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Assessing Gynecologic and Breast Cancer Survivors' Sexual Health Care Needs (Sexual Care Needs of Cancer Survivors)

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Abstract

Objectives—To identify patterns of female cancer survivors' interest in receiving care for sexual concerns.

Methods—Survey and medical record data were collected 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 health care.

Results—Participants' mean age was 55 years (range 21–88). Only 7% had recently sought medical help for sexual issues, yet 41.6% were interested in receiving care. More 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. When compared to older women (>65 years), younger women (18–47 years) were significantly more likely to report interest in receiving care to address sexual issues (OR 2.94, 95% CI 1.14–7.54), to see a physician to address sexual matters (OR 4.51, 95% CI 1.51–13.43) and more willing to be contacted for a formal program (AOR 5.00, 95% CI 1.63–15.28). Compared to those currently in treatment, women who last received treatment more than 12 months prior were significantly more interested in receiving care (AOR 2.02, 95% CI 1.02–4.01) and more willing to be contacted (AOR 2.49, 95% CI 1.18–5.26).

Conclusions—More than 40% of survivors expressed interest in receiving sexual health care, but few had ever sought such care. There is an unmet need for attention to sexual concerns among women with gynecologic and breast cancer.

Keywords

gynecologic neoplasms; breast neoplasms; sexuality; sexual dysfunction psychological; sexually dysfunction physiological; needs assessment; quality of life

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Introduction

Among nearly 5.9 million female 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 female sexual function. Several studies document 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 cancer, little has been done to clinically address psychological or physiological sexuality issues.

Studies of women with and without cancer repeatedly show that women across the life course value sexuality as an important part of life and health, and feel it appropriate to discuss sexual issues with a physician.^{2,9} Yet, physicians, including oncologists caring for women with breast and genital tract cancers, often omit 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 percent reported 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 forty-three gynecologists, medical and gynecologic oncologists and nurses reported that 98 percent of providers thought that sexual issues should be discussed, but only 21 percent actually discussed these issues with patients.¹⁰

This study aims to identify patterns of female cancer survivors' interest in receiving care for sexual concerns to inform development of an evidence-based multidisciplinary approach to sexual health care for this population.

Patients and Methods

Study Design and Eligibility

A questionnaire was administered to a sequential convenience sample of English-speaking gynecologic and breast cancer patients seen in 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 asked to complete the survey while waiting for the physician to arrive in the examination room. Subsequently, participants' medical charts were retrospectively reviewed 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 date of last treatment variable was defined as the most recent month prior to the completion of the needs assessment questionnaire that the patient received surgery, radiation or chemotherapy for treatment of 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 found. Inclusion criteria included being 18 years of age or older, 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 as the study

was retrospective, deemed of minimal risk to participants, and all personal health information was de-identified.

Survey Instrument

Patients completed a self-administered, one page questionnaire that included five items regarding interest in care for sexual issues and history of seeking care for these issues. The questionnaire introduction read: “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 originally intended for research purposes. Figure 1 outlines the five 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, stage, months since last treatment and race. When sufficient data were available, multivariable 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 included in the preliminary model were those which, based on bivariate analyses, were associated with age or the needs assessment question being modeled (p -value < 0.20). Backward selection was used to exclude covariates from the preliminary model beginning with the covariate with the largest p -value based on the Wald Chi-Square statistic. Using the likelihood ratio test, covariates were removed and the fit of the full model was compared to the reduced model. The final model retained age and those variables found to be statistically significant (p -value < 0.05) based on the likelihood ratio test results. Odds ratios and corresponding 95% confidence intervals were estimated using the final logistic regression models. These estimates were restricted to those respondents with data for all variables included in the preliminary logistic regression model. Using the same methodology, multivariable models were built to examine the association between individual needs assessment questions and months since last treatment. All tests were two-sided, and no adjustment for multiple comparisons was made. P -values less than 0.05 were considered statistically significant. Analyses were performed using Stata Version 11 (StataCorp, College Station, TX).

Results

Between June 2008 and March 2009, the gynecologic oncology faculty saw 545 unique patients. The clinic assistant rooming patients offered a survey to each patient seen during this period; on occasion, clinic volume, staffing or other logistics, or patient’s health status prohibited participation. Of 305 patients completing a questionnaire, 261 met inclusion criteria. Forty four patients were excluded due to lack of a gynecologic or breast malignancy diagnosis (for example, cervical intraepithelial neoplasia or BRCA mutation carrier without cancer). Of note, most of the breast cancer patients in the gynecology oncology clinic were presenting for pre- or post-operative evaluation for prophylactic bilateral salpingoophorectomy.

The mean age of participants was 55 years (median = 55, range 21–88) (Table 1). Reflecting the demographics of the community served by the medical center, about a third of patients were African American and more than two-thirds were married or had a current significant

other. Cancer diagnoses included: ovarian/fallopian tube/peritoneal (36.0%), endometrial (32.2%), cervical (18.8%), breast (8.8%), and vulvar/vaginal (4.2%).

Only 7.0% of patients had recently sought advice or medical help for problems related to sexuality, yet 41.6% were very or somewhat interested in receiving care to address sexual issues and 36.1% stated they were somewhat or very likely to see a physician to address sexual matters. Twelve of the 15 respondents who had recently sought advice or medical help reported their satisfaction with their care, with one in four (3/12) reporting 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 is 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 significantly related to one's marital status, cancer type, cancer stage or race. Based on final logistic regression analysis, younger women (age 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 those >65 years. Significant associations with interest in care were also observed for women age 48–55 compared to those age >65 years. Additionally, women whose last date of treatment was more than 12 months prior were significantly more interested in receiving care to address sexual issues (AOR 2.02, 95% CI 1.02–4.01) than those currently in treatment after controlling for age (Figure 3).

Demographic variables such as marital status, cancer type, cancer stage and race were not significantly associated with the likelihood of seeing a physician to address sexual matters. In the final logistic regression model, women ages 18–65 were more likely to see a physician to address sexual matters when compared to those older than 65 years (Figure 3). Length of time since treatment was not associated with likelihood of seeing a physician to address sexual matters.

Compared to women older than 65 years, women ages 18–65 were also 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 a month but no more than 12 months prior to the survey were also more likely to express willingness to be contacted for a formal program (42.4%) than women whose last treatment for cancer was within the prior month (23.6%). Nearly 40% of women whose last treatment was more than a year prior expressed willingness to be contacted for care in a specialized cancer sexuality clinic. As with other needs assessment variables, willingness to be contacted was not significantly associated with marital status, cancer type, cancer stage or race in bivariate analysis. 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) when compared to women older than 65 years. Significant associations with willingness to be contacted were also observed for women ages 48–55 compared to those older than 65 years. Additionally, women who completed treatment more than 12 months prior 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 those currently in treatment, after controlling for age (Figure 3).

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 female cancer patients' willingness to receive medical care for sexual concerns when considering investment in such clinical programs. This study, building on a small body of previous work by others, establishes not only need, but a substantial unmet need among women with breast and gynecologic cancer.

The current study finds that approximately 42% of all gynecologic and breast cancer patients seen in the gynecology oncology clinic at one urban academic medical center in Chicago were interested in seeking medical care for treatment of sexual problems, yet very few had done so. This corroborates findings by Huyghe and colleagues who found that, in a mail (26% response rate of a purposive sample) and clinic-based (17% response rate of a volunteer sample) survey of reproductive and fertility services needs among 124 female cancer survivors, that 39% of those with sexual problems would visit a medical doctor 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 Interestingly, in that study, patients with sexual problems were most likely to say that they would see a physician for sexual health care as compared to a mental health expert for personal counseling, couples therapy, or an all-female support group.¹⁵

Although the estimated prevalence of need for services to address sexuality issues in the current study is similar to Huyghe et al's Houston-based study, that study included participants with a broader variety of cancer types including leukemia/lymphoma, colorectal cancer, breast and gynecologic cancers. Additionally, the prevalence estimate for seeing a physician for sexual health concerns was constrained to sexually active women,¹⁵ suggesting a lower overall interest than the 42% found in our study. This may be reflective of differences in response bias and/or the different populations surveyed; gynecologic and breast cancers and their treatments directly affect the female sexual organs and are known to have significant impact on psychosocial aspects of sexual functioning.^{2,12,16-18} The current study advances prior findings by documenting high interest in sexual health care 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 show how few women have independently sought this care and highlights a major discrepancy between need and solicitation of care in this patient group.

The current study also finds that reported need for sexual health care in women with gynecologic and breast cancer is independent of marital status, race, cancer type or cancer stage. Huyghe and colleagues also found that marital status and cancer type were not significant correlates of intended reproductive clinic usage, although they did not report which patients specifically desired care for sexual problems rather than for fertility concerns.¹⁵ Sexual problems in women with cervical or ovarian cancer have also been found to be independent of marital status.³⁻⁴ These findings provide evidence for physicians and others 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 two groups are subject to stigma in health care encounters and may not disclose their sexual activity status to their physician, thus further isolating them from relevant care.¹⁹⁻²¹ Oncologists can easily and routinely assess need for sexual health services by ascertaining,

for all patients, sexual concerns via a single or multi-item check-box on a self-completed form (the screening items used by our gynecology oncology group are shown in Figure 2) or via 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, patients may still 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 find 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 found that more than one in five cancer survivors 65 years and older were interested in receiving sexual health care. Population and cancer registry studies demonstrate that the majority of older women⁹ and cancer survivors^{2,3,5,14,26,27} value sexuality and think that sexual matters should be addressed by physicians. This highlights the fact that discussions of sexual side effects and outcomes with their physicians can help normalize these experiences for all patients, regardless of clinical and demographic characteristics.²⁷ There is no evidence in the literature or 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 do impact women's sexual life and functioning.^{2,26–28}

In the current study, being more than 12 months from cancer treatment was significantly predictive of increased interest in care and willingness to be contacted for a sexual health program. To our knowledge prior studies do not specifically identify 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 health care is in contrast to prostate cancer care where the topic of sexuality is proactively addressed by oncologists and urologists as part of treatment planning and throughout the continuum of care.^{28,29} Our study did not survey women prior to treatment and no data exist to inform physicians about female cancer patients' willingness to discuss sexuality issues as part of treatment planning or early in the course of treatment. We also do not address whether women would be willing to undergo interventions during the course of their treatment to address sexuality issues. Timing of patient interest in sexual care may also be dependent on the type of treatment, as undergoing prolonged interventions like chemotherapy or radiation may delay interest in care more than surgery alone. We did, however, find that as many as a third of patients currently in treatment for breast or gynecologic cancer responded positively to the needs assessment questions. We have also found, in a prior study of male and female lung cancer patients, that despite a very poor prognosis, sexuality was still a valued aspect of life that patients wanted addressed by their physicians.²⁶ Although further research is needed, these findings suggest that even female cancer patients actively undergoing treatment or with uncertain prognoses are receptive to the topic of sexuality as part of their cancer care.

This study may be limited in its generalizability to populations in other care settings and with other cancer types, but complements the only other published study on the topic. The sample size in the current study limited subgroup analyses based on cancer type due to insufficient power. In addition, the survey questionnaire was created to inform clinical program development and was not initially intended for research purposes, thus limiting data collection to a very small number of items. While our study further establishes a need for sexual health care for cancer patients, there remains a lack of training and support for physicians in sexual health, evidenced by a paucity of sexual counseling services at comprehensive cancer centers in the US.¹⁵ In addition, there are few studies evaluating

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 health care but also in 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 to specifically address sexuality issues among women and girls with cancer and is actively working with clinician-researchers at Memorial Sloan-Kettering Cancer Center and other U.S.-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 stage, should be informed by their physician of the sexual impact of their cancer and their cancer treatment. 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 treatment of sexual problems in women and girls with cancer.

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How interested are you in receiving care to address sexual issues?	<ul style="list-style-type: none"> • 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?	<ul style="list-style-type: none"> • Very likely • Somewhat likely • Unlikely • Very unlikely
Have you recently sought advice or medical help for problems related to sexuality?	<ul style="list-style-type: none"> • Yes • No
If you have sought help for problems related to sexuality, how satisfied were you with the care you received?	<ul style="list-style-type: none"> • 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?	<ul style="list-style-type: none"> • Yes • No

Figure 1.
Sexual Health Needs Assessment Questionnaire

Do you currently have a romantic, intimate or sexual partner?	<ul style="list-style-type: none"> • Yes • No
Have you been sexually active during the past 12 months?	<ul style="list-style-type: none"> • Yes • No
Have you been sexually active during the past 4 weeks?	<ul style="list-style-type: none"> • 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?	<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
How important a part of your life would you say that sex is?	<ul style="list-style-type: none"> • Extremely important • Very important • Moderately important • Somewhat important

Figure 2.
Sexual Health Screening Questions

Figure 3.

Table 1

Patient Characteristics (N=261)

	N (%)
Demographics	
Age (years)	55 [13] (21–88)
Mean [SD] (range)	
Age Groups	
18–47	73 (28.0)
48–55	61 (23.4)
56–65	68 (26.1)
>65	59 (22.6)
Race/Ethnicity	
White (non-hispanic) ¹	147 (62.8)
African American (non-hispanic)	76 (32.5)
Hispanic, Asian, Native American	11 (4.7)
Marital Status	
Married/Life partner ²	156 (67.2)
Single/Widowed/Divorced	76 (32.8)
Cancer Type	
Ovarian/Fallopian/Peritoneal	94 (36.0)
Endometrial	84 (32.2)
Cervical	49 (18.8)
Breast	23 (8.8)
Vulvar/Vaginal	11 (4.2)
Stage	
I ³	110 (47.0)
II	33 (14.1)
III	73 (31.2)
IV	18 (7.7)
Months since last treatment	
In current treatment	85 (32.6)
1–12 months	63 (24.1)
>12 months	113 (43.3)

¹ Race was unknown for 27 subjects.² Marital status was unknown for 29 subjects.³ Cancer stage was unknown for 27 subjects.

Table 2Responses to Needs Assessment Questions¹

	Interest in receiving care to address sexual issues ² :	Likelihood of seeing physician to address sexual matters ³ :	Willingness to be contacted to address sexual issues ⁴ :
Overall	96/231 (41.6)	78/216 (36.1)	79/225 (35.1)
Demographics			
Age	*	**	*
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 (30.0)	3/9 (33.3)	3/8 (37.5)
Marital Status			
Married/Life partner	61/148 (41.2)	50/143 (35.0)	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 (39.0)
Breast	11/22 (50.0)	7/23 (30.4)	10/22 (45.5)
Vulvar/Vaginal	4/10 (40.0)	4/9 (44.4)	5/10 (50.0)
Stage			
I	44/99 (44.4)	36/96 (37.5)	31/99 (31.3)
II	16/29 (55.2)	11/25 (44.0)	13/26 (50.0)
III	24/63 (38.1)	21/58 (36.2)	24/63 (38.1)
IV	4/16 (25.0)	4/15 (26.7)	4/16 (25.0)
Months since last treatment			*
Currently in treatment	23/73 (31.5)	17/67 (25.4)	17/72 (23.6)
1–12 months	26/58 (44.8)	25/57 (43.9)	25/59 (42.4)
>12 months	47/100 (47.0)	36/92 (39.1)	37/94 (39.4)

Numbers in table are n/total N (%).

¹ Not all subjects responded to each needs assessment question. Response rates ranged from 81.6–88.5%. Race/Ethnicity was unknown for 27 subjects. Marital status was unknown for 29 subjects. Cancer stage was unknown for 27 subjects.

² Combines response categories “Very interested” and “Somewhat interested”

³ Combines response categories “Very likely” and “Somewhat likely”

⁴ Response category “Yes”

* Statistically significant ($P < 0.05$)

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 $P = 0.06$