



Published in final edited form as:

Gynecol Oncol. 2015 October ; 139(1): 134–140. doi:10.1016/j.ygyno.2015.08.019.

Assessment of Sexual Activity and Dysfunction in Medically Underserved Women with Gynecologic Cancers

Andrea Bradford¹, Bryan Fellman², Diana Urbauer², Jessica Gallegos¹, Kristen Meaders³, Celestine Tung³, and Lois Ramondetta¹

¹Department of Gynecologic Oncology and Reproductive Medicine, University of Texas MD Anderson Cancer Center

²Department of Biostatistics, University of Texas MD Anderson Cancer Center

³Department of Obstetrics and Gynecology, Division of Gynecologic Oncology, Baylor College of Medicine

Abstract

Background—Sexual dysfunction is a common long-term side effect of treatments for gynecologic cancer. Studies of sexual problems in gynecologic cancer survivors overrepresent White non-Hispanic, highly educated, and married women. Less is known about the sexual health needs of women in medically underserved populations. We therefore conducted a study to characterize sexual activity and sexual function in this population.

Methods—We recruited patients attending two gynecologic oncology clinics in a large public healthcare system that primarily serves uninsured and low-income patients. Participants were invited to complete a one-time survey to assess sexual function, sexual communication, sexual distress, relationship adjustment, depression, anxiety, prior help-seeking and help-seeking preferences, and reasons for sexual inactivity. Data were analyzed using descriptive statistics and multivariate models to predict sexual activity status and sexual dysfunction.

Results—Among 243 participants, the majority (n=160, 65.8%) were not sexually active in the past 4 weeks, most often due to lack of a partner or lack of desire for sex. Just over one-fourth of sexually active participants were identified as likely cases of sexual dysfunction. Greater endorsement of depressive symptoms predicted both sexual inactivity and sexual dysfunction in multivariate analyses. Prior help-seeking for sexual problems was uncommon; however, a significant minority of participants expressed interest in receiving care for sexual problems.

Corresponding Author: Andrea Bradford, Department of Gynecologic Oncology and Reproductive Medicine, University of Texas MD Anderson Cancer Center, Unit 1362, 1515 Holcombe Blvd., Houston, TX 77030; abradford@mdanderson.org; phone: 713-745-4466; fax: 713-792-7586.

Conflict of Interest Statement

Dr. Bradford is a consultant to Palatin Technologies, Inc. None of the other authors have potential conflicts of interest to declare.

Publisher's Disclaimer: This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

Conclusions—Gynecologic cancer survivors in our medically underserved population have high rates of sexual inactivity and sexual dysfunction. Future research should identify feasible strategies to address barriers to sexual health care in low-resource settings.

Keywords

Sexual dysfunction; sexual activity; depression; underserved; gynecologic cancer

INTRODUCTION

Sexual dysfunction is one of the most common long-term consequences of treatment for gynecologic cancer.[1,2] Frequently endorsed sexual complaints in survivors of gynecologic cancer include low sexual desire, vaginal dryness/atrophy, anatomical changes after surgery or radiotherapy, anorgasmia, and dyspareunia.[2,3] These problems often persist for years after completion of treatment.³ Although many prior studies of sexual outcomes in gynecologic cancer survivors have used validated instruments such as the Female Sexual Function Index,[5] generalization of these findings is limited by the fact that studies overrepresent White non-Hispanic, highly educated, and married women.[6–13] One exception was a large study of cervical cancer survivors that compared several domains of quality of life among English-speaking Latina, Spanish-speaking Latina, and European/White women.[14] The findings of this study suggested that Latina women may experience poorer sexual adjustment than European/White women following treatment of cervical cancer. However, sexual function was assessed using only a limited set of items from a cancer-specific quality of life scale. In general, sexual dysfunction has not been studied extensively in cancer survivors from medically underserved populations.

A medically underserved population is defined by the US Department of Health and Human Services as having a shortage of primary care providers, high infant mortality, high poverty, and/or a high proportion of elderly members.[15] Assessment of sexual health in both advantaged and medically underserved populations is limited by resource constraints, provider knowledge, and patient and provider discomfort. Validated self-report questionnaires are potentially cost effective tools to screen patients for sexual problems and determine unmet health service needs in low resource settings. However, low general literacy, low health literacy, and language and cultural differences pose potential barriers to questionnaire-based assessment in medically underserved populations.[16,17] Although low socioeconomic status is associated with a higher prevalence of sexual problems in the general population,[18,19] little is known about how women in underserved populations seek or would prefer to receive care for sexual problems. Thus, it is unclear how assessment of sexual problems in low resource cancer care settings could inform feasible clinical intervention strategies.

In order to better understand resource needs for sexual health in medically underserved women with gynecologic cancer, we conducted a cross-sectional study in a clinic-based sample. Our primary aim was to estimate the prevalence of sexual inactivity and clinically significant sexual dysfunction in this population. Secondary aims were to identify clinical and psychosocial predictors of sexual inactivity and sexual dysfunction. For exploratory

purposes we gathered information on help-seeking preferences and help-seeking behaviors related to sexual health.

METHODS

Population and setting

Study participants were recruited from two gynecologic oncology clinics at Lyndon Baines Johnson Hospital (LBJ) and the Smith Clinic in the Harris Health system. Harris Health is a public healthcare system that primarily serves uninsured and indigent patients in Harris County, Texas (including the Houston metropolitan region), providing more than 1.8 million outpatient visits and over 35,000 hospital admissions each year. Patients served by Harris Health are predominantly Hispanic and African American. In fiscal year 2014, 22% of Harris Health patients were insured by Medicaid, 9% were insured by Medicare, and 5% had commercial health insurance; the remainder received services on a sliding scale based on income.

Preliminary data

We conducted a preliminary study to determine the feasibility of administering the Female Sexual Function Index[5] to assess sexual dysfunction in our target population, as we anticipated possible barriers due to lower levels of education, general literacy, and health literacy. Between June 1, 2007 and December 1, 2007, 194 unique consecutive patients seen at the LBJ clinic were invited to complete a questionnaire in either English or Spanish at the time of check-in. The questionnaire included demographics items, the FSFI, and the Hospital Anxiety and Depression Scale (HADS[16]). Surveys were completed without staff assistance and were collected anonymously using a drop box in the clinic. We received completed questionnaires from 168 women (86.5% participation rate). The mean age of this sample was 49; 64% were married or cohabiting, and 39% indicated that they were currently sexually active. Twenty-six women (13.5%) declined to participate due to inability to read or write in English or Spanish (n=11), lack of interest or discomfort with the topic (n=8), or lack of time (n=7). Whereas 144 (86%) of respondents completed the HADS with no missing items, nearly half (n=78, 46%) skipped one or more missing items on the FSFI. Further analysis revealed that missing data and inconsistent responding were associated with sexual inactivity or lack of a sexual partner. These results informed the design of the present study, in which we administered the FSFI only to sexually active women and with the assistance of a research nurse. We also developed an additional item to better understand the reasons why most women in this population were not sexually active.

Design of the present study

We conducted a clinic-based, cross-sectional study using a battery of validated self-report instruments to measure sexual activity status, sexual dysfunction, sexual distress, help seeking behavior for sexual problems, and several additional variables related to sexual behavior. This study was approved by the institutional review boards of the participating institutions and their local academic affiliates.

Participants

Consecutive patients seen in the gynecologic oncology clinic at LBJ between April 2012 and June 2014 were invited to participate upon checking in for their appointments. The study was later opened to enrollment at the Smith Clinic between May 2014 and August 2014. Inclusion criteria for the present study included a documented diagnosis of gynecologic cancer (including unstaged low grade or borderline disease), willingness to participate, age 18 or older, and the ability to read and write in English or Spanish. Women with non-invasive diseases (e.g., cervical intraepithelial neoplasia) were excluded.

Procedure

Eligible patients received packets in their preferred language (English or Spanish) that included a cover letter describing the study objectives, the study questionnaires, and referral information for community health resources. Consent was implied by completion of the questionnaires. A research nurse checked questionnaires for completion and offered assistance answering questions when needed, although participants were not required to answer any items they wished to skip. Completed questionnaires were not linked with identifying information. Patients sealed questionnaires in envelopes that were placed in a designated survey drop box in the clinic.

Questionnaires—All instruments were originally developed in English and translated to Spanish by a professional translating service within the academic affiliate institution using forward and backward translation methods.

Demographics: Participants were asked to indicate their age, race, ethnicity, relationship/marital status, education level, estimated annual household income, and number of children living at home.

Cancer characteristics: Participants indicated their tumor site (e.g., cervix, ovary, endometrium), stage, type of treatment received, and remission status. A research nurse assisted with obtaining this information from the medical record when necessary.

Sexual activity status: Participants were asked whether they had sexual activity with a partner during the past 4 weeks. This criterion, though relatively strict, has been used in previous studies to define sexually active and inactive persons.[21–23] If not sexually active, participants were asked to indicate reasons for not engaging in sexual activity. For this question we adapted an item used in a prior population-based study to estimate the prevalence of sexual inactivity and reasons for sexual inactivity in women.[23] Response choices in the present study were modified slightly to pertain to common problems among cancer survivors. Response choices included: “I don’t have a sexual partner,” “I no longer desire or enjoy sex,” “Sex has become physically painful,” “I don’t feel sexually attractive now,” and “Other.”

Abbreviated Dyadic Adjustment Scale (DAS-4): The short form of the Dyadic Adjustment Scale[24] contains 4 items that assess general adjustment and functioning in the respondent’s current relationship (e.g., “How often do you discuss or have you considered

divorce, separation, or termination of your relationship?"). Previous studies have shown that scores on the DAS-4 differentiate distressed and non-distressed couples.

Dyadic Sexual Communication Scale: The Dyadic Sexual Communication Scale[25] measures the degree to which the respondent agrees with 6 statements reflecting perceptions of communication in her sexual relationship (e.g., "Some sexual matters are too upsetting to discuss with my sexual partner."). The scale differentiates between people who did and did not report sexual problems.²¹

Hospital Anxiety and Depression Scale (HADS): The HADS[20] is a 14-item, self-administered questionnaire with two subscales designed to detect depression and anxiety, respectively, in medical care settings. A score of 11 or more on either subscale is considered to be an indication of psychological morbidity, while scores of 8 to 10 are considered borderline and 0 to 7 normal.

Unwanted Childhood Sexual Experiences Questionnaire: We administered 6 items from the Unwanted Childhood Sexual Experiences Questionnaire[26,27] to assess exposure to various types of unwanted sexual encounters prior to the age of 16 (e.g., "An adult fondling you in a sexual way," "Intercourse (vaginal penetration)"). An affirmative response to any item was used as an indicator of childhood sexual abuse history.

Help seeking and self-help for sexual problems: We included a set of novel items for our exploratory aim of determining help-seeking behaviors and preferences. Participants were asked whether their health care providers or they themselves had ever inquired about sexual problems. They were also presented with a list of five therapeutic options for sexual problems: "read a self-help book," "use a self-help Internet site," "attend a class or support group for women with sexual problems," "see a counselor or psychologist," and "see a medical doctor." For each option, participants were asked to indicate whether they had tried this option in the past or, if not, whether they would be interested in doing so. Participants had the option of adding additional open-ended comments but were not required to do so.

In addition to the instruments listed above, participants who indicated any sexual activity with a partner in the past 4 weeks completed two additional questionnaires to evaluate sexual dysfunction:

Female Sexual Function Index (FSFI): The FSFI[5] is a 19-item self-report instrument that assesses 6 domains of sexual function in sexually active women: desire, arousal, lubrication, orgasm, satisfaction, and pain. The FSFI has been empirically validated and reliably distinguishes between women with and without clinician-diagnosed sexual dysfunctions.[5,28] A cutoff score of 26 yielded a sensitivity of .77 and specificity of .85 for detecting a clinical diagnosis of sexual dysfunction.[28] The FSFI was recently validated in a sample of female cancer survivors.

Female Sexual Distress Scale-Revised (FSDS): The FSDS[29] is a 12-item questionnaire developed to assess distress and negative feelings related to sexual difficulties. Scores on the FSDS distinguish between women with and without sexual dysfunction and are sensitive to

treatment response. A cutoff score of 11 has been proposed to indicate clinically significant distress.

Data Analysis—We characterized the demographic and clinical characteristics of the study sample using descriptive statistics. The primary objectives of this study were (1) to estimate the prevalence of clinically significant sexual dysfunction among survivors who were sexually active; and (2) to determine the proportion of survivors who were not sexually active and the reasons for this. We calculated 95% confidence intervals for both estimates. We limited our analysis of sexual dysfunction to women who indicated any partnered sexual activity in the past 4 weeks, as FSFI scores from women who are not sexually active are ambiguous to interpret.[30] To avoid overestimating the prevalence of sexual dysfunction, we defined sexual dysfunction using measures of both sexual function and sexual distress. [21,31,32] Specifically, women with scores beyond the clinical cutoff thresholds on *both* instruments (ie, FSFI score ≥ 26 and FSDS score ≥ 11) were classified as likely cases of sexual dysfunction.[31,32] Participants who failed to answer any items on either the FSFI or the FSDS were excluded from the analyses. Participants who answered at least half of the items on either scale had missing values substituted with the mean calculated from completed items.

Secondary objectives included testing for predictors of sexual dysfunction and sexual activity. We performed univariate logistic regression analyses to test for associations with measures of anxiety (HADS), depression (HADS), relationship adjustment (DAS-4), sexual communication (DSC), and sexual abuse. We then evaluated multivariate models controlling for age and treatment, which were chosen for inclusion in the multivariate model in order to adjust for potential confounding effects. In the statistical models, indicator variables were used for treatment type, and those women who had multiple treatment types (e.g., chemotherapy and radiation) were included under each treatment regimen. Similar methods were used to assess predictors of sexual activity. Stage was also included in the multivariate model for sexual activity because it showed association in the univariate analysis. Descriptive statistics were generated to summarize participants' responses to exploratory items about help-seeking behaviors.

RESULTS

Two hundred fifty questionnaires were returned. Of these, seven participants were noted to have non-invasive/Stage 0 disease and were excluded from further analysis. Table 1 lists summary statistics for demographic and clinical characteristics for the remaining 243 participants. The median age of the sample was 50. Scores for the HADS Depression and HADS Anxiety subscales exceeded the clinical cutoff in 7% and 17% of participants, respectively. Seventy-three participants (30%) indicated a history of one or more unwanted sexual experiences before age 16.

The majority of participants ($n = 160$, 65.8%, 95% CI: 59.5 – 71.8) reported that they had not had sexual activity with a partner in the past 4 weeks. The most commonly endorsed reason for lack of sexual activity was absence of a sexual partner (Table 2). Table 7 presents the results of univariate and multivariate regression analyses predicting lack of sexual

activity in the past 4 weeks. In univariate analysis, predictors of sexual inactivity included disease stage (Stage III or IV) and treatment type (chemotherapy or chemoradiation). These variables were therefore included as covariates in the multivariate model. In multivariate analysis, older age and higher HADS depression scores were significantly associated with lack of sexual activity (Table 3).

Approximately one-third (n=83, 34.2%) of participants indicated having had sexual activity with a partner in the previous 4 weeks. Of these 83 participants, 12 failed to answer any items on either the FSFI or FSDS. Therefore, we used data from the 71 participants who completed these scales to estimate the prevalence of sexual dysfunction. One participant skipped only one item on the FSFI; therefore the mean of the remaining items in that subscale was substituted for the missing value. Four participants failed to answer one item on the FSDS, and two participants failed to answer two items. The mean of the completed items for these individuals was used in place of the missing items when calculating the FSDS score. Among these 71 participants, the mean FSFI Total score was 25.2 (SD=6.6, range 7.2–34.8); 35.2% exceeded the FSFI clinical cutoff score and 43.7% exceeded the FSDS cutoff score. Taking both scores into consideration, 19 participants (26.8% of sexually active participants), 95% CI: 16.9% – 38.6%) met our criteria for likely cases of sexual dysfunction.

In multivariate analyses, higher HADS depression scores were associated with a greater likelihood of sexual dysfunction (Table 4). Unexpectedly, women who received chemotherapy only were less likely to be classified as having sexual dysfunction than women who only had surgery, although this was based on a small subsample. Sexual dysfunction trended towards association with time in remission ($P = 0.09$) and was more prevalent among women who had been in remission longer than 6 months (15/45 or 33.3%) than those who were not in remission or within less than 6 months of remission (3/23 or 13.0%). Remission status was unknown for 3 sexually active women.

Table 5 presents exploratory data about help-seeking for sexual problems. Just over one-third of participants reported ever having been asked about sexual problems by a health care provider; fewer had asked a health care provider themselves about sexual problems. For each type of solution, such as reading a self-help book, seeing a counselor or psychologist, or seeing a medical doctor for sexual problems, less than 15% of participants endorsed having ever personally tried this. Most who had not tried these methods indicated that they would not be interested in doing so, although a sizeable minority expressed interest in one or more modalities for help with sexual problems.

DISCUSSION

Although previous studies have addressed sexual function in gynecologic cancer survivors, these tend to underrepresent medically underserved populations, who may differ in their needs and preferences for care related to sexual health. We therefore examined self-report data on sexual activity, sexual function, and various risk factors for sexual problems in a sample of 243 women who received care in gynecologic oncology clinics within a safety net healthcare system. We found that approximately two-thirds of participants had not been

sexually active within the past 4 weeks, most often due to lack of a partner and/or a lack of sexual desire or enjoyment. Although the definition of “sexually active” varies across studies and ours was relatively strict, the rates of sexual activity in our sample appear lower than those reported in most prior studies of gynecologic cancer survivors.[4,8,33] In multivariate analyses accounting for a variety of clinical and psychosocial risk factors, only age and scores on the HADS Depression subscale predicted lack of sexual activity in the past 4 weeks. This is consistent with well-known influences of mood and age on sexual behavior in adults, although it is notable that no other predictor was significantly associated with the absence of sexual activity in the past 4 weeks.

Among participants who were sexually active, just over one-fourth met our criteria for likely cases of sexual dysfunction (i.e., scores in the clinical range on both the FSFI and the FSDS). Although this estimate seems low, we used stringent criteria to define sexual dysfunction that are more in line with formal diagnostic criteria[34] and similar to those used in other recent studies of female sexual dysfunction prevalence.[31,32] Even with these stricter criteria, the rate of sexual dysfunction in our sample was roughly twice that of women in the general US population as determined using comparable methods.[32] Moreover, if we combine the frequency of sexual inactivity and sexual dysfunction in this sample, the total rate is similar to or exceeds rates of sexual dysfunction previously reported for gynecologic cancer survivors. For instance, Carter et al. estimated a sexual dysfunction prevalence of 69% (based on FSFI scores) in gynecologic cancer survivors of mixed socioeconomic status, although a majority of participants in that study were sexually active. [7]

One possible interpretation of our findings is that relatively few women in our sample continued regular sexual activity in the face of sexual problems. It is unclear whether limited access to resources (eg, professional help, costly over-the-counter lubricants, etc.), partner behaviors, or other factors determined the impact of a sexual problem on continuation of sexual activity. Prior help-seeking for sexual problems was uncommon in our sample, though a significant minority endorsed interest in self-help or professionally-guided therapies. The percentages of women who expressed interest in seeing a medical doctor or a mental health professional for sexual problems (25% and 27%, respectively) were only slightly lower than those reported by patients in a previous surveys of cancer survivors. [35,36] Our data therefore substantiate a significant unmet need for sexual health services among medically underserved women with gynecologic cancer. Although the logistics of offering these services are challenging, at a minimum low-resource settings can provide high quality educational materials such as the American Cancer Society’s *Sexuality for the Woman with Cancer*, which is available free of charge in English, Spanish, and lower reading level English. Training in sexual counseling should be offered to social workers, counselors, and other supportive care personnel who are already present in low-resource care settings. Peer counseling is another possible modality that could be feasible to implement in low-resource healthcare settings. A peer counseling intervention for sexual health, fertility, and menopause-related concerns appeared to reduce distress and increase knowledge in a study of African-American breast cancer survivors.[37]

Our findings should give pause to those who seek to assess sexual problems in populations with frequent barriers to sexual expression. An important limitation of questionnaires that assess sexual function is that they depend on recall of recent sexual events. Although lack of a sexual partner or sexual inactivity do not necessarily preclude assessment of sexual function, questionnaires such as the FSFI were not developed primarily for women in these situations and may not perform well under these circumstances. This feature of the FSFI has been critiqued in the literature.[30,38,39] Although alternative scoring methods have been proposed, it remains unclear how valid FSFI responses are for women who are not sexually active. Moreover, it is not always clear whether women who cease sexual activity do so voluntarily or are bothered by this. For instance, open-ended comments provided by participants in our sample confirmed that, for some, lack of sexual activity was not distressing (e.g., “Not really interested in sex and this time am very happy!”, “I dont [sic] need help, I am good without sex”). In general, measurement tools for sexual dysfunction in high-risk populations should be developed to better capture the range of experiences of those who engage in little or no sexual activity. At the same time, measures of sexual function should be refined to be inclusive of women who engage in less frequent sexual activity.

One strength of our study is a high overall participation rate. We attribute this success to the mode of administration (in-person), facilitation by a research nurse in the clinic, and the availability of questionnaires in both of the languages commonly spoken within our patient population. Nevertheless, it is possible that the language of the survey was problematic for participants with low literacy levels, a possibility suggested by our preliminary data. We did not formally assess comprehension of the FSFI items among women who completed the survey, and therefore it is possible that low general literacy or low health literacy biased the responding of some participants. An additional limitation of this is the lack of a control group of women with similar demographic characteristics and no cancer history. It is possible that similar rates of sexual dysfunction would be found in non-cancer survivors from the same communities, as lower socioeconomic status has been linked to higher incidence of sexual problems in population-based studies.[18,19] Finally, it is possible that some risk factors that we did not assess might have influenced responses to sexuality questionnaires. For example, although we screen for domestic violence in the clinic, we did not capture these experiences for the purpose of our study.

In conclusion, our study adds to the literature on sexual adjustment in gynecologic cancer survivors by describing sexual activity levels and sexual function in women from a predominantly underserved population, whose sociodemographic characteristics differ meaningfully from groups that have been represented in most of the literature on this topic. Of particular interest is the finding that the majority of survivors in our clinic-based sample were not sexually active. Our future research will focus on better understanding the additional barriers facing women in this population and evaluating interventions that are feasible to implement in low-resource settings.

Acknowledgments

This research is supported in part by the National Institutes of Health through M. D. Anderson’s Cancer Center Support Grant CA016672. The funding source had no involvement in the design, conduct, or analysis of this study.

References

1. Harrington CB, Hansen JA, Moskowitz M, Todd BL, Feuerstein M. It's not over when it's over: long-term symptoms in cancer survivors-a systematic review. *Int J Psychiat Med*. 2010; 40:163–181.
2. Bodurka DC, Sun C. Sexual function after gynecologic cancer. *Obstet Gynecol Clin N Am*. 2006; 33:621–30.
3. Sadosky R, Basson R, Krychman M, et al. Cancer and sexual problems. *J Sex Med*. 2010; 7:349–73. [PubMed: 20092444]
4. Lindau ST, Gavrilova N, Anderson D. Sexual morbidity in very long term survivors of vaginal and cervical cancer: a comparison to national norms. *Gynecol Oncol*. 2007; 106:413–8. [PubMed: 17582473]
5. Rosen R, Brown C, Heiman J, et al. The Female Sexual Function Index (FSFI): a multidimensional self-report instrument for the assessment of female sexual function. *J Sex Marital Ther*. 2000; 26:191–208. [PubMed: 10782451]
6. Becker M, Malafy T, Bossart M, Henne K, Gitsch G, Denschlag D. Quality of life and sexual functioning in endometrial cancer survivors. *Gynecol Oncol*. 2011; 121:169–73. [PubMed: 21159367]
7. Carter J, Chi DS, Brown CL, et al. Cancer-related infertility in survivorship. *Int J Gynecol Cancer*. 2010; 20:2–8. [PubMed: 20130497]
8. Carter J, Rowland K, Chi D, et al. Gynecologic cancer treatment and the impact of cancer-related infertility. *Gynecol Oncol*. 2005; 97:90–5. [PubMed: 15790443]
9. Carter J, Sonoda Y, Baser RE, et al. A 2-year prospective study assessing the emotional, sexual, and quality of life concerns of women undergoing radical trachelectomy versus radical hysterectomy for treatment of early-stage cervical cancer. *Gynecol Oncol*. 2010; 119:358–65. [PubMed: 20817227]
10. Fotopoulou C, Neumann U, Klapp C, Lichtenegger W, Sehouli J. Long-term effects of neovaginal reconstruction with sigmoid loop technique on sexual function and self image in patients with gynecologic malignancies: results of a prospective study. *Gynecol Oncol*. 2008; 111:400–6. [PubMed: 18947859]
11. Frumovitz M, Sun CC, Schover LR, et al. Quality of life and sexual functioning in cervical cancer survivors. *J Clin Oncol*. 2005; 23:7428–36. [PubMed: 16234510]
12. Likes W, Stegbauer C, Hathaway D, Brown C, Tillmanns T. Use of the Female Sexual Function Index in women with vulvar intraepithelial neoplasia. *J Sex Marital Ther*. 2006; 32:255–66. [PubMed: 16809252]
13. Serati M, Salvatore S, Uccella S, et al. Sexual function after radical hysterectomy for early-stage cervical cancer: is there a difference between laparoscopy and laparotomy? *J Sex Med*. 2009; 6:2516–22. [PubMed: 19549091]
14. Ashing-Giwa KT, Tejero JS, Kim J, et al. Cervical cancer survivorship in a population based sample. *Gynecol Oncol*. 2009; 112:358–64. [PubMed: 19059636]
15. Health Resources and Service Administration, US Department of Health and Human Services. [August 12, 2015] Medically underserved areas/populations. Guidelines for MUA and MUP Designation. 2015. Available from: <http://www.hrsa.gov/shortage/mua/>
16. Al-Tayyib AA, Rogers SM, Gribble JN, Villarroel M, Turner CF. Effect of low medical literacy on health survey measurements. *Am J Public Health*. 2002; 92:1478–80. [PubMed: 12197979]
17. King G, Murray CJL, Salomon JA, Tandon A. Enhancing the validity and cross-cultural comparability of measurement in survey research. *Am Pol Sci Rev*. 2004; 98:191–207.
18. Hawton K, Gath D, Day A. Sexual function in a community sample of middle-aged women with partners: effects of age, marital, socioeconomic, psychiatric, gynecological, and menopausal factors. *Arch Sex Behav*. 1994; 23:375–95. [PubMed: 7993180]
19. Laumann, EO.; Gagnon, JH.; Michael, RT.; Michaels, S. The social organization of sexuality: sexual practices in United States. Chicago, IL: University of Chicago Press; 1994.
20. Zigmond A, Snaith R. The hospital anxiety and depression scale. *Acta Psychiatr Scand*. 1983; 67:361–70. [PubMed: 6880820]

21. Bancroft J, Loftus J, Long JS. Distress about sex: a national survey of women in heterosexual relationships. *Arch Sex Behav.* 2003; 32:193–208. [PubMed: 12807292]
22. Carmack Taylor CL, Basen-Engquist K, Shinn EH, Bodurka DC. Predictors of sexual functioning in ovarian cancer patients. *J Clin Oncol.* 2004; 22:881–9. [PubMed: 14990644]
23. Lutfey KE, Link CL, Rosen RC, Wiegel M, McKinlay JB. Prevalence and correlates of sexual activity and function in women: results from the Boston Area Community Health (BACH) Survey. *Arch Sex Behav.* 2009; 38:514–27. [PubMed: 18188686]
24. Sabourin S, Valois P, Lussier Y. Development and validation of a brief version of the Dyadic Adjustment Scale with a nonparametric item analysis model. *Psychol Assess.* 2005; 17:15–27. [PubMed: 15769225]
25. Catania J, Pollack L, McDermott L, Qualls S, Cole L. Help-seeking behaviors of people with sexual problems. *Arch Sex Behav.* 1990; 19:235–50. [PubMed: 2360873]
26. Stevenson MR, Gajarsky WM. Unwanted childhood sexual experiences relate to later victimization and male perpetration. *J Psychol Human Sex.* 1992; 4:57–70.
27. Stevenson, MR. Unwanted Childhood Sexual Experiences Questionnaire. In: Fisher, TD.; Davis, CM.; Yarber, WL.; Davis, SL., editors. *Handbook of Sexuality-related Measures.* 3. New York: Routledge; 2011. p. 12-13.
28. Wiegel M, Meston C, Rosen R. The Female Sexual Function Index (FSFI): cross-validation and development of clinical cutoff scores. *J Sex Marital Ther.* 2005; 31:1–20. [PubMed: 15841702]
29. Derogatis LR, Rosen R, Leiblum S, Burnett A, Heiman J. The Female Sexual Distress Scale (FSDS): initial validation of a standardized scale for assessment of sexually related personal distress in women. *J Sex Marital Ther.* 2002; 28:317–30. [PubMed: 12082670]
30. Brotto LA. The female sexual function index: a methodological critique and suggestions for improvement. *J Sex Marital Ther.* 2009; 35:161–3. [PubMed: 19360516]
31. West SL, D'Aloisio AA, Agans RP, Kalsbeek WD, Borisov NN, Thorp JM. Prevalence of low sexual desire and hypoactive sexual desire disorder in a nationally representative sample of US women. *Arch Intern Med.* 2008; 168:1441–9. [PubMed: 18625925]
32. Shifren JL, Monz BU, Russo PA, Segreti A, Johannes CB. Sexual problems and distress in United States women: prevalence and correlates. *Obstet Gynecol.* 2008; 112:970–8. [PubMed: 18978095]
33. Andersen BL, van Der Does J. Surviving gynecologic cancer and coping with sexual morbidity: an international problem. *Int J Gynecol Cancer.* 1994; 4:225–40. [PubMed: 11578412]
34. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders.* 5. Arlington, VA: American Psychiatric Association; 2013.
35. Huyghe E, Sui D, Odensky E, Schover LR. Needs assessment survey to justify establishing a reproductive health clinic at a comprehensive cancer center. *J Sex Med.* 2009; 6:149–63. [PubMed: 18823323]
36. Hill EK, Sando S, Abramssohn E, et al. Assessing gynecologic and breast cancer survivors' sexual health needs. *Cancer.* 2011; 117:2643–51. [PubMed: 21656742]
37. Schover LR, Rhodes MM, Baum G, et al. Sisters Peer Counseling in Reproductive Issues After Treatment (SPIRIT). *Cancer.* 2011; 117:4983–92. [PubMed: 21495025]
38. Brotto LA. Improving the Female Sexual Function Index [Letter]. *J Sex Marital Ther.* 2009; 35:83–5. [PubMed: 19266378]
39. Meyer-Bahlburg HF, Dolezal C. The Female Sexual Function Index: a methodological critique and suggestions for improvement. *J Sex Marital Ther.* 2007; 33:217–24. [PubMed: 17454519]

Research Highlights

- We examined sexual function in a sample of 243 gynecologic cancer survivors followed in a public safety net healthcare system.
- Nearly one-fourth of sexually active survivors endorsed both a sexual problem and clinically significant sexual distress.
- Approximately one-fourth of participants indicated interest in medical or psychological help for sexual problems but had not received these services.

Table 1

Sample Demographic and Clinical Characteristics (N= 243)

Characteristic	N	%
Age, Mean (SD) Min-Max	49.7 (11.8)	18 – 83
What is your race?		
American Indian or Alaska Native	2	0.8
Asian	4	1.6
Black or African-American	54	22.2
Native Hawaiian or Other Pacific Islander	1	0.4
White	133	54.7
More than one race	10	4.1
Item missed or skipped	39	16.0
What is your primary language?		
English	131	53.9
Spanish	107	44.0
Other	5	2.1
What is your ethnicity?		
Hispanic or Latino	147	60.5
Not Hispanic or Latino	86	35.4
Item missed or skipped	10	4.1
Which of the following best describes your current relationship status?		
Not in a steady relationship at this time	96	39.5
In a relationship, not living together	24	9.9
In a relationship, living together	31	12.8
Married	88	36.2
Item missed or skipped	4	1.6
How many children are living with you at home?		
0	153	63.0
1	38	15.6
2	30	12.3
3 or more	21	8.6
Item missed or skipped	1	0.4
What is the highest level of education you have completed?		
8th grade or lower	48	19.8
Some high school	47	19.3
High school diploma or GED	79	32.5
Some college or 2-year college degree (associate's)	23	9.5
4-year college degree (bachelor's)	41	16.9
Graduate or advanced degree	4	1.6
Item missed or skipped	1	0.4
Please estimate your annual household income.		
Less than \$25,000	171	70.4

Characteristic	N	%
\$25,000 – \$49,999	51	21.0
\$50,000 – \$74,999	4	1.6
\$75,000 – or more	1	0.4
Item missed or skipped	16	6.6
Diagnosis		
Cervix	68	28.0
Uterine	78	32.1
Vaginal	1	0.4
Ovary	63	25.9
Vulvar	6	2.5
Other	25	10.3
Item missed or skipped	2	0.8
Stage		
Low Grade/Borderline	9	3.7
I	91	37.4
II	36	14.8
III	44	18.1
IV	31	12.8
Item missed or skipped	32	13.2
Treatment		
Active Surveillance	2	0.8
Surgery only	67	27.6
Chemotherapy	70	28.8
Radiation	17	7.0
Chemotherapy and Radiation	74	30.5
Hormonal Therapy	6	2.5
Item missed or skipped	7	2.9
Disease Status		
Primary	206	84.8
Recurrent	30	12.3
Item missed or skipped	7	2.9
Remission?		
Yes, <6 months ago	46	18.9
Yes, >6 months ago	135	55.6
No	37	15.2
Item missed or skipped	25	10.3

Table 2

Sexual Activity Status and Reasons for Lack of Sexual Activity in the Past 4 Weeks

Characteristic	N	%
<i>"During the past 4 weeks, have you had any type of sexual activity with a partner?"</i>		
No	160	65.8
Yes	83	34.2
<i>"Please tell us why you are not sexually active at this time. Check all reasons that apply to you." (n = 160)*</i>		
I don't have a sexual partner.*		
Unchecked	87	54.4
Checked	73	45.6
I no longer desire or enjoy sex.		
Unchecked	102	63.7
Checked	58	36.3
Sex has become physically painful.		
Unchecked	140	87.5
Checked	20	12.5
I don't feel sexually attractive now.		
Unchecked	131	81.9
Checked	29	18.1
Other		
Unchecked	118	73.8
Checked	42	26.3

* Note. This and subsequent items were completed only by those who indicated no sexual activity in the past 4 weeks.

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Table 3

Predictors of Sexual Activity

Effect	Sexual Activity				Univariate			Multivariate				
	No N	%	N	%	OR	95% LB	95% UB	p-value	OR	95% LB	95% UB	p-value
Age	53.1 (10.8)	18.0 – 83.0	43.2 (11.1)	18.0 – 64.0	0.92	0.90	0.95	<0.001	0.93	0.90	0.96	<0.001
HADS Anxiety	6.3 (4.7)	0.0 – 20.0	6.2 (4.5)	0.0 – 20.0	0.99	0.94	1.05	0.857	1.09	0.98	1.20	0.110
HADS Depression	5.0 (3.9)	0.0 – 18.0	3.7 (3.0)	0.0 – 12.0	0.90	0.83	0.98	0.012	0.79	0.68	0.91	0.001
Race												
White	85	62.0	48	71.6		reference						
Other	52	38.0	19	28.4	0.65	0.34	1.22	0.178				
Diagnosis												
Cervix	43	27.0	25	30.5		reference						
Uterine	56	35.2	22	26.8	0.68	0.34	1.36	0.271				
Ovary	43	27.0	20	24.4	0.80	0.39	1.65	0.546				
Other	17	10.7	15	18.3	1.52	0.65	3.56	0.337				
Stage												
Low/Borderline	3	2.1	6	8.5		reference						
I	56	40.0	35	49.3	0.31	0.07	1.33	0.116	0.57	0.12	2.79	0.486
II	24	17.1	12	16.9	0.25	0.05	1.18	0.080	0.75	0.12	4.65	0.760
III	34	24.3	10	14.1	0.15	0.03	0.70	0.016	0.46	0.07	2.93	0.410
IV	23	16.4	8	11.3	0.17	0.04	0.86	0.032	0.52	0.08	3.41	0.495
Treatment												
Surgery only	33	21.3	34	42.0		reference						
Active Surveillance	0	0.0	2	2.5		excluded						
Chemotherapy	51	32.9	19	23.5	0.48	0.26	0.87	0.015	0.63	0.27	1.48	0.293
Radiation	13	8.4	4	4.9	0.63	0.34	1.17	0.143	0.76	0.36	1.62	0.481
Chemo and radiation	56	36.1	18	22.2	0.30	0.14	0.62	0.001 *	0.48	0.18	1.27	0.140*
Hormonal therapy	2	1.3	4	4.9	2.21	0.38	12.78	0.376	4.86	0.39	61.33	0.221
Sexual Abuse												
No	113	70.6	57	68.7		reference						

Effect	<u>Sexual Activity</u>		%	OR	<u>Univariate</u>			<u>Multivariate</u>			
	<u>No</u>	<u>Yes</u>			95% LB	95% UB	p-value	OR	95% LB	95% UB	p-value
Yes	N 47	N 26	29.4	1.10	0.62	1.95	0.753	1.16	0.54	2.50	0.710

* Note: These are linear combination of the estimators derived from the model with factors surgery, AS, chemotherapy, radiation, and hormone therapy

Table 4

Predictors of Sexual Dysfunction in Sexually Active Women

Effect	Sexual Dysfunction				Univariate				Multivariate			
	No	Yes	%	N	OR	95% LB	95% UB	p-value	OR	95% LB	95% UB	p-value
Age	41.9 (11.5)	18.0 – 63.0	45.3 (9.7)	29.0 – 61.0	1.03	0.98	1.08	0.246	1.02	0.95	1.10	0.606
HADS Anxiety	5.2 (4.7)	0.0 – 20.0	7.6 (3.6)	2.0 – 14.0	1.12	1.00	1.26	0.054	0.90	0.71	1.13	0.362
HADS Depression	2.8 (2.7)	0.0 – 12.0	5.6 (2.7)	1.0 – 10.0	1.38	1.13	1.68	0.001	1.54	1.07	2.22	0.019
DSC	36.8 (11.3)	13.0 – 65.0	36.3 (8.1)	23.0 – 55.0	0.99	0.94	1.05	0.844	1.03	0.95	1.13	0.454
DAS	15.7 (4.0)	7.0 – 21.0	13.4 (3.5)	7.0 – 19.0	0.86	0.75	1.00	0.044	0.94	0.76	1.16	0.549
Race												
White	29	72.5	12	80.0	reference							
Other	11	27.5	3	20.0	0.66	0.16	2.79	0.571				
Diagnosis												
Cervix	16	31.4	9	47.4	reference							
Uterine	11	21.6	5	26.3	0.81	0.21	3.07	0.755				
Ovary	14	27.5	3	15.8	0.38	0.09	1.69	0.204				
Other	10	19.6	2	10.5	0.36	0.06	1.99	0.240				
Treatment												
Surgery only	18	36.0	11	57.9	reference				reference			
Active Surveillance	0	0.0	1	5.3	excluded				excluded			
Chemotherapy	16	32.0	1	5.3	0.20	0.05	0.86	0.030	0.16	0.03	0.89	0.036
Radiation	2	4.0	1	5.3	2.35	0.51	10.93	0.275	1.78	0.25	12.39	0.562
Chemo and radiation	12	24.0	4	21.1	0.47	0.12	1.92	0.294*	0.28	0.04	2.14	0.221*
Hormonal therapy	2	4.0	1	5.3	0.91	0.07	11.17	0.939	1.33	0.09	20.59	0.837
Sexual Abuse												
No	36	69.2	12	63.2	reference							
Yes	16	30.8	7	36.8	1.31	0.44	3.95	0.629	0.59	0.13	2.73	0.499

* Note: These are linear combination of the estimators derived from the model with factors: surgery, AS, chemotherapy, radiation, and hormone therapy

Table 5

Help Seeking and Self-help for Sexual Problems (N=242)

Characteristic	N	%
Has a doctor/health provider ever asked you about sexual problems?		
No	154	63.6
Yes	88	36.4
Have you ever asked your doctor/health provider about sexual problems?		
No	199	82.2
Yes	43	17.8
Read a self-help book?		
Tried this in the past	34	14.0
Haven't tried, but not interested	128	52.9
Haven't tried, but would be interested	69	28.5
Item missed or skipped	11	4.5
Use a self-help internet site?		
Tried this in the past	23	9.5
Haven't tried but not interested	159	65.7
Haven't tried but would be interested	48	19.8
Item missed or skipped	12	5.0
Attend a class or support group for women with sexual problems?		
Tried this in the past	4	1.7
Haven't tried, but not interested	179	74.0
Haven't tried, but would be interested	45	18.6
Item missed or skipped	14	5.8
See a counselor or psychologist?		
Tried this in the past	12	5.0
Haven't tried, but not interested	150	62.0
Haven't tried, but would be interested	65	26.9
Item missed or skipped	15	6.2
See a medical doctor?		
Tried this in the past	30	12.4
Haven't tried, but not interested	139	57.4
Haven't tried, but would be interested	60	24.8
Item missed or skipped	13	5.4