ONCOLOGY

Sexual Function, Quality of Life, and Experiences of Women with Ovarian Cancer: A Mixed-Methods Study

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ABSTRACT

Introduction: Ovarian cancer impacts approximately 1 in 75 women. Sexual health is receiving increasing attention as a critical aspect of gynecologic cancer treatment and a component of quality of life. Therefore, investigating how women with ovarian cancer experience and express sexuality is an important area of inquiry.

Aims: To evaluate how women with ovarian cancer experience and express sexuality, a major determinant of quality of life, in the context of their illness.

Methods: In a mixed-methods approach, 6 validated self-report questionnaires (n = 64) and an in-depth focus group (n = 3) were used to gather data.

Results: The quantitative phase of the study showed that women with ovarian cancer have a poorer quality of life and higher rates of sexual dysfunction and sexual distress compared with published norms from the general population. They also have lower levels of relationship satisfaction and increased rates of depression. The qualitative phase of the study revealed 6 themes: (i) changes to relationship satisfaction; (ii) sexual difficulties; (iii) challenges with body image; (iv) gaps in communication with healthcare providers; (v) feelings of guilt, grief, resentment, anxiety, and fear; and (vi) strategies used for coping.

Conclusions: Ovarian cancer impacts women's lives beyond mere survival, including their sexual function and quality of life. Healthcare providers are urged to prepare women with ovarian cancer for these challenges and offer information and resources to help improve their quality of life and sexuality. **Fischer OJ, Marguerie M, Brotto LA. Sexual Function, Quality of Life, and Experiences of Women with Ovarian Cancer: A Mixed-Methods Study. Sex Med 2019;7:530–539.**

Key Words: Ovarian Cancer; Sexual Satisfaction; Sexual Desire; Quality of Life; Survivorship

INTRODUCTION

Ovarian cancer is the seventh-most common cancer in women, with a 1 in 75 chance of developing it in a woman's lifetime.[1] 5-year survival varies dramatically depending on the stage of cancer at diagnosis, but most women are not diagnosed until a more advanced stage because of a lack of identifiable symptoms early in the disease course.[2] Only around 15% of people with ovarian cancer are diagnosed at an early stage of the disease, and, thus, the 5-year survival rate is approximately 46%, making ovarian cancer the deadliest gynecologic cancer.[1] Thus, ovarian cancer often requires aggressive surgical and medical treatments, the outcomes of which may leave women with significant physical and psychological changes. The mean age of diagnosis is 63 years, so many women are still leading an active and engaged life at the time of diagnosis. Given the demonstrated importance of recognizing a person's quality of life, quality of life may be independent of the stage of a woman's disease. On the other hand, quality of life is likely a contributor to survival rates and response to treatment.[3–5]

Recognized as an essential aspect of quality of life, sexual health is receiving increasing attention as a critical aspect of gynecologic cancer treatment and survivorship.[6,7] Sexual morbidity has been reported in approximately half of women with gynecologic cancer, and more than 40% of women will have long-standing sexual difficulties.[8] 1 study of women with ovarian cancer found that 57% of women 2

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years after treatment reported persistently worsened sexual difficulties as a result of their cancer and its treatment.[9] Unfortunately, it is well established that most women with ovarian cancer are not provided sufficient information about the sexual implications of their disease and treatment, and, as such, healthcare professionals need to address sexual concerns and inform patients about the impact that their cancer and its treatment may have on their sexual functioning.[9,10] Women express the desire to have discussions about sexuality with their care providers, including oncology nurses, and they would prefer if their healthcare provider was the one to bring up the conversation.[10] Part of this lack of discussion may be due to a lack of understanding and inadequate data on the effects of ovarian cancer on sexual functioning and quality of life. There are many conversations between patient and healthcare provider about expectations surrounding treatments, side effects, surgery, recovery with the idea that patients can prepare themselves psychologically for what is to come. If healthcare providers spoke as openly about potential sexual impacts of ovarian cancer and its treatments, patients might be able to mentally prepare for it and feel more comfortable asking questions when issues arise. They might also pre-emptively seek sexual health resources and support long before symptoms manifest.

The bulk of research on quality of life and sexual implications in gynecologic cancer has been focused on survivors of cervical cancer.[11–13] A longitudinal study demonstrated that a radical hysterectomy for the treatment of cervical cancer results in both short-term and long-term sexual problems.[11] A meta-analysis of 32 studies evaluating sexual function after treatment of cervical cancer showed that several domains of sexual function, including vaginal dryness and pain, and sexual dissatisfaction were prominent across studies.[14] Studies have shown that among other cancer types, survivors have poorer sexual function than age-matched controls.[15]

Because ovarian cancer detection tends to occur later than cervical cancer and because the most commonly used treatments for ovarian cancer differ from those for cervical cancer, it is likely that the sexual sequelae of ovarian cancer may also differ. However, little is known about the specific sexual challenges faced by ovarian cancer survivors, because they are usually grouped with other gynecologic cancers.[16] 1 study found that among a sample of 30 ovarian cancer survivors, 66% were sexually active compared with the 51% with cervical cancer and 46% with endometrial cancer suggesting that women with ovarian cancer continue to remain sexually active and have unique factors impacting their sexual experience.[17] In this study, we sought to investigate how women with ovarian cancer experience and express sexuality—a major determinant of quality of life, in the context of their illness.

METHODS

Study Conceptualization

In this study, we use a combination of quantitative and qualitative methods to describe the sexual functioning and distress levels among a sample of women with ovarian cancer. We purposefully selected an explanatory sequential mixed methods study design. Using this 2-phase approach, we collected quantitative data about sexual functioning and quality of life in the first phase and then used the findings to design our key questions for a subsequent qualitative phase.[18] This method was chosen both to evaluate these experiences with well-recognized, validated assessment tools and to provide a more in-depth understanding of survivors' first-hand and nuanced experiences to shed light on the quantitative findings in a manner that the use of quantitative approaches alone may miss.[19]

Participants

Prospective participants were recruited through online and paper-based advertisements, from ovarian cancer support groups, and from clinics at the British Columbia Cancer Agency, the major provincial cancer center in British Columbia. Recruitment materials were worded so that potential participants were screened out if they did not meet inclusion criteria. Participants had to meet the following inclusion criteria: (i) a diagnosis of ovarian cancer and (ii) willingness to answer questions about sexual health. Partnered relationship status was not an inclusion criterion.

Procedure

This study was a cross-sectional descriptive study and gathered both quantitative data through surveys and qualitative data from an in-depth focus group. Phase 1, the quantitative portion of the study, involved completing a paper or online questionnaire. Participants in phase 1 received a $50 honorarium. On completion of phase 1, women who indicated that they would be interested in participating in the in-depth focus group (phase 2) were contacted. A focus-group method was used to explore perceptions, beliefs, and attitudes of our participants while providing the opportunity for women to discuss their experiences in a more natural conversation, build on each other's ideas, and realize that they are not alone in their challenges. 3 participants from phase 1 provided consent to participate in phase 2. These women were between 51−64 in age, identified as heterosexual and white, had at least some post-secondary education, and all had completed treatment for ovarian cancer. They, too, received a $50 honorarium after completion of the focus group. The group took place at the Diamond Health Care Centre and lasted approximately 1.5 hours. The focus group was led by 2 members of the research team with expertise in psychosocial oncology and sexuality, and the recording was later transcribed by another research team member who did not participate in the focus group.

The group facilitators began the discussion and, using a women-centered approach, occasionally probed around topics of emotional impact and interactions with healthcare providers. These topics were identified from the preliminary analysis of the phase 1 findings, in line with an explanatory sequential mixed methods design.[18] Other areas discussed included sexual experiences, difficulties, self-image, and partner relations.

Women participating in the study provided written consent, and all procedures for both phases were approved by the

University of British Columbia Research Ethics Board. All names of participants included in this article have been changed to protect the participants' identity and privacy.

Measures

We used 6 validated self-report questionnaires, which took approximately 60–90 minutes to complete. The questionnaires used included the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30), the Dyadic Adjustment Scale (DAS), Sexual Functioning Questionnaire, Female Sexual Distress Scale (FSDS), Beck Depression Inventory (BDI), and the 36-item Short Form Health Survey. These questionnaires are further described, and their reliability analysis scores are outlined in Table 1.

Quantitative Data Analysis

SPSS Version 24 for Mac IOS was used for the analysis of the quantitative data collected in phase 1 of this study. This consisted of descriptive analyses only.

Qualitative Data Analysis

Thematic analysis was used to interpret the focus group transcript. The author O.F. immersed herself in the data and identified 6 major themes, which were verified by authors M.M. and L.B. These themes included relationship satisfaction, sexual difficulties, body image, communication with healthcare providers, emotional responses, and coping strategies. The transcript was then read several times and coded by the authors O.F. and M.M., neither of whom conducted the focus group. Each theme was considered and coded independently by the authors, establishing intercoder reliability.

RESULTS

Quantitative Results

The sociodemographic and disease characteristics of our 64 study participants are displayed in Table 2. Unfortunately, age was collected for only 15 participants due to an online data collection error. Of this subgroup, the mean age was 54.7 years and ranged from 31-80. All medical data gathered were self-

Table 1. Questionnaire descriptions and reliability analysis

Questionnaire	Description	Cronbach's α
EORTC QLQ-C30	The EORTC QLQ-30 V3[40] assesses the quality of life of patients with cancer. The questionnaire assesses five functional scales, three symptom scales, global health, quality of life and other single item measures. Domain range from 0-100 with higher scores representing a higher response level. The ovarian cancer–specific scale, the QLQ-OV28,[20] was also used in this study. These questionnaires are valid, reliable, and sensitive.[40,41]	0.681
DAS	The DAS is considered the gold standard for measuring relationship quality.[21] It is divided into 4 subscales: the "dyadic consensus" measures agreement between partners; the "dyadic satisfaction" measures partner satisfaction; the "dyadic cohesion" evaluates the amount that the couple participates in activities together; and the "affectional expression" quantifies the agreement of emotional expression between partners. The scale is internally consistent, stable and reliable.[42–44]	0.994
SFQ	The SFQ was developed in 2000 by Syrjala et al[15] and is a validated measure to evaluate sexual function in women with cancer. The instrument has internal reliability above $\alpha = 0.80$ and construct validity ranging from t = 7.14–4.06[15].	Missing data, unable to perform
FSDS	The FSDS[45] assesses sexual distress in a population. It assesses guilt, frustration, stress, worry, anger, embarrassment, and unhappiness to gauge overall distress in a woman's sex life. Each assessment is added together for an overall score (0–48). A score $\geq$15 suggests than a woman is experiencing sexual distress. This cutoff score has been associated with an 81% sensitivity, a 93% specificity, a 91% positive predictive value, and a false-positive rate of 7% [9]. High validity and reliability ($\alpha = 0.80$–0.93) have been reported.[45]	0.961
BDI	The BDI[46] is one of the most widely used psychometric tests to assess depression. The reliability is up to $\alpha = 0.86$.[47] The BDI has high internal consistency, high content validity, the ability to differentiate between depressed and non-depressed subjects, and it is sensitive to change.[48] Standard cut-off scores that are used for the BDI are as follows: a score <10 indicates no or minimal depression; 10–18 suggests mild to moderate depression; 19–29 encompasses moderate to severe depression; and severe depression is 30–63.[23]	0.913
SF-36	The SF-36 assesses the health status of an individual. It evaluates eight areas of health including physical limitations, social limitations, pain, mental health, vitality, general health perception, and limitations in one's ability to fulfill one's usual role due to emotional and physical problems.[49] This survey has internal consistency,[50] reliability, and validity.[51]	0.965

BDI = Beck Depression Inventory; DAS= Dyadic Adjustment Scale; EORTC QLQ-C30 = European Organization for Research and Treatment of Cancer Quality of Life Questionnaire; FSDS = Female Sexual Distress Scale; SF-36 = 36-Item Short Form Health Survey; SFQ = Sexual Functioning Questionnaire.

Table 2. Demographic and disease characteristics

Variables	Sample (survey) (n = 64) n (%)
Marital status	
Married	29 (45.3)
Common law	9 (14.1)
Single	12 (18.8)
Separated	5 (7.8)
Divorced	8 (12.5)
Widowed	1 (1.6)
Ethnicity	
Caucasian/white	32 (50)
Chinese	3 (4.7)
Asian	1 (1.6)
Missing	36 (43.8)
Highest education	
High school	27 (42.2)
College	14 (21.9)
Undergraduate	11 (17.2)
Graduate degree	5 (7.8)
PhD	1 (1.6)
Some university	2 (3.1)
Cancer Diagnosis	
Epithelial Ovarian	16 (25.0)
Germ Cell Tumor	2 (3.1)
Sex Chord Stromal	1 (1.6)
Krukenberg (metastatic)	2 (3.1)
Unknown	43 (67.2)
Cancer stage	
Benign	1 (1.6)
1	1 (1.6)
2	3 (4.7)
3	12 (18.8)
4	2 (3.1)
Don't know	45 (70.3)
Malignant	
Yes	26 (40.6)
No	6 (9.4)
Unknown	32 (50.0)
Reported relationship satisfaction	
Yes	49 (76.6)
No	8 (12.5)
Missing	7 (10.9)

reported. Several of the study's participants did not remember the details of their ovarian cancer diagnosis, such as type of ovarian cancer, cancer stage, and its malignancy status. These patients were identified as "unknown" in these categories.

The participants' EORTC QLQ-C30 mean scores are shown in Table 3. Our study data are displayed relative to the general population and ovarian cancer population data collected in previous studies. Global Health and Quality of Life subscale was reported at a mean of 41.8 compared with the reported 71.2 for the general population, and 60.0 for the ovarian cancer population.[20] Our study sample reported similar functional scores but reported more nausea and vomiting, appetite loss, constipation, diarrhea, and more financial difficulties than the general population. Using the EORTC QLQ-OV28, our participants reported gastrointestinal symptoms and body image ratings similar to the published average of other samples with ovarian cancer, but they reported lower rates of peripheral neuropathy, chemotherapy side effects, and hormonal/menopausal symptoms.[20] Relative to other ovarian cancer samples, study participants also had a poorer attitude toward disease treatment, as well as lower levels of sexual functioning.

The mean scores from the DAS are presented in Table 4 relative to population norms for married and divorced individuals.[21] Overall study participants scored much lower than both comparison groups on their Dyadic Consensus scores (29.5 vs 57.9 and 41.1, respectively). In the Dyadic Satisfaction and Affectional Expression categories, participants scored similarly to available data for divorced individuals.

On the Sexual Functioning Questionnaire, a measure of sexual functioning in women with cancer that does not hinge on having been recently sexually active, our study participants scored lower on all measures than previously published data from the general population and compared to other cancer survivors (Table 5).[15] The overall mean score achieved by this group was 1.5 (SD 1.0), which was considerably lower than comparison groups based on a population norm of 3.93 (SD 0.8) and the mean value from other cancer survivors was 3.23 (SD 1.24).

The study participants scored a mean value of 9.1 (SD 10.1) on a measure of sex-related distress (FSDS). Within our sample, 18.6% of women were found to be sexually distressed, as determined by an FSDS score $\geq$15, compared with the 12% of women in the general population with sexual distress.[22]

Descriptive data for mood were drawn from participants' responses on the BDI. Overall, the women scored a mean value of 8.2 (SD 8.6). Based on clinical categories of depression published by Beck et al,[23] 62.5% of our sample were found to have no or minimal depressive symptoms, and 23.4% of women were found to have mild to moderate depressive symptoms. 14% of women scored >19, indicating they had moderate to severe depression. Of the women who scored >19 on this assessment, the mean BDI score was 23.8 (SD 4.9), whereas the mean was 5.6 (SD 5.9) of those who scored under this clinical cutoff.

The scores of our study participants on the 36-item Short Form Health Survey questionnaire are outlined in Table 6. They are displayed in contrast to the normative values of women between the ages of 45–54, 55–64, as well as relative to people with long-standing illness. In all subscales except for pain, our sample of survivors scored lower than most other women in the 45–54 and the 55–64 age categories. They also scored lower in most categories than those with a long-standing illness except for emotional well-being, pain, and general health.

Table 3. EORTC QLQ30 V3 and QLQ-OV28 scores of study participants and population norms

Subscale	No.	Study participants, mean (SD)	Gen Pop, mean (SD)*	Ovarian cancer (all stages), mean (SD)*
Global health status/QoL	63	41.8 (36.6)	71.2 (22.4)	60.0 (25.2)
Physical functioning	63	89.9 (17.5)	89.8 (16.2)	77.5 (21.8)
Role functioning	63	79.1 (30.7)	84.7 (25.4)	66.0 (33.5)
Emotional functioning	63	79.4 (26.0)	76.3 (22.8)	67.9 (25.3)
Cognitive functioning	63	86.0 (21.8)	86.1 (20)	81.6 (22.4)
Social functioning	63	81.0 (27.7)	87.5 (22.9)	72.1 (31.2)
Fatigue	63	19.7 (25.9)	24.1 (24)	37.6 (28.8)
Nausea and vomiting	63	7.9 (18.1)	3.7 (11.7)	11.2 (21.5)
Pain	63	16.9 (26.3)	20.9 (27.6)	26.7 (28.7)
Dyspnea	63	10.5 (19.7)	11.8 (22.8)	19.4 (27.6)
Insomnia	63	22.2 (29.3)	21.8 (29.7)	34.5 (33.7)
Appetite loss	63	13.2 (24.3)	6.7 (18.3)	25.7 (34.2)
Constipation	62	12.9 (23.7)	6.7 (18.4)	22.0 (30.6)
Diarrhea	63	10.1 (21.3)	7.0 (18)	10.8 (22.6)
Financial difficulties	63	16.9 (32.2)	9.5 (23.3)	13.2 (26.1)
Abdominal/gastrointestinal symptoms	63	22.8 (26.7)		21.9 (22.1)
Peripheral neuropathy	62	11.3 (22.7)		17.1 (27.2)
Chemotherapy side effects	60	12.4 (17.5)		19.5 (20.5)
Hormonal/menopausal symptoms	61	10.9 (20.8)		25.8 (30.3)
Body image	61	23.0 (31.4)		22.2 (27.4)
Attitude toward disease and treatment	61	32.1 (33.5)		42.3 (30.6)
Sexual functioning	44	21.6 (26.7)		28.5 (23.7)

Gen Pop = general population; QOL = quality of life.
*These values were extracted from the EORTC QLQ-30 Reference Value Manual published in July 2008.[24]

Qualitative Results

Theme 1: Relationship Satisfaction

The participants in our study spoke of fear of engaging in intimate touch because they did not want it to lead to sexual intercourse. For instance, Beth (age 65) commented:

I avoid [intimate] touching, just because I'm afraid of what it will lead to…the odd time that does happen, I will stimulate him…it's almost like a duty…I'm sort of fulfilling my role as the wife and sexual partner, but there's nothing gratifying for me. I'm not enjoying that role, which is unfortunate, because I'm sure that he can feel that. I've never asked him…We've never really sat down and talked about our lack of a sexual relationship.

This notion of sex as a duty was a common conception among women in the focus group. Beth's comment also highlights the challenges of discussing sexual issues caused by ovarian cancer within intimate relationships.

2 women spoke about how their relationship with their husbands has transformed from a focus on sex to a focus on togetherness as a result of ovarian cancer. For example, "The sex…it's evolving, and then the cancer happens, and it's almost like a new definition…it's more relationship, not just the physical sex part, it's the relationship. And working together with the sex part." [Maggie, age 51] While these women expressed a desire to reignite the sexual aspect of their relationship, their statements suggest that a relationship can thrive and grow despite the sexual challenges that accompany ovarian cancer.

Theme 2: Sexual Difficulties

Pain and loss of desire. Pain and loss of desire were often linked by the women in the focus group, remarking that the pain they experience during coitus or chronically deterred them from wanting to participate in sexual intercourse. For example, 1 woman stated: "I just have no desire, I have this fear, I have this pain, I'm still not pain-free, so the last thing I'm thinking about right now is to have sexual intercourse with my husband. It's just not in the cards right now." [Joanne, age 59]

Changes to orgasm. All focus group participants discussed the changes they experienced to orgasm and the resulting negative emotional impacts. For instance, Maggie [age 51] remarked, "Orgasm takes much longer to peak [now] and as soon as it peaks it drops off like it never happened and—there was a period of time where I would cry even after the orgasm because it was just so different."

Theme 3: Body Image

Beth [age 65] discussed the impact of hair loss on her identity as a cancer patient and her negative body image:

Table 4. Dyadic adjustment scale scores of study participants relative to population standards of married and divorced individuals

Subscale	No.	Mean (SD)	Married (SD)*	Divorced (SD)*	Total (SD)*
Dyadic consensus	55	29.5 (23.5)	57.9 (8.5)	41.1 (11.1)	52.8 (12.1)
Dyadic satisfaction	55	22.3 (17.6)	40.5 (7.2)	22.2 (10.3)	35.0 (11.8)
Dyadic cohesion	55	9.8 (7.7)	13.4 (4.2)	8.0 (4.9)	11.8 (5.1)
Affectional expression	55	5.5 (3.9)	9.0 (2.3)	5.1 (2.8)	7.8 (3.0)

*Mean values extracted from Spanier's original dyadic adjustment scale publication.[21]

It's funny how much hair has to do with the whole thing. It's so silly, but it really does, you know? When I have my wig on, I look at myself in the mirror and I don't see the cancer, but the minute my wig is off, and I'm looking at myself in the mirror, that's what I see. Cancer… I don't feel good about myself, so how could somebody else possibly want to have anything to do with me?

Joanne talked about scarring and how it has impacted her sex life: "And now that I've got [ovarian cancer] again…I'm just so scarred up, you've got the portal... he doesn't want to touch that, he even looks at it and goes, "Aah!" you know?" These findings point to body image as an important aspect of sexual desire and satisfaction for women with ovarian cancer.

The uterus and ovaries are cultural symbols of motherhood, womanhood, and femininity. Therefore, hysterectomies and oophorectomies can negatively impact a woman's perceptions of her femininity. Maggie [age 51] discussed the impact of her hysterectomy on her self-schema: "My perception of myself as a woman, since I've lost my uterus and the ability to have kids… makes a big difference… it's a lot about body image and myself as a woman, and being this sexual person."

Theme 4: Communication with Healthcare Providers

Maggie [age 51] spoke to the importance of receiving information about how her sexuality would be impacted by treatment. However, the answers that she was provided with by healthcare professionals were too basic and did not provide the depth and understanding she was searching for. Beth [age 65] spoke of how it never occurred to her to talk about sexual difficulties with her doctor, commenting, "We talk about cancer, we don't talk about sexuality."

Table 5. Sexual Functioning Questionnaire scores of study participants, the general population, and cancer survivors

Subscale	No.	Mean (SD)	Norm (SD)*	Cancer survivors (SD)*
Interest	61	1.0 (1.3)	3.73 (1.33)	3.62 (1.30)
Desire	60	1.2 (1.6)	4.67 (1.12)	3.93 (1.66)
Arousal	60	0.8 (1.4)	2.69 (0.87)	2.12 (1.24)
Orgasm	62	1.2 (1.5)	5.46 (0.88)	4.32 (2.27)
Satisfaction	57	1.1 (1.7)	4.20 (1.12)	3.52 (1.62)
Activity	61	1.0 (1.3)		
Masturbation	61	0.4 (1.0)	1.96 (1.65)	1.55 (1.41)
Relationship	51	2.1 (1.8)	4.19 (1.47)	3.27 (2.06)
Medical Impact	57	2.2 (1.4)	3.40 (1.35)	2.49 (1.68)
Problems-women	61	3.5 (1.4)	5.40 (0.68)	5.19 (0.95)
Overall score	62	1.5 (1.0)	3.93 (0.80)	3.23 (1.24)

*Values extracted from 2000 publication by Syrjala et al.[15]

Theme 5: Emotional Responses

All focus group participants discussed feelings of guilt, grief, resentment, anxiety, and fear surrounding sex. Common topics of the discussion were the guilt that surrounded not feeling sexual toward their husbands and grieving the loss of their sexuality. For example, Joanne [age 59] spoke to the "fear of having to admit that you don't have any sexual feelings" and grieving that aspect of herself. 1 participant remarked that she felt resentment toward her husband for "not being as understanding as he might be." Anxiety and fear were linked to the pain experienced during sexual intercourse. As a result, these women would avoid intimate touching in fear that it would lead to sex.

Theme 6: Coping Strategies

The final theme that emerged from the focus group was how the women coped with the sexual difficulties they were experiencing. Joanne [59] discussed maintaining intimacy with her husband through nonsexual touching such as him caressing her face and feet. Books, support services, counseling, and physical activity were reported by these women as positive factors that helped them regain some of their sexuality. Maggie [age 51] underwent some mindfulness therapy and discussed the resulting benefits of getting back in touch with her body and recovering some of her sexual feelings.

DISCUSSION

Taken together, our study participants reported that ovarian cancer resulted in both sexual difficulties and body image concerns. They also reported low levels of relationship satisfaction, poor quality of life, and higher rates of depression compared with the general population and published normative data. One-quarter reported clinically significant levels of sex-related distress. Communication from healthcare providers about the potential implications of ovarian cancer and its treatment on sexual functioning was identified as lacking.

Previous studies support our findings that survivors of ovarian cancer report a poorer quality of life than the general population

Table 6. Participants scores and population norms from the 36-Item Short Form Health Survey

Subscale	No.	Mean (SD)	Women 45–54*	Women 55–64*	Long-standing illness*,†
Physical functioning	63	48.5 (36.3)	84.8 (18.3)	74.8 (23.5)	78.3 (23.2)
Role limitations—physical	63	25.0 (40.9)	82.4 (32.0)	76.6 (36.9)	71.9 (38.9)
Role limitations—emotional	63	36.5 (44.7)	80.8 (33.6)	83.3 (32.5)	76.3 (36.4)
Energy/fatigue	63	51.6 (17.6)	59.4 (20.3)	59.0 (21.4)	54.1 (21.0)
Emotional well-being	63	57.5 (20.2)	73.2 (18.2)	74.4 (18.5)	54.0 (21.1)
Social functioning	63	57.9 (23.6)	87.0 (20.8)	85.9 (22.6)	80.2 (24.8)
Pain	63	77.4 (28.6)	77.4 (22.3)	75.0 (25.1)	69.8 (25.4)
General health	63	65.2 (16.1)	73.1 (19.9)	68.0 (22.0)	60.8 (23.0)

*These values are population norms published by Jenkinson et al.[50]
†These values are derived from both men and women with a long-standing illness.

based on the EORTC QLQ-C30 assessment.[24] Although there are many factors that may cause our participants to experience a poorer quality of life, it is likely, based on the gravity of their qualitative narratives, that impairments in sexual function may have directly contributed to their lower overall quality of life. Further studies sampling both the general population and ovarian cancer survivors simultaneously are required to control for population and sampling techniques that could account for group differences.

Both the lower DAS scores compared to available population-based data, and women's qualitative experiences during the focus group pointed to the impact of ovarian cancer on relationship satisfaction. Ovarian cancer impacts relationship satisfaction and can lead to a fear of engaging in intimate touch. This finding mirrors the findings from a qualitative study by Juraskova et al[6] that looked at the dynamics of sexual adjustment and quality of life in survivors of cervical and endometrial cancer. Survivors expressed a need to provide their partner with sexual intercourse despite their own difficulties.[6] Sexual issues caused by gynecologic cancer are not often discussed or expressed within relationships,[6] which was also borne out in the focus group. Open communication between partners can prevent or lessen the idea that sex is a duty and is an important mediating factor for resuming sexual interaction.[6] Counseling may be a useful resource for couples navigating this challenge and was mentioned in our survivors' narratives.

Participants were found to have poorer sexual function on all scales relative to the general population and other cancer survivors.[15] However, the cancer survivors included in available published data were women with a history of hematologic, not gynecologic, cancer. Thus, due to the many differences of these cancers in location, symptoms, and treatment, it is not unexpected that ovarian cancer survivors would have greater sexual side effects. This was similarly seen in a previous study that showed that ovarian cancer survivors experienced greater dysfunction and lower frequency of sexual activity than breast cancer survivors.[16] Hysterectomies performed for benign causes do not result in the same negative sexual side effects compared with malignancy, but whether oophorectomies for benign versus malignant causes have different sexual implications is less clear. Future research is needed to address this question.[13,25]

A systematic review determined that, of 34 studies, more than half of them identified pain as a significant deterrent from participating in sexual activities.[26] Compared with healthy postmenopausal women and breast cancer survivors, ovarian cancer survivors experience the greatest problems with loss of desire and sexual discomfort, which leads to greater reductions in sexual activity.[16] Our findings mirror this as participants reported pain and its effects on their sexuality. Moreover, the fact that a quarter of our participants reported levels of sex-related distress in the upper range suggests that the sex-related distress experienced by ovarian cancer survivors is higher than that in women from the general population. Offering resources and support for women with ovarian cancer can greatly improve their quality of life, assist them with the difficulties of cancer, and help them reconnect with their bodies, as has been found following mindfulness training for gynecologic cancer survivors.[27]

Changes to orgasm in ovarian cancer survivors was noted by our sample and is well documented in the literature with 75% of survivors reporting problems reaching orgasm.[16] Decreased frequency and intensity of orgasm are consistent challenges faced by women who have undergone treatment for ovarian cancer.[28,29]

Liking the appearance of one's body is a significant predictor of sexual functioning in ovarian cancer survivors.[16] In both qualitative and quantitative studies, body image has been highlighted as playing a significant role in sexual activity.[6,30] Surgical staging and cytoreduction is often the first step in management of ovarian cancer. The initial surgery, as well as any repeat surgeries for intra-abdominal adhesions or recurrence of disease, can leave a patient's body with substantial scarring depending on the approach. This accompanied by hair loss and the removal of reproductive organs can leave a woman feeling negatively about her body and sometimes patients may experience a loss of sense of self. Studies have demonstrated that after surgery, measures of body image, self-confidence, and attractiveness greatly reduce compared with before surgery.[31] These trends were borne out in our focus group and point to the need for healthcare

professionals' need to evaluate body image and ensure that their patients are receiving adequate psychological care.

As the women in this study reported, conversations with healthcare providers about sexual functioning are extremely important. According to Stead and colleagues,[10] who conducted semi-structured interviews to investigate this, only one-quarter of physicians and one-fifth of nurses discussed sexual issues with patients. This was despite the fact that most healthcare professionals expected women to experience sexual problems.[10] Healthcare professionals perceived that they should wait until the patient asked them about sex and that it was not their responsibility to broach the topic.[10] When women were asked what they would have liked to have been told, they reported wanting to know what sexual changes were normal, what changes to expect, and to be reassured that intercourse was safe. This lack of information further compounds survivors' difficulties and hinders a return to "normal" sexual functioning.[32]

The side effects that accompany ovarian cancer treatments include dyspareunia (pain with intercourse), reduced libido, decreased lubrication and sensation, premature menopause, loss of fertility, shortening of the vagina, and reduced vaginal elasticity.[30,32–35] These physical side effects have psychological and emotional consequences for women, such as fearing sexual encounters, feeling guilty about their lack of sexual desire, and resenting their partner as reported by focus group participants.

Compared with the 19.8% of an unselected adult population, 37.5% of our study participants were found to have mild to severe depression based on their BDI scores.[36] Ovarian cancer survivors have been found to have significantly higher BDI scores and rates of moderate or severe depression than the general population.[36,37] Women experiencing depression also have a much greater likelihood of reporting sexual problems than non-depressed women.[22,38] Carmack Taylor et al[16] found depression to be negatively correlated with sexual satisfaction and frequency, although positively correlated with discomfort during intercourse. Higher BDI scores have also been associated with increased genital pain, poorer relationship adjustment, and higher rates of sexual distress.[27] Interestingly, Brotto et al[27] found that women who initially had higher levels of depression were more likely to experience an improvement in their quality of life in response to psychoeducational sex therapy. Given that our study participants and other survivors of ovarian cancer have elevated rates of depression, we would advocate for psychoeducational therapy that addresses both mood and sexual health.

As far as we are aware, this is the first study to look at sexual experience and quality of life in ovarian cancer survivors through combined qualitative and quantitative methods. This combined approach has been suggested to be a more appropriate way to evaluate a woman's sexual experience than either methodology on its own.[39] Previous studies have examined the perceptions of patients with ovarian cancer regarding changes in their sexual experiences, as well as specific factors that may directly influence a person's sexual activity, but none have used qualitative and quantitative measures in the way this study has.

Our study has several limitations that are important to note. This study was of cross-sectional nature, and we did not have an age-matched control group. We relied on general population standards to compare with our study population limiting the conclusions and comparisons we could make. Nonetheless, there are ample population-based data from normative samples on the endpoints of interest. Participants were recruited through paper and online advertisements, ovarian cancer support groups, and hospital clinics. It is possible that there is some selection bias in our study due to our recruitment techniques. Our methodology of relying on self-reporting medical information did not allow us to verify the precise cancer stage and grade or type and duration of treatment received, and we relied on women's self-reports. In future studies, we would attain patients' and ethics approval to gather medical information directly from their charts. Furthermore, our focus group was small due to geographic and scheduling barriers that accounted for most women from phase 1 not being able to participate in phase 2. We cannot rule out the possibility that the sensitive nature of the group questions may have posed a barrier, and it may be that one-on-one interviews may have been preferable to probe these aspects of women's experiences. Despite the focus group size, the participants' stories fully supported and provided additional nuance to the quantitative findings observed.

An error in the online data collection resulted in age being missing for most of our participants. A previous study looking at distress in ovarian cancer patients found that younger women and women with recurrent disease were more likely to participate thus making their findings less applicable to those who are older and who are in the early stages of their disease.[37]

CONCLUSION

This study highlights the importance of sexuality in quality of life and the impact that ovarian cancer may have on a woman's sexual experience. Both the quantitative and qualitative phases pointed to poorer quality of life among ovarian cancer survivors. They also had relatively lower levels of relationship satisfaction, higher rates of sexual dysfunction and sexual distress, and increased rates of depression relative to the general population. It is important to note that we cannot make any statistical comparisons between these groups due to the nature of this study, but we hope that these findings will help pave the way for future studies and other study designs to address these important issues. These findings call out the need for healthcare professionals to prepare ovarian cancer survivors for possible changes in sexual function, and provide an opportunity for women to ask questions, and seek psychoeducational support throughout their ovarian cancer journey.

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