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Cancer prevention, treatment and survivorship in the LGBTQIA community

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Gwendolyn P. Quinn, Jane Ussher and
Janette Perz

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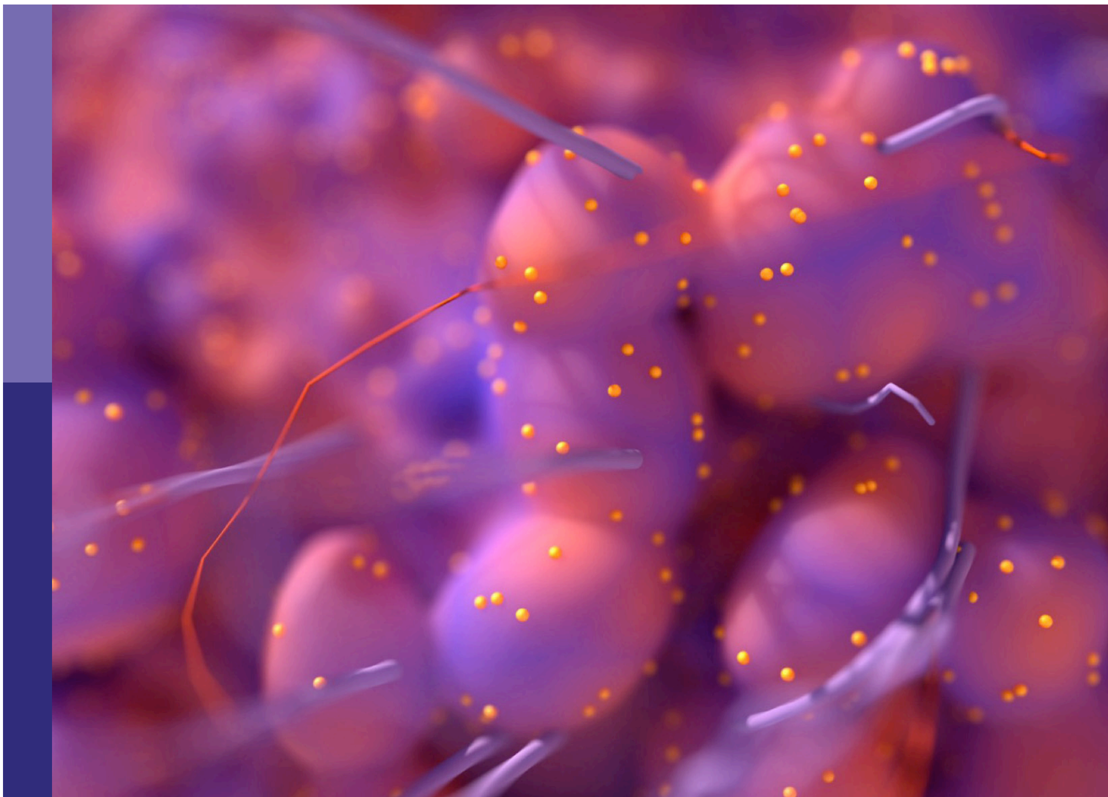

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Cancer prevention, treatment and survivorship in the LGBTQIA community

Topic editors
Gwendolyn P. Quinn — New York University, United States
Jane Ussher — Western Sydney University, Australia
Janette Perz — Western Sydney University, Australia

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EDITED AND REVIEWED BY
Dana Kristjansson,
Norwegian Institute of Public Health (NIPH), Norway

*CORRESPONDENCE
Jane M. Ussher
j.ussher@westernsydney.edu.au

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Editorial: Cancer prevention, treatment and survivorship in the LGBTQIA community

Jane M. Ussher[1]*, Gwendolyn P. Quinn[2] and Janette Perz[1]

[1]Translational Health Research Institute, School of Medicine, Western Sydney University, Sydney, NSW, Australia, [2]Department of Obstetrics and Gynecology and Population Health, New York University (NYU) Grossman School of Medicine, New York, NY, United States

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Editorial on the Research Topic
Cancer prevention, treatment and survivorship in the LGBTQIA community

1 Introduction

Sexuality and gender minorities (SGM), including those who identify as lesbian, gay, bisexual, transgender, queer, and intersex (LGBTQI+), constitute a growing and underserved population in the realm of cancer care. This community faces a greater burden of cancer (1–3) and encounters distinctive psychosocial challenges. These challenges include elevated rates of cancer-related distress and sexual concerns (2, 4, 5), reduced quality of life (QOL) (6), and diminished support from their biological families (7), when compared to non-LGBTQI+ individuals with cancer and their caregivers. Concurrently, LGBTQI+ individuals also experience heightened dissatisfaction with cancer healthcare (8, 9), which encompasses difficulties in communication with healthcare professionals (HCPs) (10), barriers in accessing cancer services (8), and a lack of LGBTQI+-inclusive cancer information or support (2, 11). Revealing their sexual orientation or gender identity (SOGI) to HCPs is a significant source of distress due to concerns about potential hostility or cis-heteronormative biases that might result in substandard care (2, 10, 12, 13). However, if SOGI is not disclosed, LGBTQI+ individuals with cancer are more likely to report unmet needs, a sense of invisibility, dissatisfaction with care, and poor psychological well-being (10, 14, 15).

The American Society of Clinical Oncology has acknowledged the existence of this healthcare disparity and determined that there is inadequate understanding of the healthcare requirements, outcomes, lived experiences, and effective interventions to enhance outcomes for LGBTQI+ communities (1). Consequently, healthcare providers and policymakers lack the necessary tools to establish inclusive and culturally-sensitive programs aimed at prevention, guidance, and support for LGBTQI+ individuals with cancer and their families (16, 17).

This Research Topic of Frontiers in Oncology aims to bridge the “knowledge-to-action” gap by bringing together cutting-edge research that explores the experiences of cancer survivorship and cancer care within the LGBTQI+ population. The Research Topic encompasses original studies utilizing quantitative, qualitative, and mixed methods designs. While previous research on LGBTQI+ cancer has primarily focused on cisgender lesbian women and gay men with breast or prostate cancer or, we expand upon this by including research on underrepresented communities. This includes LGBTQI+ individuals with various tumor types, transgender individuals (both binary and non-binary), LGBTQI+ adolescents and young adults (AYAs), LGBTQI+ individuals from diverse racial and cultural backgrounds, individuals with an intersex variation, and LGBTQI+ informal cancer caregivers. Through this research, we aim to address significant gaps in the existing literature, representing a pioneering effort to identify the concerns and experiences of this previously marginalized population of cancer survivors and their informal caregivers.

In this special edition, we also feature recent research that explores the perspectives of healthcare practitioners (HCPs) who work with LGBTQI+ individuals with cancer. Examining the beliefs and knowledge of oncology HCPs is crucial for identifying barriers and facilitators to culturally safe and inclusive LGBTQI+ cancer care (16). HCPs who possess greater knowledge of LGBTQI+ healthcare needs exhibit more positive attitudes, intentions, and behaviors toward LGBTQI+ cancer patients (18). They recognize the importance of acquiring patients' sexual orientation and gender identity (SOGI) information, avoiding cis-heteronormative assumptions by not assuming all patients are heterosexual and cisgender (i.e., identifying with the gender assigned at birth), and being willing to be recognized as LGBTQI+friendly providers (19–21). However, surveys conducted among oncology radiation therapists (22), physicians (20, 23, 24), nurses, and other advanced care professionals (19, 21) consistently reveal low levels of knowledge about LGBTQI+ patients. Consequently, training programs have been developed for HCPs to enhance cultural safety for LGBTQI+ individuals with cancer, with the goal of fostering inclusive and affirming cancer care (25, 26).

The research findings presented in this special edition will contribute to a better understanding of this often-overlooked population in cancer care. They will inform the development of future training programs, as well as provide policy and practice recommendations. A summary of the papers featured in this special edition is provided below. In describing the papers, we utilize the language employed by the authors to depict their study samples - SGM or LGBTQI+.

2 Summary of papers

This special edition of Frontiers includes several papers that investigate the levels of distress and quality of life among LGBTQI+ individuals with cancer, shedding light on the factors associated with these outcomes. Ussher et al. examined the psychosocial factors linked to distress and quality of life among LGBTQI+ individuals with cancer, drawing upon the quantitative findings of the Out with Cancer Study. The research reveals that 41% of LGBTQI+ individuals with cancer reported high or very high levels of distress, which is three to six times higher compared to previous studies conducted among non-LGBTQI individuals with cancer. The study also identifies higher rates of distress among LGBTQI+ individuals who are AYAs, transgender, bisexual, queer, and those residing in rural areas. The elevated distress levels were found to be associated with increased experiences of minority stress, including discrimination in various aspects of life and in cancer care, discomfort related to one's LGBTQI+ identity, lower disclosure of LGBTQI+ identity, and limited social support within these subgroups. These findings, based on the largest sample of LGBTQI+ individuals with cancer to date, highlight the diversity within LGBTQI+ populations in terms of health outcomes and provide valuable insights into the underlying mechanisms contributing to negative psychosocial outcomes for LGBTQI+ cancer survivors.

In a qualitative paper derived from the Out with Cancer Study, Power et al. examine the historical and contemporary experiences of discrimination, violence, family rejection, and exclusion that have created a legacy of distress and fear among LGBTQI+ individuals with cancer. The authors explore how these experiences have affected the level of trust towards healthcare professionals and contributed to distress and unmet needs in the context of cancer survivorship and care. Additionally, they investigate how social support from partners and chosen family members has mitigated the adverse impacts of minority stress, aiding LGBTQI+ individuals in coping with cancer. The study also highlights the agency and resistance demonstrated by LGBTQI+ patients and carers through collective action and advocacy. By shedding light on the unique socio-political histories and present-day psychosocial experiences of LGBTQI+ communities, this paper provides valuable insights into the factors contributing to distress during the cancer journey.

Understanding the intersectionality of identities is crucial for comprehending the experiences of LGBTQI individuals throughout their cancer journeys. Bates et al. draw upon the findings of the Restore-1 Study, and report sexual minority men of color, when compared to their white counterparts, experience lower health-related quality of life (HRQOL) scores in various domains, including bowel function, hormonal summary, hormonal function, and hormonal bother. This exploratory study provides initial evidence suggesting that sexual minority men of color may experience worse HRQOL outcomes following prostate cancer treatment compared to white, non-Hispanic sexual minority men. Rosser et al. present findings from the Restore-2 Study, which found gay or bisexual men (GBM), in comparison to heterosexual men, experienced significantly worse bowel, urinary, and hormonal function, and better sexual function and similar bother scores, aligning with previous research but in a larger sample. Additionally, GBM individuals had poorer mental health outcomes and worse quality of life. These findings highlight the presence of health disparities among sexual minority patients following prostate cancer treatment.

Research has consistently shown that GBM have higher rates of sexually transmitted infections (STIs) compared to heterosexual men throughout their lives. Moreover, evidence suggests that GBM may employ various strategies to manage sexual dysfunction, which can potentially increase the risk of acquiring STIs. Wheldon et al draw on the Restore-2 study and identify several risk factors for STI diagnosis, including engaging in non-monogamous sexual relationships, time elapsed since prostate cancer diagnosis, receiving penile injection treatment, reporting better sexual function, and having multiple sexual partners. These findings underscore the importance of integrating STI prevention into cancer survivorship plans, particularly as GBM regain sexual function over time.

The challenge of reaching LGBTQI+ populations affected by cancer is widely recognized. Myers et al. outline a multi-faceted, cost-effective, and systematic approach employed to engage LGBTQI+ communities in research, including methods to identify and filter out potentially fraudulent or suspicious online responses, ensuring data integrity. Among the strategies utilized, social media emerged as the most effective method for recruitment, surpassing direct mail outs. These study findings highlight successful strategies to effectively reach communities, enhance data quality, and mitigate the misrepresentation of data, which is crucial for improving health outcomes within LGBTQI+ communities.

During the challenging experience of being diagnosed with cancer, LGBTQ+ children and adolescents are also in a crucial stage of self-discovery regarding their gender identity and sexual orientation. Gannon et al explore the attitudes, knowledge, nd behaviors of pediatric, teenage, and young adult oncology HCPs treating LGBTQ+ patients in the UK. Using semi-structured interviews with eight HCPs, ten themes were revealed, including novel ones related to knowledge acquisition and reliance on a 'third party' as an expert. Specific concerns for LGBTQ+ patient care in pediatrics were identified, such as the influence of parental dynamics and age-related barriers to disclosure. The study highlights the interconnectedness of HCP knowledge, attitudes, and behaviors and proposes a suggested framework to improve HCP-patient interactions in LGBTQ+ cancer care than spans individual HCP education and organizational change. " Cloyes et al emphasize the importance of understanding the access and engagement of support systems within the social networks of young adult (YA) and LGBTQIA+ survivors and care partners affected by cancer. They found that LGBTQIA+ participants had less dense and cohesive support networks, with a higher concentration of LGBTQIA+ members. They also received more appraisal support, particularly from relatives, compared to non-LGBTQIA+ participants. These results demonstrate how tailored and easily accessible assessment methods offer valuable insights into how real-world support systems operate, leading to the development of culturally sensitive interventions that address specific strengths and unmet needs. Such interventions are particularly crucial for young adult (YA) and LGBTQIA+ survivors and care partners, who often receive inadequate support from formal services and are underrepresented in cancer research related to caregiving and social support.

In their study, Waters et al. examine the intensified financial challenges faced by adolescent and young adult AYA cancer survivors who identify as LGBTQIA+. The findings reveal that LGBTQIA+ AYAs experienced significantly higher levels of financial burden and reported poorer mental health outcomes, including heightened levels of stress, anxiety, and depression compared to non-LGBTQIA+ AYAs. The increased costs of cancer treatment combined with the disruptions caused by the COVID-19 pandemic contributed to significant financial stress, further exacerbating existing mental health difficulties. These results underscore the substantial financial burden and psychological distress experienced by LGBTQIA+ AYA survivors, underscoring the importance of research to address their specific challenges and alleviate financial strain and adverse mental health outcomes.

Interactions with HCPs, and HCP beliefs and practices related to LGBTQI+ culturally safe care, were explored in a number of papers. Pratt-Chapman et al explore responses to a measurement tool, the QUIRKS-Patient and QUIRKS- Provider scales, among patient and providers in the United States. The Quirks scales measures constructs for patients in the domains of SGM environmental cues, patient experience, and attitudes. The scales for health care providers assesses the clinic readiness to meet SGM healthcare needs, environmental cues for affirming care, attitudes and knowledge. Using a snowball sample, results showed clinicians reported affirming clinic cues more often than patients. Clinicians were also more likely to report asking their patients about preferences and values for care than patients recalled being asked about these things. Patients reported greater understanding and comfort as to why they were asked to provide information regarding sex assigned and birth and gender identity at higher rates than providers assumed they would. Clinician's knowledge was better for patients who identified as gay as opposed to other orientations and gender identities. Overall, their results support the need for expanded and improved provider training in the health care needs of SGM patients across the cancer care trajectory.

Ussher et al report draw on accounts of patient-HCP interactions from the perspective of LGBTQI+ patients, their caregivers and health care professionals in Australia. They identified three HCP mindsets regarding LGBTQI patients. "Inclusive and Reflective" practitioners noted the vulnerability of patients and the need for affirming care. Clinicians who approached their patients with this belief created safety and respect for patients, allowing them to freely disclose their SOGI data and report satisfaction with cancer care. Those clinicians who were characterized as "Egalitarian" reported ethical responsibility to treat all the patients the same and did not see relevance in the collection of SOGI data. As such, LGBTQI specific information was not likely to be provided and created anxiety and dissatisfaction among patients and their caregivers "Anti-inclusive" clinicians responses were those who reported hostility and prejudice for LGBTQI patients thus creating environments where patients felt distress, judged, and dissatisfied with their care. The authors conclude that a wide range of strategies are needed to improve LGBTQI cancer care including culturally competent training, redesign of environments and treating safe spaces for SOGI disclosure.

Kano et al, assessed quality of life using quantitative PROMIS measures and qualitative interviews among dyads of SGM (sexuality and gender minority) patients with cancer and their informal caregivers and heterosexual/cisgender (H/C) patients and their informal caregivers from the United States, to compare perceptions and experiences. The quantitative results showed greater anxiety, depression and social isolation among SGM patients than H/C patients. However, H/C patients more fatigue and pain but more social support. In qualitative interviews SGM patients and caregivers reported anti-SGM stigma and discrimination during their cancer care experience. SGM dyads had more medical mistrust than H/C dyads. Regarding communication, SGM patients with cancer did experience high satisfaction once trust was developed with their care team but wished for the opportunity to have more direct discussion regarding their SGM status. While some differences were observed, there were also several commonalities. Both SGM and H/C dyads noted appreciation for their health care teams. All patients and caregivers used social networks of friends and family. All caregivers felt remiss at the lack of information and support for their loved one's treatment, side effects and ways to deliver support. The authors conclude that improvements are needed in clinical care teams cultural humility and ways to support caregivers.

Kamen et al report how researchers at two cancer centers in the United States worked with a group of LGBTQAI stakeholders with lived experience of cancer care to develop a community-academic partnership. Using the ADAPT-ITT model to guide their community needs assessment, the goal was to identify evidence-based interventions that could be adapted to meet the community needs. With a multi-phase approach, beginning with an assessment phase, the council members described their experiences and concerns. Cancer caregiving was noted as a priority for a future intervention. During the decision-making phase, a literature review was conducted for interventions that focused on cancer caregiving, identifying 13 potential interventions. Each intervention was evaluated by the council members using a rubric. The FOCUS intervention was then adapted for the LGBTQAI community. In the next phase, adaptation, the council identified the primary mechanisms to be modified. As the project is on-going, Kamen et al report on a process used to establish adapted intervention through community-academic partnerships for the LGBTQAI population during the cancer experience.

Tamargo et al report on a survey conducted among the US Eastern Cooperative Oncology Group (ECOG) and the American College of Radiology Imaging Network (ACRIN), examining clinicians' experiences with SGM patients with cancer. Tamargo et al report on the qualitative analysis of the four open-ended items from the survey. Findings indicated clinicians had little experience with SGM patients, particularly transgender patients. Using correct pronouns was also reported as challenging among the 490 clinicians responding to the survey. A minority of clinicians reported SGM patients were more difficult to provide care for suspecting that prior negative experiences with the healthcare system were more likely to result in hostile patients with negative attitudes. However, the majority of respondents reported actual and potential positive experiences with SGM patients during the cancer care experience. The authors report need for clinicians desire and recognize the need for expanded training particularly for end-of-life care issues and opportunities to build trust across the SGM community

3 Conclusion

The papers featured in this special edition of Frontiers provide further evidence supporting the urgent call by The American Society of Clinical Oncology (1) to address and understand the health disparities faced by LGBTQI+ individuals with cancer. It is essential for cancer research to include questions about sexual orientation, gender identity, and intersex variation in order to identify unmet needs and shed light on the experiences of LGBTQI+ individuals in cancer and cancer care. By doing so, we can bring visibility to this potentially vulnerable population. Additionally, it is crucial to recognize the intersectionality of identities and how they influence the experiences of individuals with cancer, with a specific focus on underrepresented groups such as trans (27), intersex (28), AYA (29), and racially/ethnically diverse [Bates et al.] individuals. Engaging LGBTQI stakeholders through research co-design can help ensure that research methods and interpretations are culturally competent and culturally safe (30).

It is of utmost importance that we prioritize the development of affirmative and inclusive cancer care for LGBTQI+ people (17). This involves creating content that addresses the unique needs and experiences of the LGBTQI community as a whole, as well as content tailored to specific sub-groups such as trans, intersex, and AYA cancer patients (16, 31). A common thread throughout the publications in the field of health care interactions is the recognition of the necessity for expanded clinician training in cultural humility. It is crucial to establish opportunities for building trust through partnerships with SGM patients with cancer, their caregivers, and the healthcare institutions they rely on for care. By doing so, we can increase the likelihood of LGBTQI+ individuals with cancer and their caregivers having their needs acknowledged and met. This will result in affirmative and inclusive cancer care for LGBTQI+ communities, ultimately leading to improved health outcomes and higher levels of satisfaction with the care they receive.

Author contributions

All authors listed have made a substantial, direct, and intellectual contribution to the work and approved it for publication.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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ORIGINAL RESEARCH
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Health Disparities of Sexual Minority Patients Following Prostate Cancer Treatment: Results From the *Restore-2* Study

B. R. Simon Rosser[1]*, Elizabeth J. Polter[1], Kristine M. C. Talley[2], Christopher W. Wheldon[3], Ryan Haggart[4], Morgan Wright[1], William West[5], Darryl Mitteldorf[6], Michael W. Ross[7], Badrinath R. Konety[8] and Nidhi Kohli[9]

[1] Division of Epidemiology and Community Health, School of Public Health, University of Minnesota, Minneapolis, MN, United States, [2] Adult and Gerontological Health Cooperative, University of Minnesota School of Nursing, Minneapolis, MN, United States, [3] Department of Social and Behavioral Sciences, College of Public Health, Temple University, Philadelphia, PA, United States, [4] Department of Urology, University of Minnesota, Minneapolis, MN, United States, [5] Department of Writing Studies, University of Minnesota, Minneapolis, MN, United States, [6] Malecare Cancer Support, New York, NY, United States, [7] Department of Family Medicine and Community Health, University of Minnesota Medical School, Minneapolis, MN, United States, [8] Department of Urology, Rush Medical College, Chicago, IL, United States, [9] Department of Educational Psychology, University of Minnesota, Minneapolis, MN, United States

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Correspondence:
B. R. Simon Rosser
rosser@umn.edu

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Purpose: The NIH has identified sexual and gender minority persons as a health disparity population but little is known about cancer outcomes in these populations. The purpose of this study was to identify disparities in sexual minority prostate cancer patient-reported outcomes, to examine within group differences, and to test for alternative explanations for identified differences.

Materials and Methods: In 2019, we recruited 401 gay and bisexual prostate cancer patients into the *Restore-2* study, a randomized controlled trial of rehabilitation program tailored for sexual minority men.

Results: Compared to the normative (heterosexual) EPIC sample, participants had significantly worse urinary, bowel and hormonal function, better sexual function, and no difference on bother scores. They also had worse depression and overall mental health, and worse physical, social/family, functional, prostate specific and overall well-being quality of life outcomes. Across measures, no differences by age, gay versus bisexual orientation, race/ethnicity, and relationship status were observed. Those who had hormonal treatment had worse sexual and hormonal function than those who had radiation or surgery only. Those with a longer time since treatment had better urinary function. Differences remained when participants were matched to normative samples on cancer stage and time since treatment.

Conclusions: This, the largest study of sexual minority prostate cancer patients to date, confirms health disparities in prostate cancer quality of life outcomes. Findings appear reliable and robust. To improve the clinical care of prostate cancer, it will be important to address the health disparities experienced by sexual minority prostate cancer patients.

Keywords: health status disparities, sexual minorities, healthcare disparity, prostatic neoplams, sexual dysfunction, physiological

INTRODUCTION

Sexual and gender minority (SGM) populations experience significant cancer health disparities (1), but are under-represented to entirely missing in research on cancer patients and survivors (1–5). According to a recent review by researchers at the National Cancer Institute (NCI), "SGMs face a disproportionate burden of cancer, yet little is known about the experience and needs of these underserved populations in cancer care delivery (3)."

Of the 3.1 million men diagnosed with prostate cancer in the US, about 63,000 are sexual minorities (6). Only six quantitative studies of sexual minority prostate cancer patients have been conducted (7–11); and of these, only three used standardized patient-reported outcome measures (11–13). Hart et al. (9) conducted a study of 92 North American gay and bisexual prostate cancer patients, diagnosed within the past four years (14). Participants were recruited online and through community advertising, confirmed eligible by telephone interview, and completed an online survey. Ussher et al. (15) conducted a study of 124 gay and bisexual prostate cancer patients living mainly in Australia, North America, or the United Kingdom (13). Participants were recruited using a mix of clinic and community outreach within Australia, and online internationally. The *Restore-1* study, conducted by our team in 2015-2016, comprised of 192 gay and bisexual and 1 transgender women prostate cancer patients living in North America (11). Participants were recruited from an online cancer site providing support services for sexual minority patients. Both the Hart et al. (14) and *Restore-1* (11) studies compared results to published norms (of predominantly heterosexual patients), while Ussher et al. (13) recruited a comparison sample of Australian heterosexual patients.

To measure treatment outcomes, Hart et al. (14) and *Restore-1* (11) used the Expanded Prostate Cancer Index Composite (EPIC-50). In both studies, sexual minority patients scored worse on urinary and hormonal function and better on sexual function than published norms (11, 14). Ussher et al. only used the sexual subscale, but also found better sexual function than published norms. For bother, the results were not consistent. Hart et al. reported worse urinary, bowel and hormonal bother, while *Restore-1* only found worse hormonal bother (11). For sexual bother, there was no consistency with studies reporting better (11), same (14), and worse (13) scores than the normative sample.

All the studies, using various measures, found sexual minority patients to have worse mental health than published norms. On physical health, results were inconsistent. Ussher et al., found no differences, while *Restore-1* reported better physical health than published norms. Ussher et al. was the only study to use the FACT-P, finding sexual minority patients scored worse on the emotional and day-to-day subscales (15).

There are three main limitations to these studies. First, all the studies had relatively small sample sizes which increases the risk of Type-2 error. Second, on several scales, there has been only one study, preventing researchers from assessing the replicability of findings. Third, none of the studies explored for alternative explanations for the observed differences.

The purpose of this study was three-fold. First, we sought to document the health disparities between sexual minority patients and published norms (for heterosexual patients). Second, we examined within group differences to identify sexual minority patients at higher risk of health disparities. Third, we tried to disprove the disparities by testing for two alternate explanations: namely that differences in stage of cancer and time since treatment might explain the results.

MATERIALS AND METHODS

Participants

This paper describes the baseline survey results for all participants the *Resture-2* study, a clinical trial designed to test the effectiveness of an online rehabilitation program tailored for sexual minority prostate cancer patients. Participants needed to identify as gay, bisexual, or a man who has sex with men (regardless of whether they were currently sexually active) and live in the US. Transgender women were also welcome to participate, although none did. Enrollees had to be diagnosed with prostate cancer and either completed treatment at any point in the past, currently in treatment, or scheduled to receive treatment within two months of commencing the study. Appropriate to a rehabilitation study, participants also needed to report a current sexual and/or urinary problem. Implicit eligibility required participants to read English and be able to access intervention materials online. All data in this paper were taken from the baseline survey. The study was conducted under the oversight of the University of Minnesota Institutional Review Board.

A full description of the recruitment protocol has been published (16). To advance methods on this "hidden", "difficult to recruit" population, we conducted a naturalistic,

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Abbreviations: BSI18, Brief Symptom Inventory-18; EPIC, Expanded Prostate Cancer Index Composite; FACT-P, Functional Assessment of Prostate Cancer Treatment – Prostate; SGM, Sexual and Gender Minority.

3-arm, stratified prospective study to compare three recruitment strategies: (a) clinic based recruitment of prostate cancer patients from gay health and urology clinics; (b) directly from the gay community; and, (c) online recruitment (through cancer support, sex/dating, and social sites). For each strategy, we estimated time, workload, and direct costs involved. To study how recruitment strategy may affect sampling, we tested for retention rates, demographic and outcome differences across sites. From October, 2018 to August, 2019, participants were recruited mainly from the three online websites: a sex/dating site (*Scruff*: *n*=158), an online cancer support group network (*Malecare: n=89*) and a social site (*Facebook: n=66*). Participants were also recruited through gay media (*n*=39), word of mouth or other online sources (*n*=35) and least successfully from clinics (*n*=9). Five men from our prior study, *Restore-1*, also participated.

Prior to participation, each enrollee completed a vetting telephone interview to validate eligibility lasting about 20 minutes. Next, they completed an online consent process adapted from our prior research (17). We received a waiver of written consent for this online study.

After completing the consent process and baseline survey (from which all the data in this paper were taken), participants were randomized to either the online intervention or usual care. Participants were randomized 1:1 to either the intervention (an Internet-based, comprehensive sexual and urinary rehabilitation program) or the usual care control group. In order to ensure that both the control and intervention arms included enough recently treated men, randomization was stratified by time since prostate cancer treatment completed. Permuted block randomization in blocks of two ensured balance between the two arms of the study.

Our bio-behavioral intervention had seven key elements: *(1) PDE5-I drugs:* Participants with ED challenges were recommended to take 50mg sildenafil (i.e., Viagra©) orally, 3x per week for 2 years. These were provided at no charge by the study with a prescription from their physician. *(2) Pelvic floor exercises (a.k.a. Kegels):* To strengthen the *levator ani* muscle, to treat both urinary incontinence and climacturia, participants were instructed to do 10 quick contractions (2 sec. hold; 4 sec. relax) then one set of 10 long contractions (10 sec. hold; 10 sec. relax), repeated 3 times per day. To teach Kegels, we produced a video of a gay peer modeling how to do them. *(3). Vacuum pump and penile constriction rings:* All participants received a vacuum pump and "cock rings" to aid getting and maintaining erections. *(4) Anal dilators:* All participants received a set of 3 different sized butt plugs repurposed as anal dilators to treat pain in receptive anal sex. *(5) A Gay Man's Guide to Good Sex after Prostate Cancer:* Online, participants had access to a comprehensive guide to restore functioning, including protocols to treat urinary incontinence, erectile dysfunction, anodyspareunia (painful receptive anal sex), and problems with arousal incontinence and climaturia. In addition, we produced videos modeling how sexual minority men with PCa deal with sexual challenges (e.g., disclosing PCa to a sex partner); a male couple discussing how they have good sex, post-treatment; a FAQ section where participants could ask questions and read answers from experts; and a tracking program where users could monitor their rehabilitation. *(6). Social support:* Given the lack of social support gay and bisexual men experience and our needs assessment results showing this as a priority, participants could access to a monitored noticeboard group where they posted questions to other peers and could respond. *(7). Coach:* Given stigma and lack of social support, participants could discuss their progress with a sexual health coach (study staff trained in motivational interviewing) every three months during the 24-month trial.

Of 461 participants who completed the screening and vetting process, 17 were excluded because they failed to meet the inclusion criteria, 42 declined consent or did not complete the baseline survey, and one duplicate response was excluded. Participants were compensated $50 for the baseline survey. The final sample comprised 401 participants.

Measures

The survey was in English and comprised 338 questions. Skip and branch patterns were used to administer only those questions relevant to each participant.

Demographics, Sexual Characteristics, Medical Information and Internet Use. Demographic questions were adapted from the US Census and from the 2018 American Community Survey (18). Sexual and medical characteristics were based on the *Restore-1* study (11).

Prostate cancer treatment was investigated by asking participants to check which treatments they had undergone in nine categories, which at analysis were collapsed into: surgery only, radiation only, hormone therapy (in combination with surgery and/or radiation) and other. Participants reported their PSA levels at diagnosis, Gleason score (e.g., *3 + 3 (6)* or *3 + 4 (7)*) at diagnosis, and selected their stage (I, II, III, IV, or don't know/ don't remember) using multiple choice menus. Gleason scores were then grouped according to grade groups (19).

Disease Specific Quality of Life. The Expanded Prostate Cancer Index Composite (EPIC-50) measures urinary, bowel, sexual, and hormonal symptom frequency and perceived bother. The EPIC-50 has acceptable scale and subscale reliability ($r \geq 0.80$) and internal consistency ($\alpha \geq 0.82$) (14, 20). All scales total 100, with higher scores indicating better functioning or less bother.

Brief Symptom Inventory-1. The BSI-18 assesses mental health in four domains: somatization, anxiety, panic, and depression. Each domain consists of six Likert-type items (scores: 0-24), which are summed to create a total score (score: 0-72). Higher scores indicate worse mental health. The scale has high internal consistency, with Cronbach's Alpha coefficients ranging from 0.74 to 0.89 (21).

Functional Assessment of Cancer Treatment-Prostate. The FACT-P measures quality of life related to cancer and its treatment in four domains: physical, social/family, functional, and emotional well-being, plus a prostate cancer symptom score. Higher scores represent better quality of life. Cronbach's alpha coefficients ranged from 0.65 (for the prostate cancer domain) to 0.89 for (FACT-P total) (22).

Statistical Analysis

Patient reported outcomes were compared to the published EPIC-50, BSI-18, and FACT-P normative samples using *t*-tests (20–22). ANOVAs and *t*-tests were used to identify differences for quality-of-life measures across demographic and medical characteristics. When ANOVA findings were statistically significant, pairwise comparisons were conducted with Tukey adjustment for multiple comparisons. All reported *p* values were 2-sided. To correct for multiple comparisons, corrected *q*-values were calculated, and considered statistically significant if they had a false discovery rate (q-value) less than 0.05.

To test whether differences were due to cancer stage or time since treatment, we randomly selected a subset of participants to match the distribution of cancer stage among EPIC normative participants, and repeated this with time since treatment to match on recovery period. The data were analyzed using Stata version 16 (StataCorp, College Station, TX, USA). Due to a programming error, one item was omitted from the EPIC hormonal bother subscale in the survey. However, scores are considered valid if only one item out of six is missing (20).

RESULTS

The demographic, sexual, and medical characteristics of the participants are detailed in **Table 1**. To summarize, this sample of sexual minority patients living in the US was predominantly white, non-Hispanic (86.8%), gay-identified (92.5%) with a mean age of 63.5 years (SD=6.6). Mean years since diagnosis was 5.3 years (SD=4.8), with almost half (45.4%) within two years of diagnosis. Most participants had grade group 1 (N=70), 2 (N=106), or 3 (N=64) prostate cancer and were diagnosed Stage I or II. Most (58.1%) had undergone a radical prostatectomy, 19.0% radiation, 16.5% treatment involving hormone therapy, and 6.4%, other treatment.

Results on the EPIC-50 were compared with the original normative sample (20) and *Restore-1* study (11) (see **Table 2**). As compared with the normative sample, *Restore-2* participants had worse urinary, bowel and hormonal function, better sexual function, and no differences on any of the bother scores (*p*<.05). *Restore-2* participants had significantly worse sexual function and bother, worse bowel function, but less hormonal bother than *Restore-1* participants (*p*<.05).

Table 3 compares the results of *Restore-2* with the with the original BSI-18 (21) and FACT-P (22) normative samples and with the Ussher et al. study (13). Compared to the normative sample, *Restore-2* participants had significantly higher (i.e. worse) scores on depression and overall mental health. Compared with Ussher et al., *Restore-2* scored significantly less (i.e., healthier) on somatization, depression and overall mental health. On the FACT-P, *Restore-2* participants scored significantly worse on all quality of life outcomes (except for emotional well-being) than the normative sample. *Restore-2* participants did not differ from the Ussher et al. sample on any FACT-P scores, except prostate cancer specific wellbeing where *Restore-2* participants had less symptoms affecting their quality of life.

TABLE 1 | Demographic Characteristics of the Sample.

N	N	%
Age (N, %)		
40-49	8	2.0
50-59	112	27.9
60-69	222	55.4
70-79	57	14.2
80+	2	0.5
Ethnicity		
Hispanic/Latino	20	5.0
Not Hispanic/Latino	377	95.0
Race		
White	364	90.8
Black/African American	22	5.5
Asian	2	0.5
American Indian or Alaska Native	0	0
More than one	7	1.8
Other	6	1.5
Identity (N, %)		
Gay/homosexual	371	92.5
Bisexual	30	7.5
Current Relationship Status		
Single	114	28.5
Widowed, divorced or no longer in a relationship	37	9.3
Dating (men or women)	50	12.5
Married or in a long-term relationship (with a man)	185	46.3
Married or in a long-term relationship (with a woman)	14	3.5
Gleason Grade Groups		
1	70	17.5
2	106	26.4
3	64	16.0
4	17	4.2
5	33	8.2
Don't know/Don't remember	111	27.7
Stage at Diagnosis		
I	141	35.2
II	73	18.2
III	30	7.5
IV	18	4.5
Don't know/Don't remember	139	34.7
Treatment Category		
Radical Prostatectomy or cryotherapy (only)	233	58.1
External Beam Radiation (only)	76	19.0
Hormone therapy (Lupron) (with any combination of treatments)	66	16.5
Other[a]	26	6.5
Years Since the Initiation of Treatment		
<2 years	183	45.6
≥2 years	218	54.4

[a] *"Other" includes prostatectomy plus radiation, focal laser ablation, dutasteride.*
(N=401 gay and bisexual prostate cancer patients living in the US).

Differences Within Sexual Minority Prostate Cancer Patients

Among *Restore-2* participants, there were few demographic or treatment differences in patient-reported outcomes (see **Table 4**). The hormonal treatment group had worse scores on the EPIC sexual and hormonal subscales than those who had surgery only or radiation only. Those more than two years since treatment had better urinary scores than those who had had treatment more recently. There were no differences observed by age, race/ethnicity, relationship status, or gay versus bisexual sexual orientation.

TABLE 2 | Expanded Prostate Cancer Index Composite (EPIC) scores compared to a prior study in gay and bisexual prostate cancer patients as well as heterosexual normative validation samples.

N	*Restore-2*	*Restore-1*			Validation Sample (19)		
EPIC Domain[a]	**401**	**193**			**252**		
	Mean (SD)	**Mean(SD)**	**p-value**	**q-value**	**Mean(SD)**	**p-value**	**q-value**
Urinary Function	79.4 (17.3)	81.4 (19.4)	0.21	0.22	86.5 (15.9)	<0.001	0.001
Bother	74.7 (18.2)	74.5 (20.8)	0.90	0.66	75.8 (20.6)	0.48	0.46
Sexual							
Function	35.5 (21.2)	40.5 (23.6)	0.01	0.01	29.5 (23.8)	<0.001	0.002
Bother	39.2 (26.2)	55.0 (25.0)	<0.01	<0.01	41.1 (30.2)	0.40	0.45
Bowel							
Function	76.8 (9.4)	89.0 (12.5)	<0.01	<0.01	87.9 (14.3)	<0.01	<0.01
Bother	85.6 (15.4)	84.5 (16.7)	0.43	0.45	85.3 (19.0)	0.83	0.63
Hormonal							
Function	78.7 (16.2)	79.3 (18.1)	0.68	0.58	84.0 (15.9)	<0.01	0.001
Bother	88.3 (13.1)[b]	82.1 (18.1)	<0.01	0.001	88.7 (14.3)	0.71	0.58

[a] *Each EPIC subdomain score ranges from 0 to 100, with higher scores indicating better quality of life (better function, or less bother).*

[b] *One item on the EPIC Hormonal Bother subscale was accidentally omitted from the survey.*

Having identified disparities in patient reported outcomes, we then tried to rule out alternative explanations (see **Supplementary Tables 1**, **2**). The differences in functioning remained significant, even after controlling for cancer stage and time since treatment.

DISCUSSION

The main finding from this study is that sexual minority prostate cancer patients experience significant health disparities. Compared with heterosexual patients, sexual minority patients score worse on EPIC-50 urinary, bowel, and hormonal functioning. While they score better on sexual functioning than heterosexual patients, both groups score poorly on this scale. Similarly, on the FACT-P, sexual minority patients have worse physical, social, emotional, prostate-specific and overall wellbeing. Sexual minority patients have worse overall mental health and possibly worse depression. Overall, these disparities appear robust, reliable and cannot be explained by the sexual minority participants having more advanced cancer or differences in time since treatment. And because the differences in EPIC were in function not bother, they cannot be explained away by stereotypes of sexual minority patients being more sensitive or emotional than heterosexual patients.

It is not obvious why the disparities between sexual minority and majority patients occur. That sexual minority men have

TABLE 3 | Brief Symptom Index-18 (BSI-18) and Functional Assessment of Cancer Therapy-Prostate (FACT-P) scores compared to previous studies in gay and bisexual prostate cancer patients as well as heterosexual validation samples.

N	*Restore-2*	Ussher et al.			Validation/Normative Sample		
	401	**119**			**402 (BSI-18) (20) or 96 (FACT-P) (21)**		
	Mean (SD)	**Mean (SD)**	**p-value**	**q-value**	**Mean (SD)**	**p-value**	**q-value**
BSI-18[a]						402	
Somatization	2.09 (2.42)	2.81 (4.12)	0.02	0.02	2.34 (2.99)	0.19	0.26
Anxiety	2.57 (3.47)	1.95 (2.58)	0.17	0.08	1.42 (2.72)	<0.001	0.09
Depression	3.62 (4.51)	4.65 (5.40)	0.03	0.03	1.55 (2.72)	<0.001	0.001
Panic	0.85 (1.67)	1.27 (2.34)	0.02	0.02	–[c]	–[c]	–[c]
Overall	8.28 (8.80)	10.7 (12.4)	0.02	0.02	5.54 (7.90)	<0.001	0.001
FACT-P[b]							
Physical well-being	23.4 (4.2)	23.9 (4.5)	0.26	0.11	26.2 (2.8)	<0.001	0.001
Social/Family well-being	18.9 (5.7)	18.2 (6.0)	0.25	0.11	23.5 (4.3)	<0.001	0.001
Emotional Well-being	17.5 (3.4)	17.1 (4.5)	0.30	0.13	15.5 (4.2)	<0.001	0.001
Functional Well-being	20.1 (5.5)	20.0 (6.0)	0.86	0.33	21.6 (5.2)	0.02	0.02
Prostate Cancer Specific Well-being	33.1 (6.8)	34.5 (7.3)	0.05	0.04	36.9 (6.6)	<0.001	0.001
Overall Well-being	112.9 (19.3)	114.0 (22.7)	0.60	0.11	130.5 (16.3)	<0.001	0.001

[a] *BSI-18 subdomain scores range from 0-24, with higher scores indicating greater psychological distress. The BSI-18 score is a sum of the three subdomain scores, ranging from 0 to 72.*

[b] *FACT-P scores vary in absolute ranges, and higher scores indicate better quality of life.*

[c] *Panic subscale not included in norm manuscript.*

TABLE 4 | Bivariate analyses of quality of life scores by age, race/ethnicity, relationship status, sexual orientation, type of treatment, and time since treatment.

	EPIC[a] Domain Scores				FACT-P[b] Total	BSI[c] Total
	Urinary Overall Mean (SD)	Sexual Overall Mean (SD)	Bowel Overall Mean (SD)	Hormone Overall Mean (SD)	Mean (SD)	Mean (SD)
Age						
<65	76.7 (16.4)	38.7 (22.0)	80.7 (11.8)	82.5 (13.9)	112.6 (19.9)	9.0 (9.4)
≥65	77.5 (15.4)	35.3 (22.1)	82.0 (10.7)	84.9 (13.6)	113.3 (18.6)	7.3 (8.1)
p-value	0.66	0.13	0.25	0.09	0.72	0.06
q-value	1.00	0.51	0.73	0.49	1.00	0.38
Race/Ethnicity						
White and Non-Hispanic	77.1 (15.7)	37.2 (21.7)	81.3 (11.0)	83.4 (14.0)	112.9 (18.9)	8.1 (8.6)
Non-White or Hispanic	76.9 (17.8)	38.5 (25.0)	81.0 (13.7)	84.4 (12.3)	113.0 (22.4)	9.4 (9.8)
p-value	0.95	0.72	0.88	0.57	0.97	0.39
q-value	1.00	1.00	1.00	1.00	1.00	0.97
Relationship Status						
Single, widowed, divorced, or no longer in a relationship	76.6 (16.3)	37.4 (22.7)	81.5 (11.7)	82.1 (14.1)	110 (19.8)	9.1 (9.0)
Dating	81.3 (15.8)	41.0 (21.3)	79.7 (12.8)	82.2 (15.1)	112 (22.4)	10.1 (10.7)
Married or in a long-term relationship with a man (n=185) or a woman (n=14)	76.2 (15.6)	36.5 (21.8)	81.4 (10.8)	84.9 (13.2)	115 (17.8)	7.2 (8.0)
p-value	0.12	0.44	0.06	0.14	0.01	0.04
q-value	0.51	1.00	0.38	0.51	0.13	0.36
Sexual Orientation						
Gay/Homosexual	77.3 (15.9)	37.5 (22.2)	81.4 (11.2)	83.5 (13.8)	113.2 (18.9)	8.3 (0.5)
Bisexual	74.0 (17.1)	34.9 (21.4)	79.5 (13.2)	83.2 (14.8)	110.1 (23.9)	8.3 (1.5)
p-value	0.32	0.54	0.38	0.92	0.41	0.99
q-value	0.83	1.00	0.97	1.00	0.97	1.00
Type of Treatment						
Radical Prostatectomy/Cryotherapy only	77.1 (1.0)	38.2 (21.7)*	82.4 (10.4)	85.5 (12.4)*	114.9 (19.2)	8.3 (9.5)
Radiation only	79.7 (1.8)	45.0 (22.5)*	79.0 (13.8)	84.8 (12.7)*	113.4 (19.3)	7.7 (6.8)
Hormonal treatment (in any combination)	75.1 (2.0)	25.9 (18.8)†	80.0 (10.0)	75.0 (16.8)†	107.2 (18.8)	8.3 (8.5)
Other*	74.0 (3.2)	35.3 (21.3)*†	80.1 (13.8)	83.6 (2.9)*	108.5 (19.0)	10.4 (10.0)
p-value	0.26	<0.01	0.11	<0.01	0.48	0.63
q-value	0.73	<0.01	0.51	<0.01	1.00	1.00
Time Since treatment start						
<2 years	75.3 (17.2)	38.8 (23.7)	80.5 (11.6)	83.0 (14.3)	113 (19.2)	8.0 (8.3)
≥2 years	78.7 (14.5)	35.9 (20.5)	81.9 (11.1)	83.9 (13.4)	113 (19.5)	8.5 (9.2)
p-value	0.03	0.20	0.21	0.49	0.82	0.58
q-value	0.33	0.73	0.73	1.00	1.00	1.00

(N=401 gay and bisexual prostate cancer patients living in the US).

[a] *Each EPIC domain score ranges from 0 to 100, with higher scores indicating better quality of life (better function, or less bother). Each domain score is the average of its function and bother subdomain scores.*

[b] *The BSI-18 score is a sum of the three subdomain scores, ranging from 0 to 72, with higher scores indicating greater psychological distress.*

[c] *FACT-P scores vary in absolute ranges, and higher scores indicate better quality of life.*

Cells containing the same symbol (, †) do not have statistically significant differences.*

better sexual function is likely due to differences in sexual behavior (e.g., more frequent masturbation), possibly motivation, and strategies men in same-sex relationships use to accommodate the sexual effects of treatment (e.g., non-monogamy, changes in sex roles) (11). Alternatively, a greater percentage of heterosexual patients than sexual minority patients may not be sexually active.

The worse scores on mental health are consistent with prior research (23), minority stress theory (24), and with sexual minority patients having less social support (25), and poorer experiences in treatment (3). In a recent survey of 112 urologists in the US, most providers said they do not ask about sexual orientation, are more comfortable discussing sex with heterosexual patients, lack knowledge about sexual minority patients, and feel inadequately trained in sexual minority health care (26). Heteronormative healthcare may contribute to the worse urinary, bowel and functioning scores, although the mechanism for this is not obvious.

The lack of within group differences suggests sexual minority prostate cancer patients are a more homogeneous group than heterosexual patients. We found no evidence of differences common in heterosexual patients, including no differences by age, and no marriage benefit in sexual outcomes.

Health disparities have important implications for clinical practice. Clinicians should note the sexual orientation datum in the patient's electronic medical record or ask a patient his orientation as standard practice. When discussing treatment options, clinicians need to review the differential effects of treatment on insertive and receptive sexual functioning (6). In addition to sex, providers need to ask about urinary, bowel and hormonal function in sexual minority patients, and identify rehabilitation goals as appropriate. This may require additional time with sexual minority patients (6).

Clinicians also need to be cognizant of the additional mental health challenges this population experiences. Where providers are less comfortable in treating sexual minority patients, supplemental training should be provided. Some providers may feel they strive to provide the same high quality care to all patients (6). Such providers need to be educated in the difference between equality and equity in healthcare (27). If a minority consistently experiences worse outcomes, it suggests something (or multiple things) in the healthcare system is failing these patients.

There are three main limitations to consider in this study. First, this study (and also Hart et al. and *Restore-1*) relied on published norms for the comparison. Some scales were developed using small samples and they may be dated. While Ussher et al. overcame this by recruiting a comparative heterosexual sample, their sexual minority and heterosexuals were recruited differently introducing a confound. Second, all the sexual minority studies used cross-sectional surveys, preventing imputation of causality. For example, we cannot know whether mental health disparities in participants preceded their diagnosis, or whether treatment caused, exacerbated or decreased any preexisting vulnerability. Third, the sexual minority samples in all the studies to date are very homogeneous, comprising mainly white, gay-identified, HIV-negative, cisgender men. Caution should be exercised generalizing beyond these demographics to other sexual minority patients, and to gender minority patients as well.

To advance research on disparities, we need four types of studies. Prospective controlled studies in both heterosexual and sexual minority patients would enable us to infer causation while confirming disparities and updating norms on the key prostate cancer scales. A qualitative investigation is needed to identify what sexual minority and heterosexual patients do post-treatment to explain the improved sexual functioning in sexual minority men. And, we need studies of clinicians and clinical systems, including evaluation of training programs, to improve provision of sexual minority healthcare. Finally, we also need studies of best practices to transform clinical care to be more culturally responsive to the needs of sexual minority patients.

CONCLUSION

In the largest study of sexual minority prostate cancer patients to date, we confirm multiple health disparities in outcomes for sexual minority prostate cancer patients. As compared to published norms for heterosexual patients, sexual minority prostate cancer patients suffer worse urinary, bowel, and hormonal functioning, worse prostate quality of life and worse mental health, but better sexual functioning. We also observed few within group differences across sexual minority patients. To improve clinical care, it will be important to address the health disparities of sexual minority prostate cancer patients.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation. At the end of the study, data will be available at the Data Repository of the University of Minnesota (DRUM).

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Institutional Review Board, University of Minnesota. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

Conceptualization: BR, KT, CW, DM, MR, BK, and NK. Methodology: BR, NK, EP, and MW. Software N/A. Validation: NK and EP. Formal Analysis: NK, EP, and MW. Investigation: BR, EP, MW, RH, and NK. Resources: Not applicable. Data Curation: RH, MW, and NK. Writing – Original Draft: BR, EP, and KT. Writing – Review & Editing: All authors. Visualization – Not applicable. Supervision: BR and NK. Project administration: BR, BK, and NK. Funding acquisition: BR, KT, CW, WW, DM, MR, BK, and NK. All authors contributed to the article and approved the submitted version.

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SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fonc.2022.812117/full#supplementary-material

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ORIGINAL RESEARCH
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Exploring Social Support Networks and Interactions of Young Adult and LGBTQIA+ Cancer Survivors and Care Partners

Kristin G. Cloyes[1]*, *Jia-Wen Guo*[1], *Karrin E. Tennant*[1], *Rachael McCormick*[2], *Kelly J. Mansfield*[1], *Sarah E. Wawrzynski*[1], *Sarah C. Classen*[3], *Eric C. Jones*[3] *and Maija Reblin*[4]

[1] *College of Nursing, University of Utah, Salt Lake City, UT, United States,* [2] *Department of Health Outcomes and Behavior, Moffitt Cancer Center, Tampa, FL, United States,* [3] *Department of Epidemiology, Human Genetics and Environmental Sciences, School of Public Health, University of Texas Health Science Center at Houston, El Paso, TX, United States,* [4] *Larner College of Medicine, University of Vermont, Burlington, VT, United States*

Edited by:
Gwendolyn P. Quinn,
New York University, United States

Reviewed by:
Kimberley Allison,
Canteen Australia, Australia
Benjamin Margolis,
Albany Medical College, United States

****Correspondence:***
Kristin G. Cloyes
Kristin.cloyes@nurs.utah.edu

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Purpose: The purpose of this study was to describe the social support networks and daily support interactions of cancer-affected individuals, including young adult (YA) and LGBTQIA+ survivors and care partners.

Methods: Participants were recruited at two United States cancer centers and *via* social media for a pilot study testing a novel online method for collecting prospective, daily social support interaction data (N=28). All participants were aged 18+; survivors had a current or recent cancer diagnosis and were engaged in treatment and/or services; care partners were identified by the survivors. Enrollment also purposefully targeted YA and LGBTQIA+ survivors. Social network data (up to 10 members) were assessed at baseline. Daily online surveys assessed support interactions between participants and specific network members over 14 days. Descriptive statistics summarized data and explored between-group (YA/non-YA, LGBTQIA+/non-LGBTQIA+) differences in social network characteristics (size, heterogeneity, density, centralization, cohesion) and support interactions (support source and type).

Results: There were no significant differences between YA and non-YA participants on any measures. LGBTQIA+ participants' support networks were less dense (Mdn=0.69 vs. 0.82, p=.02), less cohesive (Mdn=0.85 vs. 0.91,.02), more centered on the participant (Mdn=0.40 vs. 0.24, p=.047), and included more LGBTQIA+ members (Mdn=0.35 vs. 0.00, p<.001). LGBTQIA+ participants reported having more interactions with LGBTQIA+ network members (Mdn=14.0 vs. Mdn=0.00, p<.001) and received significantly more of all types of support from LGBTQIA+ vs. non-LGBTQIA+ members. LGBTQIA+ participants also reported receiving more appraisal support than non-LGBTQIA+ (Mdn 21.64 vs. 9.12, p=.008) including more appraisal support from relatives (Mdn=11.73 vs 6.0, p+.037).

Conclusions: Important information related to support access, engagement, and needs is embedded within the everyday contexts of the social networks of cancer-affected people. Individualized, accessible, and prospective assessment could help illuminate how their "real world" support systems are working and identify specific strengths and unmet needs. These insights would inform the development of more culturally competent and tailored interventions to help people understand and leverage their unique support systems. This is particularly critical for groups like YA and LGBTQIA+ survivors and care partners that are underserved by formal support services and underrepresented in cancer, caregiving, and social support research.

Keywords: LGBTQIA+, cancer survivor, care partner, young adult, sexual and gender minority, social network, social support

INTRODUCTION

Social support, a social determinant of health that influences a range of outcomes (1), is a critical resource for people affected by cancer, including both cancer survivors and their care partners (2–4). Research has sought to explain how social support influences individuals' cognitive and emotional appraisal of stress and, thereby, their psychosocial and physical health outcomes (5–7). Disparities in social support among diverse groups are also being more closely examined to determine how lack of access to culturally competent, relevant, and inclusive formal services and resources contributes to inequitable cancer outcomes (8–10).

Young adult (YA, aged 18-39) (11–13) and LGBTQIA+ (14–16) individuals are members of two underserved, yet growing subgroups within the cancer-affected population (17), and these groups will increasingly intersect as adolescents and YAs identify as LGBTQIA+ at higher rates than previous generations (18, 19). Younger demographics in the US also continue to grow more racially and ethnically diverse (20). Racial and ethnic minority cancer survivors in both YA and LGBTQIA+ groups experience even greater disparities in all-cause mortality, health outcomes, mental health, and quality of life (21–23).

Both YA and LGBTQIA+ groups also share characteristics that impact access to and engagement with formal support services such as lower income and financial stress, inadequacy of insurance, less traditional family and kinship systems, and lack of access to culturally competent care, increasing risk for unmet support needs. YA and LGBTQIA+ survivors have also reported feeling excluded from typical formal support services that have been largely developed with older, heterosexual, and cisgender patients living within traditional spousal relationships centered in nuclear, biological family structures; these services are not seen as relevant to their relationships and experiences (24, 25). YA and LGBTQIA+ survivors and care partners may therefore be even more reliant on informal sources of support, which may or may not be adequate to meet their needs, but this possibility has not been widely explored within either group.

Cancer-affected individuals, particularly those in underserved groups, rely on their informal social systems for support (4, 26). In the everyday lives of survivors and care partners, social support is accessed and activated within the real-time contexts of their actual personal networks through relationships and interactions that vary daily and over weeks, months and years (27). Social support networks are unique to each individual, and often include a mix of people who provide varying types of informal and formal support at different times (24). And while for many, support networks center on biological and legal relationships within nuclear family structures, this is changing as more YAs forgo marriage and traditional family structures and adopt more flexible kinship systems (28). The concept of chosen family, defined as kinship bonds formed outside of bio-legal family structures, has long been an important facet of LGBTQIA+ community (29).

Relatively little research, however, has examined the social support networks of YA and LGBTQIA+ cancer-affected individuals (30, 31). YAs rely on a mix of family, friends, and cancer peers for social support, and receive differing types of support from these sources depending on their changing needs over time and situation (32). LGBTQIA+ cancer survivors also receive support from diverse members of their networks and chosen family, which often includes friends and other LGBTQIA+ people, and they may be more likely to identify a close friend as a primary care partner (33, 34). Diverse social networks are associated with better aging and health outcomes and help buffer the stress of homophobia and transphobia (35), yet the social networks of older LGB adults may be less diverse and more tenuous than non-LGB peers (36, 37). The very few studies addressing the social support networks of transgender and gender diverse people also highlight the protective effects of adequate social support networks for buffering effects of discrimination and stress and improving health outcomes (38, 39)

The purpose of our study was to pilot an individualized, prospective, observational approach to assess characteristics of the personal social support networks and patterns within daily support interactions of a sample of cancer survivors and care partners focusing on YA and LGBTQIA+ individuals. To do so, we developed a novel online method combining social network assessment (structural factors) and prospective daily interaction diaries (functional factors) and we report on the development, feasibility, and acceptability of these methods elsewhere (40). Here we present the results of our descriptive analysis of participants' personal social support networks and interactions with network members which included exploratory between-group comparisons (YA/non-YA and LGBTQIA+-non-LGBTQIA+.).

METHODS

Study Design

We employed a prospective cohort design. All study activities were reviewed and approved by institutional review boards for the protection of human subjects at both study sites. This study was determined to be exempt by the University of Utah IRB (#00119352) and the Advarra IRB (Moffitt Cancer Center; Review #MCC20021).

Setting and Recruitment

A purposive, non-random sample of participants meeting study eligibility criteria were recruited from populations served by two comprehensive cancer centers in the Intermountain West and the Southeast regions of the United States and nationally *via* community partners' social media channels. Rolling recruitment occurred between August 2019 and May 2020. As our primary aim was to pilot test the feasibility of our methods within hard-to-reach populations (i.e. YA, LGBTQIA, care partners) and provide proof of concept for prospective assessment of complex social network and support data, the small sample size and use of purposive sampling methods were acceptable strategies (41).

Participants

All eligible participants were 18 and older, able to speak and read English, and were either a cancer survivor (broadly defined according to the NCI definition of a person who is on a trajectory from cancer diagnosis to end of life) (42) or a care partner of a cancer survivor (a person who most often helps the survivor and is not paid to do so). Eligible survivors had at least one current or historical cancer diagnosis, were currently engaged in treatment, services, monitoring, or follow-up related to this diagnosis, and were able to identify a primary, informal care partner or support person who also consented to participate in the study. Additionally, they had to be either YA or self-identify as LGBTQIA+ or both. Eligibility criteria for care partners included a person who the survivor considers a main source of routine support who also consented to participate. We had originally intended to enroll eight YA survivor/care partner dyads and eight LGBTQIA+ survivor/care partner dyads for a target enrollment of N=32. This was complicated by the onset of the COVID-19 pandemic in the US, however, and we stopped enrollment before fully accruing as planned. Each participant was screened by research staff for inclusion criteria, participated in the informed consent process, and was compensated $100 on study completion.

Measures

At baseline, participants completed a demographic survey in REDCap (43) and an interview-based assessment in which ecomaps were constructed to assess characteristics of their personal (egocentric) social support networks. Interview responses and ecomaps were recorded and transferred by research staff into REDCap. Participants' network member data were then used to personalize a daily electronic survey that was texted or emailed to participants for 14 consecutive days. These prospective daily surveys assessed characteristics of participants' daily interactions with network members, described below. While participants included survivor and care partner dyads, individual participant data were not shared by study team members.

Demographics

Demographic data included cancer-related role (survivor or care partner), age, racial identity, Hispanic/Latinx ethnicity, sexual orientation, gender, cis- or transgender status, relationship status, highest level of education, and income.

Social Network Measures

Each participant completed an individual baseline interview with a researcher in which an eco- mapping technique was used to elicit egocentric social network information. Participants were asked to identify up to 10 people in their social network they considered to be important sources of support related to their cancer experience (e.g. spouses/partners, relatives, friends, neighbors, co-workers, spiritual advisors, case managers, therapists). For each person, participants provided the following data: First name or initials, age, gender, whether the member was LGBTQIA+, the participants' primary relationship to the network member, length of time known, closeness of the relationship between the participant and each network member, and whether/how specific network members were connected with other network members.

Daily Interaction Surveys

Based on participant preference, first names or initials of network members were then incorporated into brief daily REDCap surveys assessing characteristics of participants' interactions with the identified members (alters) of their support network. Each day for 14 days, participants received a link *via* text or email to an online survey presenting a list of their network members and were asked to select which members they had interacted with during the last 24 hours. For each network member selected, participants were then asked to focus on one interaction with that member during the past 24 hours and provide the following information about that focal interaction: the purpose of the interaction (free text response), whether the interaction was perceived as supportive (yes, no, not meant to be supportive), the type of support the interaction represented for the participant (instrumental, informational, emotional, appraisal, based on definitions and examples provided for participants), and perception of helpfulness of the interaction (5-point Likert rating, 0 = not at all helpful, 5 = very much helpful). Only interactions perceived as supportive (yes vs. no/not mean to be) and rated as at least somewhat helpful (≥ 2 Likert rating) were included in analysis.

Analysis

Study data from both sites were merged, and all study data were reviewed and checked for consistency and errors. Missing data analysis was conducted to assess the pattern of missingness for the baseline psychosocial measures; multiple imputation was used to impute missing data after missing completely at random was confirmed. Descriptive statistics were used to summarize baseline and daily interaction data using both SPSS (version 27) and R software. UCINET (44) software was used to calculate social network variables for density (the extent to which most or all participants' network members know each other), degree centralization (the extent to which connections within one's network are numerically dominated by one or few individuals, including the participant), and cohesion (the extent to which the network is more connected vs. disconnected, somewhat irrespective of density). Three network heterogeneity measures were also calculated: diversity of age of network members, the ratio of relatives to non-relatives, and the ratio of LGBTQIA+ to non-LGBTQIA+ members. Because of the small sample size and the nonnormality of psychosocial, network, and daily interaction data, Mann-Whitney U tests were used to compare between-group differences (i.e., YA vs. non-YA, LGBTQIA+, vs. non-LGBTQIA+). A significance level of p = 0.05 was set for all tests, and we report exact p values where possible.

RESULTS

Participant Demographics

Table 1 presents participant demographics. Most participants were White (n=24, 86%), not Hispanic/Latinx (n=23, 96%), female (n=19, 67.9%), and cisgender (n=25, 89%). Seventeen participants were heterosexual (61%), and 11 were either lesbian, gay, bisexual, queer, or pansexual (39.3%). There were no significant between-group differences for demographics aside from non-heterosexual and transgender and nonbinary categories.

Social Network Characteristics

Participants' support networks had a mean of six members (SD = 2.22, range 2-10) and represented a mix of relatives (e.g. sibling, in-law; M = 3.6, SD = 1.4, range 1-7) and non-relatives (e.g. friend, co-worker; M = 2.8, SD = 2.3, range 1-7). Between-group comparisons showed no significant differences in network size/ number of network members.

There were no significant differences between YA and non-YA support networks composition or structure. **Table 2** presents a comparison of LGBTQIA+ and non-LGBTQIA+ social network characteristics. The support networks of LGBTQIA+ participants were significantly less dense (Mdn = 0.69 vs. 0.82, p = .02), less cohesive (Mdn = 0.85 vs. 0.91, p = .02) and more degree centralized (Mdn = 0.4 vs. 0.24, p = .047) than those of non-LGBTQIA+ participants. They also were significantly more heterogeneous in terms of having more LGBTQIA+ members than the networks of non-LGBTQIA+ participants (Mdn = 0.35 vs. 0.00, p <.001). While not significantly different, the support networks of LGBTQIA+ participants also tended to be more heterogenous for member age (Mdn = 15.89 vs. 14.7).

Daily Interactions and Perceived Support

We examined the total number of reported support interactions overall and with unique network members for each participant, focusing on relationship type (relatives vs. non-relatives), LGBTQIA+ status (LGBTQIA+ vs. non-LGBTQIA+ network members), and on the number of support interactions for each type of perceived support (emotional, informational, appraisal, instrumental).

Participants reported a mean of 41.79 support interactions overall during the two-week period (Mdn=39, SD=26.3, range=8-108) and a mean of 27.8 interactions with different network members (M= 27.75, Mdn=25.5, SD=15.6, range=4 - 58). There were no significant differences between YAs and non-YAs for number of interactions of any specific support type (instrumental, informational, emotional, appraisal, other) overall, or when examining support type by source (relative or non-relative.)

While not statistically significant, LGBTQIA+ participants reported more daily interactions with non-relatives than with relatives overall (**Table 3**, p = .08). LGBTQIA+ participants reported more appraisal support interactions with all members in their network (relatives and non-relatives) compared to non-LGBTQIA+ participants (p = .008), including more appraisal support interactions with relatives (p = .037).

LGBTQIA+ participants reported more interactions with LGBTQIA+ members than with non-LGBTQIA+ members (**Table 4**, p <.001), and more emotional support (p <.001), appraisal support (p <.001), and instrumental support from LGBTQIA+ vs. non-LGBTQIA+ members (p <.001). LGBTQIA+ participants also reported more informational interactions with both LGBTQIA+ (p = .006) and non-LGBTQIA+ (p = .019) alters, and more appraisal support from all members (p = .008), than did non-LGBTQIA+ participants.

DISCUSSION

For an increasingly diverse population of cancer-affected people, there remain challenges to assessment and inclusion in survivorship, social support, and social network research that may limit the impact of this knowledge and its implementation in real-world contexts (45). Despite how many cancer survivors rely on informal support systems, little social support research accounts for the unique social context of the individual—this is a critical gap in achieving equity for groups whose support systems may look or work differently from the norms that currently inform assessment and intervention. Many of the influential findings related to social support in cancer and caregiving populations draw from research conducted with mostly white, heterosexual, cisgender, middle-aged, and older adults (8, 46). And while dyadic social support and cancer research expands beyond the individual perspective, it still largely ignores the possibility that other kinds of social relationships may be just as critical to supporting survivors and care partners as traditional

TABLE 1 | Participant demographics.

	All (N = 28)	LGBTQIA+ (n = 11)	Non-LGBTQIA+ (n = 17)
	Mean Yrs (SD)		
Age	40.75 (18.26)	39.64 (22.23)	41.47 (15.89)
Cancer Role		N (%)	
Survivor	14 (50)	6 (54.54)	8 (47.06)
Care Partner	14 (50)	5 (45.45)	9 (52.94)
Gender			
Man	8 (28.57)	3 (27.27)	5 (29.41)
Woman	19 (67.86)	7 (63.64)	12 (70.59)
Non-Binary	1 (3.57)	1 (9.09)	–
Trans/Cisgender			
Transgender	3 (10.71)	3 (27.27)	–
Cisgender	25 (89.29)	8 (72.72)	17 (100)
Sexual Orientation			
Heterosexual	17 (60.71)	–	17 (100)
Lesbian/Gay	3 (10.71)	3 (27.27)	–
Bisexual	4 (14.29)	4 (36.36)	–
Queer	2 (7.14)	2 (18.18)	–
Pansexual	2 (7.14)	2 (18.18)	–
Race			
Black	4 (14.29)	–	4 (23.53)
White	24 (85.71)	11 (100)	13 (76.47)
Ethnicity			
Latinx	1 (3.57)	1 (9.09)	–
Relationship Status			
Single (Never married)	3 (10.71)	–	3 (17.65)
Separated or Divorced	1 (3.57)	–	1 (5.88)
Married	15 (53.57)	4 (36.37)	11(64.71)
Registered domestic Partnership or Civil union	–	–	–
Committed relationship (not legally or officially married or registered)	7 (25)	7 (63.63)	–
Widowed	2 (7.14)	–	2 (11.77)
Education			
High school	3 (10.71)	–	3 (17.64)
Some college or vocational school	9 (32.14)	3 (27.27)	6 (35.29)
College Graduate	1 (3.57)	1 (9.09)	–
Some graduate or professional schooling	4 (14.29)	3 (27.27)	1(5.88)
Graduate or professional degree	11 (39.29)	4 (36.36)	7 (41.18)
Income			
Less than $9,999	2 (7.14)	1 (9.09)	1 (5.88)
$10,000-$24,999	6 (21.43)	4 (36.37)	2 (11.77)
$25,000-$39,999	3 (10.71)	1 (9.09)	2 (11.77)
$40,000-$49,999	1 (3.57)	–	1 (5.88)
$50,000-$74,999	–	–	–
$75,000-$99,999	1 (3.57)	1 (9.09)	–
>$100,000	11 (39.29)	3 (27.27)	8 (47.05)
Prefer not to disclose	4 (14.29)	1 (9.09)	3 (17.65)

spousal and kin relationships (47). Existing research also ignores the reality that for many groups, social support and caregiving are not centered in spouse/partner or biological parent/child dyads, but distributed across social networks comprising an array of members who may be more or less demographically and developmentally diverse (48). This pilot study uses novel methodology to address gaps in previous research and assess structural and functional aspects of personal social support networks of underserved YA and LGBTQIA+ cancer patients.

Though our analyses revealed no significant differences between social network characteristics of YA and non-YA participants, contrary to expectation (49), we did note significant differences in network characteristics based on LGBTQIA+ status (50, 51). LGBTQIA+ participants' networks were less dense and less cohesive, suggesting that LGBTQIA+ participants' connections to social support may be more diffused across network members. The higher degree centralization of LGBTQIA+ participants in their social networks (i.e., members are generally connected to the participant but less with each other) suggests that these individuals were playing a more central role in holding their own networks together. LGBTQIA+ participants' networks were also more diverse in that they included more LGBTQIA+ members, plus LGBTQIA+ participants also had more support-related interactions overall, including more with non-relatives.

These network characteristics may be strengths, offering participants a wide reach of network members with frequent contact (52, 53). Diffuse and heterogeneous networks have been shown to have benefits, including brokering diverse information and access to an array of resources (54). Further, higher levels of

TABLE 2 | Social network characteristics.

Variables	LGBTQIA+n = 11			Non-LGBTQIA+n = 17			MW	
	M	SD	Mdn	M	SD	Mdn	U	p
Number of ties (network size)	6.82	1.99	7.0	5.47	2.18	5.0	59.00	0.1
Heterogeneity-Relatives/ Non-relatives	0.34	0.18	0.38	0.31	0.21	0.38	85.50	0.71
Heterogeneity-Age	14.9	5.15	15.89	6.9	27.64	14.17	69.00	.26
Heterogeneity-SGM/ Non-SGM	0.33	0.11	0.35	0.08	.15	0.00	22.00	<.001*
Density	0.68	0.15	0.69	.834	0.16	0.82	44.50	.02*
Centralization	0.42	0.19	0.40	0.24	0.06	0.24	51.50	.047*
Cohesion	0.84	0.08	0.85	0.92	0.08	0.91	45.00	.02*

*MW, Mann-Whitney U test; M, mean; SD, standard deviation; Mdn, median; *Significant at p < 0.05 level.*

perceived support may mitigate negative health effects related to less cohesive and more diffuse networks (55, 56). However, a combination of higher heterogeneity and degree centralization with less density and cohesion may also be associated with a diffusion of social support and overall weaker connections among network relationships, which may also put LGBTQIA+ participants in a more precarious position in more volatile and high need situations, such as when participants are ill or burdened. For example, if a support network is dependent on a cancer survivor or care partner as a stabilizing node of connection, with few strong, well-resourced ties, their inability to fulfill the connecting role due to illness, lack of resources to mobilize the network, or competing demands can lead to a lack of coordinated support. This network profile may create problems for accessing or leveraging social support resources and could lead to unmet support needs. This premise should also be tested in a larger study over a longer period of time.

Emotional and appraisal support appeared to be an important type of support for LGBTQIA+ participants, as they reported more of these interactions with all network members compared with non-LGBTQIA+ participants. Appraisal support provides individuals with a sense of context that supports self-evaluation, reflection on one's situation and standing, and a sense of connection to others who know and understand you well enough to afford this perspective (57). For individuals who are also LQBTQIA+ who experience minority stress–a combination of proximal and distal stressors related to minority status that span intrapersonal, interpersonal, and structural factors, the role of appraisal-oriented support may be particularly relevant to perceptions of support and mental health outcomes (58). LGBTQIA+ individuals, including younger people, are likely to have more experience with minority stress than are their non-minority counterparts and may have more practice and facility with accessing appraisal and emotional support within their networks, which may be protective. The flip side of this dynamic, however, is the compounded risk associated with LGBTQIA+ cancer survivors and care partners not having stable connections to people who provide this support within

TABLE 3 | LGBTQIA+ and non-LGBTQIA+ support interactions with relatives and non-relatives.

Variables	LGBTQIA+n = 11			Non-LGBTQIA+n = 17			MW	
	M	SD	Mdn	M	SD	Mdn	U	p
Count of **daily interactions** with:								
Relatives	18.00	7.96	16.00	19.47	12.53	18.00	92.50	.96
Non-relatives	14.45	12.74	12.00	5.59	6.78	4.00	131.00	.08
All members	32.36	17.48	26.00	24.76	14.01	24.00	114.00	.35
Count of **emotional** support interactions with:								
Relatives	10.09	7.62	10.00	7.41	7.67	4.00	119.50	.23
Non-relatives	7.27	9.82	5.00	2.71	5.19	1.00	125.50	.13
All members	17.36	14.31	14.00	10.12	11.5	5.00	132.00	.07
Count of **informational** support interactions with:								
Relatives	3.45	3.21	3.00	6.18	7.69	4.00	80.00	.55
Non-relatives	2.09	2.63	1.00	2.00	3.48	1.00	98.00	.85
All members	5.55	5.3	4.00	8.18	9.02	4.00	85.00	.71
Count of **appraisal** support interactions with:								
Relatives	11.73	8.00	12.00	6.00	7.42	3.00	138.00	.037*
Non-relatives	9.91	10.77	7.00	3.12	4.46	0.00	134.00	.06
All members	21.64	13.69	15.00	9.12	9.33	6.00	149.00	.008*
Count of **instrumental** support interactions with:								
Relatives	8.09	6.09	9.00	6.53	6.98	3.00	111.00	.43
Non-relatives	3.55	7.09	0.00	0.71	1.53	0.00	118.00	.26
All members	11.64	7.67	12.00	7.24	7.12	7.00	130.50	.08

*MW, Mann-Whitney U test; M, mean; SD, standard deviation; Mdn, median; *Significant at p < 0.05 level.*

TABLE 4 | Support interactions with LGBTQIA+ and non-LGBTQIA+ network members.

Variables	LGBTQIA+n = 11			Non-LGBTQIA+n = 17			MW	
	M	SD	Mdn	M	SD	Mdn	U	p
Count of **daily interactions** with:								
LGBTQIA+ members	15.64	10.74	14.00	1.65	3.64	0.00	179.50	<.001*
Non-LGBTQIA+ members	16.55	14.72	12.00	25.88	14.33	26.00	58.00	.10
All members	32.64	17.06	26.00	27.53	14.93	29.00	108.00	.52
Count of **emotional** support interactions with:								
LGBTQIA+ members	11.00	6.93	10.00	0.47	1.23	0.00	176.50	<.001*
Non-LGBTQIA+ members	5.91	11.30	2.00	10.12	11.30	6.00	53.00	.06
All members	17.36	14.31	14.00	10.59	11.41	6.00	128.50	.10
Count of **informational** support interactions with:								
LGBTQIA+ members	3.27	3.04	3.00	0.41	1.00	0.00	150.50	.006*
Non-LGBTQIA+ members	1.82	2.04	2.00	7.94	9.02	5.00	44.00	.019
All members	5.55	5.30	4.00	8.35	8.91	5.00	80.50	.55
Count of **appraisal** support interactions with:								
LGBTQIA+ members	11.64	7.66	12.00	0.47	1.13	0.00	177.00	<.001*
Non-LGBTQIA+ members	9.64	10.99	5.00	9.06	9.24	5.00	95.00	.96
All members	21.64	13.69	15.00	9.53	9.26	7.00	149.00	.008
Count of **instrumental** support interactions with:								
LGBTQIA+ members	7.91	6.02	8.00	0.18	0.73	0.00	176.00	<.001*
Non-LGBTQIA+ members	3.36	3.30	2.00	7.06	7.08	7.00	67.50	.23
All members	11.64	7.67	12.00	7.24	7.12	7.00	130.50	.08

*MW, Mann-Whitney U test; M, mean; SD, standard deviation; Mdn, median; *Significant at p < 0.05 level.*

their personal networks and/or not knowing how to ask for and generate this support among members.

Implications for Intervention

Future work should examine how formal sources of support (e.g. oncologists, therapists, counselors) are integrated within survivors' and care partners' existing social networks (or not), including interactions between timing and types of support, service use, and wellbeing. The social support systems of cancer-affected people are inherently unique and—for YAs and people in minoritized populations like LGBTQIA+–may not be well-reflected in the expectations and operations of established formal services. For example, routine clinical care may hold implicit expectations of a hetero-normative network more traditionally seen in research on older adults, in which a spouse or adult child is available to provide outpatient care to patients. Those whose networks do not conform to this standard may not only experience feelings of alienation, but may be missing critical support for their care.

Developing a working understanding of more diverse social support landscapes is therefore important for clinicians as well as researchers. Clinicians can be mindful of expectations for support required for patients and caregivers to participate effectively in treatment and facilitate connections to inclusive formal resources when additional support is needed. Across healthcare systems, more tailored, less generic patient-centered clinical and support services would be particularly impactful for groups like YA and LGBTQIA+ who report feeling alienated by normative care models that do not acknowledge their individual contexts and experiences.

Researchers should focus on developing personalized interventions that boost cancer survivors' and cancer care partners' self-efficacy in accessing and leveraging social support to meet everyday challenges. This is especially critical for underserved populations, including people who are YA and LGBTQIA+ cancer survivors or care partners, who may be even more reliant on their personal social networks who feel disconnected from typical, formal support resources, and whose support systems may look different than those represented in the cancer literature. Finding ways to better coordinate holistic, high-quality cancer care is a national priority (59). Conducting more inclusive survivorship research will be important to ensure health care policy remedies, rather than reinforces, health care disparities.

Limitations

There were a number of limitations to this study. The descriptive and exploratory nature of our analyses limits the generalizability of our findings. A small sample size and purposive, non-probability sampling may have increased the risk of selection bias. There was a wide age range within the LGBTQIA+ group which may be contributing to the differences we found, although we verified that groups did not significantly differ by age. While grouping individuals of diverse sexual orientations and gender identities together in a single LGBTQIA+ group is often necessary due to small numbers of participants in these groups, it confounds important between-group differences that are relevant to understanding cancer- and minority-stress related support needs; this is compounded by the lack of representation of transgender and gender diverse participants in most studies, including this one. Finally, our data collection period spanned August 2019-May 2020 and the onset of the COVID-19 pandemic in the US slowed our study enrollment considerably, leading us to close recruitment before enrolling an equal number of LGBTQIA+ and non-LGBTQIA+ participants.

Conclusion

Every cancer-affected individual's social support system is unique. Both structural and functional aspects of social support networks–network characteristics and patterns of interactions within these networks—are likely to influence survivors' perceptions of support, appraisal of stress, capacity to cope, and ultimately their well-being. These influences may differ from person to person and by groups affected by differing social determinants of health (60). Relationship types and quality, the closeness of member connections, modality of interactions, patterns of interaction over time, and survivors' changing preferences, needs, and perceptions of helpfulness are also likely to shape how social support affects survivors' appraisal and coping (61). Examining these complexities for diverse groups of cancer survivors and their care partners should, therefore, be a priority for developing and implementing culturally-relevant interventions.

We sought to examine the personal social support networks of cancer survivors and their care partners in two groups—YA and LGBTQIA+ cancer survivors—that have been under-represented in survivorship, caregiving, and social support research and who subsequently report unmet support needs. We further sought to contextualize this by studying the survivor-care partner dyads in relation to their personal support networks. This study provides proof of concept for this strategy, and suggests that there may be important aspects of YA and LGBTQIA+ survivor cohorts in the structure and function of their personal support networks. Next steps include adapting all data collection methods for online access, repeating the protocol with a larger sample over a longer period of time, and modeling how social network characteristics and daily interaction patterns predict changes in perceived stress, support, and mental health outcomes.

DATA AVAILABILITY STATEMENT

A limited de-identified data set is available on request. Requests to access the datasets should be directed to kristin.cloyes@nurs.utah.edu.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by University of Utah IRB, and the Advarra IRB Moffitt Cancer Center. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

KGC and MR conceptualized this study and acquired project funding. KGC developed the methodology for data collection. KET, REM, and KJM coordinated project administration. J-WG developed the plan for formal analysis. KGC, J-WG, EJC, SCC, and SEW performed data analysis. KGC wrote the original draft. All authors contributed to the article and approved the submitted version.

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Racial/Ethnic Differences in Health-Related Quality of Life Among Gay and Bisexual Prostate Cancer Survivors

Alex J. Bates[1], *B. R. Simon Rosser*[1]*, *Elizabeth J. Polter*[1], *Christopher W. Wheldon*[2], *Kristine M. C. Talley*[3], *Ryan Haggart*[4], *Morgan Wright*[1], *Darryl Mitteldorf*[5], *William West*[6], *Michael W. Ross*[7], *Badrinath R. Konety*[8] *and Nidhi Kohli*[9]

[1] Division of Epidemiology and Community Health, School of Public Health, University of Minnesota, Minneapolis, MN, United States, [2] Department of Social and Behavioral Sciences, College of Public Health, Temple University, Philadelphia, PA, United States, [3] Adult and Geriatric Health, University of Minnesota School of Nursing, Minneapolis, MN, United States, [4] Department of Urology, University of Minnesota, Minneapolis, MN, United States, [5] Malecare Cancer Support, New York, NY, United States, [6] Department of Writing Studies, University of Minnesota, Minneapolis, MN, United States, [7] Department of Family Medicine and Community Health, University of Minnesota Medical School, Minneapolis, MN, United States, [8] Allina Health Cancer Institute, Minneapolis, MN, United States, [9] Department of Educational Psychology, University of Minnesota, Minneapolis, MN, United States

Edited by:
Jane Ussher,
Western Sydney University, Australia

Reviewed by:
Charles Kamen,
University of Rochester, United States
Yolanda Pardo,
Instituto de Salud Carlos III (ISCIII), Spain

***Correspondence:**
B. R. Simon Rosser
rosser@umn.edu

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Introduction: Prostate cancer treatment has established effects on the health-related quality of life (HRQOL) of patients. While racial/ethnic differences in HRQOL have been explored in heterosexual patients, this is the first study to examine racial/ethnic differences in a cohort of sexual minority prostate cancer survivors.

Methods: We used data from the Restore-1 study, an online cross-sectional survey of sexual and gender minority (SGM) prostate cancer survivors in North America, to explore the association between race/ethnicity and HRQOL. General mental and physical HRQOL was assessed using the Short-Form Health Survey version 2 (SF-12). The frequency and distress of prostate cancer specific symptoms was assessed using the Expanded Prostate Cancer Composite (EPIC) scale. Multivariable linear regression was used to estimate mean differences in HRQOL between sexual minority men of color and their white, non-Hispanic counterparts after adjustment for pertinent demographic and medical characteristics.

Results: Among 190 participants, 23 (12%) self-identified as non-white and/or Hispanic. In unadjusted analysis, sexual minority men of color compared to their white counterparts reported worse HRQOL scores in the EPIC hormonal summary (73.8 vs. 81.8) and hormonal function (70.9 vs 80.5) domains. Clinically important differences between men of color and their white counterparts were seen in the EPIC bowel function (mean difference (MD): -4.5, 95% CI: -9.9, 0.8), hormonal summary (MD: -8.0, 95% CI: -15.6, -0.4), hormonal function (MD: -9.6, 95% CI: -17.6, -1.6), and hormonal bother (MD: -6.7, 95% CI: -14.4, 1.1) domains. After adjustment for covariates, clinically important differences persisted between men of color and white, non-Hispanic men on the hormonal summary (74.4 vs. 81.7), hormonal function (71.3 vs. 80.3), and hormonal bother (77.0 vs. 82.7) domains.

Conclusions: This exploratory study provides the first evidence that sexual minority men of color may have worse HRQOL outcomes compared to white, non-Hispanic sexual minority men following prostate cancer treatment.

Keywords: prostatic neoplasms, sexual and gender minorities (SGMs), quality of life, ethnic groups/epidemiology, cancer, oncology

INTRODUCTION

Sexual minority men (i.e., those who identify as gay or bisexual) seeking cancer care face greater psychological distress (1), poorer quality of life outcomes (1), increased discrimination (2, 3), and experience significant cancer outcome disparities (2–5) when compared to their heterosexual counterparts. The proportion of adults in the United States (U.S.) who identify as a sexual minority has steadily increased in recent years, with current estimates indicating that 5.6% of U.S. adults identify as such (6). However, while sexual minority communities face disparities in cancer outcomes there is a significant gap in the literature of sexual minority cancer studies, with little known about their unique experiences and needs (2, 7–9).

Prostate cancer is the second most common type of cancer in the U.S. and the most common type of invasive cancer among men (10). In 2021 alone, over 240,000 new cases are estimated to be diagnosed in the U.S (10). The proportion of sexual minority prostate cancer patients is expected to increase from the current level of approximately 2% to 4% in the next decades (11), suggesting that over 100,000 sexual minority men will be living with prostate cancer in the U.S (12). With this increase comes a need for additional research examining the disparities faced within this community to better guide future public health policy and interventions.

Few studies have explored prostate cancer in sexual minority populations (5, 9, 13, 14). Sexual minority men experience more functional (e.g., urinary, bowel, hormonal, sexual) issues following treatment (1, 15–19), as well as lower health-related quality of life outcomes (HRQOL) (1, 13, 15, 16), compared to their heterosexual counterparts. Sexual minority men have worse quality of life outcomes in multiple prostate cancer specific domains, as well as poorer overall mental health when compared to published norms for heterosexual prostate cancer survivors (16). Past research has found older sexual minority men experience more sexual symptoms and greater distress related to these symptoms after treatment (16). Similarly, those who are HIV-positive experience greater urinary, sexual, and bowel symptoms and greater distress related to these symptoms after treatment (20).

Research in the general population has consistently shown significant racial differences in the experiences of prostate cancer in communities of color. Some Asian American subpopulations, particularly those who are foreign-born, are more likely to present with advanced disease (21, 22) and have higher mortality rates (21, 23) compared to their white, non-Hispanic counterparts. Additionally, Asian-American men have worse urinary incontinence in the first year following prostatectomy compared to white, non-Hispanic prostate cancer survivors (24). While American Indian and Native Alaskan men are less likely to be diagnosed with prostate cancer, they also have higher mortality rates compared to white, non-Hispanic men (21, 25).Compared to their white, non-Hispanic counterparts, Black men are more likely to be diagnosed younger (26–29), and have higher mortality rates (10, 29–34). Additionally, Black prostate cancer survivors are more likely to report worse urinary function with slower recovery (35–37), and worse general and mental health (35, 38), compared to white, non-Hispanic survivors. Black and Hispanic men are also more likely to be diagnosed with more advanced cancer (27–29, 39–41), and are less likely to receive definitive treatment (33, 42) when compared to their white, non-Hispanic counterparts. Among prostate cancer patients treated with surgery, Black and Hispanic men are more likely to report worse bowel function (37) and problems with their sexual function (37, 43). However, Black men report better overall sexual function after any type of treatment (37, 43) and better urinary functioning after prostatectomy (43). Whether these findings extend to sexual minority populations has not been studied.

The experiences of sexual minority men of color with prostate cancer have not been previously studied. Globally, there have been only seven other quantitative studies of sexual minority prostate cancer survivors published (1, 15, 17, 18, 44–46) with none being large enough to explore racial/ethnic differences. The experiences of sexual minority prostate cancer survivors can be explained through the lens of minority stress and intersectionality. Minority stress theory suggests that sexual and gender minority (SGM) people experience unique stressors related to their experiences of stigma and discrimination, which results in worse health outcomes (47, 48). Intersectionality theory provides a framework for understanding how multiple social identities intersect to provide individuals with experiences that are distinct from any single identity, reflecting systems of privilege and oppression present in society (49, 50). To fill in the gap in research, we used a cross-sectional survey of sexual minority prostate cancer survivors (16) to quantify racial differences in overall HRQOL and prostate cancer specific HRQOL in sexual minority men who have undergone prostate cancer treatment. Using the theories from above, we hypothesized that since sexual minority men of color face multiple stressors from racism and homophobia (2, 48, 51), they should experience worse HRQOL outcomes after prostate cancer treatment when compared to their white, non-Hispanic counterparts.

METHODS

Design and Participants

Data were from Restore-1 study which was an online cross-sectional survey conducted in 2015 of 193 gay and bisexual men and one transgender person in the U.S. and Canada who had been treated for prostate cancer (16, 52). Participants were recruited from online advertisements as well as emails sent to Malecare.org, a large North American cancer advocacy organization and support group. Participants completed a brief screening survey and were deemed eligible if they were: (1) a gay, bisexual, or other man who has sex with men, (2) 18 years or older, (3) able to read English, (4) had been treated for prostate cancer before the survey, and (5) living in the U.S. or Canada. Participants who were eligible then went through an informed consent process and, if they consented, were directed to the final survey. Each participant received a $25 gift card as compensation.

The detailed recruitment protocol for this study as well as the cross-validation and de-duplication procedures are described elsewhere (16, 52). In all, 427 surveys were received. Following online survey best practices, surveys and survey response patterns were evaluated for both fraud and duplication, resulting in 233 surveys being deemed invalid or duplicative and one insufficiently complete. These were removed from the final sample. All study procedures were approved by the University of Minnesota institutional review board.

Measures

Questions from the U.S. Census were used to assess participant demographics such as race, ethnicity, age, and education. One survey item was used to assess the participant's race ("What is your race?") with participant's selecting one or more of the following: American Indian or Alaska Native American, Asian American, Black or African American, Native Hawaiian or other Pacific Islander, White, or Other race. One survey item was used to access ethnicity ("Are you Spanish/Hispanic/Latino?"). Questions related to a participant's sexual orientation, relationship status, and HIV status were based on prior research conducted by this study's principal investigators (53, 54). Questions pertaining to prostate-specific antigen (PSA) level at time of diagnosis and Gleason score at time of diagnosis were derived from previous studies conducted on prostate cancer (55, 56). Type of prostate cancer treatment participants had received was assessed by asking participants if they had received any of the following nine treatments: surgery (e.g., radical prostatectomy), external radiation therapy, brachytherapy, cryotherapy, medical castration, surgical castration, diet and/or alternative therapy, and active surveillance. To assess whether participants were taking medications that can have sexual side effects (e.g., loss of sexual interest, erection difficulties) participants were asked if they were taking any of fourteen different medication classes, with the following classes of medications being pertinent for the current study: prostate cancer medications (e.g., Leuprolide) and chemotherapy medications. To measure discrimination encountered by participants during treatment, the Everyday Discrimination Scale (EDS), adapted for medical settings (57), was used. This seven-item scale asks participants the frequency of discrimination they experience during their provider interactions, with higher scores indicating more frequent discrimination (57).

General HRQOL was assessed using the Short-Form Health Survey version 2 (SF-12). The SF-12 contains twelve items answered with Likert scales. It contains two subscales related to mental and physical health. Each domain is normed with a mean score of fifty, with higher scores indicating better health (58). In the general population, the SF-12 has high internal consistency for the physical and mental domains (Cronbach's $\alpha \geq 0.72$), as well as high test-retest reliability ($r \geq 0.73$) (58). Minimal clinically important differences (MCID) between scores (that is, the change in score that would be noticeable to the patient) have previously been reported in general populations of prostate cancer survivors for the SF-36 version of this scale, which has been found to be highly correlated with the SF-12 version (59). These MCID estimates were 6 for the physical function domain and 8.4 for the mental health domain (60).

Prostate-cancer-specific quality of life was assessed using the Expanded Prostate Cancer Index Composite (EPIC) scale. We employed the 50-item version which yields four symptom domains: urinary, bowel, sexual, and hormonal (61). Each domain is further divided into a function and bother subdomain, which assess the frequency of symptoms related to that domain and the distress caused by those symptoms respectively. Each domain and subdomain is scored from 0 to 100, with 100 indicating better health in that particular area. Overall, domain summary scores are the combination of its corresponding functional and bother subdomain scores. In general populations the EPIC scale has high internal consistency (Cronbach's $\alpha \geq 0.82$), test-retest reliability ($r \geq 0.80$), and validity with Pearson's correlation coefficients ranging from 0.29 to 0.77 (61). MCID between scores for the 26-item version of this scale, which is highly correlated with EPIC-50 (62), have previously been estimated for each domain in the general population (63). These MCID estimates were 5–7 for the urinary irritative/obstructive domain, 6–9 for the urinary incontinence domain, 10–12 for the sexual domain, and 4–6 for the hormone and bowel domains (63). MCID estimates for the urinary irritative and urinary incontinence domains were used for the EPIC-50 urinary bother and urinary function domains, respectively (64).

Analysis

Given the small number of non-white and Hispanic participants, racial and ethnic categories were collapsed into either non-white and/or Hispanic (i.e., men of color) or white, non-Hispanic. This method of combining small numbers of non-white and Hispanic participants into one group is similar to other exploratory studies (65–67). A proxy measure of the current severity of the participant's cancer was created by summing the two classes of prostate-cancer related medications participants were asked about during the survey, that is chemotherapy medications and prostate cancer medications (e.g., Leuprolide). Participant demographic, medical, and HRQOL characteristics were summarized using means and standard deviations for continuous variables and counts and percentages for categorical variables. Participant characteristics were compared by racial/ethnic group using *t*-tests for continuous variables and chi-square tests or Fisher exact tests, when appropriate, for categorical variables. Descriptive statistics (mean and standard deviation) of each HRQOL measure were calculated for each separate racial/ethnic group (e.g., white, Black/African American, Asian American etc.) to allow for descriptive analysis.

Multivariable linear regression was used to assess the unadjusted mean differences (MD) and adjusted mean differences (AMD) between men of color and white, non-Hispanic men for all EPIC and SF-12 domains. *Post-hoc* power calculations were performed for each measure using each groups sample size, mean, standard deviation, and the corresponding MCID for that measure. Power to detect MCID between scores ranged from 0.22 (EPIC urinary bother domain) to 0.71 (EPIC sexual summary domain) for the EPIC-50, and 0.77 (physical domain) to 0.88 (mental domain) for the SF-12.

Participants were excluded from analysis if they were missing any SF-12 or EPIC domain or subdomain scores (N=2) or if they refused to answer what their race or ethnicity was (N=1).The multivariable models included variables that had a statistically significant ($p \leq 0.05$) association with ethnoracial groups. Because cancer severity may lie on the causal pathway between race/ethnicity and HRQOL (16, 27, 29, 31, 39, 68, 69) these measures (type of prostate cancer treatment, Gleason score, and count of systemic prostate cancer therapies) were not included in any models. Mean differences were considered to be statistically significant at $p < 0.05$. All reported *p*-values were two-sided. All analyses were conducted using Stata Statistical Software (StataCorp. 2021. Stata Statistical Software: Release 17. College Station, TX: StataCorp LLC.).

RESULTS

The final analytic sample consisted of 190 gay and bisexual men who had undergone prostate cancer treatment, had a score for all EPIC and SF-12 domains and responded to both the race and ethnicity survey items. Most participants self-identified as white (N=170, 89.5%) followed by Black/African American (N=9, 4.7%), with those remaining participants self-identifying as Asian American (N=4, 2.1%), other races ("EurAsian" and Hispanic) (N=3, 1.6%), American Indian/Alaska Native American (N=2, 1.1%), or multiracial (American Indian or Alaska Native American and white) (N=2, 1.1%). Participants largely self-identified as non-Hispanic (96.8%) with those remaining identifying as Hispanic (3.2%). Participants who identified as Hispanic were largely Mexican, Mexican American, or Chicano (N=3), followed by Puerto Rican (N=2), and "other" Hispanic ethnicity (N=1). Taken together, 23 (12%) participants self-identified as non-white and/or Hispanic with those remaining 167 (88%) participants being white and non-Hispanic. Participants had a mean age of 63.5 years (SD=8.2). Most participants had at least a bachelor's degree (77.4%) and over half were married or in a long-term relationship (55.4%). The preponderance of participants self-identified as gay/homosexual (90.5%) with those remaining identifying as bisexual (9.5%).

Participant's demographic and medical characteristics by race/ethnicity are presented in **Table 1**. Compared to their white, non-Hispanic counterparts, men of color were significantly younger, more likely to be HIV-positive, and more likely to be on one-or-two methods of systemic prostate cancer therapies. No other participant characteristics were significantly different between the two groups.

Descriptive statistics of the HRQOL measures (EPIC and SF-12) by each separate racial and ethnic group are reported in **Table 2**. While white, non-Hispanic men had higher or similar mean scores on all domains compared to all other ethnoracial groups, Latino men had the highest mean scores on all EPIC urinary and bowel domains as well as the SF-12 mental function domain. All other ethnoracial groups consistently had similar or lower mean scores compared to white, non-Hispanic men and Latino men.

HRQOL measures are reported in **Tables 3** and **4**. In unadjusted analysis, men of color were significantly more likely to report worse mean scores on the EPIC hormonal summary (73.8 vs. 81.8, p=0.038) and hormonal function (70.9 vs. 80.5, p=0.019) domains, when compared to white, non-Hispanic men. Across all measures, men of color consistently had worse scores on the EPIC and SF-12, though no other measures reached statistical significance. However, mean differences on the EPIC bowel function (MD: -4.5, 95% CI: -9.9, 0.8), hormonal summary (MD: -8.0, 95% CI: -15.6, -0.4), hormonal function (MD: -9.6, 95% CI: -17.6, -1.6), and hormonal bother (MD: -6.7, 95% CI: -14.4, 1.1) domains all reached MCID thresholds. After adjustment for covariates, men of color were still statistically more likely to report worse scores on the EPIC hormonal function domain (AMD: -9.0, 95% CI: -17.3, -0.8) when compared to white, non-Hispanic men. Additionally, men of color reported clinically worse scores on the hormonal summary (74.4 vs. 81.7), hormonal function (71.3 vs. 80.3), and hormonal bother (77.0 vs. 82.7) domains compared to their white, non-Hispanic counterparts. There were no other clinically-or-statistically significant differences between men of color and white, non-Hispanic men on any other EPIC or SF-12 domains.

DISCUSSION

In this cross-sectional study of 190 sexual minority prostate cancer survivors, men of color reported worse HRQOL in bowel function and all hormonal domains when compared to their white, non-Hispanic counterparts. However, the clinically significant association found in the bowel function domain, as well as the statistically significant association found in the hormonal summary domain, were explained by differences in

TABLE 1 | Characteristics of Participants by Race and Ethnicity Enrolled in Restore-1: A Survey of Sexual Minority Prostate Cancer Survivors (N=190).

Variables	SGM of color (non-white and/or Hispanic) N=23	White, non-Hispanic SGM N=167	Test of statistical difference (*p*-value)[a]
Demographics			
Age (mean, SD)	59.8 (8.7)	64.0 (8.0)	0.021
Education (N(%))			0.430
Less than Bachelor's Degree	4 (17.4%)	39 (23.4%)	
Bachelor's Degree	11 (47.8%)	56 (33.5%)	
Graduate Degree	8 (34.8%)	72 (43.1%)	
Relationship Status (N(%))			0.821
Single/Dating/Divorced/Widowed	9 (40.9%)	74 (45.1%)	
Partnered/Married	13 (59.1%)	90 (54.9)	
Sexuality			0.999
Gay/Homosexual	21 (91.3%)	151 (90.4%)	
Bisexual or Other	2 (8.7%)	16 (9.6%)	
Income			0.579
<$35,000	3 (15.8%)	35 (23.3%)	
$35,000-79,999	9 (47.4%)	52 (34.7%)	
≥$80,000	7 (36.8%)	63 (42.0%)	
Everyday Discrimination Scale (mean, SD)	2.7 (4.2)		
Medical characteristics			
HIV Status (N(%))			0.006
HIV Negative	16 (69.6%)	149 (89.8%)	
HIV Positive	7 (30.4%)	17 (10.2%)	
Treatment (N(%))			0.328
Surgery (Only)	9 (40.9%)	89 (54.6%)	
Radiation (only)	4 (18.2%)	31 (19.0%)	
Combined/Systemic	9 (40.9%)	43 (26.4%)	
Time since diagnosis in years (Mean, SD)	5.5 (5.0)	5.6 (4.5)	0.919
PSA at diagnosis (Mean, SD)	6.2 (6.1)	7.8 (6.6)	0.355
Gleason score at diagnosis (N(%))			0.585
≤6	10 (52.6%)	60 (42.9%)	
7	7 (36.8%)	53 (37.9%)	
8-10	2 (10.5%)	27 (19.3%)	
Count of methods of systemic prostate cancer therapies (N(%))			<0.001
No medications taken for prostate cancer	16 (69.6%)	142 (85.0%)	
One method of systemic prostate cancer therapy (either chemotherapy or prostate cancer medications such as Leuprolide)	5 (21.7%)	25 (15.0%)	
Two methods of systemic prostate cancer therapies (both chemotherapy and prostate cancer medications such as Leuprolide)	2 (8.7%)	0	

[a] *Participant characteristics were compared using t-tests for continuous variables and chi-square tests or Fisher exact tests, when appropriate, for categorical variables.*

HIV status. This finding is consistent with HIV disproportionally impacting sexual minority men of color (70) and compounding the impact of cancer treatment on HRQOL (20).However, after controlling for HIV status, clinically significant disparities persisted on all EPIC hormonal domain measures and statistically significant disparities persisted on the EPIC hormonal function domain.

These findings are consistent with the broader literature on intersectional stress in SGM populations. SGM people of color are exposed to greater stressors when compared to white SGMs (71–73) and report lower levels of HRQOL (74–76). Since significant differences remained after controlling for covariates, the association between worse HRQOL and race/ethnicity is robust in nature. The lack of widespread HRQOL disparities in this study may be explained by the concept of resiliency which refers to a person's quality of being able to overcome stressful and traumatic situations (2, 48, 77). Past research has suggested that SGM people of color develop unique resiliency skills to cope with racism they face in their daily lives (48, 51, 78, 79). Additionally, older SGM individuals may share common experiences (e.g., living through the height of the HIV/AIDS pandemic) that provided opportunities for this entire generational cohort to build resilience (80). Therefore, differences between racial/ethnic groups might be masked by this commonality.

Future research into sexual minority prostate cancer survivors should aim to better elucidate the unique experiences of people of color by over-sampling racial and ethnic minorities. Specifically, more studies are needed with enough Black sexual minority prostate cancer patients to find whether disparities seen in heterosexual men extends to sexual minority populations. Such studies should also explore the role of resiliency in their data.

Study Limitations

This study has several limitations that should be taken into consideration. First, only 23 (12%) participants identified

TABLE 2 | Descriptive Statistics of Health-Related Quality of Life (HRQOL) outcomes for Sexual Minority Prostate Cancer Survivors by Racial and Ethnic Group (N=189).

	White, non-Hispanic (N=167)	Black/African American (N=8)	Latino (N=6)	Asian American (N=4)	American Indian/Alaska Native American (N=2)	Multiple races[a] (N=2)
EPIC-50[b] (Mean, SD)						
Urinary summary	77.7 (16.9)	67.3 (33.1)	92.0 (9.7)	65.1 (29.4)	77.1 (26.5)	54.9 (23.6)
Function	82.0 (17.8)	72.1 (36.1)	93.3 (13.4)	72.5 (26.3)	65.0 (42.4)	61.7 (28.4)
Bother	74.6 (19.8)	63.8 (31.8)	91.1 (10.3)	59.8 (32.9)	85.7 (15.2)	50.0 (20.2)
Sexual summary	45.8 (21.8)	39.0 (23.3)	38.4 (23.4)	41.6 (9.7)	28.4 (15.8)	40.7 (15.0)
Function	41.2 (22.9)	36.8 (21.7)	33.1 (21.2)	35.0 (25.7)	19.4 (7.9)	38.0 (15.7)
Bother	55.7 (24.1)	43.8 (28.5)	50.0(31.9)	56.3 (29.8)	46.9 (30.9)	46.9 (13.3)
Bowel summary	87.0 (12.8)	83.0 (16.8)	95.2 (3.9)	73.2 (21.1)	78.6 (25.3)	80.4 (15.2)
Function	89.5 (11.4)	85.3 (15.7)	92.9 (6.0)	74.1 (22.1)	69.6 (32.8)	89.3 (15.2)
Bother	84.5 (16.2)	80.8 (18.5)	97.6 (2.9)	72.3 (22.7)	87.5 (17.7)	71.4 (15.2)
Hormonal summary	81.8 (16.7)	74.7 (27.6)	74.6 (17.5)	63.1 (18.6)	71.6 (30.5)	80.7 (1.6)
Function	80.5 (17.5)	71.9 (30.3)	75.0 (14.8)	61.3 (19.3)	60.0 (42.4)	75.0 (7.1)
Bother	82.9 (16.9)	77.1 (27.3)	74.3 (21.3)	64.6 (21.1)	81.3 (20.6)	85.4 (8.8)
SF-12[c] (Mean, SD)						
Physical function	52.5 (8.6)	50.5 (14.6)	56.1 (5.9)	55.7 (6.9)	42.5 (10.4)	50.0 (1.5)
Mental function	46.1 (11.4)	48.5 (14.5)	44.5 (6.7)	36.4 (16.4)	50.8 (9.3)	50.8 (9.3)

[a] *Multiple races=American Indian/Alaska Native American and white.*

[b] *EPIC-50=Expanded Prostate Cancer Index Composite (scores ranging from 0-100, higher scores indicate better function/less bother).*

[c] *SF-12=Short-form health survey (normed with mean 50, with higher scores indicating better HRQOL).*

[d] *"Other" races were excluded as this only applied for N=1 participant who identified as "EurAsian".*

TABLE 3 | Unadjusted Health-Related Quality of Life (HRQOL) outcomes for Sexual Minority Prostate Cancer Survivors by Racial and Ethnic Group (N=190).

	Men of color	White, non-Hispanic men	Mean difference [95% CI]
EPIC-50[a] (Mean predicted value [95% CI])			
Urinary summary	74.3 [66.8, 81.8]	77.7 [74.9, 80.5]	-3.4 [-11.4, 4.7]
Function	76.8 [68.9, 84.8]	82.0 [79.0, 84.9]	-5.1 [-13.6, 3.3]
Bother	72.5 [63.9, 81.1]	74.6 [71.4, 77.8]	-2.1 [-11.3, 7.1]
Sexual summary	40.8 [31.8, 49.7]	45.8 [42.5, 49.2]	-5.1 [-14.6, 4.5]
Function	36.3 [26.9, 45.7]	41.2 [37.7, 44.7]	-4.9 [-14.9, 5.1]
Bother	50.5 [40.4, 60.7]	55.7 [51.9, 59.4]	-5.1 [-15.9, 5.7]
Bowel summary	84.6 [79.2, 90.1]	87.0 [85.0, 89.0]	-2.4 [-8.2, 3.4]
Function	84.9 [79.9, 89.9]	89.5 [87.6, 91.3]	-4.5 [-9.9, 0.8]
Bother	84.3 [77.6, 91.1]	84.5 [82.0, 87.0]	-0.2 [-7.4, 7.0]
Hormonal summary	73.8 [66.7, 80.9]	81.8 [79.2, 84.5]	-8.0 [-15.6, -0.4]*
Function	70.9 [63.4, 78.4]	80.5 [77.7, 83.2]	-9.6 [-17.6, -1.6]*
Bother	76.3 [69.0, 83.5]	82.9 [80.2, 85.6]	-6.7 [-14.4, 1.1]
SF-12[b] (Mean predicted value, 95% CI)			
Physical function	52.3 [48.6, 55.9]	52.5 [51.2, 53.9]	-0.3 [-4.1, 3.6]
Mental function	45.9 [41.2, 50.6]	46.1 [44.3, 47.8]	-0.2 [-5.2, 4.9]

**p<0.05.*

[a] *EPIC-50=Expanded Prostate Cancer Index Composite (scores ranging from 0-100, higher scores indicate better function/less bother).*

[b] *SF-12=Short-form health survey (normed with mean 50, with higher scores indicating better HRQOL).*

themselves as men of color and the total sample size of the study was small. This resulted in an underpowered study and imprecise estimates with wide confidence intervals and an inability to investigate heterogeneity across racial/ethnic groups. We caution that the absence of a significance difference on any measure should not be misinterpreted as a finding of absence. It could simply denote a lack of power. Second, while a strong cross validation and deduplication protocol was used to detect invalid surveys, it is still possible that erroneous surveys were included in this online study. Third, combining all men of color into one group implies homogeneity and may obscure differences. Fourth, the political landscape for sexual minority groups has changed considerably since this data was collected in 2015. These changes could have a meaningful impact on the HRQOL of sexual minority prostate cancer survivors. Fifth, this sample was highly educated, gay, cisgender (i.e., identifying as the gender that was assigned at birth), and living in the U.S. or Canada. We caution these results may not generalize to those less educated, non-cisgender, and residents of other countries.

Conclusion

This current exploratory study is the first to explore HRQOL racial differences in a population of sexual minority prostate cancer survivors. After adjustment for covariates sexual minority

TABLE 4 | Adjusted Health-Related Quality of Life (HRQOL) outcomes for Sexual Minority Prostate Cancer Survivors by Racial and Ethnic Group (N=189).

	Men of color	White, non-Hispanic men	Adjusted Mean difference [95% CI][a]
EPIC-50[b] (Mean predicted value [95% CI])			
Urinary summary	75.7 [68.1, 83.3]	77.4 [74.7, 80.2]	-1.7 [-9.9, 6.4]
Function	78.2 [70.1, 86.4]	81.7 [78.7, 84.6]	-3.4 [-12.1, 5.3]
Bother	73.9 [65.2, 82.5]	74.4 [71.2, 77.5]	-0.5 [-9.8, 8.8]
Sexual summary	40.6 [31.6, 49.5]	45.8 [42.6, 49.1]	-5.2 [-14.8, 4.3]
Function	35.3 [26.0, 44.6]	41.3 [37.9, 44.7]	-6.0 [-16.0, 4.0]
Bother	51.9 [41.7, 62.2]	55.5 [51.7, 59.2]	-3.5 [-14.5, 7.5]
Bowel summary	85.8 [80.2, 91.3]	86.8 [84.8, 88.9]	-1.1 [-7.0, 4.9]
Function	86.3 [81.2, 91.4]	89.3 [87.5, 91.2]	-3.0 [-8.5, 2.5]
Bother	85.2 [78.3, 92.1]	84.3 [81.8, 86.9]	0.8 [-6.6, 8.3]
Hormonal summary	74.4 [67.1, 81.7]	81.7 [79.0, 84.3]	-7.3 [-15.1, 0.6]
Function	71.3 [63.6, 79.0]	80.3 [77.5, 83.1]	-9.0 [-17.3, -0.8]*
Bother	77.0 [69.6, 84.5]	82.7 [80.0, 85.4]	-5.7 [-13.7, 2.3]
SF-12[c] (Mean predicted value, 95% CI)			
Physical function	51.7 [48.2, 55.2]	52.5 [51.3, 53.8]	-0.8 [-4.6, 3.0]
Mental function	47.5 [42.7, 52.2]	45.9 [44.1, 47.6]	1.6 [-3.5, 6.7]

[a] *Adjusted for: age and HIV-status.*

[b] *EPIC-50=Expanded Prostate Cancer Index Composite (scores ranging from 0-100, higher scores indicate better function/less bother).*

[c] *SF-12=Short-form health survey (normed with mean 50, with higher scores indicating better HRQOL).*

**p < 0.05.*

men of color reported worse HRQOL scores on all measures when compared to white, non-Hispanic men. Future research with more granular data examining racial/ethnic differences within this sexual minority community is warranted.

DATA AVAILABILITY STATEMENT

The datasets presented in this study can be found in online repositories. The names of the repository/repositories and accession number(s) can be found below: https://www.openicpsr.org/openicpsr/project/137241/version/V1/view.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Institutional Review Board at the University of Minnesota. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

CRediT Taxonomy. Conceptualization, DM, BR, and AB. Methodology, BR, NK, EP, MW, and BK. Validation, NK and EP. Formal analysis, AB and BR. Investigation, BR, EP, MW, RH, and NK. Data curation, MW and NK. Writing – original draft, AB and BR. Writing – review and editing, all authors. Supervision, BR and NK. Project administration, BR, BK, MW, and NK. Funding acquisition, BR, KT, CW, WW, DM, MR, and BR. All authors contributed to the article and approved the submitted version.

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Prevalence and Risk Factors for Sexually Transmitted Infections in Gay and Bisexual Prostate Cancer Survivors: Results From the *Restore-2* Study

Christopher W. Wheldon[1*], Elizabeth Polter[2], B. R. Simon Rosser[2], Alex J. Bates[2], Ryan Haggart[3], Morgan Wright[2], Darryl Mitteldorf[4], Michael W. Ross[5], Badrinath R. Konety[6], Nidhi Kohli[7], Kristine M. C. Talley[8], William West[9] and Alexander K. Tatum[10]

[1] Cancer Health Equity, Education and Research Lab, Department of Social and Behavioral Sciences, College of Public Health, Temple University, Philadelphia, PA, United States, [2] Division of Epidemiology and Community Health, School of Public Health, University of Minnesota, Minneapolis, MN, United States, [3] Department of Urology, University of Minnesota, Minneapolis, MN, United States, [4] Malecare Cancer Support, New York, NY, United States, [5] Department of Family Medicine and Community Health, University of Minnesota Medical School, Minneapolis, MN, United States, [6] Department of Urology, Rush Medical College, Chicago, IL, United States, [7] Department of Educational Psychology, University of Minnesota, Minneapolis, MN, United States, [8] Adult and Geriatric Health, University of Minnesota School of Nursing, Minneapolis, MN, United States, [9] Department of Writing Studies, University of Minnesota, Minneapolis, MN, United States, [10] Department of Counseling Psychology, Social Psychology, and Counseling, College of Health, Ball State University, Muncie, IN, United States

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Jane Ussher,
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Prevention and Research, India

***Correspondence:**
Christopher W. Wheldon
chris.wheldon@temple.edu

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Background: Equitable cancer survivorship care for gay and bisexual male (GBM) prostate cancer survivors should be responsive to their sexual health needs. Rates of sexually transmitted infections (STIs) are higher among GBM compared to heterosexual men across the lifespan. In addition, evidence suggests that GBM will use a variety of strategies to cope with sexual dysfunction that may increase risk for STIs. The purpose of this study was to determine the prevalence of STIs following prostate cancer treatment among GBM and identify risk factors.

Methods: In 2019, 401 GBM previously treated for prostate cancer were recruited into the Restore-2 Study. They completed a baseline online questionnaire with items assessing STIs diagnosed since being treated for prostate cancer. Any STI diagnoses was regressed on demographic, clinical, and relationship related variables using binary logistic regression.

Results: Forty-five participants (11.4%) were diagnosed with an STI during or following their prostate cancer treatment. The mostly commonly diagnosed STI was syphilis (4.3%), followed by gonorrhoea (2.8%), and chlamydia (2.5%). Four participants were infected with HIV following their prostate cancer treatment. Independent risk factors for STI diagnosis included time since prostate cancer diagnosis (aOR = 1.18; 95% CI: 1.10-1.26), nonmonogamous sexual relationship (aOR = 11.23; 95% CI: 2.11-59.73), better sexual function (aOR = 1.02; 95% CI: 1.01-1.04), penile injection treatment (aOR = 3.28; 95% CI: 1.48-7.29), and multiple sex partners (aOR = 5.57; 95% CI: 1.64-18.96).

Conclusions: GBM prostate cancer survivors are at risk for STIs. Culturally responsive STI prevention should be incorporated into cancer survivorship plans, particularly as men are treated for and regain sexual function over time.

Keywords: oncology, STD (sexually transmitted disease), sexuality, homosexuality, risky health behaviors

INTRODUCTION

Equitable cancer care for gay and bisexual men (GBM) with prostate cancer should be responsive to their specific sexual health needs. Prostate cancer treatments are known to adversely impact sexual functioning among men in the general population as well as among GBM (1–3). Psychosocial interventions to treat sexual dysfunction following treatment are largely designed for prostate cancer survivors who are in monogamous heterosexual relationships (4, 5). Thus, these approaches are not responsive to the experiences, specific needs, or health risks disproportionately affecting GBM. As a population, older GBM differ from older heterosexual men in ways that may have a significant impact on their sexual rehabilitation needs.

Anal intercourse is a common and culturally important sexual behavior for GBM across the lifecourse (6). Older GBM are also more likely to be single or in consensually nonmonogamous relationships compared to their heterosexual peers (7, 8). Some evidence suggests that GBM will use a variety of strategies to cope with sexual dysfunction following prostate cancer treatment, including changing roles in sex (e.g., from the insertive to receptive anal sex) and opening up previously monogamous relationships to other partners (5). Both coping strategies can increase risk for STIs. In addition, late and long-term effects of prostate cancer treatment, such as chronic radiation proctitis and inflammation, may increase the risk of sexually transmitted infections (STIs) for GBM engaging in receptive anal sex (9). Rates of STIs are higher among GBM at all ages compared to heterosexual men (10, 11); however, the prevalence and predictors of STIs among older GBM cancer survivors who have experienced sexual dysfunction has not been previously studied.

The purpose of this study was to determine the prevalence of STIs following prostate cancer treatment among GBM and to identify risk factors. We hypothesized that the following variables would be positively associated with a post-prostate cancer treatment STI diagnosis: (1) nonmonogamy in the primary relationship; (2) change to an anal receptive sex role; and (3) radiation treatment compared to surgery alone. We also explored the association of sociodemographic, clinical, and behavioral variables with STI diagnosis.

METHODS

Participants were enrolled in a clinical trial designed to test the effectiveness of an online rehabilitation program tailored for GBM prostate cancer patients and survivors (Restore-2). Inclusion criteria included (1) identifying as gay, bisexual, or reporting sex with a man, (2) having been previously or currently treated for prostate cancer (e.g., prostatectomy or radiation), and at study entry, having a significant sexual function and/or urinary function challenge resulting from treatment. Since the study website and all materials were online, Internet-using and ability to read English were implicit criteria. Participants were excluded if they could not read or write English or lived outside the United States or its territories. Inclusion and exclusion criteria were the same for the parent study. The total sample in the study was 401 men, although six participants were excluded from the current analysis due to missing data on key variables. Participants were recruited in urology clinics, print advertisements, and online through cancer support groups, dating applications, and social media sites. All participants completed an online eligibility screener and a vetting telephone call with a study staff member. All study assessments were online and self-reported. This study reports on baseline data collected in 2019. The full methodology for the Restore-2 study can be found elsewhere (12).

MEASURES

Sexually Transmitted Infections

Participants were asked to indicate if they ever had the following sexually transmitted infections "diagnosed before prostate cancer treatment" or "diagnosed after prostate cancer treatment": HIV (or AIDS), syphilis, gonorrhea, chlamydia, HPV (genital or anal warts), herpes simplex virus (HSV), hepatitis A, hepatitis B, or hepatitis C. They could answer *yes* separately for each time point (i.e., before or after prostate cancer treatment). One participant who selected that they were diagnosed with HIV (N=1) both before and after prostate cancer were counted among participants diagnosed with HIV before, but not after prostate cancer. Participants who reported that they were diagnosed with syphilis (N=2), chlamydia (N=2), or HPV (N=1) both before and after cancer were counted in both categories. For the remaining STIs, no participant listed a diagnosis both before and after prostate cancer. Two composite variables were created to indicate any of the nine STIs before or after prostate cancer treatment, respectively.

Sociodemographic Variables

Demographic questions were adapted from the U.S. Census and from the 2018 American Community Survey and included age, race/ethnicity, U.S. region, and educational attainment.

Clinical Variables

Prostate cancer treatment type was investigated by asking participants to check which treatments they had undergone in nine categories, which at analysis were collapsed into: surgery or cryotherapy only, radiation only, hormone therapy (in combination with surgery and/or radiation), and other. Time since prostate cancer diagnosis was calculated in years.

Relationship Characteristics

Current relationship status (single, dating, married or in a long-term relationship, or widowed, divorced no longer in a relationship) was assessed with two items. The first asked What is your current relationship status? Responses were combined into a dichotomous variable to contrast participants who were married or in a long-term relationship with those who were single, dating, widowed, divorced or no longer in a relationship. If the response was married or in a long-term relationship with a man, a follow-up question (How many years have you been in a relationship with this man)? was used to document years in current relationship with a man. Five participants who were in a relationship with a woman were not asked this follow-up question. A participant was considered to be in a non-monogamous relationship if they were married, or in a long-term relationship and reported either (1) one sexual partner who was not their primary partner in the past month or (2) two or more sexual partners in the past month.

Disease Specific Quality of Life and Sexual Function

The Expanded Prostate Cancer Index Composite (EPIC-50) measures for the frequency and perceived bother of bowel and sexual symptoms were included. The subscale reliability ($r \geq 0.80$) and internal consistency were adequate ($\alpha \geq 0.82$) (13). All scales total 100, with higher scores indicating better functioning or less bother. To assess treatments used for sexual function, participants were provided with a list of treatment options (e.g., *Viagra, Cialis, or other erectile enhancing drugs*; *vacuum pump to help with erections*; and *Penile injections (e.g., Coverjet)*) and asked which of the following they tried in the last 90 days. They could select more than one treatment. For this analysis, they were classified as having used the treatment if they reported using it at least once in the previous 90 days.

Behavioral Risk Factors

Risky alcohol use was measured with two items that asked (1) how often a participant had a drink containing alcohol (e.g., a 12 ounce can or glass of beer or cooler, a 5-ounce glass of wine, or a drink containing 1 shot of liquor and (2) how many alcoholic drinks a participant had on a typical day when drinking alcohol. Participants were classified as having risky alcohol use if they indicated more than five drinks on any day in the previous year or more than 5 drinks per day on a typical day when drinking (14). Change in sex role was assessed in an item asking how often they had changed their sex role (from "top" to "bottom") to help with the sexual effects of prostate cancer treatment in the past ninety days. Participants were classified as changing their role in sex if they reported a change in role at least once in the previous 90 days. Participants were asked "in the last three months, with how many men (including your partner or spouse, if applicable) have you engaged in any kind of sex? (0, 1, or more than 1).

Data Analysis

Frequencies and percentages were calculated for the prevalence of each STI after prostate cancer treatment. Variables including demographics, prostate cancer treatment and time since diagnosis, relationship variables, disease-specific quality-of-life, use of therapies for erectile function, and behavioral risk variables, were calculated for participants with and without a post-prostate cancer STI diagnosis using means and standard deviations (for continuous variables) and frequencies and percentages (for categorical variables). Logistic regression was used to calculate the association of post-prostate cancer STI with each characteristic. A multivariable model was used to identify the strongest independent correlates of STI diagnosis. All hypothesis tests were two-sided, with significance level of $p \leq 0.05$. Sample size estimates were based on the parent study (12). All analyses were conducted in Stata version 16 (StataCorp. 2019. *Stata Statistical Software: Release 16*. College Station, TX: StataCorp LLC).

RESULTS

The characteristics of the sample are described in **Table 1**. The sample was primarily non-Hispanic White (87.6%) with an average age of 63.5 (SD=6.7). Prostate cancer treatment was primarily surgery (58.2%) with an average of 5.3 (SD=4.9) years since diagnosis. Most (62.1%) had used an erectile enhancing drug to treat sexual dysfunction. Approximately half were married or in a long-term relationship with a man (49.0%) and most reported a lifetime STI prior to their cancer diagnosis (55.7%).

Forty-five participants (11.4%) answered that they had been diagnosed with an STI following their prostate cancer treatment (**Table 2**). The mostly commonly diagnosed STI was syphilis (4.3%), followed by gonorrhoea (2.8%), and chlamydia (2.5%). Four participants (1.0%) were infected with HIV following their prostate cancer treatment.

Independent risk factors for STI diagnosis (**Table 1**) included time since prostate cancer diagnosis (aOR = 1.18; 95% CI: 1.10-1.26), nonmonogamous sexual relationship (aOR = 11.23; 95% CI: 2.11-59.73), better sexual function (aOR = 1.02; 95% CI: 1.01-1.04), penile injection treatment (aOR = 3.28; 95% CI: 1.48-7.29), and multiple sex partners (aOR = 5.57; 95% CI: 1.64-18.96).

DISCUSSION

The acquisition of STIs among GBM prostate cancer survivors is an area that has received almost no attention in the clinical literature. STIs among adults older than age 50 are relatively uncommon in the general population, but GBM remain at risk of acquiring new infections into late adulthood (11, 15). Our findings confirm that GBM prostate cancer survivors with treatment-related sexual dysfunction are still at high-risk for STIs. Approximately 1 in 9 of the survivors in this study reported

TABLE 1 | Correlates of acquiring sexually transmitted infection (STI) post prostate cancer treatment among gay and bisexual men (N = 395).

	Entire Sample (N = 395) n (%)[a]	**No STI (N = 350) n (%)**	**STI (N = 45) n (%)**	**Bivariate Models OR (95% CI)**	**p-value**	**Adjusted Models[b] aOR (95% CI)**	**p-value**
Sociodemographic variables							
Age, mean (SD)	63.5 (6.7)	63.5 (6.6)	63.2 (6.7)	0.99 (0.95-1.04)	0.74	0.97 (0.91-1.02)	0.25
Race/Ethnicity							
White and non-Hispanic	346 (87.6%)	305 (87.1%)	41 (91.1%)	1.00			
Non-white or Hispanic	49 (12.4%)	45 (12.9%)	4 (8.9%)	0.66 (0.23-1.93)	0.45	0.65 (0.20-2.11)	0.48
Region							
United States West	107 (27.1%)	94 (26.9%)	13 (28.9%)	1.00		1.00	
United States South	127 (32.2%)	109 (31.1%)	18 (40.0%)	1.19 (0.56-2.57)	0.65	1.81 (0.76-4.31)	0.18
United States Midwest	74 (18.7%)	70 (20.0%)	4 (8.9%)	0.41 (0.13-1.32)	0.14	0.73 (0.21-2.56)	0.63
United States Northeast	87 (22.0%)	77 (22.0%)	10 (22.2%)	0.94 (0.39-2.26)	0.88	1.24 (0.46-3.32)	0.67
Education							
High School, GED, associate's degree or some college	92 (23.3%)	83 (23.7%)	9 (20.0%)	1.00		1.00	
Bachelor's degree	131 (33.2%)	111 (31.7%)	20 (44.4%)	1.66 (0.72-3.84)	0.23	1.99 (0.78-5.07)	0.15
Graduate degree	172 (43.5%)	156 (44.6%)	16 (35.6%)	0.95 (0.40-2.23)	0.90	1.07 (0.41-2.78)	0.88
Clinical variables							
Treatment type							
Surgery alone	230 (58.2%)	203 (58.0%)	27 (60.0%)	1.00		1.00	
Radiation alone (external or brachytherapy)	74 (18.7%)	64 (18.3%)	10 (22.2%)	1.17 (0.54-2.56)	0.69	1.39 (0.57-3.38)	0.47
Hormone Therapy	65 (16.5%)	61 (17.4%)	4 (8.9%)	0.49 (0.16-1.46)	0.20	1.01 (0.31-3.36)	0.98
Other	26 (6.6%)	22 (6.3%)	4 (8.9%)	1.37 (0.44-4.27)	0.59	1.29 (0.36-4.57)	0.70
Time since diagnosis (median years, interquartile Range)	4.0 (2.0-8.0)	3.0 (2.0-7.0)	8.0 (5.0-12.0)	**1.12 (1.06-1.18)**	**<0.001**	**1.18 (1.10-1.26)**[c]	**<0.001**
Relationship variables							
Relationship Status							
Married/in a long-term relationship	193 (49.0%)	174 (49.9%)	27 (60.0%)	1.00		1.00	
Single, dating, widowed, divorced, no longer in a relationship	201 (51.0%)	175 (50.1%)	18 (40.0%)	1.51 (0.80-2.84)	0.20	1.41 (0.70-2.82)[d]	0.33
Years in current relationship[d]							
0-<5 years	35 (18.6%)	33 (19.4%)	2 (11.1%)	1.00		1.00	
5 or more years	153 (81.4%)	137 (80.6%)	16 (88.9%)	1.93 (0.42-8.80)	0.39	2.42 (0.43-13.59)	0.31
Nonmonogamous sexual relationship [e]	87 (45.5%)	71 (41.0%)	16 (88.9%)	11.49 (2.56-51.55)	0.001	11.23 (2.11-59.73)[f]	0.004
Disease specific quality of life and sexual function							
EPIC Sexual Function	35.5 (21.2)	34.6 (21.4)	42.9 (18.5)	1.02 (1.00-1.03)	<0.001	1.02 (1.01-1.04)[g]	0.01
EPIC Sexual Bother	39.2 (26.3)	38.9 (26.8)	41.8 (22.3)	1.00 (0.99-1.02)	0.48	0.99 (0.97-1.01)	0.35
EPIC Bowel Function	76.9 (9.4)	77.0 (9.3)	76.3 (10.2)	0.99 (0.96-1.02)	0.62	0.97 (0.94-1.01)	0.18
EPIC Bowel Bother	85.7 (15.5)	85.8 (15.1)	85.0 (18.4)	1.00 (0.98-1.02)	0.76	0.99 (0.97-1.01)	0.38
Use of therapies for erectile dysfunction (reference category is no/not selected for each treatment)							
Oral medication	244 (62.1%)	218 (62.6%)	26 (57.8%)	0.82 (0.43-1.53)	0.53	0.50 (0.23-1.07)	0.07
Pump	85 (21.6%)	77 (22.1%)	8 (17.8%)	0.76 (0.34-1.71)	0.57	0.61 (0.24-1.56)	0.30
Injections	73 (18.5%)	58 (16.6%)	15 (33.3%)	2.51 (1.27-4.96)	0.007	3.28 (1.48-7.29)[h]	0.004
Behavioral risk variables							
Risky drinking: >5 drinks on any day in the past year OR >5 drinks per day on average	97 (29.7%)	85 (29.5%)	12 (30.8%)	1.06 (0.51-2.19)	0.87	0.88 (0.38-2.01)	0.76
STI prior to PCa Dx	220 (55.7%)	197 (56.3%)	23 (51.1%)	0.81 (0.44-1.51)	0.51	0.79 (0.39-1.60)	0.51
Change in sex role	92 (23.5%)	79 (22.8%)	13 (28.9%)	1.37 (0.69-2.74)	0.37	0.68 (0.30-1.53)	0.35
Number of total sex partners include oral and anal							
0	98 (24.9%)	94 (26.9%)	4 (8.9%)	1.00		1.00	

(Continued)

TABLE 1 | Continued

	Entire Sample (N = 395) n (%)[a]	No STI (N = 350) n (%)	STI (N = 45) n (%)	Bivariate Models OR (95% CI)	p-value	Adjusted Models[b] aOR (95% CI)	p-value
1	128 (32.5%)	120 (34.4%)	8 (17.8%)	1.57 (0.46-5.36)	0.47	1.51 (0.40-5.76)	0.46
2 or more	168 (42.6%)	135 (38.7%)	33 (73.3%)	5.74 (1.97-16.76)	0.001	5.57 (1.64-18.96)[i]	0.006

[a] Mean and standard deviation or median and interquartile range replace frequency and percent for continuous variables where noted.

[b] Adjusted for years since diagnosis, nonmonogamous relationship (if in a relationship), use of injections to treat ED, EPIC sexual function, and number of total sex partners unless otherwise noted.

[c] Adjusted for nonmonogamous relationship (if in a relationship), use of injections to treat ED, EPIC sexual function, and number of total sex partners.

[d] Adjusted for years since diagnosis, use of injections to treat ED, EPIC sexual function, and number of total sex partners.

[e] Among 188 men who reported a current relationship with a man.

[f] Adjusted for years since diagnosis, use of injections to treat ED, and EPIC sexual function.

[g] Adjusted for years since diagnosis, use of injections to treat ED, and number of total sex partners.

[h] Adjusted for years since diagnosis, nonmonogamous relationship (if in a relationship), EPIC sexual function, and number of total sex partners.

[i] Adjusted for years since diagnosis, use of injections to treat ED, and EPIC sexual function.

Bolded values indicate $p < 0.05$.

acquiring an STI following their prostate cancer treatment. The most commonly acquired STI was syphilis, which reflects established trends in syphilis incidence among GBM in the U.S (16). The prevalence of syphilis among men in the current study (4.3%) was higher than the point prevalence in a recent study of GBM in North American and Europe, but still within range of estimates(3.4%; 95% CI: 1.8% to 5.4%) (17).

Several behavioral and clinical correlates of STIs were identified in the current study. As hypothesized, for participants in long-term relationships, nonmonogamy was associated with increased risk of STIs. Nonmonogamous relationship agreements are common among GBM (8), particularly among older age cohorts and among those in long-term relationships of five or more years (18). Clinicians treating GBM for prostate cancer related sexual dysfunction should not make the assumption that patients who are married or with a long-term partner are monogamous (19). Taking a system-wide approach to sexual health in cancer survivorship care can help to overcome organizational and interpersonal barriers to patient-provider sexual health communication (20).

Another behavioral factor associated with STI risk was having multiple recent oral or anal sex partners; however, the hypothesis about role change in sex was not supported. In other words, we failed to find evidence that changing from an insertive (i.e., "top") to receptive (i.e., "bottom") role after prostate cancer treatment was associated with greater likelihood of STIs. Despite the null finding, nearly 1 in 4 participants described a change in role. These role changes may result from decreased erectile functioning following PCa treatment and highlight the importance of STI prevention in this population.

TABLE 2 | Frequency of sexually transmitted infections among gay and bisexual male prostate cancer survivors since their prostate cancer treatment (N = 395).

Type of Sexually Transmitted Infection	N	%
Any	45	11.4
Syphilis	17	4.3
Gonorrhea	11	2.8
Chlamydia	10	2.5
Human papillomavirus (Genital or Anal Warts)	9	2.3
HIV	4	1
Herpes Simplex Virus (HSV)	4	1
Hepatitis C	4	1
Hepatitis B	3	0.8
Hepatitis A	2	0.5

Radiation treatment was also not associated with STIs in this study. It has been hypothesized that inflammatory conditions like proctitis may increase susceptibility to STI acquisition through receptive anal sex (21). While we did not measure proctitis directly in this study, radiation proctitis is a potential long term effect of prostate cancer treatment (9). Proctitis can also result from untreated STIs (22), thus it is important for oncologists treating bowel dysfunction in GBM with prostate cancer to test for STIs. Future studies should also continue to examine the role of treatment related inflammatory bowel conditions on STI risk for those engaging in receptive anal sex.

With regard to other clinical factors, years since prostate cancer diagnosis was positively associated with STI diagnosis. This finding may reflect the timeframe used to assess STI diagnoses (i.e., since prostate cancer treatment) or time-based improvements in sexual function. Relatedly, better sexual function and use of penile injections for erectile dysfunction were both independently associated with STIs; however, other treatments for erectile dysfunction were not associated with STI risk. It is unclear why penile injections, and not oral medications (e.g., sildenafil), were associated with increases in STI acquisition. Future research should explore potential explanations such as higher efficacy of injections in producing erections rigid enough for anal intercourse, the context of use, and the potential that a wound at the injection site may increase risk for STI transmission.

It is important to note that lifetime history of STIs was not predictive of post-prostate cancer treatment STIs, suggesting that risk was not solely concentrated among men with a history of STIs. The process of sexual rehabilitation following treatment for prostate cancer may involve additional behavioral and psychosocial changes that increase STI risk. For example, men may forgo the use of condoms to help manage erectile dysfunction. Safer sex negotiations with existing and new partners may also be impacted by lowered sexual self-esteem resulting from long term sexual dysfunction. Terror management theory suggests that a mortality threat (e.g., cancer) can increase sexual risk behaviors among men (23). It is theorized that when faced with a mortality threat, men may cope by engaging in self-enhancing sexual behaviors. Further research is needed to directly test this hypothesis in cancer survivors.

There are several limitations to the research design. For many of the associations reported, the temporality relative to STI acquisition could not be established. Thus, the associations do not represent cause and effect relationships. Furthermore, the measures were self-reported with no objective verification of STI diagnoses possibly leading to underreporting. External validity is limited by the non-probability sample of mostly highly educated non-Hispanic white men. Finally, the estimated associations may be unreliable due to limited distributions in some variables resulting in wide confidence intervals. Replication of these findings on ethnoracially and socioeconomically diverse samples is essential.

Despite these limitations, this analysis has several strengths. We recently conducted a systematic review of all publications (from 1995 to 2022) on GBM prostate cancer patients in English, Spanish and French. Based on this review, we confirm this is the first study to examine the prevalence and risk factors for STIs among GBM prostate cancer survivors. The findings indicate that older GBM who have completed treatment for prostate cancer and have experienced significant sexual dysfunction are still at risk for acquiring new STIs. Cancer survivorship and sexual rehabilitation care plans for GBM following prostate cancer treatment should include STI prevention.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by The Institutional Review Board at the University of Minnesota. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

Conceptualization, BR, KT, CW, DM, MR, BK, and NK; Methodology, BR, NK, EP, and MW; Validation, NK and EP; Formal Analysis, NK, EP, and MW; Investigation, BR, EP, MW, RH, and NK; Data Curation, RH, MW, and NK; Writing – Original Draft, BR, EP, and KT; Writing – review and editing, all authors; Supervision, BR and NK; Project administration, BR, BK, and NK; Funding acquisition, BR, KT, CW, WW, DM, MR, BK, and NK; All authors contributed to the article and approved the submitted version.

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Improving Sexual and Gender Minority Cancer Care: Patient and Caregiver Perspectives From a Multi-Methods Pilot Study

Miria Kano[1,2], Shoshana Adler Jaffe[2], Stephanie Rieder[2,3], Mikaela Kosich[2], Dolores D. Guest[1,2], Ellen Burgess[2], Ariel Hurwitz[4], Vernon Shane Pankratz[1,2], Teresa L. Rutledge[2,3], Zoneddy Dayao[1,2] and Larissa Myaskovsky[1,2,5]*

[1] Department of Internal Medicine, University of New Mexico School of Medicine, Albuquerque, NM, United States, [2] University of New Mexico Comprehensive Cancer Center, Albuquerque, NM, United States, [3] Department of Obstetrics and Gynecology, University of New Mexico School of Medicine, Albuquerque, NM, United States, [4] University of New Mexico School of Medicine, Albuquerque, NM, United States, [5] Center for Healthcare Equity in Kidney Disease (CHEK-D), University of New Mexico Health Sciences Center, Albuquerque, NM, United States

Edited by:
Jane Ussher,
Western Sydney University,
Australia

Reviewed by:
Rosalie Power,
Western Sydney University,
Australia
Janette Perz,
Western Sydney University,
Australia

***Correspondence:**
Miria Kano
MKano@salud.unm.edu

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Purpose: Up to 1 million lesbian, gay, bisexual, and transgender (i.e., sexual and gender minority, SGM) individuals in the United States have histories of cancer. This medically underserved population is diverse, with complex sexualities and gender identities, and distinct health concerns. SGM persons experience disproportionate risks for, and rates of, anal, breast, cervical, colorectal, endometrial, lung, and prostate cancers, in addition to cancers affecting transgender persons who have undergone sex-reassignment. SGM individuals are linked by shared experiences of stigmatization as a minority population for which little cancer research has been conducted. SGM cancer patients frequently report reluctance to seek healthcare, have poorer outcomes following diagnosis, engage in elevated risk behaviors (i.e. smoking and alcohol use) even after cancer diagnosis, have difficulty making emotional adjustment to illness, and experience higher rates of psychological distress. They report less satisfaction with cancer care, deficiencies in patient-centeredness and shared decision-making, gaps in care, and social isolation. Minority stress resulting from experiences of anti-SGM sentiment and discrimination affects cancer patients and their informal cancer caregivers. Our paper presents findings from a pilot study to identify gaps and opportunities to improve cancer care for SGM patients and caregivers at the University of New Mexico Comprehensive Cancer Center.

Methods: Between June 2020 and July 2021, we used a multi-methods research design informed by ecological theory to collect qualitative and quantitative data regarding cancer patient and caregiver quality of life (QoL) and experiences of cancer and survivorship care. We used PROMIS measures distributed *via* REDCap to assess QoL (i.e., fatigue, pain interference, pain intensity, anxiety, depression, emotional support, social isolation, and companionship), and conducted in-depth semi-structured interviews. We recruited 10 SGM cancer patients and 8 heterosexual, cisgender (H/C) patient matches, and their self-identified informal cancer caregivers (n=36, dyad total n=18). Interviews ranged from 1 to

2 hours, were audio-recorded and transcribed for analysis. The study was approved by the University of New Mexico Human Research Protections Office Institutional Review Board.

Results: Results of the PROMIS QoL assessments indicated that SGM patients reported greater anxiety [mean (SD) = 54.5 (8.8)] and depression [mean (SD) = 49.3 (4.8)] than H/C patients [mean (SD)=51.6 (7.5) and 45.4 (6.8) respectively], while heterosexual, cisgender (H/C) patients reported higher fatigue [mean (SD) =52.04 (8.18)] and stronger pain intensity than SGM patients [mean (SD)=48.3 (9.1) and 37.8 (9.1) respectively]. SGM patients reported higher levels of social isolation [mean (SD) = 48.3 (7.3) vs. 42.1 (7.4) for H/C patients, whereas H/C patients reported more emotional support (mean (SD) =57.5 (9.3) vs. 53.0 (6.9)] and companionship [mean (SD) = 55.2 (8.6) vs. 51.5 (11.0)]. SGM and H/C differences in caregiver QoL were most notable with regards to higher levels of fatigue [mean (SD) = 47.1 (6.0) for SGM, and 42.4 (11.5) for H/C] and companionship [mean (SD) = 55.3 (6.0) for SGM, and 50.9 (5.5) for H/C]. Qualitative interviews supported our quantitative results. SGM patients and caregivers articulated experiences of anti-SGM stigma and discrimination contributing to minority stress that influenced their initial cancer care encounters. SGM dyads had more trepidation and/or medical mistrust during initial cancer care encounters when compared to H/C patients and caregivers. SGM patients questioned care that was not culturally responsive to SGM preferences, while H/C patients were more apt to identify gaps in communication and perceived lack of clarity regarding cancer care delivery. Although SGM patients experienced high satisfaction with their cancer care once they developed trust with their providers, they discussed desires to have more direct conversations with their oncologists about their sexual orientation and gender identities and sexual health. All patients and providers in the study (SGM and H/C) appreciated their oncology care teams. All patients and caregivers relied on social networks comprised of friends and family, although SGM patients and caregivers had smaller social networks and relied less on biological family, and single SGM individuals experienced challenges accessing cancer care and struggled with social isolation. We discovered too, that all caregivers, regardless of Sexual Orientation and Gender Identity (SOGI), perceived a lack of support and information pertaining to their loved one's treatment, side effects and best way to provide care.

Conclusions: This study demonstrates that prior stigmatizing experiences contribute to minority stress and medical mistrust for SGM cancer patients and their informal caregivers across the cancer care experience. Findings point to specific gaps in SGM cancer patient care, including lack of conversation about patient SOGI, inadequate staff and oncology provider SGM specific knowledge and cultural competence/cultural humility training, and insufficient patient supports for those who lack social support during cancer care treatment. Further, this study reveals inadequacies in SGM specific support, and overall support services for informal cancer caregivers. Additional research is required to develop targeted interventions to address minority stress and clinic environment concerns to improve cancer care for SGM patients. Importantly, while there were differences between SGM and H/C experiences of cancer treatment, significant similarities also emerged. Caregiver expressed consensus about the current lack of support and guidance for informal caregivers of cancer patients. Future work should focus on providing caregiver-specific resources in the clinic setting and facilitating support groups for caregivers to network with one another, as well as for tailoring SGM specific caregiver support services.

Our findings highlight areas for improving cancer care for the SGM community, as well as a broader population of patients and caregivers.

Keywords: sexual and gender minority cancer, cancer care delivery, cancer health disparities, multi-methods research, lesbian, gay, bisexual and transgender

1 INTRODUCTION

Sexual and gender minority (SGM) individuals (i.e., lesbian, gay, bisexual, and/or transgender) are a diverse population with complex sexualities and gender identities who are medically underserved and at risk for disparate cancer treatment and survivorship care (1–3) According to the latest Gallup Poll, 5.6% of the U.S. population (4) or 18 million adults identify as SGM. Studies suggest that nearly 1,000,000 of these SGM individuals have histories of cancer (5); and that 106,400 will receive new cancer diagnoses and 33,600 will die of cancer in 2021 (4, 6).

When compared to heterosexual, cisgender (H/C) populations [i.e., those partnered with the opposite sex and whose sex assigned at birth matches their gender identity (7)], SGM persons experience disparate rates of anal, breast, cervical, colorectal, endometrial, lung, and prostate cancers (8). Transgender persons receiving hormone therapy may have higher risks for cancer as well (9). SGM persons exist across all populations, often occupying multiple marginalized identities as ethnic/racial minorities, those with low incomes, and/or rural residents (10). They share experiences of stigmatization and/or discrimination as a population for which little cancer research is conducted, and few cancer interventions are successfully developed (7, 8).

Barriers to sustainable SGM cancer health equity are substantial. At patient levels, studies reveal that SGM cancer patients are reluctant to access care, citing previous discrimination (11); have elevated risk behaviors including smoking and alcohol use even after cancer diagnosis (12); and have difficulty making emotional adjustment to illness (13). Some studies indicate too that SGM cancer patients experience higher rates of psychological distress when recovering (14–16) as they are more likely to experience post-traumatic stress and/or depression (17, 18). For older SGM cancer patients, lack of social support is a critical concern (19–21), as older SGM individuals, particularly bisexual and gay men, have a significantly higher likelihood of living alone, putting them at risk of social isolation (22), diagnosis at later stages of disease, lower quality of life, and poorer cancer survival (21). Due to these complex reasons, SGM cancer patients often report less satisfaction with cancer care, gaps in cancer care, unmet psychosocial needs (23), and deficiencies in patient-centeredness and shared decision-making (24).

Our previous research in primary care settings (25, 26) and that of others in cancer treatment milieus indicate that psychosocial challenges unique to SGM populations, such as "minority stress (27, 28), may compound cancer-related-stress (25, 27, 29) and patient feelings of stigmatization in health care settings. Chronic minority stress can cause SGM Individuals to internalize individuals may internalize anti-SGM attitudes and comments, accept discriminatory actions, endure microaggressions (i.e., subtle verbal and behavioral slights and insults), and come to normalize and anticipate negative experiences. Minority stress compounds for those occupying multiple marginalized social positions (i.e. racial/ethnic minorities, rural residents, the socioeconomically disadvantaged) (30, 31), resulting in 1.5 to 3 times higher rates of behavioral health and substance use disorders than heterosexual adults (32). The compounding effects of minority stress on psychological distress resulting from oncology care can exacerbate cancer health disparities for SGM patients (33–35).

Barriers to equitable SGM cancer care exist at informal cancer caregiving levels as well (36–38). Informal cancer caregivers are individuals who assist patients with domestic tasks associated with daily living. They are unpaid, and spend considerable time assisting patients with clinic visits, managing medication, and assisting with clinical decisions (39). Whereas informal caregivers for H/C cancer patients are typically family members, spouses, or partners, SGM patients more often rely on spouse/partners, friends, and community members, and not biological family due to strained relationships resulting from the patient's sexuality and/or gender identity (21). As indicated previously, gay men are more likely to be single and live alone which has also been found to affect access to care and caregiving relationships during cancer treatment (40). Although caregiver stress and burnout are recognized as a common complication of treating the chronically or terminally ill (41), caregivers of the SGM community face additional concerns. Studies find that caregivers of SGM patients tend to be younger, racially/ethnically diverse, more likely to have lower incomes, and less likely to be married (21). If they are members of the SGM community, they too may have experienced stigma, prejudice and discrimination contributing to minority stress in healthcare settings.

Improvements to SGM cancer care are often hindered by gaps in knowledge, funding, and leadership support at institutional and oncology provider levels. A 2016 national survey of more than 450 oncologists from 45 cancer centers demonstrated that multilevel factors including: 1) environmental- (i.e., sexual orientation and gender identity data collection, cancer center environment), 2) knowledge- (i.e., staff/provider education and skills), and 3) sociocultural-level barriers (i.e., cultural competence) hinder efforts to reduce SGM cancer disparities (6, 42). Thus, to document gaps and identify opportunities to improve care at institutional-, social- and individual- levels, we conducted a multi-methods pilot, informed by ecological theory (43, 44), comparing the experiences of SGM cancer patients and their self-identified cancer caregivers with those of H/C cancer patient/caregiver dyads receiving care at the University of New Mexico Comprehensive Cancer Center.

In this article, we present findings from the PROMIS [Patient-Reported Outcomes Measurement Information System (45)] validated measures used to provide a quality of life (QoL) snapshot of cancer patients and caregivers in areas of fatigue, pain interference, pain intensity, anxiety, depression, emotional support, social isolation, and companionship. We also discuss results from qualitative interviews, comparing experiences of SGM patient/caregiver dyads with those of H/C dyads, highlighting how SGM patient and caregiver experiences of anti-SGM stigma and discrimination contribute to minority stress and medical mistrust at the onset of their cancer care. We conclude by mapping participant suggestions to improve cancer care using an ecological map to demonstrate ways to address SGM cancer disparities at multiple levels of the oncology care experience, and by describing next steps for development of this pilot research.

2 METHODS AND MATERIALS

2.1 Study Design and Overview

Between 12/2020 and 07/2021, we used a multi-methods research design, informed by ecological theory, to assess cancer patient and caregiver QoL and document experiences of cancer and survivorship care. Ecological theory recognizes that cancer care occurs through a series of interdependent interactions at multiple levels and in multiple systems, thereby providing a model through which to consider the ways in which interactions at patient, caregiver, community and cancer center levels informed cancer care (46). Patients and caregivers completed a questionnaire *via* an electronic QoL and demographic survey link in REDCap (47) (Research Electronic Data Capture). We assessed experiences of cancer care through semi-structured interviews. All components of the study were approved by the University of New Mexico Human Research Protections Office Institutional Review Board (HRRC #20-385).

2.2 Study Sample

Patients were eligible to participate in the study if they were age 18 or older, English-speaking, and either currently undergoing cancer treatment or diagnosed with cancer in the last 5 years. Informal caregivers were eligible to participate if they were age 18 or older, English-speaking, and identified as providing or having provided unpaid care to a cancer patient recruited for this study. We recruited SGM patients first, and then identified their primary informal cancer caregiver. We then recruited heterosexual, cis-gender patients as comparators to the SGM patients based on sex assigned at birth and cancer type. We consented all participants individually prior to the survey and again for the interview. We compensated participants $100 for completing the survey and interview.

2.3 Instruments and Methods

2.3.1 Patient and Caregiver Quality of Life (QoL)

We used PROMIS validated instruments to collect QoL measures focused on physical, mental and social health, see **Table 1**. Physical Health was measured for patients using the Ca Bank V1.0 Fatigue – 54 items assessing self-reported symptoms, from mild subjective feelings of tiredness to an overwhelming, debilitating, and sustained sense of exhaustion; Ca Bank v2.2 Pain-Interference - 35 items assessing pain interference or the degree to which pain limits or interferes with an individual's physical, mental, and social activities. Three items are unique to CaPS in which cancer specific calibrations were used; and Scale V1.0 Pain-Intensity - 3 items measures pain intensity or

TABLE 1 | Quantitative PROMIS validated measures employed for the improving SGM cancer care pilot.

Domain	PROMIS Measure	Description	Surveyed
Physical Health	Ca Bank V1.0 Fatigue	54 items assessing self-reported symptoms, from mild subjective feelings of tiredness to an overwhelming, debilitating, and sustained sense of exhaustion	Patients
	Ca Bank v1.1 Pain-Interference	35 items assessing pain interference or the degree to which pain limits or interferes with an individual's physical, mental, and social activities. Three items are unique to CaPS in which cancer specific calibrations were used	
	Scale v1.0 Pain-Intensity	3 items measures pain intensity or severity. This measure includes a 0-to-10 numeric rating scale for pain intensity	
Mental Health	Ca Bank v1.0 Anxiety	22 items capturing anxiety, a prominent aspect of emotional distress. It contains 2 items unique to CaPS in which cancer specific calibrations were used	Patients and Caregivers
	Ca Bank v1.0 Depression	30 items capturing depression, a prominent aspect of emotional distress. It contains 7 items unique to CaPS in which cancer specific calibrations were used	
	Emotional Distress/Anger SF 8a	8 items capturing anger as a fundamental aspect of emotional distress	
Social Health	Bank v2.0 Social Isolation	16 items measuring global, physical, mental and social health	Patients and Caregivers
	Bank v2.0 Emotional Support 8a	10 items assessing perceived feelings of being cared for and valued as a person; having confident relationships	
	SF v2.0 Companionship 6a	6 items assessing the degree to which respondents have access to companionship	

PROMIS measures and descriptions are available at https://www.healthmeasures.net/explore-measurement-systems/promis/obtain-administer-measures.

severity. This measure includes a 0-to-10 numeric rating scale for pain intensity (45). Mental Health was assessed for both patients and caregivers using the Ca Bank v1.0 Anxiety – a 22 item scale capturing anxiety, a prominent aspect of emotional distress. It contains 2 items unique to CaPS in which cancer specific calibrations were used; and Emotional Distress Anger SF 8a - 8 items capturing anger as a fundamental aspect of emotional distress (45). Social Health was determined for patients and caregivers using Bank v2.0 Social Isolation - 16 items measuring global, physical, mental and social health; Bank v2.0 Emotional Support 8a - 10 items assessing perceived feelings of being cared for and valued as a person; having confident relationships; and SF v2.0 Companionship 6a - 6 items assessing the degree to which respondents have access to companionship (45).

Content experts developed PROMIS-Cancer measures (PROMIS-Ca) following review of the adult PROMIS item banks (45) PROMIS measures have been validated across multiple clinical populations, including patients with back pain, cancer, chronic heart failure, chronic obstructive pulmonary disease, major depressive disorder, osteoarthritis, and premenstrual syndrome (48, 49). Although not used extensively in SGM focused cancer studies, PROMIS measures have been used successfully to assess and compare disparities related to QoL between heterosexual, lesbian, and bisexual women cancer survivors (50).

2.3.2 Characteristics of Patient and Caregiver Participants

We collected self-reported demographic characteristics, including age, race, ethnicity, geographic location, health insurance, educational attainment, gender identity, sex assigned at birth, sexual orientation, relationship status, cancer diagnosis, and partner's gender identity, using a survey administered in REDCap and completed by the participants.

2.3.3 Quantitative Analysis of PROMIS Measures and Demographic Characteristics

Demographic data were tabulated overall and across groups. PROMIS measure responses were converted to t-scores consistent with the PROMIS scoring manual. These are based off a population mean of 50 with a standard deviation of 10, where a higher t-score represents a higher presence of the measure of interest. Average t-scores were compared between patients and caregivers within dyads, and between SGM and H/C patients across dyads, using a linear mixed effects model that accounted for the repeated measurements made within participants, and within dyads, using random intercepts. We assessed adequacy of the model by performing an analysis of the residuals to ensure that they conformed to required assumptions. Statistical significance was declared for two-sided p-values less than 0.05.

2.3.4 Qualitative Data Collection and Analyses of Patient and Caregiver Interviews

We conducted qualitative semi-structured interviews to elicit information regarding the intersection of sexual orientation, gender identity, and cancer care. To respect the differences inherent in the four participating groups (i.e., SGM and H/C patients and their two groups of caregivers), we developed four semi-structured interview guides: an SGM patient guide, an SGM caregiver guide, an H/C patient guide and an H/C caregiver guide. The first two guides had three distinct categories of questions: (1) life as a member of the SGM community; (2) experience of a cancer diagnosis/treatment; and, (3) support systems/coping mechanisms. The second two guides had the same questions as the SGM guides, but did not include questions about SGM-specific experiences. We pilot tested the interview guides with advisors from the SGM community. We selected advisors who were cancer patients and informal cancer caregivers. They also held positions as leaders of SGM organizations, healthcare providers, and SGM community advocates. We revised the interview guides according to feedback received.

Participants selected their preferred interview modality, videoconference, *via* telephone, or an in-person interview using COVID precautions. Interviews lasted 1-2 hours, were audio-recorded and transcribed for analysis. Based on initial hand coding of three de-identified, semi-structured interviews, members of the team developed a codebook and three primary coders (EB, SAJ, and SR) undertook question-level dual coding, thematic analysis using the *dedoose* research platform. The larger team met for iterative analysis, comparing and contrasting codes, grouping similar content or meaning into broader themes, describing linkages, at individual levels, dyadic levels, and cross-dyadic (SGM and H/C) levels. Recurring themes were highlighted, and presented in the following "Results" section. Qualitative findings were compared to quantitative findings to triangulate dominant qualitative themes with key domains identified in the quantitative survey. Patient and caregiver recommendations to improve care were mapped using an ecological model to organize next steps for research and intervention development.

3 RESULTS

3.1 Characteristics of Patient and Caregiver Participants

In total, 34 individuals participated in this study (n=19 SGM, n=15 H/C), see **Table 2**. The average age of participants was 68 (SD=13). The majority was white and non-Hispanic (94%), and lived in an urban area (91%). Only 1 patient reported being uninsured. Most completed graduate or professional school (73%), and described their gender identity as woman (65%). Twenty-nine percent of participants reported their sexual orientation as lesbian, 12% identified as gay, and 47% as heterosexual. The majority of participants indicated their relationship status as married (71%). Half of the patients had a diagnosis of breast cancer, followed by colorectal (13%), lung (9%), ovarian (9%), and pancreatic (9%).

3.2 Patient and Caregiver Quality of Life

We summarized the scores from these instruments with means, standard deviations, within each of the four groups, and estimated differences of interest, with their corresponding standard errors and p-values (see **Table 2**). Two of the caregivers did not complete the QoL questionnaire.

TABLE 2 | Patient and caregiver demographics.

	Dyad		Role		Total Sample
	SGM	***H/C***	***Caregivers***	***Patients***	
N	19	15	16	18	34
Age [Mean (SD)]	66.8 (10.2)	68.8 (15.8)	71.5 (12.2)	64.4 (12.8)	67.7 (12.8)
Racial Identity [N (%)] *					
American Indian or Alaska Native	0 (0)	1 (6.7)	1 (6.3)	0 (0)	1 (3.0)
Hispanic or Latino	1 (5.6)	0 (0)	1 (6.3)	0 (0)	1 (3.0)
White	17 (94.4)	14 (93.3)	14 (87.5)	17 (100)	31 (93.9)
Are you of Hispanic, Latino or Spanish Origin? [N (%)] **					
No, not of Hispanic, Latino or Spanish origin	15 (88.2)	15 (100)	14 (93.3)	16 (94.1)	30 (93.8)
Yes, Mexican, Mexican-American, Chicano	1 (5.9)	0 (0)	1 (6.7)	0 (0)	1 (3.13)
Yes, another Hispanic, Latino, or Spanish origin	1 (5.9)	0 (0)	0 (0)	1 (5.9)	1 (3.13)
Do you consider where you live either an urban or rural area? [N (%)]: Urban	16 (84.2)	15 (100)	14 (87.5)	17 (94.4)	31 (91.2)
What type of insurance did you have when your first started cancer treatment? [N (%)] ***					
Private/Commercial	7 (43.8)	6 (40)	5 (38.5)	8 (44.4)	13 (41.9)
Medicare	5 (31.3)	5 (33.3)	4 (30.8)	6 (33.3)	10 (32.3)
More than 1 type of insurance	3 (18.8)	4 (26.7)	3 (23.1)	4 (22.2)	7 (22.6)
Uninsured	1 (6.3)	0 (0)	1 (7.7)	0 (0)	1 (3.2)
What is the highest level of schooling you have completed? [N (%)] *					
Some college or vocational school	0 (0)	3 (20)	2 (12.5)	1 (5.9)	3 (9.1)
Completed a 4 year College degree	3 (16.7)	3 (20)	5 (31.3)	1 (5.9)	6 (18.2)
Graduate or Professional School	15 (83.3)	9 (60)	9 (56.3)	15 (88.2)	24 (72.7)
I describe my gender identity as: [N (%)]					
Woman	13 (68.4)	9 (60)	8 (50)	14 (77.8)	22 (64.7)
Man	3 (15.8)	6 (40)	6 (37.5)	3 (16.7)	9 (26.5)
Transgender Man	1 (5.3)	0 (0)	1 (6.3)	0 (0)	1 (2.9)
Genderqueer	1 (5.3)	0 (0)	1 (6.3)	0 (0)	1 (2.9)
Other	1 (5.3)	0 (0)	0 (0)	1 (5.6)	1 (2.9)
What sex marker is on your original birth certificate? [N (%)]: Female	16 (84.2)	9 (60)	10 (62.5)	15 (83.3)	25 (73.5)
I describe my sexual orientation as: [N (%)]					
Lesbian	10 (52.6)	0 (0)	5 (31.3)	5 (27.8)	10 (29.4)
Gay	4 (21.1)	0 (0)	1 (6.3)	3 (16.7)	4 (11.8)
Queer	2 (10.5)	0 (0)	1 (6.3)	1 (5.6)	2 (5.9)
Bisexual	1 (5.3)	0 (0)	0 (0)	1 (5.6)	1 (2.9)
Heterosexual	2 (10.5)	14 (93.3)	8 (50)	8 (44.4)	16 (47.1)
Other	0 (0)	1 (6.7)	1 (6.3)	0 (0)	1 (2.9)
What is your current relationship status? [N (%)]					
Single	5 (26.3)	0 (0)	1 (6.3)	4 (22.2)	5 (14.7)
Married	11 (57.9)	13 (86.7)	12 (75)	12 (66.7)	24 (70.6)
In a domestic partnership	3 (15.8)	0 (0)	2 (12.5)	1 (5.6)	3 (8.8)
Widowed	0 (0)	1 (6.7)	1 (6.3)	0 (0)	1 (2.9)
Divorced	0 (0)	1 (6.7)	0 (0)	1 (5.6)	1 (2.9)
What was your primary or original cancer or tumor-type diagnosis? [N (%)] **					
Breast	7 (41.2)	9 (60)	7 (50)	9 (50)	16 (50)
Colorectal	2 (11.8)	2 (13.3)	2 (14.3)	2 (11.1)	4 (12.5)
Lung	1 (5.9)	2 (13.3)	1 (6.3)	2 (11.1)	3 (9.4)
Non-Hodgkin Lymphoma	2 (11.8)	0 (0)	1 (7.1)	1 (5.6)	2 (6.3)
Pancreatic	1 (5.9)	2 (13.3)	1 (7.1)	2 (11.1)	3 (9.4)
Ovarian	3 (17.7)	0 (0)	2 (14.3)	1 (5.6)	3 (9.4)
Other	1 (5.9)	0 (0)	0 (0)	1 (5.6)	1 (3.3)
Partner's Gender Identity [N (%)] ***					
Woman	10 (62.5)	6 (40)	10 (62.5)	6 (40)	16 (51.6)
Man	3 (18.8)	7 (46.7)	4 (25)	6 (40)	10 (32.3)
Transgender Man	1 (6.3)	0 (0)	0 (0)	1 (6.7)	1 (3.2)
Genderqueer	1 (6.3)	0 (0)	1 (6.3)	0 (0)	1 (3.2)
Other	1 (6.3)	0 (0)	0 (0)	1 (6.7)	1 (3.2)
I prefer not to answer	0 (0)	2 (13.3)	1 (6.3)	1 (6.7)	2 (6.5)

1: Two sets of summaries are presented, one within the patient/caregiver dyads by SGM vs. H/C, and one within the SGM vs. H/C groupings by patient/caregiver status.

*2: * 1 missing value; ** 2 missing values; *** 3 missing values.*

We made between-group comparisons of interest while accounting for the paired nature of dyads, and for the multiple PROMIS scores obtained from each participant, using a linear mixed effects model. Analyses of the residuals indicated this choice was appropriate. Results of the linear mixed effects models suggest that patients and caregivers had significantly different profiles of PROMIS QoL responses (p=0.038), and that the differences in these overall profiles did not reach statistical significance between SGM and H/C patients (p=0.334). See **Figure 1**. In spite of a significant difference in the aggregate QoL profile between patients and caregivers, no per-measure differences were identified as being statistically significant (see **Table 3**; all p>0.05). Estimates of between-group differences that are of potential interest for future study include: patients tended to report more fatigue and anxiety than non-patients did [model-based difference (standard error [SE]) = 4.84 (2.89) and 3.65 (2.70), respectively]; SGM participants tended to report higher depression and social isolation than H/C counterparts [model-based difference (SE) = 3.75 (2.49) and 4.88 (2.76), respectively].

3.3 Qualitative Findings From Semi-Structured Patient and Caregiver Interviews

Qualitative interviews comparing the perspectives and experiences of SGM and H/C dyads highlight differing experiences of cancer care, structures of social support and coping, and allow for analysis of care delivery in order to characterize gaps in SGM cancer care.

Qualitative interview questions specific to SGM experiences of Sexual Orientation and Gender Identity (SOGI), and SOGI related stigma and discrimination, provide relevant context to the lived realities and cancer care of SGM patients and caregivers in the study. The following representative quotes are presented in the following sections: 1) SGM patient and caregiver experiences stemming from sexual orientation and gender identity; 2) SGM and H/C patient similarities and differences in experiences of cancer care; 3) SGM and H/C caregiver similarities and differences in experiences of providing support for cancer patients; and 4) Patient and caregiver suggestions to improve cancer care. Subthemes in each section highlight recurrent and significant topics identified through iterative analysis. An outline of sections, subthemes, and queried and/or contrasted participants, is presented in **Table 4**. Quotes are edited to remove verbal pauses and repetition to increase reader accessibility. Quotes are coded by interviewee role and SOGI (i.e. PT = Patient, CG = Caregiver, SGM = Sexual and Gender Minority, H/C = Heterosexual, Cisgender).

3.3.1 SGM Cancer Patient and Caregiver Experiences Relating to Their Sexual Orientation and Gender Identity

3.3.1.1 SGM Patients and Caregivers Experienced Anti-SGM Stigma and Discrimination Within Their Lived Experiences

SGM patients and caregivers in this study, all of whom have lived through periods of intense social change, described both

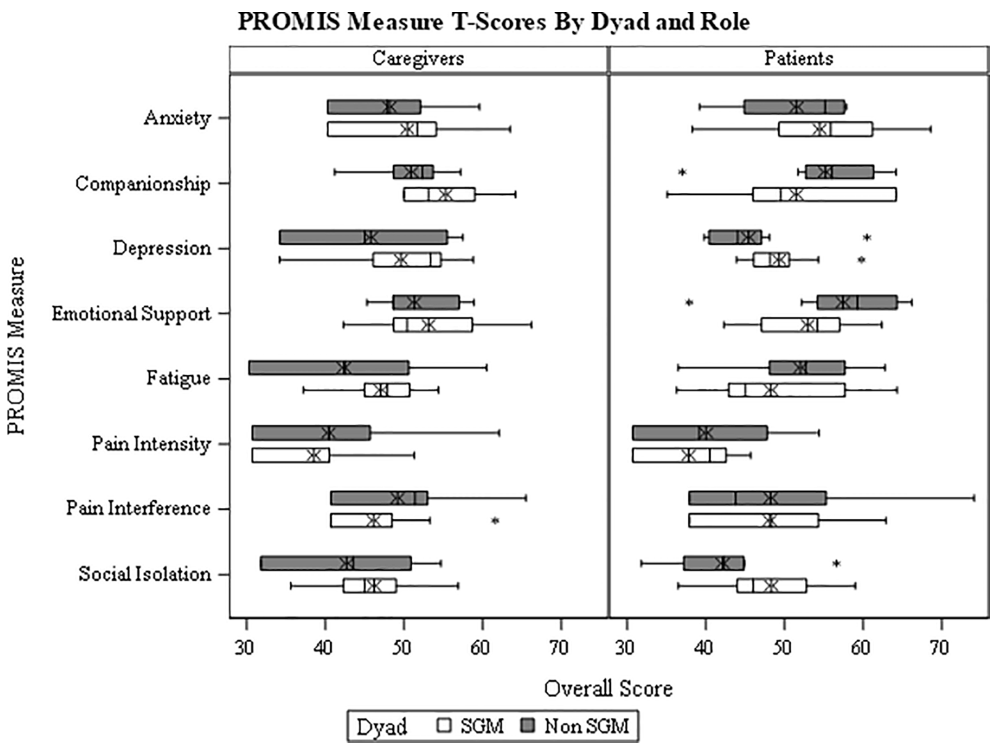

FIGURE 1 | PROMIS Validated Measure Self-Reported Quality of Life for SGM Patients and Caregivers Compared to Heterosexual, Cisgender Patients and Caregivers.

TABLE 3 | Summary of PROMIS instrument scores.

	Patients		Caregivers	
	SGM	**Non SGM**	**SGM**	**Non SGM**
Fatigue	48.3 (9.5)	52.0 (8.2)	47.1 (6.0)	42.4 (11.5)
Pain Interference	48.1 (8.5)	48.3 (13.1)	46.1 (7.5)	49.2 (9.2)
Pain Intensity	37.8 (6.4)	40.1 (9.3)	38.5 (8.5)	40.4 (11.5)
Anxiety	54.5 (8.8)	51.6 (7.5)	50.4 (8.6)	48.2 (6.7)
Depression	49.3 (4.8)	45.4 (6.8)	49.6 (8.5)	45.8 (9.3)
Emotional Suppot	53.0 (6.9)	57.5 (9.3)	53.1 (7.5)	51.3 (5.0)
Social Isolation	48.3 (7.3)	42.1 (7.4)	46.2 (6.8)	42.7 (9.5)
Companionship	51.5 (11.0)	55.2 (8.6)	55.3 (6.0)	50.9 (5.5)

challenges and opportunities relating to their SOGI and membership in the SGM community. All articulated examples of anti-SGM stigma and discrimination within their lived experiences. The majority described periods when their sexual and gender identities were not accepted in the dominant society. More than half had moments of fear and insecurity stemming from their marginalized minority status. A caregiver explained:

"…the biggest challenge is never feeling like I was quite accepted or loved enough in my family … so that would be my biggest existential crisis, feeling like there's something wrong with me." - SGM CG-7

A bi-sexual patient told us, *"Attractions to women weren't options when I was younger. I hadn't had really good role models. It was scary to me."* - SGM PT-7.

Hiding sexual orientation due to employment restrictions magnified these fears. A lesbian caregiver told us: *"I'm 80 years old, so I go way back. Being gay in the 60s and 70s was really scary, especially in the military. If you even had a friend who was gay, you could be discharged. It was very difficult to hide that. Every day, you're living a lie. Every day, you live in fear."* - SGM CG-3

A lesbian caregiver explained that fear and stress, "alters our behavior sometimes, it drives decisions." – SGM CG-5 One lesbian patient told us, "*I've always looked over my shoulder. I've always monitored what I say and how I behave. I don't walk around with a sign. When I'm with someone, I don't even know that we'd hold hands. I'm always careful about my safety. I've never felt totally safe. That's just the way it is.*" - SGM PT-2

Patients and caregivers reported how such experiences continued in their current lives. Several mentioned verbal assaults, two losing jobs due to their SOGI status, and one couple felt discriminated against when purchasing a home. Two patients lost custody of children. Gender nonconforming participants felt "*policed*" when using public restrooms.

"Anytime I was in a public space, I felt like there was somebody there who thought it was their job to not let me use the bathroom…'You can't go in that bathroom. That's the wrong

TABLE 4 | Summary of thematic qualitative findings.

Themes	
3.3.1 SGM Patient and Caregiver Experiences	
Subthemes	SGM patients and caregivers experienced anti-SGM stigma and discrimination leading to "minority stress"
	All were concerned about potential stigma and discrimination in healthcare settings
	Previous stigmatizing experiences contributed to medical mistrust in cancer care
	SGM caregivers articulated feelings of stress more acutely then did their H/C counterparts
	Single SGM patients experienced loneliness, isolation, and lacked community support
	SGM patients and caregivers are resilient and use coping strategies during cancer treatment and care
3.3.2 The Need to Improve SGM Cancer Care	
Subthemes	Oncology staff and providers lack SGM cultural competence training and SGM medical knowledge
	Oncology teams are inconsistent in the inclusion of SGM caregivers in patient decision-making
3.3.3 Heterosexual, Cisgender Patient Experiences	
Subthemes	Comfort at the cancer center
	Ability to be critical of cancer care
	Differing patterns of support
	Distinctions in the articulation of the cancer experience
3.3.4 Overlapping Themes in SGM and H/C Patient and Caregiver Interviews	
Subthemes	All patients appreciate oncologists, nurses and cancer care navigators
	All patients rely heavily on caregivers
	There is insufficient support for caregivers regardless of SOGI
3.3.5 Patient and Caregiver Suggestions to Improve SGM Cancer Care	
Subthemes	Ask patients and caregivers about SOGI
	Train staff and providers in cultural humility and communicative competency
	Gain knowledge of SGM sexual health relevant to cancer treatment
	Identify and/or offer tailored support services for SGM cancer patients
3.3.6 Patient and Caregiver Suggestions to Enhance Support for All Caregivers	

bathroom.'…It was stuff like that. I still sometimes find myself holding it when I could just go." - SGM CG-1

"I have certainly experienced situations where I felt questioned, "What are you?" When I travel, a lot of places, I'll get sir'd. I'm actually comfortable with that. What I think is uncomfortable is when people get it, like, "Actually, you're not a guy. I've never felt threatened, but I'm someone who definitely gets looks going into the women's bathroom." - SGM PT-10

All SGM patients and caregivers discussed their individual lives in relation to broader social and structural situations. Many lost friends during the AIDS Epidemic. Others experienced fear of police, hostile politicians, and anti-SGM policies. Others fought against marriage exclusions. All who were born female discussed the role of sexism in their lives. Participants acknowledged that these broader issues compounded SGM specific stressors. One patient explained how she internalized homophobia and stigma:

"…the part that's toxic is you always have to wonder … Just the fact that you even have to think about it is kind of where the toxicity comes from. It's almost an internal problem because you have no way of actually knowing, unless somebody comes up and calls you a dyke to your face and punches you. People are smarter than that, usually. It's really insidious—it's just a factor. It's an added stress factor in all of your interactions." - SGM PT-5

3.3.1.2 SGM Patients and Caregivers Experience Stigma and Discrimination in Healthcare Settings

SGM patients and caregivers encounter stigma and discrimination in healthcare settings and medical institutions. A lesbian patient shared how she and her wife experienced medical discrimination when having their son:

"When we had (son's name), …the attorney general rule said that if you're married you can fill out the birth certificate, and the other same-sex parent can go on the certificate. We filled out all that information … When we actually got his birth certificate, it was completely blank. The nurse had just not put in (partner's) information." – SGM PT-5

One lesbian patient described her strategy for coping with healthcare discrimination, saying, *"I've tried to navigate my way through discrimination by leveraging my white, straight-passing privilege. It's a little bit harder without the hair … At the hospital, there's this kind of implied "We're supportive." I think they'd like to think they're more supportive than what they are. I think they put on a good veneer. They do things that are surface-level supportive, but it doesn't feel as heart-connected."* - SGM PT-7

The patient's wife and caregiver, picked up on the same sentiments, telling us of an experience where she sensed that her relationship was unacceptable to a hospital administrator:

"[wife's name] and I were sitting on a bench at the hospital. I was kind of leaning in toward her, and the [administrator's title] went by, and I could feel her discomfort. I think she tried hard not to feel— 'Ugh.' Maybe that could be anyone … It could be any affection. I don't know. [But] I suspected that she didn't feel comfortable because we were two women, and it was near a public area." - SGM CG-7

3.3.1.3 SGM Patients and Caregivers Found Resilience and Belonging in the SGM Community

Even with such challenges, the majority of those in the study found belonging and resilience from being part of the SGM community. Many described members of the broader SGM community as "*family*." One women said, "*In the lesbian community, I have a sense of belong and affirmation*." - SGM CG-9 Another told us, ""*Community is a really big source of, if not empowerment, then inspiration. To see people who are struggling or who are dealing with or have dealt with intractable issues or traumatic issues. It is amazing … here in [city name], community is really strong*." - SGM PT-10 For others, empowerment came from community activism. One lesbian patient explained:

"I worked, for 11 years, in the HIV and AIDS community as a therapist at an AIDS agency. That was wonderful because, at the beginning of it, AIDS, two-thirds of the agency were folks who were gay, lesbians. It was very empowering. Then, being in a relationship with the love of my life for 12 years, that was empowering." - SGM PT-4

A gay male patient said:

"I've been out now for, gosh, how many years is it? I've also worked in the gay community, so I've been aligned with the community for a long time and been an activist. After all of these years, it's kind of in my gay DNA. I feel pretty empowered. In an interesting kind of way, discrimination is a reaffirmation of a very important part of my identity." - SGM PT-6

Although such experiences occurred outside of cancer care, they informed the lives, behaviors and coping strategies of SGM cancer patients and caregivers.

3.3.2 SGM and H/C Patient Similarities and Differences in Experiences of Cancer Care

3.3.2.1 SGM and H/C Patients Appreciated the Cancer Center and Oncology Care Teams, Although SGM Patients Emphasized the Need to Develop Trust With Their Physicians More so Than Did Their H/C Counterparts

Although both SGM and H/C patients appreciated the care given at the cancer center, their experiences differed. H/C patients overall described situations where they felt instantly welcomed. One patient told us, *"I can't say enough good things about UNM Cancer Center. We were given all the time; we were given wonderful explanations. They have always been welcoming and supportive and interested in more than just my cancer. I think that's really important."* - H/C PT-1

Two others mentioned patient navigators. One patient described, *"What I found extremely wonderful at the cancer center was the navigator. She would just show up. There she was this little ray of sunshine. I would be there for a test, and she'd give me a hug and a couple words….that was special." H/C PT-4 A second claimed, "I felt welcomed. [name] was my navigator. He met me at the door, and I had talked to him on the phone. He was great! He took us all around, showed us things, and then he took us up to my appointment."* – H/C PT-6

SGM patients did not describe such feelings of instantaneous welcome, instead, focusing on staff and provider efficiency and communication that led to feelings of trust. As one genderqueer patient said, "*I was super impressed. I felt like they were efficient, that they knew what they were doing. The expertise was really high. I have just a high bar for what I think is good practice.*" – SGM PT-10

One lesbian patient described the moment when she began to trust her oncologist:

"I felt a lot of hope in meeting with [Dr.'s name] … because that's when the switch flipped … she said one thing about having an 85% response rate to treatment. That just totally shifted my paradigm in the moment. Then she said, 'I still don't have enough information to give you any idea about what this looks like for you.' I feel like she is a straight shooter … all of those things make me feel positive." - SGM PT-7

Another explained that she appreciated her oncologist's responsiveness to her questions, even though had to bring up up issues relating to sex and sexuality that she felt were important to her care:

He was very focused, very responsive to my questions. I talked to *him about sexuality, sex, and the sexual experiences and how the anti-estrogen pill was affecting me … Another time, we talked about lubrication. Of all the questions that they asked you, none of them were about your sexual life and your sexual functioning. He's on some committee, and he actually told me he brought up, to the committee, that that's not asked. Now they've been negotiating how the doctor should address that issue. I was really excited that I had some influence and that he is committed to it and is working on it. He said most patients don't bring it up, but it clearly would affect their lives.* – SGM PT-4

H/C patients likewise called attention to oncology team communications. One women told us, *"I met with [Dr.'s name] and just really, really liked her so much and liked her approach and her bedside manner. I felt like she was a good fit."* - *H/C PT-2* Another patient said, *"My doctor is fantastic! She takes the time. She is busy. I know that. But if I have questions, if something's off, out of the ordinary, or whatever, she always takes the time and answers it. That means a lot. It's important that they're listening."* - H/C PT-8

3.3.2.2 SGM Patient Critiques About Cancer Care Delivery Resulted From a Lack of Culturally Appropriate Service Delivery, Whereas H/C Patients Took Issue With Gaps in Patient Provider Communication in Response to Care Needs

Although both SGM and H/C patients offered critiques of various components of cancer, lingering concerns they chose to emphasize differed. On the one hand, SGM patient concerns were rooted in discomfort caused by a lack of SGM cultural competence and heterosexist medical assumptions. A lesbian patient described an uncomfortable situation with the breast reconstruction team:

"I was weirded out by my interactions with [Dr.'s name] and how he interacted with [wife's name] as well. In the very first meeting, they have me stand in front of a green screen … a resident … or junior attending … took pictures of my breasts with his iPhone, which I think is probably not standard protocol. It just felt very slimy, the whole thing. They were talking about what my boobs would look like after the fact. I just remember being very uncomfortable; the whole thing just made me uncomfortable … it felt very much like an old boys club." - SGM PT-5

A genderqueer patient expressed discomfort with the assumptions made about breast reconstruction:

There were assumptions that were made about how important the body part of breasts were to me. It just felt like every person who inhabits a female body is really going to care about breast conservation. And I really didn't. I probably would have really appreciated being asked, "How do you feel about that part of your body? What's your relationship with your breasts?" I think it could be any part of the body that had cancer, but for people who are in a female body, the breasts are one of the most charged body parts that there are. - SGM PT-10

H/C patients, on the other hand, took issue with gaps in patient provider communication and response to care needs. One women described how she was informed of her cancer:

"…the worst of all the experiences, one morning, we're sitting here at breakfast, the phone rings. 7:00 am. A voice I can hardly hear or understand because there is a terrible connection says, 'This is [Dr.'s name] and you have breast cancer.' I was furious! Why do you call somebody up and do that?" - H/C PT-1

Another patient suggested:

Of all my experiences with UNM Cancer Center, there is only thing I would call negative, or not up to the standards of everything else I've come to expect. I've talked to two people on that side of the office, but in both cases, they were very nice. They helped them. They gave me information, but I asked for more information and never got it. I called about the status of things and never got a call back. That's the way it goes sometimes. - H/C PT-7

One woman told of a crisis resulting from medication:

"I got my infusion and then I was trying to take the pills and I *was having a really hard time and feeling very nauseous … I tried to get a hold of an oncologist after hours and I got a nurse who said there was no oncologist on call. That was absolutely horrible … The nurse couldn't even pronounce the drug that I was on, and then couldn't connect me to an oncologist … she was out of state!"* - H/C PT-5

3.3.2.3 SGM Patients Felt Were Often Uncomfortable About Their Loved Ones' Inclusion by Providers, a Sentiment Not Shared by H/C Patients

SGM and H/C patients also experienced staff and provider inclusion of their caregivers and families in very different ways. All H/C patients felt that their husbands, wives, and children were included in care. Patients told us,

"My husband is such a rock. He came with me to every single appointment up until radiation because he couldn't come into the radiation room. At that point, I had already had six months of chemo, a lumpectomy, a mastectomy. My sister came to one, and my best friend came in from Houston to hold my hand for my first and last chemo. I have an incredible network of support." - H/C PT-2

"My husband was with me throughout. And our son came with me because my husband is not medically savvy. Even though I am, I am the patient, and it still was an emotionally difficult time for me. So, to be objective and to really hear everything that was happening, our son is very capable and took a lot of notes and was

certainly a support for us to get through this all. We believe life hits you, lots of things, but it's a journey we're in together. Cancer is a family diagnosis I feel strongly about that, and that they needed and had a right to know what was happening with us." - H/C PT-4

One SGM patient, whose partner is a transman, offered a similar sentiment:

"…it's hard to retain the information we get in any kind of doctor's appointment, and he was there with me for that. I knew I would not be able to remember everything, which is what actually did happen. He is the holder. However much he remembers today, he is the holder of a lot of the information … It makes me feel sad for people who don't have partners or close relationships … I'm blessed." - SGM PT-9

Other SGM patients in the study had differing feelings regarding caregiver inclusion in their care. One couple chose to hide their partnership. They told us, "*They think [Wife's name] and I are sisters, and lots of times we just let them think that … we just let them believe whatever they want to believe, or we just say we're friends kind of thing. Some of the times we just smile and nod."* - SGM PT-3

Another woman spoke of the discomfort she and her wife experienced with the care team:

"They knew that she was my person. They just didn't know what to call her. [That] one thing was always a little awkward. Is she your wife? Is she your partner? Is she your spouse? There were a number of times where it was just fumbling for the right verbiage. I think the easy way to do that is to just ask at the beginning, like, "How should I refer to you?" - SGM PT-5

Another couple explained how they discussed their relationship with the doctor prior to care to ensure that she would be able to work with them:

We asked [Dr.'s name]. 'Are you OK working with a lesbian couple?' Because neither of us really trusted that she, or any medical professional is, because people have all kinds of stuff. There is a lot of religiosity even among doctors and healthcare *professionals, where they have biases; those biases come out. We just wanted to hear explicitly that she was—then she went into this whole thing of how she—in her undergraduate degree, she did this research on HIV. It was kind of like she was telling us that she was really queer-friendly, or at least kind of LGBT-friendly. We wouldn't have had to do that if we were a straight couple -.* – SGM PT-10

3.3.2.4 SGM and H/C Patients Had Differing Patterns of Social Support

Similarly, SGM and H/C patients indicated differing patterns of social support. H/C patients were likely to rely on family. Patients told us:

My family is just 100% with me. My wife our two kids. We *never had anything even remotely like this affect our family. This is really something where my family just came together. In that first meeting and for several meetings, all four of us were there. Everybody was involved and jumped right on and did everything they could and still are.* - H/C PT-7

I was very blessed. I have a wonderful home to be in and enough money to make myself comfortable and I had somebody to care for me … I really didn't feel that I could have gotten through the chemotherapy without help. But my husband, and my son were very helpful, and neighbors and friends brought groceries and helped us stay in our home which was very important. - H/C PT-4

SGM patients were much less likely to rely on family. Partnered SGM patients relied heavily on their spouses and partners. Others found support through friends, work colleagues and neighbors. One woman explained, *"We just decided, 'We're going to enlist our village.'… my kids' schools was supportive. We had friends that would bring us food. My parents were disasters. It wasn't surprising. It's hard when your parents aren't interested in your treatment at all."* - SGM PT-5

Three of the four single SGM patients experienced loneliness, isolation and lacked community support. One man told us:

"The biggest challenge for me has been socially, now that I'm older and single. Most other gay folks that are my age are in relationships. Especially as an older gay man who doesn't fit into the young and beautiful kind of images that are so often desired, there's a certain amount of loneliness … There's an odd thing that has happened in terms of my own sense of myself and my identity. I think of myself as a cancer patient. In a similar way as being gay, [cancer] informs my life and decisions … it exacerbates my feelings of loneliness." – SGM PT-6

An SGM woman expressed similar feelings:

I had one friend that moved to Maui. She was the one person I *could go out and have a beer with. Or we'd go and eat together, take walks, whatever. I miss that. Everybody else is in couples … I did see two women [names friends – in a partnership]. I saw them last week, and it was wonderful. I didn't want to go home. I stayed there so long that I got caught when they shut down the freeway. It took me like two hours or two and a half hours to get home. But I wouldn't have traded it because I got to see these two people.* - SGM PT-2

3.3.2.5 Cancer Center Support Services, While Underutilized by Both SGM and H/C Patients, Were Effective When Engaged

The majority of SGM and H/C patients did not take advantage of cancer support services such as counseling, support groups, financial assistance or nutritional counseling. Reasons for the lack of service use varied. Reasons for underutilization of support groups for SGM patients centered around "not wanting to identify with the disease" -SGM-PT-9, not wanting the group to "bring me down" -SGM PT-3, and a lack of SGM specific groups. One patient described her attempt to go to a non-SGM specific cancer support group in the community:

"There's a group … for women earlier than 40, that are diagnosed with breast cancer. I went to that once or twice. I think that that was the only time that I ever felt out of place because I was gay. They were talking about their husbands. I don't know. It felt very young, straight, not my people." – SGM PT-5

H/C patients generally suggested that they received support from family and friends, and did not need support groups. One patient explained:

"I know there are people we can talk to, counselors and stuff. I haven't really used them, because I do have a lot of support from my family. My parents have been very good. I talk to them a lot.

My husband has been amazing, and my sisters. My mother came out for ten days and then my sisters came out." – H/C PT-5

Two patients did access support services and found them to be effective. A single lesbian woman who was having financial difficulties stemming from cancer care described:

"I was struggling with fatigue and some anxiety about the future. Every treatment, the co-pay was $576, every three weeks. I thought, since I was still working, there wouldn't be any help, but a friend of mine, another therapist, kept nagging me, 'Call the oncology social worker.' I finally called her and asked for help, and lo and behold, there's a Patient Advocate Foundation, and they are paying my co-pays for the chemo. I felt like I won the lottery. That was so wonderful." – SGM PT-4

An H/C patient had a positive experience with nutritional *counseling as well.*

"I had a phone conversation with the nutritionist, and that was very helpful. I wanted to know is there something I should be doing during chemotherapy? During chemo radiation? To prepare for surgery? She was talking about foods that can be good for maintaining weight. She also told me during chemo radiation I might have to eat more because it's a healing process, too. One of the first nurses that I spoke to, said that I shouldn't eat fresh, uncooked vegetables and fruit during chemotherapy, because of the issues with immunocompromised people. The nutritionist said, 'Actually, this neutropenic diet is kind of old school. We now think that it's important to eat fresh fruits and vegetables.' She explained what to eat and how to clean it, so that was helpful." – SGM PT-5

3.3.2.6 SGM and H/C Patients Used a Number of Coping Strategies During Cancer Treatment and Care

Patients in the study utilized a variety of coping mechanisms to combat the stresses of cancer. The coping mechanisms appeared to have little to do with SOGI and more to do with individual patient preferences, ability and life circumstances. Many suggested that maintaining a positive attitude was key. One SGM patient said, "*My psychology is pretty chill. I've had a longtime Buddhist practice. I'm sort of someone who doesn't get thrown off. Part of it is practice."* – SGM PT-10 An H/C patient likewise said that she tends "to have a positive outlook on the world." – H/C PT-1 Another patient told us: *Cancer is a moment, a terrifying moment, but it's trying to keep it in perspective, taking some control over what you have control of, being hopeful, and perhaps living more in the moment.* – H/C PT-4

Still one H/C patient felt the need to "switch hats" and "take care of herself," a difficult challenge for women and mothers who are "caregivers by nature." -H/C PT-2. While an SGM patient needed to get tough. She said, *I'm not all that positive about the world as it is, but I took things on as a challenge and as a, "We've got to get through this." My nephew sent me a card, "Cancer is tough, but you are tougher.* – SGM PT-3 Another SGM patient refused to identify with the disease:

"The thing I remember clearly was [turning to partner] and I said, "No fucking way. I am not identifying with this disease." I've been around a long time. I know people over-identify with illness and I'm just not taking that route. I am going to take the route of, I have this disease, I'm going to get treatment, and that's it! I think that actually helped me." – SGM PT-9

Some patients coped through humor. One woman recounted a moment with her sister:

"I just felt really, really scared that I was going to die soon. After I had the hysterectomy. I was crying and I said, 'I really always thought I was going to live to be old,' and [my sister] looked at me and she started laughing and she said, 'You are old.' (Laughter.) 'Okay.' And we were able to laugh in the middle of all of this." – SGM PT-12

One woman watched movies with her husband, saying, "My *husband and I watched a lot of funny movies: oldies, Johnny Carson Show. I still laugh over I Love Lucy. Television was great. That kept me—and we could do that together."* – H/C PT-4

Some relied on alternative therapies to support their cancer care journeys including acupuncture, massage, energy work, and herbal remedies. One patient told us, "*I love acupuncture. It works for me. Energy work, all of it works for me."* SGM PT-2 A few relied on physical activity and exercise. One patient admitted, however, that she had "less ideal coping mechanisms", telling us: *"I've probably been eating more than I should. I've probably been drinking more than I should."* - SGM PT-4

3.3.3 Caregiver Similarities and Differences in Experiences of Providing Support for Cancer Patients

3.3.3.1 SGM Caregivers Did Not Always Feel Comfortably Acknowledged by Oncology Staff and Providers, an Experience Not Shared by H/C Caregivers

All H/C caregivers, like the patients discussed above, described positive feelings about the cancer center and acknowledgement of their position as caregiver in the lives of the patient they supported. One caregiver told us:

"*The first visit, it was all four of us, our two children and me. We all went. That was such a surprisingly pleasant experience … they had a cellist playing in the lobby. I thought, 'Wow, this is really something.' The whole family, the support. I've always felt that from UNM. It was very helpful and positive. We were all part of the initial treatment plan, when [Dr.'s name] was telling us what was going to happen next and how things were going to go. From the minute, you walk in … whoever you encounter is very nice and pleasant."* – H/C CG-7

Yet, SGM caregivers had very different experiences. Oncologists and oncology teams' deficits in knowledge were apparent in their inconsistent inclusion of SGM caregivers in patient meetings and patient decision-making processes. A caregiver told us:

"I didn't feel seen. I kept trying to connect with (name of doctor) in a way that would validate me. I said, 'I work in a hospital; I know the system. I lost my sister to cancer and I was her caregiver.' But I never got recognized as somebody….it wasn't worth fighting to try to impress my point. I just held onto my observation. I walked out of there feeling like I did everything but stand on my head to get acknowledged. It made me so angry." – SGM CG-7

Another caregiver recounted a "strange" interaction with her partner's doctor during the discussion about breast reconstruction where she felt the physician may have been *responding to H/C contexts.*

"She was asking [partner's name] about if she would want her breasts reduced, something about breast size or breast reconstruction. I just remember her looking at me and she was like [adamant voice], 'This is her decision to make.' I was like, 'Uh, duh, of course,' and then I was like, 'What the hell? Are you used to men saying shit? That's not me!" SGM CG-P-2

One caregiver reflected on the lack of engagement she felt from staff at the cancer center:

"I don't remember anyone asking me how I was at the cancer center or offering any support … Actually, I remember saying that if there had been a group, I would have gone. I was partly just kind of curious because I was like, "What do I not know? I'm just showing up as best I can." But if it was a group it would have to be overtly queer-friendly. I don't think I would have wanted to go and have to gender switch. I wouldn't want to have to be on guard at all."—SGM CG-2

3.3.3.2 SGM Caregivers Articulated Acute Feelings of Stress More Frequently Than Did Their H/C Counterparts

SGM caregivers were more apt to indicate that caregiving was stressful than were their H/C counterparts. One SGM caregiver recounted:

"I have medical PTSD. Everybody doesn't like hospitals, and I have a special pathological relationship to it and feeling to it. That was just really hard. I wanted so badly to be a good partner, and be there and be reliable and helpful. Every time we would go into these settings, it would just send me into orbit. Every single day we went to the cancer center for those appointments it was just like, 'Ugh," just ringing my bell all the time. Surgery … she had a lumpectomy and I was like, 'Oh, God.'" – SGM CG-9

Another SGM caregiver related:

"It was all-consuming. I pretty much ignored work and let some of my peer managers help me out and filled in for me when they needed to. I wasn't there a lot; I took as much leave as I possibly could … [it was] a huge emotional toll, but it was definitely grief and it was not something I had ever experienced before in any way like that. It's certainly the absolute hardest time in my life, no question about it." - SGM CG-5

Still another told us, "It took over my entire life … Every minute I thought about it. 'How could I do this better? How could I talk her into eating? How could I get the compression hose on easier? How long was this going to…?" I was getting up at night sometimes and going in to make sure that she was alive." - SGM CG-3

H/C caregivers, the majority of whom were male spouses, described their caretaking duties differently, as more of an expansion of roles and responsibilities. One caregiver said, "*It didn't drive me into deep depression or anything. It didn't change anything; it just was different and there was different activities, and different focus on things.*" -H/C CG-1 Another caregiver explained:

"I try to think positive. It was really tough at first. We live in a two-story house, and when we came home [wife's name] barely made it upstairs to our bedroom. Early on when she needed a lot of attention—I ran myself ragged running up and down. I lost a lot of weight, which was good. That became my day-to-day life. Now, I also never gave up golfing." - H/C CG-6

The one H/C caregiver who described extreme stress due to caregiving duties was the mother of the patient. She told us, "It's hard to keep her comfortable because after chemo her head is very warm … we put an icepack on … she's also had a problem with mouth sores. That's the hardest thing. I had no idea what to do for that. Physically, sometimes it's very difficult." – H/C CG-2

3.3.4 Patient and Caregiver Suggestions to Improve Cancer Care

At the end of the interviews, all patients and caregivers were offered the opportunity to provide suggestions to improve cancer care. SGM patients and caregivers, although satisfied with their oncology care once trust had been established and treatment was underway, offered the following suggestions.

3.3.4.1 Ask About Patients About SOGI

Patients desired staff and providers to directly address SOGI. A lesbian patient said, *"It's been challenging to come out to certain people—doctors." – SGM PT-4. A gay patient added, "It's such a big and integral part of my life, and that it's never come up." –* SGM PT-6

3.3.4.2 Train Oncology Staff and Clinicians in SGM Cultural and Communicative Competency

Staff and physicians often seemed challenged with how to interact with SGM patients and their caregivers. Patients suggested that "cultural competence training" saying, "*We need training for the doctors and front end people. Not all of them. We have run into some remarkable clinic people, doctors and nurses. It's just difficult. The best thing you can do is bring the best of yourself to it. Some of us have to work on that.*" SGM CG-8. Another caregiver suggested that it should not be a single training, saying, "*To make sure it's inviting for people who are queer, transgender, gay and lesbian, it has to be real. I know businesses have tried to go through a training, and then put up a sticker, but that has to be lived. It's not just about training.*" – SGM CG-10

3.3.4.3 Gain Knowledge About SGM Sexual Health Relevant to Cancer Treatment

Lack of discussion about SOGI prevented candid patient and provider conversations about the effects of cancer care. One lesbian patient found a therapist who was a breast cancer survivor to see for her "lack of sex drive" following cancer *treatment. – SGM PT-9. Another lesbian patient suggested:*

"I definitely would encourage the oncology team to be more informed. Be open about sexual orientation and sex life, because that's an important part of our health—physical and emotional. My doctor went online to check things out. He should already know or have recommendations, like a CBD oil or a CBD lubricant (to counteract "aging" effects of taking an anti-estrogen pill)." – SGM PT-4

3.3.4.4 Identify and/or Offer Tailored Support Services for SGM Cancer Patients

Few local support services exist to assist SGM patients and caregivers. One lesbian patient asked for, "a support group that was actually lesbian, and meets in person." -SGM-PT-4

A caregiver who had worked with those diagnosed with HIV and AIDS, suggested that cancer care might use mentorship model to enhance care for SGM patients and caregivers. He explained:

"They paired up people who are going in and being told, 'Your test came out positive' with another person who had been through it and was already alive ten years later. …the mentor had already been through this experience, had the knowledge about logistically what was going to happen, but also held the emotional knowledge, 'I've been where you are. I know how fearful this is. You're going to make it through.'" – SGM CG-9

An SGM patient mentioned that [name of another cancer center where she received a second opinion] offered a similar program.

"Basically, you fill out a form where you check off some characteristics, like what kind of cancer you had, how old you are, and I think sexual orientation is on there. But if not, you could add it. They just put you in the ranks until somebody has a similar diagnosis and offer you up as a community partner." - SGM PT-5

3.3.4.5 SGM and H/C Patients and Caregivers Interviewed Offered Suggestions to Assist Informal Cancer Caregivers

Patients and caregivers had myriad suggestions on how the Cancer Center could better include them in their loved one's cancer journey. One SGM caregiver provided an idea for people at the onset of care who may be identifying their primary caregiver(s):

"I would hope that you [could] come up with a variety of profiles of what caregiving might look like. I think sharing those stories with people broadens their perception of what caregiving can be about … [This could be helpful for] people that need care so that they can pick appropriate caregivers and they can begin to identify what are the range of their needs, and who could provide that? Those discussions are really important at the beginning of diagnosis."- SGM CG-6

Another caregiver expressed a desire for organized classes on a variety of topics including cooking for cancer patients and addressing side effects their loved one might experience:

"If they would establish some kind of formal training that would tell us what's going to happen when we get home and how to deal with that without just getting into it and trying to find your way through it. If they had something like that, I guess it would be like a caregiver support group … Maybe even cooking classes … I don't know. Anything that we could get involved in."- H/C CG 6

Interviews with all patients and caregivers, both SGM and H/C, documented needs for enhanced caregiver supports. Caregivers wanted more explicit information about their loved ones' treatment side effects and tools that they may use to mitigate side effects. Caregivers wished to receive a "roadmap" to help them navigate each step of their loved one's cancer journey.

4 DISCUSSION

This multi-methods work presents SGM patient and caregiver perspectives of cancer care, contrasting those to the experiences of H/C patient and caregivers. We documented and compared these experiences to identify gaps or misalignments in cancer care delivery that contributed to disparate experiences and outcomes for SGM patients and their caregivers. We intend to use these findings to develop interventions that will improve SGM cancer care.

Quantitative findings using PROMIS validated measures call attention to the complexity of stress and distress in the lives of SGM cancer patients and caregivers. Although this is a pilot study, with a small population, and our findings are not generalizable to the entire SGM population, they do show that SGM patients and caregivers in our study have higher perceived levels of depression, anxiety, and social isolation when compared to H/C patients and caregivers. These findings, although not statistically significant, contradict the Hutchcraft, et al. study which used PROMIS measures finding higher relative odds of psychological distress among bisexual cancer survivors, but not among lesbian cancer survivors (50). While few studies have used PROMIS measures to assess SGM QoL to date, studies have assessed psychological health in SGM cancer patients and survivors. A systematic review by Gorden, et al. indicated SGM mental health disparities in male cancer patients, but not in women (51). Studies by Jabson and Bowen (52) determined that SGM women had higher levels of perceived stress, yet studies by Kamen et al. (17) and Boehmer et al. (53, 54) that indicate little to no differences in perceived stress although some differences with regards to anxiety and/or depression between SGM and H/C women cancer survivors.

As in studies by Kamen et al. (55) and Hsieh et al. (56) ours points to the role of role of minority stress as a contributing factor in cancer care for SGM patients and caregivers. Even among a predominantly white, middle class participant population, SGM patients and caregivers recounted numerous experiences of stigma and discrimination at personal, community, and national levels that contributed to minority stress and medical mistrust. Although these experiences predated cancer diagnosis, they contextualized cancer care encounters. Feelings of medical mistrust, minority stress, and distress were heightened for patients and caregivers prior to entering the cancer center and during initial encounters with staff and physicians across various cancer care teams (i.e., oncologists, radiologists, plastic surgeons). Minority stress in SGM patient and caregiver cancer care experiences is evident when comparing accounts of SGM dyads to those of H/C dyads for whom considerations of acceptance and trust are less urgent. As examples, in initial cancer center/cancer team encounters: *"I can't say enough good things about UNM Cancer Center. We were given all the time … They have always been welcoming and supportive and interested in more than just my cancer;"* -HC-PT-1, contrasted with, *"We asked [Dr.'s name]. 'Are you OK working with a lesbian couple?' Because neither of us really trusted that she, or any medical professional is, because people have all kinds of stuff. There is a lot of religiosity even among doctors and healthcare professionals, where they have biases; those biases come out. We just wanted to hear explicitly that she was."* – SGM PT-10. Also within caregiver feelings of inclusion in cancer care, *"The first visit, it was all four of us, our two children and me*

… I thought, 'Wow, this is really something.' The whole family, the support;" - H/C CG-7 compared to, *"I didn't feel seen. I kept trying to connect with (name of doctor) in a way that would validate me … But I never got recognized as somebody….it wasn't worth fighting to try to impress my point … I walked out of there feeling like I did everything but stand on my head to get acknowledged. It made me so angry."* – SGM CG-7

Importantly, due to the size and limitations of our participant sample, our pilot had low representation of gender minorities. We can only report, therefore, on the experiences of one genderqueer patient and one transgender caregiver. Even so, both gender-nonconforming participants, identified in the text of the results/findings, clearly indicated moments where minority stress was exacerbated due to prior experiences of mis-gendering, bathroom policing, and in the case of the caregiver prior medical PTSD that made it challenging for him to support his partner during her cancer care.

Our qualitative findings, like previous studies by Kamen et al. (55) and Hsieh et al. (56) indicate that although minority stress is chronic for many SGM individuals, it may not be a consistent barrier to cancer care for all patients. SGM patients and caregivers are incredibly resilient, drawing strength and empowerment from membership in the SGM community, as well as from caregivers, social support networks, and healthy coping strategies. In the majority of cases, SGM patients and caregivers coped with familiar patterns of minority stress, and were able to focus on their cancer care, once connections with staff and providers were secured, and comfortable communication and trust established. Overall, SGM patient and caregiver experiences, even those that had challenging moments, resulted in positive cancer care experiences.

4.1 Recommendations to Improve SGM Cancer Care

These pilot findings align with scientific recommendations by Huelsman et al. (57) and Kano et al. (58) underscoring the need to include SGM specific programming and SGM affirmative practices across cancer center levels to enhance care for SGM patients and their informal cancer caregivers. Drawing from patient and caregiver recommendations that demonstrated relational gaps in optimal cancer care for SGM patients and their caregivers, we employed ecological theory, to map suggestions at multiple healthcare levels (**Figure 2**): (a) cancer center/organization, (b) administrator, provider and staff,

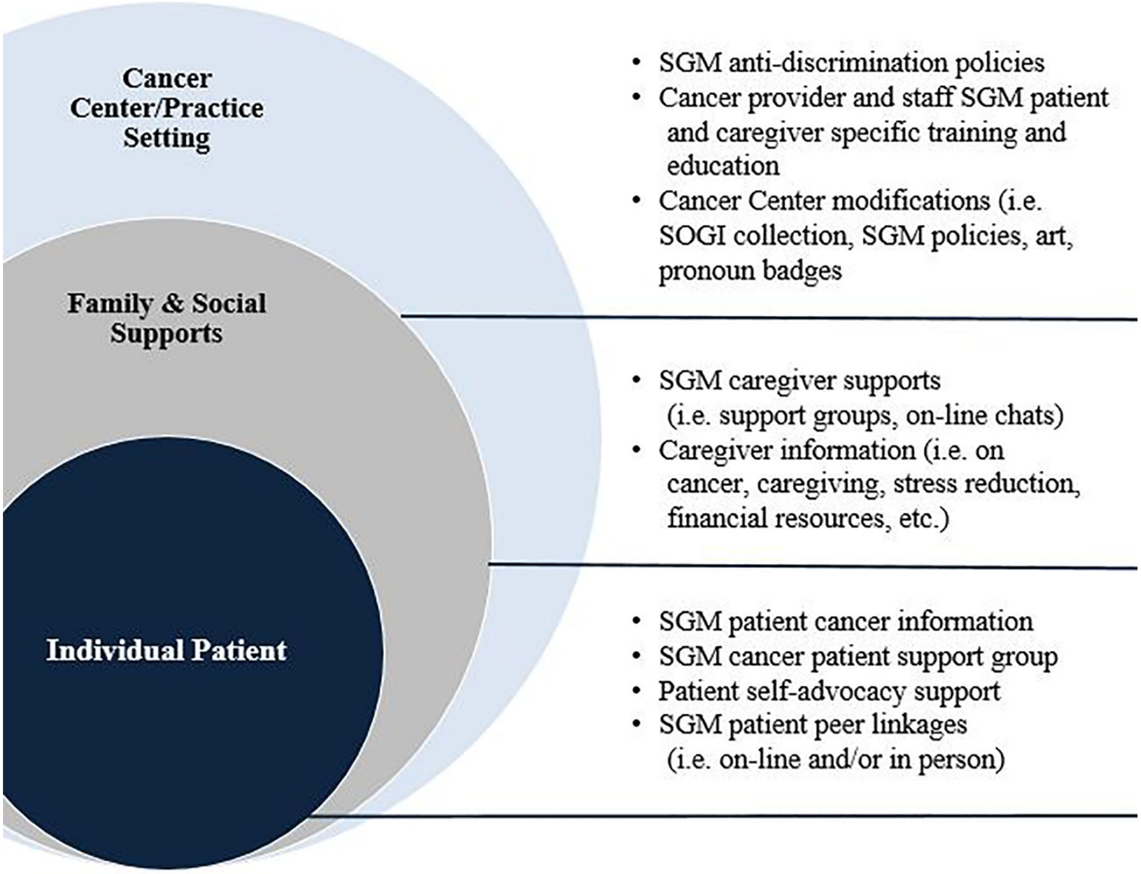

FIGURE 2 | An Ecological Model of SGM Patient and Caregiver Suggestions to Decrease Gaps in Cancer Care.

(c) caregiver and social support, and (d) individual SGM cancer patient (59). At the cancer center/practice setting level, immediate and regular training for staff and clinicians in SGM culturally competent communication and care provision would facilitate quick connection between SGM patients and caregivers and oncology care teams to alleviate medical mistrust and stress/distress stemming from minority stress. Providing visual cues around the cancer center would also facilitate patient and caregiver feelings of acceptance. Provider and staff training would increase SOGI data collection, and decrease heterosexist models of cancer care that fail to account for SGM recognition and care preferences, previous traumas, and alternative family/caregiver structures. At the family and social support level, our study emphasizes the need to develop culturally tailored support for SGM caregivers. Although no two cancer journeys are the same, development of a general packet of information targeted at caregivers could ease stresses associated with caregiving. At the patient level, our study highlights the need to develop and provide SGM tailored supports through groups and/or one-on-one formats, increase patient self-advocacy, and enhance patient information. Care should be taken to support single SGM patients who may be experiencing loneliness and isolation, or for whom support is lacking hindering access to care and positive recovery from cancer. Likewise, all interviewed mentioned the importance of nurse/patient navigation as critical to their overall experience at the cancer center. However, provision of such services did not appear consistent throughout patient care, leading to patient and caregiver frustration. This issue could be addressed by implementing a model where patient/nurse navigation occurs at regular intervals throughout the entire cancer journey.

4.2 Study Limitations

We received funding for this study at the onset of the COVID-19 pandemic, a factor that delayed the start of the study due to research closures, and caused a shift in methodology from face-to-face interaction to electronically (Zoom) mediated encounters. Furthermore, changes in cancer care delivery hindered our ability to recruit a diverse (i.e. racial/ethnic, socioeconomic, and rural) participant population by limiting most in-person cancer center visits to patients undergoing active treatment, increasing utilization of telehealth for rural and follow-up patients, and drastically limiting caregiver entrance to the cancer center. Therefore, we relied on self-recruited patients, who came into the cancer center for treatment, and saw our flyers. The majority of our study population was non-Hispanic white, had college degrees, and were not subjected to serious financial hardship as a result of their cancer diagnoses. It is quite possible that given the uncertainties of the pandemic, national attention to police violence against racial/ethnic minorities in the United States (i.e. Black Lives Matter), and contentious political climate, multiply-marginalized patients and caregivers simply did not feel sufficiently safe to participate in research that they may have feared would affect their cancer care. Even so, this pilot revealed relevant information about gaps in care for SGM patients and their caregivers.

5 CONCLUSIONS

This study demonstrates that prior stigmatizing experiences contribute to minority stress and medical mistrust for SGM cancer patients and their informal caregivers across cancer care encounters. Findings point to specific gaps in SGM cancer patient care, including lack of SOGI discussion, inadequate staff and oncology provider SGM specific knowledge, and insufficient SGM specific patient supports for those who lack social support during cancer care treatment. While we know that consideration of SOGI, SGM recognition, and caregiver preferences are important across all fields of healthcare, these needs are heightened with the stress of cancer diagnosis.

This study also reveals inadequacies in SGM specific support, and overall support services for informal cancer caregivers. Although there were differences between SGM and H/C experiences of cancer treatment, caregivers expressed consensus about the current lack of support and guidance for informal caregivers of cancer patients. Future work should focus on providing caregiver-specific resources in the clinic setting and facilitating support groups for caregivers to network with one another, as well as for tailoring SGM specific caregiver support services.

Overall, this study speaks to the importance of decentering normative assumptions regarding patient and caregiver SOGI, roles and needs, and degrees of social support and isolation, at an individual as well as societal level. Creating safe spaces involves open conversations with patients and caregivers regarding these issues at the outset of treatment and throughout the cancer care experience, along with creating inclusive instruments for assessing physical and mental health, especially in regards to sexual health and quality of life measures. Increasing collection of SOGI data will facilitate provision of care at an individual level and contribute to the development of inclusive initiatives at broader levels. Cancer centers need to do more to acknowledge SGM patient preferences in order to optimize care for underserved SGM cancer patients and their caregivers.

DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/supplementary material. Further inquiries can be directed to the corresponding author.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by University of New Mexico Human Research Protections Office Institutional Review Board (HRRC #20-385). The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

MKa, SJ, SR, DG, EB, and AH reviewed literature on the topic, analyzed qualitative data, and contributed to the writing of this manuscript. MKo and VP provided analysis of quantitative data and writing of the manuscript. TR, ZD, and LM contributed to writing and critical review of this manuscript. All authors contributed to the article and approved the submitted version.

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ORIGINAL RESEARCH
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LGBTQI Inclusive Cancer Care: A Discourse Analytic Study of Health Care Professional, Patient and Carer Perspectives

Jane M. Ussher[*†], *Rosalie Power*[†], *Janette Perz*, *Alexandra J. Hawkey*, *Kimberley Allison* *and on behalf of The Out with Cancer Study Team*

Translational Health Research Institute, School of Medicine, Western Sydney University, Sydney, NSW, Australia

Background: Awareness of the specific needs of LGBTQI cancer patients has led to calls for inclusivity, cultural competence, cultural safety and cultural humility in cancer care. Examination of oncology healthcare professionals' (HCP) perspectives is central to identifying barriers and facilitators to inclusive LGBTQI cancer care.

Study Aim: This study examined oncology HCPs perspectives in relation to LGBTQI cancer care, and the implications of HCP perspectives and practices for LGBTQI patients and their caregivers.

Method: 357 oncology HCPs in nursing (40%), medical (24%), allied health (19%) and leadership (11%) positions took part in a survey; 48 HCPs completed an interview. 430 LGBTQI patients, representing a range of tumor types, sexual and gender identities, age and intersex status, and 132 carers completed a survey, and 104 LGBTQI patients and 31 carers undertook an interview. Data were analysed using thematic discourse analysis.

Results: Three HCP subject positions – ways of thinking and behaving in relation to the self and LGBTQI patients – were identified:'Inclusive and reflective' practitioners characterized LGBTQI patients as potentially vulnerable and offered inclusive care, drawing on an affirmative construction of LGBTQI health. This resulted in LGBTQI patients and their carers feeling safe and respected, willing to disclose sexual orientation and gender identity (SOGI) status, and satisfied with cancer care. 'Egalitarian practitioners' drew on discourses of ethical responsibility, positioning themselves as treating all patients the same, not seeing the relevance of SOGI information. This was associated with absence of LGBTQI-specific information, patient and carer anxiety about disclosure of SOGI, feelings of invisibility, and dissatisfaction with healthcare. 'Anti-inclusive' practitioners' expressed open hostility and prejudice towards LGBTQI patients, reflecting a cultural discourse of homophobia and transphobia. This was associated with patient and carer distress, feelings of negative judgement, and exclusion of same-gender partners.

Conclusion: Derogatory views and descriptions of LGBTQI patients, and cis-normative practices need to be challenged, to ensure that HCPs offer inclusive and affirmative care.

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Hannah Arem,
George Washington University,
United States

Reviewed by:
Cathy Berkman,
Fordham University, United States
Timo O. Nieder,
University Medical Center Hamburg-Eppendorf, Germany

****Correspondence:***
Jane M. Ussher
j.ussher@westernsydney.edu.au

[†]*These authors share first authorship*

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Building HCP's communicative competence to work with LGBTQI patients needs to become an essential part of basic training and ongoing professional development. Visible indicators of LGBTQI inclusivity are essential, alongside targeted resources and information for LGBTQI people.

Keywords: cancer care, cultural competence, LGBTQI, qualitative study, discourse analysis, healthcare professionals, patients and carers

1 INTRODUCTION

Attention to the nature and impact of interactions between oncology healthcare professionals (HCPs) and lesbian, gay, bisexual, transgender (trans), queer, and intersex (LGBTQI) patients is increasing (1, 2). This follows recognition of the vulnerability and unique concerns of this underserved patient population, who have a high rate of unmet needs (3–6). LGBTQI individuals are at higher risk of cancer compared with the general population (4, 5, 7), but are less likely to engage in cancer screening or have a regular healthcare provider (8–10). More specifically, LGBTQI patients report high levels of dissatisfaction with cancer healthcare (3, 11), barriers to accessing cancer services (3), and difficulties in communication with HCPs (4, 12). This includes heteronormative assumptions on the part of HCPs, or overt HCP hostility and discrimination, leading to LGBTQI patient anxiety associated with disclosure of sexual orientation or gender identity (SOGI) (4, 12–14). The absence of LGBTQI-specific cancer information or support serves to render LGBTQI people and their carers invisible (4, 15). Unique psychosocial challenges are often not acknowledged or addressed by HCPs, including sexual concerns related to same-gender relationships (15–17), the impact of minority stress (18), absence of support from biological family (6, 19), and the specific concerns of trans and intersex individuals (20–22). As a result, many LGBTQI individuals report anxiety, isolation and frustration throughout their cancer care (3, 4), leading to higher rates of distress (20, 23, 24) and lower quality of life (18), compared with the general cancer population.

Awareness of the unmet needs of LGBTQI patients has led to calls for HCPs to be trained in the practice of inclusive and affirmative cancer care (3, 5, 6), variously described as cultural competence (2, 25–27), cultural humility (28), or cultural safety (29). Whilst these concepts were originally developed to address health inequities experienced by indigenous people (30), they are increasingly being applied to other marginalised populations (29), including LGBTQI people (31). Culturally competent healthcare involves cultural awareness, cultural knowledge and cultural skill, applied in all areas of practice, including the clinical setting, administration, policy development, and HCP education (32). The concept of cultural humility places less emphasis on acquisition of specific communication skills, focusing on the ongoing commitment of HCPs to engage in self-reflection and to addressing power imbalances implicit in patient-HCP interactions through open and empathic supportive interactions (30, 33, 34). Cultural safety focuses on creating an environment within the healthcare system that is emotionally, socially and physically safe, with no actions taken to challenge or diminish the identities of an individual (30, 35). HCPs who practice cultural safety are responsive to the personal circumstances and cultural needs of their patients and are free from bias and discrimination in a way that the patients experience as safe (30, 35). Inclusive and affirmative LGBTQI cancer care involves these three complementary concepts: cultural competence, cultural humility and cultural safety.

Consideration of oncology HCPs' perspectives is central to identifying barriers and facilitators of the provision of inclusive and affirmative LGBTQI cancer care (2). Greater knowledge of LGBTQI healthcare needs is associated with positive attitudes and intentions to offer inclusive and affirmative care for LGBTQI cancer patients (36–38). However, surveys of oncology physicians (1, 2, 37), radiation therapists (39), nurses and other advanced care professionals (36, 38, 40, 41) consistently report low levels of knowledge about LGBTQI patients. This includes lack of knowledge about cancer risk factors and psychosocial vulnerabilities specific to LGBTQI people (1, 38, 40), and feeling ill-informed about LGBTQI cancer patients' unique needs (2, 39, 42). Lack of knowledge has implications for HCP confidence and comfort in treating LGBTQI patients (1, 2, 37), with sexual health (43), fertility (44), and the needs of trans (1, 14, 45) and intersex patients (41) being areas where communication challenges are most likely. Moreover, even the majority of HCPs who report being comfortable treating LGBTQI patients in cancer care surveys (1, 2, 40, 42), report a desire for education and training (1, 36, 37, 41) focused on the needs and best ways of working with the LGBTQI population.

A number of strategies and models have been developed to raise HCPs awareness of LGBTQI patients, with the aim of improving communicative competence (4, 6, 28, 42). Such models operate on the premise that if HCPs are knowledgeable of the unique needs of LGBQTI patients with cancer, and provided with guidelines on how to communicate appropriately, they will do so. Underpinning these models and strategies is a 'one size fits all' approach, which assumes a universality of context and complexity in HCP-LGBTQI patient interactions. This does not account for HCPs often engaging in negotiating information provision and communication on a case-by-case basis, in a context that is shaped by the interaction of structural, personal and socio-cultural constraints (43). Little attention has been paid to the ways in which socio-cultural constructions of LGBTQI people, and the subject positions adopted by HCPs in relation to LGBTQI patients, inhibit or facilitate the provision of affirmative and inclusive cancer care, and the impact of HCP subject positions on patients. This is the focus of the present study.

It has been recognized that it is important to understand the "nuances of communication" that occur between HCPs and LGBTQI patients, in particular challenges in when and how to address sexual orientation and gender identity (SOGI) disclosure (14), in order to develop effective and targeted communicative competence interventions for HCPs. It is also important to be cognizant of the intersection of identities of LGBTQI patients, including age, sexual orientation, gender identity and cultural background, which may influence healthcare interactions (20). With the exception of two mixed-methods studies that included open-ended survey responses (14, 45), previous research on HCP perspectives on LGBTQI cancer care has utilized quantitative survey methods. There is a need for in-depth qualitative methods, including interviews and open-ended survey responses, to develop deeper, richly textured insight into the subject positions adopted by HCPs in relation to LGBTQI cancer care, and the implications of HCP positioning and practice for patients (43, 45). There is also a need for research that includes the perspectives of medical, nursing and allied HCPs, as well as those in leadership positions, in a range of clinical settings (37), reflecting the multidisciplinary model of care cancer (46). Most published studies to date focus on USA-based oncology physicians (1, 2, 37, 45), with a minority including oncology social workers (42), advanced healthcare practitioners (36), or nurses (38).

Research on the perspectives of LGBTQI cancer patients has identified that in the absence of visible indicators (e.g., rainbow flag) that health care settings or individual HCPs are inclusive and affirmative, many LGBTQI people fear that they will face HCP hostility and discrimination, and be offered substandard cancer care (4, 12, 13, 47, 48). Patients who experience negative HCP reactions can experience distress and disengagement with cancer care (4, 12, 13). Previous research on patient perspectives on interactions with oncology HCPs has focused on cisgender adults with breast or prostate cancer, who identify as lesbian, gay or bisexual (4, 6, 20). There is need for research that includes the perspectives of LGBTQI individuals across a wider range of cancer types, adolescents and young adults (AYAs), as well as transgender, gender diverse and intersex people with cancer (20). There is also a need to include the perspectives of partners and other caregivers, an understudied group in cancer research who report high rates of distress (49, 50). For LGBTQI people, caregiving is often provided by 'chosen family' (51), which includes intimate partners and friends (19).

The aim of the present study was to examine the construction and experience of LGBTQI cancer care from the perspective of HCPs, LGBTQI patients and their caregivers, using qualitative methods. The research questions were: What subject positions do oncology HCPs occupy in relation to the provision of care to LGBTQI people? What are the implications of HCP positions for LGBTQI patients and their caregivers?

1.1 Summary of Key Acronyms

AYA, Adolescents and young adults
HCP, Healthcare professionals
iKT, Integrated knowledge translation
LGB, Lesbian, gay and bisexual
LGBQ, Lesbian, gay, bisexual and queer
LGBT, Lesbian, gay, bisexual and transgender
LGBTQI, Lesbian, gay, bisexual, transgender, queer and/or intersex
SGM, Sexual and gender minority
SOGI, Sexual orientation and gender identity
TGD, Transgender and gender diverse

2 METHODS

2.1 Study Design

This cross-sectional study was part of a broader mixed-methods project, the 'Out with Cancer Study' (41, 52). The overall project examined LGBTQI cancer and cancer care from the perspectives of LGBTQI patients and their caregivers, and HCPs; audited Australian cancer resources for LGBTQI cultural competence and reviewed international LGBTQI cancer resources; and produced targeted LGBTQI cancer resources and healthcare professional practice guidelines (**Figure 1**). This paper presents the analysis of qualitative survey responses and interviews related to interactions between oncology HCPs with LGBTQI patients and their partners and other caregivers (carers). The survey facilitated data collection from a large group of LGBTQI individuals, including a range of sexual and gender identities, ages, and tumor types, with the interviews allowing for in-depth exploration of experiences in a selected sub-section of survey respondents (**Figure 1**).

In the study design, data collection, analysis and dissemination, we drew on principles of integrated knowledge translation (iKT), a dynamic process of collaboration between researchers and knowledge users to achieve actionable research outcomes (53). Following principles of iKT, a steering committee comprising LGBTQI people with cancer, cancer HCPs and representatives from LGBTQI health and cancer support organizations were actively involved throughout all stages of the study. Ethics approval was provided by Western Sydney University Human Research Ethics Committee (H12664). All participants provided informed consent.

2.2 Participants and Recruitment

2.2.1 Health Care Professionals

HCPs providing services to people with cancer and their carers were eligible to participate in this study. Participants were recruited through targeted advertisements on social media (e.g., Facebook, Twitter), *via* professional networks (e.g., Clinical Oncology Society of Australia, Cancer Nursing Society of Australia) and through cancer-related community organizations. We specifically targeted oncology medical practitioners, nurses, allied health professionals (e.g., social workers, psychologists, occupational and physiotherapists) and individuals working in leadership roles in cancer care, health and preventative agencies such as support group leaders, program/service managers and consumer representatives/advocates. The study procedures and quantitative survey results from HCPs have been published elsewhere (41). Briefly, a sample of 357 HCPs working with people with cancer in nursing (40%),

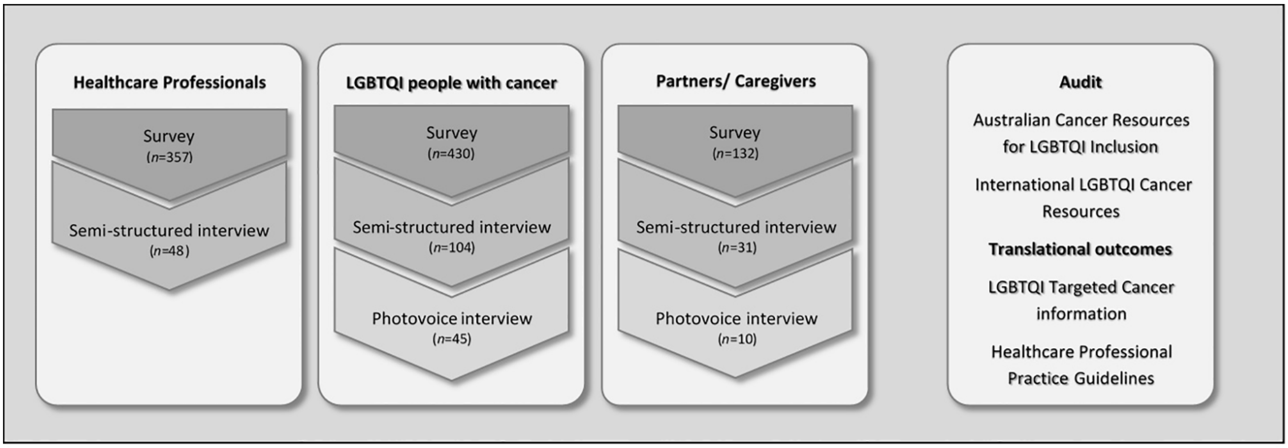

FIGURE 1 | The Out with Cancer Study overall design.

medical (24%), allied health (19%) and leadership (11%) positions, took part in an online anonymous survey. The majority (88%) were based in Australia, with a mean age of 47 (SD =10), and an average of 14 years' experience in cancer care (see **Table 1** for HCP demographics). Survey participants were invited to volunteer for a follow-up interview to examine their perspectives on LGBTQI cancer care in more detail. Of those who agreed to participate, a subset of 48 HCPs was selected, representing a range of professional backgrounds and gender identities. The one-to-one interviews lasted between 30 to 60 minutes, and were recorded. The study was open to HCPs from May 2020 to March 2021.

2.2.2 LGBTQI People With Cancer and Their Partners/Carers

A sample of 430 LGBTQI people who currently or previously had cancer (patients) with a range of tumor types and 132 partners or other caregivers (carers), aged 15 years and older, took part in an online anonymous survey, the details and results of which are published elsewhere (54). **Table 2** contains demographic details of the survey participants, by patients and carers. The majority of patients were living in Australia (72.3%), Caucasian (85.2%), and identified themselves as lesbian, gay or homosexual (73.7%), with 10.9% identifying as bisexual, and 10.5% as queer. Greater diversity was evident in participants' gender identities: 50.2% were cis women, 33.7% cis men, 16.1%

TABLE 1 | Sociodemographic and Professional Characteristics of Participating Health Care Professionals.

Demographic/Professional characteristic	Survey participants	Interview participants
	M (SD), range	*M (SD)*, range
Age (years) (n = 356)	47.29 (12.45), 22-82	45.94 (13.04), 24-68
Time working in cancer care (years) (n = 303)	14.31 (10.21), 0.33-45	13.15 (9.89), 0.50-40
	n (%)	*n* (%)
Gender (n = 357)		
Female	278 (77.9%)	36 (75.0%)
Male	76 (21.3%)	12 (25.0%)
Non-binary	3 (0.8%)	0
Ethnicity (n = 352)		
Caucasian	305 (85.4%)	42 (87.5%)
Asian	22 (6.2%)	2 (4.2%)
Middle Eastern/African	6 (1.7%)	3 (6.3%)
Mixed background	8 (2.2%)	1 (2.1%)
Other/unclear background[1]	11 (3.1%)	0
LGBTQI+ themselves (n = 328)		
Yes	60 (18.3%)	18 (37.5%)
No	264 (80.5%)	30 (62.5%)
Prefer not to answer	4 (1.2%)	0
Has LGBTQI+ family (n = 328)		
Yes	135 (41.2%)	25 (52.1%)

(Continued)

TABLE 1 | Continued

Demographic/Professional characteristic	Survey participants *M (SD)*, range	Interview participants *M (SD)*, range
No	191 (53.5%)	22 (45.8%)
Prefer not to answer	2 (0.6%)	1 (2.1%)
Has LGBTQI+ friend/s (n = 328)		
Yes	300 (91.5%)	47 (97.9%)
No	28 (7.8%)	1 (2.1%)
Country (n = 357)		
Australia	315 (88.2%)	44 (91.7%)
United States of America	17 (4.8%)	0
United Kingdom	10 (2.8%)	3 (6.3%)
New Zealand	5 (1.4%)	0
Canada	3 (0.8%)	1 (2.1%)
Other	7 (2.0%)	0
Professional discipline (n = 356)		
Medical	87 (24.4%)	12 (25.0%)
Nursing	142 (39.9%)	15 (31.3%)
Allied health	69 (19.4%)	15 (31.3%)
Leadership	38 (10.7%)	4 (8.3%)
Other[2]	20 (5.6%)	2 (4.2%)
Workplace location (n = 355)		
Urban	247 (69.2%)	38 (79.2%)
Regional	85 (26.6%)	9 (18.8%)
Rural	9 (2.5%)	1 (2.1%)
Remote	4 (1.1%)	0
Healthcare sector*		
Public	230 (64.4%)	29 (60.4%)
Private	72 (20.2%)	10 (20.8%)
Primary healthcare	9 (2.5%)	0
Community-based	11 (3.1%)	2 (4.2%)
Not for profit	88 (24.6%)	16 (33.3%)
Something else	24 (6.7%)	2 (4.2%)
Number of patients seen per week (n = 318)		
0-25	189 (59.4%)	23 (48.9%)
26-50	75 (23.6%)	12 (25.5%)
51-75	29 (8.1%)	9 (19.1%)
76+	25 (7.9%)	3 (6.4%)
Age groups seen* (n = 320)		
Paediatric	17 (5.3%)	1 (2.1%)
Adolescent and young adult	86 (26.9%)	18 (38.3%)
Adult	279 (87.2%)	39 (83.0%)
Older adult/elderly	177 (55.3%)	29 (61.7%)
Estimated proportion of patients who are LGBTQI+ (n = 317)		
None	29 (9.1%)	0
<5%	154 (48.6%)	24 (51.1%)
6-10%	58 (18.3%)	13 (27.7%)
11-15%	10 (3.2%)	1 (2.1%)
16-20%	4 (1.3%)	0
> 20%	2 (0.6%)	2 (4.3%)
Unsure	57 (18.0%)	7 (14.9%)
N/A	3 (0.9%)	0
Had formal education about healthcare needs of…* (n = 355)		
Sexuality diverse people	96 (27.0%)	23 (47.9%)
Trans and gender diverse people	74 (20.8%)	18 (37.5%)
People born with an intersex variation	52 (14.6%)	11 (22.9%)

**Participants could select multiple options for questions about healthcare sector, age groups seen, and LGBTQI healthcare training.*

[1] Ethnicity Other/unclear background: Latin American (n = 4), Jewish (n = 3), Aboriginal (n = 1), not clearly described (n = 3).

[2] Professional background - Other: Research (n = 7), administration (n = 3), dentistry (n = 1), paralegal (n = 1), education/training (n = 1), none/retired (n = 7).

TGD. Thirty-one (7.2%) participants reported intersex variation. The average patient age was 52.5 years (SD 15.7), with 22% in the AYA age-group (age 16-39).

Survey participants were invited to take part in an interview for the purpose of understanding their experiences in greater depth. A subset of 104 LGBTQI patients and 31 partners/carers, representing a cross-section of participants in gender, sexuality, age and tumor type, completed a 60-minute interview. **Table 3** provides a demographic breakdown of interview participants, by gender, sexuality and intersex status. The study was open

TABLE 2 | Demographic and cancer characteristics of LGBTQI patients and carers - Survey Participants.

Demographic/Cancer Characteristic	**Patient Survey**		**Carer Survey**			
	Patients		**Carers**		**Patients carer for by carers[1]**	
	N	***M (SD)*, range**	***N***	***M (SD)*, range**	***N***	***M (SD)*, range**
Age at time of study (years)	429	52.5 (15.7), 16-92	132	50.2 (17.0), 15-76	–	–
Age at diagnosis (years)	363	46.3 (15.3), 1-79	126	42.8 (16.6), 0-70	120	50.3 (15.6), 1-92
	N	*n* (%)	*N*	*n* (%)	*N*	*n* (%)
Country	430		132		–	–
Australia		311 (72.3%)		93 (70.5%)		
United States of America		62 (14.4%)		14 (10.6%)		
United Kingdom		29 (6.7%)		9 (6.8%)		
New Zealand		8 (1.9%)		6 (4.5%)		
Canada		7 (1.6%)		4 (3.0%)		
Other		13 (3.0%)[2]		6 (3.6%)[3]		
Gender	430		132		132	
Cis female		216 (50.2%)		83 (62.9%)		90 (68.2%)
Cis male		145 (33.7%)		26 (19.7%)		36 (27.3%)
Non-binary		34 (7.9%)		16 (12.1%)		2 (1.5%)
Trans female		13 (3.0%)		5 (3.8%)		1 (0.8%)
Trans male		8 (1.9%)		2 (1.5%)		0
Different or multiple identities		14 (3.3%)[4]		0		3 (2.3%)
Sexuality	430		132		131	
Lesbian, gay or homosexual		317 (73.7%)		95 (72.0%)		81 (61.8%)
Bisexual or pansexual		47 (10.9%)		17 (12.9%)		5 (3.8%)
Queer		45 (10.5%)		12 (9.1%)		5 (3.8%)
Straight or heterosexual		10 (2.3%)		5 (3.8%)		33 (25.2%)
Different or multiple identities		11 (2.6%)		3 (2.3%)		1 (0.8%)
Not sure		–		–		6 (4.6%)
Intersex variation	430		132		132	
Yes		31 (7.2%)		5 (3.8%)		0
No		388 (90.2%)		127 (96.2%)		127 (96.2%)
Prefer not to answer		11 (2.6%)		0		0
Not sure		–		–		5 (3.8%)
Race/ethnicity	425		132		–	–
Caucasian		362 (85.2%)		109 (82.6%)		
Asian		11 (2.6%)		5 (3.8%)		
Australian Aboriginal, Torres Strait Islander or Maori		9 (2.1%)		4 (3.0%)		
Mixed background		19 (4.5%)		6 (4.5%)		
Other/unclear background		24 (5.6%)[5]		8 (6.1%)[6]		
Education	422		131		–	–
Less than secondary		10 (2.4%)		7 (5.3%)		
Secondary		45 (10.7%)		17 (13.0%)		
Some post-secondary		55 (13.0%)		9 (6.9%)		
Post-secondary		312 (73.9%)		98 (74.8%)		
Location	429		132		–	–
Urban		234 (54.5%)		69 (52.3%)		
Regional		145 (33.8%)		48 (36.4%)		
Rural or remote		50 (11.7%)		15 (11.4%)		
Relationship to PWC	–	–	132		–	–
Partner/ex-partner				84 (63.6%)		
Family				31 (23.5%)		
Friend				12 (9.1%)		
Different relationship				3 (2.3%)		
Multiple PWCs/relationships				2 (1.5%)		
Cancer diagnosis (first)	370		–	–	129	
Brain		11 (3.0%)				9 (7.0%)
Breast		90 (24.3%)				37 (28.7%)
Cervical		11 (3.0%)				4 (3.1%)
Colorectal		17 (4.6%)				8 (6.2%)
Head/neck		14 (3.8%)				10 (7.8%)
Leukaemia		17 (4.6%)				5 (3.9%)
Lymphoma		24 (6.5%)				6 (4.7%)
Ovarian		17 (4.6%)				13 (10.1%)
Prostate		59 (15.9%)				8 (6.2%)

(Continued)

TABLE 2 | Continued

Demographic/Cancer Characteristic	Patient Survey		Carer Survey			
	Patients		Carers		Patients carer for by carers[1]	
	N	*M (SD)*, range	*N*	*M (SD)*, range	*N*	*M (SD)*, range
Skin		25 (6.8%)				3 (2.3%)
Uterine		23 (6.2%)				4 (3.1%)
Other		58 (15.7%)[7]				19 (14.7%)[8]
Not sure or unknown		4 (1.1%)				3 (2.3%)
Cancer stage	369		–	–	129	
Localised		228 (61.8%)				55 (42.6%)
Regional		88 (23.8%)				43 (33.3%)
Distant/metastatic		32 (8.7%)				23 (17.8%)
N/A (e.g. blood cancer)		5 (1.4%)				1 (0.8%)
Not sure or unclear		16 (4.3%)				7 (5.4%)
Subsequent cancers*	370		–	–	129	
Recurrence		57 (15.4%)				30 (23.3%)
New primary cancer		40 (10.8%)				20 (15.5%)
Treatment status	370		–	–	129	
No treatment yet		37 (10.0%)				5 (3.9%)
On active curative treatment		37 (10.0%)				14 (10.9%)
On maintenance treatment		60 (16.2%)				19 (14.7%)
In remission/completed treatment		217 (58.6%)				35 (27.1%)
Receiving palliative care (no further active reatment)		4 (1.1%)				2 (1.6%)
Deceased		–				51 (39.5%)
Not sure, unclear, or multiple		8 (2.2%)				3 (2.3%)

[1] Key demographic and cancer characteristics of the patients who carers cared for.
[2] Austria (n=4), Bahrain, Chad, Costa Rica, Denmark, Germany, Morocco, Poland, Russian Federation, Serbia (n=1 each).
[3] Belize (n=2), Argentina, Lebanon, Germany, Uganda (n=1 each).
[4] Intersex (n=4), female with fleeting genderfluid moments, intersex woman, intersex nonbinary woman, female but questioning, trans (n=1 each).
[5] Jewish (n = 9), Hispanic/Latine (n = 4), Middle Eastern, Native American, Romani (n=1 each), not clearly described (n = 8).
[6] Hispanic/Latine, Jewish (n = 2 each), African, Native American (n=1 each), not clearly described (n = 2).
[7] Sarcoma (n=9), kidney, testicular (n=8 each), bladder, thyroid (n=6 each), lung (n=5) anal, pancreatic (n=4 each), liver (n=2), something else (n=6).
[8] Lung (n=7), bladder, liver, pancreatic (n=2 each), kidney, mesothelioma, pseudo myxoma perotini, sarcoma, stomach, thymus (n=1 each).
**Participants could selected multiple options, if applicable.*

TABLE 3 | LGBTQI patient and carer interview participants by sexuality, gender and intersex status.

	Patient n,%	Carer n,%
Gender		
Cis female	48 (46.2%)	18 (58.1%)
Cis male	42 (40.4%)	6 (19.4%)
TGD	11 (10.6%)	6 (19.4%)
Different identity	3 (2.9%)	1 (3.2%)
Sexuality		
Lesbian, gay or homosexual	86 (82.7%)	19 (61.3%)
Bisexual	5 (4.8%)	3 (9.7%)
Queer	9 (8.7%)	6 (19.4%)
Straight or heterosexual	1 (1.0%)	0 (0.0%)
Different or multiple identities	3 (2.9%)	3 (9.7%)
Intersex variation		
Yes	3 (2.9%)	1 (3.2%)
No	100 (96.2%)	29 (93.5%)
Prefer not to answer	1 (1.0%)	1 (3.2%)

TGD, trans and gender diverse.

internationally, although recruitment focused on Australia and other English-speaking countries such as the USA, UK, New Zealand and Canada. Participants were recruited through social media (e.g., Facebook, Twitter, Instagram), cancer and LGBTQI community organizations (including the study partner organizations), cancer research databases (e.g., Register 4, ANZUP), LGBTQI community events (e.g., Sydney Gay and Lesbian Mardi Gras) and cancer support groups. The study was open to LGBTQI patients and their partners/carers from September 2019 to September 2021.

2.3 Measures

2.3.1 Qualitative Survey Items

The HCP survey (41) assessed attitudes toward LGBTQI cancer care, knowledge of LGBTQI health needs and LGBTQI inclusive practice behaviors. At the end of each section, HCP participants were asked to provide written responses to the open-ended question, "is there anything you would like to tell us about your answers to these questions?". The LGBTQI patient survey assessed demographics, minority stress, disclosure, satisfaction with care, health literacy, end of life care issues, social support and relationships and sexual, physical and emotional wellbeing [described in (54)]. The carer survey assessed the same items, with the addition of items about caregiving experiences. At the end of most quantitative items, LGBTQI patients and partners/carers were asked to provide written responses to the open-ended question, "is there anything you would like to tell us about this issue?", with responses ranging from one sentence to 15 sentences, with an average of 2 sentences. This paper focuses on qualitative responses to items on HCP interactions and the provision of cancer care, across participant groups.

2.3.2 Semi-Structured Interviews

Semi-structured interviews with HCPs, LGBTQI patients and carers were completed over the telephone or online using videoconferencing software, depending on the preference of the participant. All interviews were audio-recorded and transcribed verbatum. Healthcare professionals were asked about their experiences providing care for LGBTQI patients, including how they identified LGBTQI patients, how well their workplaces were meeting the needs of LGBTQI patients and carers, and what they considered were important issues for LGBTQI patients and carers. LGBTQI patients and carers were asked about their experiences of cancer care, including interactions with HCPs, decision-making pertaining to disclosure of their LGBTQI status and the consequences of this for their cancer care; the impact of cancer on their lives, including on their identities; relationships and sexual wellbeing; support networks and experiences of finding information as an LGBTQI cancer patient. This paper focuses on HCP interactions and disclosure of LGBTQI status in cancer care.

2.4 Data Analysis and Theoretical Framework

Thematic discourse analysis or decomposition (55–57) was used to examine the qualitative survey responses and interviews. This analytic technique combines post-structuralist discursive approaches (58, 59) with thematic analysis (60), informed by the notion that meanings are socially formed through discourse (61). In this context, discourse refers to a 'set of statements that cohere around common meanings and values… (that) are a product of social factors, powers and practices, rather than an individual's set of ideas' [(62), p.231]. Discourse analysis focuses on the subject positions that are taken up in talk, and their consequences in interactions for the self and others, including the way someone speaks or is spoken to, how a speaker describes herself and others, and the broader social discourse that a speaker draws upon (63, 64). Once a person takes up a particular subject position, they see the world from the vantage point of that position, influenced by the "particular images, metaphors, storylines and concepts which are made relevant within the particular discursive practice in which they are positioned" (61). Subject positions are not fixed, and are not properties of the individual, which means that participants may adopt more than one subject position, or move between subject positions (61). The possibility of choice is implicitly present, because there are many potentially contradictory discursive practices in which each person could engage (61).

The focus of analysis in this paper is on the subject positions made available to oncology HCPs through discourse and the implications of these subject positions for LGBTQI patients and carers. The analysis was conducted using an inductive approach, with the development of discursive themes and identification of subject positions being data driven, rather than based on pre-existing research on HCP interactions with LGBTQI cancer patients and carers. HCP, patient and carer interviews were transcribed, verified for accuracy by reading the transcripts while listening to the audio-recording and then de-identified by replacing participant names with pseudonyms. Through a collaborative process with stakeholder committee members, a subset of interviews for HCPs, patients and carers were independently read and re-read to identify first-order codes within the HCP and patient/carer data sets that represented commonality across accounts, such as 'lack of knowledge', 'discrimination' (HCPs) 'feeling unsafe', 'difficulties in communication' (patients/carers). Each team member brought suggestions of the first order codes to the meeting and the final coding frames for HCPs and patients/carers were devised through a process of consensus. This included codes such as 'culturally safe care, services and support', 'barriers to providing good LGBTQI care', 'experiences with LGBTQ patients and carers' (HCPs); and 'disclosure of identity', 'positive/negative interactions with HCPs' (patients/carers). Open-ended survey and interview data were coded by four members of the research team using NVivo. Consistency in coding across codes and coders was checked by a senior member of the team. Coded data were read through and summarized in a tabular format to facilitate identification of commonalities in the data. The codes were then re-organized and grouped into discursive themes focused on subject positions adopted by HCPs in relation to LGBTQI cancer care and the implications of these subject positions for patients and carers. Themes were then refined through discussion, reorganized and, when consensus was reached, final themes and sub-themes developed. Throughout, the analysis was informed by an intersectional theoretical framework. This acknowledges the interaction and mutually constitutive nature of gender, sexual identity, age and other categories of difference in individual lives and social practices, and the association of these arrangements with health and wellbeing (65).

3 RESULTS

Three subject positions adopted by HCPs were identified (**Figure 2**): Inclusive and Reflective practitioner; Egalitarian

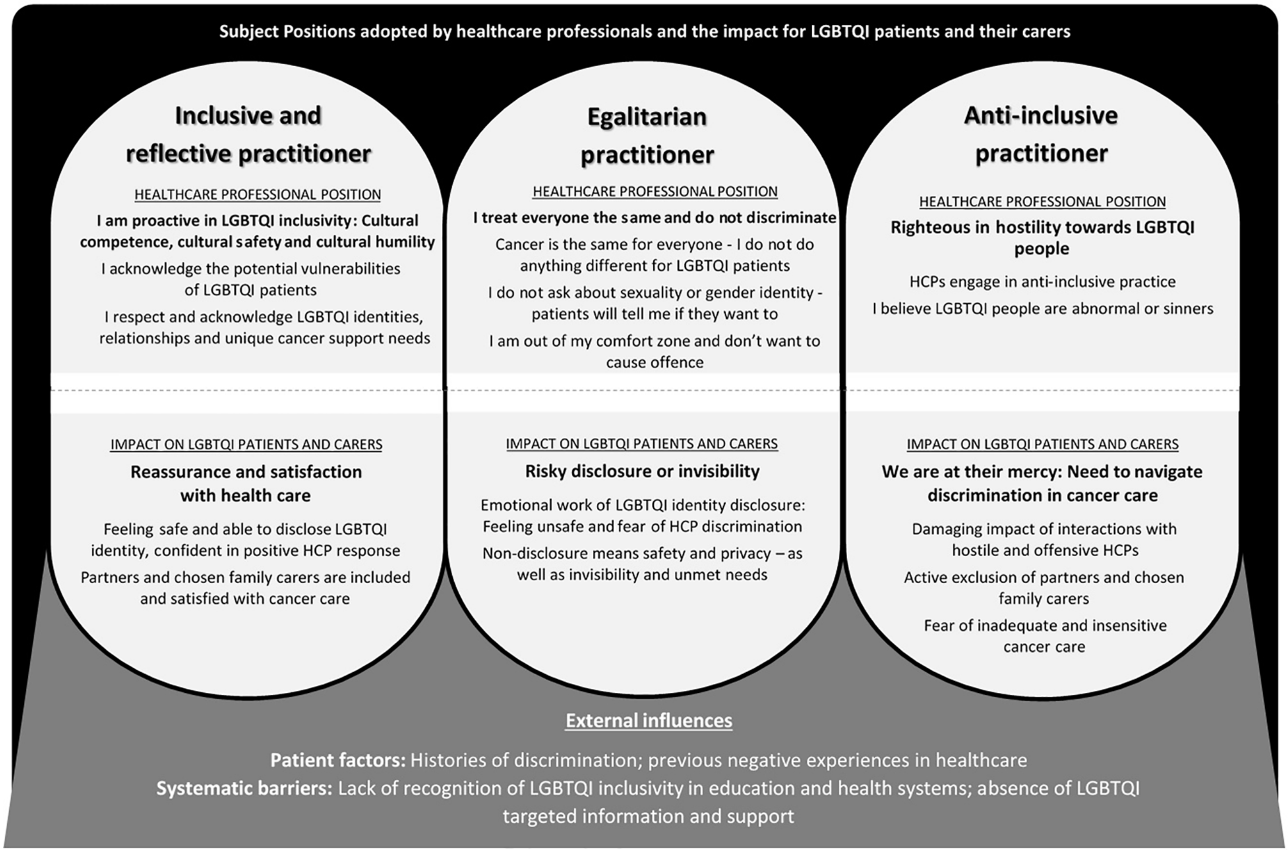

FIGURE 2 | Subject Positions Adopted by Health Care Professionals and the Impact for LGBTQI Patients and their Carers.

practitioner; and Anti-Inclusive practitioner. HCPs adopted these subject positions across the range of professional backgrounds, gender, sexual orientation and age groups. A number of HCPs adopted more than one subject position, with adoption of the Inclusive and Reflective Practitioner in some contexts and the Egalitarian Practitioner in others, identified. Each subject position had direct consequences for the positioning and experiences of LGBTQI patients and their carers (**Figure 2**).

In the presentation of results below, we outline each HCP subject position, followed by the patient and carer accounts of interactions with HCPs who adopted this subject position. Key demographic details are provided for longer quotes; Med= medical practitioner, Allied = allied health worker. LGBTQI patients and carers are identified by pseudonyms (interview participants) or "survey", with demographic details of age, SOGI and intersex status, and cancer type provided for longer quotes (medical intervention = intervention to prevent cancer). In the patient/carer sections, participants who are carers are identified as such; all other quotes are from patients. For readability, demographic details for HCP and LGBTQI patient/carer short quotes are provided in **Table 4**, alongside a longer version of the quote for readability.

3.1 Inclusive and Reflective Practitioner

3.1.1 "I am Proactive in LGBTQI Inclusivity": HCPs Practice Cultural Competence, Cultural Safety and Cultural Humility

3.1.1.1 "A Legacy of Trauma": HCPs Acknowledge the Potential Vulnerabilities of LGBTQI Patients

HCPs who adopted a position of inclusive and reflective practice demonstrated cultural competence, proactively creating a place of cultural safety for LGBTQI patients and their partners through practicing cultural humility. The starting point was HCP awareness of the need to "differentiate between people depending on what their sexuality or their gender is" and being open to "change the way we care for people" [Izzie, Allied, 28, Straight], based on this knowledge. Cultural humility also involved HCPs acknowledging the potential vulnerability of LGBTQI people, who may need "more care" because of "extra mental health factors" resulting from "societal discrimination" and potential difficulties in "coming out to family", or the "potential trauma involved in transitioning" [Amy, Nurse, 55, Lesbian]. HCP recognition of the "legacy of trauma" within healthcare contexts was also evident. This included a "legacy of fear" that LGBTQI identity is "not going to be recognized" or that partners will be excluded by HCPs. As a medical HCP commented:

TABLE 4 | Additional Quotes from Health Care Professionals, and LGBTQI Patients and Carers.

Inclusive and Reflective Practitioner
I am Proactive in LGBTQI Inclusivity: HCPs Practice Cultural Competence, Safety and Humility.
As a gender-diverse and queer person, when I go in, I don't make those assumptions about my patients and when they talk about like, I'll refer to their spouse or their partner, I don't put those assumptions on them. And I think that makes queer patients a lot more comfortable because they don't feel like they have to have the awkward correctional coming out. [Lane, Clinical Trials coordinator, 26, Queer, Non-binary] (1)#
They need to feel welcomed, they need to be able to feel that they can come out in health care without having to struggle over all these barriers. [Emily, Allied, 54, Lesbian] (2)
Establishing early contact and building report early and creating a safe space and thinking about hetero normative language is really important for AYAs. [Natasha, Allied, 30, Lesbian] (3)
To be seen by the health practitioner is really important. An aspect of respect, I think, is to respect people's terminology and self-identification. Another aspect is really respecting and making the relationship or relationships visible. [Suzanne, Med, 40, Queer] (4)
If somebody is trans and they've grown out their hair, are they going to feel like they've taken a step backwards or something if they lose their hair? [Amelia, Nurse, 35, Lesbian] (5)
They would be having a different experience of it, because when we talk patients we talk about the impact it's had on their body and also their sense of identity. And things like, weight loss or weight gain, it can very much impact on body image and identity for gay men. [Lexie, Allied, 27, Straight] (6)
This diversity of information should be considered mainstream and the norm rather than an exception to routine practice. For example, being able to give advice to a gay/bisexual man about factors influencing PSA testing, safe timing and approaches to resumption of anal sex after prostate radiotherapy [Survey, Allied, 62, Straight] (7)
The majority of our staff talk about using condoms for intercourse and don't divulge into, you know, what about other types of barrier protection that's not heterosexual penetrative sex, that doesn't just focus on using a condom. [Jessica, Nurse, 38, Straight] (8)
I ask questions explicitly- that will tend to be how it will come up, if somebody has a same-sex partner, then it comes out that way in talking about what their support networks are. […] So for me, it will come up whenever I get into sort of discussion about who somebody has in their life, who's going to support them through their cancer diagnosis. [Brett, Med, 37, Gay] (9)
It's essential that everybody assiduously takes note of the preferred gender pronouns and doesn't dead name them. To be aware that sometimes the name in the medical notes is not the preferred name. And if you don't know, ask, you know. [Suzanne, Med, 40, Queer] (10)
It's quite daunting, for every patient but particularly for LGBTQI patients. Those kinds of things, like a poster or sticker or whatever it is, I think they make like a big difference for the communities. [Belinda, Med, 44, Lesbian] (11)
Reassurance and Satisfaction with Health Care: LGBTQI Patient and Carer Perspectives on Inclusive and Reflective Practice
Of my cancer-care doctors, my sexuality has mainly been treated as a non-issue. My GP is a gay man so it is openly discussed. My surgeon was welcoming to anyone I brought with me to appointments including my female partner. [Survey, 39, Queer, Breast] (12)
The nurses always refer to me as my kids mom and they even went out of their way to say to my kids, what's this mum called and what do you call that mom. They interacted positively with my children, with my partner and with me. [Virginia, 48, Lesbian, Lymphoma] (13)
Because we live in a rural, small town area, where everyone knows everyone - I think we experience little discrimination, it helps with being respected. [Survey, Partner, 57, Lesbian, Lung] (14)
There was no sign of [HCP] discomfort or not knowing how to handle it. I felt at ease being there as his same sex partner. And they respected our relationship and didn't have any issues whatsoever. [Nathan, Partner, 50, Gay, Head/Neck] (15)
Egalitarian Practitioner
"I treat everyone the same and am not biased in any way": HCPs Self-Position as Egalitarian Practitioners
I don't tailor the care, because I don't want to be like, oh, you're a lesbian couple, come here and I'll do all this fancy stuff with you. I guess I try to treat everyone the same" [Naomi, Allied, 28, Straight] (16)
I don't take a lot of time to say, 'so is your partner male or female?' I don't know whether or not that's an important thing to do. I think that people that want to tell you and feel comfortable with you will tell you. [Belinda, Med, 44, Lesbian] (17)
I would be asking about some of these social networks, you know, who's in their life? Do you have a partner? That's very often how they're going to get through. It becomes very much patient led, so the patient can tell you about whatever they want to, if they wish, or not, disclose or whatever. [Brett, Med, 37, Gay] (18)
I let them lead the conversation a little bit. I'd have it if they were prepared to. I don't have any problems talking about anything that anybody wants to talk about, but probably my confidence in initiating those conversations would be low because I don't know enough about it. [Jessica, Nurse, 38, Straight] (19)
Risky Disclosure or Invisibility: Patient Perspectives on Egalitarian Practitioners
I think it's really the vibes that they give off. You can't really pin it to one sort of thing. I think if they're sort of open, if they're seeming open and interested in how your life is then that's a bit of an opening and then you explore a bit and sort of see how they react to other sort of lifestyle things. [Aaron, 32, Gay, Bowel] (20)
You're constantly having to decide whether it's worth disclosing to this person, and whether that cost-benefit ratio of how much privacy you have to give up for your care is actually going to pay off. [Dylan, 32, Gay, Non-binary, Leukaemia] (21)
It's nobody's business what I do in my private life. I would have to have an enormous amount of trust in them. So, I won't share none of it with no one. Of course, they are not stupid, they can guess all they want. [Survey, 67, Gay, Head/Neck] (22)
There wasn't anything specific to same gender couples. There might have been one page out of the whole resource, out of the whole collection of resources. [Cameron, Partner, 38, Queer, Non-binary, Breast] (23)
Anti-inclusive or exclusionary practice
Righteous in Hostility: HCP Engagement in Anti-inclusive Practice
I've heard nurses say, well, I'm entitled to my beliefs that homosexuality is wrong. [Amy, Nurse, 55, Lesbian] (24)
There's no way anyone is going to openly discriminate or be openly prejudiced. And so those acts are a lot more insidious and subtle. The clinicians will say, oh, no, we do everything great, when in fact they don't because if you ask the patients, they'll say, no, they don't. [Jodi, Allied, 39, Lesbian] (25)
"You are at their mercy": LGBTQI Patients and Carers Navigate Anti-inclusive Cancer Care
I thought that maybe he was just having an off day. But it turns out it wasn't, he was just a homophobic jerk. He clearly read me as a lesbian and he was dismissive of me as a person, It felt like I was being treated like a lesser person. And that judgment was based on his belief system. [Jasper, 50, Queer, Breast] (26)
That kind of discrimination that is just so constant and covert and daily that it gradually chips away at your confidence and sense of self-worth. [Jessie, 37, Queer, Non-binary/Gender-fluid, Medical Intervention] (27)

(Continued)

TABLE 4 | Continued

Inclusive and Reflective Practitioner
At times it felt like medical professionals were reluctant to provide me with any information, and treated me lesser than because I was not a heterosexual white individual. [Survey, Carer, 40, Queer, Non-binary/gender-fluid, Bowel] (28)
You just get that look or that raised eyebrow, or you don't get referred to properly. I reckon about two out of every ten professionals that we've had to deal with, have been a little bit uncomfortable or a little bit weird about it. [Barry, Partner, 56, Gay, Lung] (29)
A couple of times doctors have questioned whether my partner has other family even though I am listed as next of kin on the paperwork. I have found this to be a bit insensitive and it feels like they are looking for more legitimate people to engage with. [Survey, Partner, 39, Lesbian, Brain] (30)
I had difficulty engaging various healthcare professionals because of my presentation as non-binary/trans. I often felt mainstream services did not willingly provide me with the support I needed. So I chose to present as female and made a point to shave off facial hair and present as more feminine. [Survey, Carer, 40, Queer, Non-binary/Gender-fluid, Bowel] (31)
I suspect that the underlying issue with why I would be mis-diagnosed with anxiety might just be that people think gay people are overdramatic or maybe hypochondriacs or something. I certainly wasn't taken seriously. [Noah, 44, Gay, Lymphoma] (32)
I've had operations where I've had no pain relief afterwards because the nurse doesn't like trans people. When you're on over the night shift and she's locked your mobile phone in the safe so you can't call anyone and denied you your drugs. I mean, that's what we're talking about with abuse and that's what bad treatments like and that's what having someone with you stops. [Scott, 55, Trans man, Gay, Multiple] (33)

 # numbers are linked to short quotes cited in the results.

> There's a legacy of fear within the queer community that you, as a queer person and your queer partner in a queer relationship, are not going to be recognized, and so if something takes a turn for the worse, in terms of somebody's health, that the partner will be locked out of the room because they're not officially married, and people fear that. [Suzanne, Med, 40, Queer]

Services could also be "scary" for "people who are intersex" and have had "medical interventions done to you", meaning that interactions with HCPs in the context of cancer "could be a triggering thing" [Lexie, Allied, 27, Straight].

Inclusive and reflective practitioners recognized "barriers" to patient disclosure of LGBTQI identity within a cis-heteronormative healthcare context. For example, it was recognized that individuals "in that vulnerable situation" have to "go through hoops" and be "brave enough to speak up not knowing what the response is going to be" if they chose to disclose their LGBTQI identity, often having to correct the heteronormative "assumptions" of HCPs [Emily, Allied, 54, Lesbian]. For some HCPs, self-reflection as a "queer person"[1] precipitated this awareness; for others it was from having LGBTQI friends or family, hearing a "talk at a conference", or "doing my own research". Interactions with LGBTQI patients could also result in a moment of enlightenment. For example, one HCP said, "it just really hit me, that it shouldn't be this way" when a gay male patient "was more worried what I would think about him having a same-sex partner, than actually that he had cancer" [Patrick, Med, 57, Straight].

3.1.1.2 "Non-Judgmental Communication and Support": HCPs Respect and Acknowledge of LGBTQI Identities, Relationships and Unique Cancer Support Needs

HCPs who adopted a position of inclusive and reflective practice endeavored to ensure LGBTQI patients and their partners felt "welcomed"[2] and "safe"[3] by facilitating supportive healthcare interactions within a model of person centred care. Actively demonstrating openness, understanding, respect and acceptance of LGBTQI identities and relationships without a sense of superiority were key attributes of this practice. This reflected an understanding among HCPs that "it's actually more important to understand and respect who [patients] are before we start telling them what they should or shouldn't do" [Ayomi, Med, 35, Straight]. Central to inclusive practice was respect for "people's terminology and self-identification" as well as "really respecting and making their relationship or relationships visible"[4]. Understanding and respect were central to "collaborative decision-making and engagement of our patients", manifested through "non-judgmental communication and support" and "meeting people where they are at", rather than "pigeon-holing them in a certain place" [Paula, Program manager, 59, Lesbian].

Sensitivity to the unique meaning of treatment-induced changes for LGBTQI people was part of inclusive practice. This might include the impact of hair loss on "somebody who is trans and they've grown out their hair"[5], "weight loss or weight gain on body image and identity for gay men"[6], the need for information about the "resumption of anal sex after prostate radiotherapy"[7], or safe sex information that "doesn't focus on using a condom"[8] for lesbian couples. Absence of support networks of some LGBTQI people was also acknowledged: "when you're looking at an age group of gay men in their 50s and 60s. Life has been difficult for them. Often, they don't have any family support. They rely on friends for their support" [Cindy, Nurse, 58, Straight]. However, at the same time, not "making assumptions" about the impact of cancer in an individual patient and a willingness to discuss patient needs and concerns were central to inclusive care.

> It depends on the individual. If it's important to them, I think it's important that they know it's a platform they are welcome to talk about it. And that's why I think we need to have an environment that's very welcoming, but not assume that everybody wants to declare everything all the time. [Melanie, Nurse, 50, Straight]

A cornerstone of inclusive and reflective practice was acknowledgement that it was the responsibility of HCPs to facilitate LGBTQI identity disclosure actively at first meetings with patients, through avoiding cis-heteronormative language and assumptions, "bringing things up proactively" [Russell, Med, 42, Gay]. This could be done through asking questions about "support networks" and "who somebody has in their life, who's going to support them through their cancer diagnosis"[9]. This then gives the HCP the opportunity to acknowledge the patient's SOGI status.

> I will ask exploring questions around a partner, who's caring for you, who's around, who are your supports. And often that sort of open question, to just invite them to describe a bit more, enables them to say, "well, it's my partner and she is". And that sort of gives me the opportunity then to acknowledge that they're same sex attracted [Alison, Allied, 66, Straight].

Directly addressing the question of gender identity by saying to a patient "I'm just going to ask you a few questions about sexuality and gender. And I was just wondering, you know, how do you identify?" can also serve to "provide the space" to allow people to "make the decision themselves as to how much they want to share with you" [Brooke, Nurse, 30, Straight] as a trans or non-binary person.

Respectful reflective practice includes recognition that it is important "to be aware that sometimes the name in the medical notes is not the preferred name" of trans and non-binary patients. This meant it was important "to be very sure, to never dead name them"[10] [use the name given at birth, before gender affirmation]. If a HCP is unsure about terminology, the identity label, or the name a patient prefers to use, the solution was to "ask them" rather than worrying about "getting pronouns correct". Avoiding incorrect heteronormative assumptions about the support person of a patient is also important. One HCP said "over the years I've found you can make judgments thinking it's a brother, but it's a partner or even a father" and thus the solution was to "ask them who they have come with today and often they'll say, oh, this is my partner. We've been together X number of years" [Cindy, Nurse, 58, Straight].

Many HCPs recognized the positive impact of affirmative and inclusive practice on patients in a context where they might be expecting to experience prejudice or discrimination. One medical practitioner who welcomed a male patient's male partner said, "it was almost like a wall of ice just broke. He [the patient] actually became teary almost of, like of relief" [Patrick, Med, 57, Straight]. A lesbian patient's wife was described as initially "very defensive of their relationship and her place of next of kin" because of "backlash" at a previous religious hospital, but became "much calmer" once she was "aware that we [the HCPs] took her position as the patient's partner and main support person seriously" [Survey, Nurse, 27, Straight]. Affirmative and reflective practitioners spent the time "establishing a relationship and letting them [LGBTQI patients] feel that they can talk to you if they want to", knowing that "over time they tell you all sorts of things" if they feel "safe" [Cindy, Nurse, 58, Straight].

Most HCPs who adopted a position of inclusive and reflective practitioners accepted that it was the responsibility of HCPs to "do the work" to understand the evolving language and terms associated with SOGI identities, and "sit with" their own "discomfort", if they were unsure about how to interact with LGBTQI patients, reflecting cultural safety and humility.

> I think it should sit with us to do our own work to understand the history, to stay abreast of all the evolving language and terms. I think the discomfort as clinicians, we have to be the ones to sit with that. It should not be patients or their families who are feeling like they can't either disclose important information for their care. And I think as individuals we need to figure out how we can provide better care and more equitable care across all of our patients and keep learning and pushing those agendas through our own teams and organizations [Brooke, Nurse, 30, Straight]

Inclusive and reflective HCPs acknowledged gaps in their own knowledge and confidence, with many commenting on the need for training and communication in addressing the needs of trans and intersex patients. For example, HCPs told us: "say you were a medical practitioner who had no idea what it was to be intersex or trans or non-binary gender, it's really essential to do your own research and communicate with the patient around about exactly what their own goals and their beliefs and their values are" [Suzanne, Med, 40, Queer]; and "it's even harder for somebody who's gender nonconforming or trans to navigate the health care system. I didn't really deal with that. I'm trying to, trying to learn and do better" [Emily, Allied, 54, Lesbian]. Lack of "support from the top" [Allison, Allied, 66, Straight] for HCP training and education on LGBTQI inclusivity made this process difficult: "We're hungry for knowledge, I think we have the capacity. We just don't know where to channel that capacity, and it would be nice to come from a place that's official" [Amelia, Nurse, 34, Lesbian].

It was recognized that it was the responsibility of those designing healthcare settings and services to provide visible signifiers of inclusivity, such as rainbow flags, stickers and posters in waiting rooms, specific information for LGBTQI people on websites, and identification of gender diversity and sexual orientation on intake forms. This would be "comforting" and indicate "this is a safe space", making a "big difference for the [LGBTQI] communities" for whom the healthcare setting is potentially "daunting"[11]. However, the majority of inclusive and reflective HCPs described visible signifiers of LGBTQI inclusion in their workplace as an ideal that they would like to aspire to, or "something we could do" to indicate "we respect and celebrate gender diverse individuals here"[12], rather than the practice at their current place of work. Systemic barriers to signs of inclusivity included difficulties in "accessing the [LGBTQI] material … and we have to get approval from further up the line to do these sort of things" [Cindy, Nurse, 58, Straight]. Others identified the need for education of management and colleagues about LGBTQI inclusivity. For example, one HCP demonstrated agency in adding gender diversity and sexual orientation to patient registration forms and "that was promptly taken off because we had a few patient complaints". She reflected that "in retrospect, I should have done a bit of teaching and said, 'right, this is why we're putting this on there'" [Naomi, Allied, 28, Straight]. Financial barriers in introducing "new models of care" were also identified: "I have to have the business-y, the budget-y hat on. How will this save money. Instead of spending more money. Because we are constrained by that" [Deborah, Nurse, 36, Straight]. These accounts indicate acknowledgement of the institutional barriers to provision of affirmative and inclusive cancer care.

3.1.2 LGBTQI Patient and Carer Perspectives on Inclusive and Reflective Practice: Reassurance and Satisfaction With Health Care

3.1.2.1 "I Knew I Was in Good Hands": Patients and Carers Feel Safe and Able to Disclose LGBTQI Identity

LGBTQI patients and their carers described interactions with HCPs who adopted a position of inclusive and reflective practice as having direct and positive consequences. Visible signifiers of LGBTQI inclusivity, such as rainbow flags, provided "reassurance" that patients were "going to a safe space", with "correct values" because of "knowing that the hospital you're going to is going to be nonjudgmental and treat you as anybody else" [Nathan, Partner, 50, Gay, Head/Neck]. HCPs who were clearly comfortable working with LGBTQI patients served to facilitate feelings of safety, as a carer told us, "I was very lucky to have an accepting environment, especially in the aspects of [HCPs] being comfortable and making me feel safe" [Survey, Daughter, 20, Queer, Adrenal]. Interactions with HCPs who openly identified as part of the LGBTQI community were highly valued in relation to feelings of safety: "out medical staff made me feel safe"; "My GP is a lesbian. I feel very safe".

Feeling safe meant that patients were confident in disclosure of LGBTQI identity, in the knowledge that they would be accepted without judgement, "my sexuality has mainly been treated as a non-issue. My GP is a gay man so it is openly discussed"[12]; "medical staff never judged my gayness". Patients and carers commended HCPs who avoided heteronormative assumptions when asking questions, "my experience with the medical practitioners has been positive and inclusive. They have not presumed my sexuality and have asked open questions" [Survey, 43, Gay, Leukaemia]. A lesbian patient with lymphatic cancer praised HCPs who "interacted positively with my children, with my partner and with me"[13], through asking her children what did they call their two mothers. Sensitivity of HCPs to LGBTQI patients' fear of discrimination, as well as confidentiality in response to disclosure of identity, was also valued.

> My medical team knew that I was transgender and that I feared discrimination. They were very supportive and went an extra step to reassure me. My status as a trans female remained as knowledge with only those that it impacted in my treatment [Survey, 68, Straight, Transgender Female, Head/Neck].

Many patients and carers positioned geographical location as a factor in instilling confidence that they would receive affirmative and inclusive healthcare. For example, participants told us, "I think living and being treated in the inner city means you can take a fair punt on disclosing to health professionals" [Survey, 75, Lesbian, Breast] and "I might not be as accepted as a lesbian in different parts of Sydney and in regional, rural or remote areas of Australia" [Survey, 55, Lesbian, Head/Neck]. Conversely, others valued living in a "rural, small-town area where everyone knows everyone" and which contributed to "being respected"[14].

3.1.2.2 "There Was Never an Eyebrow Raised": Partner and Chosen Family Included and Satisfied With Cancer Care

Partner and chosen family inclusion in decision-making processes and day-to-day interactions with HCPs was an important consequence of feeling safe and being able to disclose identity in an accepting and inclusive health care environment. Many patients introduced their partner at a first meeting, "I was deliberately out to my nurses and doctor who's a world expert. They handled it well, acknowledged my husband, and we use joint decision-making" [Survey, 63, Gay, Prostate]. A lesbian patient said, "I had no trouble at all. My girlfriend participated in meetings and there was never an eyebrow raised or any exclusionary gestures made towards me or her" [Rita, Patient, 61, Lesbian, Cervical). Many partners reported that there was "no sign of [HCP] discomfort or not knowing how to handle it", which meant that they "felt at ease being there as his same-sex partner"[15].

HCPs who went beyond non-discriminatory practice in demonstrating cultural safety were highly valued by patients and their carers. One participant said that HCPs "embraced family irrespective of make-up of family". The partner of a gay man said his husband's GP had "no issue with (us) going in the consulting room together" and "were just so excited when we got married" [Anthony, Partner, 65, Gay, Prostate]. A lesbian participant described the warmth of HCPs towards her wife:

> I usually introduce [wife's name] as my wife, and we haven't had anyone flinch or look twice or nothing. We've both been included in everything, so they'll just call us in and just take both our hands on every occasion. Last time when we left the oncologist because my results were really promising he grabbed both of us and gave us a big hug and said 'you are such a good team' [Martha, 48, Lesbian, Bowel].

Being able to disclose LGBTQI identity and include partners and other chosen family without meeting prejudice or judgement was also associated with satisfaction with health care, with HCPs described as "brilliant", "fantastic", "excellent", or "great". For example, participants told us: "All the nurses knew. And all of them were great"; "My own GP is absolutely brilliant … very caring, nonjudgmental and he's been very good". Satisfaction was also linked to HCPs being "respectful", a key attribute of inclusive care. As the trans intersex partner of a woman with breast cancer told us:

> As far as the medical people have been with us, we had zero issues. They have always been respectful, and I would always go to an appointment … everyone in the hospitals, doctor's surgery was brilliant. Surprisingly brilliant. There was never a problem [Kai, Partner, 50s, Bisexual, Trans, Intersex, Breast].

Others said "all of the medical staff involved treated me with respect. They also treated my wife with respect [and] I felt acknowledged and respected as a partner and carer" [Survey, 69, Lesbian, Endometrial]. HCPs acknowledging LGBTQI status, while treating the patient "as a person" was manifestation of this respect, "he just treats the person as a person he doesn't go, 'Oh well, I'm going to have to put a label on you now because you told me that you're bisexual'" [Grace, 56, Bisexual, Cervical]. In combination, this resulted in the positioning of HCPs as "really fantastic in terms of communicating (and) supporting" [Ruby, Partner, 60, Lesbian, Bowel], "really great", "really good", and as "exceptional".

3.2 Egalitarian Practitioner

3.2.1 "I Treat Everyone the Same and Do Not Discriminate": HCPs Self-Position as Egalitarian Practitioners

3.2.1.1 "Cancer Is the Same for Everyone": HCPs Don't Need to Do Anything Different for LGBTQI Patients

HCPs who adopted the subject position of egalitarian practitioners reported that they treated "everyone the same", regardless of gender and sexuality. Many HCPs stated that cancer was the same for everyone and "I don't see that there's a huge difference in the care of the cancer itself" [Omar, Med, 60, Straight], hence "I don't think there's a need to do anything different" for LGBTQI people [Patrick, Med, 57, Straight]. As long as patients were "getting good care for their cancers", organizations were believed to be "doing enough", with "other problems identified" being "referred to psychological services", implicitly pathologizing LGBTQI identities [Kylie, Nurse, 60, Straight]. LGBTQI patients were considered to be no different from any other cancer patient in facing "concerns about survival and the concerns of recurrence of disease", or in palliative care, "the same end of life physical, emotional and psychosocial issues".

> As a gastroenterologist I don't think it's that important. For treating cancer, so you're talking about people coming in for chemotherapy, sitting for hours, feeling sick. I think there it might be important to have something visual for them … that you are welcome here. I don't think in my context there's necessarily a need to do anything different … we don't have anything special for them [Patrick, Med, 57, Straight].

HCPs told us that information about "safe sex in regards to treatment … doesn't need to be any different for a gay or straight person" [Darren, Allied, 53, Gay] and hence "I try to treat everyone the same"[16]. Some HCPs positioned others as responsible for affirmative and inclusive care, arguing that there was no need for acknowledgment of LGBTQI status in "frontline care work", because "support services probably are doing all that stuff" [Melanie, Nurse, 50, Straight]. Others made a distinction between cancers of the reproductive organs, such as prostate and breast cancer that "might affect their identity" and cancers such as lung, gastrointestinal and bowel cancer "where the effect is the same. It's kind of fairly similar regardless of your gender or your sexuality" [Ayomi, Med, 35, Straight]. Many egalitarian HCPs reported "comfort and confidence" in providing cancer care for LGBTQI patients even though they had not "looked outside for training or things that exist that could help my knowledge" [Cristina, Allied, 35, Straight].

Egalitarian HCPs believed that there was no need to "display anything" that was explicitly LGBTQI inclusive, such as "wear a rainbow lanyard", or "do anything that says I'm one of the people you're welcome to talk to" [Melanie, Nurse, 50, Straight] because they were "friendly to everyone" [Ken, Med, 50, Straight]. Drawing on discourses of ethical responsibility, these HCPs said that all patients were "given the same respect and care, no matter race colour or sexual outlook" [Valentina, Nurse, 56, Straight] and LGBTQI patients were treated "how I would treat every other patient" [Kylie, Nurse, 60, Straight]. A number of HCPs who adopted the position of egalitarian practitioner stated that they were unsure why there was a need to "single out a particular population" as "surely we are well past that", and "if you start being too demonstrative being LGBT friendly, it almost … draws particular attention to it" [Brett, Med, 37, Gay]. Many HCPs positioned themselves as "inclusive" and non-discriminatory because they treat everyone equally, providing the same "high quality" service to "anyone who needs it [Cristina, Allied, 35, Straight].

> I do think that we are quite inclusive and we don't discriminate. Therefore … we're treating everyone equally, and I think that's what it should be about, is everyone getting equally good support [Darren, Allied, 53, Gay].

From this standpoint, LGBTQI identity disclosure was positioned as irrelevant to the provision of patient care, including disclosure of sexuality, gender identity and intersex status. This draws on a discourse of equality, suggesting that everyone is treated the same, rather than equity, whereby everyone is provided with what they need for good healthcare provision.

"Patients Will Tell Me If They Want to": HCPs Do Not Facilitate LGBTQI Identity Disclosure

HCPs who adopted the position of egalitarian practitioner did not explicitly facilitate disclosure of LGBTQI status as it was assumed that "people that want to tell you and feel comfortable with you will tell you"[17]. As a result, disclosure was "very much patient-led". Some healthcare professionals did use neutral language to ask about "social networks", such as, "who's in their life?" or "do you have a partner?"[18] if they "sensed" or "picked up" that the patient may be LGBQTI, suggesting awareness of the importance of inclusivity. However, it was acknowledged that "if they didn't have a partner then maybe it wouldn't come up. It doesn't get asked at all" [Amelia, Nurse, 35, Lesbian]. Patients who did not appear to the HCP to be LGBTQI would also be overlooked as the HCP would not adopt neutral language. Equally, identification of a person as trans, non-binary or having an intersex variation would not follow on from questions about social networks or partners, resulting in HCPs "missing people".

> I don't tend to ask people. I don't proactively ask people do you identify as LGBTIQ. I sort of pick up on it if it's there. But, you know, that probably means that even I am missing people. Sometimes, I've been in a situation where I've had a trans patient, for example, and they just really pass. I've only realized that they are

> trans when I do a physical exam [Suzanne, Med, 40, Queer].

This HCP did demonstrate some reflectivity, commenting, “it’s maybe something that I could improve on in my own practice”, but explained “it’s not sort of something that’s taught to us”.

3.2.1.3 “My Capacity to Actually Get It Wrong Is Massive”: HCPs Are Out of Their Comfort Zone and Don’t Want to Cause Offence

A number of HCPs accounted for the fact that they did not ask about LGBTQI status, or actively facilitate disclosure, by stating that they did not want to “make assumptions” due to the fear they would be seen to be “overstepping” or “going down a track that could be offensive” to non-LGBTQI patients [Darren, Allied, 53, Gay]. It was also argued that some “people that did identify [as LGBTQI] might think ‘it’s none of your business’” or might experience the HCP as voyeuristically “gaping” at them, or respond negatively to uninformed or “insensitive” HCP questions. Other HCPs were concerned about displaying LGBTQI inclusive signage because of concern “it would antagonize one or more of my conservative patients” [Lynette, Med, 58, Lesbian] and “there are still a lot of people out there who are not comfortable with gay and lesbian couples” [Patrick, Med, 57, Straight]. As a result, HCP participants said, “it’s probably better to stay neutral” and let “patients … identify to you” or “lead the conversation”[19].

After a patient’s disclosure, a number of HCPs were concerned that they “would offend somebody because of my lack of information” [Katrina, Allied, 64 Straight] or were “worried about calling them the appropriate term”, “which could serve to “take away from them just being my patient and treating them well” [Survey, Nurse, 48, Straight]. More specifically, lack of knowledge and confidence in “language to do with transgender people” was described as making a number of HCPs feel “inadequate and probably a little bit embarrassed” or “nervous and cautious” [Kelly, Nurse, 60, Straight]. This was because of a fear that their “capacity to actually get it wrong is massive”, which could “cause offence or damage rapport” [Leanne, Allied, 47, Straight]. As a result of this “fear of stepping on toes with fear of being offensive”, many HCPs simply said “nothing at all”, which was acknowledged by some to be “not very good either” [Alia, Allied, 31, Straight].

3.2.2 Risky Disclosure or Invisibility: Patient and Carer Perspectives on Egalitarian Practitioners

3.2.2.1 “Another Layer of Things to Worry About”: The Emotional Work of LGBTQI Identity Disclosure

HCPs who adopted a position of egalitarian practitioner and did not “open up” the discussion of SOGI status, were seen by patients and their carers as assuming a patient was “straight” and cisgender, and that their partner was “a friend”. This was a source of dissatisfaction with healthcare, which LGBTQI participants said, “really pisses me off” and “creates a lot of stress”, because “if they didn’t make that assumption automatically that I was heterosexual then I think it would have been a lot easier to handle” [Christine, 53, Lesbian, Ovarian and Uterine]. Failure to acknowledge gender diversity was also a concern for many patients.

> What I would have liked them to do was to ask me what pronouns I would like. Would I like to be called ‘he’ or ‘him’ or ‘she’ and ‘her’ or ‘they’ and ‘them’. They didn’t ask [Lauren, 63, Queer, Trans, Prostate]

Egalitarian practice puts the onus on patients and their carers to disclose in a context where they are unsure about the response they will receive from HCPs. As one participant reported, “having to explain every time that you are not straight was another layer of things to worry about or have to deal with. I already had enough going on just with the treatment” [Survey, 56, Lesbian, Breast]. The “anxiety around disclosure” and repeated decision-making before an encounter with a new HCP about “when do I bring it up, how do I bring it up?” [Dylan, 32, Gay, Non-binary, Leukemia] was described as “emotionally extremely draining” [Scott, 55, Gay, Trans man, Multiple] and “a little bit wearing after a while” [Paulette, 67, Lesbian, Colorectal]. LGBTQI patients and their carers were thus “on a merry-go-round” of “outing yourself the whole time” as well as “outing your partner if they’re with you”. This meant they were leaving themselves open to HCPs “not being too receptive”, fearing that HCPs will “change their mindset and how they treat you” after disclosure. This was “emotional effort” and a “burden” on LGBTQI patients [Paulette, 67, Lesbian, Colorectal].

> Being part of a marginalized community brings additional pressures and stresses, and the anticipation of potential discrimination, or everyday misunderstanding, is always there. This creates additional burdens which impact on health and wellbeing. This awareness needs to be out there [Survey, 52, Lesbian, Breast].

There were a number of ways LGBTQI patients and carers responded to their uncertainty about HCP responses to disclosure. Some individuals would assess “the vibes they [HCPs] give off”[20] at a first meeting, or “call the doctor’s office and tell them in advance so I can gauge their reaction before I go in”. Selective disclosure on a “needs basis” was also reported, only happening if the patient “considered it relevant” to their care or felt confident in a positive HCP response. Others, most commonly older cisgender gay and lesbian cisgender individuals, said that they were “always open and honest with our providers”, and because I am “out and comfortable with who I am” or “proud of who I am. I don’t hide any more”, expecting “others to treat me accordingly, especially around such an emotional and fraught issue as cancer” [Survey, Carer, 77, Lesbian, Ovarian] and include their partner in all discussions. Some self-proclaimed “very out” participants reported a more “assertive” response, refusing to “tolerate any kind of homophobic bullshit”, or saying, “if you don’t like who I am, I don’t care, you’re shit” [Rita, 50, Lesbian, Cervical].

If HCPs who adopted a position of egalitarian practitioner responded positively to LGBTQI disclosure, this had positive consequences in terms of patient satisfaction, engagement with care and inclusion of partners, as reported in interactions with inclusive practitioners. For example, a carer of her partner with ovarian cancer, said she was “always wary wherever I am …

judging it all the time so that I can act appropriately to be safe", but "not once did I feel a lesser person or was judged", even though "a few of the health care professionals might have made a mistake and thought that we were sisters". She drew on a metaphor of horse training to describe how she interacted with HCPs:

> I used to breed horses and train and break horses, so we had this joke that I always had someone else to break in. But we do it very well. And I think it is very helpful in how they [HCPs] treat you. You know, they're humans and they lack knowledge as well. It's a two-way street. But I didn't feel any homophobic times through all of [partner's name]'s treatment, which I think is just amazing. It just goes to show how far we've come [Claire, Carer, 66, Lesbian, Ovarian].

However, many other LGBTQI patients and carers reported feeling "judged", or positioned as a "weirdo" or as a "Martian" following SOGI disclosure in interactions with HCPs who were well meaning but "needed more education on inclusivity and how to discuss these topics without being offensive" [Survey, Partner, 20, Queer, Non-binary/Gender-fluid, Breast]. For example, a non-binary participant reported feeling like a "fascinating test subject" whose use was in educating HCPs, while paying for the privilege through private health care.

> I find it really hard to even transfer between medical professionals because people want to hold on to me cause I'm like a valuable patient to have on their books. There was one health practitioner last year … I just felt like she was ripping me off and just finding me really fascinating, like I was like educating her and then paying for it at the same time. [Jessie, 37, Queer, Non-binary/Gender-fluid, Medical intervention, multiple cancers]

Some participants dealt with visible HCP discomfort or lack of knowledge calmly by being "personable and engaging" and assuming HCPs would accept them: "I've never made being gay a 'problem' and if there was a 'problem'. I have always approached its resolution in a caring open way" [Survey, 67, Gay, Prostate]. Others reported feeling "a bit uncomfortable" because of the obvious "discomfort" of HCPs following disclosure, or felt it was "insulting and insensitive" to have the impact of cancer dismissed after they disclosed.

> I had two people (HCPs) say, 'it doesn't matter, you're a lesbian'. And I said, 'I don't understand what you mean, why does it not matter that I've got cancer because I'm a lesbian?' And after the blushing, they go 'well you're not having [penetrative] sex'… There was an assumption that it's okay to have breast cancer if you're lesbian because a lover will understand your situation or your lack of sex drive, and it won't matter because you're not with a bloke. [Myra, 68, Lesbian, Breast]

Lack of HCP awareness of the intersection of cultural identity and LGBTQI identity was also commented upon. For example, a participant from a Chinese cultural background said, "few [HCPs] consider the points of differentiation for lesbians from culturally and linguistically different backgrounds" [Violet, 53, Lesbian, Uterine], and an Aboriginal man told us, "there's a lot of complexity around the intersection of sexuality and cultural background and race, and health care settings in Australia are not geared towards acceptance around that" [Ryan, 60, Gay, Prostate]. HCP assumptions based on the cultural background of the patient were sometimes incorrect: "I'm not out to my parents and there were a lot of cultural assumptions. Being Chinese the doctors were assuming that my parents should be involved in the decision making, whether or not I wanted them to be involved" [Ash, 40, Non-binary, Bisexual, Unknown cancer].

"They Never Ask; I Never Tell": Non-Disclosure Means Safety and Privacy, as Well as Invisibility and Unmet Needs

Many LGBTQI patients and carers dealt with uncertainty about HCP responses to disclosure by choosing not to disclose their SOGI status. As one participant told us, "Doctors? They never ask; I never tell" [Survey, 69, Queer, Prostate]. Non-disclosure had both positive and negative consequences. Some participants described concealment of LGBTQI status as "easier" and "safer" because the "cost-benefit"[21] analysis of coming out resulted in feelings of "trepidation", with disclosure positioned as "too scary" and "even opening this conversation" as "often-impossible". It was believed that "in not being out, you get treated better", with some participants describing a sense of agency in "determin[ing] when and how others know", thereby allowing them to avoid discrimination.

> I always tick women on the forms because it's so discriminatory if I don't. It is just absolutely not worth it to me to identify as anything other than cis in the health system because people make a mockery of trans bodies. I ride off the privilege of my gender fluidity constantly in order to grin and bear it, deal with the cis-normativity that it takes to avoid that aspect of discrimination. [Jessie, 37, Queer, Non-binary/Gender-fluid, Medical Intervention, multiple cancers]

Ticking "woman on the forms" was not without cost, however, with Jessie saying "I had to sacrifice that part of my identity to get treatment in the health system". This had negative implications for their health, as they had "come to points in my life where I've avoided help seeking or opted out of the health system just because I couldn't be a binary person that day".

For others, LGBTQI status was deemed "irrelevant" or "not necessary to declare" in relation to cancer care as it was "nobody's business what I do in my private life"[22]. However, non-disclosure meant that cis-heteronormative assumptions remained unchallenged, which could leave individuals feeling "awkward and uncomfortable", "silenced", "angry", "guilty" and "not understood", because their LGBTQI status was erased or made invisible by HCPs.

Frustration was common when requests for LGBTQI specific information were ignored, or "general information" provided in response to requests. For example, the response to a gay man who asked for information about "what to look out for" when having sex after treatment was "a verbal off the cuff 'practice safe sex', in general terms" [Carter, 21, Gay, Leukemia]. The "absence of targeted information" and support to address LGBTQI patient needs reinforced feelings of invisibility as "there wasn't anything specific to same-gender couples"[23], or for "trans and non-binary bodies" available for most participants. As one carer commented, "It's really difficult to find support [online or face-to-face groups] that include lesbian women. My partner had a gynecological cancer, so all the supports were aimed at male partners" [Survey, Partner, 54, Lesbian, Ovarian]. Another said, "there are resources for carers and resources for individuals with cancer, what is lacking are services who understand the complexities when you add LGBTQI+ into the mix" [Survey, Parent, 40, Queer, Non-binary/Gender-fluid, Colorectal]. This led to many patients and carers feeling "despondent" and "isolated by mainstream cancer supports".

3.3 Anti-Inclusive Practitioner

3.3.1 Righteous in Hostility Towards LGBTQI People: HCPs Engage in Anti-Inclusive Practice

HCPs who adopted a position of anti-inclusive practice demonstrated negative attitudes or outright hostility toward LGBTQI patients. This was evident in the accounts of a small minority of HCP participants who complained that the "abnormal behaviour" of LGBTQI people was being "forced" onto them and that they "just don't need to hear about their (patients) sexual orientation if it has nothing to do with treating their condition" [Survey, Nurse, 61, Straight].

> I don't see why everyone has to force their sexual orientation on others. Heterosexual people don't go around talking about their sexual orientation. I am now forced into hearing about and watching abnormal behavior on TV and more advertisement of non-heterosexuals. [Survey, Nurse, 61, Straight].

More commonly, the anti-inclusive practices of colleagues were observed by other HCP participants. This included accounts of HCPs who were righteous in their exclusion of LGBTQI patients, feeling "entitled" to their beliefs "that homosexuality is wrong"[24]. HCPs were observed to behave in "insulting", "disgusting" and "unnecessary" ways that "show lack of understanding and lack of respect" for LGBTQI patients. This was particularly acute in relation to trans patients. For example, HCPs described observing "misgendering practices" by "a few of the doctors and some nurses" in an outpatients clinic; or HCPs "intentionally using the wrong pronouns and saying derogatory things" [Amelia, Nurse, 35, Straight] about a trans patient who was attending for an appointment; and behavior described as "an aggressive act" and "micro-aggressions" [Amy, Nurse, 55, Lesbian]. HCPs also reported anti-inclusive practices in the form of "insidious and subtle"[25] micro-aggressions. This included colleagues "tutt[ing] under their breath" at "the badges around the place saying trans ally", or providing "lip service" to LGBTQI inclusion, while concealing their "implicit biases" because they were "too clever to be openly discriminate" [Jodi, Allied, 39, Lesbian].

Some HCPs acknowledged that the anti-inclusive practices they observed had material consequences, with cis-heteronormative assumptions about patients resulting in "important pieces of information … missing from that interaction", which meant that "the patient might not feel safe to ask the questions, clarify or seek support" [Tammy, Nurse, 48, Straight]. One HCP observed the withholding of fertility preservation advice for a man because he was gay:

> The consultant looked at me and said, 'oh, I don't think that'll be an issue'. I knew that the consultant was assuming he was gay, but then taking that next step and assuming that he wouldn't be having children. To me, that wasn't an appropriate assumption to make [Ayomi, Med, 35, Straight].

It was acknowledged that anti-inclusive comments between colleagues could be damaging because "even if the patient didn't hear, it's still encouraging that sort of culture in the workplace" [Amelia, Nurse, 35, Straight].

Many of the HCPs recognized that challenging anti-inclusive practice observed in colleagues was important. HCPs who it was assumed were "well-meaning" and "don't come from a bad place" were seen to "need a bit of a fact check" about comments that were "really just not appropriate" or "careless". However, trying to "educate" colleagues "who are prejudiced to LGBTQI patients" and are coming "from a place of harm" [Alia, Allied, 31, Straight] was reported to be more difficult, as negative attitudes and "discrimination" toward LGBTQI people was often "ingrained". HCPs explained that they "could spend three minutes or three hours here and your mind might never be changed" [Jessica, Nurse, 38, Straight], as "there's a lot of bigots out there and there's a lot of bias still in health" [Kelly, Nurse, 68, Straight]. Others explained that prejudicial behaviour on the part of their colleagues that "could go to disciplinary action" was not pursued, in part due to lack of confidence that "upper management would have really recognized the importance" [Amy, Nurse, 55, Lesbian].

3.3.2 "We Are at Their Mercy": LGBTQI Patients and Carers Need to Navigate Anti-Inclusive Cancer Care

3.3.2.1 "The Biggest Area That I've Felt Discriminated in": The Damaging Impact of Interactions With Hostile and Offensive Health Care Professionals

The impact of anti-inclusive practice on LGBTQI patients and their carers was universally described as negative and damaging. A substantial number of patients and carers concurred, "not everyone in the medical team was accepting or supportive", providing examples including doctors, nurses and allied health professionals. LGBTQI patients and their carers described having to navigate the "constant", "covert" and "daily discrimination" in cancer care. Believed to be "everywhere", anti-inclusive HCPs were described as "positively hostile", "dismissive", "paternalistic and judgmental" of LGBTQI patients. This resulted in the feeling of "being treated like a lesser person"[26] because it can "gradually chip away at your confidence and sense of self-worth"[27]. It was "stressful" to sense a negative "vibe" from an anti-inclusive HCP, suggesting that they "don't want you here", leading to feelings of "distrust" towards HCPs.

> 2011_may_w_g2.ddsIn health, where you are just naked all the time … everything that is intimate and important to me has been clinically invaded by people who don't respect me for who I am. So those people are everywhere. That systemic discrimination makes me distrust people in the system who do really good work and do really care [Jessie, 37, Queer, Non-binary/ Gender-fluid, Medical Intervention].

Some anti-inclusive HCPs were reported to change from being "warm and helpful" to "cold" and "shorter in their responses", or to have "stopped speaking to me" when patients disclosed their sexual orientation, intersex variation, or trans status:

> Two of my specialists stopped speaking to me after my sharing about being intersex. It's clear there is a great deal of stigma surrounding it [Terry, 40, Queer, Non-Binary, Intersex, Medical Intervention]
> Due to my gender presentation, I often felt mainstream services did not willingly engage with me or provide me with the support I needed [Survey, Parent, 40, Queer, Non-binary/Gender-fluid, Colorectal]
> I've had some that I've said I'm gay and they've just sort of shut down after" [Aaron, 32, Gay, Bowel].

Some HCPs were overtly exclusionary, stating to patients that they don't agree with "that sort of thing'", or that the patient was not "living according to God's will" because of being gay. One HCP reportedly "dropped her hand and said 'not in this hospital' and left" [Myra, 61, Lesbian, Breast] when she realized she was discussing assisted reproduction with a lesbian woman. Patients also told us that their HCP ignored their disclosures of identity, for a participant said; "I had told him that I was a gay woman. He still asked to talk to my husband" leaving her feeling as though "he didn't see me", "didn't hear me", "didn't understand who I was" [Barbara, 48, Lesbian, Uterine]. Trans and non-binary patients explained that it could be "difficult" to get HCPs to "use gender-neutral language", including one young person who "had to beg" their oncologist "to stop mis-gendering me". These responses to disclosure reinforced "distrust" and a distinct lack of safety. As one participant told us:

> I don't feel safe. I have to think ALL THE TIME in medical situations if it's safe to come out. Correcting, educating, making formal complaints – I am enraged that my energy has been taken up by this my whole life when I'm in pain; very sick; recovering; scared. [Survey, 39, Queer femme, Medical Intervention].

Offensive comments or actions by HCPs could also be a source of distress for LGBTQI patients. For example, one lesbian participant reported, "a doctor told me I shouldn't have an issue with her putting her fingers inside of me 'to test' something … because 'people like you like this kind of thing'" [Survey, 40, Lesbian, Cervical]. A bisexual woman who disclosed to her doctor that her fiancé was a woman was asked "do you consider yourself to be a man?", leading to the reflection "that was another situation where I become the educator instead of being a patient" [Catherine, 61, Bisexual, Vulval]. Anti-inclusive practices were experienced as more all-pervasive for some patients living in regional and rural locations, because HCPs can "get away with having biases and being discriminatory when there are limited options for the patients" [Survey, 63, Straight, Breast]. As a trans participant told us, "If you live in one of the small towns, you don't get to choose who your GP is. They might be very transphobic and you're stuck with them" [Victor, 47, Straight, Trans Man, Ovarian].

3.3.2.2 Denigrated or Ignored: Active Exclusion of Partners and Chosen Family Carers

Many partners and other carers reported being impacted upon by anti-inclusive practices, feeling that HCPs were "reluctant" to engage with them, or treated them as "lesser than" because they were not "a heterosexual white individual"[28]. Partners reported, "you just get that look or that raised eyebrow, or you don't get referred to properly"[29], with HCPs "insisting on referring to me as his friend" despite "being told we were married". Another HCP "questioned" whether the patient had "other family", as though they were "looking for more legitimate people to engage with"[30]. Patients also spoke of partner exclusion:

> My radiation oncologist clearly thought my life was absolutely disgusting, refused to acknowledge my partner. If she was in an appointment with me, he'd just completely ignore her. I had ticked the de facto box and he actually scribbled out my tick on that box and put single [Catherine, 41, Lesbian, Vulval].

Another patient told us that it was "difficult for my partner to get any answers and yet when my parents turned up they were more than happy to talk to them" [Survey, 42, Lesbian, Uterine]. Administrative staff, who selectively applied hospital policies, also perpetrated "woeful" exclusionary practices. For example, a lesbian lung cancer patient's wife and partner of 25 years was required "to stay outside" on the basis that she "wasn't family yet", an incident that happened just before marriage equality was legalized in Australia. Hostilities were also extended to chosen family, such as "lesbian friends" who would "come and visit" such as being treated "quite offhandedly", "eye rolling" and with lack of "respect" [Elsie, 55, Lesbian, Lung]. Intentional refusal to recognize LGBTQI partners had "horrible" consequences for one gay man who, despite having "power of attorney and enduring guardianship" for his partner, found that "the doctor in charge wouldn't let me see my partner when he was dying because we're gay". He concluded "I think the doctor just did not like gay people", evidenced by broader homophobic assumptions on display:

> I felt my partner wasn't treated with dignity and respect. And I wasn't treated with any dignity or respect when my partner was dying. They were quite rough, without even warning me. Like he's from out of space or like he's got AIDS. Taking it for granted

> because he's gay then he's got AIDS [Neal, 68, Gay, Prostate].

3.3.2.3 "They Don't Want Me to Live Because I'm Gay": Fear of Inadequate and Insensitive Cancer Care

Numerous LGBTQI patients reported instances wherein they perceived their medical care to be inadequate, or feared being denied health care services because they were LGBTQI, with direct implications or their willingness to engage in cancer healthcare. As one young lymphoma patient told us, "what if people don't want to treat me because they don't want me to live because I'm gay" [Oscar, 27, Gay, Lymphoma]. Issues included, "difficulty engaging" HCPs "because of my presentation as non-binary/trans"[31]; being misdiagnosed due to beliefs that "gay people are overdramatic or hypochondriacs"[32]; "fertility issues" not being discussed "as part of cancer care because I'm gay"; and being denied "pain relief" after an operation "because the nurse doesn't like trans people"[33].

> When we go into a random appointment, we might be looking at someone who actually wants us dead. That is how hard it is to get medical care. You've randomly got to work out a way to protect yourself against someone who really doesn't know where the problem is and hates your guts [Scott, 55, Gay, Trans man, Multiple].

Patients also reported the distress they experienced following encounters with HCPs who deliberately enforced cis-heteronormative ideals through their clinical decision-making. For example, one HCP was reportedly "focused entirely" on maintaining a lesbian patient's vagina with dilators post-surgery "so that a man could put his penis in it" if she decided to be in "a proper relationship one day". This was despite the patient telling him "that was not an issue, he [HCP] would just ignore me, just talk over the top of me" [Catherine, 61, Bisexual, Vulval]. A number of participants reported feeling judged in their choices in relation to reconstruction following breast surgery. A non-binary participant said that they "had to fight really hard to not have a reconstruction after a mastectomy", and another patient said that there was a "lack of understanding" of LGBTQI patients' "desire to go flat" [Jasper, 50, Queer, Breast]. A carer told us:

> My partners' surgeon made her feel like a weirdo for the plastic surgery options she requested and didn't really know how to be neutral on the topic of gender nonconformity and transgender identities with her other patients. She needed more education around how to discuss these topics without being offensive and making us feel like total oddballs for who we are [Survey, Partner, 33, Queer, Breast].

LGBTQI patients and their carers reported detrimental impacts of anti-inclusive and exclusionary care, including feeling as though it "prevents me from help-seeking for my current maintenance care" [Patricia, 65, Lesbian, Uterine]. Although many patients positioned themselves as "assertive" in their lives generally, in the context of cancer care they reported feeling "at the mercy" of their HCPs [Hannah, Partner, 45, Lesbian, Uterine]. A number of patients reported feeling that "you can't really complain" and that "not seeing that person again" was "not a choice that you get", as anti-inclusive HCPs may be "the only thing standing between you and death at that point in time. You don't have the luxury of just walking out" [Catherine, 61, Bisexual, Vulval].

4 DISCUSSION

The aim of the present study was to examine the construction and experience of LGBTQI cancer care from the perspective of HCPs, LGBTQI patients and their caregivers. We identified three subject positions adopted by HCPs in relation to the provision of care to LGBTQI people: inclusive and reflective practitioner, egalitarian practitioner, and anti-inclusive practitioner, which had implications for LGBTQI cancer patients and their partners, and other chosen family caregivers.

HCPs who took up the subject position of inclusive and reflective practitioner demonstrated LGBTQI cultural competence and cultural humility, creating a place of cultural safety (33–35) for LGBTQI patients and their carers, through a range of inclusive verbal and non-verbal strategies (1, 14, 45). Inclusive and reflective HCPs regarded LGBTQI patients as potentially vulnerable and needing nuanced care, following best practice models of person-centered care tailored to individual patient needs (66). They recognized the impact of societal discrimination and the legacy of trauma in health care, including difficulties related to disclosure of SOGI status (67) and violations to bodily autonomy for some intersex patients (68), drawing on an affirmative construction of LGBTQI health (69). Inclusive and reflective HCPs acknowledged the need for sensitivity and acceptance of SOGI status in interactions with LGBTQI patients, and the intersection of identities in LGBTQI patient outcomes, including sexuality, gender, age and cultural background, which can lead to discrimination across "multiple axes of oppression" (20). Inclusive HCP practice involved non-judgmental respectful treatment and welcoming and open dialogue, accompanied by reflective awareness of gaps in their own personal knowledge and skills (1, 14, 45). The importance of knowing patients' SOGI status information was acknowledged (14, 28), and the assumption that all patients are heterosexual and cisgender was avoided, by HCPs taking responsibility to facilitate disclosure of patient SOGI status, and including partners and other chosen family in consultations and care. Inclusive and reflective HCPs recognized the importance of the relationship between clinicians and LGBTQI patients in the provision of affirmative health care (31).

This model of inclusive and reflective practice is an exemplar of communicative competence, identified in previous research on LGBTQI cancer care (1, 6, 14, 28, 45). This practice had direct positive consequences for LGBTQI patients and their carers, in terms of feeling safe and respected in interactions with HCPs, willingness to disclose SOGI status with the knowledge that there would be a positive response, and satisfaction with cancer care, aligned with prior literature (4, 12, 13, 48). Our LGBTQI patients and carers told us that this is what they want in cancer care. Previous research has established that LGBTQI patients who disclose SOGI status in the context of general healthcare, and who receive a positive and accepting response from HCPs, report greater satisfaction with care and increased likelihood of engagement with health screening (9, 13, 70–72). This has direct positive benefits for physical and mental health (72–74). At the same time, inclusive and reflective HCP provision of tailored information in response to individual needs, access to LGBTQI specific support groups if available, and acknowledgment of the need for visible signs of LGBTQI inclusion, serves to address gaps in generic cancer information and support for LGBTQI people and their carers (4, 6, 28). It also ensures that treatment decision-making is informed by LGBTQI patient needs and the potential impact of cancer treatment on identities and relationships (15, 75).

HCPs who adopted the subject position of egalitarian practitioner drew on discourses of ethical responsibility to position themselves as offering an inclusive high-quality service to all patients, a mode of patient-clinician interaction identified in previous research (1, 14, 45). Knowledge of SOGI status was deemed irrelevant in the provision of cancer care for some egalitarian HCPS, or only relevant for patients with cancer affecting sexual or reproductive organs. This reflected a construction of LGBTQI identity as primarily about sexuality (76, 77), negating the importance of acknowledging LGBTQI patient needs in all tumour types (3). It also confirmed previous reports that the majority of oncology HCPs do not inquire about a patient's sexual orientation when taking a history (1, 2, 14, 38, 41), with many not seeing the relevance of knowing the SOGI status of their patients (1, 37, 45).

Some HCPs who adopted a position of egalitarian practitioner did have knowledge about gender-neutral non-heteronormative language, such as referring to 'partners' rather than 'husband or wife' and recognised its importance in the provision of inclusive and affirmative cancer care. However, affirmative language was only used in interactions with patients identified by HCPs as LGBTQI, implicitly drawing on stereotypical notions of LGBTQI appearance (78) and overlooking the substantial proportion of LGBTQI people whose SOGI or intersex status is not visibly identifiable to others (79, 80). Self-positioning by some egalitarian HCPs as being uncomfortable, unskilled or lacking in confidence, reflected in concerns about causing offence to non-LGBTQI patients, or use of correct terminology with LGBTQI patients, in particular with transgender patients, has been reported previously (1, 2, 14, 37, 45). This demonstrates lack of awareness of specific strategies of communicative competence needed to care for LGBTQI patients (81), potentially compounded by the many challenges associated with uptake of best practice guidelines (82). It also demonstrates lack of awareness of the negative impact on LGBTQI patients if HCPs do not adopt inclusive and affirmative strategies (4, 9). However, the evidence of self-reflection in these accounts suggests that some practitioners who adopt an egalitarian subject position may be able to move to an inclusive, reflective practitioner position with the right skills, education and support.

There is growing acknowledgement the position of treating all patients the same is an unhelpful mode of practice, described as a 'micro-aggression' (45) that serves to minimize health disparities experienced by LGBTQI patients. It also exonerates HCPs from needing to acquire specific knowledge or training in order to care for LGBTQI patients, or need to engage in reflective practice in their clinical interactions (1, 83). Egalitarian practitioners who use the 'same yardstick' to address the concerns of their patients are implicitly signaling a cis-heteronormative subject position, which does not acknowledge the unique needs of their LGBTQI patients (1, 14). This is not following guidelines for equitable person-centered care (66), and serves to render LGBTQI patients and their carers invisible (84). Cis-heteronormative assumptions on the part of oncology HCPs and absence of opportunities for SOGI disclosure are associated with LGBTQI patient dissatisfaction with healthcare (4, 12) and anxiety about disclosure of SOGI status (4, 12–14), and this was confirmed by patients and carers in the present study. In the absence of visible indicators that healthcare settings or individual HCPs were inclusive and affirmative in their practice, many LGBTQI patients and their carers feared that they would face HCP hostility and discrimination, and be offered substandard cancer care (4, 12, 13, 47, 48). This added to the psychological burden of dealing with cancer diagnosis and treatment, resulting in feelings of distress and frustration throughout the cancer care process (4, 13).

A minority of HCP participants in the present study adopted the subject position of anti-inclusive practitioner, expressing open hostility and prejudice toward LGBTQI patients. Many other HCPs in this study reported having witnessed discriminatory behavior in their colleagues, including derogatory language, refusal to use appropriate pronouns, and lack of respect towards LGBTQI people, as reported in previous research (14, 45). These findings demonstrate that LGBTQI patient concerns with disclosure of SOGI status and potential HCP discrimination are a reality, evidenced by accounts of negative judgement and hostility, exclusion of same-gender partners, and cis-heteronormative interventions during cancer care. LGBTQI patients who experienced negative HCP reactions following SOGI disclosure, or experience anti-inclusive care report distress in and disengagement from cancer care (4, 12, 13). This distress may be compounded by previous experiences of discrimination in general health care, which is commonly reported by LGBTQI people, with higher rates of HCP hostility reported toward trans and non-binary people, those from culturally and ethnically diverse backgrounds (9, 70), and people with an intersex variation (85). The ability of HCPs to take up an anti-inclusive subject position and the reluctance of some colleagues to challenge them reflect a broader cultural discourse wherein homophobia and transphobia are still regarded as acceptable (86, 87). In Australia, this is reflected hostile media and public commentary associated with marriage equality (88) and the Safe Schools initiative which aimed to address LGBTQI bullying in primary and secondary schools (89), and government attempts to introduce of a religious discrimination bill, which would legitmate discrimination against LGBTQI people (90). This discourse serves to normalize anti-inclusive and discriminatory practices toward LGBTQI patients and their carers (9), as well as discrimination toward LGBTQI healthcare professionals who disclose their SOGI status at work (91). This may explain why few HCPs in the present study were active in lobbying for LGBTQI inclusivity at a service level, or felt confident in challenging anti-inclusive behavior they witnessed in their colleagues, reinforced by feelings of disempowerment within health system hierarchies.

LGBTQI patients and carers were not passive in response to fears of discriminatory cancer care, demonstrating agency and resistance to invisibility through a process of decision-making and actions. The informal 'screening' of HCPs to assess their level of inclusivity and selective disclosure of SOGI status based on HCP response are common strategies adopted by LGBTQI cancer patients (4, 48, 92). The alternative strategy of always disclosing SOGI status to HCPs in the expectation of a positive response demonstrates the intersubjective character of the HCP-patient interaction, with patient self-positioning potentially facilitating HCPs taking up a more inclusive subject position. However, each of these strategies requires additional emotional work by LGBTQI patients and carers, in addition to dealing with the burden of cancer. Disclosure of SOGI status to HCPs who do not adopt an inclusive and affirmative subject position can be a difficult process, involving the emotional work of planning, anticipation of HCP response, and the rehearsal of strategies (9, 48, 71, 92, 93). Patients who are less experienced in SOGI disclosure, such as adolescents and young adults (AYAs), or those who have had previous experiences of HCP or societal discrimination, may be less likely to risk the negative reactions that may follow disclosure (9). This is reflected in lower levels of outness reported by AYAs, TGD and intersex participants in the present study, demonstrating the impact of intersecting identities that produce a matrix of multiple marginalization, in what has been described as a double or triple jeopardy (54). Having to educate HCPs on LGBTQI patient needs and dealing with awkward or ill-informed HCP responses are additional emotional work for LGBTQI patients and carers. HCPs in this study were less confident in their knowledge of the needs of TGD and intersex people (41), and were less likely to adopt reflective and inclusive practice with these groups. This highlights the importance of LGBTQI inclusive and reflective cancer care which creates a place of cultural safety for all patients, whilst recognizing the greater vulnerability and specific concerns of some groups (54).

Non-disclosure of SOGI status can be a place of safety for patients and carers, serving to protect against insensitive or inappropriate HCP responses (9, 48). Indeed, some patients consider their sexual orientation private or irrelevant to cancer care, obviating the need for disclosure (4, 12, 94). However, non-disclosure can be associated with feelings of LGBTQI patient and partner invisibility (4), regret (12) and burden of secrecy (95), as well as absence of specific information relevant to LGBQTI patient needs, which add to the stress of having cancer and to the likelihood of poor psychological wellbeing (96).

5 CONCLUSION

Lack of knowledge or confidence on the part of HCPs in caring for LGBTQI cancer patients has been reported in previous research (1, 2, 36–38, 40). This has led to the development of training programs (25, 26, 97, 98) and publication of practical strategies to facilitate communicative competence in the provision of LGBTQI cancer care (4, 6, 28, 99–103). However, the success of such strategies depends on HCPs being reflective in their practice, acknowledging their own limitations and accepting the necessity of professional training or development, and understanding the complexities and differences within LGBTIQ communities (41). If HCPs position LGBTQI patients as no different from non-LGBTQI patients, or are hostile to LGBTQI people, as was the case with some participants in the present study, such professional development is unlikely to be adopted or effective. These barriers are not immutable, however, as is evidenced by accounts of HCPs in the present study who positioned themselves as knowledgeable and confident in offering inclusive and affirmative care for LGBTQI patients. If oncology HCPs were to adopt this agentive subject position and conceptualize reflective and inclusive care as a routine part of communication with patients, they are more likely to address the needs of their LGBTQI patients (28).

The findings of this study suggest that interventions to improve culturally competent LGBTQI cancer care need to focus on a range of strategies. The materiality of the clinical context needs to be improved in order to facilitate SOGI disclosure and address LGBTQI patient needs. This includes visible indicators of LGBTQI inclusivity in clinics, health service websites, and patient support information; acknowledgement of SOGI status on intake forms, and provision of LGBTQI-specific information on issues such as sexual health, bodily changes, and the concerns of transgender and intersex people (22, 75, 104). Onward referral services are needed to provide support for HCPs when patients require LGBTQI-specific expert interventions (28). Clinical management teams and clinical mentors also need to acknowledge the importance of addressing the needs of LGBTQI patients, and support the development of HCP communicative competence (105), facilitating HCPs to adopt an inclusive and reflective subject position. Specific training in offering inclusive and affirmative cancer care as part of basic communication training and ongoing professional development is essential (25, 28). Such programs can increase HCP confidence, challenge homophobic and transphobic stereotypes and increase the likelihood of LGBTQI patients receiving inclusive and affirmative cancer care.

Derogatory constructions of LGBTQI patients, or representations of LGBTQI patients as no different from any other patient, need to be challenged in order to undermine discursive strategies that exonerate HCPs from offering inclusive and affirmative care. There is a need for HCPs to be aware of the potential vulnerability of LGBTQI patients, in particular difficulties in SOGI disclosure and the impact of invisibility in health care. There is also a need for awareness that HCPs have responsibility for facilitating SOGI disclosure with their patients, as many LGBTQI patients are too fearful to disclose, or are concerned that they will receive negative responses. Providing equitable care to LGBTQI cancer patients and their carers is a human rights issue. We know what patients want, and we know the barriers to provision of inclusive and affirmative person-centered LGBTQI cancer care. It is time to translate this knowledge into education and training for all oncology HCPs and to ensure there are appropriate and targeted resources and information for LGBTQI patients and their carers.

THE OUT WITH CANCER STUDY TEAM MEMBERS

Chloe Parton[1], Antoinette Anazodo[2], Fiona E. J. McDonald[3], Katherine Boydell[4], Kerry H. Robinson[5,]. Gary W. Dowsett[6], Suzanne Chambers[7], Martha Hickey[8], Ian D. Davis[9], Cristyn Davies[10] and Felix Delhomme[11]

[1] School of Health, Te Herenga Waka – Victoria University of Wellington, Wellington, New Zealand

[2]Kids Cancer Centre, Sydney Children's Hospital and School of Women's and Children's, University of New South Wales, Sydney, Australia

[3]Canteen and Faculty of Medicine and Health, The University of Sydney, Sydney, Australia

[4]Black Dog Institute, University of New South Wales, Sydney, Australia

[5]School of Social Sciences and Translational Health Research Institute, Western Sydney University, Sydney Australia

[6]Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne, Australia

[7]Faculty of Health Sciences Australian Catholic University, Brisbane, Australia

[8]Department of Obstetrics and Gynaecology, University of Melbourne and the Royal Women's Hospital, Melbourne, Australia

[9]Eastern Health Clinical School, Monash University and Eastern Health, Melbourne, Australia.

[10]Specialty of Child and Adolescent Health, Faculty of Medicine and Health, University of Sydney, Australia; and School of Social Sciences and Psychology, Western Sydney University

[11]ACON, Sydney, Australia

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Western Sydney University Human Research Ethics Committee (H12664). Written informed consent to participate in this study was provided by the participants' legal guardian/next of kin.

AUTHOR CONTRIBUTIONS

JU and JP designed the study and prepared the application for funding, in collaboration with The Out with Cancer Study Team members. Data were collected and coded by RP, KA, and AH. JU and RP conducted analysis of the data in collaboration with AH, JP, and KA. The Out with Cancer Study Team made critical commentary on the coding, the analytic plan and on the written paper. All authors contributed to the article and approved the submitted version.

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Reaching the “Hard-to-Reach” Sexual and Gender Diverse Communities for Population-Based Research in Cancer Prevention and Control: Methods for Online Survey Data Collection and Management

Katie J. Myers[1], Talya Jaffe[1], Deborah A. Kanda[1], V. Shane Pankratz[1,2], Bernard Tawfik[1,2], Emily Wu[1,3], Molly E. McClain[4], Shiraz I. Mishra[1,5], Miria Kano[1,2], Purnima Madhivanan[6,7,8] and Prajakta Adsul[1,2]*

[1] Comprehensive Cancer Center, University of New Mexico, Albuquerque, NM, United States, [2] Department of Internal Medicine, School of Medicine, University of New Mexico, Albuquerque, NM, United States, [3] Department of Obstetrics and Gynecology, School of Medicine, University of New Mexico, Albuquerque, NM, United States, [4] Department of Family and Community Medicine, School of Medicine, University of New Mexico, Albuquerque, NM, United States, [5] Department of Pediatrics, School of Medicine, University of New Mexico, Albuquerque, NM, United States, [6] Department of Health Promotion Sciences, Mel & Enid Zuckerman College of Public Health University of Arizona, Tucson, AZ, United States, [7] Comprehensive Cancer Center, University of Arizona, Tucson, AZ, United States, [8] Public Health Research Institute of India, Mysuru, India

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***Correspondence:**
Prajakta Adsul
padsul@salud.unm.edu

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Purpose: Around 5% of United States (U.S.) population identifies as Sexual and Gender Diverse (SGD), yet there is limited research around cancer prevention among these populations. We present multi-pronged, low-cost, and systematic recruitment strategies used to reach SGD communities in New Mexico (NM), a state that is both largely rural and racially/ethnically classified as a “majority-minority” state.

Methods: Our recruitment focused on using: (1) Every Door Direct Mail (EDDM) program, by the United States Postal Services (USPS); (2) Google and Facebook advertisements; (3) Organizational outreach *via* emails to publicly available SGD-friendly business contacts; (4) Personal outreach *via* flyers at clinical and community settings across NM. Guided by previous research, we provide detailed descriptions on using strategies to check for fraudulent and suspicious online responses, that ensure data integrity.

Results: A total of 27,369 flyers were distributed through the EDDM program and 436,177 impressions were made through the Google and Facebook ads. We received a total of 6,920 responses on the eligibility survey. For the 5,037 eligible respondents, we received 3,120 (61.9%) complete responses. Of these, 13% (406/3120) were fraudulent/suspicious based on research-informed criteria and were removed. Final analysis included 2,534 respondents, of which the majority (59.9%) reported hearing about the study from social media. Of the respondents, 49.5% were between 31-40 years, 39.5% were Black, Hispanic, or American Indian/Alaskan Native, and 45.9% had an annual household income below $50,000. Over half (55.3%) were assigned male, 40.4% were assigned female, and 4.3% were assigned intersex at birth. Transgender respondents made up 10.6% (n=267) of the respondents. In terms of sexual orientation, 54.1% (n=1371) reported being gay or lesbian, 30% (n=749) bisexual, and 15.8% (n=401) queer. A total of 756 (29.8%) respondents reported receiving a cancer diagnosis and among screen-eligible respondents, 66.2% reported ever having a Pap, 78.6% reported ever having a mammogram, and 84.1% reported ever having a colonoscopy. Over half of eligible respondents (58.7%) reported receiving Human Papillomavirus vaccinations.

Conclusion: Study findings showcase effective strategies to reach communities, maximize data quality, and prevent the misrepresentation of data critical to improve health in SGD communities.

Keywords: cancer screening (MeSH), sexual orientation, gender identity (MeSH), recruitment, cancer, cancer prevention

INTRODUCTION

In the United States (U.S.), about 5% of the population identifies as Sexual and Gender Diverse (SGD) (1). SGD is an umbrella term used to describe individuals who are part of the LGBTQIA+ (lesbian, gay, bisexual, transgender, queer, intersex, asexual, and many other sexual orientations and gender identities) community. Despite SGD individuals representing a significant proportion of the population, there is limited research to identify and understand cancer prevention practices among SGD populations, both nationally and in NM.

NM is a minority-majority state, with 49.3% of the population being Hispanic or Latino, 11% being American Indian/Alaska Native, and 36.8% being non-Hispanic White (2). Additionally, about one third of New Mexicans report speaking a language other than English at home, with Spanish being the top language (3). NM is the third poorest state in the union with an average poverty rate of 16.2% compared to the U.S. average of 11.2% (4). Additionally, the Congressional Research Office considers 14 out of 33 NM counties to be Persistent Poverty Counties (poverty rates of 19.5% or greater), based on 1990 Census, Census 2000, and 2019 Small Area Income and Poverty Estimates (5). NM is also a very rural state, which can further contribute to disparities (6). Applying the most recent 2010 Rural-Urban Commuting Area (RUCA) codes, approximately 36% of New Mexicans live in rural areas, as defined by the Health Resources and Services Administration (HRSA) (7).

Recent data from the Williams Institute that reports results from the Gallup Survey (1) suggests that 4.5% of the New Mexico (NM) population identify themselves as Lesbian, Gay, Bisexual, or Transgender (LGBT) (8). Among NM SGD populations, 45% report male gender and 55% report female gender. The average age is 37.7 years and they are primarily Latino/a (49%) with 43% being white. Thirty nine percent report a high school education as their highest educational attainment and 14% report being uninsured. Finally, 26% of LGBTQ individuals in New Mexico report having an income less than $24,000 (8). Overall, the SGD communities in NM are relatively younger and primarily belong to groups that experience racial and socioeconomic inequities.

Collectively, the social determinants of health highlighted above can contribute to significant health disparities experienced by people living in NM, further highlighting the need to better understand population perspectives for designing and developing equity-oriented health interventions. For SGD populations, these determinants of health can intersect with their sexual and gender identities, and further exacerbate disparities (9, 10). For example, a transgender man who belongs to a group experiencing racial inequities and has a lower socioeconomic status would face greater barriers to access care as each one of these aspects of his identity is associated with lower access to care (11–13). The most recent (2014) epidemiological data from the NM Department of Health show differences in cervical and breast cancer screening uptake based on sexual orientation, but these data do not document disparities based on gender identity and for other types of cancer (2).

There is a dearth of data around NM SGD populations, especially for rural SGD populations. These populations can face different challenges than SGD populations in urban areas due to the complexity associated with socially conservative locals where they may not feel safe being "out" (14, 15). Juxtaposed with this notion, much of the extant SGD studies have been conducted in large urban cities, with these populations considered as "hard-to-reach" (16, 17). To address this gap, we sought to understand the determinants to cancer prevention practices (e.g. smoking, vaccination, cancer screening, among others) in order to develop future interventions. We proposed conducting a state-wide survey to better understand cancer prevention and control related practices among NM's SGD populations. This paper presents the systematic and innovative

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Abbreviations: EDDM, Every Door Direct Mail; HPV, Human Papillomavirus; HRSA, Health Resources and Services Administration; LGBTQIA, Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, Asexual + many other sexual orientations and genders; REDCap, Research Electronic Data Capture; RUCA, Rural-Urban Commuting Area; SAAB, Sex Assigned at Birth; SGD, Sexual and Gender Diverse; SOGI, Sexual Orientation and Gender Identity; UNMCCC, University of New Mexico Comprehensive Cancer Center; USPS, United States Postal Service.

strategies that were employed for reaching the NM SGD populations, with the goal of recruiting them to participate in a cross-sectional, purposive sampled, web-based survey.

The purpose of this paper is to present empirical data supporting the multi-pronged, low-cost, and systematic recruitment strategies to engage SGD communities in NM, a state that is largely rural, poor, and racially/ethnically classified as a "majority-minority" state. Additionally, we describe the characteristics of the study sample that was recruited using the aforementioned strategies. Data from the SGD communities were collected using online questionnaires which presented unique threats to sample and data validity. We also provide a detailed description on using research-informed strategies to detect fraudulent or suspicious responses and ensure data quality, and these methods can inform similar future efforts.

METHODS

Recruitment Strategies

Recruitment for the survey took place from January to March 2021. To ensure state-wide reach, we focused on four methods (1): Every Door Direct Mail (EDDM) program, by the United States Postal Services (USPS) (2); advertisements on Google and Facebook (3); organizational outreach *via* emails to SGD-friendly businesses; and (4) personal outreach *via* flyers at clinical and community settings across NM. All flyers, ads, and emails contained QR codes (optical labels that contain links that can be accessed using a cellphone camera) and/or links to a survey in both English and Spanish.

The EDDM program by the USPS was the team's primary method employed to reach SGD populations across the state. This program was originally designed to help businesses promote their products by mailing promotional materials to certain audiences in neighboring mailing routes (18). We worked with Taradel® which is an affiliate of the USPS, that provides access and services in addition to EDDM (i.e. digital ads on Google, email outreach, and Facebook ads) (19). Taradel® provides an online mapping tool (See **Figure 1**), which allowed the team to select mailing routes based on attributes such as residential or business addresses, household income, age, home ownership, gender, and presence of children, collated using data from the US Census Bureau (20). To inform the selection of the mailing routes, three criteria could be chosen from a drop-down menu, which then generated a heatmap overlay of mailing routes, indicating how each mailing route matched up with the specified criteria (**Figure 1**). We selected three criteria for this study: residential addresses, household income below 50,000, and age of residents 25 and older. These criteria allowed us to recruit individuals below the median income of NM of $50,000 per year (21) and around the age range at which cervical, breast, colorectal, and lung cancer screening tests are recommended (22–25). Based on the heatmaps generated with these criteria, we selected mailing routes across NM with at least a 50% match probability, oversampling where we had local knowledge of SGD friendly neighborhoods. This resulted in the selection of 61 mailing routes, with a total of 27,369 individual addresses.

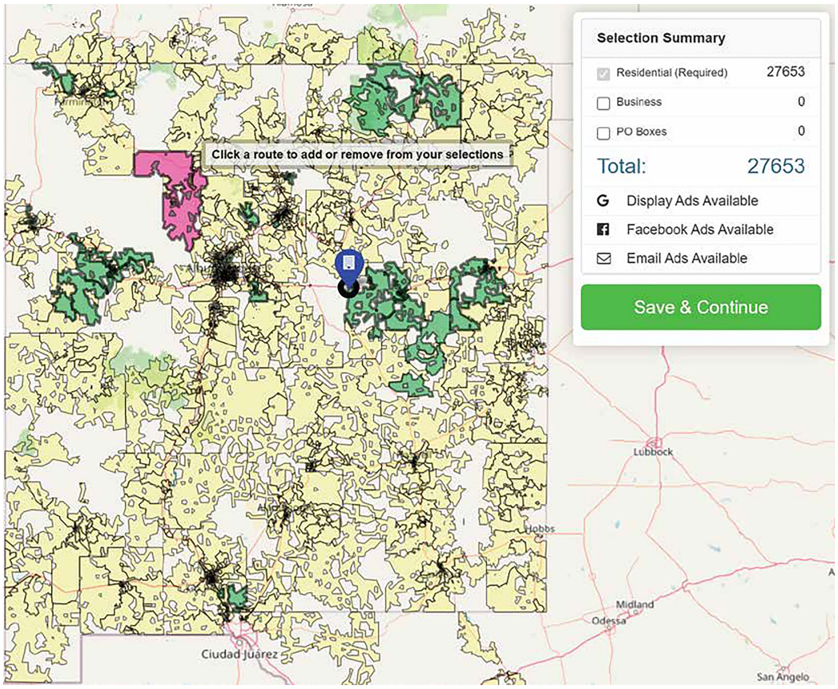
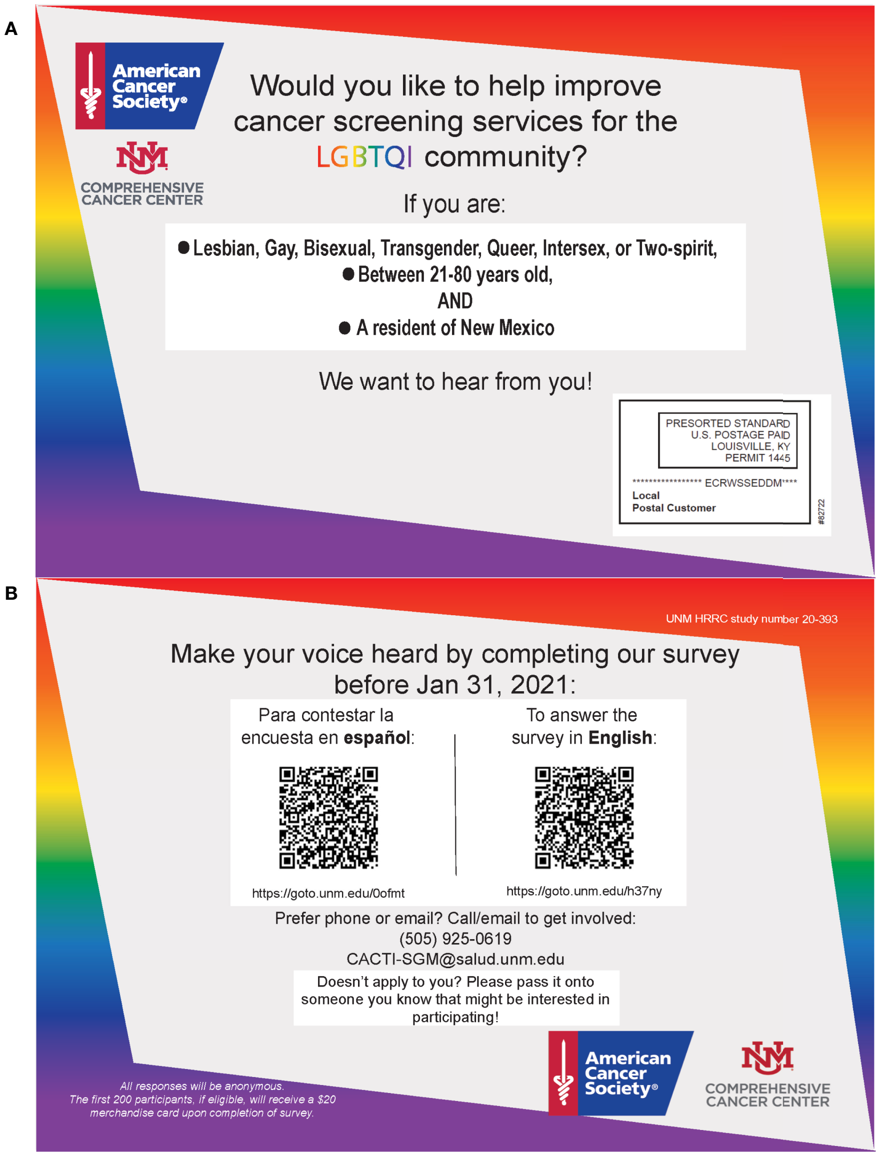

Selection Summary
☑ Residential (Required) 27653
☐ Business 0
☐ PO Boxes 0
Total: 27653
Display Ads Available
Facebook Ads Available
Email Ads Available

FIGURE 1 | Online Mapping tool provided by Taradel to select specific mailing routes.

Flyers for the study were then sent to these addresses (See **Figure 2** for flyers).

The second method of using Google and Facebook ads was an added service provided by Taradel®, that overlapped with the 61 selected mailing routes for the flyers. With the help of their digital services department, we created digital ads that could be displayed through Google and Facebook Ads (See **Figure 3** for Google and Facebook Ads). To create these ads, we used publicly-available stock photos provided in The Gender Spectrum Collection (26) that represent transgender and nonbinary individuals. The Facebook Ads were created in collaboration with the UNM Comprehensive Cancer Center (UNMCCC), that allowed for the Ads to be hosted on UNMCCC's Facebook page, lending credibility to the study recruitment. Both Google and Facebook Ads were disseminated using targeted e-mail and Facebook services provided by Taradel®.

The two other methods for reaching and recruiting individuals into the study relied on building organizational and interpersonal relationships with the NM community to help distribute the flyers and ads created in the previous strategies *via* email outreach. The NM OUT Business Alliance is an advocacy organization that seeks to "advance the common business interests, economic growth, and equality in the workplace and society for its LGBTQ members, businesses, and allies by providing educational, networking, and community building opportunities" (27). Toward their goal of cultivating certified suppliers, they offer a free certification for businesses and approximately 100 business in NM were advertised on their



American Cancer Society®

COMPREHENSIVE CANCER CENTER

Would you like to help improve cancer screening services for the LGBTQI community?

If you are:

- Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, or Two-spirit,
- Between 21-80 years old,

AND

- A resident of New Mexico

We want to hear from you!

PRESORTED STANDARD
U.S. POSTAGE PAID
LOUISVILLE, KY
PERMIT 1445

****************** ECRWSSEDDM****
Local
Postal Customer

#82722

UNM HRRC study number 20-393

Make your voice heard by completing our survey before Jan 31, 2021:

Para contestar la encuesta en **español**:
https://goto.unm.edu/0ofmt

To answer the survey in **English**:
https://goto.unm.edu/h37ny

Prefer phone or email? Call/email to get involved:
(505) 925-0619
CACTI-SGM@salud.unm.edu

Doesn't apply to you? Please pass it onto someone you know that might be interested in participating!

All responses will be anonymous.
The first 200 participants, if eligible, will receive a $20 merchandise card upon completion of survey.

American Cancer Society®

COMPREHENSIVE CANCER CENTER

FIGURE 2 | Flyers created for the study **(A)** Front of flyer, **(B)** Back of flyer.

University of New Mexico Comprehensive Cancer Center
February 9 ·

[UNM HRRC study approval number: 20-393]
Help improve cancer-screening services for the LGBTQI community in New Mexico!

We are calling on Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, or Two-spirit New Mexico residents between 21-80 years old to complete this survey!

Please help spread this information by sharing!

CTSCTRIALS.HEALTH.UNM.EDU
CTSCTRIALS.HEALTH.UNM.EDU
Help improve LGBTQI health!

Would you like to help improve cancer screening services for the community?

American Cancer Society
COMPREHENSIVE CANCER CENTER

Make your voice heard by completing our survey before Feb 28, 2021:

To answer the survey in English: https://goto.unm.edu/h37ny

Para contestar la encuesta en español: https://goto.unm.edu/0ofmt

Prefer phone or email?
Call/email to get involved:
(505) 925-0619
CACTI-SGM@salud.unm.edu
Doesn't apply to you?
Please pass it onto someone you know that might be interested in participating!

All responses will be anonymous. The first 200 participants, if eligible, will receive a $20 merchandise card upon completion of survey.

FIGURE 3 | Facebook **(A)** and Google **(B)** ads created for the study.

webpage in early 2021. We identified the publicly available email addresses for contacts listed on their online directory and sent them flyers.

We also partnered with the UNMCCC's Office of Community Outreach and Engagement to promote the study outreach activities (e.g., regular newsletters sent out to members) and listservs. Similar efforts were undertaken through connections made with the NM Cancer Council (28), New Mexico State University's Community Health Education Core, the University of New Mexico Health Sciences Center (UNM HSC) LGBTQ Collaborative (29), the UNM LGBTQ Resource Center (30), and Transgender Resource Center of New Mexico (31). Finally, laminated flyers (a requirement imposed due to the ongoing COVID-19 pandemic in order to make them easy to disinfect and clean) were placed in clinical and community settings (including the Southeast Heights Family Health Clinic (32) and the UNM Truman Clinic (33), (both providing care for the SGD populations in Albuquerque, NM) across the state, through study team relationships. Additionally, study team members searched for LGBTQIA+ Facebook groups throughout the state and sent them a message containing the flyer and Facebook ad, asking them to post to their pages.

Survey Design and Distribution Methods

All study procedures received approval from University of New Mexico's Human Research Protection Office (Study number 20-393). All surveys were managed using Research Electronic Data Capture (REDCap) tools hosted by the University of New Mexico (34, 35), that provides a secure, web-based application designed to support data collections for research studies. The surveys were designed in English and translated into Spanish by a certified translation specialist, and both English and Spanish versions were used for data collection. All surveys were pilot tested by the research team and a small group of volunteers prior to data collection. The surveys were designed with two specific objectives (1): to screen individuals that could participate in the survey, and (2) to elicit individual's self-report of cancer screening and prevention practices.

The eligibility survey (**Supplementary Appendix 1A**, **1B**) queried about their age range, NM resident status, whether they were a member of SGD community, and how they heard about the study. If respondents answered that they were between 21-80 years old, were a resident of NM, and were members of the SGD community, they were considered eligible These criteria were used to specifically recruit individuals in the age range where cervical (21 – 65 years), breast (50 – 75 years), colorectal (45 – 36), and lung cancer (50 – 80 years) screenings are recommended (18, 19, 34, 35) and those who were members of the NM SGD community. All flyers, ads, and emails contained QR codes and/or links to a survey in both English and Spanish. All responses to the eligibility screener were reviewed by the study team weekly and duplicate emails, incomplete, and ineligible responses were removed.

All eligible respondents received the cancer prevention practices survey (**Supplementary Appendix 2A**, **2B**) which was adapted from the annual and lifetime surveys developed by the PRIDE study (37). We asked questions about demographics, body organs, physical health, Human Papillomavirus (HPV) vaccination, health care access, cancer screening practices (for cervical, breast, colorectal, and lung cancer) as well as what influenced these practices, and whether they would like to hear from us regarding study findings. Branching logic was applied depending on the age of the participant, their current body organs, whether they had been diagnosed with the type of cancer that was being asked about, and certain behaviors (i.e., if they had smoked at least 100 cigarettes in their lifetime for lung cancer screening). Two open-ended questions asked about anything else they would like to share about their health and if they had any additional comments about the survey. A total of 45-73 close-ended questions and two open-ended questions were included in the final survey. The survey was pre-tested and estimated to take 10-20 minutes, depending on branching logic.

To determine how many respondents were residents of rural counties, we asked the survey respondents to provide zip codes. We matched these with State-County-Tract FIPS codes, which were then matched with 2010 RUCA codes (7). The HRSA definition defines rural as all non-metro counties, tracts with RUCA codes between 4-10, and large metro tracts of at least 400 square miles in an area with a population density of 35 or less per square mile with RUCA codes 2-3. HRSA uses this definition to decide which areas are eligible for rural health funding (38). This definition of rural was then used to determine the percentage of respondents that provided a zip code in a rural area in NM.

The cancer prevention practices survey was sent to the eligible respondents either by email with a unique link to the survey or a paper copy of the survey mailed to their addresses, either in English or Spanish depending on their indicated preference in the eligibility survey. Emails that failed to deliver or bounced back were removed by default. We sent three reminders to those who requested the online version of the survey. The first 200 eligible participants who completed the survey received $20 provided in acknowledgement of the respondent's time and expertise *via* Amazon gift card codes.

Ensuring Data Quality for Survey Research

Having respondents complete the eligibility survey before the cancer prevention practices survey allowed researchers to exclude social bots [software that is programmed to enter many responses in order to receive incentives (39)], duplicates, and ineligible respondents. Despite these phased approaches, there were instances of duplicate qualitative responses in the survey data, which triggered an additional search for strategies to ensuring data quality. We followed the detailed and systematic guidance provided by Pozzar and colleagues (40), in ensuring quality of data collected through social media research. Based on guidance from this research, we defined and operationalized four fraudulent and 17 suspicious criteria (details on the list of fraudulent and suspicious criteria are provided in **Table 1**). We removed responses with one fraudulent criterion or three or more suspicious criteria.

For fraudulent criteria, we considered responses that had (1) mismatched email addresses noted in answers from the same respondent (2); exact matches in qualitative responses greater than three words (3); reported non-US zip codes; and (4) reported to be heterosexual and cisgender. The 17 suspicious criteria broadly fell under four categories of responses with (1): non-NM zip codes (2); Height greater than or equal to 7feet or less than 4 feet and weight less than 90 pounds (3); nonsensical qualitative responses; and (4) incongruence between SAAB (sex assigned at birth), gender identity, sexual orientation, and current body organs. This last category considered suspicious were based on definitions of terms (i.e., "transgender", "cisgender", "straight" and "lesbian") (42, 47) as well as current practices in genital gender affirmation surgeries (43–46).

RESULTS

Reaching the NM SGD Populations

The strategies of recruitment and data quality assurance detailed above collectively contributed to the recruitment of the overall sample of 2,534 respondents included in the analysis for this study. The overall study flow is shown in **Figure 4**. With the EDDM program, we selected over 61 mailing routes across the state where 27,369 flyers (highlighted as Direct Mail in **Figure 5**; this figure was altered in the form of color change to increase visibility and accessibility) were distributed to the residential addresses. The EDDM vendor provided detailed data (see **Figure 5**) on the overlapping strategy for the targeted Google Ads and Facebook Ads to residents on these mailing routes that collectively led to 393,523 impressions [i.e. how many times an ad was displayed on a person's screen for Facebook (48) or on a search result page for Google (49)], resulting in 686 clicks (i.e. how many times a person clicked on the ad). The same vendor also sent 15,284 emails, of which 7,595 were delivered, 52 were opened, and 15 people clicked on the content inside the email. Based on these numbers, we believed we reached a total of

TABLE 1 | Fraudulent and suspicious criteria applied to ensure data quality.

Fraudulent criterionN = 489 removed		**Justification**
Duplicate emails	1	These emails were duplicated in the responses for how individuals would like to hear about the study or how they would like to receive their merchandise card, indicating they were from the same respondent.
Exact matches in qualitative responses greater than 3 words	2	These responses were under the two qualitative questions we asked on the survey and there were several duplicate responses in these fields across respondents.
Non-US zip code	3	Non-US zip codes indicated that these respondents were not part of our desired study population and therefore likely bots.
Respondent that they were heterosexual and cisgender	4	These individuals were not part of the study population we were wanting to query and were therefore removed from the analysis.
Suspicious criterion N = 97 removed		
Non-NM zip code	1	One criterion for inclusion in this study was that the respondent was a resident of New Mexico. However, we felt that individuals that were residents of New Mexico could be receiving their mail in a location outside of the state, so we made the decision to make this criterion suspicious rather than fraudulent.
Height greater than or equal to 7 feet or less than 4 feet	2	Using the Body Mass Index table, we identified the range of heights that were likely, and considered heights outside of that range suspicious (41).
Weight less than 90 pounds	3	Using the Body Mass Index table, we identified the low end of weight considered and considered weights under than suspicious (41).
Nonsensical qualitative responses	4	Responses were considered suspicious if they didn't make sense in response to the question asked. Examples of these responses include "Establish a federal bullying task force" in response to the question "Is there anything else you would like to share with us about your health or well-being?" and "Provide emergency shelters and support services" to the same question.
Respondent indicated that they were a transgender woman and AFAB	5	These responses were considered suspicious because the term "transgender" refers to someone whose gender does not align with the sex assigned at birth. Therefore, if a respondent were AFAB and identified as transgender, they would be a transgender man or one of the other nonbinary options, not a transgender woman.
Respondent indicated that they were transgender man and AMAB	6	These responses were considered suspicious because the term "transgender" refers to someone whose gender does not align with the sex assigned at birth. Therefore, if a respondent were AMAB and identified as transgender, they would be a transgender woman or one of the other nonbinary options, not a transgender man.
Respondent indicated that they were a cisgender woman and AMAB	7	These responses were considered suspicious because the term "cisgender" refers to someone whose gender aligns with the sex they were assigned at birth. Therefore, if a respondent were AMAB and identified as cisgender, they would be a cisgender man and not a cisgender woman.
Respondent indicated that they were a cisgender man and AFAB	8	These responses were considered suspicious because the term "cisgender" refers to someone whose gender aligns with the sex they were assigned at birth. Therefore, if a respondent were AFAB and identified as cisgender, they would be a cisgender woman and not a cisgender man.
Respondent indicated that they were a masculine gender (cisgender man, transgender man, or man) and a lesbian	9	These responses were considered suspicious because the term "lesbian" refers to a woman who is attracted to other women. Therefore, if someone's gender is masculine, it is unlikely that they also identify as a lesbian.
Respondent indicated that they were heterosexual and another sexual orientation other than asexual	10	The term "straight" indicates that one is attracted primarily to members of the opposite gender, and is generally exclusive of other orientations. This is not to say that straight individuals are not sometimes attracted to people of the same sex or even have sex with them, but that they do not generally also identify as a member of the SGD community (42). However, the sexual orientation of asexual can exist on a spectrum and refers to individuals who have little or no attraction to others, and it does not indicate what gender(s) they may be either sexually or romantically attracted to.
Respondent indicated that they were AMAB and had a vagina and a penis	11	These responses were considered suspicious because genital gender affirmation surgeries for individuals who are AMAB usually consist of a vaginoplasty (creation of a vagina) that is created through some form of penile inversion procedure, where the lining of the vaginal canal is created from the skin of the penis (43). Therefore, if an individual AMAB had genital gender affirmation surgery that consisted of the creation of a vagina, they would no longer have a penis as part of the vaginoplasty is inversion of the penis.
Respondent indicated that they were AMAB and had a uterus	12	These responses were considered suspicious because, while the technology of uterine transplantation is being developed and looks promising, this is currently not approved as part of genital gender affirmation surgeries and therefore someone who was AMAB would likely not have a uterus.
Respondent indicated that they were AMAB and had a cervix	13	These responses were considered suspicious because, while the technology of uterine transplantation is being developed and looks promising, this is currently not approved as part of genital gender affirmation surgeries and therefore someone who was AMAB would likely not have a cervix (44).
Respondent indicated that they were AMAB and had ovaries	14	These responses were considered suspicious because, much like uterine transplantation, ovarian transplantation is currently not approved as part of genital gender affirmation surgeries and therefore someone who was AMAB would likely not have ovaries (45).
Respondent indicated that they were AFAB and had a uterus and no vagina.	15	These responses were considered suspicious because, in genital gender affirmation surgery for individuals AFAB, a vaginectomy (removal of the vaginal canal) is never performed if a total hysterectomy (removal of the uterus along with the cervix) has not already been performed. This is because the vaginectomy would make it impossible to screen for cancer (46).

(Continued)

TABLE 1 | Continued

Fraudulent criterionN = 489 removed		Justification
Respondent indicated that they were AFAB and had a cervix and no vagina.	16	These responses were considered suspicious because, in genital gender affirmation surgery for individuals AFAB, a vaginectomy (removal of the vaginal canal) is never performed if a hysterectomy (removal of the uterus along with the cervix) has not already been performed. This is because the vaginectomy would make it impossible to screen for cancer (46).
Respondent indicated they were AFAB and had a prostate	17	These responses were considered suspicious because a prostate is not present in individuals who were AFAB and prostate transplants are not currently an option for masculinizing genital gender affirmation surgery (26).

AMAB = Assigned Male at Birth; AFAB = Assigned Female at Birth.

436,177 individuals, with the total cost of 3¢ per person reached (i.e. 436,177 impressions) or approximately $6 per complete response (i.e. 2,534 responses included in the final analyses) including incentives for the first 200 respondents (50).

Although it was difficult to estimate the reach of the other strategies that utilized the team members and organizational connections in the community, we asked survey respondents how they heard about the study in both the eligibility survey and the cancer screening practices survey. **Tables 2.1**, **2.2** presents detailed data on these responses; overall, however, respondents noted social media as the most common way they heard about the study. In seven weeks of data collection, we received a total of 6,920 responses on the eligibility survey (English:6,139; Spanish:781). Of these, 27% (n=1,888) were duplicate, incomplete, or ineligible responses with the majority (98%) being duplicate responses that were likely sent from bots. We sent 5,032 unique survey links and mailed five paper surveys. No paper surveys were returned, and we received 3,120 complete online responses (English:2,811; Spanish:309), indicating a response rate of 62%. Survey responses were received from 163 unique NM zip codes and 18% reported living in rural areas in NM as defined by the HRSA (38).

Data Quality Check

As shown in **Table 1**, of the 3,120 responses, 16% (n=489) were fraudulent and were removed. Of the remaining 2,631 respondents, 4% (n=97) met three or more criteria for being deemed suspicious and were excluded from analysis, leaving a total of 2,534 responses included in analysis. Thirteen percent (n=330) met two or more of the suspicious criteria and 30% (n=788) met at least one suspicious criterion, neither of which were grounds for removal from analysis.

Overall Characteristics of the Population Sample

Table 3 provides detailed data about the characteristics of the survey respondents included in the final analysis (n=2534). Over half of the respondents (55.3%) were assigned male at birth, 40.4% were assigned female at birth, and 4.3% were assigned intersex at birth. Transgender respondents made up 10.6% (n=267) of the study sample, while 46.1% of respondents reported being cisgender men and 33.8% reported being cisgender women. In terms of sexual orientation, 54.1% (n=1371) reported being gay or lesbian, 30% (n=749) bisexual, and 15.8% (n=401) queer. Around 85% of the respondents were between the age of 21-40 years. Black, Hispanic, and American Indian/Alaska Native respondents comprised 39.6% of the respondents. Regarding education, income, and employment, 43.7% reported high school or some vocational training as their highest level of education, 45.9% had an annual household income below $50,000, and 19% reported being unemployed.

In relation to their access to health care (shown in **Table 4**), 22.3% (n=564) reported being uninsured, 27.3% (n=691) reported not having a place to go to for routine check-ups, and 42.2% (n=1069) reported unnecessary delays in getting medical care in their lifetime. Overall, 66.3% reported having a primary care provider, however, in the past 12 months, 30% had not seen

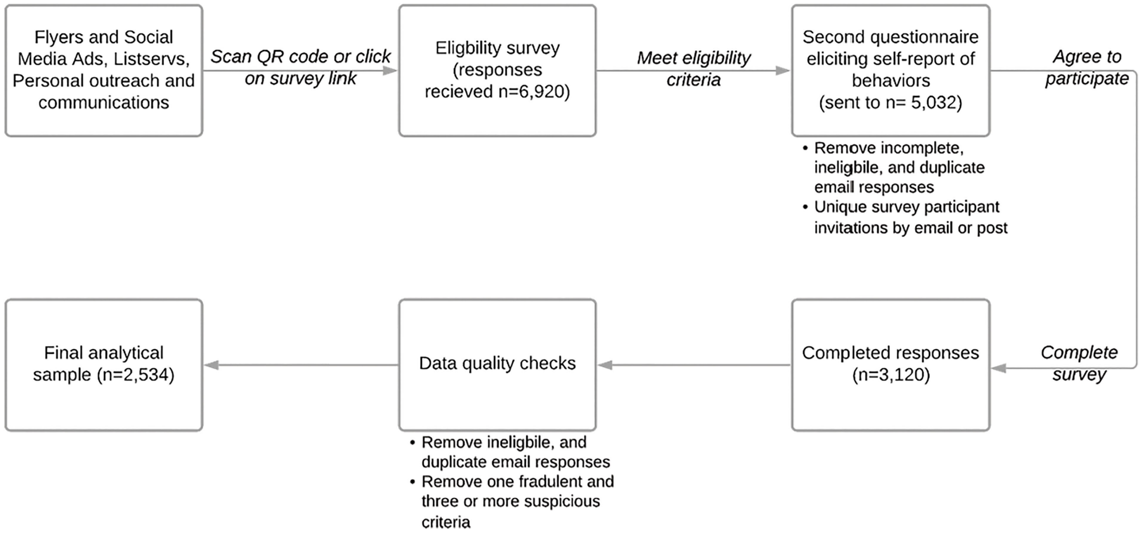


FIGURE 4 | Study Flow.

their provider. In the past 12 months, 47% reported having no insurance, 34% had trouble finding a provider, and 55.5% reported being unable to obtain care. Overall, 31.1% reported being denied or given lower quality medical care in the past 12 months. Among the 797 respondents that were asked about cervical cancer screening, 66.2% (n=528) of pap smear-eligible respondents reported ever being screened with Pap smears. Similarly, 78.6% (n=55) of the 70 mammogram-eligible respondents reported ever receiving a mammogram, 84.1% (n=53) of the 63 colorectal cancer screening-eligible respondents had ever been screened for colorectal cancer, and 33.3% (n=5) of the 15 lung cancer screening-eligible respondents reported ever being screened for lung cancer. A total of 756 (29.8%) people reported receiving a cancer diagnosis. Of respondents who were eligible (i.e. below 46 years old) for the HPV vaccine (n=2379), 58.7% reported receiving a vaccine for HPV.

A total of 1752 (69%) respondents confirmed that they would like to hear from us regarding study findings and 371 (47%) respondents with a cervix answered that they would be interested in participating in a focus group about cervical cancer screening. On the open-ended questions, many respondents expressed their appreciation of the inclusive nature of the survey in queries around sexual orientation and gender identity (SOGI) status. For example, a respondent stated,

"Appreciated the survey trying really hard to be gender and orientation inclusive! I think fat shaming comes up for a lot of queer and trans folks as well so I appreciated that note…"

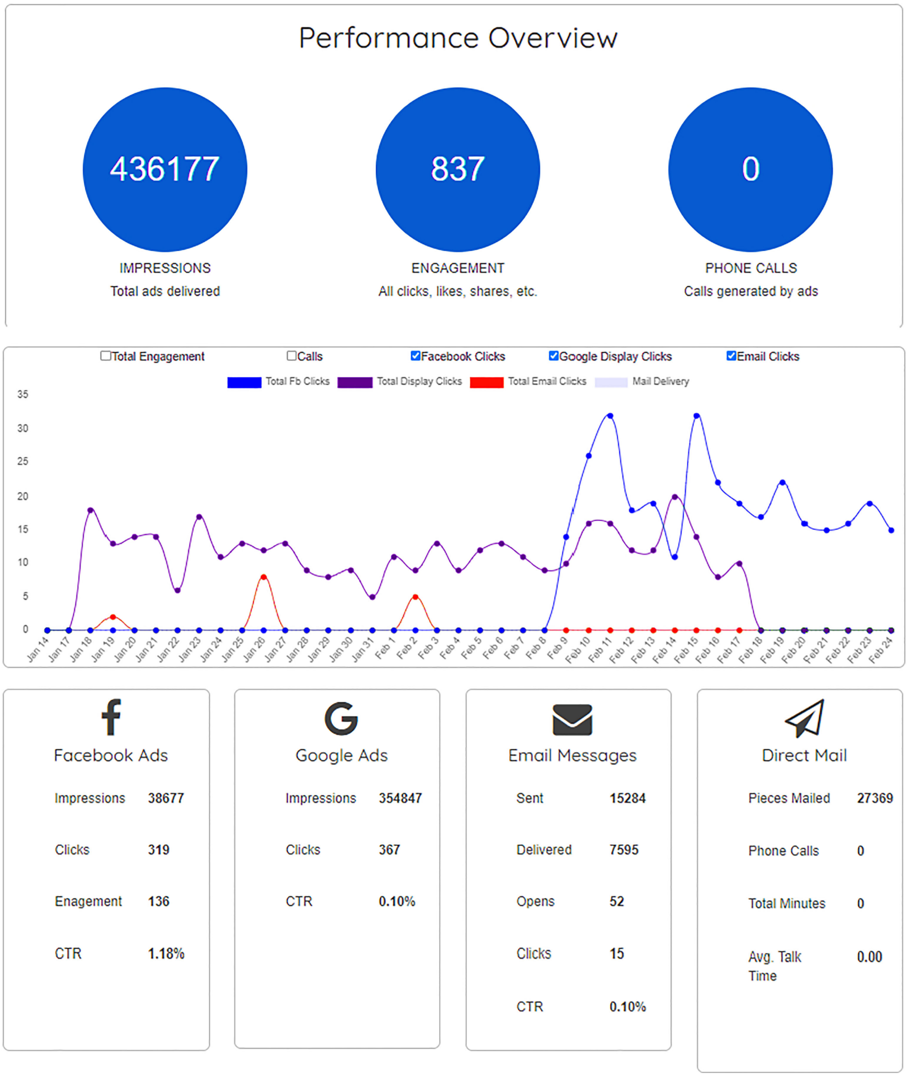
Other participants noted the importance of such a study and the resources for their community, stating:

"Thank you for doing this study! It's very important and I appreciate that you are doing this work … Thank you for conducting a survey on such an important topic and for providing excellent resources at the end. I didn't know about some of these resources and hope to reach out for myself and share them with others".

DISCUSSION

Reaching SGD populations has been a challenge for the field of health research and it is crucial to find ways to mitigate this issue, especially in regards to research on healthcare and health behaviors (51, 52). This paper highlights the variety of methods (i.e. flyers, social media, organizational, and personal outreach) available to the cancer research community to reach diverse populations. We also present additional considerations to ensure that survey questions are asked in a respectful, culturally appropriate manner, which is especially important when surveying populations that have been marginalized. Finally, as opposed to conceptual guidance, we present detailed guidance on how we applied strategies, informed by prior social media research (40, 51, 53), to ensure data quality for SGD research.

To our knowledge, this is one of the few studies to employ EDDM to distribute flyers for an online, population-based health survey (54, 55). This survey's ability to reach individuals from rural areas of the state indicates that utilizing social media and USPS is likely to be an effective method for states with significant rural populations when seeking diverse engagement. Among younger SGD populations, social media has been used successfully to engage and recruit participants (56). However, its use remains limited in engaging rural and adult populations (15), both of whom remain significantly underrepresented in population-based SGD research. Innovative and systematic efforts are needed in order to develop meaningful interventions that address the healthcare needs of marginalized rural SGD individuals (57). In this study, more than 85% of respondents were between 21-40 years old, so additional methods may be



Performance Overview

436177	837	0
IMPRESSIONS Total ads delivered	ENGAGEMENT All clicks, likes, shares, etc.	PHONE CALLS Calls generated by ads

☐Total Engagement ☐Calls ☑Facebook Clicks ☑Google Display Clicks ☑Email Clicks

Facebook Ads

Impressions	38677
Clicks	319
Enagement	136
CTR	1.18%

Google Ads

Impressions	354847
Clicks	367
CTR	0.10%

Email Messages

Sent	15284
Delivered	7595
Opens	52
Clicks	15
CTR	0.10%

Direct Mail

Pieces Mailed	27369
Phone Calls	0
Total Minutes	0
Avg. Talk Time	0.00

FIGURE 5 | Detailed data on the Facebook Ads, Google Ads, Emails, and Direct Mail from Taradel.

needed to support recruitment for the over-40 SGD community. Some studies have had success with crowdsourcing platforms (58) and other methods, such as referrals from current participants and review of electronic medical records to identify eligible participants (59). However, social media provides an important opportunity to engage the SGD community with the potential for future public health interventions and behavioral research. In previous public health studies, impressions have been considered to be equivalent to reaching populations, while clicks indicated the actual behavior of the person (53, 60).

Advocates for promoting SGD research express that these populations are eager to participate in research, especially if their participation can benefit their community (57). This might partly explain the overwhelming response to our recruitment strategies (i.e. 62% response rate). The survey took anywhere from 10-20 minutes to complete and had a monetary incentive, which may have further influenced the response rate. We surmise that another reason for the high number of responses was because people spent most of their time at home during a major wave of the COVID-19 pandemic that occurred in early 2021, which was when we started recruiting participants. However, other research done during the COVID-19 pandemic provides contrasting data. While survey-based research increased significantly during the pandemic, people's responses to surveys tended to decline. The Census found that responses to surveys initially increased at the start of the pandemic, but declined and remained lower than non-pandemic years around the summer of 2020 (61). It has been suggested that the three-fold increase in social media-based recruitment and online survey administration during the pandemic likely led to "survey fatigue." (62)

Another potential justification for the large number of respondents may be that we ensured an appropriate inquiry into

TABLE 2.1 | Survey respondents from eligibility screener and pre-cleaned main survey responses.

Participant’s response to the question“How did you hear about this survey?”	Number of Responses (n)	Percentage of Responses* (%)
Eligibility survey (n = 6,920)		
Social media (Facebook/Twitter)	5,249	75.9
Email	2,582	37.3
Mailed flyer	2,305	33.3
Family/friend/colleague	2,526	36.5
Other**	13	0.2
Missing	24	0.3
Main survey (n = 3,120)		
Social media (Facebook/Twitter)	1866	59.9
Email	1299	41.7
Mailed flyer	470	15.1
Family/friend/colleague	232	7.5
Other**	6	0.2
Missing	8	0.3

*Respondents were given the option to select all that apply

**“Other” responses included: LGBTQ collaborative, PFLAG Silver city, NM, Pop-up [Ads], listservs, flyers, newsletters, and don’t remember

SOGI status for the respondents. As mentioned above, the comments left at the end of the survey indicated appreciation for the respectful ways in which the questions were asked, and gratitude that the research was being conducted in the first place. These responses underscore the importance of gender expansive, non-heteronormative language in both research and healthcare. Using gendered and heteronormative language can alienate SGD populations and lead to reduced care-seeking practices (63). This highlights the need for using gender expansive language in educational materials as well as in intake forms and when speaking to patients and other healthcare providers.

Social media and other internet-based methods are considered to be cost-effective and often provide greater reach to the populations of interest (64, 65). However, they do present issues with people enrolling more than once, social bots, and respondents who do not fit the eligibility criteria (40, 65). Additional strategies to manage this type of data collection and prevent/detect fraudulent responses are necessary (40). We created consistent criteria with which to evaluate responses in order to determine authenticity and mitigate fraud. We also filtered out-of-country zip codes, along with removing any users with identical answers to open-ended questions. These methods

TABLE 3 | Demographic characteristics of the population sample.

Characteristic	n (%)
Sex assigned at birth	
Female	1025 (40.4)
Intersex	108 (4.3)
Male	1401 (55.3)
Gender	
Cisgender man	1169 (46.1)
Cisgender woman	857 (33.8)
Non-binary	241 (9.5)
Transgender man	126 (5.0)
Transgender woman	141 (5.6)
Sexual orientation	
Bisexual	749 (30.0)
Lesbian/gay	1371 (54.1)
Queer	401 (15.8)
Straight	13 (0.5)
Age	
21-30y	901 (35.5)
31-40y	1255 (49.5)
41-50y	308 (12.2)
51-60y	52 (2.1)
61-70y	14 (0.6)
70-80y	4 (0.2)
Race	
American Indian or Alaska Native	75 (3.0)
Black, African American, or African	299 (11.8)
Hispanic	628 (24.8)
White	1324 (52.2)
Other	135 (5.3)
Missing	73 (2.9)
Education	
High school or less	239 (9.4)
Some college or vocational training	869 (34.3)
College and/or advanced degree	1411 (55.7)
Missing	15 (0.6)
Income	
$0-$30,000	314 (12.4)
$30,000-$50,000	849 (33.5)
$50,000-$70,000	872 (34.4)
$70,000+	495 (19.5)
Missing	4 (0.2)
Employment	
Employed	1990 (78.5)
Unemployed	482 (19.0)
Missing	62 (2.4)
Rural/Non-Metropolitan *vs* Metropolitan	
Rural/Non-metropolitan	449 (17.7)
Metropolitan	1675 (66.1)
Missing	410 (16.2)

TABLE 2.2 | Survey respondents from final data.

Participant’s response to the question “How did you hear about this survey?” (n=2,534)	Sex Assigned at Birth n (%) *			Gender n (%) *		Sexual orientation n (%) *			
	Female (n=1025)	Intersex (n=108)	Male (n=1401)	Transgender/ non-binary (n=508)	Cisgender (n=2026)	Lesbian/Gay (n=1371)	Bisexual (n=749)	Queer (n=401)	Straight (n=13)
Social media (Facebook/Twitter)	716 (69.9)	44 (15.1)	863 (61.6)	253 (49.9)	1370 (67.6)	878 (64.0)	505 (67.4)	238 (59.4)	2 (15.4)
Email	367 (35.8)	44 (15.1)	567 (40.5)	238 (46.9)	740 (36.5)	548 (40.0)	467 (62.3)	155 (38.7)	8 (61.5)
Mailed flyer	93 (9.1)	18 (16.7)	133 (9.5)	47 (9.3)	197 (9.7)	126 (9.2)	86 (11.5)	31 (7.7)	1 (7.7)
Family/friend/colleague	72 (7.0)	10 (9.3)	88 (6.3)	58 (11.4)	112 (5.5)	80 (5.8)	46 (6.1)	37 (9.2)	7 (53.8)
Other**	4 (0.4)	0 (0)	2 (0.1)	2 (0.4)	4 (0.2)	4 (0.3)	1 (0.1)	1 (0.2)	0 (0)

* Respondents were given the option to select all that apply.

** “Other” responses included: LGBTQ collaborative, PFLAG Silver city, NM, Pop-up [Ads], listservs, flyers, newsletters, and don’t remember.

TABLE 4 | Characteristics of the population in terms of access to care and cancer prevention practices.

Characteristic	n (%)
Insurance	
Yes	1911 (75.4)
No	564 (22.3)
Don’t know	47 (1.9)
Missing	12 (0.5)
Place to go for routine check up	
Yes	1702 (67.2)
No	691 (27.3)
Don’t know	115 (4.5)
Missing	26 (1.0)
Unnecessary delay in getting medical care	
Yes	1069 (42.2)
No	1346 (53.1)
Not applicable	96 (3.8)
Missing	23 (0.91)
Primary care physician	
Yes	1681 (66.3)
No	767 (30.3)
Don’t know	63 (2.5)
Missing	23 (0.9)
Seen primary care in past 12 months (n=1681)*	
Yes	1147 (68.2)
No	504 (30.0)
Don’t know	15 (0.9)
Missing	15 (0.9)
Uninsured in past 12 months	
Yes	1277 (50.4)
No	1191 (47.0)
Don’t know	53 (2.1)
Missing	14 (0.6)
Trouble finding provider past 12 months	
Yes	861 (34.0)
No	1355 (53.5)
I haven’t tried	267 (10.5)
Don’t know	34 (1.3)
Missing	17 (0.7)
Unable to obtain care in the past 12 months	
Yes	1010 (39.9)
No	1407 (55.5)
Not applicable	95 (3.7)
Missing	22 (0.9)
Denied or given lower quality medical care in the past 12 months	
Yes	787 (31.1)
No	1621 (64.0)
Not Applicable	115 (4.5)
Missing	11 (0.4)
Previous cancer diagnosis	
Yes	756 (29.8)
No	1760 (69.5
Don’t know	0 (0)
Missing	18 (0.7)
Ever received cancer screening	
Cervical (n=797)	528 (66.2)
Breast (n=70)	55 (78.6)
Colorectal (n=63)	53 (84.1)
Lung (n=15)	5 (33.3)
HPV Vaccination (n = 2379) **	
Yes	1396 (58.7)
No	862 (36.2)
Don’t know	112 (4.7)
Missing	9 (0.4)

**Only asked for the respondents that said they had a primary care provider.*

***Calculated using eligible respondents (under 46 years old).*

proved to be efficient for removing many of the most obviously fraudulent responses. Less apparent instances of fraud were difficult to detect, but employing parameters such as height and weight, as well as incongruent answers to SAAB and gender, to deem a response fraudulent or suspicious worked well in this study’s data cleaning process. These criteria, however, were challenging to apply for the intersex population in this study and may partially explain their higher proportion (4.3%) in the study sample compared to rest of the population (1.7%) (66).

Compared to the Williams Institute, there were slightly more respondents in our study who reported male gender, with 51% of study respondents reporting male gender versus 45% from the Williams Institute. There were also more white respondents in our study (52.2% *vs* 43%). Respondents in our study had higher educational attainment with 55.7% of them reporting post-graduate schooling versus 16% reported from the Williams Institute (2). Access to care for this study population reflects previous studies (67), in that it shows lower insurance rates among SGD populations as well as a lower number of SGD individuals reporting having a primary care provider. The uninsured rate in this study population (22.0%) higher than the state average for adults 19 – 64 years old (18.8%) (68, 69), and the percentage of individuals with a primary care provider (66.3%) is also lower than the state average of 71.5% (70). These data represent a troubling trend around access to care for SGD populations which can lead to decreased rates of cancer screening services as well as treatment for other serious conditions (71). This disparity in access to care is likely multifactorial with stigmatization and discrimination in healthcare (72, 73) as well as in the workplace being a large contributor (74). Stigmatization and discrimination in healthcare can lead to SGD individuals’ decreased interaction with the healthcare system (71, 72), while discrimination in the workplace can lead to lower insurance rates among this population (74). Additionally, results gathered by this study illustrate the impact that COVID-19 has had on the healthcare field and the accessibility of services for all populations (75)., showing decreased access to care over the previous 12 months. This impact was more pronounced among populations that experience inequities due to their rural residence, since a common solution for access to care during the pandemic was telehealth, which, further exacerbated the digital divide in these communities and a considerable drop in cancer screening (36, 76).

About 69% of the survey respondents expressed interest in staying engaged and finding out more about the study. Respectful of this enthusiasm and in line with the guidance from the cancer research community working with SGD populations, we are committed to centering the study findings and future research within community perspectives (40, 63, 64). We utilized the Community Engagement Studio (CES) as a strategy to build relationships within the community. The CES is a consultative model that allows for research specific consultations from community members, often led by the Clinical Translational Center (60, 61). We conducted a Community Engagement Studio (CES) with 11 members from the NM SGD community. Conversations with the community members helped gather insights on communication strategies, future research endeavors, and opportunities to collaborate with the SGD community in NM. When asked about engagement, studio participants described their preferences in not using the term "sexual gender diverse communities" because they did not identify with the term, and instead preferred being referred to as the "LGBTQ+" community. Several mentioned the need for quick, relevant communication materials to engage the community (e.g., a 60-90 second video *via* Tik-Tok, YouTube, or Instagram/Facebook stories, or an Instagram/Twitter infographic with a "link in bio" or QR code). The group mentioned engaging young adults early in prevention, educating clinicians on the importance of inclusive language, collaborating with clinics that have direct trans and queer healthcare provision experience, and addressing the bias against the community from the medical providers. The majority of the community experts expressed interest in continued future discussions and we hope to engage them as a study-specific advisory council for gathering guidance on future research endeavors.

As with most research, this study is subject to certain limitations. These limitations primarily result from the use of a purposive sampling technique, volunteer bias, and the use of the internet to both recruit participants and to administer the survey. Purposive sampling, a process in which researchers pick particular segments of the population to recruit for a study, is prone to researcher bias and can result in a lack of generalizability (77). Such a strategy was suitable, because this was a pilot study aimed at gaining a preliminary understanding of the cancer screening practices of the SGD community in NM. Using purposive sampling to determine whether or not a perceived issue needs more research and resources devoted to it is widely regarded as a reasonable and effective use of this sampling method despite its inherent limitations (77). Even though two of our four methods relied on personal and organizational outreach, these relationships (i.e., community outreach and engagement offices in cancer centers, and LGBTQ-friendly businesses, among others) exist in several academic-community environments and could be leveraged for similar research studies. We also did not send survey links to people who requested paper surveys because they only provided a postal mailing address in the eligibility. Similarly, we did not attempt to send a paper survey to respondents who did not complete the online survey because they did not provide a postal mailing address. Older people are less likely to respond to web-based surveys (78) and it is likely that we could have had a higher proportion of older LGBTQIA+ adults with the paper survey.

Volunteer bias may have also played a role in our research, as it does in most survey-based studies. The pool of respondents was undoubtedly limited by the fact that participants were asked to answer questions regarding their sexual orientation and gender identity. Many people are not willing or not able to be open with such intimate information. This also applies to other portions of the survey, such as questions that asked about anatomy, cervical cancer screening, or colorectal cancer screening. Many people are not comfortable discussing such topics, and thus those who chose to participate in this survey were likely only a subset of the SGD population in NM. Furthermore, the recruitment flyers advertised a monetary incentive, which may have biased participation towards those experiencing financial need.

Finally, using the internet for reaching these populations can be limiting, as internet access in NM is poor, ranking 45th in the country (18). Internet-based research also typically reaches individuals of higher socioeconomic status and a younger population sample, which may not be representative of the target population (79). Younger people tend to use technology more than older people, which aligns with our findings that over 80% of survey respondents were under 40 years old (80). We believe that some of these barriers were overcome by mailing out flyers. Flyers however, were only delivered to individuals with residential addresses. This is especially pertinent information to take into account when doing research with the SGD community whose members, on average, experience homelessness more than twice as much as their cisgender, heterosexual counterparts (81).

CONCLUSION

To reach state-wide SGD communities and engage them in population-based research, innovative and systematic efforts are needed. Social media and postal flyers may provide successful recruitment opportunities with potential to use these methods for future public health interventions in these populations. When using the online surveys to maximize reach, additional strategies to manage these data and prevent/detect fraudulent responses are needed. While time-intensive, the methods in this study were an effective way to ensure accurate data and to narrow down the responses to include only genuine answers that each represented one individual. Findings from this paper have the potential to maximize data integrity and prevent misrepresentation of health data for these communities.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by University of New Mexico's Human Research Protection Office (Study number 20-393). The participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

PA, conceptualized the article and PA, KM, and TJ drafted the manuscript. DK, VP, BT, EW, MM, SM, MK, and PM participated in the workgroup discussions that informed the manuscript making substantial contributions to the design and analysis presented in the paper and revised it critically for important intellectual content. All authors contributed to the article and approved the submitted version.

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SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fonc.2022.841951/full#supplementary-material

Supplementary Appendix 1A | Eligibility survey in English.

Supplementary Appendix 1B | Eligibility survey in Spanish.

Supplementary Appendix 2A | Cancer prevention practices survey in English.

Supplementary Appendix 2B | Cancer prevention practices survey in Spanish.

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Financial Burden and Mental Health Among LGBTQIA+ Adolescent and Young Adult Cancer Survivors During the COVID-19 Pandemic

Austin R. Waters[1,2], *Sara Bybee*[3], *Echo L. Warner*[1,3], *Heydon K. Kaddas*[1], *Erin E. Kent*[2]* *and Anne C. Kirchhoff*[1,4]

[1] *Cancer Control and Population Sciences Research Program, Huntsman Cancer Institute, Salt Lake City, UT, United States,* [2] *Department of Health Policy & Management, Gilling's School of Global Public Health, University of North Carolina Chapel Hill, Chapel Hill, NC, United States,* [3] *College of Nursing, University of Utah, Salt Lake City, UT, United States,* [4] *Department of Pediatrics, University of Utah, Salt Lake City, UT, United States*

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Jane Ussher,
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***Correspondence:**
Erin E. Kent
erin.kent@unc.edu

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Background: In the United States, the cost of cancer treatment can lead to severe financial burden for cancer survivors. The economic impacts of the COVID-19 pandemic compound cancer survivors' financial challenges. Financial burden may be particularly challenging for lesbian, gay, bisexual, transgender, queer, intersex, asexual and other sexual and gender minority (LGBTQIA+) survivors. LGBTQIA+ survivors who are adolescent and young adults (AYA) may face elevated financial burden due to multiple, intersecting identities.

Methods: An explanatory sequential mixed methods design was applied, beginning with a survey of AYA cancer survivors in the Mountain West region of the United States. Survey measures included demographics, COVID-19 impacts, the COmprehensive Score for financial Toxicity (COST), Perceived Stress Scale-4 (PSS-4), and PROMIS anxiety and depression scales. Two-way t-tests were used to analyze differences in outcomes between LGBTQIA+ and non-LGBTQIA+ AYAs. All LGBTQIA+ survey participants were invited to complete an interview, and those who agreed participated in descriptive interviews about financial burden due to cancer, COVID-19, and LGBTQIA+ identity. Interviews were audio recorded, transcribed, and analyzed using Dedoose.

Results: Survey participants (N=325) were LGBTQIA+ (n=29, 8.9%), primarily female (n= 197, 60.6%), non-Hispanic White (n= 267, 82.2%), and received treatment during COVID-19 (n= 174, 54.0%). LGBTQIA+ interview participants (n=9, 100%) identified as a sexual minority and (n=2, 22.2%) identified as a gender minority. Most were non-Hispanic White (n=6, 66.7%) and had received treatment during COVID-19 (n=7, 77.8%). Statistical analyses revealed that LGBTQIA+ AYAs reported significantly worse COST scores than non-LGBTQIA+ AYAs (p=0.002). LGBTQIA+ AYAs also reported significantly higher PSS-4 (p=0.001), PROMIS anxiety (p=0.002) and depression scores (p<0.001) than non-LGBTQIA+ AYAs, reflecting worse mental health outcomes. High costs of cancer treatment and employment disruptions due to COVID-19 contributed to substantial financial stress, which exacerbated existing mental health challenges and introduced new ones.

Conclusions: LGBTQIA+ AYA survivors reported substantial financial burden and psychological distress exacerbated by cancer, the COVID-19 pandemic, and LGBTQIA+ stigma. Given their multiple intersecting identities and potential for marginalization, LGBTQIA+ AYA survivors deserve prioritization in research to reduce financial burden and poor mental health.

Keywords: SGM, LGBTQIA$^+$, AYA, financial hardship, financial toxicity, mental health

1 INTRODUCTION

Rising costs of cancer care in the United States put a substantial proportion of cancer patients at risk of financial harm (1, 2). Financial burden due to cancer care is associated with poor economic, psychological, and physical health outcomes, and it may be worsened by the economic and psychological impact of the COVID-19 pandemic (3, 4). A variety of factors influence cancer patients' likelihood of experiencing financial burden, including low socioeconomic status, younger age, minority race/ethnicity, social network wealth, employment disruptions, and health insurance access and quality (2, 5). While currently an unexplored area of research, adolescent and young adult (AYA) cancer patients, particularly those who are a part of the lesbian, bisexual, gay, transgender, queer, intersex, asexual, plus (LGBTQIA+) community may experience worse and unique financial burden in comparison to heterosexual, cisgender AYAs due to their multiple intersecting identities and experiences.

AYA cancer survivors are those who were diagnosed between the ages of 15 and 39, a developmentally dynamic time of life that positions them at greater risk of financial burden than older cancer survivors who often have more stable finances, careers, and health insurance coverage (6, 7). AYAs also have little to no experience navigating the healthcare system prior to their cancer diagnosis, potentially fostering financial burdens that those with experiential learning may know how to circumvent (e.g., knowing how to file insurance appeals, utilizing or having employment that allows for FMLA, or applying for financial aid) (6, 8).

LGBTQIA+ populations of all ages experience disparities within and outside of the cancer context that may influence LGBTQIA+ AYA survivors' financial burden (9, 10). Furthermore, identity development and the process of coming out for LGBTQIA+ individuals typically occurs during adolescence and young adulthood (11, 12). LGBTQIA+ identity development during the cancer experience can further complicate the already intersecting identities of this population and may lead to additional burden (13). Among LGBTQIA+ populations, some sub-groups of the community have lower incomes and experience workplace discrimination more often than their non-LGBTQIA+ peers (14, 15). Due to intertwined structural and interpersonal factors, LGBTQIA+ individuals are more likely to struggle with mental health issues, exhibit negative coping behaviors such as binge drinking, and are more likely to commit suicide than cisgender, heterosexual individuals (16, 17) Within the cancer context, LGBTQIA+ populations experience a disproportionate cancer burden, provider-based discrimination, unwelcoming cisheternomative clinic spaces, worse mental health, and cancer morbidity (18–20).

The aim of this study was to first assess differences in financial burden and mental health outcomes between LGBTQIA+ and non-LGBTQIA+ AYA survivors during the COVID-19 pandemic. Second, we aimed to describe how the COVID-19 pandemic, cancer treatment, LGBTQIA+ identity and related stigma impacted LGBTQIA+ AYA survivors' financial burden and mental health. Our findings underscore the importance of considering intersecting identities and the historical and structural forces that influence LGBTQIA+ AYA survivors' financial burden. These findings serve as a first look at an understudied population and have the potential to inform future research and equity-based interventions aimed at mitigating financial burden.

2 MATERIALS AND METHODS

To describe LGBTQIA+ AYA survivors' financial burden during the COVID-19 pandemic, we deployed a sequential explanatory mixed methods study design (21). First, we surveyed AYA cancer survivors of all sexual orientations and gender identities who received AYA patient navigation services in the Mountain West region of the United States. Survey findings documented differential financial burden among LGBTQIA+, which led us to conduct one-on-one semi-structured video interviews with a subset of AYA survivors who identified as LGBTQIA+.

2.1 Participants and Data Collection

Eligible survey participants were 18 years or older at time of survey, diagnosed with cancer between the ages of 15 and 39 years, and received services through the Huntsman-Intermountain Adolescent and Young Adult (HIAYA) Cancer Care Program in Utah, which serves AYAs with cancer in the Intermountain West region of the United States. All survivors who had received services through HIAYA were emailed a link to the one-time survey in October 2020. A total of 675 survivors were eligible and contacted *via* email. Follow up occurred between October 2020 to January 2021 *via* email, mail, and text messages, resulting in 341 participants (response rate of 50.5%). Our survey analyses are restricted to respondents who completed the sexual orientation and gender identity questions (N=325).

Participants who were eligible for the LGBTQIA+ interviews took part in the larger AYA survey and self-identified as LGBTQIA+. A total of 29 (8.9%) participants from the larger survey sample (N=325) self-identified as having a sexual orientation or gender identity other than heterosexual, cisgender, and binary and were therefore categorized as LGBTQIA+. Of these, there were 25 respondents who agreed to be re-contacted for future research. These potential participants were emailed an invitation to participate in an individual semi-structured video interview between August and November 2021 and received follow-up emails and text messages inviting them to take part in an interview about their financial experiences. Potential participants who agreed to partake in the interview completed the informed consent process and engaged in an interview *via* videoconferencing software. All interviews were conducted by ARW, a male doctoral student in public health with four years of experience in AYA cancer research. Nine participants agreed to be interviewed (participation rate of 36%). Six participants declined to participate (often citing their willingness to participate in a survey but not an interview), three were lost to follow up, and seven were unable to be contacted. Participants received one $20 gift card for participating in the survey or two $20 gift cards for participating in both the survey and interview as a thank you for their time. All study procedures were approved by the University of Utah Institutional Review Board (IRB#00091443).

2.2 Survey Design

Survey questions included sociodemographics, cancer diagnosis, mental health, and the COVID-19 pandemic. The HIAYA research team, which includes health services researchers, clinicians, and research staff with expertise in AYA cancer and LGBTQIA+ research, designed the survey for a larger study to document the financial experiences and healthcare utilization of AYA cancer survivors during the COVID-19 pandemic. Herein we report on selected items relevant to LGBTQIA+ survivors' financial and mental health experiences during COVID-19.

2.3 Survey Measures

Outcome measures from the survey included: COmprehensive Score for financial Toxicity (COST), Perceived Stress Scale – 4 (PSS-4), Patient-Reported Outcomes Measurement Information System (PROMIS) short form measures for anxiety, and a custom short form PROMIS measure for depression. This custom short form was created with the cancer population as a control sample and included 7 items in the cancer depression bank and was scored through the PROMIS Assessment Center (22). COST is a measure of perceived financial stress due to cancer treatment. COST scores range from 0-44 with lower scores indicating greater financial toxicity (23, 24). PSS-4 is a measure of perceived stress with scores ranging from 0-16 with higher scores indicating greater stress (25, 26). The PROMIS anxiety short form is a measure of perceived anxiety with scores ranging from 37.1-83.1 with higher scores indicating worse anxiety (27). The custom PROMIS depression short form is a measure of perceived depression with scores ranging from 38.3-81.5 with higher scores indicating worse symptoms of depression.

The study team reviewed medical records to supplement missing demographic (e.g., gender, race, and ethnicity) information. We combined two survey variables (employment status and changes in employment during the COVID-19 pandemic) to operationalize change in employment status (still employed, decrease in hours/job loss, and increase in hours). Individuals who wrote in responses for their employment status and change in employment status were manually categorized. Treatment status was dichotomized (on treatment/off treatment) based on type of treatment that they were receiving at time of survey (intravenous chemotherapy, oral chemotherapy/pills, surgery, radiation, hormone therapy, immunotherapy, and/or other treatment). Individuals who wrote in responses for their treatment status were manually categorized, and those who responded they were not currently undergoing any of these treatment types were classified as being off treatment. Age at diagnosis was calculated from date of birth and date of first cancer diagnosis. Age at diagnosis was dichotomized (18-26 years/27-39 years), due to changes in insurance coverage that occur at this age in the United States (28). Education was collapsed to three categories (college graduate or higher, some college, high school education or less). Race and ethnicity were collapsed into a single variable (non-Hispanic White, Hispanic, non-Hispanic other). Information on sexual orientation and gender identity were dichotomized (cisgender heterosexual/ LGBTQIA+).

2.4 Survey Data Analysis

Chi-square or Fisher's Exact tests were applied to examine sociodemographic differences between individuals identifying as LGBTQIA+ and individuals identifying as cisgender, heterosexual. For each outcome measure (COST, PSS-4, PROMIS anxiety and depression), two-way t-tests were used to examine differences in the mean between individuals who identified as LGBTQIA+ and individuals identifying as cisgender, heterosexual. Significance was set at $p<0.05$. All analyses were done in STATA 17 (College Station, TX: StataCorp LLC).

2.5 Interview Guide Design

Upon discovering higher financial toxicity among LGBTQIA+ AYAs and the inability to explore driving forces of financial burden in the survey data, our interview guide was developed to disentangle drivers of financial hardship and explore unique experiences faced by LGBTQIA+ AYAs during the COVID-19 pandemic. The interview guide focused on how LGBTQIA+ AYA survivors' cancer, the COVID-19 pandemic, and their LGBTQIA+ identity impacted their financial experiences. The interview guide was modeled to encompass three domains of financial hardship: 1) Material – out of pocket expenses, employment issues, and ability to meet financial needs; 2) Psychological – stress experienced due to costs and lost income; and 3) Behavioral – coping behaviors engaged in as a response to financial hardship including changes in health service utilization and adherence, as well as changes to non-healthcare spending (29, 30). In this analysis the three domains of financial hardship used in the interviews and the COmprehensive Score for financial Toxicity (COST) was used in the survey. Both financial hardship and financial toxicity were used to assess overall financial burden of LGBTQIA+ AYA survivors.

2.6 Qualitative Data Analysis

Interviews were audio recorded, transcribed, and quality checked for accuracy of transcription. They were then de-identified and imported into Dedoose qualitative analysis software. Interpretive descriptive methods of analysis were applied to provide an in-depth account of the financial burden experienced by AYA LGBTQIA+ survivors. Interpretive description is a qualitative technique that acknowledges the constructed nature of experiences of phenomenon but also allows for shared realities (31, 32). This analytical approach is particularly well suited for describing LGBTQIA+ AYA survivors' experiences with cancer, COVID-19, and their LGBTQIA+ identity because of the focus on a strategic synthesis of new understanding and clinical applications (31, 32). As the transcripts were coded, emergent concepts were labeled and emergent codes were sorted into the three financial hardship domains (material financial hardship, behavioral financial hardship, and psychological financial hardship) and an additional domain called mental health challenges. The research team first read through all interview transcripts to gain familiarity with the content and created analytic memos (33). ARW then coded 33% of the interviews to create the initial coding matrix. ARW and SB then coded an additional 33% of the interviews and refined the coding matrix *via* coder consensus. Coder consensus is an activity wherein all coders agree on the labeling of each code within a sub-set of the transcripts to ensure the coding structure is reliably and consistently applied (34). A finalized coding matrix was developed *via* coder consensus (ARW, SB, and ELW) and then used to code all transcripts. To maximize reflexivity, interviews and qualitative analyses were conducted iteratively.

Qualitative analyses were performed by ARW, SB, and ELW in Dedoose; interpretation of the data occurred through iterative weekly author discussions to gain consensus and consistency of the reported findings. The research team approached the analysis and interpretation of the codes from a variety of lenses and identities including "insider" and "outsider" perspectives (i.e., LGBTQIA+ as well as cisgender, binary, heterosexual researchers).

2.7 Data Integration

Data integration occurred at all stages of the study. In conceptualization, an explanatory sequential mixed methods design was chosen to first identify differences in financial hardship among AYA cancer survivors by demographic factors (e.g., LGBTQIA+ identity) and then to explore drivers of those differences using individual interviews (**Figure 1**). Integration *via* connecting also occurred through the sampling frame, meaning that interviewees were a subset of survey participants; thus, interview participants' feedback is connected to the survey results because these participants took part in both the survey (quantitative) and interview (qualitative) portions of the study (35). Lastly results were integrated using a weaving approach in which survey and interview findings are reported in the results by concept rather than analytical method (21, 35). Integration also occurred in the creation of **Figure 2** that visualizes how survey and interview data are presented *via* the weaving approach to data integration. Each finding in **Figure 2** was also linked back to our outcomes of interest and the outcome measure or framework that was used to capture each outcomes of interest in both the survey and interview findings.

3 RESULTS

In **Table 1**, survey participants (N=325) were primarily female (60.6%), non-Hispanic White (82.2%), and received cancer treatment during COVID-19 (54.0%). Nearly half were college graduates or higher (46.0%) and 21.9% reported a decrease in hours or job loss during the COVID-19 pandemic. Differences between LGBTQIA+ and cisgender heterosexual AYA survey respondents included more LGBTQIA+ respondents identifying as female (p-value=0.001), reporting less education (p-value=0.003), and a higher proportion reporting decrease in hours or job loss (p-value=0.001). LGBTQIA+ interview participants (N=9) all identified as sexual minority (100%), while two of the participants also identified as a gender non-binary (22.2%). Interview participants were mostly non-Hispanic White (66.7%) and had received cancer treatment during COVID-19 (77.8%). Most interview participants were college graduates or higher (55.6%) and most reported a decrease in hours or job loss during the COVID-19 pandemic (66.7%). Survey and interview findings are reported by the two main outcomes of interest – financial burden and mental health – visualized in **Figure 2**.

3.1 Financial Burden: Toxicity and Hardship

In the survey, LGBTQIA+ AYAs reported a mean COST score of 14.9 (SD=10.9) while cisgender, heterosexual AYAs reported a mean COST score of 21.6 (SD=10.5). LGBTQIA+ AYAs COST scores were significantly lower, indicating worse financial burden than non-LGBTQIA+ AYAs (p=0.002; **Figure 3**). These survey findings can be grounded by the interview findings which are described under the three domains of financial hardship (29). The interview findings provide context for how financial hardship manifested in LGBTQIA+ AYAs due to their identity, cancer, and the COVID-19 pandemic. Additional illustrative quotes are in **Table 2**.

3.1.1 Material Domain of Financial Hardship

Interview participants faced substantial financial hardship influenced by the high costs of cancer care, the economic impacts of the COVID-19 pandemic, and the impact of their LGBTQIA+ identity on their economic mobility. Many participants reported being laid off or having their hours/pay reduced due to the COVID-19 pandemic, which was further

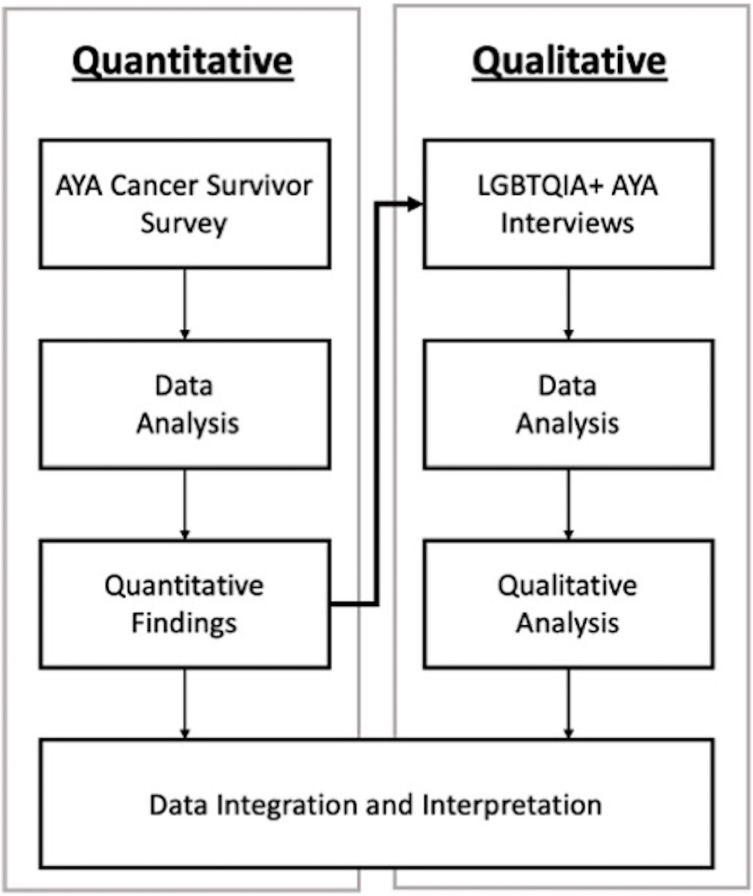
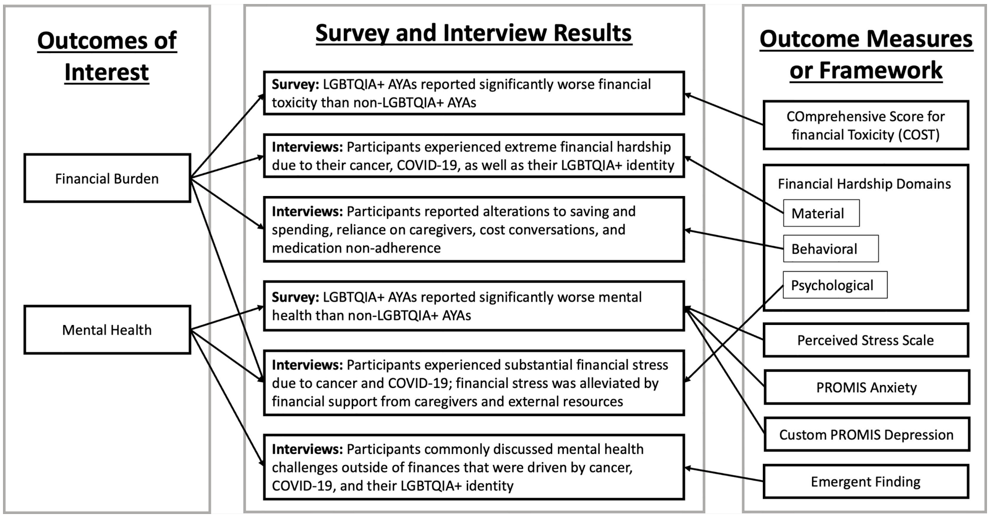


FIGURE 1 | Explanatory Sequential Mixed Methods Study Design Diagram.



Survey: LGBTQIA+ AYAs reported significantly worse financial toxicity than non-LGBTQIA+ AYAs

Interviews: Participants experienced extreme financial hardship due to their cancer, COVID-19, as well as their LGBTQIA+ identity

Interviews: Participants reported alterations to saving and spending, reliance on caregivers, cost conversations, and medication non-adherence

Survey: LGBTQIA+ AYAs reported significantly worse mental health than non-LGBTQIA+ AYAs

Interviews: Participants experienced substantial financial stress due to cancer and COVID-19; financial stress was alleviated by financial support from caregivers and external resources

Interviews: Participants commonly discussed mental health challenges outside of finances that were driven by cancer, COVID-19, and their LGBTQIA+ identity

FIGURE 2 | Integration of Survey and Interview Results and Corresponding Outcome Measures or Framework.

TABLE 1 | Characteristics of Quantitative Survey and Qualitative Interview Participants and Differences by LGBTQIA+ Status among Survey Participants (N=325).

Sociodemographic Factors	**Surveys**							**Interviews**	
	Total (N=325)		**LGBTQIA+ (N=29)**		**Cisgender, Heterosexual (N=296)**		**p-value**	**LGBTQIA+(N=9)**	
	N	**%**	**N**	**%**	**N**	**%**		**N**	**%**
Age at Diagnosis									
18-25 years	164	50.5	17	58.6	147	49.7	0.20	6	66.7
26-39 years	161	49.5	12	41.4	149	50.3		3	33.3
Gender									
Non-binary	2	0.6	2	6.9	–	–	0.001	2	22.2
Female	197	60.6	21	72.4	176	59.5		6	66.7
Male	126	38.8	6	20.7	120	40.5		1	11.1
Ethnicity and Race									
Non-Hispanic White	267	82.2	22	75.9	245	82.8	0.07	6	66.7
Hispanic	30	9.2	6	20.7	24	8.1		2	22.2
Non-Hispanic other	28	8.6	1	3.5	27	9.1		1	11.1
Education[a]									
College grad or higher	149	46.0	5	17.9	144	48.7	0.003	5	55.6
Some college	139	42.9	17	60.7	122	41.2		4	44.4
High school education or less	36	11.1	6	21.4	30	10.1		–	–
Employment Status Changes During Pandemic[b]									
No change	176	56.9	7	26.9	169	59.3	0.001	1	11.1
Decrease in hours/job loss	68	21.9	13	50.0	55	19.3		6	66.7
Increase in hours	67	21.5	6	23.1	61	21.4		2	22.2
Received Cancer Treatment During Pandemic[c]									
Yes	174	54.0	17	58.6	157	53.6	0.60	7	77.8
No	148	46.0	12	41.4	136	46.4		2	22.2

[a] *Missing N=1.*
[b] *Missing N=14.*
[c] *Missing N=3.*
The N=9 interview participants were a sub-set of the N=29 LGBTQIA+ survey participants.
p-values were calculated using Chi-squared or Fisher's exact tests.

complicated by their increased susceptibility to COVID-19 due to their cancer status. One female survivor (26-39 years of age) shared *"It was very difficult because I lost two of my jobs that were giving me that income."* Another non-binary participant (18-25 years of age) stated *"I was barely able to afford rent at the time, rent, and cancer treatment, and all of that [COVID-19] at the same time."* Many participants worked customer facing jobs prior to the pandemic that led some participants to avoid working out of fear of being infected with COVID-19. However, some participants reported situations in which they received employer accommodations after being diagnosed with their cancer to protect them from COVID-19 infection, such as being moved to a less customer facing role. One female participant (18-25 years of age) shared *"It's just hard. Because I don't want to be exposed to anybody or anything like that. I feel like I couldn't work any jobs that involve interacting with other people."* Overall, participants reported that together COVID-19 and cancer drastically reduced their income and ability to make ends meet financially.

Furthermore, some participants reported their LGBTQIA+ identity impacted their material conditions in the form of employment discrimination, which was dependent on their outness. Few participants reported overt discrimination the workplace; however, many participants who were out reported taking lower paying jobs or leaving jobs to find more queer-accepting employment environments, which often manifested in lower paying, customer facing employment. Although one participant reported being called slurs related to their sexual orientation in the employment setting, more commonly participants reported employers "*being weird*" about their identity. One male (18-25 years of age) participant shared *"I had a customer here and there that were just, "Oh, you fucking [LGBTQIA+ slur]," you know."* Another participant (female aged 18-25 years) shared their perception on employers being weird by stating *"One of the ladies who was in there, her eyebrows kind of raised. I'm not gonna say they didn't hire me for that [being LGBTQIA+]. I honestly think it was my schedule because I didn't really know my schedule if I was gonna be sick from the medicine, you know, all of that, but I know they were kind of weird about it."* This weirdness was identified by participants as a factor that influenced not being hired for a job or choosing not to take a job due to their identity. However, discrimination was not reported by participants as the main cause of not receiving an offer of employment. Loss of employment or taking lower paying jobs among out participants further exasperated financial hardship caused by high out-of-pocket costs and instability of income due to COVID-19.

3.1.2 Behavioral Domain of Financial Hardship

In response to financial hardship experienced, participants reported a variety of behavioral responses including: alterations to saving and spending habits; a reliance on caregivers and other external mechanisms for financial support; having cost conversations with clinicians and supportive healthcare staff;

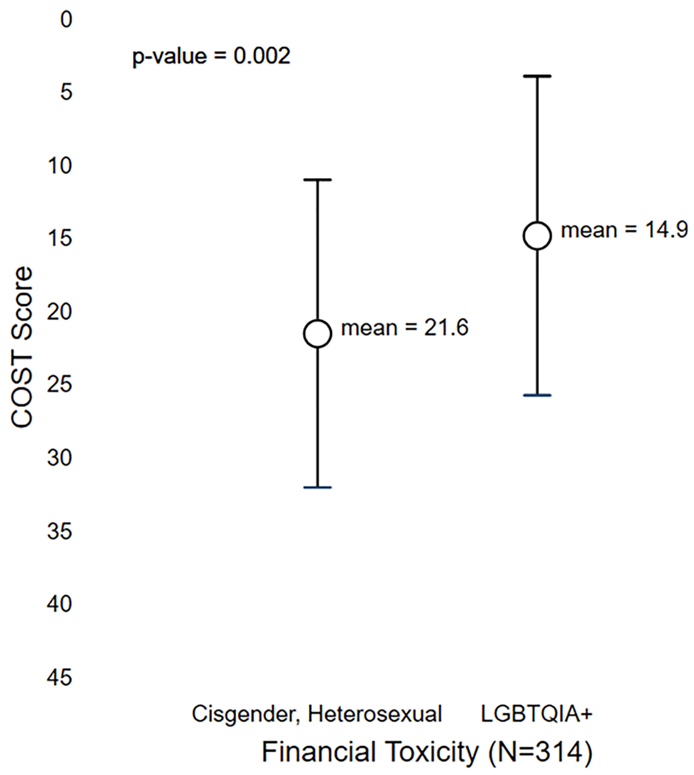


FIGURE 3 | Differences in COST Scores Between Cisgender, Heterosexual and LGBTQIA+ AYA Cancer Survivors.

and rationing of prescription medications. The most commonly reported behavioral response to financial hardship was alterations to spending and saving habits. This reduction in spending ranged from small alterations (e.g., not eating take-out as frequently) to large life-altering spending changes (e.g., moving in with parents when unable to pay rent). A female participant aged 26-39 years of age shared *"And before I got diagnosed with cancer, I was actually living like, in [the city] on my own and then I had to – I couldn't afford anything, so I had to move out and I had to move back in with my parents."* In an extreme case, one participant reported losing their job and becoming homeless. Extreme outcomes, such as homelessness, were driven by job loss resulting from COVID-19 combined with familial non-acceptance of LGBTQIA+ identity. It was common for participants to rely financially on caregivers and crowdfunding platforms; however, when participants were not accepted by their families due to their LGBTQIA+ status, they lost the corresponding financial support. One participant discussed not coming out because of the potential loss of financial support during their cancer treatment and because they already felt marginalized as a person of color.

When asked about their experience and or willingness to discuss treatment costs with providers, most participants indicated they had spoken with a member of their care team or that they were willing to consider having a cost conversation with providers. Few participants reported in-depth conversations with medical providers about costs. Participants were frequently referred to social workers, patient navigators, or hospital financial aid services. Some participants found the resources and aid were extremely helpful while others were frustrated because they did not meet eligibility requirements. In particular, one participant was unable to receive aid because they did not have US citizenship. When cancer costs were unmanageable, participants reported medication non-adherence including skipping doses or delaying filling prescriptions for weeks to months until they could afford the co-pay. One participant (non-binary, aged 26-39 years) shared their experience with skipping unaffordable prescription medication by stating *"Yeah. Like, I mean, a lot of my prescriptions are really expensive. And for instance, one of my prescriptions is $1,500 a month, and that's just one of them. I have several that are, like, $1,000. And, my insurance wouldn't pay for it a couple of months ago, and, I just went without it for a month because I couldn't afford to buy it."* In addition to medication non-adherence, some participants partook in drastic behaviors to cope with situations that arose because of their financial hardship. For example, one participant stopped cancer treatment after losing their health insurance, because they were laid off due to COVID-19: *"I had to stop [treatment] because I lost my insurance [when I lost my job],"* shared a female participant 26-39 years of age. Another reported intentionally infecting themselves, *via* intravenous drug use, with an infectious disease

TABLE 2 | Material and Behavioral Financial Hardship – Sub-categories and Illustrative Quotes.

Sub-categories	Illustrative Quotes
Material Domain of Financial Hardship	"I was not fired, but I was under a pay freeze and asked to take on continuously more and more work, while I was still doing chemotherapy treatment" - Non-binary participant 18-25 years of age "Yeah, but – yeah. No, it was definitely still a challenge because when I was going through treatment, throughout all of treatment, and then for the first couple months afterward, I was making almost half of what I do now." - Non-binary participant 18-25 years of age "It came to a time where I had to have three [procedure/scans] in less than three months, so just on that, it was $2,100.00 out of my pocket that I needed to pay that. And then, on top of that, there was a lot of copays. Some of them were not much. Some of them were higher, but dime by dime you make a million." - Female participant 18-25 years of age "Being in a more queer accepting job that also has recognized that I have talent and have capability has been a really big boon for me. And I would not be in the same position both financially and out to my work community if I had stayed in [my old job]." - Non-binary participant 18-25 years of age "Yeah [I'm not out], it's usually just fear of rejection, because people just kind of treat you differently, or weirdly, or like, "Okay, that's weird." - Non-binary participant 26-39 years of age "I haven't been without a job because I was gay. I have turned down jobs – good paying jobs – because of bosses [who were weird about my LGBTQIA+ identity]" - Male participant 18-25 years of age
Behavioral Domain of Financial Hardship	"But you know, that's also been stressful because I also wanna save, I wanna buy a house, and then it's just too much bills on top of too much bills" - Male participant 18-25 years of age "Life pre-diagnosis and pre-COVID, I mean, I had a little bit more of that flexibility of being able to spend money on fun things for myself. Soon as cancer hit, that entirely mentality had to go away. It was pretty much like, if this is not an essential need, you don't need it. So, this is not something you get right now. Or if you really want something like that, then maybe you can ask your nice friends to take care of things for you because there's a lot of people who really wanna know how they can help right now." - Non-binary participant 26-39 years of age "My husband was still taking care of other bills that were much major and much need of a more attention to also because my health is important, but we still need a roof over our head." - Male participant 18-25 years of age "I'm just kind of existing. I was a full-time cancer patient for my treatment, and right now, I'm just living at home. My spouse has a full-time job with good health insurance, so that's kind of what I'm living off of right now." - Female participant 26-39 years of age

so they would be eligible to receive free treatment for the infectious disease, which they perceived could also be used as an off-label treatment for their cancer that they could not afford otherwise.

3.2 Psychological Financial Hardship and Mental Health

LGBTQIA+ AYAs reported significantly worse stress (mean=9.6 [SD=33] *vs.* 7.5 [3.3]; p=0.001), anxiety (64.7 [11.1] *vs.* 58.4 [9.9]; p=0.002), and depression (61.1 [11.6] *vs.* 53.4 [10.0]; p<0.001) scores in comparison to cisgender, heterosexual AYAs (**Figure 4**). Interviewees explained that financial hardship resulted in substantial financial stress which was exacerbated by existing mental health challenges experienced by LGBTQIA+ AYAs. Existing mental health challenges related to social support, acceptance, and LGBTQIA+ identity emerged as integral to the psychological impact of financial hardship but persisted as a distinctly different topic explored below. Additional, illustrative quotes can be found in **Table 3**.

3.2.1 Psychological Domain of Financial Hardship

The stress participants felt in response to the financial hardship was substantial. Nearly all participants reported feeling highly stressed due to the overlapping of COVID-19 and their cancer. A

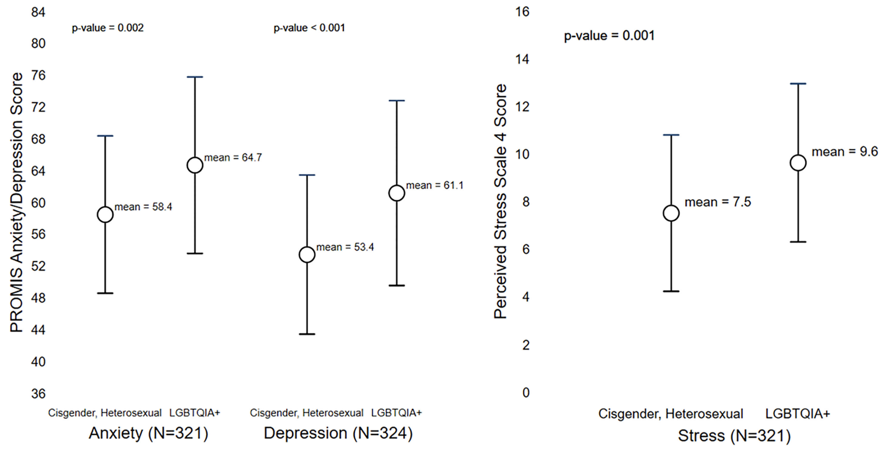


FIGURE 4 | Differences in Mental Health Outcomes Between Cisgender, Heterosexual and LGBTQIA+ AYA Cancer Survivors.

TABLE 3 | Psychological Financial Hardship and Mental Health Challenges – Sub-categories and Illustrative Quotes.

Sub-categories	Illustrative Quotes
Psychological Domain of Financial Hardship	"I had nothing left of my life [after coming out and going through treatment] … And it was lonely. And it was hard. And it was scary. And it was painful" - Female participant 26-39 years of age "I think it impacted it [the COVID-19 pandemic] just in terms of thinking. Like, okay, well, what if I do get really sick and I'm not able to work?" – Non-binary participant 26-39 years of age "But yeah, I guess looking to the future, too, my cancer can come back within the next two years is kind of how it behaves, so I'm trying to just think ahead and be smart about financial decisions to be prepared next time if it ever comes back, which I hope it doesn't." - Female participant 26-39 years of age "I don't feel [stressed] now other than, looking forward at like, what scans will I need? Like, if I get cancer again, how will I handle that financially?" – Non-binary participant 26-39 years of age
Mental Health Challenges	"it's pretty much stressful because you never know if any little thing could be cancer, or any little thing could not be cancer" - Male participant 18-25 years of age "I struggled a lot with mental illness in my early 20s and I think I kind of, that was the priority. It's like Maslow's needs, you know, that staying alive was the priority" – Non-binary participant 26-39 years of age "So many times this year, I got put into a box that I didn't belong in. All these boxes, everybody kept shoving me in. And I was, "Don't put me in your box." So, that's my new thing. But they keep putting me in a box. Not fair" - Female participant 26-39 years of age "Also the fear of overt discrimination or anything like that, of more like, subconscious discrimination. So, you know, even smaller things, just like, to this day I'm still terrified" - Female participant 18-26 years of age

female participant (26-39 years of age) shared,*"It was like – it was 100 percent [stressful]. It's on a scale of like 1 to 10, it would probably be a 12 only because like, in that timeframe, it was the worst. It was COVID and then my cancer diagnosis, those were probably the most stressful times of my life."* Some participants talked about their cancer and COVID-19 experiences as the most stressful of their lives. Participants who reported being the most stressed were those receiving treatment or still paying bills from treatment during the pandemic. Participants commonly mentioned that resources provided by the cancer center, financial support from caregivers, expanded governmental unemployment/stimulus checks, and crowdfunding helped alleviate stress. However, some participants continued to feel a sense of despair about their financial situation when they felt they had run out of options for support. This feeling was shared by a female participant (aged 26-39 years): *"I've wrung out my resources. There is nothing left. I am an AYA girl. I can call every number, every email. I can fill out every application in that whole place, especially the [Cancer Center] resource booklet that they got for you. Oh, man, that resource book got me through. I am out of [financial] choices."* Feelings of despair, fear, and loneliness caused by financial hardship were not uncommon among participants but were substantially elevated among those with existing mental health challenges.

3.2.2 Mental Health Challenges

Unprompted by the interview guide, many participants discussed previous challenges with mental health that occurred before their cancer diagnosis and COVID-19 to contextualize the toll that their cancer and COVID-19 had taken on their mental health. One non-binary participant aged 26-39 years shared their mental health challenges prior to diving into how the questions being asked fit in their life stating, *"I actually had some mental health problems, and that's another thing I didn't talk about at all actually."* Participants often discussed prior mental health challenges, such as being institutionalized or traumatic loss of family members, as a starting point for the impact of their financial stress. Participants felt it important to first explain their mental health prior to the COVID-19 pandemic and cancer diagnosis to fully describe how the financial stresses layered on top of their existing challenges.

Most participants who were off treatment reported anxiety surrounding recurrence. Many participants were fearful of being infected with COVID-19 due to their increased susceptibility to severe infections as a cancer patient. [quote] Furthermore, discussion revolving around LGBTQIA+ identity and mental health was common. Some participants reported not being accepted by family due to LGBTQIA+ identity and this nonacceptance having a severely negative impact on their mental health. One female participant, aged 26-39, reported doing drugs to cope with the mental toll of identity non-acceptance during cancer stating, *"After all of that loss [due to non-acceptance], I kind of started self-medicating 'cause why not?"* Other participants who were not out felt fear of discrimination or loss of relationships and support if their family or employers (i.e., sources of financial support) learned of their LGBTQIA+ identity. In one case, a non-binary participant aged 26-39 was currently experiencing suicidal ideation at the time of interview due to conflict with a familial caregiver surrounding their LGBTQIA+ identity and dependence on that caregiver for financial and other support, stating: *"Yeah. Well, I do think so [that my prior mental health challenges were due to my LGBTQIA+ identity]. I'm gonna cry a little because, I mean, you don't feel good when you can't be yourself and when you feel like you have to pretend … I mean, that is the one thing that just makes me not want to be alive."*

4 DISCUSSION

Our findings suggest that LGBTQIA+ AYA survivors face substantial financial burden and mental health challenges that were enhanced by the ongoing economic and psychological uncertainty from COVID-19. Financial burden was often driven by intertwined factors including their cancer, COVID-19, and stigma surrounding their LGBTQIA+ identity. While financial burden among LGBTQIA+ AYA survivors has not been explored previously, AYA cancer survivors of all sexual orientations and gender identities are at an elevated risk of financial hardship compared to older adults due to high cancer related out-of-pocket costs (36, 37). Our findings fit into the existing literature by highlighting an unexplored demographic group of cancer survivors at risk for severe financial burden. In general, the COVID-19 pandemic has impacted both LGBTQIA+ and young adults' financial burden and mental health more severely than non-LGBTQIA+ and older individuals (38, 39), which is consistent with the findings of our study.

Due to the largely unexplored nature of financial hardship in the LGBTQIA+ AYA survivor population, we first identified theoretical and conceptual underpinnings within and outside of the cancer context to begin to root our findings into the literature. The Sexual and Gender Minority (SGM) Health Disparities Research Framework provides a theoretical basis for interpreting our finding of disproportionate adverse outcomes experienced by LGBTQIA+ AYA cancer survivors. Disparities in financial burden and mental health can be understood through the four levels of influencing factors in the SGM health disparities research framework: societal, community, interpersonal, and individual (40). Our findings relate to the individual and interpersonal factors such as self-acceptance and the coming out process. Specifically, participants reported not coming out to avoid losing financial support as well as experiencing societal factors such as structural stigma (e.g., employer discrimination and nonaccepting work environments). Our findings can be contextualized further using the conceptualization of stigma as fundamental cause which asserts that stigma, or the co-occurrence of labeling, stereotyping, separation, status loss, and discrimination in the context of power being exercised, is a primary driver of population health disparities (41, 42). Specifically, the mediators or the ways that stigma manifests and leads to disparities (i.e., resources, social isolation, psychological and behavioral responses to stigma, and stress) (41, 42) can be used to further explain our findings as they overlap substantially with the financial hardship domains used to develop our interview guide (29). Suggesting that future research into LGBTQIA+ cancer survivors financial burden should be theoretically driven, incorporating both cancer related financial hardship frameworks and LGBTQIA+ disparities frameworks/theories which may enhance research on the financial impacts of cancer in this population.

LGBTQIA+ AYAs reported significantly worse COST scores than non-LGBTQIA+ AYA survivors. This finding was explained by the interview findings in which participants reported experiencing severe material financial hardship. This is consistent with the well-established literature that a large proportion of cancer survivors experience financial hardship, which is particularly true among AYA survivors who report financial hardship during a dynamic time of development (37). Our findings contribute to the literature in demonstrating that LGBTQIA+ AYAs experienced worse employment outcomes, which has been exacerbated during COVID-19. While financial hardship among LGBTQIA+ survivors has not been explored prior, our findings suggest that LGBTQIA+ AYA survivors may experience different and worse financial hardship than cisgender heterosexual AYAs and older survivors. Our finding regarding stigma and employment discrimination faced by our interview participants is consistent with the literature outside of the cancer context. LGBTQIA+ populations face severe employment discrimination and structural stigma because of their identities throughout the United States (43). Consistent with our findings, and particularly relevant to LGBTQIA+ survivors who are AYA, employees outness impacts the amount of employment discrimination they suffered, with more than one third of LGBTQIA+ individuals reporting not being out at work (43). Further sub-groups of the LGBTQIA+ community are at an elevated risk for employment discrimination including transgender individuals (44). While employment discrimination and stigma surrounding LGBTQIA+ identities vary based on the state and region of the United States, nowhere is free from either (45, 46). Further, educational attainment of LGBTQIA+ and non-LGBTQIA+ AYAs in our sample differed substantially. Education was not a concept that emerged in our qualitative findings but is a known predictor of economic outcomes and differential treatment in the healthcare system in other minority populations and warrants further inquiry (47). Our findings suggest that an LGBTQIA+ identity may substantially worsen the financial hardship experienced by AYA survivors due to the added hurdle of LGBTQIA+ stigma and employment discrimination. As sexual orientation and gender identity data becomes more commonly collected, quantifying the economic impact of LGBTQIA+ AYA disparities is of the upmost importance.

In addition, participants reported behavioral financial hardship including alterations to their saving and spending habits, reliance on caregivers, cost conversations with providers, as well as rationing prescription medications. While behavioral responses to financial hardship have been reported by AYA survivors regardless of sexual orientation or gender identity, some responses may be highly influenced by an LGBTQIA+ identity. Specifically, the reliance on caregivers for financial support is complicated for LGBTQIA+ AYA survivors as families do not always accept LGBTQIA+ identities (48). This familial non-acceptance is represented in our findings regarding an individual who lost familial financial support after coming out resulting in homelessness and medication rationing and another participant who reported hiding their identity for fear of losing familial financial support. Homelessness among LGBTQIA+ youth is not uncommon resulting in an estimated 20-40% of homeless youth identifying as LGBTQIA+ (49, 50). Furthermore, medication rationing due to cost was reported by multiple LGBTQIA+ AYAs in our study. In the literature medication non-adherence is a fairly common behavioral response to financial hardship and has severe and life-threatening consequences (51–53). Future inquiry should explore LGBTQIA

+ survivors medication adherence and long-term survival as well as ways to support survivors who face familial non-acceptance. Further our findings suggest that cancer centers should create formal relationships with LGBTQIA+ community organizations in order to more directly support survivors who lose their caregiver support due to their identity. Additionally, further studies are needed to quantify the economic impact of cancer among LGBTQIA+ populations, to support LGBTQIA+ survivors who lose familial support, and to provide robust population specific mental health services to LGBTQIA+ survivors.

In addition to financial burden, LGBTQIA+ AYAs reported significantly higher stress, anxiety, and depression than non-LGBTQIA+ AYA survivors in the survey. These findings were contextualized by participant's descriptions of their financial stress, which was often described alongside existing mental health challenges, primarily due to prior trauma and other factors involving their LGBTQIA+ identity. Due to identity related conflict with their caregiver, one participant reported suicidality during the interview; most participants reported other significant mental health challenges. The minority stress model suggests that the stressors experienced by LGBTQIA+ populations positions them at an increased risk for mental health issues such as depression, anxiety, and suicidality (54). Our findings suggest that cancer centers should assess survivor mental health and have specific strategies to support LGBTQIA+ AYAs before mental health challenges arise. Stress experienced by participants, heightened by financial burden may differ based on other intersecting identities. For example, one participant did not want to come out due to already feeling marginalized as a person of color. Thus, our findings support the need for a more intersectional approach to financial burden and LGBTQIA+ disparities in cancer research and further exploration into how race, gender, ability, and sexuality all concurrently influence minority stress in the cancer context (55, 56).

4.1 Limitations

Our study has limitations including the changing nature of COVID-19 during the data collection periods. Further recall bias may be present as interviews were conducted several months after the survey data were collected. Bias may have been introduced during interview recruitment as individuals who agreed to participate may have fundamentally different experiences than those who did not participate. Our survey lacked the racial and ethnic diversity needed to perform sub-analyses among racial and ethnic minority LGBTQIA+ AYA survivors. Our interview sample size was fairly small; however, it provided the first in-depth exploration of financial burden in LGBTQIA+ AYA survivors and was more racially and ethnically diverse than the survey sample. Overall, the limitations to this study are far outshined by the novel findings.

5 CONCLUSIONS

This study is the first in-depth exploration of financial burden among LGBTQIA+ AYA cancer survivors. LGBTQIA+ AYA cancer survivors experienced worse financial and mental health outcomes during the COVID-19 pandemic. Financial burden and mental health in our findings were highly complex and intertwined for LGBTQIA+ AYA survivors due to the unique compounding impacts of cancer treatment, COVID-19, and economic instability caused by LGBTQIA+ identity-based stigma. Given their multiple intersecting identities and potential for marginalization, LGBTQIA+ AYA survivors deserve prioritization in research to help reduce financial and psychological distress throughout the cancer continuum.

DATA AVAILABILITY STATEMENT

The datasets presented in this article are not readily available because informed consent for data sharing was not obtained. Requests to access the datasets should be directed to erin.kent@unc.edu.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by University of Utah Institutional Review Board (IRB#00091443). The patients/participants provided their informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

Conceptualization: ARW, ELW, EEK, and ACK; Methodology: AW, SB, EW, HKK, EEK, and ACK; Software: ACK and ELW; Formal analysis: ARW, SB, and ELW; Writing—original draft preparation: ARW; Writing—review and editing: ARW, ELW, SB, HKK, EEK, and ACK; Supervision: EEK, ELW, and ACK; Project administration: ARW; Funding acquisition: ACK. All authors contributed to the article and approved the submitted version.

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Community-Driven Identification and Adaptation of a Cancer Caregiving Intervention for LGBTQIA Populations

Charles S. Kamen[1], Theresa A. Hastert[2], Megan Mulvaney[2], Forrest Hosea[2], Alexandra M. VanBergen[1], Ali Fakih[2], Knoll Larkin[3], Evan Killingsworth[4] and Hayley S. Thompson[2]*

[1] Cancer Control Unit, Department of Surgery, University of Rochester, Rochester, NY, United States, [2] Karmanos Cancer Institute, Department of Oncology, Wayne State University, Detroit, MI, United States, [3] National LGBT Cancer Network, New York, NY, United States, [4] LGBT Detroit, Detroit, MI, United States

Background: Lesbian, gay, bisexual, transgender, and other LGBTQIA cancer patients experience significant disparities in cancer-related outcomes. Their relationships may not be acknowledged in care systems designed to serve primarily heterosexual and cisgender (H/C) patients, and resources for partners and caregivers of H/C patients may not address the needs of LGBTQIA caregivers. Tailored interventions are needed to address disparities in LGBTQIA patients and caregivers.

Methods: To address this gap, researchers from Karmanos Cancer Institute in Detroit, MI and Wilmot Cancer Institute in Rochester, NY worked with a cancer action council (CAC) of LGBTQIA stakeholders with lived experience of cancer in a community-academic partnership. This group used the ADAPT-ITT model to guide their process of assessing needs in this community, identifying evidence-based interventions that could be adapted to meet those needs, and beginning the process of adapting an existing intervention to meet the needs of a new population.

Results: In the Assessment phase of the model, CAC members shared their own experiences and concerns related to cancer and identified cancer caregiving as a priority area for intervention. In the Decision-Making phase of the model, researchers and CAC members performed a review of the literature on interventions that reported outcomes for cancer caregiver, identifying 13 promising interventions. Each of these interventions was evaluated over a series of meetings using a scoring rubric. Based on this rubric, the FOCUS intervention was established as an appropriate target for adaptation to the LGBTQIA population. In the first stage of the Adaptation phase, CAC members reacted to the intervention content and identified principal components for adaptation.

Conclusion: While the FOCUS intervention adaptation is still in process, this manuscript can serve as a guide for others establishing community-academic partnerships to adapt interventions, as well as those developing interventions and resources for LGBTQIA persons coping with cancer.

Keywords: health disparities, cancer, caregiving, adaptation, sexual orientation, gender identity, sexual and gender minorities (SGM)

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Janette Perz,
Western Sydney University, Australia

Reviewed by:
Ronit Elk,
University of Alabama at Birmingham, United States
Matthew Schlumbrecht,
University of Miami Health System, United States

****Correspondence:***
Charles S. Kamen
charles_kamen@urmc.rochester.edu

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INTRODUCTION

Between 530,000 and 1,300,000 lesbian, gay, bisexual, transgender, queer, intersex, asexual (LGBTQIA) cancer patients are estimated to be living in the United States; this acronym includes diverse individuals who do not identify as heterosexual and cisgender, or H/C (1–5). The National Institutes of Health has identified LGBTQIA people as a health disparity population, and the American Society for Clinical Oncology released a position statement on reducing health disparities in LGBTQIA cancer patients (6, 7). However, LGBTQIA patients are underrepresented in existing cancer research, and existing cancer control interventions have not been adapted to address disparities in these communities (6).

Across time and in multiple research studies, LGBTQIA persons have been shown to be at higher risk for depression, anxiety, and substance use than their H/C counterparts (8, 9). Systematic reviews of the literature have attributed disparities in mental health and substance use issues among LGBTQIA persons to "minority stress," or the chronic stress engendered by living with a stigmatized identity (10). Minority stress may also contribute to the unique needs of LGBTQIA populations in the context of cancer care (11, 12), including higher rates of psychological distress and depression, poorer quality of life, and more unmet cancer care needs than H/C patients (13, 14). Additionally, LGBTQIA cancer patients must navigate decisions about whether and how to disclose their sexual orientation and gender identity, or SOGI, to their cancer care providers, a process colloquially known as "coming out." (15–17) LGBTQIA patients may fear exposure to discrimination and prejudice if they disclose their SOGI to cancer care providers due to prior discrimination in health care settings (3, 18, 19). However, lack of disclosure limits the ability of providers to acknowledge and include LGBTQIA patients' support structures in care or refer these patients to appropriately tailored supportive care interventions.

Many cancer patients rely on family or friends to act as informal (unpaid) caregivers, providing emotional, logistical, and financial support (7). Caregivers are often called upon to help patients with activities ranging from feeding, bathing, and dressing, to helping with transportation, finances and housework (6, 10). Nearly 75% of cancer caregivers provide medical care services (e.g., administering injections, tube feedings, and catheter care) typically performed by health professionals, despite most reporting that they received no preparation for these tasks (6). Caregiver burden can result from imbalances between caregiving demands, caregivers' preparation, and caregivers' physical, emotional, financial, and time resources (14, 18, 20, 21). As a result of caregiving burden, informal cancer caregiving is associated with depression, anxiety, distress, fatigue, and disturbed sleep among caregivers (6, 22–24). Caregiver wellbeing is also influenced by the psychosocial wellbeing of the cancer survivors for whom they care (22, 23).

Informal caregivers of LGBTQIA cancer patients are underrepresented in cancer research, despite their unique needs and experiences (24). LGBTQIA people with cancer may be less likely to rely on support from biological family due to historical rejection or non-acceptance by family members (7) and may instead include LGBTQIA-identified friends and current and former partners in their caregiving network (6). LGBTQIA caregivers may not be acknowledged by the cancer care team or included in medical decision making in the same ways that H/C romantic partners or biological family members might be (3). These caregivers may have difficulty accessing support services that primarily serve H/C individuals and may find that available services do not always meet their needs. In some cases, sexual minority cancer patients report not bringing their same-sex partners to clinic appointments to avoid tacitly coming out (16, 25). In others, LGBTQIA caregivers are marginalized when they access services not designed for them. For example, lesbian or transgender caregivers may feel out of place in a support group for caregivers of breast cancer patients where all other participants are patients' H/C male partners (26). Several interventions have been developed to improve quality of life and other health-related outcomes among cancer patients and their caregivers; however, this work has not included or been designed to address the unique needs of LGBTQIA cancer patients and caregivers.

Through a community-academic partnership, an established group of LGBTQIA community stakeholders including cancer survivors, caregivers, and advocates worked alongside academic investigators to identify priority areas of research and intervention for LGBTQIA patients and caregivers. We then identified and began adapting evidence-based interventions using the ADAPT-ITT framework (27). In this manuscript, we describe our formative process, including identification of caregiving as a priority area of intervention (Assessment phase); results of a literature review of existing interventions that demonstrated improvement in psychosocial outcomes among informal cancer caregivers outcomes, identifying the FOCUS intervention (28, 29) as an appropriate target for LGBTQIA-specific tailoring based on community evaluation (Decision-making phase); and identification of specific components of the intervention for adaptation by community stakeholders (Adaptation phase).

In addition to highlighting the feasibility of our specific process of community engagement, findings presented in this manuscript can be used to inform the work of investigators interested in developing community-academic partnerships to address the unique needs of LGBTQIA cancer patients and caregivers.

METHODS

Participants

Formation of the KCI LGBT CAC

The work presented here was undertaken in collaboration with the Karmanos Cancer Institute (KCI) LGBT Cancer Action Council (CAC), a group of LGBTQIA community members convened to discuss cancer-related health issues in the

LGBTQIA community and work with KCI to address these issues. The KCI LGBT CAC is one of several CACs formed through Michigan Cancer HealthLink, a PCORI-funded community-academic partnership developed by KCI's Office of Cancer Health Equity and Community Engagement (OCHECE) to increase research capacity in local communities and to empower communities and community members to identify, mobilize, and address social and public health problems *via* research (30). The HealthLink model is informed by a participatory research approach in which researchers and community members collaborate on an ongoing basis through an iterative process of problem definition, problem solving, and evaluation, building research and programmatic skills, and broadening and deepening relationships (31–35). Michigan Cancer HealthLink is represented by a network of CACs: groups of cancer survivors, caregivers, and advocates who use their knowledge of their respective communities to inform KCI's research. These CACs contribute knowledge of their communities, tailor programs to meet their communities' needs, and advance cancer prevention and control research priorities aligned with those needs. There are currently 10 CACs across the state of Michigan with approximately 130 members.

All CAC members receive training in research methods through an adapted version of the Tufts Clinical and Translational Science Institute curriculum, "Building Your Capacity (BYC): Advancing Research through Community Engagement." (36) The BYC program provided participants with a basic understanding of the academic research process and familiarized them with research terminology and concepts, with the goal of increasing their overall level of confidence in engaging with academic researchers.

In 2017, LGBTQIA-identified cancer survivors, caregivers, and advocates were sought for participation in the KCI LGBT CAC. This CAC was convened in partnership with LGBT Detroit, a grassroots organization with a focus on youth and young adult development, sexual orientation and gender identity education and advocacy, and promotion emotional and physical well-being among LGBTQIA communities. Potential CAC members could apply for core membership (mandatory attendance at all meetings with stipend) or associate membership (attend at least 2-3 meetings per year with no stipend).

KCI LGBT CAC Members

In total, 13 people have participated in the LGBT CAC (**Table 1**). The initial CAC included 10 members, of whom 7 were cancer survivors and 3 were caregivers, 7 were White and 3 were Black, 7 were cisgender women and 3 were cisgender men. Membership within the CAC fluctuated due to the COVID-19 pandemic, changing health status and death; the council lost 2 members due to cancer in 2018-2019. To increase membership and diversify perspectives, KCI staff conducted a short recruitment in 2019 and brought on one white, nonbinary core member and one Black, nonbinary associate member, in addition to a Black cisgender man who represented LGBT Detroit, a community organization. See **Table 1**.

TABLE 1 | Demographic characteristics of the LGBT cancer action council members (2017–2021).

Total	**N (%)** **13 (100)**
Average age (Range)	54 (26-70)
Gender identity	7 (53.8)
Female	4 (30.8)
Male	2 (15.4)
Non-binary	
Sexual orientation	6 (46.2)
Lesbian	4 (30.8)
Gay	1 (7.7)
Bisexual	2 15.4)
Queer	
Race/Ethnicity	7 (53.8)
Non-Hispanic White/European	5 (38.5)
Black/African American	1 (7.7)
Prefer not to disclose	
Cancer experience	6 (46.2)
Patient	2 (15.4)
Caregiver	2 (15.4)
Patient and caregiver	3 (23.1)
Advocate	

Procedures

ADAPT-ITT Framework

Initially developed to facilitate the adaptation of evidence-based interventions that proved effective at preventing new HIV infections, ADAPT-ITT is a framework designed to guide the efficient adaptation of evidence-based interventions to be appropriate for specific at-risk populations (27). ADAPT-ITT includes 8 sequential phases. Here we describe our findings from the first three phases: 1) Assessment, or conducting interviews, focus groups, or needs assessments to understand the needs of the new target population; 2) Decision-making, including reviewing existing evidence-based interventions and deciding which to select to meet the needs of the target population and whether to adopt the existing version or adapt it; and 3) Adaptation, including collecting feedback and ideas from members of the target population for how to enhance its relevance and efficacy for that population.

Qualitative Feedback

Throughout the phases of the ADAPT-ITT model in the current study, LGBT CAC members and key informant interviewees provided qualitative data on priorities, response to reviewed intervention literature, and areas for further adaptation of an intervention. In lieu of a formal qualitative data analysis, notes from the review sessions were collated by members of the research team and illustrative quotes were extracted. These quotes are presented below to represent specific reactions from the community throughout the ADAPT-ITT process.

Ethics Approval

The procedures reported in this manuscript (convening a community advisory board and conducting a literature review) do not constitute human subjects research, and so no ethics approval or informed consent was required.

RESULTS

Phase 1. Assessment Phase

Identification of Priorities

As part of completing the BYC curriculum, the CAC facilitators led the group through the process of identifying priorities and forming a research question to address these priorities. Beginning with voicing their cancer experiences and concerns, CAC members worked together with KCI facilitators to identify some of the biggest challenges facing LGBTQIA cancer patients and caregivers. Their input was translated into a visual concept map, grouping concerns by relevance. Concept maps are a tool for gathering and organizing group input about a complex topic and are well-suited for community-based participatory research (37). A finalized list of themes was created from this concept map, and CAC members cast votes to set research priorities, being asked to consider both their own experiences and unmet needs and the general needs of the community.

Based on initial concept mapping, key issues for the LGBT CAC were as varied as HIV-cancer comorbidity, psychological well-being, caregiving issues, financial burden including uninsurance and underinsurance, screening and prevention, and patient-provider communication, including the need for trauma-informed care. After these issues were collated and presented, the group voted to focus efforts on developing an intervention for LGBTQIA cancer caregivers.

Literature Review to Identify Needs of LGBTQIA Caregivers

A literature review was conducted to define the scope of the existing research addressing the unmet needs of LGBTQIA caregivers. We searched peer-reviewed journal articles indexed in Michigan State University's library database that were published between 2010-2020. Our search terms were "LGBT+ caregiving." A total of 37 articles met our search criteria. A KCI researcher (MM) presented summaries of the 37 articles to the LGBT CAC. Key points extracted from these articles included: a) LGBTQIA caregiver-patient relationships and demographics are unique, with a high proportion of friends serving as caregivers in the LGBTQIA community; b) LGBTQIA caregivers experience unique barriers, including anxiety about coming out to healthcare providers and assumed heteronormativity when expressing health and relationship concerns; d) LGBTQIA caregivers experience burnout and trauma, due in part to a high financial burden of caregiving for LGBTQIA patients; and e) LGBTQIA caregivers rely on community supports due to a lack of established empirically-based interventions. These published findings were consistent with the experiences and needs shared by the CAC members.

Phase 2. Decision Phase

Literature Review to Identify Cancer Caregiving Interventions for Adaptation for LGBTQIA Populations

A literature review (**Figure 1**) was conducted to identify potential interventions that could be adapted to meet the needs of LGBTQIA cancer caregivers. We searched peer reviewed journal articles indexed in PubMed that were published between 2015-2020, with a narrower time window than the prior search to focus on more recent literature. Our search terms were "cancer caregiver" and "clinical trial." This review was managed using Covidence (38). A total of 352 peer-reviewed articles were identified as testing a cancer-specific intervention for caregivers. Next, we reviewed each study's abstract to determine if it met the following criteria: 1) related to cancer caregiving, 2) included an adult population, 3) was conducted in the United States, and 4) reported caregiver-specific outcomes. Of the original 352 abstracts, 84 met these criteria and full versions of these articles were evaluated for inclusion in the review.

To be included in the final review, the LGBT CAC recommended that studies needed to meet three additional criteria. First, the intervention must have shown a statistically significant impact on caregiver outcomes. Second, intervention components must have addressed caregiver skills and/or support. Third, it must have been feasible to adapt to an online format. Of the 84 articles that were reviewed in the initial process, 13 studies met all three of these criteria and were included in the final review.

All included articles were reviewed independently by two members of the research team (FH, MM), using a Covidence-provided template to extract information. This included comparisons of titles, abstracts, study locations, and significant results. In cases where relevance of information was unclear, a third reviewer independently corroborated the other two reviewers' extraction. We then presented the extracted information from all 13 articles to the LGBT CAC in a summarized format. The template used and the extracted summaries of the articles are presented in **Table 2**, edited for readability. Overall, these interventions sought to address coping (5), distress (4), caregiver burden (3), and other aspects of quality of life (1). Some sampled patients with a range of cancers (5), while others focused on breast (3), lung (2), prostate (1), gastrointestinal (1), and hematologic malignancies (1). The majority (12) of the interventions sampled patient/caregiver dyads, but 1 focused solely on caregivers. Delivery modalities included in-person face-to-face sessions (8), phone or video sessions (3), web-based delivery (1), or mixed modalities (1).

Selection of Final Interventions

After reviewing the 13 article summaries, the LGBT CAC rank ordered the articles based on their preference for a specific focus on caregivers, including individual time for caregivers to complete portions of the intervention. Based on this rank ordering, we identified the top half of the articles (n=7) as being most in line with CAC members' preferences. To ensure that a diversity of perspectives informed our selection of an intervention, these 7 articles were presented to three community members affiliated with the CAC (1 Black LGBTQIA cancer caregiver, 1 white LGBTQIA cancer caregiver, and 1 Black LGBTQIA cancer survivor). We conducted individual key informant interviews with these three community members

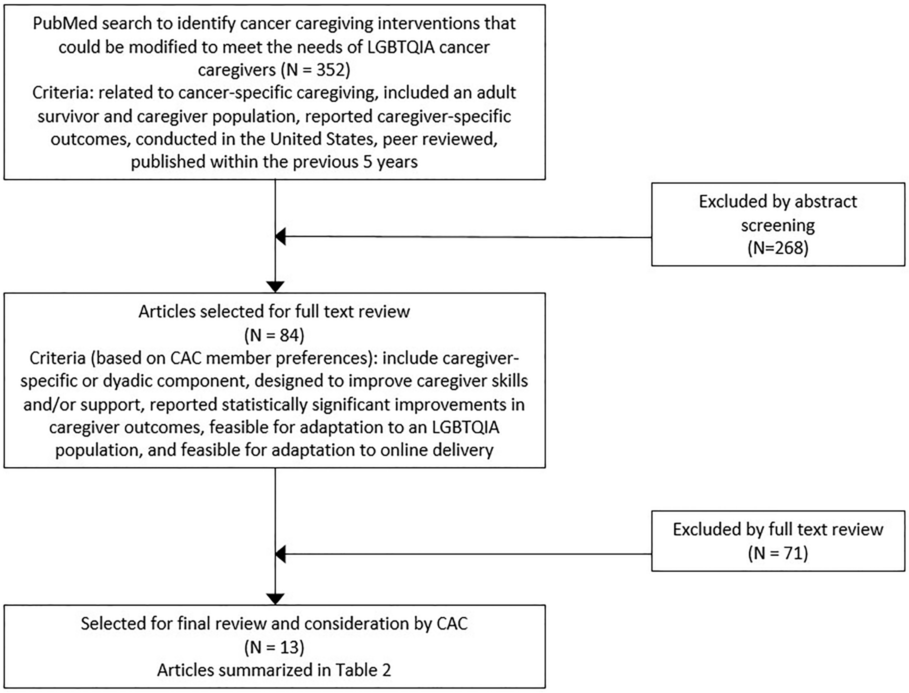

FIGURE 1 | Flow diagram of studies included in literature review of interventions that improved informal cancer caregiver wellbeing for potential adaptation for LGBTQIA caregivers.

about the articles. Interviewees emphasized the importance of brief interventions to fit into caregivers' busy lives, asking that the selected intervention be no longer than 6-7 sessions. Only two intervention concepts met this criterion: the FOCUS program (28) and a caregiver-specific written emotional disclosure intervention (39).

The FOCUS program (**Table 3**) aims to provide information and support to cancer patients and their caregivers together. It contains five modules, each of which are reviewed with the patients' family: family involvement (F), optimistic attitude (O), coping effectiveness (C), uncertainty reduction (U), and symptom management (S). While initially tested as a nurse-led intervention including three in-person sessions with follow-up phone check-ins (50), FOCUS has also been adapted to an entirely web-based format. The interviewees highlighted the FOCUS program because of its "homework" component, length of intervention, topics covered, and "it seemed like the content was committed to meeting [caregiver] needs and was conducted with lay language." They also thought the dyadic approach would be beneficial for some session topics, like communication between the patient and the caregiver.

By contrast, the written emotional disclosure intervention was provided only to caregivers, and guided caregivers to complete three home-based writing sessions focused either on expressive disclosure or benefit finding. The interviewees felt this writing program was interesting, but worried that future participants would be intimidated by the writing requirement, creating a barrier to use. Ultimately, the interview participants and CAC members felt it would be worth considering Harvey (2018) as an additional homework component to the FOCUS program adaptation, leaving the FOCUS program as the final chosen intervention.

Phase 3. Adaptation Phase

In talking with the LGBT CAC members and interviewing key stakeholders, several potential areas for adapting the FOCUS program to address the needs of LGBTQIA caregivers emerged. These same adaptation principles could apply to other dyadic interventions. First, given the context of same-gender relationships in the United States and the ongoing legislative opposition to same-gender marriage rights at the time of writing this manuscript, the FOCUS program and other programs that include same-gender couples must account for the impact of legal recognition or opposition on these relationships (40). Due to systemic issues, including historical lack of legal recognition of same-gender relationships, barriers such as financial toxicity may also look different in LGBTQIA caregiver/patient dyads than in H/C dyads. CAC members stressed that the FOCUS family involvement module must account for these systemic issues, the history of healthcare discrimination against LGBTQIA people, and personal stressors related to cancer and relationship strain.

Another major area for adaptation centered on disclosure of LGBTQIA identities and relationships in cancer care settings. CAC members and interviewees stated that lack of disclosure of LGBTQIA identity to oncology providers could lead to lack of

TABLE 2 | Literature review articles presented to LGBT CAC (N=13).

Study	Primary Aim	Participants	Patient Diagnosis	Caregiver-Patient Relationship	Intervention	Key Results
Mosher, et al. (2018) (1)	Examine whether peer helping and a coping skills intervention leads to improved meaning in life/ peace among cancer patients and caregivers	50 patient/ caregiver dyads (Patients: 38% female, mean age 58.2 years; caregivers: 66% female, mean age 53.9 years); one or more dyad members had to report severe distress	Stage IV gastrointestinal cancer 8+ weeks prior to enrollment	Family; lived with the patient or visited the patient at least twice a week for the past month	Coping skills intervention (comparison condition) plus the dyads helped create an informational resource on quality of life issues for other cancer patients and their caregivers	Means of meaning in life/peace measures stable for the intervention group but increased slightly in the comparison (coping only) group at 1 week post intervention, and remained higher at 5 weeks
Dockham, et al. (2016) (2)	Examine effectiveness of FOCUS Program on cancer survivors' and caregivers' outcomes; determine program feasibility	34 cancer survivor/ caregiver dyads (Survivors: 73% female, mean age 53.8 years; caregivers: 35% female, mean age 53.4 years)	Any cancer type; no limitations on time since diagnosis	Family caregivers (anyone who provided emotional support, physical support)	FOCUS Program, nurse-delivered home-based program modified to a small-group format and delivered by Cancer Support Community social workers	Dyads showed significant improvements in total, physical, emotional, and functional quality of life; benefits of illness; and self-efficacy
Hendrix, et al. (2016) (3)	To examine the effects of an enhanced informal caregiver training (Enhanced-CT) protocol in cancer symptom and caregiver stress management to caregivers of hospitalized cancer patients.	138 cancer survivor/ caregiver dyads (Survivors: 36% female, mean age 57.0 years; caregivers: 83% female, mean age 55.3 years)	Any cancer type; actively being discharged home with care needs and has identified caregiver	Any type of relationship; expected to care for patient after discharge and spend 2 hours in hospital for training	Enhanced caregiver training (Enhanced-CT), nurse-delivered training for caregiver conducted at patient's bedside addressing management of patient symptoms and caregiver stress management	Enhanced-CT group has greater increase in caregiver self-efficacy and preparation for caregiving at post-training assessment as compared to comparison group; but not at 2- and 4-week post-discharge assessments. No intervention group differences in depression, anxiety, and burden.
Steel, et al. (2016) (4)	To examine the efficacy of a collaborative care intervention to reduce depression, pain and fatigue and improve quality of life.	261 patients, 179 caregivers (All: 27% female, mean age 61)	Multiple cancers that have metastasized to the liver	Family caregiver	Access to psycho-educational website, professionally trained coordinator; telephone contact with coordinators every 2 weeks, face-to-face every 2 months; CBT	Survivors: reduction of pain, decrease in depression, and fatigue Caregivers: decrease in caregiver stress and depression
Porter, et al. (2011) (5)	Test the efficacy of a caregiver-assisted coping skills training protocol	233 patient/ caregiver dyads (Patients: 53% female, mean age 65.3 years; caregivers: 31% female, mean age 59.3 years)	Early-stage lung cancer (non-small-cell lung cancer Stages I-III or limited-stage small-cell lung cancer)	Primary caregiver - Any friend or family member who provided practical and/or emotional support	Two intervention arms, each including 14 45-minute telephone-based sessions: 1) caregiver-assisted coping skills training, or 2) cancer education / support including the caregiver	Patients in both treatment groups reported improvements in pain, depression, quality of life, and self-efficacy. Caregivers in both treatment groups reported improvement in anxiety and self-efficacy.
Malcarne, et al. (2019) (6)	To test the efficacy of problem-solving therapy (PST) to reduce distress and improve QoL for spouses of men with prostate cancer.	164 patient/ caregiver dyads (Patients: 100% male; Caregivers: no demographic information provided)	Prostate cancer diagnosis within past 18 months	Married or long-term cohabitation with partner	Adapted from Bright IDEAS Problem-Solving Skills training and PST manual; trained staff-delivered at-home intervention; 6-8 sessions to develop problem-solving skills	In treatment group, constructive problem solving increased, less cancer-related distress; no significant changes in mood or physical and mental health; dyadic adjustment was significantly better
Harvey, et al. (2018) (7)	Test whether benefit finding or expressive disclosure forms of writing improve caregiver outcomes	64 caregivers (88% female; mean age 56 years)	Hematopoietic stem cell transplant recipient within past 3 years (0-14 years since	Romantic partner or spouse	Two writing intervention arms included 1) expressive disclosure or 2) benefit finding via 3 15-minute at-home writing sessions at one-week intervals	Writing interventions resulted in greater reduction in posttest depression vs. control, but not with caregiver burden or stress overall

(Continued)

TABLE 2 | Continued

Study	Primary Aim	Participants	Patient Diagnosis	Caregiver-Patient Relationship	Intervention	Key Results
			cancer diagnosis)			
Lewis, et al. (2019) (8)	To test the short-term efficacy of a 5-session, fully manualized marital communication and interpersonal support intervention for couples facing recently diagnosed breast cancer.	322 patient/ caregiver dyads (Patient: 100% female, mean age 53.1 years, Caregivers: no demographic information provided)	Breast, stage 0-III, diagnosed within 6 months	Spouse or partner	In-person biweekly reading, writing, interactional components led by Masters prepared patient educator for 30-60 min; homework assignments	At 3 months caregivers and patient significantly improved on standardized measures of depressed mood, anxiety, cancer-related marital communication, interpersonal support, and self-care.
Lapid, et al. (2016) (9)	To assess changes in various QOL domains after participation in a QOL intervention for caregivers of patients having newly diagnosed advanced cancer.	129 patient/ caregiver dyads (no demographic information)	Advanced cancer, diagnosed within 12 months, estimated 5-year survival rate of 0-50%, had planned radiation therapy for at least 1 week	Primary caregiver	15 min physical therapy, 30 min health/symptom education; 30 min spirituality/mood education; 15 min relaxation. Caregivers included in 4/6 sessions	Caregivers improved on Spiritual Well-being; Vigor/Activity, and Fatigue/ Inertia; and Adaptation. At 27 weeks, caregivers retained improvement in Fatigue/Inertia and gained improvements in Disruptiveness and Financial Concerns.
Northouse, et al. (2014) (10)	Test preliminary effect of intervention on patient and caregiver outcomes, examine program satisfaction, determine feasibility of web-based format	38 patient/ caregiver dyads (Patients: 58% female, mean age 54.8 years; caregivers: 61% female, mean age 50.6 years); one or more dyad members had to report severe distress	Lung, colorectal, breast, or prostate cancer; early stage (Stage I or II) or advanced stage (Stage III or IV)	"Family caregiver;" the family member or significant other identified by the patient as their primary source of emotional and/ or physical support	Self-administered, web-based program designed to deliver the Family Involvement Module of the face-to-face FOCUS intervention; 3 sessions over 6 weeks	Dyads reported significant decrease in emotional distress and significant improvements in quality of life over time
Mosher, et al. (2016) (11)	To examine the preliminary efficacy of telephone-based symptom management (TSM) for symptomatic lung cancer patients and their family caregivers.	106 patient/ caregiver dyads (Patient: 53% female; Caregiver: 73% female)	Lung cancer	Family caregiver	4 weekly 45 min telephone sessions. Telephone Symptom Management for anxiety, depression, pain, fatigue, breathlessness, plus handouts and relaxation CD	No significant group differences were found for all patient outcomes and caregiver self-efficacy for helping the patient manage symptoms and caregiving burden at 2 and 6-weeks post-intervention. Small effects in favor of TSM were found regarding caregiver self-efficacy for managing their own emotions and perceived social constraints from the patient.
Badger, et al. (2020) (12)	To test two 2-month psychosocial interventions (Telephone Interpersonal Counseling [TIPC] and Supportive Health Education [SHE]) to improve quality of life (QOL) outcomes for Latinas with breast cancer and their informal caregivers.	230 patient/ caregiver dyads (Patient: 100% female, mean age 50 years; Caregiver: mean age 44 years)	Breast cancer, in active treatment or within 1 year post-treatment	Informal caregiver designated by Latina survivor	SHE (Supportive Health Education) standardized educational materials vs. TIPC (telephone interpersonal counseling)	For caregivers: TIPC - decrease in depression scores SHE - reduced number of symptoms, lower distress, lower anxiety; improved self-efficacy for symptom management
Rush, et al. (2015) (13)	Established a multi-level partnership among Latina survivors, caregivers, community-based organizations (CBOs),	100 patient/ caregiver dyads (Patient: 100% female; Caregivers: 60% female)	Breast cancer	Primary caregiver	8 sessions, 2x per month; Latina survivors and their caregivers arrive at the group together, separate into	Patients: no significant changes; Caregivers: decrease in fatigue

(Continued)

TABLE 2 | Continued

Study	Primary Aim	Participants	Patient Diagnosis	Caregiver-Patient Relationship	Intervention	Key Results
	clinicians and researchers to evaluate a survivor-caregiver QOL intervention.				different rooms to learn the coping and communication skills, and then join together for discussion of the topic.	

disclosure of LGBTQIA relationships. This in turn could increase caregiver stress, as an LGBTQIA caregiver could end up sidelined, not supported, or even actively excluded from clinical interactions with the patient. By contrast, the need to repeatedly disclose LGBTQIA identities to multiple providers (oncologists, nurses, imaging techs, etc.) could add additional stress and burden to LGBTQIA caregivers and patients. CAC members and interviewees stressed that the FOCUS program and similar interventions should give LGBTQIA caregivers skills to disclose their identities to providers, to advocate for themselves and their relationship with the cancer patient, and to communicate about stressors they experience in providing care to the patient and navigating cancer care services. Thus, an LGBTQIA-adapted version of FOCUS could use the coping effectiveness module to provide support, acknowledge these stressors, and teach skills to help to manage stressors through effective coping and communication.

Other areas for adaptation identified by the CAC and interviewees included generational and cohort effects: LGBTQIA older adults who came of age in a time before Stonewall are both more likely to be diagnosed with cancer than younger people and less likely to feel comfortable “coming out” in healthcare settings. Interventions should acknowledge these generational differences. Family structures may look different for LGBTQIA caregivers and patients than their H/C counterparts, with a reduced emphasis on biological family and an increased emphasis on chosen family, many of whom may be LGBTQIA identified. FOCUS and other interventions should help caregivers and patients to navigate inclusion of chosen family into the cancer care experience. Spirituality can be a major source of comfort and resource for coping among cancer patients, but LGBTQIA caregivers and patients may struggle to incorporate religious or spiritual coping approaches given the history of discrimination leveled against LGBTQIA people by religious institutions. FOCUS, through its coping effectiveness module, should address this reality and help LGBTQIA caregivers and patients to consider the role of spirituality as they cope with cancer. CAC members and interviewees stressed the importance of a strengths-based approach: the FOCUS optimistic attitude module could acknowledge not only the many disparities LGBTQIA people confront, but the ways in which they are already resilient and can develop further resilience. Finally, side effects of treatment may differ for LGBTQIA cancer patients. The FOCUS symptom management module should address topics including resuming receptive anal intercourse following colorectal cancer treatment, or navigating use of hormones in the context of cancer therapies.

DISCUSSION

This manuscript presents the feasibility of a process of forming a community-academic partnership to identify and adapt an intervention, guided by the ADAPT-ITT model. As such, it can serve as a guide for others wishing to engage in a community-focused approach to intervention development. Our adaptation process consisted of convening an LGBTQIA-focused CAC, undertaking literature reviews in collaboration with KCI scientists and LGBT CAC members, evaluating the selected literature in accordance with CAC priorities, and choosing a final intervention for adaptation using qualitative in-depth interviews with community stakeholders. CAC perspectives and interview data were also used to identify areas for intervention adaptation.

There remains an urgent need for interventions adapted to LGBTQIA populations. This is particularly true in the context of cancer, where stark disparities confront LGBTQIA communities at every stage of the cancer continuum. Minority stress is a documented factor in health disparities among LGBTQIA individuals, including cancer-related disparities. However, social support and strong relationship functioning has been shown to protect from the detrimental impact of minority stress (41), supporting the need for dyadic interventions to combat minority stress and stress-related health disparities in the context of cancer.

As our results highlight, choosing an appropriate intervention modality through community-academic partnerships requires considerable effort and engagement by both community members and academic researchers. In this project, the initial idea to adapt an intervention came from the community, as part of the formation of the KCI LGBT CAC. Researchers and KCI staff then trained CAC members in developing a research question, undertook concept mapping, and assisted with the literature review. At each stage, the community was directly involved in providing feedback and guiding the next step of the process. The community also provided input about how they preferred to work alongside researchers. The end result of this approach is identification of an intervention that is both evidence-based and, with appropriate modifications, responsive to community priorities.

TABLE 3 | Core components of the FOCUS program and potential adaptations for LGBTQIA cancer survivors and caregivers (adapted from Northouse, et al., 2005)(50).

Core component	Interventions	Proposed Adaptations or Additions for LGBTQIA Populations
1. Family involvement	* Promote open communication * Encourage mutual support and teamwork * Identify family strengths * Help children in the family as needed	* Acknowledge and address needs of LGBQIA survivors and caregivers who are not biological family or H/C romantic partners * Address situations where survivor has more than one caregiver
2. Optimistic attitude	* Encourage optimistic thinking * Help dyad share fears and concerns * Assist dyad to maintain hope * Help dyad to stay hopeful in the face of death	* Adapt content to enable LGBTQIA patients and caregivers share fears and concerns in a way appropriate for their relationship * Acknowledge resilience of LGBTQIA people
3. Coping effectiveness	* Help dyad deal with overwhelming stress * Encourage healthy coping and lifestyle behaviors * Assist caregivers to manage the demands of illness	* Help dyad deal with stress related specifically to LGBTQIA identification * Identify strategies for coping effectiveness that account for intersectionality and the multiple identities of cancer patients and caregivers
4. Uncertainty reduction	* Educate dyad about disease and treatments as needed * Teach dyad how to be assertive to obtain additional information * Help dyad learn ways to live with uncertainty	* Include strategies for LGBTQIA cancer patients and caregivers to be assertive and obtain information and resources in the face of fear of coming out and potential discrimination from members of the cancer care team
5. Symptom management	* Assess symptoms in patient and family caregiver * Teach self-care strategies to manage symptoms	* Adapt self-care strategies to address issues arising specifically from minority stress

However, identifying an intervention is far from the final phase in community-driven adaptation. Community input is crucial to the adaptation process itself. In the example we describe, community members had a clear sense of key issues confronting LGBTQIA cancer caregivers and constituted previously "untapped knowledge reserves" as described by Gaventa & Bivens (p. 73) (42). Their insights shaped the selection of the FOCUS intervention as ready for adaptation, and shaped intervention content and the context of intervention delivery. Community input about historical discrimination toward LGBTQIA caregivers in medical settings indicates a need for content within FOCUS dedicated to coping with minority stress and self-advocacy with oncology providers. Input about the importance of friends as caregivers for LGBTQIA people could influence the context of FOCUS, broadening it from a purely dyadic intervention to one that can serve and support a chosen family system.

A community-academic partnership also relies on input from academic researchers to guide intervention adaptation. From the perspective of KCI and Wilmot researchers, the science of intersectionality emphasizes that interventions for LGBTQIA persons should also consider other identities that have been historically marginalized, such as racial and ethnic minorities, acknowledge the impact of multiple marginalization (43), and better understand intersectional minority stress experiences (44). This is especially true for interventions like FOCUS that are designed to address psychological distress, as differences in mental distress have also been documented across racial-ethnic minority groups of SGM individuals (45, 46). LGBTQIA disparities research has also underscored differences in distress based on specific LGBTQIA identity; for example, bisexual adults disclose their identities less often (47) and report more mental distress than lesbian and gay adults (48), due in part to bisexual-specific forms of minority stress (49). Thus, the researchers in this partnership emphasized that an adapted version of FOCUS for diverse LGBTQIA persons may need to include content specific to different segments of the LGBTQIA community.

Next steps for this community-academic partnership involve continuing the adaptation process by following the remaining steps of the ADAPT-ITT model, as follows. 3) Adaptation: The community-academic partners will conduct a "theater test," in which the adapted FOCUS intervention (including SGM-specific content) is presented to groups of LGBTQIA cancer patients and their caregivers to elicit feedback. 4) Production: The partners will then produce a manualized version of adapted FOCUS based on theater test feedback. 5) Topical experts: The opinions of experts in LGBTQIA cancer-related health about the manual will be elicited. 6) Integration: Feedback from these experts will be incorporated into the manual. 7-8) Training and Testing: Finally, interventionists will be trained and the adapted intervention will be tested in a pilot study to assess feasibility and preliminary efficacy.

Limitations and Strengths

The current manuscript describes a single community-academic partnership. While the principles described thus far are abstracted from the details of this partnership, they may not apply equally to all communities, academic centers, or research projects. Due to our guiding principle of involving the community in all stages of intervention identification and adaptation, parts of this process were not as scientifically rigorous or replicable as would be expected from a purely academic project. Formal qualitative analyses or meta-analyses of the literature were not undertaken. However, involvement of the community at all stages of intervention selection and adaptation led to collection and prioritization of data that may not have occurred in a purely academic effort, and ultimately made the project a better reflection of the community it was designed to serve.

When asked about their perspectives on limitations, the LGBT CAC stated that the timeline of the researchers did not always match the timeline of community members, who "need time to read and internalize." This difficulty was compounded by the fact that the articles were "not written for lay persons" and so the CAC relied on "brief summaries" with "2-3 points of information to make decisions." However, the LGBT CAC also highlighted several strengths of this process, including that "a supportive precedent was set" by the partnership, group members "felt listened to," and the end result "shows what the group does and how it works together." As one CAC member said, "The council allows me to be of service to others in my community. It helps take the fear out of cancer." Another member said, "Participating in the group has made me feel useful and productive. I think our work will prove very worthwhile."

Conclusion

A community-academic partnership between LGBTQIA cancer patients/caregivers and cancer researchers is feasible to establish and can lead to critical insights in intervention adaptation. This manuscript can serve as a guide for others embarking on community-driven adaptation work, as well as providing targets for development of interventions and resources for LGBTQIA persons coping with cancer. Future groups should consider the importance of undertaking literature reviews guided by community input, collecting qualitative feedback from diverse community members, and using patient and caregiver feedback in all phases of intervention identification and adaptation.

DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/supplementary material. Further inquiries can be directed to the corresponding author.

ETHICS STATEMENT

The procedures reported in this manuscript (convening a community advisory board and conducting a literature review) do not constitute human subjects research, and so no ethics approval or informed consent was required.

AUTHOR CONTRIBUTIONS

EK, MM, KL, and HT contributed to conception and design of the study. CK wrote the first draft of the manuscript. CK, TH, MM, AV, FH, and AF wrote sections of the manuscript. All authors contributed to manuscript revision, read, and approved the submitted version.

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Knowing to Ask and Feeling Safe to Tell - Understanding the Influences of HCP-Patient Interactions in Cancer Care for LGBTQ+ Children and Young People

Tamsin Gannon[1]*, *Bob Phillips*[2], *Daniel Saunders*[3] *and Alison May Berner*[4,5]

[1] Paediatric and Teenage and Young Adult Oncology, The Royal Marsden NHS Foundation Trust, Sutton, United Kingdom, [2] Paediatric and Teenage and Young Adult (TYA) Oncology, Leeds Children's Hospital, Leeds, United Kingdom, [3] Clinical Oncology, The Christie NHS Foundation Trust, Manchester, United Kingdom, [4] Barts Cancer Institute, Queen Mary University of London, London, United Kingdom, [5] Gender Identity Clinic, Tavistock and Portman NHS Foundation Trust, London, United Kingdom

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Edited by:
Jane Ussher,
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Liz Margolies,
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United States

****Correspondence:***
Tamsin Gannon
younglgbtqcancerstudy@gmail.com

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Background: Lesbian, gay, bisexual, transgender, queer or questioning (LGBTQ+) people experience healthcare inequalities in cancer care. Previous studies have focused on knowledge, attitudes and behaviours of healthcare professionals (HCPs) treating adults with cancer and how these contribute to inequalities. To date, no research has focused on HCPs treating LGBTQ+ children and adolescents with cancer in the UK. This is important given that this group may be at a critical time for exploring their gender identity and sexual orientation, whilst also facing a cancer diagnosis. We aimed to explore the knowledge, attitudes and behaviours of paediatric, teenage and young adult oncology HCPs treating LGBTQ+ patients in the UK.

Methods: We carried out semi-structured interviews with 8 HCPs in paediatric, teenage and young adult (TYA) oncology from the Royal Marsden NHS Foundation Trust. Eight questions were asked, which centred around participants' knowledge, attitudes and behaviours regarding management of LGBTQ+ patients in oncology. Interview transcripts were analysed by inductive thematic analysis.

Results: We identified 10 themes, including novel themes (how HCPs acquire knowledge and expectations of a 'third party' to be the expert) which may underlie previously observed trends in knowledge, attitudes and behaviours of HCPs. We highlight other themes and HCP concerns specific to care of LGBTQ+ patients in paediatrics (influence of the parental-carer dynamic, concerns around patient age and development as a barrier to disclosure) which require further research. We found evidence of the interrelatedness of HCP knowledge, attitudes and behaviours and the ability of these elements to positively influence each other. We mapped our themes across these elements to form a new suggested framework for improving HCP-patient interactions in LGBTQ+ Cancer Care. We found a need both for individual HCP education and organisational change, with creation of a culture of psychological safety to improve patient care.

Conclusion: Knowledge, attitudes and behaviours of HCPs are closely interdependent when providing care to young LGBTQ+ patients with cancer. The authors suggest that future efforts to improve care of these patients address this complexity by spanning the domains of our suggested framework. Whilst HCP education is essential, change must also occur at an organisational level.

Keywords: LGBTQ+, sexual orientation, gender identity, healthcare professional attitudes, healthcare professional knowledge, healthcare professional behaviour change, paediatric oncology, teenage and young adult cancer

1 INTRODUCTION

Sexual minorities are those who identify with any sexual orientation (SO) other than heterosexual, including gay, lesbian, bisexual, asexual, pansexual. It also includes those questioning their SO. Gender minorities are those whose gender identity (GI) is different from the sex they were assigned at birth. This includes a range of identities including transgender and gender diverse which are also umbrella terms. Here we will use the acronym LGBTQ+ (lesbian, gay, bisexual, transgender, queer or questioning) to encompass sexual and gender minority communities.

Estimates from western countries suggest that 2.7%-7.1% of people identify as LGBTQ+ (1–3) and this is rising due to increased disclosure as a result of changing society attitudes (4). In 2016, sexual and gender minorities (SGMs) were identified as a health disparity population in research by the National Institute for Health (5) and a recent UK Government Equalities Office review reported an urgent need to address the 'inequality in service provision and delivery, particularly in health' for this group (6).

SGM people experience minority stress and poorer health outcomes compared to cisgender, heterosexual people. Challenges are worse for those who identify in more than one minority group (7). Intersectionality, is the term used to describe this interconnected nature of social categories that creates overlap of discrimination.

LGBTQ+ populations experience myriad inequalities across healthcare (8–12) with poorer experience, worse health outcomes and being more likely to access mental health services (likely as a result of the minority stress). They cite a lack of healthcare professional (HCP) knowledge on specific LGBTQ+ needs, experiences of heteronormativity and discrimination (6).

Cancer is a particular area of unmet need. LGBTQ+ adults experience disparities across the continuum of cancer care from screening, through diagnosis and management, to end of life care (8, 13–17). They are at higher risk of some cancers due to higher rates of risk behaviours (7). They are more likely to delay initial presentation to healthcare due to prior discrimination or negative experiences. They report lower satisfaction with cancer treatment, higher rates of psychological distress in survivorship and poorer health outcomes (7). A major concern for LGBTQ+ cancer patients is whether to disclose their GI and/or SO, considering if this will result in discrimination and poor care (18).

In 2017, the American Society of Clinical Oncology published a statement on reducing cancer health disparities for this population (19). In 2021, a statement from the Joint Collegiate Council for Oncology made a set of commitments signed by organisations across cancer care in the UK, which included greater research and improved education on LGBTQ+ cancer care (20).

There are features unique to cancer care in children and adolescents, such as increased prominence of the carer-patient relationship, that may affect interactions with HCPs and a recent study found that young LGBTQ+ people with cancer experienced higher distress and confirmed they were less likely to disclose their SO or GI than older adults (21). However, there remains a relative lack of research into healthcare experiences of LGBTQ+ youth specifically, and much of our current knowledge is based on research on LGBTQ+ adult health. In 2019, Australian researchers published a call to action aimed at reducing the research gap in Teenage and Young Adult (TYA) cancer care. They categorised LGBTQ+ young people with cancer as at-risk group due to the psychosocial and systemic vulnerabilities experienced by this group in healthcare (7). Common challenges for TYAs through their cancer journey include body image concerns, mental health and the loss of independence. The impact of questioning ones SO or GI through their cancer journey is often overlooked (7).

Young people aged 16 to 24 years are the most likely age group to identify as LGB with 4% belonging to a sexual minority group (3). There is no robust UK data on younger age groups but 9.5% of those aged 13-17 years from the USA identify as LGB (22).Population estimates on trans youth in the UK are lacking, but international data suggest that 1.2% to 2.7% of children and adolescents identify as transgender (23). A freedom of information request found that as of 31st December 2019 there were 4220 under 18s on the waiting list for GI services (24).

Disclosure to an HCP may also be a greater challenge for TYAs who may not want or be able to disclose to their family/friends, who may not have the language or understanding of their emotions to be able to discuss their emerging SO or GI (21). Disclosure is made even more difficult in adolescent care due to the family centred approach if the reason for non-disclosure is family or carer presence. In a study of 102 LGBTQ+ young people, 75% of participants reported they did not disclose as they did not want to discuss SO in front of parents/carers (25). Previous studies also suggest paediatricians do not address SO or GI and a study on LGBTQ+ adolescents identified only 35%

had disclosed their identity to their healthcare professional whilst 64% would have communicated this information if they were asked (26). Research shows disclosure of LGBTQ+ identity has a positive impact on patients' health experience and improved well-being (27). LGBTQ+ youth expressed a desire for more open discussions regarding their sexual and emotional health (28).

Several studies have focussed on the attitudes and knowledge of HCPs treating LGBTQ+ adults with cancer. These are mainly from the USA, one from the UK and one from Australia (29–36). Some focused solely on individual HCP groups such as doctors (29, 32, 33), oncology advanced nurse practitioners (31), radiotherapists (35), and a few have examined the broader multi-disciplinary team (30, 34, 36) reflecting the multi-disciplinary approach of cancer care.

Despite the heterogeneity in location and HCP surveyed, there has been a consistent finding of a paucity of self-perceived knowledge in the specific healthcare needs of LGBTQ+ patients accessing cancer services, and a desire for greater education. In those studies where knowledge was tested, the percentage of participants that could correctly answer all questions ranged between 3% and 50% (30, 34, 36). Across studies, it was felt knowledge of GI, sex assigned at birth and intersex variations were more important than SO to provide the best cancer care (32, 33) and yet there tended to be the least confidence in knowledge on care of gender diverse patients (29, 33, 34), suggesting this attitude did not prompt knowledge acquisition.

Non-physicians tended to be more confident than physicians in their knowledge and also tended to have a greater interest for education on LGBTQ+ health (34). Further, a higher percentage of nurses and allied health professionals felt this topic should be mandatory compared to medical practitioners (34) These differences of opinion may be the result from differing perceptions around the relevance of this topic to one's job role. Other reasons cited by HCPs for their low knowledge of LGBTQ + health were competing clinical and educational demands and lack of evidence-based guidelines (32).

Across studies the majority of participants regardless of profession reported feeling comfortable treating LGBTQ+ patients (30–32). However, comfort did not appear to correlate with knowledge overall (30) or to translate into behaviours of active enquiry around LGBTQ+ identity (30) though in UK oncologists it resulted in a greater confidence in overall communication (29).

With regards to specific behaviours, only 2-48% of HCPs across studies explicitly encouraged disclosure of LGBTQ+ identity (29, 30, 36). Assumptions about SO and GI were high (29, 30, 32, 34). However, as these studies have been mostly quantitative, they cannot fully capture relationships between these behaviours and underlying knowledge and attitudes. The qualitative interview-based study by Sutter *et al.* provided more detail and aided current understanding of this topic in adult cancer care. HCPs stated LGBTQ+ concerns may be neglected because 'survival took precedence' and due to HCP fears around using the correct language and making assumptions (32).

To-date there have been no published studies solely on the knowledge, attitudes and behaviours of HCPs in Paediatric Oncology. Ussher *et al.* include HCPs caring for Paediatric and TYA patients but responses for this subgroup were not analysed (34). In Sutter *et al.* adolescent cancer care was also described and the benefit of having clinical expertise in LGBTQ+ health was highlighted when an oncologist reported having a specialist from a gender dysphoria clinic was invaluable in assisting them care for a transgender adolescent patient. Effects of family conflict were also raised and the importance of providing a supportive place to disclose SO and GI in hospital if it was not safe to do so at home (32).

In the UK, the doctors delivering cancer care for children, teenagers and young people are mainly paediatricians. In a Canadian study, knowledge regarding LGBTQ+ issues were limited amongst paediatricians (37) and LGBTQ+ young people describe a lack of LGBT-tailored knowledge/support when accessing healthcare (38, 39). However, oncology care involves a multidisciplinary team of HCPs from different disciplines and there have been no studies specific to HCPs delivering paediatric and TYA cancer care in the UK. LGBTQ+ healthcare education in UK medical schools and in the undergraduate curriculum of other HCPs is variable and poor, with a few notable exceptions of good practice (40, 41). Rarely is LGBTQ+ health discussed specifically with curriculum documents (42).

We therefore set out to explore the knowledge, attitudes and behaviours of paediatric oncology HCPs treating paediatric, teenage and young adult LGBTQ+ patients in the UK, and to do so qualitatively, to more deeply explore reasons behind the findings observed in previous studies of HCPs treating adults. We then aim to use our findings to better define the educational need of HCPs treating young LGBTQ+ patients with cancer and make recommendations around its delivery.

2 MATERIALS AND METHODS

2.1 Ethics Approval

The study was approved by the Royal Marsden NHS Foundation Trust and the Institute of Cancer Research Ethics committee (Ref No: SE 1132).

2.2 Recruitment

Recruitment was *via* an advertising email sent to all HCPs working in Paediatric Oncology and the project was advertised at handovers/multi-disciplinary meetings.

Participants needed to be; 1) working at Royal Marsden Hospital NHS Foundation Trust, 2) a paediatric oncologist or haematologist, clinical nurse specialist, nurse practitioner, psychologist or psychology assistant, allied health professionals or play therapists 3) caring for paediatric, teenage or young adults with cancer currently and for a minimum of 6 months prior to the interview. All participants provided written informed consent.

2.3 Participants

Discussion of how many participants from each HCP group was decided amongst the study team. It was decided to review whether there was thematic saturation once at least 8 participants had been interviewed.

Participants comprised of 3 Paediatric Oncologists, 2 Clinical Nurse Specialists, 1 Speech and Language Therapist, 1 Occupational Therapist and 1 Psychologist. They were aged between 24-59 years (median 39 years). All participants identified as female which correlates with the high percentage of women in Paediatrics (there are more female consultants than male and 74% of trainees are female) (43). Participants had been in their role for a median of 7 years (range 18 months to 23 years). All participants worked with children, teenagers and young adults and none identified as LGBTQ+. We define children as those aged under 13 years, teenagers aged 13-18 years and young adults 19–25 years. One participant did not consent to their demographic details being published. Three participants had attended a recent education session by a Paediatric Oncologist during Pride about LGBTQ+ history.

2.4 Setting

Interviewed staff were based at the Royal Marsden Hospital based in Sutton, England. The Royal Marsden is a tertiary oncology centre, a leader in the field of cancer treatment and research and is expected to be ahead of other centres regarding education and training such as LGBTQ+ cancer care. Patients have access to a multidisciplinary team which includes Paediatric Oncologists, Paediatric Haematologists, Adult Haematologists, Advanced Nurse Practitioners, Clinical Nurse Specialists, Allied health professionals, Psychologists etc.

Data for this study was collected in November 2021 post COVID-19 pandemic. The NHS Rainbow badge had been introduced several months prior to interviews in early 2021.

2.5 Interviews

Virtual semi-structured interviews (duration range: 30-60 minutes) were carried out *via* Microsoft Teams. Interviews were recorded and stored *via* Microsoft Teams and automated transcription was used. Participants were advised to carry out the interviews in a private space. All interviews were carried out by TG. Eight questions were asked which centred around participants' knowledge, attitudes and behaviours regarding management of LGBTQ+ patients in oncology including how to manage a hypothetical scenario.

2.6 Patient and Public Involvement

Development of our interview questions were guided by patient/public involvement groups. We attended two focus groups. The first was run virtually by the Teenage Cancer Trust charity and comprised 2 participants, both aged 22 years old, both on active treatment for cancer and who stated they were part of the LGBTQ+ community. The second group was the Youth Forum run at The Royal Marsden hospital. There were 7 participants in this group, aged between 18-24 years who were either on active treatment, in remission or post treatment. 5 identified as part of a minority group.

2.7 Data Analysis

All interviews were re-watched, and automated transcripts were anonymised and edited by TG. Transcripts were then read and re-read. We conducted a thematic analysis of interview responses using an inductive, experiential and critical realist approach in line with previously published recommendations (44). TG and AMB carried out data familiarisation separately. Initial coding was carried out by TG with separate checking and additional coding by AMB. Codes were then reviewed with an inductive approach to group similar codes and identify themes that may be relevant to the overarching research question and aims. During coding of the last 2 interviews few new codes were created and therefore no new patterns/themes were found in the data therefore it was felt we had reached thematic saturation. Themes, their evidence and their interrelatedness were discussed among the whole study team to develop the suggested framework.

2.8 Reflexivity Statements

The authors acknowledge that the approach they bring as researchers will influence their approach to research, and specifically the themes that are identified and developed through the analysis. For clarity, as AMB and TG worked with the primary data, they here provide reflexivity statements as to how they approach the work.

Author AMB approaches this study through the lens of both a LGBTQ+ health researcher and a cancer physician, as well as a sexual minority cisgender woman. Author TG approaches this study through the lens of a trainee paediatrician as well as an ethnic minority who is interested in health equality and equity. As a cisgender woman she is aware she has not experienced the discrimination members of the LGBTQ+ community may face. However, as a member of a minority group is interested in intersectionality in healthcare. Both researchers acknowledge an implicit bias that comes from their knowledge of the existing literature on this topic and from the assumptions of a need for training of HCPs on this topic that has driven the research question.

3 RESULTS

Dual coding produced 191 tentative codes, which were rationalised to 151 final codes. These produced 10 themes (**Table 1**) following iterative discussion and rationalisation.

3.1 Benefits and Harms of Disclosure and *Non-Disclosure*

Disclosure of LGBTQ+ identity was a common recurring theme throughout all interviews. Disclosure is at the core of this topic as without it many clinicians may assume heterosexuality and cisgender identity, and be unable to tailor their care for LGBTQ+ patients. Evidence reported by LGBTQ+ TYAs highlighting their negative experience of healthcare included a lack of active enquiry by HCPs regarding their SO as a negative factor (7). Inclusive discussion of SO by HCPs (as opposed to

TABLE 1 | Themes identified through analysis of HCP interviews.

1. Benefits and harms of disclosure and non-disclosure
2. Barriers and facilitators of disclosure and enquiry
3. Lack of confidence in knowledge of LGBTQ+ cancer care
4. Knowledge of appropriate language
5. How knowledge of LGBTQ+ cancer is acquired
6. The 'third party' as the expert on the topic of LGBTQ+ cancer care.
7. Parental-carer and patient dynamic
8. The patient as an individual
9. Discussing sex as part of cancer care
10. Visible LGBTQ+ affirming materials

SO, sexual orientation; GI, gender identity; HCPs, healthcare professionals.

heteronormative assumptions) has been linked to positive health and mental health (45, 46). Previous studies in adult patients have identified the perception that disclosure improves overall care and improves trust with the HCP (47) but also that it entails risks including discrimination and unequal care (48, 49).

Participants were aware of some of the previously reported benefits of encouraging disclosure of LGBTQ+ identity by patients. These included improvement of trust in the HCP-patient relationship: 'if they feel able to do that (share their SO/GI), that can foster the sense of trust between the clinician and the patient' and provision of better overall healthcare by tailored support to their needs: 'if we don't know a patient identifies as LGBTQ+ we don't know a lot of their life perspective and we don't know about a really important part of their identity, so it's going to be more difficult to meet their needs adequately.'

However, participants highlighted many more specific situations where this was of particular relevance, such as discussion of the benefits of hormone replacement therapy could have for the patient's sex life; 'when we had a conversation about sexuality and that hormones helped your vagina become moist and cushioned and that might help sexual pleasure … they started taking their HRT.'

Participants also felt that there were more unique benefits of knowing a patient's GI was different from their sex assigned at birth. One such reason was so that the patient can be correctly identified and addressed accordingly: 'If it's important that we identify the patient as they want to be, then we should know' and 'it might help, I'm thinking in terms of how people use their pronouns'. There was also acknowledgement of how trans status may impact the future health risks for the patient 'if we're specifically talking about something that involves sexual organs … if someone identifies as male, but has a womb and I need to talk about the risk.'

Examples were raised where a lack of acknowledgement of someone's SO or GI could cause harm such as the insensitive discussion of contraception, and a gender diverse young person not wanting to exercise due to body dysphoria. Another participant described how the consequences of cancer treatment for gendered body development needed to acknowledge the patients' feelings towards their gender to be sensitive and support the patient to engage with healthcare.

Previous studies involving both HCPs and patients have been less specific about the apparent health benefits to care. Much literature discusses the relevance in terms of patient-provider relationship and of risk of cancer according to bodily organs and behaviours in adults (27, 50–52), but the perceived benefits here relate to the ongoing health and experience of the young person living with and beyond cancer, and deserve special attention in the education.

While participants recognised the relevance of patients' SO and GI to their psychological needs due to the likelihood of poorer mental health: 'missing what may be contributing to mental health problems and suicidal ideation,' some participants identified this as the sole harm of non-disclosure 'the harm is if they're having psychological difficulty, and it's something that we could help with'. While poorer mental health outcomes in LGBTQ+ young people are well recognised (53, 54), this view overlooks other important aspects to care and perhaps even indicates a level of stigma from the healthcare clinician that LGBTQ+ identity is in itself a mental health concern. There was agreement amongst participants that exploring LGBTQ+ identity at the same time as having cancer treatment may cause additional stress which is important for HCPs to acknowledge: 'just thinking of like the wider picture that we're kind of here about the cancer diagnosis and that maybe the patient has a lot of other thoughts going on at the moment whether they were planning a transition.'

Exclusion of chosen family was a key harm identified, with one participant commenting: 'maybe not understanding partnerships that might want to be involved in the care or you know involved in providing some sort of support' as a harm of non-disclosure. Participants discussed the detrimental impact of assumptions about the relationship of the person that a patient is bringing to a consultation, which is well recognised in adults (48).

Despite much literature detailing the perceived risks of stigma and discrimination from disclosure of SO/GI (27, 36, 45, 46, 48, 55–58) this was recognised by only two participants: 'you just have to be careful that knowledge doesn't allow the opportunity for prejudice', 'you'll probably find a range of attitudes within the health care team … sometimes people unconscious behaviour can have an impact on our patients.' Multiple other participants commented that this was not an issue they had witnessed in their careers: 'I've never really come across sexuality being an issue within a healthcare setting … I've never personally come across it affecting any decisions or making anyone feel uncomfortable'. This may reflect the fact that direct discrimination often does not take place in the presence of other HCPs or that it is indirect and may not be viewed as such by HCPs who lack cultural competence. A recent UK study looking at HCP care of LGBTQ+ youth during the pandemic noted the challenge of managing prejudice within teams as one of its themes, with one participant stating this was "silence more than with nasty comments" (59).

3.2 Barriers and Facilitators of Enquiry by HCP/Disclosure From Patient

While existing literature has been less specific as to the benefits of disclosure of SO/GI, much more exists detailing its barriers and facilitators. HCP behaviours that cause LGBTQ+ patients to hesitate when disclosing identity include perceived HCP discomfort post disclosure, failing to answer LGBTQ+ specific care questions adequately, using inappropriate language, stereotyping and presumptions of incorrect relationships such as friend or relative between the patient and their partner (7).

Brooks *et al.* carried out a systematic review of literature across healthcare and found four broad themes: "the moment of disclosure", "the expected outcome of disclosure", "the healthcare professional', and "the environment or setting of disclosure" (48). Banerjee *et al.* looked at this area specifically within oncology by surveying 1,253 HCPs in the USA using open ended questions on how HCPs encouraged disclosure, communication challenges, structural/system challenges and their own recommendations on the management of LGBTQ+ patients (36).

These broad categories are mirrored in some of our own findings.

3.2.1 Expected Outcomes of Disclosure

A key apparent barrier for enquiry about LGBTQ+ identity was not being aware of its general relevance to the patient's healthcare, and the benefits and harms discussed above, as well as our later themes around knowledge. Most participants felt they needed a specific reason to ask about LGBTQ+ identity: 'I suppose if we're specifically talking about something that involves sexual organs that might be important to share.' Brooks and colleagues described the theme of expected outcome of disclosure as relevant to the patient's choice to disclosure (48) but here we also see it relevant to the HCPs willingness to enquire. If they see no difference in the outcome, they will not enquire, or at least place it lower on the HCP agenda.

This led to views that SO/GI was only relevant to the consultation if it was particularly relevant to the patient: 'I feel like I don't need to know unless you want to tell.' Most HCPs interviewed also thought that if LGBTQ+ identity was important to the patient they would bring it up, which is in contrast to recent studies that suggest LGBTQ+ young people may not disclose SO or GI so readily in this context. (21)

In some cases, these attitudes appeared to stem also from a place of respect for the patient's wishes: 'it's up to the patient if they want to disclose how they identify themselves' and the fact that teenagers in particular may find this information sensitive 'sexuality during your teen years can be something that is private to yourself'. All participants felt patients should only disclose if they feel comfortable to do so and disclosure should not be mandatory: 'I just am mindful I wouldn't want people to feel like they would have to share it.' Whilst this is true, over-emphasis on the assumptions that patients wish this information to be private and will disclose, represent barriers to disclosure and a risk to the patient in accessing optimal care.

One participant did comment on the patient's expectations of disclosure and how this might underlie their reasons for doing so: 'is it that they're telling me this because they have been hurt, are they telling me this because they're asking for help? Are they telling me this because something negative has happened or are they telling me because they're very comfortable in their GI?' Cultural humility ("ability to maintain an interpersonal stance that is other-oriented (or open to the other) in relation to aspects of cultural identity that are most important to the person") (60) is needed to understand the range of emotions associated with disclosure and something HCPs can develop to facilitate disclosure and provide more tailored care (61).

Other previously noted facilitators (48) that relate to the patients expected outcomes following disclosure observed in our study include respect of confidentiality: 'it's about reassuring that young person that, unless they're at harm or someone else is at harm, than it does, stay private & really explicitly agreeing with that patient who else is allowed the privilege of that information'. SO and GI documentation on a computer system to avoid repeated disclosure: 'sometimes people say. I'm really tired of coming out all the time it's quite exhausting having to retell my story time and time again, so actually having a really clear documentation on the electronic patient record (or) shared with the team *via* email can often be a relief to a patient'.

3.2.2 HCP Factors

The work of both Brooks *et al.* and Banerjee *et al.* separates those facilitators and barriers that relate directly to the HCP (including their communication), the setting of disclosure and context and the overall healthcare system (36, 48). Our study found factors within each of these realms that affected disclosure. Whilst some of these were previously noted they showed greater prominence in our work. For example, while low HCP confidence has often been noted in this literature (29–36), we found that a commonly cited barrier for enquiry by HCPs was overt fear. This included fear of: 'getting it wrong', 'embarrassing themselves' and 'making (patients) feel uncomfortable'. Some of these were also highlighted in the aforementioned study by Banerjee *et al.*

HCPs also spoke of a culture where questions regarding SO/GI are only being asked secondary to assumptions that have been made about the patient, especially those based on appearances. HCP are fearful to voice these assumptions and cause offence: 'we're worried about falling into stereotypes…".

Naming the barriers as specific 'fears' better allows these to be tackled head on in efforts to improve confidence and overall care. For example, increased awareness and dialogue amongst colleagues was found to be a facilitator for disclosure conversations. One participant noted that one such discussion 'brought down all barriers to be able to talk about [SO/GI] between staff because it was something that became very comfortable following that'. This also shows that while a barrier may be specific to the HCP, overcoming it may not be down to the individual HCP alone.

Another HCP-specific factor is the belief that equal care is equitable care which again feeds the participant's view that LGBTQ+ identity was not important to cancer care: 'I don't treat people differently. You know, if they're a different race or … it makes no difference to me. From my point of view, it doesn't really change how I treat the person.' This view may result in a lack of insight into potential for unconscious bias and fails to acknowledge the unique healthcare needs of some minority groups. Such an approach was noted by Ussher *et al.* (22) who named it an 'egalitarian' approach.

Other participants felt a conscious bias by other HCPs who may hold anti-LGBTQ+ beliefs were a barrier to broaching the topic: 'there might be some people who would treat them differently because of their own belief system'. While fear of discrimination and perception of HCP prejudice have both been noted as barriers for disclosure (46, 48). This view may mean that the detrimental effect of prejudice is therefore more far reaching as it indirectly impacts access to tailored care through reduced enquiry by other HCPs who do not themselves hold prejudice.

By contrast, a facilitator of disclosure was the attitude that all HCPs should be taking an active role into enquiry rather than waiting for the patient to disclose: 'I think that healthcare professionals can be taking responsibility for asking people if its ok to have a conversation about SO/GI and for that to be done with everybody.'

The need to consider the HCP experience related to LGBTQ+ identity was raised by some participants. This includes whether they themselves identify as LGBTQ+, as well as interactions with friends or family who are LGBTQ+. Previous studies have described this as a facilitator (48) but depending on the HCP experience can lead to personal biases, which was noted by one of our participants.

Most participants felt it was important for the HCP to have developed a good relationship and rapport with the patient before disclosure: 'I think that's probably the most important thing is a kind of a trusting relationship that develop where people can speak about it if they wish'. It was also noted that the type of relationship formed between HCP and patient was more a facilitator of disclosure compared to the duration of relationship: 'there was a little bit of a relationship there, a couple of sessions in, not like weeks and weeks or months like you know, we see patients for a very long time sometimes.' Both short and long duration of relationship have previously been found to be facilitators (48).

HCPs from different professions may prioritise information on patient's SO/GI differently depending on how it relates to the sort of care they provide. Placing this information higher on a clinician agenda is likely to encourage greater disclosure. One allied health professionals who described treating numerous LGBTQ+ patients in their short career disclosed: 'in my experience, it's actually come up very casually' in conversation compared to an oncologist who believed they 'haven't looked after anybody who was gay'. It was felt that nurses also place this higher on their agenda than doctors: 'TYA nurses, for example, are quite tuned into it. Maybe the clinicians less so probably. I guess that might vary between different clinicians as to how comfortable they are'.

The data also suggested that knowledge and awareness of the disadvantage and discrimination the LGBTQ+ community faces may result in this information being higher on the HCP agenda: 'I think the evidence would tell us that people who identify as being in the LGBTQ+ community face social disadvantage … if you don't know that your patient has had that in their background you can't support them and be sensitive to their needs.'

3.2.3 Consultation Skills

Our participants described many of the same aspects of the HCP-patient consultation that were noted as facilitators or barriers to disclosure in previous work (34, 36, 48) under themes that cover communication skills, setting and environment. These included open questioning style, consultation space, time allocated for the consultation and who is present during the consultation. Although many of these practices are good practice for consultations discussing sensitive issues more broadly, they are of particular value when approaching topics that may be sensitive for the patient, and so it is crucial to reinforce their necessity.

One participant facilitated disclosure by providing patients with the reasoning as to why these personal questions were being asked: 'I give the rationale … I try to allow people to understand where I'm coming from and why it's important that I do this … I want to get to know who they are'. If patients are aware that these questions are being asked so that HCPs can tailor their healthcare in order to improve it, they may be more willing to discuss other parts of their life. This technique has been described previously but we note its reliance on the HCPs knowledge of the importance of enquiry about SO/GI and its relevance to healthcare, demonstrating the interrelatedness of these two concepts.

3.2.4 Structural Factors

Participants noted structural barriers to providing good care of LGBTQ+ people overall (such as encouraging disclosure) within the UK health system.

Participants felt changing the attitude around this topic was needed: 'it's just got to become more mainstream.' One participant cited competing priorities in an overwhelmed healthcare system as to why there was not greater focus on LGBTQ+ identity: 'in an NHS pressed on resources and time and energy it sometimes feels like yet another thing to have to worry about, and I know certain professionals just don't see it as a priority.' Time for continuing professional development was also highlighted 'there are so many competing demands when it comes to providing good health care'. Such concerns around prioritisation were also highlighted in work by Ussher *et al.* and are clearly not unique to the UK healthcare system (34). However, there were notable absences from the list of structural biases in our study due to the free nature of the NHS including those related to insurance, and patient rooms, where the NHS has recently published clear guidance (62).

Several participants suggested a way to make the topic of disclosure easier to broach could be to have questions regarding SO and GI as standard on registration forms with an option to opt out from answering: 'if it was a standard on the registration form, how do you identify? that would automatically raise it as everyone gets asked.' This normalisation has previously been used by HCPs in the USA (36).Our participants took this one step further and suggested the inclusion of these questions in a commonly used health assessment tool used in their long term follow up clinics: 'because they fill that in, they're already on the wavelength that we will be talking about more than just their cancer.' Another participant reflected that these questions could be asked indirectly through a psychosocial risk assessment tool used in the UK, the HEADSSS (Home, Education & Employment, Activities, Drugs/Drinking, Sex Self-harm, depression & suicide, Safety) assessment (63): 'I think there's a HEADSSS questionnaire for teenagers that I've heard of and used in the past and maybe thinking about more in my consultations right at the beginning and that would bring up things about relationships and I guess will bring up SO.' Facilitators of disclosure may be adapted to the tools and processes of specific healthcare systems.

3.2.5 Participant Age and Development

There is a notable absence in the literature of the challenges in facilitating SO or GI disclosure across different age groups. However, one of our participants described discomfort in dealing with LGBTQ+ identity in young people stating that they were: 'very conscious that we're dealing with people whose identity is forming.' Belief that one's patients may be too young to fully identify as part of the LGBTQ+ community therefore proved a further barrier to enquiry and engaging with this topic. This underlying assumption may in fact be a reason that this topic arises so rarely in the literature on HCP attitudes, because a proportion assume that the younger age groups that they treat will not be questioning their SO or GI, or at least will not have settled on a particular identity, and so never enquire about it, and do not discover anything to the contrary.

3.2.6 The Role of the Healthcare Team

Another novel finding was that participants in our study particularly highlighted the role of members of the multi-disciplinary team (MDT) leading on a patient's care in leading by example in respecting LGBTQ+ identity and encouraging disclosure conversations: 'there is something about leadership, leading that care, introducing those questions (on SO/GI) I think that spreads … when it comes to creating cultural shift.' Another participant felt secure to adopt a consultation style facilitating disclosure through being friendly and informal because they were 'very well supported in my approach from my lead.' While a supportive healthcare community has been shown to facilitate disclosure by the patient (55, 58), it appears that it also facilitates comfort with enquiry by the HCP.

3.3 Parental-Carer and Patient Dynamic

Many of our themes were those that appeared to influence LGBTQ+ patient care beyond simply disclosure. One such was the carer-patient dynamic, which takes on a unique form in young people where that carer is often a parental figure rather than a partner or child as is frequently the case in older adults. There is extensive literature on the influence of parents on the overall health and wellbeing of LGBTQ+ young people (64). Family acceptance of LGBTQ+ identity is associated with improved mental and physical health (63) and individual family dynamics are known to be affected by cultural background and whether a patient is 'out'. HCPs in the study by Banerjee *et al.* also noted more strained communication in cancer care for young people who were not out to carers, parents or family (36).

The carer and patient dynamics were found to impact LGBTQ+ patient care both positively and negatively depending on the individual family dynamic. The patient's carer could act as a barrier to HCPs asking more personal questions on SO and or GI. At times, HCPs felt the focus of the consult was addressing the parents' questions and the patient did not engage. One participant described a situation of the lack of open dialogue between carers and patients regarding their cancer diagnosis: 'we still have parents who don't tell their child that they've had cancer'. This dynamic was uncomfortable for the HCP and this environment does not set the tone for enquiry, disclosure or prioritisation of the patient's needs.

However, the role of parents as potential advocates for their child's LGBTQ+ identity was noted: 'we had a (patient) who came in with his mum. His mum told the front desk that he wanted to be named by a male name and that was his identity.' Support from the parent encouraged the HCP looking after this patient to ensure documentation reflected his GI and new name. Acceptance from the carer, can make this topic easier for HCPs to broach and discuss openly.

Another consideration raised was the importance of the HCP to build a trusting relationship with the carer to be able to look after their child: 'respect and trusting relationships are three-way thing. It's not just with the young person that's with their parents and carers as well.' This adds a unique complexity to caring for LGBTQ+ young people with cancer. There was a suggestion that if a parent is not comfortable with their child having an LGBTQ+ identity, then visual materials that display clinician comfort or what may be perceived as encouragement of LGBTQ+ identities may harm the clinician's relationship with the parent: 'if you're a parent, you wouldn't want to see things like that on the wall you have to take parents kind of concerns and feelings into consideration as well.'

The factors of being 'out' to parents and of culture/ethnic background noted in the general literature as being crucial in the parent-child dynamic (64) were also born out in our discussions with participants about this dynamic in their consultations: 'if there's a significant other that they've (the patient) not told their parents about, for example, which might be the case, that might come out.' And 'if there was a somebody from an ethnic minority, and they're in a gay, lesbian relationship, which might not be so acceptable in their culture.' The latter point also brings out the importance of intersectionality and how we need to consider the multiple factors that may affect someone's experience of healthcare.

Another topic raised was the change in dynamic between patient and carer as there is less space for privacy once a patient is diagnosed with cancer: 'when a young person particularly is diagnosed with cancer often you know they might be quite independent before, and then suddenly they're in this situation where they're having their parents more involved again'. HCPs may have a role to play in supporting patients to maintain independence at this time and LGBTQ+ identity may feature in this. They may require more specific training to do so.

3.4 The Patient as an Individual Outside of Their Cancer Diagnosis

Some of our participants recognised that teenagers/young adults may be going through more than their cancer treatment: 'maybe the cancer is not the important thing at the moment or there's other things going on in the background that are quite important to the patient, either less, more, or just as important as their diagnosis'. This may include dynamics with parents or family in relation to 'coming out'.

Unlike adults whose carers are frequently also partners, children and teenagers are unlikely to have a partner present within the consultation. Fish *et al.* recognised partners as 'a potential salutogenic resource' for disclosure of SO in their interviews with adult LGB oncology patients (45). The lack of this aid to disclosure and advocacy in the room can be partially overcome by enquiry about their wider lives, including inquiry around partners.

Some HCPs also emphasised the importance of understanding the wider context of their patients' lives for better overall patient care. One participant that did this as part of their consultation felt 'it seemed quite natural for people to talk about their health care in the context of their life more broadly.' Work by Fish and colleagues (45) interviewing LGB cancer patients found that disclosure of SO was driven by authenticity achieved by 'a positive response to the disclosure of SO and a shared recognition by both patient and professional that the whole self is relevant to health.'

Given Rossman and colleagues (65) previously found that a major reason for non-disclosure by LGBTQ+ young people to HCPs was perceived lack of relevance to healthcare, this appreciation of the whole patient beyond their cancer may indeed facilitate greater disclosure as well as yielding other benefits.

3.5 Discussing Sex as Part of Cancer Care

Cancer diagnoses in young people may result in a delay in both the biological and social aspects of psychosexual development and education; its assessment is variable and clear consistent guidelines are lacking (66). LGBTQ+ young people report less satisfaction with this aspect of their oncology care than those who do not identity as LGBTQ+ (67).

However, the suggestion that you can talk about sex without discussing SO or GI was seen commonly throughout our interviews. Sexual activity tended to be discussed in a heteronormative form such as in discussions regarding contraception to avoid pregnancy and preserving fertility: 'if you're consenting for treatment and you're talking about risks of getting pregnant.' The interview sparked realisations from one HCP such as 'that might make them feel uncomfortable.… talking in a way which clearly wouldn't apply to their situation, if you're talking about your husband and if you're sexually active then it's important you use contraception' in reference to a patient in a same gender relationship.

Having appropriate tailored conversations around sexual behaviour may be particularly important in those with chronic health conditions as it has been linked to increased risky sexual behaviour (68).

When discussing a new weekly clinic which caters specifically for the holistic needs of the teenage and young adult patients, one HCP explained: 'sexuality and fertility for sure is discussed there but I don't know how easy or difficult it would be to discuss SO in that particular clinic'.

Russel et al. reported that LGBTQ+ cancer survivors reported less distress and concerns around infertility (69). This does not mean it does not deserve discussion but perhaps that it can be better balanced with the patient's other psychosexual priorities.

It appears that, as noted in previous literature, appropriate education is lacking. One participant had attended a workshop about sex with cancer. She explained that it was: 'about sex, not gender and it was fairly practical … it didn't address anything specific about the different sexualities.' Yet some HCP had still felt able to have these conversations with an LGBTQ+ young person 'we had a conversation about sexuality … that might help sexual pleasure and playing with toys and things' and that this yielded other benefits for the patients' overall healthcare

Discussion of sex is of course another area of care where the patient-carer dynamic may be relevant: 'it's quite often difficult because you're consenting patients, when often the parents are in the room, like about contraception … you have to be so sensitive because some people get really offended if you ask them if they are sexually active', and links the importance of the appropriate setting for such discussions.

Patients also appear to be more likely to disclose LGBTQ+ identity if their cancer is related to their sexual or gynaecological health (70). Sensitive discussions around sex during cancer care provide a key opportunity to encourage disclosure of LGBTQ+ identity to then better tailor other information and management, and invite questions from the patient.

3.6 Lack of Confidence in Knowledge of LGBTQ+ Cancer Care

A number of studies have looked at LGBTQ healthcare knowledge across different HCPs within and outside oncology (29–37, 56, 71–76). Most recently a UK study of oncologists treating adults found that only 8% felt confident in their knowledge of the specific needs of this group (29). In the UK, the majority of oncologists treating children and teenagers are paediatricians and knowledge has also shown to be limited in this group (38). In a survey of US oncologists by Schabath *et al*, measures of confidence in knowledge fell after questions that tested specific LGBTQ+ healthcare knowledge had been answered, suggesting that studies such as these act to uncover educational blind spots (33).

Lack of confidence in knowledge on LGBTQ+ identities and healthcare was a common theme throughout the interviews. Most participants felt they lacked knowledge of LGBTQ+ cancer care and the importance of knowing your patient was part of the LGBTQ+ community: 'I'm no expert, maybe it is more important that we do know.'

There were some areas of LGBTQ+ healthcare that HCPs felt were particular knowledge gaps. For example, how much to question their patients' feelings regarding SO and GI: 'this whole issue of emerging identity is very tricky'. This is a specific issue of concern in treating paediatric patients and has not been given focus in previous literature.

Based on the literature, HCPs are less knowledgeable and confident regarding trans and gender diverse patients (29, 33, 34, 77) as opposed to LGB healthcare. All interviewees in our study stated they did not have knowledge on this topic. Sutter *et al.* found this in part to stem from a relative lack of clinical experience with transgender patients (31). HCPs were also unaware as to when during their journey on questioning GI would a patient warrant a referral to an outside organisation such as the Gender Identity Clinic for an assessment.

Length of clinical experience was suggested as a barrier to accepting new education and improving confidence: 'I have an assumption that the longer you've been doing this and the older you are the harder it becomes to stay in touch with more recent developments in what good health care looks like.' However, this suggestion is in contrast to qualitative studies in this field. Berner et al. and Schabath et al. saw no significant effect of duration of experience in responses to their surveys on knowledge, attitudes and behaviours of oncologists treating LGBTQ+ patients in the UK and US respectively (29, 33). This is perhaps as these types of survey may attract greater numbers of professionals invested in the topic.

There was awareness of not treating members of the LGBTQ+ community as one homogenous group: 'I think there are loads of nuances in terms of the needs of the community that often go unnoticed' yet there was little discussion about the nuances of addressing LGBTQ+ identity across different age groups, perhaps highlighting a further 'blind spot'.

Finally, however, some participants had little insight into their lack of knowledge of LGBTQ+ healthcare. Some of the most confident statements given by HCPs were that knowing a patient identified as LGBTQ+ would not change their medical management stating, 'it wouldn't impact on the treatment decisions.' The underlying assumption here is that someone's LGBTQ+ identity would not be directly relevant to their medical management, which is not the case (71, 78). Other quantitative and qualitative studies have also demonstrated cohorts of HCPs who continue to hold these views (34).

3.7 Knowledge of Appropriate Language

An increasing awareness and acceptance of different SOs and GIs has brought about terminologies and a change to language used to address patients, and to describe their identities and bodies. Use of appropriate language is key to cultural competence and humility in LGBTQ+ healthcare (79, 80).

Studies measuring knowledge, attitudes and behaviours of HCPs have focused less on knowledge and use of correct terminology. However, the commonly measured behaviour of enquiry on pronouns is low (29).

Knowledge of understanding the correct language to use with regard to LGBTQ+ identities was a theme throughout the data: 'I don't think I feel comfortable with those terminologies because I don't quite understand some of the broader terms', 'I have to confess it was not that long ago I got something that said LGBTQ+ and I was like what is the Q and what is the +.' This lack of knowledge included many aspects of language including pronouns, terminologies for identities and when to use neutral or gendered language.

Participants were aware of the importance of using the appropriate pronouns and appropriate name for trans young people and patients questioning their GI: 'if a patient is just coming out as trans and they want to identify as a different sex with a different name to what their birth certificate name is written and their medical notes, then you know it's discussed very openly so the team know how to address the patient.' The use of gender neutral terms such as partner vs gender specific terms such as boyfriend/girlfriend was also highlighted by one participant: 'I always use the term partners or partner.'

One participant cited a lack of consensus regarding different terminology as a barrier to knowledge and use of appropriate language: 'it's because there's a lack of agreement … I know that some people even oppose the term LGBTQ+ and some people are using LGBTQI+, so you know, it's very basics we can't even agree on the language then having these conversations does feel impossible.' Educational materials must therefore not only teach language and how to how to use it, but also how to stay up to date and manage mistakes. One strategy discussed was to follow the language used by the young person, 'I very much rely on the language that young person uses.'

3.8 How Knowledge of LGBTQ+ Cancer Care Might Be Acquired

Participants also spoke about where they had acquired knowledge of LGBTQ+ healthcare and how they would fill gaps in their knowledge. None of the participants received specific training on LGBTQ+ health during their professional education: 'I think this is something that in medical school … when I joined, it just wasn't an open topic and people weren't taught … how to support these patients. It's probably an area that's missing from my training.' Some participants had attended a departmental teaching session on this topic which served to increase knowledge but also increase confidence to discuss this topic: 'I think that just brought down all barriers to be able to talk about that between staff.'

The majority of participants said they would turn to self-education if there was something they didn't know about LGBTQ+ health. At least half admitted they would need to go online to use google or social media to find LGBTQ+ friendly information for their patient: 'I would basically start just looking on Google and social media.' This presents a danger given the misinformation that can be present online from unreliable sources, and that transgender healthcare best practices can differ between countries.

Participants discussed acquiring knowledge through conversations amongst colleagues in order to increase one's confidence to have these conversations with patients: 'start these conversations professional to professional before they're going to feel confident having those conversations professional with family.'

Others stated they would seek advice from colleagues or personal friends who identified as part of the LGBTQ+ community: 'I have a lot of friends that identify as LGBTQ+ and so I would ask them and I know a lot of doctors as well that identify and you know I would just go and ask for support from a lot of reputable people that I very much trust and ask them how I could help.' HCPs who had family members who were part of the

LGBTQ+ community also drew on their own experiences: 'I have got some personal experience … which is pertinent to my answers.' However, in all of these cases, this relies on quality of the knowledge and experience of the person being approached. As the LGBTQ+ community is not a homogenous group, personal experience does not guarantee cultural humility, or indeed health expertise. While these methods are an adjunct to professional education and training, they are not a substitute for it.

Participants spoke about the experiential learning during consultations with LGBTQ+ patients: 'I would continue to probably learn every time you know and build upon that'. This is of course an important aspect of continuing professional education but requires some baseline knowledge, and a degree of reflective practice. Indeed, one participant found the discussions from the interview for this study were a start to initiate reflection and how their practice could be changed to improve LGBTQ+ health: 'having research forums like this and being able to sit and reflect and think about it probably makes it easier to think about how you do this in real time.'

3.9 The 'Third Party', as the Expert on the Topic of LGBTQ+ *Cancer*

A recurring theme in our interviews was the assumption that it was the responsibility of a 'third party' to be the expert in the topic of LGBTQ+ cancer rather than the individual themselves, as that person had more knowledge.

When HCPs were asked how they would manage a hypothetical scenario of a patient who was questioning their GI, the majority of participants stated they would include another member of the MDT: 'I will obviously ask him if they want me to seek somebody who might be able to support them with that because I wouldn't be best placed' and 'ensuring that I was well supported and had someone to turn to that had more experience would be really important.' While it is good practice seek assistance from those with greater knowledge and experience, this should not be used as an excuse to not upskill oneself.

Specifically, oncologists felt their role was to focus on the medical management whilst the rest of the MDT would provide holistic care. One comment in regard to discussing SO and GI was: 'that would come up in the holistic needs assessment. The CNS' and ANP's do that, we don't, we tend to be focusing on the diagnosis and the treatment plan.'

Interestingly, whilst the oncologists would turn to other members of the MDT: 'Our MDT have people within the team who are hopefully more knowledgeable in that area than me', 'these are very often issues that come out with our nurse specialist', 'there will probably be others in the team and psychologists in particular, who might have more insight into than me', an allied health professional would seek support from the consultants: 'I will follow it up in some way or another by speaking with a consultant'.

One participant expected staff wearing the NHS Rainbow badge to provide support: 'having those (badges) within the trusts and particularly identifying people that you know have started to wear them very proudly they are the people you can turn to when you really do need advice on these sorts of issues and patients and how you could support them.' As we have discussed, this may be an indicator of moral support but not expertise.

Some participants suggested a referral to psychology was important for a patient questioning their GI asking: 'whether this was something they'd like to disclose with the psychology team who might have better training and how to help them with the process.' Whilst many gender diverse individuals do seek psychological support, in some cases this may not be necessary and in others, not sufficient in terms of support.

While learning within the team is important, deferral to other professionals to explore topics specific to LGBTQ+ health, robs the individual clinician from valuable learning and disincentives them from educating themselves. This is an example of where a clinician attitude can have a direct impact on both knowledge and behaviour.

3.10 Visible LGBTQ+ Affirming Materials

Most participants were in agreement of the importance of visible LGBTQ+ affirming material in the healthcare setting as a visual symbol of support and safety. This included the NHS Rainbow Badge, rainbows lanyards and poster boards displaying LGBTQ+ colours/imagery and specific information.

Multiple studies in the UK and US have found the inclusion of LGBTQ+ affirming symbols in the healthcare environment to be welcomed by LGBTQ+ people of all ages as they facilitate disclosure and a feeling of acceptance to identity (45, 59, 81, 82). They have also been recommended by several best practice reviews on the topic (77, 83).

The NHS Rainbow Badge initiative was launched in 2018 at the Evelina Children's hospital and is a popular visible LGBTQ+ symbol in UK healthcare (84). This badge has the NHS logo on the backdrop of the rainbow pride flag and has become a symbol of allyship throughout the NHS (85).

The knowledge of, and attitudes towards, the rainbow badges varied between participants. Some felt wearing them was a positive movement and a way to show support to members of the LGBTQ+ community: 'I think the rainbow badges and the rainbow lanyards have made it a topic of conversation', others felt attempts at allyship needed to be more genuine: 'I think we're a little bit guilty of talking the talk, but not walking the walk, it's almost if I'm honest, feels a little bit tokenistic at the moment.' Wearers of this badge are required to sign a pledge in order to wear one and so one would hope that it at least signifies a positive attitude of the HCP towards engaging with LGBTQ+ healthcare needs. However, no test of specific knowledge or ability to signpost to support is needed, and there is therefore a danger that patients could be met with misinformation.

This outward impression of knowledge on this topic was also felt by participants: 'identifying people that you know have started wearing them very proudly, they are the people you can turn to when you really do need advice on these sorts of issues and patients and how you could support them' while others recognised that wearing a badge does not necessarily mean knowledge on this topic: 'the thing about wearing the badge. I can highlight for myself; I don't know what their needs (trans or non-binary patients) would be.'

Healthcare institutions need to assess how ready its staff are to provide inclusive care, before using symbols which advertise it as inclusive (85).

4 DISCUSSION

This study identified 10 key themes related to the delivery of LGBTQ+ cancer care for young people (**Table 1**). As highlighted, many of these echo findings of previous studies with both HCPs and patients, though the qualitative nature of this study allowed us to identify novel findings related to HCP knowledge, attitudes and behaviours, and the factors underlying them. Some of these such as the influence of the patient-parental carer dynamic on HCP attitudes were unique to the treatment of children and young people whereas others (how HCPs acquire LGBTQ+ knowledge, the expectation of a 'third party' to be the LGBTQ + expert) have general relevance to wider LGBTQ+ healthcare.

The fact that disclosure of LGBTQ+ identity was a major theme within our work was unsurprising given it is a gateway to further tailoring of cancer care and that disclosure of LGBTQ+ identity has been shown to be associated with greater emotional wellbeing and satisfaction with cancer care (45, 57). HCPs felt comfortable for patients to disclose to them but tended not to initiate these discussions and suggest that 'the patient will bring it up if it is important'. This fits with the 'egalitarian' approach in line with the work of Ussher et al. who suggest that HCPs may adopt one of three 'positions' to LGBTQ+ cancer care; anti-inclusive, pro-actively inclusive, or egalitarian, the latter being where LGBTQ+ identity is accepted but is not seen as a priority for enquiry as it does not represent a particular healthcare need (34). This approach may not be the most appropriate given the lower rate of disclosure of TYAs patients with cancer compared to older adults (34) despite the younger LGBTQ+ population having higher disclosure rates in general (23). Factors specific to the interaction with healthcare may mean patients do not recognise the relevance of this information to their healthcare, so are less likely to disclose in this context (86).

It is reassuring that many of the facilitators of, and barriers to, disclosure we identified had been highlighted in previous literature, adding weight to the evidence that informs education on training on this topic. A novel barrier identified was a concern around patient age and development when discussing LGBTQ+ identity, and this deserves focussed research and a greater education for all paediatric HCPs. Unsurprisingly, parental-carer/patient dynamic clearly influenced clinician attitudes treating patients, and this could be both positive and negative. We recommend more focused research into this area and how best to balance supporting parents and preserving the autonomy and identity of the young person.

We identified leadership within the healthcare team as a facilitator of disclosure, perhaps because it addressed culture of fear amongst HCPs, as they knew they had support in case of mistakes. As questions about LGBTQ+ identity are not currently asked as standard, HCPs feared being seen as making assumptions, causing offence and using the wrong language. Although some of these specific fears have been highlighted in the literature (46, 48), they may remain 'hidden' by the findings of apparent HCP 'comfort' in treating LGBTQ+ patients that is seen in quantitative studies. Of course, patients may also fear to disclose due to anticipated discrimination and our findings highlight the need to create psychological safety (87) for both patient and HCP to facilitate disclosure. Education and training would also be greatly improved by explicitly tackling the explicit fears and difficult situation discussed in our study and others (34).

A plethora of studies have shown a lack of LGBTQ+ specific education across both oncology and paediatrics (29, 31–34, 36, 38, 56, 71, 72) and young people describe a lack of LGBT-tailored knowledge/support when accessing healthcare (21). We found specific lack of knowledge of, and confidence in using, language related to LGBTQ+ care. This may explain some of the poor performance measures of related behaviours in previous studies (29, 30, 32, 34, 36, 88) and for cases where clinicians in such studies felt less confident or comfortable. Adequate education in LGBTQ+ cancer care is clearly not being delivered through current undergraduate or postgraduate education (29, 33). Our study was able to uncover where HCPs were currently seeking information, such as through social media or trusted colleagues. These findings will enable us to target how best to upskill the current workforce. Although our study was small, it appeared that allied HCPs placed LGBTQ+ identity higher on their consultation agenda, and it may be that the physician's curriculum could be improved by drawing on the education of other HCPs.

We highlighted an interesting novel theme of HCPs expecting a 'third party' such as a fellow colleague, a colleague from the LGBTQ+ community or even a friend from the LGBTQ+ community to be an expert on this topic. If everyone is presuming someone else is the expert, this can result in a situation where nobody is self-educating. This attitude indicates that there may be a role for 'LGBTQ+ care champions' (89) within the healthcare setting to act as role models and to help direct colleagues towards appropriate sources of education and training. However, this does not negate the responsibility of the individual HCP to continuously learn and upskill themselves in areas of health inequality.

Participants also looked to patients as the educators on LGBTQ+ identity. Whilst taking each patient experience as a learning experience is positive, relying on this as the sole method of education may result in errors in communication particularly with the first few consultations (and beyond if they do not have the correct feedback). This has important implications as if poor quality care is experienced by patients, it may increase their reluctance to disclose in future consults. It may also provide an inaccurate source of specific medical knowledge depending on sources that patients have used to educate themselves on their healthcare (75). Finally, it places an unnecessary burden on the young person with cancer, who is already navigating the challenges of their diagnosis and identity (7).

Overall, the lack of HCP knowledge on this topic highlights the importance of training to incorporate more than the medical context. Learning and working through a biopsychosocial model (a model of health and illness which reflects the need to consider the complex interaction of biological factors, psychological factors and social factors when understanding and managing a patient's health) will hopefully give HCPs the confidence to practice their professions through a holistic lens. New initiatives such as the "Cancer in LGBTQ+ Populations' chapter in the forthcoming ESMO-ASCO curriculum will help to reinforce that this knowledge is not 'optional', and should be an area of learning sought by those looking after teenage patients as well.

A New Framework: The Cycle of Influence for HCP-Patient Interactions in LGBTQ+ Cancer Care

As authors, we sought to create a framework on which to hang our findings and make recommendations to improve cancer care for LGBTQ+ young people. Much of the work investigating the HCP role in LGBTQ+ healthcare has taken the role of the Knowledge-Attitude-Practice (KAP) Survey, originally developed to study anthropological behaviours such as family planning (90). Studies using this method tend to assume the linear relationship that knowledge affects attitudes which affect practices/behaviours (91). However, others have noted the reflexive relationship between behaviours and capabilities (including knowledge and training) as well as the ability for those capabilities to act *via* motivations and attitudes (92). Banerjee *et al.* noted the ability of increased knowledge of LGBTQ+ patients' health needs with more positive attitudes and open-communication behaviours (36).

In our study, we saw examples of the interrelatedness of these aspects in our interviews. Most clearly, we also saw the influence of knowledge on attitudes: "certainly by our TYA ANP's who are very tuned into this. They would engineer conversation … so that the patient can discuss it" (on discussion of GI/SO). Further, a key barrier to enquiry about LGBTQ+ identity was a lack of awareness of its relevance to the patient's healthcare and increased knowledge appeared to raise its priority in the HCP agenda.

We also saw the effect of attitudes on behaviours around discussion of LGBTQ+ health: "I think the attitudes are massively changed, and I assume the knock-on effect is that it makes people feel more comfortable to talk about it too" and the ability of knowledge to change behaviour *via* a shift in attitudes: "they did it as a really, really amazing interactive kind of quiz discussion/teaching session, and I think that that just brought down all barriers to be able to talk about that between staff because it was something that was just became very comfortable following that." The ability of personal and organisation behaviours to change attitudes directly was also noted: "having boards, having the rainbow badges and lanyards, and just having it as something that is not a taboo to talk about, just something that is easy to discuss."

Consultation behaviours that involved SO and GI enquiry were also able to bring about increased knowledge, and reinforce the behaviour: "I think you gain a lot of knowledge from young people, so you know I do feel quite happy to facilitate those sorts of conversations and I would continue to probably learn every time". Knowledge may also directly influence behaviour e.g., in knowing the correct language to use with a patient.

Thus, we posit a highly reinforcing relationship of knowledge, attitudes and behaviours of HCPs in LGBTQ+ cancer care where influences may be cyclical and reciprocal (**Figure 1**). We also note some redundancy in that, for example, a positive attitude can be present without specific knowledge; 'I don't think you have to be an expert on this I think you just have to be open and sensitive' but that the most effective behavioural change might come from working through this cycle: 'I couldn't say yes. I understand what they need … I would respect their decision, but I can't say that I would have any insight in how to manage other than to use the pronouns that they've requested.'

The authors felt that our themes could be mapped to this framework directly such that 6 fell strictly under knowledge, attitudes or behaviours whilst 4 spanned the transitions (**Figure 1**). For example, barriers and facilitators of disclosure could be both attitudinal and behavioural, and frequently an interrelation of the two (although a major facilitator was knowledge of relevance of identity to healthcare). Knowledge of the correct language to use could directly influence communication behaviours. The authors suggest that future efforts to improve LGBTQ+ cancer care *via* HCP education should consider this so-called 'Cycle of Influence for HCP-Patient Interactions in LGBTQ+ Cancer Care' (**Figure 1**).

Recommendations

We suggest that our framework, if utilised along with other published tools (92) could stimulate a 'feed forward' process whereby HCPs upskill in a self-driven way. It may be incorporated into educational initiatives or used to review existing local practice.

Given the dearth of knowledge we observed, we recommend basic improvements with postgraduate clinician education on a number of topics (**Table 2**). There also specific behaviours of individual HCPs (**Table 3**) and organisations (**Table 4**) which could facilitate increased disclosure of LGBTQ+ identity and improved care.

As HCPs appreciated that 'there may be someone more knowledgeable on this topic than them', each hospital speciality could have an appointed dedicated LGBTQ+ lead or 'champion' who needs to undertake regular training to stay up-to-date and supports education of others. This practice has been successfully employed elsewhere (89). This can act to change organisational culture and influence both knowledge and attitudes, but care must be taken that it does not provide an excuse for individual HCPs not to self-educate.

Strengths and Limitations

To our knowledge, this is the only qualitative study in the UK addressing HCPs knowledge, attitudes and behaviours when

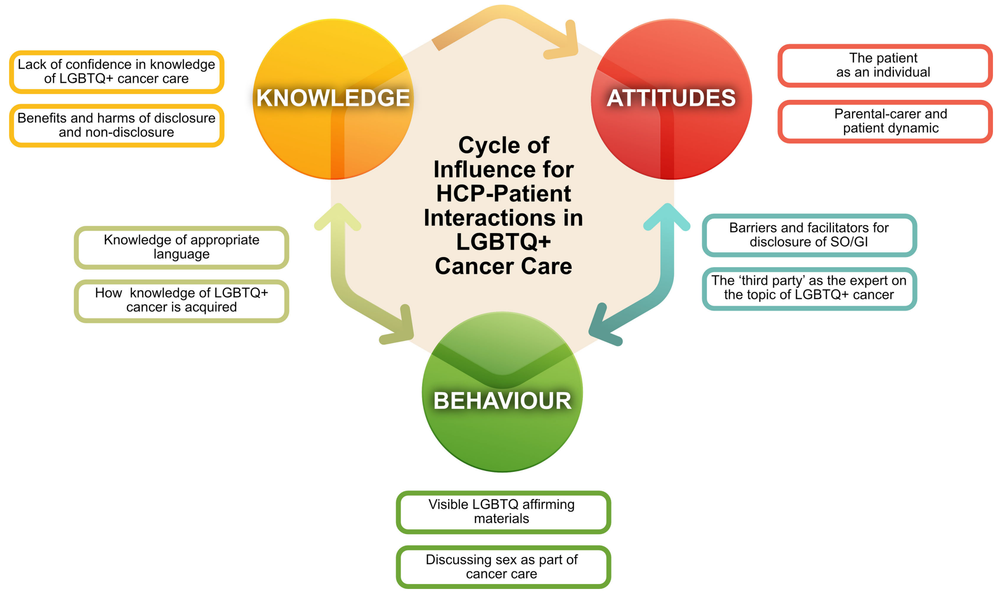

FIGURE 1 | Cycle of Influence for HCP-Patient Interactions in LGBTQ+ Cancer Care. This framework describes how knowledge, attitudes and behaviours of healthcare professionals (HCPs) may interact and provides a tool from which to plan interventions for HCP education and organisational change.

TABLE 2 | List of topics recommended to improve postgraduate education for on LGBTQ+ health and cancer care for healthcare professionals.

- LGBTQ+ terminology and appropriate language
- Why, when and how to facilitate disclosure of SO and GI
- Intersection of gender-affirming and cancer care
- Sex during cancer treatment

(SO – sexual orientation, GI – gender identity).

TABLE 3 | Individual practice points for improving cancer care for LGBTQ+ youth.

- Ensure appropriate space for consultations.
- Ensure enough time for consultations. If not possible organise a follow up meeting.
- Aim for appropriate members of the MDT to be present in the consultation
- Enquire with CYP if they would like their carers present during the consultation.
- Offer one-on-one time with the CYP without their cares.
- Explain confidentiality to the CYP and abide to this when possible.
- Provide the CYP with reasoning as to why questions on LGBTQ+ identity may improve their care.
- Encourage the HCP leading in the CYP's care to enquire about SO/GI and to lead by example.
- Increase dialogue amongst colleagues regarding LGBTQ+ health.
- Increase use of a psychosocial risk assessment tools to assist in asking question regarding SO and GI.
- Discuss sex and contraception in a non-heteronormative way.

(CYP - Children/Young Person, MDT - Multidisciplinary team, SO – sexual orientation, GI – gender identity).

treating LGBTQ+ young people with cancer. Its UK specificity means its findings and recommendations are directly applicable to the workings of the NHS. We uncover novel themes in this area that might underlie some of the trends in knowledge, attitudes and behaviours seen in other studies (36).

We acknowledge several limitations to this study including its single-centre nature. Three interviewees had attended a recent education session which may have influenced responses. HCPs with more interest in changing LGBTQ+ cancer health may have been biased to participate. We had difficulty in recruiting male participants in a predominantly female paediatric oncology department. Interviews being conducted by a researcher visiting from outside the organisation may have led to both increased comfort of participants and reluctance to disclose some views.

To address these limitations, this work will be extended to gain a broad national picture with a UK-wide survey which developed in conjunction with the findings from this study and previous literature (29). We will use this to gather further evidence for our themes, suggested framework and recommendations.

5 CONCLUSIONS

Paediatricians are often the first health-care contacts for LGBTQ+ adolescents who are developing their sexual and gender identities therefore they have the chance to make a difference of their experience of healthcare.

Our work pointed to disclosure as a key starting point to ensure this topic is more commonly discussed in healthcare. We found a feed-forward relationship to improving HCP knowledge, attitudes and behaviours related to LGBTQ+ healthcare which we term the 'Cycle of Influence for HCP-Patient Interactions in LGBTQ+ Cancer Care'. We suggest that interventions with the greatest impact on patient care are those spanning the domains of these framework, addressing psychological safety and

TABLE 4 | Recommended changes at the organisational level to bring lasting change for LGBTQ+ health.

LGBTQ+ affirming materials	• NHS Rainbow badge • Name badges stating one's pronouns • LGBTQ+ supportive posters (explaining the importance of disclosure) • TYA leaflets with same sex couples
Registration forms with gender neutral language including appropriate options SO, GI and trans status	
Appointed LGBTQ+ lead or 'champion' who undertakes regular training and facilitates education of others.	

(TYA, Teenage and Young Adult, SO – sexual orientation, GI – gender identity).

impacting the organisation as well as the individual HCP. We look forward to its utilisation for improvements in NHS services and clinician education in the UK and beyond.

DATA AVAILABILITY STATEMENT

Raw interview transcripts and quotes will not be made available but lists of raw codes will be made available on request. Requests to access the datasets should be directed to TG, younglgbtqcancerstudy@gmail.com.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Royal Marsden NHS Foundation Trust and the Institute of Cancer Research Ethics committee (Ref No: SE 1132).The participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

TG –Ethics application, patient and public involvement, conducting of interviews, interview transcription, interview coding, thematic analysis, reviewing of framework, manuscript drafting and reviewing; AB – Interview coding, thematic analysis, derivation of framework, manuscript drafting and reviewing; BP – Revision of themes, reviewing of framework, manuscript reviewing and editing;

DS – Revision of themes, reviewing of framework, manuscript reviewing and editing. All authors contributed to the article and approved the submitted version.

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“Surviving Discrimination by Pulling Together”: LGBTQI Cancer Patient and Carer Experiences of Minority Stress and Social Support

Rosalie Power[†], *Jane M. Ussher*[*†], *Janette Perz*, *Kimberley Allison*, *Alexandra J. Hawkey* *and on behalf of The Out with Cancer Study Team*

Translational Health Research Institute, School of Medicine, Western Sydney University, Sydney, NSW, Australia

Background: Lesbian, gay, bisexual, transgender, queer and/or intersex (LGBTQI) people with cancer and their carers report poorer psychological outcomes than the general non-LGBTQI cancer population. There is growing acknowledgement that these health inequities can be explained by minority stress, which can be buffered by social support.

Study Aim: To examine subjective experiences of minority stress and social support for LGBTQI people with cancer and their carers, drawing on qualitative findings from the Out with Cancer study.

Method: An online survey including open ended items was completed by 430 LGBTQI cancer patients and 132 partners and other carers, representing a range of tumor types, sexual and gender identities, age and intersex status. A sub-sample of 104 patients and 31 carers completed an interview, with a follow-up photovoice activity and second interview completed by 45 patients and 10 carers. Data was thematically analysed using an intersectional theoretical framework.

Results: Historical and present-day experiences of discrimination, violence, family rejection and exclusion created a legacy of distress and fear. This impacted on trust of healthcare professionals and contributed to distress and unmet needs in cancer survivorship and care. Social support, often provided by partners and other chosen family, including intimate partners and other LGBTQI people, buffered the negative impacts of minority stress, helping LGBTQI patients deal with cancer. However, some participants lacked support due to not having a partner, rejection from family of origin and lack of support within LGBTQI communities, increasing vulnerability to poor psychological wellbeing. Despite the chronic, cumulative impacts of minority stress, LGBTQI patients and carers were not passive recipients of discriminatory and exclusion in cancer care, demonstrating agency and resistance through collective action and advocacy.

Conclusion: LGBTQI people have unique socio-political histories and present-day psycho-social experiences that contribute to distress during cancer. Social support serves to buffer and ameliorate this distress. There is a need for cancer healthcare professionals and support services to be aware of and responsive to these potential

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Showket Hussain,
ICMR-National Institute of Cancer Prevention and Research, India

Reviewed by:
Doris Mangiaracina Benbrook,
University of Oklahoma Health Sciences Center, United States
Pranay Tanwar,
All India Institute of Medical Sciences, India
Sajad Ahmad Dar,
Jazan University, Saudi Arabia

***Correspondence:**
Jane M. Ussher
j.ussher@westernsydney.edu.au

[†]*These authors share first authorship*

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vulnerabilities, including the intersectional differences in experiences of minority stress and social support. There is also a need for recognition and facilitation of social support among LGBTQI people with cancer and their carers.

Keywords: cancer, LGBTQI, minority stress, social support, discrimination, intersex, transgender (binary and non-binary), adolescents and young adults (AYA)

1 INTRODUCTION

The experience of cancer diagnosis, treatment and survivorship can be very stressful for people with cancer and their carers, leading to depression and anxiety (1). There is growing evidence that lesbian, gay, bisexual, transgender queer and/or intersex (LGBTQI) people who have experienced cancer, and their carers, report poorer mental health outcomes than the general non-LGBTQI cancer population. This includes higher levels of cancer-related distress (2, 3), and higher depression and anxiety (4, 5). To date, most LGBTQI cancer research has focused on adult cisgender individuals with breast or prostate cancer (6). Recent systematic literature reviews highlight the need to understand the complexity of LGBTQI experience of cancer across cancer streams, age, and sexual identity subgroups, including people who are trans (binary and non-binary) and intersex (4, 7–9). An intersectional theoretical framework has been recommended (10) to analyze how the complex spheres of identity intersect (11) to affect health outcomes among LGBTQI people with cancer (4, 10, 12).

There is also a need to examine the perspectives and experiences of informal carers, who are often invisible within LGBTQI cancer research and care (13). Caring for a partner, family member or close friend with cancer can have significant negative consequences for health and wellbeing (14, 15). LGBTQI caregivers report higher caregiving burden and unique support needs compared to non-LGBTQI caregivers, including experiences of minority stress and lack of inclusion in cancer care (16–18). In comparison to the general cancer population, LGBTQI people with cancer are more likely to be unpartnered, and to receive support from 'chosen family', including friends and other LGBTQI people (2, 19). There is evidence that LGBTQI chosen family caregivers experience the same levels of stress as partner caregivers, yet they often lack access to social support, increasing their vulnerability to poor psychological wellbeing (20, 21).

Health inequities reported by LGBTQI people with cancer and their carers can be explained by minority stress theory (3, 22, 23). Minority stress is the experience of chronic stress associated with living with a marginalized LGBTQI identity. It is manifested by experience and anticipation of stigma, exclusion, discrimination, and violence (described as distal stressors). The internalization of anti-LGBTQI sentiments contributes to negative self-views, identity concealment and expectations of rejection, hostility and potential future victimization (described as proximal stressors) (22–24). Supporting this theory, distress reported by LGBTQI cancer patients is significantly associated with experiences of discrimination in life and cancer care (3, 25, 26), accompanied by identity concealment and expectations of future hostility (27). LGBTQI people report lower satisfaction with cancer care (28) and greater unmet care needs (29) in comparison with the general cancer population. This includes a lack of adequate information and support (6), and reluctance to 'come out' in healthcare settings due to fear of discrimination (30).

Previous research has reported that LGBTQI people experience high rates of discrimination in their everyday lives, including physical and sexual violence (31, 32), and hostile social environments that compromise wellbeing (33, 34). Throughout history, people now referred to as LGBTQI have been viewed as immoral, enabling their relationships and bodies to be subject to state-sanctioned violence and systemic injustice (35, 36) including discrimination in healthcare during the HIV/AIDS epidemic of the 1980s (37). Until 1973, homosexuality was classified as a mental illness by the American Psychiatric Association (38), and until 1991 consensual homosexual acts were criminalized in parts of Australia (39), the primary site for the present study. There is continued pathologization of trans and intersex people within mainstream health systems (40, 41). LGBTQI people's behaviors remain criminalized, sometimes punishable by death, in many parts of the world (42). LGBTQI people are also subject to hostile public and political discourses that legitimize discrimination and attempt to roll back LGBTQI human rights (43–46), with negative implications for mental health and feelings of safety (47, 48).

Social support can buffer the negative impacts of distal and proximal minority stressors (3, 49) and is associated with improved quality of life (15, 50) and reduced distress (51), depression and anxiety (5) in cancer survivorship and caregiving. However, LGBTQI people may lack social support, due to having no intimate partner, experiences of family rejection, or the impact of stigma and social exclusion where they live (24, 52). Low social support has been found to be a unique predictor of distress in LGBTQI cancer patients (3, 53). However, the subjective meanings and experiences of minority stress and the ways in which social support may ameliorate or buffer distress for LGBTQI cancer patients and their carers within intersecting identities remains unexplored (8).

The present analysis aimed to address this gap in the research literature by examining subjective experiences of minority stress

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Abbreviations: ANZUP, Australian and New Zealand Urogenital and Prostate Cancer Trials Group; AYA, Adolescents and young adults (15-39 years); HCP, Healthcare professional; LGB, Lesbian, gay and bisexual; LGBQ, Lesbian, gay, bisexual and queer; LGBT, Lesbian, gay, bisexual and transgender; LGBTQI, Lesbian, gay, bisexual, transgender, queer and/or intersex; SGM, Sexual and gender minority; Trans, Transgender people, binary and non-binary.

and social support among LGBTQI people with cancer and their carers, drawing on the qualitative findings from the mixed method Out with Cancer study (27, 53–55). This complements quantitative analysis from this study, which found higher rates of distress among LGBTQI people with cancer compared with general cancer populations, associated with minority stress and lack of social support (53). High rates of minority stress were reported by both LGBTQI cancer patients and their carers, including discrimination in life and in cancer care, and concealment of LGBTQI identity (53, 55).

This paper enables further interpretation of these findings, through in-depth qualitative examination of the nature and perceived impact of minority stress and social support for LGBTQI cancer survivors and their carers.

2 METHODS

2.1 Study Design and Theoretical Framework

This study was part of the broader mixed methods Out with Cancer project (27, 53–55). The project examined LGBTQI experiences of cancer from the perspectives of LGBTQI patients, their caregivers, and healthcare professionals (HCPs), in order to inform LGBTQI inclusive cancer care. This paper presents the qualitative analysis of open-ended survey responses, interviews and a photovoice activity, related to LGBTQI cancer patient and carer experiences of minority stress and social support.

The project uses an intersectional theoretical framework, which acknowledges that individuals inhabit multiple interconnected social identity categories, such as gender, sexuality, cultural background and age (56). These identity categories are embedded in systems of social stratification, associated with power inequalities (57–59), and influence social practices and health and wellbeing (60). An intersectional perspective recognizes that identity cannot be reduced to the summary of social groups to which a person belongs; instead, attention is paid to how social identities interact to produce a meaningful whole in a way that cannot be explained by looking at one social identity alone (58), and influence social practices and health and wellbeing (60).

Integrated knowledge translation (iKT), a dynamic collaborative process between researchers and knowledge users to achieve actionable research outcomes, guided the study design, data collection, analysis and dissemination. Following principles of iKT, a steering committee comprising LGBTQI people with cancer, cancer HCPs, and representatives from LGBTQI health and cancer support organizations, were actively involved through co-design in all stages of the study. Discussion between the researchers and the steering group facilitated reflexivity (61), critical evaluation of the ways in which our positions as LGBTQI people, clinicians, researchers, and/or cancer survivors influenced the research process and outcome. The study received ethics approval from Western Sydney University Human Research Ethics Committee (ref. no. H12664, with secondary approval from the ACON (formerly the AIDS Council of New South Wales) (ref. no. 2019/09).

2.2 Recruitment

Participants were eligible for this study if they: (a) had been diagnosed with cancer, had undergone a medical intervention related to cancer risk or had cared for someone with cancer; (b) they or the person they cared for identified as LGBTQI, and (c) were at least 15 years old. Participants were recruited through cancer and LGBTQI community organizations, including the study partner organizations, social media (Facebook, Twitter, Instagram), cancer research databases (Register 4, ANZUP), cancer support groups and LGBTQI community events. Snowball sampling was also used, asking participants to pass the study information to someone they knew who fitted the study criteria. The study was open internationally, although recruitment focused on Australia and other English-speaking countries such as the USA, UK, New Zealand, and Canada. Recruitment strategies engaged LGBTQI patients and their carers in a range of sexual and gender identities, ages and tumor types. Individual strategies were used for each LGBTQI sub-group and to engage participants from intersecting minority backgrounds, including Indigenous Australians, people from migrant backgrounds, and adolescents and young adults (AYAs). Data were collected between September 2019 and September 2021.

2.3 Participants and Procedure

Participants took part in a three-stage study: A total of 430 LGBTQI people (patients) who currently or previously had cancer (82.8%), or a medical intervention related to cancer risk (17.2%), and 132 partners and other carers (hereafter, carers), aged 15 years or older, completed an online survey. A subset of survey participants, 104 patients and 31 carers, completed a 60-minute interview to investigate their experiences in greater depth. Forty-five patients and ten carers completed an additional photovoice activity.

Demographic characteristics of patients and carers are reported in **Table 1**. Most patients and carers were cis women, Caucasian, older adults, living in Australia and identified as lesbian, gay, or homosexual. Greater diversity was evident in participants' regionality and cancer types. A minority of participants identified as trans (binary and non-binary; hereafter trans), bisexual or pansexual, queer, reported an intersex variation, or were AYA. A minority identified as Indigenous Australian, or Māori, Asian, or from a mixed ethnic background. Most carers were partners of LGBTQI people with cancer (63.6%).

2.4 Materials

2.4.1 Survey

The survey comprised a series of closed and open-ended measures. Full details of the patient (53) and carer (55) surveys are described in detail elsewhere. This paper focuses on responses to open-ended questions on minority stress and social support. Following quantitative measures about minority

TABLE 1 | Demographic characteristics of LGBTQI patients and carers.

Age at time of study (mean years, standard deviation; range)	**Patients (*n*=430)** ***M*=52.5, *sd*=15.7; range 16-92**	**Carers (*n*=132)** ***M*=50.2 *sd*=17.0; range 15-76**
	***n* (%)**	***n* (%)**
Country		
Australia	311 (72.3%)	93 (70.5%)
United States of America	62 (14.4%)	14 (10.6%)
United Kingdom	29 (6.7%)	9 (6.8%)
New Zealand	8 (1.9%)	6 (4.5%)
Canada	7 (1.6%)	4 (3.0%)
Other country	13 (3.0%)	6 (3.6%)
Race/ethnicity		
Caucasian	362 (85.2%)	109 (82.6%)
Asian	11 (2.6%)	5 (3.8%)
Australian Aboriginal, Torres Strait Islander or Māori	9 (2.1%)	4 (3.0%)
Mixed background	19 (4.5%)	6 (4.5%)
Other/unclear background	24 (5.6%)	8 (6.1%)
Location		
Urban	234 (54.5%)	69 (52.3%)
Regional	145 (33.8%)	48 (36.4%)
Rural or remote	50 (11.7%)	15 (11.4%)
Gender		
Cis female	216 (50.2%)	83 (62.9%)
Cis male	145 (33.7%)	26 (19.7%)
Trans (binary and non-binary)[1]	63 (14.7%)	23 (17.4%)
Different gender identity	6 (1.4%)	–
Sexuality		
Lesbian, gay or homosexual	317 (73.7%)	95 (72.0%)
Bisexual or pansexual	47 (10.9%)	17 (12.9%);
Queer	45 (10.5%)	12 (9.1%)
Straight or heterosexual	10 (2.3%)	5 (3.8%)
Different or multiple identities	11 (2.6%)	3 (2.3%)
Intersex variation		
Yes	31 (7.2%)	5 (3.8%)
No	388 (90.2%)	127 (96.2%)
Prefer not to answer	11 (2.6%)	0
Cancer Type[2]		
Brain	11 (3.0%)	9 (7.0%)
Breast	90 (24.3%)	37 (28.7%)
Cervical	11 (3.0%)	4 (3.1%)
Colorectal	17 (4.6%)	8 (6.2%)
Head/neck	14 (3.8%)	10 (7.8%)
Leukaemia	17 (4.6%)	5 (3.9%)
Lymphoma	24 (6.5%)	6 (4.7%)
Ovarian	17 (4.6%)	13 (10.1%)
Prostate	59 (15.9%)	8 (6.2%)
Skin	25 (6.8%)	3 (2.3%)
Uterine	23 (6.2%)	4 (3.1%)
Other	58 (15.7%)	19 (14.7%)
Not sure or unknown	4 (1.1%)	3 (2.3%)
Medical intervention for cancer risk	74 (17.2%)	27 (22.9%)
Carer relationship to patient		
Partner/ex-partner	–	84 (63.6%)
Family	–	31 (23.5%)
Friend	–	12 (9.1%)
Different relationship	–	3 (2.3%)
Multiple care relationships	–	2 (1.5%)

[1] *Patients: 34 (7.9%) non-binary, 13 (3.0%) trans female, 8 (1.9%) trans male, 8 (1.9%) different TGD identity; Carers: 16 (12.1%) non-binary, 5 (3.8%) trans female, 2 (1.5%) trans male.*

[2] *Cancer type for carers is of patient cared for.*

stress (discrimination in life and in cancer care, internalized prejudice and identity concealment) and social support (access to support from others), participants were asked "is there anything you would like to tell us about this issue?".

2.4.2 Semi-Structured Interview

Semi-structured, one-to-one interviews, using a conversational style, were undertaken by a number of researchers to explore subjective experiences in-depth. Interviews were conducted over the telephone or using video-conferencing software with LGBTQI patients and their carers. These were audio-recorded. Participants were asked about their experiences of cancer, including interactions with HCPs, decision-making pertaining to disclosure of their LGBTQI status and the consequences of this for their cancer care; the impact of cancer on their lives, including on their identities and relationships; experiences of finding support networks and information as an LGBTQI cancer patient.

2.4.3 Photovoice Activity

Interview participants were invited to engage in a photovoice activity. Photovoice involves participants taking photographs that visualise elements within an individual's life pertinent to a particular phenomenon (62). Situated within an action-research model, photovoice methods facilitate involvement and empowerment of research participants and have been described as an innovative way of working with marginalised people, including LGBTQI communities (63, 64). The method implicitly challenges traditional structures of power and traditional modes of knowledge production (65). Participants were invited to submit three to five photographs that represented their experiences with cancer, which were then discussed in a second interview. Written and visual instructions were provided to participants to aid in the photovoicep process. Participants used their devices (smartphones, digital cameras) to take photographs and electronically submit them to the research team. The photographs were used as the basis for subsequent discussions to understand more about participants' experiences of cancer and often eliciting in-depth descriptions of specific events. Participants were asked questions such as "Could you please talk me through these photos and explain what they mean to you?" and "How does this photo capture your cancer experience?". All participants provided informed consent for their photographs to be used in analysis and in publications.

2.5 Data Analysis

Thematic analysis was used to analyse the open-ended survey, interview and photovoice data, as an appropriate method to capture richness across multiple data types (66). All interviews were professionally transcribed verbatim, and integrity checked for any errors. The transcripts were de-identified and participant names replaced with pseudonyms. Transcripts and open ended survey question responses were read line by line in close detail, with notes added to capture relevant first-order concepts or codes. Through a process of discussion and decision-making, the researchers grouped first-order concepts where commonalities were identified to create concise, overarching or higher-order codes. This process allowed for defining and refining codes and consultation with the stakeholder advisory group on which data should be included within each code. Having formulated the coding framework, transcripts, open-ended survey questions and photographs with their participant description were imported into NVivo software to facilitate the organization of the qualitative data into relevant codes. Once coding was complete, each of the coded sections was summarized within a coding summary, which further helped to identify commonalities and facilitated theme identification across the data set. Members of our stakeholder advisory group were involved in the development of codes and themes and read and provided comment on the interpretation and reporting of the data. The analysis was revised to incorporate feedback on language and interpretation.

In the presentation of results, LGBTQI patient and carer participants are identified by pseudonyms (for interviewees) or the word "survey", with demographic details of age, sexual and gender identity and/or intersex status, and cancer type provided for longer quotes. For readability, demographic details for short quotations are provided in **Supplementary Table 1**, with a longer version of the quotation identified by superscript numerical indicators in the text. Photographs (**Figures 1–6**) are accompanied by a brief summary in the words of the participant.

3 RESULTS

Two primary themes were identified, each with sub-themes, see **Figure 1**. The first primary theme, "Living with minority stress: Discrimination, exclusion and fear of hostility" describes the cumulative and ongoing experiences of prejudice, discrimination and exclusion which shaped participants' feelings of safety during cancer treatment, survivorship and care, including impacts on interactions with HCPs and support networks. The second primary theme, "Resisting the margins: Social support and activism buffer the effects of minority stress" documents the role of social support in buffering the negative effects of minority stress in the context of cancer and demonstrates the agency and resistance of LGBTQI patients and carers to discrimination and marginalization during cancer care. The results describe participant experiences of violence, abuse and discrimination; some readers may find these accounts distressing.

3.1 Living With Minority Stress: Discrimination, Exclusion, and Fear of Hostility

3.1.1 Homophobia, Transphobia and Prejudice When We Were Younger: An Era of "Open Discrimination and Hostility"

Across participant accounts there was widespread evidence of minority stress in terms of experience of distal stressors. As reported previously, 83.6% of participants reported discrimination in their lives in general because of being LGBTQI (53). In the qualitative analysis, this was described as experiences of stigma, exclusion, hostility and violence. These experiences of minority stress were a legacy that impacted upon LGBTQI patients and carers as they navigated cancer survivorship and care, in relation to feelings of trust and safety.

Participants recounted "a lot of open discrimination and hostility"[1] and "traumas in our backgrounds"[2], such as being "bullied at school for being gay"[3,] including by other children, "parents and teachers"[4]; "bullied for being effeminate"[5]; "verbally abused" and "assaulted"[6], or "gay bashed"[7]. Discrimination and

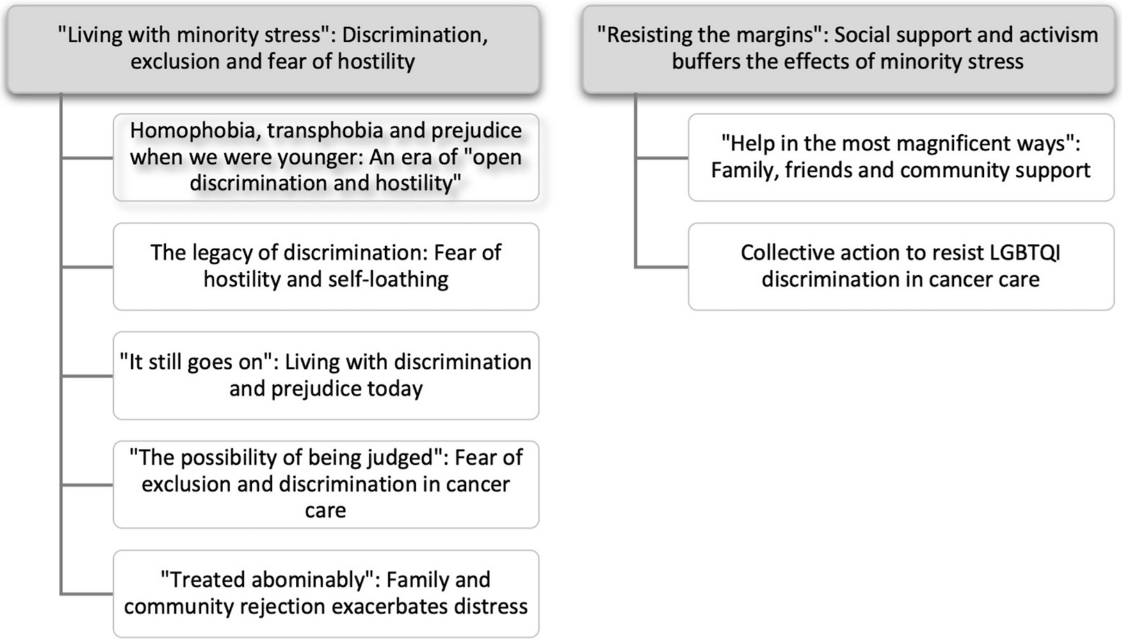

FIGURE 1 | Thematic map.

abuse were perpetrated everywhere, from “family to society”[8]. For example, a 20-year-old lesbian survey participant who was caring for her father who had head/neck cancer said:

> My mother and one of my brothers would make homophobic comments in regard to me. I also attended a religious school for most of my life, where it was taught that being LGBT was a sin.

Claire, a 66-year-old lesbian, whose partner had ovarian cancer, said “You couldn’t even be a schoolteacher back in those days”. Discrimination was also inclusive of institutional violence, as a 67-year-old lesbian survey participant with breast cancer commented, “I have PTSD from police violence and witnessing police violence against lesbian and gay people and against Indigenous people in the 70s”.

Many older participants lived through an era when “it was illegal to be gay”[9], with a minority reporting that they lived in countries where homosexuality is still criminalized. For example, Anthony, a 65-year-old gay man, caring for his husband with prostate cancer, said that for the first seven years of his relationship with his now-husband, “We could have gone to jail”. Lachlan, a 75-year-old queer intersex man with bowel cancer, described growing up during the era of criminalization as “pretty hard” because “everyone’s against you.” He said, “You had to go behind the door sort of thing. You couldn’t tell anyone what you were going through. You had to keep it to yourself.” The widespread persecution of gay men resulted in some participants receiving criminal records for engaging in consensual sex, which contributed to the suicide of friends, and these records that have only recently been expunged. Grace, a 56-year-old bisexual woman with cervical cancer explained the impact of criminalization in her life:

> It’s taken me a long time [to embrace my sexual identity] because I grew up in the 70s seeing my friends who were gay being targeted. One guy I worked with took his own life. He had a record because he was involved in a sexual act and that was illegal at that stage. So, seeing all of these things, all of these repercussions, I sort of thought I need to squash the gay side of me.

Some participants commented on the fact that historically, homosexuality and gender dysphoria were “defined as a mental illness”[10]. This cultural discourse positioned sexuality and gender diversity as perversity and a sickness, justifying medical regulation of LGBTQI bodies through practices such as “ECT [Electroconvulsive therapy]” to treat “body dysphoria and sinful sexual desires (attracted to women)”[11]. Scott, a 55-year-old gay trans man with many cancers explained that his partner “was incarcerated in prison for being trans and went through conversion therapy that involved being stripped naked and sitting on the laps of male guards” to “teach you how to be a woman”. A 52-year-old trans woman survey participant with soft tissue cancer said she “failed” conversion therapy, resulting in her being “kicked out onto the street after a particularly bad belting with an electric power cord and a razor strap” and was consequently homeless, “surviving the next 10 years on the streets”. Intersex participants also described medical regulation of their bodies, including “medical violence”[12] of “forced [sex] assignments” as children, causing “far-reaching consequences”[13]. A 36-year-old queer non-binary/gender fluid survey participant with intersex variations who had medical interventions for cancer said:

> The medical community has been nothing but abusive and exploitative regarding my intersex body. I've been subjected to medical photography, forced sedation, forced invasive examinations, forced surgical procedures, and lied to about needing surgical procedures under the claim that I had cancerous growths.

During this era of criminalization and pathologization, LGBTQI "people were much more closeted" and "everything was much more hidden"[14] due to the "threat of losing your job, your housing and definitely family"[15] if outed in the wrong context. For many participants, coming out as LGBTQI was shrouded in "shame and guilt"[16] and, for a minority, "being gay was unthinkable" when they were younger[17]. Troy, a 71-year-old gay man with prostate cancer explained that he "didn't have the courage to come out" and, instead, pursued a heterosexual marriage with children. When he eventually did come out, it "destroyed" and "threatened" his family and was "a very big deal". These pervasive and cumulative minority stressors experienced by participants over their lives were reference points that contributed to fear, distrust and distress during their cancer journey.

3.1.2 The Legacy of Discrimination: Fear of Hostility and Self-Loathing

There was some evidence of minority stress in terms of proximal stressors, the internalization of anti-LGBTQI sentiments (53), directly impacting upon participants during cancer treatment, survivorship, or as caregivers. Several LGBTQI patients and carers reported that the legacy of prejudice, discrimination, and criminalization, "when we were younger shaped […] responses to things now"[18], resulting in being "fearful of violence"[19], "prepared for hostility"[20] and contributing to "low self-esteem"[5] and "internalized oppression"[21]. For some, this extended to self-blame for cancer, with Finn, a 56-year-old gay man with throat cancer saying, "I've brought this on myself" after a friend joked his cancer resulted from "sucking too much cock"[16]. "Internalized oppression" was also linked to high rates of "smoking, drinking, drug use" in lesbian communities, which are risk factors for cancer[21]. Kai, a 50-year-old, bisexual, trans woman with intersex variations, whose partner had breast cancer, explained that "when you are treated like a leper, you take it out on yourself" and described struggling with "suicide ideation" and "thinking I'm just a burden, I should end it. I should kill myself". Bernice, a 61-year-old lesbian woman with breast cancer explained the lifelong impact of being the recipient of bullying and marginalization:

> When you grow up as a lesbian and the age group that I grew up, your attitudes and the way you deal with the world because of the condemnation, you had to hide things, hide yourself or not be yourself. Or you'd be yourself, but you've got to be prepared for hostility or be prepared to shut down, shut down all the external stuff. I think to understand your response to the world, people do need to understand that you are very much affected by that feeling of derision, hatred, whatever, that you've blocked out.

Other participants described the long-term and cumulative impact of structural discrimination. For example, Patty, a 71-year-old lesbian woman, whose partner had many cancers, explained that due to LGBTQI and gendered discrimination many lesbian women were excluded from employment opportunities, resulting in their having "less access to good jobs" over the course of their lives. This meant that a number of women were on a "lower-income" and, consequently, "rented for a long time", negatively affecting their financial scrutiny and putting them "in a very vulnerable position", when diagnosed with cancer. Patty also noted that many of her peers became isolated as they aged:

> I think the other problem is that past discrimination has meant that, probably, some people in my age group and a bit older are hidden away. And they are isolated from family, isolated from the community; and if their partner dies then they're on their own. And if they've got a disability, they don't get out, so they lose the network. That's what happens.

Historical discrimination against LGBTQI communities left a legacy of fear for many of these participants, that meant "the anticipation of potential discrimination" was "always there", contributing to ongoing anxiety and impacting on "health and wellbeing"[22], irrespective of present-day exposure to such moments. Glenn, a 66-year-old gay man with head/neck cancer said he needed to "very quickly develop a very strong survival code to live in a heterosexual world", while Anita, a 34-year-old lesbian with uterine cancer, explained that she and her wife:

> Used to carry around our marriage certificate everywhere [during cancer care]. We changed our names as soon as we could so if we had to, we could pass off as sisters. We did what we could so that we could make sure that everything was ok. It was a safety concern.

Participants described an "under the skin awareness"[23] of the potential for prejudice and discrimination during cancer treatment and when caregiving and that they were "judging all the time" so they could "act appropriately to be safe" because "when you've feared for your life at different times because of your sexuality, you carry that with you for the rest of your life" [24]. This legacy of fear created additional layers of stress during cancer diagnosis, treatment and survivorship.

3.1.3 "It Still Goes On": Living With Discrimination and Prejudice Today

For many participants, prejudice and discrimination were not in the past but were reported as something that "still goes on"[25], with material and psychological consequences including anxieties about discrimination in cancer care. A 42-year-old lesbian, trans woman, survey participant with skin cancer explained that "being trans", "discrimination is everywhere.

FIGURE 2 | Interiority landmines cycle. In this tunnel, it's mostly safe but it's like walking in an area that has landmines. You can walk through fine for most of the time and most of the people that you meet will be professional and inclusive. But you're always cautious. You don't know if you're going to step on a landmine. So you have to walk gingerly. This is what it means to navigate the health system as a lesbian woman. [Ellen, 36, lesbian, gynecological cancer]

Many people have a deep and visceral hatred of people like me". The potential for this hatred to culminate in violence was evident in the account of trans participants. A 53-year-old, trans woman, survey participant with soft tissue cancer said:

> I've been assaulted seriously in the last 24 months, six times. Last year, someone attacked me in my own front yard in daylight. Bathroom use has also been 'problematic'. I have been verbally abused and physically assaulted on several occasions inside my local shopping center.

Ongoing hostility and prejudice from family of origin was reported by some participants, including being "treated abominably" and in ways that were "totally degrading and frankly inhumane"[26], because of being LGBTQI. Riley, a 53-year-old lesbian with ovarian cancer, explained that her family "had issues when I came out" causing her to be "estranged from them for a long time because I was an embarrassment". Catherine, a 61-year-old bisexual woman with vulval cancer, commented, "My actual mother believes that God has told her that me being gay makes me evil and, therefore, it would poison her life to have any contact with me". Aaron a 32-year old gay man with bowel cancer said;

> I think it would be probably a lot easier, like if I wasn't gay then I would probably have a lot of friends from high school and probably be closer to family members.

Although discrimination could be overt, many participants also reported micro-aggressions pervading all aspects of their lives. Ash, a 40-year-old, bisexual, non-binary person with an unknown primary cancer, said that the relationship with their employer "shifted very quickly" after they were 'outed' by a colleague, resulting in increased scrutiny, despite previously "winning awards and getting commendations" at work.

Several participants discussed an "ominous"[27] increase in recent years of anti-LGBTQI public discourse, including "redneck" comments[27] and "transphobia in the media"[28]. This engendered fear that the conservative minority would legislate discrimination against and erode LGBTQI rights as "a revenge tactic for 'you gays and lesbians who got your way'" in relation to marriage equality[27]. As Raymond, a 55-year–old gay man with prostate cancer, commented, "What a lot of us rainbowians, rainbow community people, want is just for the right-wing people to not ruin how things have progressed over the years". Anti-LGBTQI discourse was experienced by participants as

FIGURE 3 | Shutters. When you're going through cancer treatment, and you've had your diagnosis and everything, it's really important to choose who to let in. Most of the people I spent quality time with were people who I'd intentionally chosen to let into my life. [Mary, 54. Lesbian, breast cancer].

"incredibly tough"[29] and "very stressful when you are sick [with cancer] and having to listen to all that"[30].

3.1.4 "The Possibility of Being Judged": Fear of Exclusion and Discrimination in Cancer Care

Fear of discrimination due to anti-LGBTQI public discourse had material consequences for participants' engagement in cancer healthcare, illustrated well in the photograph 'interiority landmine' (**Figure 2**). Participants described concerns that transphobic and homophobic public discourses would "exacerbate people [HCPs] who are tunnel-visioned and hateful"[31], thereby legitimizing discrimination. For example, Elsie, a 55-year-old lesbian with lung cancer, said she was concerned that the Australian Religious Discrimination Bill (currently lapsed in federal parliament) would "give doctors an opportunity to say, 'Well, it's against my religion to treat you, so I'm not going to treat you'", causing her to be "nervous" about "going to see a doctor that I'd never met before" due to "the possibility of being judged". Raymond, a 55-year-old gay man with prostate cancer, worried that prejudiced HCPs "might withhold things or they'll do indirect discrimination. They'll do it in sneaky ways, so it won't look like it's being discriminatory".

Participants described feeling "trepidation"[32] and being "wary"[33] when deciding if to disclose being LGBTQI to their cancer HCPs, "especially at the time [when] some doctors in Australia were openly against marriage equality"[34]. Some participants said they would "avoid" disclosing being LGBTQI

FIGURE 4 | My husband. This is my husband. He, of course, was my main support. As the most important person in my life by way of- well, lots things, but way of support through this. He looked after me in that period no questions asked, no ifs or buts. He took on that role of caring for me. [Rodney. 57, gay man, skin cancer]

FIGURE 5 | Lesbian support. This painting is about celebrating lesbianism and same-sex relationships. There are about 40 women that come to this group. We all get together and help each other; we're all working for a common cause – to look after each other as lesbians and to provide support to each other.Maybe there's been a bit of discrimination when you were being treated or some of the nurses were a bit snarky and you could tell they weren't comfortable having your partner in the room, you can talk about all of that with these women because at some point they'd all been there and they probably all experienced it. [Paulette, 67, lesbian, colorectal]

"with medical professional[s] except where it's clinically relevant"[35]. Oscar, a 27-year-old, gay man with lymphoma said:

> I don't want them [HCP] to know I'm gay because I don't want them to treat me different. If they realize I'm gay … if they're religious, are they going to have less motivation to treat me, cure me?

Others said, "I do not refer to it, even though it might be relevant"[36]. Some participants described avoiding medical care because of perceived discrimination:

> The world we live in - read the news - affects our health. The more we know we are hated and feared (religious freedoms act; trans hate; The Australian [a News Corporation newspaper]), the less likely we are to access care or feel safe when we do. One of my specialists was showing me an app on her phone and it was surrounded by Christian apps and Bible apps, and I was instantly terrified and will not go back. (Survey, 40, intersex, queer, medical intervention)

For many participants, discrimination in cancer care or as part of caregiving was a lived reality, with 33% of participants reporting discrimination in cancer care, as reported previously (53). Participants reported exclusion of same-sex partners and inadequate care. Ryan, a 60-year-old gay man with prostate

FIGURE 6 | LGBTQ+ activism. Here we are at a pride march. We all had t-shirts and arrows saying different things about our sexualities, genders and interests. Showing that we as a community are completely diverse. I also wore a t-shirt that said, "know your prostate" and as we walked along, I handed out pamphlets about a prostate cancer support group for LGBT people. It felt really important to me to be involved in this activism around sexuality and prostate cancer. [Ryan, 60, gay, prostate cancer]

cancer, said "I didn't feel supported. I didn't feel like my husband was included", and a 57-year-old, asexual, trans man, survey participant, who had medical interventions for cancer risk and was caring for his partner with many cancers, said,

> Discrimination has been around if we are really in a relationship. We have had many times where me, or my partner, have been refused entry into the ICU saying, "only family may visit!" It is extremely distressing to be denied the support of your partner.

Several trans patients described micro-aggressions and exclusion in having to navigate healthcare settings, which were underpinned by dominant discourses of a binary conception of gender. Trans patients and carers reported being "misgendered"[37] by HCPs, having to receive treatment in cancer spaces that did not align with their gender identity, or concealing their trans status to pass as "cis", causing negative psychological consequences. A 38-year-old, queer, non-binary person, who stopped taking hormones to present as more feminine when caring for their grandmother who was in hospital with bowel cancer, explained that "to feel that I had to pretend to be someone else was upsetting and stressful".

Other patients described religious prejudice enacted by HCPs: "One of the nurses was quite religious and said that she would pray for her … because she was gay, not because she had cancer" [Mary, 54, lesbian, breast]:

> He [healthcare professional] clearly read me as a lesbian and he was dismissive of me as a person. It kind of felt like I was being treated like a lesser person. And that judgment was based on his belief system. Early on in the conversation, he identified as a religious person and then I kind of pieced together why he was being rude and paternalistic and judgmental. [Jasper, 50, queer woman, breast]

Exclusion was also experienced at the intersections of cultural background, gender and sexuality, evident in cancer information resources, as a 38-year-old, non-binary/gender fluid lesbian, queer survey participant with many cancers said: "It's all really white, and white Australian. My partners have not always been white, and they felt actively excluded from all of the materials I brought home for their sexuality, gender and race".

A number of participants described experiencing prejudice from "other patients", including a 58-year-old survey participant caring for her lesbian friend with cervical cancer, who said, "My friend was in a waiting room and there was a segment about LGBTIQ+ rights, and a couple sitting next to her said some terrible things about LGBTIQ+ people. It was very upsetting for her".

3.1.5 "Treated Abominably": Family and Community Rejection Exacerbates Distress

Many participants reported rejection from their families of origin, local communities or LGBTQI sub-groups, adding to minority stress and impacting on feelings of connection and support during cancer treatment and survivorship and caregiving.

Several participants reported anti-LGBTQI prejudice and exclusion from their families of origin. Lucinda, a 59-year-old queer woman whose partner had ovarian cancer, recounted telling her partner's niece, "It's your fault that she [partner] died because you don't believe in God". Some participants "choose not to interact with"[38] family members who were not accepting of them being LGBTQI, including a 22-year-old, bisexual, survey participant caring for her mother with breast cancer, who said that "cancer showed me that my family is not just poor support, but is a burden, so I have distanced myself from them to take better care of myself." Being discerning about support during cancer was illustrate by the photograph "Shutters", **Figure 3**.

Others had to navigate relationships with hostile relatives, either to give or receive care during cancer. Kai, a 59-year-old, bisexual, trans, intersex woman whose partner had breast cancer, explained the impact of family prejudice on caring for her partner with cancer:

> I have had to care for my partner from afar as some of my family have rejected me for being trans. This has been a nightmare. We had the discussion after diagnosis as to what life meant and we both agreed that it is important to be truly happy. I then got the courage up to transition, with her full support, and now her family and some of my own have rounded on me for this. So, not only was she fighting cancer, she was fighting prejudice and such as well. It's put a whole lot of extra layers of extra stress on her, on her health.

Other participants said they concealed their sexuality or gender identities due to a "realistic concern"[39] of being disowned and fear of judgement, or due to safety concerns. However, this sometimes meant that their partners were unable to access support during cancer, as a 26-year-old gay male survey participant, caring for his partner who had prostate cancer, commented:

> My partner is an Asian Muslim and has to hide his sexuality totally from his family in fear of his psychological wellbeing and, possibly, his life too. Because of this, I have no one to share my thoughts and feelings with. During chemotherapy, I was privately scared that he would die, and I felt I could not share that with him or my own family and friends because of the consequences.

For a minority of participants, lack of family support during cancer placed additional pressure and stress on intimate relationships. A number of participants described their relationships ending or becoming abusive:

> My partner of four years broke up with me after a diagnosis. She did not feel she had the support around her to support me or to see me die. I was in a six–week period between two major surgeries and two different diagnoses. The mental health impacts during such a time were devastating. (Survey, 37, queer, non-binary/gender-fluid, medical intervention)

Lack of family support also exacerbated economic vulnerability during cancer treatment as "we don't have security from our parents as some people in our generation might because we're gay"[40]. This vulnerability accumulated for some, mostly younger participants, to create housing insecurity and homelessness. For example, Alex, a 35-year-old gay, non-binary person with testicular cancer did all his radiation treatment "with no firm place where I was living, no place to call home". Exclusion and isolation from family were described as "emotionally distressing"[41] and meant that some participants "don't particularly have anyone to rely on for much care or help, so it's just me dealing with it when I need to go to appointments, [or] be in hospital"[42]. A 57-year-old, asexual, trans man, survey participant who had medical interventions commented, "There is very little support out there when you don't have family of origin supporting you. General services, like hospital social workers or council home-help range from totally ignorant to outright prejudice".

A number of participants said they felt unwelcome and alone in their local communities, particularly those living in conservative, religious and regional/rural communities. For example, an 18-year-old, bisexual, survey participant, caring for her father with lung cancer, said, "I don't feel welcome anywhere as I live in a very Bible belt area". Carter, a 20-year-old gay man with leukemia, living in a regional area, said:

> There just aren't many people, in general, around that area. You know, you could go into town and there'll be a few people, but none of them would be gay. So, meeting other gay people, that wasn't really an option, where I lived.

A 34-year-old, queer, non-binary/gender fluid, survey participant, caring for their partner with breast cancer, said, "I constantly looked for groups of people like me, but I never found anyone. I assume the few others out there, who are the same age and community as me, were just as isolated and stressed and also couldn't make the contact with anyone to get peer support". At the same time, cancer support groups including "online communities" were described as "very heteronormative". A 42-year-old, queer, non-binary/gender fluid, survey participant with breast cancer said that accessing support through these pathways left them feeling "more isolated and 'different' than I have ever felt".

For some participants, particularly trans and bisexual participants, LGBTQI communities were experienced as unwelcome, hostile, and discriminatory. A 39-year-old bisexual, woman, survey participant with cervical cancer said that "mainstream gay and lesbian culture is hostile to bisexuals" and a 49-year-old trans man survey participant with ovarian cancer said that "people assume the LGBTQI community is a source of support … it often isn't. Transgender people face discrimination from within LGBTQI communities". Others described LGBTQI communities as "superficial" and "lacking in compassion and empathy", with "no old-fashioned caring", just "strangers looking out for their own needs"[43]. This perspective was evident in the accounts of older gay men, who contrasted their present-day experiences of exclusion with the culture of community caregiving experienced during the HIV epidemic of the 1980s and 90s. These participants said that, despite being at the forefront of fighting for rights earlier in their lives, they now felt "old" and "invisible" in contemporary LGBTQI spaces[44].

3.2 Resisting the Margins: Social Support and Activism Buffer the Effects of Minority Stress

3.2.1 "Help in the Most Magnificent Ways": Family, Friends, and Community Support

Social support played an important role in buffering the negative impacts of minority stress and in helping LGBTQI participants deal with cancer (53), with 78% of participants reporting strong social support (53). This was described as access to "a very large support network"[45] of "family, friends, acquaintances and work colleagues", who offered "unconditional and full support"[46]. This was experienced as "nourishing"[47] and "revealed new depths of connection, love and respect"[48]. For Carol, a 40-year-old gay woman with breast cancer, having a reliable, supportive network meant that she could focus on "just being sick", She described feeling that she could "just float around because there were really big groups of people who were looking after my [wife] and my kids".

For many patients, intimate partners were their "main support", illustrated by the photograph 'My husband', **Figure 4**. Partners often "paved the way"[49] and helped navigate cis-heteronormativity and discrimination in cancer care. It was commonly reported that "going on hospital visits and that sort of thing together"[50] with same-gender partners helped disclose to HCPs, get information, and advocate for needs. Anita, a 34-year-old lesbian with uterine cancer, said "She [my partner] was the best supporter, helped me advocate for myself and keep everything straight and figure out what I supposed to – what I wanted to say, help me think through stuff but also support me in my own decisions". Barry, a 56-year-old gay man whose husband had lung cancer, said that navigating cancer together had strengthened their relationship:

> It's really shown what an incredibly resilient couple we are. It's really brought forward all of the beautiful things that have underpinned our relationship over the last 24 years. They suddenly light up large in big print. The reasons that we have worked so well as a couple.

Participants also reported strong support from family and friends (53). This family support was positioned as crucial to wellbeing, as "people survive longer when they've got things like cancer if they've got family support"[51]. A 40-year-old, queer, non-binary/gender fluid, survey participant caring for their partner with breast cancer. said that "my parents and in-laws […] would help us in a heartbeat when we asked for it" and an 80-year-old lesbian survey participant, whose wife had kidney cancer, told us: "My family rallied around my wife as she battled cancer and then supported me after she died". Participants often described being "grateful"[52] for support from their families, and this was seen as a reflection of acceptance of being LGBTQI. Sandra, a 69-year-old lesbian, who had cared for her partner with breast cancer, said she felt "fortunate" because:

> My [partner's] parents could have come into step at any time and pushed me out. They didn't. They didn't stop me going into Emergency. They always deferred to me and at the funeral made sure I was included. I think they wished she [partner] wasn't a lesbian because it's not natural to them. But they never, ever rejected me.

Other participants said that cancer "increased my family's respect and perseverance of me"[53], resulting in them having "grown closer"[54].

For many participants, support from other LGBTQI people, described as chosen family, was crucial during cancer. Chosen family served to ameliorate strained or estranged relationships with the family of origin and "were the ones that were there for me"[55], providing support "in the most magnificent ways"[56]. Paulette, a 67-year–old lesbian woman with colorectal cancer, explained:

> My [natal] family wasn't terribly supportive at that time or since, basically. I think that's why I have so much emphasis on my chosen family, which is a lesbian community. They've kind of replaced my biological family.

Chosen family created an important sense of belonging and reinforced LGBTQI identities, particularly among older lesbians. A 78-year-old lesbian survey participant said, "Being a lesbian carer for my lesbian lover was a very empowering and emotional time because the radical lesbian feminist community we were part of were very supportive". She explained that it was "an opportunity for us all to pull together in quite extraordinary ways". Being part of a community where everyone "shares the load of caring for one another"[57] was regarded as protective against isolation and loneliness in the context of living with cancer. As a 75-year-old lesbian survey participant caring for her partner with breast cancer commented, "Without the love of my lesbian friends, I would feel very alone". A 55-year-old lesbian survey participant with ovarian cancer said, "Almost every weekend since diagnosis, we've had someone visit. I've felt so lucky, so loved, like all my birthdays come at once. And that's made everything easier". Alice, a 48-year-old lesbian caring for her ex-partner with breast cancer, explained that support from her chosen family was often all-encompassing due to shared experiences of marginalization:

> When you think about the queer community compared to the straight community, it just seems to be there's a sense of all-hands on deck and everybody bringing what they can to a situation, and I think that really comes from needing chosen family to navigate your way, through being othered so much. The sense of community and chosen family is very, very strong.

Some participants described receiving support during cancer from unexpected sources, including work colleagues. A 40-year-old lesbian survey participant whose partner had uterine cancer, said that she was usually quite private at work, but that cancer was a catalyst for disclosing both her LGBTQI status and partner's cancer diagnosis. When she did, it enabled her to engage more authentically with colleagues, access support and negotiate flexible work arrangements: "I had to come out to a lot of colleagues during this process. However, they were all very supportive, which made it easier." Other participants living in regional areas said that, despite the potential for social isolation due to there being few other visible LGBTQI people, they received "nothing but love and care" from within their local communities during cancer. This experience was often discussed by older participants who were "unapologetically out" as LGBTQI in their communities. Barry, a 56-year-old gay man whose husband had lung cancer said:

> We made the decision before we moved into our regional town to go in from the outset as an out, gay, mixed-race couple, which was a little bit brave. Weirdly enough, we've been wrapped with more love than we expected to be in the country. And sometimes, it's actually been quite beautiful. Not once have I had anyone come up and say, "I'm sorry to hear about your friend". Everyone has said, "I'm really sorry about your husband".

For many participants, pets were an important source of companionship and support that helped ameliorate loneliness and regulate emotional distress including anxiety and grief. Pets were described as "the most incredible companion"[58] that was "always by my side"[59] offering "constant company"[60]. Leonard said his dog had "given me more support over the last, nearly seven years than anything else in my life". For Neal, a 68-year-old gay man with prostate cancer whose partner had died, his dog played an important role during long nights when he was struggling with anxiety and loneliness.

3.2.2 Collective Action to Resist LGBTQI Discrimination and Exclusion in Cancer Care

Collective activism, combined with social support for others, was described by participants as having served to buffer the impact of minority stress. Participants discussed positive experiences in LGBTQI-specific support groups, shared experience in the context of both cancer and LGBTQI community, illustrated in the photograph "Lesbian Support" (**Figure 5**). A number of participants said that "having this cancer has made me realize I will never be put in the closet again"[61], motivating them to become "politically involved"[62] and "very vocal about my experiences"[63], to advocate for LGBTQI-specific cancer information and support for their communities. A 30-year-old intersex lesbian who had medical interventions for cancer risk said that after being "closeted for seven years as being intersex due to doctors telling my parents and I to keep my diagnosis a secret from everyone I knew, I got angry and shared my story with a local newspaper and now advocate for youth internationally". A 49-year-old trans man survey participant with ovarian cancer said that they were now "providing presentations to colleagues with the aim to increase understanding of working with transgender cancer patients". For other participants, activism involved "coming out"[64] within cancer care as a way to "challenge the systems that I come in touch with"[65]:

> I came out to so many people in the hospital – staff and other 'cancer families' – often for the reason of increasing visibility of rainbow families in the hope that this would reduce homophobia, and increase people's awareness of rainbow families and just how similar/normal we are when compared with families headed by a heterosexual couple or heterosexual single parent (Survey, parent, 47, lesbian, leukemia)

Several participants set up "support groups"[66,67,68] in their local area offering connections to other LGBTQI people with cancer. This included one person who started "a charity to support other LGBTIQ cancer patients"[69] and another who had "produced a booklet"[70] to share information about cancer in LGBTQI communities including cancer screening and cancer survivorship. Participants explained that their LGBTQI cancer advocacy was motivated by the desire to "use our experiences to be of help"[68] and "because they [LGBTQI cancer information/ services] weren't there for me so I want to make sure they can be there for someone else"[69]. Being involved in LGBTQI cancer advocacy was also discussed as affirming identity and helped to build community connection, illustrated in the photograph "Know your prostate!", **Figure 6**. Dylan, a 35-year-old gay non-binary/gender-fluid person with leukemia explained that it "brought me around many LGBT+ people where I can express who I am". Paulette, a 67-year-old lesbian with colorectal cancer, said that being involved in LGBTQI cancer support helped her to feel "a bit more part of the community and to be with people who don't question who you are and why you are the way you are and that type of stuff" and experience she described as "like coming home".

4 DISCUSSION

The aim of this paper is to examine subjective experiences of minority stress and social support for LGBTQI people with cancer in intersecting sexual and gender identities, intersex status, age, and tumor types. Our findings provide insight into the chronic and cumulative nature of minority stress and multiple systems of oppression that have shaped historical and present-day anti-LGBTQI prejudice, discrimination, family rejection and exclusion from communities. These experiences have exacerbated fear and distress during cancer survivorship and caregiving. However, social support and advocacy did ameliorate minority stress for LGBTQI patients and carers, and for some, affirmed their identities. That said, some participants lacked social support, or experienced rejection from those whom they turned to for support, exacerbating their distress.

Our findings confirm previous reports that LGBTQI people with cancer and their carers experience unique stressors during their lives, which serve to exacerbate distress in cancer survivorship (3, 6). Many of the older participants became adults during an era when homosexuality was criminalized and considered a mental illness, resulting in societal and institutional discriminations, stigma and violence. Lack of LGBTQI legislative protections during that era legitimized abuse, allowing bullying and hate crimes to go unprosecuted (67). So-called reparative practices, such as LGBTQ conversion therapies, were administered under the guise of a therapeutic framework (68) and "normalizing" medical interventions were conducted as routine practice on infants with intersex variations (69). Recently, LGBTQ conversion therapies were publicly acknowledged to be cruel, degrading forms of torture (68) and there is growing acknowledgement that sex assignments conducted in infancy on individuals with an intersex variation violate bodily autonomy and deny human rights (69, 70). The long-lasting proximal stress caused by these traumatic experiences, such as distrust and fear of prejudice, concealed identities and internalized stigma (23), were evident in the accounts of participants in the present study, sometimes years after the events had taken place. This creates a vulnerability that impacts the experience of cancer and cancer care (3, 27, 53). Such minority stress has also been demonstrated to cause long-lasting negative psychological consequences (71) and is a risk factor for premature cognitive decline (72).

In liberal democracies, LGBTQI people experience greater equality today, including legislative protections in their everyday lives. Many countries have decriminalized same-sex relationships, passed anti-discrimination legislation, and have put in place protections against hate speech and hate crimes (73). However, there are continued political and legislative efforts to prevent further equity and to roll back established LGBTQI rights (44, 45). Anti-LGBTQI legislative processes and political campaigns are demonstrated to affect LGBTQI people's mental health adversely (74, 75), causing higher levels of stress, depression and anxiety, and increased exposure to harassment and discrimination (76). The "pitting" (73) of LGBTQI rights against other human rights, such as religious freedoms (45), has meant that LGBTQI people continue to live in hostile and discriminatory environments that contribute to internalized, health-eroding stressors, including distress and fear during cancer survivorship and care (27).

Our findings demonstrated the intersection of identities in the experience of minority stress, providing insight into the quantitative findings of the Out with Cancer Study, where trans, intersex and AYA patients and carers reported higher rates of minority stress (53, 55). Our findings confirm previous reports that trans people experience high rates of verbal, physical and sexual violence (63, 77) and discrimination in healthcare (78–80). This is compounded by anti-transgender discourse that appears in the news, with negative implications for feelings of safety and wellbeing (47, 48). People with intersex variations also face numerous societal discriminations and hostility (70), as well as mistreatment in medical settings, including violations to bodily autonomy that deny human rights, leading to distress (69). Younger LGBTQI people can experience bullying and social exclusion, at a time when many are exploring their sexuality and identities (81). Young people have also been the target of recent transphobic media reports, with negative consequences for mental health (47). The impacts of minority stress were also evident in LGBTQI patient and carer accounts of discrimination and or fear of discrimination in cancer care. LGBTQI patients who feared discrimination, or had previous negative experiences in healthcare, reported poorer mental health outcomes, greater distress and unmet needs (6, 53, 82) and may avoid care (83). This results in concealment of LGBTQI identities from HCPs (80), as was evident in the accounts of some participants in the present study. Whilst concealment of LGBTQI identity can be a self-protective mechanism (80), it is associated with invisibility (6, 84), regret (82), unmet needs (6, 8), and can compound the stress of cancer and lead to poor psychological outcomes (85).

Our findings confirmed and extended previous research that social support can ameliorate the negative impacts of minority stress in LGBTQI populations (3) and is protective against distress (86). Cancer caregivers in the non-LGBTQI community are typically intimate partners (15). For many LGBTQI people, chosen family, including partners, friends and other LGBTQI people, provide support and connection (24, 87). Support from chosen family affirmed LGBTQI identities and relationships and offered group solidarity, confirming previous reports (24). The culture of mutual caregiving within LGBTQI communities is partly a cultural legacy of the HIV/AIDS era, whereby caregiving was "thrust" (88) upon gay and bisexual communities as a result of discrimination in healthcare and family rejection (89). There is also a long history of feminist lesbian community activism and connectiveness (90), and more recently, trans community visibility and mutual support (91). However, for a minority of LGBTQI people with cancer, trans and bisexual participants in particular, experiences of in-group microaggressions meant that broader LGBTQI communities were experienced as exclusionary, hostile and unsafe (92), increasing vulnerability to social isolation and distress. This further highlights the way in which intersecting identities can lead to vulnerability, precluding the buffering effect of social support for some LGBTQI people with cancer. It is important to note we found no discussion of microaggressions within LGBTQI cancer support groups.

For younger LGBTQI participants, support and acceptance from family of origin were important to psychological wellbeing, as reported in previous research (49, 93). However, the ameliorating role of social support was dependent on families affirming LGBTQI identities; support that was hostile or required LGBTQI people to conceal their identities added to minority stress. Younger LGBTQI people with cancer and carers living outside of metropolitan hubs often lacked LGBTQI community support due to the absence of other LGBTQI people where they lived (94). Young people who are discovering or exploring their identities, and who do not have strong connections to LGBTQI chosen family, may also lack affirming social support (81). These findings highlight the ways in which LGBTQI identity and age intersect to create a position of marginalization for adolescents and younger adults with cancer.

Our findings also demonstrated that LGBTQI cancer carers experience minority stress, which can be ameliorated by social support, as is the case for LGBTQI people with cancer. Support for LGBTQI caregivers is associated with better mental health (95), reinforcing the need for LGBTQI carers to be included in cancer support (6). Due to the pervasive impacts of cis-heteronormativity in cancer care and support groups (27), LGBTQI carers may be uncomfortable accessing services and support available to non-LGBTQI carers (13). It is essential that the needs and experiences of carers are included in future LGBTQI cancer research, and in programs of LGBTQI cancer care.

LGBTQI patients and carers were not passive recipients of discrimination and exclusion in cancer, demonstrating agency and resistance through collective action and advocacy. The provision of support to other LGBTQI people with cancer through support groups or other forms of activism served to affirm identities in the face of minority stress among participants of all ages. LGBTQI communities have a history of mobilizing to affect change and improve LGBTQI rights, which has had the effect of building community and solidarity (90, 91). However, the requirement for people experiencing adversity to address health inequities within their communities places an undue burden on marginalized individuals and communities, highlighting the need for systemic changes to reduce minority stress in cancer survivorship and care.

5 CONCLUSION

In conclusion, our findings demonstrated that LGBTQI people have unique socio-political histories and present-day experiences that have created a legacy of distrust and fear and may contribute to distress and unmet needs in cancer survivorship and care (6). For LGBTQI individuals, minority stress compounds the impact of other stressors associated with cancer, including fear of cancer recurrence, uncertainty of treatment outcome, co-morbidity and symptomatology (3, 96, 97). Social support serves to buffer the impact of minority stress (3, 49), and is widely recognized to be associated with better quality of life and psychological wellbeing for people with cancer (15), including LGBTQI cancer populations (5, 51, 98).

Our analysis across the mutually constitutive intersections of gender, sexuality, intersex status, cultural background and age identified intersectional differences in the nature and impact of minority stress and social support for LGBTQI people with cancer and their carers. The impacts of minority stress are compounded for LGBTQI people who occupy multiple marginalized positions (99), with those who are trans or gender diverse, intersex and/or of younger age being particularly vulnerable (53). However, strong social support serves to buffer minority stress, with both family of origin and chosen family, including partners and other LGBTQI people, serving as vital and empowering sources of support for LGBTQI patients and carers.

Our findings have implications for LGBTQI cancer care and support services. Environments in which LGBTQI patients and carers access care and support during cancer need to be culturally safe and inclusive (27, 100). This can be achieved through professional education and training, ensuring HCPs are knowledgeable about the potential impacts of historical and present-day minority stressors on cancer survivorship, including higher risks of distress and barriers to social support, particularly for trans, intersex and AYA patients and carers. Awareness of the needs of LGBTQI patients and carers will enable HCPs to adopt inclusive and reflective practices (27, 101). Due to the pervasive impacts of cis-heteronormativity in cancer care and support groups, LGBTQI patients and carers can be uncomfortable accessing services and support for non-LGBTQI people (13), further exacerbating isolation and vulnerability to poor psychological wellbeing (20, 21). Visual indicators of LGBTQI inclusivity, such as pride flags, can signal awareness and safety for LGBTQI patients, as can acknowledgement of sexual and gender identity or intersex status on patient intake forms and presence of anti-discrimination health service policies (100, 102). The inclusion of partners and chosen family in consultations and support services is also essential (27). There is also a need for investment in peer-led initiatives that provide connection and support to LGBTQI people with cancer and carers to help to overcome barriers to social support. Minority stress is pervasive in the lives of many LGBTQI people. We have a duty of care to ensure that the impact of minority stress on wellbeing and on interactions with HCPs is recognized and addressed within professional cancer care.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

ETHICS STATEMENT

The study received ethics approval from Western Sydney University Human Research Ethics Committee (ref. no. H12664, with secondary approval from the ACON (formerly the AIDS Council of New South Wales) (ref. no. 2019/09). Written informed consent to participate in this study was provided by the participants' legal guardian/next of kin. Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

THE OUT WITH CANCER STUDY TEAM MEMBERS

Chloe Parton[1], Cristyn Davies[2], Gary W. Dowsett[3], Katherine Boydell[4], Fiona McDonald[5], Antoinette Anazodo[6], Kerry H. Robinson[7], Felix Delhomme[8], Martha Hickey[9]

[1] School of Health, Te Herenga Waka – Victoria University of Wellington, Wellington, New Zealand

[2] Specialty of Child and Adolescent Health, Faculty of Medicine and Health, University of Sydney, Australia; and School of Social Sciences and Psychology, Western Sydney University

[3] Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne, Australia

[4]Black Dog Institute, University of New South Wales, Sydney, Australia

[5] Canteen and Faculty of Medicine and Health, The University of Sydney, Sydney, Australia

[6]Kids Cancer Centre, Sydney Children's Hospital and School of Women's and Children's, University of New South Wales, Sydney, Australia

[7] School of Social Sciences and Translational Health Research Institute, Western Sydney University, Sydney Australia

[8]ACON, Sydney, Australia

[9]Department of Obstetrics and Gynaecology, University of Melbourne and the Royal Women's Hospital, Melbourne, Australia

AUTHOR CONTRIBUTIONS

JU and JP designed the study and prepared the application for funding, in collaboration with The Out with Cancer Study team. The survey was developed by JU, KA, and RP in collaboration with the Out with Cancer Study team, and our stakeholder advisory group. Data were collected by RP and KA. RP conducted qualitative analysis of the data, in collaboration with JU. RP and JU wrote the paper, with critical input from JP, AH, and KA. The Out with Cancer Study Team provided critical commentary on the written paper. All authors approved the final paper.

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SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fonc.2022.918016/full#supplementary-material

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EDITED BY
Lore M. Dickey,
Retired, Flagstaff, AZ, United States

REVIEWED BY
Maryam Farooqui,
Qassim University,
Saudi Arabia
Maria Beatriz Torres,
Mercyhurst University,
United States

*CORRESPONDENCE
Matthew B. Schabath
matthew.schabath@moffitt.org

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"I need more knowledge": Qualitative analysis of oncology providers' experiences with sexual and gender minority patients

Christina L. Tamargo[1], Edith P. Mitchell[2], Lynne Wagner[3], Melissa A. Simon[4], Ruth C. Carlos[5], Bruce J. Giantonio[6], Matthew B. Schabath[7]* and Gwendolyn P. Quinn[8]

[1]Department of Internal Medicine, Johns Hopkins Hospital, Baltimore, MD, United States, [2]Department of Medical Oncology, Thomas Jefferson University, Philadelphia, PA, United States, [3]Department of Social Sciences and Health Policy, Wake Forest University, Winston-Salem, NC, United States, [4]Department of Obstetrics and Gynecology, Robert H. Lurie Comprehensive Cancer Center, Feinberg School of Medicine, Northwestern University, Chicago, IL, United States, [5]Department of Radiology, University of Michigan, Ann Arbor, MI, United States, [6]Department of Hematology/Oncology, Massachusetts General Hospital, Boston, MA, United States, [7]Department of Cancer Epidemiology, H. Lee Moffitt Cancer Center & Research Institute, Tampa, FL, United States, [8]Department of Obstetrics and Gynecology and Population Health, NYU Grossman School of Medicine, New York, NY, United States

Background: While societal acceptance for sexual and gender minority (SGM) individuals is increasing, this group continues to face barriers to quality healthcare. Little is known about clinicians' experiences with SGM patients in the oncology setting. To address this, a mixed method survey was administered to members of the ECOG-ACRIN Cancer Research Group.

Materials and methods: We report results from the open-ended portion of the survey. Four questions asked clinicians to describe experiences with SGM patients, reservations in caring for them, suggestions for improvement in SGM cancer care, and additional comments. Data were analyzed using content analysis and the constant comparison method.

Results: The majority of respondents noted they had no or little familiarity with SGM patients. A minority of respondents noted experience with gay and lesbian patients, but not transgender patients; many who reported experience with transgender patients also noted difficulty navigating the correct use of pronouns. Many respondents also highlighted positive experiences with SGM patients. Suggestions for improvement in SGM cancer care included providing widespread training, attending to unique end-of-life care issues among SGM patients, and engaging in efforts to build trust.

Conclusion: Clinicians have minimal experiences with SGM patients with cancer but desire training. Training the entire workforce may improve trust with, outreach efforts to, and cancer care delivery to the SGM community.

KEYWORDS

cancer, oncology, clinicians, healthcare disparities, sexual and gender minorities, LGBT

Introduction

Sexual and gender minority (SGM) populations include, but are not limited to, those who identify as lesbian, gay, bisexual, transgender, or queer (LGBTQ), as well as asexual, intersex, and/or two-spirit; individuals with same-sex or -gender attractions or behaviors, those with differences in sexual development, and those who identify with non-binary constructs of sexual orientation, gender, or sex are also included (Sexual and Gender Minority Research Office, 2019). Roughly 4.5% of the United States population, which amounts to over 11 million people, is estimated to identify as LGBT, though this may not include other SGM populations that do not identify as cisgender LGB or transgender (Conron and Goldberg, 2020). SGM populations face a multitude of health disparities compared to cisgender heterosexual populations, stemming from issues including increased poverty (Badgett et al., 2019), denial of care due to their sexual or gender identity (Lambda Legal, 2010), fears related to discrimination (Eckstrand and Potter, 2017; McNeill et al., 2021), and inadequate training by healthcare professionals (Lambda Legal, 2010), among others.

In addition to facing barriers to quality healthcare, SGM patients have unique medical concerns in multiple areas, including oncology (Quinn et al., 2015). Many cancers disproportionately affect SGM patients, which is attributed to higher prevalence of risk factors like alcohol use and obesity, reduced cancer screening, and the aforementioned barriers to care (Institute of Medicine Committee on Lesbian G, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities, 2011; Machalek et al., 2012; Agénor et al., 2014; Quinn et al., 2015; Tabaac et al., 2018; Charkhchi et al., 2019). Despite these well-described health disparities among SGM patients, there is a deficiency of research on SGM patient populations, evidence-based guidelines regarding oncologic care in SGM patients, and training on SGM-related cancer care (Quinn et al., 2015; Sutter et al., 2020).

As oncology providers play essential roles in SGM patients' interactions with the healthcare system, examining their knowledge and attitudes regarding SGM cancer patients may shed light on the current state of the healthcare system and identify specific areas for improvement regarding SGM patient care. Prior studies by our group conducted among oncologists at National Cancer Institute (NCI)-designated cancer centers demonstrated that oncology providers are generally comfortable with sexual minority patients, but less so with specific gender minorities such as transgender patients. Additionally, these studies demonstrated that knowledge about SGM-specific oncology healthcare needs is limited, but oncologists expressed interest in receiving education and training about such issues (Shetty et al., 2016; Tamargo et al., 2017; Schabath et al., 2019; Sutter et al., 2020). Building on our prior work that focused on oncologists at NCI-Designated Cancer Centers, the current study was conducted among a more diverse population of providers that included oncologists, nurses, and physician assistants who are members of the ECOG-ACRIN Cancer Research Group (merger of Eastern Cooperative Oncology Group and American College of Radiology Imaging Network) and practice medicine at diverse academic and non-academic medical centers. The current study reports the results from the qualitative portion of the survey.

Although other studies have examined barriers to healthcare for SGM populations, including in the field of oncology, there are limitations to existing research. First, many United States studies are from the perspective of SGM individuals rather than healthcare providers, or are combined studies with limited responses from healthcare providers (Stover et al., 2014; Agénor et al., 2015; Simoni et al., 2017; Burton et al., 2020). With the exception of a recent study by Ussher et al., very few studies of healthcare providers are as large or encompass multiple types of healthcare providers (i.e., nurses, physicians, etc.; Carabez et al., 2015; Bjarnadottir et al., 2019; Burton et al., 2020; Sutter et al., 2020; Ussher et al., 2021). Finally, no studies thus far have examined qualitative comments on provider attitudes and behaviors to this extent. This study seeks to bridge that gap in research by performing an in-depth analysis of all qualitative comments from a large quantity of multiple types of oncology providers.

Materials and methods

Study population and survey design

We administered a web-based survey to members of the ECOG-ACRIN Cancer Research Group in late 2019. The validated survey was developed from published surveys on the knowledge, attitudes, and practice behaviors of clinicians regarding providing cancer care to SGM individuals, and has been revised and utilized by our group in other studies (Bonvicini and Perlin, 2003; Garcia, 2003; Kelley et al., 2008; Kitts, 2010; Reed et al., 2010; Abdessamad et al., 2013; Lim et al., 2013; Schabath et al., 2019). The survey included 19 demographic questions, 12 items on attitudes toward treating SGM patients, seven SGM-related knowledge questions, four practice-related questions focusing on intake forms, and four open-ended questions. The open-ended questions were, "Please describe any personal experiences treating LGBTQ patients that you consider important or informative," "Please explain any reservations in treating the LGBTQ population," "What suggestions do you have for improving the cancer care of the LGBTQ population?" and "Please provide any additional comments." We report here on the results of the open-ended questions.

Analysis

Inductive and deductive content analyses as well as the constant comparison method were used to guide analysis (Elo and Kyngäs, 2008; Constant Comparison, 2011). Two members of the team conducted the coding and analysis process. First, using the survey questions, one team member performed open coding to develop an initial codebook using the *a priori* themes from the survey questions. Next, each team member separately attempted to apply the *a priori* codes from the original list to 25 survey responses with the additional goal of identifying any new or emergent themes. Then the two coders met to compare their coding and discuss emergent themes. The code list was then revised, emergent themes were added to the list and applied again to another 25 responses, and conflicts were resolved through discussion. Once the two coders had reached an acceptable interrater reliability rate (81%; McHugh, 2012), then each coder read all 558 survey responses, and both team members independently identified themes associated with each response. Final differences in coding were resolved *via* discussion among team members until consensuses were reached. Finally, the coders reviewed all coding from each of the four questions and chose the most commonly reported and unifying themes to highlight in the manuscript.

Results

Among the 490 healthcare providers who responded to the survey, 228 (46.5%) provided responses to one or more open-ended questions, amounting to 558 total individual responses. Among respondents who reported their demographic information, the average age was 48.3 (SD 12.1), and most identified as white (74.6%), non-Hispanic/Latino (89.0%), heterosexual (81.1%), Christian (53.9%), and female (73.2%; Table 1). Over one-third (37.3%) were registered nurses, followed by 30.3% who were licensed medical doctors specializing predominantly in hematology and/or oncology. The majority of respondents (60.1%) reported seeing zero to 25 patients per week, and the greatest proportion (46.1%) approximated that 1–5% of their patients in the last year had identified as LGBTQ.

We identified multiple themes from the 558 responses. The major themes we highlighted were lack of experience treating SGM patients, challenges related to gender identification and pronoun use, providers' perceptions of SGM patient attitudes, positive experiences with SGM populations, end-of-life issues related to SGM oncologic care, specific clinical care scenarios involving SGM populations, and the need for education and training (Supplementary Table 1).

Lack of experience

Providers may feel uncomfortable when treating, or be unprepared to treat, SGM patients because they have limited experience with this patient population. Furthermore, even when they do interact with SGM patients, they may not be aware of the patients' sexual orientations or gender identities. One provider reported this experience precisely:

TABLE 1 Characteristics of clinicians who responded to open-ended question(s).

Characteristic	
Age, mean (SD)	48.3 (12.1)
Gender, *n* (%)	
Female	167 (73.2)
Male	48 (21.1)
Male-to-female transgender	1 (0.4)
Prefer not to answer	11 (4.8)
Did not answer	1 (0.4)
Sexual orientation, *n* (%)	
Heterosexual	185 (81.1)
Bisexual	8 (3.5)
Gay	6 (2.6)
Lesbian	6 (2.6)
Other	2 (0.9)
Prefer not to answer	18 (7.9)
Did not answer	3 (1.3)
Race, *n* (%)	
White/Caucasian	170 (74.6)
Multiracial	14 (6.1)
Black/African–American	12 (5.3)
Asian	9 (3.9)
American Indian/Alaska Native	1 (0.4)
Hawaiian/Pacific Islander	1 (0.4)
Other/not sure	1 (0.4)
Prefer not to answer	17 (7.5)
Did not answer	3 (1.3)
Ethnicity, *n* (%)	
Not hispanic/Latino	203 (89.0)
Hispanic/Latino	7 (3.1)
Prefer not to answer	17 (7.5)
Did not answer	1 (0.4)
Religious identity, *n* (%)	
Christian	123 (53.9)
Not religious	32 (14.0)
Atheist/agnostic	27 (11.8)
Jewish	6 (2.6)
Hindu	5 (2.2)
Muslim	4 (1.8)
Buddhist	1 (0.4)
Other	10 (4.4)
Prefer not to answer	18 (7.9)
Did not answer	2 (0.9)
Political leaning, *n* (%)	
Liberal	62 (27.2)
Somewhat Liberal	32 (14.0)
Centrist/moderate	25 (11.0)
Very liberal	24 (10.5)
Conservative	22 (9.6)
Somewhat conservative	18 (7.9)
Very conservative	3 (1.3)
Other	5 (2.2)

(Continued)

TABLE 1 Continued

Characteristic	
Prefer not to answer	36 (15.8)
Did not answer	1 (0.4)
Geographic region, *n* (%)	
East North Central	50 (21.9)
Middle Atlantic	37 (16.2)
West North Central	33 (14.5)
South Atlantic	28 (12.3)
New England	24 (10.5)
Pacific	19 (8.3)
East South Central	14 (6.1)
West South Central	13 (5.7)
Mountain	8 (3.5)
Did not answer	2 (0.9)
Practice setting[a]	
Main campus of AMC[b]/Medical School	109 (47.8)
Community Hospital	59 (25.9)
NCORP[c] community site	43 (18.9)
Medical center not affiliated with medical school	21 (9.2)
Office-based	32 (14.0)
Satellite clinic of AMC[b]	12 (5.3)
NCORP[c] minority/underserved site	9 (3.9)
VA or other government entity	1 (0.4)
Other	12 (5.3)
Licensure[a]	
Registered Nurse (RN)	85 (37.3)
Doctor of Medicine (MD)	69 (30.3)
Doctor of Philosophy (PhD)	7 (3.1)
Nurse Practitioner (NP)	7 (3.1)
Doctor of Osteopathic Medicine (DO)	2 (0.9)
Physician Assistant (PA)	1 (0.4)
Other	45 (19.7)
Prefer not to answer	17 (7.5)
Did not answer	22 (9.6)

[a] Able to give multiple answers.
[b] Academic Medical Center.
[c] National Cancer Institute Oncology Research Program.

> "I have no experience speaking with patients of the LGBTQ community. If I did, it was not [to] my knowledge."

Notably, many providers indicated limited exposure to some SGM patient populations, particularly transgender patients, but greater familiarity with others, such as gay and lesbian patients:

> "I have had limited experience with transgender [patients], I feel more comfortable with gay/lesbian individuals as I have had more work/social experiences with them."
>
> "Quite minimal. Live in a rural area. Only have had interaction with gay/lesbian patients (that I am aware of)"

Pronouns and gender identification

Many SGM individuals, particularly those who identify as transgender, nonbinary, or genderqueer, use pronouns different from those assigned at birth, including traditional pronouns such as "he" and "she" or gender-inclusive pronouns such as "zie." One of the most prevalent themes that emerged was providers' concerns about using the proper pronouns for SGM patients, or clinical scenarios complicated by pronouns. Multiple providers recounted experiences of improper pronoun use in the clinical setting, as evidenced by the quote below where the patients should have had "she/her" in the medical record:

> "I treated a transgender woman and all the pronouns in the notes were he/him."

Clinicians also provided comments suggesting they had trouble keeping track of pronouns in relation to sex assigned at birth:

> "We had a transgender [patient] who felt the MD was being mean by referring to **his** birth gender but it was a factor in the genetics of **her** disease."

One provider relayed a similar experience and highlighted weaknesses in the healthcare system that contribute to the problem:

> "… Also no obvious area in … patient's EMR to identify their gender identity/preferred (sic) pronouns. I would hope this would be something that would be listed right next to something as important as their DOB."

Some providers focused not on pronouns directly, but rather on institutional barriers related to gender identity, particularly among transgender patients:

> "Screened a [transgender] patient for an oncology clinical trial, neither the physicians at our hospital, nor sponsors with the drug company, could say with conviction if we should enroll the patient according to her presenting gender identity or gender assigned at birth. Ultimately, the patient declined being screened for the study because of the hesitation regarding treatment. I believe we did the patient a disservice."

Perceived patient attitudes

When asked about reservations in treating SGM patients, a minority of respondents made assumptions about SGM patients' previous negative experiences with healthcare providers:

> "More suspect of health care providers"

> "Due to discrimination, the LGBTQ patients I have worked with are very hostile at first expecting they are going to be treated differently and judged."

Positive experiences

Although many providers focused on challenges they faced with SGM patients, others recounted favorable encounters:

> "I worked in an AIDS clinic for 16 years and had many wonderful experiences with the LGTBQ population. They taught me may things!"
>
> *"Treating LGBTQ patients can be very rewarding …"*
>
> *"Excellent experience with the LGBTQ community[.]"*
>
> *"My experience with this patient [population has] been positive."*

End-of-life care

Three respondents recounted their own experiences with end-of-life care in SGM patients:

> "I have a female patient with advanced lung cancer who has adult children from a former male partner. She has a female partner now that she's been … with for 18 years. The patient has estranged relationships with some of her adult children because of this. It is important to understand the personal/social issues our patients are going through in order to provide the best care. At some point, this patient will encounter end-of-life issues, and her family dynamics will be an issue and a worry for her."
>
> "Treating terminal cancer patients, it was important to know about decision makers and ensure the patient has a living will."
>
> "Have treated LGBTQ patients with AIDS/HIV and assisted with End of Life Care. Majority of time [the patients were] alone at the End of Life."

Clinical care

While some providers had little to no experience with SGM patients, others saw them regularly. Such providers reported difficulty determining when to apply institutional sex-based policies among SGM patients:

> "Sometimes we have a hard time convincing lesbian women about getting a pre-study urine pregnancy test. They insist they are not pregnant and haven't had sex with a male. But I tell them [it's] an institutional policy …"

Other respondents highlighted clinical scenarios in which sexual and/or gender orientation were objectively and inextricably linked to patient care:

> "I have seen a couple of patients that wish to convert from a female chest to a male chest hoping that [bilateral] mastectomies for high risk would achieve the desired cosmetic appearance"

Other respondents described situations in which it seemed imperative to know a patient's sex at birth:

> "In radiation oncology practice, received a referral on a gender-reassigned individual for squamous cell 'cervical' cancer. No mention in the [medical] record that this patient was male at birth and 'cervix' was actually penile tissue transplanted in gender-reassignment surgery. In calculating drug dosing (e.g. carboplatin)[,] [estimated glomerular filtration rate, a measure of kidney function] is different for males/females. QTc [an interval on an electrocardiogram] ranges are different for males/females. I believe it's important to know if the patient's organs are male organs or female organs."
>
> "Was surprised by my [patient's] gender at the time of surgery when a Foley [catheter] was being placed. This led to a potential crisis of … [misidentification]."

Still others asked questions about SGM-specific clinical needs in the oncology setting:

> "I treat breast cancer patients and while I have not treated a transgender patient, I would think that lowering a patient's estrogen levels to avoid cancer recurrence could negatively impact a transgender patient's quality of life. I would be interested in knowing what other clinicians do in this scenario."
>
> "I work with survivorship and feel there should be a booklet on sexual problems that they may face. For instance: Are there issues with postmenopausal women and vaginal dryness for lesbians?"

Education and training

While a vast array of additional themes emerged, perhaps the most unifying was the recognition that more education and training for providers on SGM healthcare is needed. When asked, "What suggestions do you have for improving the cancer care of the LGBTQ population?," 97 of 184 responses were related to this need:

> "I think that there should be mandatory training on different things we should be aware of when interacting with the LGBTQ population."
>
> "Education in all healthcare settings regardless if healthcare setting is backed by a religious organization"
>
> "Training and ensuring all providers and staff are aware of appropriate interactions. We have had nurses who have worked hard to ensure all staff address transgender patients appropriately. Everyone should be responsive without a nurse having to be the champion for the transgender patient any more than they are champions for all patients."
>
> "Sensitivity training is a must"
>
> "Educate providers on sensitivity to the topic. If they need specifically different care, publish in [the National Comprehensive Cancer Network] guidelines or update them."
>
> "As a part of the LGBT community myself, this survey is making me aware of my own lack of knowledge regarding the health disparities and challenges that the LGBT community might face, so I would be really interested in seeing healthcare providers educated on these issues."

Building rapport

Many providers also highlighted ways they attempt to connect and build rapport with their SGM patients. These efforts included using inclusive language, disclosing their own identities as SGM when applicable, and getting personally involved in the SGM community:

> "I am gay and I would think very inclusive. I use open conversation (a/k/a do you live with a loved one?) … I recently had a gay man, after I gently coaxed that he had a partner/male, and then I shared that I had a husband …"
>
> "I have many [LGBTQ] friends and have tried to be an active part of the community"
>
> "I am a Gay male physician and have significant involvement in my community, medical center and medical school in relation to LGBTQ issues, education and awareness"

Few providers demonstrated negative attitudes toward this population, exemplifying ways to not build rapport:

> *"I personally think it is wrong"*
>
> *"Don't be so sensitive, stop [having] a victim attitude"*

Discussion

Building on our prior work conducted among oncologists at NCI-Designated Cancer Centers, the current study was conducted among oncologists, nurses, and physician assistants within the ECOG-ACRIN Cancer Research Group. As such, the goal of this study was to identify the range of oncology care providers' experiences with, reservations toward, and suggestions for improvement in SGM cancer care to generate potential targets for intervention to improve care for this underserved population. Almost half of the 490 respondents provided at least one answer to an open-ended question, and together these responses evoked several common themes. Respondents reported largely positive or neutral experiences with SGM patients, with very few outright negative attitudes toward this population.

Many respondents described a lack of exposure to SGM patients, most notably transgender patients; with this came provider concerns about correct pronoun use among transgender patients. A lack of experience with transgender patients has been seen in our group's previous studies; however, this concern for pronoun use is more prominent in the current study (Shetty et al., 2016; Schabath et al., 2019; Sutter et al., 2020). This may reflect the growing cultural sensitivity surrounding SGM-specific issues in society as a whole – i.e., providers were familiar enough with transgender issues that many of them independently recognized the more nuanced topic of pronouns as a challenge facing this population. This awareness of pronouns as an issue in SGM health was also seen in a recent survey of medical students, wherein most participants believed incorrect pronoun use may lead to patients' nondisclosure of SGM status (Jamieson et al., 2020). However, these same findings demonstrate there is still room to grow in competence with respect to caring for SGM patients.

Other studies of healthcare providers and transgender patients have confirmed these shortcomings and demonstrated that they serve as barriers to care. For example, Sanchez et al. noted that the most frequently reported barrier to care among male-to-female transgender patients surveyed was access to a provider knowledgeable about transgender health issues (32%), followed by access to a transgender-friendly healthcare provider (30%; Sanchez et al., 2009). A study of transgender youths and their caregivers confirmed that inconsistent use of one's chosen name and/or pronouns was a major barrier to care (Gridley et al., 2016). A recent survey of oncologists in the United Kingdom showed that 49% of surveyed providers never asked a patient's gender identity, 64% never asked a patient's pronouns, and 87% stated they always or often assumed a patient was cisgender (Berner et al., 2020). Among gay men and lesbian women, interactions with healthcare providers who demonstrated fear of behaving incorrectly hindered communication with providers (Röndahl et al., 2006); this provider fear may apply to the use of gender pronouns as well.

In addition to these highly prevalent themes of lack of experience and challenges with pronouns, smaller numbers of providers raised two unique considerations: perceived distrust of providers among SGM patients and end-of-life care. Regarding the former, providers' perceptions of SGM patients' hesitations is not commonly surveyed, but anecdotal reports of hostility and suspicion toward healthcare providers may be rooted in previous negative experiences with healthcare providers. A series of studies by Nadal et al. identified microaggressions that SGM people face, such as use of heterosexist terminology and endorsement of heteronormative culture, as well as common SGM responses to these microaggressions including behavioral, cognitive, and/or emotional reactions (Nadal et al., 2011a,b, 2016). Although these studies were not exclusively conducted in the healthcare setting, other studies have confirmed that SGM patients face similar microaggressions from – in addition to overt discrimination by – healthcare providers (Dean et al., 2016). Thus, we hypothesize that suspicion toward healthcare providers is a product not of sexual or gender orientation *per se*, but of previous negative experiences.

With regard to end-of-life care, respondents noted challenges related to advance directives, decision-making, and family dynamics. Although the end of life can be physically, emotionally, and ethically challenging regardless of a person's sexual or gender orientation, SGM patients face their own unique concerns at this juncture (Sprik and Gentile, 2020). The responses here highlight some of the nuances to end-of-life care in SGM patients. For example, they may face homophobia from healthcare providers (Bristowe et al., 2016); may avoid end-of-life healthcare altogether due to previous discrimination by healthcare providers (Bristowe et al., 2018); and often encounter legal and financial barriers related to lack of relationship recognition (Bristowe et al., 2016, 2018; Sprik and Gentile, 2020). End-of-life care is a fundamental component of many cancer patients' journeys. Therefore, to more fully care for SGM patients at the end of life, oncology providers must understand their SGM patients' relationships with their partners and families and any system barriers, which requires patient-provider trust and rapport. In-depth goals-of-care discussions, which may or may not include concerns directly related to SGM status, must be an active component of end-of-life care. Training in culturally responsive care and cultural humility, involving components of knowledge, self-reflection, and active listening, has been proposed to reduce SGM health disparities at the end of life, though proper care at this essential juncture will require provider engagement and enthusiasm as well (Sprik and Gentile, 2020).

A larger proportion of providers mentioned aspects of clinical care specific to SGM populations that they found challenging, ranging from screening guidelines to sexual health. The findings from the current study confirm our previous findings of oncologists at NCI-Designated Cancer Centers where providers requested increased dissemination of guidelines for screening and treatment of various conditions in this population (Sutter et al., 2020). Furthermore, we previously demonstrated lack of knowledge of appropriate screening practices in SGM patients (Tamargo et al., 2017; Schabath et al., 2019).

Largely in response to such limited knowledge in treating SGM patients with cancer, the single most important theme that emerged from the qualitative responses in the current study was the need for increased provider education and training. Thus, there is a pressing need for curriculum development to address cancer disparities in SGM patients and to promote culturally responsive care. Provider training programs have been developed by the Fenway Institute and National LGBT Health Foundation, but training specifically for oncology providers has been limited. The Curriculum for Oncologists on LGBT populations to Optimize Relevance and Skills (COLORS) training program was developed for this purpose, and offers modules focused on SGM basics, inclusive environments, initiating oncology care with SGM patients, and issues in cancer survivorship among SGM patients (Seay et al., 2020). Training programs like the online Educating Nurses about Reproductive Issues in Cancer Healthcare (ENRICH) effectively engage non-physician oncology care providers as valuable team members and may improve the healthcare experience of SGM populations (Quinn et al., 2019; Sutter et al., 2020).

Some providers highlighted an additional need for institutional and policy changes to further SGM oncologic health. Multiple providers mentioned challenges in enrolling transgender patients in clinical trials, citing lack of clarity regarding whether transgender patients were eligible for studies and regarding how to classify transgender patients in terms of gender. Although to our knowledge there has not been research further delineating or quantifying these limitations to clinical trial enrollment, multiple studies have identified other institutional barriers to SGM health. One major barrier is a lack of concrete screening guidelines for SGM patients, especially transgender patients, as most published guidelines are based on cisgender patients (Haviland et al., 2020); furthermore, it may be more difficult for transgender patients to get appropriate screening tests approved if such screening tests are recommended for the opposite gender (Agénor et al., 2015). Thus, in addition to needing improved education and training for providers, institutional policy changes are needed to provide better SGM healthcare. Another institutional barrier is lack of collection of sexual orientation and gender identity data (SOGI) in the medical record (Institute of Medicine Committee on Lesbian G, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities, 2011; Alexander et al., 2020); the Centers for Medicare and Medicaid Services and the Department of Human Services now require electronic health records to include structured fields for SOGI data, but barriers to thorough and consistent collection remain, and many prominent cancer registries do not include SOGI data (Burkhalter et al., 2016). Furthermore, while some institutions have non-discrimination policies, it is often unclear who can access SOGI data or that a patient has a right to verbally relay this information and not have it in their medical records (Thompson, 2016; Brooks et al., 2018).

A final theme highlighted in this study centered on providers' efforts to build rapport with their SGM patients through both their one-on-one interactions with patients and their involvement in the SGM community. Encouragingly, these reported provider behaviors reflect greater acceptance of SGM patients – this increased acceptance is also supported by the many positive experiences respondents recounted. These themes together suggest provider desire and enthusiasm for improving one's ability to care appropriately for SGM oncologic patients. This desire and enthusiasm may enhance the effects of knowledge and training in culturally responsive care and significantly improve the experience of SGM patients, as the success of such training depends also on the providers undertaking it.

We acknowledge several limitations to the study, most importantly the moderate response rate (46.5%) to qualitative questions among survey respondents. Additionally, although approximately 4.5% of the population identifies as LGBTQ, 8.7% of respondents stated they were lesbian, gay, or bisexual, suggesting that a disproportionate number of respondents identify as SGM (Conron and Goldberg, 2020). This may contribute to nonresponse bias, with those less familiar or less comfortable with SGM patient populations or alternatively do not believe this is a significant care delivery issue being less likely to respond. Clinicians more invested in SGM health disparities and/or healthcare delivery, including those who themselves identify as LGBTQ, may have been more likely to complete the survey, particularly the optional qualitative questions. Additionally, the large proportion of positive or neutral to negative responses may reflect social desirability bias, in which survey respondents answered questions in ways more likely to be viewed favorably (Hebert et al., 1997).

Overall, the qualitative comments of this survey highlight oncology care providers' need for increased exposure to and training on SGM cancer care and culturally responsive care. This and our prior studies demonstrate that oncology care providers are not only willing to engage in such training, but also independently recognize this need. Furthermore, this training should extend beyond physicians and include the broader healthcare team to influence the most meaningful change.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Author contributions

CLT, MBS, and GPQ were responsible for conceptualizing the article, performing the formal analysis and all methodology, project administration, resources, software, supervision, validation, and visualization. EPM, LW, MAS, RCC, BJG, and MBS curated the data and acquired funding. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

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Dana Kristjansson,
Norwegian Institute of Public Health (NIPH), Norway

REVIEWED BY
Mike Rennoldson,
Nottingham Trent University, United Kingdom
Jason McIntyre,
Liverpool John Moores University, United Kingdom

*CORRESPONDENCE
Jane M. Ussher
j.ussher@westernsydney.edu.au

†These authors share first authorship

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LGBTQI cancer patients' quality of life and distress: A comparison by gender, sexuality, age, cancer type and geographical remoteness

Jane M. Ussher*†, Kimberley Allison†, Janette Perz, Rosalie Power and The Out with Cancer Study Team

Translational Health Research Institute, School of Medicine, Western Sydney University, Sydney, NSW, Australia

Background: There is growing acknowledgement of the psycho-social vulnerability of lesbian, gay, bisexual, transgender, queer and/or intersex (LGBTQI) people with cancer. The majority of research to date has focused on cisgender adults with breast or prostate cancer.

Study Aim: This study examined psycho-social factors associated with distress and quality of life for LGBTQI cancer patients and survivors, across a range of sexualities and gender identities, intersex status, tumor types, ages and urban/rural/remote location using an intersectional theoretical framework.

Method: 430 LGBTQI people with cancer completed an online survey, measuring distress, quality of life (QOL), and a range of psycho-social variables. Participants included 216 (50.2%) cisgender women, 145 (33.7%) cisgender men, and 63 (14.7%) transgender and gender diverse (TGD) people. Thirty-one (7.2%) participants reported intersex variation and 90 (20%) were adolescents or young adults (AYA), aged 15-39. The majority lived in urban areas (54.4%) and identified as lesbian, gay or bisexual (73.7%), with 10.9% identifying as bisexual, and 10.5% as queer, including reproductive (32.4%) and non-reproductive (67.6%) cancers.

Results: Forty-one percent of participants reported high or very high distress levels, 3-6 times higher than previous non-LGBTQI cancer studies. Higher rates of distress and lower QOL were identified in TGD compared to cisgender people, AYAs compared to older people, those who identify as bisexual or queer, compared to those who identify as lesbian, gay or homosexual, and those who live in rural or regional areas, compared to urban areas. Elevated distress and lower QOL was associated with greater minority stress (discrimination in life and in cancer care, discomfort being LGBTQI, lower outness) and lower social support, in these subgroups. There were no differences between reproductive and non-reproductive cancers. For the whole sample, distress and poor QOL were associated with physical and sexual concerns, the impact of cancer on gender and LGBTQI identities, minority stress, and lack of social support.

Conclusion: LGBTQI people with cancer are at high risk of distress and impaired QOL. Research and oncology healthcare practice needs to recognize the diversity of LGBTQI communities, and the ways in which minority stress and lack of social support may affect wellbeing.

KEYWORDS

cancer, LGBTQI, distress, quality of life, minority stress, intersectionality, discrimination transgender

1 Introduction

There is growing acknowledgement of the psycho-social vulnerability and health disparities experienced by sexual and gender minority (SGM) people with cancer, who are lesbian, gay, bisexual, transgender, queer and/or intersex (LGBTQI) (1, 2). Epidemiological studies report that cisgender lesbian, gay and bisexual (LGB) women and men are at higher risk of anal, breast, gynecological and lung cancer in comparison to their heterosexual counterparts (3). There is also evidence emerging of higher cancer burden in transgender and gender diverse (TGD) people (4, 5), including those who reject a binary gender, or who report a gender identity that is different from sex assigned at birth. These disparities are partly explained by higher rates of smoking and alcohol consumption and low rates of cancer screening in LGBT communities (6, 7). Obesity and nulliparity are additional risk factors for lesbian and bisexual women, with anal sex and higher rates of HPV infection, as well as the impact of HIV, acting as risks factors for gay men (3) and TGD people (5). Exogenous hormone use as part of gender affirmation has also identified as a potential risk factor for cancer (8). In 2017, the American Society of Clinical Oncology recognized the needs of this "medically underserved" (3) population, concluding there is "insufficient knowledge about the health care needs, outcomes, lived experiences and effective interventions to improve outcomes" for LGBTQI populations.

1.1 Psycho-social vulnerability of LGBTQI people with cancer

Evidence of greater psycho-social vulnerability of SGM people with cancer is primarily based on research with white cisgender adults, predominantly with breast or prostate cancer (1). It has been reported that gay or bisexual cisgender men with prostate cancer report higher psychological and cancer-related distress and lower quality of life (9–14), in comparison to heterosexual men. Cisgender breast cancer survivors who identify as lesbian, bisexual or queer (LBQ), report higher levels of distress and lower quality of life than heterosexual women (1, 15, 16). There is also some evidence that LBQ women with gynecological cancer report significantly higher rates of depression, anxiety and post-traumatic stress disorder (17), than their heterosexual counterparts. A national survey including a range of cancer types reported higher rates of poor self-reported health in lesbian women and higher rates of psychological distress in bisexual women, compared to heterosexual women (16).

There are significant gaps in research on the psycho-social health of LGBTQI people with cancer. There is limited research on LGBTQI cancer across non-reproductive tumor streams, and on reproductive cancers other than breast and prostate cancer (1, 3). There is also little research on LGBTQI adolescent and young adult (AYA) experiences of cancer (18), other than two recent studies reporting higher rates of anxiety (19, 20) and depression (20) in LGBTQ AYAs, compared to non-LGBTQ adolescent and young adult (AYAs). There is little research on psycho-social outcomes of TGD people with cancer (1, 3, 21), other than a recent study reporting higher rates of depression in TGD compared to cisgender people (22), and small scale qualitative research studies of TGD cancer survivorship experiences (8, 23, 24). This is also little research including LGBTQ people of color, migrants, and Aboriginal and Torres Strait Islander people (3, 25). There is no research to date on the cancer experiences of people with intersex variations (1). Recent systematic literature reviews have concluded that research is needed to understand psycho-social outcomes and the complexity of LGBTQI experiences of cancer comparing across ages and SGM subgroups, including people who are TGD and intersex (1, 3, 6, 18). There is also a need to explore potential differences between reproductive and non-reproductive tumor types, given the absence of research on non-reproductive cancers

(1, 3) and healthcare professional assumptions that LGBTQI status may not be relevant for these diagnoses (26). This is the aim of the present study. It has been recommended that any new research needs to recognize the diversity of LGBTQI communities and investigate how this diversity may affect cancer survivorship and wellbeing (6, 27). It has been suggested that an intersectional theoretical framework is the most appropriate way to meet these aims (28), through facilitating understanding of how the complex spheres of identity intersect and the ways that “multiple axes of oppression” (29) may affect health outcomes among LGBTQI people with cancer (1, 30).

1.2 Factors associated psycho-social vulnerability in LGBTQI people with cancer

Understanding the factors associated with psycho-social vulnerabilities identified within the LGBTQI cancer population is also essential, to ameliorate distress and inform the development of LGBTQI inclusive cancer care (1, 26). Concerns about sexual wellbeing, embodied change and intimate relationships are recognized to be a major source of distress in the general cancer population (31, 32). There is some evidence that gay men with prostate cancer report greater distress about changes to sexual (33), urinary, and bowel functioning (14, 34, 35), and greater sexual and ejaculatory bother (10, 36, 37), compared to heterosexual men. This is accompanied by anxiety about the impact of cancer on gay identity and relationships (11, 38–40), and lower masculine self-esteem (9, 35). Gay and bisexual men with prostate cancer have been reported to be less likely to be in an ongoing relationship than heterosexual men (9, 41), and to receive less affection from partners (35). However, there is some evidence that gay and bisexual men experience higher sexual functioning (14, 42), sexual confidence, and a greater likelihood to attempt sexual rehabilitation, in comparison with heterosexual men (42).

Distress in adult LBQ breast cancer survivors has been associated with greater social and relationship difficulties (43), and disruption in sexual activity and desire (44), in comparison to heterosexual women. Conversely, other research has reported lower levels of concern with sex and appearance and less disruption in sexual activity in lesbian and bisexual women with breast cancer (45–47), compared with heterosexual women. In one study, lesbian and bisexual women with breast cancer who had a woman partner had better physical and mental health than heterosexual women who were unpartnered, or with a male partner (48). There is a need for further research to examine changes to sexuality, physical embodiment, gender identity and LGBTQI identity in a broader range of intersecting LGBTQI identities and age groups.

Fear of cancer recurrence (FCR) is associated with anxiety, depression, and decreased quality of life in the general cancer population (49). There is some evidence of greater FCR in gay and bisexual men with prostate cancer, in comparison to heterosexual men (34, 50). Conversely, lower FCR was reported by lesbian women with breast cancer, in comparison with heterosexual women (51). Younger age has consistently been associated with greater FCR (49, 52), however, there is no research to date that has examined FCR in AYA LGBTQI people with cancer.

Minority stress, the chronic and cumulative stress on those with stigmatized sexual and gender identities (53, 54), has been put forward as an explanation for the high rates of distress reported in the general LGBTQI population (55–59), and as a factor contributing to distress in LGBTQI cancer survivors (1, 60). Minority stress includes stigma, social exclusion, and discrimination commonly associated with LGBTQI identities (described as distal stressors), as well as negative self-beliefs and expectations of LGBTQI people, including internalized homophobia, concealment of identity, and stigma consciousness – vigilance and expectation of rejection in social interactions (described as proximal stressors) (61, 62). There is evidence of an association between discrimination and anxiety, depression and poor physical health in LBQ breast cancer survivors (15, 53, 63). LBQ women with breast cancer who were more ‘out’ in disclosing their sexual identity in general life reported higher distress in one study (53). This may be the result of stigmatization and negative cancer health care professional reactions to patient disclosure of LGBTQI identity (2, 26, 64). In this vein, LBQ women with breast cancer (65), and gay men with prostate cancer (9) report lower satisfaction with cancer care than their heterosexual counterparts. Economic hardship, which can be a consequence of minority stress, has also been associated with distress in LBQ breast cancer survivors (53, 63). For LGBTQI individuals, minority stress potentially compounds the impact of other stressors associated with cancer diagnosis and treatment, including uncertainty of treatment outcome, fear of cancer recurrence, co-morbidity, and disease stage (53, 66, 67). The impact of minority stress, and other factors associated with distress and poor quality of life, across intersecting LGBTQI identities remains unexplored (3).

Social support can ameliorate the impact of sexual and relationship difficulties (37, 44), embodied change (68) and minority stress in the context of cancer (43, 69), resulting in better quality of life and functioning (70). Higher social support is also related to better psychological outcomes in LGBQ cancer populations (19, 71, 72). For older LGBTQI people, social support is often provided by ‘chosen family’ (73), which includes intimate partners and friends (43, 51), and through social connectedness with LGBTQI people (62, 74). Parental and sibling support and acceptance is of particular importance for younger LGBTQI people in relation to psychological wellbeing (75). However, some LGBTQI people experience low social support, due to not having an intimate partner (37), family rejection (76), or because of living in rural or remote areas where they feel isolated from other LGBTQI people (62) and impacted by stigma and social exclusion (77). The absence of social safety, reflected in low social support, has been described as the "missing piece" in understanding the impact of minority stress on the health of LGBTQI people (78). The association between social support and distress for LGBTQI cancer survivors requires further exploration, across intersecting identities, cancer types and geographical remoteness (3).

1.3 Research aims and questions

This exploratory cross-sectional study aims to address these gaps in the research literature by examining distress and quality of life for LGBTQI people with cancer, and a range of psycho-social factors reported to be associated with distress and quality of life, comparing sexuality and gender identities, intersex status, age groups, reproductive and non-reproductive tumor types and geographical remoteness (urban/rural/regional), using an intersectional theoretical framework.

Our research questions were:

1. For LGBTQI people with cancer, does distress and quality of life differ by gender, sexuality, intersex status, age, cancer type, or remoteness?
2. Do sexual concerns, physical concerns, impact of cancer on gender and LGBTQI identity, FCR, minority stress, and social support differ across gender, sexuality, age, intersex status, cancer type, or geographical remoteness?
3. Are sexual concerns, physical concerns, impact of cancer on gender and LGBTQI identity, FCR, minority stress, and social support associated with distress and quality of life for LGBTQI people with cancer?
4. Does this association differ across gender, sexuality, intersex status, age, cancer type, or geographical remoteness?

1.4 Summary of key acronyms

AYA, Adolescents and young adults
HCP, Health care professional
LBQ, Lesbian, bisexual and queer
LGB, Lesbian, gay and bisexual
LGBQ, Lesbian, gay, bisexual and queer
LGBT, Lesbian, gay, bisexual and transgender
LGBTQI, Lesbian, gay, bisexual, transgender, queer and/or intersex
SGM, Sexual and gender minority
TGD, Transgender and gender diverse
QOL, Quality of Life

2 Methods

2.1 Study design and theoretical framework

This study was part of a broader mixed methods project, the *Out with Cancer Study*, which explored LGBTQI experiences of cancer and cancer care from the perspectives of LGBTQI people with cancer, caregivers, and healthcare professionals (26, 60, 79). This paper presents the findings of an online survey completed by 430 LGBTQI people with cancer, examining the psycho-social factors associated with distress and quality of life (QOL).

The project adopts an intersectional theoretical framework, which acknowledges that all people inhabit multiple interconnected social identity categories, such as gender, sexuality, cultural background and age (80), and that these categories are embedded in systems of social stratification, associated with inequality or power (81–83). An intersectional perspective recognizes that identity cannot be reduced to the summary of social groups to which a person belongs; rather, attention is paid to how social identities intersect to produce a meaningful whole in a way that cannot be explained by looking at one social identity alone (82). These categories are properties of individuals in terms of their identities, as well as characteristics of social contexts, and influence social practices and health and wellbeing (84). Whilst intersectionality theory has predominantly been used in qualitative research designs (81), it can also inform quantitative research by informing research questions and analysis that acknowledges the multiplicative effects of identity positions (85). We are adopting a *both/and* framework (29, 82), which considers *both* the "master category" of LGBTQI identity *and* the "subordinate categories" (29, 82) of age, TGD status, sexuality, intersex status, ethnicity and cultural background, geographical remoteness, and type of cancer. While these subordinate categories and identities are analyzed separately in statistical analyses, the "emergent effects" that occur when multiple identities intersect is interpreted through an intersectional lens (82).

The project was guided by principles of integrated knowledge translation (iKT) (86), with a stakeholder advisory group (comprising LGBTQI people with cancer and carers, cancer HCPs, and representatives from LGBTQI health and cancer support organizations) involved at all stages. The study received ethics approval from Western Sydney University Human Research Ethics Committee (ref. no. H12664), with secondary approval from the ACON (formerly the AIDS Council of New South Wales) (ref. no. 2019/09).

2.2 Participants and recruitment

Participants were eligible for this study if they: (a) identified as LGBTQI; (b) had been diagnosed with cancer or had undergone a medical intervention related to cancer risk; and (c) were at least 15 years old. The study was advertised on social media (Facebook, Twitter, Instagram), *via* cancer and LGBTQI community organizations (including partner organizations), through cancer research participation databases, and at in-person LGBTQI events and cancer support groups. Participants were also encouraged to share the survey link with others who might be eligible for participation. Participant demographics were monitored and recruitment strategies were refined through the data collection period with the aim of increasing the recruitment of underrepresented groups. The survey was open from September 2019 to September 2021.

2.3 Measures

The survey comprised a series of closed and open-ended measures, with questions tailored for: (a) people who were lesbian, bisexual or queer (LGBQ); (b) people who were TGD; and (c) people who had an intersex variation. Participants could choose which version of the survey to complete and could complete more than one pathway. Closed-ended questions presented in this paper are described below. Open-ended questions are presented in additional publications (26, 60).

2.3.1 Distress

Psychological distress was measured using the ten-item Kessler Psychological Distress Scale (K10) (87), which asked participants to rate how frequently they have experienced various distressing feelings over the past 30 days. Participants responded using a five-point Likert scale (*none of the time – all of the time*) and scores on individual items were summed to produce a total distress score ranging from 10 to 50. Scores were categorized as indicating low (10-15), moderate (16-21), high (22-29) or very high (30-50) distress in accordance with Australian Bureau of Statistics guidelines (88). In this study, the K10 had excellent internal consistency (Cronbach's α=.926).

2.3.2 Quality of life

A single item derived from the EORTC-QLQ-C30 (89), which is widely used as a QOL scale in cancer research (90), asked participants to rate their overall QOL over the past week using a seven-point Likert scale (1 = *very poor* – 7 = *excellent*).

2.3.3 Sexual concerns

Eleven items from the EORTC Sexual Health Questionnaire [EORTC SHQ-C22 (91, 92)] were used to assess sexual health. The EORTC was adapted to remove gendered designations of questions ("for men/women only") to be inclusive of TGD and intersex bodies; to remove items overlapping with other sections of our survey; and to assess sexual issues both before *and* after cancer. Participants were asked to rate the extent to which they experienced sexual satisfaction and concern before and after cancer, using a four-point Likert scale (*not at all – very much; N/A*s excluded). Sexual concerns were operationalized as a decrease in satisfaction scores or an increase in concern scores from pre- to post-cancer. The total number of sexual concerns reported was then calculated (range 0-11).

2.3.4 Physical concerns

Fourteen items assessed the presence and extent of concerns with changes to the body related to cancer. These were adapted from a previous survey on prostate cancer in gay/bisexual men (9), with modifications made to be inclusive of the broader LGBTQI cancer population. Participants reported the extent to which they were concerned with potential bodily changes using a four-point Likert scale (*not at all* to *very much*). Responses were dichotomized as no concern (*not at all*) or some concern (*a little/ quite a bit/very much*). The total number of physical concerns reported was then calculated (range 0-14).

2.3.5 Impacts of cancer on LGBTQI identity

Three items were developed based on the format of the Illness Intrusiveness Ratings Scale (IIRS) (93) to assess the impact of cancer on feelings about being LGBTQI, openness about being LGBTQI, and involvement with LGBTQI communities. These questions were asked separately about for sexuality, TGD identity, and intersex variations, with responses averaged for participants who completed this item for more than one identity. Participants responded using a four-point Likert scale (1 = *not at all* to– 4 = *very much*; *N/A*s excluded), with scores summed to produce a total impact score (range 3-12, higher scores indicating greater impact). Cronbach's alpha for the three items was .571.

2.3.6 Impact of cancer on gender identity

A single item was developed to assess the impact of cancer on feelings on gender identity, based on the format of the IIRS (93) and the content of items on masculinity/femininity from the EORTC-SHQ-C22 (91, 92). Participants responded using a four-point Likert scale (1 = *not at all* to 4 = *very much*) to assess whether cancer has impacted on their 'feelings about gender identity (e.g. as a man, woman, transgender, non-binary or gender fluid person)'.

2.3.7 Fear of cancer recurrence

A single item from the unidimensional FCR4 and FCR7 scales (94) was used to assess the extent to which participants were afraid their cancer may recur over the past week.

Participants responded using a five-point Likert scale (1 = *not at all* – 5 = *all the time*).

2.3.8 Minority stress

Ten items measuring distal and proximal aspects of minority stress were identified through review of existing LGBTQI minority stress measures (95–97), described below.

2.3.8.1 Discrimination in general life and cancer care

A single item based on a previous study of sexual minority breast cancer survivors (43) was adapted to ask "have you experienced discrimination for being LGBTQI in your life in general?" (asked in separate survey pathways for LGBQ, TGD and intersex participants as relevant). A second item was added to assess experiences of discrimination "as part of your cancer care". Response options were modified to use a four-point Likert scale (1 = *not at all* to 4 = *very much*), consistent with other measures in the survey.

2.3.8.2 Discomfort in being LGBTQI

Three items assessing comfort, concealment and feelings about LGBTQI identity were selected from existing LGBT minority stress and identity measures (95–97). Participants were asked to report their agreement to statements about being "comfortable being LGBTQI", "keep[ing] careful control over who knows you are LGBTQI" (concealment motivation), and if they "wish they were not LGBTQI" (internalized prejudice). All questions were asked using separate wording for LGBQ, TGD and intersex participants (e.g., focusing on sexuality, TGD or intersex status). Responses were made using a five-point Likert scale (*strongly disagree* to– *strongly agree*); after reverse coding for some items, scores were summed to produce a total minority stress score (range 3-15, with higher scores indicating greater minority stress). Cronbach's alpha for the three items was .655.

2.3.8.3 Outness to others

The 5-item disclosure subscale of the Nebraska Outness Scale (98), measuring details of disclosure and concealment of LGBTQI identities, was adapted for use in this study. The "strangers" item was replaced with "healthcare professionals", and the response scale was changed from percentages to *none/a few/some/most/all* to be consistent with other survey items. Participants reported the proportion of people in five social groups (immediate family, extended family, friends and acquaintances, people at work/school, healthcare professionals) who were aware they were LGBTQI using a five-point Likert scale. An overall outness scale was computed by taking the average of items (range 1-5) with higher scores indicating participants were out to more people. The adapted measure had excellent internal consistency (Cronbach's α=.902).

2.3.9 Social support

The social support subscale of the Health Literacy Questionnaire (99) was used to assess social support. Participants were asked to rate their agreement with five statements on whether they were supported by others, using a five-point Likert scale (*strongly agree* to *strongly disagree*). Items included access to several people for support, feeling understood by others, having a person to attend medical appointments with, and strength of support. An overall social support score was computed by taking the average of items (range 1-5, higher scores indicating stronger support). In this study, the scale had good internal consistency (Cronbach's α=.842). Participants were also asked who their primary support people were during the cancer experience.

2.4 Data handling and analysis

2.4.1 Data cleaning

All survey responses were downloaded from Qualtrics into IBM's Statistical Package for the Social Sciences (SPSS). Participant responses were screened and excluded if they had not completed any survey measures beyond demographics/cancer characteristics (n=630), were not LGBTQI (n=6), or had only entered non-serious or nonsensical responses (n=2). Thirteen cases were identified where participants had completed the survey multiple times, as identified through IP addresses, provided contact details, and responses. In these instances, the more complete survey was retained (or the earliest recorded, where completion was the same across records). The final dataset comprised 430 surveys.

2.4.2.Statistical analyses

2.4.2.1 Comparing psycho-social variables across LGBTQI groupings

Sexuality and gender identity questions were developed and recoded following advice from our LGBTQI partner investigators and stakeholder group. Gender was recoded into three categories (cis female, cis male, and TGD), based on participants' self-reported gender (male, female, non-binary, other) and sex assigned at birth. Sexuality was recoded into three categories, lesbian/gay/homosexual, bisexual, and queer. The variable capturing whether participants had intersex variations retained two categories (yes, no). Age at survey completion was converted into a categorical variable, with participants classified as adolescents and young adults (AYAs, 15-39 years) or older adults (40+ years), following published recommendations for definition of AYA status (100). Cancer types were categorized as reproductive (breast, gynecological, prostate, testicular) or non-reproductive cancers, following previous research (101).

Analyses of variance (ANOVAs) were run to explore differences in distress, QOL and psycho-social variables previously reported to be associated with distress and QOL in LGBTQI cancer populations (sexual and physical concerns, impacts on LGBTQI and gender identities, minority stress variables, fear of cancer recurrence, and social support), by gender, sexuality, intersex variation, age, cancer type, and geographical remoteness. A Bonferroni correction was applied to account for the increased potential for type I errors when running multiple comparisons. An alpha cut-off of.008 (.05 divided by 6 types of between-group testing) was used to indicate significance. Ten TGD and intersex participants who identified as heterosexual were excluded from analyses of differences between sexualities, due to small sample size. These participants were included in other analyses. All other participants were included in each ANOVA, based on the grouping demographic variable of interest. Valid percentages are presented in the reporting of results and the proportion of participants responding to each measure.

2.4.2.2 Identifying factors associated with distress and QOL

Bivariate correlation analyses were conducted to examine the association between distress and QOL and factors potentially associated with distress and QOL (sexual and physical concerns, impacts on LGBTQI and gender identities, minority stress variables, fear of cancer recurrence, and social support). These analyses were run for the whole sample and for subgroups defined by gender, sexuality, intersex status, age, cancer type and geographical remoteness. Chi-square test was used to compare equality of independent correlation coefficients, standardized for analysis, to assess differences in observed correlations for distress and QOL by gender, sexuality, intersex status, age, cancer type, and geographical remoteness.

3 Results

3.1 Participant characteristics

Tables 1, 2 present the demographic and cancer characteristics of survey respondents, respectively. Most participants were cisgender (83.9%; 50.2% cis women, 33.7% cis men), Caucasian (85.2%) older adults (77.9%), living in Australia (72.3%), who identified themselves as lesbian, gay, or homosexual (73.7%). Greater diversity was evident in participants' geographical regional (54.4% urban; 33.8% regional; 11.7% rural or remote), and cancer types (Table 2). A minority of participants identified as TGD (14.7%), bisexual (10.9%), or queer (10.5%); 7.2% reported an intersex variation. A minority identified as Australian Aboriginal, Torres Strait Islander or Maori (2.1%), Asian (2.6%), or from a mixed ethnic background (4.5%). A range of cancer types were represented, including both reproductive (32.4%) and non-reproductive (67.6%) cancers.

3.2 Distress and QOL

Addressing research question 1, means and standard deviations for distress and QOL for the whole sample and by gender, sexuality, intersex variation, age, and cancer type, are reported in Table 3. Of 316 participants who completed the K10, 114 (36.1%) reported low distress, 73 (23.1%) reported moderate distress, 73 (23.1%) reported high distress, and 56 (17.7%) reported very high distress. The mean distress score for the sample was 20.9 (*SD* = 8.6, range 10-48), and the mean QOL score was 4.7 (*SD* = 1.6, range 1-7).

Distress differed significantly by gender, sexuality, age and geographical remoteness: higher distress was reported by TGD participants, relative to cis men and women ($F_{2,309}$ =7.084, *p*=.001); by bisexual and queer participants, relative to lesbian/gay participants ($F_{2,302}$ =8.095, *p*<.001); by AYAs, relative to older adults ($F_{1,314}$ =31.959, *p*<.001); and by those living in rural or regional areas compared to those living in urban areas ($F_{2,313}$ =5.557, *p*<.004). Distress did not differ significantly between those with and without intersex variations after Bonferroni correction; or between reproductive and non-reproductive cancers (see Appendix Table A1 for effect sizes and statistics). QOL also varied significantly by gender, sexuality and intersex status: higher QOL was reported by cis women and men, relative to TGD participants ($F_{2,326}$ =12.167, *p*<.001); by lesbian/gay participants, relative to bisexual and queer participants ($F_{2,318}$ =12.718, *p*<.001); and by those without intersex variations, relative to those with intersex variations ($F_{1,324}$ =16.360, *p*<.001). QOL did not differ significantly by age (after Bonferroni correction), cancer type or geographical remoteness (Appendix Table A1).

3.3 Comparing psycho-social variables associated with distress and QOL between LGBTQI groups

Addressing research question 2, Table 4 presents the means and standard deviations of study variables (sexual and physical concerns, impacts on LGBTQI and gender identities, minority stress variables, fear of cancer recurrence, and social support), for the whole sample, and for subgroups defined by gender identity, sexuality, intersex status, age and cancer type. Statistics relating to the tests of differences are presented in Appendix Table A2 and summarized in the text where significant differences were found.

TABLE 1 Demographic characteristics of survey participants.

Demographic Characteristic	*N*	*M (SD)* range
Age at time of study (years)	429	52.5 (15.7), 16-92
	N	*n* (%)
Country	430	
Australia		311 (72.3%)
United States of America		62 (14.4%)
United Kingdom		29 (6.7%)
New Zealand		8 (1.9%)
Canada		7 (1.6%)
Other		13 (3.0%)
Location	429	
Urban		234 (54.5%)
Regional		145 (33.8%)
Rural or remote		50 (11.7%)
Race/ethnicity	425	
Caucasian		362 (85.2%)
Asian		11 (2.6%)
Australian Aboriginal, Torres Strait Islander or Maori		9 (2.1%)
Mixed background		19 (4.5%)
Other/unclear background		24 (5.6%)
Gender	430	
Cis female		216 (50.2%)
Cis male		145 (33.7%)
TGD[1]		63 (14.7%)
Different identity		6 (1.4%)
Sexuality	430	
Lesbian, gay or homosexual		317 (73.7%)
Bisexual		47 (10.9%)
Queer		45 (10.5%)
Straight or heterosexual		10 (2.3%)
Different or multiple identities		11 (2.6%)
Intersex variation	430	
Yes		31 (7.2%)
No		388 (90.2%)
Prefer not to answer		11 (2.6%)
Relationship status[2]	368	
Not in a relationship		126 (34.2%)
Casually dating		16 (4.3%)
Relationship with one other person		216 (58.7%)
Multiple relationships		16 (4.3%)
Social support network	374	
Partner/s		226 (60.4%)
Parents		94 (25.1%)
Other family		130 (34.8%)
Friends		189 (50.5%)
Colleagues		46 (12.3%)
Other		14 (3.7%)
No support people		35 (9.4%)
Supported by other LGBTQI people	418	318 (76.1%)
Education	422	
Less than secondary		10 (2.4%)
Secondary		45 (10.7%)
Some post-secondary		55 (13.0%)
Post-secondary		312 (73.9%)

[1] 34 (7.9%) non-binary, 13 (3.0%) trans female, 8 (1.9%) trans male, 8 (1.9%) different TGD identity; [2] Participants could indicate multiple options if applicable

TABLE 2 Cancer characteristics of survey participants.

Cancer Characteristic	***N***	***M (SD)*, range**
Age at diagnosis (years)	363	46.3 (15.3), 1-79
	N	***n* (%)**
Medical intervention for cancer risk	430	74 (17.2%)
Cancer diagnosis (first)	370	
Brain		11 (3.0%)
Breast		90 (24.3%)
Cervical		11 (3.0%)
Colorectal		17 (4.6%)
Head/neck		14 (3.8%)
Leukaemia		17 (4.6%)
Lymphoma		24 (6.5%)
Ovarian		17 (4.6%)
Prostate		59 (15.9%)
Skin		25 (6.8%)
Uterine		23 (6.2%)
Other		58 (15.7%)
Not sure or unknown		4 (1.1%)
Cancer stage	369	
Localised		228 (61.8%)
Regional		88 (23.8%)
Distant/metastatic		32 (8.7%)
N/A (e.g. blood cancer)		5 (1.4%)
Not sure or unclear		16 (4.3%)
Treatment status	370	
No treatment yet		37 (10.0%)
On active curative treatment		37 (10.0%)
On maintenance treatment		60 (16.2%)
In remission		217 (58.6%)
Receiving palliative care (no further active treatment)		4 (1.1%)
Not sure		8 (2.2%)
Subsequent cancers[1]	370	
Recurrence		57 (15.4%)
New primary cancer		40 (10.8%)
Other health condition, disability or impairment	338	135 (39.9%)

[1] Participants could indicate multiple options if applicable.

3.3.1 Sexual concerns

Concerns about changes to sexual wellbeing since cancer were reported by 71.3% (n=275) of participants, with these participants reporting 3.60 concerns on average (*SD* = 3.18, range 0-10). Participants who indicated that the question was not applicable, because they were diagnosed or had medical intervention for cancer as children, were excluded from the analysis. The most commonly endorsed sexual concerns were decreased satisfaction with the level of sexual desire (48.5%), decreased satisfaction with sex life (43.8%), fatigue or lack of energy affecting sex life (43.1%), decreased satisfaction with the ability to orgasm (39.9%), decreased enjoyment of sexual activity (39.2%) and decreased satisfaction with physical intimacy (37.5%).

Participants with intersex variations reported significantly lower sexual concerns than participants without intersex variations ($F_{1,265}$ =7.433, *p*=.007). There were no significant differences in sexual concerns by gender, sexuality, age, cancer type (after Bonferroni correction) or geographical remoteness.

3.3.2 Physical concerns

Participants reported 5.3 physical concerns on average (*SD* = 2.9, range 0-12, N=303). The physical concerns reported included reduced body strength (69.0%), muscle loss/wastage (61.5%), weight gain (58.2%), reduced mobility (55.4%), scarring (52.0%), changes in genital sensitivity (45.7%), incontinence (40.9%), hair loss (37.5%), early menopause (30.8%) and weight loss (25.3%); loss of one/both breasts 54 (16.7%); shortened penis 54 (16.7%); stoma 16 (5.0%).

Significantly higher physical concerns were reported by AYAs compared to older adults ($F_{1,301}$ =10.235, *p*=.002), and by participants who identified as queer, compared to those who identified as lesbian, gay or bisexual ($F_{2,291}$ =7.993, *p*<.001).

TABLE 3 Means and standard deviations of distress and quality of life, for total sample and subgroups.

Variable	Total sample*M* (*SD*)	Gender			Sexuality			Intersex status		Age		Remoteness*			Cancer type	
		Cis women *M(SD)*	Cis men *M(SD)*	TGD *M(SD)*	Lesbian/gay *M(SD)*	Bisexual *M(SD)*	Queer *M(SD)*	Intersex *M(SD)*	Non-intersex *M(SD)*	AYA *M(SD)*	Older adult *M(SD)*	Urban *M(SD)*	Regional *M(SD)*	Rural *M(SD)*	Reprod *M(SD)*	Non-reprod *M* (*SD*)
Distress	20.9 (8.6)	20.0 (7.6)	20.4 (8.9)	**25.6 (10.6)**	19.7 (8.1)	**24.9 (9.1)**	23.3 (8.7)	25.3 (8.4)	20.3 (8.4)	**25.9 (9.3)**	19.5 (7.9)	19.5 (8.6)	**22.7 (8.4)**	**22.7 (8.1)**	19.2 (8.7)	21.0 (8.3)
QOL	4.7(1.6)	**4.9 (1.4)**	4.8 (1.5)	3.7 (1.8)	**5.0 (1.4)**	4.2 (1.5)	3.9 (1.5)	3.6 (1.6)	**4.8 (1.5)**	4.3 (1.6)	4.8 (1.5)	4.8 (1.5)	4.5 (1.6)	4.8 (1.7)	5.0 (1.5)	4.8 (1.5)

Where differences between groups are statistically significant (p≤.008, using Bonferroni correction), the highest value/s are bolded. *Urban, in a major city of 100,000+ people, or the surrounding suburbs; Regional, in a smaller city; Rural, outside of a city. AYA, adolescent and young adult (15-39 years); cis, cisgender; QOL, quality of life; reprod, reproductive; TGD, transgender and gender diverse.

There were no significant differences in physical concerns by gender, intersex status, cancer type, or geographical remoteness.

3.3.3 Impact of cancer on LGBTQI identity and gender identity

Many participants reported that their cancer and cancer care had impacted upon their experiences as LGBTQI people. Overall, 173 (41.3%) participants reported cancer impact on their feelings about being LGBTQI (LGBQ n=147, 37.5%, TGD n=25, 59.5%, intersex n=15, 69.2%). 280 (66.7%) reported impact of cancer on openness about being LGBTQI (LGBQ n=244, 65.6%, TGD n=31, 73.8%, intersex n=14, 60.9%). Impact in involvement with LGBTQI communities was reported by 250 (59.4%) participants (LGBQ n=216, 57.9%, TGD n=30, 71.4%, intersex n=12, 52.2%). Additionally, 101 (30.5%) participants reported that cancer had impacted upon their feelings about their gender identity, as a man, woman, transgender, non-binary or gender fluid person.

Impact on LGBTQI identity was significantly higher for TGD participants than cis women and cis men ($F_{2,408}$ =9.308, *p*<.001). There were no significant differences in impact on LGBTQI identity by sexuality, intersex status, age, cancer type or geographical remoteness.

Impact on gender identity was significantly higher for TGD participants than cis women and cis men ($F_{2,323}$ =27.245, *p*<.001); for queer participants in comparison to those who identified as gay/lesbian or bisexual ($F_{2,316}$ =21.586, *p*<.001); and for AYAs compared to older adults ($F_{1,329}$ =9.535, *p*<.002). There were no significant differences in cancer impact on gender identity by intersex status (after Bonferroni correction), cancer type or geographical remoteness.

3.3.4 Fear of cancer recurrence

Two-thirds of participants (67.0%) reported that they were afraid of their cancer recurring. There were no significant differences in FCR by gender, sexuality, intersex status, age (after Bonferroni correction), cancer type or geographical remoteness.

3.3.5 Minority stress

3.3.5.1 Discrimination in general life and cancer care

Experiences of discrimination were common among respondents: 351 (83.6%) reported discrimination in their life in general, including 309 (82.8%) LGBQ participants, 35 (83.3%) TGD participants and 20 (90.9%) participants born with intersex variations, because of their sexuality, TGD status, or intersex variation, respectively (Figure 1). Furthermore, a third of participants (n=138, 33%) reported experiencing discrimination as part of their cancer care because of being LGBTQI, including 104 (31.0%) LGBQ participants, 22 (52.4%) TGD participants and 11 (50.0%) participants with intersex variations (Figure 2).

Significantly higher discrimination in life was reported by TGD participants compared to cisgender women and men

TABLE 4 Means and standard deviations of study variables, for total sample and subgroups.

Variable	Total sample*M* *(SD)*	Gender			Sexuality			Intersex status		Age		Remoteness*			Cancer type	
		Cis women *M(SD)*	Cis men *M(SD)*	TGD *M(SD)*	Lesbian/gay *M(SD)*	Bisexual *M(SD)*	Queer *M(SD)*	Intersex *M(SD)*	Non-intersex *M(SD)*	AYA *M(SD)*	Older adult *M(SD)*	Urban *M(SD)*	Regional *M(SD)*	Rural *M(SD)*	Reprod *M(SD)*	Non-reprod *M(SD)*
Sexual concerns	3.6 (3.2)	3.5 (3.1)	4.0 (3.2)	2.9 (3.1)	3.6 (3.2)	4.0 (3.1)	3.9 (3.2)	1.6 (2.4)	**3.7 (3.2)**	3.5 (3.1)	3.6 (3.2)	3.7 (3.3)	3.5 (3.0)	3.6 (3.3)	4.4 (3.2)	3.4 (3.0)
Physical concerns	5.3 (2.9)	5.6 (3.0)	4.8 (2.7)	5.6 (2.8)	5.1 (2.9)	5.6 (2.5)	**7.2 (2.1)**	5.3 (3.3)	5.3 (2.9)	**6.3 (2.9)**	5.0 (2.9)	5.1 (2.8)	5.7 (3.0)	5.2 (3.1)	5.1 (2.9)	5.5 (2.9)
LGBTQI impact	6.2 (2.4)	5.7 (2.2)	6.5 (2.5)	**7.1 (2.7)**	6.1 (2.4)	6.1 (2.2)	6.8 (2.5)	6.5 (2.4)	6.1 (2.4)	6.6 (2.4)	6.1 (2.4)	6.1 (2.5)	6.3 (2.4)	6.1 (2.3)	6.4 (2.6)	6.1 (2.4)
Gender impact	1.6 (1.0)	1.4 (0.8)	1.4 (0.9)	**2.5 (1.3)**	1.4 (0.8)	1.9 (1.0)	**2.3 (1.3)**	2.1 (1.1)	1.5 (1.0)	**1.9 (1.2)**	1.5 (0.9)	1.6 (1.0)	1.6 (1.0)	1.6 (1.0)	1.6 (1.0)	1.5 (0.9)
FCR	2.4 (1.3)	2.3 (1.2)	2.3 (1.3)	2.5 (1.4)	2.3(1.3)	2.3(1.3)	2.7 (1.3)	2.1 (1.3)	2.4 (1.3)	2.7 (1.3)	2.3 (1.2)	2.4 (1.3)	2.3 (1.2)	2.5 (1.3)	2.3 (1.3)	2.4 (1.2)
Minority stress																
Discr (*gen*)	2.3 (0.9)	2.2 (0.8)	2.1 (0.9)	**2.8 (1.0)**	2.2 (0.8)	2.3 (0.9)	2.5 (0.9)	**2.8 (1.0)**	2.2 (0.8)	**2.5 (0.9)**	2.2 (0.8)	2.2 (0.9)	2.3 (0.9)	2.3 (0.9)	2.1 (0.8)	2.2 (0.8)
Discr (*care*)	1.5 (0.8)	1.4 (0.6)	1.4 (0.8)	**2.0 (1.1)**	1.4 (0.8)	1.3 (0.6)	**1.9 (1.1)**	**2.2 (1.2)**	1.4 (0.7)	**1.7 (0.9)**	1.4 (0.8)	1.5 (0.8)	1.5 (0.8)	1.6 (0.9)	1.4 (0.8)	1.4 (0.7)
Discomf LGBTQI	5.8 (2.5)	5.6 (2.4)	5.6 (2.3)	**7.1 (2.8)**	5.5 (2.2)	**7.6 (3.0)**	6.1 (2.6)	**7.0 (2.9)**	5.7 (2.4)	**7.0 (2.8)**	5.5 (2.3)	5.8 (2.4)	5.9 (2.5)	6.0 (2.8)	5.5 (2.2)	5.9 (2.5)
Outness	4.1 (1.1)	4.1 (1.1)	**4.3 (0.9)**	3.7 (1.1)	**4.4 (0.8)**	2.8 (1.1)	3.9 (1.0)	3.8 (1.0)	4.2 (1.0)	3.5 (1.1)	**4.3 (1.0)**	4.2 (1.0)	4.0 (1.1)	4.1 (1.1)	4.2 (1.0)	4.1 (1.0)
Social support	3.9 (0.9)	4.1 (1.1)	**4.3 (0.9)**	3.7 (1.1)	**4.0 (0.9)**	3.5 (1.0)	3.8 (0.9)	3.4 (0.9)	**3.9 (0.9)**	3.6 (0.8)	**4.0 (0.9)**	3.9 (0.9)	3.8 (1.0)	3.9 (0.8)	4.0 (0.8)	4.0 (0.9)

Where differences between groups are statistically significant (p≤.008, using Bonferroni correction), the highest value/s are bolded. *Urban, in a major city of 100,000+ people, or the surrounding suburbs; Regional, in a smaller city; Rural, outside of a city. AYA, adolescent and young adult (15-39 years); cis, cisgender; discomf LGBTQI, discomfort being LGBTQI; discr (care), discrimination in cancer care; discr (gen), discrimination in general life; FCR, fear of cancer recurrence; QOL, quality of life; reprod, reproductive; TGD, transgender and gender diverse.

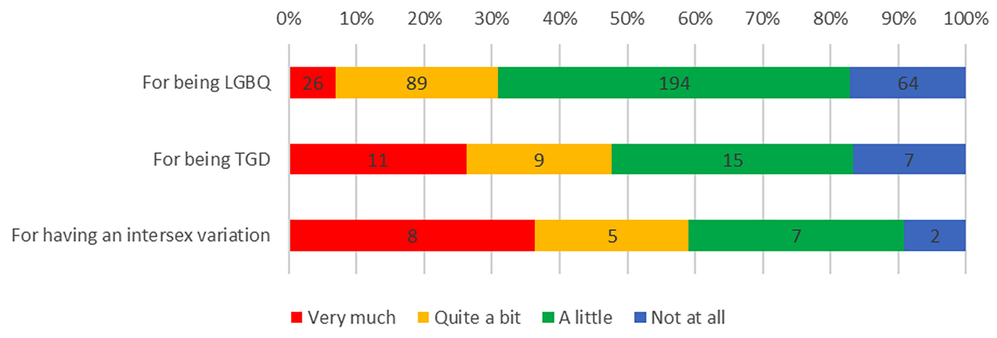

FIGURE 1
Experiences of Discrimination for being LGBQ, TGD, or for having an Intersex Variation.

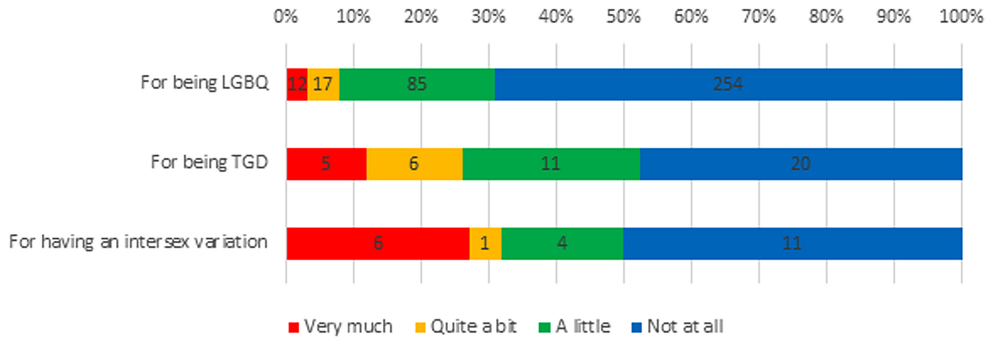

FIGURE 2
LGBTQI+ Experiences of Discrimination in Cancer Care. LGBQ, lesbian, gay, bisexual or queer; TGD, transgender/gender diverse.

($F_{2,411}$ =13.476, $p<.001$); by intersex compared to non-intersex participants ($F_{1,408}$ =13.556, $p<.001$); and by AYAs compared to older adults ($F_{1,417}$ =7.876, $p=.005$). There were no differences in reporting of discrimination in life by sexuality, cancer type or geographical remoteness.

Significantly higher discrimination in cancer care was reported by TGD participants compared to cisgender women and men ($F_{2,406}$ =15.886, $p<.001$); by queer participants in comparison to gay/lesbian and bisexual participants ($F_{2,397}$ =6.556, $p=.002$); by intersex compared to non-intersex participants ($F_{1,403}$ =27.439, $p<.001$); and by AYAs compared to older adults ($F_{1,412}$ =7.413, $p<.007$). There were no differences in reporting of discrimination in cancer care between participants with reproductive and non-reproductive cancers, or by geographical remoteness.

3.3.5.2 Discomfort in being LGBTQI

Most participants agreed that they were comfortable being LGBTQI (n=383; 91.0%), with greater comfort reported by LGBQ participants (n=347, 93.0%) compared to TGD (n=35, 83.3%) and intersex participants (n=16, 69.6%). A small proportion of the sample (n=29, 6.9%) wished they were not LGBTQI, reflecting relatively low levels of internalized prejudice, including 20 (5.4%) LGBQ participants, 8 (19.0%) TGD participants and 4 (17.4%) intersex participants. A large proportion of participants kept careful control over who knew they were LGBTQI (n=128, 30.8%), reflecting concealment motivation: 104 (28.3%) LGBQ participants, 23 (54.8%) TGD participants and 12 (52.2%) participants with intersex variations.

Significantly greater discomfort in being LGBTQI was reported by TGD participants compared to cisgender women and men ($F_{2,403}$ =13.476, $p<.001$); by bisexual compared to gay/lesbian and queer participants ($F_{2,394}$ =17.493, $p<.001$); by intersex compared to non-intersex participants ($F_{1,401}$ =13.556, $p<.001$); and by AYAs compared to older adults ($F_{1,409}$ =24.698, $p<.001$). There were no differences in discomfort in being LGBTQI by cancer type or by geographical remoteness.

3.3.5.3 Outness

The average score on the outness measure was 4.09 (*SD* = 1.08). On average, participants were most likely to have disclosed that they were LGBTQI to immediate family (*M* = 4.41, *SD* = 1.18) and friends/acquaintances (*M* = 4.37, *SD* = 0.90), followed by general HCPs (*M* = 4.06, *SD* = 1.35), extended family (*M* = 3.90, *SD* = 1.39) and at work/school (*M* = 3.84, *SD* = 1.31).

Cisgender men were significantly more likely to be out compared to cisgender women and TGD participants ($F_{2,393} = 7.448$, $p<.001$); significantly more gay/lesbian participants were out, compared to bisexual and queer participants ($F_{2,385} = 54.461$, $p<.001$); and older adults were more likely to be out than AYAs ($F_{1,399} = 39.800$ $p<.001$). There were no differences in outness by intersex status, cancer type, or geographical remoteness.

3.3.6 Social support

Current social support was generally high amongst participants, with the majority agreeing that they had strong support from family and friends (n=289, 78.3%), could get access to several people who understand and support them (n=296, 79.5%) and had at least one person who could attend medical appointments with them (n=291, 79.8%). The mean social support score was 3.88 (*SD* 0.92, range 1-5). When asked to report their primary support people during their cancer experience, participants largely nominated intimate partners (n=226, 60.4%), friends (n=189, 50.5%), parents (n=94, 25.1%), other family (n=130, 34.8%), and colleagues (n=46, 12.3%). A minority (n=35, 9.4%) reported that they did not have support people at the time. Most participants (n=232, 63.0%) had one intimate partner (n=216, 58.7%), with a minority having multiple partners (n=16, 4.3%)[1].

Social support was significantly higher for cisgender men compared to cisgender women and TGD participants ($F_{2,365} = 7.448$, $p<.001$); higher for gay/lesbian compared to bisexual and queer participants ($F_{2,357} = 6.577$, $p=.002$); higher for non-intersex compared to intersex participants ($F_{1,363} = 9.338$, $p=.002$); and higher for older adults compared to AYAs ($F_{1,372} = 9.585$, $p=.002$). There were no differences in social support by cancer type or geographical remoteness.

3.4 Identifying psycho-social variables associated with distress and QOL

Addressing research question (RQ) 3 and 4, Tables 5, 6 presents the analysis examining bivariate correlations between potential predictors of distress and QOL, for the sample as a whole and for subgroups, comparing by gender, sexuality, intersex status, age and cancer type. Tables Appendix Table A3 and Appendix Table A4 report differences in the correlations within subgroups. In the whole sample (RQ 3), distress was significantly positively correlated with discomfort with being LGBTQI, discrimination in general life and in cancer care, physical and sexual concerns, and impact on LGBTQI and gender identity. Distress was negatively correlated with QOL, outness, and social support. Additionally, QOL was positively correlated with outness and social support, and negatively correlated with discomfort with being LGBTQI, discrimination in life and cancer care, physical concerns, and impact on LGBTQI and gender identity.

For most subgroups (RQ 4), physical concerns, FCR, discomfort in being LGBTQI, and social support were significantly associated with distress and QOL, in the same direction as for the whole sample. For some of the subgroups with relatively small participant numbers (TGD, bisexual, queer, intersex, AYA), several the correlations failed to reach significance, suggesting larger sample size may reach significance. These findings suggest that higher physical concerns, higher FCR, greater discomfort in being LGBTQI, and lower social support are associated with higher distress and lower QOL for most participants, when compared across subgroups. There were few significant differences within subgroups in correlations (Table A3 and A4). The association between distress and impact of cancer on gender identity varied significantly by gender and was higher for cisgender women than for cisgender men and TGD participants (A3). Associations between social support and QOL were more positive in non-intersex participants, but did not reach significance for intersex participants (A4).

4 Discussion

This is the first large scale study to systematically examine distress and QOL and key psycho-social concomitants for LGBTQI people with cancer, comparing intersecting identity groups, including cisgender and TGD, intersex and non-intersex, lesbian/gay, bisexual and queer, AYAs and older adults, reproductive and non-reproductive tumor types, and those living in urban, rural and regional areas.

Average levels of distress for the whole sample were comparable or slightly elevated relative to a recent Australian study of predominantly heterosexual cisgender cancer survivors (101) and Australian cancer population reference values using the same measure (102). Similarly, the average QOL rating was almost identical to EORTC cancer population reference data (90). However, the proportion of participants reporting high or very high distress levels in the present study (41%) was

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[1] Chi-square tests indicated that there were no significant differences in the likelihood of being partnered by gender, sexuality, intersex status, age, geographic location or cancer type, after Bonferroni correction.

TABLE 5 Correlations between distress and other study variables, for total sample and subgroups.

Variable	**Total sample**	**Gender**			**Sexuality**			**Intersex status**		**Age**		**Remoteness***			**Cancer type**	
		Cis women	**Cis men**	**TGD**	**Lesbian/gay**	**Bisexual**	**Queer**	**Intersex**	**Non-intersex**	**AYA**	**Older adult**	**Urban**	**Regional**	**Rural**	**Reprod**	**Non-reprod**
QOL	**-.606****	**-.564****	**-.605****	**-.578****	**-.591****	**-.438****	**-.509****	-.315	**-.622****	**-.561****	**-.613****	**-.588****	**-.629****	**-.633****	**-.755****	**-.541****
Sexual concerns	**.204****	**.321****	.189	.044	**.250****	**.364****	-.091	.319	**.221****	.235	**.211****	**.206****	**.231****	.158	.225	.152
Physical concerns	**.356****	**.359****	**.379****	**.360****	**.364****	**.394****	.046	.182	**.356****	**.263****	**.337****	**.385****	**.307****	.288	**.488****	**.323****
LGBTQI impact	**.210****	**.223****	.144	.163	**.258****	-.077	.163	.079	**.186****	**.295****	**.155****	**.229****	.172	.220	.168	**.242****
Gender impact	**.258****	**.330****	-.066	.089	**.266****	.057	.172	.409	**.219****	.253	**.208****	**.203****	**.312****	**.339****	**.316****	**.214****
FCR	**.448****	**.345****	**.383****	**.403****	**.414****	**.461****	.143	.120	**.384****	.143	**.417****	**.456****	**.210****	**.381****	**.451****	**.316****
Minority stress																
Discr (*gen*)	**.265****	**.287****	.130	.222	**.281****	.288	-.156	.222	**.195****	.062	**.307****	**.230****	**.241****	**.487****	.124	**.388****
Discr (*care*)	**.271****	**.253****	**.220****	.156	**.275****	.177	-.002	-.135	**.249****	.006	**.339****	**.294****	.164	**.416****	**.261****	**.267****
Discomf LGBTQI	**.309****	**.282****	**.326****	.222	**.261****	.204	**.380****	**.575****	**.269****	**.279****	**.231****	**.308****	**.336****	.285	**.239****	**.374****
Outness	**-.216****	**-.297****	-.106	-.002	**-.147****	-.267	.027	-.256	**-.196****	-.185	-.116	**-.168****	**-.285****	-.166	-.127	**-.265****
Social support	**-.475****	**-.535****	**-.403****	**-.342****	**-.425****	**-.662****	**-.627****	-.314	**-.475****	**-.542****	**-.428****	**-.518****	**-.415****	**-.448****	**-.445****	**-.489****
Social support	**.417****	**.455****	**.391****	.199	**.436****	**.394****	.222	-.314	**.442****	**.409****	**.406****	**.365****	**.454****	**.547****	**.336****	**.471****

*Urban, in a major city of 100,000+ people, or the surrounding suburbs; Regional, in a smaller city; Rural, outside of a city. **p≤.05; significant correlations indicated in bold. AYA, adolescent and young adult (15-39 years); cis, cisgender; discomf LGBTQI, discomfort being LGBTQI; discr (care), discrimination in cancer care; discr (gen), discrimination in general life; FCR, fear of cancer recurrence; QOL, quality of life; reprod, reproductive; TGD, transgender and gender diverse.

TABLE 6 Correlations between QOL and other study variables, for total sample and subgroups.

Variable	Total sample	Gender			Sexuality			Intersex status		Age		Remoteness*			Cancer type	
		Cis women	Cis men	TGD	Lesbian/gay	Bisexual	Queer	Intersex	Non-intersex	AYA	Older adult	Urban	Regional	Rural	Reprod	Non-reprod
Sexual concerns	-.097	**-.186****	-.095	.032	**-.162****	**-.372****	.368	.039	**-.139****	-.114	-.096	-.106	-.003	-.265	-.199	-.098
Physical concerns	**-.300****	**-.296****	**-.327****	-.289	**-.300****	-.295	-.151	.121	**-.337****	**-.284****	**-.284****	**-.303****	**-.220****	**-.435****	**-.399****	**-.297****
LGBTQI+ impact	**-.149****	**-.150****	-.124	.064	**-.146****	-.293	-.072	.081	**-.138****	**-.313****	-.093	-.127	**-.213****	-.067	**-.242****	**-.147****
Gender impact	**-.281****	**-.229****	**-.287****	.060	**-.208****	-.145	-.153	-.198	**-.244****	**-.317****	**-.251****	**-.195****	**-.443****	-.224	**-.398****	**-.197****
FCR	**-.190****	-.123	**-.236****	-.253	**-.190****	-.215	-.267	-.037	**-.217****	-.196	**-.173****	**-.332****	.036	-.141	**-.222****	**-.213****
Minority stress																
Discr (*gen*)	**-.193****	**-.193****	.001	-.203	**-.199****	.127	.054	-.164	**-.130****	-.168	**-.186****	-.096	**-.318****	**-.312****	-.041	**-.251****
Discr (*care*)	**-.226****	**-.172****	-.094	-.230	**-.145****	-.003	-.295	.231	**-.198****	**-.310****	**-.183****	**-.258****	-.178	-.223	**-.248****	**-.183****
Discomf LGBTQI	**-.240****	**-.193****	**-.287****	-.126	**-.193****	-.238	-.080	-.206	**-.212****	-.156	**-.237****	**-.227****	**-.201****	**-.374****	-.198	**-.282****
Outness	**.222****	**.196****	**.216****	.110	**.195****	**.339****	-.217	.176	**.209****	.225	**.183****	**.186****	**.228****	.299	.184	**.253****
Social support	**.417****	**.455****	**.391****	.199	**.436****	**.394****	.222	-.314	**.442****	**.409****	**.406****	**.365****	**.454****	**.547****	**.336****	**.471****

*Urban, in a major city of 100,000+ people, or the surrounding suburbs; Regional, in a smaller city; Rural, outside of a city. **p≤.05; significant correlations indicated in bold. AYA, adolescent and young adult (15-39 years); cis, cisgender; discomf LGBTQI, discomfort being LGBTQI; discr (care), discrimination in cancer care; discr (gen), discrimination in general life; FCR, fear of cancer recurrence; QOL, quality of life; reprod, reproductive; TGD, transgender and gender diverse.

approximately three to six times higher than previous Australian cancer population studies using the same measure (7-12%) (103–105). This finding confirms previous reports of greater distress in LGBTQI cancer populations, in comparison with non-LGBTQI cancer populations (1, 2). Levels of high distress were also proportionately greater than rates of depression and anxiety reported in previous cancer research with LGB people. For example, a study of sexual minority breast cancer survivors (43) recorded clinically relevant depression and anxiety in 31% and 25% of participants respectively. A study of LGB people with gynecological cancer (17) reported depression and anxiety in 32% at 25% of participants respectively; and clinical levels of distress were reported by 13.7% of participants in a study of gay and bisexual men with prostate cancer (9).

The higher rates of distress reported in the present study in comparison with previous LGBTQI cancer research can be interpreted in relation to variations identified in intersecting identity sub-groupings. Significantly higher levels of distress and lower QOL were found in TGD, AYA, queer and bisexual sub-groups, in comparison with cisgender, older, lesbian/gay sub-groups—the later sub-groups have been the focus of previous LGBTQI cancer research (1, 2). Rates of QOL were significantly lower in intersex compared to non-intersex groups, with rates of distress close to significance. In combination, this suggests that psychological outcomes may be worse for LGBTQI people with cancer than has previously been estimated (106) as there has been a dearth of research that included TGD, AYA and intersex people with cancer, as well as those who identified as bisexual or queer (1). These differences in health outcomes in LGBTQI sub-groups are reflected in differences in the psycho-social concomitants of distress and QOL, which can be conceptualized as intersecting stigma-related stressors (107). TGD, intersex, AYA, queer and bisexual subgroups reported higher levels of a number of these stressors, including discomfort with being LGBTQI, discrimination in life and in cancer care, lower outness, greater impact of cancer on LGBTQI identity and gender identity, and lower social support, likely contributing to their higher distress and poorer QOL.

These findings confirm previous reports of higher levels of societal discrimination (108) and discrimination in health care (109) reported by TGD people compared with other SGM groups. This is an explanation for higher rates of distress found in TGD populations outside of the context of cancer (56, 110), and impacts upon experiences of cancer survivorship and interactions with health care professionals (26, 60). In previous research, TGD people of color, and those who identify as LBQ, are at highest risk of discrimination, harassment and violence (111, 112). Individuals who have intersex variations also face societal discrimination and hostility (113), as well as normalizing medical interventions that are conducted in infancy without consent, serving to deny bodily integrity and autonomy (113, 114) and violate human rights (115). People with intersex variance experience a higher incidence of anxiety, depression and psychological distress compared with the general population, which has been linked to stigma and discrimination (116). Both TGD and people with an intersex variation continue to face pathologization in standardized psychiatric classification systems (115, 117), resulting in stigma and negative impact on identity and wellbeing (118). TGD and intersex individuals have been described as the most stigmatized and the least understood members of LGBTQI communities (116, 119). Prior to the present study, they were the least understood groups in LGBTQI cancer research (1, 2).

Previous research has noted that those who identify as queer (120) or bisexual (118, 121) report significantly higher rates of depression and anxiety when compared with people who identify as gay or lesbian (122). The findings of the present study confirm that this is the case with bisexual people with cancer, in line with a recent study that reported that bisexual women with cancer are more likely to report severe distress (12.5%) than lesbian (5.5%) and heterosexual (4.0%) women (16). This stands in contrast to other studies that have not reported differences in distress between bisexual and gay/lesbian people with cancer (43, 123). Higher rates of distress that have been observed in queer and bisexual individuals in the general LGBTQI population have been attributed to greater minority stress (120), associated with concealment of sexuality, struggles with identity and low social support (124). These findings are confirmed in the present study, in the context of queer and bisexual people with cancer, who report higher discomfort with being LGBTQI and greater impact on gender identity, with queer people reporting greater discrimination in cancer care, compared with lesbian/gay/homosexual identified participants. Indications that the direction of the association between some psycho-social variables and distress or QOL is different for the bisexual or queer sub-groups, in comparison to the lesbian/gay subgroup, although statistically non-significant, deserves further investigation. This includes impact of cancer on LGBTQI identity and discrimination in life in general, for the bisexual subgroup; sexual concerns, discrimination in general life and in cancer care, outness, for the queer subgroup.

AYAs are recognized to be a unique and complex population, reporting higher rates of distress and lower QOL than older adults with cancer (125). For example, a recent study reported that AYA cancer survivors report more anxiety (15.1% vs. 6.6%) and mood disorders (14.8% vs. 8.9%) than older adults (126). The only previous study of AYA SGM cancer survivors to date reported that cisgender women who identified as sexual minorities were twice as likely to experience anxiety than those who identified as heterosexual (19). The findings of the present study provide an explanation for this effect and demonstrate that AYA LGBTQI people with cancer are at higher risk of negative psycho-social outcomes than older adults (18). Adolescence and young adulthood is a time when many LGBTQI individuals define their sexual and gender identity, with increasing numbers of young people today estimated to be same sex attracted or gender diverse – 20-30% in recent Australian research (127). This can be a time when the effects and meanings of having a variation in sex characteristics are negotiated for the first time for intersex people (113). Whilst a cancer diagnosis interrupts any person's developmental milestones, LGBTQI AYA survivors are vulnerable, because they risk rejection by family or friends when they "come out" or explore their gender identity (127), removing their main source of social support (128). Coming out can be a very difficult process for AYAs (129), reflected in the lower level of outness in AYAs in the present study. This is compounded for those who experience negative societal views or bullying (130), and by the double stigmatization of being an LGBTQI person with cancer (19, 131).

The higher rates of distress identified in rural and regional subgroups reinforces the need for attention to be made to the experiences and health care needs of LGBTQI people living outside of urban areas (77, 132). Higher rates of distress were not accompanied by higher levels of minority stress, or differences in any other psycho-social variables. This stands in contrast to previous research that identified higher minority stress and lower social support in LGBT people living in rural and regional Australia, in comparison to those living in urban areas in Australia (62). LGBT people living in rural areas of the USA also report high rates of minority stress (77) and difficulties in interactions with health care providers (132). In the qualitative arm of the *Out with Cancer Study*, some participants living in a rural or regional area reported social isolation and social stigma (60), whereas others reported high levels of community and health care practitioner support due to living in a "rural, small-town area where everyone knows everyone" and which contributed to "being respected" (26). There needs to be further investigation of LGBTQI cancer survivorship and care outside of urban areas, in order to understand potential health disparities experienced by rural and urban LGBTQI cancer survivors.

The lack of significant differences across cancer types suggests that LGBTQI people with reproductive and non-reproductive cancers experience similar levels of distress, minority stressors, and LGBTQI and gender impacts. This runs counter to healthcare professionals' assumptions that sexual orientation, gender identity and intersex variations are only relevant to reproductive cancers (26), indicating that tailored support resources for LGBTQI communities are relevant across diagnoses. Given that previous studies have predominantly focused on reproductive cancers (1, 3), this necessitates further research into how LGBTQI people are impacted by other cancer types in order to inform subsequent resource development.

Our findings clearly demonstrate that for the sample as a whole group, distress and poor QOL are associated with physical and sexual concerns, the impact of cancer on gender and LGBTQI identities, minority stress (including discrimination in life and in cancer care, discomfort with being LGBTQI and outness to others), and lack of social support.

The association between concerns about physical and sexual changes after cancer and distress, reflect previous findings in the general cancer population (31, 133). Rates of physical and sexual concerns following cancer treatment were comparable to non-LGBTQI cancer populations (92, 134), and did not significantly differ across gender, sexuality, age or cancer type. A near significant trend towards higher sexual concerns in participants who had reproductive cancers confirms previous research (68, 133, 135, 136), and is deserved of further investigation. The finding of significantly lower sexual concerns in the intersex subgroups may be explained by the fact that many intersex participants had undergone medical intervention to avoid cancer as infants, as described in our qualitative analysis (60), rather than cancer treatment as adults, thereby avoiding the impact of cancer treatment on sexual wellbeing (137).

Physical and sexual changes associated with cancer can impact upon LGBTQI identity (37, 40) and gender identity (31, 32, 92, 138), factors found to be associated with distress and QOL for many participants in the present study. This is because embodiment is central to gendered and sexual identities (139–141). Our finding of a greater impact of cancer on gender identity in the TGD subgroup compared to cis male and female subgroups needs further investigation. The measure used in the survey did not ascertain the direction of the impact on gender identity – whether it was positive or negative. Qualitative findings from the *Out with Cancer* study (142), and previous research on TGD cancer survivorship (143, 144), suggest that cancer treatment can facilitate gender affirmation for some TGD people, resulting in a positive impact on gender identity. Future research should use a more complex measure of impact of cancer on gender and LGBTQI identity, ascertaining direction and nature of any impact, for all LGBTQI subgroups, alongside in-depth qualitative examination of identity impact.

Fear of cancer recurrence (FCR) was associated with distress, as reported in previous research in the general cancer population (49). We also found a significant association between FCR and low QOL, contrary to a recent study of non-LGBTQI cancer survivors, where no such association was found (145). Whilst there was no evidence of significant differences in FCR across LGBTQI identities or cancer type, there was a near significant trend towards higher FCR in AYAs, as reported in previous research (49, 52). There is a need for further research on FCR and its concomitants in LGBTQI people with cancer, across age groups.

It is widely accepted that high rates of distress found in the general LGBTQI population (55–57), and reported in previous research with cisgender LGB cancer survivors (1), are associated with minority stress (53, 54), as found in the present study. Minority stress theory (61) explains the link between stigma-related distal stressors in a person's environment, such as

LGBTQI discrimination, social rejection, homophobia and transphobia, and health. Research drawing on this framework suggests that living in a hostile, discriminatory context can elicit internal, health-eroding proximal stress processes related to individuals' minority status, including anxious expectations of rejection, identity concealment, and internalized stigma (107, 146). This is reflected in the chronic stress experienced by LGBTQI people, as the result of stigmatization and discrimination within heterosexist and transphobic societies (147, 148).

Minority stress is acute in contexts where, until recently, LGBTQI relationships did not have the same status as heterosexual relationships (55, 149). There is evidence of LGBTQI discrimination in Australia (150) and the USA (151), where the majority of our participants reside. This is manifested by political and public debate about the right of religious organizations, schools, and health practitioners to exclude or discriminate against LGBTQI people (150). Homophobic and transphobic public discourse associated with marriage equality debates have been described as an act of "symbolic violence" (149). For young LGBTQI people, discrimination and hostility have been reflected in the "moral panic" (152) and "cultural bullying" (130), associated with political and media condemnation of initiatives addressing LGBTQI bullying in primary and secondary schools (152), or the right for trans and non-binary people to participate in sport (153). There has been widespread media coverage of "homosexual acts" being associated with bestiality, incest and pedophilia (154), or with abusive relationships (155) and the insistence transgender students identify as "the gender that God bestowed" (154). Prejudicial LGBTQI public discourse is often accompanied by discriminatory practices in healthcare (109) and the workplace (156, 157) as well as acts of hate speech and violence (112, 158) in both Australia, the USA and other international contexts where our participants resided.

This cultural milieu of hostility towards LGBTQI people is reflected in the finding that the majority of participants in the present study (84%) reported experiences of anti-LGBTQI discrimination at some point in their lives. These rates are higher than previously reported for sexual minority breast cancer survivors in the USA, using similar measurement tools (48%) (43). A further 33% had experienced discrimination as part of their cancer care, which is higher than most rates (2-41%) reported in previous research on discrimination in LGBTQI general healthcare (109). Oncology health care professionals report a lack of knowledge and confidence in treating LGBTQI patients (159, 160), in particular patients who are TGD or have an intersex variation (79), which can lead to levels or forms of care that are not LGBTQI inclusive, including inappropriate comments, exclusion of partners and hostility (26). Previous research has demonstrated that inappropriate comments, hostility and discriminatory practice on the part of health care professionals was associated with negative psychological and physical outcomes for LGBTQI people (109, 161), including LGBTQI people with cancer (2, 64). These findings are confirmed in the present study, with the mechanisms of this effect including cis-heteronormative health care professional practices, hostility toward LGBTQI patients and their carers, and a lack of LGBTQI cancer information. This has been explored further in the qualitative arm of the *Out with Cancer Study* (26, 60).

Social support has also been demonstrated to be associated with better QOL and functioning in the general cancer population (70). Social support can also reduce the negative impact of minority stress (43), through buffering or protecting against stress (162), explored in the qualitative arm of the *Out with Cancer Study* (60). In the present study, social support was negatively correlated distress and positively correlated with QOL for LGBTQI people with cancer. This confirms previous reports that low social support was associated with distress in lesbians with breast cancer (43, 163, 164) and gay/bisexual men with prostate cancer (165, 166), validating the argument that absence of social safety is a fundamental cause of mental and physical health disparities in LGBTQI populations (78). It has been reported that many LGBTQI individuals report sustained social isolation because of cancer (166, 167). In the non-LGBTQI community the primary carers of adults with cancer are typically their intimate partners (70), whereas LGBTQI individuals often look for support through broader social support networks and communities. For example, in a recent study of Australian gay men with prostate cancer, 39% were partnered (9), compared with 61% of the general population of the same age (55). However, social support is high in the present study, comparable to or higher than social support reported in the non-LGBTQI people with cancer (168–170), with the majority of participants reporting a range of supportive networks, including intimate partners, friends, other LGBTQI people, family and colleagues. These findings confirm previous reports that 'chosen family' and LGBTQI communities provide social support and connectedness for older LGB people (62, 73, 74, 171). TGD, intersex, AYA, queer and bisexual sub-groups in this study report significantly lower levels of social support, in line with previous findings that people who identify as queer, transgender, or genderqueer reported lower support than other SGM people with cancer (172). There is no previous research examining social support in AYA or intersex LGBTQI people with cancer. It is widely recognized that family support and acceptance is a protective factor for the mental health and wellbeing of LGBTQ AYAs in the general population (75, 128), alongside quality relationships with friends (173). Further research is needed to systematically examine the interactive effects of social support and psycho-social variables associated with distress and QOL for LGBTQI cancer survivors, to determine if social support reduces negative effects.

4.1 Study limitations

There are several limitations to the present study. It is a cross sectional study, with a small sample size in some subgroups. Further research is needed including larger numbers of AYA, TGD, bisexual and queer subgroups. Longitudinal research to examine experiences of LGBTQI cancer survivorship would also be useful. A further limitation is the use of truncated measures for some indices, due to the wide range of indices examined in this exploratory study, and the use of unvalidated measures where validated measures developed for the general cancer population were not appropriate for LGBTQI communities. Future research should use expanded and validated scales and validate existing scales for the LGBTQI population. The study may have been affected by sampling and self-report biases. As participants responded to invitations to take part in the online survey, the sample may not be representative of all LGBTQI people with cancer, particularly those who have limited digital literacy or access to technology, or who were not members of the platforms or organizations through which the survey was advertised. A further limitation is that the study relies on self-reported cancer diagnosis collected by anonymous survey methods. However, as LGBTQI status is not recorded by most cancer registries and hospital clinics, participants could not be accessed through medical records.

4.2 Conclusion

Our findings add further insight into the mechanisms of negative psycho-social outcomes for LGBTQI cancer patients and survivors, highlighting the impact of minority stress and the buffering effects of social support, and identifying diversity within LGBTQI populations related to health outcomes (1, 28). Those who are TGD, who have a variation in sex characteristics, who identify as queer or bisexual, and younger LGBTQI people with cancer, may be more vulnerable to distress and low QOL. However, these sub-groups of individuals are not independent identity positions that can be considered separately from each other (82). A person may be multiply marginalized due to their gender, their sexuality, their intersex status and their age, in what has been described as a double or triple jeopardy, within a "both/and" framework (29, 82). Equally, the social meaning and power relationships inherent in sexuality, gender identity, age and intersex status cannot be considered separately from each other (82). Our multiple comparison points thus reflect intersecting identities and vulnerabilities, suggesting a "matrix of domination" (174) in which multiple marginalized identities (29), based on social or LGBTQI sub-group membership, intersect to create life situations and psychological outcomes that are qualitatively different depending on one's location in the matrix (82). There is a need for further research to examine the ways in which intersecting identities and stressors operate to produce both positive and negative psycho-social outcomes for LGBTQI people with cancer, using both qualitative and quantitative methods. Further research is also needed to examine the intersection of cultural background and ethnicity with LGBTQI status. This was not possible in the present study, due to the small number of participants who did not identify as white/Caucasian and the disparities in background in the non-white/Caucasian grouping.

Our findings reinforce the conclusion of The American Society of Clinical Oncology (6) that it is imperative that attention is paid to health disparities experienced by LGBTQI people with cancer. Oncology research needs to include measures of sexuality and gender diversity, and intersex variation, as a matter of course, to avoid rendering invisible this potentially vulnerable group of patients and survivors and to identify unmet needs in LGBTQI experiences of cancer and cancer care. More information is needed about the unique experience of LGBTQI cancer patients, survivors and their carers, with a particular focus on the overlooked and intersecting groups of TGD, intersex and AYA people. Co-design of research and collaboration with LGBTQI stakeholders can help to ensure the LGBTQI cultural competence and cultural safety of methods and interpretation (175).

It is essential that we develop inclusive and affirmative cancer care for LGBTQI patients (176), including content related to the needs and experiences of the LGBTQI community overall, as well as content specific to each sub-group (79). Practical initiatives start with provision of LGBTQI content in health care professional education and training curricula to facilitate understanding of this often-overlooked population in cancer care and to challenge bias and ingrained cis-heteronormative practices (26, 159, 176). Specific practices to develop inclusive and affirmative LGBTQI cancer care include: avoiding the assumption that patients are heterosexual and cisgender by asking what patients prefer as names and pronouns; not making assumptions about the patients' relationships with the persons accompanying them to appointments; including same-gender partners in care; not assuming only heterosexual cisgender people want to discuss sexual health and fertility concerns; and encouraging LGBTQI patients to connect with peers (2, 176–178).

In order to be LGBTQI inclusive, cancer centers, hospitals and cancer community organizations should display LGBTQI images and logos, provide gender neutral bathrooms, tailored LGBTQI-inclusive supportive resources, and include LGBTQI people in general cancer information (2, 79, 159, 176). Services need to be accountable through formal mechanisms for addressing complaints about discrimination and poor care, which includes clear information about complaints processes for patients, and taking such complaints seriously. Intake forms should include sexuality, gender identity, preferred name and pronoun and intersex variation (159, 176), in order to facilitate

LGBTQI patient disclosure (179). In combination, these measures will increase the likelihood of the needs of LGBTQI people with cancer being acknowledged and met, resulting in non-discriminatory and inclusive cancer care for LGBTQI patients and their carers, with positive implications for patient health outcomes.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving human participants were reviewed and approved by Western Sydney University Human Research Ethics Committee. All participants provided written informed consent to participate in this study.

Author contributions

JU and JP designed the study and prepared the application for funding, in collaboration with The Out with Cancer Study team members. The survey was developed by JU, KA, and RP in collaboration with the Out with Cancer Study team, and our stakeholder advisory group. Data were collected by RP and KA. KA conducted statistical analysis of the data, in collaboration with JP and JU. JU and KA wrote the paper, with critical input from JP and RP. The Out with Cancer Study Team provided critical commentary on the written paper. All authors contributed to the article and approved the submitted version.

The Out with Cancer Study team members involved in this paper

Chloe Parton[1], Alexandra Hawkey[2], Gary W. Dowsett[3] Fiona E. J. McDonald[4], Antoinette Anazodo[5], Suzanne Chambers[6], Martha Hickey[7], Kerry H. Robinson[8], Felix Delhomme[9] Scout[10] and Katherine Boydell[11]

[1] School of Health, Te Herenga Waka – Victoria University of Wellington, Wellington, New Zealand

[2] Translational Health Research Institute, Western Sydney University, Sydney, Australia

[3] Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne, Australia

[4] Canteen and Faculty of Medicine and Health, The University of Sydney, Sydney, Australia

[5]Kids Cancer Centre, Sydney Children's Hospital and School of Women's and Children's Health, University of New South Wales, Sydney, Australia

[6] Faculty of Health Sciences, Australian Catholic University, Brisbane, Australia

[7]Department of Obstetrics and Gynaecology, University of Melbourne and the Royal Women's Hospital, Melbourne, Australia

[8] School of Social Sciences and Translational Health Research Institute, Western Sydney University, Sydney Australia

[9]ACON, Sydney, Australia

[10]National LGBT Cancer Network, USA

[11] Black Dog Institute, University of New South Wales, Sydney, Australia

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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Appendix

TABLE A1 Effect sizes and tests of difference for distress and quality of life (by gender, sexuality, intersex status, age, cancer type).

	Gender			Sexuality			Intersex status			Age			Remoteness*			Cancer type		
	η^2	*F*	*p*	η^2	*F*	*p*	η^2	*F*	*p*	η^2	*F*	*p*	η^2	*F*	*p*	η^2	*F*	*p*
Distress	.044	7.084	**<.001**	.051	8.095	**<.001**	.021	6.662	.010	.092	31.959	**<.001**	.034	5.557	**.004**	.010	2.782	.096
QOL	.069	12.167	**<.001**	.074	12.718	**<.001**	.048	16.360	**<.001**	016	5.311	.022	.007	1.206	.301	.005	1.319	.252

Note: statistically significant p-values (p≤.008, using Bonferroni correction) are indicated in bold text. *Urban = in a major city of 100,000+ people, or the surrounding suburbs; Regional = in a smaller city; Rural = outside of a city. QOL = quality of life.

TABLE A2 Effect sizes and tests of difference for other study variables (by gender, sexuality, intersex status, age and cancer type).

	Gender			Sexuality			Intersex status			Age			Remoteness*			Cancer type		
	η^2	*F*	*p*	η^2	*F*	*p*	η^2	*F*	*p*	η^2	*F*	*p*	η^2	*F*	*p*	η^2	*F*	*p*
Sexual concerns	.014	1.852	.159	.003	0.351	.704	.027	7.433	**.007**	.000	0.076	.783	.000	0.038	.962	.022	5.261	.023
Physical concerns	.018	2.645	.073	.052	7.993	**<.001**	.000	0.003	.958	.033	10.235	**.002**	.010	1.479	.229	.006	1.445	.230
LGBTQI impact	.044	9.308	**<.001**	.010	1.952	.143	.002	0.764	.383	.008	3.232	.073	.001	0.188	.829	.005	1.835	.176
Gender impact	.144	27.245	**<.001**	.120	21.586	**<.001**	.018	5.757	.017	.028	9.535	**.002**	.001	0.222	.801	.001	0.384	.536
FCR	.002	0.355	.702	.011	1.768	.172	.004	1.278	.259	.019	6.322	.012	.001	0.218	.804	.003	0.971	.325
Minority stress																		
Discr (*gen*)	.062	13.476	**<.001**	.014	2.840	.060	.032	13.556	**<.001**	.019	7.876	**.005**	.003	0.545	.580	.003	1.251	.264
Discr (*care*)	.073	15.886	**<.001**	.032	6.556	**.002**	.064	27.439	**<.001**	.018	7.413	**.007**	.002	0.377	.714	.000	0.035	.851
Discomf LGBTQI	.043	9.066	**<.001**	.082	17.493	**<.001**	.018	7.352	**.007**	.057	24.698	**<.001**	.001	0.233	.792	.004	1.412	.236
Outness	.057	7.448	**<.001**	.221	54.461	**<.001**	.008	2.350	.126	.091	39.800	**<.001**	.006	1.275	.281	.002	0.448	.504
Social support	.046	7.448	**<.001**	.036	6.577	**.002**	.025	9.338	**.002**	.025	9.585	**.002**	.005	0.865	.422	.000	.002	.966

Note: statistically significant p-values (p≤.008, using Bonferroni correction) are indicated in bold text. *Urban = in a major city of 100,000+ people, or the surrounding suburbs; Regional = in a smaller city; Rural = outside of a city. Discomf LGBTQI = discomfort being LGBTQI; discr (care) = discrimination in cancer care; discr (gen) = discrimination in general life; FCR = fear of cancer recurrence; QOL = quality of life.

TABLE A3 Chi-square analyses exploring differences within groups (by gender, sexuality, intersex status, age, remoteness and cancer type) in correlations between quality of life and other study variables.

Variable	Gender	Sexuality	Intersex status	Age	Remoteness**	Cancer type
Sexual concerns	2.456	3.211	0.128	0.027	0.126	0.275
Physical concerns	0.032	2.923	0.502	0.324	0.612	2.153
LGBTQI impact	0.570	3.363	0.191	1.107	0.218	0.361
Gender impact	**10.806***	1.450	0.679	0.116	1.202	0.724
FCR	0.196	2.573	1.222	4.489	4.627	1.489
Minority stress						
Discr (*gen*)	1.730	5.546	0.013	3.344	2.884	4.910
Discr (*care*)	0.315	2.344	2.440	6.163	2.290	0.002

(Continued)

TABLE A3 Continued

Variable	Gender	Sexuality	Intersex status	Age	Remoteness**	Cancer type
Discomf LGBTQI	0.361	0.064	2.304	0.133	0.099	1.306
Outness	4.112	1.419	0.061	0.250	0.980	1.252
Social support	2.776	4.871	0.556	1.148	1.059	0.192

*Bold text denotes chi-square values which are statistically significant (p≤.008, using Bonferroni correction). **Urban = in a major city of 100,000+ people, or the surrounding suburbs; Regional = in a smaller city; Rural = outside of a city. AYA = adolescent and young adult (15-39 years); B = bisexual; CF = cis female; CM = cis male; Discomf LGBTQI = discomfort being LGBTQI; Discr (care) = discrimination in cancer care; Discr (gen) = discrimination in general life; FCR = fear of cancer recurrence; LG = lesbian/gay; Non = non-reproductive; Q = queer; Reg = regional; Repr = reproductive

TABLE A4 Chi-square tests exploring differences within groups (by gender, sexuality, intersex status, age, remoteness and cancer type) in correlations between distress and other study variables.

Variable	Gender	Sexuality	Intersex status	Age	Remoteness**	Cancer type
Sexual concerns	1.381	8.506	0.423	0.014	1.701	0.532
Physical concerns	0.084	0.640	3.764	0.000	1.474	0.770
LGBTQI+ impact	1.448	0.940	0.950	2.733	0.803	0.612
Gender impact	3.622	0.192	0.042	0.268	5.147	3.051
FCR	1.151	0.190	0.601	0.029	9.392	0.006
Minority stress						
Discr (*gen*)	2.851	4.506	0.024	0.018	4.252	2.914
Discr (*care*)	0.695	1.474	3.724	0.953	0.457	0.287
Discomf LGBTQI	1.057	0.484	0.001	0.369	1.032	0.484
Outness	0.346	6.049	0.023	0.099	0.510	0.330
Social support	4.382	1.623	**12.546***	0.001	2.059	1.643

*Bold text denotes z-scores which are statistically significant (p≤.008, using Bonferroni correction). **Urban, in a major city of 100,000+ people, or the surrounding suburbs; Regional, in a smaller city; Rural, outside of a city. AYA, adolescent and young adult (15-39 years); B, bisexual; CF, cis female; CM, cis male; Discomf LGBTQI, discomfort being LGBTQI; Discr (care), discrimination in cancer care; Discr (gen), discrimination in general life; FCR, fear of cancer recurrence; LG, lesbian/gay; Non, non-reproductive; Q, queer; Reg, regional; Repr, reproductive.

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Cancer patient and provider responses to companion scales assessing experiences with LGBTQI-affirming healthcare

Mandi L. Pratt-Chapman[1,2,3]*, Yan Wang[2,3], Gwendolyn P. Quinn[4], Sylvia Shirima[2], Sarah Adler[2], Ruta Brazinskaite[2], Charles Kamen[5], Asa Radix[6], Barbara Warren[7], Kristen Eckstrand[8] and Ana Maria Lopez[9]

[1]Department of Medicine, The George Washington University School of Medicine and Health Sciences, Washington, DC, United States, [2]The George Washington University Cancer Center, Washington, DC, United States, [3]Department of Community Health and Prevention, The George Washington University Milken Institute School of Public Health, Washington, DC, United States, [4]Departments of OB-GYN and Population Health, Grossman School of Medicine, Perlmutter Cancer Center, New York University, New York, NY, United States, [5]Department of Surgery and Wilmot Cancer Institute, University of Rochester, Rochester, NY, United States, [6]Callen-Lorde Community Health Center, New York, NY, United States, [7]Mount Sinai Health System and School of Medicine, New York, NY, United States, [8]Department of Psychiatry, University of Pittsburgh, Pittsburg, PA, United States, [9]Sidney Kimmel Cancer Center, Thomas Jefferson University, Philadelphia, PA, United States

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EDITED BY
Edward Callahan,
University of California, Davis, United States

REVIEWED BY
Cameron Haas,
National Cancer Institute (NIH),
United States
James L. Fisher,
The Ohio State University, United States

*CORRESPONDENCE
Mandi L. Pratt-Chapman
mandi@gwu.edu

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Background: Sexual and gender minority (SGM) persons are at a higher risk for some cancers and may have poorer health outcomes as a result of ongoing minority stress, social stigma, and cisnormative, heteronormative healthcare environments. This study compared patient and provider experiences of affirming environmental and behavioral cues and also examined provider-reported knowledge, attitudes, behaviors, and clinical preparedness in caring for SGM patients among a convenience sample.

Methods: National convenience samples of oncology providers (n = 107) and patients (n = 88) were recruited separately *via* snowball sampling. No incentives were provided. After reverse coding of appropriate items for unidirectional analysis, lower scores on items indicated greater knowledge, more affirming attitudes or behaviors, and greater confidence in clinical preparedness to care for SGM patients. Pearson chi-square tests compared dichotomous variables and independent samples t-tests compared continuous variables. Other results were reported using descriptive frequencies.

Results: Both patient and provider samples were predominantly female sex assigned at birth, cisgender, and heterosexual. Providers were more likely than patients to report affirming cues in clinic, as well as the ability for patients to easily document their name in use and pronouns. Providers were more likely to report asking about patient values and preferences of care versus patients' recollection of being asked. Patients were more likely to report understanding why they were asked about both sex assigned at birth and gender identity compared to providers' perceptions that patients would understand being asked about both. Patients were also more likely to report comfort with providers asking about sex assigned at birth and gender identity compared to providers' perceptions of patient comfort. SGM providers had greater knowledge of SGM patient social determinants of health and cancer risks; felt more prepared to care for gay patients; were more likely to endorse the importance of knowing patient sexual orientation and gender identity; and were more likely to indicate a responsibility to learn about SGM patient needs and champion positive system changes for SGM patients compared to heterosexual/cisgender peers. Overall, providers wished for more SGM-specific training.

Conclusion: Differences between patient and provider reports of affirming environments as well as differences between SGM and heterosexual/cisgender provider care support the need for expanded professional training specific to SGM cancer care.

KEYWORDS

cultural competence, affirming care, patient experience, provider experience, measurement, LGBTQI

Introduction

The percentage of Americans who identify as lesbian, gay, bisexual, transgender, queer, or intersex (LGBTQI) has been steadily increasing (1). Recent data from Gallup showed that LGBT identification in the United States rose to 7.1% in 2022 (1). While LGBTQI is commonly used in public discourse, these groups are often referred to as sexual and gender minority (SGM) persons in the research literature to acknowledge that letters of "LGBTQI" do not include how all people identify and in an effort to be inclusive. Here, we use SGM to be inclusive; however, we refer to LGBTQI in measurement items that are public-facing and when quoting open-ended comments from the surveys.

SGM persons experience disparities that may place them at a higher risk for adverse health effects (2). Previous research suggests that in response to minority stress and stigmatization, the SGM community may exhibit higher tobacco use, poorer mental health, and higher maladaptive drug use and alcohol use compared to general population rates (3–6). These behaviors put SGM persons at higher risk for some cancers and poorer quality of life when diagnosed with cancer (7). Healthcare experiences for SGM persons can be challenging due to lack of provider competence, societal prejudice, discrimination, and patient reticence (8, 9). Policies promoting training on needs of SGM people, routine collection of sexual orientation and gender identity (SOGI) data in electronic health record (EHR) systems, and provision of affirming care and support are yet to be common practice in most oncology settings (10, 11).

In 2017, the American Society of Clinical Oncology (ASCO) issued a position statement calling for improved provider training and quality improvement to advance health equity for SGM patients with cancer as well as collection of SOGI data (12). Subsequently, ASCO surveyed practicing oncologists to assess individual and institutional predictors of SOGI data collection (13). In that study, over a third of respondents indicated that their institutions did not collect SOGI data and a fifth of respondents were not sure if their institutions collected SOGI data (13). Collection of SOGI data was associated with leadership support and resources to collect SOGI data. Most respondents appreciated the value of collecting SOGI data with a minority indicating that SOGI was unimportant for cancer care.

Since the ASCO position statement, there is a growing literature describing patient and provider perspectives on SGM-affirming care as well as collection of SOGI data in clinical practice. In one study, patients were willing to disclose SOGI and staff were willing to collect it, but patient confidentiality and safety remained concerns (14). In another study, patients suggested that providers ask about SOGI and sexual practices multiple times and avoid euphemisms and vague references to sexual health (15). Useful communication practices include asking direct questions about sexual orientation and behavior, using the term "partner," and proper pronoun use (16). Another study found that when patients disclosed gender identity, it was typically unprompted (17). The same study suggested that provider training and space in the EHR were critical supports for SOGI data collection and affirming care (17). These findings were reinforced by a study showing a dramatic increase in SOGI data documentation when the EHR was modified to support these data (18).

Our study contributes to this growing literature by comparing patient- and provider-reported experiences with affirming environmental cues, such as SOGI data collection and questions asking about other relevant characteristics and preferences for care. This was a secondary analysis using data from a psychometric analysis of two scales developed and validated to compare patient- and provider-reported experiences of SGM-affirming care in convenience samples. These scales, entitled QUeering

Individual and Relational Knowledge Scale (QUIRKS)-Provider and the QUIRKS-Patient, respectively, assess SGM-affirming environmental and behavioral cues as well as provider-reported knowledge, attitudes, and clinical preparedness in caring for SGM patients. To our knowledge, these are the first scales to disaggregate subpopulations when assessing provider preparedness, an important step forward to detect differences in provider preparedness for these heterogeneous groups. This secondary analysis provides a cross-sectional view of SGM-affirming cancer care from a diverse convenience sample of patients and providers across the U.S.

Materials and methods

Instrumentation

The QUIRKS-Patient and QUIRKS-Provider scales were developed based on theorized constructs and refined through cognitive interviews (19). Psychometric analyses were run to test the validity of theorized factors for each scale (20). Details on the cognitive interviews and psychometric analyses are published separately (19, 20).

Demographics. For both QUIRKS-Patient and QUIRKS-Provider, samples were asked about demographics including age, race, sex assigned at birth, gender identity, sexual orientation, and state of residence. Items and response options for demographics are listed verbatim in Tables 1 and 2 (see also footnotes for response items not listed directly in the table due to zero respondents selecting the option). Importantly, for gender identity, respondents were able to select more than one category (e.g., “transgender” and “male”). Providers were also asked about professional role, specialty, and number of training hours specific to SGM health they had received.

Constructs measured. The QUIRKS-Provider survey included five questions about clinical preparedness in meeting the healthcare needs of SGM patients; four questions about environmental cues for SGM-affirming care; eight questions assessing attitudes toward SGM patients; six questions about clinical behaviors relevant to SGM-affirming care; and nine objective knowledge questions. Six questions were reverse coded to ensure that directionality of scores for affirming care were consistent (in this case, lower scores for each question reflected more affirming care).

The QUIRKS-Patient asked five questions about environmental cues relevant to SGM-affirming care; four patient experience questions about discrimination, clinical communication, and quality of and satisfaction with care; and six questions assessing attitudes about healthcare providers asking about sex assigned at birth, sexual orientation, gender identity, and sexual and psychosocial health.

Comparing constructs measured. All items are listed in Tables 3–5. Eight questions in each scale were similar in order to compare patient-reported and provider-reported experiences. Questions asking about the clinic environment were similar for both surveys to allow for comparisons. For example, patients were asked about cues in the healthcare practice that welcome SGM patients, cues in the healthcare practice that welcome racial/ethnic minorities, and opportunities to easily document name in use, pronouns, and sexual orientation. Providers were asked the same questions except for the question about racial/ethnic minorities (see Table 3). Questions about environmental cues had answer options: Yes, No, and I don’t know. Six items in the QUIRKS-Patient relevant to comfort in being asked about sexual orientation, gender identity, and sexual health included a five-item Likert scale from 0 = Strongly Agree to 4 = Strongly Disagree and a fifth

TABLE 1 Similar items assessed on QUIRKS-Patient and QUIRKS-Provider surveys.

QUIRKS-Patient Item	QUIRKS-Provider Item
There are cues in my cancer care provider’s office that welcome lesbian, gay, bisexual, and transgender (LGBT) patients.	There are cues in my healthcare practice that show I welcome lesbian, gay, bisexual, and transgender patients.
At my cancer care provider’s office, I have opportunities to easily document my name in use if different from my legal name.	Patients have opportunities to easily document their name in use (if different from legal name) in my healthcare practice.
At my cancer care provider’s office, I have opportunities to easily document my pronouns if I choose to do so.	Patients have opportunities to easily document their pronouns in my healthcare practice
At my cancer care provider’s office, I have opportunities to easily document my sexual orientation if I choose to do so.	Patients have opportunities to easily document their sexual orientation in my healthcare practice
My cancer care provider asks me about my values and preferences when establishing goals of care.	I initiate conversations about patient values and preferences when establishing goals of care.
I understand why my healthcare provider asks me about both sex assigned at birth and gender identity	My patients would not understand why they are being asked about both sex assigned at birth and gender identity^R
I am comfortable when my healthcare provider asks me about my sex assigned at birth.	If I explained why I was asking about both sex assigned at birth and gender identity, my patients would be comfortable with me asking.*
I am comfortable when my healthcare provider asks me about my gender identity.	If I explained why I was asking about both sex assigned at birth and gender identity, my patients would be comfortable with me asking.*
I appreciate when my healthcare provider asks me about my sexual health.	I am as comfortable discussing sexual health concerns with LGBTQI patients as I am with heterosexual, cisgender patients.

^{R}Indicates reverse scoring. *QUIRKS-Provider item was compared to two separate QUIRKS-Patient items.

TABLE 2 Participant characteristics.

Characteristic	Patient (*n* = 88)	Provider (*n* = 107)
Age, M (SD)	53.76 (12.77)	46.29 (12.02)
Race, *n* (%)[1]	3 (3.41)	1 (0.93)
American Indian/Alaska Native	2 (2.27)	5 (4.67)
Asian	19 (21.59)	5 (4.67)
Black, African American	5 (5.68)	6 (5.61)
Hispanic, Latino, Spanish	1 (1.14)	0 (0)
Native Hawaiian/Pacific Islander	0 (0)	1 (0.93)
Middle Eastern or North African	63 (71.59)	91 (85.05)
White	0 (0)	2 (1.87)
Other	1 (1.14)	1 (0.93)
Prefer not to answer		
Sex assigned at birth, *n* (%)[2]	71 (80.68)	92 (85.98)
Female	17 (19.32)	15 (14.02)
Male		
Gender identity, *n* (%)[1,3]	15 (17.05)	15 (14.02)
Cisgender man	65 (73.86)	88 (82.24)
Cisgender woman	0 (0)	1 (0.93)
Genderqueer	2 (2.27)	1 (0.93)
Nonbinary	1 (1.14)	0 (0)
Two-spirit	2 (2.27)	1 (0.93)
Another gender	1 (1.14)	1 (0.93)
Prefer not to answer	3 (3.41)	2 (1.87)
I do not understand the question		
Sexual orientation, *n* (%)[1,4]	7 (7.95)	1 (.93)
Asexual	7 (7.95)	12 (11.21)
Bisexual	6 (6.82)	8 (7.48)
Gay	10 (11.36)	3 (2.80)
Lesbian	1 (1.14)	2 (1.87)
Pansexual	3 (3.41)	3 (2.80)
Queer	1 (1.14)	1 (0.93)
Questioning	56 (63.64)	76 (71.03)
Straight/Heterosexual	0 (0)	1 (0.93)
Two-spirit	0 (0)	1 (0.93)
Another sexual orientation	0 (0)	3 (2.80)
Prefer not to answer	0 (0)	1 (0.93)
I do not understand the question		
Professional role (*n* = 115)	Not applicable	3 (2.80)
Community health worker		12 (11.21)
Nurse		7 (6.54)
Nurse practitioner		17 (15.89)
Nurse navigator		11 (10.28)
Patient navigator		15 (14.02)
Physician		31 (28.97)
Social worker		11 (10.28)
Other clinical role		
Specialty (*n* = 107)	Not applicable	75 (70.09)
Oncology		5 (4.67)
Primary care		12 (14.02)
Other specialty area		12 (11.21)
Not clinical		
Training hours, M (SD)	Not applicable	9.72 (14.45)

[1] Select all that apply.
[2] Intersex was a response option, but no participants selected this option.
[3] Agender, Transgender male, Transgender female, and Questioning were response options, but no participants selected these options.
[4] Same gender loving was an option, but no participants selected this option.

response option: “I have never been asked this question.” The fifth response was recoded as missing. All other items had responses based on a five-point Likert scale from 0 = Strongly Agree/Always to 4 = Strongly Disagree/Never (see Table 4).

Open-ended questions. The study asked providers four open-ended questions regarding (1) experiences with LGBTQI cancer care, (2) reservations about caring for LGBTQI patients, (3) suggestions for improving LGBTQI cancer care; and (4) “any

TABLE 3 Patient and provider reported experiences of environmental cues for LGBTQI-affirming care.

QUIRKS-Patient			QUIRKS-Provider			Pearson chi-square test *p*-value
Item	*N*	*N* (%)	Item	*N*	*N* (%)	
There are cues in my cancer care provider's office that welcome lesbian, gay, bisexual, and transgender (LGBT) patients.	88	Yes = 12 (13.64)	There are cues in my healthcare practice that show I welcome lesbian, gay, bisexual, and transgender patients.	107	Yes = 54 (50.47)	**<0.01**
		No/Don't know = 76 (86.36)			No/Don't know = 53 (49.53)	
There are cues in my cancer care provider's office that welcome various racial and ethnic groups.	88	Yes = 30 (34.09)	Not applicable		Not applicable	
		No/Don't know = 58 (65.91)				
At my cancer care provider's office, I have opportunities to easily document my name in use if different from my legal name.	88	Yes = 35 (39.77)	Patients have opportunities to easily document their name in use (if different from legal name) in my healthcare practice.	107	Yes = 60 (56.07)	**0.02**
		No/Don't know = 53 (60.23)			No/Don't know = 47 (43.93)	
At my cancer care provider's office, I have opportunities to easily document my pronouns if I choose to do so.	88	Yes = 25 (28.41)	Patients have opportunities to easily document their pronouns in my healthcare practice.	107	Yes = 45 (42.06)	**0.05**
		No/Don't know = 63 (71.59)			No/Don't know = 62 (57.94)	
At my cancer care provider's office, I have opportunities to easily document my sexual orientation if I choose to do so.	84	Yes = 35 (39.77)	Patients have opportunities to easily document their sexual orientation in my healthcare practice.	107	Yes = 53 (49.53)	0.17
		No/Don't know = 53 (60.23)			No/Don't know = 54 (50.47)	

$p < 0.05$, statistically significant. p-values represent whether patient and provider responses to each item listed are statistically significantly different.
Bold values represent statistical significance.

additional comments." Patients in the study were only asked for "any additional comments" in an open-ended final question.

Participant recruitment

A convenience sample of healthcare professionals and individuals with a history of cancer were recruited *via* snowball sampling to complete the QUIRKS-Provider and QUIRKS-Patient surveys, respectively. GW Cancer Center provides technical assistance to a broad range of clinical and public health providers across the U.S. through its Centers for Disease Control and Prevention funded technical assistance and training. Recruitment was conducted *via* dissemination through GW Cancer Center newsletters, social media, and professional networks to reach patients and providers from diverse health systems across the U.S. The informed consent indicated that the purpose of the study was to "examine the experiences of those with a history of cancer and their healthcare providers on topics related to patient-centered care." Anyone with a history of cancer was invited to participate in the QUIRKS-Patient survey. Anyone who provided care to cancer patients was invited to participate in the QUIRKS-Provider survey. No incentives for participation were provided.

Data collection

Data were collected *via* a disseminated link to the Research Electronic Data Capture (REDCap) system. REDCap is a secure, web-based application designed to support data capture for research studies, providing (1) an intuitive interface for validated data entry; (2) audit trails for tracking data manipulation and export procedures; (3) automated export procedures for seamless data downloads to common statistical packages; and (4) procedures for importing data from external sources.

Data management

Questions that were similar for the QUIRKS-Patient and QUIRKS-Provider were compared (see Table 1). Items with response options "Yes," "No," and "I don't know" were

TABLE 4 Patient and provider reported experiences of LGBTQI-affirming provider behaviors.

	Patient									Provider				
	N	Never asked the question	Patient Report, M (SD)	Het/Cis *N*	Het/Cis Patient, M (SD)	LGBT *N*	LGBT Patient, M (SD)	*t*	*p*		*N*	Provider Report, M (SD)	*t*	*p*
I have personally experienced discrimination in a cancer care interaction.	86	Not applicable	3.19 (1.08)	53	3.53 (1.75)	33	2.64 (0.23)	3.60	**<0.01**	–	–	–	–	–
My cancer care team provides high-quality clinical care to me personally.	86	Not applicable	0.56 (0.92)	53	0.43 (0.84)	33	0.76 (1.00)	−1.61	0.11	–	–	–	–	–
My cancer care provider asks me about my values and preferences when establishing goals of care.	86	Not applicable	1.34 (1.17)	53	1.25 (1.04)	33	1.48 (1.37)	−0.86	0.36	I initiate conversations about patient values and preferences when establishing goals of care.	103	0.91 (1.02)	2.63	**0.01**
Overall, I am satisfied with my cancer care.	86	Not applicable	0.58 (0.87)	53	0.45 (0.77)	33	0.79 (0.99)	−1.75	0.10	–	–	–	–	–
I understand why my healthcare provider asks me about both sex assigned at birth and gender identity.	26	58	0.62 (0.70)	17	0.65 (0.79)	9	0.56 (0.53)	0.31	0.76	My patients would not understand why they are being asked about both sex assigned at birth and gender identity.^{R}	102	1.98 (0.92)	−7.04	**<0.01**
I am comfortable when my healthcare provider asks me about my sex assigned at birth.	34	50	0.65 (0.92)	23	0.39 (0.78)	11	1.18 (0.98)	−2.54	**0.02**	If I explained why I was asking about both sex assigned at birth and gender identity, my patients would be comfortable with me asking.	102	1.63 (0.90)	−5.47	**<0.01**
I am comfortable when my healthcare provider asks me about my gender identity.	36	48	0.58 (0.91)	24	0.33 (0.82)	12	1.08 (0.90)	−2.51	**0.02**	If I explained why I was asking about both sex assigned at birth and gender identity, my patients would be comfortable with me asking.	102	1.63 (.90)	−5.97	**<0.01**
If I understand the reason why my healthcare provider is asking, I am comfortable disclosing my	56	28	0.50 (0.79)	34	0.35 (0.81)	22	0.72 (0.70)	−1.77	0.08	–	–	–	–	–

(Continued)

TABLE 4 Continued

		Patient								Provider				
sexual orientation.														
I appreciate when my healthcare provider asks me about my sexual health.	61	23	0.84 (0.80)	39	0.85 (0.84)	22	0.82 (0.73)	0.13	0.90	I am as comfortable discussing sexual health concerns with LGBTQI patients as I am with heterosexual, cisgender patients.	102	1.06 (1.13)	−1.35	0.18
I appreciate when my healthcare provider asks me about my psychosocial health.	73	11	0.53 (0.67)	47	0.43 (0.62)	0.73 (0.72)		−1.90	0.06	–	–	–	–	–

^{R} indicates reverse scoring. p < 0.05 = statistically significant. Scores below 2 = more affirming care. Scores over 2 = less LGBTQI-affirming care. p-values represent whether patient and provider responses to each item listed are statistically significantly different.
Bold values represent statistical significance.

dichotomized to “Yes” and “No/I don’t know.” All other questions were Likert scale questions. After reverse coding appropriate items, mean scores for all items closer to zero (range: 0 < 2) indicated more SGM-specific knowledge, affirming attitudes or behaviors, or clinical confidence. Higher scores (range: 2 > 4) indicated less affirming knowledge, attitudes, or behaviors and less confidence in clinical preparedness to care for SGM patients. Six Likert scale items had the option for participants to indicate they had never been asked the question. For these items, the response option “Never asked this” was descriptively analyzed and then recoded as missing before calculating mean scores for Likert scale comparisons (see Table 4, column 2).

Data analysis

Demographic data were summarized using descriptive counts and frequencies. Similar QUIRKS-Patient and QUIRKS-Provider questions with response options dichotomized to “Yes” versus “No/I don’t know” were compared using chi-square tests. Similar QUIRKS-Patient and QUIRKS-Provider questions with Likert scale response options were compared using independent samples *t*-tests. When Levene’s test of equal variances was violated, statistics for unequal variances were reported. All other items were descriptively summarized. Patient vs. provider perceptions of environmental cues and provider behaviors were examined. Among patient respondents, differences between SGM and heterosexual/cisgender (het/cis) respondents were examined.

While qualitative analysis was not a primary aim of the study, content analysis was conducted on open-text questions to share important insights from providers and patients participating in the study.

Ethical review

The George Washington University IRB approved this study (NCR213247).

Results

Quantitative

Characteristics

A convenience sample of healthcare providers (n = 107) and individuals with a history of cancer (n = 88) completed the QUIRKS-Provider and QUIRKS-Patient, respectively (see Table 2). Over 80% of participants in both patient and provider samples identified as female. Over 90% of both samples identified as cisgender. A greater percentage of SGM respondents were present in both samples than in the general population; however, the majority of respondents were still heterosexual (64% of patient and 71% of provider respondents, respectively).

Environmental cues

Providers were more likely than patients to report the existence of SGM-affirming cues in the clinic (50% vs. 14%, $p < 0.01$) as well as the ability for patients to easily document their name in use (56% vs. 40%, $p = 0.02$) and pronouns (42% vs. 28%, $p = 0.05$) (see Table 3).

Patient–provider interactions

Providers were more likely to indicate that they asked about patient values and preferences to a greater extent than patients reported being asked about values and preferences (M = 0.91, SD = 1.02 vs. M = 1.34, SD = 1.17, *p* = 0.01). Patients were statistically significantly more likely to report understanding why their provider might ask about both sex assigned at birth and gender identity (M = 0.62, SD = 0.70) compared to providers reporting that patients would understand being asked about both (M = 1.98, SD = 0.92, *p* < 0.01). Patients were also statistically significantly more likely to report being comfortable with providers asking about sex assigned at birth (M = 0.65, SD = 0.92) and gender identity (M = 0.58, SD = 0.91) compared to providers even when providers were asked this in the context of explaining the importance of asking these questions (M = 1.63, SD = 0.90). LGBT patients were more likely than het/cis patients to report having experienced discrimination in a cancer care interaction (M = 2.64, SD = 0.23 vs. M = 3.53, SD = 1.75, *p* < 0.01) (see Table 4).

SOGI data collection in clinical practice

The majority of patients reported never being asked about both sex assigned at birth *and* gender identity (69%), and a third reported never being asked about sexual orientation (33%). Nearly a third indicated never being asked about sexual health (27%) while 13% of patients reported never being asked about psychosocial health. Due to the high number of individuals who had never been asked these questions, the patient sample sizes comparing these items to provider-reported behaviors were small and varied (see Table 4).

Differences among SGM and non-SGM providers

As shown in Table 5, SGM providers had greater knowledge of SGM patient social determinants of health and cancer risks; however, only knowledge about higher smoking rates within the SGM population were statistically significantly different (M = 0.69, SD = 0.79 vs. 1.35 SD = 0.79, *p* < 0.01). SGM providers were also more likely to endorse the importance of knowing patient sexual orientation (M = 0.75, SD = 1.00 vs. M = 1.45, SD = 1.34, *p* = 0.01) and gender identity (M = 0.61, SD = 0.96 vs. M = 1.24 SD = 1.26, *p* = 0.01). SGM providers were also more likely to indicate a professional responsibility to learn about SGM patient needs (M = 0.04, SD = 0.19 vs. M = 0.46, SD = 0.73, *p* < 0.01) and champion positive system changes for SGM patients (M = 0.04, SD = 0.19 vs. M = 0.53, SD = 0.83, *p* < 0.01) compared to het/cis peers.

TABLE 5 Provider's knowledge, attitudes, and clinical preparedness in caring for LGBTQI patients.

Construct/Item	Total *N*	M (SD)	Het/ Cis *N*	M (SD)	LGBT *N*	M (SD)	*t*	*p*
Knowledge								
Everyone has implicit bias.	98	0.64 (0.80)	72	0.72 (0.86)	26	0.42 (0.58)	1.97	**0.05**
Gender is biological.^{R}	98	1.45 (1.36)	72	1.58 (1.40)	26	1.08 (1.20)	1.64	0.11
Transgender people are more likely to be rejected by their families.	98	0.81 (0.77)	72	0.83 (0.79)	26	0.73 (0.72)	.58	0.56
Many LGBTQI people experience significant trauma.	98	0.62 (0.67)	72	0.67 (0.71)	26	0.50 (0.51)	1.28	0.21
If a transgender patient wanted psychosocial support, I would know who to refer them to.	98	1.35 (1.19)	72	1.49 (1.15)	26	0.96 (1.22)	1.96	**0.05**
Sexual and gender minority people have higher smoking rates than the general population.	98	1.17 (0.84)	72	1.35 (0.79)	26	0.69 (0.79)	3.63	**<0.01**
It is impossible for transgender women who have had gender-affirming surgery to get prostate cancer. ^{R}	98	1.32 (1.22)	72	1.44 (1.22)	26	0.96 (1.18)	1.74	0.09
Transgender men are at a lower risk for cervical cancer after being on gender affirming hormonal therapy for 5 years. ^{R}	98	1.46 (0.95)	72	1.56 (0.96)	26	1.19 (0.90)	1.68	0.10
Sexual orientation is relevant when it comes to breast reconstruction preferences among breast cancer survivors.	98	1.27 (1.12)	72	1.25 (1.14)	26	1.31 (1.35)	-0.21	-0.83
Attitudes								
Because I treat all my patients the same, it is not important to know their sexual orientation. ^{R}	102	1.25 (1.29)	74	1.45 (1.34)	28	0.75 (1.00)	2.84	**0.01**
Because I treat all my patients the same, it is not important to know their gender identity. ^{R}	102	1.07 (1.21)	74	1.24 (1.26)	28	0.61 (0.96)	2.74	**0.01**
I would like more training on how to better care for LGBTQI patients.	102	0.69 (0.84)	74	0.72 (0.61)	28	0.61 (0.88)	0.58	0.56

(Continued)

TABLE 5 Continued

Construct/Item	Total *N*	M (SD)	Het/ Cis *N*	M (SD)	LGBT *N*	M (SD)	*t*	*p*
It is my professional responsibility to learn about LGBTQI patient needs.	102	0.34 (0.65)	74	0.46 (0.73)	28	0.04 (0.19)	4.63	**<0.01**
It is my professional responsibility to champion positive system changes to support LGBTQI patients.	102	0.39 (0.75)	74	0.53 (0.83)	28	0.04 (0.19)	3.09	**<0.01**
Behaviors								
I consider endogenous and exogenous hormones when managing patients' medical conditions.	95	2.03 (1.46)	69	2.09 (1.42)	26	1.88 (1.56)	0.60	0.55
If I witness people discriminating against an LGBTQI patient, I actively challenge that behavior.	103	0.73 (1.04)	75	0.83 (1.08)	28	0.46 (0.88)	1.58	0.12
If I witness people making jokes about LGBTQI people, I actively challenge that behavior.	103	0.72 (0.95)	75	0.79 (0.96)	28	0.54 (0.92)	1.19	0.24
In my practice, patients may designate any person of their choice, including an unmarried partner, as a medical decision-maker.	103	0.35 (0.78)	75	0.35 (0.81)	28	0.36 (0.68)	-0.06	0.95
I encourage my LGBTQI patients to document advance directives.	103	0.72 (1.15)	75	0.71 (1.19)	28	0.75 (1.04)	−0.17	0.87
Clinical Preparedness								
I feel clinically prepared to meet the healthcare needs of gay patients.	95	1.29 (1.03)	69	1.43 (0.99)	26	0.92 (1.06)	2.20	**0.03**
I feel clinically prepared to meet the healthcare needs of lesbian patients.	95	1.29 (1.03)	69	1.41 (0.99)	26	1.00 (1.10)	1.73	0.09
I feel clinically prepared to meet the healthcare needs of bisexual patients.	95	1.39 (1.06)	69	1.46 (1.02)	26	1.19 (1.17)	1.11	0.27
I feel clinically prepared to meet the healthcare needs of transgender patients.	95	2.01 (1.09)	69	2.12 (1.02)	26	1.73 (1.22)	1.55	0.12
I feel clinically prepared to meet the healthcare needs of intersex patients.	95	2.29 (1.10)	69	2.29 (1.11)	26	2.27 (1.08)	0.08	0.94

^{R} indicates reverse scoring. p < 0.05 = statistically significant. Scores below 2 = more affirming care. Scores over 2 = less LGBTQI-affirming care.
Bold values represent statistical significance.

SGM-identifying providers were also statistically more likely than het/cis peers to feel clinically prepared to meet the healthcare needs of gay patients (M = 0.92, SD = 1.06 vs. M = 1.43, SD = 0.99, *p* = 0.03), but this was not true for meeting the needs of lesbian, bisexual, transgender, and intersex patients. Regardless of SOGI, providers reported being less clinically prepared to meet the needs of transgender and intersex patients. Additionally, regardless of sexual orientation or gender identity, providers trended in the direction of not considering endogenous and exogenous hormone balance when managing patient medical conditions.

Qualitative

In open-ended responses, providers reported more often having experience with lesbian and gay patients and less experience with transgender patients. One provider said, "I am not aware if I have cared for any patients who identify as LGBTQI." Another provider said they had experience with same-sex partners, but were "unaware of any other patients who may have been bisexual, transgender, queer, or intersex." Another respondent indicated they had worked with SGM patients but had "no different experiences" with them. Another respondent indicated that sexual orientation did not particularly matter for cancer care: "I've had patients come in with their same-sex partner, but their sexual orientation is not usually discussed. I just assume they are significant others. Their sexual orientation didn't seem particularly relevant to the reason for their visit—chemo clearance, symptom management, etc."

Some participants indicated negative clinical scenarios with SGM patients and colleagues. One provider reported guilt and regret over an experience with a transgender patient.

I once had a Burkitt's lymphoma patient that was a transgender female [and] I felt extremely underprepared to navigate her care. There was nowhere in the EMR where her pronouns or female name was—for chemotherapy and all procedures, we were checking off of her birth name, which was extremely traumatic and emotionally damaging to her. I still hold a lot of guilt over her experience and she died with her birth name and our healthcare staff treating her as a male. I just started as a palliative care NP and I first ask patients what they want to be referred to. Sexual orientation and gender identity are frequently skipped over, just like illicit drug use, in social history screening.

Another respondent indicated comfort with lesbian, gay, and bisexual patients but challenges with remembering correct pronouns for a transgender colleague: “I have a friend/coworker that is transitioning and I know her as a man and sometimes have a hard time remembering the correct thing to say.”

When asked about reservations in working with SGM people, several respondents indicated worry about inadvertently exhibiting bias or insulting SGM patients. One respondent said, “I feel worried at times that I will not be up to date on terminology and could offend someone.” Another provider said: “I feel worried about unknowingly perpetuating harm/discrimination to my LGBTQI patients and families, so I can often be somewhat inhibited or intimidated as a result of this worry and the underlying bias informing it.” This concern was echoed by another participant who feared they would “unknowingly hurt or insult” SGM patients. Another provider indicated some concern about not knowing of any unique care needs of SGM patients: “I would just treat them like other patients, but I’m not aware of anything different that I should be assessing for, so in that regard, I do have some reservations.”

Providers indicated a range of comfort levels in working with SGM patients. One participant indicated “reservations … due to my lack of knowledge and training about unique needs of LGBTQI patients.” Another respondent framed this differently, indicating: “No reservations, but rather need for ongoing training in caring for the LGBTQIA population in the cancer setting.” A third participant indicated: “I don’t believe I have reservations. If clinically beyond my scope of practice, I would refer out or collaborate with another clinician.” One respondent indicated significant experience and comfort with SGM oncology patients, having “worked with other [healthcare providers] in creating cancer screening resources for people in the LGBTQI population, focusing on those that are using hormone therapy.”

Less commonly, there were respondents who indicated they would prefer not to care for SGM patients. One respondent said: “Due to my past experiences, I am not interested in working with transgender patients but have colleagues who are available and highly skilled to do so.” Another respondent indicated fear of “saying the wrong thing, because I truly don’t understand it. It feels so unnatural to me.”

Overall, there was a strong indication of a need for provider training. One provider indicated discomfort in “how to approach the subject of sexuality in a same-sex couple and the issues that arise when one partner’s ability to engage in sex [is affected] due to surgery or side effects of chemo/radiation.” Another respondent indicated: “I just wish for more training, knowledge, and more resources, especially for transgender patients. Managing hormone-sensitive cancers (I’m a breast cancer oncologist) in the transgender population is tricky.” Another provider said:

> I feel that I may not have adequate training to work with a transgender woman who is interested in receiving exogenous hormones. Additionally, I would like additional training in how to appropriately care for gynecological needs of transgender men in a way that is affirming and respectful.

Respondents also indicated lack of training and confusion regarding patients with intersex conditions: “I would need more training on intersex issues - who identifies as intersex, and how do their needs differ from transgender patients’ needs?”

Patient-reported open-ended feedback varied widely from a lesbian reporting experiences of healthcare discrimination and appreciation for the survey to straight respondents reporting discomfort with the survey. A lesbian living in a rural town said:

> Living in a rural evangelical town in Virginia, most or all doctors would have no idea about gender identity and sexual orientation. They all get confused when they ask me what my husband’s name is because I listed myself as married, or because I’m on her insurance the people checking me in are either confused, give looks of disgust, change their treatment of me when I tell them I have a wife … My oncologist is not from this area, so he is probably the most understanding and “friendly” to my wife. He doesn’t acknowledge she’s my wife but speaks with her and talks to both of us as a couple when discussing my health. My PCP I’m not sure gets it even when I introduce her as my wife and my wife’s PCP completely ignored and did not acknowledge I was at the appointment for my wife. He turned his back to me to just talk [ed] to her … [My wife] and I have been together over 33 years.

In contrast, other respondents voiced discomfort with the survey questions and lack of appreciation for the utility of the assessment. One patient respondent said: “I can understand and appreciate the importance of this survey; however, it is the kind of survey that would make people feel uncomfortable regardless of their gender identify or sexual orientation.” Another respondent said, “I really do not think there is a need to discuss sexuality in the primary care’s office, only with a social emotional doctor. Why is this necessary to discuss sexuality when I am more concerned with surviving, unless solutions are discussed for people having sexual issues.”

Discussion

Given the dearth of measures to assess affirming SGM oncology care, the QUIRKS companion measures were developed to use as the primary outcome of an educational intervention that aimed to improve provider competence in caring for these populations (21). Collection of SOGI data in clinical practice and research is critical to advance clinical guidelines and interventions responsive to SGM populations. However, in the context of clinical care, it would be inappropriate to provide the QUIRKS assessment only to persons a provider or front desk staff assumed was queer; therefore, the convenience sampling process sought the perceptions of all patients with a history of cancer and allowed the respondent to disclose their SOGI. The inclusion of cisgender, heterosexual persons was intentional to test the scale among diverse people in diverse settings across the U.S. for pragmatic clinical and research use. Yet, 69% of patients indicated never being asked about both sex assigned at birth *and* gender identity and nearly 60% said they had not been asked about *either* sex assigned at birth *or* gender identity. Over a third indicated they had never been asked about sexual orientation and 27% indicated they had never been asked about sexual health compared to only 13% who had never been asked about psychosocial health. Given the important implications of cancer care on sexual health of all patients regardless of sex assigned at birth, sexual orientation, or gender identity, this is a missed opportunity for quality cancer care. Statistically significantly more patient respondents indicated not having a place to indicate legal name or pronouns compared to provider reports of available welcoming cues. Only 14% of patient respondents indicated that SGM-affirming cues were present compared to 34% who noticed racially affirming cues. Reinforcing extant studies (22, 23), our study found that patients were more likely to understand the relevance of being asked about their sex, sexual orientation, and gender than providers thought they would. It is important to note that the low reporting of SGM-affirming cues could be due to lack of cues or lack of remembering cues due to lack of relevance for a primarily heterosexual sample.

The variation in provider comfort levels with caring for SGM patients and confusion regarding the needs of these heterogenous populations suggest the possibility of overestimating affirming care practices and demonstrate the need for training. Notably, SGM-identifying providers were objectively more knowledgeable of SGM patient health needs and reported being more clinically prepared to meet the needs of these patients, although this difference was only statistically significant in the case of gay patient health. This finding suggests the need for more lesbian, bisexual, transgender, and intersex providers with lived experience, as well as a critical gap in training for oncology providers when it comes to meeting the needs of these SGM subpopulations. Responding to this need, a training called Together Equitable Accessible Meaningful Care for Sexual and Gender Minority Patients (TEAM SGM) was piloted in 2021. Results from the 20-h training showed improvements to provider-initiated affirming environmental cues, provider knowledge, clinical preparedness, and clinical behaviors relevant to SGM patients (21). The same scales used for the present study were used as evaluation tools for the training. Sustained education is needed to increase the capacity of the workforce to meet the needs of SGM patients.

Our study is limited by separately recruited independent convenience samples that contributed to uneven representation. Likewise, patients and providers were not necessarily reporting experiences from the same systems of care; therefore, it should be considered exploratory and not conclusive in nature. Samples were recruited from a national listserv and professional networks of healthcare providers. Because participation was not contingent on being queer, a large percentage of respondents were het/cis. However, because of the nature of the study, self-selection bias may have led to a larger than proportionate distribution of sexual minority respondents for both samples compared to general population rates. Another limitation of convenience sampling was that no intersex, transgender male, or transgender female participants responded to the survey, although some respondents did indicate status as nonbinary or another gender; thus, results primarily represent different perceptions of care by sexual orientation. Lack of compensation for participation in the study may have unintentionally limited the diversity of the sample. For the QUIRKS-Patient, respondents were not asked about time since cancer diagnosis; thus, recall of environmental cues and affirming care could be biased and clinical environments may have changed since respondents were provided care. Strengths of our study include national recruitment for samples and results comparing patient and provider's perceptions of care.

Conclusion

This study provides early data on oncology patient and provider experiences of SGM-affirming care using independent, unrelated national samples. Based on these data, providers report having more affirming environmental cues and behaviors than patients observe. The lack of alignment between incorrect responses to objective knowledge questions and provider-reported clinical preparedness suggests the need for additional professional training specific to SGM cancer risks. The lack of consensus in open-ended feedback of patients indicates a need to tailor care to the values and preferences of each patient.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving human participants were reviewed and approved by The George Washington University IRB approved this study (NCR213247). The patients/participants provided their written informed consent to participate in this study.

Author contributions

MP-C: Conceived and designed the study. MP-C: Acquired funding, and analyzed and interpreted data. All authors: Drafted the work or reviewed it critically for important intellectual content. All authors: Provided approval for publication of the content. All authors: Agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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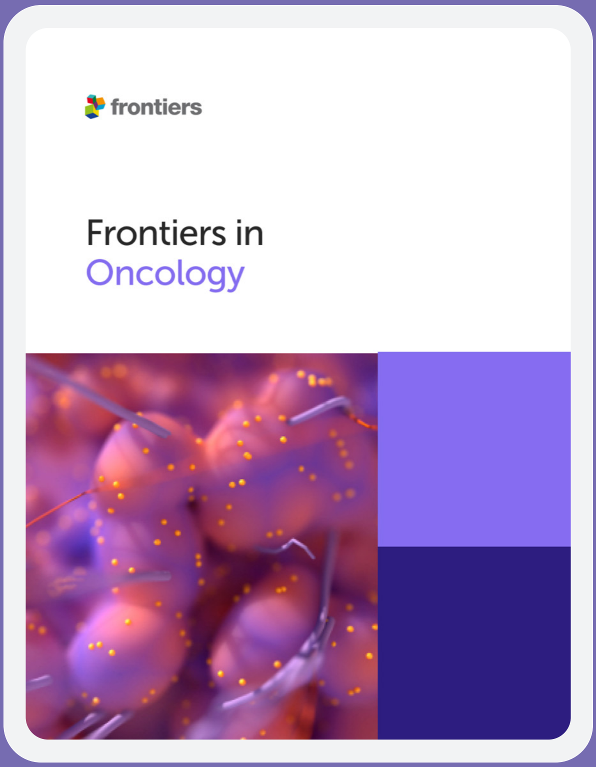

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