



Published in final edited form as:

J Geriatr Oncol. 2020 May ; 11(4): 576–578. doi:10.1016/j.jgo.2019.08.003.

How (and Why) to Ask the Older Cancer Patient about Sexual Health and Sexual Minority Status

Elizabeth Cathcart-Rake¹, Jennifer M. O'Connor¹, Alison Jacobson¹, Lois McGuire², Aminah Jatoi¹

¹Department of Oncology, Mayo Clinic, 200 First Street SW, Rochester, Minnesota, 55905

²Department of Obstetrics and Gynecology, Mayo Clinic, 200 First Street SW, Rochester, Minnesota, 55905

Abstract

Sexual health and sexual minority status are often undiscussed during oncology visits. Yet, these topics should be addressed in older cancer patients in order to help mitigate the sexual side effects of cancer treatment and to acknowledge – and, at times, help provide – the social support older patients need during their cancer journey. This paper describes 4 tips on how cancer healthcare providers can broach the topics of sexual health and sexual minority status in an oncology clinic.

Keywords

sex; sexuality; gender identity; disparities; cancer care

Why Ask?

Sexual health and sexual minority status appear to be undiscussed topics during oncology visits, especially when the patient is older. 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. To our knowledge, rates at which oncologists ask patients about sexual health and sexual minority status are unknown, but, in other, clinical settings, far fewer than 50% of healthcare providers are asking patients about these issues [1–3]. In an oncology setting where often times the majority of patients are older, this percentage is likely even lower, suggesting that healthcare providers are ignoring dyspareunia, erectile dysfunction as well as other important issues in older cancer patients [1–3].

Sex health and sexual minority status should be discussed with older adult cancer patients for at least two reasons. First, contrary to prevalent assumptions, older patients are sexually active. A recent survey showed that 40% of individuals between 65 and 80 years of age are

Correspondence: Aminah Jatoi, M.D., 200 First Street SW, Rochester, Minnesota 55905; phone: 507-266-9160; fax: 507-284-1803; jatoi.aminah@mayo.edu.

Author contribution statement: All authors contributed equally to this work.

Conflict of interest statement: The authors have no relevant conflicts of interest to disclose.

having sex [4]. This percentage may be lower in older cancer patients who are suffering from sexual side effects of cancer therapy: hormonal therapies may suppress sexual desire; the psychological traumas of a cancer diagnosis may diminish libido; the presence of an ostomy may cause sexual inhibition on the part of a patient or a partner; and prostate cancer surgery may cause nerve impairment with resulting impotence. All of these can negatively impact sexual desire and activity and should therefore be the subject of query. Healthcare providers have an opportunity to improve the quality of life for older cancer patients by asking about sexual health and sexual minority status and then by managing patients' sexual health concerns or referring to the appropriate healthcare providers who are able to do so.

Second, oncology healthcare providers need to know patients' self-identify as a sexual or gender minority in order to better address the unique healthcare needs of each and every patient, as described below. In reality, it remains unknown how many cancer survivors in the United States identify as sexual and gender minority patients, based on, for example, definitions from the American Psychological Association because patients are not asked [5]. However, estimates suggest anywhere between half a million to 1 million adults with cancer identify as belonging to a sexual minority group.

Why Ask (Continued)?

Although the above number might not be viewed as mammoth, belonging to a sexual minority group, as defined to earlier, has healthcare implications. As one example, the Trans MetLife Survey reported that among 384 transgender patients who were 50 years of age or older, only 63% had disclosed their sexual identify to their physician and, poignantly, only 13% were confident that their healthcare provider would treat them with dignity [6]. Conversely and sadly, the vast majority feared they would not be treated with mutual respect during the delivery of healthcare.

And, indeed, patients who identify as belonging to a sexual minority group have a tumultuous cancer journey [7–9]. These patients suffer longer periods of depression and appear to agonize with more frequent and severe side effects from cancer treatment. These patients also have poorer social support, or less social and emotional back up from family and friends. A recent study from the United Kingdom identified that sexual minority patients report a lack of patient-centered care, less direct involvement in decision-making, and substantial social isolation [10]. Older cancer patients who identify as sexual minorities – even in the setting of a legal union -- sometimes contend with an absence of visitation rights during the hospitalization of their life-partner. They sometimes must contend with direct challenges with respect to end-of-life decision-making from biological next-of-kin who question the voice of the patient's life-partner. Social mores, legal matters, and untoward circumstances can make a patient's wish to be close to a life-partner nearly impossible to realize. For oncology healthcare providers, an awareness of these issues and an ability to help are markedly limited if oncologists are not asking about sexual health and sexual minority status.

Four Tips on How to Ask.

Clearly, healthcare providers should be asking. So, how should they ask? Based on our group's previous work that entailed qualitative interviews of patients – some with cancer, some transgender without cancer, and some with a family member who belonged to a sexual minority group – as well as interviews of healthcare providers, we derived 4 instructive recommendations to make it easier and more effective for cancer healthcare providers to ask patients about sexual health and sexual minority status. These recommendations are summarized below.

Of note, some medical records “intake forms” ask patients to complete questions about sex assigned at birth, sexual orientation, and sexual identity; such information enters the electronic medical record and is available prior to a clinic appointment. Certainly, those cancer patients who worry about privacy can opt out of form completion. However, even with the completion of such a form, the need to assess a patient's comfort in pursuing a discussion remains; the suggestions below might help to facilitate such discussions.

#1: Gauge a Patient's Willingness to Talk about It.

Gauge the patient's willingness to talk about sexual health and sexual minority status with an instrument familiar to most cancer patients. Healthcare providers frequently ask cancer patients about pain and about a variety of other symptoms by requesting that they rate the severity of a specific symptom on a scale of 1 to 10. Hence, it seems reasonable – and patients report the same – to query patients, “On a scale of 1–10 with 10 indicative of you're being really, really comfortable, how comfortable are you in discussing sex-related matters?” If the patient answers with a 0 to 3, the healthcare provider might want to cautiously retreat from the discussion based analogously on responses to validated symptom scales [11]. However, if the patient responds with a higher number, that response should be viewed as a desire on the part of the patient to talk further; and a discussion with the patient about their sexual health should then ensue.

Again, many oncology healthcare providers have described how patients appear to find it easier to divulge issues relevant to sex and sexuality with a form that eventually goes into the medical record. These healthcare providers also describe how they are better prepared at the time of the face-to-face visit with the patient. Nonetheless, we contend using a form only complements the use of a scale.

#2: Ask Early and Repeatedly.

The best timing for asking varies from patient to patient. Some patients are overwhelmed with other information early on, and others wish they had been told about sex-related issues up front. Furthermore, the patient's comfort level in having such a discussion can change over time; not surprisingly, the patient's need for having such a discussion can also change over time. In view of this variability, it seems reasonable to attempt to initiate these discussions early on – again, gauging a willingness to talk with the 1–10 scale. The same scale can then be used for reassessment over time at certain points: the time of first meeting with the patient, when talking about side effects of cancer treatment, after completion of one

component of cancer treatment, and periodically during survivorship care or near the end-of-life.

#3: Make Yourself Comfortable Talking about Sex.

Asking about sexual health and sexual minority status should not be a source of stress for the patient and healthcare provider, particularly as these issues impact the quality of life of the majority of patients with cancer. The American Society of Clinical Oncology reports that as many as 40–80% of cancer patients report sexual concerns [12]. Thus, encouraging healthcare providers to acquire training and integrating queries about sex into a routine checklist during the visit makes it easier for patients to talk about such concerns over time. Importantly, patients have described to us that healthcare provider demographics, such as gender and age, are irrelevant when it comes to ease of discussion. However, patients have also told us that, if a healthcare provider appears ill at ease with these discussions, this sense of uneasiness permeates the entire conversation and makes it difficult for the patient to voice concerns or information about sexual health and sexual minority status.

#4: Use Plain and Direct Language.

Eliminate euphemisms. A healthcare provider's awkwardness in having these discussions often triggers euphemisms, such as "sexual health" or "sexual issues." In our conversations with patients, these terms often resulted in confusion on the part of patients; and, in turn, healthcare providers' appeared to resort to stammering and to time-consuming and convoluted explanations only to witness patients' recoil after an initial attempt to describe their sexual concerns. Direct and simple language -- perhaps, "Could you describe your sexual activity." -- appears to make these conversations more effective.

Concluding Comments.

Do older patients struggle with talking about sexual issues more so than younger patients? To our knowledge, comparative data between older and young patients with cancer are unavailable. However, in our discussions with older cancer patients both within the context of the qualitative data alluded to above and within the context of seeing patients over the years, the age of the patient seems to be a minor factor in determining whether or not these conversations should take place and in deciding their nature and outcome. It might be the healthcare provider -- not the older patient -- who stalls the dialogue.

The omission of these conversations results in older patients' suffering in silence. As cancer healthcare providers, we have talked with older cancer patients who have suffered vaginal pain -- sometimes dyspareunia and sometimes unrelenting, frank pain -- while waiting for a healthcare provider to ask about symptoms and to offer symptom relief, or, at the very least, to provide a referral to a healthcare provider with expertise in the management of pelvic symptoms. We have also encountered at least one older transgender patient who struggled to acquire a gender-affirming, non-gynecology oncology clinic appointment in order that he might find himself in an acceptable environment to receive cancer care for a life-threatening

malignancy that arose within a female organ. Similar situations are likely occurring quietly at cancer centers everywhere.

The more cancer healthcare providers ask all adult patients, regardless of their age, about sexual health and sexual minority status, the more skilled they will become at doing so and the more proficient they will be at providing high-quality cancer care to everyone. As one colleague explained, “You know, we’re sexual beings up until we die.”

Support:

Research reported in this publication was supported by the National Cancer Institute of the National Institutes of Health under the Award Number UG1CA189823 (Alliance for Clinical Trials in Oncology NCORP Grant) and U10CA180790. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health. <https://acknowledgments.alliancefound.org>.

REFERENCES

1. Maragh-Bass AC, Torain M, Adler R, et al. Risks, benefits, and importance of collecting sexual orientation and gender identity data in healthcare settings: a multi-method analysis of patient and provider perspectives. *LGBT Health* April 1, 2017.
2. Cathcart-Rake EJ, Zemla T, Jatoi A, et al. Acquisition of sexual orientation and gender identity data among NCI Community Oncology Research Program practice groups. *Cancer* 125:1313–1318.
3. Sobocki JN, Curlin FA, Rasinski KA, Lindau ST. What we don’t talk about when we don’t talk about sex: results from a survey of US obstetrician/gynecologists. *J Sex Med* 2012; 9:1285–94. [PubMed: 22443146]
4. <https://www.healthyagingpoll.org/>; last accessed June 24, 2019.
5. <https://www.apa.org/pi/lgbt/resources/sexuality-definitions.pdf>; last accessed June 24, 2019.
6. Witten TM. End of life, chronic illness, and trans-identities. *J Soc Work End Life Palliat Care* 2014; 10:34–58. [PubMed: 24628141]
7. Kamen CS, Alpert A, Margolies L, et al. “Treat us with dignity:” a qualitative study of the experiences and recommendations of lesbian, gay, bisexual, transgender, and queer (LGBTQ) patients with cancer. *Support Care Cancer* 2019; 27:2525–2532. [PubMed: 30411237]
8. Lesbian Kamen C., gay, bisexual, and transgender survivorship. *Seminars in Oncology Nursing* 2018; 34:52–59. [PubMed: 29275016]
9. Kamen C, Jabson JM, Mustian KM, Boehmer U. Minority stress, psychosocial resources, and psychological distress among sexual minority breast cancer survivors. *Health Psychol* 2017; 36:529–537. [PubMed: 28165265]
10. Bristowe K, Hodson M, Wee B, et al. Recommendations to reduce inequalities for LGBT people facing advanced illness: ACCESSCare national qualitative interview study. *Palliat Med* 2018; 32:23–35. [PubMed: 28502218]
11. Boonstra AM, Stewart RE, Koke AJA, et al. Cut-off points for mild, moderate, and severe pain on the numeric rating scale for pain in patients with chronic musculoskeletal pain: variability and influence of sex and catastrophizing. *Front Psychol* 2016; 7:1466. [PubMed: 27746750]
12. Griggs J, Maingi S, Blinder V, et al. American society of clinical oncology position statement: strategies for reducing cancer health disparities among sexual and gender minority populations. *J Clin Oncol* 2017; 35:2203–2208. [PubMed: 28368670]