Culturally Competent Care for Sexual and Gender Minority Patients at National Cancer Institute-Designated Comprehensive Cancer Centers

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Abstract

Purpose: This study sought to identify the policies and guidelines regarding culturally competent care of sexual and gender minority (SGM) cancer patients and survivors at National Cancer Institute (NCI)-Designated Comprehensive Cancer Centers.

Methods: This study used an in-depth interview qualitative approach. Semistructured interviews were conducted via telephone with representatives from 21 of the 45 NCI-Designated Comprehensive Cancer Centers in 2015. Verbatim transcripts were created from the audiotapes for content analysis.

Results: Two main themes were identified as follows: (1) patient-focused experiences and support and (2) organization-focused development activities. Most of the cancer centers in this study had an advisory committee to assist with SGM policies and guidelines. Despite the existence of these committees, the majority of centers did not have explicit policies, guidelines, or routine practices addressing the following issues: the collection and integration of sexual orientation and gender identity information in the medical record, gender-neutral language on patient forms, patient educational materials with SGM-specific health concerns, SGM-specific support for cancer survivors, or required SGM-specific cultural competency trainings for medical and nonmedical staff.

Conclusion: In general, the cancer centers in this study lacked institutional policies, guidelines, and practices focused on patient-centered cancer care for SGM populations. Coordinated efforts are needed to systemically improve patient-centered cancer care for these populations.

Keywords: cultural competency, oncology care, organizational change, sexuality

Introduction

SEXUAL AND GENDER MINORITY (SGM) populations experience a range of cancer-related disparities. For example, starting at young ages, sexual minorities are more likely than their heterosexual peers to engage in multiple cancer-related risk behaviors.¹ There are also some indications that sexual minority men are more likely than heterosexual men to be diagnosed with cancer in their lifetime,^{2,3} sexual minority women are affected by breast cancer at younger ages and may respond differentially to treatment compared with heterosexual women,^{4,5} and SGM cancer survivors collectively experience

more symptoms of psychological distress.⁶ Sexual minority populations also report lower satisfaction with patient-centered care and shared decision-making relating to cancer care.^{7,8} Inclusion of family or significant others in care and decision-making also differs between SGM and heterosexuals/cisgender persons, perhaps related to different expectations and needs of cancer care.⁹ In addition, many sexual minority cancer survivors experience discrimination, gaps in care, insufficient social support, and increased social isolation.¹⁰

Patient centeredness is a fundamental feature of quality healthcare and an important aspect of high-quality oncology care.^{11,12} Central to patient-centered care is a meaningful

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engagement with patients and their families by healthcare providers to coordinate treatment and survivorship plans that are considerate of an individual's medical, social, and cultural needs.¹³ To facilitate meaningful engagement, it is essential that patients are provided with opportunities to disclose their sexual orientation and gender identity (SOGI) in ways that are considerate and respectful. Systematic changes to patient education and support, provider workforce development, quality improvement, and institutional policies to reduce cancer health disparities among SGM populations have been recommended by the American Society of Clinical Oncology (ASCO).¹⁴ However, there is a dearth of information regarding the current state of organizational engagement and commitment to improving cancer care for SGM populations. This type of assessment is important as it provides a baseline understanding of organizational activities related to proposed ASCO guidelines.

The purpose of this study was to identify existing policies and guidelines at National Cancer Institute (NCI)-Designated Comprehensive Cancer Centers focused on the provision of culturally competent care for SGM cancer patients and survivors. We focused on NCI-Designated Comprehensive Cancer Centers because of the large number of patients who receive a cancer diagnosis and/or treatment at these centers nationwide, as well as their explicit focus on training oncology providers, public education, and community outreach with special attention paid to the needs of underserved populations.¹⁵

Methods

This study used an in-depth interview qualitative approach. Data were collected using cross-sectional semistructured interviews with representatives from 21 NCI-Designated Comprehensive Cancer Centers.¹⁵

Interviews were conducted over the phone using a semistructured interview guide (Table 1), audio-recorded, and verbatim transcripts created from the recordings for content analysis. The study was approved by Liberty Institutional Review Board (IRB) (now Chesapeake IRB, Columbia, MD), and a waiver of written informed consent was granted [§46.116(d)]. Verbal consent for the audiotaping of the interview and for reporting the information in aggregate form was obtained before the interview.

Study design and procedures

Participants. In 2015, the websites of all 45 NCI-Designated Comprehensive Cancer Centers were searched for contact information for a person who held a title related to "diversity." If none were found on a website, we contacted a representative from the Human Resources department and asked who would be the best person with whom to speak. Our goal was to identify participants who held the role of a diversity representative or were an employee with knowledge of diversity policy and training information for their cancer center.

Interviews. Interviews were conducted by two trained research coordinators. Coordinators established a time for the interview through e-mail or phone, and respondents called into a conference line that allowed for taping of the call. Respondents provided verbal consent for the use of audiotaping and the reporting of data in aggregate form.

Analysis

Drs. Quinn and Hudson and the research coordinators analyzed the data. Transcripts were coded for a priori themes from the interview guide (Table 1) using content analysis and the constant comparative methods in an attempt to identify emergent themes.¹⁶ A preliminary code list was created from the interview guide questions and applied to two transcripts by the four coders independently. The code list was reviewed and adjusted for discrepancies and a final code list created. Inter-rater reliability was established at 0.95.

Results

A total of 45 NCI-Designated Comprehensive Cancer Centers were contacted and we made three attempts to contact each center. Eleven did not respond to any of the three invitations, six did not participate in the scheduled interview, five stated that they did not have a diversity representative who could speak to the issues measured in this study, and two declined to participate. There was at least one cancer center representative interviewed from each of the nine U.S. Census Divisions. From the 21 completed interviews, two main themes were identified encompassing a total of 10 unique codes. These categories were (1) patient-focused experiences and support and (2) organization-focused development activities. Table 2 provides each of the 10 codes with representative quotes.

Patient-focused experiences and support

Collecting patient SOGI. At the majority of cancer centers surveyed, SOGI information is not collected routinely. Only four (19%) cancer centers distinguished current gender identity from sex assigned at birth on intake forms or in the electronic health record (EHR). Only three (14%) cancer centers collect information routinely on sexual orientation; in these cases, this information was recorded systematically in the EHR. Some representatives noted that sexual orientation was more commonly collected in clinics focusing on sexual health or HIV/AIDS. In most other cases, if SOGI information was collected, it would likely be recorded in an open-ended field—sometimes in the clinic notes—provided in the EHR but not as part of a patient's demographic information.

Gender-neutral language on forms. Only four (19%) cancer centers indicated that they used gender-neutral language and terminology on patient forms. In some cases, the diversity representatives expressed awareness and sensitivity regarding gender-neutral language and indicated that this is something their institutions are working on developing.

Preferred names and pronouns. Twelve (57%) cancer centers indicated that their institution collected preferred name or preferred gender pronoun information. The other nine (43%) representatives noted that while their centers do not collect this information routinely, they would accommodate patient preferences.

Creating a welcoming environment. All representatives reported the explicit posting of nondiscrimination policies as a way to communicate openness to SGM patients. These policies were usually available on the organizations' websites (71%), posted in common areas where patients could

TABLE 1. DIVERSITY REPRESENTATIVE INTERVIEW GUIDE

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- (1) Does your healthcare institution currently collect sexual orientation and gender identity data from patients?
 - (a) If collecting SOGI data is a current practice, can you give me the mode of this data collection?
 - (i) For example, is it a question in the patient intake form?
 - (ii) Can you provide the exact wording and/or phrasing?
 - (iii) Do you state that this disclosure is voluntary?
 - (b) Does your healthcare institution provide intake forms with gender-neutral terminology and language?
 - (c) Does your healthcare institution allow the patient to take the lead and reflect the patient's choice of language when referring to self? For example, are there options on intake forms and/or electronic medical records for preferred name or preferred gender pronoun?
 - (2) Does your healthcare institution have an advisory board or committee to advise on LGBTQ policy issues? (If yes, see below)
 - (a) Can you tell me a little more about it?
 - (i) How many members are there?
 - (ii) Are there certain qualifications for being on the board/committee?
 - (3) Does your healthcare institution have any current policies, regulations, or guidelines pertaining to the Lesbian, Gay, Bisexual, Transgender/Transsexual, Queer/Questioning (LGBTQ) population?
 - (a) If so, can you give me some examples? (Nondiscrimination policy inclusive of sexual orientation and gender identity, equal visitation policy, and patient's right to identify support person of choice, incorporate broad definition of *family* within institutional policies, etc.)
 - (b) How did these policies come to be? Are they modeled off another entity?
 - (c) When were these policies established?
 - (d) Have you come across any barriers to implementing these policies?
 - (4) Does your healthcare institution have a nondiscrimination policy that is visible and easy to locate?
 - (a) Who does the nondiscrimination policy apply to or include?
 - (5) How does your healthcare institution create a welcoming and inclusive environment for LGBTQ individuals?
 - (6) Does your healthcare institution provide inclusive educational materials, for example, materials with pictures of two women, two men, or transgender or gender-neutral individuals?
 - (a) (If the participant says "No" or "Don't know") Do you think those materials would be useful for your healthcare institution?
 - (7) Do you provide educational information and guidance for those patients with LGBTQ-specific health concerns?
 - (8) Does your healthcare institution have any policies regarding LGBTQ survivorship issues?
 - (a) Healthcare perceptions and concerns of members of the LGBTQ population, sexual issues relevant to individual orientations within the LGBTQ population
 - (9) Does your healthcare institution require and/or offer LGBTQ cultural competency training to healthcare providers?
 - (a) How often is it offered/encouraged?
 - (b) Does someone employed by your institution instruct these trainings or is an outside consultant brought in?
 - (c) Does your healthcare institution have any plans to provide cultural competency training in the future?
 - (10) Is your healthcare institution a HEI (Healthcare Equality Index) designated hospital? The Healthcare Equality Index (HEI) is the national LGBTQ benchmarking tool that evaluates healthcare facilities' policies and practices related to the equity and inclusion of their LGBTQ patients, visitors, and employees. Last year's HEI (2014) evaluated a total of 1504 healthcare facilities nationwide.
 - (a) If you would like more information on how your institution can become an HEI designated facility, you can go to www.hrc.org/campaigns/healthcare-equality-index to register your facility for review and locate and view current criteria required for the designation.
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SOGI, sexual orientation and gender identity.

read them (43%), or included in admission packets (29%). One representative mentioned taking important pieces from the policies and creating "reader-friendly" variations that could be understood better by patients. Three (14%) cancer centers distributed rainbow stickers or other similar symbols to wear on lanyards indicating that the employee (e.g., a provider or staff) had completed SGM-focused training (equivalent to Safe Zone trainings¹⁷). Overall, one-third (33%) of representatives indicated that their cancer center did not do anything specific for SGM populations, but they treated every patient equally to create a welcoming environment.

Culturally competent patient educational materials. Five (24%) representatives reported that their cancer centers

had SGM-inclusive educational materials that contained images or descriptions inclusive of SGM populations (e.g., same-sex couple). The other 16 (76%) cancer centers did not have such materials or were in the process of developing them. The majority (67%) of representatives reported not having educational materials on SGM-specific health concerns. In some institutions, inclusion of SGM-inclusive materials varied across clinics, described by one participant as, "specialized and separate." There was a perception that clinics providing care relevant to sexual health or sexual dysfunction, for example, in a urology clinic in which issues of sexuality and gender identity may be more salient to patients, would have access to SGM-specific educational materials.

TABLE 2. QUALITATIVE CODES, DEFINITIONS, AND REPRESENTATIVE QUOTES

<i>Code</i>	<i>Definition</i>	<i>Quote</i>
Patient-focused experiences and support Collecting patient SOGI	Identifies whether the institution routinely collects patient SOGI and how this information is recorded	<p>“So we have sex “assigned” at birth and we can choose female, male, decline to state, other and then we can choose gender identity now, female, male, trans f to m, trans m to f, queer/gender queer, questioning or unsure, declined to state or other.”</p> <p>“... if the patient volunteers it for orientation we have a place to chart that. For transgender status, if the patient wants it to be know, we’ll collect it, but there’s not a place yet to actually chart it like ... like you can put it in the clinic notes but there’s not a prompt for it or a click-box or anything, but we’re working on getting that.”</p> <p>“... currently we don’t have a specific field when we’re filling out, like, the patient demographics area. It is collected in some ... specifically with our [clinic name removed for confidentiality] clinic, which the majority of the patients are being treated for AIDS and HIV. So, there we’re able to indicate it within the electronic medical record but there is not currently a specific field in it.”</p>
Gender-neutral language on forms	Identifies if intake forms use gender-neutral language	<p>“Yes, so for instance when we, for our pediatric patients, instead of saying mother and father we say, ‘parents’ or ‘parent, guardian 1’, ‘parent, guardian 2’ ... and we, when people are talking about spouses, we say, ‘spouses’ rather than ‘husband/wife’.”</p> <p>“We do in some forms, but it has not been corrected across the board. So, for many programs we talk in terms of spouse or partner, but I would say that a lot of our other intake forms do not currently provide that.”</p>
Preferred names and pronouns	Identifies if intake forms allow for patient choice in preferred pronouns	<p>“... on our patient profile, which is the electronic documentation that the nurse does when [she] admits the patient, it has a mutuality question that ask how would you like to be addressed. But that would really be the only place where the patient would have that specific prompted option.”</p> <p>“... not in electronic medical record. There is a place that it can be done handwritten and if a clinician wants to make notes that can be done, but if the original question is can patients make that known on their own in their EMR, they cannot”</p> <p>“It is evolving, and we always listen to our patients ... they tend to be very vocal so responding to their feedback and looking at ways to ... kind of meet their needs.”</p>
Creating a welcoming environment	Describes organizational civilities that were done to create a welcoming environment for sexual and gender minorities	<p>“I don’t think we do anything specifically for them. I think it’s assumed that we treat them like we treat other patients and if we didn’t that would be a problem and somebody would be censored for professionalism or lack thereof but I don’t know that we do anything proactively to encourage nondiscrimination. To encourage not to be discriminatory towards those people.”</p>
Culturally competent patient educational materials	Describes the attempt to represent sexual and gender minorities or provide relevant content in patient education materials	<p>“And when we prepare patient materials, information materials, etc., we do include two women and two men in the images that we use for those materials. I don’t have off the top of my head the exact document. I’d have to do a little bit of research because we’ve done maybe close to 300 documents. But we do—we are mindful and do include images that reflect same-sex families and partners.”</p> <p>“We have an LGBT resource center, as well as a [clinic name removed for confidentiality]. And we have a youth clinic for gender nonconforming youth. And so, we are specific and directive in our advertising and our communications such that there is inclusive language and messaging in our print ad, on our website.”</p> <p>“... it really depends on who they see when they’re here sometimes. If they—I know the behavioral health psychiatry, they have material. Well, if the patient doesn’t come through that channel, I don’t know if they would receive it. It really just depends... Here everything is specialized and separate. You know, depending on your disease, you may or may not—your team of people that are training you are different. And some of the nurses may have specific information for that one group versus another. So like I said with the sexual health, if</p>

(continued)

TABLE 2. (CONTINUED)

<i>Code</i>	<i>Definition</i>	<i>Quote</i>
Survivorship resources for sexual and gender minorities	Describes the availability of psychosocial resources specific to SGM cancer survivors	<p>you visited—you know, the prostate, urology cancer is a lot of men who go through treatment sometimes, they have the treatment and it may lead to sexual dysfunction, so there may be a nurse that comes in, and then those questions about sexuality, gender, and things like that, they come up more specifically. So then they would have maybe a list of resources for them, but I can't say that across the board about all the services."</p> <p>"... that's something that we implemented last year because one of our focuses for last year was—you know, we do a lot for cancer care here but what was missing was work for our survivors. Our survivors, they are our biggest champions, number one. And we're their biggest champions. So we started doing different events based on survivors. And there's also an LGBTQ survivor's group that meets with us here that's part of the Pride Center at [name withheld]"</p>
Organization-focused development activities Advisory committee	Characterizes the presence and activities of a formalized group tasked with addressing SGM issues within the organizations	<p>"... it is comprised of individuals across our health system. So we have the academic medical center, we have the outpatient clinics, and then as part of the [named university] School of Medicine and we're affiliated with the local county hospital as well. So we have members from all of those different entities that are on this committee. And they took...we took a large role in making sure that all of our policies were updated and to kind of get everybody aligned between the different parties. So we did this alongside with the county hospital."</p>
Current SGM-focused policies and guidelines	Describes current policies, regulations, or guidelines pertaining to SGM populations	<p>"all of the policies that are related to whether it is equal employment opportunity, nondiscrimination, sexual harassment, any of the policies that are related to equity, including the patient bill of rights, all include gender identity and gender expression and sexual orientation."</p> <p>"... we don't segment groups by LGBTQ and then minority and women; everything is underneath one umbrella. That includes Title 9, as well. And we talk collectively about the issues that are impacting our staff, our students or our faculty."</p> <p>"... the biggest policy change was related to their [transgender patients] ability to self-identity, and their ability—and having on our form—having on our bill of rights that we don't discriminate based upon sexual orientation."</p>
Cultural competency training	Describes the presence and types of trainings available at the organization focusing on SGM issues	<p>"We are in the process of developing an online LGBTQ-specific cultural competency module that people can take and will be available to them to assign to employees if they feel it's appropriate. Most of our educational work is either because an issue comes up in a particular department and we reach out to them ... And then we've targeted specific departments within the hospital so right now we're focusing on our frontline staff service section, [office name removed for confidentiality], and patient advocates to make sure that they are up to speed in dealing with LGBTQ patients and more specific issues."</p> <p>"... some of our nursing staff, they've taken it upon themselves to have more focused training on the LGBT health. So, everybody gets the 30 minutes of why diversity is important, and underneath that kind of diversity umbrella are race and ethnicity, socioeconomic, LGBT, but again other departments have really taken it and moved further into having more focused training."</p>
Healthcare Equality Index	Characterizes discussion about the Human Rights Campaign's HEI designation	<p>"The health system for the last years has been certified by HRC as a health equity index leader in LGBTQ healthcare equality and that designation is posted both on the website and in the lobby of most of our affiliated hospitals."</p> <p>"So, a part of our application last year to the Human Rights Campaign Healthcare Equality Index, we went through our policies that pertained to patient nondiscrimination, equal visitation and we also looked at out employment policies."</p>

SGM, sexual and gender minority.

Survivorship resources for sexual and gender minorities. Three (14%) cancer centers had resources specifically for SGM cancer survivors. Among these three centers, two had an “LGBTQ survivor group.” At the third cancer center, there was a “Lesbian, gay, bisexual, transgender/transsexual, queer/questioning, intersex (LGBTQI) arm” of a peer navigator program, where patients are matched to an individual who has been through the treatment, and some of those relationships continue posttreatment, although it was unclear if this was a formalized part of the program.

Organization-focused development activities

Advisory committee. Almost all (86%) of the representatives interviewed indicated that their cancer centers had an advisory board or committee to advise on SGM policy issues, and most committees were created specifically to address SGM issues. In some cases, there were more general groups that included SGM issues as part of larger diversity and inclusion activities. Most of the groups focused specifically on patient issues; however, in a few cases the advisory panel was employee focused. The composition of the advisory committees or groups varied across centers and ranged in size from 10 to 30 members. They were largely multidisciplinary, including clinical and administrative members from across the organization, as well as community members. In some cases, there were efforts to involve medical students, residents, and fellows. There was a concerted effort in a few committees to involve leadership and representatives from disparate divisions within the larger organizational structure (e.g., the academic medical center and county hospitals). One representative mentioned efforts to distinguish members of their diversity resource group on their ID badges to “indicate that we’re available as resources to people who are LGBTQ.”

Current SGM-focused policies and guidelines. In general, there were two types of organizational policies that addressed SGM issues. These policies either focused on patients or employees, typically in the form of nondiscrimination policies and/or a “Bill of Rights” (e.g., “Patient Bill of Rights”). All but one center reported having these types of general policies that included SOGI explicitly.

Four (19%) cancer centers had policies created specifically to address SGM issues such as healthcare decision-making for same-sex partners, visitation and overnight guests, gender transitions for employees, and standard procedures to record gender identity from patients. In some cases, these policies were structured based on state laws (e.g., laws banning antidiscrimination policies), but in general, representatives perceived institutional support for these policies. Noted barriers to SGM policy development were technological limitations that complicated name changes that might occur during the gender-affirmation process, discomfort in exacerbating stigma by singling out SGM individuals in specific policies, and state laws that prohibit antidiscrimination protections for SGM individuals (e.g., North Carolina’s Public Facilities Privacy & Security Act).¹⁸ One participant noted that their institution was “coming out of an era of don’t ask, don’t tell” and that organizational culture is slow to change.

Cultural competency training. Eighteen representatives (86%) reported that their cancer centers required a broad

training on nondiscrimination and cultural competency, but did not require any specific SGM cultural competency training. Nine (43%) centers offered SGM-specific cultural competency trainings, which were coordinated in a variety of ways, including partnerships with local community-based organizations and national civil rights advocacy groups. Some centers took advantage of internal resources such as trainings offered by affiliated universities or from social work units within the centers. Some cancer centers purchased commercial products that included SGM training modules. Trainings were offered in-person and/or through online webinars or self-learning modules. The content ranged from compliance with organizational nondiscrimination policies, to providing care, to courses on “LGBTQ Elders of Color.” In a few cases, there was a requirement to complete these trainings—mostly for those focusing on compliance with nondiscrimination policies for employees. Respondents noted that the courses focusing on cultural competency for SGM populations were offered sporadically and were typically initiated by individuals or groups with interests in these topics.

Healthcare Equality Index. Thirteen representatives (62%) reported that their cancer centers received a designation from the Human Rights Campaign under the Healthcare Equality Index (HEI).¹⁹ This designation was viewed as a point of pride for the institution and the impetus behind activities such as policy review and implementing SGM-specific cultural competency trainings.

Discussion

The themes identified in this study, those targeting patient experiences and others focused on organizational change, represent two broad categories of policies and guidelines aimed at improving culturally responsive care for SGM patients at NCI-Designated Comprehensive Cancer Centers. These themes align closely with the more recent strategies to reduce cancer health disparities among SGM populations proposed by ASCO.¹⁴ Although this study was conducted two years before the ASCO recommendations and includes responses only from 21 of the 45 cancer centers, our findings underscore the wide variability across cancer centers in their approaches to reducing these disparities within their institutions. It is also important to consider the collection of policies and guidelines as a whole and the likelihood that those activities will result in improved patient-centered care for SGM populations.

Overall, our findings demonstrate that SOGI information is not collected systematically at NCI-Designated Comprehensive Cancer Centers, and there is wide variability regarding when and how this information is collected within a single institution. The collection of SOGI data is important for quality improvement, to facilitate patient education and to provide culturally competent support services. Recent research suggests that SGM individuals are more likely to disclose SOGI information if asked and are willing to disclose SOGI information if they know why they are being asked.^{20,21} Several commentaries and opinion-based articles suggest that the collection of SOGI data can improve patient outcomes and patient–physician communication.^{22–24} There was a misperception identified in this study, which has also been identified in previous research, that sexual orientation is only relevant if the issue at hand is directly related

to sexuality.^{25,26} This belief may contribute to the lack of systematic collection of these data at centers participating in this study and in other healthcare settings.²⁷

Although the systematic collection of SOGI information is important, it is essential that this information is incorporated into the medical record in a way that will improve patient-centered care. This means that SOGI information should be incorporated into the medical record so that it can be queried easily and be used to inform patient education and support services. Our data demonstrate that when SOGI information is collected, it is likely added to open field notes in the EHR or annotated in a written chart. The lack of routine and automated collection limits the use of this information in terms of linking to appropriate services (e.g., survivorship care). Furthermore, data may not readily reach providers or alert them to the patient's SGM status and, therefore, prevent assumptions being made about gender or sexual identity. Open field text collection of data also limits the ability of the institution to query this information for quality assurance or improvement purposes.

SOGI data can only improve patient-centered care if this information is accessible by medical providers and if those providers are knowledgeable and skilled in addressing the unique needs and concerns of SGM populations. This underscores the importance of SGM-focused cultural competency training for clinical staff that is both knowledge and skill based. Medical providers, in general, receive limited information about SGM health issues,²⁸ and oncology providers specifically report gaps in knowledge concerning SGM patient needs.²⁹

Creating an environment where SGM patients, their friends, and families feel safe and included is an important task for cancer centers seeking to improve the experiences of their patients. Our findings suggest that the most common method that institutions in this study use to convey an inclusive welcoming environment for SGM populations is to include SOGI in nondiscrimination policies (e.g., patient bill of rights) and post these policies so that they are visible to patients. Although this is an important first step, the policies themselves are unlikely to result in improved care unless they are supported through systematic activities. Such activities can include cultural competency trainings for all staff that address SGM issues and concerns, inclusive intake forms, and routine climate surveys that include SOGI information. In addition, representatives noted that although their cancer center did not have anything specific in place for SGM populations, they felt that they treated every patient equally, thus creating a welcoming environment. This sentiment likely reflects a lack of awareness regarding the stigma experienced by SGM populations and barriers to healthcare commonly encountered by these populations.³⁰ Furthermore, the centers in this study generally lacked patient-centered education materials and survivorship resources reflective of the lives of SGM patients and their families.

Although individuals, such as the diversity representatives who participated in our interviews, may report strong desires to improve the environment for and outreach to SGM populations, some organizations and their structure may pose a barrier to such implementation. Although the majority of centers in this study had an advisory board or committee to advise on SGM policy issues, future research will be needed to assess system-wide progress regarding the

strategies outlined by ASCO to improve patient-centered care and reduce cancer health disparities among SGM populations. Some cancer centers in this study existed within larger organizations and operate under different hierarchies and policies such as those of the university with which they are associated. Possible solutions to strengthen the effectiveness of advisory committees and to facilitate organizational support are to include patients and advocates with first-hand knowledge of the experiences of SGM populations and to systematically include members from across the organization(s) and from leadership positions who have the potential to harmonize policies across disparate systems and who may aggregate political power to make change.

There are also opportunities at the national level to improve cancer care for SGM populations. A majority of centers in this study received a designation from the Human Rights Campaign under the HEI, and HEI designation served as a guiding framework for some centers.¹⁹ Harmonizing the HEI index, or some variation of this index focused specifically on cancer centers, with criteria outlined by ASCO and other SGM cancer advocacy groups focused on improving cancer care, can help to increase awareness of these issues and provide more effective benchmarks to improve patient-centered care.^{14,19,31}

Limitations

Limitations of our study should be noted. First, only 21 of the 45 NCI-Designated Comprehensive Cancer Centers participated in this study; thus, these results may not be descriptive of all cancer centers. Reasons for nonresponse from the other 24 centers are unknown. Second, only one person was interviewed at each participating institution, and therefore, the information provided may not reflect the practices or policies of the institution completely. There is also the possibility of social desirability response bias in that representatives may wish for their institutions not to be perceived in a negative light and thus may not share information that could reflect poorly on their institution. However, the promise of aggregated results and confidentiality of respondents' identifying information should have limited this bias. Lack of detail regarding some organization practices limits complete assessment of those practices. For example, we did not receive detailed descriptions of cultural competency trainings, such as the percentage of staff trained and who is specifically attending these trainings (e.g., administrators and medical staff).

Recommendations

Consistent with the recommendations set forth by ASCO,¹⁴ healthcare institutions and oncology providers should establish multilayered policies and guidelines to ensure high-quality patient care for SGM populations. These efforts should focus on increasing cultural competency related to the collection of SOGI data. Current research efforts intended to identify best practices for the collection of SOGI information should be replicated and expanded to the oncology care setting.²² Institutions should incentivize the standardized application of SOGI data collection for all patients system wide and tailor EHR data entry options to allow for limited free text and discrete options. As with

other institutional quality metrics, the collection of SOGI data should be monitored and audited carefully.

To facilitate these changes, diversity representatives should be elected for each unit of a healthcare institution to receive specialized education and training on SOGI data collection methods. Partnering with patient advisory boards and members of SGM communities can improve quality and provide feedback regarding policies related to the collection of SOGI information and the development of cultural competency interventions. Furthermore, SGM-specific cultural competency trainings should be standardized and incorporated into new hire orientation for all employees entering healthcare systems, with frequent refresher trainings provided. Finally, oncology providers should ensure that inclusive patient education materials and social support services, or a referral for these materials and support, are made available to all patients.

Conclusion

The 21 (out of a total of 45) cancer centers in this study lacked institutional policies, guidelines, and practices focused on patient-centered cancer care for SGM populations. Implementing the strategies recommended by ASCO¹⁴ and advocacy groups³¹ to foster culturally competent oncology care for SGM populations will require organizational change. Coordinated efforts involving cancer center leadership, clinical staff, and patient advocates are needed to facilitate change at the organizational and system levels.

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Disclaimer

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