Women's Experiences After Ovarian Cancer Surgery: Distress, Uncertainty, and the Need for Occupational Therapy

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Importance: Despite the growing literature on the association of functional, physical, and quality-of-life (QOL) deficits with poor postoperative outcomes, there is a gap in the literature identifying women's occupational performance needs after ovarian cancer surgery.

Objective: To describe the experiences of women hospitalized after ovarian cancer surgery to identify potential areas for intervention. Goals were to (1) identify functional needs and limitations at time of discharge as measured by the typical acute care occupational therapy evaluation and semistructured interview and (2) understand the women's perspectives of their needs for occupational therapy and a safe return to home.

Design: Single-arm, cross-sectional descriptive study. Mixed-methods data collection and analysis.

Setting: Academic cancer center.

Participants: Women with ovarian cancer ($N = 11$) who had completed surgery.

Intervention: Semistructured interviews and patient-reported outcome measures (PROMs) completed postsurgery.

Outcomes and Measures: PROMs included the National Comprehensive Cancer Network (NCCN) Distress Thermometer and Problem List, the PROMIS® Global Physical Health (GPH) and Global Mental Health (GMH) scales, and the Possibilities for Activity Scale–Women (PActS–W).

Results: The mean NCCN Distress score was 6.0 (standard deviation [SD] = 3.1, with the top three concerns being pain (80%), worry (80%), and fatigue (78%). Mean GPH and GMH T scores were 38.0 ($SD = 8.8$) and 48.2 ($SD = 8.4$), respectively. Women scored a mean of 39.2 ($SD = 11.2$, range = 26–58) on the PActS–W. Thematic analyses found that the women were uncertain about potential functional limitations and significantly distressed.

Conclusion and Relevance: Women with ovarian cancer experienced high levels of uncertainty and distress after surgery. Integrating in-home or community-based occupational therapy into routine care could decrease functional distress and uncertainty and help women manage concerns related to pain, worry, and fatigue.

What This Article Adds: This study suggests that occupational therapy evaluation and intervention are needed to decrease distress and improve QOL of women upon discharge after ovarian cancer surgery.

Ovarian cancer is the eighth most common cancer type in the United States and the fifth leading cause of cancer death for women (Centers for Disease Control and Prevention, 2017). The primary treatment modality for ovarian cancer is surgery, followed by adjuvant chemotherapy. Surgery is often radical; rates of postoperative morbidity are 20%–30%, and rates of hospital readmission are 10%–15% (Wright, Herzog, Neugut, et al., 2012; Wright, Herzog, Siddiq, et al., 2012; Wright et al., 2011). Women who rate their physical and functional quality of life (QOL) as low presurgery are more likely to have a difficult time recovering from their surgery (Doll et al., 2014). Despite the growing literature on the association of functional, physical, and QOL deficits with poor postoperative outcomes, there is a gap in the literature identifying the occupational performance needs for women after ovarian cancer surgery.

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Occupational performance, functional status, and QOL are modifiable and constitute the main goals of occupational therapy, yet the literature regarding occupational therapy after cancer surgery lacks in-depth qualitative research to determine a pragmatic and patient-centered approach to specific postoperative needs (Cheville & Tchou, 2007; Germain, 2007; Shin et al., 2011; Yadav, 2007). A growing number of studies addressing lifestyle intervention have focused on behaviors such as increasing physical activity, improving nutrition, and losing weight (Smits et al., 2015). Although addressing these lifestyle behaviors is important, many women still struggle with their basic activities of daily living after surgical intervention, which increases the risk of hospital readmission and lasting morbidity. Evidence supports the importance of postoperative cancer rehabilitation; however, referrals to cancer rehabilitation remain low, and women endure with many unmet needs (Waltke, 2014).

During and after cancer, treatment can disrupt simple daily activities and sometimes eliminate work and social outings because of increased symptoms such as pain or fatigue (Beck, 2003). Several randomized controlled trials with female cancer survivors support using an individualized exercise protocol to increase physical activity and address fatigue (Andersen et al., 2013; Namour et al., 2012; Stevinson et al., 2009). Despite the types of exercise programs available to women with cancer, there is widespread dissatisfaction with those services, and physical activity programs can be difficult to maintain (Dilworth et al., 2014; Dodd et al., 2010).

Women with ovarian cancer experience additional symptoms after surgery that can be addressed through occupational therapy. For example, many women begin menopause early, which potentially affects body image and sexual function (Buković et al., 2008). Health care providers rarely ask women about sexual activity, leading many women to erroneously believe that sexual intercourse and activity are physically harmful (Fitch, 2003). Several phenomenological studies have reported that women feel unequipped to address changes in their sexual function (Buković et al., 2008; Holm et al., 2012; Ponto & Barton, 2008). Women with ovarian cancer do not feel they receive enough support throughout their treatment (Ekwall et al., 2014). There is some evidence in support of occupational therapy professionals being equipped to evaluate and treat sexual function along with other participation restrictions potentially experienced by women with ovarian cancer (Hunter et al., 2017).

This study is the first to identify potential areas of remediation for functional limitations for postoperative women with ovarian cancer. This project collected data to design an evidence-based occupational therapy intervention that seeks to improve outcomes of patient function, QOL, and hospital readmission for this population. Our objective was to describe the experiences of women with ovarian cancer after surgery and before discharge to identify potential areas for intervention. Our aims were to (1) identify women's functional needs and limitations at the time of discharge as measured by the typical acute care occupational therapy evaluation and interview and (2) understand women's perspectives of their needs for occupational therapy and a safe return to home.

Method

Research Design

The current study was a single-arm cross-sectional descriptive study of 11 women with newly diagnosed ovarian cancer recovering from primary debulking surgery.

Participants

We recruited 11 women who had been diagnosed with ovarian cancer (including primary peritoneal and fallopian tube), who were hospitalized at the time of the study after ovarian cancer debulking surgery. Participants were older than age 18 yr and fluent in English. Exclusion criteria included women in intensive care, those who were deemed inappropriate for study by their primary surgeon, women with benign histology, and women who were pregnant. We collected

demographic and clinical data, including cancer site and stage, operative details, comorbid conditions, insurance type, self-reported race/ethnicity, and age. Ethical approval was obtained from the University of North Carolina institutional review board, and all women provided informed consent.

Data Collection

This mixed-methods study used functional assessments, structured surveys, and semistructured interviews to meet study aims. We used the National Comprehensive Cancer Network (NCCN) Distress Thermometer and Problem List to measure distress levels and perceived challenges. On the basis of a rating scale ranging from 0 to 10, scores of 4 or greater indicate significant distress (Carlson et al., 2012; Donovan et al., 2014; Jacobsen et al., 2005; Johnson et al., 2010). We used the Patient-Reported Outcomes Measurement Information System (PROMIS) Global Physical Health (GPH) and Global Mental Health (GMH) measures (Hays et al., 2009) to evaluate physical, mental, and social well-being. This 10-item questionnaire includes nine items ranked on a 5-point scale and an additional pain rating made on a 10-point scale. The PROMIS measures use *T* scores and are standardized to the U.S. general population with a mean of 50 and a standard deviation (*SD*) of 10 (Hays et al., 2009). Higher scores indicate a higher health-related QOL. Our final measure, the Possibilities for Activity Scale–Women (PActS–W), assessed activity expectations and self-efficacy (Pergolotti et al., 2019). This instrument yields scores ranging from 12 to 60, with higher scores indicating congruence between the two constructs. Each of these measures, although not typical occupational therapy assessments, relates to occupational therapy domains. For example, the NCCN Distress Thermometer and PROMIS global assessments relate to client factors, specifically body functions, both physical and mental, and the PActS–W relates to the client's social environment and cultural context (American Occupational Therapy Association, 2014). Interviews were audio-recorded and transcribed for analysis.

Data Analysis

Descriptive analysis was conducted with demographic data and for all structured surveys. Occupational therapy evaluations, formatted as semistructured interviews, were analyzed using an inductive thematic analysis to better understand the experiences of these women after surgery. Two authors (Bailliard and McCarthy) completed the qualitative analysis process separately, with a period of peer debriefing.

Results

Demographics

Study participants were 11 women with an average age of 63 yr (range = 45–74). The sample's racial profile was 81.8% White and 18.2% Black. Interviews were completed between 2 and 8 days after surgical intervention at a large tertiary care women's hospital.

Functional Challenges After Surgery

Women reported challenges in most categories on the NCCN Problem List in the week after surgery (Table 1). They reported concerns with 33 of the NCCN's 38 different problem areas. Most women reported distress regarding physical and emotional problems. The top five problem areas reported by participants were pain (80%), worry (80%), fatigue (78%), fears (73%), and nervousness (70%; see Table 1 for more details). Mean PROMIS GPH and GMH scores were 38.0 (*SD* = 8.8, range = 19.9–47.7) and 48.2 (*SD* = 8.4, range = 31.3–56.0), respectively, indicating that many participants scored more than 1 *SD* below the general population on physical health categories. Women had a mean score of 39 (range = 26–58) on the PActS–W, indicating lower congruence between activity expectations and self-efficacy (what women feel like they should be and could be doing). Higher scores are significantly correlated with QOL (Pergolotti et al., 2015).

Table 1. Percentage of Women Reporting Distress Problems on the NCCN Distress Thermometer and Problem List for Patients, by Type and in Order of Concern ($N = 11$)^a

Problem	%
Practical problems	
Treatment decisions ^b	55
Insurance/financial	45
Work/school	45
Transportation	18
Child care	9
Housing	9
Family problems	
Family health issues	36
Dealing with partner	10
Dealing with children	0
Ability to have children	0
Emotional problems	
Worry ^b	80
Fears ^b	73
Nervousness ^b	70
Sadness ^b	60
Depression ^b	55
Loss of interest in usual activities	36
Spiritual/religious concerns	11
Physical problems	
Pain ^b	80
Fatigue ^b	78
Eating ^b	70
Breathing ^b	70
Sleep ^b	60
Appearance ^b	60
Skin itchy/dry ^b	56
Feeling swollen ^b	56
Bathing/dressing ^b	56
Nausea ^b	55
Changes in urination ^b	55
Constipation ^b	55
Memory/concentration ^b	50
Getting around	40
Tingling in hands/feet	40
Nose dry/congested	40
Indigestion	30
Diarrhea	18
Fever	0
Mouth sores	0
Sexual	0

Note. NCCN = National Comprehensive Cancer Network.

^aSome categories had missing data due to nonresponse, as follows: $N = 10$: dealing with partner, worry, nervousness, sadness, pain, eating, breathing, sleep, appearance, bathing/dressing, memory/concentration, getting around, tingling in hands/feet, nose dry/congested, indigestion; $N = 9$: spiritual/religious concerns, feeling swollen; $N = 8$: fatigue, skin itchy/dry.

^bMore than 50% of the sample reported distress with this symptom.

Uncertainty in Functioning

Although participants identified specific areas of concern in the days after surgery, they reported high uncertainty regarding their functional needs during interviews. One participant said, “I don’t know how much of that I’m going to be able to do . . . I don’t know the answer to that.” Like other women in the study, this participant was unable to assess whether she could carry out personal care needs. Although a few women indicated that they were able to move with assistance, they reported difficulty imagining what life would look like outside of the hospital:

The way you feel before surgery is very different from the way you feel after surgery. . . . You go in hoping you can do everything. And when you get at this stage, I have no idea what I’ll be able to do. I imagine I might be able to do everything. Or not.

At the time of their interviews, women were undergoing immense changes and were unable to assess their functional limitations.

Emotional Distress and Uncertainty

Women experienced significant emotional distress following their diagnosis of ovarian cancer. The mean NCCN Distress score was 6.0 ($SD = 3.1$) at the time of interview, which indicates moderate distress levels when compared with the cutoff score of 4 (Donovan et al., 2014). Recovering from a radical surgical intervention and a diagnosis of ovarian cancer was overwhelming: “You hear the ‘C’ word and you automatically start thinking life as you know it is over.”

Participants experienced a rapid journey to surgery and reported learning of their respective cancer diagnoses only days to weeks before surgery. One woman reported noticing symptoms 2.5 wk before the surgery. She noted, “A week after [the computed tomography scan] I was having surgery. And I have cancer. I mean, it was just that fast. So, it’s been a lot to process. It has been a lot to take in.” She had not had a chance to reflect on her new diagnosis and what it meant for her future. Later during the interview, she elaborated,

I think I can [associate] ovarian cancer with death. Because it is one of the worst cancers a woman can get, from what I understand. And when I heard it, it was like, ovarian cancer, [I thought] I probably have maybe a couple of years.

Discussion

This study demonstrates that women report high levels of distress and uncertainty associated with multiple functional or physical and emotional domains after ovarian cancer surgery. There is a major gap in rehabilitative research focused on women with gynecological cancers, and evidence to support best practices in cancer

rehabilitation to address the numerous needs of this population is insufficient (Stout et al., 2018). A better understanding of the experience of women with gynecological cancers to develop targeted, evidence-based interventions that meet real-world needs is imperative. The physical, social, and emotional problems and the distress and uncertainty reported by this population regarding their functional abilities can be addressed by occupational therapy and fall within the profession's scope of practice.

With regard to functional abilities, the women in this study expressed distress regarding their ability to complete basic and instrumental activities of daily living (IADLs). Occupational therapy can help women with cancer problem solve the challenges of daily life, including work, IADLs, and physical activity (Lyons et al., 2015; Maher & Mendonca, 2018). Given the profound uncertainty at the time of hospital discharge that was expressed during the interviews, these findings highlight the need to integrate in-home or community-based outpatient occupational therapy into routine care for postoperative ovarian cancer patients.

On average, women after gynecological surgery reported levels of physical health at least 1 *SD* below the general population. Zhou et al. (2016) found that in some women, levels of physical- and mental-health-related QOL rebounded 1 yr after treatment. However, persistent low levels of physical QOL were associated with poor outcomes of disease recurrence and heavy symptom burden. Early intervention with occupational therapy in the home or community setting could mitigate loss of functional ability and improve QOL.

Poor physical QOL may also be compounded by a loss of control after diagnosis (Brown et al., 2015). How women perceive their possibilities for activity and what they feel that they should or could be doing are targets for occupational therapy. In our sample, women reported low levels of congruence between what they felt was expected and their confidence to participate in those activities. This could be related to the sense of loss of control in addition to their new cancer diagnosis. A woman's perception of a lack of congruence between what she thinks she can do and what she is expected to do could potentially lead to restriction in participation in meaningful activity (Pergolotti et al., 2015), resulting in a decrease in QOL.

The women in this study reported severe levels of distress and numerous problem areas. Understanding the underlying mechanisms of this distress is important to inform the development of interventions that can target this important area. Unmet needs are strongly correlated with decreased QOL and psychological distress (Butow et al., 2014; Carlson et al., 2012; Sleight & Duker, 2016); however, population-based studies have demonstrated that, among patients with gynecological cancers, one-third need physical rehabilitation and one-third need psychological rehabilitation (Holm et al., 2012). This is consistent with our findings of severe distress and uncertainty regarding future needs. Without community- and home-based occupational therapy evaluation, these needs will likely remain unidentified and unmet by medical care.

Occupational therapy professionals have the ability to spearhead the movement to address the unmet needs of women with ovarian cancer and maximize physical and psychosocial function in their environment and context (Alfano & Pergolotti, 2018; Pergolotti et al., 2016, 2017). By incorporating comprehensive occupational therapy services with goals of targeting participation in meaningful activity and functional psychosocial domains, women may improve their QOL, leading to potentially improved oncology outcomes and lower cost and health care use overall.

As shown in our study, women with ovarian cancer experience serious distress and uncertainty after surgery. This is similar to survivors of other cancers for which postoperative distress can be concerning (Hoffmann et al., 2017; Mitchell et al., 2011); however, women with ovarian cancer experience distress at significantly higher levels than women without cancer (Watts et al., 2015). Because these issues can continue past the active treatment phase (Werner et al., 2012), identifying and addressing them early in treatment is imperative. For example, sexual dysfunction can be highly distressing for women after treatment of ovarian cancer, yet preliminary data suggest that sexual dysfunction can be treatable with rehabilitation (Bober et al., 2018). Although the women in our sample did not report sexual dysfunction

right after surgery, we recommend that occupational therapists still ask women about sexual health. Occupational therapists must collaborate with oncology care clinicians to solicit adequate referrals and to advocate for the provision of their services to women after gynecological surgery (Silver et al., 2013). By working to integrate holistic in-home or community-based outpatient services, occupational therapists can focus on identified areas of pain and fatigue while resolving the distress and uncertainty with functional ability.

Limitations

The small sample size of 11 mostly White women limits the strength and generalizability of our quantitative survey-based findings; however, our interview results are robust and further support the current literature on the effects of an ovarian cancer diagnosis and treatment. This study was carried out in one cancer center in a larger southeastern medical institution, which also limits generalizability.

Future Research

Despite limitations, the results of this study suggest that support is needed for evaluating these women on their return to their home environment to decrease distress and improve QOL. Larger sample sizes with more diverse populations are needed to fully understand the experience of women after ovarian cancer surgery and to develop comprehensive interventions. Although women reported mixed results regarding functional needs, it was clear that they were unsure of what they would or would not be able to do after hospital discharge and thus were highly distressed. Further research in the home environment and in community-based settings is warranted so that we can gain a better understanding of the needs of this population. With a better understanding of women's functional needs, it will be possible to build an evidence-based occupational therapy intervention program to best support them.

Implications for Occupational Therapy Practice

The emergent themes and supporting evidence developed throughout this study demonstrate the complex nature of these women's experiences. Our findings suggest incorporating psychosocial concerns into occupational therapy evaluation and intervention models to better serve this population. Problems such as pain and fatigue can cause severe restriction in participation and affect QOL (Hwang et al., 2016; Maher & Mendonca, 2018). Early intervention and interdisciplinary collaboration are imperative to best serve this population (Alfano & Pergolotti, 2018).

The results of this study have the following implications for occupational therapy practice:

- Women with ovarian cancer may have severe levels of distress after primary surgery, with problems in physical, practical, and emotional areas.
- Women reported experiencing uncertainty about their ability to take care of themselves after surgery and throughout treatment.
- Occupational therapy interventions can help address patients' distress and uncertainty.

Conclusion

This mixed-methods descriptive study shows that women report high levels of distress and uncertainty about their functional ability when they return home after ovarian cancer surgery. Previous studies have focused on the need for physical and psychological rehabilitation (Holm et al., 2012). These findings add to the literature while highlighting and shedding light on potential opportunities for occupational therapy evaluation and interventions that are needed to support women after ovarian cancer surgery. ■

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