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Can you ask? We just did! Assessing sexual function and concerns in patients presenting for initial gynecologic oncology consultation

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Abstract

Objectives—To describe patterns of response to, and assess sexual function and activity elicited by, a self-administered assessment incorporated into a new patient intake form for gynecologic oncology consultation.

Methods—A cross-sectional study of patients presenting to a single urban academic medical center between January 2010 and September 2012. New patients completed a self-administered intake form, including six brief sexual activity and function items. These items, along with abstracted medical record data, were descriptively analyzed. Logistic regression was used to assess the association between sexual activity and function and disease status, adjusting for age.

Results—Median age was 50 years (range 18–91, N = 499); more than half had a final diagnosis of cancer. Most patients completed all sex-related items on the intake form; 98% answered at least one. Among patients who were sexually active in the prior 12 months (57% with cancer, 64% with benign disease), 52% indicated on the intake form having, during that period, a sexual problem

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lasting several months or more. Of these, 15% had physician documentation of the sexual problem. Eighteen women were referred for care. Providers reported no patient complaints about the inclusion of sexual items on the intake form.

Conclusions—Nearly all new patients presenting for gynecologic oncology consultation answered self-administered items to assess sexual activity and function. Further study is needed to determine the role of pretreatment identification of sexual function concerns in improving sexual outcomes associated with cancer diagnosis and treatment.

Keywords

Gynecologic neoplasms; Sexuality; Sexual function

Introduction

Female sexual dysfunction is prevalent in the general population, but not routinely assessed in medical care [1,2]. Many studies, across a variety of disease types and patient populations, have investigated the relationship between gynecologic cancer and sexual function in women. Plausible biopsychosocial mechanisms have been proposed, mostly from observational studies, to explain the pathways through which cancer and its treatment can impair female sexual function [3, 4]. Few studies have reported on female sexual function using data collected prior to cancer diagnosis or treatment. A prospective measure of sexual function prior to cancer diagnosis and treatment is needed to establish causal pathways of sexual dysfunction and to inform counseling about prognosis for sexual outcomes after cancer in this patient population.

Although gynecologic oncologists and other cancer care providers recognize female sexual function as a legitimate health issue, several persistent barriers to communication with patients about sexual function in the context of cancer care have been identified [5,6]. Commonly cited barriers include fear of causing patient distress, feeling it is not the physician's responsibility, lack of time or training, perception that sexuality is not important to address at the initial oncology visit, and the belief that patients will or should raise these issues if they have concerns [5,6]. Repeatedly, in studies of cancer patients and the general adult population, women of all ages say that they value their sexual function, regard sexual function as relevant for health, and feel it is appropriate to discuss matters of sexuality with a physician [7–10]. Several studies have shown that women and men, of all ages and across health conditions, feel that the physician should initiate discussions of or counseling about sexual matters [7,11–13].

This study uses data collected by the Program in Integrative Sexual Medicine for Women and Girls with Cancer (PRISM) in the Section of Gynecology Oncology at the University of Chicago. PRISM aims to provide evidence-based patient care while systematically learning how to improve prevention, diagnosis and treatment of sexual disorders in this patient population. The objectives of the current study were twofold. First, we aimed to assess whether new patients presenting for gynecologic oncology consultation would answer questions regarding sexuality on a clinic intake form. Second, we aimed to establish the prevalence and physician recognition of sexual activity and function concerns in this

population. We hypothesized that rates of patient cooperation with sexual function assessment would be high, as would rates of sexual activity and sexual function concerns.

Materials and methods

Study design and eligibility

This cross-sectional, retrospective chart review assessed responses to a brief set of sexuality items among patients presenting for gynecologic oncology consultation at the University of Chicago Comprehensive Cancer Center between January 2010 and September 2012.

Three physicians in the gynecologic oncology practice at the time of the study participated. Patients were considered eligible for inclusion if they were 18 years of age or older, did not have a history of prior treatment for a gynecologic malignancy, and had a completed intake form in the medical record. Each patient was assigned an anonymous, unique numerical identifier.

All procedures and protocols were reviewed and approved by the Institutional Review Board at the University of Chicago. Because the study was a retrospective chart review of data obtained in the course of routine patient care, and all personal health information (PHI) was de-identified, the project was granted approval with a waiver of consent. To minimize the risk of including a patient who may not have wished to participate, the participating physicians were asked to review a list of their own patients meeting inclusion criteria and were given the opportunity to exclude any patient for any reason. These patient records were not included in the study.

Data collection

The sexuality items were embedded in the self-administered New Patient Information and Medical History Form (University of Chicago, Department of Obstetrics and Gynecology, Section of Gynecologic Oncology, 2008) which all new patients were requested to complete. Typically, patients received the intake form via email, mail or fax, to complete and return in advance of the visit, but some completed the intake form at the clinic before the physician visit. The location of form completion was not documented. Forms were considered incomplete if fewer than half of all items were answered.

The intake form queried patient demographic characteristics, personal medical and surgical history, obstetric and gynecologic history, family health history, medications and allergies, social history and a detailed review of systems checklist, including the yes/no item: "problems with sexual functioning." Following the review of systems checklist, the intake form included five additional items adapted, with input from the gynecologic oncology physicians, from items used in other studies to assess female sexual activity and function in the general population (Table 1) [14–16]. Incorporating input from the gynecologic oncologists, these items were preceded by this statement: "To ensure that we are addressing all aspects of your health, we ask you to complete the following questions." The brief items assessed sexual partnership status, current (past 4 weeks) and recent (past 12 months) sexual activity status, persistent sexual problems (among people who reported recent sexual activity), and importance of sex to life. Each item was formatted with space for patients to

write in additional information. In contrast to general population surveys [16–18], a definition for the term “sexual activity” was not provided on the intake form. These questions were added to the end of the intake form, following the review of systems checklist.

For this study, patient age, marital status, menopausal status, hormone replacement use history, select review of systems responses, and responses to the sexuality assessment items were abstracted from the intake form. Menopause was not defined on the intake form; patients were asked (yes/no): “Are you post-menopausal?” Additional data were abstracted from the electronic health record, including: race and ethnicity; pathology diagnosis (hereon referred to as disease status), and physician documentation of, discussion about or recommendations for managing sexual function concerns that had been identified by the patient on the intake form or during the index visit.

Statistical analysis

Descriptive statistics were used to summarize cooperation rates, sexuality item responses, and patient demographic and health characteristics. Chi-square tests or Fisher’s exact tests were used to examine the association between responses to the sexuality items and key demographic and health characteristics. The response rates for questions were compared using McNemar’s test for correlated proportions since the response rates were based on the same sample of patients. Multivariable logistic regression was used to examine the association between disease status (benign vs. malignant) and sexual outcomes, controlling for age. Analyses were performed using Stata software (version 12.1; Stata Corp., College Station, TX).

Results

Between January 2010 and September 2012, 861 unique new patients were seen in the gynecologic oncology clinic for consultation by participating physicians; 92 patient charts (10.7%) could not be located on site. Of 769 charts (89.3%) available for review, 499 were included. Charts were excluded if the intake form was missing or incomplete ($n = 122$), the patient was found to have received prior treatment for gynecologic malignancy ($n = 88$), or by participating physician exclusion ($n = 59$). Cited reasons for physician exclusion included the patient being in hospice or terminal status at the time of consultation, or physician belief that the patient would not have wanted to be included. One chart was excluded due to patient age less than 18 years (Fig. 1).

Patient demographic and health characteristics are summarized in Table 2. Median patient age was 50 years (range 18–91); almost half were post-menopausal at the time of initial consultation. Sixty percent of patients were currently married or had a life partner (Table 2). Definitive pathology diagnosis was available for 91% of patients. Of these, 57% were found to have cancer. Patients without a final diagnosis recorded by the end of the study period ($n = 44$, “cancer status unknown”) were either managed conservatively for presumed benign disease or did not follow up for a diagnostic procedure. Endometrial (41%) and breast (16%) cancers were the most prevalent cancer types. Patients older than 50 years were more likely to be diagnosed with cancer (70% versus 44% of patients < 50 years of age, $p < 0.001$).

Non-response rates for the partner and sex-related items ranged from 7% to 12%; 98% of patients completed at least one of the sex-related questions and 70% of patients completed all of the items for which they were eligible. The non-response rate for the item “concerns about sexual functioning” in the review of systems checklist was 7%. This was similar to non-response to the review of systems checklist items “anxiety interfering with life” (6.2%, $p = 0.53$) and “feelings of depression” (6.4%, $p = 0.65$), but was significantly higher compared to the non-response rates for “hot flashes” (4.6%, $p = 0.03$) and “unexplained weight loss or weight gain” (4.0%, $p = 0.003$). Non-response rates for the other sexuality items were as follows: 7% for sexual partnership, 12% for sexual importance, 10% for sex in the past 12 months, 10% for sex in the past 4 weeks, and 7% for the question regarding sexual problems in the past 12 months.

Sixty-one percent of all patients reported being sexually active in the past 12 months (57% of women with cancer, 64% of women with benign disease, $p = 0.15$). Thirty-nine percent of patients overall reported sexual activity in the past 4 weeks (30% of those with cancer and 49% of those with benign disease, $p < 0.001$). When looking only at women who were sexually active in the past 12 months, 67% reported sexual activity in the past 4 weeks: 55% of women with cancer, 79% of women with benign disease, $p < 0.001$ (Table 2). The difference in sexual activity in the past 4 weeks by disease status remained statistically significant once adjusted for age (AOR = 0.36, 95% CI (0.19, 0.67), $p = 0.001$).

More than two-thirds of patients reported having a current romantic, intimate or sexual partner (Table 3); approximately 20% of these women identified their marital status as single, widowed or divorced. In addition, more than half of post-menopausal women and a quarter of women ages 71–91 years reported a current romantic, intimate or sexual partner. Patients with cancer were less likely to report having a romantic, sexual or intimate partner than patients with benign disease, 63% and 74%, respectively ($p = 0.02$). This difference was no longer significant when adjusted for age (AOR = 0.94, 95% CI (0.59, 1.49), $p = 0.78$).

The prevalence of “problems with sexual functioning” identified in the review of systems checklist was 9% of all patients (10% of those who were sexually active in the prior 12 months) presenting for initial gynecologic oncology consultation and was similar among patients with cancer and benign disease status ($p = 0.71$). Fifty-two percent of sexually active patients responded that there had been a period of several months or more in the prior 12 months when they had experienced sexual problems such as lack of interest, dryness, pain, or difficulty with orgasm “a few times,” or more often; this did not differ by disease status ($p = 0.99$). Of the 130 sexually active patients who reported a sexual problem on the self-administered intake, 15% had a sexual problem documented in their index visit physician note. Eighteen women had physician documentation of a referral for specialized care for women with cancer and sexual concerns. Twelve patients included in this study were seen for consultation in the PRISM clinic.

Overall, 62% of patients rated sex as a “moderately,” “very” or “extremely” important part of their life (83% among sexually active versus 27% among inactive women, $p < 0.001$); and 21% felt it was “not at all” important (4% of sexually active versus 52% among inactive

women, $p < 0.001$). Women 50 years and younger were more likely to rate sex as “moderately” to “extremely” important than those older than 50 years (77% vs. 44%, respectively; $p < 0.001$). Fifty-eight percent of patients with cancer and 67% of those with benign disease felt that sex was “moderately” to “extremely” important ($p = 0.04$). This difference was no longer statistically significant after adjusting for age (AOR = 0.96, 95% CI (0.61, 1.51), $p = 0.86$).

During the study period, gynecologic oncology providers reported no patient complaints about the inclusion of sexual items on the intake form.

Discussion

Despite a growing appreciation of the importance of addressing sexual function concerns among female cancer patients, normative data on pre-treatment sexual function in this population are limited. This study finds that more than half of women seeking initial gynecologic oncology consultation, who had been sexually active in the past year, were also sexually active in the four weeks prior to presentation. Patients found to have cancer were significantly less likely to report sexual activity in the past 4 weeks, even when adjusting for age. Several studies have sought to evaluate changes in sexual function in relation to specific medical interventions, such as pelvic exenteration [19,20], but few have described function prior to treatment. This study reports pretreatment sexual function across all patients presenting for gynecologic oncology consultation. This initial gynecologic oncology consultation provides an important opportunity to assess and document pre-diagnosis and pre-treatment sexual function.

Our findings reveal that virtually all patients seen for consultation at a single urban academic medical center were willing to answer self-administered questions regarding sexuality on an intake form. Response rates for the sexual activity and function questions ranged from 88% to 93%, and were comparable to response rates for other portions of the form. The intake form has been revised since this study to eliminate redundant items and to reorder items so they flow more logically (Supplementary material S1). These changes included moving the sexuality items up to flow logically in the form, rather than left at the end of the form. Originally, these items were added at the end because providers were concerned that patient reaction to these items could affect completion of the rest of the form, a concern that did not pan out. This method of collecting pre-treatment sexual activity and function information has several benefits. The use of self-administered questions avoids many of the commonly cited barriers given by providers for not addressing these issues [6,21]. Inclusion of sexual function issues on an intake form also elevates the issue of sex from the taboo to an issue as worthy of attention as other components of overall health and well-being [22]. Finally, broaching the topic of sexual function in this way may be less threatening for both patients and physicians, and therefore may facilitate discussion of these issues prior to, during and after treatment [22]. This study should help to eliminate previously reported physician concerns about causing patient distress or harm by inquiring about sexual issues in the context of cancer care for women [6,21].

In addition to demonstrating that most patients will answer these questions, our results also give an account of pre-treatment sexual activity and function in this patient population. These findings indicate that sexual function concerns are prevalent among women presenting for gynecologic oncology consultation, with just over half of sexually active women reporting a sexual function concern in the past year. Of note, problems were not more common in patients with cancer than those with benign disease. These clinical results were compared to population-based findings from the 2005–06 National Social Life, Health and Aging Project (NSHAP) [16]. The rate of sexual partnership in the current study was consistent with that reported in NSHAP, but a higher proportion of similar aged women in this clinical study reported that sex was not at all important (45% vs. 35% in NSHAP). Among sexually active women, 68% of women ages 57–85 in this clinical study, as compared to 70% of same age women in the general population based on NSHAP, reported at least one sexual problem persisting several months or more in the prior 12 months. This clinical study used a single question to assess for any one of the several kinds of sexual problems, whereas NSHAP assessed each kind of problem separately. Still, among patients who were sexually active in the prior 12 months, the rate of endorsement (52%) was several fold higher with this item as compared to the general item in the review of systems checklist (10%). A recent psychometric study of sexual function assessment in a population-based sample of women with and without cancer similarly found a higher rate of problems when each problem was assessed individually (unpublished written correspondence with K. Flynn, 07/28/2014); information that may be useful for the development of future self-administered items.

This study may be limited in its generalizability to women presenting in other care settings or those with concern for a different cancer type. Additionally, the sexual function questions were added to the intake form to improve patient care and facilitate utilization of resources, but were not intended initially for research purposes. Data collection was thus limited to these particular questions. Distress related to sexual concerns, a factor that is routinely addressed in our female sexual medicine clinic, was not included in the brief measures on the gynecology oncology intake form. It is possible that distress related to a patient's sexual concern was communicated during or perceived by the treating physician and could have influenced the physician's documentation of the problem or the decision to refer the patient for specialty care. Similarly, data collection was limited to those patients with available intake forms that were at least partially completed. This retrospective study was not able to evaluate whether inclusion of the sex-related questions contributed to overall non-cooperation or insufficient completion of the self-administered intake form.

In addition to showing patient cooperation with such an assessment, our results also revealed that practitioners were unlikely to address such issues, even when presented with the information. Only 15% of patients who indicated a sexual problem had either documentation of the problem in the note or evidence of referral for specialty care. This issue highlights the critical importance of improving both provider education and resources regarding these issues. As reviewed in the Introduction, there are many reported barriers to addressing sensitive issues such as patient sexual function, particularly at an initial consultation. Despite agreement among patients and physicians regarding the importance of discussing sexual activity and function concerns, these discussions are not yet part of the routine

assessment of most gynecologic oncologists. These findings should inform a shift in gynecologic oncology practice to include sexual function in the broader, routine assessment of physical function in patients presenting for consultation. While a proportion of patients may feel that sex is not at all important, we are unable to predict which patients will fall into this category, and many in this study were still willing to answer some sex-related questions; therefore all patients should be assessed before treatment. Such routine assessment is also supported by the National Comprehensive Cancer Network Clinical Practice Guidelines in Oncology for Survivorship (NCCN Guidelines®) which state, “At regular intervals, female cancer survivors should be asked about their sexual function, including their sexual functioning before cancer treatment, their present activity, and how cancer treatment has impacted their sexual functioning and intimacy” [23]. To minimize recall bias, the best time to assess sexual function before cancer treatment is before cancer treatment. Further study is needed to determine whether early identification of sexual function concerns impacts long-term sexual outcomes associated with cancer diagnosis and treatment.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <http://dx.doi.org/10.1016/j.ygyno.2015.01.451>.

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HIGHLIGHTS

- Sexual function in new gynecologic oncology patients is unknown.
- Most patients answered sex-related questions on a new patient intake form.
- More than half of sexually active patients who responded reported a sexual problem.

Fig. 1.
Enrollment flow diagram.

Table 1

Sexual function and activity questions.

Review of Systems: Please check yes if you have recently experienced any of the following	
Problems with sexual functioning? (within Review of Systems)	<ul style="list-style-type: none">• Yes• No
To ensure that we are addressing all aspects of your health, we ask you to complete the following questions	
1. Do you have a romantic, intimate, or sexual partner?	<ul style="list-style-type: none">• Yes• No
2. Have you been sexually active during: the past 12 months? ^a (If no, please go to question 4) the past 4 weeks? ^a	<ul style="list-style-type: none">• Yes• No
3. During the last 12 months, has there ever been a period of several months or more when you experienced sexual problems such as lack of interest, dryness, pain, difficulty with orgasm? ^a	<ul style="list-style-type: none">• Almost always or always• Most times (more than half the time)• Sometimes (about half the time)• A few times (less than half the time)• Almost never or never
4. How important a part of your life would you say that sex is? ^a	<ul style="list-style-type: none">• Extremely important• Very important• Moderately important• Somewhat important• Not at all important

^a Area available for patient to write comments after each of these questions

Table 2Demographics and clinical data (n = 499).^a

Variable	No. of women (%)
Age, years	
Median (range)	50 (18–91)
Age group	
18–30	46 (9.2)
31–50	210 (42.1)
51–70	192 (38.5)
71–91	51 (10.2)
Race/ethnicity ^b	
White, non-Hispanic	266 (65.8)
African American, non-Hispanic	96 (23.8)
Hispanic, Asian, other	42 (10.4)
Marital status ^c	
Married/life partner	289 (60.2)
Single/divorced/widowed	191 (39.8)
Menopausal status ^d	
Pre-menopausal	242 (55.4)
Post-menopausal	195 (44.6)
Median age of menopause, y	50
Hormone replacement therapy use ^e	
None	451 (93.8)
History of hormone replacement therapy	30 (6.2)
Final diagnosis	
Benign disease	196 (39.3)
Cancer	259 (51.9)
Unknown	44 (8.8)
Cancer type ^f	
Endometrial	106 (40.9)
Breast	41 (15.8)
Cervical	39 (15.1)
Ovarian, fallopian tube, peritoneal	39 (15.1)
Other	29 (11.2)
Vulvar	7 (2.7)
Gestational trophoblastic neoplasia	6 (2.3)
Vaginal	3 (1.2)
Sexual activity in the past 12 months ^g	271/447 (60.6) ^h
Sexual activity in the past 4 weeks ^{g,i}	165/245 (67.3) ^h

^aNot all individuals responded to each field.

^b Race and ethnicity was unknown in 95 patients.

^c Marital status was unknown in 19 patients.

^d Menopausal status was unknown in 62 patients.

^e History of hormone replacement therapy use was unknown in 18 patients.

^f Eleven patients had more than one cancer diagnosis.

^g The response category “yes” was used.

^h No. of respondents/total number (%).

ⁱ The patient was only asked to answer this question if they answered “yes” to “Have you been sexually active in the past 12 months?”

Table 3Responses to sexual function questions.^a

Variable	No. of respondents/total no. (%)			
	Romantic/intimate/sexual partner ^b	Importance of sex ^c	Problems with sexual functioning ^b	Sexual problems in the last 12 months ^{d,e}
Overall	315/466 (67.6)	274/440 (62.3)	41/464 (8.8)	130/252 (51.6)
Age, years	p < 0.001	p < 0.001	p = 0.05	p = 0.28
18–30	38/42 (90.5)	29/41 (70.7)	8/45 (17.8)	19/30 (63.3)
31–50	160/203 (78.8)	158/203 (77.8)	20/201 (9.9)	72/150 (48.0)
51–70	105/174 (60.3)	78/158 (49.4)	12/171 (7.0)	38/68 (55.9)
71–91	12/47 (25.5)	9/38 (23.7)	1/47 (2.1)	1/4 (25.0)
Race/ethnicity	p = 0.001	p = 0.04	p = 0.45	p = 0.79
White, non-Hispanic	172/246 (69.9)	153/231 (66.2)	18/248 (7.3)	78/151 (51.7)
African American, non-Hispanic	46/93 (49.5)	43/85 (50.6)	7/88 (7.9)	17/35 (48.6)
Hispanic, Asian, other	27/37 (73.0)	23/36 (63.9)	5/39 (12.8)	10/17 (58.8)
Marital status	p < 0.001	p < 0.001	p = 0.20	p = 0.06
Married/life partner	240/269 (89.2)	188/261 (72.0)	27/268 (10.1)	99/179 (55.3)
Single/divorced/widowed	67/181 (37.0)	83/166 (50.0)	12/182 (6.6)	28/67 (41.8)
Menopausal status	p < 0.001	p < 0.001	p = 0.33	p = 0.02
Pre-menopausal	181/233 (77.7)	171/227 (75.3)	22/231 (9.5)	77/166 (46.4)
Post-menopausal	102/181 (56.4)	74/161 (46.0)	12/176 (6.8)	40/62 (64.5)
Final diagnosis	p = 0.02	p = 0.04	p = 0.71	p = 0.99
Benign disease	132/179 (73.7)	116/172 (67.4)	16/185 (8.7)	54/103 (52.4)
Cancer	157/248 (63.3)	133/231 (57.6)	23/237 (9.7)	66/126 (52.4)

^aNot all individuals responded to each sex-related question. Response rates varied from 88% to 93%. Race/ethnicity was unknown for 95 patients, marital status was unknown for 19 patients, menopausal status was unknown for 62 patients, and final diagnosis was unknown for 44 patients.

^bThe response category “yes” was used.

^cThe response categories “moderately”, “very”, and “extremely” important were combined.

^dThe patient was only asked to answer this question if she answered “yes” to “Have you been sexually active in the past 12 months?”.

^eThe response categories “a few times”, “sometimes”, “most of the time”, and “almost always/always” were combined.