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Sexual Morbidity in Very long-term Survivors of Vaginal and Cervical Cancer: A Comparison to National Norms

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Abstract

Objectives—To compare sexuality among very long-term survivors of vaginal and cervical cancer to national norms and assess quality of care for sexual problems.

Methods—A survey of survivors in a cancer registry ($n=221$) provided data comparable to the 1992 National Health and Social Life Survey (NHSLs). The NHSLs sample was individually matched on age and race to survivors at a 2:1 ratio. Responses were compared using conditional logistic regression and 2-sample t-tests. Correlates of sexual problems among survivors were analyzed using multivariate logistic regression.

Results—Survivors' mean age was 49 years ($SD=6.0$); median survivorship was 26.8 years (range 5.5–39.7). Survivors and controls reported similar levels of sexual partnership and activity, but sexual problems were significantly more prevalent among survivors (mean number of problems 2.6 versus 1.1, $P<.001$). Satisfaction with care for sexual problems was lower than with cancer care overall (5.5 versus 8.0/10, $P<.001$). While 74% believed that physicians should discuss sex, 62% reported never discussing the effect of genital tract cancer on sexuality. In adjusted analysis, survivors reporting no such discussion were significantly more likely to exhibit current complex sexual morbidity (≥ 3 concurrent sexual problems) (OR 2.74, 95% CI 1.14 – 6.58).

Conclusions—Despite profoundly more sexual problems, survivors' rate of sexual partnership and activity were similar to population controls. Satisfaction with care relating to sexuality was significantly lower than with cancer care overall. Conversation with a physician about the sexual effects of cancer is associated with significantly lower likelihood of complex sexual morbidity among very long-term survivors.

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Introduction

Information about very long-term (more than 15–20 years [1,2]) cancer survivorship is scarce. According to the National Cancer Institute, as of January 2003, about 10.5 million Americans are survivors of cancer. Approximately 14% of these individuals have survived more than 20 years following their initial cancer diagnosis. About two-thirds of adults diagnosed with cancer will live at least five years with cancer; nearly 80% of those surviving cancer diagnosed in childhood will be alive after 5 years [3]. Analysis of 1992 National Health Interview Survey and Connecticut Tumor Registry data indicates that nearly 70% of cancer survivors are women. Gynecologic cancers comprise the most prevalent cancer type among adult survivors, followed by breast cancer [4].

Sexual problems can have an additive, negative effect on physical and psychological health of individuals with cancer and their partners [5]. Aging may exacerbate or ameliorate these problems; cancer survivors can feel uncertain about whether sexual problems are a consequence of cancer or aging [6]. Gynecologic and breast cancers and their treatments directly affect the sexual organs and may disrupt the physical and psychological phases of the female sexual response cycle [7,8]. Several studies of shorter-term survivors describe health [9–12], quality of life [10–12] and sexuality [9,10,12] after diagnosis of gynecological cancer. However, little is known about how sexuality and sexual function relate to the health and well-being of very long-term survivors of gynecologic cancers.

This study aims to increase understanding about the sexual effects of cancer and cancer treatment experienced by very long-term survivors of genital tract cancer by surveying a unique registry of women followed longitudinally for more than 25 years, on average, since diagnosis with clear cell adenocarcinoma of the vagina and/or cervix. We describe sexual relationships, activity, attitudes, and function in this cohort in comparison to national norms, investigate the relationship between sexuality and overall health, and assess quality of care pertaining to sexual health.

Methods

Study Design and Recruitment

Long term genital tract cancer survivors were identified via the National Cancer Institute Registry for Research on Hormonal Transplacental Carcinogenesis (the “Registry”), housed in the Department of Obstetrics and Gynecology at the University of Chicago. This registry, established in 1971, contains information on 708 women treated across the U.S. with a diagnosis of vaginal and/or cervical clear cell adenocarcinoma (CCA), a histologic subtype highly associated with in-utero exposure to diethylstilbestrol (DES) [13]. Subjects were excluded for the following reasons: deceased (n=193), no current mailing address (n=137), unknown age (n=11) or <18 years of age (n=2). Due to the Health Insurance Privacy and Portability Act of 1996 [14], registrants for whom documented permission for future contact was missing could not be contacted for participation (n=144). Self-administered questionnaires were sent by mail in two waves to each of 221 eligible registrants, initially in June 2004 and again in September 2004. In response to these mailings, we were notified that two additional registrants had been deceased. Of 219 eligible registrants, 162 returned a completed questionnaire. Two registrants having cancers other than CCA were excluded from these analyses.

In order to compare characteristics of the Registry sample to the U.S. population, female cases within the age range in the Registry sample (30 – 61 years) were extracted from the 1992 public use NHSLs data file (n=1239), the only national study on sexual norms in the United States (ages 18–59years) [15,16]. All comparisons were made using identical questions; some

additional data were obtained from Registry respondents to characterize sexual problems particular to genital tract cancer or cancer treatment as well as quality of cancer care. Because survivors were significantly older and more were Caucasian compared to the 1992 NHSLs sample, we individually matched the population-based control group to survivors at a 2:1 ratio on age (within 4 years) and race. Differences in income were controlled for using multivariate adjustment procedures.

The University of Chicago and National Cancer Institute (NCI) Institutional Review Boards approved the study protocol; completion and return of the confidential questionnaire constituted informed consent for all participants.

Measures

Survey instrument development engaged a multidisciplinary team (epidemiology, psychology, gynecology, oncology), as well as women with a history of in utero DES exposure in an iterative process, including pilot-testing, to achieve face validity and to maximize comprehensibility of the questions. Members of the NCI DES Steering Committee, including survivors, also critically reviewed the questionnaire. The instrument was divided into 4 major sections: 1) sociodemographic characteristics, 2) health, 3) sexuality and intimacy, and 4) psychological well-being. The latter domain will be assessed in future analyses. Variables used in the analyses presented here were constructed from the following items:

1. *Survival time*: Recognizing the variable approaches in the literature to this definition [17], this is defined as time since diagnosis with genital tract cancer.
2. *Sexual Partnership, Activity, Attitudes and Problems*:. Questions were designed for comparability to the 1992 National Health and Social Life Survey [16] and consistent with DSM IV-TR criteria [18] and established clinical instruments for assessing female sexual dysfunction (e.g. Female Sexual Function Index) [19]. Sexual partnership was assessed using dichotomous responses to a question about the presence of a sex partner in the preceding 12 months. Frequency of sexual activity over the prior 12 months was determined by the following categorical responses: "Once a day or more," "3–6 times a week," "Once or twice a week," "2 to 3 times a month" and "Once a month or less." Sexual attitude questions (listed in Table 3) were coded dichotomously by combining the categories "strongly agree" with "agree" and "strongly disagree" with "disagree." Satisfaction with frequency of sex was measured on 5-point scale using the answer to the question "During past 12 months would you say that you had sex "much more often than you would like," "somewhat more often than you would like," "about as often as you would like," "somewhat less often than you would like" and "much less often than you would like." Satisfaction with sex life was measured on 5-point scale using responses to the question: "If you were to spend the rest of your life with your sex life the way it is today, how would you feel about this?" (responses ranging from very satisfied to very dissatisfied). Seven domains of sexual function were comparable between the two groups (listed in Tables 4 and 5) and were assessed by "yes" or "no" response to the following: "Please indicate whether, during the last 12 months, there has ever been a period of several months or more when you experienced any of the following problems." [15]. Indication of a concurrent problem in three or more of these seven domains constituted "complex sexual morbidity." Additional questions of particular relevance to sexual issues faced by genital tract cancer survivors were designed for this study and are listed in Table 4.
3. *Quality of Care*: Treatment data were extracted from Registry medical records. History of vaginal reconstruction surgery was assessed on the basis of self-report. Satisfaction with cancer care and care related to sexual health, adopted from and asked

for comparability to a prior survey of this cohort [20], was assessed on a 10-point scale ranging from “very unsatisfied” to “very satisfied.” Patient-physician communication about sex was assessed using dichotomous responses to questions about receptivity to and physician initiation of such discussion.

4. *Global Self-rated Health and Quality of Life* were assessed on a 7-point scale ranging from very poor to excellent. The questions were taken from the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire - Core 30 (version 3.0) [21,22]. For logistic regression analyses, self-rated health was collapsed into three categories: “poor” (the worst three points), “fair/good” and “very good/excellent.”

Data Analysis

Analyses were conducted using Stata 9.0 [23]. Demographic characteristics, sexual activity and partnership, attitudes and problems were described. Two-sided Chi-square and t-tests were used, and Pearson’s correlations were used to test for monotonic associations between sexual satisfaction and: (1) global self-rated health and (2) quality of life. The associations between sexual morbidity and CCA survival in a matched sample were analyzed by conditional logistic regression for univariate analysis and for multivariable analysis adjusting for partner status, income, and self-reported health. The crude and adjusted odds ratios (ORs) with their 95% confidence intervals were reported.

Unconditional logistic regression was used for modeling, among survivors, the likelihood of having complex sexual morbidity, controlling for age, age at diagnosis, partner status, self-reported health, cancer treatment type, and past or current hormone replacement therapy (HRT) use. The model also included a variable indicating patient-physician communication regarding changes in sex life after cancer treatment. Statistical significance was set at $P \leq 0.05$.

Quotations from respondents included in the Discussion section, to contextualize the quantitative findings, are taken verbatim from open-ended questions or additional comments written on the survey instrument by respondents. Identifying information such as age or geographic location were altered or omitted to maximize respondent confidentiality.

Results

The response rate for the survey was 74%. Survey respondents did not differ significantly from non-respondents by mean age (49.4 and 48.2 years, respectively) or median age at diagnosis (22 years in both groups). Table 1 compares survivors to NHSLs controls by sociodemographic, sexual partnership and sexual activity characteristics. Cancer diagnosis and treatment characteristics among survivors are summarized in Table 2. Cancer treatment, in nearly every case (94%), involved removal or radiation of the genitopelvic organs.

Sexual Partnership, Activity, Attitudes, and Problems

Similar to the NHSLs sample, most survivors reported at least one sexual partner in the past 12 months and engaged in sexual activity at least twice monthly (Table 1). Attitudes about sexuality in relation to desired frequency of activity, satisfaction, relationships and health are reported in Table 3. Satisfaction with sex life was significantly correlated with global self-reported health (correlation coefficient $[r] = 0.37$, $P < 0.001$) and overall quality of life (correlation coefficient $[r] = 0.47$, $P < 0.001$) for survivors. There were no significant differences in responses to these attitudinal measures by cancer treatment group or current or past HRT use (data not shown). These attitude questions were not asked of NHSLs participants. A significantly higher proportion of survivors reported that physical health interfered with having

sex all or most of the time, compared to the population-based comparison group (16.9% vs 4.1%, $P<.001$).

Sexual problems were significantly more prevalent among survivors than in the population-based comparison group (Tables 4 and 5). For example, the prevalence of dyspareunia (pain during intercourse) and difficulty lubricating were, respectively, nearly 7 and 3 times higher among survivors. More than a third were affected by feeling unattractive because of physical appearance and by bladder infections or incontinence following sex.

Survivors were also significantly more likely than those in the population-based sample to exhibit complex sexual morbidity, defined as concurrent sexual problems in three or more of seven domains ($P<0.001$; Table 5), and to report avoiding sex because of sexual problems (62% versus 43%, $P=0.003$).

Quality of Care for Sexual Issues

Overall, survivors' satisfaction with their cancer care rated very high (mean 8.0/10). In contrast, satisfaction with quality of information and services received for sexual health was significantly lower (5.5/10, $P<.001$). Most survivors (74%) believed that physicians should "regularly ask patients about sexual issues," 70% reported that they would be comfortable discussing sexual issues with a doctor, and 55% reported having initiated such a dialogue with a physician. However, 62% of survivors reported that a doctor had never initiated a conversation about the effects of cancer or treatments for genital tract cancer on sexuality. Bivariate analysis reveals that a conversation with a physician about the sexual effects of genital tract cancer and cancer treatment is associated with significantly fewer sex morbidities (mean 2.2 versus 3.0 out of 7 problems among survivors reporting no such conversation, $P=0.02$). In multivariate logistic regression analysis, the odds of complex sexual morbidity among very long-term survivors is significantly higher for women reporting never having a conversation with a physician about the sexual effects of cancer or cancer treatment (Table 6). Neither time since diagnosis or last treatment nor treatment type were significantly associated with having been counseled by a physician about sexual issues (data not shown).

Discussion

Very few studies of any aspect of very long-term cancer survivorship exist. To our knowledge, this is the first to look at sexual functioning among very long-term survivors (more than 25 years, on average) of genital tract cancer and, further, to put these findings in the context of population-based norms. We find that very long-term survivors of genital tract cancer, most of whom have had their sexual organs removed or destroyed in the course of cancer treatment, value sexuality and participate in sexual relationships and activities at a rate similar to a population-based comparison group. In spite of this, these women exhibit very high prevalence and complexity of sexual problems, including pain and lack of pleasure. Sexuality among these women is significantly related to health and quality of life. While survivors rate their cancer care very high overall, satisfaction with care for sexual health is significantly lower. Women reporting that a physician had not discussed the sexual effects of genital tract cancer were nearly 3 times more likely than others to exhibit complex sexual morbidity.

By making comparisons to a national sample of similarly aged women, we find that sexual problems experienced by long-term survivors are due to more than age alone. Half of survivors, versus 15% of the age- and race-matched national sample, reported three or more concurrent sexual problems, and the odds of complex sexual morbidity were almost 5 times greater. Furthermore, compared to studies of shorter-term genital tract cancer survivors [9,12,24], this cohort of very long-term survivors exhibited similar or higher rates of sexual problems, yet had a relatively high rate of marriage, sexual partnership and activity.

The comparisons with a population-based sample and within the cohort of survivors suggest what some may regard as a paradox in the sexual behavior of very long-term genital tract cancer survivors. However, similar observations have been made with shorter-term breast [25,26] and genital tract [12,27] cancer survivors where, in spite of highly prevalent problems with sexual functioning, positive attitudes, partnership and behavior are maintained. Understanding how and why some very long-term survivors maintain sexual partnerships and positive attitudes toward sexuality even with severely compromised sexual function may help physicians and survivors better understand the role of sexual and intimate relationships in coping with cancer and maximizing survival and quality of life.

Although some reported negative interactions with physicians regarding sexual issues, the vast majority of survivors stated that they would be receptive to and believed physicians ought to initiate discussion about sexuality. Consistent with previous findings [28], most patients, particularly when age or gender differences exist, will not initiate discussion about sex with a physician. Nearly two thirds of survivors reported that a physician had never discussed the effects of genital tract cancer or cancer treatment on sexual life or function, and they allude to the psychological impact.

“While the physical care I received probably saved my life, there was no attention to my emotional needs...Nobody could or would talk about it...Any young woman with an illness that so seriously effects (sic) her sexuality and fertility should be counseled with compassion and expertise.”

“I received excellent care health-wise. However nothing was done to help me psychologically...I could have really used some counseling.”

“It seems unbelievable to me that a surgeon would remove one’s sexual organs and never talk about sex.”

Lack of communication with genital tract cancer patients about sexuality may impair optimal decision-making regarding treatment options, erode satisfaction with care, increase or sustain anxiety or impair quality of life. Strong evidence for the negative impact of medical illness and treatments on sexual functioning exists [7,20,29–31], but concern for sexual matters remains largely on the margin of medical care, particularly for older women. This study presents an extreme case: women who have undergone extirpation, destruction, or severe compromise to their reproductive and sexual organs, many prior to coitarche and reproduction, report that physicians infrequently discussed the impact of their cancer treatment on sexual functioning. One might argue that if such discussions are not occurring in this clinical context, they are even less likely to occur where the connections between disease or treatment and sexual functioning are less obvious.

It is possible that the experiences of this particular cohort of women are unique among women with gynecologic cancer and therefore limited in their generalizability. Because the large majority of these cancer cases are attributable to in utero exposure to DES, the psychological milieu of survival and relationship dynamics between physician and patient may also be distinct. [32] For many survivors, the cancer diagnosis occurred in adolescence, prior to coitarche and childbearing; several commented that lack of sexual experiences prior to diagnosis and treatment left them without a frame of reference for “normal” sexual functioning. Although no association was found between time since last treatment and having talked to a physician about sexual issues, the data are limited in that we do not know, among women who did discuss sex with a physician, when such a conversation occurred. Finally, survivors with sexual problems versus those without may differentially recall their experiences with health care providers around these issues, and individuals’ assessment of quality of care may also change over time [33]. Prospective, longitudinal data are needed to elucidate causal and

reciprocal relationships between survivor health and factors influencing duration and quality of survival following cancer, including quality and impact of sexual and intimate relationships.

These findings advance knowledge about an important aspect of cancer survivors' health and health care and suggest that improved communication with patients about sexuality may help maximize the experience of very long-term survivorship with gynecologic cancer.

Furthermore, the comparison to a population-based control sample reveals that the high prevalence and complexity of sexual problems experienced by long-term survivors of vaginal and cervical cancer likely cannot be attributed solely to aging.

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Table 1
Comparison of vaginal and cervical cancer survivors with the National Health and Social Life Survey (NHSLS) population-based controls

	Registry (cases) n=160	NHSLS (controls) n=320	P ^a
Demographic characteristics			
Current Age (years), mean value (SD) ^b	49.4 (6.0)	49.0 (6.3)	0.51
Race/Ethnicity, %			1.00
White/Caucasian	93.1	93.1	
Black/African-American	0.6	0.6	
Latino	4.4	4.4	
Other/unknown	1.9	1.9	
Percent Married	73.8	65.3	0.06
Income, %			
Less than \$30,000	10.3	43.4	
More than \$30,000	89.7	56.6	<0.001
Sexual characteristics			
Having sexual partner in the last 12 months, %	83.1	78.4	0.22
Frequency of sex in the last 12 months (for women having sex partner)			0.002
Once a week or more	39.3	48.8	
2 – 3 times a month	23.2	29.8	
Once a month or less	37.5	21.4	

^a All P values are univariate and were derived using the Student's t-test for continuous variables and likelihood-ratio test for categorical variables

^b SD – standard deviation

Table 2

Diagnosis and treatment characteristics of vaginal and cervical cancer survivors

Variable		
Age at Diagnosis (years), median (range)		
		22 (10–45)
Time Since Diagnosis (years), median (range)		
		26.8 (5.5–39.7)
Time Since Last Treatment (years), median (range)		
		25.8 (2.5–39.5)
Surgical treatment		
		78.1
Radical hysterectomy		
		72.3
Vaginectomy	Partial	51.3
	Total	26.3
Bilateral Oophorectomy		
		18.5
Exenteration		
		3.8
Radiation treatment		
		28.1
HRT treatment (percent ever used)		
		56.7
Vaginal reconstruction *		
		56.0

* self-reported

Numbers in table are percentages unless otherwise noted.

Table 3
Sexual attitudes among vaginal and cervical cancer survivors

Statement about sexual attitude	Percentage of positive answers
During the past 12 months having sex	
- much more often or somewhat more often than respondent would like	10.92
- about as often as respondent would like	40.34
- much less often or somewhat less often than respondent would like	48.74
Feeling	
- very satisfied or somewhat satisfied	42.28
- neither satisfied nor dissatisfied	16.78
- very dissatisfied or somewhat dissatisfied if spend the rest of life with sex life the way it is today	40.94
Agree or strongly agree with the following statements:	
An active sex life is good for health	92.05
Satisfactory sexual relations are essential to the maintenance of a relationship	89.47
Sexual satisfaction is an important part of feeling fulfilled in life	85.53

Table 4

Prevalence of reported sexual problems* in vaginal and cervical cancer survivors as compared to population-based controls (percent, unless otherwise specified)

	Registry (cases) n=160	NHSLS (controls) n=320	P**
Total Number of Problems (Mean (SD); Range: 1–7)	2.6 (2.0)	1.1 (1.4)	<0.001
Lacked interest in having sex	69.7	33.1	<0.001
Had trouble lubricating	68.6	23.6	<0.001
Experienced physical pain during intercourse	57.0	8.5	<0.001
Unable to climax	43.2	19.8	<0.001
Felt anxious about the ability to perform sexually	31.2	8.9	<0.001
Did not find sex pleasurable	30.7	13.5	0.001
Climaxed too quickly	14.5	7.4	0.08
Felt unattractive because of physical appearance	43.6	--	
Bladder infection or incontinence following sex	33.1	--	
Felt unattractive because of scars	23.8	--	
Post-coital bleeding	20.9	--	
Felt that sex was uncomfortable for the partner	18.3	--	
Had problems with vaginal discharge	15.7	--	
Felt unattractive because of body odors	14.2	--	
Felt uncomfortable because of the presence of any ostomy	5.7	--	

* Positive responses to the question “whether, during the last 12 months, there has ever been a period of several months or more when you experienced any of these problems.”

** All P values are univariate and were derived using the Student’s t-test for continuous variables and likelihood-ratio test for categorical variables.

Table 5

Association between vaginal and cervical cancer survival and reported sexual problems as compared to population-based controls

Sexual Problem	Crude odds ratio (95% CI)	P	Adjusted odds ratio (95% CI)	P
Lacked interest in having sex	4.53 (2.82 – 7.28)	<0.001	5.67 (2.89 – 11.13)	<0.001
Had trouble lubricating	6.52 (3.93– 10.80)	<0.001	6.28 (3.22 – 12.26)	<0.001
Experienced physical pain during intercourse	10.47 (5.52– 19.87)	<0.001	8.56 (3.71 – 19.76)	<0.001
Unable to climax	2.69 (1.71 – 4.22)	<0.001	2.24 (1.21 – 4.15)	0.01
Felt anxious about the ability to perform sexually	4.33 (2.32 – 8.07)	<0.001	2.89 (1.29 – 6.50)	0.01
Did not find sex pleasurable	2.33 (1.39 – 3.88)	0.001	1.96 (0.99 – 3.86)	0.053
Climaxed too quickly	1.96 (0.91 – 4.21)	0.08	2.23 (0.74 – 6.71)	0.153
Had three or more sexual problems listed above	5.47 (3.44 – 8.70)	<0.001	4.87 (2.68 – 8.82)	<0.001

All ORs were derived using conditional logistic regression. Adjusted ORs were derived from models including partner status, income, and self-reported health.

Table 6

Factors associated with complex sexual morbidity in vaginal and cervical cancer survivors (multivariate analysis)*

Factor	OR	95% CI	P
Age	0.91	0.84 – 0.99	0.032
Age at diagnosis	1.04	0.98 – 1.11	0.191
<i>Health/sexuality</i>			
Perceived health in the last week			
Very Good/Excellent	Referent		
Fair/Good	2.62	1.10 – 6.25	0.030
Poor	3.27	0.68 – 15.78	0.140
Partner in the last 12 months			
No	Referent		
Yes	10.89	2.09 – 56.90	0.005
<i>Clinical characteristics</i>			
Surgical treatment	0.71	0.24 – 2.14	0.547
Radiation treatment	0.49	0.16 – 1.46	0.198
Ever usage of HRT	2.66	1.00 – 7.02	0.049
Communication with physician **			
Yes	Referent		
No	2.74	1.14–6.58	0.024

* Odds ratio (OR) estimate and confidence interval (CI) of the likelihood of having complex sex morbidity (3 or more individual sex morbidities listed in Table 4) using a multivariate logistic regression model.

** Responses to the question “has a doctor ever started a conversation with you about the changes to your sex life that come with the type of treatment you received.”