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Sexual concerns in cancer patients: a comparison of GI and breast cancer patients

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Abstract

Purpose—Although sexual concerns have been examined in breast cancer (BC), these concerns remain understudied and undertreated for patients with gastrointestinal (GI) cancer. Objectives were to: (1) assess sexual concerns in GI cancer patients compared with breast cancer patients; (2) examine whether sexual concerns are stable over time in GI and breast cancer patients; and (3) evaluate whether sexual concerns in GI and breast cancer are significantly associated with quality of life, symptom severity, and disease interference, and whether these associations change over time.

Methods—Data were collected from GI and breast cancer patients during four outpatient clinic visits over 6 months. Measures included sexual concerns (reduced sexual enjoyment, interest, or performance), quality of life (FACT-G), symptom severity, disease interference (MD Anderson Symptom Inventory), and disease-related distress (NCCN Distress Scale). Linear mixed model analyses were conducted.

Results—Sexual concerns were common in both samples, with 57% of GI cancer patients and 53% of breast cancer patients reporting at least mild sexual concerns. Sexual concerns were stable over time and were significantly associated with lower levels of functioning in multiple domains (e.g., quality of life, symptom severity, disease interference, and disease-related distress), irrespective of length of time since diagnosis. Cancer type (GI/breast cancer) was not a moderator of this relationship.

Conclusions—Self-reported sexual concerns were common, stable, and related significantly to quality of life, symptom severity, disease interference, and disease-related distress for both GI and breast cancer patients. Limitations and implications for future research are discussed.

Keywords

Gastrointestinal neoplasms; Breast neoplasms; Sexuality; Quality of life; Sexual dysfunction, physiological

As treatments for common cancers improve, many patients live with ongoing threats to quality of life, including sexuality and intimacy. While there is a relatively large body of research examining the sexual difficulties in patients with cancers of the breast and prostate [3, 5], considerably less is known about the sexual concerns of patients with gastrointestinal (GI) cancer (e.g., colon, rectum, pancreatic, stomach, esophageal, or hepatobiliary). This is surprising given that GI cancers are the third most common type of cancer in men and women, with over 153,000 new cases reported in 2007 [21]. Research studies conducted in GI cancer patients have focused on sexual dysfunction (i.e., problems in performance) following various surgical interventions in rectal cancer, showing that sexual dysfunctions are frequently experienced by both male and female patients after surgical interventions for rectal cancer [16, 29]. These studies are limited in that they are cross-sectional, focus almost exclusively on physical sexual dysfunction (i.e., sexual dysfunction involving changes in physiological functioning) rather than on broader aspects of sexual quality of life (i.e., interest and enjoyment), and primarily involve rectal cancer patients. Little is known about sexual concerns (i.e., concerns about sexual enjoyment, interest, and performance) in a more diverse sample of GI cancer patients and how these perceptions vary over time.

Despite the fact that GI cancer patients are undergoing treatments known to negatively impact sexual function, physicians rarely discuss these concerns with patients [9]. This lack of communication may reflect commonly held beliefs that sexual concerns are not important to patients, that any concerns in this area resolve over time, and that sexual concerns are not meaningfully related to other important aspects of functioning (e.g., psychosocial functioning, symptom severity, and disease interference) [19, 20]. The fact that there has been little research attention in this area may further reinforce health care providers' beliefs that sexual concerns are not important to these patients. Understanding how sexual concerns relate to domains such as quality of life, symptom severity, disease interference, and disease-related distress is critical in identifying patient needs and tailoring interventions to address these needs.

In fact, data from breast cancer samples suggest that patients who report greater sexual difficulties actually do report poorer functioning in other domains (e.g., global quality of life, relationship difficulties, and psychological well-being) [2, 13, 14, 24, 31]. Further, there is growing evidence showing that cancer and its treatment negatively impact sexuality for women with breast cancer, with over one third of breast cancer survivors in two separate studies reporting that cancer treatment negatively impacted their sex life [14, 24]. In a sample of 55 breast cancer survivors who had completed their primary treatment, Speer et al. found that the survivors not only scored more poorly on a sexual function inventory than healthy peers but also resembled women with a diagnosed sexual arousal disorder in their scores in sexual desire and pain domains [31]. Thus, sexual concerns are prevalent and appear to be related to poorer functioning in other domains for breast cancer survivors.

Given the ample evidence that breast cancer can lead to sexual difficulties and concerns, breast cancer patients may serve as a particularly appropriate group against which to compare the sexual concerns of other cancer populations. Surprisingly, no prior studies have

compared reports of sexual concerns of GI cancer patients with those of breast cancer patients. Thus, it is unclear whether GI and breast cancer patients would report similar levels of sexual concerns, or whether the relationships between sexual concerns and other important domains of function (e.g., psychosocial functioning, symptom severity, and disease interference) differ for GI cancer and breast cancer patients.

In the present study, we analyzed data obtained from patients with GI cancer and breast cancer treated in outpatient cancer clinics at Duke University Medical Center (DUMC). We had the following objectives in this study: (1) to assess sexual concerns, defined as “problems with reduced sexual enjoyment, interest, or performance,” in GI cancer patients compared with those of breast cancer patients; (2) to examine whether sexual concerns change over time in GI and breast cancer patients; and (3) to evaluate whether sexual concerns in GI and breast cancer are significantly associated with functioning in several important domains including quality of life, symptom severity, disease interference, and disease-related distress, and whether these associations change over time.

We hypothesized that sexual concerns would be common in GI cancer patients and similar to those reported by breast cancer patients. Based on data from breast cancer studies showing that sexual concerns frequently persist [13], we hypothesized that sexual concerns would not change significantly over time for GI and breast cancer patients and that they would be significantly associated with poorer quality of life and higher symptom severity, disease interference, and disease-related distress. Moreover, we hypothesized that the relationship between sexual concerns and other domains of functioning in GI cancer patients and breast cancer patients would not change significantly over time.

Methods and materials

Participants

Eligible participants were: (1) adults with a pathologic diagnosis of breast cancer or GI cancer (i.e., colon, rectum, pancreatic, stomach, esophageal, or hepatobiliary), (2) expecting at least four further visits (including prechemo-therapy checks) to the Duke Breast or Gastrointestinal Cancer Clinic in Duke South Hospital over the ensuing 6 months, (3) able to speak and read English, and (4) consenting. Data collection from the GI cancer sample took place from February 13 to December 21, 2007, and from the breast cancer sample took place from March 19 to October 31, 2006. Of 120 GI cancer patients screened, five patients declined to enroll, 115 eligible patients enrolled (96% acceptance rate), and 113 completed the study, with 91 completing all four visits. Of 73 breast cancer patients screened, nine patients declined to enroll, 66 eligible patients enrolled (90% acceptance rate), and 65 completed the study, with 55 completing all four visits. The final sample sizes are 113 and 65 for the GI and breast cancer samples, respectively. At baseline, GI cancer study completers did not differ significantly from noncompleters on gender, months since diagnosis, disease status, educational level, ethnicity, or marital status (all p values > 0.23). GI Cancer completers ($N=91$) were younger ($M=56.8$, standard deviation (SD)=10.9) than noncompleters ($N=22$, $M=62.0$, $SD=10.8$; $p=0.05$) but did not differ significantly from noncompleters on sexual concerns, quality of life, symptom severity, disease interference, or disease-related distress (all p values > 0.13). For the breast cancer sample at baseline, completers did not differ significantly from non-completers on age, time since diagnosis, educational level, or ethnicity (all p values > 0.11). They also did not differ significantly on sexual concerns, quality of life, symptom severity, disease interference, or disease-related distress (all p values > 0.20). Significantly more noncompleters than completers had metastatic or recurrent disease (90% vs. 45.5%) and were married (100% vs. 64.0%), Fisher's exact test statistics=0.04 and 0.02, respectively. Both completers and noncompleters were included in the analyses.

Procedures

The protocol and all procedures were approved by the Duke University Health System institutional review board and have therefore been performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki. Informed consent was obtained by each participant prior to participation in the study. e/Tablets, wireless tablet personal computers used to collect survey information in the clinic, were used to collect data from GI and breast cancer outpatients during four visits over <6 months. Data were collected in two separate but nearly identical parent study protocols conducted at DUMC in Durham, North Carolina. The main objective of the parent studies was to evaluate the reliability and validity of the e/Tablets system to capture patient-related outcomes electronically, in relation to traditional paper and pencil measures (i.e., equivalence testing). The e/Tablets technology uses a secure wireless interface and meets all HIPAA standards. The e/Tablets system uses a validated Patient Care Monitor instrument [12] to assess symptoms, psychological distress, and quality of life. Participants were reimbursed \$25 per visit.

Measures

Sexual Concerns

Sexual concerns were assessed through an item from the Patient Care Monitor (PCM) inquiring about “problems with reduced sexual enjoyment, interest, or performance.” Responses to this item are scored on 11-point scales anchored at 0 (“not a problem”) and 10 (“as bad as possible”), and reference the past week. The PCM has been previously validated against standard symptom inventories and QOL scales.[12] In the present study, this item was highly correlated with the sexual satisfaction item taken from the Functional Assessment of Cancer Therapy-General (FACT-G) [7] in both samples ($r=-0.56$, $p<0.001$; $r=-0.71$, $p<0.001$, respectively).

Quality of life

Quality of life was assessed using the FACT-G [7], a 27-item measure assessing physical well-being, social/family well-being, emotional well-being, and functional well-being using responses on a 5-point Likert scale, where 0=“Not at all” and 4=“Very much.” The scale references the past week. Particular items were reversely scored such that a higher score indicates higher quality of life. In order to limit overlap between the predictor variable of the sexual item from the PCM and the FACT-G, the item in the FACT-G assessing sexual satisfaction was removed from the scale for the analyses.

Symptom severity and disease interference

Participants also completed the MD Anderson Symptom Inventory (MDASI), [10] a 19-item measure using an 11-point scale where 0=“Not present/did not interfere” and 10=“As bad as you can imagine/interfered completely.” Thirteen symptom items assess severity and six items assess interference of symptoms over the past 24 h, yielding mean symptom severity and interference scale scores.

Disease-related distress

A distress item drawn from the NCCN Distress Management Measure [17, 18] was also used. This item assesses distress “over the past week, including today.” Responses are scored on a 0–10-point scale anchored at the zero point with “No distress,” the mid-point with “Moderate distress,” and at scale point ten with “Extreme distress” [17].

Statistical analyses—Descriptive statistics are provided for demographic and medical variables for the GI and breast cancer groups. Medical and demographic characteristics of

both groups were compared at baseline using *t* tests for independent samples for continuous variables and chi-square or Fisher's exact tests for categorical variables. Descriptive statistics and correlations were also performed for study variables. Pearson correlation coefficients were calculated among all patient-related outcomes at baseline. Longitudinal linear mixed models were conducted using SPSS [25] to examine changes in sexual concerns over time, and to examine whether sexual concerns were associated with other domains of functioning. In models, cancer type was coded as GI cancer=0; breast cancer=1. Time was coded as months since cancer diagnosis. For a detailed description of each model, see the Results section. Statistical significance was considered at the level of $p < 0.05$, two-tailed, unless otherwise noted. For all *t* tests and significant tests of fixed effects in the linear mixed models, the Satterthwaite correction was used to adjust degrees of freedom due to unequal group sizes.

Results

Demographic characteristics are presented in Table 1. In general, the samples were married and highly educated. Twenty percent of the GI cancer sample and 22% of the breast cancer sample were members of minority groups. The GI cancer sample exhibited a significantly shorter length of time since diagnosis in comparison to breast cancer patients. Other than time since diagnosis and the gender difference between the samples, no other differences were statistically significant between the two samples. Approximately half of the GI cancer sample had colon or rectal cancer; the next most common cancer types were esophageal and pancreatic. Twelve patients in the GI cancer sample reported use of an ostomy appliance (10.6%; 21.4% of colorectal cancer patients).

Baseline sexual concerns in GI and breast cancer samples

Baseline scores on sexual concerns and outcome variables are presented in Table 2. No significant differences were found between GI and breast cancer groups on any of these variables (all p values > 0.05). We classified sexual concerns into four categories (0=no concerns; 1–3=mild sexual concerns; 4–6=moderate sexual concerns; 7–10=severe sexual concerns) for descriptive purposes. These four categories have been used in prior research and clinical practice [1]. For GI cancer patients at baseline, 43.4% ($N=49$) reported no sexual concerns, 20.4% ($N=23$) reported mild sexual concerns, 16.8% ($N=19$) reported moderate sexual concerns, and 18.6% ($N=21$) reported significant sexual concerns. Proportions of sexual concerns were similar for the breast cancer sample (see Table 2). We also conducted a *t* test comparing colorectal cancer patients with an ostomy appliance on sexual concerns ($N=12$, $M=2.7$, $SD=3.2$) with colorectal cancer patients without an ostomy ($N=56$, $M=2.6$, $SD=3.2$) appliance and found no significant differences ($t=1.3$, $p=0.89$). Therefore, we did not include ostomy appliance as a control variable in our analyses.

As an exploratory analysis, we examined the rates of sexual concerns in the three cancer subgroups that contained the highest number of participants (i.e., colon or rectum, esophageal, and pancreatic). For colon or rectal cancer patients at baseline, 43.6% ($N=24$) reported no sexual concerns, 20.0% ($N=11$) reported mild sexual concerns, 18.2% ($N=10$) reported moderate sexual concerns, and 18.2% ($N=10$) reported severe sexual concerns. For the esophageal patients, the similar proportions were 50.0% ($N=9$), 22.2% ($N=4$), 11.1% ($N=2$), and 16.7% ($N=3$). Finally, for pancreatic cancer patients, these proportions were 38.9% ($N=7$), 11.1% ($N=2$), 22.2% ($N=4$), and 27.8% ($N=5$).

Correlations among psychosocial variables at baseline for both the GI and breast cancer samples are presented in Table 3. Consistent with our hypotheses, sexual concerns were highly correlated with quality of life, symptom severity, disease interference, and disease-related distress. Thus, patients reporting high levels of sexual concerns were much more

likely to report poorer functioning in multiple domains. As can be seen in Table 3, correlation coefficients between sexual concerns and quality of life and symptom severity were significant in the GI but not the breast cancer sample and the magnitude of correlations between sexual concerns and domains of functioning were higher in the GI cancer sample than in the breast cancer sample.

Stability of sexual concerns over time in GI and breast cancer patients

Longitudinal mixed modeling (LMM) was used. This model involved two levels: (1) at the within-subjects level, sexual concerns vary within participants over time (coded as months since diagnosis), as a function of a person-specific growth curve and (2) at the between-subjects level, the person-specific change parameters vary randomly across participants as a function of level2 variables (i.e., cancer type). The dependent variable was level of sexual concerns measured at each of the four assessments. The mean length of time between visits for the GI sample was 2.24 weeks ($SD=1.44$) and for the breast cancer sample was 1.54 weeks ($SD=0.74$). This model estimated time, cancer type (GI cancer vs. breast cancer), and time X cancer type effects. The time effect tested whether sexual concerns changed across the four assessments with the intercept reflecting the level of sexual concerns at the initial assessment. Because the timing of the assessments differed across participants, the strategies recommended by Singer and Willett [30] for variably spaced measurement occasions were used. The cancer type effect tested whether the value of sexual concerns at the initial assessment covaried with cancer type. The time X cancer type effect, if significant ($p<0.05$), indicated that the rate of change in sexual concerns covaried with cancer type. As recommended [25], we first determined the general form of change that best fit the data. According to the likelihood ratio test, the fit of the quadratic model was not significantly better than the linear model, and thus the linear model was retained.

The time effect was not significant ($\beta=-0.005$, standard error (SE)=0.01, $t=-0.48$, $p=0.63$), and furthermore, the magnitude of the slope strongly suggests that sexual concerns remained quite stable over time. Cancer type was not associated with sexual concerns at the initial assessment ($\beta=-0.37$, $SE=0.54$, $t=-0.69$, $p=0.49$), or the rate of change in sexual concerns over time ($\beta=0.001$, $SE=0.01$, $t=0.13$, $p=0.90$). These results suggest that perceived sexual concerns were similar across both samples.¹

We conducted a follow-up analysis to examine whether sexual concerns differed by gender within the GI cancer group. We used an LMM that estimated time, gender (male=0 and female=1), and time X gender effects. The gender effect was not significant ($\beta=-0.99$, $SE=0.71$, $t=-1.40$, $p=0.17$), suggesting that sexual concerns did not differ by gender significantly at the initial assessment for GI cancer patients. The time X gender effect was also not significant ($\beta=-0.02$, $SE=0.02$, $t=1.02$, $p=0.31$), indicating that the rate of change in sexual concerns did not differ by gender.²

Relationships between sexual concerns and multiple domains of functioning

We used LMM [25] to examine the relationship between sexual concerns and domains of functioning. Separate models were conducted with each of these domains as the dependent variables: quality of life, symptom severity, disease interference, and disease-related distress. Each model estimated the effects of time (coded as months since diagnosis), cancer type, sexual concerns, and all two- and three-way interaction terms. Sexual concerns,

¹To examine the possibility that metastatic/recurrent disease state might be related to the reporting of sexual concerns, we conducted an LMM in which we estimated the effects of time, disease state (dummy coded as metastatic/recurrent disease vs. nonmetastatic/recurrent disease), and time X disease state effects in the combined GI and breast cancer dataset. Neither the effect of disease state ($p=0.68$) nor the time X disease state effect was significant ($p=0.38$).

measured at each of the four assessments, were included as a time-varying predictor. Thus, the main effect of sexual concerns indicated whether domains of functioning covaried with sexual concerns at each of the assessments. The cancer type X sexual concerns interaction term, if significant, indicated that the relationship between sexual concerns and the outcomes varied by cancer type. Finally, interaction terms that included time and sexual concerns tested whether the relationships between sexual concerns and the outcomes varied across waves of assessment. For interpretability, the variable for sexual concerns was centered around the baseline mean.

As recommended [25], we first determined the general form of change that best fit the data. According to the likelihood ratio test, the fit of the quadratic model was not significantly better than the linear model for each of the models, and thus the linear models were retained. We computed partial correlation coefficients using t values and degrees of freedom to estimate effect size [28]. Table 4 displays the fixed effects for each model. Significant relationships are in bold-faced type.

For quality of life, the effect of time was not significant (p value >0.05), suggesting that quality of life did not change over time. There was a significant effect of sexual concerns (p value <0.05), such that greater sexual concerns were associated with lower quality of life at each of the four assessments. The relationship between sexual concerns and quality of life did not vary across waves of assessment (sexual concerns X time, p value >0.05). Neither the main effect of cancer type nor any of the interaction terms with cancer type were significant (p values >0.05). These results indicate that quality of life (baseline levels and rate of change) did not differ across the GI and breast cancer groups, and the relationship between sexual concerns and quality of life did not differ by cancer type.

Models examining the domains of functioning of symptom severity, disease-related interference, and disease-related distress revealed a similar pattern of results. Greater sexual concerns were significantly associated with higher disease severity, disease-related interference, and disease-related distress. These relationships did not vary over waves of assessment or by cancer type.

Discussion

Sexual concerns remain largely understudied and undertreated in cancer. In this study of GI and breast cancer patients, sexual concerns, as measured by problems with sexual enjoyment, interest or performance, were common and distressing without improving over time. Over half of study participants reported some degree of sexual concerns, which were at least moderate in severity for over a third. Women and men suffered equally. The prevalence of sexual concerns was similar between diseases, and importantly, the GI cancer population mirrored the breast cancer population, which is often thought of as particularly sexually distressed [13, 24]. These results support our hypotheses that sexual concerns

²In order to further examine the possible effect of gender on sexual concerns, we examined both the stability of sexual concerns over time and the relationships between sexual concerns and multiple domains of functioning in female patients only (i.e., female GI cancer patients and all breast cancer patients). We ran the identical two LMM analyses initially conducted in the mixed gender sample in which we: (1) estimated the effects of time, cancer type (GI vs. breast cancer), and the time X cancer-type interaction effect on sexual concerns and (2) estimated the effects of time, cancer type, sexual concerns, and all two- and three-way interaction terms on four domains of functioning (i.e., quality of life, symptom severity, disease-related interference, and disease-related distress). The results generally paralleled those obtained using both genders in the GI sample. For the first analysis on the outcome of sexual concerns, the time, cancer type, and time X cancer-type interaction effects were nonsignificant (all p values >0.51). For the analyses examining the effects of time, cancer type, and sexual concerns on the domains of functioning, sexual concerns was the only significant predictor of quality of life, disease-related interference, and disease-related distress (all p values <0.01) and these relationships did not vary over waves of assessment or by cancer type, as was found in the mixed gender sample. The effect of sexual concerns on symptom severity, however was not significant ($p=0.18$).

would be highly prevalent and distressing and extend prior findings of sexual difficulties in rectal cancer [16, 29] to include patients with other gastrointestinal cancers. The high prevalence in unstudied cancers like nonrectal GI malignancies, such as pancreatic and esophageal, incites concern that the prevalence is also high in other gender-agnostic cancer types like lung cancer, sarcoma, and head and neck cancer.

A particularly important finding is that sexual concerns remained quite stable over time for both GI and breast cancer groups. This finding is consistent with previous research in breast cancer patients as well as a few preliminary studies in patients with rectal cancer [13, 29]. In the current study, participants varied in time since diagnosis and their cancer treatment trajectory. However, despite this, the majority of patients had metastatic or recurrent cancer and were undergoing chemotherapy or radiation treatment. Our data suggest that sexual concerns are present and quite stable throughout a broad period in the cancer disease trajectory into and including advanced cancer care. Despite multiple interactions with the health care system, these sexual concerns apparently were not getting resolved. There are several potential reasons for this. First, patients may not be sharing these concerns with health care providers. Second, health care providers may not routinely ask patients about these concerns. Third, the medical system may not be geared toward helping patients or providers address sexual issues. Finally, sexual concerns may be seen as less critical to patient's well-being in the context of advanced cancer treatment.

Considering the large number of males in the GI cancer sample, we examined the relationship between gender and sexual concerns in this sample. Importantly, our data showed no gender differences in reported levels of sexual concerns at the initial assessment for GI cancer group, or in the rate of change in sexual concerns over time, suggesting that sexual concerns were equally prevalent and equally stable in both genders. Further, we also conducted an analysis comparing female GI cancer patients with breast cancer patients on sexual concerns and found no significant difference, suggesting that female GI cancer patients appear to have a similar level of sexual concerns as breast cancer patients. Considering that research has shown providers to be less likely to raise sexual side effects with female patients [9], it may be especially important to note the lack of significant gender effects in our sample of GI cancer patients. These findings argue strongly for the importance of addressing sexual issues in patients of both genders. The lack of significant effect of gender is noted in light of inconsistent findings in the literature. While several studies have found similar rates of sexual dysfunction in both men and women with rectal cancer [5, 13, 20], other studies have suggested that men may be more vulnerable to sexual dysfunctions following treatment for certain types of GI malignancies [4, 8]. Differences in findings across studies may reflect differences in measurement of sexual concerns or the samples used and should be investigated further.

A major clinical finding of the present study is that patients in this study who reported higher levels of sexual concerns were much more likely to report lower quality of life, and higher symptom severity, disease interference, and disease-related distress. Moreover, we found that the relationships between sexual concerns and other domains of functioning did not vary over waves of assessment. These findings expand prior research studying the associations between sexual difficulties and quality of life in rectal cancer [32]. Taken together, these findings suggest that issues of sexuality are meaningfully related to the well-being and functioning of people with cancer. These results cast doubt on the commonly held beliefs that sexual concerns are not often experienced by GI cancer patients, that concerns in this area resolve over time, and that sexual concerns do not relate meaningfully to other aspects of functioning [19, 20]. While we cannot assume a causal relationship between sexual concerns and worse functioning, these data all suggest that this is a persistent and important topic, that is, to date, incompletely addressed. Clinically, a particularly important

group of patients is the 19% of GI and 18% of breast cancer patients in the study who reported severe sexual concerns. This subgroup would very likely benefit from a more detailed examination of their sexual concerns and potential treatments (e.g., counseling) to help address these concerns.

To our knowledge, this is the first study to compare the sexual concerns of a sample with gastrointestinal cancer to the sexual concerns of a sample of breast cancer patients. We found that rate and stability of sexual concerns did not differ significantly by cancer type, that sexual concerns were significantly related to multiple domains of functioning, and that this relationship did not vary by cancer type. These findings showed that gastrointestinal cancer patients reported similar rates of sexual concerns as a cancer sample with much more well-documented sexual concerns (i.e., breast cancer). The rates of patients reporting sexual concerns in this study are generally comparable to those found in similar studies in breast cancer [11]. The rates found in the current study are elevated with respect to those found in Laumann et al.'s national probability study, in which 31% of men and 43% of women reported a sexual dysfunction [22]. First, this higher rate suggests that sexual concerns are likely to be present for some GI and breast cancer patients prior to their cancer treatment. Second, the higher rate of sexual concerns in these samples suggests that these concerns may be related to some aspect of the cancer and/or its treatment. The fact that at least one third of breast and GI cancer patients consistently report that cancer treatment made their sexual lives worse, supports this notion [14, 16, 24]. Because sexual concerns may exist for patients prior to treatment and may be either caused or exacerbated by cancer and its treatment, it is important to assess both changes in patients' sexual lives after cancer as well as the presence and severity of sexual problems at the time of assessment.

Considering the average age of participants in the present study, it may be important to consider the role of age on sexual concerns. For instance, it is possible that sexual concerns reported by participants in the current study could be age-related rather than cancer-related. Because we did not compare patients in the present study with age-matched control groups, we cannot say for certain whether they would report more sexual concerns than their peers. However, given prior research findings that patients with rectal and breast cancer often score worse than age-matched controls on measures of sexual function [16, 31], we suspect that participants in the current study would likely report more sexual concerns than those in an age-matched peer group. Further, the impact of cancer treatment on sexual quality of life may be especially salient for younger patients, whose sexual difficulties may be nonnormative, such as those that result from early menopause. In particular, younger female patients with breast or rectal cancer appear to be especially vulnerable to sexual difficulties [15, 29]. Additional research is needed to clarify the relationship between age and sexual concerns, such as how sexual changes are experienced in younger as opposed to older patients with breast and GI cancers.

Strengths of the current study include a prospective design with multiple assessment time points, the use of validated instruments to assess quality of life and perceived disease impact, and the use of a relatively large sample of gastrointestinal cancer patients. Limitations of the current study include the relatively small sample size of breast cancer patients, the use of a single item to assess sexual concerns rather than a validated scale with multiple items, and the relatively brief time span in which data were gathered (i.e., 6 months). Future studies would benefit from using larger samples, including validated measures of sexual outcomes with multiple items such as the Female Sexual Function Index [26] and the International Index of Erectile Function [27] and a longer period of time in which to conduct assessments. Additional studies should also be done in GI cancer that assess a broader range of sexual issues and concerns, including sexual dysfunction, marital distress, and relationship function.

Other limitations of the current study pertain to the subjective nature of the sexual concern item and the lack of information concerning the type of treatments obtained. As opposed to the sexual satisfaction item from the FACT-G, we chose to use the sexual concern item for this study because it specifically assessed “reductions” in aspects of patients’ sexuality, which may better reflect cancer-related changes, because it provided more information about the nature of sexual concerns than would a general sexual satisfaction item, and because the FACT-G item gives patients the option to opt out of responding, leading to less available data for this item. However, because patients were not given definitions of the terms “interest,” “enjoyment,” or “performance” as they appeared in the sexual concerns item in the current study, this item may be considered subjective and may therefore have confounded various aspects of sexuality. Future studies should examine patients’ understanding of sexually relevant terms (e.g., “sexual performance”) as well as include definitions of terms included in sexual outcomes measures. Research studies should also collect information on the type of treatments obtained by patients both during and prior to participation in the study as such information may help untangle how types of treatment and stages in the treatment phase relate to sexual changes and concerns. Additionally, several interventions specifically addressing sexual and/or intimacy-related concerns have been conducted in breast, gynecological, and prostate cancer samples [4, 6, 8, 23]. Results of the present research strongly suggest that similar interventions addressing sexual concerns are also needed for patients with GI cancer. Finally, results of this study suggest the importance of investigating sexual concerns in populations with other gender-agnostic cancer types such as lung cancer, sarcoma, and head and neck cancer.

Conclusions

Sexual concerns remain largely understudied and undertreated in cancer. This study demonstrated that self-reported sexual concerns are common, stable, and related significantly to multiple domains of functioning, including quality of life, symptom severity, disease interference, and disease-related distress in gastrointestinal and breast cancer patients. Sexual concerns were similarly common and problematic in GI and breast cancer samples. Findings of the present study show that sexual concerns are a persistent and important topic to patients, that, to date is incompletely addressed. Further, these findings argue strongly for the importance of addressing sexual concerns as part of the routine care of GI and breast cancer patients. In particular, findings from this study go against common misconceptions of clinicians that sexual concerns eventually dissipate on their own or are unimportant to patients’ quality of life and well-being during treatment [19]. Findings from this study highlight the need for interventions that address sexual concerns in GI and breast cancer patients.

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Table 1

Demographic characteristics of participants at baseline

Demographic characteristic	Sample GI cancer		Sample breast cancer		<i>p</i>
	<i>N</i>	%	<i>N</i>	%	
<i>Gender</i>					N/A
Female	37	33	65	100	
Male	76	68	–	–	
<i>Race</i>					0.85
White, Caucasian	90	80	51	79	
Non-white/other	23	20	14	22	
<i>Education</i>					0.20
<12 (less than high school)	10	9	5	8	
12<16 (high school, some college or 2-year degree)	56	50	28	43	
16 (bachelor's degree or higher)	46	41	33	51	
<i>Marital Status</i>					0.18
Married or partnered	88	78	44	68	
Unmarried or unpartnered	25	22	20	31	
Prefer not to say	0	0	1	2	
<i>Disease State</i>					0.18
Non-metastatic or recurrent	34	30	26	40	
Metastatic or recurrent	79	70	39	60	
<i>GI Tumor Location</i>					
Colon or rectum	56	50			
Esophageal	18	16			
Pancreas	18	16			
Stomach	3	3			
Liver	3	3			
Anus	1	1			
Small intestine	2	2			
Other	2	2			
Unknown primary	2	2			
Missing	8	7			
		Mean (<i>SD</i>)		Mean (<i>SD</i>)	
Age		57.77 (11.02)		54.65 (11.95)	0.09
Time since diagnosis (in months)		20.50 (27.47)		54.55 (74.43)	0.001

Due to rounding up, percentages may add up to more than 100.

Table 2

Baseline scores on psychosocial variables

Variable	Sample GI cancer			Sample breast cancer			<i>p</i>
	Mean (<i>SD</i>)	Median	<i>α</i>	Mean (<i>SD</i>)	Median	<i>α</i>	
Sexual concerns ^a	2.79 (3.26)	1.00	N/A	2.63 (3.33)	1.00	N/A	0.77
Quality of life ^b	77.63 (14.59)	80.00	0.90	77.09 (17.10)	80.5	0.93	0.83
Symptom severity ^c	1.73 (1.39)	1.38	0.87	1.92 (1.90)	1.50	0.92	0.50
Disease interference ^d	2.11 (2.16)	1.33	0.93	1.94 (2.22)	1.17	0.93	0.64
Disease-related distress ^e	2.29 (2.47)	2.00	N/A	2.47 (2.78)	2.00	N/A	0.67
Level of sexual concerns	<i>N</i> (%)			<i>N</i> (%)			0.75
No sexual concerns (0)	49 (43.4%)			29 (46.8%)			
Mild sexual concerns (1–3)	23 (20.4%)			15 (24.2%)			
Moderate sexual concerns (4–6)	19 (16.8%)			7 (11.3%)			
Severe sexual concerns (7–10)	21 (18.6%)			11 (17.7%)			

FACT-G total scores ranged from 23–104 in the current sample. Scores on all other variables listed above ranged from 0–10.

^aItem from PCM inquiring about reduced sexual enjoyment, interest or performance

^bFACT-G Total score

^cMDASI Severity scale

^dMDASI Interference Scale

^eNCCN Distress

Table 3

Correlation coefficients for domains of functioning at baseline in GI and breast cancer patients

Measures	(1)	(2)	(3)	(4)	(5)
(1) Sexual Concerns	–	–0.25	0.15	0.32*	0.28*
(2) Quality of Life	–0.48***	–	–0.60***	–0.83***	–0.75***
(3) Symptom Severity	0.35***	–0.63***	–	0.61***	0.52***
(4) Disease Interference	0.42***	–0.65***	0.61***	–	0.69***
(5) Disease-related Distress	0.34***	–0.58***	0.45***	0.53***	–

Correlation coefficients above the diagonal line are for breast cancer patients; below the diagonal line are for GI cancer patients.

*
 $p < 0.05$;**
 $p < 0.01$;***
 $p < 0.001$

Table 4

Fixed effects for linear mixed models examining the associations among time, sexual concerns, and domains of functioning

Outcome	Fixed effects	Repeated effects	<i>B</i>	<i>SE</i>	<i>T</i>	<i>p</i>	95% CI	<i>pr</i>
Quality of life	Time	Visit	-0.08	0.05	-1.53	0.13	-0.19, 0.02	-0.12
	Sexual concerns		-0.90	0.28	-3.24	0.001	-1.44, -0.35	-0.14
	Cancer type		-0.74	2.97	-0.25	0.80	-6.59, 5.11	-0.02
	Time X sexual concerns		-0.00	0.01	-0.26	0.79	-0.02, 0.02	-0.01
	Time X cancer type		0.04	0.06	0.72	0.47	-0.07, 0.16	0.05
	Sexual concerns X cancer type		-0.34	0.46	-0.75	0.45	-1.24, 0.56	-0.03
	Time X sexual concerns X cancer type		0.01	0.01	0.71	0.48	-0.01, 0.03	0.03
Symptom severity	Time	Visit	0.01	0.00	1.26	0.21	-0.00, 0.02	0.10
	Sexual concerns		0.10	0.03	3.32	0.001	0.04, 0.16	0.14
	Cancer type		0.16	0.27	0.59	0.56	-0.37, 0.68	0.05
	Time X sexual concerns		0.00	0.00	0.50	0.62	-0.00, 0.00	0.02
	Time X cancer type		-0.01	0.01	-1.24	0.22	-0.02, 0.00	-0.09
	Sexual concerns X cancer type		0.06	0.05	-1.09	0.28	-0.15, 0.04	-0.05
	Time X sexual concerns X cancer type		-0.00	0.00	-0.90	0.37	-0.00, 0.00	-0.04
Disease interference	Time	Visit	0.01	0.01	0.87	0.39	-0.01, 0.02	0.07
	Sexual concerns		0.26	0.05	5.79	0.000	0.17, 0.35	0.24
	Cancer type		-0.05	0.37	-0.15	0.88	0.78, 0.67	-0.01
	Time X sexual concerns		-0.00	0.00	-0.20	0.84	-0.00, 0.00	-0.01
	Time X cancer type		-0.00	0.01	-0.51	0.61	-0.02, 0.01	-0.04
	Sexual concerns X cancer type		-0.11	0.08	-1.45	0.15	-0.27, 0.04	-0.06
	Time X sexual concerns X cancer type		0.00	0.00	0.20	0.84	-0.00, 0.00	0.01
Disease-related distress	Time	Visit	0.00	0.01	0.26	0.80	-0.01, 0.02	0.02
	Sexual concerns		0.13	0.06	2.37	0.02	0.02, 0.24	0.10
	Cancer type		0.03	0.42	0.08	0.94	-0.79, 0.86	0.01
	Time X sexual concerns		0.00	0.00	0.38	0.71	-0.00, 0.00	0.02
	Time X cancer type		0.00	0.01	0.24	0.81	-0.02, 0.02	0.02
	Sexual concerns X cancer type		-0.04	0.10	-0.40	0.69	-0.22, 0.15	-0.02
	Time X sexual concerns X cancer type		0.00	0.00	0.16	0.87	-0.00, 0.00	0.01