



Sexual quality of life after the treatment of gynecologic cancer: what women want

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Abstract

Purpose While the incidence of sexual dysfunction after treatment for gynecologic malignancies is well documented, few studies describe how patients want healthcare providers to address these concerns. The objective of this study was to evaluate changes in sexual function and describe patient preferences regarding healthcare provider roles in addressing and treating sexual dysfunction in gynecologic cancer survivors.

Methods Patients undergoing gynecologic cancer treatment from 2013 to 2014 at a single University-based Gynecologic Cancer clinic were surveyed using a modified Changes in Sexual Function Questionnaire (CSFQ), along with questions relating to healthcare provider interactions and preferences.

Results Among 277 eligible patients approached to participate, 85 (30.7%) completed the survey. The mean age was 52.2 ± 12.3 years; most were non-Hispanic White (78.8%), partnered (73.2%), had endometrial or ovarian cancer (30.6% and 44.7%, respectively), and were in surveillance (57.3%). Most women (64.7%) reported much or great sexual enjoyment 1 year prior to cancer treatment which decreased to 27.4% currently; 33.3% report only rare sexual activity. There were no statistically significant differences in mean total CSFQ scores by treatment modality. A minority wanted healthcare providers to initiate sexual health discussions (25.3%); the remaining reported not wanting sexual health addressed or preferred raising the issue themselves. The most commonly cited barrier to communication was the feeling that there are more important issues to discuss with their oncology providers (46.2%).

Conclusions While gynecologic cancer patients report changes in sexual function following cancer therapy, many believe there are other issues more paramount to be addressed. Further studies are warranted to develop better strategies for addressing sexual health in women receiving treatment for gynecologic cancers.

Keywords Sexual health · Gynecologic cancer · Sexual dysfunction · Quality of life

Introduction

The reported rates of sexual dysfunction among women with a diagnosis of gynecologic cancer during the course of

treatment and recovery range from 40 to 100% [1, 2], which is higher than the reported rate in the general female population (43%) [3]. As the effectiveness of cancer treatments continues to improve, the number of female survivors will continue to rise, with over 1 million gynecologic cancer survivors estimated in 2016 [4]. The National Comprehensive Cancer Network (NCCN) presented guidelines for survivorship and highlighted sexual health originally in 2013 as an “important part of an individual’s overall physical and emotional well-being” [5]. In the 2017 NCCN guidelines for Sexual Function, it is suggested that healthcare providers ask about sexual function at regular intervals.

Given that the majority of patients seen for cancer follow-up report sexual dysfunction, it is imperative to understand how to improve communication between healthcare providers and patients and address this aspect of patient well-being. For

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healthcare providers, barriers include time constraints, training limitations, personal biases, and perception that patients will report their own sexual concerns [6–10]. When healthcare providers do discuss the impact of cancer treatment on sexual function, patients are generally satisfied with both the quality (68%) and length (66%) of discussion [11]. Numerous barriers exist for patients as well. Women cite feelings of embarrassment, a belief that healthcare providers are unable to help them, or do not view sexual health something that requires medical assistance [12]. In a survey study of 3807 women, 77% reported low desire/interest in sexual activity. Of these women, the authors found that 42% sought help from their OB/GYN. Only 39% of those surveyed believed that the physician was earnest in appreciating the significance of their problem [12]. Another study interviewed 15 patients with ovarian cancer and found that most women felt healthcare professionals should have provided written information or discussed sexual issues with them [9]. A prospective study of breast cancer patients found increased satisfaction with sexually related information following spontaneous dissemination of information by healthcare providers at the time of cancer diagnosis [13].

The objectives of this study were to characterize sexual dysfunction in women undergoing treatment or being seen in follow-up for gynecologic cancers and to identify patient barriers to discussion of sexual health with their healthcare providers.

Materials and methods

Study design and patient population

Following approval from the University of Minnesota Institutional Review Board, a cross-sectional survey of women with a gynecologic cancer diagnosis being seen in follow-up was conducted. Any established patient with a diagnosis of a gynecologic malignancy seen in the Gynecologic Oncology Clinic at the University of Minnesota between December 2013 and December 2014 was eligible. Exclusion criteria included age less than 18 and no gynecologic malignancy diagnosis. Patients were approached at the time of a scheduled appointment in the outpatient clinic by study personnel and invited to complete a one-time survey about changes in sexual function related to treatment for their gynecologic cancer. They were provided with a letter that outlined the goals of the study and included all sections related to study consent, however, in order to ensure anonymity, consent was implied by completing and returning the survey. The surveys were completed in the waiting room or in the private clinic room as desired by the participant.

Measures

The Changes in Sexual Function Questionnaire (CFSQ) is a structured questionnaire that has been validated and found to be reliable to evaluate illness- and medication-related changes in sexual function [14]. For this study, we modified the CFSQ to evaluate cancer and associated treatment-related changes in sexual function in the setting of patients with gynecologic malignancies. Women were asked to rate their pleasure or enjoyment with various aspects of sexual function both prior to and after cancer treatment. Each item was measured on a scale from no (0), little (1), some (2), much (3), to great (4) enjoyment or pleasure. Patients were also asked to rate the frequency of various sexual states pre- and post-cancer, rated on a scale from never (0), rarely or much less than half the time (1), sometimes or about half a time (2), often or much more than half the time (3), to always (4). Following the original CFSQ, changes in sexual function were grouped into five areas of the sexual experience: pleasure, desire/frequency, desire/interest, arousal/excitement, and orgasm/completion. For each patient, a change in sexual functioning sub-score was calculated for each of the areas of sexual experience and a global sexual function score was obtained by summing each of the five areas. A higher score indicates better sexual function. Further, patients were defined as having sexual dysfunction overall or for each subscale if their score was equal to or less than established cut-offs: total CSFQ score: 41, sexual desire/frequency: 6, sexual desire/interest: 9, sexual pleasure: 4, sexual arousal/excitement: 12, and sexual orgasm/completion: 11.

The CFSQ also includes two items relating to preferences for and barriers to discussions surrounding sexual dysfunction with their gynecologic cancer provider. Suggested barriers included lack of comfort, feeling healthcare provider did not want to discuss, lack of time, or that there were more important issues to discuss. Preference regarding options for treatment of their sexual dysfunction included written information, single versus group counseling, and/or medication if it were available.

Demographic data, including age, race, education, spiritual beliefs, marital status, and number of children were collected via the survey. Clinical data, including diagnosis, disease stage, treatments received, and current disease status were ascertained through both patient self-report and the electronic medical record.

Statistical analysis

Patient demographics, clinical data, CSFQ sub-score and total scores and proportions with sexual dysfunction, and questions regarding communication preference, barriers, and treatment preferences for sexual dysfunction were summarized using descriptive statistics. The total modified CSFQ scores were compared for treatments received (surgery, chemotherapy, radiation—yes/no) using *t* tests assuming unequal variances.

The proportions of patients with sexual dysfunction were compared by treatments received using chi-squared tests. Analyses were performed using SAS version 9.3 (Cary, NC) and p values < 0.05 were considered statistically significant.

Results

Of the 277 women who presented to clinic for routine follow-up during the study period and were offered participation in the study, 85 (30.7%) met eligibility criteria and completed the survey. The mean age of subjects was 52.2 ± 12.3 years; most women were non-Hispanic White (78.8%), partnered (73.2%), had either endometrial or ovarian cancer (30.6% and 44.7%, respectively), and were in surveillance for their cancer (57.3%; Table 1). The majority had undergone surgery (91.8%) and received chemotherapy (63.5%); a minority (23.8%) had received radiation therapy.

Most women reported much or great enjoyment in their sex life 1 year prior to cancer treatment (64.7%); this decreased to 27.4% at the time of the survey. Many women (43.5%) stated their sexual enjoyment significantly changed since cancer treatment and 33.3% reported they currently rarely engage in sexual activity. More than half (52.5%) reported never or rarely having adequate vaginal lubrication during sexual activity at the time of the survey.

Summary total and scale CSFQ scores and the proportions of each with sexual dysfunction are provided in Table 2. Over half of all of the patients reported dysfunction in each of the scales and 43.5% had overall sexual dysfunction. There were no statistically significant differences in mean total CSFQ scores or the proportion with sexual dysfunction by cancer treatment, though those who had not undergone surgery, while a minority, did have a higher total score but this was not significant ($44.5 \pm .2$ vs. 41.1 ± 10.8 , $p = 0.14$).

Regarding discussion of sexual function with their healthcare provider, few women reported wanting their healthcare provider to bring up the topic of sexual issues (25.3%); the remainder reported either not wanting it addressed or wanting to ask about the topic themselves (Table 3). The most commonly endorsed barrier to addressing sexual issues with healthcare providers was the feeling that there are more important issues to discuss (46.2%). For those who chose “other”, most stated there was not a current issue. The largest proportion of patients (37.5%) reported not wanting any treatment for their sexual health concerns; among those who did report a preference, most preferred written resources (32.9%).

Discussion

While there is a known link between sexual health and overall quality of life in gynecologic cancer patients [15], data are

Table 1 Demographic and clinical information ($N = 85$)

Question	<i>N</i>	%
Race		
White, non-Hispanic	67	78.8
Other	18	21.2
Highest education		
High school graduate	11	13.3
Some college/technical school	25	30.1
College graduate	32	38.6
Professional school	15	18.1
Missing	2	
How important are religious/spiritual beliefs in daily life?		
Very important	50	60.2
Moderately important	25	30.1
Not important	6	7.2
Prefer not to answer	2	2.4
Missing	2	
Marital status		
Single	10	12.2
Married/partnered	60	73.2
Divorced	11	13.4
Widowed	1	1.2
Missing	3	
Number of children		
None	21	25.3
1	11	13.3
2	23	27.7
3	16	19.3
4 or more	12	14.5
Missing	2	
Gynecologic cancer diagnosis		
Cervical	15	17.7
Endometrial	26	30.6
Ovarian/fallopian tube/primary peritoneal	38	44.7
Vulvar	4	4.7
Endometrial and ovarian	2	2.4
Cancer stage		
I	36	42.4
II	12	14.1
III	23	27.1
IV	7	8.2
Unknown	7	8.2
Surgery		
Yes	78	91.8
No	7	8.2
Chemotherapy		
Yes	54	63.5
No	31	36.5
Radiation—brachytherapy		
Yes	20	23.8
No	64	76.2

Table 1 (continued)

Question	N	%
Missing	1	
Radiation—external beam radiation		
Yes	20	23.8
No	64	76.2
Missing	1	
Current treatment status		
Before surgery	2	2.4
After surgery	14	17.1
Currently receiving treatment	19	23.2
In surveillance, not currently receiving treatment	47	57.3
Missing	3	
Another cancer type		
No	74	88.1
Yes	10	11.9
Missing	1	

needed on patient preferences surrounding discussions with healthcare providers. The decrease in sexual function following cancer treatment indicates a major lifestyle change for many of the participants in the current study. Despite the incidence of sexual dysfunction observed in this population, nearly one-third of the patients surveyed did not want healthcare providers to address issues of sexual dysfunction and among those who did, written material was cited as the preferred mode. Further, many patients reported that sexual dysfunction was a low priority in their clinic visits.

Different treatment modalities have distinct physical impacts on sexual health, which may vary in their overall effect on total sexual enjoyment. The lack of observed differences in sexual enjoyment based on treatment modality suggests other non-physical or treatment-related factors may be contributing to the development of subsequent sexual dysfunction in cancer patients. Previous studies have shown a wide variety of manifestations of sexual dysfunction including physical, emotional, psychological, and inter-partner sequelae in the setting of gynecology malignancies [16]. Through discussions about sexual dysfunction among patients and healthcare providers, it has been suggested that patients can normalize their

conditions, anticipate complications, and find treatment approaches [9].

When examining patient preferences regarding discussing or addressing sexual function, three distinct groups of patients emerged: those not wanting treatment, those wanting educational material, and those wanting medication. In our study, 46% of women reported that other topics were more important to discuss than sexual health which was similar to other studies which have shown that patient feel there are more important topics to discuss during the time available in clinic. Other authors have found in their study of long-term vaginal and cervical cancer survivors that patients desire their healthcare providers address sexual concerns. Lindau et al. found that of 160 surveyed, 70% felt their healthcare provider should address sexual issues. Sixty-two percent of survivors reported that a doctor had never initiated a conversation about the effects of cancer or treatments for genital tract cancer on sexuality. The authors found significantly fewer sexual concerns in patients who underwent conversations with their healthcare providers regarding the impact of gynecological cancer and sexuality [17].

In their study of 15 women with gynecologic cancer, McCallum et al. concluded that barriers to discussion and low rates of study participation may result from emotional and practical barriers including patients wanting healthcare providers to initiate discussions on sexual function [18]. Kennedy et al. suggest that initiating conversations regarding sexual dysfunction early during oncological assessment could remove some of these barriers. In their study of patient sexual function, these authors argue that including sexual function evaluation at patient intake serves to further normalize sexuality for both patient and healthcare provider as part of general medical health and invites discussion regarding sexual health early on in the patient-provider relationship [19]. Such efforts may serve to alleviate documented concerns patients have expressed regarding anticipation of sexual dysfunction and stress regarding unexpected changes in sexual function following treatment [9]. In contrast, our study found significantly lower rates of preference for physicians addressing sexuality which may be due in part to the time interval from diagnosis and treatment to study survey. Because our patients were surveyed along a continuum of the course of their cancer care rather than at the outset, this may have influenced their desire to have a physician introduce the topic of sexual dysfunction.

There are several inherent limitations to this study. First, the results reported herein are subject to recall and selection bias. Patients were asked to recall their sexual function prior to their cancer diagnosis and/or

Table 2 Changes in Sexual Functioning Questionnaire (CSFQ) scores

Scale	N	Mean (SD)
Pleasure	84	2.55 (1.25)
Desire/frequency	84	4.87 (1.82)
Desire/interest	84	7.56 (2.83)
Arousal/excitement	82	7.77 (2.87)
Orgasm/completion	81	9.90 (3.72)
Total score	78	41.4 (10.5)

Table 3 Preferences for provider interactions regarding sexual issues

Question	<i>N</i>	%
How would you like your provider to address issues related to sexual activity?		
I would not like them to address it	27	34.2
I would like to ask my provider myself	24	30.4
I would like my provider to bring up the topic	20	25.3
Other	8	10.1
Missing	6	
Barriers that cause you not to address sexual activity with your provider (Check all that apply)		
I do not feel comfortable discussing this with my provider	9	11.7
I do not feel my provider wants to discuss this topic	1	1.3
I do not feel we have time to discuss the topic	3	3.9
I feel that other things are more important to discuss than sexual health	36	46.2
Other	35	44.9
Types of treatment options would you be interested in learning more about in regard to changes in sexual activity and health following cancer treatment? (Check all that apply)		
I do not want any treatment options for my sexual health concerns	30	37.5
I would like written education	26	32.9
I would like personal one-on-one counseling	7	8.8
I would like to participate in group discussion	4	5.0
I would like medications to help with my sexual health concerns	18	22.5

therapy, which could have been months to years prior. As with most sexuality research, an additional limitation of the study is the fact that data were self-reported. Our survey was obtained at a single time point and thus may not reflect changes in perception of sexual function at different time points following treatment. The low response rate suggests that selection bias may threaten the validity of the study as patients who elected to participate may be more likely to report sexual dysfunction and or desire for intervention. We acknowledge that the sample size was relatively small and limited comparisons among subgroups did not allow for regression models examining multiple factors simultaneously. However, the 85 patients that we report on are similar, if not greater than, the numbers previously reported in the gynecologic literature exploring sexual dysfunction in this population [20–23]. As this was a one-time questionnaire to assess for sexual dysfunction and to make comparisons by diagnosis and treatment, this study did not have a control non-cancer group. The heterogeneous nature of the patient population (e.g., age, cancer type, treatment modality) limits our ability to form generalizable conclusions. Structured interviews regarding sexual dysfunction by cancer diagnosis would be one way in which to better assess this population. Future studies in this area should carefully describe patients who do and do not choose to participate in such a study that

addresses sensitive topics. Further, these patients should be followed from diagnosis over time. Not only should sexual health be ascertained but also their relationship context and interest in sexual activity to determine what changes occur following cancer diagnosis and treatment.

Conclusions

The current study adds to an increasing body of literature documenting significant rates of sexual dysfunction in gynecologic cancer patients. This study highlights the challenges healthcare providers and patients face when addressing sexual dysfunction. Next steps include developing tools to identify and educate patients at risk for developing sexual dysfunction, ascertaining patient-specific preferences for discussions surrounding the sexual dysfunction, and understanding the role that partner care and issues play in sexual dysfunction.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no competing interests.

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