Lesbian Cancer Voices: A narrative inquiry into the lived experience of being lesbian with cancer

Invitation

I would like to invite you to take part in my research study. Joining the study is entirely up to you. Before you decide I would like you to understand why the research is being done and what it would involve for you. I will go through this information sheet with you, to help you decide whether or not you would like to take part and answer any questions you may have. I'd suggest this should take about twenty minutes. Please feel free to talk to others about the study if you wish.

The first part of the Participant Information Sheet tells you the purpose of the study and what will happen to you if you take part. Then I give you more detailed information about the conduct of the study.

Do ask if anything is unclear.

Summary

My study aims to explore the experiences of women, who identify as lesbian or gay (cisgender[6] or transgender[7]), who have been diagnosed with cancer, in order to better understand their individual thoughts, feelings and journey through this illness.

Cancer is an extremely common disease however there has been very little research that has explored this illness from the perspective of women who identify as lesbian. By gaining a better understanding of your experiences I hope to be able to inform and guide health care professionals in how they can support this group more effectively.

I aim to talk to fifteen women who self-identify as lesbian or gay, who have been diagnosed with cancer in the last 10 years, or are currently being treated for cancer.

I would like you to participate in a one to one interview with me that will explore your experiences of being lesbian (or gay) and your experiences of having cancer. I will be tape recording the interview and may make notes as we talk. The interview will take place at a time and place we agree on and may last up to two hours, including breaks. The study will take about three years to complete but it should not take up more than three hours of your time.

Contents

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[6] Cisgender is a term for people whose gender identity matches the biological sex assigned at birth (Oxford 2014).

[7] Transgender is a term for people whose gender identity differs from the sex they were assigned at birth (GLAAD 2014)

What’s involved?

What is the nature and purpose of your research?

This is an interview based research study which aims to explore your experience of being lesbian with cancer.

What is already known (or not known) and how will this study help you learn more?

There are very few studies that have asked lesbian or gay women to discuss their experiences of living with cancer. Studies that have spoken to women with breast cancer or cancers affecting the ovaries or cervix suggest that their experiences are different from those of heterosexual women, including how health care professionals interact with them and their partners and whether they attend cancer screening.

This study will help us learn more as it will be asking women with a range of cancers to tell us in their own words what it is like to be lesbian and to have cancer. It is important that health care professionals understand what it is like to have cancer from all perspectives in order to make sure that the care they offer is person centred and reflects your individual needs.

How many others will be in the study?

There will be about fifteen women in the study. I am inviting you to take part in this study as you are a woman who self-identifies as lesbian or gay and you have been diagnosed with a cancer in the last 10 years or you are currently being treated for a cancer.

Who can take part in the study?

To take part in this study you should be:

a. A woman (cisgender or transgender);
b. 18 years or older;
c. Self-identify as lesbian or gay;
d. Diagnosed with any cancer in the last 10 years or currently being treated for cancer that was diagnosed more than 10 years ago.
e. Able to give informed consent at the beginning of the study.
f. English speaking

How long will I be involved in the research?

We will only meet once to do the interview, however, I will contact you by post on two further occasions:

i. Firstly we will meet so we can carry out the interview

ii. Within one month I will type up exactly what we said during our conversation. I will return this to you for you to read and add comments to.

iii. When I have analysed your interview I will write a detailed report on the findings. I will send a summary of this report to you and ask you to comment on it, particularly whether I have missed anything from the report you think is important to include.

For up to two hours	Within 1 month	Within 6 months
Take part in a tape recorded one to one interview	Receive a typed copy of the interview to review and comment on	Receive a 4 page summary of the analysis of the interview to comment on

How long will the research last?

The study will last for about three years in total.

How will I be contacted by the researcher?

If you have expressed an interest in taking part in this study through your Cancer Clinical Nurse Specialist (CNS) they will send me your contact details and I will contact you within one week of receiving your details to answer any questions you may have about the study. If you would like to go ahead with the study we will arrange a mutually convenient time and place for the interview to take place.

If you have contacted me directly, as you have heard about the study through adverts, posters, or from a friend, I will send you a copy of the study information pack and contact you in one week to answer any questions you have and to see if you would like to go ahead with the study. At this point we will arrange a mutually convenient appointment for the interview.

How often will I need to meet a researcher?

You will normally only meet with me once during this study.

How long will the meeting last?

Our meeting may last up to 2 hours with breaks.

What exactly will happen during the interview and what information is to be collected?

When we meet I will go through this Participant Information Sheet with you and answer any questions you may have about the study. Once I have answered all your questions to your satisfaction I will ask you to sign a consent form.

During the interview I will ask you for some personal details including your name and age and how you describe your gender and sexuality. I will then ask you to choose a name for yourself (a pseudonym) that I will use throughout the study. This is to ensure your confidentiality.

I will also ask you for some information about your cancer including, where it is, when you were diagnosed and what treatments (if any) you have had.

During the interview we will talk about your background and significant events in your life particularly those that you think are important about being lesbian and having cancer.

I will tape record our conversation so that I can type up exactly what we said. I will also make some written notes as we talk.

Who will have access to this information and how you will protect my confidentiality?

I will have access to your personal details, including your name, age, address, type of cancer and type of treatment. To protect your confidentiality you will chose a pseudonym for yourself during the interview.

Your personal information will be stored in a locked filing cabinet in a locked office and separately from your interview transcript. My research supervisors will have access to the anonymised interview transcripts.

What will happen to my information during the study and once the study has been completed?

An electronic copy of your information will be stored in a password protected file on a password protected computer. Your personal information will be stored for twelve months and then destroyed. An electronic copy of your interview will be stored for five years and then destroyed.

The anonymised information you give me during the interview may be used by me in further studies once this study has been completed. The anonymised information may also be shared with other researchers to ensure the research is open to peer scrutiny, to improve the use of good quality research data and to support policy and other decision making.

What are the possible benefits of taking part?

The aim of this study is to help health care professionals improve the care they offer lesbian women with cancer, as you may be using these services you may benefit from any improvements made. Secondly, although this study is not designed to be a care intervention there is evidence that suggests being given an opportunity to share your experience can be beneficial to you. You may also feel that you have had the opportunity to help the wider Lesbian community though sharing your experiences in a safe, confidential and non-discriminatory setting.

What are the possible disadvantages and risks of taking part?

During the interview you may feel tired (fatigue). If you would like to stop the interview and continue on a separate day we can arrange to do this.

You may find that recalling painful memories or emotional experiences may leave you feeling upset. We will talk about these experiences during the interview but if you feel, after the interview, that you would like to talk to someone, together, we can arrange to make contact with a support person or group.

You may feel that as the stories you talk about are individual to you it may be possible to recognise you. To make this risk as small as possible I will ask you to choose a name for yourself. We will also make changes to any identifiable information, for example place names (schools, hospitals etc.) and change other people's names (for example family members, doctors, nurses). I will also send you a copy of your interview to read to make sure that you are still happy to be involved in this study.

You may be worried that taking part in this study will disclose your sexuality. I will protect your confidentiality and not disclose your personal details and your agreement to be involved in this study to anyone.

You may regret taking part in this study. You are able to withdraw from the study up until the point that I send you the summary analysis of your interview.

What if I lose mental capacity to make decisions for myself during the study?

Only people who have capacity to give informed consent at the beginning of the study can be involved.

If you lose capacity during your involvement in the study your interview transcript will be included in the study unless you wish otherwise.

What will happen if I raise an issue about the care I or others received during the interview?

During the interview you may raise issues of serious professional concern or highlight where a breach of a professional code of conduct has occurred. In this instance I would have a professional responsibility, as a registered nurse, to address this with the service provider. However I will not identity you to the service.

If you tell me you are being harmed, are harming yourself or others I will have to report this.

What if something goes wrong?

If you have a concern about any aspect of this study, you should contact me on 01227 782104 or email p.kuzbit46@canterbury.ac.uk and I will do my best to answer your questions.

If you remain unhappy and wish to complain formally, in the first instance you can do so by contacting Dr Toni Wright on 01227 782940 ext. 3133 or email toni.wright@canterbury.ac.uk or you can contact the Faculty of Health and Wellbeing's Director of Research to discuss your concerns on 01227 767700.

What will happen if I don't want to carry on with the study?

Your decision to take part in this study is entirely voluntary. If you decide to decline this invitation or to withdraw from this study your care will not be affected in any way.

You can change your mind and withdraw from the study at any time up until I send you the summary analysis of your interview.

After your interview you may decide not to have any further involvement in the study but for your interview transcript to be included in the final report (for example you may chose not to review the transcript of your interview).

If you have any questions about withdrawing from the study please contact me.

Will my information be kept confidential?

Your personal information will be kept confidential.

What will happen to the results of the study?

At the end of the study I will send you a summary of the findings of the research by post.

This study is being completed for a PhD in Health and Social Care and the results will be published in a thesis to be held by Canterbury Christ Church University library. The results of the study will be published in scientific journals and books and may help inform local and national strategies on improving care for women with cancer who identify as lesbian or gay.

Who is organising and funding the study?

This study is sponsored by Canterbury Christ Church University and is organised and funded by the Chief Investigator.

How have patients and public been involved in this study?

Service users and members of the public have read and commented on the study proposal, protocol, advertising materials, consent form and the Participant Information Sheet. Their comments have been included into the final versions of these documents.

Who has reviewed this study?

This study has been reviewed by NHS Ethics, NHS Research and Development, my academic supervisors, an independent academic within the Faculty of Health and Wellbeing at CCCU and an independent academic at the National Institute of Health Research, Research Design Service. Their comments have been included.

How will I give my informed consent?

At the interview appointment we will review the PIS together and I will answer any questions you have about the study. If you would like to go ahead with the study I will ask you to sign two copies of the consent form. You will keep one copy of the consent form and I will keep the second copy.

Will my general practitioner (GP) and other health care professionals be involved/ informed?

No. In order to protect your confidentiality your GP or other health care professionals will not be informed of your involvement in this study.

Where can I get further information from?

For further information please contact me at:

Paula Kuzbit
School of Nursing,
Faculty of Health and Wellbeing,
Canterbury Christ Church University,
North Holmes Road,
Canterbury,
Kent,
CT1 1QU

Telephone: 01227 782104 (direct line)

Email: p.kuzbit46@canterbury.ac.uk

Twitter: @paulakuzbit

Version Control

Version	Date	Author	Reviewed by
1	08/12/14	Paula Kuzbit	Service User 1
2	11/12/14	Paula Kuzbit	Dr T Wright, Prof J Burns
3	19/12/14	Paula Kuzbit	Service User 2
4	19/01/15	Paula Kuzbit	CCCU Ethics
5	27/02/15	Paula Kuzbit	NHS Ethics
6	01/05/15	Paula Kuzbit	Final Version

Appendix 7 Lesbian Cancer Voices Flyer and Poster

This study aims to explore the experiences of women, who identify as lesbian or gay who have been diagnosed with cancer, in order to better understand their individual thoughts, feelings and journey through this illness.

Canterbury Christ Church University

Version 1 20/02/15

LESBIAN CANCER VOICES

A Research Study

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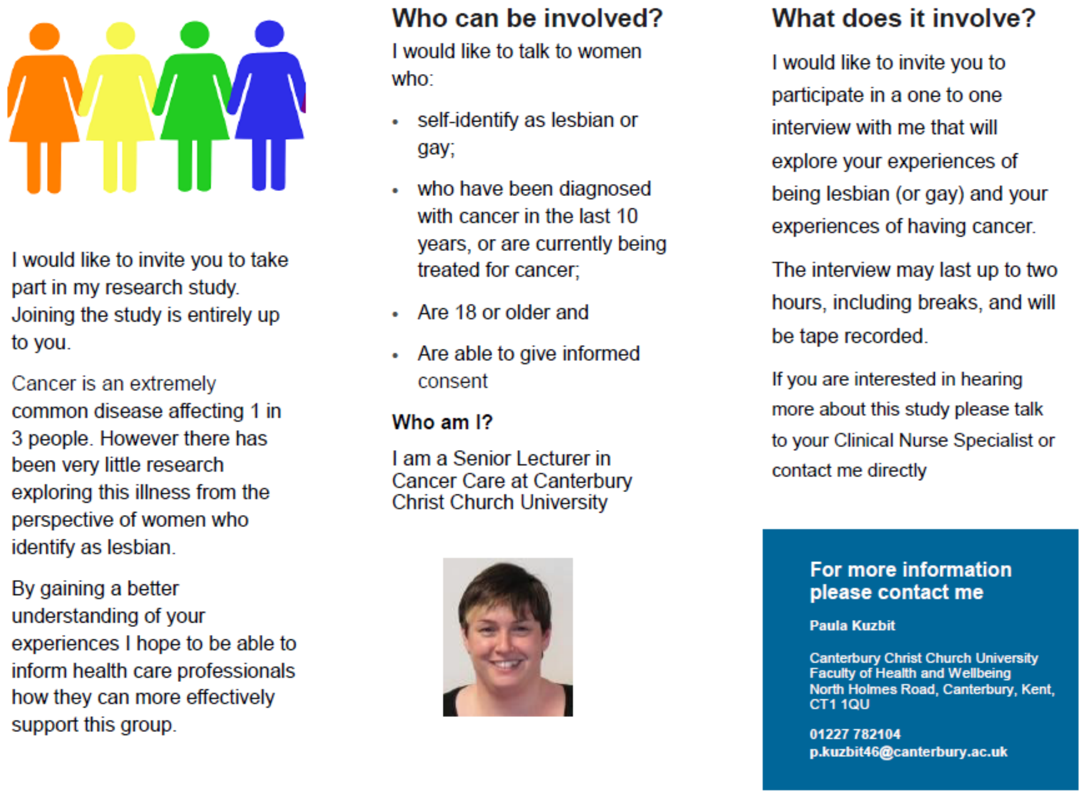


I would like to invite you to take part in my research study. Joining the study is entirely up to you.

Cancer is an extremely common disease affecting 1 in 3 people. However there has been very little research exploring this illness from the perspective of women who identify as lesbian.

By gaining a better understanding of your experiences I hope to be able to inform health care professionals how they can more effectively support this group.

Who can be involved?

I would like to talk to women who:

- self-identify as lesbian or gay;
- who have been diagnosed with cancer in the last 10 years, or are currently being treated for cancer;
- Are 18 or older and
- Are able to give informed consent

Who am I?

I am a Senior Lecturer in Cancer Care at Canterbury Christ Church University

What does it involve?

I would like to invite you to participate in a one to one interview with me that will explore your experiences of being lesbian (or gay) and your experiences of having cancer.

The interview may last up to two hours, including breaks, and will be tape recorded.

If you are interested in hearing more about this study please talk to your Clinical Nurse Specialist or contact me directly

For more information please contact me

Paula Kuzbit

Canterbury Christ Church University
Faculty of Health and Wellbeing
North Holmes Road, Canterbury, Kent, CT1 1QU

01227 782104
p.kuzbit46@canterbury.ac.uk

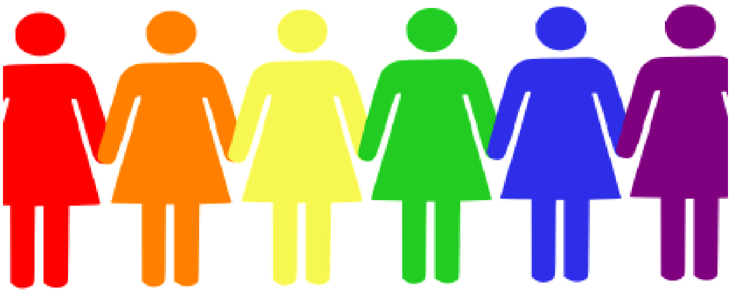
Canterbury
Christ Church
University

LESBIAN CANCER VOICES

A Research Study

This study aims to explore the experiences of women, who identify as lesbian or gay, who have been diagnosed with cancer in order to better understand their individual thoughts, feelings and journey through this illness.

If you would like to know more about this study please contact me



For more information please contact

Paula Kuzbit

Canterbury Christ Church University

North Holmes Road,
Canterbury, Kent
CT1 1QU

Tel: 01227 782104

Email: p.kuzbit46@canterbury.ac.uk

Version 1 20/2/15

Appendix 8 Focused narrative interview guide

1. Thank the participant for their involvement in the study.
2. Review PIS and sign consent form.
3. Ensure the participant is comfortable and that they have everything they think they will need for the interview.
4. **Turn on digital recorder.**
5. Ask the participant if they are comfortable and to confirm that they are still happy to proceed with the interview.
6. Explain the format the interview will take and that it will be a conversation rather than a formal list of questions to go though.
7. Explain the life history grid to the participant and that you will write into the grid for them significant events that have happened to them during their life, focusing on those events and stories related to being lesbian and on the events and stories that relate to them having cancer. These events will then be used as a focus to explore their experience of being lesbian and having cancer and whether the two focuses converge, diverge, or help explore each other.
8. Explain that there is no correct way of completing the life history grid but that they may find it easier to follow a chronological pattern.
9. There are no fixed questions in the focused narrative interview, instead the interviewer responds to the stories shared by the participant. Prompt questions can then be asked.
10. Participants will be asked to talk about how they define their sexuality and if this has been shaped by their life experiences.
11. Complete any demographic information that has not already been discussed in the interview.

Opening statement:

"I am interested in hearing about your life and the events that are important to you, particularly in relation to being lesbian and to having cancer.

So that we can shape our conversation I would like to use a life history grid. We can then use this to look at some areas in more depth. Although not essential it is sometimes easiest to start this in a chronological order as it helps us remember things. Shall we start with when and where you were born?"

Focused questions

"We have looked at some of your life events, now can you tell me about significant life events that relate to your life as a lesbian"

"I am also interested in hearing about your life with cancer what times stand out for you?"

Example follow up questions:

a) Tell me more about… [for example your coming out story]
b) On your grid you've mentioned [xxx], tell me more about this
c) Can you describe the day you… [e.g. were told you had cancer]
d) you've mentioned your (partner/family/ support group etc.), tell me a little more about them

e) We haven’t talked about [xxx], would you like to add anything about this?
f) Is there anything else you would like to add?

Appendix 9 Life history grid

Name:	Age
Type of cancer:	Treatments
Gender identity:	Self-identified sexuality:
Ethnicity:	Disability:
married/ civil partnered/ single/ cohabiting/ divorced/ separated/ other:	Pseudonym:

Year/ month	Significant life event	Significant event relating to being lesbian/gay	Significant event related to having cancer
e.g. april 1st 1968	Born		

Appendix 10 Transcription confidentiality form

Contact Details

Direct line	01227 782104
E-mail	p.kuzbit46@canterbury.ac.uk

Study No.: IRAS165782

Title of Project: Lesbian Cancer Voices

Name of Researcher: Paula Kuzbit

This research study is being undertaken by Paula Kuzbit, School of Nursing, Canterbury Christ Church University.

As the transcriber for Lesbian Cancer Voices, I understand that I will be hearing recordings of confidential interviews. These conversations have been held with interviewees who agreed to participate in the research on the condition that their confidentiality be maintained. I understand that I have a responsibility to honour this confidentially agreement. Any violation of the terms detailed below would constitute a serious breach of ethical standards and I confirm that I will adhere to the agreement in full.

I agree to:

1. Not to share any information on these recordings with anyone except the researcher Paula Kuzbit.
2. Keep all the information shared with me confidential by not discussing or sharing the content of the interviews in any form or format (e.g. WAV files, transcripts) with anyone other than Paula.
3. Keep all research information in any form or format (e.g. WAV files, transcripts) secure while it is in my possession.
4. Return all research information in any form or format (e.g. WAV files, transcripts) to Paula when I have completed the transcription tasks.
5. After consulting with Paula, erase or destroy all research information in any form or format regarding this research project that I am not able to return to Paula (e.g. information stored on my computer hard drive).

______________________	______________________	______________________
Name of Transcriber	Date	Signature
______________________	______________________	______________________
Name of Researcher	Date	Signature