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Querying Cancer Patients About Sexual Health and Sexual and Gender Minority Status: A Qualitative Study of Healthcare Providers

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Abstract

Background: Although national organizations advocate that healthcare providers ask patients about sexual health and sexual and gender minority status –to learn, for example, about side effects of treatment and to understand patients’ social support -- these conversations often do not occur. This study explored healthcare providers’ reasons for having/not having these conversations.

Methods: This single-institution study recruited healthcare providers from medical oncology, hematology, radiation oncology, and gynecology. Face-to-face interviews were recorded, transcribed, and analyzed qualitatively.

Results: Three main themes emerged: 1) patient-centric reasons for discussing/not discussing sexual health and sexual and gender minority status (“So I think just the holistic viewpoint is important”); 2) healthcare provider-centric reasons for discussing/not discussing these issues (“That’s going to take more time to talk about and to deal with...” or “I was raised orthodox, so this is not something we talk about...” and 3) reasons that appeared to straddle both of the above themes (for example, acknowledgement of the sometimes taboo nature of these topics).

Conclusion: Although many healthcare providers favor talking with cancer patients about sexual health and sexual and gender minority status, limited time, personal reluctance, and the taboo nature of these topics appear at times to hamper the initiation of these conversations.

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Keywords

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INTRODUCTION

Sexual health is defined as “a state of physical, mental, and social well-being in relation to sexuality,” and sexual minorities are defined as individuals who are not exclusively heterosexual and/or who do not exclusively identify with their assigned gender at birth [1-4]. Sexual health difficulties are pervasive among patients with cancer: an estimated 40% to 100% of patients with cancer suffer from such issues [1-4]. Furthermore, among cancer survivors, it is estimated that 500,000 to 1 million are sexual or gender minority patients -- or those who identify as lesbian, gay, bisexual, transgender, queer, intersex, or other -- a group too large to remain unacknowledged and too large to endure unaddressed needs [1-4].

Despite the foregoing, the topics of sexual health and sexual and gender minority status are often unaddressed in cancer care. Over 90% of patients report that their oncologist infrequently addressed sexual health concerns [5]. Three quarters of community oncology research sites report that they do not routinely collect information on cancer patients' sexual orientation, and 9 in ten do not ask about gender identity [6]. Cancer patients may want such conversations to learn more about the short- and long-term impact of cancer and cancer therapy, such as the symptoms of vaginal dryness, decreased libido, and erectile dysfunction; about their reproductive health; and even about end-of-life decision-making. With respect to the latter, a growing body of literature describes sometimes limited social support among sexual and gender minority patients, especially at the end of life, and the resulting in the need to ask patients whom they have as a life-partner as decisions are made about ongoing cancer therapy and end of life [7,8]. If cancer healthcare providers are not asking about sexual health and sexual and gender minority status, the foregoing issues likely remain unaddressed, thereby compromising the quality of cancer care.

The goal of the current qualitative study was to understand healthcare providers' perspectives of what contributed to the presence or absence of discussions of sexual health and sexual and gender minority status among cancer patients in the clinic. The longer term ambition of this line of investigation is to work toward surmounting barriers to these discussions with the abiding aim of improving cancer care for all patients.

METHODS**Overview.**

An Institutional Review Board approved this study, which was conducted per IRB #18-006459. All participants were healthcare providers who provided informed consent prior to being interviewed.

Participants.

Eligible healthcare providers had direct patient care responsibilities at a large Midwestern medical center. A variety of recruitment methods, including a widely distributed e-mail invitation; one-on-one e-mail invitations between study staff and healthcare providers who worked in disciplines such as medical oncology, hematology, radiation oncology, gynecology, and primary care; and face-to-face invitations from study staff to specific healthcare providers all were used for recruitment. Purposeful sampling was used to acquire a broad range of perspectives. In view of the single-institution nature of this study and the sensitive nature of the interview data, the decision was made to record and to report healthcare providers' demographics in only very general terms.

Interview Process.

A single trained investigator (JO) conducted all interviews. Healthcare providers participated in audio-recorded, semi-structured interviews in a quiet room. The main objective of these interviews was to understand whether healthcare providers perceived a need to talk about sexual health and sexual and gender minority status with cancer patients; the rationale for perceiving such conversations as important/unimportant; and, when undertaken, how such conversations were broached. An interview guide was formulated, shared with multiple members of the team, and then revised until a consensus was reached on content (Table 1). Additional open-ended questions, as relevant to the goals of the study, were also allowed based on responses that arose during the interview. Audio files were then transcribed verbatim by trained transcriptionists.

Data Analysis.

Three study team members (JO, EC, AJ) reviewed interviews on a regular basis until a range of responses were seen and until no new information appeared to be emerging (saturation). At that point recruitment was halted.

These same three investigators (JO, EC, AJ) then independently and later collaboratively reviewed, organized, and developed a preliminary code book, which was then refined and finalized over time after repeated discussions. Interview transcripts were then reviewed independently by these investigators (JO, EC, AJ) and systematically coded. Using an inductive approach, two of these investigators (JO and AJ) then met face-to-face to discuss and develop data themes and to review quotations that appeared to substantiate candidate themes, which were further revised after input from the lead investigator (EC). Conclusions were subsequently shared with all other members of the multidisciplinary team in order to allow discussion and challenge of interpretations.

RESULTS

Demographics:

Between November 2018 and February 2019, a total of 20 healthcare providers were interviewed: 18 worked in an oncology clinic, 15 were physicians, and 5 were nurses (4 of these were advanced practice nurses) (Table 2). The median interview time was 14 minutes (range: 30 to 11 minutes).

Themes:

These interviews gave rise to three main themes: 1) patient-centric reasons for discussing/not discussing sexual health and sexual and gender minority status; 2) healthcare provider-centric reasons for discussing/not discussing these issues; and 3) reasons that straddled these first two themes. It should be emphasized that the so-called patient-centric reasons were, of course, provided by healthcare providers. Importantly, most reasons for discussing/not discussing these issues were patient-centric, or focused on the welfare of the patient. Some healthcare providers tended to show evidence of patient-centric, healthcare provider-centric, and overlapping themes during the interviews.

Theme #1: Patient-Centric Reasons for Discussing/Not Discussing:

Healthcare providers offered patient-centric reasons for why discussions of sexual health and discussion of sexual and gender minority status should be undertaken with cancer patients. These topics were deemed important because they enabled patients to be aware of sexual side effects of cancer therapy, and they enabled healthcare providers to learn about such side effects among cancer patients. One healthcare provider explained, “With many of the gynecologic cancers, there are some side effects of treatment that take place in the sexual organs, and that can affect sexual function, pain and so forth, and those aspects I’ve been somewhat trained to assess and to address” (healthcare provider #12).

Importantly, some healthcare providers specifically talked about their role of discussing fertility preservation with younger patients prior to starting chemotherapy. For example, one healthcare provider commented, “With a few young cancer patients I’ve had, I always bring up fertility preservation at the initial consult” (healthcare provider #9). Healthcare providers also described how sexual health covers multifaceted aspects of a person as a whole and therefore should be discussed during cancer care appointments. One healthcare provider explained, “[With] holistic care like [in] Oncology, [one] has to know.... somebody’s family” (healthcare provider #11). Another explained, “So I think just the holistic viewpoint is important” (healthcare provider #5). Yet another explained, “Well...there’s a lot to lose with... [a] cancer diagnosis, whether it’s financial or jobs or physical loss. A lot of....stressors, and so I’m sure sexual health is also impacted significantly....and that can be very important for some people, and perhaps their family dynamics change” (healthcare provider #2).

Some healthcare providers who assumed this patient-centric stance appeared to do so in an effort to better understand the patients’ support system, describing how it is important to ask about relationships between the patient and others at the clinic appointment and not make assumptions. One healthcare provider explained, “Just reminders of when you’re meeting a room of people the first time not to assume who is whom and ask open-ended questions about who is there” (healthcare provider #8).

Others described a desire for further education to discuss such matters more effectively with patients. One healthcare provider noted, “I certainly hope I make my patients feel more comfortable... I think providers need education on this for sure” (healthcare provider #3). Interestingly, a few healthcare providers described how they had educated themselves on

such matters: “So as providers, if you are accepting and non-judgmental, you’re really doing a big service to them and ourselves because our goal is to be able to listen, be the expert in our field, and let them be in charge, again, because they are competent adults” (healthcare provider #20). This same healthcare provider commented, “And if one doesn’t understand something, to be forthcoming, to be, you know, saying it openly” (healthcare provider #20). Elaborating on self-education, one interviewee commented, “I had never had another experience with a transgender patient.... I think it was very important education for me” (healthcare provider #1).

Interestingly, not all healthcare providers who took a patient-centric approach voiced that patients should always be asked about sexual health and sexual and gender minority status. Some described patients’ right to privacy, and, described how if patients thought these matters should be addressed by another healthcare provider, the cancer healthcare provider should respect such boundaries. One healthcare provider explained, “I have had some concern about what’s the right way to bring this up, specifically since the main reason they’re there is their cancer, not their sexual health”(healthcare provider #12). Another commented, “I think most people probably... want to treat somebody with respect.... but [are] probably scared of somehow offending them” (healthcare provider #6). Yet another explained, “You know, [patients] trust the system to keep it private, you know, so that would be another thing to maybe ask the patients about” (healthcare provider #6).

Theme #2: Healthcare Provider-Centric Reasons for Discussing/Not Discussing.

Healthcare provider-centric reasons focused primarily on why sexual health and sexual and gender minority status need not/should not be discussed in an oncology clinical setting from the healthcare provider’s perspective. First, healthcare providers frequently described time constraints, noting they were unable to address such issues with patients because of limited time. One healthcare provider explained, “That’s going to take more time to talk about and to deal with... I just want to get through cancer-related issues”(healthcare provider #14). A number of others used similar wording.

Second, in a few instances, healthcare providers described their personal and moral beliefs to suggest such discussions should not be undertaken. One healthcare provider described, “I was raised orthodox, so this is not something we talk about....” (healthcare provider #13). Referring to sexual minorities, that same healthcare provider commented, “I’ve found this to be not that dissimilar with sort of psychiatric disorders” (healthcare provider #13). Another healthcare provider stated, “I have my own values.... if somebody’s having frustration or troubles specifically related to being transgender, I don’t have the tools to help them” (healthcare provider #12).

Along similar lines, some healthcare providers commented on how colleagues or others in the community appeared to be pass judgment. One healthcare provider explained, “An LGBT person... cannot assume that [their] care provider believes that [they] are a moral person.... I mean, I know some of my colleagues down the hall do not believe that an LGBT person is living a moral life, and I am acutely aware of that, you know, my daughter and my daughter-in-law know that, and I think that that’s true of people who identify as LGBT” (healthcare provider #10). This same interviewee explained, “We have learned in the last two

years, many people really don't care what the facts of the matter are. They don't care about even a person who may even be biologically transgender.... whose physical characteristics may not be binary" (healthcare provider #10). Talking about colleagues, another healthcare provider explained, "I don't know if this happens anymore, but I bet it does, where people wouldn't touch a transgender patient, you know, like they're a leper or something" (healthcare provider #11). Referring to issues that his children are confronting in school, another explained, "I'm a dad, and there's a lot of confusion in my children's age group, my older two kids, and I know that some of their friends have a fair amount of angst because there's some confusion as to who they are" (healthcare provider #12).

Overlap of Patient-Centric and Healthcare Provider-Centric Reasons for Discussing/Not Discussing.

Some themes coincided with both provider-centric and patient-centric concerns. Both patient-centric and healthcare provider-centric comments acknowledged the potentially taboo nature of this subject matter. The more patient-centric comments seemed to suggest that, although sexual health discussions may be difficult or awkward, omitting these conversations may be detrimental to patient care. One healthcare provider summarized the situation as follows: "We want sexually healthy young adults, older adults, and by talking about it, I think we can all achieve that a little bit better versus having all of these secretive conversations or things that we don't feel we can ask somebody" (healthcare provider #11). In contrast, the more healthcare provider-centric comments described how broaching the sensitive topic could potentially lead to a patient's criticizing or admonishing the healthcare provider. One healthcare provider described it as follows: "And I think there's the potential that I could offend or bother a patient" (healthcare provider #12). In effect, avoidance of the topics of sexual health and sexual and gender minority status appeared to be an attempt at self-preservation on the part of the healthcare provider.

Furthermore, both patient- and provider-centric comments described the pros and cons of asking about sexual health and sexual and gender minority questions by means of a form. For example, patient-centric comments described how providing patients with a form to complete ("give them the sexual health form for a male with cancer, and if they are a woman they get the sexual health for females" (healthcare provider #1)) would make these topics more routine and easier to broach and would enable the healthcare provider to be better prepared for such discussions. However, another patient-centric comment described a form as "weird" (healthcare provider #14), alluding to a need to bring personalization and humanity to such questions. In contrast, the more healthcare provider-centric comments seemed to suggest a routine form would enable the healthcare provider to opt out of having to ask: "That's why I like the.... forms because you don't have to spend time asking those things" (healthcare provider #4).

DISCUSSION

This study was undertaken to better understand healthcare providers' perspectives about talking to cancer patients about sexual health and sexual and gender minority status. The work described here is in direct alignment with two position statements from the American

Society of Clinical Oncology (ASCO), both of which focused on these same topics: “It is recommended that there be a discussion with the patient, initiated by a member of the health care team, regarding sexual health and dysfunction resulting from the cancer or its treatment... this is a vital recommendation” [1,9]. Consistent with these ASCO position statements, our findings suggest that many healthcare providers want to educate patients on potential sexual side effects of cancer or cancer treatment and to support patients’ close personal relationships through discussions of sexual health and sexual and gender minority status.

However, these discussions can be challenging. Healthcare providers in this study expressed concerns about breaching patient privacy and contributing to stigma and discrimination, particularly against sexual and gender minority patients. Healthcare providers in other clinical settings have expressed similar concerns [10-12]. A small group of healthcare providers in the current study expressed even their own biases against patients of differing sexual orientations and gender identities and their reluctance to discuss issues related to sexual health. Whether this bias impacted their care of patients or whether these healthcare providers made a deliberate decision to not ask patients in order to circumvent this possibility of rendering biased care remains unknown. An even more pervasive concern was the issue of time constraints during clinic visits. The notable influx of medical information to be covered in one oncology clinic visit poses competing demands for time. One potential time saver -- a patient-completed intake form to ask patients whether they choose to discuss sexual health concerns and to report on sexual orientation and gender identity -- was met with mixed opinions from healthcare providers with some describing how it appeared too impersonal for such a sensitive topic.

Importantly, the current study raises possibilities for future qualitative research in this area. Topics such as the influence of healthcare provider characteristics in shaping opinions; proactive interventions to address the challenges of a healthcare provider-centric stance; the engagement of healthcare providers from other specialties, such as palliative care; and how best to mitigate strong negative feelings among healthcare providers are all areas that merit further examination with qualitative methodology. The current study provides an initial foray into the complicated topic of sexual health and sexual and gender minority status .

It should be noted that the current study has limitations. First, this research was undertaken at a large medical center in the Midwestern United States. The generalizability of findings remains unknown. Second, the healthcare providers who consented to being interviewed represent a culled group who were presumably interested in or perhaps sympathetic to the topics of sexual health and sexual and gender minority status. This potential for bias appears unavoidable. Third, a wide range of comments led to no consensus on when or how this topic should be broached. This last point speaks to the complexity of these issues. Finally, this work focused heavily on cancer healthcare providers. As alluded to above, engaging other healthcare providers in the interview process – perhaps palliative care healthcare providers -- would provide additional insight.

Nonetheless, addressing sexual health and sexual and gender minority status might improve the quality of cancer care – with better management of sexual side effects of cancer and

cancer treatment and less patient isolation during the cancer journey. Moreover, a leading oncology organization, ASCO, has endorsed the importance of addressing these topics. In general, although not specifically discerned from these interviews, it appears that at an institutional level, gender neutral verbiage, gender neutral restrooms, and a diverse healthcare staff might help all patients seek better healthcare. Importantly, a notable opinion that arose from these interviews was healthcare providers' willingness to receive education that would enable them to talk more effectively with cancer patients about sexual health and sexual and gender minority status. If nothing else, the current study underscores a clear need to develop efficient educational efforts to help oncology healthcare providers address these topics with the goal of improving the quality of cancer care.

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Table 1:**Interview Guide**

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?
What are other healthcare providers' concerns in asking patients about their gender identity or sexual orientation?
What are other healthcare providers' concerns in asking cancer patients about their sexual health or problems related to their sexual health?
How easy or difficult is it for you to ask patients about their gender identity or sexual orientation? Tell me more.
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.

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Table 2:

Demographics; n=20

Characteristic	Number (%)
Sex	
Male	10 (50)
Female	10 (50)
Medical Specialty	
Oncology	18 (90)
Gynecology	1 (5)
Primary Care	1 (5)
Healthcare Provider Training	
Physician	15 (75)
Nurse	5 (25)

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