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University of Southampton

Faculty of Environmental and Life Sciences

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What Psychological mechanisms are used to understand how people make sense of a metastatic breast cancer diagnosis?

by

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Thesis for the degree of Doctorate in Clinical Psychology

November 2023

University of Southampton

Abstract

Faculty of Environmental and Life Sciences

School of Psychology

Doctor of Clinical Psychology

What psychological mechanisms are used to understand how people make sense of a diagnosis of metastatic breast cancer.

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Chapter One of this thesis is a systematic review exploring the experiences of sex and intimacy for LGBTQ+ persons following cancer. APA PsycArticles, APA PsycBooks, APA PsycExtra, APA PsycInfo, CINAHL Plus with Full Text, MEDLINE, and Cochrane Library were searched for relevant literature. A thematic synthesis of was used to identify analytic and descriptive themes from 32 qualitative research papers on this topic. Five analytical themes were identified: ‘‘Positioning of self in relation to sex determines acceptance of sexual dysfunction’, ‘Experience of sex and intimacy varies depending on relationship status’, ‘Moving away from penetrative sex’, ‘Distress is due to disruption to sexual identity’ and ‘Communication with others informs how sex after cancer is experienced’. This review suggests that changing sexual behaviours to encompass non-penetrative sexual practices may be helpful by allowing the person to continue to engage in altered sexual practice. It highlights how communication with others is important when working with sexual dysfunction and discusses how professionals can support this.

Chapter Two explores how people make sense of a diagnosis of Metastatic Breast Cancer (MBC). It was suggested that the Dual Processing Model (DPM) or the Reintegration Model could be used to understand this process. 14 women with MBC were interviewed using a semi-structured interview, which was then subject to Deductive Thematic Analysis. In line with this approach, pattern matching was then completed to explore which models offer a good fit to the data. It was identified that both the DPM and the Reintegration Model offer a good fit to the data however an amalgamation of the two models is suggested to encompass external factors and internal processes that may contribute to the process of making sense of MBC. This research highlights the importance of oscillation and suggests that clinicians are mindful of this within their clinical practice.

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CORE-Q Checklist – Can be found in Appendix H

Research Thesis: Declaration of Authorship

Print name: Olivia Ferrie

Title of thesis: What psychological mechanisms are used to understand how people make sense of a diagnosis of metastatic breast cancer?

I declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before submission

Signature: ....Date: 09/11/2023

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To my parents who have been a constant source of emotional support and grammar checking, thank you for believing in me.

Definitions and Abbreviations

MBC	Metastatic Breast Cancer, also known as Stage 4 (IV) Breast Cancer or Advanced Breast Cancer. Refers to a cancer that started within the breast and has spread to other parts of the body.
LGBTQ+	Lesbian, Gay, Bisexual, Transgender, Questioning and more. This is the shortened phrase that refers to sexual and gender minorities.
NVivo	Data Analysis Software that supports qualitative research by facilitating electronic codes and recording of themes.
PCa	Prostate Cancer, is a cancer that starts in the prostate gland.
LO	Loss-Oriented, a component of the dual processing model which describes a focus on tasks and processes that centre around the loss
RO	Restoration-Oriented, a component of the dual processing model which describes a focus on tasks and processes that centre around restoration and re-engaging with life.
DPM	Dual Processing Model, initially developed by Stroebe & Schut (1999) this model poses that people oscillate between loss-oriented and restoration-orientated processes as they come to terms with a loss.
RM	Reintegration Model, initially developed by Knight & Emanuel (2007), this model poses that people move through a process of comprehension, creative adaptation and reintegration as they make sense of a terminal diagnosis.

Chapter 1 The experiences of Sex and Intimacy for LGBTQ+ persons after cancer; A systematic review

1.1 Abstract

Objective: This systematic review aims to explore the experiences of sex and intimacy after cancer for the LGBTQ+ community.

Methods: APA PsycArticles, APA PsycBooks, APA PsycExtra, APA PsycInfo, CINAHL Plus with Full Text, MEDLINE, and Cochrane Library were searched for relevant literature. A thematic synthesis was used to identify analytic and descriptive themes from qualitative research published on this topic.

Results: 32 studies were identified for inclusion. Five analytic themes were identified: ‘Positioning of self in relation to sex determines acceptance of sexual dysfunction’, ‘Experience of sex and intimacy varies depending on relationship status’, ‘Moving away from penetrative sex’, ‘Distress is due to disruption to sexual identity’ and ‘Communication with others informs how sex after cancer is experienced’.

Conclusion: This review has highlighted the significant impact that treatment for cancer has on the experience of sex and intimacy for LGBTQ+ persons. There is recognition of the disruption to sexual identity and the distress this causes. It suggests that changing sexual behaviours to encompass non-penetrative sexual practices may be helpful by allowing the person to continue to engage in altered sexual practice. This research highlights how communication with others is important when working with sexual dysfunction. It is recommended that clinicians complete training to better support the LGBTQ+ community and suggests there could be more LGBTQ+ specific information leaflets created to become more inclusive.

1.2 Keywords

Cancer; Oncology; Sexual and Gender Minorities; Sexual Behaviour.

1.3 Introduction

Sex and intimacy is an important part of one's life that contributes to well-being and quality of life (Kashdan et al., 2018). However, following a diagnosis of cancer there can be a significant impact on sex and intimacy (Hordern, 2008). This may be due to a variety of reasons including physical changes, changes in identity and changes to relationship role. In recent years research has started to explore these issues in more depth, with a variety of empirical and qualitative studies documenting that challenges of sex and intimacy after cancer (Chan et al., 2021; Mcinnis & Pukall, 2020; Rhoten, 2016; SKorzewska et al., 2021; Souza et al., 2021; Stulz et al., 2020). In her critical review of the literature in this area Hordern (2008) identified that often the research has focused on the link between cancer treatment and subsequent impact on sexual functioning, giving little space for the consideration of the emotional and psychological impact of cancer treatment on sex and intimacy.

The impact of cancer on LGBTQ+ persons may be different to that of the heterosexual population. In a recent review by Webster and Drury-Smith (2021), the unmet needs of the LGBTQ+ population was discussed. This review highlighted how stigma and lack of knowledge around LGBTQ+ needs and culture from health care professionals can significantly impact on those with cancer, causing an increase in poor mental health. In addition to this it referred to the lack of support groups and information specific to the LGBTQ+ community, often leaving individuals having to do their own research, translate heteronormative information and support themselves independently. However, this review did not explicitly explore the impact on the experience of sex and intimacy. When considering the physical impact of cancer on sex and intimacy, there has been increased awareness over the last decade that gay and bisexual men are significantly impacted by the treatment for prostate cancer (PCa; Doran et al., 2018; Hoyt et al., 2020; Lee et al., 2015; Mitchell & Ziegler, 2022; Rosser et al., 2016; Ussher et al., 2017; Wassersug et al., 2017). There has been less research considering the impact of cancer on sex and intimacy for lesbian, bisexual women, and transgender persons.

Within the research on the impact of cancer on sex and intimacy there has been some consideration of the needs of marginalised populations including women of colour (Arthur et al., 2022), gay and bisexual men (Mcinnis & Pukall, 2020) as well as consideration of the specific impact of mastectomy from an LGBTQ perspective (Skorzewska et al., 2021). These reviews offer a valuable description of the needs of marginalised communities in relation to sex, intimacy and sexuality; however much of the evidence reviewed in the mentioned studies utilises a quantitative methodology. To gain a better understanding of how sex and intimacy is experienced following a diagnosis of cancer, a review focussing on the qualitative evidence is needed. In addition, a qualitative methodology ensures that the voices and experiences of marginalised communities are heard and represented within research.

To the best of our knowledge there have been no thematic syntheses of the impact of cancer on sex, sexuality, and intimacy for LGBTQ+ persons. This methodology offers a novel contribution to current literature by drawing on the experiences documented in qualitive research and synthesising this into analytic themes that may offer unique insights into the experiences reported across studies. The robust qualitative research design will also reduce the risk of bias which is essential when exploring the experiences of marginalised communities (Sofaer, 1999).

1.4 Methods

1.4.1 Eligibility Criteria

The search strategy and protocol for this systematic review was registered on PROSPERO on the 07/11/2022 (CRD42022372481; Appendix A). The inclusion and exclusion criteria for this review are detailed in Table 1.

1.4.2 Information Sources

The following online databases were searched, APA PsycArticles, APA PsycBooks, APA PsycExtra, APA PsycInfo, CINAHL Plus with Full Text, MEDLINE, Cochrane Library. In addition to this, the references of included articles were hand searched to identify literature that had not been sourced in the literature search.

1.4.3 Search Strategy

To build on the previous research, search terms reported in previous reviews were compiled to ensure replicability of previous methods. The search terms relating to LGBTQ+ populations were the same as those reported by Skorzewska et al., (2021). The search terms for cancer and sex terms were adapted from the terms reported by Arthur et al., (2022).

The following search terms were used (adenocarcinoma* OR cancer OR carcinoma* OR leukaemia* OR malignan* OR metasta* OR melanoma* OR neoplasms* OR sarcoma* OR (tumour OR tumor OR tumours OR tumors)) AND (LGBTQ OR Lesbian OR Gay OR Bisexual OR Transgender OR Queer OR Questioning OR transmen OR transwomen OR heterosexual OR homosexual OR "sexual minority”) AND (sexual well-being OR sexual wellbeing OR sexual function OR sexual dysfunction OR sexual satisfaction OR relationship satisfaction OR partner relationship OR sexuality OR intimacy OR intimate OR libido).

1.4.4 Selection Process

The first search for papers was conducted on the 07/11/2022 and all retrieved references were imported to Rayyan (Ouzzani et al., 2016) for review. To ensure inclusion and exclusion criteria were replicable and accurate, inter-rater reliability was calculated for a portion of the sample. Initially 20% of the papers were screened by three reviewers, however, this produced a percentage agreement of 59.61%, which indicates poor agreement. Therefore, the inclusion and exclusion criteria were reviewed, and clarification was made around the content of the papers: Specifically, that included papers must include content around the experience of sex and intimacy. Following this an additional 20% of papers were screened and an agreement of 80.63% was found, indicating improved inter-rater reliability.

1.4.5 Data Extraction

This review followed the process for qualitative data extraction outlined by Thomas and Harden (2008), whereby data is considered to be all text reported in the results section of the included paper. This method of synthesis has three stages: coding text 'line by line', development of descriptive themes and then generation of analytic themes by developing the descriptive themes further to encompass meaning. Initial coding of the data was undertaken by the primary researcher (OF) who then developed descriptive themes. Initial codes, descriptive themes, and analytic themes were discussed with the research team throughout analysis (See Appendix B). The primary researcher also kept a reflexive log to support analysis (See Appendix D).

For each of the included papers the following data were extracted: author, year of publication, country of origin, research design, setting, patient characteristics and main themes. The results sections of included studies were extracted and imported to the software package NVivo (*NVivo Qualitative Data Analysis Software*, 1999). Where included studies had employed a mixed method design, only the results relating to the qualitative aspect of the study were extracted.

Some of the studies included in this review had included participants that did not meet the inclusion criteria. During analysis, where it was not possible to determine that the quote was stated by our target population (e.g., use of patient identifiers) these quotes were not included in the analysis.

1.4.6 Reflexivity

It is important for qualitative researchers to maintain a reflexive stance throughout the process of research (Berger, 2015). To support this the main researcher (OF) kept a reflexive log (Appendix D). It is important to note that the researcher is a white, cis-gender, heterosexual female. Being an outsider may offer a unique and new perspective to the research question however it may open up more opportunity for judgements and personal biases, which increases the importance of reflective practices. In addition to the reflexive log, themes and interpretation of the data was regularly discussed within supervision offering the opportunity for peer engagement and challenge.

1.5 Results

1.5.1 Study characteristics

Please see the PRISMA flowchart in Figure 1 for details of study selection process. Of the 31 studies included, 23 reported the experiences of Gay and Bisexual men (GBM), 3 reported the experiences of LGBT persons, 2 reported the experiences of lesbian women, 2 reported the experiences of men who have sex with men (MSM), and one reported the experiences of sexual and gender minorities. It is important to make clear distinctions between these identities.

Twenty-four of the studies specifically focused on those who had received a diagnosis of Prostate cancer, five included persons who had a range of cancers, one study reported the experiences of persons with breast cancer, and one study reported the experiences of one woman with colorectal cancer. The most common method of analysis was Thematic Analysis (n=19), two studies utilised Grounded Theory and two used Content Analysis with one reporting using IPA. It must be noted that three of the studies were personal reflections and therefore are less robust, this was taken into consideration by using a quality analysis (discussed further below). Additional characteristics of the studies included within this review are detailed in Table 3.

1.5.2 Assessment of bias

To assess the quality of the selected articles, an optimised version of the Critical Appraisal Skills Programme (Long et al., 2020) was used. This method of quality analysis is widely supported by qualitative researchers and is recommended by Cochrane reviews (Noyes et al., 2018).

Following Long and collegues (2020) the results of the CASP screening were used to determine a hierarchy of quality for the included papers. For the purposes of this review, higher quality studies were considered to have a sufficiently rigorous data analysis procedure (item 9 on the CASP). This is particularly important when working with the LGBTQ+ community as researcher biases and experiences may influence analysis and without reflection and consultation could potentially introduce stigmatising interpretation of results. It is also important to note that item 7, ‘has the relationship between researcher and participant been adequately considered?’ is particularly important in research with marginalised communities as it acknowledges potential bias between researcher and participant. Twelve of the included studies within this review addressed this within their methodology, therefore reducing their risk of bias.

Papers that were deemed to have a higher quality (100-90%) were used to develop initial codes. Papers of a medium quality (80%) were coded using the codes identified from the higher quality papers, but allowance of new codes was permitted if deemed necessary. Papers of a lower quality (<70%) were coded using the codes identified by the higher and medium quality papers, with no additional coding being allowed. See Table 2 for details of the quality of each of the included studies.

1.5.3 Reporting biases

It should be noted that within the included studies, four of the studies utilised the same population (Rose et al., 2017; Ussher et al., 2018; Ussher, Perz, et al., 2017; Ussher, Rose, et al., 2017). This is due to much of the research on gay and bisexual men's experiences of sex and intimacy coming from the same research lab in Australia. This may introduce an element of bias in that the some of the participants will have increased representation amongst the analysis.

In addition, there is a clear bias within the included studies towards the experiences of gay and bisexual men, with the majority of the available literature focussing on this population. In addition, much of this research was focused on gay and bisexual men diagnosed with Prostate Cancer. There were few articles that included the views and experiences of lesbian and bisexual women's experiences. The authors of this study were unable to find any studies that specifically included the experiences of transgender persons when considering sex and intimacy after cancer.

1.5.4 Certainty of evidence

To assess the certainty of the review findings the Grade CERQual (*GRADE-CERQual*, 2023) tool was used to explore the methodological limitations, coherence, adequacy, and relevance of the extracted data for each of the five analytic themes. **Error!**

Reference source not found. displays the summary of this assessment. The evidence profile table can be found in Appendix C.

1.5.5 Results of syntheses

1.5.5.1 Themes

There were five analytical themes, 11 descriptive themes and six sub-themes developed within this analysis. The analytical themes were 'Positioning of self in relation to sex determines acceptance of sexual dysfunction', 'Experience of sex and intimacy varies depending on relationship status', 'Moving away from penetrative sex', 'Distress due to disruption in sexual identity' and 'Communication with others informs how sex after cancer is experienced'. These are presented in **Error! Reference source not found.**.

1.5.5.2 Positioning of self in relation to sex determines acceptance of sexual dysfunction.

1.5.5.2.1 Positioning along the life course

Within the gay community included within this review, there was discussion around the meaning of age, with older men often being considered to be unattractive or no longer sexually desirable: *"as an old gay man, you're not particularly marketable"(Male, Gay, Prostate Cancer;* Ussher, Rose, et al., 2017). For those who positioned themselves as older and therefore considered the impact of cancer on sexual functioning as part of natural ageing, this appeared to support acceptance:

> *I'm a half century old and you know like seems like the normal kind of trajectory that sex is less important and I think that was happening even pre-surgery and I feel like, you know, to a certain degree that what post-surgery is part and parcel of the aging process.(Male, Gay, Prostate Cancer; Hartman et al., 2014)*

> *These sort of things happen when you get older any-way, regardless of your health state" (Tony, gay, single, age 74; Ussher, Rose, et al., 2017).*

This could also be informed by the perceived cultural expectation that gay men will engage in sexual activity much later in life than heterosexual males. To continue engaging in sexual activity later in life, perhaps there is a conscious positioning of themselves as 'younger' and therefore more sexually attractive. However, when faced with sexual dysfunction due to cancer there may be a shift in positioning to that of an 'older' person therefore removing the expectation to engage in sexual activity later in life as there will be natural changes in bodily functioning. Danemalm Jägervall and colleagues (2019) recognised this when they summarised their findings by stating *"men who used the trope of ageing as an explanation are normalizing their pathologized body"*. This theme was also discussed in detail by Ussher and Colleagues (2017).

Another way in which some participants were more accepting of sexual dysfunction was if they positioned themselves as having had a previously satisfying sexual life and were thankful for this. This phenomena has been referred to as 'backwards glancing' (Watson, 2000) in previous literature. However, in some accounts this backwards glancing appeared to create a sense of loss that they could no longer continue to be an active sexual being.

> *I think I've had my time...I've been there and done that. I'll leave it to the young ones. (Gareth, gay, 65; Ussher et al., 2018)*

> *I was quite a sexual being...And the people that I played with were, you know, we made this circle, this quite wide circle. We made each other quite, quite happy...And now I can't do that. I feel—I feel that I'm—that I've made this sort of leap from being the person that could do*

> *that to being now the person who has to instead sit at home and read a book or listen to a piece of music or watch the TV at night, whereas that wasn't me...It's almost like I've taken up knitting...It's like I've retired...I just feel like I've been retired out to pasture (Scott, gay, single, 59; Ussher, Perz, et al., 2017)*

1.5.5.2.2 Re-evaluating the importance of sex

Studies included within this review have noted that there appeared to be a process of re-evaluating the importance of sex within the lives of some participants. This occurred in a variety of ways that included reframing the loss of sexual function as choosing life:

> *Better I have the operation and survive, than I should keep my prostate and the cancer, and have sex for the next two years and then die or something' (Male, Gay, Prostate Cancer; Fergus, Gray & Fitch, 2002)*

For others there was more of a shift in focus to other areas of their life, which became more important to them as sex became less important:

> *in life if my sexual function diminishes further, there are other aspects of life that will take over from that which will continue to make life satisfying and rewarding (Alex, 69, gay; Ussher et al., 2017)"*

1.5.5.3 Experience of sex and intimacy varies depending on relationship status.

The theme 'experience of sex and intimacy varies depending on relationship status' offers a view of how relational factors can significantly impact the experience of sex and intimacy after cancer, ranging from the positive to the negative. There are specific nuances within this relating to LGBTQ+ relationships and culture which are important to consider.

1.5.5.3.1 Importance of stable and supportive relationship

For those who positioned themselves as within a stable and accepting relationship, this appeared to have a positive impact on the acceptance of sexual dysfunction and there were descriptions of the ways in which partners enabled them to re-engage with sex and intimacy following cancer.

> *An understanding partner is a big plus. I have found a steady improvement in performance and learned to relax and take my time. There has been a significant increase in foreplay time which my partners like very much. Viagra helps and so does standing. In all I am moderately happy with the progress and my partners seem satisfied. (163NH; Male, Non-heterosexual, Prostate Cancer; Wassersug et al., 2017)*

1.5.5.3.2 Relationship difficulties and rejection

In contrast to this, those who positioned themselves as single appeared to have more difficulties with sex and intimacy after cancer and described how this is often linked to experiences of rejection. In one study the authors made a poignant reflection that experiences of sexual dysfunction were often spoken about within the context of relationships, rather than the loss of one’s own physical pleasure (Danemalm Jägervall et al., 2019). For the gay community this appeared to be specifically related to expectations that men should be ‘powerful sexual beings.

> *One single, gay man was troubled by the idea of disappointing a prospective lover. Ever since radiation treatments had caused him to have retrograde ejaculation and dry orgasms, he no longer felt equipped to live up to the ‘Big Daddy’ image that his height and physical stature conveyed (Author quote; Fergus et al., 2002)*

Within the gay community, it is perceived that single men will engage in casual sex with multiple partners, and for some couples they spoke about how sex outside of the relationship enabled them to develop a sense of vicarious pleasure and maintain a close relationship.

> *Because a lot of gay men don't have that kind of, intimate kind of sexual contact [as do married heterosexual couples].That sometime it's more like meeting in saunas or things like that, or beats, or something like that.(Male, Gay, Prostate Cancer; Filiault et al., 2008)*

> *I recognize that he's got physical needs [partner] and I don't have a problem with that. And he comes home to me all the time, and in fact, shares part of his fantasy life with me anyway (Bruce, 61, gay; Ussher, Perz, et al., 2017)*

1.5.5.4 Moving away from penetrative sex

The analytic theme 'moving away from penetrative sex' represents how there is a process of recognition of sexual dysfunction and then an active change in sexual behaviours in order to re-engage with the sexual experience. This was most often represented by the move away from penetrative sex. Within the LGBTQ+ community this can have several different implications, for lesbian and bisexual women, there was a specific advantage for them as prior to cancer and treatment for cancer, non-penetrative practices are often part of the sexual repertoire for this population, meaning that there was less change in sexual practices required to adapt to physical changes caused by treatment for cancer:

> *sex is penetrative sexual intercourse, well as a lesbian, it's not, not necessarily. It can be but it's often not (Bronwyn, lesbian; Ussher et al., 2014)*

However, for gay and bisexual men who engaged in penetrative sex with other men, they faced a specific challenge that is unique to this population: A firmer erection is needed for penetrative anal sex. Therefore, in order to re-engage with sex there was a move away from penetrative practices to encompass non-penetrative acts:

> *When my libido got switched off I thought that was the end of the world ... I thought I was in charge, my dick was in charge ... I don't think men realise how we are designed until it got switched off and I discovered sensuality, it's like shit I can have better sex without my cock getting in the way, I have never experienced that before (Norman, gay man, aged 52; Fish, 2019)*

> *Insertive anal sex: I buckle. That's the best word I can think of. I can't do the penetration. But, again, it's not something that I find to be necessary as part of my sex play. (MSU10; Rosser et al., 2016)*

Some of the papers within this review included accounts from individuals who re-evaluated the importance of sex and appeared to place a greater focus on intimacy and affection as a move away from penetrative sexual practices. This contrasts some of the narratives around increased focus on sexual activity within the gay community, and may have significant emotional impact for members of this community as they change sexual practices:

> *[functioning] not like it was before the surgery. [. . .] But, you know I'm putting more emphasis on the, sort of the comfort of company and companionship and there's a lot of physical touching and that seems to help. (Male, Gay, Prostate Cancer; Hartman et al., 2014)*

1.5.5.4.1 Adaptations to facilitate physical sex.

Within many of the papers reviewed, there were discussions around the use of sexual aids to facilitate penetrative sex, with mixed rates of success. This was most discussed within the papers that included accounts of gay and bisexual men as aids are often used to support erectile functioning. For some this allowed them to engage in penetrative sex, thus facilitating pre-cancer levels of satisfaction. However, for some the use of sexual aids could still not enable pre-treatment levels of functioning but instead did offer some relief as they could experience some functioning which was positioned as better than nothing.

> *The upside of not being able to cum is, um, I have to Inject myself so I can get an erection—that will give me a really—a good, strong erection for up to twelve hours. So while I've got that erection, I can have really amazing sex, you know, just—just blows all, you know——all the buttons all over the shop, you know, ah, you get such a hard cock and—and fuck for so long, you know, it's just brilliant. (Nick, bisexual, single, age 66; Ussher et al., 2019)*

> *Fear usually makes me react with strength and I was determined to not give up on my erections. Even to have just one would be of huge psychological benefit. I went in for the appointment [for penile injections] (Male, Gay, Prostate Cancer; Santillo, 2005).*

Although there were many positives of using sexual aids reported, there were also many pitfalls that had specific impact on the gay community. For men who liked to frequent saunas and engage in casual sex, the lack of spontaneity presented a challenge to their usual sexual behaviours.

> *Depending on their degree of successful recovery and the type of sexual aid(s) employed, participants report significant emotional loss*

> *related to spontaneity describing sex more in terms of a series of difficult challenges to be navigated or an overly planned activity robbed of surprise.*

Within the literature surrounding lesbian and bisexual women, there were no accounts of needing to use sexual aids to facilitate sexual activity after treatment for cancer. The authors of the current study suggest that this does not mean that sexual aids are not used within the lesbian and bisexual women community, rather that the studies included in this review have not specifically addressed the use of sexual aids within this population.

1.5.5.4.2 Increasing intimacy and affection

There were several accounts of how some people developed a more emotionally intimate and affectionate way of being with others as penetrative sex became less available due to physical changes within the body:

> *Forced menopause and pain and body changes have led to less sex. Lots of affection, but much less sex (Female, Lesbian, Breast Cancer; Brown & McElroy, 2018)*

This intimacy and affection served as a way for people to remain in romantic relationships, as well as also offering alternative ways of inhabiting a sexual being. As discussed above, for some of the participants they developed increased intimacy and affection by creating more focus on companionship, which included increased touching such as hand holding and hugging.

1.5.5.5 Communication with others informs how sex after cancer is experienced.

The fourth analytic theme describes how sex after cancer is experienced differently depending on the communication with others.

1.5.5.5.1 Communication is important in understanding sexual dysfunction.

Sex and intimacy are often considered to be a relational act, an interaction between two or more people, and may also be something that is discussed with people outside of the sexual partnership. The authors of this study recognise that masturbation is often considered to be a solo sexual practice, however it can also be an act that is included within the sexual repertoire and therefore for the purposes of this analysis discussions around masturbation have been included.

Within the context of a stable relationship, it appeared that communication with partners around the experience of sexual dysfunction was important. This offered the chance for emotional support from partners as well as more practical solutions to problems presented by sexual dysfunction:

> *In keeping the sexual relationship alive…that's meant coming to terms with medication and cock rings and a whole range of sex aids that actually mean communicating pretty openly with, or very openly with my partner. (M, 65, gay, prostate; Ussher et al., 2015)*

> *I emphasize open and honest communications, people talk to each other they're saying what the other party wants to hear, but I really think you have to express your true feelings so that the other person in your life really understands what you're going through (Male, Gay, Prostate Cancer; Hartman et al., 2014)*

When communication between partners faltered, this lead to sex and intimacy being challenging:

> *all couples inevitably experienced communication lapses that challenged their ability to successfully manage sexual dysfunction (Author quote; Hartman et al., 2014)*

1.5.5.5.2 Interactions with Health Care Professionals

Outside of the relationship, communication with others could also have a significant impact on the experience of sex and intimacy. An issue that was specific to the LGBTQ+ community was experiencing homophobia at the hands of Health Care Professionals:

> *he asked his doctor about reduction in penis size, which had stopped him from having sex, and his doctor replied ''I don't want to know anything about your sex life,'' which Gareth concluded ''was because I was gay.'' (Gareth, 65, gay, Ussher, Perz, et al., 2017)*

In addition to perceived homophobia, the LGBTQ+ community also faced a lack of LGBTQ+ specific information. This was particularly obvious in the comments from gay men with Prostate cancer, who spoke of having to 'translate' information about sex after cancer from a heteronormative version into something that would be meaningful for them:

> *The widely recommended book, The Prostate: A Guide for Men and the Women Who Love Them (1995) said it all in its title. I had to "translate" heterosexual sexual references into my own experience. (Male, Gay, Prostate Cancer; J. Harris, 2005)*

Together these experiences of verbal and written communication impacted on their experience of sex and intimacy. Without the proper information from health care professionals, participants were left feeling fearful of re-engaging in sexual activity, with some experiencing negative side effects due to lack of information:

> *Although leaflets included advice about when it was safe to resume sex following the procedure, men were unsure whether this only applied to those who engaged in vaginal intercourse (Author quote; Doran et al., 2018)*

> *...that caused me inflammation of the prostate... there are sexual practices that could have actually aggravated that... because they never talk about that, you know, when I said to them in the beginning, is there anything sexually I should be aware of, they said no, carry on. The thing is, they don't ask you what your sexual practices are. (Male, Gay, Prostate Cancer; Doran et al., 2018)*

1.5.5.6 Distress due to disruption in sexual identity

The theme 'distress due to disruption in sexual identity' describes how individuals experienced sustained and disruptive distress as a result of the change in their sexual identity due to cancer treatment.

1.5.5.6.1 Physical changes from cancer treatment directly impact identity.

A sub theme within this was that of sexual role, which can be seen as a significant part of a person's identity. Within the gay community men can take the role of a 'top' (insertive partner) or 'bottom' (receptive partner). For some men this is a stable sexual role, from which they do not deviate, whereas others are more flexible in their sexual role. Those who did not wish to deviate from their preferred sexual role experienced more distress if they were then prevented from fulfilling that role as a result of sexual dysfunction:

> *I've gotten to this point where I hate it when people say, 'Well, you know, as a gay man, you have an option. You can always bottom.' It isn't that simple. You can't just change your sexual focus like that.... I*

> *don't think I could suddenly become a bottom any more than I could suddenly decide to go out and fly a 747. [MSU01: (Rosser et al., 2016b)*

> *emotionally they couldn't do it [change sexual roles] ... in fact somebody who is not used to being on top tries to be on top, often they lose their erection. (Patient; Mehta et al., 2019)*

Specific to the gay and bisexual men included in this review, was the impact that treatment for cancer had on their sense of masculinity. It is suggested that one's sense of masculinity informs their identity. This was most prominent when there had been erectile dysfunction or a loss of ejaculate. For gay men there is a culture around the exchange of semen as an important part of the act of sex, without it they are open to judgements of being a lesser man:

> *So that's a real cultural thing...this is the nub of the problem... guys end up dry cumming [dry ejaculation], or retro-ejaculation, or none. With gay guys faking it, it's not an option, we need to see other options of ways of providing climactic endings to our sex, love making. (ID 4)(Doran et al., 2018)*

> *I'm still a viable man. And take that away from me and, I'm no longer a viable man—I'm a eunuch, I'm a gelding. (Fergus et al., 2002)*

This challenge to masculine identity caused significant distress for many men with some even suggesting that if they had known how significant the side effects of treatment would be, they would opt to take their chances against cancer:

> *If I had the choice again, I would take my risks with cancer and not have the operation"; he described the loss of erections after robotic prostatectomy as "a defining moment in my life… the impact on my life*

> *as a gay male has been really profound, and in a negative sense.(Scott, 59, gay, Ussher et al., 2018)*

From the studies included in this review it can be distinguished that an element of why the LGBTQ+ community experience increased distress after sexual dysfunction is due to the importance of sexual function as part of their identity. The authors of one of the included papers noted the actions of participants before and after treatment that aimed to prevent or adjust to sexual impairment were largely due to the *"profound identity struggles arising from sexual losses, over and above the desire for physical pleasure"* (Author quote, Fergus et al., 2002):

> *a lot of our history and a lot of our presence is dealt around sex and sexual identity and the sex act and the imagery of sex. However, we dress that up, its there.(Doran et al., 2018)*

> *It's ruined my sex life and hurt my relationship. Doctors don't value the importance of sex in gay relationships [MSU17] (Simon Rosser et al., 2016)*

This importance of sexual function continued into older age for the gay and bisexual men included in this review, distinguishing themselves from heterosexual males of the same age. This created additional challenges for these men as often Prostate Cancer is diagnosed later in life:

> *Sam (74, gay) commenting that ''gay men tend to engage in sex for a longer period,'' differentiating himself from heterosexual men in his age group, of whom he said ''none of these men would be sexually active.' (Author quote; Ussher, Rose, et al., 2017)*

This created a sense of distress as there was then comparison between themselves and other gay or bisexual males who were still able to embody a sexually active identity:

> *Clive (70, gay) said ''you look at other guys who are your age, but still active, and you think, 'What about me? It isn't fair. I've paid my money, I want my share'.'' (Author quote; Ussher, Rose, et al., 2017)*

Within the lesbian and bisexual women included in this review, there was limited discussion around the importance of sexual function later in life. However, this may reflect the age of the women included within this review, as the average age in many of the studies which included women, was between 50 and 54. In comparison, men who discussed the importance of sex later in life were often in their 70s or older.

1.5.5.6.2 Physical changes post cancer treatment cause emotional impact and distress.

Many of the participants in this study reported emotional distress in response to physical changes after treatment for cancer. This included accounts of people requiring support for clinical depression, feeling inadequate, hopeless, and fearful of isolation from sexual partners:

> *many participants 'feeling isolated', 'outside of the sexual community', 'inferior', 'faced with a big sense of failure', 'depressed' at the prospect of 'facing life alone', or as a 'liability' to partners as a result of sexual changes after treatment. (Author quote; Rose et al., 2017)*

> *I feel devastated; the erection functioning is a really emotional thing for me (Male, Gay, 64, Prostate Cancer; Ussher et al., 2018)*

> *‘it’s probably the most horrific thing that I’ve ever been through psychologically (Finn, 69, gay; Ussher, Rose, et al., 2017)*

1.6 Discussion

This review draws together the findings from 32 studies that have explored the experiences of sex and intimacy after cancer for LGBTQ+ persons. The use of thematic synthesis supported the development of five analytic themes; “Positioning of self in relation to sex determines acceptance of sexual dysfunction”, “experience of sex and intimacy depends on relationship status”, “moving away from penetrative sex”, “distress due to disruption in sexual identity” and “communication with others informs how sex after cancer is experienced”.

These findings contribute to the literature on sex and intimacy after cancer for the LGBTQ+ community. The results of this study have highlighted that there is significantly more available research on the experiences of gay and bisexual men’s experiences of sex and intimacy and that studies that explore the experiences of lesbian, bisexual women and transgender individuals is lacking. It is plausible that one of the factors that has contributed to this imbalance is that much of the research for gay and bisexual men, has focussed on their experiences after treatment for prostate cancer.

The results of this review suggest that there may be many similarities between the experiences of heterosexual participants and the LGBTQ+ community following treatment for cancer. In the literature exploring the experiences of women’s sexuality after breast cancer, there was recognition of the acute distress experienced by the detrimental impact on sexual functioning as well as the significant impact on relationships (Sheppard & Ely, 2008). There has also been recognition of the impact to masculinity following a diagnosis of prostate cancer in heterosexual males (Bokhour et al., 2001) which is similar to the results of this review, namely that the loss of sexual functioning can trigger a disruption to one’s sense of masculinity and this causes significant distress for both heterosexual and non-heterosexual males.

In relation to the theme ‘communication with others informs how sex after cancer is experienced’ much of the previous literature for heterosexual participants has identified similar themes, for example women diagnosed with breast cancer also identified that communication and support from their partners positively impacted their interpretation of sex and intimacy after cancer (Sheppard & Ely, 2008), however for the LGBTQ+ population this communication and support may have different nuances. Stigma surrounding LGBTQ+ sex can often create a barrier between patient and professional and in this review, it was identified that stigma was potentially leaving participants unsure about how and whether they could engage with sex. Although stigma around heterosexual sex still exists, the increasing amount of research aimed at exploring heterosexual sex after cancer may suggest that this stigma is becoming less prevalent within the countries that the research is based in.

Prostate Cancer is currently the most prevalent cancer diagnosed in men (*Facts and Figures*, 2022) whilst Breast Cancer is currently the most prevalent cancer in women (*Breast Cancer Incidence*, 2023). Both of these cancers have been subject to increased scientific research and exploration, which has incorporated a focus on sex and intimacy within the heterosexual population.

Given the imbalance in the research towards gay and bisexual men’s experiences, it is not possible to conclude whether the themes described in this review would be applicable to the transgender community. This review tentatively suggests that these themes are relevant for the lesbian and bisexual women’s community however, further exploration is needed to add weight to this finding. Therefore, future research should explore the experience of transgender persons after cancer. Recently the Annals of Surgical

Oncology have called for more research to be focussed on supporting the transgender community through screening for cancer, identification of cancer and treatment of cancer (Clarke et al., 2022), it should therefore also be a priority to explore their experiences as this will give a richer understanding of the barriers and challenges this population face to engaging with oncology services.

1.6.1 Connection to theory

This research has not explored what theories or models may be applicable in understanding the experience of sex and intimacy after cancer, however it does offer an insight into the unique experiences of the LGBTQ+ community. The findings of this research highlight the importance of considerations of values and identity for this community. When considering values and identity it may be useful to refer to the literature around acceptance and commitment therapy (ACT; R. Harris, 2019). When we are not living in line with our values this can cause cognitive dissonance and distress, for example in this review it has been highlighted that many individuals valued their identity as a sexual being. When sexual dysfunction interrupted this identity, they experienced distress and struggled to deal with this. However, when individuals were able to shift their positioning, for example when they associated sexual dysfunction with old age, and this was natural and expected they appeared less distressed. This could represent psychological flexibility, which ACT aims to develop.

1.6.2 Strengths and Limitations

A strength of this research is the use of thematic synthesis which is a review methodology that offers a more robust analytical review of the available qualitative literature. The use of the protocol outlined by Thomas and Harden (2008) gives a clear framework for how to combine qualitative literature, increasing the confidence in our findings. Given the increase in confidence in this methodology this review offers a unique contribution to the literature on sex and intimacy after cancer for the LGBTQ+ population. However, during analysis it was noted that by only including the results section of selected studies reduced the capacity for analysis of each author's interpretation of findings, therefore minimising the 'meta' element of analysis. It could be suggested that inclusion of the discussion sections would have provided a more complete review of author and participant experiences in relation to sex and intimacy after cancer for the LGBTQ+ population.

This research builds on the previous work that has identified that many LGBTQ+ persons experience stigma from health professionals, but also noted that some health care professionals may not have a good understanding of the needs of the LGBTQ+ population. Both of these factors impact how participants then engage with sex and intimacy after cancer.

It is plausible that there was human bias when completing the screening of potential studies. This is suggested due to the initial low agreement rate amongst reviewers, and a noticeable difference between one reviewer in comparison with the others. Although review of the inclusion and exclusion criteria counteracted this, it highlights the subjective nature of what we determine sex and intimacy to be and how this can impact research if review and reflexivity are not used. To ensure that this research accurately represents the LGBTQ+ community, PPI review has been requested. This was not complete at the time of submission and therefore it is plausible that some of the interpretations within this review may require adaptations to be sensitive to the needs of the LGBTQ+ community.

It was noted there was overlap with the review article by Alexis and Worsley, (2018) which explored the experiences of gay and bisexual men after treatment for prostate cancer. This research did not specifically address sex and intimacy after treatment for cancer, however five of the six included studies in Alexis and Worsley (2018) also met the inclusion criteria for this study. Therefore, it could be suggested that our research has built on this previous research and offers a different perspective by focusing on sex and intimacy.

Further research on the lesbian and bisexual women's experience of sex and intimacy after cancer would also be beneficial to the progression of understanding within this area. This review picked up on some themes that may suggest that the sexual practices of lesbian and bisexual women may offer a protective factor to sexual dysfunction due to the increased use of non-penetrative sexual practices. Further research into this is needed to clarify this effect.

1.6.3 Clinical Implications

This research suggests that there may be significant sexual challenges for the LGBTQ+ community after treatment for cancer. The most worrying of these was the reported homophobia that this population have experienced at the hands of health care professionals. The review article by Radix and Maingi (2018) offers specific guidance on how to increase the cultural competence of staff working in oncology and includes recommendations of education sessions and reflective practice.

There were multiple quotes that described a lack of LGBTQ+ specific information around sex and intimacy after cancer. Therefore, it is important that Health Care Professionals ensure that within clinics and on websites there is up-to-date, LGBTQ+ information leaflets or handouts. It may also be worth exploring whether LGBTQ+ support groups could be facilitated within healthcare facilities to offer a safe space for reflection and support to this population. In addition to this, any training or service development aimed to increase staff awareness and understanding of LGBTQ+ needs, should include co-design or collaboration with members of this community to avoid 'doing to' practices.

To conclude, this systematic review has found five main themes in relation to the experiences of LBGTQ+ persons following cancer. These are: ‘Positioning of self in relation to sex determines acceptance of sexual dysfunction’, ‘Experience of sex and intimacy varies depending on relationship status’, ‘Communication with others inform how sex after cancer is experienced’, ‘Moving away from penetrative sex’ and ‘Distress due to disruption in sexual identity’. By including all sexualities within this review, this research offers a new perspective to the experiences of LGBTQ+ persons as a whole. However, this research also highlights the significant disparities within this field of research, particularly the lack of research exploring the experiences of the transgender community. Of importance to clinicians working in oncology, this research recommends that further training around sexuality and different sexual practices is needed so that clinicians can meaningfully engage in conversations around sex and intimacy with all clients.

1.7 Acknowledgments

I would like to acknowledge Naomi Willingham and Megan Armstrong for their support and contributions to this project, without whom it would not have been possible to complete a thorough screening process.

1.8 Conflict of Interest Statement

There are no conflict of interests in relation to this piece of research. This research forms part of the submission to the University of Southampton for the Doctorate in Clinical Psychology Thesis.

Chapter 2 Empirical Chapter

2.1 Abstract

The devastating impact of receiving a diagnosis of Metastatic Breast Cancer (MBC) has been well documented. However there have been limited explorations into how people make sense of receiving this diagnosis. The current research explored whether the Dual Processing Model or the Reintegration Model could be used to understand the psychological mechanisms used when comprehending this diagnosis. To explore this, 14 semi-structured interviews were conducted with individuals who were living with MBC. In line with a Deductive Thematic Analysis approach, the interviews were then coded used pre-determined codes that aimed to highlight the core processes within both models. Using pattern matching it was found that both models offer a good fit to the data, however an amalgamation of the two models is suggested to encompass external factors and internal processes that may contribute to the process of making sense of a diagnosis of MBC.

2.2 Keywords

Oncology; Metastatic Breast Cancer; Formulation; Qualitative

2.3 Purpose/Objectives

The negative impact of a life-limiting diagnosis of Metastatic Breast Cancer (MBC; Lewis et al., 2016; Mosher et al., 2013; Sarenmalm et al., 2009; Willis et al., 2015) is well documented. The research often depicts narratives around loss, adjustment to life with symptoms, adjusting values in life and living with constrained time. In addition to this, a review of the literature has suggested that women with advanced MBC have a higher prevalence of depression (Caplette-Gingras & Savard, 2008). Specifically, the impact of breast cancer recurrence has been found to be distinctly challenging and has been framed as ‘living under the shadow of death’ (Sarenmalm et al., 2009).

A systematic review of the benefits of psychological intervention for those living with MBC has indicated that engaging with psychological support can have a positive impact on survival after one year and short-term benefits on psychological outcomes and pain scores (Mustafa et al., 2013).

A good formulation should be grounded in theory (Johnstone & Dallos, 2014). There is limited discussion in the literature around what theory is used to underpin psychological formulations of people living with MBC who are struggling to make sense of their diagnosis. To understand how people may make sense of a diagnosis of MBC, two psychological models could be considered as potential means of understanding this process; the dual processing model (DPM; 8) and the reintegration model (Knight & Emanuel, 2007). These models are briefly discussed here to provide context to this research.

2.3.1 Dual Processing Model

The DPM (Stroebe & Schut, 1999) is most well-known for its use within bereavement and grief services. The model posits that within the context of a loss, a person will oscillate between two main processes: loss-oriented (LO) processes and restoration-orientated (RO) processes. LO processes are ways of coping that centre on the loss that has occurred. RO processes are ways of coping that centre on moving forward with life, not focussing on the loss. It is proposed that it is normal for a person to oscillate between these two processes as they make sense of the loss they have experienced.

There is recognition of eight specific process that can occur within each domain of the DPM, these include: Positive Reappraisal, Revised Constructive Goals, Positive Event Interpretation, Expressing Positive Affect, Rumination and Wishful Thinking, Revised Unconstructive Goals, Negative Event Interpretation and Ventilating Dysphoria (expression of strong negative emotions)(Stroebe & Schut, 2010).

It has been recommended that empirical research explores whether the DPM is applicable to chronic illness and life-limiting diagnoses (Stroebe & Schut, 2010). To the best of our knowledge, no empirical research has yet explored whether the DPM is applicable to making sense of a life-limiting diagnosis. In this article we consider that the DPM may be applicable to understanding how people make sense of a life-limiting diagnosis, specifically MBC. It is considered that receiving the diagnosis can be interpreted as a loss, for example the loss of future, loss of meaningful times with others and often actual loss of some physical ability. Therefore this model may be an appropriate framework of understanding adjustment to MBC.

2.3.2 Reintegration Model

The Reintegration Model (RM; Knight & Emanuel, 2007) differs from the DPM in that it was specifically developed with life-limiting diagnoses in mind. It builds upon the DPM (Stroebe & Schut, 1999) by suggesting that such a diagnosis could result in anticipated or actual loss in one or more of four separate domains: physical, psychological, social, and existential. Similar to the DPM, the RM incorporates the process of oscillation between different stages, recognising that this may shift frequently depending on the stage and development of the diagnosis. The processes described in the model are comprehension, creative adaptation, and reintegration. It is suggested that the process by which one oscillates between these stages can be mediated by a variety of factors. However, there has been limited empirical research on this model and to the best of our knowledge, its application has largely been theoretical in nature.

Therefore, this study asks:

Are the psychological processes used to understand how people make sense of a diagnosis of MBC comparable with those proposed by the DPM (Stroebe & Schut, 1999) or the RM (Knight & Emanuel, 2007)?

2.4 Methods

2.4.1 Research Design

This study utilised a qualitative research methodology. A qualitative approach is considered the most appropriate method of analysis to answer this research question, as research was conducted from a critical realist position, which uses robust methodological design to account for the notion that reality can never be understood perfectly (Moon & Blackman, 2014).

Ethical approval for this study was granted by the University of Southampton Ethics committee (Ethics no 72094) and by NHS North Scotland Research Ethics Committee on the (ethics no 312569).

2.4.2 Participants and Procedures

Participants were recruited from a support group for people living with MBC. Recruitment was facilitated by a PPI representative who gave out information leaflets about the study. If participants consented to being approached by the research team, their details were forwarded on. All potential participants were then screened by a member of the research team (JH), to ensure that they met the inclusion criteria. The inclusion criteria was that all participants had a confirmed diagnosis of MBC and attended a support group for MBC. The study was open to all genders. All participants were over 18. Participants were excluded if they were physically unable to manage the interview, unable to consent or known by care team to be significantly distressed about their diagnosis.

A semi-structured interview lasting 60 minutes was completed with participants. The main researcher (OF) completed all interviews and did not have a relationship with participants prior to study commencement.

2.4.3 Data Collection

The interview schedule was developed to ensure that key theoretical points from the DPM and RM would be incorporated. A pilot interview was conducted with a PPI representative to ensure sensitivity and applicability (See Appendix E for details of interview schedule).

In total 15 people consented to be interviewed however, 14 participants were interviewed as one participant dropped out due to physical health reasons. All interviews were conducted face to face bar one, which was completed using Microsoft Teams, all interviews were recorded using a secure audio recording device. In addition to this the interviewer kept field notes for each interview alongside a reflective journal. Interviews were transcribed by two research assistants.

2.4.4 Data Analysis

Deductive Thematic Analysis was used to analyse the interviews from this study, using the framework suggested by Pearse (Pearse, 2019). The eight processes relating to the DPM (Stroebe & Schut, 1999) and the three processes and five moderating factors from the RM (Knight & Emanuel, 2007) were used to create an a-priori coding manual. During analysis additional subcodes were added to capture nuances within participant experiences (see the coding manual in Appendix F).

Deductive Thematic Analysis considered by the authors to be the most appropriate methodological approach, given the critical realist position. Content Analysis was considered; however, the methodology is not as robust, and would not offer the additional analytical process that DTA offers. For example, in practice, Content Analysis has often stayed close to the descriptive nature of the topic being studied (Lindgren et al., 2020). Within this research the aim was to fully explore and expand on the meaning of what participants described in their interview.

2.5 Findings

2.5.1 Participant characteristics

All participants identified as Female and White British, there was a mean age of 56.6 (34-86) and average length of time since diagnosis of MBC was 64 months (8-156). Two participants received their diagnosis of MBC over the phone while the rest were told face to face.

In general, both models captured the experiences of the participants. However, some of the processes were more endorsed than others and these are discussed in detail in the following findings. Further detail, pattern matching and example quotes relating to other processes can be found in Table 5 and Table 6 for the DPM and RM respectively. For more information on additional codes see Appendix F.

2.5.2 How do patient experiences fit within the DPM?

2.5.2.1 Loss-Orientated Processes

2.5.2.1.1 Negative Event Interpretation

All of the participants in this study described LO Negative Event Interpretation at some point since their diagnosis. For many this was aligned with the moment of diagnosis and period of time shortly afterwards and was most commonly expressed as thoughts such as “I’m going to die” or “how long do I have left?”. For some there were also descriptions of how they believed that MBC would not happen to them, as they had gone so long since their primary diagnosis. These descriptions all centre around the loss and describe how participants have interpreted this negatively.

2.5.2.1.2 Ventilating Dysphoria

Within our sample there was a high amount of LO Ventilating Dysphoria, whereby participants were expressing strong negative emotions in relation to their diagnosis. Many described feeling shocked, terrified, and sad for themselves and their families. For some this was expressed by crying, whereas others found themselves going into a state of shock. Across all of the participants this high level of emotion was often connected with the moment of diagnosis, however they also described how strong emotions could overcome them at any point.

2.5.2.1.3 Positive Reappraisal

There were descriptions of the ways in which participants made positive reappraisals of the loss in order to cope with their diagnosis. For example, some of the participants described comparing MBC with other types of cancer that have a shorter life expectancy and therefore felt a sense of gratitude that they would have longer to live. This positive reappraisal often allowed participants to recognise what has happened to them but without allowing it to become overwhelming.

2.5.2.2 Restoration-Oriented Processes

2.5.2.2.1 Revised Constructive Goals

Within our sample there were many descriptions of how they revised their goals for life in a constructive manner, this revision of goals was often centred around restoration and how they could move forward with their diagnosis. There were frequent descriptions of the use of distraction as a way of moving away from the loss and focussing on the future. For some there was a recognition that 'bad days' will be a part of their lives and an acceptance of these was necessary to move forwards.

2.5.2.2.2 Positive Reappraisal

There was also descriptions of the process of positive reappraisal for RO focussed tasks, for example, one participant stated, *"if I can cope with this, I can cope with anything"* (P3). This was echoed across many participants where they appraised their coping as 'positive' and this created a sense of confidence and security. There were also descriptions of the positive reappraisal of life, whereby participants spoke of a newfound respect for life and taking each day as it comes.

2.5.2.2.3 Positive Event Interpretation

For some of our participants there were clear descriptions of how events unrelated to their cancer had had a positive impact on how they coped. For example, upcoming life events such as the birth of grandchildren or weddings gave our participants something to look forward to and influenced how they felt about their cancer.

2.5.2.2.4 Oscillation

Nearly all of the participants in this study described a process of oscillation, whereby they moved between LO and RO processes and between feeling better or worse about their diagnosis. Within this there were clear descriptions of how one's physical health determined which processes they were more likely to sit within. For example, when physical health was poor, participants often described LO processes such as rumination and wishful thinking. Whereas when they were physically well there were more descriptions of feeling positive and engaging in RO processes, such as revised constructive goals.

Many participants noted that this oscillation often coincided with medical scans, appointments, or treatments. For example, in the lead up to a scan, participants described worrying about whether the cancer had progressed. However, once they had recovered from the side effects of the treatment, they described feeling more hopeful and able to re-engage with life. This cycle continued as long as the participant remained engaged in treatment.

2.5.3 How do patient experiences fit with the RM?

2.5.3.1 Comprehension

When considering the process of comprehension, there were many descriptions from our participants of the ways in which they came to comprehend their diagnosis. The most frequently described was how they made attempts to understand how much time they have left, with many initially assuming that they would die imminently. Within this there were also descriptions of trying to understand what the diagnosis means for them, for example, do they need further surgery or more treatment? Within a few of the interviews there were moments where participants started to connect previous bodily sensations with their diagnosis and spoke of a sense of knowing that something had been wrong prior to receiving the diagnosis.

2.5.3.2 Creative Adaptation

Creative adaptations are the unique ways that people try to incorporate their diagnosis and the meaning of this into their lives. Within our participants there were multiple stories around how they went about this. One participant described wanting to have two funerals, one where she is alive and can attend, then the second once she has died. She described how this would bring her comfort as she would have that time to celebrate her life with her family, but also be able to take some control over how she is remembered. Others described using humour to minimise the severity of the diagnosis or using alcohol as a way to cope with strong negative feelings.

2.5.3.3 Reintegration

There were several descriptions of how participants had reintegrated their diagnosis into their lives and were able to move forward with a meaningful life. Several of the descriptions focussed around normalising cancer and positioning it more as a life-long condition that needs to be carefully managed rather than as a terminal diagnosis. This appeared to serve two purposes within this sample, firstly by positioning it as a lifelong condition this allowed them to then engage with life alongside the diagnosis, secondly it minimised the stigma attached to cancer and offered hope that others would respond to them positively.

However, within this sample there was often a clear distinction that ‘reintegration’ was not a permanent state as there were multiple dialogues around how they have oscillated between different processes. For some there was a clear distinction around how future deterioration may interrupt their current levels of reintegration and they wondered how they would cope with potential pain and loss of ability.

2.5.3.4 Moderating Factors

The RM considers five moderating factors, all of which were discussed by our participants. The most frequent of this was ‘social support’ and participants described a range of experiences with the social support around them. For some this was overwhelmingly positive, with recognition of family members taking on new roles or becoming more emotionally supportive. For some, this support was obtained through professionals, such as a psychologist. Few had negative experiences, however where social support was lacking the descriptions around this highlighted the challenging nature of facing an MBC diagnosis with minimal support.

Within our sample there were often discussions around the characteristics of the loss, specifically the impact on women’s sense of womanhood and sexual functioning. This was often due to treatments such as mastectomy, lumpectomy, or chemotherapy and/or radiotherapy, which can significantly alter the body. The women described feeling unattractive, ashamed of their bodies and for some this had directly impacted their ability to maintain an intimate relationship with their partners. This was often positioned as a significant loss to our participants and was connected to negative emotions such as sadness and shame.

2.5.4 What is the overlap between these two models and our patient experiences?

It was noted that our participant experiences often could be reflected by both models, suggesting a reasonable degree of overlap. The moderating factors suggested by the RM were often found to encompass the processes suggested by the DPM. There was also notable overlap between Comprehension (RM) and many of the LO processes (DPM) and there was a sense that the two may be describing a very similar process. For a visual representation of how the processes from each model relate to each other see Figure 3.

There was not found to be any overlap between LO and RO Positive Event Interpretation processes and any of the domains suggested by the RM. In our study, there was limited evidence of the RO processes (Rumination and Wishful Thinking, Negative Event Interpretation and Ventilating Dysphoria) being discussed by participants. In particular there was no evidence of participants expressing strong negative emotions about RO tasks or experiences (RO Ventilating Dysphoria) and only one account of a participant ruminating over RO tasks and experiences (RO Rumination and wishful thinking). This could be due to a self-selecting bias within our participants whereby participants who perceived themselves as ‘doing well’ may be more likely to engage with this research, meaning that there are fewer descriptions of the negative meanings around RO processes.

2.6 Interpretation

To summarise, this research has explored the psychological mechanisms that are used to understand receiving a diagnosis of MBC. It was determined that both the DPM (Stroebe & Schut, 1999) and the RM (Knight & Emanuel, 2007) fit participants experiences, with multiple similarities between the models observed. It was determined that many of the processes suggested by the DPM are also evident in the RM. Theoretically this makes sense, as the RM aimed to build upon the

DPM from the position of making sense of a life-limiting diagnosis. Our study offers qualitative support that these models are based around the same psychological processes.

However within this study, the process of Reintegration (Knight & Emanuel, 2007) did not fully explain the experiences of this sample. Within our sample, those who spoke about the concept of accepting their diagnosis and then reintegrating this into their lives (which is the basis of reintegration) also recognised that this position was not stable. Across multiple interviews there was a recognition that further deterioration is inevitable and when this occurs, they may have to comprehend new losses and develop new ways of coping. These descriptions provide support for the concept of oscillation as not only a method of moving through comprehension and creative adaptation, but also as an ongoing process throughout the progression of a life-limiting diagnosis such as MBC.

This echoes previous qualitative research that explored the experiences of people living with terminal cancer, whereby individuals spoke of having to ‘accept’ that death was approaching, despite the intense fear of deterioration (Kyota & Kanda, 2019). This research was conducted with a Japanese population who referred to this process as ‘Shouganai’ which translates into ‘I have to accept it’ or ‘it cannot be helped’ which is a widely held position in Japanese culture when faced with situations that cannot be changed. This may contrast with the British cultural narrative around ‘being strong’ or ‘being a survivor’ which were evident across the interviews in this study.

This research has also highlighted the importance of recognising additional factors that may interact with psychological processes. The factors suggested by the RM (Knight & Emanuel, 2007) were evident across our sample and provided a more holistic view of how people may come to understand their diagnosis. For example, many of our participants commented on how having a large social support network offered them a sense of being loved and supported, which in turn influences their ability to engage with creative adaptation. This contrasts some of the previous literature which has identified the phenomena of ‘Social Death’ (Borgstrom, 2017) whereby the social network around a person decreases following a life-limiting diagnosis. Additionally, when thinking about how the characteristics of the loss impact on coping, previous research has highlighted that patient perceptions of their diagnosis can have an impact on the way in which they understand and cope with their diagnosis (Hopman & Rijken, 2015).

The recognition of moderating factors may also be beneficial in supporting health care professionals (HCPs) to consider what challenges a patient is likely to experience; for example, many of our participants held strong beliefs around wanting to have a peaceful death which was in line with much of the previous literature around factors that patients have identified to contribute to a ‘good death’ (Krikorian et al., 2020). By exploring this with patients, HCPs can support them to develop advanced care plans that are tailored to their wishes (LO Revised Constructive Goal). Which has been found to have a positive impact on one’s quality of life during end of life care (Brinkman-Stoppelenburg et al., 2014).

2.6.1 Strengths and Limitations

PPI consultation was used throughout, which has enabled them to develop a protocol that is both sensitive and robust as recommended in previous research (Jones et al., 2021).

The interviewer for this study identified as female and this may have been beneficial for the study as it offered a similarity for the women being interviewed, which may have opened up some of the more personal and sensitive lines of questioning around sex, intimacy, and participant’s identity as women.

In the analysis it was observed that nearly all of the participants included in this study positioned themselves as ‘coping well’ with their diagnosis, with one participant stating, *“it looks like me”* (P4) when asked ‘what does it look like to be coping well with a life limiting diagnosis?’. Therefore, this calls into question whether the findings of this study can be applicable to those who are ‘not coping’. Further to this, in advancements on the DPM (Stroebe & Schut, 2016) it was recognised that at times someone may become ‘overloaded’ by LO and RO stressors that they need to contend with. The current study has not fully captured this experience within our participants as overload was not considered within the analysis.

From a methodological perspective, this research has explored two models which have multiple theoretical similarities. This meant that neither model challenges the other and it is difficult draw conclusions around which model best fits our participant experiences. It may have been appropriate to consider other models such as the Common Sense Model (Leventhal et al., 2016). Which considers how the participant has perceived their diagnosis using the framework of, identity, cause, timeline, control, consequences, coherence and emotional representations.

The authors of this study reflected on the fluid nature of ‘coping’ within this study and wondered whether within the context of the research interview, participants would have been able to position themselves as ‘not coping’? Within the context of British culture, it still remains very difficult to openly admit that you are struggling and there remains a strong narrative around cancer survivors being ‘strong’. Further research is needed to explore whether the findings of this study could be replicated when participants consider themselves to be ‘not coping’.

2.6.2 Implications for Psychosocial care providers

The findings of this research offer important considerations for those working with individuals living with MBC. The most important is the recognition of the process of oscillation in coming to understand a diagnosis of MBC. This supports previous literature that has identified oscillation between loss orientation and life engagement in those living with advanced cancer (Vehling et al., 2018). Both the DPM and the RM included this as a core process and this study offers qualitative evidence that people move between different processes as they make sense of their diagnosis. This awareness of oscillation among clinicians should support the acceptance of distress, LO processes and comprehension as a part an ongoing process. However, when oscillation is not happening and a person is ‘stuck’ in one process, this may signal the need for support.

For clinicians working within the field of psycho-oncology, this research supports the use of Acceptance and Commitment Therapy (ACT; R. Harris, 2019). ACT offers clinicians a way to support people living with life-limiting conditions when they become ‘stuck’ in either loss or restoration. For example, it may be helpful to use the DPM to describe or formulate what a person is going through and then utilise some of the techniques outlined in ACT, such as using the choice point to help someone make committed action towards living in line with their values. In addition, ACT has been found to increase psychological flexibility in oncology settings (Fashler et al., 2018) and therefore could be beneficial in supporting individuals to move between loss and restoration more freely.

2.6.3 Conclusion

By using pre-determined codes that aimed to explore how these models fit onto interviews with people living with MBC this research posits that both models match onto the experiences of people living with MBC and could be used as a way to understand their experiences. Oscillation was highlighted as a main component of how people make sense of their diagnosis, whereby a person moves between LO processes and RO processes. It suggests that an amalgamation of the two models which combines LO and RO processes from the DPM with the recognition of interpersonal factors suggested by the RM as a suitable model to explain how people make sense of a diagnosis of MBC. This model offers a framework of understanding for which clinicians can build a formulation of how a person is making sense of their diagnosis.

Appendix A PROSPERO Registration

Review question

What are the experiences of Sex and Intimacy for LGBTQ+ persons after cancer?

The aim of the review is to systematically identify, analyse and critique the current evidence using a narrative review in relation to LGBTQ+ persons experience of sex and intimacy following cancer.

Searches

A systematic and comprehensive literature search of APA PsycArticles, APA PsycBooks, APA PsycExtra, APA PsycInfo, CINAHL Plus with Full Text, MEDLINE, Cochrane Library, and Google Scholar.

The following search terms will be used:

- Cancer: (adenocarcinoma* OR cancer OR carcinoma* OR leukemia* OR malignan* OR metasta* OR melanoma* OR neoplasms* OR sarcoma* OR (tumour OR tumor OR tumours OR tumors)
- LGBTQ+: (LGBTQ OR Lesbian OR Gay OR Bisexual OR Transgender OR Queer OR Questioning OR transmen OR transwomen OR heterosexual OR homosexual OR "sexual minority")
- Sex: (sexual well-being OR sexual wellbeing OR sexual function OR sexual dysfunction OR sexual satisfaction OR relationship satisfaction OR partner relationship OR sexuality OR intimacy OR intimate OR libido)

Reference lists of all the included papers will also be searched to identify any additional studies that meet the selection criteria and are not already included.

Restrictions: limited to peer-reviewed papers published in English.

Types of study to be included

Inclusion criteria:

- Adult population (18+) who have a cancer diagnosis
- Participants identify as LGBTQ+ or from a sexual minority
- Qualitative research, including case reports, case series and focus groups.
- Mixed method research papers, where only qualitative data will be extracted
- Peer-reviewed papers

Exclusion criteria:

- Interventional studies (e.g., medication trials)
- Participant is not the person with the diagnosis e.g., nurse, caregiver, family member
- Studies in languages other than English.
- Quantitative research
- Conference abstracts or any short papers with incomplete data presented
- Conference abstracts or any short articles with incomplete data presented
- Reviews, opinion articles

- Animal studies
- Letters, comments, editorials

Condition or domain being studied

In recent years there has been significant interest and improvement in the research around how sex, sexuality and intimacy is impacted by a diagnosis of cancer. For example research that has explored how sex is impacted by a cancer diagnosis in Chinese populations highlighted themes around a lack of education about sexual well-being following cancer treatments, concern over health and well-being and a lack of sexual activity and intimacy can cause relationship problems (Chan et al., 2021). In another review of women of colour's experience of sex and intimacy following cancer, the impact of treatment was highlighted as having a negative impact on sex and body image (Arthur et al., 2022).

However, the impact of cancer on LGBTQ+ persons may be different to the heterosexual population. In a key review of the impact of mastectomy from the perspective of LGBTQ+ persons it was highlighted that bilateral mastectomy is often performed within the context of gender-affirming surgery for transmen and may therefore be viewed positively (SKorzewska et al., 2021), whereas lesbian and bisexual women who undergo mastectomy within the context of a cancer diagnosis may experience this to alter their identity as a woman and have subsequent impact on their sexuality. Additionally, a review of gay and bisexual men's experiences of prostate cancer identified that treatment related sexual dysfunction was one of the most pressing issues and had significant impact on their sexual experiences (Mcinnis & Pukall, 2020). Recently, the issue of sex and intimacy was discussed in a review of the needs of LGBTQ+ persons with cancer, identifying that people do not feel comfortable discussing sexual health with care providers and highlighting the importance of physical appearance within gay culture (Webster & Drury-smith, 2021).

This review aims to provide an overarching review of the impact cancer has on sex, sexuality and intimacy for LGBTQ+ persons. Other than the previous review on mastectomy (SKorzewska et al., 2021) and prostate cancer (Mcinnis & Pukall, 2020), the researchers could not find an overarching review of the impact of cancer on sex, sexuality and intimacy for LGBTQ+ populations. Therefore, this review aims to expand on the previous research to provide a comprehensive review for the LGBTQ+ population.

Participants/population

Studies concerning LGBTQ+ persons using any well-established criteria in conjunction with a cancer-based diagnosis.

Intervention(s), exposure(s)

N/A

Comparator(s)/control

This systematic review aims to explore the lived experiences of sex, sexuality and intimacy following a cancer diagnosis for LGBTQ+ persons. As such, there is no control/experimental group comparison taking place.

Main outcome(s)

A qualitative exploration of the impact of receiving a cancer diagnosis on sex, sexuality and intimacy following cancer for LGBTQ+ populations.

Measures of effect

NA

Additional outcome(s)

Measures of effect

None

Data extraction (selection and coding)

All studies will be recorded in a Mendeley library file and duplicates removed.

To reduce potential bias two reviewers OF and VRA will independently inspect the articles identified by the search using the inclusion/exclusion criteria. Any disagreements regarding the inclusion of the studies will be resolved by discussion with the third reviewer (AM).

Excluded articles will have their reason for exclusion recorded. The systematic review will be undertaken based upon the recommended PRISMA statement guidelines (http://www.prisma- statement.org). Extracted data will include author, year of publication, country of origin, research design, setting, patient characteristics, qualitative data from study including main themes and quotes.

Risk of bias (quality) assessment

To reduce potential bias three reviewers (OF, MA and NW) will independently inspect the articles identified by the search using the inclusion/exclusion criteria. Any disagreements regarding the inclusion of the studies will be resolved by discussion with the third reviewer (AM).

The Critical Appraisal Skills Programme (CASP) qualitative checklist tool for quality appraisal will be used to assess potential bias. Data synthesis will incorporate the outcome of quality assessments where relevant.

Strategy for data synthesis

The included studies will be used to create a qualitative synthesis centred on the experience of sex, sexuality and intimacy for LGBTQ+ persons following a cancer diagnosis.

The authors do not anticipate that the data extracted will be suitable for meta-analysis due to the exploratory nature of the research question.

Analysis of subgroups or subsets

None planned

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Systematic Review (qualitative synthesis)

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Conflicts of interest

Language

English

Country

United Kingdom

Appendix B Coding Manual

Analytic Theme: *"Positioning of Self in relation to sex determines acceptance of sexual dysfunction*

Descriptive Theme:	**Code:**	**Description:**	**Quote:**
"Positioning of self along the life course"	Previous sexual behaviour	Description of participant sexual behaviour prior to diagnosis of cancer	*"I think I've had my time...I've been there and done that. I'll leave it to the young ones." (Gareth, gay, 65; Ussher, Rose & Perz, 2017)*
	Choosing to view changes because of ageing	Description of how participants view change in sexual functioning as a natural part of ageing	*"I'm a half century old and you know like seems like the normal kind of trajectory that sex is less important, and I think that was happening even pre-surgery and I feel like, you know, to a certain degree that what post-surgery is part and parcel of the aging process." (Patient 1; Hartman et al., 2014)*
	Using experience to mentor others	Discussion of using previous sexual experience to mentor others by either participant or author.	*"Finn (gay, partnered,69) told us he "found satisfaction" by utilizing his life experience and aged status by becoming a "mentor" or "guide" to men he met through a Web site designed for younger men seeking older men" (Ussher, Rose & Perz, 2017)*
	Those who were more sexually active prior to cancer feel the loss more keenly	Descriptions of being more distressed if participant had previously had an active sex life.	*"I was quite a sexual being...And the people that I played with were, you know, we made this circle, this quite wide circle. We made each other quite, quite happy...And now I can't do that. I feel—I feel that I'm—that I've made this sort of leap from being the person that could do that (...) It's like I've retired...I*

			just feel like I’ve been retired out to pasture. (Scott, gay, single, 59)”(Ussher, Rose & Perz, 2017)
	Old age considered negative within gay community	Description of how being old was considered a negative within the gay community by either participant or author.	*Jack commented (gay, partnered, 59): “I’m nearly sixty now, look [sighs]. That means I’ll probably have to go out and have sex with some other sixty-year-old man. The thought of that horrifies me.”(Ussher, Rose & Perz, 2017)*
“Re-evaluating the importance of sex”	Lack of ejaculate impact relationships	Description of how the lack of ejaculate impacts relationships by either participant or author	*‘... amongst gay men there’s this big thing about the actual show of cum. You can’t do that anymore so that’s gone as well.’ (Karl, gay man, aged 59; Fish, 2019)*
	Choosing life over sex	Description of participant focusing on life rather than sex	*‘Better I have the operation and survive, than I should keep my prostate and the cancer, and have sex for the next two years and then die or something’ (Fergus, Gray & Fitch, 2002)*
	Positive Perspective to loss of function	Discussionabout having a positive perspective to the loss of sexual function	*“Four participants in the study by Thomas et al. (2013, p. 525) responded with a positive perspective and a sense of empowerment at gaining insight into what was important and worthwhile in their lives” (Alexis & Worsley, 2018)*
	Re-evaluation of importance of sex	Description of how participants have re-evaluated the importance of sex in their life by either the participants or the author.	*‘‘in life if my sexual function diminishes further, there are other aspects of life that will take over from that which will continue to make life satisfying and rewarding’’ (Alex, 69, gay; Ussher et al., 2017)*

Analytic theme: *Experience of sex and intimacy varies depending on relationship status*

Descriptive Theme:	**Code:**	**Description:**	**Quote:**

"Importance of stable and supportive relationship"	Sex outside the relationship	Descriptions of one or both partners engaging in sex outside of the relationship as a method of coping with sexual dysfunction	*"we've got Plan B [. . .] we do have an open relationship, like in the sense that I've told him point blank that if you need to get fulfilled or whatever, feel free"(Hartman et al., 2014)*
	An understanding partner helps improve sexual performance	Description of how partners being understanding has helped sexual performance	*"Harry also reported being 'lucky' because he has a 'very good understanding partner' who 'didn't get upset if it didn't work', 'made me feel that I was okay' and never 'made me feel inadequate' (68, gay, prostate cancer; Gilbert et al., 2012)*
	Benefit of stable relationship	Descriptions of how a stable relationship has had a positive impact on experience of sex and intimacy	*"…having a stable relationship, even anon-monogamous one, either a long term or newly formed one, might lessen the impact of sexual side effects" (Lee et al., 2015)*
	Vicarious pleasure through partners ejaculation	Description of finding pleasure in watching partner ejaculate	*"Since I don't have it [ejaculate], I would just love to go down there, obviously… oh, my God, to just taste it again and swallow it and just have it in my mouth. It's like a much more powerful motivator now. (MSU12; Rosser et al., 2016a)*
"Relationship difficulties and rejection"	Social and sexual isolation due to erectile dysfunction	Descriptions of being socially and sexually isolated due to erectile dysfunction	*"…since his prostatectomy, "I've become a basically inactive gay male without the sex part." The result was social and sexual isolation (Scott, 59, gay; Ussher, Perz, Rose, Dowsett & Latini, 2018)*
	Rejection from sexual partners	Descriptions of being rejected by sexual partners due to sexual dysfunction	*"I met this guy, and it was just a hook-up. I got to his house, and we started trying to play around, and nothing was happening, and I opened up when I started talking to him. Maybe it was too much*

		information, I don't know, but he wouldn't even touch me after that. Freaked out, wouldn't touch me, and it was very clear that he wanted me to leave. (MSU01; Rosser et al., 2016b)
Loss of intimacy	Discussions around the loss of intimacy within a relationship after cancer	*"He just is probably turned off by the fact that I could dribble on him. It's kind of put a damper on our intimacy altogether. There's very little intimacy in our relationship. (MSU17 – underwent surgery 7C years ago; Rosser et al., 2016)"*
Dysfunction within a relational context	Description of how sexual dysfunction impacts both parties within a relationship	*"the patients and the partner identified that they experienced strains and changes in their romantic relationships, and relationships with other gay men, as a result of the diagnosis of PCa." (Filiault, Drummond & Smith, 2008)*
Concern over perception of others	Description of how the participant is concerned about the perception of others in relation to their sexual dysfunction	*"being a gay man…you are obviously with another man, and experiencing him, and comparing what I'm like compared to him there beside me…that sometimes hits me" (P8 Jim; McConkey & Holborn, 2014)*
Lack of ejaculate impact relationships	Description of how the lack of ejaculate impacts relationships	*'... amongst gay men there's this big thing about the actual show of cum. You can't do that anymore so that's gone as well.' (Karl, gay man, aged 59; Fish, 2019)*
Climacturia experienced as embarrassing	For male participants who had received treatment for PCa, they spoke about climacturia being embarrassing	*Kevin (P4) put it "I think dry orgasms are bad, as bad and all as they were, are better than when you are urinating on yourself or somebody else… I would be more embarrassed ya know if there is any element of urine coming out, it just, ya know, it*

	created fear of rejection	*would take me a month again before I would even contemplate doing anything" (McConkey & Holborn, 2014)*
Fear of isolation due to dysfunction	Descriptions of being fearful of becoming isolated from sexual and romantic partners due to their dysfunction.	*"[The biggest challenge is]… the lack of intimacy. I continue not wanting to put myself in a situation where there's rejection because of my disability. [MSU15]"(Rosser et al., 2016b)*

Analytic Theme: *"Moving away from penetrative sexual practices"*

Descriptive Theme:	**Code:**	**Description:**	**Quote:**
"Cancer treatment can have impact on sexual functioning"	Side effects of treatment create barrier to having sex	Description of how side effects from cancer treatment create a barrier to having sex	*"Negative reactions from prospective casual partners who were being informed of potential leakage of urine or blood were common, with Gordon (56, bisexual) explaining that when he met men online he would say ''when I climax there's usually some spurting of urine,'' which acted as a ''turn-off,'' and sex would not happen" (Ussher et al., 2017)*
	Deterioration in pleasure	Description of a deterioration in pleasure following treatment for cancer	*"the release that was there prior to the surgery… that is not there anymore" (P8 Jim), "…there is no real pleasure to it…" (P7 Jerry; McConkey & Holborn, 2014).*
	Range of impact on functioning	Descriptions of a variety of durations in impact on functioning	*"And it (sex) didn't really stop, it didn't reduce. I mean there were times, when I was having chemo and stuff I felt crap, so it wasn't a happening thing. But pretty well, yeah the attraction and the sexual part of our relationship continued" (50,*

		pwc, breast, lesbian; Ussher, Perz & Gilbert, 2014).
Erectile function rendered men vulnerable to failing to perform sexually	Descriptions around how erectile function specifically created side effects that left men vulnerable to performing sexually by either the participant or the author	*Several men expressed an ongoing situational anxiety specific to sex and focused to uncertainty about their ability to sexually perform (e.g. with a new partner), or risk of urinary incontinence and/or climacturia. (Rosser et al., 2016b)*
Lack of sex drive post treatment	Descriptions of how treatment for cancer has caused a lack of sex drive	*"I have no sex drive - AIs have taken care of that. I have no breasts so no sense of pleasure there" (Brown & McElroy, 2018)*
Loss of sexual function negatively impacts intimacy	Descriptions of a loss of intimacy following sexual dysfunction	*"One participant felt that the burden of prostate cancer diagnosis and treatment was increased by his inability to engage sexually with his partner resulting in less intimacy in their relationship" (Thomas, Wooten & Robinson, 2013)*
Loss of spontaneity	Descriptions of the loss of spontaneity due to sexual dysfunction	*'The spontaneity is gone. It is as if you have to schedule your sex life. To go out and try to pull someone, that would simply not work' (Danemalm et al., 2019)*
More intense orgasms	Descriptions of having more intense orgasms	*"For me, actually, I have to say my sex life is better. The orgasms are way more intense than they ever were before, much more longer lasting." (MSU03; Rosser et al., 2016a)*
Prostate is pleasure centre	The prostate centre was positioned as the pleasure centre for men by either the participant or the author	*"Well, I always saw my prostate as a pleasure centre. And I knew from sexual experiences that you know, massaging a prostate gland...could increase the pleasure of sexual intercourse enormously. And, you, to me, the prostate gland is a sort of*

			major part of the male sexual experience” (Filiault, Drummond & Smith, 2008)
	Treatment can reduce anal pleasure	Descriptions of how treatment for cancer has reduced the sensation of anal pleasure	*‘‘it’s a very sensitive part of a man’s body, and it is a great part of the enjoyment of anal sex…and so without them [prostate] a great deal of the enjoyment disappears’’ (Jack, 59, gay; Ussher et al., 2017)*
	Treatment impacts on sexual activity	Descriptions of how treatment for cancer impacts on sexual activity	*“Forced menopause and pain and body changes have led to less sex” (Brown & McElroy, 2018)*
	Unable to show pleasure without erection	Male participants spoke about being unable to show sexual pleasure without an erection	*Aaron (59, gay) commented, ‘‘erections are important, but they’re important visually,’’ with an erect penis signifying desire and pleasure (Ussher et al., 2017)*
“Adaptations to facilitate physical sex”	Change in sexual behaviours	Descriptions of using different sexual behaviours since treatment for cancer	*“Other participants talked of enjoying ‘‘gentler and slower, more intimate, sort of, process’’ of ‘‘sexual play,’’ compared with the ‘‘aggressiveness’’ pre-cancer sex (Bruce, 61, gay; Ussher et al., 2017).*
	Masturbation	The use of masturbation to offer different sexual practice and satisfaction	*One respondent, who stated that he only masturbates, added: “Can attain non-ejaculative orgasm/spasm. Learning what sexual activity I can do, regaining my confidence” (288NH; Wassersug, Westle & Dowsett, 2017)*
	Non-penetrative sex as alternative	Descriptions around how non-penetrative sex was used as an alternative	*Another factor that may account for sexuality remaining the same is the inclusion of non-penetrative sexual practices in the repertoire of lesbian and poly women, as Bronwyn commented ‘‘sex is penetrative sexual intercourse, well as a lesbian,*

			it’s not, not necessarily. It can be but it’s often not,’’ (Ussher, Perz & Gilbert, 2014)
	Sex as exercise to keep function	Using sex as an exercise to maintain functioning of sexual organs post treatment	*My excursions out to [gay sex] venues these days are less to do with feeling horny and sexual, but more to do with…pumping a little bit of oxygen into my dick, just so that I won’t seize up altogether….There’s no love or sexuality involved in it anymore (Scott, 59, gay; Ussher et al., 2017)*
	Sexual aids	The use of single or multiple sexual aids to accommodate or adapt to change in sexual functioning	*“I have to inject myself so I can get an erection—that will give me a really—a good, strong erection for up to twelve hours. So while I’ve got that erection, I can have really amazing sex” (Nick, bisexual, single, 66; Ussher, Perz, Rose, Kellet & Dowsett, 2019)*
Increasing affection and intimacy	Increased affection and intimacy	Descriptions of how participants showed more affection and intimacy with their partners by either the participant or the author.	*“Forced menopause and pain and body changes have led to less sex. Lots of affection, but much less sex” (Brown & McElroy, 2018)*

***Analytic Theme:** “Communication with others informs how sex after cancer is perceived”*

Descriptive Theme:	**Code:**	**Description:**	**Quote:**
Communication is important in understanding sexual dysfunction	Communication is important in understanding sexual dysfunction	Descriptions of how participants highlight how important communication is for understanding sexual dysfunction	*“Communication was a key factor in this renegotiation, as Vicky illustrated:* *We tend to be very open communicators in the bedroom” (36, pwc, melanoma, lesbian; Ussher, Perz & Gilbert, 2014)*
	Selective over who to confide in	Descriptions of thinking carefully about who to confide in about sexual dysfunction	*Charles, a 71-year-oldman, explained, “I’m always a little embarrassed that I can’t achieve an erection, because partners wonder what’s going on . . . I just say, ‘Oh, I prob-ably need to take a Cialis or Viagra’. I never tell them the truth*

			that I had surgery."(Lee et al., 2015)
Interactions with HCPs influence experience of sex	Heterosexual norms in information	Descriptions around how the available literature on sex and intimacy after cancer does not account for LGBTQ+ norms	*"I'd read somewhere ... that really men should wait about 3-4 weeks before resuming anal sex but I can-not find that literature anywhere on the NHS or Bupa [private health insurance company] I have scoured the internet. (ID 1)"(Doran, Williamson, Wright and Beaver, 2018)*
	Homophobia from HCPs impacts on sex life	Descriptions of varying degrees of homophobia from HCPs which prevented them from re-engaging in a meaningful sex life.	*Gareth (65, gay) reported that he asked his doctor about reduction in penis size, which had stopped him from having sex, and his doctor replied ''I don't want to know anything about your sex life,'' which Gareth concluded ''was because I was gay.''(Ussher et al., 2017)*
	Professionals not able to support sexual needs	Descriptions of how professionals did not support participant sexual needs	*"I've never had a straight doctor do anything to inquire about anal intercourse."(Alexis & Worsley, 2018)*

Analytic Theme: *"Distress due to disruption to sexual identity"*

Descriptive Theme:	**Code:**	**Description:**	**Quote:**
Physical changes from cancer treatment directly impact identity	Impact of treatment made people feel old	Descriptions of how the impact of having treatment for cancer had made them feel old	*"I think prostate cancer has made me feel older than I need to at this stage. I think if I didn't have prostate cancer I would still be very sexually active" (Jack, gay, partnered, 59; Ussher, Rose & Perz, 2017)*
	Impact on body image	Descriptions around how participants body image changed after treatment for cancer	*"I think some discomfort, but not and, I mean, I would have some discomfort ordinarily disrobing (with a new partner) So I'm trying to differentiate how much would be my old stuff anyway, and how much would be the new stuff connected with my mastectomy."(Nina, lesbian, breast cancer; Whitney, 1989)*
	Impact on gay identity	Descriptions around how participants sense of identity as a gay person	*"I think gay men are a lot more sexually aware, or I think part of our identity is that it's about sex and our ability to function sexually, and I think we take a harder hit*

		changed following treatment for cancer	*when it [ED] happens. (Rick, 59, gay; Ussher et al., 2017)”*
	Importance of sexual function	Descriptions of the importance of sexual function, pre and post cancer treatment	*“I think we might be able to discuss more openly how sex and sensuality can be an important part of coping/healing/recovery processes. I thought this aspect was underplayed and even stigmatized in most environments, but to me it was one of the reasons I fought to survive.”(Margolies & Scout, 2013)*
	Masculinity	Descriptions of how the impact of treatment for cancer impacted their sense of being a man, manhood and perception as a masculine being by either the participant or author.	*‘You threaten a man’s sex life, you threaten the man’ (Fergus, Gray & Fitch, 2002)* *“Jerry (P7) who said that prostate cancer treatment* *“….annihilated who I am…like someone took my manhood out …just got it and took it away from me and I can’t, I can’t address that…”(McConkey & Holborn, 2014)*
	Sexual role	Descriptions of how someone’s sexual role influences their experience of sex. For example, being a ‘top’ or a ‘bottom’.	*Being a top [insertive partner] was part of my identity and not being able to satisfy in that way really messed up my sense of who I was. (Participant 104; Hoyt et al., 2017)*
	Value of physical attractiveness	Descriptions of how physical attractiveness was valued within the gay community	*Nick (gay, partnered, 66) told us:* *“I’ve got a nice body and all that sort of thing, and I’ve looked after myself and I think it’s really good that people still see me as an attractive male. Actually, most of them are blown away when I tell them how old I am.”(Ussher, Rose & Perz, 2017)*
Physical changes post cancer treatment cause emotional impact and distress	Distress over unpredictable side effects	Descriptions around how unpredictable side effects caused by treatment for cancer can cause significant distress	*“The couple considered climacturia to be a deterrent for engaging in sexual activity. Following these distressing encounters, they questioned if it was worth pursuing sexual activity at all” (Hartman et al., 2014)*
	Emotional impact of sexual dysfunction	Descriptions of negative emotional impact due to participant	*“I was absolutely furious with my penis for being completely dead.” (Santillo, 2005)*

	experience of sexual dysfunction	
Failure of interventions to improve erectile functioning caused depression in some men	Descriptions of experiencing depression after interventions to correct erectile dysfunction failed	*"We both knew that I was going to take it [Viagra] And just nothing would happen, and it just puts me deeper and deeper [into] depression"(Hartman et al., 2014)*
Feeling inadequate due to dysfunction	Descriptions of how participants felt inadequate after treatment for cancer had left them with sexual dysfunction.	*"For many gay men, if my erection isn't as, not just as long and as big and as fat around, but as prolonged as his, just like if my muscles aren't pumped—my other muscles, my pectorals for example, aren't as pumped as his— then I'm lesser than. And you become lesser, not only lesser male, you become lesser gay I think." (Fergus, Gray & Fitch, 2002)*
Minority stress impacts ability to cope	Discussion around how minority stress complicated a participants ability to cope with sexual dysfunction	*"Sexual adaptation in the face of the limitations of physical dysfunction is adaptive for most men. However, for men with histories of responding to minority stress experiences, this process might be particularly challenging to self image and identity" (Hoyt et al., 2017)*
Sense of hopelessness over loss of erection	Gay and Bisexual men described feeling hopeless after the loss of erectile functioning following treatment for cancer.	*David (64, gay) said ''I feel devastated; the erection functioning is a really emotional thing for me,'' (Ussher et al., 2017)*
Sense of loss from lack of ejaculate	Specific to males was the discussion around experiencing a sense of loss when lack of ejaculate was a side effect of treatment.	*"I don't ejaculate anymore. I never will. I miss it a great deal,"(Ussher, Perz, Rose, Dowsett & Latini, 2018)*

Appendix C Evidence Profile Table

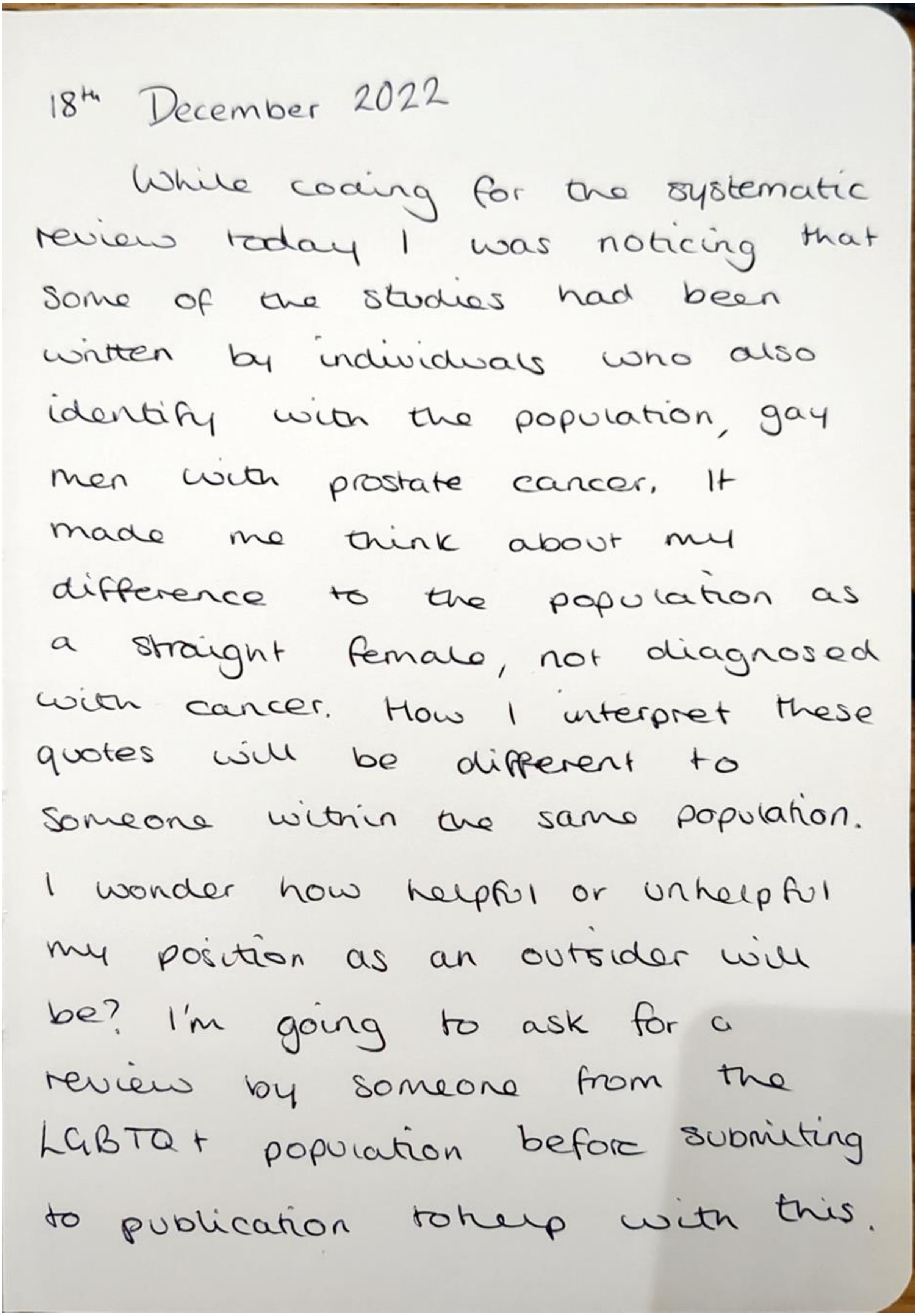
#	Summarised review finding	Methodological limitations	Coherence	Adequacy	Relevance	GRADE-CERQual assessment of confidence	References
1	Distress is due to disruption to sexual identity	Minor concerns **Explanation:** Minor concerns regarding methodological limitations because of the inclusion of singular case studies, which although provide lots of descriptive detail, do not adhere to rigorous scientific protocols.	No/Very minor concerns **Explanation:** This review finding was consistent across the studies included, the ways in which distress presented varied but underlying was the disruption to sexual identity	No/Very minor concerns **Explanation:** Studies included in this review offered rich quotes and descriptions of the participants experiences allowing a large amount of data to be lifted for this analysis.	No/Very minor concerns **Explanation:** Data included in this review appears to be relevant and offers a good foundation for analysis.	High confidence **Explanation:** Minor concerns regarding methodological limitations, No/Very minor concerns regarding coherence, No/Very minor concerns regarding adequacy, and No/Very minor concerns regarding relevance	Danemalm Jägervall et al. 2019; Doran et al. 2018; Fergus et al. 2002; Filiault et al. 2008; Fish 2019; Gilbert et al. 2013; Harris 2005; Hartman et al. 2014; Hoyt et al. 2020; Kelly 2004; Lee et al. 2015; McConkey & Holborn 2018; Mehta et al. 2019; Rose et al. 2017; Rosser et al. 2016; Santillo 2005; Simon Rosser et al. 2016; Thomas et al. 2013; Ussher et al. 2014; Ussher et al. 2015; Ussher et al. 2017; Ussher et al. 2017; Ussher et al. 2018; Ussher et al. 2019; Wassersug et al. 2017; West et al. 2018; Whitney 1988;
2	Communication with others inform how sex after cancer is experienced	Minor concerns **Explanation:** Minor concerns regarding methodological limitations because	No/Very minor concerns **Explanation:** There are very minor concerns around the coherence between	No/Very minor concerns **Explanation:** There were no concerns around the adequacy of	No/Very minor concerns **Explanation:** There were no concerns	High confidence **Explanation:** Minor concerns regarding methodological limitations,	Doran et al. 2018; Fergus et al. 2002; Harris 2005; Hartman et al. 2014; Hoyt et al. 2020; Lee et al. 2015; Margolies & Scout 2013; McConkey & Holborn 2018; Mehta

#	Summarised review finding	Methodological limitations	Coherence	Adequacy	Relevance	GRADE-CERQual assessment of confidence	References
		of the inclusion of individual case study written from personal perspective which lacks formal scientific rigour.	extracted data and the finding. From the data there were multiple, consistent references to how communication influences the experience of sex and intimacy in both positive and negative ways.	data for this finding. With 21 references that supported this finding and much of these providing rich and detailed quotes that often went beyond the descriptive and provided analytic interpretations as well.	around the relevance of the included studies that would alter the findings of this review.	No/Very minor concerns regarding coherence, No/Very minor concerns regarding adequacy, and No/Very minor concerns regarding relevance	et al. 2019; Rosser et al. 2016; Simon Rosser et al. 2016; Ussher et al. 2014; Ussher et al. 2015; Ussher et al. 2017; Ussher et al. 2017; Ussher et al. 2018; Ussher et al. 2019; West et al. 2018; Whitney 1988;
3	Moving away from penetrative sexual practices	Minor concerns **Explanation:** Minor concerns regarding methodological limitations because of the inclusion of individual case reports that may have lacked sufficiently rigorous data analysis.	Minor concerns **Explanation:** Minor concerns regarding coherence because although most of the quotes spoke to moving away from penetrative sexual practices, there were some from the lesbian and bisexual women that were already engaging in non-penetrative sex	No/Very minor concerns **Explanation:** There were many quotes and discussion of the theme moving away from penetrative sex, with richness and analytic interpretations present.	No/Very minor concerns **Explanation:** The data included within this finding was relevant to the overall finding.	Moderate confidence **Explanation:** Minor concerns regarding methodological limitations, Minor concerns regarding coherence, No/Very minor concerns regarding adequacy, and No/Very minor concerns regarding relevance	Brown & McElroy 2018; Danemalm Jägervall et al. 2019; Doran et al. 2018; Fergus et al. 2002; Filiault et al. 2008; Fish 2019; Gilbert et al. 2013; Hanly et al. 2014; Harris 2005; Hartman et al. 2014; Hoyt et al. 2020; Kelly 2004; Lee et al. 2015; Margolies & Scout 2013; McConkey & Holborn 2018; Rose et al. 2017; Rosser et al. 2016; Santillo 2005; Simon Rosser et al. 2016; Thomas et al. 2013; Ussher et al. 2014; Ussher et al. 2015; Ussher et

#	Summarised review finding	Methodological limitations	Coherence	Adequacy	Relevance	GRADE-CERQual assessment of confidence	References
			prior to the diagnosis of cancer.				al. 2017; Ussher et al. 2017; Ussher et al. 2018; Ussher et al. 2019; Wassersug et al. 2017; West et al. 2018; Whitney 1988;
4	Positioning of self in relation to sex determines acceptance of sexual dysfunction	Minor concerns **Explanation:** Minor concerns regarding methodological limitations because of the inclusion of singular case studies which may not have been subject to sufficiently rigorous data analysis.	Minor concerns **Explanation:** Minor concerns regarding coherence because there could be some alternative interpretations of the data in relation to this theme. For example this could also have been interpreted as more to do with age and the meaning of age, rather than whether someone positions themselves as old or young.	No/Very minor concerns **Explanation:** The data was sufficiently rich and there were multiple descriptions that included analytic interpretation	No/Very minor concerns **Explanation:** The underlying studies were relevant to the review question.	Moderate confidence **Explanation:** Minor concerns regarding methodological limitations, Minor concerns regarding coherence, No/Very minor concerns regarding adequacy, and No/Very minor concerns regarding relevance	Danemalm Jägervall et al. 2019; Doran et al. 2018; Fergus et al. 2002; Filiault et al. 2008; Fish 2019; Gilbert et al. 2013; Harris 2005; Hartman et al. 2014; Hoyt et al. 2020; Lee et al. 2015; McConkey & Holborn 2018; Rosser et al. 2016; Santillo 2005; Simon Rosser et al. 2016; Thomas et al. 2013; Ussher et al. 2015; Ussher et al. 2017; Ussher et al. 2017; Ussher et al. 2018; Wassersug et al. 2017;
5	Experience of sex and intimacy varies depending on relationship status	Minor concerns **Explanation:** Minor concerns regarding	No/Very minor concerns **Explanation:**	No/Very minor concerns **Explanation:**	No/Very minor concerns **Explanation:**	High confidence **Explanation:** Minor concerns regarding	Filiault et al. 2008; Fish 2019; Gilbert et al. 2013; Hartman et al. 2014; Lee et al. 2015; McConkey & Holborn 2018; Rosser et al. 2016; Simon

#	Summarised review finding	Methodological limitations	Coherence	Adequacy	Relevance	GRADE-CERQual assessment of confidence	References
		methodological limitations because of the inclusion of some individual case reports that may not hold up to the scientific rigour of other studies.				methodological limitations, No/Very minor concerns regarding coherence, No/Very minor concerns regarding adequacy, and No/Very minor concerns regarding relevance	Rosser et al. 2016; Ussher et al. 2018;

Appendix D Reflexive Log Excerpt



18th December 2022

While coding for the systematic review today I was noticing that some of the studies had been written by individuals who also identify with the population, gay men with prostate cancer. It made me think about my difference to the population as a straight female, not diagnosed with cancer. How I interpret these quotes will be different to someone within the same population. I wonder how helpful or unhelpful my position as an outsider will be? I'm going to ask for a review by someone from the LGBTQ+ population before submiting to publication to help with this.

Appendix E Interview Schedule

Opening Statement

"Thank you for coming in today. Before we begin, I just wanted to cover a few things: Firstly, today I will be recording our conversation using this recording device, which will record audio only [*if in lockdown "will be recording using Microsoft Teams which will record audio only"*]. This recording will be stored securely by myself and deleted once the analysis is completed. Secondly, as mentioned in the letter I sent you, we will be discussing your metastatic breast cancer diagnosis today and how you have coped with this. If at any point you feel uncomfortable or upset, we can take a break or stop the interview. You do not have to answer any questions that feel too much or too intrusive for you, however, please be as honest as you can throughout the interview."

"Given all of this, do you still consent to taking part in this research and having our conversation recorded?"

- If YES then continue, if NO then end interview –

Questions

1. What was it like to be told you have metastatic cancer?

Prompt: What did you think when you were told?

Prompt: What did you feel when you were told?

Prompt: What did you do when you were told?

2. What do you find yourself thinking about in relation to the future and what will happen next?

Prompt: Can you tell me more about that?

Prompt: What things have you found keep coming into your mind?

Prompt: How do you feel about those thoughts?

Prompt: What do you do when this happens?

3. How have your relationships been affected by your diagnosis?

Prompt: In what ways have these changed?

Prompt: In what ways have others supported you?

Prompt: How did this help you cope with your diagnosis?

4. How have your cultural and family traditions affected how you cope with your diagnosis?

Prompt: Are there any times where your cultural and family traditions are not helpful in coping with your diagnosis?

5. Before your diagnosis what were your thoughts on life limiting illnesses?

Prompt: How has this changed since diagnosis?

6. Tell me how you move between feeling better or worse about your diagnosis?

Prompt: How often does this shift happen?

7. In your opinion what does it mean to be coping well with a life limiting diagnosis?

Prompt: What does this look like?

Prompt: What would it mean to you to be not coping with a life limiting diagnosis?

Prompt: What does this look like?

8. In what way has your identity changed since diagnosis?

Prompt: Can you tell me about why you think this has changed?

Closing Statement

"Thank you for taking part in this interview with me today and sharing your experiences with me. If you have found this interview brings up challenging thoughts and feelings for you moving forward, please be aware that you can access support through Mountbatten Psychology service by calling this number *{gives participant debrief form with number for self-referral to psychology}*.

We expect that this research will be completed in 2023, if you would like to receive updates around completion and final results, please leave your email here which will be stored securely with Mountbatten and only used to contact you with the final results of the study *{if participant agrees then give form for contact around dissemination of results}."*

Appendix F Final Coding Manual

Theme:	*Code:*	*Description:*	*Quote:*
*LO - Positive Reappraisal** [1]		The participant has made a positive reappraisal of the losses they have experienced due to cancer (e.g. loss of future, loss of hair)	*"Do you see it as well, this is the green light to really go for it. You've got to live life to the full. And I mean, people should live their life to the full anyway, but. So. Yeah. I just think if. If you've been given that news. Should go for it for sure and do everything." (P7)*
	Minimisation of Primary Cancer	Participant made a positive reappraisal of their situation by minimising their primary diagnosis of breast cancer	*"Because when I was first told I just it was just in the breast and they said you can have a little operation and chemo. And I thought, oh, that's good because I'm. You know, that'll be it then"(P5)*
*LO – Revised Constructive Goals**		The participant describes changing or revising their life goals in a constructive way because of their experienced loss	*"And now I might have treatment on Tuesday, and it might hit me straight away. I don't know. But. But at the moment I've got, I've got to listen to my body. And I've got to be honest. And I I say to you know, friends and and my family, I just don't feel right." (P14)*
	Creating new ways to be remembered	Descriptions of participants making an active effort to create a lasting memory of themselves for when they are gone	*"Just started like a little journal thing. I only write like a little sentence a day of what we've done for the day. So she's got something to read. If I'm not here at some point." (P10)*
	Preparing for death	Ways people have prepared for their death	*"I've got everything in place. And there's a relief. Honestly, it's like a weights been lifted. You know, I'd hate to just leave this world with all my affairs upside down and leave that all to my family to deal with. Yeah. So this way, whoever looks after me. Has got an idea of how I want to be looked after" (P13)*

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[1] * Denotes a pre-determined code

	Adapting to physical changes	Participants describe revising their goals by making adaptations in line with physical changes	_“So I kind of have to make a really conscious effort to do all the things that I know, help with the fatigue to try and keep my mental health well. It's like a balancing act.” (P12)_
LO - Positive Event Interpretation*		The participant interprets some of the events that have happened since diagnosis of cancer to be positive	_“At least now I knew what was wrong with me, and it all made sense.” (P1)_
LO - Expressing Positive Affect*		The participant expresses that they are feeling positive or happy about an element of the loss	_“That's what my daughter did when she first found out that she sat by my side in the hospital, day in, day out for a week. And that's that's priceless. Absolute prices. Wonderful.” (P4)_
LO - Rumination and wishful thinking*		Participant describes ruminating over the loss or cancer diagnosis, whereby the rumination is on symptom of distress or meaning associated with distress/symptom	_“I mean, for good. I don't know, 3-4 years it, uh, cancer is the first thing I thought about soon as I woke up, I would think about it multiple times a day.” (P12)_
	Time since primary diagnosis	Descriptions of how participants reflected on the length of time since primary diagnosis	_“So I thought I'd turned the chapter on cancer cause I had it back in 2015. And finished all the treatment in 2016. So I thought I'd kind of turned the chapter, closed the books on helping cancer charities so much and stuff like that” (P10)_
LO - Revised Unconstructive Goals*		When thinking about their loss the participant revises their goals for life in an unconstructive way	_“Not being able to get past the next week because I'm not focusing too far ahead, I've just been and that hasn't done me any good. I think I I need to sort of look, keep looking a little bit further ahead and planning a little bit further, further.” (P3)_
LO - Negative Event Interpretation*		The participant has interpreted events that cancer diagnosis has caused to be negative	_“That has been the worst thing about it. It has stripped each thing that I enjoyed doing. I love going to the cinema. I can't go to the cinema anymore.” (P1)_
	Attempts to understand time remaining	Descriptions of how participants tried to understand how much time they would have left after their diagnosis	_“the first thing was I sort of said was how long have I got, you know, because you just (.) I don't know. My_

			understanding was it was, you know, a death sentence and it was 'oh' so terrific." (P9)
	Cancer becomes identity	Participants described how cancer became a part of their identity and this was perceived negatively	*"And that's why I don't like telling people. Because, don't want them to see me differently. Want them to see me exactly the same" (P7)*
	'I didn't think it would happen to me'	Comments about how participants didn't think this would happen to them	*"Well, I suppose you don't think it's gonna happen to you, do you?" (P1)*
	Impact on appearance	Descriptions about how participants thought cancer has had a negative impact on their appearance	*"the hair loss again, that's like wearing a badge saying I've got cancer. Yeah. Um and your hair is kind of like your. I mean, I've just shoved it up. I'm knackered today but your hair is your identity. It's part of you." (P12)*
	Impact on sexual functioning	Negative interpretations of the change to sexual functioning and organs due to cancer.	*"And especially being the age that I was. Um because before I got diagnosed, I was very sexually active, I was a completely different person uh, that has been one of the hardest things, I think, because they've taken my ovary. So I'm meno- post menopause now. Um and It's gone from being like, really. What's the word? Horny, I can't think of a better word. Uh to absolutely nothing like overnight and that's been really difficult" (P12)*
*LO - Ventilating Dysphoria**		In relation to the loss, participant expresses negative emotions and dysphoria	*"I think now at the moment I'm at the point where I feel. Hopeless. Useless. Redundant. Because I'm not working. I can't drive. I can't go out without my husband taking me or asking my daughter or friend to take me somewhere. So, like the in the last couple of years. Umm, I found it really tough. Finding it tough" (P11)*
	Loss of womanhood	Descriptions of strong negative emotions connected to the perceived loss of womanhood	*"Very much so massive impact. You don't you don't you don't love yourself. You don't feel like. Umm. Yeah. You don't feel beautiful. You don't, you feel as if you lost your womanhood completely and that that's hard." (P4)*

*Oscillation**		The participant describes moving between loss-orientated and restoration-orientated practices.	*"For the first few years, you're in (.) cancer is your life, and then the bubble is your family and your friends and and that's your have fun and you manage to just get into that bubble for a few days a week or a few days a month and then you'll come out again now (.) my life is my life and then cancers, this bubble that I pop into like today, or when I go for treatment or when I have to talk to people about it. And then I come out of the bubble." (P14)*
	Living scan-to-scan	Descriptions of how scans and treatment influence process of oscillation	*"I think the only shift I've seen so far really is leading into the scans and scan results and ??? that everyone talks about. Going back into the same scan room that you know showed bad scan results back last year. It mentally messes with you. Then your lying thier thinking, well, you know, my blood results are good. The treatment was working last time. I've got no new symptoms. You know, they'll be fine. And then when it takes like six weeks to get results, you start querying stuff and then you're like, I've got headache. So that's ???" (P10)*
	Mental state dependent on physical state	Participants describe how their mental state changes depending on how well they are physically, including whether or not they experience pain	*"I think the only time I I I moved to more negative thoughts is when I don't feel well which is natural I suppose." (P6)*
*RO – Positive Reappraisal**		The participant describes a positive reappraisal that allows them to move forward in a positive manner.	*"So initially I was okay with it because I was like just like, well I'll have my breast removed get myself a perky pair and get on with my life." (P2)*
	Faith provides comfort	Descriptions of how having faith in higher power gave people comfort	*"I'm in full conviction that that I'll meet my maker and he'll see me through to the end. He's not gonna leave me now I'm 77." (P8)*
	Being treated as if nothing is wrong	Participants described how being treated as if nothing is wrong allowed	*"You just could you just wanna feel normal? You want somebody to come in, you want them to moan about how bad their day was so you can help them" (P14)*

		them to re-engage with life in a positive way	
	Not looking unwell	Participants spoke about how they don’t appear unwell and this offers them some protection from others interpretation of cancer	*“When I went to church. I I said to one lady. Ohh, you know, I've I've had a mastectomy, she said “you haven't”. I said “I have” And I think, and she said “I never noticed anything” and I said. Well, I don't think you're supposed to” (P8)*
*RO – Revised Constructive Goals**		The participant reconstructs their life goals in a constructive way in order to make the most out of life.	*“I enjoy cooking and gardening and and everything, you know, hobbies. And I I just love my family to bits. So it's little keep me going. So you all my. My life has changed in that way. So the things that are important to me become more important. You know” (P13)*
	Acceptance of bad days	When making revisions of their goals, participants spoke of accepting that they would have bad days	*“And I've got to accept. It can't be good all the time. I can't be good all the time” (P7)*
	Distraction	Discussions around the use of distraction as a method for coping with diagnosis	*“Try to distract myself, really with a hobby or. Talk to family member. You know that often lifts me out of it” (P13)*
*RO – Positive Event Interpretation**		Participant expresses positive interpretation of events not related to cancer, that are focussed on restoration (e.g. spending more time with family, starting a new hobby)	*“There's there's there's got to be something every day that will make you smile, you know, whether it be an animal, whether it be the sun shining, whether it be something funny on telly.” (P4)*
*RO – Expressing Positive Affect**		Participant expressed positive emotions in relation to restoration orientated tasks (e.g. spending more time with family, starting a new hobby)	*“It was his birthday on the [recent date] and I just it I get quite tearful almost cause I think Oh my God, I am lucky. Am I still here? You're seeing all this.” (P9)*
	Spiritual connection opens up emotional expression	Descriptions of how having a spiritual connection can open up emotional expression, even in the absence of faith	*“I'm not a church person. I'm not. I'm not a Christian. I've got, you know, I've no faiths or anything but I like churches. And whether it is that as well because as soon*

			as I walk in that is it's, you know, I'm a wreck and a mess.” (P5)
RO – Rumination and wishful thinking*		Descriptions of rumination or wishful thinking about restorative tasks for example, ruminating over their coping styles or behaviour of others in relation to them	*“The longer my treatment works and all I'm gonna be here. So as long as I can get her to 18. Just another 16 years to go on treatment, but. And. Yeah, the longer everything stays stable the more memories she's got with me and we can kind of broach it as and when necessary. She's only two, like, she's still diddy” (P10)*
RO – Revised Unconstructive Goals*		Participants describe the revision of life goals that are unconstructive in relation to restoration orientated tasks	*“Six weeks later they were monitoring my blood levels, my neutrophils, and they dropped. They dropped to sort of below 1. And they said what? Why? And I said because I went on a diet. And they said, well, don't go on a diet. But I wanted to lose some weight” (P4)*
	Being strong for everyone else	Participants described having to alter their behaviour to be strong for everyone else	*“I had emotional moments when I was on my own. A lot of the time. And then when I was at home with my husband and my, my daughter and my older son. It's like okay lets keep it together haha. I've gotta keep strong for everybody else.” (P3)*
RO – Negative Event Interpretation*		Interpretations of restorative tasks as being negative	*“It's really hard because I (.) Since having been diagnosed. Umm, I can't look too far ahead. You know, I and I people say to me oh oh, what about next year? Do you fancy doing this… I was all (.) Let's just you know what I mean. Well, yeah. Yeah. Ask me with a few months to go and then I can, you know, think about it. So I'm really struggle with looking at that, you know” (P9)*
	Worry about genetic aspect of cancer	Worry that cancer will be passed onto children	*“I worry about my three daughters in case there's this gene, you know, and then I have to. I have to push it to one side and think that's that's almost nothing to do with me because that's their life what their genes produce” (P8)*

*RO - Ventilating Dysphoria**		Participant describes negative emotions around the new challenges that they face?	*No quotes found.*
*Comprehension**		The participant describes how they came to understand their initial diagnosis and what this meant for them.	*"I think it was more of a gradual, but maybe it's because I I came up to some meetings with some ladies here who had called seconds. And because they started talking about things and there was one lady who was talking about the process of going through the different treatments and when you and and I knew when you stop one, you can't go back to it. And she said, you know, her list is getting shorter and shorter. And then I think at that point I realised. Ohh (.) That's how it works" (P11)*
	Sense that something was wrong prior to diagnosis	As participants came to comprehend what was happening to them they speak about a sense of something being wrong prior to diagnosis	*"To be quite honest you I knew that something was wrong from (.) the very beginning and there's cancer in my family anyway, so it wasn't such a shock at all." (P5)*
	Attempts to understand time remaining	Descriptions of how participants tried to understand how much time they would have left after their diagnosis	*"the first thing was I sort of said was how long have I got, you know, because you just (.) I don't know. My understanding was it was, you know, a death sentence and it was 'oh' so terrific." (P9)*
	Time since primary diagnosis	Descriptions of how participants reflected on the length of time since primary diagnosis	*"So I thought I'd turned the chapter on cancer cause I had it back in 2015. And finished all the treatment in 2016. So I thought I'd kind of turned the chapter, closed the books on helping cancer charities so much and stuff like that" (P10)*
	Inability to comprehend meaning of loss all at once	Participants describe not being able comprehend the whole meaning of the loss	*"I just didn't take it in straight away." (P3)*
*Creative Adaptation**		Descriptions of how the participant adapted their life around their diagnosis and changed identity	*"Umm, I've already planned my funeral, though I'm having two, I'm having one when I'm alive. So we can*

			celebrate with everybody and then they can do what I like then after so yeah" (P5)
	Distraction	Discussions around the use of distraction as a method for coping with diagnosis	*"Try to distract myself, really with a hobby or. Talk to family member. You know that often lifts me out of it" (P13)*
	Creating new ways to be remembered	Descriptions of participants making an active effort to create a lasting memory of themselves for when they are gone	*"Just started like a little journal thing. I only write like a little sentence a day of what we've done for the day. So she's got something to read. If I'm not here at some point." (P10)*
	Spiritual connection opens up emotional expression	Descriptions of how having a spiritual connection can open up emotional expression, even in the absence of faith	*"I'm not a church person. I'm not. I'm not a Christian. I've got, you know, I've no faiths or anything but I like churches. And whether it is that as well because as soon as I walk in that is it's, you know, I'm a wreck and a mess." (P5)*
	Faith provides comfort	Descriptions of how faith in higher power gave people comfort	*"I'm in full conviction that that I'll meet my maker and he'll see me through to the end. He's not gonna leave me now I'm 77." (P8)*
	Unique methods of adaption	The participants describe a range of methods of adaptation	*"I suppose there's a bit of mindfulness about the the now and some days, if somebody were mentioned mindfulness and you just wanna tell them where to go, just away. But other days, it's brilliant. Absolutely brilliant" (P14)*
*Reintegration**		The participant describes how they reintegrated their new identity into life	*"Then other people are living quite well with it, so 10 years down the line one of the girls. I think she's coming up here as well as to her interview. At some point she might already done it. But we met up at at some cancer network. Same sort of age and she was secondary and that was seven years ago, 6-7 years ago. And she still living well with it now. So I'm like, well, OK, if you can do seven years, that gives me, hey, alright, slightly different diagnosis but it gives me hope that you're similar sort of age similar sort of diagnosis and you're living really quite well with it" (P10)*

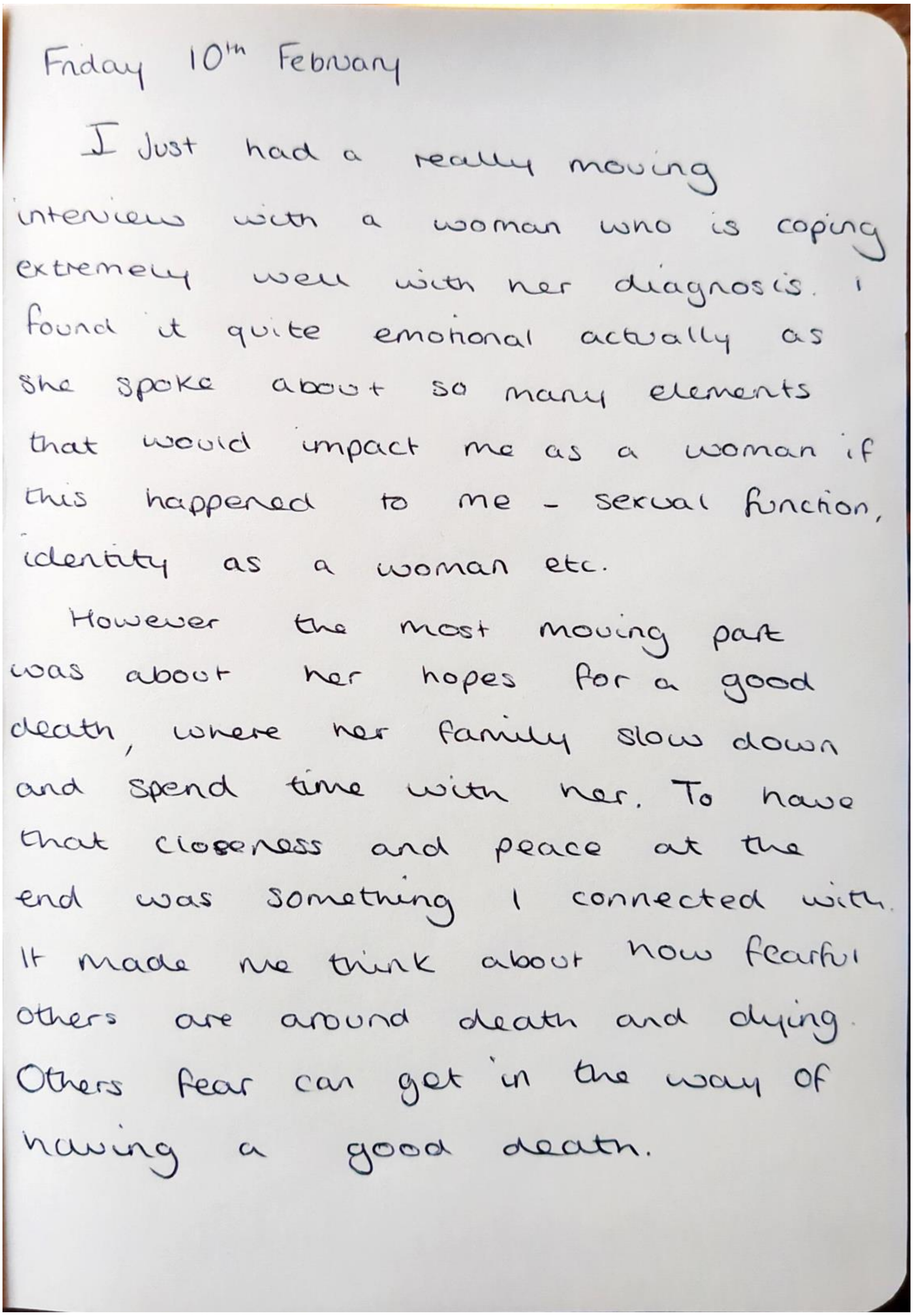
	Being strong for everyone else	Participants described having to alter their behaviour to be strong for everyone else	*"I had emotional moments when I was on my own. A lot of the time. And then when I was at home with my husband and my, my daughter and my older son. It's like okay lets keep it together haha. I've gotta keep strong for everybody else." (P3)*
	Being treated as if nothing is wrong	Participants described how being treated as if nothing is wrong allowed them to re-engage with life in a positive way	*"You just could you just wanna feel normal? You want somebody to come in, you want them to moan about how bad their day was so you can help them" (P14)*
*Social Support**		Descriptions of the social support around the participant	*"It is because we as a group, we meet up every three weeks. We meet up in the Hospice actually, which is lovely. Umm I mean, and it's great because you can ask questions to them that only them and you know they're going through these things. You know, if you don't like different medication and stuff like that, and there's always somebody that have had that or haven't had that and they just help each other, which is really nice" (P5)*
	Cancer creates changes in family dynamics	Participants describe how there has been a change in their family dynamics due to their diagnosis	*"But he's he even he's become quite, you know, I love you, mum. You know things that he would never have said before he. I know he meant it. But he didn't. He just never said it." (P6)*
	Stigma around cancer	Descriptions of how stigma around cancer has impacted the participant	*"We were insured through the bank with travel insurance, but it's not like it's that that always reminds you that you're not. You know, you're like taboo. They don't wanna touch you, you know." (P8)*
	Negative responses from others	Participants described how people have responded in negative ways to them	*"And I've cut a lot of other people out of my life. I found there was a called them grief tourists. There was quite a lot of them popped up, which is like random old acquaintances that I hadn't spoken to in years and years. And as soon as they knew that I was ill, like, hello, how are you? What's going on? How long have you got left to live?" (P12)*

	Support from pets	Support comes from pets as well as from humans	*"I've got my dog he's my absolute I mean if I didn't have that dog, I think, when you're so, you're lucky he's not here because he's normally he doesn't leave my side." (P4)*
	Psychological support	Some of the participants also accessed professional psychological support to cope with their diagnosis	*"Well, that's following [psychologist's name] that she's stuck in my head with her amazing helpfulness. You know what mean she really. Ohh. She's amazing woman really helped me so much." (P9)*
*Beliefs about death and dying**		Descriptions of participant beliefs about death and dying prior to their diagnosis of cancer	*"I'll be honest, death to me is something that I thought about for many years and I I'm an ex nurse, so it's not something that's new to me and. I've sort of. I've looked after lots of people you know in the in, dying with them. Terminal diseases. And it's something I've always thought about and reflected on" (P13)*
	Hopes for a peaceful death	Participants described wanting a peaceful death when the time comes	*"That's the bit I fear is that everyone's gonna be rushing around because that's their way of coping. And actually, all I would probably want is just to, just to be held and to be sat with and do all those calm and quiet things that are really, really important. We don't make enough time for each other, and I think that's my biggest fear, is not having that quality time at the end with my people I love." (P4)*
	'I didn't think it would happen to me'	Comments about how participants didn't think this would happen to them	*"Well, I suppose you don't think it's gonna happen to you, do you?" (P1)*
*Psychological Resilience**		Descriptions by the participant about their own psychological resilience	*"OK, so from the first diagnosis it was ohh. 'Ohh you know' {surprised voice}. They tell me what (.) Operations I had had to have and then what treatment? And I just, I just got on with it. Just got on with it. Umm. Resilience, I think, came into it. I think that's the word resilient." (P11)*
*Demographic Characteristics**		Descriptions about the demographics of the participant that influence how	*"I worry about my kids and my husband." (P3)*

		they have made sense of their diagnosis (e.g. age, gender, motherhood)	
	Beliefs about self	The beliefs that people hold about themselves impacted how they coped with diagnosis	*"I've always been. Should I put it? I've been quite a strong person." (P1)*
	Financial ability to support changes	Recognition of financial ability (or lack of) to support themselves through changes to lifestyle	*"Thankfully myself and my partner are in a good financial position that we can go on holiday quite a lot. So there's always a little holiday somewhere to keep looking forward to. Yeah, you know and just get on with it." (P5)*
	Impact of ageing	Discussions around how age influenced the sexual function of participants more than the cancer	*"Sex is not high on our agenda, although I understand it is important for a lot of people in the yeah, they're in my age group, but companionship at the moment is. It's overtaken." (P13)*
	Being a mother	Many of our participants were mothers and this influenced how they coped with their diagnosis	*"But also it's the the children don't need me like they used to. So that's a feeling of redundancy really" (P11)*
	Previous experience of cancer	Participants describe how their previous experience of cancer in the people close to them informs their thinking	*"And it was a couple of years ago with about the same time that she told me she she was. She didn't tell me at first (0.5) she had lung cancer. She was diagnosed with lung cancer. And within a matter of months, she she was gone. And I think at that point, I realized that that's that's (.) that's gonna be my journey. And I I think I just went to pieces then." (P11)*
*Characteristics of the Loss**		Descriptions from the participant about the characteristics of their loss	*"Set my alarm to go to work is hard because I suffer with really bad night sweats, which we're still trying to get under control, which we can't. So I only get about 45 minutes and I'll go. I I never sleep for more than an hour. I've got used to that. But it makes me super tired. All the time (.) so that I find frustrating" (P2)*
	Impact on sexual organs	Specific details of the impact on sexual organs	*"And I have vaginal dryness. And I've also say over the course of the journey had got a anal fistular as well. I*

		think it was as a result of the chemo but they might not that they'd agreed to that. But so yeah, it's just all these added things." (P12)
Multiple losses to comprehend	Participants have to come to terms with multiple losses	*"And then it was found in the other leg, and I've had that leg pained. But during that operation, my leg broke. It broke, so I had to deal with that. That was that was really, really tough, very, very tough. And then when did I have the chemotherapy? But I found it in my lung and my liver. So between this leg and that leg, I uh did my lung and my liver. So then I had to have chemotherapy. So it was at that point. And I think I've been dealing with it for about 11 years by then." (P11)*
Not looking unwell	Participants spoke about how they don't appear unwell and this offers them some protection from others interpretation of cancer	*"When I went to church. I I said to one lady. Ohh, you know, I've I've had a mastectomy, she said "you haven't". I said "I have" And I think, and she said "I never noticed anything" and I said. Well, I don't think you're supposed to" (P8)*

Appendix G Reflexive Journal Excerpt

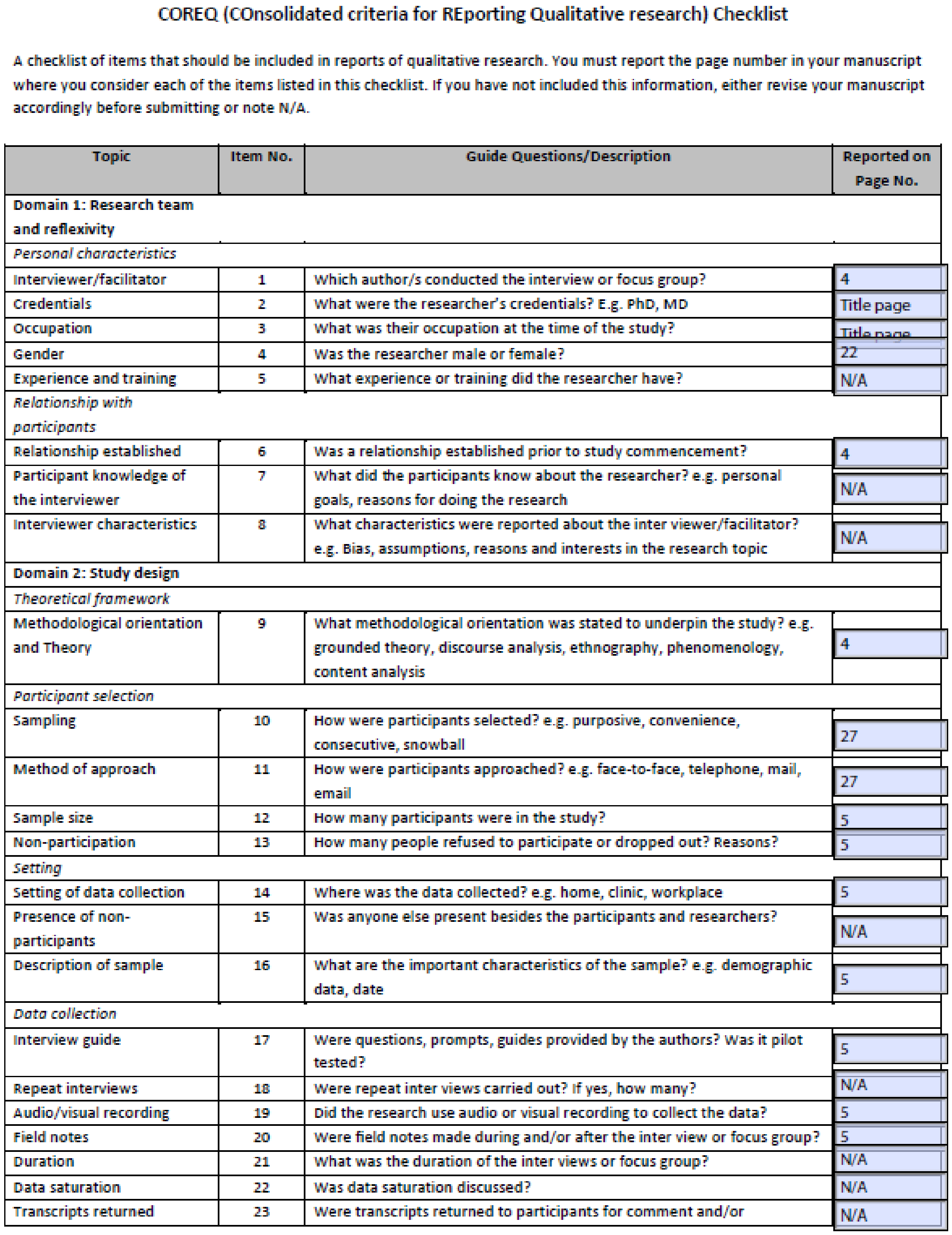


Friday 10th February

I Just had a really moving interview with a woman who is coping extremely well with her diagnosis. i found it quite emotional actually as she spoke about so many elements that would impact me as a woman if this happened to me - sexual function, identity as a woman etc.

However the most moving part was about her hopes for a good death, where her family slow down and spend time with her. To have that closeness and peace at the end was something I connected with. It made me think about how fearful others are around death and dying. Others fear can get in the way of having a good death.

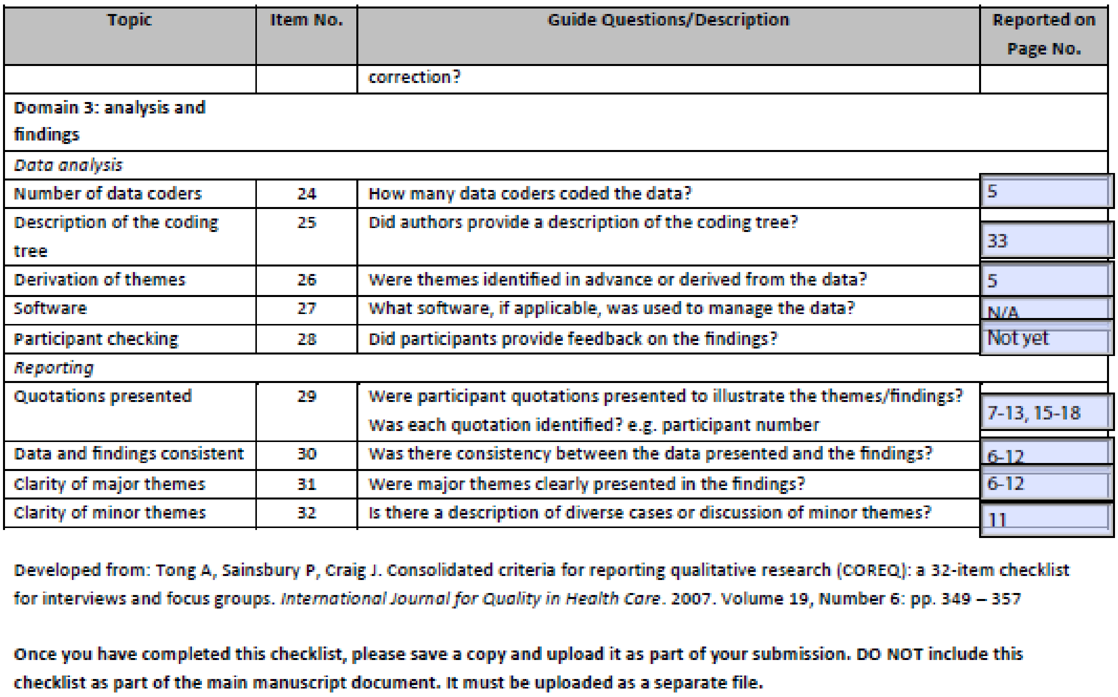
Appendix H COREQ



COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	4
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	Title page
Occupation	3	What was their occupation at the time of the study?	Title page
Gender	4	Was the researcher male or female?	22
Experience and training	5	What experience or training did the researcher have?	N/A
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	4
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	N/A
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	N/A
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	4
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	27
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	27
Sample size	12	How many participants were in the study?	5
Non-participation	13	How many people refused to participate or dropped out? Reasons?	5
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	5
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	N/A
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	5
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	5
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	N/A
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	5
Field notes	20	Were field notes made during and/or after the inter view or focus group?	5
Duration	21	What was the duration of the inter views or focus group?	N/A
Data saturation	22	Was data saturation discussed?	N/A
Transcripts returned	23	Were transcripts returned to participants for comment and/or	N/A



Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	5
Description of the coding tree	25	Did authors provide a description of the coding tree?	33
Derivation of themes	26	Were themes identified in advance or derived from the data?	5
Software	27	What software, if applicable, was used to manage the data?	N/A
Participant checking	28	Did participants provide feedback on the findings?	Not yet
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	7-13, 15-18
Data and findings consistent	30	Was there consistency between the data presented and the findings?	6-12
Clarity of major themes	31	Were major themes clearly presented in the findings?	6-12
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	11

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.

Tables

Table 1. Inclusion and Exclusion Criteria

Table 1. Inclusion and Exclusion Criteria

Inclusion Criteria	**Exclusion Criteria**
Adult population (18+) who have a cancer diagnosis	Interventional studies (e.g., medication trials) that do not have qualitative feedback.
Participants identify as LGBTQ+ or from a sexual minority	Participant is not the person with the diagnosis e.g. nurse, caregiver, family member
Qualitative research, including case reports, case series and focus groups	Studies in languages other than English.
Topic of paper is sex, intimacy and sexuality.	Topic of paper is not sex, intimacy and sexuality.
Mixed method research papers, where only qualitative data will be extracted	Quantitative research
Studies and/or intervention trials that have reported	Conference abstracts or any short articles with incomplete data presented

individual experiences in a qualitative response	
Peer-reviewed papers	Opinion articles
	Reviews, including non-systematic reviews
	Animal studies
	Letters, comments, editorials
	If it is not possible to identify quotes from LGBTQ+ population then study was excluded.

Table 2. CASP Quality Assessment

Table 2. CASP Quality Assessment

Reference	1	2	3	4	5	6	7	8	9	10	11	Rating
Doran, Williamsom, Wright & Beaver, 2018	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Identifies gaps in treatment guidelines and suggests solutions	100%
Hartman et al., 2014	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Offers a valuable research design by employing several interviews at different points of recovery to give a longitudinal perspective	100%
McConkey & Holborn, 2014	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Contributes to the literature of a population that is hard to reach and often underrepresented in research	100%
Ussher et al., 2013	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	This study adds to the literature about the importance of reconfiguring the definition of sex to include non-penetrative acts	100%
Ussher et al., 2017	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Valuable because it discusses sex and	100%

Reference	1	2	3	4	5	6	7	8	9	10	11	Rating
											intimacy in great depth	
Ussher, Rose, Perz, 2017	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Valuable because it builds on previous research and discusses what could be done in the future too	100%
Wasserug, Wrestle & Dowsett, 2017	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Valuable because it explains specific findings and takes ethics into consideration	100%
Brown & McElroy, 2018	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Confirmed theories and recommends a change in practice for healthcare providers	90%
Danemalm et al., 2019	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Met aims and offered unexpected insights, talks about further research needed	90%
Filiault, Drummond & Smith, 2008	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	This study indicates that more support is needed for GBM with prostate cancer around sex and intimacy	90%

Reference	1	2	3	4	5	6	7	8	9	10	11	Rating
Hoyt et al., 2017	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Findings bolster existing ideas and identified new areas of concern	90%
Lee et al., 2015	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Confirms previous research and provides base for further research	90%
Rose, Ussher & Perz, 2017	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	This study offers an interesting view into the relationship between gay and bisexual men and healthcare providers and offers suggestions on how to improve the relationship	90%
Thomas, Wooten & Robinson, 2013	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Valuable because there are clear findings and conclusions drawn about sex and intimacy after prostate cancer	90%
Ussher, Perz & Gilbert, 2014	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Valuable because it builds on previous research and has good ethics	90%

Reference	1	2	3	4	5	6	7	8	9	10	11	Rating
Ussher, Perz, Rose, Kellet & Dowsett, 2019	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Valuable because the results are broken up into many different sections which provide a lot of information	90%
Fergus, Gray & Fitch, 2002	Y	Y	Y	Y	Y	Y	N	N	Y	Y	This study offers a valuable contribution to the understanding that identity is impacted following Prostate Cancer and by widening the definition of what is sex, this can be limited.	80%
Gilbert et al., 2013	Y	Y	Y	Y	N	Y	N	Y	Y	Y	Offers valuable information surrounding the experience of sex and intimacy after any cancer, not just cancers of reproductive organs	80%
Hanley, Mireskandari & Juraskova, 2014	Y	Y	Y	N	Y	Y	N	Y	Y	Y	Highlights the need for early support for men diagnosed with PCa, including offering psycho-social support	80%

Reference	1	2	3	4	5	6	7	8	9	10	11	Rating
Mehta et al., 2019	Y	Y	Y	N	Y	Y	N	Y	Y	Y	By including the voices of patients in the development of a web-based support programme this study offers a valuable solution to supporting individuals with prostate cancer	80%
Rosser et al., 2016a	Y	Y	Y	N	Y	Y	N	Y	Y	Y	Offers a clear description of the impact that surgery has on GBM and how this can be minimised by HCP's actions	80%
Ussher, Perz & Gilbert, 2015	Y	Y	Y	Y	Y	Y	N	Y	N	Y	A mixed methods approach offers value by giving an insight to statistics relating to the experiences described in the qual report. Additional value for this study comes from the inclusion on non-coital sexual practices and a wider definition of sex.	80%

Reference	1	2	3	4	5	6	7	8	9	10	11	Rating
West et al., 2018	Y	Y	Y	Y	Y	Y	N	N	Y	Y	Valuable because it discusses sex and intimacy in great depth	80%
Whitney, 1989	Y	Y	Y	Y	Y	Y	Y	N	Y	N	Offers a thorough methodological framework however, findings are not reported in an easily accessible fashion.	80%
Margolies & Scout, 2013	Y	Y	N	N	Y	N	Y	Y	Y	Y	A valuable aspect of this report is that each theme is combined with a suggestion for teaching, making the research highly applicable to clinical practice	70%
Rosser et al., 2016b	Y	Y	Y	Y	N	Y	N	N	Y	Y	Builds a base for further research and identifies previously unknown issues specific to the research target	70%
Fish, 2019	N	Y	Y	N	Y	Y	N	Y	Y	N	This study highlights the need for specific LGBTQ+ support and recognises the	60%

Reference	1	2	3	4	5	6	7	8	9	10	11	Rating
											current lack of this within the UK.	
Kelly, 2004	Y	Y	Y	N	Y	Y	N	N	N	N	Recognition of the complexity around sexual function following prostate cancer, however limited discussion of the implications of this in relation to LGBTQ+ population included within study.	50%
Ussher, Perz, Rose, Dowsett & Latini, 2018	Y	Y	Y	Y	N	N	N	N	Y	N	Offers real life experiences from patients, however ethics could have been further discussed	50%
Chandler, 2020	N	Y	N	N	N	N	N	N	N	N	This individual case study offers a unique insight into the experience of one lesbian woman	10%
Harris, 2005	N	Y	N	N	N	N	N	N	N	N	This was a case study that offers a unique perspective into the experiences of one man	10%

Reference	1	2	3	4	5	6	7	8	9	10	11	Rating
Santillo, 2005	N	Y	N	N	N	N	N	N	N	N	This was a case study that offers a unique perspective into the experiences of one man	10%[2]

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1. Was there a clear statement of the aims of the research?
2. Is a qualitative methodology appropriate?
3. Was the research design appropriate to address the aims of the research?
4. Are the study's theoretical underpinnings clear, consistent and conceptually coherent?
5. Was the recruitment strategy appropriate to the aims of the research?
6. Was the data collected in a way that addressed the research issue?
7. Has the relationship between the researcher and participants been adequately considered?
8. Have ethical issues been taken into account?
9. Was the data analysis sufficiently rigorous?
10. Is there a clear statement of findings?
11. How valuable is the research?

Table 3. Study Characteristics

Table 3. Study Characteristics

Author(s)	Year of Publication	Title	Country of Origin	Research Design	Analysis	Participant Characteristics		Main themes
Brown & McElroy	2018	Unmet support needs of sexual and gender minority breast cancer survivors	United States of America (USA)	Mixed-methods	Thematic Analysis	Sexual and Gender Minority Patients	Breast Cancer	• Self-disclosure of SOGI to providers • Need for recognition and support of partners • Need for appropriate social supports for patients and partners • Impact of breast cancer treatment on intimate relationships
Chandler	2020	Lesbian, gay, bisexual and transgender	UK	Reflective case study	Personal reflections	One Lesbian Woman	Bowel Cancer	• Not applicable

Author(s)	**Year of Publication**	**Title**	**Country of Origin**	**Research Design**	**Analysis**	**Participant Characteristics**		**Main themes**
		(LGBT) inclusion in nursing services: a reflective case study from stoma care						
Danemalm et al.,	2019	Gay men's experiences of sexual changes after prostate cancer treatment—a qualitative study in Sweden	Sweden	Qualitative interviews	Thematic Analysis	11 Gay Men	Prostate Cancer	• Changes to the physical body • Elements related to a perceived sense of identity that incorporated sexuality and age • Issues precipitated from relationships and relational practices
Doran, Williamson, Wright and Beaver	2018	"It's not just about prostate cancer, it's about being a gay man": A qualitative study of gay men's experiences of	UK	Qualitative Interviews	Hermeneutic Phenomenology	12 Gay Men	Prostate Cancer	• Information needs • Relationship with healthcare providers • Support networks

Author(s)	**Year of Publication**	**Title**	**Country of Origin**	**Research Design**	**Analysis**	**Participant Characteristics**		**Main themes**
		healthcare provision in the UK						• Relationships
Fergus, Gray & Fitch	2002	Sexual Dysfunction and the Preservation of Manhood: Experiences of Men with Prostate Cancer	Canada	Qualitative Interviews	Grounded Theory	4 Gay Men	Prostate Cancer	• Enhancing the odds • Disrupting a core performance • Baring an invisible stigma • Effortful mechanical sex • Working around the loss
Filiault, Drummond & Smith	2008	Gay men and prostate cancer: voicing the concerns of a hidden population	Australia	Qualitative pilot study	Thematic Analysis	2 Gay Men	Prostate Cancer	• Concerns related to relationship changes and strains • Altered sexual function and associated implications for gay identity

Author(s)	**Year of Publication**	**Title**	**Country of Origin**	**Research Design**	**Analysis**	**Participant Characteristics**		**Main themes**
								• The perception of heteronormative attitudes within the healthcare field
Fish	2009	Intersecting identities of age, gender and sexual orientation in gay and bisexual men's narratives of prostate cancer	Unknown	Qualitative interviews	Thematic Analysis	7 Gay and Bisexual Men	Prostate Cancer	• Embodied sense of self • Managing the emotional rollercoaster of prostate cancer diagnosis and treatment • Intimate and sexual relationships following cancer
Gilbert et al.,	2013	Men's experiences of sexuality after cancer: a material discursive intra-psychic approach	Australia	Qualitative interviews	Thematic Analysis	5 Gay Men	Range of Cancers	• Material changes to sexuality: the effects of cancer treatment

Author(s)	**Year of Publication**	**Title**	**Country of Origin**	**Research Design**	**Analysis**	**Participant Characteristics**		**Main themes**
								• Discursive constructions of sexuality: erectile difficultly prevents ‘normal’ sex • Intra-psychic changes to men’s sexuality • Relational contexts of changes to sexuality
Hanley, Mireskandari & Juraskova	2014	The struggle towards ‘the New Normal’: a qualitative insight into psychosexual adjustment to prostate cancer	Australia	Qualitative Interviews	Thematic Analysis	1 Gay Man	Prostate Cancer	• Psychosexual impact • Communication and support • Integration Process
Harris	2005	Living with Prostate Cancer:	USA	Case study	Personal reflections	1 Gay Man	Prostate Cancer	Not applicable

Author(s)	Year of Publication	Title	Country of Origin	Research Design	Analysis	Participant Characteristics		Main themes
		One Gay Man's Experience						
Hartman et al.,	2014	Exploring Gay Couples' Experience With Sexual Dysfunction After Radical Prostatectomy: A Qualitative Study	Canada	Qualitative interviews	Interpretive Phenomenological Analysis	3 Gay couples	Prostate Cancer	• Acknowledging change in sexual experience • Accommodating change in sexual experience • Accepting change in sexual experience
Hoyt et al.,	2017	Gay men's experiences with prostate cancer: Implications for future research	USA	Qualitative Focus Groups	Content Analysis	11 Gay Men	Prostate Cancer	• Minority stress • Intimacy and sexuality concerns • Impact on life outlook • Healthcare experiences

Author(s)	Year of Publication	Title	Country of Origin	Research Design	Analysis	Participant Characteristics		Main themes
								• Social support and the gay community • Intersectional identities
Kelly	2004	Male sexuality in theory and practice	UK	Qualitative interviews and Ethnographic approach	Inductive & Ethnographic analysis	1 Gay Man	Prostate Cancer	• The body in balance: sexual function and decision making • Facing the reality of impotence or incontinence • Impotence: an etic view • Impotence: an emic view • The accommodation of impotence
Lee et al.,	2015	Impact of Prostate Cancer Treatment	Canada	Qualitative interviews	Thematic Analysis	16 Men-who-have-	Prostate Cancer	• Erectile, urinary, ejaculation and

Author(s)	**Year of Publication**	**Title**	**Country of Origin**	**Research Design**	**Analysis**	**Participant Characteristics**		**Main themes**
		on the Sexual Quality of Life for Men-Who-Have-Sex-with-Men				sex-with-men		orgasmic dysfunctions • Challenges to intimate relationships • Lack of MSM-specific oncological and psychosocial support for PCa survivorship
Margolies & Scout	2013	LGBT patient-centred outcomes	USA	Mixed-methods	Thematic Analysis	256 LGBT persons	Range of cancers	• Stigma plays a prominent role in LGBT healthcare • The local healthcare environment determines one's experience and is highly variable • Disclosure is often related to perceived safety

Author(s)	**Year of Publication**	**Title**	**Country of Origin**	**Research Design**	**Analysis**	**Participant Characteristics**		**Main themes**
								• Respecting LGBT patients means respecting their support teams • The pervasive expectation of gender conformity can be alienating • LGBT survivors need more culturally appropriate support and information
McConkey & Holborn	2014	Exploring the lived experience of gay men with prostate cancer: A phenomenological study	UK	Qualitative Interviews	Descriptive phenomenological approach	8 Gay Men	Prostate Cancer	• The experience of diagnosis, treatment decision making, and the impact of treatment

Author(s)	Year of Publication	Title	Country of Origin	Research Design	Analysis	Participant Characteristics		Main themes
								• Treatment related side effects • The experience of healthcare services • Sources of support and mean of coping
Mehta et al.	2019	What Patients and Partners Want in Interventions That Support Sexual Recovery After Prostate Cancer Treatment: An Exploratory Convergent Mixed Methods Study	USA	Focus groups and interviews	Thematic content analysis	3 Gay Men	Prostate Cancer	• Improved provider understanding of gay men's sexual identity and experiences
Rose, Ussher & Perz	2017	Let's talk about gay sex: gay and bisexual men's sexual communication with healthcare	Australia	Qualitative Interviews	Thematic Analysis	46 Gay and Bisexual Men	Prostate Cancer	• Cancer-centred care negates sexual needs • HCPs assume heterosexuality

Author(s)	**Year of Publication**	**Title**	**Country of Origin**	**Research Design**	**Analysis**	**Participant Characteristics**		**Main themes**
		professionals after prostate cancer						• Navigating sexual orientation disclosure • HCP responses to sexual orientation disclosure and requests for gay specific information
Rosser at al.,	2016b	The effects of radical prostatectomy on gay and bisexual men's mental health, sexual identity and relationships: qualitative results from the restore study	USA	Qualitative interviews	Content analysis and grounded theory approach	19 Gay and Bisexual Men	Prostate Cancer	• Emotional and mental health challenges • Sexual identity • Disclosure and relationship challenges

Author(s)	Year of Publication	Title	Country of Origin	Research Design	Analysis	Participant Characteristics		Main themes
Rosser et al.,	2016a	The effects of radical prostatectomy on gay and bisexual men's sexual functioning and behavior: qualitative results from the restore study	USA	Qualitative interviews	Thematic analysis and grounded theory appraoch	19 Gay and Bisexual Men	Prostate Cancer	• Anatomical changes & challenges • Behavioural Challenges • Changes across sexual response cycle
Santillo, V. M.	2005	Prostate Cancer and Treatment of a 33-year old gay man	USA	Case Study	Personal reflections	1 Gay Man	Prostate Cancer	• Not applicable
Thomas, Wooten & Robinson	2013	The experiences of gay and bisexual men diagnosed with prostate cancer: results from an online focus group	Australia	Online focus group	Thematic Analysis	10 Gay and Bisexual Men	Prostate Cancer	• Emotional response to PCa diagnosis • Accessing help and support • Impact of incontinence • Impact of sexual changes on identity

Author(s)	Year of Publication	Title	Country of Origin	Research Design	Analysis	Participant Characteristics		Main themes
								• Emotional state moderated by the ability to re-evaluate life • Changed sexual relationships • Finding the right healthcare professional • Current needs to improve quality of care • Experience of taking part in online focus group
Ussher et al.,	2017	Threat of Sexual Disqualification: The Consequences of Erectile Dysfunction and Other Sexual Changes for Gay	Australia	Qualitative Interviews	Thematic Analysis	46 Gay and Bisexual Men	Prostate Cancer	• Erectile dysfunction: “a defining moment in life” • Anal sensitivity and changed

Author(s)	**Year of Publication**	**Title**	**Country of Origin**	**Research Design**	**Analysis**	**Participant Characteristics**	**Main themes**
		and Bisexual Men With Prostate Cancer					sexual roles: “It’s a very sensitive part of a man’s body” • Loss of sexual pleasure and libido: “it’s a profound change of identity” • Non-ejaculatory Orgasms: Loss of “an essential part of sexual enjoyment to both partners” • Urinary incontinence and climacturia: “You lose your body management” • Reduction in penis size: “it’s a blow to the ego”

Author(s)	Year of Publication	Title	Country of Origin	Research Design	Analysis	Participant Characteristics		Main themes
								• Health care professional support for gay sexual concerns: “we’re usually not considered”
Ussher, Perz & Gilbert	2014	Women's Sexuality after Cancer: A Qualitative Analysis of Sexual Changes and Renegotiation	Australia	Qualitative interviews	Thematic Analysis	4 non-heterosexual, 3 lesbian, 1 polysexual person	Range of cancers	• Changes to sexuality after cancer • Renegotiating sex
Ussher, Perz & Gilbert	2015	Perceived causes and consequences of sexual changes after cancer for women and men: a mixed methods study	Australia	Mixed-methods	Thematic Analysis	15 non-heterosexual women, 9 non-heterosexual mean	Range of cancers	• Material changes to the body • Intrapsychic factors • Body Image concerns • Relationship context

Author(s)	Year of Publication	Title	Country of Origin	Research Design	Analysis	Participant Characteristics		Main themes
Ussher, Perz, Gilbert, Wong & Hobbs	2013	Renegotiating Sex and Intimacy After Cancer: Resisting the Coital Imperative	Australia	Qualitative Interviews	Thematic Analysis	7 Gay Men, 3 Lesbians, and 1 polysexual person	Range of cancers	• Resisting the coital imperative: redefining ‘sex’ • Resisting the coital imperative: embracing intimacy • Adopting the coital imperative: refiguring the body though techno-medicine.
Ussher, Perz, Rose, Dowsett & Latini	2018	Threat to gay identity and sexual relationships: The consequences of Prostate Cancer Treatment for Gay and Bisexual men	Australia	Qualitative interviews	Thematic Analysis	46 Gay and Bisexual Men	Prostate Cancer	• Erectile dysfunction: “it’s a big thing for a man not, being able to have erections” • Reduction in penis size: “it’s a blow to the ego” • Effect of prostate cancer treatment on GBM sexual relationships:

Author(s)	**Year of Publication**	**Title**	**Country of Origin**	**Research Design**	**Analysis**	**Participant Characteristics**		**Main themes**
								“disqualification in the sexual experience” • Absence of ejaculate: “it’s more difficult to talk about than erection issues” • Urinary incontinence and climacturia: “you loose your body management”
Ussher, Perz, Rose, Kellet & Dowsett	2019	Sexual Rehabilitation After Prostate Cancer Through Assistive Aids: A Comparison of Gay/Bisexual and Heterosexual Men	Australia	Qualitative interviews and open-ended questions on survey	Thematic Analysis	124 Gay and Bisexual Men	Prostate Cancer	• “there is no way I would have functioned without it”: Successful Sexual Rehabilitation • The artificiality of an Assisted Erection

Author(s)	**Year of Publication**	**Title**	**Country of Origin**	**Research Design**	**Analysis**	**Participant Characteristics**		**Main themes**
								• Loss of sexual spontaneity • Physical side effects • Medical assistive aids do not work • Cost of assistive aids • Absence of information and support
Ussher, Rose & Perz	2017	Mastery, Isolation, or Acceptance: Gay and Bisexual Men's Construction of Aging in the Context of Sexual Embodiment After Prostate Cancer	Australia	Qualitative interviews	Thematic Decomposition	46 Gay and Bisexual Men	Prostate Cancer	• "Mastering youth" • "The lonely old recluse" • "Accepting embodied ageing"

Author(s)	**Year of Publication**	**Title**	**Country of Origin**	**Research Design**	**Analysis**	**Participant Characteristics**		**Main themes**
Wassersug, Wrestle & Dowsett	2017	Men's Sexual and Relational Adaptations to Erectile Dysfunction After Prostate Cancer Treatment	Australia	Open-ended question on survey	Thematic Analysis	96 Non-heterosexual men	Prostate Cancer	• Recovery of erectile function • Reframing sexual practices • The importance of partners • Exploring anal sex • The use of masturbation
West et al.	2018	The effects of radiation therapy for prostate cancer on gay and bisexual men’s experience of mental health, sexual functioning and behaviour, sexual identity and relationships	USA	Qualitative interviews	Thematic Analysis and grounded theory approaches	25 Gay and Bisexual Men	Prostate Cancer	• Anatomical changes • Changes in ejaculate • Behavioural changes • Sexual response changes

Author(s)	Year of Publication	Title	Country of Origin	Research Design	Analysis	Participant Characteristics		Main themes
								• Emotional reaction to diagnosis • Emotional reaction to going through treatment • Sex-specific situational anxiety • Change in sexual confidence
Whitney	1989	The impact of breast cancer and breast loss from mastectomy on the sexuality of single lesbian and heterosexual women	USA	Qualitative Interview	Grounded Theory	1 Lesbian Woman	Breast Cancer	• Recognising interest in being sexual • Asserting self socially/sexually • Telling others about having a mastectomy and cancer • Showing body to others

Author(s)	Year of Publication	Title	Country of Origin	Research Design	Analysis	Participant Characteristics	Main themes
							• Being sexual with another person • Being in a relationship

Table 4. GRADE CER-Qual Assessment

Table 4. GRADE CER-Qual Assessment

#	Summarised review finding	GRADE-CERQual Assessment of confidence	Explanation of GRADE-CERQual Assessment	References
1	Distress is due to disruption to sexual identity	High confidence	Minor concerns regarding methodological limitations, No/Very minor concerns regarding coherence, No/Very minor concerns regarding adequacy, and No/Very minor concerns regarding relevance	McConkey & Holborn 2018; Santillo 2005; Rose et al. 2017; Thomas et al. 2013; Filiault et al. 2008; Fish 2019; Whitney 1988; Harris 2005; Kelly 2004; Rosser et al. 2016; Ussher et al. 2015; Simon Rosser et al. 2016; Mehta et al. 2019; Ussher et al. 2019; Hoyt et al. 2020; Ussher et al. 2014; Lee et al. 2015; Ussher et al. 2018; Ussher et al. 2017; Doran et al. 2018; Danemalm Jägervall et al. 2019; Hartman et al. 2014; West et al. 2018; Fergus et al. 2002; Gilbert et al. 2013; Ussher et al. 2017; Wassersug et al. 2017;
2	Communication with others inform how sex after cancer is experienced	High confidence	Minor concerns regarding methodological limitations, No/Very minor concerns regarding coherence, No/Very minor	Margolies & Scout 2013; McConkey & Holborn 2018; Whitney 1988; Harris 2005; Rosser et al. 2016; Ussher et al. 2015;

#	Summarised review finding	GRADE-CERQual Assessment of confidence	Explanation of GRADE-CERQual Assessment	References
			concerns regarding adequacy, and No/Very minor concerns regarding relevance	Simon Rosser et al. 2016; Mehta et al. 2019; Ussher et al. 2019; Hoyt et al. 2020; Ussher et al. 2014; Lee et al. 2015; Ussher et al. 2018; Ussher et al. 2017; Doran et al. 2018; Hartman et al. 2014; West et al. 2018; Fergus et al. 2002; Ussher et al. 2017;
3	Moving away from penetrative sexual practices	Moderate confidence	Minor concerns regarding methodological limitations, Minor concerns regarding coherence, No/Very minor concerns regarding adequacy, and No/Very minor concerns regarding relevance	Margolies & Scout 2013; McConkey & Holborn 2018; Santillo 2005; Brown & McElroy 2018; Rose et al. 2017; Thomas et al. 2013; Filiault et al. 2008; Fish 2019; Whitney 1988; Harris 2005; Kelly 2004; Rosser et al. 2016; Ussher et al. 2015; Simon Rosser et al. 2016; Ussher et al. 2019; Hoyt et al. 2020; Ussher et al. 2014; Lee et al. 2015; Ussher et al. 2018; Ussher et al. 2017; Doran et al. 2018; Danemalm Jägervall et al. 2019; Hartman et al. 2014; West et al. 2018; Fergus et al. 2002; Gilbert et al. 2013; Ussher et al. 2017;

#	Summarised review finding	GRADE-CERQual Assessment of confidence	Explanation of GRADE-CERQual Assessment	References
				Wassersug et al. 2017; Hanly et al. 2014;
4	Positioning of self in relation to sex determines acceptance of sexual dysfunction	Moderate confidence	Minor concerns regarding methodological limitations, Minor concerns regarding coherence, No/Very minor concerns regarding adequacy, and No/Very minor concerns regarding relevance	McConkey & Holborn 2018; Santillo 2005; Thomas et al. 2013; Filiault et al. 2008; Fish 2019; Harris 2005; Rosser et al. 2016; Ussher et al. 2015; Simon Rosser et al. 2016; Hoyt et al. 2020; Lee et al. 2015; Ussher et al. 2018; Ussher et al. 2017; Doran et al. 2018; Danemalm Jägervall et al. 2019; Hartman et al. 2014; Fergus et al. 2002; Gilbert et al. 2013; Ussher et al. 2017; Wassersug et al. 2017;
5	Experience of sex and intimacy varies depending on relationship status	High confidence	Minor concerns regarding methodological limitations, No/Very minor concerns regarding coherence, No/Very minor concerns regarding adequacy, and No/Very minor concerns regarding relevance	McConkey & Holborn 2018; Filiault et al. 2008; Fish 2019; Rosser et al. 2016; Simon Rosser et al. 2016; Lee et al. 2015; Ussher et al. 2018; Hartman et al. 2014; Gilbert et al. 2013;

Table 5. Patient Experiences and the DPM

Table 5. Patient Experiences and the DPM

Model Components		**Interviews**	**Quotes**	**Key Points**	**Example Quote**
Loss Oriented	Positive Reappraisal	11	38	Participants identified aspects of the loss and then reappraised them in a positive manner Generally, spoke to the idea of making the most of the time you have left and developing a positive attitude	*"I just thought well, there's two ways of looking at this. I can either waste another day. Of feeling down, depressed and hopeless. Or. I can be grateful for the things I can do, so that's how I've dealt with it really. That's that's my attitude towards it" (P13)*
	Revised Constructive Goals	11	25	Participants made adjustments to their lives to accommodate changes needed to manage diagnosis Often descriptions of acknowledging need for support from others	*"Yeah, I wish I'd gone sooner [to support group]. Especially the way I was feeling at the time because it was only when I started to feel really down. And I I realized that speaking to people. In a similar situation, which was good for me." (P11)*
	Positive Event Interpretation	9	21	Events which stem from the diagnosis are interpreted to have a positive impact Recognition of closer relationships forming as a result of limited left time together	*"But he's he even he's become quite, you know, I love you, mum. You know things that he would never have said before he. I know he meant it. But he didn't. He just never said it" (P6)*

	Expressing Positive Affect	3	5	Expression of positive emotions in relation to the loss Participants expressed positive emotions around the changes in their relationships and new ways of living	*"I think it's. I think it's enhanced all my relationships, really all the ones that that matter definitely. And this made me a better person. Absolutely" (P14)*
	Rumination and Wishful Thinking	13	50	Often linked to the initial point of diagnosis and period of time shortly afterwards Rumination was often around 'why me?' and how long it had been since primary diagnosis	*"It was a shock because I'd gone so long before my initial breast cancer, which was into 1992. So to find out some 18 years later" (P6)*
	Revised Unconstructive Goals	6	13	Often linked to not listening to new physical limitations	*"I don't always stop when I should and I get very tired." (P1)*
	Negative Event Interpretation	14	141	Most often associated with the point of diagnosis and period of time shortly afterwards Descriptions of the assumptions that they would die imminently	*"Well, I suppose you don't think it's gonna happen to you, do you?" (P1)*
	Ventilating Dysphoria	13	63	Descriptions of strong negative emotions was most commonly spoken about at the point of diagnosis and period of time shortly afterwards	*"It's been like, running into a brick wall, or like a train suddenly having no, no more track to to go on. You know your life stops" (P4)*
Restoration Oriented	Positive Reappraisal	12	32	Often connected with how participants viewed themselves	*"I'm very positive" (P5)*

			as positive or living well with cancer	
Revised Constructive Goals	14	87	Distraction was often discussed as something that enabled them to move forwards with their life	*"Try to distract myself, really with a hobby or. Talk to family member. You know that often lifts me out of it." (P13)*
Positive Event Interpretation	12	24	Participants recognised the increase in available treatments and interpreted this as positive for them or for cancer patients as a whole Some discussion around cancer as a 'lifelong condition' rather than terminal diagnosis	*"There's so much hope out there that this is going to become a lifelong condition rather than a terminal diagnosis. And as long as I keep that in my head at this moment, and I'm living well, that's all that matters to me" (P10)*
Expressing Positive Affect	6	10	Some participants connected this to spirituality and being able to express emotions in a church.	*"All I know is when I've been into a church or cathedral. Sort of quite emotional… That, uh, dunno almost a feeling of belonging." (P7)*
Rumination and Wishful Thinking	1	1	Participant spoke about hopes for her death and how she would like family to show up for her	*"That's the bit I fear is that everyone's gonna be rushing around because that's their way of coping. And actually, all I would probably want is just to, just to be held and to be sat with and do all those calm and quiet things that are really, really important. We don't make enough time for each other, and I think that's my biggest fear, is not having that quality time at the end with my people I love." (P4)*
Revised Unconstructive Goals	11	40	Often centred around making goals with other people in mind and not considering their adjusted needs	*"I've gotta keep strong for everybody else." (P3)*
Negative Event Interpretation	7	12	Looking too far into the future was particularly challenging	*"It's really hard because I (.) Since having been diagnosed. Umm, I can't look too far ahead. You know, I and I people*

					say to me oh oh, what about next year? Do you fancy doing this… I was all (.) Let's just you know what I mean. Well, yeah. Yeah. Ask me with a few months to go and then I can, you know, think about it. So I'm really struggle with looking at that, you know" (P9)
	Ventilating Dysphoria	0	0	Not found in this study	*N/A*
Oscillation		13	56	Oscillation was influenced by physical health status Scans had an impact on how someone oscillated between processes	*"For the first few years, you're in (.) cancer is your life, and then the bubble is your family and your friends and and that's your have fun and you manage to just get into that bubble for a few days a week or a few days a month and then you'll come out again now (.) my life is my life and then cancers, this bubble that I pop into like today, or when I go for treatment or when I have to talk to people about it. And then I come out of the bubble. So that's what helps me." (P14)*

Table 6. Patient Experiences and the RM

Table 6. Patient Experiences and the RM

Model Components		Interviews	Quotes	Key Points	Example Quotes
Processes	Comprehension	14	78	Most often spoken about at the point of diagnosis and period of time shortly after Attempts to understand what the diagnosis means for them ‘how long do I have left?’ High levels of negative emotion described during comprehension	*“I think people were more concerned for me than I probably was aware of. I think the severity of it (.) was (.) much bigger than I sort of realized” (P4)*
	Creative Adaptation	14	55	Ways in which people started to make adaptations in the lives to encompass their diagnosis Humour was used by some participants to minimise the negative meaning of cancer Some discussion around making plans for the ways in which they would be remembered once they have died (e.g. funeral planning and mementos for family)	*“We laugh about it. Even my daughter. We laugh about it. You know, until I'm actually told (.) that I've only got a short time at the moment we laugh about it and we we deal with it that way. A lot of jokes” (P2)*

	Reintegration	12	53	Integrated sense of cancer diagnosis and self Descriptions around it being ok to have cancer and 'living with cancer' rather than positioning of self as 'having cancer'	*"OK, it's OK to have cancer. It's not. It is not the end of the world. It's not. You don't have to be. Anyone else but you. So for them being you know (.) Normal. I've still got normal life. Still got a good life" (P14)*
Moderating factors	Characteristics of the loss	9	28	Descriptions around how cancer has impacted them, for example needing a mastectomy, lumpectomy or other treatment Recognition of the impact of cancer on identity as a woman and sexual being.	*"I only had a lumpectomy, but still, you know, there are wonky and I got a bloody great scar. I've got a port in my chest as well, which I couldn't be without cause I can have my drugs through that" (P9)*
	Clinical and Demographic characteristics	14	68	Descriptions of demographic characteristics such as being a mother, being a wife or financial status	*"Thankfully myself and my partner are in a good financial position that we can go on holiday quite a lot. So there's always a little holiday somewhere to keep looking forward to. Yeah, you know and just get on with it" (P5)*
	Social Support	14	119	Many descriptions of the ways in which others have supported them, often close family members Several people recognised the support of a local psychologist.	*"I found everybody's being wonderful. All my friends, family, everybody has been great. There have been people… Who have shopped for us. Come round to us. I can't. I can't fault all the support I've had." (P1)*
	Psychological Resilience	6	10	Some participants identified that they have high levels of resilience	*"OK, so from the first diagnosis it was ohh. 'Ohh you know' {surprised voice}. They tell me what (.) Operations I had had to have and then what treatment?*

				and this helped them manage the hardships they faced. Often more general descriptions of being ‘strong’ or ‘positive’.	*And I just, I just got on with it. Just got on with it. Umm. Resilience, I think, came into it. I think that's the word resilient” (P11)*
	Beliefs about death and dying	9	23	Experience of other deaths interpreted as either good or bad. Expressed desires for a good death, often including descriptions of wanting to be free of pain	*“Yeah, I mean. I've experienced in other people good deaths. I've experienced bad deaths. And. One in particular, and it was just because it was badly organized. And that worries me. So I'm sort of fearful for that, really not just with me, but with any for anybody. I just hope that everybody can have a good experience or. A peaceful experience” (P13)*
Oscillation		13	56	Oscillation was influenced by physical health status Scans had an impact on how someone oscillated between processes	*“If it's bad, I don't tend to fight it. I just sort of have to go with it and the generally put myself in bed. Have a good old cry. And. I know the next day I will be totally fine” (P7)*

Figures

Figure 1. PRISMA Flowchart

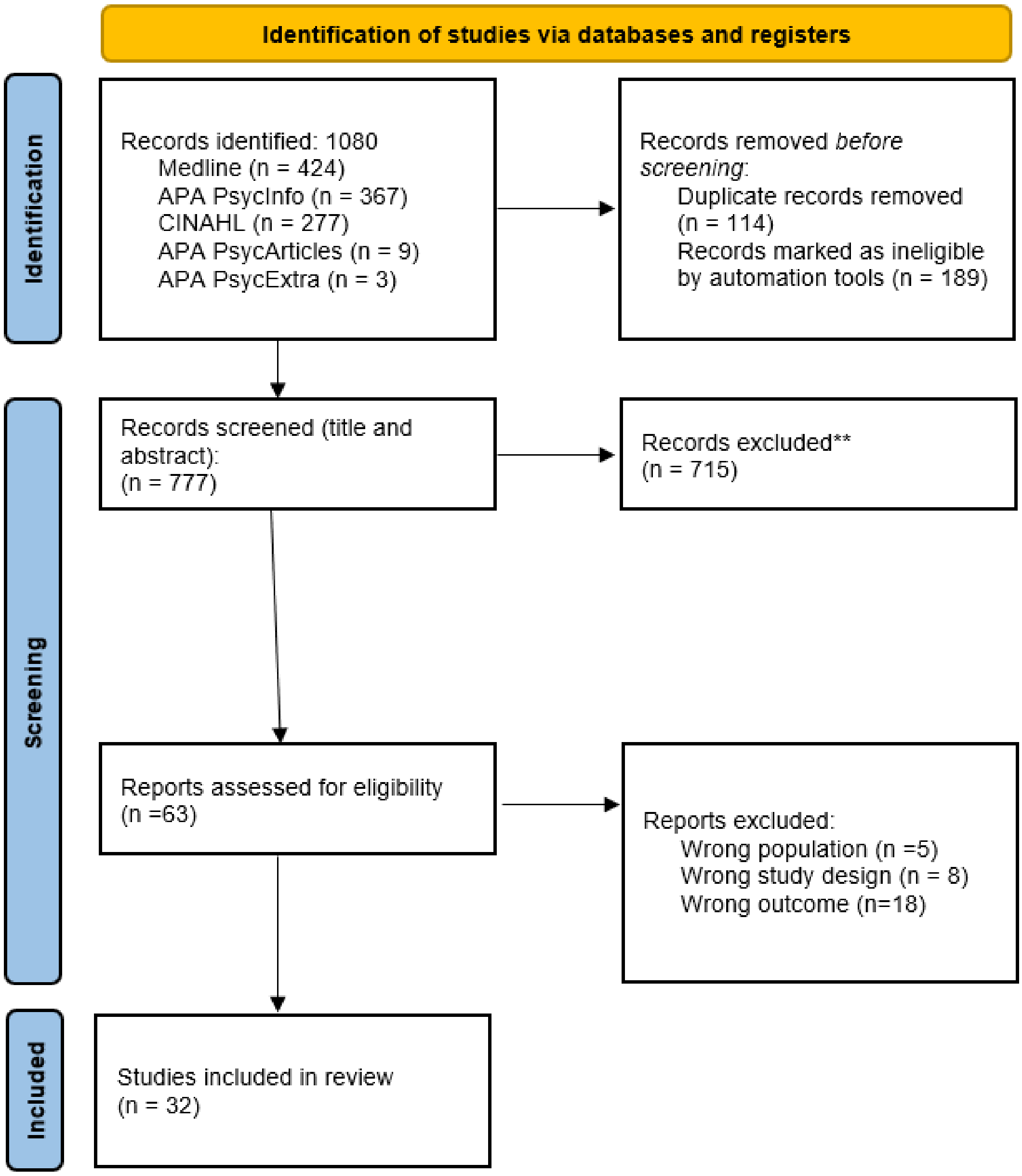

Figure 1. Prisma Flowchart

Figure 2. Thematic Map

Figures

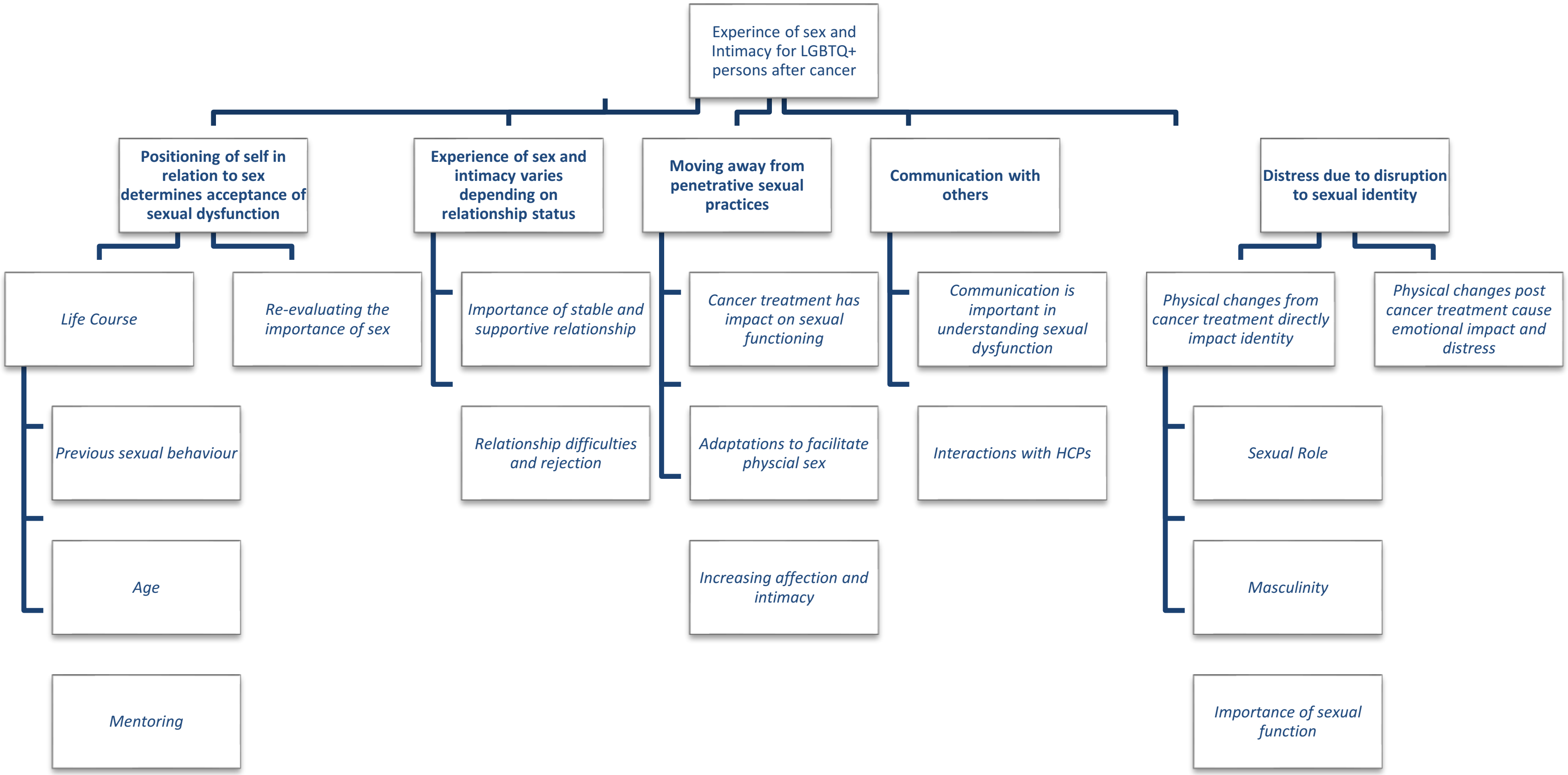

Figure 2. Thematic Map

Figure 3. Amalgamation of the DPM and RM

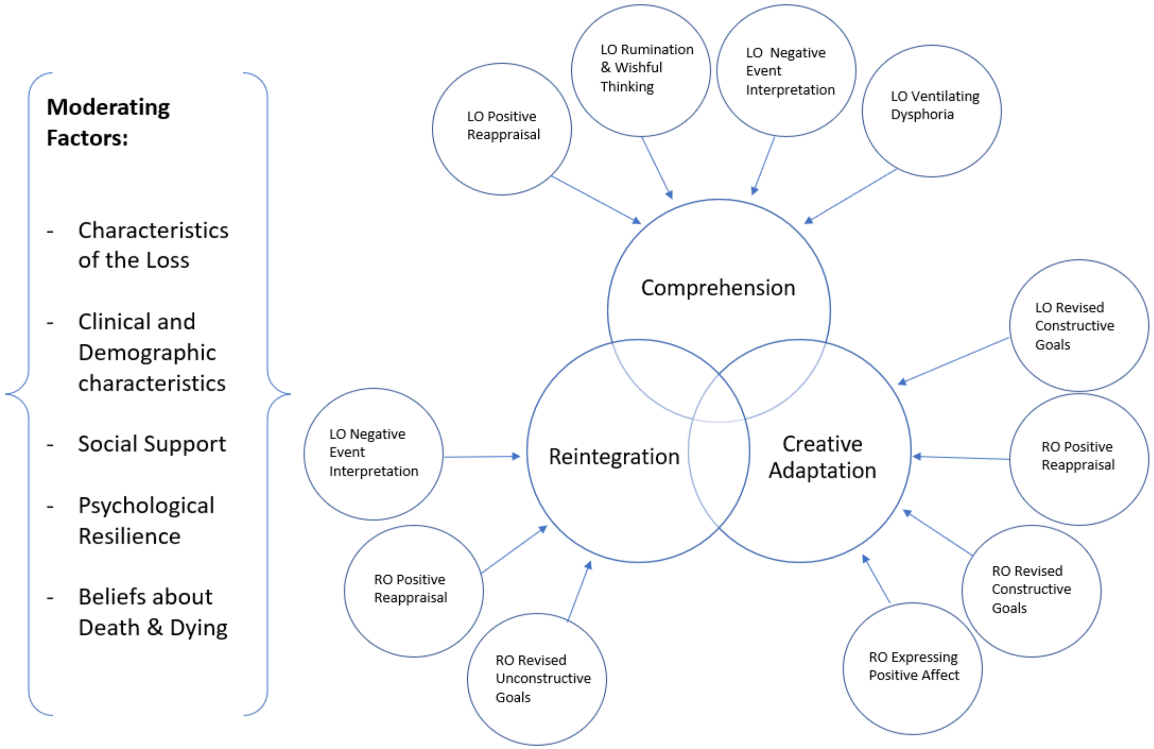

Figure 3. Amalgamation of the DPM and RM

Figures

[3]

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[3] LO = Loss-Oriented
RO = Restoration-Oriented

Glossary of Terms

Positive Reappraisal	*Where a negative event or action is re-evaluated and positive meaning is found by the observer*
Revised Constructive Goals	*Where goals for life are revised in a manner that is helpful or constructive to the person*
Positive Event Interpretation	*Where an event or action is interpreted positively by the observer.*
Expressing Positive Affect	*The expression of positive emotions*
Rumination	*Where a person, thinks about the same thought or subject continuously and is unable to move on from the thought*
Revised Unconstructive Goals	*Where goals for life are revised in a manner that is unhelpful or unconstructive to the person*
Negative Event Interpretation	*Where an event or action is interpreted negatively by the observer*
Ventilating dysphoria	*The expression of strong negative emotions*
Comprehension	*The process of coming to understand an event, or piece of information*
Creative Adaptation	*Creative ways in which a person adapts their life to incorporate a terminal diagnosis*
Reintegration	*Where a person has understood their diagnosis and incorporated this into their new ways of living and understanding of themselves*

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