

# Integrating Quantitative and Qualitative Methods to Evaluate an Online Psychoeducational Program for Sexual Difficulties in Colorectal and Gynecologic Cancer Survivors

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Sexual health is an integral component of quality of life for cancer survivors, and is often negatively impacted by treatment. Geographic limitations often prohibit survivors from accessing sexual health programs designed to address their needs. This study examined the efficacy of an online, 12-week psychoeducational program, which included elements of mindfulness meditation, for sexual difficulties in survivors of colorectal or gynecologic cancer. Complete pre- and postintervention data were available for 46 women (mean age 55.0, *SD* 9.6) and 15 men (mean age 59.7, *SD* 6.8). Women experienced

significant improvements in sex-related distress ( $p < .001$ ), sexual function ( $p < .001$  and  $p < .01$ ), and mood ( $p < .001$ ); these results were maintained at six months follow-up. Men's improvement in desire was not significant ( $p = .06$ ), whereas intercourse satisfaction was ( $p < .05$ ) immediately after the program, but not at follow-up. In order to more fully explore women's experiences, interviews were carried out with six participants and analyzed using narrative inquiry. Women shared a feeling of renewed hope for regaining their sex lives, and expressed that they would have valued an interactive component to the program. These findings suggest that an online, unidirectional psychoeducational program is feasible, and may be effective for women survivors of gynecologic and colorectal cancer, but further work is needed to ensure that online interventions address the sexual health needs of male survivors.

## INTRODUCTION

Cancer and its treatment affect the physiological, psychological, and sociocultural realms of a survivor's life including sexual health (Ofman, Kingsberg, & Nelson, 2008). Across cancer types and treatments, estimates of distressing sexual sequelae range from 40% to 100% in men and women survivors (Flynn et al., 2011) and can persist for years after cancer has remitted (Burns, Costello, Ryan-Woolley, & Davidson, 2007). The mechanisms by which treatments for cancer impact upon sexuality are multifaceted and not limited to impaired physiological function, but also injury to body image, psychological well-being, and partner-related dynamics.

### Effects of Gynecologic Cancer on Sexual Function

It is not surprising that women with gynecologic cancers experience difficulties in sexual response and satisfaction given that the cancers target sexually intimate areas. Even four to six years following treatment for early-stage cervical cancer, up to a quarter of survivors report distressingly insufficient vaginal lubrication and elasticity (Bergmark, Åvall-Lundqvist, Dickman, Henningsohn, & Steineck, 1999). Sexual pain is also common among survivors and can impact all other aspects of sexual response (Greimel, Winter, Kapp, & Haas, 2009; Lindau, Gavriloiva, & Anderson, 2007). Long-lasting sexual difficulties seem to persist regardless of whether treatment included pelvic radiation therapy or not (Pieterse et al., 2006).

### Effects of Colorectal Cancer on Sexual Function

Colorectal cancer and its treatments also negatively impact sexual function and quality of life (QoL). Among men, the most common sexual difficulties include problems with erectile function and ejaculatory control (Breukink et al., 2008; Hendren et al., 2005), and women most often report genital pain and lack of lubrication. Reduced sexual frequency is common to both sexes (Böhm et al., 2008; Hendren et al., 2005). These sexual difficulties have consequences beyond sexual response, including reduced QoL in regards to social functioning, financial difficulties, body image, self-esteem, and distress (Di Fabio, Koller, Nascimbeni, Talarico, & Salerni, 2008; Hendren et al., 2005).

## Interventions for the Sexual Sequelae of Cancer

Despite the high prevalence of posttreatment sexual dysfunction, the topic is often not addressed by cancer specialists. One study found that nearly all participating survivors reported that their cancer provider failed to discuss sexuality preoperatively and did not discuss sexual dysfunction treatment options postsurgery (Di Fabio et al., 2008). These findings may relate to inadequate information on the part of the provider on how to assess and manage sexual difficulties and/or treatment availability. Embarrassment, lack of privacy, and less than optimal training are also known barriers that impede the management of sexual dysfunction in survivors by care providers (Wiggins, Wood, Granai, & Dizon, 2007).

Among available treatments to address sexual difficulties, most of the existing literature has focused on pharmacological options, with mixed results. For example, although phosphodiesterase type-5 inhibitors (sildenafil, vardenafil, and tadalafil) are effective in reversing iatrogenic erectile dysfunction in men, issues with compliance arise, and these medications are not globally effective (Zippe, Kedia, Kedia, Nelson, & Agarwal, 1998). These medications have not been found to be effective for women, and topical testosterone for low sexual desire in women is also usually not an option among cancer survivors due to potential safety risks (Schover, 2008). As a result, psychological interventions for the sexual sequelae of cancer represent a desirable option—especially as they target the individual in his or her entirety, and not just the specific sexual symptoms.

There is evidence that a face-to-face psychoeducational intervention incorporating skills in mindful meditation along with education and elements of sex therapy can significantly improve sexual dysfunction among gynecologic cancer survivors (Brotto et al., 2012; Brotto et al., 2008). Both of these studies involved three monthly, individual sessions led by a psychologist with expertise in sexual health and psychosocial oncology. Psychoeducation and mindfulness skills were discussed during the face-to-face sessions, and participants were encouraged to practice homework between sessions.

The goal of the current study was to adapt this face-to-face intervention for online delivery, given that online treatments are able to overcome some of the emotional and geographic barriers in place. We first examined outcomes to treatment using quantitative endpoints and validated measures, followed by in-depth individual interviews based on narrative inquiry and subsequently analyzed qualitatively. We elected to integrate both quantitative and qualitative methodologies, given evidence that such an approach within sex research can be particularly essential for understanding the nuances of the sexual experience (Tolman & Szalacha, 1999). We focused primarily on sex-related distress, and secondary endpoints included sexual functioning, mood, and relationship satisfaction among colorectal and gynecologic cancer survivors.

## METHOD

### Participants

A total of 72 women and 40 men who had received surgical treatment for either gynecologic, colon, or rectal cancer in the past five years and who experienced a sexual dysfunction at the time of study participation consented to participate. Participants were required to be between the ages of 19 and 70 and in a relationship, and were excluded if they lacked proficiency in English, lacked

access to a computer with Internet connection, or were not able to commit to a 12-week program. For the qualitative phase, a purposive sample of six women who had completed all aspects of the program and assessments were selected.

## Procedure

Our primary source of recruitment was a patient registry of the British Columbia Cancer Agency (BCCA). Analysts from data records retrieved cases that met our study inclusion criteria. We also recruited cancer survivors who met the same study criteria but who were treated either at Memorial Sloan Kettering Cancer Center in New York or the Cancer Program at Windsor Regional Hospital, Ontario, Canada.

Prospective participants were provided with detailed information about the study and then took part in a telephone screen to determine study eligibility. Following receipt of the signed consent form, participants were given access to a password-protected website housing all assessment measures, intervention materials, and the discussion board. Questionnaires were completed online at three time points: study entry, study completion, and 6-month follow-up. The study was approved by the ethics review boards at all three recruitment sites (British Columbia Cancer Agency Research Ethics Board, Memorial Sloan Kettering Cancer Centre Institutional Review Board, University of Windsor Research Ethics Board).

## Description of Online Intervention: Psychoeducational Intervention for Sexual Health in Cancer Survivors (OPES)

One new topic was made available each week for 12 weeks, and included the following: (1) the importance of sexuality to QoL and information on the prevalence of sexual difficulties; (2) consideration of the predisposing, precipitating, perpetuating, and protective factors; (3) sexual beliefs/maladaptive thoughts; (4) mindfulness; (5) genital anatomy and physiology; (6) body image; (7) enhancing relationship satisfaction and communication; (8) mindfulness and awareness of body sensations; (9) thought records; (10) mindfulness of thoughts; (11) using sexual aids (e.g., stimulators, erotica) to enhance arousal; and (12) relapse prevention. Homework exercises were assigned with each new topic. All participants had access to a moderated and password-protected bulletin board to which participants could post anonymous questions and to which the investigator team responded.

The 12 weekly topics map onto those presented in the original in-person intervention (Brotto et al., 2012). Psychoeducational information that was verbally provided in the face-to-face intervention was translated into easily readable passages of text. Mindfulness meditations that took place in the face-to-face intervention were adapted for online administration via audio recordings. The material was generally the same for men and women, although some segments described gender-specific content for men and women separately. The material did not differ in terms of cancer type. On average it took approximately 60 minutes to complete a module.

Participants were instructed to log on to the site at least once per week in order to access the material and submit feedback and experiences with the homework. Material for the next week's topic was made available only after a participant had completed his or her responses to the prior

week's material. In cases where a participant did not submit responses during the expected time frame, reminder e-mails and telephone calls were made by the study coordinator.

## Measures

### *Demographic and Health-Related Information*

We assessed age, ethnicity, education, and relationship duration, current medications, type and duration of cancer treatment, and time since cancer diagnosis. Health-related information was assessed by self-report.

### *Baseline Sexual Knowledge*

The Sexual Beliefs and Information Questionnaire-Revised (SBIQ-R; Adams et al., 1996) is a 25-item scale composed of statements that assess sexual knowledge and beliefs. Items are scored as *correct*, *incorrect*, or *don't know*. It was administered to establish the baseline level of sexual knowledge. Cronbach's alpha in our sample was moderate at 0.696.

### *Program Acceptability*

At the end of each of the 12 weekly modules, participants were asked to answer several questions pertaining to their satisfaction and ease of use navigating the website: (1) Overall, how informative and/or useful did you find the information? (2) Did you have any difficulties understanding the information? (3) Did you experience any technical difficulties? Item responses were measured on a 5-point Likert scale from 1 (*not at all*) to 5 (*extremely*).

### *Primary Outcome: Sex-Related Distress*

The 12-item Female Sexual Distress Scale (FSDS; Derogatis, Rosen, Leiblum, Burnett, & Heiman, 2002) was used to assess our primary outcome of distress associated with sexual difficulties. Given the gender-neutral language, we administered it to male and female participants. Cronbach's alpha for the full current sample was excellent at 0.954.

### *Secondary Outcome: Sexual Functioning*

Investigator-derived questions asked about any history of sexual abuse and whether treatment for sexual difficulties had previously been sought.

Women completed the Female Sexual Function Index (FSFI; Rosen et al., 2000), a 19-item self-report scale designed to assess several dimensions of sexual function over the previous 4 weeks. A total score, as well as scores on domains of desire, arousal, lubrication, orgasm, satisfaction, and pain, was obtained, with higher scores indicating better sexual function. Cronbach's alpha on the current sample of women was very good at 0.872.

Men completed the International Index of Erectile Function (IIEF; Rosen et al., 1997), a 15-item self-report questionnaire that assessed desire, erectile function, orgasmic function, sexual satisfaction, and frequency of sexual activity over the past 4 weeks. Higher scores for all domains corresponded to higher levels of sexual function. Cronbach's alpha on the current sample of men was very good at 0.864.

### *Secondary Outcome: Dyadic Adjustment*

The 32-item Dyadic Adjustment Scale (DAS; Spanier, 1976) was used to measure relationship satisfaction over the preceding 12 months. Subscales included Consensus, Satisfaction, Affectional Expression, and Cohesion. Lower scores are associated with greater relationship distress. Cronbach's alpha in the current sample was excellent at 0.938.

### *Secondary Outcome: Mood*

The Beck Depression Inventory (BDI; Beck & Beamesderfer, 1974) was used to assess the severity of depressive symptoms. Cronbach's alpha in the current sample was excellent at 0.927.

## Quantitative Data Analysis Plan

Subtotals for sexual desire, arousal, pain, orgasm satisfaction, and distress, the DAS, and the total score on the BDI were computed for each of the three time points. Independent *t* tests were used to examine baseline differences in primary and secondary endpoints among men and women. Composite scores for the three time points were then entered into a repeated measures analysis of variance (ANOVA) controlling for age. Pairwise contrasts were used to detect significant changes between time points. Between-within repeated measures ANOVA with sex as the between-subjects factor and treatment (pre- to post-) as the within-subjects factor were used to examine interactions between treatment and sex.

## Qualitative Interviews

The use of in-depth, unstructured interviewing is essential in qualitative research, particularly to elicit participants' experiences and meaning making (Kvale, 1996; Kvale & Brinkmann, 2009; Mishler, 1986; Riessman, 2008). Kvale (1996) described the richness of qualitative interviewing as "attempts to understand the world from the subjects' points of view, to unfold the meaning of peoples' experiences, to uncover their lived world prior to scientific explanations" (p. 1). Each of six participants was interviewed twice by an experienced interviewer. The first interview was largely unstructured, and focused on eliciting an in-depth and detailed story of the participant's experiences of working through and completing the OPES program. These interviews lasted anywhere between 90 minutes and 3 hours. A second, shorter, interview was also conducted to determine trustworthiness of responses. A new consent form, detailing the procedures of the interview, was then signed. A handheld digital recorder was used to record all interviews. Guiding questions are presented in the Appendix.

## Qualitative Analyses

First, the entire interview was transcribed, including noting any striking features of the conversation. The transcripts were scrutinized by reading and rereading across all participants' interviews and then noting the common themes. Next, sections of the text that reflected the form of a story or captured a seemingly poignant experience were identified.

A thematic analysis was conducted for each individual narrative where the emphasis was placed on the context of the transcribed text—*what* was said rather than how it was said, resulting in several emerging themes and subthemes within each narrative account. The structural analysis of each narrative placed emphasis on *how* a story was told or the *way* it was told. Following the completion of each narrative data analysis, a second interview was conducted with each participant to review and ensure that the “co-constructed” narrative that emerged was an accurate reflection of the participant's experiences (Lincoln & Guba, 1985; Riessman, 1993).

## RESULTS

### Demographic Characteristics

Although consent was obtained from a total of 113 individuals, only 49 (43.3%) completed the program and provided complete pre- and posttreatment data. However, an additional 12 participants partially completed the full intervention and provided complete pre- and postintervention data. Demographic characteristics are based on this sample ( $n = 61$ ) of 46 female (mean age 55.0,  $SD$  9.58) and 15 male (mean age 59.7,  $SD$  6.77) participants (Table 1). Women (48.6%) were more likely to complete the modules and assessments than men (32.5%),  $p = .052$ . Compared to those who completed the OPES program, those who dropped out had significantly lower relationship satisfaction, and among the men, overall sexual satisfaction was lower for noncompleters.

A total of 52 individuals ( $n = 27$  women,  $n = 25$  men) dropped out after completing the baseline questionnaires (Figure 1). Women were most likely to drop out during module 8 (mindfulness of body sensations) and module 6 (body image), and men were most likely to drop out during module 8.

The mean number of years since cancer diagnosis did not significantly differ between the groups, nor did ethnicity or relationship duration (Table 1).

For the qualitative phase, six female participants who were treated for gynecologic ( $n = 3$ ), colorectal ( $n = 2$ ), or breast cancer ( $n = 1$ ) and who completed the 12 OPES program modules as well as the pre-, post-, and 6-month follow-up questionnaires between 2011 and 2013 participated. The time between their having completed the program modules to the time of the interview ranged from 14 months to 3 years. Women ranged in age from 46 to 71, and all were in long-term, committed relationships ranging from 7 to 40 years.

### Baseline Sexual Knowledge, Distress, and Functioning

There was no significant difference in baseline sexual knowledge between women and men,  $t(59) = 1.01$ ,  $p > .05$ , and scores suggested a below-average level of sexual knowledge (Table 1).

TABLE 1  
Demographic Characteristics of Female ( $n = 46$ ) and Male ( $n = 15$ ) Participants who Provided Complete Pre- and Postintervention Data

Variable	Female	Male
Type of cancer ( $n$ )		
Gynecologic	30	0
Colorectal	8	15
Other	8	—
Years since cancer diagnosis ( $SD$ )	3.7 (3.15)	4.1 (1.85)
Mean ( $SD$ ) relationship length (months)	266.9 (170.59)	323.1 (169.8)
Ethnicity (%)		
Euro-Caucasian	93.5	100
East Asian	6.5	0
Education (%)*		
High school	13.0	20.0
College/trade school	34.8	60.0
Undergraduate degree	34.8	13.3
Postgraduate degree	13.0	6.7
SBIQ-R (mean, $SD$ )	13.26 (3.63)	14.33 (3.44)
FSFI (mean, $SD$ )		
Desire	2.18 (1.15)	—
Arousal	2.84 (1.25)	—
Lubrication	2.51 (1.29)	—
Orgasm	3.12 (1.53)	—
Satisfaction	3.49 (1.35)	—
Pain	4.11 (1.44)	—
Total	18.62 (5.43)	—
IIEF (mean, $SD$ )		
Erectile Function	—	18.89 (7.03)
Orgasmic Function	—	6.23 (1.88)
Sexual Desire	—	5.67 (1.91)
Intercourse Satisfaction	—	8.63 (2.45)
Overall Satisfaction	—	5.93 (2.02)
Total	—	48.13 (9.89)
SDS	25.57 (11.39)	15.67 (10.05)

Note. \*Four percent of women participants chose not to answer the question on education. SBIQ-R = Sexual Beliefs and Information Questionnaire-Revised; FSFI = Female Sexual Function Index; IIEF = International Index of Erectile Function; SDS = Sexual Distress Scale.

Sex-related distress was significantly higher for women than men,  $t(59) = -3.00$ ,  $p = .004$  (Table 1), and all participants had clinically significant distress. Among women, baseline FSFI scores for the desire, arousal, lubrication, satisfaction, and total sexual functioning domains were in the clinically significant range (Table 1). For men, scores on sexual desire, orgasmic function, and overall satisfaction, but not erectile function, met the clinical cutoff for dysfunction (Table 1). Women also had more depressive symptoms than men at baseline, though this difference was not statistically significant,  $t(59) = -1.59$ ,  $p > .05$ .



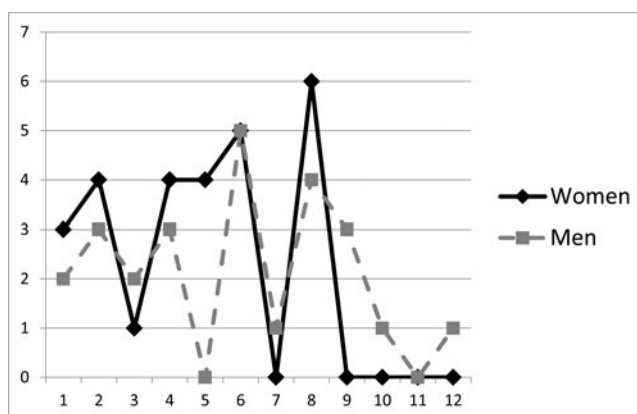


FIGURE 1 Participant dropouts by module for women ( $n = 27$ ) and men ( $n = 25$ ).

### Program Acceptability

There was considerable variability in the duration of time required to complete the 12 modules with a mean of 29.9 weeks,  $SD$  19.4 (range 8–111 weeks). A repeated measures analysis of variance (ANOVA) showed significantly different ratings in “informativeness” across the 12 modules,  $F(11, 484) = 2.13$ ,  $p = .017$ , with a mean rating of 3.62 ( $SD$  0.74) which corresponded to a qualitative rating between “moderately” and “very much.” Participants rated module 1 (sexual complaints and definitions of sexual response), module 5 (anatomy and physiology of sexual response), module 10 (mindfulness), and module 12 (relapse prevention) as being the most informative.

The mean rating of difficulty understanding the information presented was 1.58 ( $SD$  0.79), which corresponded qualitatively between “not at all” and “a little.” A repeated measures ANOVA showed significant differences module to module,  $F(11, 484) = 10.61$ ,  $p < .001$ , with modules 2 (factors impacting the development of the sexual difficulty) and 9 (thought records) showing higher ratings of participants’ having difficulty understanding the material.

The mean rating of experiencing technical difficulties with the modules was 1.43 ( $SD$  0.72), which corresponded to a rating between “not at all” and “a little.”

### Effect of Treatment on Sex-Related Distress

A between-within repeated measures ANOVA with sex as the between-subjects factor and treatment (pre- to post-) as the within-subjects factor revealed a significant interaction between treatment and sex,  $F(1, 59) = 16.90$ ,  $p < .001$ , such that women started out more distressed and experienced a significant reduction in scores, whereas men began as less distressed and showed no significant change with treatment. The main effect of sex was not significant,  $F(1, 59) = 2.97$ ,  $p = .09$ , nor was the main effect of treatment  $F(1, 59) = 1.85$ ,  $p > .05$ .

TABLE 2  
Effects of Treatment on Women's and Men's Sexual Functioning and Depressive Symptoms

Sexual Functioning Subscale	Pretreatment		Posttreatment		<i>t</i> , <i>df</i>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	
<b>Women</b>					
Desire ( <i>n</i> = 46)	2.18	1.15	2.92	1.18	-4.40, 45***
Arousal ( <i>n</i> = 35)	2.83	1.28	3.95	1.48	-4.95, 34***
Lubrication ( <i>n</i> = 32)	2.42	1.31	3.11	1.69	-3.47, 31**
Orgasm ( <i>n</i> = 34)	3.07	1.57	4.09	1.60	-3.77, 33***
Satisfaction ( <i>n</i> = 34)	3.56	1.35	4.55	1.27	-4.23, 33***
Pain ( <i>n</i> = 27)	3.99	1.45	4.64	1.44	-3.13, 26**
Total Score ( <i>n</i> = 24)	18.07	5.50	24.51	6.80	-6.17, 23***
Depressive Symptoms	11.11	9.10	8.17	6.09	
<b>Men</b>					
Erectile Function ( <i>n</i> = 7)	19.43	7.48	18.43	6.90	1.15, 6
Orgasmic Function ( <i>n</i> = 11)	6.73	1.56	6.64	2.58	0.13, 10
Sexual Desire ( <i>n</i> = 15)	5.67	1.91	6.27	1.39	-2.07, 14 <sup>o</sup>
Intercourse Satisfaction ( <i>n</i> = 6)	9.50	2.17	10.50	2.07	-3.87, 5*
Overall Satisfaction ( <i>n</i> = 15)	5.93	2.02	5.87	2.64	0.15, 14
Total Score ( <i>n</i> = 6)	51.67	7.37	54.0	9.21	-1.99, 5
Depressive Symptoms	7.07	6.42	8.33	6.22	

Notes. Analyses were carried out with a dependent samples *t* test,

\*\*\**p* < .001,

\*\**p* < .01,

\**p* < .05,

<sup>o</sup>*p* = .06.

## Effect of Treatment on Sexual Functioning

### Women

As shown in Table 2, women had significant improvements in sexual desire, arousal, lubrication, orgasmic function, sexual satisfaction, overall sexual function, as well as a decrease in genital pain.

### Men

Among the 15 men who provided complete data, there was a significant improvement in intercourse satisfaction and a marginally significant increase in sexual desire, but no significant effect of treatment on erectile function, orgasmic function, overall satisfaction, or overall sexual functioning (Table 2).

## Dyadic Adjustment

### Consensus

The interaction between sex and treatment on DAS consensus scores was significant,  $F(1, 59) = 3.74, p = .05$ , such that men experienced a decline in consensus scores with treatment whereas

there was no significant change for women. The main effect of treatment was significant,  $F(1, 59) = 11.39, p = .001$ , but the main effect of sex was not,  $F(1, 59) = 1.02, p > .05$ .

### *Satisfaction*

The interaction between sex and treatment,  $F(1, 59) = 1.34$ , the main effect of treatment,  $F(1, 59) = 0.31$ , and the main effect of sex,  $F(1, 59) = 1.49$ , were not significant for dyadic satisfaction, all  $ps > .05$ .

### *Cohesion*

The interaction between sex and treatment,  $F(1, 59) = 2.38$ , the main effect of treatment,  $F(1, 59) = 0.80$ , and the main effect of sex,  $F(1, 59) = 0.11$ , were not significant for cohesion, all  $ps > .05$ .

### *Affectional Expression*

The interaction between sex and treatment for affectional expression was not significant,  $F(1, 59) = 3.25, p > .05$ . The main effect of treatment was significant,  $F(1, 59) = 4.09, p = .048$ , with scores decreasing posttreatment. The main effect of sex,  $F(1, 59) = 0.35$  was not significant,  $p > .05$ .

### **Mood**

A significant interaction between treatment and sex on depressive symptoms emerged,  $F(1, 59) = 7.06, p = .01$ , such that women started out with more depressive symptoms than men, and exhibited a significant decline in scores, whereas men started with fewer depressive symptoms and showed no change in symptoms following treatment. The main effect of treatment,  $F(1, 59) = 7.06$ , and main effect of sex,  $F(1, 59) = 0.89$ , were not statistically significant,  $ps > .05$  (Table 2).

### **Sex-Related Distress at Follow-Up**

We examined sexual distress outcomes across the three time points: pretreatment, posttreatment, and at 6-month follow-up. Given the significant mood by treatment interaction observed from pre- to posttreatment, we included pretreatment BDI scores as a covariate. There was a significant treatment by sex interaction,  $F(2, 102) = 5.75, p = .004$ , but no treatment by mood interaction,  $F(2, 102) = 0.33, p > .05$ . Table 3 illustrates the reduction in sex-related distress for women with treatment that was retained at 6-month follow-up. Men showed no significant overall effect on sex-related distress scores at follow-up.

TABLE 3  
Effects of Treatment on Sex-Related Distress Scores at Pre-, Posttreatment, and at 6-Month Follow-Up for Women ( $n = 46$ ) and Men ( $n = 15$ )

	<i>Women</i>		<i>Men</i>	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Pretreatment	25.17	11.38	15.77	10.83
Posttreatment	19.66	12.08	18.92	13.54
6-month follow-up	18.83	10.97	15.92	10.34

### Qualitative Findings

Five themes emerged after analyzing women's stories. These are described below with accompanying excerpts from the women.

- (1) Participating allowed them to bring attention back to the importance of sexuality in their lives and in their relationships. Specifically, women described how the program provided opportunities for self-reflection and thinking about sexuality and their sexual relationship that they would not have done otherwise:

When I chose to do the program ... it was me, giving myself permission to do something for me ... I remember the [exercise] that asked us to have a conversation ... it was hard to choose a topic because I wanted to talk about all of them ... And it was interesting because we, we probably wouldn't have sat down in that context to discover that, but it was something that we needed to talk about. (Terry, mid-40s)

- (2) There was new information provided to them that would not have been accessible otherwise. Women noted that this new information provided unique opportunities for self-reflection that they found meaningful:

Well, there's certainly a new aspect of openness. Now I would, you know, I feel quite comfortable telling my husband what I was doing in the program. Yeah, I think it helped with just being more open about everything. (Paula, age 60)

- (3) Women described a renewed sense of intimacy and openness in their relationship as a result of the program. They shared stories that suggested a new dialogue with their partners about sex and overall increased comfort discussing sexuality:

If I would have frustrations, or I really need you to do this because I got to go back to the study, and just to make the time. So, we'd make a date to talk about it. (Natasha, age 62)

- (4) Women provided specific feedback on the format of the online program in that they found the modules easy to read and access, they enjoyed working through one module at a time,

they liked the self-directed pace of the program, and they appreciated the opportunity to revisit any earlier module:

I wouldn't say I enjoyed doing it, but it was enjoyable in the fact that it was different for me and I enjoyed working through a task on the computer and like that .... I did not find anything that I disliked in the program. (Paula, age 60)

- (5) Women provided specific feedback on the content of the online program in that they liked the homework exercises, and they appreciated the step-by-step nature of the instructions:

I think you need that structure in order to get people talking about it, or writing about it, thinking about it for sure, and then responding to it. (Maggie, age 64)

Women also provided some critiques of the program that they felt could be improved upon in the future. They reported that the homework exercises took too long and noted that such a program would not be feasible in conjunction with a full-time job. They did not like the discussion board, and thus preferred not to use it to post their questions.

Most also commented on the difficulties in reengaging in sexual activity (or even in having conversations about sex) after such a prolonged period of sexual abstinence. In regard to specific modules, several participants would have appreciated more guidance on the "using sexual aids" section, and all expressed frustration about the forced-choice validated questionnaires that they felt did not capture the nuance of their experiences after cancer and after treatment.

Women also shared information in four broad domains relating to how the online program might be improved in the future. Firstly, they missed the opportunity to interact with a facilitator, and would have benefitted from a two-way exchange of information. This contributed to their not utilizing the discussion board. They also would have liked to interact with one another. Many of the women felt that they had additional, specific needs related to sexual health that were not addressed in this broad program. For example, sexual pain was not addressed, nor was the impact of having an ostomy. Women shared that they would have preferred a customizable program in which they could take as much time as they needed for each module, and they would have preferred the option of skipping a module that they found difficult or not relevant. Finally, although women reported finding the discussion about addressing barriers and obstacles to benefitting from an online program to be very useful, we hypothesize that this information may have been better received if it were presented at the start of the program instead of during the final module.

In addition to these common themes, some women brought up a concern that the program did not address their more general levels of psychological distress, which impacted both their sexual functioning as well as their ability to complete the program on schedule. These domains were not specifically addressed in the current intervention. Some women noted that this impacted their motivation to continue, and that they contemplated dropping out at times. There were also considerably varied reactions to the section on erotic aids, with some embracing the challenge of introducing these into their sex lives, and other women reporting a sense of fear and embarrassment, which led them to skip that module.

## DISCUSSION

### Summary of the Findings

Because of the pervasiveness of sexual side effects following cancer, our goal was to adapt an existing and effective face-to-face intervention to address sexual difficulties to an online modality. Study participants exhibited significant sex-related distress at baseline, consistent with the literature that shows high rates of sexual difficulty in cancer survivors (Ofman et al., 2008). A significant interaction between sex and treatment emerged, suggesting that whereas women experienced significant declines in sex-related distress, men experienced no such benefit. These gains were retained only for women at the 6-month follow-up. Women's pretreatment scores of sexual desire, arousal, lubrication, satisfaction, and total sexual functioning were in the clinically significant range, and with treatment, there was a significant improvement in each of these areas. For men, the sexual desire, orgasmic function, and overall satisfaction scores were in the clinically significant range, yet only intercourse satisfaction significantly improved with treatment and sexual desire was only minimally improved.

In-depth narrative interviews allowed for some of these quantitative findings to be further explored. The six female participants shared stories of how their participation was effective in bringing their attention to the importance sexuality had in their lives and relationships, after a long period of avoidance. Participating improved women's hope that their sexual well-being would improve with time and effort. Participating provided women with opportunities to think more deeply about their sexual well-being and encouraged self-reflection on what they wanted with respect to their sexual lives. To the frustration of participants, this enhanced introspection about sexuality was not captured in any of the validated questionnaires.

On dyadic measures, men surprisingly experienced a reduction in relationship consensus and affectional expression, suggesting that this online intervention, which targeted individuals but not their partners, may have been missing critical elements that could have improved relationship adjustment. Because of the logistical difficulties in recruiting survivors and their partners, and because of the pilot nature of this study, we elected to limit participation to the survivors themselves, despite several of our participants expressing a wish to have their partners participate.

Mood significantly improved for women, but not men. The relationship between depressive symptoms and sexual dysfunction is well established (Bodenmann & Ledermann, 2008), and there is evidence that women with higher levels of depressive symptoms may respond to a greater degree to psychological interventions focused on sexual difficulties after cancer (Brotto et al., 2008). The fact that mood was not one of the core modules in the OPES intervention, but rather was discussed throughout various modules in a more indirect manner, may account for the lack of improvement in men's mood symptoms. On the other hand, the level of depressive symptoms for men was very low at program entry, thus, a floor effect may have accounted for the lack of treatment on men's mood.

### Program Feasibility

Of note, this 12-week program took an average of 29 weeks to complete for participants, with a sizeable degree of variability, and a few outliers took just over 2 years to finish the program.

As was borne out in the narrative interviews, some participants stated that the introduction of a new topic each week may have been too rapid for participants who may have wanted a more gradual exposure to topics and exercises. However, participants found the material presented to be between a “moderate” and “very much” in terms of how informative the material was, and the average rating of “difficulty understanding” the material was between “not at all” and “a little,” indicating that materials were prepared and presented in a manner that most participants found accessible. The mean level of technical difficulty was also very low, which bodes well for considering an online delivery format.

### Sex Differences: Is an online module effective only for female participants?

There were significant sex differences in response to treatment such that women demonstrated improvement on all sexual function domains from baseline to postintervention, but men only had improvement on intercourse satisfaction and marginal improvements on sexual desire. Although it is known that depression and sexual difficulties are associated with poor erectile functioning in male survivors (Nelson, Mulhall, & Roth, 2011), it is unclear if participants need to be experiencing high levels of distress or depression to benefit from an online intervention.

Timing of the intervention could have also contributed to the lack of change on domains of men’s sexual functioning. The men consisted of colorectal cancer survivors, and past research with this population reveals that the ideal time to intervene with interventions to address QoL is 2 to 3 months following cancer treatment (Ball et al., 2013). The mean years since diagnosis for our sample was 4.1 years, and therefore outside the window of opportunity to maximally activate change.

Interventions that specifically target sexual-function treatment options (including medications) and causes of dysfunction have also been identified as preferred by colorectal survivors (Ball et al., 2013). The modules that received higher ratings of informativeness were those that delivered new information. For men, an intervention may need more of a focus on education about the physical side effects of treatment, with information about specific treatment strategies to address erectile dysfunction.

Interestingly, men had improvement in intercourse satisfaction with a marginal increase in sexual desire. Since erectile dysfunction can lead to avoidance of intimacy, sexual satisfaction, and sexual frequency (Bokhour, Clark, Inui, Silliman, & Talcott, 2001), our program may have assisted in correcting avoidance patterns through the provision of information, thereby facilitating discussion and activity and translating into improved satisfaction with intercourse.

### Limitations and Conclusion

Several limitations of the current research must be taken into consideration: Only cancer survivors with computer and Internet access were eligible to participate; only cancer survivors in a relationship at the time of study participation were eligible to participate, given that several of the home activities included participation of a partner; our sample size was small and may have reduced the power to detect treatment effects in men; and attrition was significant. Moreover, given the pilot study nature of the project and our primary interest in feasibility, we did not carry out

any statistical corrections. A related issue that arose was noncompliance, in this context referring to a tendency of participants to work through the program more slowly than intended. A more significant limitation of the study relates to the lack of a control group, thus, the extent to which improvements are due specifically to the intervention versus nonspecific therapeutic effects or expectations cannot be determined.

Taken together, although sexual difficulties improve following online treatment for women with sexual difficulties (Jones & McCabe, 2011), the persistence of symptoms seen in one third of the sample calls for supplementary options, such as the availability of a chat group component for participants in which a therapist with expertise in sex therapy could facilitate group process and answer questions. In the current study, the lack of a “live” component as well as the asynchronous nature of the intervention may have contributed to the finding that only 43% of participants who began the program completed it. Nonetheless, the present pilot study offers important data from which future online interventions targeting sexual concerns and incorporating mindfulness-based approaches may be developed. We have demonstrated that an online, mindfulness-based intervention targeting sexual concerns is feasible. There is preliminary evidence from this pilot study that such an approach is also efficacious for women survivors, and that benefits are retained 6 months following participation. Future modifications of this online program must be mindful of the unique needs and experiences of male cancer survivors with sexual concerns to ensure that such a program is both feasible and effective for them.

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## APPENDIX

### Guiding Questions for In-Depth Narrative Interviews

#### Overarching Question:

1. “How did you experience the OPES online psychoeducational program for sexual difficulties after cancer treatment, and what changes did you experience in terms of your sexual life and relationship, during and following completion of the program?”

#### Sample Follow-Up Questions:

1. What were your thoughts and feelings during that (experience, module, exercise, conversation with your partner)?
2. How do you think going through the OPES program changed your sexual self-perceptions? What about your sexual well-being?
3. How has the program influenced your relationship with your partner?
4. What were the challenges you experienced in completing the OPES program? When you bumped up against these challenges, how did you overcome them?
5. What were the benefits you experienced in completing the program?
6. What motivated you to complete the program?