Journal of Cancer Research and Clinical Oncology (2019) 145:495–502
https://doi.org/10.1007/s00432-018-2813-3

ORIGINAL ARTICLE – CLINICAL ONCOLOGY

Gynecologic radiation oncology patients report unmet needs regarding sexual health communication with providers

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Received: 27 November 2018 / Accepted: 4 December 2018 / Published online: 11 December 2018

Abstract

Purpose Following radiation therapy (RT), women with gynecologic malignancies report high rates of sexual dysfunction, but little is known regarding sexual health communication between these patients and health-care providers. This study assessed these patients' beliefs/attitudes toward providers' sexual history taking.

Methods Surveys were administered to women who presented for follow-up care for gynecologic cancers in an academic radiation oncology department. The surveys assessed patient sexual health beliefs and inquiry preferences. Sexual functioning was assessed using the Female Sexual Function Index (FSFI). Ordered logistic regressions were performed to assess for correlations between survey responses, FSFI, and demographic characteristics.

Results Seventy-five subjects participated. Most (89.8%) had FSFI scores indicating sexual dysfunction. Most patients agreed that sexual function is an important component of overall health (78.7%) and that providers should inquire regularly (62.8%). Few (12.0%) reported embarrassment around provider discussions. Most (62.7%) preferred discussion with female providers, especially married patients ($p=0.03$). Half (53.4%) agreed that sexual problems are an unavoidable part of aging, a view that was more common as education level decreased ($p=0.01$). Most (62.7%) patients agreed that providers should regularly ask about their sexual history, with patients having significant differences in education level. Patients with low FSFI scores were less likely to report inquiry from their OB/Gyn ($p=0.03$).

Conclusions Gynecologic cancer radiotherapy patients want to discuss sexual health, but report suboptimal provider inquiry. Patient views and experiences varied based on marital status, education level, and FSFI score. This work highlights the need for improved sexual health communication between cancer patients and providers.

Keywords Sexual dysfunction · Sexual history taking · Radiation therapy · Gynecological cancer

Introduction

Women receiving pelvic radiation therapy (RT) for gynecologic cancers often suffer from sexual dysfunction (Damast et al. 2012; Incrocci and Jensen 2013; Song et al. 2012). This is frequently a result of a multifactorial process involving biological (cancer and treatment related), psychological, and social factors (Sadovsky et al. 2010). Women who experience sexual dysfunction often report reduced quality of life as well as overall health, with many suffering from

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low self-esteem, frustration, confusion, embarrassment, and discontent (Anastasiadis et al. 2002; Moreira et al. 2006).

To maximize patients' quality of life, sexual health of gynecologic cancer patients must be addressed. Obtaining an accurate sexual history from patients at risk of experiencing sexual dysfunction can lead to referral to specialists who can provide relevant care. Despite the importance of discussing sexual health, both primary care and specialist physicians frequently omit taking a complete sexual history (Hinchliff and Gott 2011; Sobecki et al. 2012). Physicians have cited lack of time and training, lack of effective treatment options, perceived patient embarrassment, and personal discomfort as barriers to regular inquiry (Goldstein et al. 2009; Roos et al. 2012). Patients have expressed hesitancy to disclose sexual health information due to fear of being dismissed or embarrassed (Geiss et al. 2003; Roos et al. 2012). While many patients do wish to speak to their physicians about their sexual health, many are not comfortable initiating this conversation (Ekwall et al. 2003; Hendren et al. 2005; Juraskova et al. 2003; Stead 2003). As a result, a lack of effective communication surrounding the sexual history presents a barrier to improving quality of life outcomes in this patient population. This is significant because undiagnosed or untreated sexual dysfunction can lead to depression and social withdrawal, and one-quarter of adults with a sexual problem report avoiding sex due to their dysfunction (Araujo et al. 1998; Nicolosi et al. 2004). It is essential to identify and rectify these barriers, as patients who report good communication with their physicians also report higher satisfaction with care and are more likely to share pertinent information with providers and adhere to prescribed treatments (Alazri and Neal 2003; Arora 2003; Chen et al. 2007; Greenfield et al. 1985; Hall et al. 1981; Harmon et al. 2006; Herndon and Pollick 2002; Kaplan et al. 1989; Kindler et al. 2005; O'Keefe 2001; Roter 1983).

In this study, we aimed to characterize the beliefs and preferences regarding sexual health history taking in female patients receiving pelvic RT for gynecological malignancies. A better understanding of how these patients view their sexual function in context of their disease and overall health should offer physicians a valuable perspective on this important, but often neglected component of patient care.

Methods

Participants

Institutional Review Board approval was obtained for this study (HUM00080992). Women presenting for follow-up care in the Department of Radiation Oncology at Michigan Medicine were asked to participate in this study. Patients eligible for this cross-sectional survey study were all women who had been treated with pelvic RT (external beam and/or brachytherapy) for gynecologic cancers. Surveys were distributed to sequential patients and collected in person by nursing staff during patient visits, but the patients completed the questionnaires privately. Participation was voluntary and anonymous and informed consent was obtained from all individual participants included in the study.

Assessment

We created a survey for this study to assess patients' attitudes about and experience with sexual history taking in their clinical care. The survey included assessments of attitudes/beliefs surrounding sexual health, quality of life, and sexual function. The questionnaires also included demographic information on type of cancer, race, ethnicity, marital status, preferred gender of sexual partners, and education level. The first portion of the survey asked patients to respond to statements on Likert scales with options including strongly disagree, disagree, neutral, agree, and strongly agree. Survey questions included statements that asked if medical providers should regularly take a sexual history, if being happy with one's sexual life is important for overall well-being, if they are embarrassed to talk about their sexual health, and if they believed sexual decline is unavoidable with age (Table 1). The survey also assessed how often their primary care physician and obstetrician/gynecologist (OB/Gyn) inquired about sexual health, in addition to how and to whom they preferred to give their sexual health history. The surveys also included the 19-item Female Sexual Function Index (FSFI), a validated questionnaire for self-assessment of sexual function (Cronbach's α values of 0.82 and higher for each domain) (Baser et al. 2012; Rosen et al. 2000). FSFI domains include desire, subjective arousal, lubrication, orgasm, satisfaction, and pain(Rosen et al. 2000). Higher FSFI scores indicate better sexual function, and a total score ≤ 26.5 has been validated as a cutoff score for sexual dysfunction (Wiegel et al. 2005). Patients completed paper versions of the survey, and study data were then collected and managed using REDCap electronic data capture (Harris et al. 2009).

Data analysis

Frequency statistics were used in describing sample demographic characteristics and responses to the first portion of the survey. FSFI total scores were calculated according to the authors' algorithm (Rosen et al. 2000). Frequency statistics described the sample's scores on the FSFI. Ordered logistic regression was carried out with demographic variables and FSFI scores to identify predictors of agreement with survey statements. Missing responses to survey questions are recorded in the accompanying figures, but were

Table 1 Descriptive characteristics of surveyed patients, $n=75$

Type of cancer	
Endometrial	21 (28.0%)
Cervical	15 (20.0%)
Uterine	14 (18.7%)
Vulvar	2 (2.7%)
Vaginal	1 (1.3%)
Unknown	22 (29.3%)
Race	
White	65 (86.7%)
African American	6 (8.0%)
American Indian/Alaska native	2 (2.7%)
Asian	1 (1.3%)
Missing	2 (2.7%)
Ethnicity	
Non-Hispanic	54 (72.0%)
Hispanic	2 (2.7%)
Unknown	19 (25.3%)
Marital status	
Married	41 (54.7%)
Single	9 (12.0%)
In a relationship	8 (10.7%)
Divorced	9 (12.0%)
Unknown	1 (1.3%)
Sexual partners	
Men	67 (89.3%)
Women	2 (2.7%)
Unknown	6 (8.0%)
Education	
Completed high school	18 (24.0%)
Some college	22 (29.3%)
Associate's degree	6 (8.0%)
Bachelor's degree	13 (17.3%)
Postgraduate degree	15 (20.0%)
Unknown	1 (1.3%)
Religion	
Christian	61 (82.4%)
Atheist/agnostic	1 (1.3%)
Other	7 (9.5%)
Black	5 (6.8%)

not included in in the regression models. Analysis was performed in Stata Version 15.

Results

Demographics

Seventy-five women completed the survey. The cohort was predominantly white (86.7%), married (54.7%), heterosexual (89.3%), and Christian (82.4%), which is largely representative of the adult patient population at Michigan Medicine. The distribution of cancer sites was as follows: endometrial, cervical, uterine, vulvar, and vaginal cancer. Table 1 includes more specific demographic information on our cohort of patients.

FSFI results

Women responding to the survey reported low FSFI scores, indicating high rates of sexual dysfunction. The mean FSFI score was 9.9 (SD 10.3), range 1.2–31.8, and 53 of 59 patients (89.8%) who completed the entire FSFI reported scores below the threshold for sexual dysfunction of 26.5. There was a trend toward higher FSFI in those who were married $p=0.055$ (Fig. 1).

Patient views about importance and impact of sexual function

Regarding patient views about their sexual function, the majority (78.7%) of patients surveyed agreed or strongly agreed that being happy with their sexual life is an important part of overall well-being. Half (52.4%) of the patients also agreed that sexual problems were an unavoidable part of aging, while 22.7% disagreed, and 22.7% were neutral. Deceasing education level, but not FSFI score or marital status, was associated with the view that sexual problems are an unavoidable part of aging ($p=0.01$, Fig. 2).

Patient views on whether sexual health should be discussed

Most patients agreed (62.7%) that medical providers should ask about their sexual history on a regular basis. This preference was significantly associated with education level, and strongest among those with some college education ($p=0.02$, Fig. 3) compared to the other four categories. The majority (86.7%) reported that they were not embarrassed (or neutral) to talk about their sexual health with their health-care providers.

Patient preferences on how and with whom sexual health should be discussed

When asked about the gender of the provider with whom patients prefer to discuss their sexual health, most (62.7%) respondents expressed a preference for a female provider, with the remainder expressing no preference; none preferred discussions with a male provider. Marital status (married v. not), but not education or FSFI was associated with this gender preference ($p=0.03$). Regarding preferences for reporting sexual history, patients preferred providing their sexual

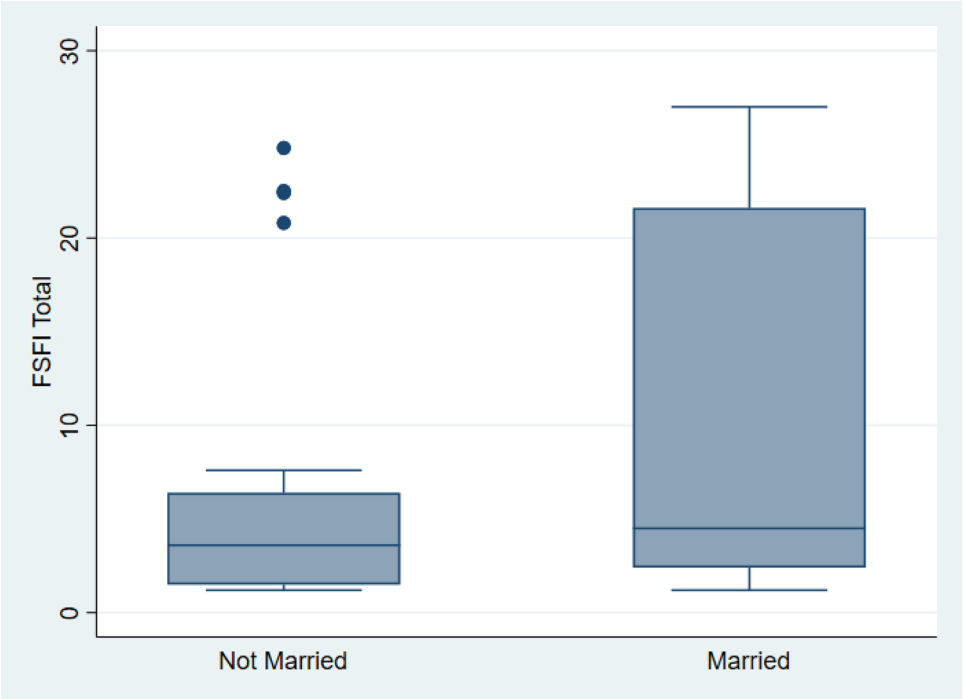

Fig. 1 FSFI score based on marital status

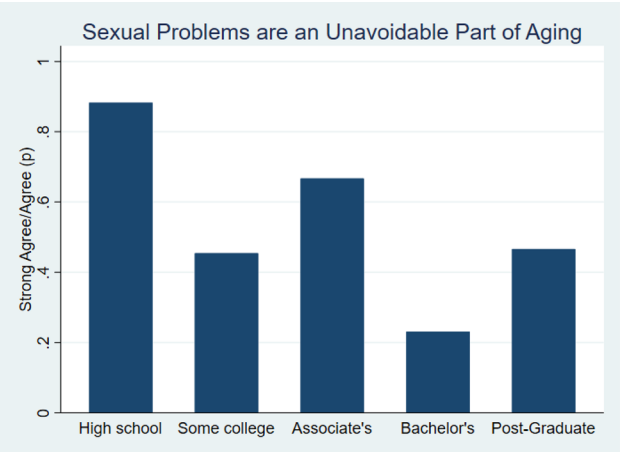

Fig. 2 Responses to "Sexual problems are an unavoidable part of aging" by level of education

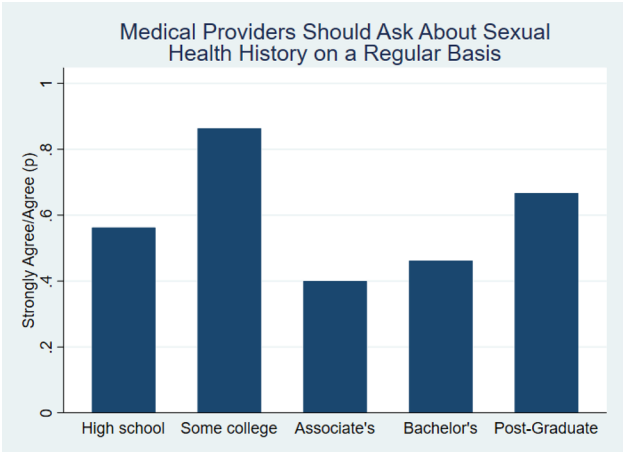

Fig. 3 Responses to "Medical providers should ask about sexual health history on a regular basis by level of education"

health history by filling out a form (29.3%), followed by with OB/Gyn in person (28.0%), with primary care physician in person (16.0%), with nursing staff in person (9.3%), by taking an online survey (4.0%), and 10.7% of patients left this question blank.

Patient-reported experiences regarding provider sexual health inquiry

Regarding patient-reported communication about sexual health, a majority (58.7%) of patients who saw a non-OB/Gyn primary care physician reported never or almost never being asked about their sexual health, and only 4.0% reported always or almost always being asked. Comparatively, only about one-quarter (22.7%) of patients reported never or almost never being asked about their sexual health by their OB/Gyn, while 17.3% reported being asked always or almost always (Table 2). On univariate analysis, decreasing FSFI was associated with lower patient report of sexual health inquiry by a specialist, but not by a primary care provider ($p = 0.03$, Fig. 4). Marital status and education were not significantly associated.

Table 2 Survey questions

	Strongly agree	Agree	Neutral	Disagree	Strongly Disagree	Missing
Medical providers should ask patients about their sexual health history on a regular basis	14.7	48.0	26.7	4.0	2.7	4.0
Being happy with one's sexual life is an important part of overall well-being	20.0	58.7	12.0	0	8.0	1.3
I am embarrassed to talk about sexual health with health-care providers	1.3	10.7	30.7	45.3	10.7	1.3
Sexual problems are an unavoidable part of aging	2.7	50.7	22.7	18.7	4.0	1.3
	Almost always or always	Most times (more than half of the time)	Sometimes (about half of the time)	A few times (less than half o the time)	Almost never or never	Missing
If your primary care provider is not an OB/Gyn, how often has your PCP asked about your sexual health?	4.0	8.0	12.0	13.3	58.7	4.0
How often has your OB/Gyn asked about your sexual health?	17.3	22.7	18.7	16.0	22.7	2.7
	Filling out a form	Taking on online survey	With my OB/Gyn in person	With my PCP in person	With nursing staff in person	Missing
I would prefer to provide my sexual health history	29.3	4.0	28.0	16.0	9.3	13.3
	Female Providers	Male Providers	No preference			
I would prefer to discuss my sexual health history with	62.7	0	37.3			

Discussion

Our study demonstrates that women who have received pelvic RT for gynecologic cancer suffer from high rates of sexual dysfunction, consistent with previous reports on this patient population (Incrocci and Jensen 2013). We found that despite low levels of sexual functioning, women overwhelmingly felt that sexual health is an important and non-embarrassing topic to discuss with providers. Despite their willingness to discuss this important topic, women reported that providers rarely inquired about sexual health. We also identified associations between education level, sexual health inquiry preferences, and views on the inevitability of sexual decline with aging.

The vast majority (78.7%) of the women in this sample felt that being happy with their sexual life is an important component of overall health. In the general population, the American Association of Retired Persons (AARP) has reported that 61.0% of 508 women over 45 surveyed believe that sex is important to overall quality of life as well (Fisher et al. 2010). The increased proportion of patients in our survey agreeing with this statement may be related to higher rates of sexual dysfunction than the general population and a reflection on its impact on quality of life. Sexual activity declines with age in the general population, but a considerable number remain active into advanced age, with the AARP survey revealing that 73% of respondents who were 57–64 years of age, 53% among respondents who were

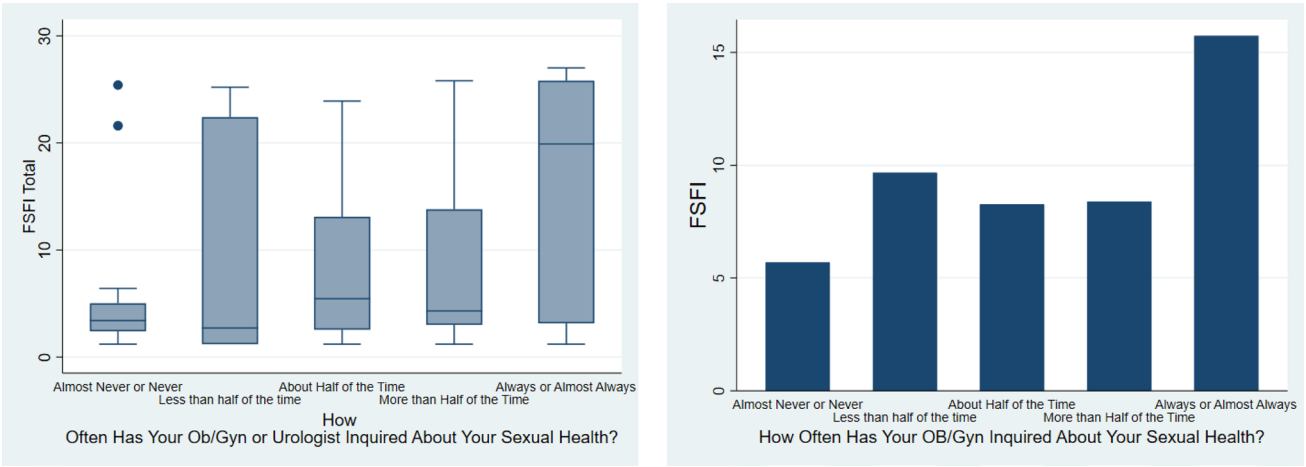

Fig. 4 Responses to "How often has your OB/Gyn or Urologist inquired about you sexual health" by FSFI score median w/box plot (**a**) and mean (**b**)

65–74 years of age, and 26% among respondents who were 75–85 years of age reported being sexually active (Lindau et al. 2007). While RT clearly has a significant impact on sexual function, patients should be counseled that age alone does not necessarily preclude sexual activity.

Very few women reported embarrassment associated with discussing their sexual health with health-care providers. This is a significant finding that could encourage physicians to inquire more often about sexual health in their patients treated with pelvic RT. This result was somewhat unexpected and contradicts a common belief among practitioners that patients are embarrassed to discuss this sensitive topic (Goldstein et al. 2009; Roos et al. 2012). Further, a majority of our patients believe that physicians should regularly ask about sexual health and function, indicating that not only are patients not embarrassed to discuss their sexual health with their physician, but many of them expect to. This corresponds well to previous reports on sexual history taking preferences in women with sexual dysfunction, as reported by the Women's Sexual Health Foundation. In a survey of women suffering from sexual dysfunction, 72.0% of patients stated they would feel comfortable discussing their problems with their physician, but 73% of these patients wanted their physicians to broach the conversation first (Association of Reproductive Health Professionals 2010). Further research should elucidate the optimal intervals for inquiry about sexual health and dysfunction in women who have undergone radiotherapy for cancer.

In our sample of women treated for gynecologic cancer, a majority suffering from significant sexual dysfunction, most patients reported never or almost never being asked by their primary care providers about their sexual function. This is in striking contrast to prostate cancer, where sexual function is serially assessed by providers [often with the aid of validate instruments (Wei et al. 2000)] and is a commonly specified end point in clinical trials (Donovan et al. 2016). Our finding of infrequent sexual health inquiry is in concordance with other data from the general population showing that only 22.0% of women report having discussed sexual health with a physician since age 50 years (Lindau et al. 2007). While patients were queried about their sexual function more often by their OB/Gyn physicians, a quarter of patients report never or almost never being asked about their sexual health in this setting. Although physicians may assume that patients are less concerned about sexual function when undergoing treatment for a serious malignancy (Incrocci 2011), data show than sexual dysfunction is among the most common concerns of female cancer survivors (DeSimone et al. 2014). Additionally, physicians have also reported assumptions regarding patient age, prognosis, and partnered status as reasons to not address sexual function in certain patients (Hordern 2000; Hordern and Street 2007). Our study provides evidence that physicians should engage patients in discussions about their sexual health regardless of their relationship status. This shows a disconnect between physicians and patients and an area that could be improved with better training of physicians.

Regarding preferences related to sexual history collection, filling out a physical form was the number one option selected, followed closely by disclosing in person with their OB/Gyn. In retrospect, reformulating this question to allow patients to rank their order of preference may have given a better picture of patient preferences. Although filling out a form was the most popular choice selected, upon combining results, more patients chose either in person with their OB/Gyn or primary care physician than disclosing this information using an online form. These results indicate a majority of patients are comfortable disclosing this information in

person. It was interesting that so few patients selected filling out an online survey as their most preferred option, as this would potentially offer the most privacy with disclosing such sensitive information. This may not be a big concern of patients surveyed, however, as reported levels of embarrassment were very low. These practices could be adapted for women with gynecologic malignancies, given their similarly high rates of sexual dysfunction after cancer treatment.

Women in our survey showed a strong preference for disclosing their sexual health history to female providers, although one-third indicated no gender preference. In the general population, there is some evidence to suggest that in female–female gender concordant physician–patient relationships, female patients receive increased patient-centered care (Bertakis and Azari 2012). This, in combination with the sensitive nature of the sexual history, could play a role in women preferring female providers in this setting.

There were a few predictive demographic variables of note in our study, particularly related to marital status and education level. Although it is well accepted that the incidence of sexual dysfunction increases with age, it is concerning that patients with less than a college education are more likely to view this decline as inevitable. This disparity should be explored further because it might suggest that patients with lower levels of education are at even higher risk for neglect of discussion and treatment of sexual dysfunction.

Limitations of this study include the relatively small sample size, unknown response rate, and potential self-selection bias in survey completion, which could bias the results in either direction with respect to embarrassment, level of sexual functioning, or other factors. Patients were asked to answer very sensitive questions and previous reports have found that not all patients are entirely truthful when disclosing their sexual health history (Castelo-Branco et al. 2010). We did not collect patient ages, which limits generalizability. Additionally, responses could differ by time since completion of radiotherapy, receipt of other cancer therapies (surgery/chemotherapy) or disease stage/status (localized v. metastatic, active v. no evidence of disease) and we did not collect this information. Additionally, we used formal marital status categories, and other relationship status or sexual activity categorizations might help better interpret the outcomes (e.g., whether or not sexually active within a given timeframe.) This study is valuable because it gave patients an opportunity to anonymously disclose their personal beliefs about sexual function and the sexual history. Patients also reported their own perceptions of what occurs during visits with their primary care and OB/Gyn physicians, offering a valuable perspective on the physician patient relationship.

Overall, this study highlights the need for improvement in communication surrounding sexual health between physicians and patients treated for gynecologic cancer. FSFI scores indicate that women in this population are at high risk for sexual dysfunction and survey results indicate they are not being asked regularly about their sexual function. The results of this study call into question the common notion that patients are embarrassed to talk about their sexual health and show that many patients actually expect physicians to inquire more often. We suggest that health-care providers caring for women with gynecologic cancers more regularly inquire about their patients' sexual health and function as this has potential to improve quality of life in many cancer patients. Providers should also receive training to increase their comfort and confidence in addressing sexual health in their practice with cancer patients, as this currently seems to be an unmet need in this population. Organizations that develop cancer surveillance guidelines could also include sexual health inquiry as a standard component of survivorship care for women with gynecologic malignancies.

Funding Investigator support for MBB was provided by Eunice Kennedy Shriver National Institute of Child Health and Human Development BIRCWH Career Development Award # K12 HD001438. Institutional support for use of the REDCap application was provided through CTSA, National Center for Advancing Translational Sciences Grant UL1TR000433.

Compliance with ethical standards

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Conflict of interest The authors declare that they have no conflict of interest.

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