

Assessing Gynecologic and Breast Cancer Survivors' Sexual Health Care Needs

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BACKGROUND: The objective of this study was to identify patterns of interest in receiving care for sexual concerns among women who were survivors of gynecologic and breast cancers. **METHODS:** Survey and medical records data were collected from June 2008 to March 2009 from 261 gynecologic and breast cancer patients. Logistic regression was used to estimate the effect of age and months since treatment on interest in receiving sexual healthcare. **RESULTS:** The mean participant age was 55 years (range, 21-88 years). Only 7% of women had recently sought medical help for sexual issues, yet 41.6% were interested in receiving care. Greater than 30% responded that they would be likely to see a physician to address sexual matters, and 35% of all women were willing to be contacted if a formal program was offered. Compared with older women (aged >65 years), younger women (ages 18-47 years) were significantly more likely to report interest in receiving care to address sexual issues (odds ratio [OR], 2.94; 95% confidence interval [CI], 1.14-7.54) and to see a physician to address sexual matters (OR, 4.51; 95% CI, 1.51-13.43), and they were more willing to be contacted for a formal program (adjusted OR [AOR], 5.00; 95% CI, 1.63-15.28). Compared with women who were currently in treatment, women who last received treatment >12 months previously were significantly more interested in receiving care (AOR, 2.02; 95% CI, 1.02-4.01) and were more willing to be contacted (AOR, 2.49; 95% CI, 1.18-5.26). **CONCLUSIONS:** Greater than 40% of survivors expressed interest in receiving sexual healthcare, but few had ever sought such care. The current results indicated that there is an unmet need for attention to sexual concerns among women with gynecologic and breast cancers. *Cancer* 2011;117:2643-51. © 2010 American Cancer Society.

KEYWORDS: gynecologic neoplasms, breast neoplasms, sexuality, sexual dysfunction psychological, sexually dysfunction physiologic, needs assessment, quality of life.

Among nearly 5.9 million women who are cancer survivors, the majority have breast or gynecologic cancers.¹ Cancers affecting the breasts and genital tract and the treatment of these cancers almost always have some effect on sexual function in women. Several studies have documented significant and lasting sexual morbidity in this population, including severe dyspareunia, decreased sexual interest and satisfaction, vaginal dryness, difficulty experiencing arousal and orgasm, and body image concerns that interfere with desire, feelings of attractiveness or femininity, and overall quality of life.²⁻⁸ Despite well documented sexual dysfunction in women with gynecologic and breast cancers, little has been done clinically to address psychological or physiologic sexuality issues.

Studies of women with and without cancer repeatedly indicate that women across the life course value sexuality as an important part of life and health and believe it appropriate to discuss sexual issues with a physician.^{2,9} Yet physicians, including oncologists who care for women with breast and genital tract cancers, often omit the topic or inadequately counsel patients about the sexual implications of their cancer or cancer treatment, citing lack of time, knowledge, experience, and resources for support among their reasons.^{5,10} Vaginal and cervical cancer survivors rate their satisfaction with quality of sexual health information and services significantly lower than overall cancer care, and 62% report having never had a physician-initiated conversation about the sexual effects of cancer or treatment. In addition, those who had not had a discussion with a physician were significantly more likely to report having complex sexual morbidity.² A 2002 British survey of 43 gynecologists, medical and

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How interested are you in receiving care to address sexual issues?	• Very interested • Somewhat interested • Not at all interested
How likely is it that you would come to see one of our colleagues to have sexual matters addressed?	• Very likely • Somewhat likely • Unlikely • Very unlikely
Have you recently sought advice or medical help for problems related to sexuality?	• Yes • No
If you have sought help for problems related to sexuality, how satisfied were you with the care you received?	• Very satisfied • Somewhat satisfied • Dissatisfied • Very dissatisfied
Would you be willing to be contacted if we develop a formal program to address sexual issues for women?	• Yes • No

Figure 1. The sexual health needs assessment questionnaire is shown.

gynecologic oncologists, and nurses reported that 98% of providers believed that sexual issues should be discussed, but only 21% actually discussed these issues with patients.¹⁰ The objective of the current study was to identify patterns of interest in receiving care for sexual concerns among female survivors of breast and gynecologic cancers to inform the development of an evidence-based, multidisciplinary approach to sexual healthcare for this population.

MATERIALS AND METHODS

Study Design and Eligibility

A questionnaire was administered to a sequential convenience sample of English-speaking gynecologic and breast cancer patients who visited the ambulatory gynecologic oncology practice of an urban academic medical center between June 2008 and March 2009. Patients were approached by the clinic nurse on presentation and were asked to complete the survey while they waited for the physician to arrive in the examination room. Subsequently, participants' medical charts were reviewed retrospectively for patient age, partner status, race and/or ethnicity, type of cancer diagnosis, stage of cancer, and length of time since their last cancer treatment. The variable "date of last treatment" was defined as the most recent month before the completion of the needs assessment questionnaire in which the patient underwent surgery or received radiation therapy or chemotherapy as treatment for her cancer. All medical chart data were abstracted by a single researcher; however, to assess data reliability, data for a randomly selected subset of 10 participants were reviewed for accuracy by a second

researcher, and no inconsistencies were identified. Inclusion criteria included age ≥ 18 years, a diagnosis of gynecologic or breast cancer, and not having completed the questionnaire on a prior clinic visit.

All procedures and protocols were reviewed and approved by the Institutional Review Board at the University of Chicago. The project was granted consent-exempt status, because the study was retrospective, deemed of minimal risk to participants, and all personal health information was deidentified.

Survey Instrument

Patients completed a self-administered, 1-page questionnaire that included 5 items regarding their interest in care for sexual issues and their history of seeking care for these issues. The questionnaire introduction reads as follows: "Many women affected by gynecologic and/or breast cancer experience changes in their sexual lives and sexual functioning. We'd like your input as we consider expanding our program to include physician and other services to address sexual issues for women affected by cancer." The survey was developed to assess gynecologic oncology patients' need for and interest in a new clinical program that would provide care for sexual concerns of women and girls with cancer and was not intended originally for research purposes. Figure 1 outlines the 5 needs assessment survey questions.

Statistical Analysis

Descriptive statistics were calculated for each needs assessment question and independent variable. Chi-square tests

were used to examine the association between responses to each needs assessment question and age, marital status, cancer type, disease stage, months since last treatment, and race. When sufficient data were available, multivariate logistic regression was used to examine the association between individual needs assessment questions and age. The model was built using backward variable selection.¹¹ Covariates that were included in the preliminary model were those that, based on bivariate analyses, were associated with age or with the needs assessment question that was being modeled ($P < .20$). Backward selection was used to exclude covariates from the preliminary model beginning with the covariate that had the largest P value based on the Wald chi-square statistic. By using the likelihood-ratio test, covariates were removed, and the fit of the full model was compared with the reduced model. The final model retained age and those variables that were identified as statistically significant ($P < .05$) based on the likelihood-ratio test results. Odds ratios (ORs) and corresponding 95% confidence intervals (CIs) were estimated using the final logistic regression models. These estimates were restricted to those respondents who had data available for all variables that were included in the preliminary logistic regression model. By using the same methodology, multivariate models were built to examine the association between individual needs assessment questions and months since last treatment. All tests were 2-sided, and no adjustment for multiple comparisons was made. P values $< .05$ were considered statistically significant. Analyses were performed using Stata software (version 11; Stata Corp., College Station, Tex).

RESULTS

Between June 2008 and March 2009, the gynecologic oncology faculty saw 545 unique patients. The clinic assistant who assigned patients to rooms offered a survey to each patient who visited during this period; on occasion, clinic volume, staffing or other logistics, or patient's health status prohibited participation. Of 305 patients who completed a questionnaire, 261 met inclusion criteria. Forty-four patients were excluded because they did not have a diagnosed gynecologic or breast malignancy (for example, women who had a diagnosis of cervical intraepithelial neoplasia or a breast cancer gene [*BRCA*] mutation carrier without cancer). It is noteworthy that most of the breast cancer patients who visited the gynecologic oncology clinic were presenting for preoperative or

Table 1. Patient Characteristics (N=261)

Variable	No. of Women (%)
Demographics	
Age, y	
Mean [SD] (range)	55±13 [21-88]
Age group	
18-47	73 (28)
48-55	61 (23.4)
56-65	68 (26.1)
>65	59 (22.6)
Race/ethnicity	
White, non-Hispanic ^a	147 (62.8)
African American, non-Hispanic	76 (32.5)
Hispanic, Asian, Native American	11 (4.7)
Marital status	
Married/life partner ^b	156 (67.2)
Single/widowed/divorced	76 (32.8)
Cancer type	
Ovarian/fallopian/peritoneal	94 (36)
Endometrial	84 (32.2)
Cervical	49 (18.8)
Breast	23 (8.8)
Vulvar/vaginal	11 (4.2)
Stage	
I ^c	110 (47)
II	33 (14.1)
III	73 (31.2)
IV	18 (7.7)
Time since last treatment, mo	
In current treatment	85 (32.6)
1-12	63 (24.1)
>12	113 (43.3)

SD indicates standard deviation.

^aRace was unknown for 27 respondents.

^bMarital status was unknown for 29 respondents.

^cCancer stage was unknown for 27 respondents.

postoperative evaluation for prophylactic bilateral salpingo-oophorectomy.

The mean age of participants was 55 years (median age, 55 years; range, 21-88 years) (Table 1). Reflecting the demographics of the community served by the medical center, approximately 33% of patients were African American, and >66% were married or had a current significant other. Cancer diagnoses included ovarian/fallopian tube/peritoneal cancers (36%), endometrial cancer (32.2%), cervical cancer (18.8%), breast cancer (8.8%), and vulvar/vaginal cancer (4.2%).

Only 7% of patients had recently sought advice or medical help for problems related to sexuality, yet 41.6% were very interested or somewhat interested in receiving care to address sexual issues, and 36.1% stated that they were somewhat likely or very likely to see a physician to

Table 2. Responses to Needs Assessment Questions^a

Variable	No. of Respondents/Total No. (%)		
	Interest in Receiving Care to Address Sexual Issues ^b	Likelihood of Seeing Physician to Address Sexual Matters ^c	Willingness to be Contacted to Address Sexual Issues ^d
Overall	96/231 (41.6)	78/216 (36.1)	79/225 (35.1)
Demographics			
Age, y	— ^e	— ^f	— ^e
18-47	32/67 (47.8)	29/66 (43.9)	31/68 (45.6)
48-55	30/57 (52.6)	23/54 (42.6)	23/55 (41.8)
56-65	24/62 (38.7)	18/57 (31.6)	18/59 (30.5)
>65	10/45 (22.2)	8/39 (20.5)	7/43 (16.3)
Race/ethnicity			
White, non-Hispanic	50/131 (38.2)	42/121 (34.7)	41/131 (31.3)
African American, non-Hispanic	31/64 (48.4)	23/62 (37.1)	22/63 (34.9)
Hispanic, Asian, Native American	3/10 (30)	3/9 (33.3)	3/8 (37.5)
Marital status			
Married/life partner	61/148 (41.2)	50/143 (35)	52/146 (35.6)
Single/widowed/divorced	23/58 (39.7)	19/51 (37.3)	18/56 (32.1)
Cancer type			
Ovarian/fallopian/peritoneal	32/86 (37.2)	26/80 (32.5)	24/82 (29.3)
Endometrial	29/70 (41.4)	23/63 (36.5)	24/70 (34.3)
Cervical	20/43 (46.5)	18/41 (43.9)	16/41 (39)
Breast	11/22 (50)	7/23 (30.4)	10/22 (45.5)
Vulvar/vaginal	4/10 (40)	4/9 (44.4)	5/10 (50)
Stage			
I	44/99 (44.4)	36/96 (37.5)	31/99 (31.3)
II	16/29 (55.2)	11/25 (44)	13/26 (50)
III	24/63 (38.1)	21/58 (36.2)	24/63 (38.1)
IV	4/16 (25)	4/15 (26.7)	4/16 (25)
Time since last treatment, mo			— ^e
Currently in treatment	23/73 (31.5)	17/67 (25.4)	17/72 (23.6)
1-12	26/58 (44.8)	25/57 (43.9)	25/59 (42.4)
>12	47/100 (47)	36/92 (39.1)	37/94 (39.4)

^aNot all individuals responded to each needs assessment question. Response rates ranged from 81.6% to 88.5%. Race/ethnicity was unknown for 27 respondents, marital status was unknown for 29 respondents, and cancer stage was unknown for 27 respondents.

^bThe response categories "very interested" and "somewhat interested" were combined.

^cThe response categories "very likely" and "somewhat likely" were combined.

^dThe response category "yes" was used.

^eStatistically significant ($P < .05$).

^f $P = .06$.

address sexual matters. Twelve of the 15 respondents who had recently sought advice or medical help reported their satisfaction with their care, and 3 of those 12 respondents reported that they were dissatisfied or very dissatisfied with the care they received. Thirty-five percent of all women were willing to be contacted if a formal program to address sexual issues for women was offered (Table 2). The results relating to recent solicitation of medical advice and satisfaction with that advice are reported in the text rather than by inclusion in Table 2, because there were so few positive responses.

In bivariate analysis (Table 2), younger age was associated with greater interest in receiving care to address sexual issues. Interest in receiving care was not related significantly to marital status, cancer type, cancer stage, or race. On the basis of final logistic regression analysis, younger women (ages 18-47 years) were significantly more likely to be at least somewhat interested in receiving care to address sexual issues (OR, 2.94; 95% CI, 1.14-7.54) than women aged >65 years. Significant associations with interest in care also were observed for women ages 48 to 55 years compared with women aged >65

years. In addition, women whose last date of treatment was >12 months before the survey were significantly more interested in receiving care to address sexual issues (adjusted OR [AOR], 2.02; 95% CI, 1.02-4.01) than women who currently were receiving treatment after controlling for age (Fig. 2).

Demographic variables, such as marital status, cancer type, cancer stage, and race, were not associated significantly with the likelihood of seeing a physician to address sexual matters. In the final logistic regression model, women ages 18 to 65 years were more likely to see a physician to address sexual matters compared with women aged >65 years (Fig. 2). Length of time since treatment was not associated with the likelihood of visiting a physician to address sexual matters.

Compared with women aged >65 years, women ages 18 to 65 years also were more likely to report willingness to be contacted for participation in a clinical program designed to address sexuality issues (Table 2). In addition, women whose last date of treatment was at least 1 month but no more than 12 months before the survey also were more likely to express willingness to be contacted for a formal program (42.4%) than women whose last treatment for cancer was within the previous month (23.6%). Nearly 40% of women whose last treatment was >1 year before the survey expressed willingness to be contacted for care in a specialized cancer sexuality clinic. Like with other needs assessment variables, willingness to be contacted was not associated significantly with marital status, cancer type, cancer stage, or race in bivariate analyses. In the final logistic regression analysis (after controlling for months since completion of treatment), younger women (ages 18-47 years) were significantly more likely to be willing to be contacted for a formal program to address sexual issues (AOR, 5.00; 95% CI, 1.63-15.28) compared with women aged >65 years. Significant associations with willingness to be contacted also were observed for women ages 48 to 55 years compared with women aged >65 years. In addition, women who completed treatment >12 months before the survey were significantly more willing to be contacted for a formal program to address sexual issues (AOR, 2.49; 95% CI, 1.18-5.26) than women who currently were receiving treatment after controlling for age (Fig. 2).

DISCUSSION

Many gynecologic and breast cancer survivors are sexually active despite a high prevalence of sexual problems.^{2-9,10,12,13}

Several major cancer centers are exploring the creation of clinical programs to address these issues.¹⁴ However, physicians and institutions need data to demonstrate the willingness of these patients to receive medical care for sexual concerns when considering investment in such clinical programs. The current study, building on a small body of previous work by others, establishes not only a need but a substantial, unmet need among women with breast and gynecologic cancer.

The results indicate that approximately 42% of all patients with gynecologic and breast cancers who visited the gynecology oncology clinic at a single urban academic medical center in Chicago were interested in seeking medical care for the treatment of sexual problems, yet very few had done so. This corroborates findings by Huyghe and colleagues, who observed that, in a mail-based (26% response rate of a purposive sample) and clinic-based (17% response rate of a volunteer sample) survey of reproductive and fertility service needs among 124 women who were cancer survivors, 39% of those with sexual problems would visit a physician for help for a sexual problem if the visit were covered by insurance (this decreased by almost 50% if the patient had to pay out of pocket).¹⁵ It is noteworthy that, in that study, patients with sexual problems were most likely to say that they would visit a physician for sexual healthcare compared with a mental health expert for personal counseling, couples therapy, or an all-woman support group.¹⁵

Although the estimated prevalence of need for services to address sexuality issues in the current study was similar to that reported by Huyghe et al in a Houston-based study, their sample included participants with a broader variety of cancer types, including leukemia/lymphoma, colorectal cancer, and breast and gynecologic cancers. In addition, the prevalence estimate for visiting a physician for sexual health concerns was constrained to sexually active women,¹⁵ suggesting lower overall interest than the 42% that we observed in the current study. This may reflect differences in response bias and/or in the populations that were surveyed; gynecologic and breast cancers and their treatments directly affect the female sexual organs and have a known, significant impact on psychosocial aspects of sexual functioning.^{2,12,16-18} The current results advance previous findings by documenting high interest in sexual healthcare in a larger, highly relevant sample of gynecologic and breast cancer survivors in the clinical setting with a substantially higher response rate. In addition to establishing a high prevalence of need for services, our findings demonstrate how few women have sought this care independently

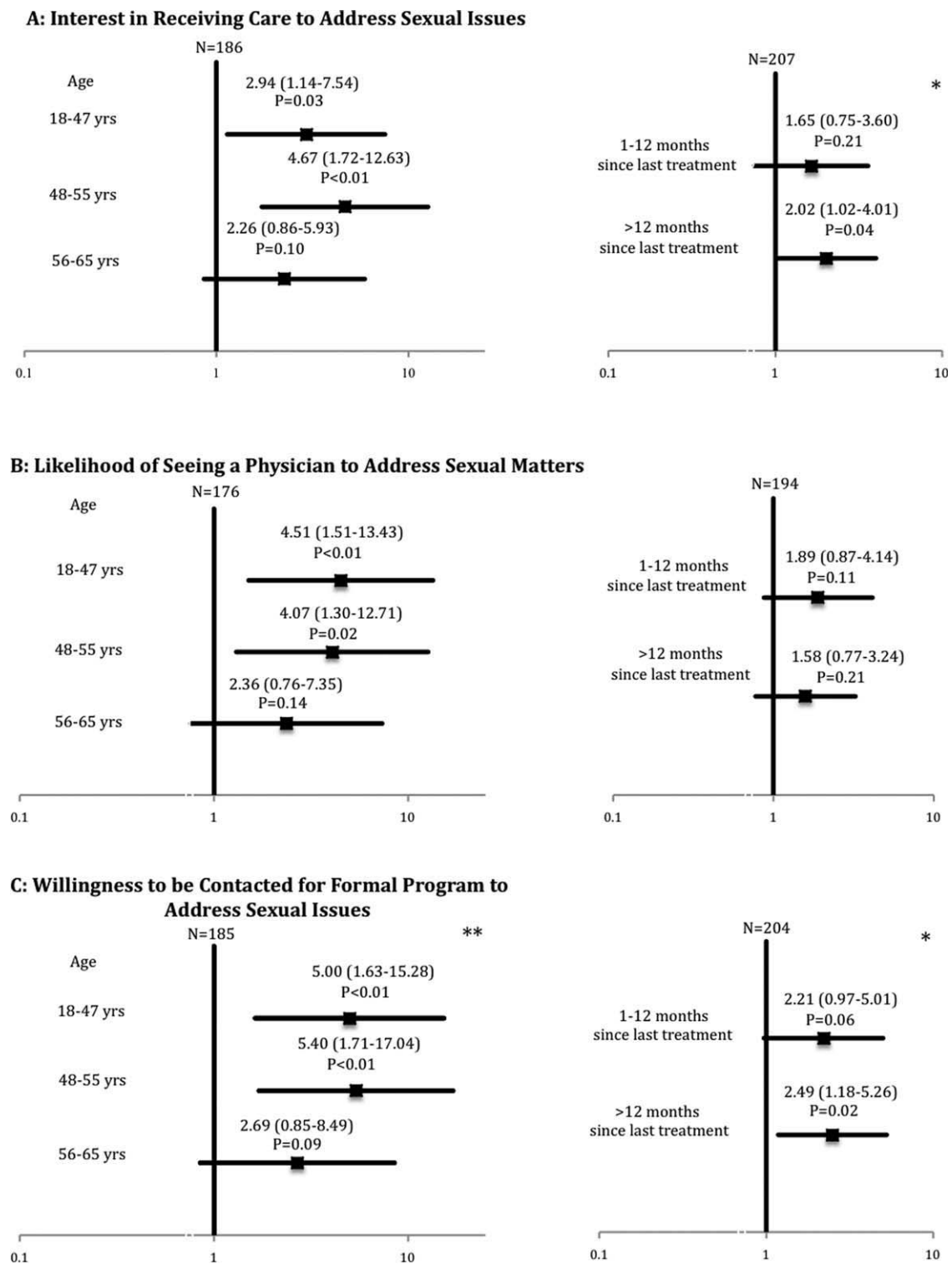


Figure 2. (A-C) The final logistic regression models for the needs assessment questions are shown. Reference groups are women aged >65 years and those currently in treatment. An asterisk indicates that the analysis was controlled for age; double asterisks indicate that the analysis was controlled for the number of months since last treatment.

Do you currently have a romantic, intimate or sexual partner?	• Yes • No
Have you been sexually active during the past 12 months?	• Yes • No
Have you been sexually active during the past 4 weeks?	• Yes • No
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?	• 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
How important a part of your life would you say that sex is?	• Extremely important • Very important • Moderately important • Somewhat important

Figure 3. The sexual health screening questions used to screen patients presenting to the oncology clinic at the University of Chicago. These questions are designed for consistency with the National Social Life, Health, and Aging Project and other large population studies of sexual activity and problems.

and highlight a major discrepancy between need and solicitation of care in this patient group.

The current results also indicate that the reported need for sexual healthcare in women with gynecologic and breast cancer is independent of marital status, race, cancer type, or cancer stage. Huyghe and colleagues also observed that marital status and cancer type were not significant correlates of intended reproductive clinic use, although they did not report which patients specifically desired care for sexual problems rather than for fertility concerns.¹⁵ It also has been reported that sexual problems among women with cervical or ovarian cancer are independent of marital status.^{3,4} These findings provide evidence for physicians and others who are caring for women with cancer that marital status should not be used to profile which patients want or need help for sexual concerns. In our clinical experience at the Program for Integrative Sexual Medicine for Women and Girls with Cancer, we see married women, unmarried women with and without sexual partners, and lesbian women. The latter 2 groups are subject to stigma in healthcare encounters and may not disclose their sexual activity status to their physician, further isolating them from relevant care.¹⁹⁻²¹ Oncologists easily and routinely can assess need for sexual health services for all patients by ascertaining their sexual concerns through a single-item or multi-item check box on a self-completed form (the screening items used by our gynecology oncology group are shown in Figure 3) or in a face-to-face review of systems during the physician visit. However, physician willingness to screen depends heavily on the

availability of such services.^{10,22} If clinical services to address sexuality concerns among women with cancer are not locally available, then patients still may benefit from the physician's expression of empathy for the issue and direction to patient-oriented reading materials.^{5,23-25}

In contrast to marital status, cancer type, and cancer stage, we did observe that younger age was associated with somewhat greater interest in care to address sexual issues and willingness to be contacted by a formal sexual health program. However, we also observed that more than 1 in 5 cancer survivors aged ≥ 65 years were interested in receiving sexual healthcare. Population and cancer registry studies have demonstrated that the majority of older women⁹ and cancer survivors^{2,3,5,12,26,27} value sexuality and believe that sexual matters should be addressed by physicians. This highlights the finding that discussions of sexual side effects and outcomes with their physicians can help normalize these experiences for all patients, regardless of clinical or demographic characteristics.²⁷ To our knowledge, there is no evidence in the literature or in clinical practice that patients are offended by physician attention to the topic of sexuality. To the contrary, asking about this aspect of a patient's life signifies the physician's concern for the patient's and her partner's overall well being and openly acknowledges that cancers of the genital organs—and their treatment—often have an impact on women's sexual life and functioning.^{2,26-28}

In the current study, a time since cancer treatment > 12 months was significantly predictive of increased interest in care and willingness to be contacted for a sexual health

program. To our knowledge, previous studies have not specifically identified time since cancer treatment as a predictor of women's interest in receiving sexual care. That women farther out from treatment were more interested in sexual healthcare is in contrast to prostate cancer care, in which the topic of sexuality is addressed proactively by oncologists and urologists as part of treatment planning and throughout the continuum of care.^{28,29} In our current study, we did not survey women before treatment, and no data exist to inform physicians about the willingness of women who are cancer patients to discuss sexuality issues as part of treatment planning or early in the course of treatment. We also have not addressed whether women would be willing to undergo interventions during the course of their treatment to address sexuality issues. The timing of patient interest in sexual care also may depend on the type of treatment, because undergoing prolonged interventions like chemotherapy or radiation may delay interest in care more than surgery alone. However, we did observe that as much as 33% of patients who were receiving current treatment for breast or gynecologic cancer responded positively to the needs assessment questions. In a previous study of men and women with lung cancer, we also observed that, despite a very poor prognosis, sexuality still was a valued aspect of life that patients wanted their physicians to address.²⁶ Although further research is needed, these findings suggest that even women with cancer who are actively undergoing treatment or who have an uncertain prognosis are receptive to the topic of sexuality as part of their cancer care.

The current study may be limited in its generalizability to populations in other care settings and with other cancer types, but it complements the only other published study on the topic. The sample size in the current study limited our subgroup analyses based on cancer type because of insufficient power. In addition, the survey questionnaire was created to inform clinical program development and was not intended initially for research purposes; thus, data collection was limited to a very small number of items. Although our results further establish a need for sexual healthcare for cancer patients, there remains a lack of training and support for physicians in sexual health, as evidenced by a paucity of medical or counseling services at comprehensive cancer centers in the United States.¹⁵ In addition, few studies have evaluated the efficacy of interventions for sexual health morbidity in cancer survivors.^{27,30} Future studies should focus not only on identifying those most likely to benefit from sexual healthcare but also on developing and evaluating specific types of interventions and their success at treating sexual

dysfunction in this patient population. The Program in Integrative Sexual Medicine at the University of Chicago Medical Center was opened in October 2008 specifically to address sexuality issues among women and girls with cancer and is actively working with clinician-researchers at Memorial Sloan-Kettering Cancer Center and other US-based cancer centers to build a network that will advance evidence-generating research and evidence-based practice in the field.³¹

Women with gynecologic and breast cancer have an unmet need for attention to sexual concerns. Women who have been treated for these cancers, regardless of marital status, age, cancer type, or cancer stage, should be informed by their physician of the sexual impact of their cancer and their cancer treatment. The identification of sexual concerns among this patient population requires physicians to incorporate screening into their clinical practice and throughout the continuum of cancer care. Further research is needed to expand the range of evidence-based options for prevention and treatment of sexual problems in women and girls with cancer.

CONFLICT OF INTEREST DISCLOSURES

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