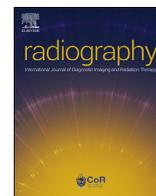




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Help me to come out gracefully! Working with lesbian, gay, and bisexual, people affected by cancer to develop a national practitioner guide supporting inclusive care

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ABSTRACT

Introduction: The healthcare support needs of the lesbian, gay, bisexual (LGB) and transgender community are becoming an emerging area of healthcare research. Providing person-centred care is World Health Organisation policy and as such it is important that Radiography services can demonstrate areas in which they are working with people to design, develop and feedback on the services that they receive. This research aimed to establish how cancer treatment impacted on the identities of LGB people, their experiences of care, and their engagement with developing a practitioner guide.

Methods: This cooperative inquiry is underpinned by person-centred philosophy and participatory research principles. Participants were nine lesbian, gay, and bisexual people affected by cancer. Each engaged in two facilitated, audio-recorded conversations to explore their experiences of cancer care. An analytical framework based on Mezirow's Transformational Theory was used to organise the data, followed by detailed content analysis to develop themes.

Results: Participants included men and women, aged 45–68, who had experienced different cancers. They explored how cancer treatment had impacted on them, and worked with the researcher and stakeholders to establish a seven-recommendation practitioner guide aimed at improving LGB people's care experiences. Their accounts revealed a broad range of issues that both corroborate and build on existing evidence. Themes highlighted expectations and experiences of both assumptions and prejudice in healthcare interactions. These experiences, along with misinterpretation of relationships with significant others, led to feelings of discomfort and reserve about self-expression. Findings of the research are presented in the following key areas: Dilemmas of attending oncology appointments; Inclusive experiences of care; and Formulation of the practitioner guide.

Conclusion: The research findings enabled development of a national practitioner guide with the participants and key stakeholders to raise awareness of the needs of LGB persons affected by cancer and support better care.

Implications for practice: By providing real-life accounts this research adds to understanding of how LGB persons interact with services, developing evidence to support cultural competence within the profession of Radiography and oncology services more broadly.

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Introduction

The healthcare support needs of the lesbian, gay, bisexual and transgender (LGBT) community are becoming an emerging area of healthcare research.^{1–3} There is increasing recognition that

healthcare services should be delivered in a person-centred way,⁴ placing the individual as the primary focus of their care and delivering this in an empowering and holistic way.⁵ Providing person-centred care is World Health Organisation policy and services must work with people in relation to their design and development.⁶ Aligning with these priorities, we report findings of a participatory inquiry undertaken between 2018 and 2022. The inquiry aimed to establish how cancer treatment impacted on the identities of Lesbian, Gay and Bisexual (LGB) people, focusing on experiences related to sexual orientation (who someone is

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attracted to) rather than gender identity (personal sense of one's own gender). This article reports the exploration of the participants' experiences of care and their engagement with developing a practitioner guide. The guide was aimed at improving the experiences of LGB people who are affected by cancer. Although initially aimed at radiography services, the practice learning is applicable across pathways, therefore the final guide was published for all healthcare practitioners.⁷

Literature review

Due to the variation in societal attitudes towards sexual orientation and the general treatment of those in the LGBT community, experiences of care differ vastly for LGB people.⁸ International qualitative and quantitative research focusing on the experiences of cancer treatment among LGB people has identified several key issues. Themes revolve around LGB people's experiences of care, emotional wellbeing, and lack of inclusive support.

Qualitative studies in the US and Canada explore discriminatory attitudes in the care setting, and how this makes it difficult for LGB people to be their true selves.^{9–11} Assumptions that people are heterosexual, known as heteronormativity, make many LGB people feel they need to correct their health providers.¹² This can be problematic, as many LGB people affected by cancer are older and will have lived for significant periods of time where it was illegal to be open about who they are.^{13,14} Coming out and correcting health practitioners can be a dilemma for many LGBT people, supported by several surveys undertaken in North America.^{15,16} The need to cope with frustration and anger at discrimination and poor experiences in the care setting is also reported within Australian and Canadian studies, with partners feeling unwelcome in consultations,¹⁷ and negative attitudes from staff being reported.¹⁸

Research from the North America shows an overall lack of emotional support during cancer treatment.^{19–21} This is concerning, as studies also show older LGB people are more likely to live alone and can have poor relationships with their family origin,²⁰ and therefore rely on more formal mechanisms of support rather than family members and partners.²¹ Several focus groups and secondary analyses of surveys examining mental resilience during the cancer journey demonstrates lower mood, coping, and higher stress levels amongst LGB people when compared with their straight counterparts.¹⁹

North American and Australian studies provide insight into LGB peoples experiences in managing the physical effects of cancer treatment, particularly when impacting on sexual function following prostate cancer and considering body image after breast cancer.^{22–25} Findings suggest that LGB people are often disadvantaged by most advice being tailored towards heterosexuals and their sexual practices.²⁵

These findings all provide insights into the experiences of LGB people when accessing services and their support needs, however, there may be variation depending on culture and health service delivery structures. On searching it was only possible to find four published studies from the UK which suggested challenges for LGB people when accessing UK cancer services.

A secondary analysis of 68,737 respondents to the UK's National Cancer Patient Experience Survey was undertaken in 2013.²⁶ Results indicated statistically significant differences between responses from LGB people (0.8% of sample) and their heterosexual counterparts. LGB respondents were only offered a single treatment option ($p < .01$), wanted to be more involved in treatment decisions ($p < .01$) and had less contact with healthcare professionals ($p < .01$). They felt as though professionals talked about them as if they were not there ($p < .02$) and were less likely to have family members or friends with them during consultations

($p < .01$). LGB people were found to lack adequate aftercare arrangements when compared with heterosexual people ($p < .02$). The results indicate negative experiences and inequality for LGB persons within the UK when accessing cancer services.

Phenomenological research using in-depth interviews with twelve people explored experiences of gay and bisexual men who had received treatment for prostate cancer.²⁷ Four key themes emerged: information needs, relationships with healthcare providers, the need for support networks, and sexual wellbeing. Participants wanted candid discussions with health professionals about how treatment would affect their lives and sexual function, without heteronormative assumptions. They felt that culturally relevant support for gay and bisexual men should be developed and available before and after treatment. Participants felt that their health practitioners had little understanding about their needs and about how their experiences were different because of their sexual orientation. Another qualitative study of fifteen LGB people affected by cancer described an 'awkward choreography around disclosure', whereby participants felt they had to correct health practitioners' assumptions and were concerned that this might impact on the care they would receive.²⁸ Participants found it hard to make sense of sub-optimal care and felt alienated from psychosocial cancer support. Repeated dilemmas were described about how and when to come out to health practitioners. They described feeling discriminated against due to the attitudes of some health practitioners, which they perceived through micro-aggressions and heteronormative health practices. Similar themes resulted from a qualitative study of thirty LGB people attending oncology clinics for different types of cancer across England.²⁹ Participants explained that the ability to be open about who they are, including disclosure of their sexual orientation in a non-confrontational manner, was a key need. Involvement of partners was valued as well as safe and healing environments that can facilitate disclosure.

The progression of research in this area is valuable, however, there are limitations that include lack of diversity in participants. LGBT legislative reforms have evolved at different rates in each UK nation and societal attitudes vary between urban and rural communities.^{30,31} The studies have primarily included people from England and there is a lack of participants from Black and Asian minority ethnic communities and bisexual women.^{26–29} Study participants tend to be out and open about their sexual orientation.^{27–29} It is important to design studies that focus on other parts of the UK and explore more varied experiences.

The subject of the LGB person's cancer experience is a newly emerging research field, and the pace of change of LGB persons' social acceptability and legal reforms vary considerably across the world.³² The findings of research to date are therefore not wholly transferable to the UK population and therefore our study aimed to:

- Explore with LGB persons affected by cancer, their experiences throughout the cancer care pathway,
- Find out with LGB persons any distinct aspects of their treatment and care, and
- Work with LGB persons and their representatives and key stakeholders to develop a practitioner guide addressing the needs of LGB persons.

Methods

This study used person-centred and critical theory as a foundation and followed a participatory research design, based on Heron and Reason's Cooperative Inquiry (1997).³³ Ethical approval was granted by the supervising academic institution (Protocol ref: LGBPH_20182505_VERSION_1.0).

Purposive sampling aimed to include up to twelve adults who self-identified as LGB and had been closely affected by cancer in the last five years. Persons who were currently undergoing, or about to undergo invasive treatments within three months were excluded from participation.

Sexual orientation monitoring is not currently captured in the UK at cancer registration which meant that targeted recruitment was not possible within the care setting. Therefore, a comprehensive public awareness campaign was devised to increase awareness of the research. The researcher worked with cancer support groups, key charities, and organisations from across the LGBTQ plus community in Scotland. Snowball sampling was employed to increase further potential recruitment. Interested participants contacted the researcher and were provided information and explanation of the study. If willing to participate, they provided informed consent.

The inquiry method was piloted with a community of twelve doctoral researchers to develop the researcher's competence and skills, and to test whether the stages of the planned inquiry could translate into the real world. The pilot participants created an identity map, then reflected on a healthcare experience and its impact on their personhood. Participants were divided into teams of three or four and were invited to share selected experiences. This process provided useful information on a range of creative materials that participants could use to explore their identity and experiences, a process for agreeing the means to record conversations, and developed the researcher's facilitation skills.

People who had consented to participate in the research were invited to an initial face-to-face session. They were invited to have a key support person present. In the first session the researcher supported the participant in exploring their personhood, or sense of identity. Creative methods facilitated reflection, including art, drawing, timelines, sculpture, photography, artefacts, and collage. In a second session, participants explored their experiences of cancer treatment and impacts on their long-term wellbeing and personhood. The sessions were audio-recorded, transcribed verbatim by a research administrator, and creative materials were photographed. Copies of the transcripts were sent to the participants to check for accuracy and comment if they wished.

An initial content analysis of the data was used to organise the data using an analytical framework based on Mezirow's Transformational Theory.³⁴ Data within each framework category were then inductively themed using a systematic coding process. Participants were invited to comment on the resulting themes. Care was taken to minimise potential impacts of researcher bias by using a reflexive journal and engaging in debrief discussions with a supervisory team. Field notes were written to describe what the researcher did, felt, saw, and heard in each face-to-face session, consistent with practice development methods.³⁵

The intention had been to use the research findings to co-design practice guidelines with participants and other key stakeholders in a workshop. Due to the Covid-19 pandemic, however, face-to-face workshops were not possible. Instead, research themes which focused on improving practice were sought during analysis. These were used to develop a draft practitioner guide, which was shared with the participants for feedback and development. A co-created draft guide was then shared with key stakeholders, including from the Scotland-based cancer charities and LGBT community groups that had initially lent their support in the recruitment phase. Participants and stakeholders were invited to complete a feedback sheet which sought responses to the information, recommendations, and resources within the guide using 5-point likert scales (responses ranging from 'very poor' to 'excellent') and free text responses. Participants were also given the opportunity to provide feedback over the phone, by email or by post, and were offered the choice to edit the text contained within the guide if they wished.

Results/findings

Nine participants were recruited into the research, explored how cancer treatment had impacted on them, and worked with the researcher and stakeholders to establish a seven-recommendation practitioner guide aimed at improving LGB people's care experiences. Participants had experience of different cancer pathways, including breast, pelvic, head and neck cancer (Table 1). The participants were aged between 45 and 68 and resided across rural and urban communities across Scotland. Two described themselves as 'non-scene' i.e. non-participative in the LGBT community, and one of the participants was not openly gay i.e. 'out'. Findings of the research are presented in the following key areas: *Dilemmas of attending oncology appointments*; *Inclusive experiences of care*; and *Formulation of the practitioner guide*. Quotations are provided using pseudonyms to illustrate key points and demonstrate analytical rigour.

Dilemmas of attending oncology appointments

Participants in the research discussed the anxiety they felt when attending outpatient appointments. Some remarked that when attending appointments, they felt as though other people may be homophobic and this contributed to additional apprehension. Related to this, some participants did not feel comfortable with showing physical affection with their partners when supporting loved ones in front of healthcare staff and other patients. For example, Tate explained: "Not only am I waiting to find out if I have cancer or not, I'm also worrying about the people in the waiting area. Are they thinking that I'm weird... It's like just another thing" (Tate Session 1). Evan also explained: "I don't express affection, physical affection with my partner, very much in public. The reason for that is that's quite loaded, I think to do with LGBT history and the social acceptability, and we get very good I think hiding who we are" (Evan Session 2).

Participants agreed that practitioners should support the disclosure of sexual orientation and that this should be done in a non-judgemental way. Susy suggested: "I would like to come out gracefully, just drop it into the conversation, but make it just seem the most natural thing in the world, so there's no awkwardness about it" (Susy Session 2). There were occasions when healthcare staff were surprised when participants came out to them, resulting in embarrassment and unease in healthcare interactions. Tate described such a scenario: "I'm forever asked if I could possibly be pregnant – every time I'm scanned, for example. Only once have I jokingly said that would be impossible as I'm a lesbian, as well as the fact I have had my ovaries removed! The woman I was speaking to didn't laugh or make any further comments. Anyway, I just answer, 'No' now" (Tate Session 1).

Despite civil partnerships and marriage between same-sex couples having been legalised for some time, participants described experiences of healthcare staff not realising that same-sex partners could be next of kin. Susy described an incident

Table 1
Summary table of participant characteristics.

Participant pseudonym	Gender	Age	Cancer Pathway	Home setting
Drew	Male	67	Anal	Rural
John	Male	67	Head and Neck	Rural
Sisi	Female	55	Uterine	Urban
Lewis	Male	63	Bladder	Rural
Tabitha	Female	54	Colorectal	Urban
Susy	Female	45	Breast	Urban
Tate	Female	45	Breast	Urban
Agnes	Female	68	Ovarian	Rural
Evan	Male	67	Unknown Primary	Urban

during her first chemotherapy visit: *"She came back, actually quite discreetly, managed to say 'ooh, you know, your form says you were widowed, but then you said you were lesbian', and then I had to say, well actually, it was my civil partner that died, and I ticked the widowed box. That was horrible"* (Susy Session 1).

On occasion healthcare staff even expressed homophobic and prejudiced views towards participants, allowing their own personal beliefs and views to impact on the support and care they were providing. Lewis explained: *"I was talking to my GP about my situation, and she said you know that being gay is wrong. She said you need to accept that you are in the wrong. She was a real demon in the church"* (Lewis Session 1). Participants described how they sought private treatment alternatives in an attempt to find more inclusive staff; Susy: *"I said, look, I'm gonna pay for my own, I'm gonna find someone else can you recommend someone who is gonna be good at both bereavement and is gonna be OK with the LGBT thing?"* (Susy Session 2).

During the interviews participants were asked about what they understood about being part of the LGBTQ community and what this meant to them. On occasion they had seen literature and promotional materials relating to targeted support for Queer persons. Some participants remarked on the term 'Queer,' revealing differing views about the term amongst the group. Lewis found the term triggering of previous instances of homophobia: *"Queer, don't get that. Don't ever, ever, call me queer, to me that's such an insult. I don't get that word, I think it's appalling, it's one of the worse things you could ever call someone when I was a kid. Why would you want to own that?!"* (Lewis Session 1). Whereas Agnes felt: *"Queer, it's a shorter word but it's a happier word I don't think it carries, as far as we're concerned, any stigma. We're just us. I don't think of myself as a label."* (Agnes Session 1)

Inclusive experiences of care

Participants in this research also described affirming and positive experiences in care. Tabitha described: *"she had such a shit time with the cancer, she had so much pain, it was just a nightmare. I did this bereavement group at Maggie's, they were fantastic with Catherine all the way through. And with me too."* (Tabitha Session 1). Examples were given of healthcare practitioner being supportive by including partners in consultations. Agnes's partner said: *"At the very first appointment at the oncology unit, I dropped you off, and was driving out when I got a phone call saying, 'Oh you've to stay here too!"* (Agnes Session 2). Tate also described the importance of this: *"The oncologist will answer her questions, she'll look at her (partner), she'll involve her in the conversation as if as if she was my husband, as a man. So that makes me at ease. It's like okay you're respecting the fact that I'm a lesbian, and this is my partner. And you're involving her in the conversation like you should"* (Tate Session 2). John also described the need to not be singled out or made to feel uncomfortable because of their sexual orientation: *"I think it's possibly... the way ethnic minorities feel I just don't want to be singled out."* (John Session 2).

Formulation of the practitioner guide

Following analysis, agreed areas which highlighted a need for change were formulated with the participants. These formed the basis of a draft set of recommendations for practitioners. This initial draft was sent to all participants within the inquiry for feedback. All nine participants responded by email within three weeks using the feedback questionnaire, indicating that the contents of the guide were good (n = 6) or excellent (n = 3). There were some suggestions regarding specific wording of the draft text, and these were all incorporated into the guide. In addition, three participants

explicitly stated that they were happy to have been involved in the research and were pleased to have seen the guidance created as a result. Lewis fed back: *"Being part of your research helped me enormously. It was tough in a lot of ways, but it opened up 'me' to myself and I'm thankful for that."*

After the research participants had agreed the text stakeholders were invited to contribute. Their feedback provided verification they approved of the content and writing of the guide. Stakeholders included 53 representatives from third sector organisations, academia, and healthcare, as well as LGB cancer survivors who had become known to the researcher throughout the course of the participatory inquiry. Those willing to participate completed the same eight open questions, which sought free text responses, and the same five-point Likert scales, as used with the research participants. Similarly, a draft of the final guide was also offered for stakeholders to make suggested modifications and corrections. Forty-three feedback replies were received from a range of representatives and employees of various organisations within eight weeks (Table 2) Final approval for the guide was then sought from the participants to ensure that after all modifications from stakeholders, the guide still reflected their views and addressed their needs.

Discussion

The findings of this research demonstrate distinct aspects of LGB people's experiences of treatment during cancer journeys. Although some positive interactions with healthcare providers were described, there were numerous negative and discriminatory experiences, offering insight into when instances of poor care are likely to be experienced. These findings are consistent with other UK-based studies, in that there are examples of healthcare providers allowing their own heteronormative views to lead to misunderstandings.^{28,29} This has had the effect of making LGB people feel uncomfortable when correcting their health professionals' assumptions. As with international research, this includes assumptions being made about relationships and lack of inclusive approaches.^{21,23} This can be seen as sub-optimal care, leaving people feeling unable to be open about who they are or able to provide or receive physical affection and comfort when receiving care.

The positive experiences of LGB people within the care setting are under-reported in research, and insights from our study add can influence improvements in practice through our practitioner guide. Participants felt most comfortable and at ease when their needs were addressed and partners were openly accepted. Openness in communication style, caution over use of labels, and a lack of assumptions made by health professionals enabled care journeys to be easier for LGB people and left them feeling positive as a result. The study succeeded in its aim of developing a practitioner guide addressing the needs of LGB persons which has been adopted by the Society and College of Radiographers as national guidance.⁷ It is hoped that this guide can serve as a learning tool for healthcare and a source of advice for those who wish to improve services and practices.

Although this study included participants residing in Scotland, there are many findings that can translate to other geographical areas, and the vulnerabilities of the LGB people encountered in this research should not be viewed as only applicable to Scotland or as isolated cases. Published evidence from several countries, including England and Wales, demonstrate poor aspects of the cancer care journey for LGB people due to their sexual orientation.^{27,28} Our findings affirm that LGB people can have poorer experiences of cancer and related support, as demonstrated in the UK National Cancer Patient Experience Survey and other UK literature.^{26–29}

This study was successful in recruiting participants who were not 'out' and who were 'non-scene'. As such, their views add further

Table 2
Results of Stakeholder likert feedback responses to practitioner guide.

Please indicate how happy you are with the introductory information contained within the guidance on the scale below:					N responses ^a
Very poor 1	Poor 1	Average 5	Good 24	Excellent 12	43
Please indicate how happy you are with the recommendations contained within the guidance on the scale below:					
Very poor 1	Poor 1	Average 5	Good 20	Excellent 16	43
Please indicate how happy you are with the additional resources section within the guidance on the scale below:					
Very poor 1	Poor 1	Average 7	Good 24	Excellent 10	43

^a Feedback responses received from: Maggie's Cancer Centres, MacMillan Cancer Support, Prostate Cancer UK, Out With Prostate Cancer Support Group (Manchester), Lesbian Gay Foundation Manchester, Society of College of Radiographers professional officers, Society and College of Radiographer's Council representatives, LGBT cancer academics employed at universities in the UK and Canada, Eighteen NHS employed oncology professionals from 8 different trusts and boards, which included therapeutic and diagnostic radiographers, health managers and policy makers, oncologists, specialist oncology nurses, counsellors and psychologists. Four members of the public who had cancer and identified as Lesbian Gay or Bisexual, but were not in themselves participants in the research inquiry, LGBT Health Edinburgh, The Equality Network Scotland.

dimensions to this research, as their voices do not currently feature in much of the published research to date^{19–21,27–29}. In addition, this research recruited participants with a diverse range of cancers not represented within UK literature.^{27–29} Although we sought to include a greater diversity of LGB people, we did not manage to involve people from a non-white background or with a disability. Challenges to involving people who are seldom heard in research may be further increased due to intersectionality, where people are members of more than one minority group. This may also have influenced the challenges recruiting people to the study. Although the participant number is similar to other research studies in this field, it is small for definite conclusions, and would be valuable to hear more voices.

A further limitation of the research is that it relied on a binary classification of a person's sexual orientation. There needs to be an ongoing recognition that terminology in respect of sexual orientation and a person's feelings towards labels are in an ever-changing flux that is influenced by culture, background, and belief. The needs of Transgender people when accessing healthcare also need to be explored. Due to the focus of this research on sexual orientation rather than gender identity, we do not want to misrepresent the experiences of the participants as being from across the entire LGBT community.

Conclusions

The main findings of this research corroborate current literature within the field, provides further insights into LGB people's attitudes towards labels, and points in care pathways where misunderstandings are more likely to occur. As well as documenting negative experiences which enable practitioners to learn from mistakes, there are also examples where health professionals succeeded in providing inclusive care, which should be taken on board. The research findings enabled development of a national practitioner guide with the participants and key stakeholders, which is freely available,⁷ and raises awareness of the needs of LGB persons affected by cancer to support better care.

Conflicts of interest

There are no conflicts of interest to declare.

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