How can we meet the support needs of LGBT cancer patients in oncology? A systematic review

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Introduction

"Lesbian, Gay, Bisexual and Transgender (LGBT) inclusive practice begins with an active choice to change practice so that all are welcome and treated with dignity and compassion." Acquavia 2017. [1]

In the UK, 3.6 million people identify as LGBT accounting for 5% of the total population. [2,3] The specific healthcare needs of lesbian, gay, bisexual and transgender (LGBT) people are often different to heterosexual people, and many find that their needs are not met by healthcare service. [4, 5] Sexual orientation and gender identity (SOGI) information is not routinely collected and some LGBT people may be reluctant to 'come out' over fear of discrimination, and therefore avoid healthcare services. [6] Minority stress is the stress and stigma of living in an area where discrimination, marginalisation and homophobia continues to impact on the individual and has [7] been suggested to be linked with physical health problems and an increase in smoking, alcohol and drug misuse; however there is limited research in this area. [8] A survey identified those that self-identify as gay or lesbian were more likely to smoke [9, 10]; Roberts. et al (2017) discovered that 45.7% of LGBT people asked smoked daily and 22.7% smoked occasionally. [11] The Equality and Human Rights Commission found LGBT people were 1.5 times more likely to suffer from alcohol and substance misuse. [12] These lifestyle choices increase the risk of preventable cancers in the future. [13]

One third of cancer diagnosis are those aged over 65; therefore, these patients would have lived through times where being LGBT was illegal or treated as a mental illness. [14] Around 55% of LGBT patients have experienced assumptions within the National Health Service about SOGI with a quarter of health care professionals

(HCP) having overheard colleagues make negative comments about LGBT people. [15, 16] This prejudice could stop a patient disclosing SOGI, over fear of not receiving adequate care from HCP. [17] Many healthcare services are orientated towards heterosexual, cisgender people and can exclude LGBT people.

It has also been noted that mental health problems are more prevalent in the LGBT community with anxiety and depression 1.5 times higher. [10, 18] If LGBT people are already experiencing greater mental health problems, the addition of cancer may increase stress. Mehnert (2017) identified 52% of participants had clinically significant levels of psychological distress from cancer, however the study did not ask for SOGI.[19] Some LGBT people may have limited familial support, which could increase the need for appropriate support within the NHS.[20]

The aim of this systematic review is to critically analyse primary research studies that investigate psychosocial support needs of LGBT cancer patients during and after cancer treatment.

Method

A systematic literature review was conducted to analyse the current research for LGBT patients who are diagnosed with cancer and the specific support needs of this community. The original search was conducted on January 2018, and then repeated in May 2020 for publication.

Inclusion and Exclusion Criteria

Evidence was retrieved spanning from 2000 to present day to ensure the most recent data is obtained. This also takes into account major law changes which were introduced in the early 21st century such as the Civil Partnership Act 2004, Equality

at Work Rights and the repeal of section 28 in Local Government Act. Sources included were available online, full text, primary research, qualitative and quantitative and written in English. Sources were excluded if they not LGBT in aim or participant, not cancer related, not psychosocial in focus, systematic review or non-peer reviewed or discussion papers.

Search Strategy

The databases used to find literature were Medline and PubMed, as they are two of the largest databases of healthcare and medical research. Medical Subject Heading (MeSH) aided in finding key words and expanding search terms, then AND/OR qualifier tools were used. The search terms recorded (Figure1) were used to encompass all studies of LGBT people, psychological and supportive care and cancer and oncology.

Study Selection

Records were screened by one researcher following the eligibility criteria and removing of duplicates. The records were screened firstly by title, then abstract and finally full text. Results were recorded on a PRISMA flowchart (Figure 2). Due to the range of evidence found, three critical appraisal tools used to evaluate the quality of the research; these were the Critical Appraisal Skills Programme (CASP) for qualitative research, the Effective Public Health Practice Project (EPHPP) for quantitative research and the Specialist Unit for Review Evidence (SURE) for cross sectional studies. [21, 22, 23]

Thematic and Content Analysis

Themes were created by one researcher by coding the literature, searching for key words and phrases that were recurring and most prevalent across the results. These keywords were then developed into themes.

Figure 1: Search Terms

Figure 2: Prisma Flow Chart

Results

Results of the search included 20 studies (Figure 3). [24-43] Of these studies, ten were qualitative, seven quantitative and three mixed method approaches. The appraisal tools were used to assess quality of each study, depending on the methodology of the study (Figures 3). All the studies that were included in the critical analysis were used in the results due to the lack of studies that included all people under the LGBT umbrella. Majority of the participants were white cisgender gay males and lesbian cisgender females. Only two of the studies had focus on transgender and gender non-conforming patients. [29, 42] One of the studies is focused on radiotherapy, while all other are broadly “cancer services” or oncology. [29]

Figure 3: Results of the literature search

Results of the thematic analysis are summarised in Figure 5. The main themes highlighted include: HCP knowledge and education, negative impact on mental health, lack of LGBT inclusive support groups and resources, prevalence of discrimination within healthcare services and the disclosure or non-disclosure of SOGI.

Figure 4: Thematic Analysis

Health care professional's knowledge and education

The results highlight that a lack of understanding and knowledge of the LGBT community and the specific needs throughout the cancer pathway contributed to distress and distrust in the health care services. Participants in the studies expressed a lack of respect and loss of dignity from HCPs when they have dismissed or excluded partners or access to non-traditional support networks. [36] Assumptions, misunderstanding and mis-gendering can impact patient experience and some people can feel 'pushed back into the closet'. [33, 36]

When HCPs are not knowledgeable in LGBT health, patients had higher unmet needs in survivorship. [40] Only 4.6% of HCP's were able to answer all the LGBT health question correctly in Banerjee et al (2018) study. [25] However, this was based on one hospital in USA so may reflect only one centres education. Gay cisgender men indicated unmet needs in sexual side effects and management. Patients felt unable to talk to HCP's as was a "taboo" subject and were therefore unsure of who to ask and where to find information. [39] Shetty. et al (2016) found that 36% of HCPs in the USA wanted extra training on LGBT health needs. [41] Transgender and gender non-conforming patients had different support needs and experiences in cancer to the LGB patients. Taylor & Bryson (2016) highlights a lack of HCP knowledge and understanding with the overlap of cancer care and gender affirming care. [42] Lack of information with regards to impact of cancer on gender affirming care, for example in hormone treatment, causing difficulties for patients to make informed decisions about care.

Negative impact on mental health

The literature indicates that LGBT cancer patients are more likely to experience depressive symptoms and post-traumatic stress. [37, 38] However, Boehmer. et al (2012) found that there was no significant difference between sexual orientation and poor mental health after cancer diagnosis, but LGBT discrimination impacted physical health. [27] Feelings of isolation and impact on relationships were reported. [28, 31] Brown & McElroy (2018) and Fish & Williamson (2018) also found that participants felt uncomfortable in mainstream support groups, feeling alienated and had experienced heterosexism. [28, 33]

Impact on body image was reported in gay cisgender men. [32, 38, 39, 42] Impact on sexual identity and gay identity were reported, and that physical appearance is important gay culture. Some of the transgender and non-gender conforming participants welcomed the radical surgery as a positive and the freedom it brings. [42] However, some felt this was forcing them into conforming to gender and having to become a binary gender by default. In majority patient participant studies felt there is lack of psychological support for LGBT patients. [30, 31, 32, 33, 37, 39, 40, 42, 43]

Lack of LGBT inclusive support groups and resources

Mixed feelings were reported about mainstream support groups. [33] Six of the studies found that patients felt uncomfortable talking about sexual health. [24, 31,32, 33, 39, 43] Cancer non-specific groups were more inclusive as there was less focus on appearance and more focus on psychological issues. [35] Patients want opportunities to speak candidly about sexual health and morbidity without fear of discrimination. [32] Some support groups were unwelcoming for LGBT patients, with patients trying to seek out LGBT support. [28] Results from all of the studies uncovered that although a bespoke service is not necessary, an LGBT non cancer site specific support group would be beneficial. Gay cisgender men had no access to a gay cancer support

group without travelling a great distance, creating isolation and loneliness. [30] For transgender and gender non-conforming there was no resources or cancer support that was inclusive of their needs. [42] Similarly in lesbian cisgender females, patients felt uncomfortable and that there was a focus on traditional gender stereotypes of being a “girly girl”, “pink and fluffy”. [33]

LGBT people have found homophobic behaviour and comments on some cancer forums. One mainstream support group fell short in supporting lesbian breast cancer patients, focussing mainly on their appearance and the need for ‘pleasing husbands’. [43] This was interesting as participants were unaware of being studied due to the forum being on a public site, giving a more realistic viewpoint as there is less participant bias.

Prevalence of discrimination within healthcare services

Heterosexism is a big issue among LGBT people when visiting healthcare providers. In one study, 27% of HCPs assumed heterosexuality. [41] Heterosexism and heteronormative behaviours can impact dignity and trust building between HCP’s and the patient and can promote an ‘anticipated fear of discrimination’ whether it is done consciously or not. [26] LGBT patients may feel ‘pushed back into the closet’, as they are unable to be open and themselves. Acknowledging same sex partners and differing support networks is important in receiving good care. Hulbert-William. et al (2017) had a high proportion of LGB patients did not have family or close friends involved in treatment, and a high amount of bisexual patient’s report being treated as a set of symptoms. [35]

Carr (2018) expressed that healthcare providers should have clear signs and posters stating that discrimination of all forms is not tolerated. [31] Only one participant went forward to make a formal complaint about homophobia, even though it is a theme

throughout the literature. Patients felt some HCP's were overtly homophobic or subconsciously with assumptions regarding sexuality and gender which were inaccurate or offensive. [26, 29, 31,33, 36, 43] Kamen. et al (2019) reported intersectionality from patients that experience not just homophobia, but discrimination such a sexism, racism and ageism. [37] This was also the experience of transgender and gender non-conforming patients where it is unclear how their experiences were influenced by particular elements of their social location, for example, ethnicity, gender and sexuality. [29,42]

Disclosure or non-disclosure of sexual orientation and gender identity

Only 26% of HCPs collected sexual orientation data and another study states only 8% of participants had sexual orientation on hospital form and only 1% had gender identity. [40, 41] Not all patients feel comfortable disclosing SOGI may fear a negative reaction or discrimination. [28, 33, 36] However, patients felt that being "out" to HCP's was important but not always relevant. [26, 28, 31, 32, 38, 39] Fish & Williamson (2018) states that sexual orientation is not always relevant to healthcare, especially in urgent care, but patients also felt they had poor care by not being able to be open with HCPs. [33] One participant said it was important when asking things relevant to care, such as anal sex after rectal surgery or pelvic radiotherapy. [26] Opportunities to disclose should be made clear on forms and hospital databases. [31, 33, 41]

Discussion

Healthcare providers in the UK have a duty of care to treat all people fairly and equally by the Health and Social Care Act 2012 and the Equality Act 2010. HCPs do not need to change religious or moral beliefs to provide good care to LGBT people, but it is important to treat each individual with respect, dignity and excellent care. [1]

Resources are available that advise healthcare providers and HCPs on LGBT health disparities and how to be an inclusive organisation. Stonewall and Macmillan have many publications for LGBT health. [7, 44] These documents provide vital information about experiences of LGBT patients, where there are gaps in data and service provision, and how healthcare providers can improve practice. The LGBT foundation is working together with Macmillan offer education days for HCPs and volunteers regarding LGBT cancer specific issues, such as increased prevalence of depression and anxiety. LGBT Public Health Outcomes Framework Companion document sets out recommendations for health services, states that cancer service providers should consider staff training on LGBT issues including promotional materials that use LGBT language and imagery. [45]

One in four LGBT people experienced inappropriate curiosity from HCPs stemming from a lack of understanding, one in eight has experienced unequal treatment from HCPs as a result of being LGBT, and one in seven avoids treatment for fear of discrimination. [47] Transgender and non-binary people have found themselves being an 'expert patient' having to educate HCPs, even when it is not relevant to their care. [46] LGBT people may look for LGBT friendly posters, leaflets and information when in a new healthcare environment to check that they are welcome and safe. [4] By healthcare services displaying rainbow flag this is actively showing the public that LGBTQ+ is supported, however this is insufficient on its own. [48] Using neutral language such as "partner", "they/them" pronouns and "person" instead of gendered language minimised heteronormative assumptions.

It is argued that poor mental health prior to cancer diagnosis would contribute a poorer mental health after. [49] 52% of LGBT people have reported depression and

46% of trans* people reported suicidal thoughts, an increase of these rates following a cancer diagnosis has been found. [50, 37] When looking for support groups to help these psychological issues, patients found that there were few LGBT specific support groups and resources available, with online resources deemed to be crucial. [28, 43] Face to face and online support groups should be a safe space to discuss emotions, experiences and voice concerns amongst people that have had similar experiences, and it has been demonstrated using both simultaneously provides maximum support. [51,52] However, the results show these are not inclusive and have heteronormative or homophobic attitudes. [24, 28, 31, 33, 38, 39 42, 43] ACCESSCare suggested that there is not a need for 'bespoke' services for LGBT patients, but for HCPs to perhaps think differently to ensure equality in patient centred care. [53] Providing access to professionally led and peer led support groups have found to improve emotional function, coping skills, quality of life, personal relationships and cancer knowledge. [54] Support networks, for example a partner, family, friends, through the cancer pathway is shown to be important to give emotional support. [55] LGBT people may have 'non-traditional' support networks that need to be included, if the patient wishes, that will help with emotional toll that cancer can have.

At present, SOGI data is not regularly collected; missing this key data set means that LGBT people are often 'invisible' on the National Cancer Registry. Monitoring and recording will fill gaps in service provision where LGBT people have been overlooked or assumed to be heterosexual. LGBT Public Health Outcomes Framework Companion document, which is supported by Clinical Commissioning Groups and NHS England, state that a service user's SOGI should be collected and monitored, and that this data is used to improve services. [45] Having forms that include sex and

gender identity sends a strong message to transgender people that they are accepted and safe to be who they are. [48] Despite recent changes in legislation and policies to improve supportive care, LGBT people still experience inequalities and exclusion in health and social care. [16, 47, 53]

Recommendations

Figure 5: Recommendations for Practice

The results from the review clearly show a lack of knowledge and understanding of LGBT community and health. Including LGBT awareness and health education in HCPs training programmes, such as radiography BSc courses, would tackle this. Furthermore, education in LGBT health and cancer is important in understand how we can prevent unmet needs in future. SOGI monitoring should be included when collecting information from patients. In radiotherapy this could be implemented of patient treatment systems such as Mosaiq and Aria. Healthcare providers should have the option for service users to disclose SOGI, with accordance to the sexual orientation monitoring fundamental information as standard. [56, 57] By including this information, organisations will be demonstrating that there is equitable access, have an improved understanding of the impact of health and care outcomes and be able to better identify health risks for LGBT people.

Written information and resources need to be more inclusive, for example same sex couples on posters, gender neutral information and reference to LGBT health. LGBT cancer support groups should be established, as the results are clear that patients are actively looking for this resource. These should be linked with cancer charities and local LGBT organisations to promote service and signpost to resources that are

inclusive of their needs. Future research is needed for LGBT cancer patients so we can further improve patient experience, cancer outcomes and ensure the LGBT patients are represented equally in research. Many of the studies struggled with recruitment and used advertising, snowball sampling and “word of mouth” to gain participants. Organisations should look at how to improve recruitment to studies and include SOGI in patient characteristics, so they are represented in research data.

Limitations

Thirteen of the twenty studies were conducted in USA, which is a limitation due to differing healthcare systems, policies and agendas therefore not necessarily fully representative of the UK population. However, the discrimination and prejudice that LGBT people have experienced was seen as similar in both USA and the UK as the studies from both countries reported similar results.

There was a lack of transgender and gender non-conforming representation in the research studies. Only two of the studies were based solely on transgender and gender non-conforming people. Transgender and non-binary people may have specific health needs that differ from LGB people, such as on-going gender reassignment treatment, being mis-gendered, not being able to use a preferred name and a worry that HCPs will not take gender identity seriously. [47] Many other publications from Macmillan, Stonewall, Seeing People as People and the ACCESSCare study highlight issues where HCPs fail transgender and non-binary people. [7 16, 47, 53]

Radiotherapy was rarely mentioned in the evidence, with only one study was solely focussed on radiotherapy. Therefore, evidence-based recommendations cannot be accurately applied to radiotherapy. However, the overarching issues within oncology

and wider healthcare will impact radiotherapy departments, such as the prevalence of discrimination and SOGI recording. Further research is needed to investigate if/how radiotherapy specifically impacts LGBT people, for example in survivorship and side effect management, and to make LGBT patients visible in radiotherapy. Finally, the literature review was conducted by one researcher, therefore thematic analysis and coding is open to researcher bias. Future reviews should have multiple researchers cross checking codes and discussing themes until a consensus is agreed. This would increase validity of the study and protect from potential bias.

Conclusion

The results of the review highlights gaps in healthcare services in terms of HCP knowledge, cancer support and unmet psychosocial needs of LGBT patients. The recommendations are a start in increasing inclusivity in oncology and radiotherapy and being able to rectify the issues LGBT face navigating services, such creating more LGBT cancer support services in a support groups and resources. Further research is necessary in radiotherapy to better support LGBT patients in cancer journey.

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