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Experiences and unmet needs of lesbian, gay and bisexual people with cancer care: a systematic review and meta-synthesis

Running title: Experiences and needs of LGB people with cancer care: systematic review

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Abstract

Objectives: To explore the cancer care experiences and unmet needs of people who identify as a sexual or gender minority.

Methods: A qualitative systematic review and meta-synthesis was undertaken based on a registered protocol. Following literature searching and study selection, study quality was examined using the Critical Appraisal Skill Programme Checklist.

Qualitative data were extracted verbatim from included studies and synthesised using thematic analysis.

Results: Fifteen studies that included lesbian, gay and bisexual (LGB) people living with or beyond cancer were included in the review. Studies including gender minorities were not identified. The majority of study participants were sexual minority women with breast cancer or sexual minority men with prostate cancer. Meta-synthesis of 106 individual findings generated six overarching themes pertaining to sexual orientation disclosure, experiences and fear of homophobia, positive and negative healthcare professional behaviours, heterocentric systems and care, inadequacy of available support groups, and unmet needs for patient-centred care and LGB-specific information. LGB people often reported feelings of anxiety, invisibility, isolation and frustration throughout the cancer care continuum.

Conclusions:

Analysis of the experiences of LGB people with cancer care shows that LGB people face numerous challenges due to their sexual orientation and receive care that does not adequately address their needs. Training and education of healthcare professionals is strongly recommended to address some of these challenges and practice gaps. Culturally appropriate care includes avoiding heterosexual assumptions, use of inclusive language, the provision of tailored information and involving partners in care.

Keywords:

Homosexuality, gay, lesbian, bisexuality, cancer, supportive care, patient experience, unmet needs, qualitative, meta-synthesis

Introduction

Cancer is often accompanied by experiences of emotional distress, anxiety, depression and uncertainty.[1] The psychological impacts of cancer may be present at any point of the cancer journey and for some individuals, may persist and have long-term consequences for quality of life (QoL).[1]

Previous experiences of psychological illness or stressful life events are known risk factors for development of cancer-related depression and anxiety.[2] People with cancer who identify as lesbian, gay, bisexual or transgender (LGBT) may be at greater risk of inferior psychosocial outcomes following a cancer diagnosis compared with their heterosexual cisgender counterparts. LGBT people are more likely to experience stressful circumstances and life events as they are more likely to be targets of violence, harassment and discrimination, more likely to be estranged from their families of origin, and for older LGBT people, be less likely to have adult children who may provide care.[3] The minority stress conceptual framework proposes that the discrimination, stigma, prejudice and internalised homophobia that LGBT people experience leads to increased risk of psychological and mood disorders.[4] Indeed, elevated rates of depression, mood and anxiety disorders,

suicidal ideation and suicide attempt are observed in LGBT populations compared with heterosexual cisgender populations.[3]

An estimated 420,000 to 1,000,000 LGBT people were living with a prior cancer diagnosis in the United States in 2015.[5] Despite this large number, the LGBT population remains a largely understudied group in the context of cancer care. There are numerous gaps in knowledge regarding LGBT cancer care experiences and needs (reviewed in [6]), and available quantitative data show varied outcomes. Some reports indicate that sexual minority status is not associated with reduced QoL [7, 8] or increased levels of anxiety and depression [9] relative to heterosexual samples. Interpretation of these results is however complicated by study design, with acknowledged limitations including utilisation of convenience sampling and over-representation of educated, economically stable, white and married/partnered LGBT participants. The use of non-specific or generic measures to assess patient-reported outcomes (PROs) including QoL in these studies may be a further limitation as generic measures may not be sensitive to issues relevant to LGBT groups.

Conversely, other studies have reported disparities in PROs between LGBT and heterosexual people with cancer. Utilising population-wide samples and study-specific questionnaires, these studies show LGBT people with cancer experienced more depressive symptoms and social and relationship difficulties,[10] inferior outcomes across care-related domains such as inclusion in decision making and being treated with dignity and respect,[11] and less satisfaction with care.[12] Differences between LGBT and non-LGBT groups have also been observed using

more specific assessments of disease impact. Examples include studies examining prostate cancer-specific QoL, which revealed poorer outcomes for gay and bisexual compared with heterosexual men, including greater psychological distress, lower masculine self-esteem, greater dissatisfaction with treatment and greater ejaculatory bother.[13, 14]

How may we understand these diverse findings? It is apparent that existing quantitative evidence describing LGBT experiences and outcomes in the context of cancer care is limited and largely unable to offer knowledge users rich insight. Quality of life and other broad or generic PROs regularly measured in quantitative studies involving LGBT people with cancer may not adequately capture their experiences or identify all domains of concern. These studies may further be confounded by methodological issues inherent in recruiting LGBT participants.[3] Available data are also limited by the range of outcomes measured, and do not describe outcomes such as unmet needs or preferences, for example, that may be useful for developing acceptable supportive care interventions for LGBT people with cancer or to inform policy and practice change.

A recent integrative review examined nurse and midwife attitudes, knowledge and beliefs regarding the healthcare needs of LGBT and queer (Q) people and concluded that issues of inadequate care may be related to heteronormative culture and a lack of education in LGBTQ issues.[15] It is important that LGBT peoples' experiences with healthcare be examined and understood. Existing qualitative data may usefully illuminate the cancer care experiences of LGBT people by affording direct

descriptions and analyses of participants' experiences and needs in their own words. While qualitative evidence cannot be used to form generalisations of population groups, it does allow knowledge users to explore and understand the breadth of perspectives which may then be used to develop hypotheses for further research and to influence practice change. Qualitative studies may allow detailed examination of individual experiences and perspectives that may go unmeasured or unrepresented in quantitative studies.

In order to investigate and understand the cancer care experiences and unmet needs of LGBT people living with and beyond cancer, we undertook a systematic review and meta-synthesis of the available qualitative literature. This systematic review was based on an *a priori* protocol registered with PROSPERO (ID CRD42017067753).

Aims

To explore the cancer care experiences and unmet needs of people who identify as a sexual or gender minority.

Methods

Inclusion Criteria

Qualitative studies were included if: 1) participants were people living with or after cancer (defined as a cancer diagnosis at any time prior) who identified as a sexual or gender minority (including lesbian, gay, bisexual or transgender); 2) one or more of the following phenomena were reported: experiences, needs and/or preferences regarding cancer care and/or interactions with healthcare professionals (HCPs) or healthcare systems; and 3) were published in English. Studies reporting on general experiences of sexual and gender minority people with cancer, without mention of experiences with cancer care or care-related needs, were excluded.

Search Strategy

A broad search strategy was developed using keywords and subject headings for concepts related to sexual and gender minority status, cancer and qualitative research. The basic search strategy (modified for each database) was (gay OR lesbian OR homosexual OR bisexual OR transgender OR LGBT* OR "sexual orientation" OR "sexual preference" OR "sexual minority" OR "gender minority") AND cancer AND (qualitative OR experience* OR interview* OR perspective*). Literature searches were conducted on 22/3/2017; the PubMed search was limited to English language studies and the PsycINFO search was limited to English language studies and journal articles only. Google Scholar results were sorted by relevance and the first 100 results were screened.

Study Selection

Search results were imported into EndNote. Duplicates were removed and all remaining articles were screened by title and abstract by one reviewer. Full texts of potentially eligible studies were retrieved and assessed against review inclusion criteria by one reviewer, and included/excluded studies were confirmed by the review team.

Quality Appraisal

Studies were assessed for quality using the Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist.[16] Two reviewers appraised all studies independently and discussed any disagreements to reach consensus.

Thematic Analysis

All qualitative papers were read and re-read, with key themes and messages extracted as verbatim text from included articles. Only themes and messages relevant to the review question (i.e. themes regarding experiences of care, interactions with HCPs, and unmet care needs) were considered, with themes describing general experiences of having cancer omitted. Qualitative data were synthesised using thematic analysis and a data-driven approach.[17] Prominent and recurrent themes were identified from the extracted qualitative data using an iterative process, where each data unit was coded into one or more sub-themes. These were read and re-read by two reviewers and grouped according to similarity in meaning to give overarching descriptive themes.

Results

Study Selection

The search returned 518 unique articles that were screened by title and abstract (Figure 1). Eighteen papers were screened in full, with two studies excluded for not including qualitative data [10, 13] and one study excluded for not addressing the phenomenon of interest. [18] Fifteen articles were critically appraised and all were included in the review.

Characteristics of Included Studies

Overall, 15 articles were included that described 13 studies. Of the 15 included articles, eight focused on sexual minority women, with seven articles [19-25] including women with breast cancer and one [26] including women with any kind of cancer (Table 1). Two of these articles described separate analyses drawn from the same parent study.[19, 20] The six included articles with exclusively male participants focused on sexual minority men with prostate cancer.[27-32] Two of these articles described different analyses arising from the same data set.[29, 32] One study investigated a broader population that included lesbians, gay men or bisexual people previously diagnosed with any type of cancer.[33] Some studies included participants who identified as homosexual (gay or lesbian), or bisexual, while others also included participants who reported partnering or having sex with

the same gender (for example men who have sex with men [28] and women who report partnering with women [19-21]). Although our aim was to include transgender people or those who identified as a gender minority, no such studies were located, reflecting a significant gap in the current literature. Ten of the 15 included articles were published within the last five years (from 2012 onwards), indicating a recent increase of research effort towards understanding sexual minority cancer experiences. No relevant studies published before 2002 were located. All included studies were from high-income countries (The World Bank definition [34]) with seven studies from the United States, three from Australia, two from Canada and one from the United Kingdom.

The methodological quality of the included articles was assessed and no studies were excluded for lacking in rigour (Appendix I). Overall, studies were deemed to be of moderate to high quality with studies meeting from five to nine out of nine quality criteria. Only two studies provided clear explanations regarding the relationship between the researcher(s) and participants (criterion 6). Clear reporting of the consideration of ethical issues (criterion 7) was considered insufficient in four studies, and four studies lacked clear descriptions of how data were analysed and interpreted (criterion 8). Based on the methodological assessment, reviewers agreed that across the studies, results could be considered valid in terms of their credibility (believability from the perspective of research participants), transferability (capacity for the results to inform understandings in similar contexts), and dependability (that the results are likely to be true if studies were repeated).

Thematic Analysis

Twenty eight sub-themes emerged from the thematic analysis, with six overarching themes identified and discussed below (Figure 2). There was overlap between the six overarching themes, with some concepts feeding reciprocally into one or more themes. The acronym LGB (lesbian, gay and bisexual) is used throughout the results of the review as studies did not include transgender participants; results therefore cannot be extended to include this group.

Disclosure

Issues surrounding disclosure of sexual orientation arose in five studies.[19, 21, 22, 29, 33] Issues included feeling uncomfortable disclosing sexual orientation to HCPs or feeling there were no appropriate opportunities for disclosure. Some participants suggested that HCPs may provide opportunities for disclosure and that it should be the responsibility of HCPs to ask patients how they self-identify. When patients did not disclose their sexual orientation to HCPs, they often reported additional psychological burden. Non-disclosure may be a source of regret (“I should have just taken the bull by the horns and said it straight out, that I’m a gay man. I [then] wouldn’t have to complain about their lack of communication on that subject.”[29], p5). Conversely, some patients felt their sexual orientation was not important or relevant to their cancer care or perceived their sexual orientation to be private (“I don’t think it [my sexual orientation] has anything to do with my breast cancer diagnosis. Again, I’m a woman first, and I guess a lesbian somewhere down the line,

but that's a not a part of my diagnosis." [21], p76). Others described fear of homophobia or discrimination as reasons for non-disclosure, and conversely, perceptions of safety of the environment as reasons for disclosure, explored in more depth below.

Homophobia

Five studies contributed to the overarching theme of 'Homophobia'. [19, 26, 29, 30, 33] Some themes overlapped with issues surrounding disclosure, as fear of homophobia or fear of substandard care if LGB identity was known were both reasons for non-disclosure. Disclosure was seen as a 'risk' to patients, clearly revealed in this quote "And having to worry about is she homophobic and will she take another snip out of me that she's not supposed to? I mean, it's crazy, but you do have those thoughts: Is this doctor homophobic, and will he treat me equally or she treat me equally?" ([19], p1885).

Sexual minority participants reported conducting preparatory work or research, or 'screening' HCPs to assess their attitudes regarding sexual orientation, their knowledge and comfort in discussing issues important to LGB patients, and the overall safety of the healthcare environment. Some respondents directly experienced homophobic reactions or described being denied standard care, while others reported fear of poorer treatment or poorer quality of care due to their sexual minority status. There were also reports of feeling apprehensive or a heightened sense of alertness around providers due to their sexual orientation. When homophobic

reactions were absent, participants reported feeling grateful for receiving equitable treatment.

Healthcare Professional Behaviour

Eight articles contained data relevant to the theme 'HCP Behaviour'. [19, 20, 22, 28, 29, 31-33] HCP behaviour that was seen as neutral following disclosure of sexual orientation, or behaviour that was seen as rude or suggested that HCPs were uncomfortable, were both perceived negatively and interpreted as being associated with sexual orientation. Other specific HCP behaviours that were perceived negatively by LGB people included dismissive language, arrogance, making disparaging remarks or displaying a lack of interest in the patient. Positively perceived HCP behaviours included verbal and nonverbal displays of compassion, respectful treatment of the person with cancer and their partner, treating the patient as an equal and showing genuine interest in the patient as a person. Some participants expressed a preference for LGB or LGB-friendly providers, and this was sometimes a consequence of previous experiences of inadequate care and support.

HCPs were frequently perceived to be reluctant to discuss LGB sexuality ("My health care providers seemed more uncomfortable than me to discuss prostate cancer and sex." [32], p10). In some cases this ranged from 'over-sanitised' discussions of sexuality and sexual concerns to discomfort and open refusal to discuss LGB sexual matters raised by patients. HCPs were also often perceived to be lacking in knowledge of LGB sexuality and on the impacts of cancer and cancer treatments on

LGB sex. In instances when HCPs did not have the required information or knowledge to answer patients' questions, showing an interest and making an effort to seek resources and support for the patient was appreciated.

It was considered important by LGB patients that their same-sex partners/spouses be treated equally to heterosexual partners/spouses if the patient chose to include them in their care. Inclusion of partners in appointments, treating partners with respect and recognising partners as legitimate next of kin are examples of this and were perceived positively by participants. ("You know, this was the first time we met. We were very up front [about being lesbians], and she didn't bat an eye. And she included [partner] in everything, talked to both of us when she was talking you know, made eye contact with both of us, and I think was very cognizant of the fact that I was sort of in shock. And so she was making sure that [partner] understood what she was saying, because it was just going in one ear and out the other, and I was just sitting there." [20], p50)

Heterocentric Care

The theme 'Heterocentric Care' arose from the findings of nine articles.[19, 22, 25, 26, 28-30, 32, 33] Assumed heterosexuality was widely reported ("He said, 'Would I like to bring my partner along. What is she doing?' And I just said to him, 'Oh, my partner is male.' And he just sat there for a minute and his jaw dropped and he said, 'Oh, I haven't come across this before.'"[29], p5). This assumption added to patients' distress and feelings of being invisible. Discourse between HCPs and LGB patients

tended to be heterocentric and 'one-size-fits-all' that did not address the needs and concerns of sexual minority patients. LGB people often experienced care and systems that were heterocentric and ignored the social context of sexual minorities. Some LGB people felt that they were left to self-educate and adapt recommendations aimed at heterosexual patients to themselves, with little or no guidance from HCPs. Most available support resources were perceived as heterocentric, irrelevant and inappropriate, and left sexual minority patients feeling dissatisfied and isolated. Written support information and literature often did not address LGB needs, cover LGB issues or include LGB relationships, and many participants noted a lack of targeted literature for sexual minority people with cancer.

Support Groups

Eight studies contributed to the overarching theme of 'Support Groups'. [22, 23, 25-28, 31, 33] Sexual minority people with cancer often reported a lack of available, adequately resourced LGB-specific support groups. There was also a reported lack of support groups and services for the partners of LGB people with cancer. Support groups that were available did not address the specific needs and concerns voiced by LGB people. In predominantly heterosexual support groups, some LGB people did not feel comfortable disclosing their sexual orientation ("...you don't want to be shunned away from the only place that you can go... You know what I mean? Like, what if you got into a support group, came out [as a lesbian], and then had to deal with homophobia on top of everything else? Then you'd be left with no place to go. So it's almost better to go and hide, or not go at all, than deal with the stigma." [26],

p179) LGB people felt limited benefits from mainly heterosexual groups and described the irrelevance of discussions in these support groups to the issues they were experiencing. This was particularly evident for lesbian women with breast cancer who rejected the focus on appearance and discussion of the importance of breasts for appearing attractive to men (“I sat through two...heterosexual support groups. So finally I had had it...[The issue] was the man’s attachment to the woman’s breast. It had nothing to do with whether she was going to get better.” [22], p1461), and for gay men with prostate cancer whose specific sexual concerns were not discussed (“It’s horrifying because there’s this old man talking about sex with the wife. They don’t want to hear about my problem. I didn’t want to hear about theirs. It didn’t work for me.” [27], p1332). LGB people with cancer who had access to LGB-specific support groups reported positive experiences. LGB-specific cancer support groups were experienced as safe spaces that provided emotional support and allowed LGB people to openly discuss relationships, sexuality and other issues.

Unmet Needs

All themes described above include unmet care needs described by LGB people with cancer that may be extrapolated from the data, for example, needs for LGB-specific support groups or needs for the inclusion of same-sex partners in patient care. The overarching theme ‘Unmet Needs’ is distinct in that it includes specific areas of need clearly articulated by participants within the included studies. Seven articles contributed to this theme.[24, 27, 29-33]

LGB cancer survivors reported needs for ongoing supportive care, structured care plans, and a desire for shared care between the patient and HCP, needs which may apply to a wider cancer population and not necessarily pertain to sexual minority status. A need for patient-centred care for LGB people with and after cancer was also articulated. One example was not only the need for HCPs to consider and respect individual patient preferences for breast reconstruction following mastectomy, but the need for HCPs to firstly discuss the option to decline breast reconstruction with their patients. LGB people reported dissatisfaction with the level of information received from HCPs. When requests for LGB-specific information were not answered, LGB patients were left to seek information themselves and reported feeling anxious and frustrated. Domains of unmet information needs included LGB-specific information on sexuality and relationships, side-effects of treatment, different treatment options such as the option to decline a breast reconstruction following mastectomy, and psychological impacts of treatments. Some participants reported a desire to hear first-hand experiences from other LGB people with cancer to aid in their decision making. Gay and bisexual men in particular expressed a need for open and frank discussions of sexual matters and reported care that did not adequately address their sexual wellbeing (“...we need to have urologists clued up to deal with gay men, we need understanding that our needs and issues are not the same as (those of) a heterosexual man.” [31], p526). An ability and willingness to discuss LGB sexual matters was perceived as being the responsibility of the HCP.

Discussion

This systematic review has synthesised qualitative data of the experiences of LGB people with cancer care to reveal numerous areas of concern and need voiced by research participants. Six major themes of disclosure, homophobia, HCP behaviour, heterocentric care, support groups and unmet needs were identified.

Issues surrounding disclosure of sexual orientation were frequently reported, with results highlighting that some LGB people with cancer feel the responsibility for asking about orientation rests with the HCP. Some HCPs, however, consider that sexual orientation is not relevant to healthcare, or believe the patients will disclose their orientation if it is important to them.[35] For people with past experiences of discrimination due to their sexual or gender identity, this may be a challenge. While some participants indicated that their sexual orientation had little or no relevance to their cancer experience or care, this may be a defensive stance for those worried about negative reactions to disclosure.[19] It may be that a form of 'double bind' exists for some LGB people, where disclosure may be both desirable and potentially threatening; while disclosure may offer an opportunity for openness to discuss specific issues and concerns, it may also lead to risk of discrimination and inequitable treatment. Conversely, non-disclosure may add to the stress of having cancer.[22] The burden of secrecy felt by some LGB people together with data suggesting being 'out' or open about sexual orientation may have beneficial effects

on mental and physical health [36] [37] underscore the importance of understanding and acting upon patient preferences for sexual orientation disclosure.

Disclosure of sexual orientation may be beneficial if reactions are positive, if HCPs are equipped to respond to the specific needs of LGB patients, and if resources and services relevant for LGB people are available. Frequent issues expressed by LGB people with cancer included the lack of HCP knowledge of LGB relationships and sexuality and a reluctance to discuss LGB issues. Data from the perspective of HCPs supports these findings, revealing some HCPs found discussing LGB sexuality 'embarrassing' and described prejudiced behaviour towards LGB patients and delivery of inequitable healthcare, though it must be noted that this data is over ten years old.[38] Nevertheless, review findings demonstrate a need to include cultural competency training encompassing LGB sexuality, relationships and other LGB-specific issues in HCP education, and to provide clear anti-discrimination policies to HCPs.

A recent qualitative study of LGBT people with advanced illness and their carers corroborates many of the findings of our review.[39] Assumed heterosexuality, a variety of preferences regarding disclosure, failure to acknowledge same-sex partners, lack of LGBT-specific support services and fear of discrimination were issues raised by LGBT participants. Importantly, the sample included three participants identifying as a gender minority and highlighted novel issues for this group including treatment complications from taking hormone therapies, being refused gender confirmation surgery due to their illness, and HCPs not using the

correct gender pronouns.[39] Clearly, research must extend to include transgender people as this group experiences a range of unique issues.

Focusing on bisexual people as a distinct group with unique care needs is also warranted. Research indicates that bisexual people face additional stigma and ‘double discrimination’ from both heterosexual and homosexual people,[40, 41] and greater psychological distress and suicidality,[42] compared with homosexual people. Though most studies within this review included bisexual participants, themes exclusively pertaining to bisexual people, such as experiences of biphobia,[43] were not present.

Concerns and needs raised by LGB people in this review indicate that further research and evidence-based changes to cancer care policy and practice are needed. Routine collection of sexual and gender identity data has been repeatedly recommended,[6] and questions about sexual orientation and gender identity are accepted by LGBT people in a variety of healthcare settings.[3, 44] However, recent removal of questions about sexual and gender identity from a national aging survey in the United States contravenes such recommendations and may negatively impact current and future research efforts needed to improve care.[45] To facilitate further research and drive practice and policy change, we support inclusion of sexual and gender identity questions in population-level surveys, cancer registries, and across healthcare settings. Such initiatives will likely advance knowledge of PROs of LGBT people with cancer and enable care improvements.

Based on the findings of this review, and borne from the previously discussed challenges associated with using generic PRO measures with sexual minority populations, we further propose domains of LGB cancer care experiences that may form the basis of future enquiry. Domains include: patient preferences for disclosure of sexual and gender identity and acceptable or preferred modes of disclosure; experiences of homophobia or biphobia, and also experiences of fear, anxiety or expectation of homophobia or biphobia or discrimination; HCP knowledge of and willingness to discuss LGB issues; inclusion of partners in care; and LGB inclusiveness and relevance of information provided.

Clinical implications

To support improved LGB cancer care, a series of recommendations for clinical practice at individual and system levels are proposed (Table 2).

Use of inclusive language that does not assume heterosexuality (for example partner instead of opposite sex usage of wife or husband) may enhance feelings of comfort and safety for people who identify as LGB. Sensitive enquiry about sexual orientation may be appropriate, however some people may wish for their orientation to remain private and this should be respected. Once LGB identity is disclosed, HCP traits and behaviours that may be received positively by LGB people include warmth, sincerity, showing interest in the person and treating them and their same-sex partner with respect. It is also important that people are (where possible) provided with tailored

information and person-centred care, whether this be discussion of the impacts of cancer treatment on sexuality or discussion of various treatment options. Where available, referral to LGB-specific support groups may benefit LGB people with cancer and their partners. Educating HCPs in LGB sexuality and relationships may increase HCPs' knowledge of these aspects of LGB lives which were repeatedly expressed as being important and overlooked by LGB people with cancer. Training may also may also increase HCPs' confidence and comfort in discussing or raising subjects related to sexuality with their patients.[46]

Healthcare services and individual HCPs may consider displaying diverse and LGB-friendly material to ameliorate some of these fears and help LGB patients feel welcomed and safe. Displaying material that reflects the diversity of human relationships may also begin to address the heterocentric nature of healthcare services and systems as perceived by many LGB patients.

Limitations of the Review

The majority of studies included in the review focused on female participants with breast cancer and male participants with prostate cancer. There is therefore significant under-representation of people who have been affected by other cancer types. The age ranges of participants were typically younger than average cancer populations (for example see [47] where median age was 69 years) and most participants were partnered, which is not typical of older LGB populations.[33] It is

possible that LGB people who are willing to participate in research and be open about their identity may not adequately represent the views and experiences of the general LGB population. No studies in this review included transgender participants, highlighting a knowledge gap around the experiences of gender minority people with cancer.[33] This absence of qualitative evidence from transgender people was also found in a 2012 review regarding care for sexual minorities at the end of life.[48]

Conclusion

This systematic review and meta-synthesis highlights the numerous challenges that LGB people with cancer face in the context of cancer care due to their sexual orientation. It is clear that some LGB people continue to experience discriminatory and inequitable treatment, and that many experience fear or anxiety about how they will be treated once their LGB identity is known. Though there are varying opinions about the relevance of LGB identity to cancer care, and uncertainty regarding with whom responsibility to raise sexual orientation lies, non-disclosure may add to the cancer burden. HCPs often lack knowledge regarding LGB sexuality and relationships or may be unwilling to discuss issues important to the wellbeing of LGB people, leaving LGB people frustrated and left to seek their own information. LGB people further expressed feelings of isolation and invisibility due to assumptions of heterosexuality and the heterocentric nature of the care they received. Training and education of HCPs are strongly recommended to address some of these challenges.

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None. Ethical approval to conduct the study was not required.

Conflicts of Interest

The authors declare they have no conflicts of interest.

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Table 1. Characteristics of included articles

Study	Country	Participants	Cancer	Aim
Boehmer and Case 2004	US	39 sexual minority women (lesbian, bisexual, women who report partnering with women) Mean age 49.2 +/- 8.2 years 69.2% partnered	Breast	To describe disclosure of sexual orientation to HCPs among sexual minority women with breast cancer.
Boehmer and Case 2006	US	39 sexual minority women (lesbian, bisexual, women who report partnering with women) Mean age 49.2 +/- 8.2 years 69.2% partnered	Breast	To describe sexual minority women's experiences with breast cancer care physicians.
Boehmer and White 2012	US	22 sexual minority women (lesbian, bisexual, women who report partnering with women) Mean age 54.6 years 68.2% partnered	Breast	To explore the perceptions of sexual minority women who were long-term breast cancer survivors.
Capistrant et al 2016	US	30 gay and bisexual men Age range 48-74 years	Prostate	To investigate social support received or needed by gay and bisexual men with prostate cancer.
Filiault et al 2008	Australia	2 gay men, 1 male partner*	Prostate	To examine, experiences, frustrations and perspectives of gay men with prostate cancer.
Fish and Williamson 2012	UK	15 participants; 6 lesbian, 8 gay men and 1 bisexual man Age range 41-71 years 80% partnered	Any	To investigate the experiences of LGB people with cancer care.
Lee et al 2015	Canada	16 men who have sex with men (MSM) Age range 58-71 years; mean age 65 years 75% partnered (25% in monogamous, 50% in non-monogamous relationships)	Prostate	To describe the impact of prostate cancer treatment on sexual QoL.
Matthews et al 2002	US	13 lesbian and 28 heterosexual women (only findings from lesbian women were extracted) Age range of all participants 36-75 years; mean age 51 years	Breast	To compare lesbian and heterosexual breast cancer survivors regarding cancer experiences, medical interactions and QoL.

		54% of lesbian respondents partnered		
Paul et al 2013	US	13 sexual minority women (lesbian or bisexual) Age range 29-56 years; mean age 43.9 years	Breast	To understand the support and resource needs of sexual minority women breast cancer patients.
Rose et al 2016	Australia	54% partnered 46 gay or bisexual men, 7 male partners Age range 45-89 years; mean age 64.3 +/- 8.2 years	Prostate	To examine gay and bisexual men's experiences of sexual communication with HCPs since the onset of prostate cancer.
Sinding et al 2006	Canada	26 lesbian women Age range 36-72 years; mean age 50 years	Any	To investigate lesbian women's experiences of cancer and cancer care.
Thomas et al 2013	Australia	65.4% partnered 10 participants; 9 gay men, 1 bisexual man Age range 47-70 years; mean age 59.9 +/- 6.9 years	Prostate	To identify the experiences, concerns and information needs of gay and bisexual men with prostate cancer.
Ussher et al 2016	Australia	20% partnered 46 gay or bisexual men, 7 male partners Mean age 64.3 +/- 8.2 years	Prostate	To examine the meaning and consequences of erectile dysfunction and other sexual changes in gay and bisexual men.
Wandrey et al 2016a	US	49.6% partnered Lesbian women (53 users of an online lesbian-specific discussion forum)*	Breast	To understand the perceptions and attitudes of lesbian women with breast cancer on breast reconstruction.
Wandrey et al 2016b	US	Lesbian women (unknown number of users of an online lesbian-specific discussion forum)*	Breast	To examine sexual minority women's experiences of and perspectives on mainstream cancer support services.

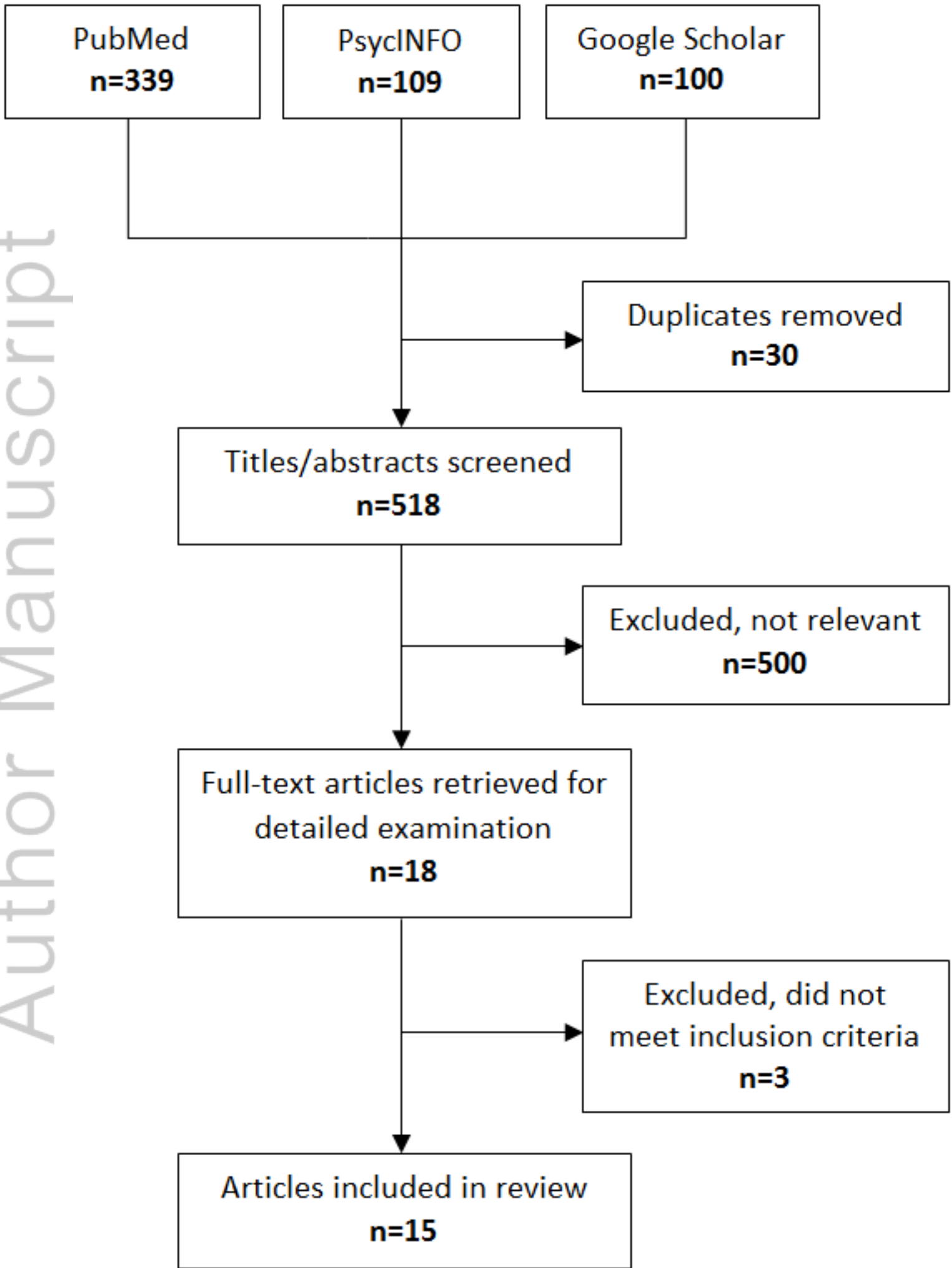
*Further participant characteristics not given

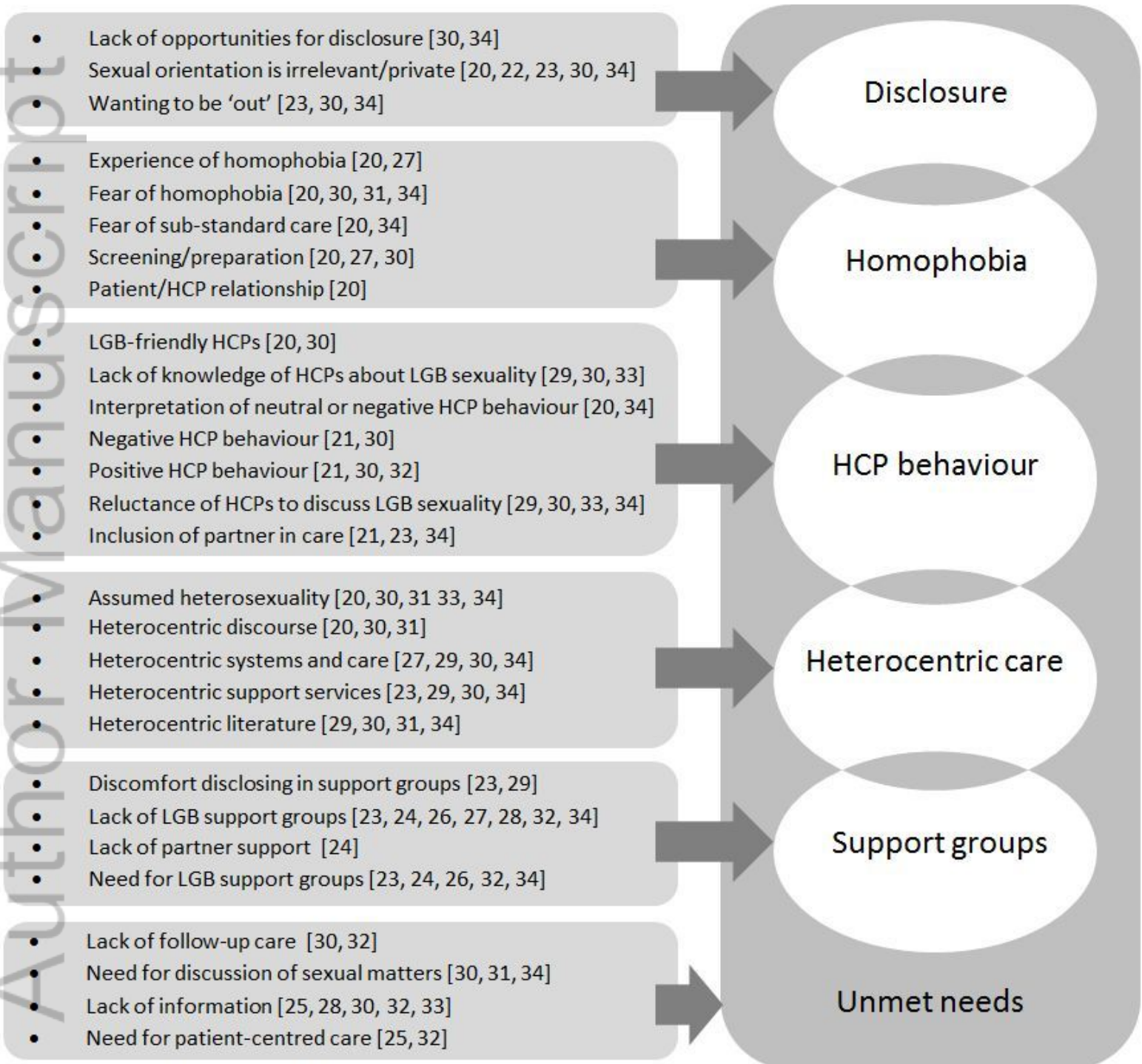
Table 2. Recommendations for practice and policy arising from review findings

<p>Recommendations for HCPs</p>	<ul style="list-style-type: none"> • Avoid assumptions of heterosexuality • Avoid heteronormative language and information • Enquire about sexual orientation and gender identity in a sensitive and respectful manner • If LGB status is disclosed, respond in a positive and reassuring manner • Develop competence in discussing sexual matters with LGB people; when needed, refer to other services or seek additional information • Include same-sex partners in care and treat same-sex partners with respect and courtesy • Provide tailored information in response to individual needs, for example regarding different treatment options or side effects of treatment • Where available, recommend appropriate support groups for LGB people and their carers
<p>Recommendations for services/systems</p>	<ul style="list-style-type: none"> • Display LGB/LGBTI images, logos and other materials • Where possible, provide relevant, inclusive supportive resources, including written information, for LGB people with cancer and their carers • Include LGB material in cultural competency and diversity training for HCPs • Include LGB sexuality in education for HCPs • Link to LGB-specific or friendly support groups or services, if available • Provide and adhere to clear anti-discrimination policies

Figure 1. Search and study selection flow diagram

Figure 2. Twenty eight sub-themes and six overarching themes arose from the analysis. Themes are overlapping, and the theme 'unmet needs' is considered to encompass elements from the themes disclosure, homophobia, HCP behaviour, heterocentric care and support groups.





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