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Teaching Health-Care Providers to Query Patients With Cancer About Sexual and Gender Minority (SGM) Status and Sexual Health

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Abstract

End of life is difficult for all patients but sexual and gender minorities (SGM) are prone to isolation and loneliness, especially if their SGM status is unknown or unaccepted. In oncology clinics, where goals of care discussions about end of life are integral and frequent, querying patients about their SGM status and sexual health is of particular importance. The American Society of Clinical Oncology recently released a position statement that called for greater focus on SGM populations with the goal of reducing and eventually eliminating disparities in cancer care within this group. An important first step in addressing such disparities is learning how best to train cancer health-care providers to ask patients about their SGM status and about sexual health in general. This article summarizes the mandate for understanding cancer issues in SGM populations and the dearth of cancer-related data within this group. This article also describes an ongoing 3-part study intended to build a mini curriculum with the goal of helping cancer health-care providers to ask patients with cancer about SGM status and to ask all patients with cancer about sexual health issues. The results of this ongoing study could potentially improve end-of-life care for subgroups of patients.

Keywords

sexual and gender minorities; transgender health; LGBTQ health; sexual health; oncologic disparities; disparities

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Introduction

Over 10 million adults in the United States are identified as sexual and gender minorities (SGM). Not only does the SGM population encompass individuals who identify as lesbian, gay, bisexual, and transgender but it is also inclusive of queer, questioning, intersex, 2-spirit, and others. This is an extremely diverse group of people, with individuals expressing differing gender identities and/or sexual orientations, as well as differing experiences and beliefs about how their identity interplays with the health-care system.

Sexual and gender minority individuals experience unique challenges when faced with cancer diagnoses, and they also face major challenges at the end of life.[1-5] Gay men diagnosed with cancer are more likely to report poor mental health, and lesbian and bisexual breast cancer survivors have more frequent and severe sexual side effects from cancer therapy compared to their heterosexual counterparts.[1-6] These issues are magnified when patients feel that their sexual orientation and gender identity are poorly understood or ignored, a situation which worsens their distress and heightens their concerns of isolation and invisibility.[5,7-9] After cancer diagnoses and at the end of life, patients need their health-care providers' support but sexual minority patients report a lack of patient-centered care and a need for health professional training to negate the isolating effects of heteronormativity.[10] For instance, recognition of the importance of relationship partners and friends, and identification of other sources of support may be particularly helpful for sexual minority patients at the end of life.[4,11] Oncology health-care providers, in particular, have a unique opportunity to improve this aspect of SGM health care because they frequently have highly personal, long-term relationships with patients and find themselves needing to discuss highly sensitive goals of care and end-of-life issues.

Furthermore, in 2017, the American Society of Clinical Oncology (ASCO) released a position statement that called for greater focus on SGM populations in cancer care and research[12]:

> ASCO is committed to addressing the needs of sexual and gender minority (SGM) populations as a diverse group at risk for receiving disparate care and having suboptimal experiences, including discrimination, throughout the cancer care continuum.

Despite the foregoing, oncology health-care providers rarely ask patients about sexual issues of any sort, in large part because they feel inadequately trained to do so.[13-15] A 2018 ASCO guideline on this topic states, "There remains an overall reluctance from both clinicians and patients to talk about cancer- and treatment-related sexual difficulties. Barriers from the clinician's perspective can include feeling inadequately trained…"[16(p497)] Additional mitigating factors, including time constraints during a clinic visit or fear of offending patients, may be present but require further study to know for sure.[17,18] The current article focuses on the fundamental need to begin to ask patients with cancer about SGM issues as well as about other sexual issues with the goal of addressing the important mandate described in these ASCO position articles and improving cancer care and end-of-life care in these vulnerable patient groups. We will first review the current literature on SGM cancer care and then describe a novel study to improve SGM cancer care by improving discussions of sexual orientation and gender identity within oncology clinics. The oncologic needs within the SGM community appear to be sizable, as described above.[1-6]

The foregoing issues described about patient-reported distress and isolation might represent only a fraction of the health disparity–related issues faced by SGM patients with cancer. The cancer-specific needs of SGM patients appear to be underreported and therefore understudied.[19,20] The risks of cervical cancer after gender reassignment surgery are unknown, as is the role of Pap smear screening of transmasculine patients.[21] Moreover, 1 study of 148 gender nonconforming women showed that these individuals are less likely to receive screening clinical breast exams if their health-care provider did not know of or felt uncomfortable with their sexual orientation.[22]

Substandard screening or poorly defined guidelines appears to lead to substandard oncologic outcomes. Indeed, what little we do know suggests that sexual minority patients have higher rates of cancer-specific mortality.[23] The US Veterans Health Administration conducted the largest study on cancer outcomes and identified that 3 of the 10 identified transgender veterans with breast cancer were diagnosed at late stages, which led to their presumably premature death.[24] Importantly, the fact that the largest such study, as referenced above, focused on only 10 patients further underscores this paucity of data. Along similar lines, in an effort to describe the experience of transgender individuals with cancer, Cathcart-Rake and others conducted a search of a large tumor registry and observed that, among 385 820 patients, only a single transgender patient was able to be reported upon—despite the fact that members of the research team knew of other transgender patients with cancer who had received their care at the health-care facility.[19] This dearth of information within a tumor registry speaks directly to ASCO's statement of need to "promote the inclusion of SGM status as a required data element in cancer registries and clinical trials."

This underreporting is pervasive and extends well beyond a single institution. Among 227 national, community-based NCI Community Oncology Research Program (NCORP) research sites that responded to a survey, only 24% reported that they collect information on patients' sexual orientation and only 10% collected information on patients' gender identity.[20] NCI Community Oncology Research Program sites were more likely to collect gender identity information if they were in the West or Northeast regions of the United States, as compared to the South and Midwest regions. They were also more likely to collect such data if they served a lower proportion of non-Hispanic ethnicity patients, were independently owned, or had a higher proportion of dual Medicare–Medicaid patients. The vast majority of NCORP sites do not ask patients with cancer about SGM status—this problem of marked underreporting is a shortcoming that we propose to begin to remedy through the project described below.

The current article describes a series of projects that focus on training health-care providers to ask patients with cancer about SGM status and to have conversations about sexual health issues. The primary aim of the described projects is to eliminate SGM cancer disparities and to improve the sexual health of all patients with cancer through the development of a mini curriculum for cancer health-care providers.

Methodology of an Upcoming Study

Overview: This upcoming study has 3 parts. First, we will use qualitative interviews to gain insight into reasons why patients and health-care providers might not discuss sexual orientation and gender identity or general sexual health issues in oncology clinics. Second, these interviews will inform the development of a video-based mini curriculum for health-care providers, which will educate oncology health-care providers on how to acquire information on SGM status and sexual health from all patients with cancer. Third, this curriculum will preliminarily be tested by asking health-care providers to take the validated Implicit-Association Test (IAT), a test that examines bias in the test-taker, before and after participating in this mini curriculum. Our goal is to develop and pilot test a curriculum for health-care providers prior to future multisite setting aimed at improving the quality of care for SGM patients with cancer as well as other patients with cancer. We expound upon this upcoming study in more detail directly below.

Part 1: Learning From Qualitative Interviews

The first part of this study will be to conduct qualitative interviews to identify reasons why patients and health-care providers might not discuss sexual orientation, gender identity, and general sexual health issues in oncology clinics.

We anticipate interviewing 20 to 30 patients from oncology clinics in a large medical practice in the Midwestern United States. We will interview participants of differing sexual and gender identities. As we anticipate that recruiting from oncology practices alone may not readily allow for the recruitment of patients with differing gender identities, we will also recruit patients from a large gender reassignment clinic. Overall, we plan to include at least 5 to 10 individuals who identify as SGM, with the goal of recruiting as diverse of an SGM population as possible. Similarly, we anticipate interviewing 20 to 30 oncology providers, including physicians, advanced practitioners, and nurses.

These interviews will seek to learn how patients and health-care providers can feel most comfortable in broaching discussions on SGM status and sexual health. The semi-structured interview guides are reported in Tables 1 and 2; the interview will be flexible and other open-ended questions will be added as topics related to the goals of the study emerge during the interviews.

Finally, data collection and analysis will occur concurrently—but will occur separately for patient interviews and oncologist interviews—to allow emerging issues to be explored in later interviews. The study team will develop a preliminary codebook representing concepts in the interviews. After all the interviews are completed, transcripts will be coded and entered into NVivo (version 11, QSR International Ltd, Dorcaster, Victoria, Australia) to organize, code, and annotate data; 3 of the investigators will independently review and systematically code transcripts and meet to harmonize coding and begin interpretation. Interpretation will entail identifying themes among the coded concepts. We will allow this interview data to guide our hypotheses regarding how to improve health-care provider discussions of SGM status. Thus, these findings will inform the content of the mini curriculum.

Part 2: The Development of a Video-Based Mini Curriculum

After completion of the qualitative data collection and analysis, we will da mini curriculum. The knowledge gained and themes developed by the qualitative interviews described above will inform the educational content of the mini curriculum. For example, if the qualitative interviews were to identify a theme that discussions of gender identity can generate a sense of stigma, then we would incorporate information into the mini curriculum such that oncology health-care providers learn how to destigmatize such discussions prior to broaching them with patients.

A video team at the Mayo Clinic will work with the study team to collaboratively create an educational video. The research team will provide the content, as derived from the qualitative interviews described above and the video team will provide the technical and aesthetic expertise to produce an educational video. Depending on the number and type of themes that emerge from the first, qualitative part of our study, we anticipate that one or two 15-minute videos will be developed; these videos will be intended to help health-care providers as they broach the topic of SGM identity in patients with cancer and sexual health in patients with cancer in general.

Importantly, we view the development of these videos as an iterative process. To this end, transcripts of the content of each video will be shown to cancer health-care providers, using the same eligibility criteria for selection as described in the initial qualitative part of this study. Using qualitative methods, cancer health-care providers will be asked about the content of the videos with a series of semi-structured questions, such as “Tell me your thoughts on this video.” “What can be done to make it more instructive?”

Part 3: A Preliminary Test of the Mini Curriculum

We acknowledge that true validation and testing of this mini curriculum will require the development and completion of a large, multi-institutional study, but as a preliminary first-pass assessment, we will test this mini curriculum among cancer health-care providers to explore whether it might change attitudes about asking about SGM status.

Building upon the preliminary NCORP data cited above that show geographic diversity influences acquisition of data on patients’ SGM status, health-care providers from 3 geographically separate regions will participate in preliminary testing of the mini-curriculum. This portion of the study will be tested within a clean, unbiased sample of cancer health-care providers who had no input into the development of the mini curriculum.

Cancer health-care providers will complete the IAT, an online, well-validated test, which examines unconscious bias as specifically relevant to sexual orientation: https://implicit.harvard.edu/implicit/Study?tid=-1. Cancer health-care providers will complete the IAT twice: within 24 hours before and again 24 hours after completing the mini curriculum. Participants will also answer pretest and posttest surveys about their views on the importance of sexual orientation and gender identity training, their experiences treating SGM patients and their level of comfort in taking care of SGM patients.

Based on our cited NCORP data on SGM query rates, we anticipate that 20% of health-care providers (1 in 5) will score “slight” on the IAT both before and after taking the mini curriculum. A 30% improvement (derived from extensive data on placebo/sham effects[25]) or a score of “slight” within a total of 50% of the cohort after completing the mini curriculum will be sought; 20 health-care providers will enable us to capture this effect with 80% power and a 2-tailed P value of .05.

Future Directions and Discussion

Our broader vision is to test this soon-to-be-developed mini curriculum as part of a larger, multisite study to determine whether it truly will improve acquisition rates of SGM status and whether it garners more data on sexual health in patients with cancer. We anticipate that a cluster (by institution), randomized controlled trial would best help us validate this mini curriculum. In one arm of this envisioned trial, we would include sites with health-care providers who had taken the mini curriculum and the other arm would include health-care providers who had not. An educational initiative is likely to have a pervasive effect throughout a single institution, so cluster randomization reduces such educational “contamination” to other health-care providers within a given institution. The primary end point of this future envisioned randomized, controlled trial would be rates of SGM status and sexual health reporting among patients enrolled to ongoing cancer clinical trials.

To recapitulate, SGM individuals are underscreened, underdiagnosed, and undertreated for cancer.[26-29] Although the SGM population is diverse and comprised of individuals with differing experiences, some persons may be more likely to report higher levels of distress and isolation after cancer diagnoses and at end of life.[10-13] A major barrier to improving the care of SGM patients after a cancer diagnosis and at end of life is health-care providers’ reluctance to ask about sexual practices and sexual health. This reluctance translates into a pervasive lack of data that precludes our ability to grasp the scope of health disparities within this group and that thereby leads to inadequate care for SGM individuals. Educational initiatives, such as the ongoing series of projects described in this article, can improve on this inadequacy, serve as a starting point for a larger multisite trial, and hopefully, in the future, reduce cancer disparities.

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Table 1.

Example Questions for Patients Based Upon the Theory of Behavior.

	Example Questions/Solicitation Items for Patients
Attitude toward act or behavior	How comfortable are you in discussing your sexual health with your cancer health-care provider? How comfortable are you discussing sexual orientation or gender identity with your cancer health-care provider? What are some things that might result from discussing your sexual health with your cancer health-care provider? What about your sexual orientation or gender identity with your cancer health-care provider?
Subjective norm	How do you think other patients might feel if their health-care provider asked them about their sexual health? How about their gender identity or sexual orientation?
Perceived behavior control	How difficult would it be for you to discuss your own sexual health with your cancer health-care provider? How about your sexual orientation or gender identity with your cancer health-care provider?
Behavioral intention	Would you be willing to discuss your sexual health or gender identity or sexual orientation with your provider? Tell me more

Table 2.

Example Questions for Health-Care Providers Based Upon the Theory of Behavior.

	Example Questions/Solicitation Items for Health-Care Providers
Attitude toward act or behavior	How comfortable would you feel in talking with patients about their gender identity and sexual orientation? How comfortable are you in talking with patients about their sexual health?
Subjective norm	What are other health-care providers' concerns in asking patients about their gender identity or sexual orientation? What are other health-care providers' concerns in asking patients with cancer about their sexual health or problems related to their sexual health?
Perceived behavior control	How easy or difficult is it for you to ask patients about their gender identity or sexual orientation? Tell me more
Behavioral intention	Would you be willing to ask patients about their gender identity or sexual orientation? If yes, please explain further. If no, please explain. Would you be willing to ask patients about their sexual health? If yes, please explain further. If no, please explain