Published in final edited form as:

Patient Educ Couns. 2021 April; 104(4): 871-876. doi:10.1016/j.pec.2020.09.022.

Oncologists' experiences caring for LGBTQ patients with cancer: Qualitative analysis of items on a national survey

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Abstract

Objectives: Sexual and gender minority (SGM) individuals experience cancer-related health disparities and reduced quality of cancer care compared to the general population in part due to a lack of knowledgeable providers. This study explored oncologists' experiences and perspectives in providing patient-centered care for SGM individuals with cancer.

Methods: We conducted a qualitative analysis of oncologists' responses to four open-ended items on a national survey eliciting their experiences, reservations, and suggestions in treating SGM patients.

CRediT authorship contribution statement

Megan E. Sutter: Formal analysis, Writing - original draft, Writing - review & editing. Vani N. Simmons: Writing - original draft, Writing - review & editing. Steven K. Sutton: Writing - original draft, Writing - review & editing. Susan T. Vadaparampil: Writing - original draft, Writing - review & editing. Meghan Bowman-Curci: Data curation, Writing - original draft, Writing - review & editing. Matthew B. Schabath: Conceptualization, Methodology, Writing - review & editing, Supervision, Funding acquisition.

Gwendolyn P. Quinn: Conceptualization, Methodology, Formal analysis, Writing - review & editing, Supervision, Funding acquisition.

Declaration of Competing Interest

The authors report no declarations of interest.

Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:https://doi.org/10.1016/j.pec.2020.09.022.

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Results: Over 50 % of the 149 respondents of the national survey responded to at least one open-ended item. Many oncologists reported positive experiences reflecting personal growth and affirmative care practices, such as open, non-judgmental communication, compassion, competence, and supporting patients' identity. There was a notable lack of experience with transgender patients in particular. Lack of knowledge, interpersonal communication concerns (e.g., fear of offending patients), and microaggressions ("don't ask, don't tell") were identified as barriers to providing affirming care.

Conclusions: Oncologists recognize their knowledge deficits and need strategies to overcome communication barriers and microaggressions among the cancer care team to provide SGM-affirming care.

Practice implications: Curricula are needed to train oncologists in SGM healthcare needs and affirming communication skills to facilitate patient-centered care for SGM individuals with cancer.

Keywords

Sexual and gender minorities; LGBTQ; Oncology; Health care providers; Health

1. Introduction

Sexual and gender minority (SGM) populations include, but are not limited to, individuals who identify as lesbian, gay, bisexual, transgender, and/or queer (LGBTQ), or whose sexual orientation and/or gender identity or expression is not aligned with binary or categorical constructions of sexuality, gender, or sex. Recent estimates suggest 10.7 million adults (4.5%) in the United States identify as LGBTQ. [1] SGM populations experience health disparities across a variety of health-related domains, including cancer [2]. Cancer-related disparities specific to SGM populations include higher prevalence of cancer-related behavioral risk factors (e.g., cigarette smoking) and lower utilization of cancer-screening and other health services than their heterosexual and cisgender counterparts [2-5], which may contribute to poorer outcomes and higher rates of late-stage diagnoses [6].

Patient-centeredness is essential to delivering high-quality oncology care; [7,8] however, SGMs report lower satisfaction with the health care they receive, suggesting care may not be tailored to their expectations which in turn can affect their experience across the cancer care continuum [9,10]. The U.S. Department of Health and Human Services, the National Institutes of Health, and the American Society for Clinical Oncology, among other organizations recommend several strategies to reduce health disparities among SGM populations including patient education and support, provider workforce development, quality improvement, institutional policies, expanding knowledge in cultural competency and capacity building to provide quality care [11-13].

To execute the aforementioned recommendations in the oncology care setting, it is important to understand oncologists' perspectives on caring for SGM populations and their level of comfort with prior training in this context. We conducted a national survey to improve our understanding of oncologists' training needs, which included quantitative questions about their knowledge and attitudes, as well as open-ended questions on their experiences with

SGM populations as well as barriers and strategies for providing patient-centered care for SGM populations. The published quantitative results [14] indicated comfort with sexual minorities and to a lesser extent gender minority (transgender, non-binary) patients, and despite overall low knowledge, oncologists demonstrated high interest in receiving education regarding LGBTQ patients' needs. The current study presents the results from the qualitative analyses of the oncologists' responses to the open-ended questions. Together, these data can inform the development of future strategies and interventions for improving care for SGM populations in the oncology care setting.

2. Methods

The study procedures and quantitative results from this survey have been published elsewhere [14]. Briefly, a random sample of 450 oncologists from 45 NCI-Designated Comprehensive Cancer Centers (as of January 2016) were selected from the American Medical Association Physician Masterfile. Moffitt Cancer Center (Tampa, FL) was excluded because a pilot study was previously conducted among these oncologists [15]. Oncologists were mailed an anonymous paper survey in January 2016 with a prepaid self-addressed return envelope, as well as a link for a web-based version of the survey and a \$20 bill for incentive. This study was deemed exempt by the Institutional Review Board (Advarra, Columbia, MD).

2.1. Materials and methods

The survey consisted of 33 quantitative items and 4 open-ended items. The quantitative survey items assessed demographics, knowledge, attitudes, and practice behaviors regarding LGBTQ health. Respondents were asked to provide written responses to the following open-ended items: 1) "Please describe any personal experiences treating LGBTQ patients that you consider important or informative"; 2) "Please explain any reservations in treating the LBGTQ population"; 3) "What suggestions do you have for improving the cancer care of the LGBTQ population?"; and 4) "Please provide any additional comments."

2.2. Data analyses

Inductive content analysis and the constant comparison method [16] were used to analyze the data, guided by Consolidated criteria for reporting qualitative research (COREQ) [17-19]. Content analysis was used to code responses to each of the 4 open-ended questions. Open coding was used to inductively identify themes within and across each question. A theme was considered salient if it represented a meaningful pattern from the data. Using an Excel file created from all responses, and divided by the question to which it pertained, two coders (MS, GQ) reviewed all responses and generated a list of potential codes, noting the strength (e.g., the majority, a few). Codes were refined via comparison and discussion, and re-organized until consensus was reached. Refinement was repeated until coding discrepancies were resolved and no new codes emerged (i.e., thematic saturation). The level of agreement between the two coders was .90 (kappa coefficient) [20]. Results are shown by key themes and exemplary quotes to characterize each theme.

3. Results

Among the 149 survey respondents, 86 (58 %) provided written responses to at least one open-ended item. Among these 86, the average age was 46.4 years of age (SD = 9.0) and 19.9 years (SD = 9.7) post-medical school graduation. The majority self-identified as male (64.0 %), White (64.0 %), non-Hispanic (88.4 %), heterosexual (91.9 %), medical oncologist (43.0 %), and primarily treating adult patients (ages 40–64, 84.9 %). Using U.S. census regions [21], the most frequently represented regions were Pacific (18.6 %), East North Central (16.3 %), and West North Central (10.5 %); and the least frequently represented regions were West South Central (9.3 %), East South Central (4.7 %), and South Atlantic (1.2 %). Over half (57.0 %) reported that between 0–5% of their patients identified as LGBTQ. About three-in-five (62.5 %) reported they did not have a family member who identified as LGBTQ.

Four overarching themes emerged including *experiences*, *reservations*, *suggestions for improving cancer care*, *and microaggressions*.

3.1. Experiences with LGBTQ patients with Cancer

3.1.1. Positive experiences—Many of the experiences described by oncologists indicated they had positive experiences with sexual and/or gender minority patients. In their descriptions of their experiences, several respondents highlighted the importance of interpersonal aspects of LGBTQ-affirming care, such as "open honest communication" and "open nonjudgmental treatment." A few positive experiences reflected a growing experience for the oncologists:

"Lesbian AYA [adolescent and young adult] [patient] with congenital HIV and lymphoma [showed me the] importance of establishing open/honest/non-judgmental relationship without reservation."

"I am caring for a patient who began the public transition from male to female and I have learned much from this patient's experience in the context of greater possibility of transgender persons."

A few oncologists described the involvement of interdisciplinary team members facilitated a positive patient experience, such as social workers and gender specialists. Particularly for transgender adolescent patients, one oncologist noted having expertise from their gender dysphoria clinic was "*invaluable in assisting ... in the care of my patients.*" Other oncologists described the involvement of social workers in identifying unique needs of their patients.

3.1.2. Negative experiences—Oncologists described some negative experiences that reflected psychosocial needs on behalf of the patient, as well as institutional issues related to care coordination. For example, some noted the presence of family conflict and emphasized the importance of the support system in cancer care. In addition, room assignment was raised as a challenge for transgender patients, women in particular.

3.1.3. Ambivalent experiences—Several oncologists stated that they had "no issues" or "unusual experiences" treating LGBTQ patients. It is possible that when physicians claim to have experience with LGBTQ patients with comments such as: "no conflicts" or "no known negative patient experiences reported," that may reflect either a positive outcome, or a lack of awareness on behalf of the clinician.

3.1.4. Lack of experience—Several oncologists noted their lack of experience in general, but also specifically with transgender patients.

"I am more comfortable/experienced with LGB. I have no experience with T,Q [transgender/queer] and would value education. I would approach very openly/nonjudgmental but anticipate the need for more knowledge."

"Have had/have several LGB [patients]; have not (yet) had transgender patients."

Some oncologists also noted along with their lack of experience that they "do not routinely ask about sexual orientation, identity, etc."

3.2. Reservations in treating LGBTQ patients

Several themes emerged when oncologists were asked to reflect on any reservations in treating LGBTQ patients, including patient-provider communication and lack of knowledge. Overall, the majority of oncologists indicated that they had "no reservations" with regard to caring for LGBTQ patients, largely reflecting willingness to provide care but lack of skills and information to do so.

3.2.1. Patient-provider communication barriers—A few oncologists noted patient perceptions and interpersonal communication as a potential barrier to treating LGBTQ patients. They reported concerns that patients would not be comfortable to be "completely open" with them, thereby "creating an interpersonal barrier." This concern for one oncologist was centered around their own identity as a "'straight' physician" and questioned whether they would be "viewed as non-sympathetic." Additionally, some oncologists reported fear of offending someone by using inappropriate language, and one highlighted there is a balance between asking personal information due to need versus curiosity.

"I just want to feel comfortable using appropriate words and being able to engage and connect as I need to. Also to not ask information that isn't relevant to the issue at hand. To suppress my curiosity in other words given the power dynamic in the relationship."

3.2.2. Knowledge/information-related barriers—Several oncologists noted that while they did not have reservations about treating LGBTQ patients, they noted their own lack of knowledge and/or experience as a barrier.

"I have none [reservations] however my education as to their medical needs/differences is sorely lacking."

Specifically, a lack of knowledge and understanding of "transgender patient needs [and] risks" was noted by several oncologists.

3.3. Suggestions for improving cancer care

3.3.1. Information-related—Oncologists were asked for suggestions to improve cancer care for LGBTQ patients, and the majority of responses related to the need for more information. Many oncologists suggested training/education for "unique aspects of [disease] and care." One oncologist emphasized education for all providers and "not just physicians."

Some specifically cited their own lack of knowledge as evidence for this need:

"Education programs would be helpful. Based on my answers to the questions posed in the survey, I do not know the answers to many of the issues raised."

Importantly, education is needed around more than just awareness of LGBTQ patients' unique medical needs, but also "why" these populations have unique needs, as one oncologist noted. Education on social determinants of health, such as "bias," "access" and "barriers to care for the LGBTQ population" were also noted by a few oncologists.

While some oncologists suggested education within their own institution, others highlighted the difficulty of making this education mandatory. One limitation presented was time:

"Uptake of additional training by health providers will be limited ... I have a hardenough time keeping up on the medical literature."

Another oncologist suggested providing free continuing medical education credits to facilitate implementation of trainings. Despite this need and interest in education, it was noted that other important mandatory and necessary cultural sensitivity trainings would take precedence over LGBTQ health training:

"Mandatory education is tricky as physicians and staff have many mandatory obligations and this would add another. At our institution we have had issues with cultural sensitivity in regards to underrepresented racial/ethnic minorities, so that would probably be the first educational priority."

Other forms of information-related suggestions included knowledge synthesis and dissemination efforts, such as "reference materials [of] special needs" and "review articles." Others suggested increasing "publicity" of educational materials through national societies such as ASCO. Guidelines for screening and treatment while on gender-affirming hormones was noted by a couple of oncologists. This highlighted a lack of evidence and a suggestion for "more studies" and "more data" regarding hormones during and post-cancer treatment as one oncologist describes their experience treating an adolescent patient with leukemia:

"We do have a clinic for LGBTQ youth that I was able to consult but there was little to no data on hormonal therapy post cancer."

3.3.2. Providing affirming care—Several suggestions included patient-centered methods of communicating affirmative care such as "*providing non-judgmental environment for medical oncology care*" and "*acceptance*." A couple of comments emphasized not denying patients equitable care:

"Treat them [and not] discriminate [against] them."

Another important aspect of providing affirming care is inquiring about patients' sexual orientation and gender identity (SOGI), and subsequent documentation and use this information in the provision of care. Several oncologists noted that having SOGI information on intake forms would facilitate better care and improve discussions with their patients.

"Improving our intake forms and becoming more informed about their specific needs."

"Being open to discussing sexual identity in the beginning is something we don't always do.

3.4. Microaggressions

An emergent theme was oncologists perpetuating or describing a situation that involved microaggressions. When describing their experiences, some oncologists revealed their lack of understanding of the importance of knowing gender identity, many stated that they provide the same care regardless of identity.

"Providing health care the same to LGBTQ population as any other group."

Some oncologists explicitly stated they do not ask about sexual orientation and/or gender identity.

"I am trying to treat them on original gender. Do not ask. Do not tell."

"I have very little experience treating this population of patients, and do not routinely ask about sexual orientation, identity, etc."

A few oncologists noted SGM identity was only relevant if patients had a Hepatitis C or HIV infection.

"Only if they are Hep-C or HIV and they do not communicate it."

"HIV status knowledge is important to treatment decision making but not [patients'] sexual orientation or gender identification in my specific practice."

One oncologist described their direct observation of another faculty member using transphobic language and the difficulty of educating others.

"I was recently consulted on the inpatient side on an M-to-F transgender patient who had developed [X], and one of the other consult service faculty members referred to the patient as [transphobic slur]. I found this problematic and politely pointed this out. The other faculty member laughed, and didn't quite think there was anything wrong with the use of an insensitive pronoun to describe someone who clearly identified as female."

When reflecting on reservations in treating LGBTQ patients, the conflict of personal beliefs was raised. One oncologist explicitly stated their religious-based prejudice toward the LGBTQ community.

"No specific reservations but I strongly disagree with aspects of the LGBTQ community based on personal preferences and religious beliefs."

Another oncologist expressed their hesitancy to be listed as an LGBTQ friendly provider for fear of making other patients uncomfortable and then avoid seeking care with them. They attributed this to their patient population being from rural communities in a conservative state.

3.5. Additional analyses

As suggested by an anonymous reviewer, we evaluated the cooccurrence of thematic codes including experiences, LGBTQ affirmative suggestions, and microaggression codes. We found no overlap in codes with either positive, negative or ambivalent experiences. Next, we there were a few overlapping codes with microaggressions, demonstrating that a couple of oncologists who reported positive experiences or made affirmative statements (e.g., compassion) also revealed microaggressions such as reportedly providing the same care to all their patients or that sexual orientation and/or gender identity (SOGI) information is not relevant to their care. Finally, we examined the occurrence of themes by the number of LGBTQ patients reportedly treated per week; those who indicated they had any LGBTQ patients were more likely to report any kind of experience, and those who reported having no LGBTQ patients did not have experiences to report on.

4. Discussion and conclusion

4.1. Discussion

The goal of the current study was to identify barriers and strategies for improved cancer care for SGM populations. Over 50 % of the 149 respondents answered at least one of four openended items. Qualitative analysis of the written comments revealed several themes that shed light on affirming care practices as well as gaps in knowledge and communication skills. The majority of the sample reported generally positive experiences in treating LGB patients, although there was a noted lack of experience with transgender patients. Our findings also revealed other barriers to patient-centered care including lack of knowledge, interpersonal communication concerns (e.g., fear of offending patients), and microaggressions (e.g., "don't ask, don't tell"). This study reflects an extension of our quantitative survey assessing oncologists' knowledge, attitudes, and practice behaviors related to working with LGBTQ patients. [15] Similar to the quantitative study, greater discomfort and lack of knowledge was expressed for treating transgender patients.

Oncologists described different facets of providing patient-centered and LGBTQ-affirming care, such as listening to patients' experiences and understanding the importance of open, honest, and nonjudgmental communication in order to make patients comfortable. Some oncologists highlighted the importance of knowing their patients' sexual orientation and gender identity, such as providing support for their partner, knowing their sex assigned at birth for medical reasons, and knowing their gender and pronouns to affirm their identity and form a therapeutic relationship. These affirming practices are consistent with characteristics that are important to LGBTQ patients, such as having an educated provider who listens, treats them with respect and free of judgements, and honors their individual identity. [22]

Oncologists also noted patient perceptions and interpersonal communication as a potential barrier to treating LGBTQ patients, specifically the patient not feeling comfortable to disclose SOGI information. These findings are consistent with themes identified in a similar survey conducted at one cancer center in the Northeast region of the U.S. that identified healthcare provider and patients' reciprocal discomfort in discussing disclosure in both fear of offending patients in asking SOGI information as well as uncertainty if patients would be comfortable disclosing to them. [23] Given that LGBTQ patients are most likely to receive their cancer diagnosis from someone who is unaware of their identity [24], providers should create this opportunity and establish rapport to encourage patient disclosure. Creating safe spaces that make patients aware the clinic and/or provider is welcoming to LGBTQ populations could help build rapport with patients even before starting the discussion. Some strategies include providers and staff wearing affirming accessories (e.g., rainbow/pride or pronoun pin), posting LGBTQ pride flags or affirming posters in waiting areas, and having patient education materials that include LGBTQ individuals [22]. However, beyond such symbols/signage, it is important that all staff receive training in LGBTQ healthcare.

Indeed, many respondents were forthcoming in their lack of knowledge and consistently noted a desire for more education, further supporting the need for development for curriculum to train oncologists on cancer disparities and communication with LGBTQ patients. Currently a few national programs deliver provider training such as those offered by the Fenway Institute and the National LGBT Health Foundation. However, most existing trainings are not tailored to the specific needs of oncology patients. Recently, a web-based training was developed for oncologiststhe Curriculum for Oncologists on LGBT populations to Optimize Relevance and Skills (COLORS) training. [25] The COLORS training includes four 30-minute modules that focus on LGBT basics, inclusive environments, oncology care, and cancer survivorship, and has demonstrated preliminary efficacy for improving knowledge, attitudes, and clinical practices among oncologists [26]. Additionally, beyond provider-based education, respondents also recognized a need for clinic/system-level approaches such as standard collection of patients' SOGI information. This approach may serve to reduce patient and provider barriers related to asking about and/or disclosing SOGI related information as well as facilitate communication.

Survey respondents also noted that LGBTQ trainings should extend beyond oncologists to include other members of the healthcare team who also have frequent interactions with patients, such as allied health professionals. Online training programs, such as the Educating Nurses about Reproductive Issues in Cancer Healthcare (ENRICH) that focus on other healthcare team members, have proven to be effective and have a broader reach than oncologist-only trainings because of the low ratio of oncologists to allied health professionals in the oncology workforce. [27]

A theme relating to microaggressions emerged in both direct and indirect ways. Similar to a study among clinicians in rural and Appalachian Tennessee that identified themes related to microaggressions, [28] many oncologists demonstrated *microinvalidations* – a form of microaggression in which verbal or nonverbal communications negate the thoughts, feelings, or existence of LGBTQ individuals – through stating they treat all patients the same. Several oncologists noted that they communicate their compassion and competence regardless of

patient characteristics – and while this is likely a well-intended comment, it ignores unique aspects of care for LGBTQ patients. Many respondents stated that they did not need to know not sexual orientation or gender identity as their clinical care did not change based on these characteristics (including a couple of oncologists who stated that only HIV status was relevant), they have no LGBTQ patients, and that they don't routinely ask for patients' SOGI information. This lack of inquiry about SOGI and assumptions about patients' identity may unwittingly foster an unwelcoming environment and will not likely encourage patients to disclose, which may explain why these physicians believe they don't have any LGBTQ patients. With microinvalidations, oncologists perpetuate erasure of personal identities, reinforce long-standing stigma such as the conflation of HIV with LGBTQ health, and demonstrate a lack of understanding of the importance of non-medical aspects of knowing SOGI information. Curricula should incorporate information on social determinants of health and the importance of psychosocial health to cancer care in order to illustrate to clinicians why they need to know patients' SOGI information in addition to any unique medical needs among LGBTQ people with cancer.

Oncology clinicians may not be aware of what constitutes a microaggression or may feel disempowered when they observe microaggressions. One respondent indicated reluctance to be listed as an LGBTQ friendly provider for fear of a negative reaction on behalf of their conservative patients. Invisibility of modern biases, fear of retaliation and lack of self-efficacy are barriers to combating microaggressions. [29] Interventions to educate oncology clinicians should incorporate strategies to overcome these barriers, such as improving skills to call attention to microaggressions and self-efficacy to disarm microaggressions in receptive ways [29].

4.1.1. Limitations and future directions—Despite several methodological strengths, this study is not without limitations. The findings represent perspectives of oncologists at NCI-Designated Comprehensive Cancer Centers and may not be generalizable to other healthcare providers in other academic and community settings. Future research should sample from other cancer care delivery settings. It would be important to understand these results within the context of affirmative policies in the provision of care by region. Unfortunately, we are unable to link this type of information to our data specifically. Future research should consider examining responses in relation to policies of the cancer center as well as whether or not the cancer center has Healthcare Quality Index designation. [30] Given the national representation from most regions of the U.S., this study extends the findings from a similar study limited to one NCI-Designated Comprehensive Cancer Center in the Northeast [23]. Also, not all respondents who completed the quantitative survey provided qualitative responses. As such, this may represent a form of selection bias. It is possible that oncologists who did not respond had more negative attitudes toward LGBTQ populations or are disinterested in the topic, presenting a challenge to disseminating educational information in the future. We received a mixture of positive and negative sentiments, but this does not eliminate the possibility of bias. Future research should employ methods to collect implicit or objective measures of bias to provide more breadth and depth to understanding.

4.2. Conclusion

This study examined oncologists' open-ended responses in a national survey to enhance our understanding of their experiences, barriers, and suggestions in providing patient-centered care for LGBTQ individuals with cancer. Cross-cutting themes included approaches to LGBTQ-affirming care such as compassionate, open and nonjudgmental communication, and overcoming lack of knowledge and bias. These findings highlight a need for a curriculum to train oncologists (e.g., COLORS training [26]) and other allied health professionals in LGBTQ healthcare needs and affirming communication skills. In addition to education, future research should identify strategies to overcome deep-seated prejudice and structural inequities that perpetuate LGBTQ cancer health and healthcare disparities.

4.3. Practice implications

The majority of oncologists have had positive experiences in treating LGB patients but lacked experience with transgender patients with cancer. Barriers to the provision of patient-centered care included lack of knowledge, fear of offending patients, and a "don't ask, don't tell" approach. These findings highlight a need for a curriculum to train oncologists and other allied health professionals in LGBTQ healthcare needs and affirming communication skills. Results suggest oncologists want additional training in the care of LGBTQ patients with cancer. Allied health oncology professionals may also benefit from training, which would also help ensure all care team members can coordinate the most knowledgeable and competent care for LGBTQ patients with cancer.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgements

Dr. Sutter's effort is supported by the Agency for Healthcare Research and Quality Award Number T32HS026120. The content is solely the responsibility of the authors and does not necessarily represent the views of the AHRQ.

Funding

This study was funded by a Miles for Moffitt Milestone Award (Awarded to Drs. Quinn and Schabath) from the H. Lee Moffitt Cancer and Research Institute. This work was also supported, in part, by a Cancer Center Support Grant at the H. Lee Moffitt Cancer Center & Research Institute (grant number P30-CA76292), an NCI-Designated Comprehensive Cancer Center.

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