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Sexual Health Needs and Educational Intervention Preferences for Women with Cancer

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Abstract

Purpose—To assess sexual/vaginal health issues and educational intervention preferences in women with a history of breast or gynecologic cancer.

Methods—Patients/survivors took a cross-sectional survey at their outpatient visits. Main outcome measures were sexual dysfunction prevalence, type of sexual/vaginal issues, awareness of treatments, and preferred intervention modalities. Descriptive frequencies were performed, and results were dichotomized by age, treatment status, and disease site.

Results—Of 218 eligible participants, 109 (50%) had a history of gynecologic and 109 (50%) a history of breast cancer. Median age was 49 years (range, 21–75); 61% were married/cohabitating.

Seventy percent (n=153) were somewhat-to-very concerned about sexual function/vaginal health, 55% (n=120) reported vaginal dryness, 39% (n=84) vaginal pain, and 51% (n=112) libido loss.

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Informed Consent: Informed consent was obtained from all individual participants included in the study.

Many had heard of vaginal lubricants, moisturizers, and pelvic floor exercises (97%, 72%, 57%, respectively). Seventy-four percent (n=161) had used lubricants, 28% moisturizers (n=61), and 28% pelvic floor exercises (n=60). Seventy percent (n=152) preferred the topic to be raised by the medical team; 48% (n=105) raised the topic themselves.

Most preferred written educational material followed by expert discussion (66%, n=144/218). Compared to women ≥50 years old (41%, n=43/105), younger women (54%, n=61/113) preferred to discuss their concerns face-to-face (p=0.054). Older women were less interested in online interventions (52%, p<0.001), despite 94% having computer access.

Conclusion—Female cancer patients/survivors have unmet sexual/vaginal health needs. Preferences for receiving sexual health information vary by age. Improved physician-patient communication, awareness, and educational resources using proven sexual health promotion strategies can help women cope with treatment side effects.

Keywords

breast cancer; gynecologic cancer; sexual health; vaginal health; intervention; patient preference

INTRODUCTION

Survival rates for women with breast and gynecologic cancers are on the rise, and these women will comprise a large portion of the expected 18 million cancer survivors in the US by 2020. Over 1 million women are facing the challenges of gynecologic cancer [1], and almost 2.8 million women are breast cancer survivors in the United States [2]. Beyond treating the cancer, issues of survivorship include quality of life (QoL), sexual function, and vaginal health, which are often unaddressed by medical providers [3–7]. Furthermore, it is unclear how patients prefer to receive information and interventions to address these concerns.

Research on cancer care demonstrates low satisfaction related to information received about treatment sequelae and survivorship issues [7, 8]. There are also many unmet survivorship needs, which can vary based on the patient population [9–11]. Patients with breast and gynecologic cancer have identified high levels of unmet needs regarding sexual health information [12–14].

Patient-physician communication regarding sexual health is essential yet challenging in the oncologic setting. Several studies have shown that patients expect health care professionals to initiate discussions about sexual health [15–17], but busy clinics, inadequate knowledge, lack of resources, and clinician and/or patient embarrassment can preclude conversations [12, 18]. Rather than discussing topics related to intimacy, sexuality, or QoL, clinicians often prefer to focus on combating the disease [15, 19]. In a recent survey, 74% of cancer patients/survivors felt communication with oncology professionals regarding sexual issues was important, but few had received this information [20].

Simple strategies (e.g., vaginal lubricants and moisturizers, dilator therapy, and/or pelvic floor exercises) can be implemented to relieve vaginal discomfort and could be part of the education received after undergoing cancer treatment. When applied 3–5 times per week,

moisturizers can help alleviate vulvovaginal symptoms by hydrating the vulvovaginal tissues and reducing vaginal pH [21]. Dilator therapy is used to promote elasticity of the vaginal tissues. Although the vaginal area is not directly targeted during breast cancer treatment, patients with breast cancer may also experience the benefits of dilator therapy to address dyspareunia, especially if they are placed on endocrine therapy that decreases vaginal moisture [21]. Endocrine therapy, particularly aromatase inhibitors reduce estrogen to sub-physiological levels, causing vaginal atrophy, and can lead to stenosis and obliteration of the vaginal rugae and sexual distress. Relaxation and control of the pelvic floor muscles can be extremely helpful in treating and preventing pain with intercourse and pelvic exams [22]. In addition, poor pelvic floor strength has been found to be associated with arousal dysfunction [23]. Drawing blood flow to the pelvic floor through physical therapy may have restorative effects [24].

Recommendations have been made for healthcare teams to discuss sexual function with their cancer patients and offer simple solutions [25], but there are limited data on the preferred methods of raising and addressing these issues. Technology-driven modalities, such as computer or telephone psychosexual educational interventions, have not been thoroughly compared to in-person interventions. We sought to assess the prevalence of unmet sexual and vaginal health needs of patients and survivors of breast and gynecologic cancers and investigate how they prefer to receive sexual and vaginal health information.

METHODS

Study Sample and Recruitment

This was an Institutional Review Board (IRB)-approved study at Memorial Sloan Kettering Cancer Center (MSK). Eligible study participants were screened by electronic medical record review at MSK's Breast Medicine and Gynecologic Surgery outpatient clinics from 03/10–07/13. Women over 21 years of age with a history of gynecologic or breast cancer (any stage) were recruited at follow-up outpatient visits. Informed consent was obtained from all participants.

Two hundred eighty patients were invited to participate. Of the 280 patients, 49 refused participation, with many stating they had too much on their minds at their follow-up appointments or because they felt that the survey was not pertinent to them. Two hundred thirty-one women consented (83% participation rate). Of the 231 participants, surveys from 218 were included in the analyses (94% response rate). One participant was eventually deemed ineligible due to psychiatric issues, one was less than 21 years of age, and 4 were lost to follow-up. Seven participants were excluded from analysis, because they had both gynecologic and breast cancer diagnoses.

Study Instrument

Participants completed a hardcopy self-report survey on the same day of consent. Questions were formatted as multiple choice or rating scale items. The study survey assessed basic medical and demographic information, presence of sexual and vaginal symptoms (i.e., vaginal dryness, pain with intercourse, loss of libido) before and after their cancer diagnosis,

and comfort with and prior experience in communicating any vaginal and/or sexual health issues to their provider, a sexual health clinician, or therapist, as well as any barriers to communication using Likert scales. It also evaluated current knowledge and utilization of sexual/vaginal health promotion strategies. Additionally, participants were asked to rate their level of preference in receiving sexual health information (i.e., patient information cards or educational interventions [telephone, in-person, or online]), and were also asked to rate their most acceptable form of sexual and vaginal health promotion strategies (i.e., lubricants, moisturizers, pelvic floor exercises, dilator therapy, and/or hormonal supplementation) to combat their symptoms. These Likert rating scales were scored from 1–5, with 1 being the most acceptable and 5 being the least acceptable. A medical extraction form collected basic medical information for each participant (i.e., cancer and treatment history).

Statistical Analysis

Descriptive statistics were performed. Means, ranges, and standard deviations were calculated for all continuous variables and frequencies for all categorical variables in order to describe sexual health intervention preferences. The study participants were then dichotomized by cancer type (breast versus gynecologic), and then each group was further dichotomized by age (<50 versus ≥50 years) for subgroup analyses. These analyses were pre-planned. Bivariate analyses and significance tests were conducted to analyze and identify treatment factors associated with survey responses (e.g., use of hormonal therapy, on versus off treatment). All statistical analyses were performed using SAS software, Version 9 (SAS Institute Inc., 2008).

RESULTS

Sample Characteristics

Of the 218 respondents, 109 (50%) had or had a history of gynecologic cancer and 109 (50%) breast cancer. Median age was 49 years (range, 21–75); 61% were married/cohabitating. Ninety-one percent (n=198) were not on current treatment. Of the 9% (n=20) on current chemotherapy or radiation therapy, 90% (n=18) were on chemotherapy. Twenty-three percent (n=50) were on current endocrine therapy (i.e., tamoxifen, aromatase inhibitors [AIs], megestrol acetate, leuprolide), and 13% (n=29) were on hormonal supplements (i.e., estradiol, conjugated estrogens). Ninety-seven percent (n=212) had undergone surgery, 62% (n=134) had undergone chemotherapy, and 40% (n=88) had undergone radiation therapy. Fifty-five percent (n=120) of the participants were experiencing menopausal symptoms at the time they took the survey. Demographic and clinical characteristics are summarized in Table 1.

Total Study Sample

Sexual and Vaginal Health Resources—Per Likert scale questions, 29% (n=64) of the participants were moderately-to-very dissatisfied with their sexual and/or vaginal health and 70% (n=153) felt somewhat-to-very concerned about it. Eighty-seven percent (n=189) felt that sexual function and/or vaginal health was somewhat-to-very important to their current QoL. Seventy-three percent (n=159) felt they had options or resources to improve their sexual health, with 61% (n=132) stating they knew where to go or with whom to speak.

Additionally, 69% (n=150) thought it would be helpful to speak with a sexual health expert. Despite participants' concerns and knowledge of available resources, 48% (n=105) never spoke to their healthcare providers about this issue. Barriers associated with not seeking help to improve sexual function and vaginal health included: financial/insurance coverage, embarrassment, privacy and confidentiality, others' lack of understanding, and insufficient time. Although 79% (n=173) said they would be comfortable bringing up sexual health with their healthcare providers, 70% (n=152) preferred the topic to be raised by the healthcare team.

Sexual and Vaginal Health Issues—Fifty percent (n=108) of the participants reported being somewhat-to-very bothered by vaginal discomfort and/or pain. Forty-five percent (n=98) had discomfort and/or pain with gynecological examinations, and 47% (n=102) with sexual activity. Forty-five percent (n=99) rated their discomfort or pain as moderate-to-very high with sexual penetration.

Participants reported symptoms of vaginal dryness (55%, n=120) and loss of libido (51%, n=112), which were problems prior to diagnosis for 41% (n=89) and 37% (n=80) of the participants, respectively. They also reported vaginal pain and/or dyspareunia (39%, n=84), which was a pre-existing issue in 35% (n=77). Forty-two percent (n=91) of the participants had no symptoms before their cancer diagnosis but experienced sexual dysfunction after their diagnosis (Table 2).

Knowledge of Sexual/Vaginal Health Promotion Strategies and Preference for Intervention—Participants answered questions regarding knowledge and use of four common sexual health promotion strategies: vaginal lubricants, vaginal moisturizers, pelvic floor exercises, and dilator therapy (Table 3). Many reported knowledge of vaginal lubricants, moisturizers, and pelvic floor exercises (97%, 72%, 57%, respectively), but only 74% (n=161), 28% (n=61), and 28% (n=60) had used each, respectively (Table 3). Vaginal lubricants and moisturizers were viewed as the most favorable and acceptable strategies (79%, n=172 and 68%, n=148, respectively.

Seventy-three percent (n=158) indicated a preference to speak with their medical team or other medical professionals, and 66% (n=144) preferred receiving written information followed by a discussion with the medical team. The least-preferred method for discussing sexual health concerns was in a group setting (16%, n=34). Seventy percent (n=153) did not favor telephone-based interventions to address sexual health issues.

Subgroup Analysis by Cancer Type

There were no significant differences between patients with breast and gynecologic cancers with regard to vaginal symptoms, sexual concerns, and intervention preferences.

Subgroup Analysis by Current vs Previous Treatment

Among women with breast cancer, 45% (n=49) were currently on endocrine therapy. There were no differences in current symptoms (all $p>0.05$) or past symptoms (all $p>0.05$) based on whether or not the woman was currently receiving endocrine therapy. There were no

differences in sexual health strategy or intervention preferences among the patients with breast cancer based on current endocrine therapy (all p>0.05).

For patients with gynecologic cancers, 24 had received radiation therapy. There were no differences in current symptoms (all p>0.05) or past symptoms (all p>0.05) based on history of radiation therapy. Those treated with radiation therapy were more likely to be using a vaginal moisturizer compared to those who had not received radiation therapy (46% versus 11%; p<0.001). Those who received radiation therapy compared to those who had not were also more likely to know about the use or benefit of dilator therapy (13% versus 60%; p<0.001), to have dilators (67% versus 19%; p<0.001), and to consider using dilator therapy in the future (29% versus 11%; p=0.026). Additionally, women who received radiation therapy were more likely to currently perform pelvic floor exercises to help with vaginal pain (21% versus 2%; p=0.006).

Subgroup Analysis by Age Group

The 105 women ≥50 years of age had more vaginal dryness (62%, n=65, p=0.026) compared to the 113 younger women, and had this as a pre-existing condition before cancer (51%, n=53, p=0.003). There were no differences in knowledge or use of vaginal health promotion strategies by age. However, there were significant differences in intervention preference.

Patients of all ages preferred to review and discuss written information with their medical team (age <50 years: 74%, n=83; age ≥50 years: 58%, n=61). Older women preferred to read material on their own (52%, n=55, p=0.012), whereas younger women wanted to discuss them with the medical team directly (74%, n=83, p<0.017). Younger women reported more interest in the online intervention modality (58%, n=65, p<0.001). Older women were not as interested in participating in the online sexual health interventions (52%, n=55, p<0.001), despite 93% having email and 94% having computer access. While 53% (n=115) of the women had participated in a research study at MSK, only 11% (n=23) had ever participated in a study or intervention specifically addressing sexual health issues. Being younger than 50 years of age (p=0.024) and having a gynecologic cancer diagnosis (p=0.05) was significantly associated with participation in a sexual health study and/or counseling.

DISCUSSION

The importance of sexual and vaginal health to QoL was reported by 87% of the participants in this study, but most reported a lack of knowledge and attempt at using vaginal and sexual health promotion strategies.

Women treated for cancer with pelvic radiation, systemic chemotherapy, and/or endocrine therapy often experience adverse vaginal and sexual dysfunction, including severe vaginal atrophy [26]. Simple solutions, as detailed above, may be helpful if they are used consistently and at an adequate frequency, with full knowledge of the product and technique of intervention.

This study showed dilator therapy preference and use was extremely low. Lack of acceptability of dilator therapy in 75% (15% did not respond to this item) demonstrates a need for increased patient education, as dilators are an excellent strategy for women experiencing pain by mechanically stretching for improved vaginal elasticity and addressing stenosis/adhesions [27]. It can also assist women in gaining confidence and decreasing anxiety/fear about pain. Gynecologic cancer patients treated with radiation were more likely to use and endorse dilators; however, any patients experiencing painful exams or dyspareunia can potentially benefit from this strategy, such as breast cancer patients taking AIs and women undergoing bilateral salpingo-oophorectomy as part of cancer treatment or risk reduction [28–31].

A key finding is that there were no significant differences between patients with breast and gynecologic cancers with regard to vaginal symptoms and sexual concerns. There are, however, some differences between the two groups that should be noted, particularly with regard to hormonal therapy for those with breast cancer and loss of libido.

Approximately one-third of the participants reported pre-existing vulvovaginal symptoms (i.e., dryness, irritation, dyspareunia), which persisted or worsened after their diagnosis and treatment. Data on vulvovaginal atrophy in the general population show adverse physical and emotional effects in postmenopausal women, including increased vaginal discomfort, reduced desire, and low self-esteem [32, 33]. Studies have shown that women do not communicate vulvovaginal atrophy-related symptoms to their clinical team, and may endure symptoms that directly affect their sexual health and QoL [32–34]. This is partly due to patients' lack of knowledge regarding the vaginal changes associated with menopause [33]. Unique data provided in this study highlights the importance of addressing menopausal symptomatology in cancer patients. Greater awareness and education regarding vulvovaginal atrophy is necessary due to the cumulative effects and acute symptoms during and post-cancer treatment.

Although sexual health may not be a chief concern in all cancer patients/survivors, vaginal health should remain a priority even for those who are not interested in sexual activity. Maintaining adequate vaginal health is crucial for comfort with gynecological and pelvic examinations, as they are a necessary component of routine care and cancer surveillance. Regular moisturizer use and pelvic floor exercises are strategies that should be discussed for women's overall health.

Several small studies have found that education can help decrease the morbidity of vaginal atrophy [35–37]. Telephone counseling and online psycho-educational interventions have been shown to be effective modalities for extending psychosocial services to cancer survivors [38–43]. In one study, significant findings were shown for a telephone intervention in addressing sexual function at 12 ($p=0.03$) and 18 ($p=0.04$) months post-study enrollment [38]. Despite the demonstrated effectiveness and feasibility in that study, our study participants showed little interest in such modalities. Younger patients, however, stated that they would consider participating in an online intervention (58%, $n=65/113$, $p<0.001$), suggesting there is a need to tailor the provision of information based on the individual.

Although there are several tools to evaluate sexual dysfunction in cancer patients [44–47], they are not used as frequently as they could be. Evidence suggests that healthcare professionals rarely discuss sexual health issues with women diagnosed with cancer, citing reasons such as a lack of knowledge, time constraints, embarrassment, and a lack of resources [4, 5, 12]. The current study yielded more optimistic results in certain areas of communication than those in the literature. For example, in a recent survey of patients with gynecologic cancer, only 7% had sought medical help for sexual issues and only 30% were likely to see a physician to address sexual health matters [48]. These conflicting results confirm that communication and interest in discussing sexual health may be dependent on the sample population, and may not be generalizable to all cancer patients.

Study Limitations

The sample was one of convenience, with broad inclusion criteria, which may have implications for the external validity of the study results. This was mitigated by an acceptable sample size, good response rate, and diversity of patient population (i.e., stage, types of treatment, age of patients). The self-report survey design may have recall bias, resulting in inaccurate report of treatment for vaginal health issues; however, research has shown that self-report is an optimal way to obtain information about sensitive topics [49], although women do not typically understand the differences between vaginal moisturizers and lubricants and could have inaccurately reported use. There was no adjustment for missing data. This study offered a unique perspective by surveying women about pre-existing issues that persist or worsen after cancer treatment. To improve the precision of the results, future research should consider a prospective or longitudinal design and other explanatory variables.

CONCLUSION

This cross-sectional survey indicated a high prevalence of sexual and vaginal health issues and concerns in women with a history of gynecologic or breast cancer, yet with low engagement with their physicians to address their needs. This study offers insight for the potential design of appropriate interventions and resources to address the needs of gynecologic and breast cancer patients/survivors (e.g., direct communication with physician, online interventions for young people).

Although the oncology and sexual medicine fields have grown over the past several decades, targeted information and interventions that address sexual/vaginal health issues are still needed. As the prevalence of women living after cancer diagnosis continues to increase, there is an enormous need for clinicians to acknowledge and understand the impact of treatment on sexual health and QoL. Oncology professionals may be able to offer effective solutions for adjustment to sexual changes. Greater physician awareness of available resources for patients will help patients survive cancer and thrive for years to come.

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Table 1

Patient sociodemographic and medical characteristics, N=218

Variable	n	%
Age, years	Median, 49	
<50	113	52%
≥50	105	48%
Education		
High School Graduate/GED	17	8%
Some College	30	14%
College Graduate	86	39%
Graduate School/Higher	84	39%
Missing	1	0.5%
Marital Status		
Single	53	24%
Married	119	55%
Living with Significant Other	14	6%
Separated/Divorced	26	12%
Widowed	6	3%
Primary Cancer Type		
Breast	109	50%
Gynecologic	109	50%
Diagnosis Year		
1961–2000	19	9%
2001–2005	60	28%
2006–2012	139	64%
Active Treatment at Time of Survey (RT, chemotherapy, endocrine therapy, other)		
Yes	20	9%
No	198	91%
Past Treatment [Surgery, RT, chemotherapy, endocrine therapy, other]		
Yes	215	99%
No	3	1%
Past Treatment Regimen		
Surgery	212	99%
Chemotherapy	134	62%
Radiation Therapy	88	41%
Endocrine/Other (other surgery, if multiple)	46	21%
Menopausal at Time of Survey	120	55%

RT, radiation therapy

Table 2

Sexual and vaginal health issues

Sexual Health Issues	**Total Sample N=218**	**Breast n=109**	**GYN n=109**	**<50 years old n=113**	**≥50 years old n=105**
	N (%)	**n (%)**	**n (%)**	**n (%)**	**n (%)**
Are you currently experiencing any of the following?					
Vaginal dryness	120 (55)	63 (58)	57 (52)	55 (49)	65 (62) *
Vaginal pain or dyspareunia	84 (39)	43 (39)	41 (38)	46 (41)	38 (36)
Loss of libido or interest in sexuality	112 (51)	64 (59)	48 (44)	61 (54)	51 (49)
Arousal difficulties	64 (29)	38 (35)	26 (24)	33 (29)	31 (30)
Other	7 (3)	3 (3)	4 (4)	4 (4)	3 (3)
In the past, have you ever experienced any of the following sexual health concerns?					
Vaginal dryness	89 (41)	47 (43)	42 (39)	36 (32)	53 (50.5) **
Vaginal pain or dyspareunia	77 (35)	39 (36)	38 (35)	43 (38)	34 (32.4)
Loss of libido or interest in sexuality	80 (37)	42 (39)	38 (35)	39 (35)	41 (39.0)
Arousal difficulties	47 (22)	21 (19)	26 (24)	23 (20)	24 (22.9)
Other	5 (2)	2 (2)	3 (3)	3 (3)	2 (1.9)

* p=0.026;

** p=0.003

Table 3

Knowledge and prior use of sexual/vaginal health promotion strategies

Sexual Health Resources	N (%)	Breast n (%)	GYN n (%)	<50 years old n (%)	≥50 years old n (%)
Have you heard of any of the following types of strategies for sexual health issues?					
Vaginal lubricant	211 (97)	107 (98)	104 (95)	111 (98)	100 (95)
Vaginal moisturizers	156 (72)	78 (72)	78 (72)	78 (69)	78 (74)
Dilator therapy	62 (28)	17 (16)	45 (41) ***	32 (28)	30 (29)
Pelvic floor exercises	125 (57)	69 (63)	56 (51)	67 (59)	58 (55)
If you have ever tried any of these options, please check the options you have tried.					
Vaginal lubricant	161 (74)	80 (73)	81 (74)	87 (77)	74 (71)
Vaginal moisturizers	61 (28)	29 (27)	32 (29)	27 (24)	34 (32)
Dilator therapy	40 (18)	5 (5)	35 (32) ***	21 (19)	19 (18)
Pelvic floor exercises	60 (28)	27 (25)	33 (30)	35 (31)	25 (24)
Never tried any of these options	41 (19)	21 (19)	20 (18)	19 (17)	22 (21)
Other	4 (2)	2 (2)	2 (2)	1 (1)	3 (3)

*** p<0.001