

Sexual minority experiences of cancer care : a systematic review

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Review

Sexual minority experiences of cancer care: A systematic review

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ABSTRACT

There is a lack of published evidence from within the UK examining the needs of LGB cancer patients. A full systematic review of the worldwide literature was carried out with the aim to ascertain the experiences of sexual minority cancer patients and identify specific needs required.

Key databases were searched with a variety of terms relating to the sexual minority cancer experience. Suitable literature was reviewed and references within all articles were searched to ensure as inclusive a review as possible. Articles were subject to critical appraisal and scoring using The Support Unit for Research Evidence (SURE 2013) critical appraisal tools to assess eligibility for inclusion within the review. Twenty-five articles were selected for inclusion and were analysed. The papers were categorised into the emerging themes from the literature: Experiences of care ($n=6$), Coping and Wellbeing ($n=6$), Emotional Support ($n=4$), Body Image ($n=3$), and Sexual Function ($n=6$). The data extraction revealed contrasting views and experiences of LGB individuals' experience of cancer care. Lesbian and gay individuals have different perspectives of cancer care and needs from heterosexuals. Discriminatory attitudes were found to be present in many studies as well as inequalities and gaps within care and support.

There is evidence that supports the development of sexual minority specific cancer support groups. Further research of sexual minorities affected by cancer in the UK should be carried out to increase the evidence base and better identify the needs in this cultural group.

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1. Introduction

Her Majesties Treasury Department estimates that 5–7% of the population in the UK are lesbian, gay or bisexual, which equates to approximately 3.6 million people [1]. Based on Cancer Research UK (2014) figures approximately one third of these individuals will develop cancer at some point in their lives [2]. Reports released by Macmillan (2013) and Cancer Research UK (2008) discuss the increased need of Lesbian Gay and Bisexual (LGB) individuals affected by cancer to have specialised support services [3,4]. Progress has started to be made with the recent introduction of gay cancer support groups in the UK and the formation of organisations such as the LGB cancer alliance [5,6]. There is however a lack of published evidence from within the UK examining the needs of LGB cancer patients and as such the full extent of their needs has yet to be fully determined. Therefore, the aim of this paper is to carry out a full systematic review of the worldwide literature to ascertain the experiences of sexual minority cancer patients and identify any specific needs required.

2. Objectives

This project sought to carry out a thematic analysis encompassing the worldwide literature base to evaluate and assess if the development of specialised sexual minority cancer support services is required, and to obtain a perspective of sexual minority experiences of cancer care.

For the purpose of this article the term sexual minority will be used as it encompasses all those that identify as having a sexual orientation whereby they engage in sexual activity with those that are of the same sex.

The following objectives were established for this review.

1. To determine the psychological and emotional needs of sexual minority individuals affected by cancer.
2. To determine the factors that could influence the quality of life of sexual minority individuals affected by cancer.
3. To determine if there is an evidence base behind developing sexual minority specific cancer support services.
4. To critically evaluate the evidence uncovered in the review and assess its merit to influence services.

3. Methodology

This review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) methodology to increase the rigour of the work. PRISMA is a widely recognised evidence-based set of items for reporting in systematic reviews and meta-analyses for academic journals and as such was deemed an appropriate methodology for this study, ensuring the transparent and complete reporting of the results [7].

The search strategy included the initial identification of peer review articles following a broad-ranging literature search carried out on several health and social science databases. These included The Cochrane Library, Medline, Embase, CINAHL, AMED, Science Direct and ASSIA databases. Key terms were identified that related to LGB health and oncology, then Boolean operators were applied (Table 1). Articles were reviewed and selected on the basis of complying with inclusion and exclusion criteria:-

- English language only sources of literature were selected as there was no means of translating other languages.
- Peer reviewed only publications were included to ensure the academic rigour required of this review.

Table 1

List of search terms used.

Gay OR Lesbian OR Bisexual OR Bisexuality OR Homosexual OR Homosexuality OR LGB OR LGBT OR GLBT OR BLAG OR LGBTQ OR Sexual Minorities OR Sexual Minority Men OR SMM OR Sexual Minority Women OR SMW OR Sexual Orientation OR sex orientation OR Men-who-have-sex-with-men OR women-who-have-sex-with-women
AND
Cancer OR Neoplasm OR Malignancy OR Malignant cells OR Oncology OR Tumour OR Radiotherapy OR Chemotherapy
AND
Survivorship OR Experiences OR Quality of Life OR QOL OR Outcomes OR anxiety OR depression OR Support OR Social Support OR Discrimination OR psychological inhibition OR psychological OR psychosexual OR Psychosocial OR psycho-sexual OR Psycho-social OR distress OR perceived stress OR Stress OR health-services accessibility OR needs assessment OR psychosocial adjustment OR physician-patient relations OR Doctor-Patient relations OR sexual Function OR body Image OR stigma

- Articles had to be published within the last ten years to ensure that only current or recent experiences of sexual minority care were taken into account.
- Papers related to targeting screening programmes, HPV vaccination and health awareness in the LGB community were excluded as were not the primary focus of this review.
- Other Meta-Analysis or systematic Cochrane reviews were excluded from this study, but hand searching of reference within these articles was carried out to identify other potential primary studies for inclusion.

Articles were then subject to critical appraisal and scoring to assess their eligibility to be included within the study. The Support Unit for Research Evidence (SURE 2013) critical appraisal tool was determined to be the most appropriate tool to use in the evaluation of the articles given that the studies for review were qualitative in nature [8]. Once suitable articles were appraised they were then analysed and coded by subject matter to classify emergent themes within the literature, these themes are then appraised in this paper.

4. Results

Two-hundred-and-Thirty articles from a variety of publications were uncovered as part of this review. Fig. 1 indicates the number of included articles in the review from the hits identified from the database searches. One-Hundred-and-Thirty were deemed worthy of analysis and were screened using eligibility criteria leaving Forty-seven research articles to analyse. The articles were then reviewed and fifteen were rejected because they related to targeting health promotional programmes and cancer screening programs focused on LGB individuals. Thirty-two studies remained and were then analysed for this paper using the SURE critical appraisal tool. Twenty-five articles were selected for inclusion (Table 2). No minimum score for the SURE tool was established, but seven articles were rejected as they were replicated studies and such demonstrated duplicate results.

The data extraction was carried out and revealed contrasting views and experiences of LGB individuals' experience of cancer care and this formed the body of the discussion of this paper. The papers were categorised into the emerging themes from the literature: Experiences of care ($n=6$), Coping and Wellbeing ($n=6$), Emotional Support ($n=4$), Body Image ($n=3$), and Sexual Function ($n=6$), the groupings then formulated a structure to the discussion of LGB experiences of cancer care for this review.

Studies methodologies were a combination of online and postal surveys ($n=8$), face-to-face or telephone based semi structured interviews ($n=15$), or focus groups ($n=2$). Of the articles uncovered, all were found to be qualitative in nature and provided an

Table 2
Summary results table of included studies.

Citation	Authors	Country	Purpose/aims	Methodology	Cohort size	Key findings	Coded theme
[10]	Barnoff et al.	Canada	Research focused on "heterosexism" and strategies to counter it in a health care context.	SMW were interviewed face-to-face about their experiences of cancer diagnosis, treatment, health care and social support, and their feelings and perceptions about shifts in identity, body, sexuality and relationships	26 SMW with Breast or gynaecological cancer	Findings revealed a need to transform the ways in which cancer support services are currently provided in order to make them welcoming to SMW. Respondents to the interviews had poor experiences of health care, suffered discrimination and found a heterosexist approach to care	Experiences of care
[12]	Sinding et al.	Canada	This qualitative study examines "what is lesbian" about lesbians' experiences of cancer and cancer care.	26 SMW interviewed about their experiences of cancer diagnosis, treatment, and support, and their feelings and perceptions about shifts in identity, body, sexuality, and relationships.	26 SMW with cancer	A minority of participants were targeted, denied standard care, or had aspects of their identity and social context relevant to cancer care dismissed. The majority commented on the lack of attention to lesbian realities in psychosocial support. Heterosexism appears to prompt strategic efforts to avoid homophobia and also appears to foster gratitude for equitable care.	Experiences of care
[13]	Sinding et al.	Canada	A study examining the Canadian lesbians' experiences with breast or gynaecological cancer and their care.	Semi-structured face-to-face and telephone interview of themes related to participants' experiences of treatment, cancer care, and support.	26 SMW with either breast or gynaecological cancer	Findings reveal the complex and contradictory ways that the lesbian community unfolds in the lives of SMW with cancer. Most participants experienced robust and competent community support; participants also reported instances of isolation and disconnection linked to fear of cancer, homophobia in the broader community, and patterns of exclusion within lesbian communities.	Experiences of care
[15]	Boehmer and Case	USA	The study was undertaken to describe the disclosure of sexual orientation among SMW with breast carcinoma.	Individual semi-structured interviews were conducted with a sample of SMW with a diagnosis of breast carcinoma.	39 SMW with breast carcinoma	Sexual minority patient-provider relationships were marked by apprehension, and providers did not inquire about sexual orientation. The majority of women actively disclosed their sexual orientation, whereas 11 women passively refused disclosure.	Experience of care
[20]	Jabson et al.	USA	Cross sectional study examining SMW perceptions of discrimination as one of the multiple facets of the breast cancer survivorship process.	Sixty-eight purposefully sampled sexual minority breast cancer survivors completed assessments of quality of life, perceived discrimination, social support and stress via an online survey	68 SMW breast cancer survivors	Statistical analyses pointed towards perceived discrimination and social support as important indicators for predicting SMW's quality of life.	Experience of care
[22]	Katz	Canada	A study to investigate the cancer experience of SMM and SMW.	In-depth, face-to-face interviews were conducted with a semi-structured interview guide.	3 SMM and 4 SMW with various cancer.	Overt homophobia or discrimination within the cancer care system was not experienced by this study's participants. Participants valued the central role of their partners in coping with cancer. Some gaps in the cancer care system relating to support groups were identified.	Experiences of care/emotional support/body image

Table 2 (Continued)

Citation	Authors	County	Purpose/aims	Methodology	Cohort size	Key findings	Coded theme
[24]	Thomas et al.	Australia	A study examining the experiences of SMM diagnosed with prostate cancer	An online focus group was conducted over a 4-week period with participants responding to a range of discussion questions concerning their experiences following a prostate cancer diagnosis.	10 SMM prostate cancer survivors.	Some participants gained a positive perspective and adopted a sense of empowerment, some spoke about emotional responses to a diagnosis of prostate cancer, accessing help and support, the impact of incontinence, the impact of sexual changes on identity, a re-evaluation of life, changed sexual relationships, the need to find the most suitable healthcare professionals and identification of current needs to improve quality of care.	Coping and wellbeing
[36]	Rubin and Tenenbaum	USA	Research exploring SMW's experience of mastectomy and decision making about reconstruction	Individual In-person qualitative interviews exploring decisions to have, or not have, breast reconstruction.	13 SMW with breast cancer, (purposely selected patients who had not taken up reconstruction)	Findings suggest that sexual identity is not the only influence on women's decisions for or against breast reconstruction. participants described sexual, gender, and political identities and orientations as influences on their decision making, for most participants, experiences with physicians who encouraged reconstruction and concerns about stigmatisation of illness in romantic, professional, and social contexts were also central to decision making.	Body image
[26]	Torbit et al.	Canada	A study to determine the relationship between greater physical symptoms and worse fear of recurrence (FOR) among SMM prostate cancer survivors.	Self-report questionnaires that assessed symptom function, self-efficacy for prostate cancer symptoms, satisfaction with healthcare, and fear of recurrence	92 SMM with various cancers	The study found that worse bowel function, hormone function, and sexual function were significantly associated with greater FOR.	Coping and wellbeing
[27]	Boehmer et al.	USA	Study explores prevalence of cancer survivorship by sexual orientation and cancer survivors' self-reported health.	Analysis of pooled data from California Health Interview survey from 2001, 2003, and 2005. Examining the cancer Prevalence and self reported health of SMW and SMM	Sample size of 122,394 individuals Consisting of 51,259 men and 71,135 women.	No significant differences in cancer prevalence by sexual orientation, but lesbian and bisexual female cancer survivors had 2.0 and 2.3 the odds of reporting fair or poor health compared with heterosexual female cancer survivors. Among men, significant differences in cancer prevalence, with gay men having 1.9 the odds of reporting a cancer diagnosis compared with heterosexual men.	Coping and wellbeing
[28]	Boehmer et al.	USA	Study comparing coping strategies of heterosexual and SMW with breast cancer.	Heterosexual and SMW with breast cancer recruited from a cancer registry had telephone based questionnaires to assess coping.	257 heterosexual and 69 SMW with breast cancer	While survivors with a sexual minority orientation had more adaptive coping than heterosexual survivors, these differences in coping did not relate to benefit Finding.	Coping and wellbeing

Table 2 (Continued)

Citation	Authors	Country	Purpose/aims	Methodology	Cohort size	Key findings	Coded theme
[29]	Boehmer et al.	USA	A study to identify the factors associated with adjustment to breast cancer among SMW with breast cancer and their support person (SP).	A cross-sectional study, SMW with breast cancer and their support provider were asked to self-report social support, distress, and coping, using standardised measures.	Women without SP (n=7) Women with SP (n=23)	Disclosure of sexual orientation, less helpless-hopeless coping, and support provider perception of high fighting spirit were related to lower patient distress. Lower support provider distress was related to more patient disclosure of sexual orientation, a larger social network, and an underestimation of fatalistic patient coping. An overestimation of patients' anxious preoccupation coping was linked to higher support provider distress.	Emotional support
[30]	White and Boehmer	USA	The aim of this study was to investigate the social support experiences of long-term breast cancer survivors who have female partners.	One-on-one interviews were conducted by telephone. Interviews were semi-structured through the use of an interview guide. A purposive convenience sample of partnered SMW (SMW) (e.g., women with female partners) diagnosed with nonmetastatic breast cancer from 2000 to 2005.	15 partnered SMW (SMW) with Breast cancer	Six salient themes describe SMW survivors' perceptions of support: (a) female partners are the singular source of survivors' most valuable support; partners support survivors by (b) discussing survivors' health and distress, which survivors associate with (c) perceived partner distress, and (d) managing the home and caretaking, which survivors associate with (e) perceived partner burden; and partners support survivors by (f) sharing in a life beyond cancer	Emotional support
[33]	Varner	USA	Experiences and effects of spirituality and religion among lesbians diagnosed with cancer	A convenience sample of SMW diagnosed with cancer responded to advertisements for the study. Each woman was interviewed, and interview transcripts were analysed thematically.	8 self-identified SMW	Results indicated that all participants found support in spirituality, though definitions of this term varied. Five women found religion supportive, but not one participant still worshipped in the tradition in which she was raised. The participants' identification as lesbian affected their relationships with all sources of support, including spirituality and religion.	Emotional support
[34]	Laurie et al.	USA	A study examining support needs and resources of SMW (SMW) breast cancer patients.	Semi-structured interviews were conducted with SMW, who were recruited from community-based organisations and had undergone mastectomy for treatment of breast cancer. Interviews explored support needs and resources.	13 SMW breast cancer survivors.	Participants emphasised the value of cancer support groups and resources tailored to SMW while stating that other dimensions of identity or experience, particularly age and cancer stage, were also important. Participants noted the dearth of social support resources for same-sex partners. Family of origin and partners were typically participants' primary sources of tangible and emotional support. Single women faced the greatest challenges in terms of support needs and resources. Former partners were often key sources of support.	Emotional support

Table 2 (Continued)

Citation	Authors	County	Purpose/aims	Methodology	Cohort size	Key findings	Coded theme
[35]	Boehmer et al.	USA	Study exploring issues SMW considered when making decisions on reconstructive surgery after breast cancer.	Individual semi-structured interviews with SMW who had been treated with mastectomy and 12 "support persons".	15 SMW breast cancer survivors and 12 support persons	Women who chose reconstruction experienced difficulties and regrets, whereas women without reconstruction adjusted well after time. Partners of SMW matched the level of satisfaction with reconstructive choice achieved by the women themselves.	Body image
[37]	Filiault et al.	Australia	A study investigating the difficulties encountered by SMM with prostate cancer.	In-depth, face-to-face interviews were conducted with a semi-structured interview guide	2 SMM prostate cancer survivors with one long term romantic partner	Major themes expressed included concerns related to relationship changes and strains, altered sexual function and associated implications for a gay identity, and the perception of heteronormative attitudes in the health care system.	Body image
[40]	Asencio et al.	USA	A study examining the knowledge and experiment of SMM diagnosed with prostate cancer	five focus groups with a total of 36 participant	36 SMM prostate cancer survivors	The data suggest that gay men have little to no understanding of their prostate and the range of sexual challenges associated with prostate cancer and its treatment. In addition, gay men's reactions to potential sexual problems arising from treatment are shaped by their sexual practices, sexual roles, and beliefs about gay relationships and the gay community	Sexual function
[41]	Lee et al.	Canada	Research to post-treatment QoL in PCa patients who are SMM, and to investigate the utility of current QoL assessment tool	Each participant completed a Male Sexual Health Questionnaire (MSHQ), and a questionnaire focused on insertive and receptive roles of anal intercourse.	7 SMM treated with surgery and 8 treated with radiation	While the two validated assessment tools suggested similar QoL scores including sexual function for both surgical and radiation groups, post-treatment sexual function related to anal intercourse may be better in the radiation group, as compared to the surgical group. Larger studies in PCa patients from MSM community are warranted to verify these data	Sexual function
[45]	Wassersug et al.	International	A study comparing diagnostic and treatment outcomes of heterosexual and SMM.	An anonymous online survey assessing how "bothered" patients were about certain treatment related side effects after prostatectomy	466 heterosexual and 96 SMM	Finding indicated that both groups of men were generally similar, SMM might experience more intensive screening for disease, as indicated by lower Gleason scores at diagnosis. SMM appear more distressed by loss of ejaculation after prostatectomy.	Sexual function
[46]	Hartman et al.	Canada	Study examining the experience of three gay couples managing sexual dysfunction as a result of radical prostatectomy	Patient, partner, and couple face-to-face semi-structured interviews were conducted to explore the effect of sexual dysfunction at three stages: 3–6 months, 12–15 months, and 21–24 months after radical prostatectomy	3 SMM couples with a history of prostatectomy	This study revealed that SMM can engage in novel accommodation practices, such as opening their relationship to alternate sexual partners, and that SMM have specific roles in their sexual relationships which uniquely compromised their sexual functioning and satisfaction.	Sexual function

Table 2 (Continued)

Citation	Authors	County	Purpose/aims	Methodology	Cohort size	Key findings	Coded theme
[47]	Boehmer et al.	USA	Study examining sexual difficulties after cancer in sexual minority women (SMW).	Telephone survey with a sample of convenience comparing SMW either and without breast cancer to undertake sexual function test.	85 SMW with breast cancer 85 controls without cancer.	Cases and controls did not differ in sexual dysfunction or level sexual functioning. However, SMW after cancer treatment had lower sexual frequency, desire and ability to reach orgasm, and scored higher on pain compared to controls.	Sexual function
[52]	Arena et al.	USA	To ascertain any differences between heterosexual and SMW with breast cancer	This study compared the experiences of though a questionnaire completed at home and returned by post.	78 women 50:50 heterosexual and lesbian. All with breast cancer.	Compared to the heterosexual women, lesbians reported less thought avoidance, lower levels of sexual concern, less concern about their appearance, and less disruption in sexual activity, but also substantially lower perceptions of benefit from having had cancer.	Sexual function
[53]	Boehmer et al.	USA	A study to determine differences between SMW breast cancer survivors to examine whether sexual minority-specific issues contribute to survivors' adjustment.	A 35-minute telephone interview using the breast cancer module of the EORTC Quality of Life Questionnaire.	180 SMW breast cancer survivor	Sexual minority-specific factors contributed toward explaining lesbian and bisexual survivors' anxiety and depression but did not contribute toward explaining survivors' physical and mental health.	Coping and wellbeing
[54]	Jabson et al.	USA	A study exploring similarities and differences between SMW and heterosexual breast cancer survivors quality of life.	Participants were required to complete an Online surveys regarding quality of life.	204 breast cancer survivors (143 heterosexual and 61 SMW)	Quality of life scores were similar between heterosexual and lesbian breast cancer survivors	Coping and wellbeing

overview of the experiences of sexual minority individuals, or carers or partners who had come into contact with an LGB person that had undergone treatment for cancer.

5. Discussion

5.1. Experiences of Care

The articles uncovered as part of this review reveal that sexual minority individuals sometimes experience discriminatory attitudes from oncology health care workers [10,12,13,15,21,22]. The levels of discrimination experiences throughout the studies reviewed varies, but further studies conducted in the UK demonstrate that individuals who feel discriminated against experience social stressors, which in turn can increase their risk of experiencing mental health problems [9].

A Canadian study found in this review recruited a cohort of twenty-six Sexual Minority Women (SMW) from Ontario to discuss their experiences of care after treatment for breast or gynaecological cancer [10]. The study aimed to interview participants face-to-face, but nine interviews were carried out over the phone indicating inconsistencies and possible limitations. The interviews were semi-structured in design and revealed that the majority of participants had poor experiences of health care. The majority of SMW interviewed had suffered aspects of discrimination based on their sexuality by not being offered breast reconstructions based on the belief that lesbians had less of a desire to take up this treat-

ment. All participants experienced a “heterosexist” approach to care within the hospital setting, for example one participant was presumed to be heterosexual in consultations leading to a need for the women to have to correct this assumption and feel embarrassed. The study concluded that the SMW recruited had a desire for gender neutral consultations to avoid heterosexist attitudes and the need for the creation of specialist support groups whereby lesbian or bisexual women could be provided with opportunities to explore their experiences and their feelings in a more comfortable setting. Participants all came from the same geographical area and this may indicate isolated heterosexist discriminatory attitudes in one particular care provider. The study followed a Participatory Action Research (PAR) methodology [11], allowing the collaboration of those affected by the issue being studied to help collate the findings and as such indicated a potential to introduce bias in the study's findings.

Two further papers uncovered in this review were produced from the same PAR cohort of 26 SMW in Ontario, Canada [12,13]. The articles reiterated the views of the previous study but offered more information with additional extracts from the interview transcripts discussing heterosexist assumptive attitudes of health care practitioners [12]. Participants were asked by health care providers to discuss treatment interventions such as breast reconstruction with their assumed husbands, and examples were given of genetic counsellors not being understanding towards an individual's inability to contact relatives who were estranged as a result of their families attitudes towards their sexuality [12]. The SMW desired

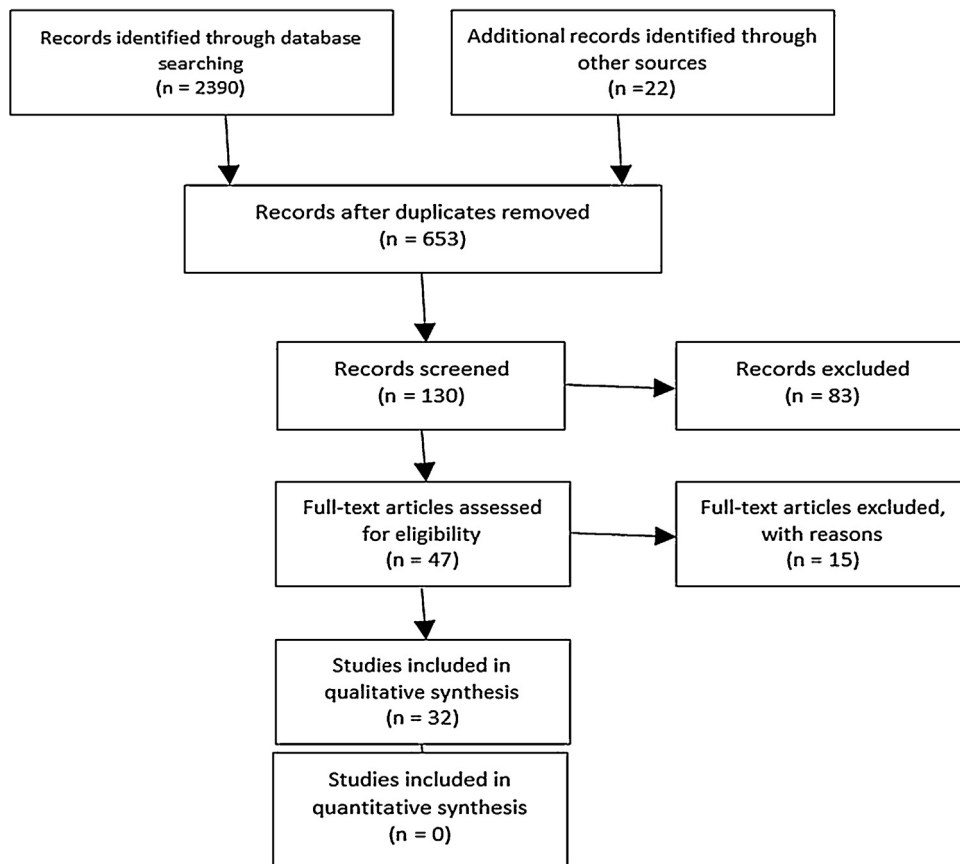


Fig. 1. PRISMA flow diagram.

to have their care provider explain that they were welcoming and open to discussing sexual minority issues [13]. It was felt that due to the perceived historical failure of health professionals to respect lesbians or grant legitimacy to lesbian relationships, lesbians with cancer sometimes did not expect that they or their partners would be offered equitable care. In the UK The Lesbian and Gay Foundation (LGF) have launched the “Pride in Practice” campaign to address issues similar to those raised by the Ontario studies. Healthcare providers can apply for “Pride in Practice Awards” to demonstrate their commitment providing inclusive services and recognise the specific needs of lesbian, gay and bisexual people [14].

The Ontario PAR team’s work revealed relevant findings about a lack awareness of sexual minority issues regarding estrangement from family members and a lack of support services for SMW affected by cancer. However, the studies were all conducted by the same project group with motivations to campaign and change services in the area indicating a strong potential for bias.

A USA study used semi-structured interviews examining the attitudes of 39 SMW with breast cancer when disclosing their sexual orientation to their health providers [15]. The study discussed how the participants were mainly younger white women, who might be more likely to self-disclose as opposed to older women from ethnic minority groups. The majority of women actively disclosed their sexual orientation, whereas eleven women passively refused. Findings indicated that prior to disclosure sexual minority patient-provider relationships were marked by apprehension, and providers did not tend to enquire about sexual orientation. Lesbians within the study that went on to disclose their sexuality were met with a largely positive response. Whilst deemed to be helpful, research suggested that patients who wanted to talk about their sexual orientation often preferred their health provider to initiate

these conversations [16], concluding that disclosure of sexual orientation can be a barrier to positive patient experiences and the existence of self-perceived feeling of discrimination amongst the participants. There are several reasons why an individual may not want to disclose their sexual orientation. The Sexual Offences Act 1967 decriminalised homosexuality [17], but it wasn’t until the UK government passed the Equality Act in 2010 that it became unlawful for public services, including the NHS, to discriminate against protected characteristics such as sexual orientation [18]. This combined with society’s negative attitudes towards homosexuality throughout the 20th Century as well as the AIDS epidemic in the 1980s could explain why LGB individuals of an older generation might be reluctant to disclose their sexuality [19]. In the UK sexual minority cancer patients will be demographically older and will have lived at time when homosexuality was illegal [20].

A cross sectional study in the USA examined SMW perceptions of discrimination as one of the multiple facets of the breast cancer survivorship process [21]. Sixty-eight purposefully sampled sexual minority breast cancer survivors completed assessments of quality of life and perceived discrimination via an online survey. Statistical analyses pointed towards perceived discrimination and social support as important indicators for predicting SMWs’ quality of life. This study, although valuable in its conclusions, had several limitations. For example ethnic minority groups are underrepresented, and the survey was carried out online resulting in only computer literate participants and a lack of a comparison with heterosexuals. Although not statistically significant this paper draws attention to the fact that if an individual perceives aspects of discrimination within their care, it has the potential to impact on their overall quality of life.

Another Canadian study investigated the experiences of three Sexual Minority Men (SMM) and four SMW with various types of cancer [22]. In-depth, face-to-face interviews were conducted with a semi-structured interview. The study was deemed important for inclusion within this review to offer a balanced perspective, overt homophobia or discrimination within the cancer care system were not experienced by this study's participants. Participants valued the central role of their partners in coping with cancer but there were gaps in the cancer care system relating to support groups identified such as, Participants in this study discussed worries about the perceived reaction by their gay peers towards their health, and their concerns of being associated with having AIDS, revealing an insight into the gay community's attitude towards illness.

The majority of acts of minor discrimination found in this review appear to arise due a lack of awareness amongst staff of using gender neutral language when discussing partners and heterosexual assumptions. A novel approach of raising awareness of sexual minority patients has been trialled in Ireland, offering a training programme directed at oncology professionals [23]. Participants offered the training found that they became more familiar with LGB-related language and terminology, more knowledgeable of LGB health issues, and more confident in providing care to LGB patients. Training programmes and raising awareness of LGB cancer patients could address misunderstandings in care that have been revealed in this review.

5.2. Coping and wellbeing

The ways in which LGB individuals are affected by cancer and how they cope were discussed within several papers, indicating many sexual minority attitudes are common with heterosexual cancer survivors, but sexual minorities may report poorer health [24,26–28,53,54].

An Australian study examined the experiences of ten SMM diagnosed with prostate cancer, the results indicated that some participants adopted a sense of empowerment regarding their cancer journey whilst others felt isolated as a result of their treatments [24]. The data was gathered through online focus groups. Participants felt isolated after diagnosis and the majority of men within the study were single stating that the existence of a support group may have assisted them to connect with others going through the same experiences. One participant described themselves as 'damaged goods' in the eyes of the gay community so no longer felt they were able to enjoy the lifestyle that they had had prior to their treatments. No specific tool was used to assess quality of life after treatment but participants discussed their feelings of isolation from the rest of the gay community, feeling closer to friends, and being empowered to provide advice to those that they knew who were going through similar experiences. Sexual minority individuals in the UK over the age of 55 are more likely to live alone, when coupled with feelings of isolation from the gay community; this could signify a potential lack of emotional support for LGB persons with cancer [25].

A Canadian study examined SMM Fear of Reoccurrence (FOR) and noted that there was a relationship between (FOR) and the initial physical presenting symptoms of their cancer [26]. Ninety-two SMM with various cancer types completed self-report questionnaires that assessed symptom function, self-efficacy for prostate cancer symptoms, and FOR. The study found that worse bowel function, hormone function, and sexual function were significantly associated with greater FOR. The study didn't compare FOR with heterosexual individuals and as such might not be a sexual minority-only issue, but did highlight SMM fear and psychological wellbeing.

In the USA a study used the breast cancer module of the EORTC Quality of Life Questionnaire through telephone interviews with

180 SMW breast cancer survivors [53]. Sexual minority specific factors such as discrimination in health, contributed toward survivors' anxiety and depression. The study benefitted from having a large cohort of participants, but failed to have a control or comparison of non-breast cancer SMW or heterosexuals. Levels of stress between heterosexuals and SMW have been compared in one study uncovered in this review. A further USA study compared 68 SMW and 143 heterosexual women levels of stress, and found that minority breast cancer survivors had higher perceived stress compared to heterosexual breast cancer survivors, had an uneven balance of participants and may influence the quality of the findings [54]. An analysis of pooled data from a USA California Health Interview survey from 2001, 2003, and 2005 examined and the self-reported health of sexual minority individuals were compared with heterosexuals [27]. The study concluded that of the 51,259 men and 71,135 women analysed there were no significant differences in cancer prevalence by sexual orientation, but lesbian and bisexual female cancer survivors had between 2.0 and 2.3 times the chances of reporting fair or poor health compared with heterosexual female cancer survivors. Among men there were significant differences in cancer prevalence, with gay men having 1.9 times the odds of reporting a cancer diagnosis compared with heterosexual men. This study provided a context when comparing sexual minority experiences of cancer with the rest of the heterosexual population and was large enough to conclude that sexual minority individuals report poorer health after cancer diagnosis. Another study in the USA compared the coping strategies of 257 heterosexuals and 69 SMW with breast cancer using telephone-based questionnaires recruited from a cancer registry, finding that survivors with a sexual minority orientation had more adaptive coping strategies and were less fatalistic than heterosexual survivors [28].

5.3. Emotional support

Four studies uncovered in this review discussed the importance of spousal or peer emotional support for sexual minority individuals [22,29,33,34]. A USA cross-sectional study compared 7 single SMW with breast cancer and 23 SMW with partners finding women without partners to be more fatalistic, whereas SMW with partners were more resilient and had lower levels of distress [29]. The study used questionnaires and interviews to determine the extent of support, but had a disproportionate number of single women within the study to serve as a comparison. The social support experiences of long-term SMW breast cancer survivors were investigated in another study through one-on-one interviews by telephone [30]. Fifteen partnered SMW with breast cancer described female partners as being the source valuable support by discussing survivors' health and distress. The central role of partners in coping with cancer was investigated in another small study using interviews with 7 SMM and SMW [22]. The evidence suggested that having a supportive person, partner or otherwise, is significant when preventing sexual minority mental health problems after cancer diagnosis. Unfortunately none of the above studies compared levels of mental wellbeing and support with heterosexuals and should not be assumed to be a sexual minority-only area for concern. All the above studies were small but corroborated each other's findings that a support person is key to providing guidance through the cancer journey. The need for support is not unique to sexual minority individuals and similar studies examining heterosexual couples corroborate these findings [31], but sexual minority individuals are more likely to be single [25].

Many cancer patients draw strength from religious or support groups in addition to their partners [32]. A study in the USA explored the effects of spirituality and religion among lesbians diagnosed with cancer [33]. A sample of eight SMW diagnosed with cancer were interviewed and all participants found support in spir-

ity, though definitions of this term varied. Five women found religion supportive, but no participant still worshipped in the tradition in which they were raised. The participants' identification as lesbian affected their relationships with all sources of support, including spirituality and religion. Another study examined the support needs and resources of 13 SMW breast cancer patients [34]. Semi-structured interviews were conducted with SMW, who were recruited from community-based organisations and had undergone mastectomy for treatment of breast cancer. Participants emphasised the value of cancer support groups and resources tailored to SMW while stating that other dimensions of identity or experience, particularly age and cancer stage, were also important. Single women faced the greatest challenges in terms of support needs and resources, and former partners were often key sources of support for these individuals. Both of these studies were small scale, but highlighted the importance and usefulness of support for SMW affected by cancer from religious and support groups targeted at sexual minorities.

5.4. Body image

This review found contrasting views on body image and sexual minority individuals appear to be affected by this in different ways [35–37]. One study uncovered examined 15 SMW and their partners who had either received or declined reconstructive surgery after mastectomy [35]. Individual semi-structured interviews were undertaken suggesting that women who chose reconstruction experienced difficulties and regrets, whereas women without reconstruction adjusted well after time. Partners of the SMW matched the level of satisfaction with reconstructive choice achieved by the women themselves. The study concludes that SMW place less emphasis on external appearance compared with heterosexual women. A contrasting study conducted with 13 SMW with breast cancer who had deliberately not taken up breast reconstruction suggests that sexual identity is not the only influence on women's decisions for or against breast reconstruction [36]. Participants described sexual, gender, and political identities and orientations as influences on their decision making. For most participants, experiences with physicians who encouraged reconstruction and concerns about stigmatisation of illness in romantic, professional, and social contexts were also central to the decision making process. Both studies have limitations and were carried out retrospectively which may introduce a recall bias for the participants.

An Australian study examined the effects of prostate cancer in three SMM using in-depth face-to-face interviews [37]. The study uncovered several themes. Some participants discussed the effects of body changes and the negative attitudes of the gay community. Relationship changes and strains were also observed as a result of surgical scars and weight gain. The significance of body image and physical appearance in relation to quality of life were also discussed in another study that used face-to-face interviews with men who had various cancers [22]. Three other men were recruited who were all partnered at the time of diagnosis. Of these, one separated from their partner due to appearance issues and it was raised by several participants that the gay community's sexualised attitude towards appearance was a large factor in how participants viewed themselves. Homosexual attitudes towards appearance are documented in several other studies and appear to be a greater factor for wellbeing than in heterosexual men [38].

5.5. Sexual function

A report released by Prostate Cancer UK and Stonewall UK discussed the possible needs of gay and bisexual men after prostate cancer treatment [39]. The report discussed how gay and bisexual

men may be more vulnerable to the side-effects of pelvic cancer treatments than straight men. This study corroborated these findings uncovering a variety of sources exploring the sexual function of SMM after cancer treatment.

Within the USA a cohort of 36 SMM who had a diagnosis of prostate cancer were placed in a study using focus groups [40]. The participants were asked to discuss their knowledge of their side effects and revealed that the gay men in this study had little understanding of their prostate and the range of sexual challenges associated with prostate cancer and its treatment. The study found that the men's reactions to potential sexual problems arising from treatment are shaped by their sexual practices. For example if the individual was usually anally receptive during sexual intercourse they could more easily accommodate the associated loss of erectile function, but those who valued being able to anally penetrate during intercourse suffered from being unable to do so. All the participants were concerned about the gay community's reaction to their physical appearance when gaining weight due to hormone treatments and the pressure of being unable to perform sexually in a sexually charged community. Further studies conducted in Canada revealed similar findings where 15 SMM were given sexual health questionnaires after treatment for prostate cancer with prostatectomy or external beam radiotherapy finding that post-treatment sexual function related to anal intercourse may be better in the radiation groups compared to the surgical group [41]. The study did not indicate the point at which the former patients were given the questionnaire and this could impact on the reliability of this study as prostate cancer-associated problems can become worse over time due to delayed side-effects [42]. Both of these studies were small and as such their findings lack the corroboration of other SMM experiences or a lack of comparison with heterosexual men. Studies conducted with heterosexual men indicate that loss of sexual function can be equally problematic but SMM sexual practices may be specifically impacted on by cancer treatments [43,44]. A larger international study comparing diagnostic and treatment outcomes of heterosexuals and SMM was carried out using an online survey to assess how "bothered" patients were about certain treatment related side-effects after prostatectomy, looking at 466 heterosexuals and 96 SMM. Both groups of men were generally similar, but the SMM appeared more distressed by loss of ejaculation after prostatectomy [45].

A Canadian study examining the experience of three gay couples managing sexual dysfunction as a result of radical prostatectomy conducted patient, partner, and couple face-to-face semi-structured interviews to explore the effect of sexual dysfunction at three stages: 3–6 months, 12–15 months, and 21–24 months after radical prostatectomy [46]. This study found that participants engaged in novel accommodation practices when their sexual function changed, such as opening their relationship to alternate sexual partners, and corroborated the findings of other studies in this review that SMM have specific roles in their sexual relationships which uniquely compromised their sexual functioning and satisfaction. Unfortunately the study did not use any sexual assessment tool to aid in quantifying the level of dysfunction at the different intervals and as such limits the study.

This review found two studies related to sexual function in SMW in the USA [47,52]. One, a telephone survey approached SMW either with or without breast cancer to undertake sexual function tests, the other used of a postal questionnaires. Both studies demonstrated good practice as used equal numbers of SMW and heterosexuals to compare, 85 SMW compared with 85 heterosexuals and 39 SMW compared with 39 heterosexuals respectively, although the sampling was purposeful and were not randomised. Cases and controls did not differ in sexual dysfunction or level sexual functioning. However, SMW after cancer treatment had lower sexual frequency, desire and ability to reach orgasm, and scored

higher on pain compared to controls [47], whereas the other study found lower levels of sexual concern and less disruption in sexual activity. The studies have different findings but indicate that sexual function after cancer treatment is not a male-only issue and has yet to be explored in any of the other studies uncovered as part of the SMW cancer experience.

5.6. Limitations

There is a breadth of terminology in use to identify people as being homosexual and this presented a challenge when searching for studies that include those that are lesbian, gay, bisexual, or those that do wish not to be labelled [48]. Several articles uncovered in this review studied the same population of sexual minority individuals who were predominantly white and middle class, therefore several of the studies had potential to have repeated participant bias and were not wholly inclusive of all sexual minority views [49]. The majority of the studies in this review do not have controls and lack quantitative data making it harder to draw conclusions and measure their impact [50]. Differing laws and attitudes towards homosexuality vary worldwide making it difficult to draw comparisons between studies and should be noted when considering their application to UK populations [51].

6. Summary and conclusions

This review succeeded in establishing its objectives; the literature uncovered indicated that the psychological and emotional needs of sexual minorities are largely similar to that of heterosexual cancer patients by wanting to have support from a variety of sources such as family members, partners and support groups to maintain psychological health and wellbeing, but sexual minority individuals may not have access to these mechanisms of support in all cases. The evidence revealed that sexual minorities are affected physically by cancer like heterosexuals through weight gain, body changes and image, as well as sexual function, but sexual minorities appear to have differing social attitudes to one another and different sexual practices meaning that the physical effects of cancer have specific consequences on LGB populations. Given these conclusions there is an evidence base to warrant the exploration of sexual minority specific advice and services, but exact extent and needs of support required within the UK is yet to be established. This review has uncovered evidence of a range of acts of discrimination in healthcare towards sexual minorities overseas; differing attitudes towards homosexuality and dissimilarities in rights legislation from country to country denote that the UK population of sexual minority cancer survivors may have a different perspective or needs of current cancer services in the NHS. It is the conclusion of this review that sexual minority cancer patients needs have to be investigated and researched further within the UK to better formulate management and treatment policies.

Conflic of interests

No conflicting interests to declare.

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