clinical reviews

What Oncologists Should Know About Treating Sexual and Gender Minority Patients With Cancer

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abstract

Sexual and gender minority (SGM) individuals encompass a broad spectrum of sexual orientations and gender identities. Although SGM is a research term, this population is often known as lesbian, gay, bisexual, transgender, queer (LGBTQ). Typically, LGB refers to sexual orientation, T refers to gender identity, and Q may refer to either. Although each group is distinct, they share the common bond of experiencing health disparities that may be caused, in part, by stigma and discrimination, as well as by the oncology provider's lack of knowledge and, therefore, lack of comfort in treating this population. One challenge in improving the quality of care for SGM patients with cancer is the lack of collection of sexual orientation and gender identity (SOGI) data in the medical record. Furthermore, national studies suggest that many oncologists are unsure of what to do with this information, even when it is collected, and some are uncertain as to why they would need to know the SOGI of their patients. This clinical review offers insight into the health disparities experienced by SGM individuals and strategies for improving the clinical encounter and creating a welcoming environment.

JCO Oncol Pract 16:309-316. © 2020 by American Society of Clinical Oncology

BACKGROUND

Sexual and gender minority (SGM) individuals are those who identify as, but are not limited to, lesbian, gay, bisexual, pansexual, asexual, transgender, queer, genderfluid, nonbinary, gender-diverse, and gender nonconforming, or whose sexual orientation, gender identity, and/or expression are not limited to binary constructs.[1] National polling and research studies have reported that 1.2% to 12% of the population in the United States identifies as SGM or lesbian, gay, bisexual, transgender, queer (LGBTQ).[2-4] The American Cancer Society has estimated that in 2020, 1.8 million people in the United States will be newly diagnosed with cancer and 606,520 people will die as a result of cancer.[5] Thus, it is expected that between 21,600 and 216,000 SGM people will be newly diagnosed with cancer, and approximately 2,782 to 7,278 SGM people will die as a result of cancer in 2020.

SGM populations are medically underserved and experience health disparities; a growing body of evidence has demonstrated an increased risk of some cancers.[1] For example, lesbian women may have increased breast cancer risk because of higher body mass index, lower likelihood of pregnancy before the age of 30 years, higher rates of nulliparity, and decreased contraceptive use.[6] Higher rates of alcohol use among gay men and bisexual women compared with heterosexual men and women confers increased risk of breast and liver cancers.[1] Black sexual minority women have been highly underrepresented in research regarding breast cancer risk factors, and key conclusions are not fully applicable in this population.[7] People who have receptive anal sex have higher rates of persistent human papillomavirus infection and thus a greater incidence of anal cancer.[1] Chronic stress caused by increased rates of persistent trauma (ie, allostatic load) may also predispose the SGM populations to cancer.[8-10] SGM populations are also less likely to access cancer screening and prevention, possibly because of perceived discrimination and other barriers. The combination of increased risks, decreased screening, and minority stress may increase cancer in these communities and worsen outcomes.[11] Cancer disparities among SGM populations are not caused by sexual orientation and gender identity (SOGI), but instead by exposure to interpersonal stressors and structural barriers that precipitate increased risk behaviors that put all humans at risk, including those who identify as heterosexual or cisgender.[1]

SGM people with cancer experience substantial health disparities after definitive treatment, including poor quality-life outcomes.[12] SGM people with a history of cancer report greater distress, relationship difficulties, substance abuse, worse overall health, lower quality of life, and less satisfaction with their cancer care/treatment compared with their heterosexual and/or cisgender counterparts.[13-15] Some SGM people with

ASSOCIATED CONTENT

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Accepted on April 6, 2020 and published at ascopubs.org/journal/op on June 10, 2020: DOI https://doi.org/10.1200/OP.20.00036

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cancer may not discuss their SOGI information with their clinicians for fear of discrimination, even when that information is relevant to their care. Oncology clinicians may also feel uncomfortable and/or unprepared to discuss SOGI, which may inhibit SGM people with cancer from including their partner and/or family of choice in their cancer care and diminish rapport. In sum, SGM patients have unique cancer care needs that remain unaddressed.[16]

This article presents practice-based recommendations and commentary to address SGM patients' cancer care needs. First, we describe strategies for oncologists to improve cultural humility related to SOGI. We then review the significance of SOGI data collection. Finally, we describe specific skills and practices oncologists and institutions should sharpen to improve their provision of care to SGM people.

STRATEGIES TO IMPROVE CULTURAL HUMILITY FOR THE CARE OF SGM PATIENTS WITH CANCER

ASCO is committed to addressing the needs of SGM people.[12] The majority of oncologists in institutional and national surveys reported not feeling knowledgeable regarding SGM health and feeling uncomfortable caring for SGM patients primarily because of this lack of knowledge.[17-19] Seventy percent of 149 oncologists surveyed at National Cancer Institute–designated cancer centers reported interest in education on SGM health needs.[19,20] Medical school curricula on SGM health are sparse, and even less didactic content is included specific to oncology.[21] SGM patients often report feeling stigmatized in health care settings.[22] "Othering," described as a process of identifying those thought to be different from oneself, can reinforce and perpetuate the power dynamics that oppress SGM individuals.[23] Advancing clinician knowledge may function to improve health care access for SGM patients. Multiple strategies may be effective, and we recommend that all clinicians become involved in strengthening traditional curricula in the medical training associated with their institutions. In addition, engaging in the practice of cultural humility (a continuous process of self-reflection aimed at maintaining a respectful, unpresuming, and open-minded perspective toward others' valued cultural identities and experiences) can improve care for all patients.[24] Cultural humility is distinct from "cultural competence," which emphasizes knowledge acquisition about the other person's culture and prioritizes the comfort of those in positions of power. In contrast, the process of cultural humility involves committing to lifelong "evaluation and self-critique...to redressing the power imbalances in the patient-physician dynamic, and to developing mutually beneficial and non-paternalistic clinical and advocacy partnerships with communities…".[24,25(p118)] Clinicians asking patients which name and pronouns should be used and refraining from using gendered, heteronormative language to ask about partners and spouses are examples of displaying cultural humility. We further address cultural humility later in the text.

COLLECTING SOGI DATA

A substantial hurdle to addressing health disparities for SGM people with cancer is the lack of data regarding cancer risks, prevalence, treatment, and outcomes for these populations. Data are currently unavailable because individual oncologists, cancer centers, and most population-based surveys do not routinely collect SOGI information.[1] Yet these data are essential to the development of prevention and treatment interventions to decrease disparities and improve outcomes for SGM people with cancer.[26,27] When clinicians inquire about SOGI data, they also communicate to patients that they are aware of SGM populations. Knowledge of SOGI data may, in some clinical scenarios, also inform and improve shared clinical decision making. We recommend that all oncology clinicians collect SOGI data during each new medical encounter.

Controversy remains regarding the optimal way to ask about gender identity. A 2-step process for querying gender identity in the health care setting has been recommended by researchers and institutions.[27-32] This process includes asking (1) gender (eg, man, woman, nonbinary) and (2) sex assigned at birth (eg, male, female, intersex). However, transgender individuals have expressed concerns that questions regarding sex assignment are sensitive and patients may not answer them.[27] Patients may wish to provide information on sexual orientation and gender, which aligns with their identity, but sex assigned-at-birth questions can be stigmatizing by asking people to conform to cisgender expectations rather than affirming their identities. Currently, a widely used electronic health record system software, EPIC, uses the following questions to collect SOGI data: "What is your sexual orientation?" and "Is your gender identity different from your sex assigned at birth?" These questions may be a preferred strategy over queries that include having to state "sex assigned at birth." Should clinicians need more information regarding anatomy, hormone levels, or name and pronouns, we recommend that these questions be asked separately as needed.[31]

SKILL BUILDING

SGM individuals want clinicians to be comfortable with them, but this expectation is often unmet[21,33,34] with SGM patients reporting verbal harassment, refusal of touch, and denials of care.[34,35] Oncology clinicians can increase their comfort in treating SGM patients by engaging in SGM-focused stigma-reduction strategies, including attending lectures on stigma and SGM health, skills-building workshops, and SGM patient panel discussions in which clinicians may ask questions.[36] Online training modalities may increase confidence and reduce uncertainty during interactions with SGM patients. Clinicians can also promote

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policy and structural changes at their institutions, as described later in the text.

One area of uncertainty for clinicians is how to address patients. Transgender and nonbinary patients with and without cancer describe clinicians using the wrong name or pronouns for them or their support networks. Clinicians may introduce themselves with their name and pronouns and ask the patient, "What name would you like to be called?" and "What are your pronouns?" Names and pronouns are important markers of identity[33,34]; asking for and consistently using them correctly are essential to treating patients with respect and dignity.[37] Furthermore, if a mistake is made, the clinician can briefly apologize and use the correct name/pronouns in the next sentence.[38] In addition, clinicians can avoid using gendered language in regard to illness (eg, generally, this is a disease of young women) or citing gendered statistics.

SGM patients receive more effective care when members of their support networks are included.[33] We recommend that clinicians ask about patients' support networks using gender-neutral language. Some examples are as follows: "Who do you have with you today?" and "How are you related?" or "Is there anyone who supports you emotionally, and if so, who?" Using open-ended questions like these will assist clinicians in avoiding cisgender or heterosexual assumptions that harm patient-clinician communication, and instead demonstrates clinicians' inclusion of SGM people and relationships without shaming or othering them.[7]

Shared decision making is vital to quality health care.[39-44] SGM patients have historically experienced paternalism in health care, such as conversion therapy[39-48] and gatekeeping gender-affirming care with stipulations for psychotherapy before interventions could be provided.[49] In the setting of oncology therapy, clinicians may make recommendations and treatment plans that are shaped by patriarchal, heterosexist, and/or cissexist ideologies. For example, patients may be pushed toward breast implants after mastectomy when this may not be what they want.[50] Regardless of patients' demographics, we recommend asking about patients' surgical needs and preferences and centering their priorities before making recommendations.

Clinicians may struggle with recommendations regarding the continuation or discontinuation of hormone therapy for transgender or nonbinary patients during specific types of oncologic treatment. No data exist to suggest that hormone therapy increases cancer risk or worsens cancer outcomes. Numerous studies have not found a definitive increased risk of cancer in transgender or nonbinary people receiving hormone therapy.[1,51-58] Prevalence studies have noted an increased percentage of infection-related cancers among transgender people; these are likely secondary to social determinants of health, rather than a result of hormone therapy.[59,60] Given the lack of definitive data regarding the optimal timing of surgical interventions for transition or the risks of continuing hormone therapy in the context of cancer treatment, thoughtful conversations must be undertaken with patients regarding their priorities and preferences. These conversations must carefully balance the known benefits of hormone therapy and surgeries with the unknown risks in the oncologic context.[61-64]

FERTILITY AND SEXUAL HEALTH

All patients of reproductive age should be informed about the potential impact of prospective cancer treatments on their future fertility. ASCO guidelines recommend informing all patients, regardless of risk, about fertility preservation options and the possibility of referral to reproductive health specialists.[65] The National Comprehensive Cancer Network guidelines state, "Fertility preservation as well as sexual health and function should be an essential part in the management of adolescents and young adults with cancer who are at any risk for infertility due to cancer treatments,"[66(p71)] reflecting an important expansion to emphasize the broader definition of reproductive health beyond fertility to include sexual health and function.

Clinicians should not assume that SGM patients are less interested than cisgender and/or heterosexual patients in fertility preservation. Conversely, the oncologist's obligation is merely to provide information and referrals. Some SGM patients will be interested in a referral and some will not, and the same is true of cisgender and heterosexual patients.[67]

Talking about fertility loss or uncertainty may be similar with SGM people and cisgender, heterosexual people. However, in some cases, the conversations may differ. For example, transgender and other SGM people may have specific ways they would like clinicians to refer to their anatomy, and as such, it is important to ask all patients how to refer to their body parts. Reminding individuals that stored gametes can be used in a variety of ways (eg, stored oocytes and sperm can be used with a gestational carrier to create a genetically related child) may also be relevant. Clinicians may improve their ability to care for SGM patients by familiarizing themselves with fertility preservation options that are relevant to SGM people.

The financial aspects of fertility preservation can be limiting for anyone.[68,69] Clinicians should know whether the state in which they practice mandates fertility preservation coverage for patients receiving gonadotoxic treatment because this information will be essential for patients who may otherwise struggle to afford the high costs often associated with preservation and assisted reproductive technologies. As of January 2020, 8 states (California, Connecticut, Delaware, Illinois, Maryland, New Jersey, New York, and Rhode Island) have passed mandates requiring insurance coverage for fertility preservation for patients facing iatrogenic infertility.[70]

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CREATING WELCOMING ENVIRONMENTS

The physical environment in oncology waiting areas, examination rooms, and inpatient rooms commonly indicates whether a practice or institution is welcoming to SGM populations. Visual cues include SGM-affirming stickers, pronoun pins, pride flags, posters, SGM-inclusive patient education materials, and clearly displayed nondiscrimination policies.[71,72] These visual cues of SGM inclusion facilitate disclosure of SOGI information, which is vital to understanding patients' support needs. SGM-inclusive patient education materials may also facilitate diagnosing and treating cancer in a timely manner (Table 1).[73]

For transgender and nonbinary patients, aspects of the structural environment that signal safety and inclusion include gender-neutral bathrooms and waiting areas, and gender-affirming rooming policies. For example, transgender men and nonbinary individuals diagnosed with breast and/or gynecologic cancers report feeling unwelcome in oncology practices and cancer support groups because of the feminine-gendered expectations of the settings.[74] Cisgender men may also feel similar in breast cancer practices. If an in-patient center has shared rooms, transgender and nonbinary patients should either be prioritized for an available private room or be assigned a shared room on the basis of their gender preference. If there are objections by a cisgender roommate, the facility policy and procedures should indicate that the roommate with objections be removed from the room, not the transgender or nonbinary patient.[75] Oncology care centers should develop explicit policies and procedures for practice and support staff (eg, security officers) to support patients in accessing bathrooms and to enforce rooming policies that protect SGM patients against discrimination or victimization.[60,61]

System-level factors are also important in creating a SGM-affirming clinical environment. The mission statement, policies, patient bill of rights, and intake forms should explicitly indicate protections so that SGM populations can receive care without discrimination and have their support network included.[72,76] Including SGM individuals in health care organizations' mission statements describing their commitment to diversity is important.[72] Healthcare leadership, administration, and clinicians can refer to the Human Rights Campaign Health Equality Index (HEI), a standard for hospitals and health care facilities to be considered leaders in SGM health care equality through evaluation of nondiscrimination policies and staff training, patient services and support, employee benefits and policies, and patient and community engagement.[77]

Intake forms should ask patients about their SOGI, pronouns, and name. Patients may prefer to describe these nonverbally in online or written form, but individual preferences vary, and both nonverbal and verbal options should be presented.[78] Patients' gender expressions may not align with staff or oncologists' expectations on the basis of the information specified on the patients' intake forms. For example, women who were assigned male at birth may choose the option "woman" for their gender identity or "female" for sex assigned at birth. It is important to understand that patients' identity markers do not indicate which organs they have, and clinicians should use an organ inventory as needed to provide the most relevant care and to make appropriate referrals. If patients desire, their current name, pronouns, and an organ inventory should be integrated into the electronic medical record, if possible, to easily coordinate care across departments and to prevent patients from having to disclose private information at every encounter.[37] Patients' identification bracelets should indicate their current name. Insurance may deny benefits for

TABLE 1. Guidelines for Providing Culturally Humble Care for SGM Patients With Cancer

1. Educate yourself on the impact of stigma and marginalization on minority groups.
2. Ensure your institutional policies are inclusive and respectful of SGM patients.
3. Include sexual orientation, gender identity, preferred name, and pronouns on intake forms.
4. Create welcoming environments that may include: gender-neutral bathrooms, health literature that is inclusive of SGM populations, pronoun pins, and rainbow flags.
5. Rename any gendered spaces such as "women's breast practice" or "men's prostate center."
6. Reduce use of pink and blue to gender clothing or other aspects of the clinical encounter.
7. Ask patients, "What is your preferred name?"
8. Ask patients what pronouns they use (eg, they/them, he/him, she/her).
9. When relevant, ask patients what terms to use for their reproductive organs.
10. Do not make assumptions about the person accompanying a patient to appointments. Find out if patients have support and by whom.
11. Offer every patient of reproductive age the option to discuss fertility preservation and make referrals to reproductive specialist.
12. Ensure institutional policies are in place to enforce SGM inclusion.
13. Ensure input from local SGM populations to improve SGM inclusion.

Abbreviation: SGM, sexual and gender minority.

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TABLE 2. Resources for Additional Training and Information

Organization	Web Site
Centers for Disease Control and Prevention	https://www.cdc.gov/hiv/clinicians/transforming-health/health-care-clinicians/additional-resources.html#Protocols
National LGBT Cancer Network	https://cancer-network.org/
American Cancer Society	https://www.cancer.org/content/dam/cancer-org/cancer-control/en/booklets-flyers/lgbtq-people-with-cancer-fact-sheet.pdf
Essential Access Health	http://www.essentialaccess.org/sites/default/files/Providing-Inclusive-Care-for-LGBTQ-Patients.pdf
The Fenway Institute	https://fenwayhealth.org/
GLMA: Health Professionals Advancing LGBTQ Equality	http://www.glma.org/
Human Rights Campaign	https://www.hrc.org/explore/topic/health-and-aging
UCSF Center for Transgender Excellence	https://transcare.ucsf.edu/
WPATH	https://www.wpath.org/

Abbreviations: LGBT, lesbian, gay, bisexual, transgender; UCSF, University of California, San Francisco; WPATH, World Professional Association of Transgender Health.

medically necessary procedures when a patient's legal gender marker is changed to align with their identity, an important aspect of gender-affirmation for some people. Administration and oncology clinicians should be aware that they might need to advocate for their patient by calling the insurance company directly.

Patients often research online for an SGM-friendly and knowledgeable clinician when seeking care in a new facility. Clinicians committed to providing SGM-affirming care can indicate so on their Web site biography and sign up to be listed in a clinician directory (eg, GLMA: Health Professionals Advancing LGBT Equality or World Professional Association for Transgender Health). Health care facilities can include the following on their Web sites: HEI rating, patients' bill of rights, additional protections including nondiscrimination policies, and other information highlighting their commitment to SGM inclusion.

Before initiating new efforts to advertise as SGM inclusive, institutions should first assess their practice's readiness to provide SGM-inclusive care. Feedback from SGM patients should be elicited, and problem areas should be identified with plans made to address them. Practice clinicians and staff should be trained.

Grievance mechanisms should be put in place to support policies to address situations in which clinicians are not providing SGM-inclusive care or are discriminating against SGM people. Additional steps may be taken to review patient electronic medical records to ensure SOGI data are collected. Ideally, the use of feedback from local SGM communities would be incorporated for ongoing institutional improvement. These mechanisms would ensure that all clinicians have an impetus to change practice.

In summary, there are numerous ways to become better educated and better prepared to offer compassionate and culturally humble oncology care (Table 1). Clinicians who feel they lack SGM competencies are not alone, and guidelines and resources are available for them and their teams (Table 2). Health care is a human right. Although not all clinicians will be able to overcome their biases, they are ethically bound to do so, and should be held accountable by their individual institutions. Clinicians and administrators must consider both the WHO and the United Nations' Universal Declaration of Human Rights, which states that health care is a fundamental human right, broadly defined as "a state of complete physical, mental, and social well-being."[79(p1)-81] This is what clinicians should want for all people, regardless of their SOGI.

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SUPPORT

M.S. is a post-doctoral fellow funded by Agency for Healthcare Research and Quality Grant No. T32HS026120.

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AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST AND DATA AVAILABILITY STATEMENT

Disclosures provided by the authors and data availability statement (if applicable) are available with this article at DOI https://doi.org/10.1200/OP.20.00036.

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Manuscript writing: All authors
Final approval of manuscript: All authors
Accountable for all aspects of the work: All authors

ACKNOWLEDGMENT

The authors wish to thank Jami Claire for her input as well as Roman Ruddick and Charlie Manzano, cofounders of the Transgender Cancer Patient Project and members of a national community advisory board, for their meaningful input on this manuscript. We are appreciative of Meghan Bowman Curci's assistance with the references and formatting.

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AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

What Oncologists Should Know About Treating Sexual and Gender Minority Patients With Cancer

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No other potential conflicts of interest were reported.

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