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Patients with advanced ovarian cancer and their experiences and perceptions of sleep disturbance and fatigue across the treatment trajectory: A qualitative study

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HIGHLIGHTS

- Patients with advanced OC described their sleep disturbance & fatigue as intense, which negatively impacted their HRQoL.
- Patients experienced qualitatively different types of fatigue & sleep disturbances across the treatment trajectory.
- Sleep disturbance & fatigue were most intense & periodic during chemotherapy, & less intense but persistent during maintenance.
- Increased communication, fatigue & sleep disturbance screening, and scaled interventions for symptom management are needed.

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ABSTRACT

Objective. Sleep disturbance and fatigue are prevalent among patients with advanced ovarian cancer (OC) and associated with poor health-related quality of life (HRQoL). This study aimed to illustrate the lived experiences of OC patients with sleep disturbance and fatigue and the range of factors that they perceive as contributing to these symptoms.

Methods. Individual semi-structured interviews were conducted with twenty patients with Stage III and IV OC diagnosed and treated within three years (17/20 receiving treatment). Interview transcripts were analyzed based on emergent themes in the data and study goals.

Results. Participants reported high levels of sleep disturbance and fatigue, which interfered with their cognitive, social, and physical function. The nature of their sleep and fatigue issues varied across the treatment trajectory. The majority (16/20) used chemotherapy as a benchmark to assess their current symptom burden. Fatigue and sleep disturbance were described as more intense and cyclic, with the highest symptom burden immediately following chemotherapy infusions followed by periodic improvement between treatments, whereas symptoms were less intense, but more persistent during maintenance therapy. Participants pursued a variety of strategies to manage symptoms, but fatigue persisted among thirteen of twenty participants. Participants were dissatisfied with providers' lack of communication and recommendations to manage symptoms.

Conclusion. Findings underscore that while sleep disturbance and fatigue are intense among participants with OC, the lived experiences of these symptoms are qualitatively distinct at different points during treatment. Participants' dissatisfaction with providers' communication suggests the need for improved screening and scaled interventions for advanced OC patients.

1. Introduction

Sleep disturbance and fatigue are among the most common and distressing symptoms reported by cancer patients [1,2]. Sleep disturbance encompasses a range of behaviors, including difficulties falling

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and staying asleep, waking earlier than normal, and experiencing non-restorative sleep or excessive daytime sleepiness [3]. Fatigue refers to persistent, intense feelings of tiredness or exhaustion that are not relieved by rest [4]. Sleep disturbance and fatigue are both associated with poorer health-related quality of life (HRQoL) and distress [2,5], as well as increased anxiety, depression, and poor health outcomes [6–11]. The National Comprehensive Cancer Network (NCCN) [4] recommends that oncologists screen for symptoms, including sleep disturbance and fatigue, before, during and after treatment, typically using brief (1–2 item) screening instruments.

Most patients with gynecological cancers experience some degree of sleep disturbance and fatigue following diagnosis. More than 86 % of patients with gynecologic cancers reported clinically significant fatigue during treatment, and this fatigue remained moderate-to-severe in 57 % of survivors after treatment [12,13]. Similarly, Webber et al. [14] found that 60 % of survivors of ovarian cancer (OC) report significant fatigue two years after chemotherapy completion. Eighty percent of patients with gynecologic cancer reported significant sleep disturbance as well [1,9,15]. Among patients with OC, the release of inflammatory cytokines from the tumor is associated with sleep disturbance and fatigue [16], and treatment can disrupt the hypothalamic-pituitary-adrenal (HPA) axis and activate the nervous system [17,18]. Psychosocial distress about diagnosis and treatment can exacerbate the disruptions to the HPA-axis and inflammatory cytokine release, worsening sleep disruptions and fatigue [19,20].

Extant research predominantly examines sleep disturbance and fatigue at key treatment milestones, such as immediately following chemotherapy [13], after surgery [11], or when taking oral poly ADP-ribose inhibitor (PARPi) maintenance therapy [15]. However, it remains unclear how patients with advanced OC experience sleep disturbance and fatigue across the treatment trajectory. Recent studies show that patients' sleep disturbance levels vary by the time since treatment [9], and fatigue experiences differ from chemotherapy during maintenance therapy [15]. Patients taking PARPi reported milder fatigue as compared to chemotherapy, but their fatigue continued to limit their daily activities [15]. This study expands upon prior work by illustrating how patients' perceptions and experiences of sleep disturbance and fatigue vary across their treatment trajectory.

2. Data and methods

The study aimed to assess OC patients' lived experiences and perceptions of sleep disturbance and fatigue using individual, semi-structured interviews with 20 patients diagnosed with OC. Inclusion criteria included: 18 years of age or older, residing in the U.S., English fluency, and receipt of a diagnosis of stages III or IV OC within the past three years. During semi-structured interviews, participants were asked to describe their sleep disturbance and fatigue experiences prior to diagnosis, during each phase of treatment, and following treatment using open-ended questions with specific probes to examine the intensity and impact of symptoms. Interviews were conducted by study team members (EA and AN) on Zoom between December 2022 and January 2023.

2.1. Recruitment and sampling

Participants were recruited from a national network of patient advocacy partners, including the Ovarian Cancer Research Alliance (OCRA), UniteForHer, and affiliated Cancer Support Community locations via support groups, digital communities, and direct outreach. Multiple recruitment partners and communication channels were leveraged to maximize the sociodemographic and clinical diversity of the sample. Interested patients were sent an electronic informed consent form to complete, describing the study's goal as understanding sleep disturbance and fatigue experiences among patients with OC, followed by a survey used to determine eligibility, collect sociodemographic and clinical information, and assess current levels of sleep disturbance and fatigue using 1) PROMIS Sleep Disturbance – Short Form (SF) 8b; and 2) PROMIS Fatigue – Short Form (SF) 8a. PROMIS SFs have been used to assess sleep and fatigue across several disease contexts, including oncological settings [21] and ovarian cancer [22]. Participants' responses were used as baseline measures of sleep disturbance and fatigue and compared to open-ended responses during semi-structured interviews. PROMIS SF raw scores were converted to T-scores based on the general population mean of 50 (standard deviation, SD = 10) [23], with higher scores indicating worse symptoms.

Sixty-four eligible participants completed the screener survey. To maximize diversity, we employed purposive sampling to invite twenty-four participants for individual interviews who varied in five characteristics: 1) stage at diagnosis, 2) treatment types received, 3) race/ethnicity, 4) geography, and 5) socioeconomic status (household income & education). To minimize selection bias, participants' responses to sleep and fatigue items were not used to select interview participants. Among the twenty-four invited to participate, twenty-four participants completed interviews. The goal of qualitative sampling is to include a sample large enough to assess variability and small enough to allow for in-depth analysis of each case [24]. Thematic saturation was reached at 20 interviews, in which no new themes were identified.

2.2. Analytic strategy

Interviews were transcribed verbatim and de-identified before being imported into *NVivo 14* software for analysis. Data were analyzed using an iterative deductive-inductive approach. Deductive codes were developed using a combination of study goals and extant literature, and inductive codes were developed based on emergent themes from the data. During open coding, a codebook was developed, including name, definition, and exemplar quotes, which was reviewed and finalized by two team members (EAJ & AN) [25]. Team members engaged in axial coding to assess the relationship between codes [26]. Interrater reliability was measured using Cohen's kappa coefficient to calculate the proportion of agreement in coding as approximately 92 %. A list of the most prevalent codes and exemplar quotes are summarized in Table 2. Each participant was assigned a pseudonym to protect their anonymity. Pseudonyms were selected based on first names popular during their birth year and among their racial and ethnic group to provide relevant sociodemographic context about participants' identities and experiences, which are obscured by assigning participants numbers or codes [27,28].

3. Results

Most interview participants were diagnosed with Stage IV disease (12/20); ten were in active treatment, seven receiving maintenance therapy, and three had completed treatment at the time of interview. Participants' average age was 57 years old (range: 37–72) (*See* Table 1 *for participant characteristics*). Participants were White, non-Hispanic (14/20), Hispanic or Latina (3/20), Black or African American (2/20), or multiple races (1/20). Eight had a graduate degree, six had a college degree, and six had less than a college degree. Six were working for wages, seven were receiving disability, and six were not working because they were retired or not looking for work. Seven earned less than $59,000 a year.

3.1. Screener responses among interview participants

Participants reported elevated levels of sleep disturbance and fatigue when completing the screener survey for the study. The mean PROMIS Fatigue T-score was 58.03 (SD = 2.91), indicating significantly more fatigue than the population mean ($t = 2.76$, $p = .007$), and half (10/20) of participants were more than one standard deviation above the

Table 1
Participant Characteristics at Interview.

	n (%)		n (%)
Race & Ethnicity		*Treatment Status*	
Black or African American	2 (10)	Active treatment	10 (50)
Latino or Hispanic	3 (15)	Maintenance therapy	7 (35)
Multiple races	1 (5)	Completed Treatment	3 (15)
White	14 (70)	*Stage at Diagnosis*	
Education		III	10 (50)
Less than a college degree	6 (30)	IV	8 (40)
College degree	6 (30)	Don't know / Unsure	2 (10)
Graduate degree	8 (40)	*Recurrence*	
Employment Status		Once	10 (50)
Working	6 (30)	Twice	2 (10)
Disabled	7 (35)	Never / Don't know	8 (40)
Retired	4 (20)	*Time since diagnosis*	
Not working	2 (10)	Diagnosed <1 year ago	2 (10)
Prefer not to share	1 (5)	Diagnosed between 1 and 2 years ago	9 (45)
Household income		Diagnosed between 2 and 3 years ago	9 (45)
<$20 k-$59 k	7 (35)	*Treatment types**	
$60 k-$99 k	4 (20)	Surgery, chemo	3 (15)
$100 k to $139 k	2 (10)	Surgery, chemo, PARPi	3 (15)
>$140 k	5 (25)	Surgery, chemo, PARPi[1], VEGF[2]	4 (20)
Prefer not to share	2 (10)	Surgery, chemo, PARPi, VEGF, others	3 (15)
Age range:	38–72	Surgery, chemo, VEGF, others (no PARPi)	7 (35)
Mean:	57.1		

N = 20; "Other" treatment types include hormone therapy, immunotherapy, other targeted therapy, or therapy as part of a clinical trial.
[1] poly-ADP ribose inhibitor (PARPi)
[2] Vascular endothelial growth factor (VEGF)

population mean. Participants' mean Sleep Disturbance T-scores was 57.57 (SD = 1.57), significantly higher than the general population ($t = 4.83$, $p = .0001$), and nine participants' scores that were more than one standard deviation above the mean.

3.2. "It felt like a constant anxiety that I wasn't going to be able to be well-rested.": Sleep Disturbance and Distress

All participants reported intense sleep disturbance and fatigue, which severely limited their activities of daily life, including completing household chores (17/20) and workplace productivity (5/6 among those working); sleep disturbance and fatigue also generated emotional distress (18/20) and disrupted social relationships (15/20). Participants described their sleep disturbance as difficulty staying asleep (14/20), trouble falling asleep (13/20), not getting restorative sleep (12/20), and not getting enough sleep (10/20). Sleep disturbance generated high emotional (13/20) and social (11/20) distress. Even those who had completed treatment (3/20) reported that sleep disturbance and fatigue negatively impacted their daily lives while receiving treatment for OC and these symptoms continued into survivorship. Participants reported added pressure to get quality sleep because they felt that rest was crucial to their recovery:

> "I would sleep for about 3 hours, and then wake up and go to the bathroom, so I was feeling really exhausted and also anxious about not getting more sleep... it felt like a constant anxiety that I wasn't going to be able to be well-rested."- Amy, a 49-year-old White woman with Stage IV OC, receiving chemotherapy at the time of interview; previously received surgery, chemotherapy, PARPi maintenance therapy.

In turn, participants' distress about their poor sleep quality interfered with their ability to have restorative sleep. Sleep disturbance also contributed to social toxicity by reducing their physical and emotional energy to socialize and increasing their irritability and interfering with participants' social relationships:

> "I was never [alone] in my house like I am now. I can't go out because I snap at people. I don't want to be around people because I don't sleep... I can't do anything [with other people] – and that, for me, is really hard." - Angie, a 51-year-old White woman with Stage IV OC, completed treatment; received surgery and chemotherapy.

3.3. "I'm pretty much tapped out for the day by 5 or 6 o'clock": Emotional and Cognitive Fatigue

All participants reported intense fatigue that significantly curtailed their ability to complete activities of daily living (ADLs), including household chores and paid work. Seventeen of 20 participants described their fatigue as persistent, debilitating physical exhaustion, but participants also described fatigue as emotionally (7/20) and cognitively (8/20) draining:

> "Coming home [from work] and even just making dinner takes a lot out of me. Before, I used to just make dinner and do the dishes and be fine. [Now] if I'm making a family meal... I have to stop and take a break because I get tired, and then it's bedtime, and then first thing in the morning, I'm already feeling drained." - Elena, a 41-year-old Hispanic woman with Stage III OC, receiving chemotherapy at the time of interview; previously received surgery, chemotherapy, vascular endothelial growth-factor (VEGF) inhibitor therapy, and other targeted therapies.

Fatigue also contributed to a mental fog for participants that limited their productivity in the workplace. One participant was forced to work part-time due to cognitive fatigue they attributed to chemotherapy they had completed six months prior:

> "I think [my] fatigue and brain fog make it hard to do the thought work I do, so it's been tough, and I'm only working part-time now... By the afternoon I'm dragging and a lot of time, I'll nap... I'm pretty much tapped out for the day by 5 or 6 o'clock." Jamie, a 38-year-old non-binary person with Stage III OC, receiving chemotherapy at the time of interview; previously received surgery, chemotherapy, VEGF inhibitor therapy, and other targeted therapies.

3.4. Distinct Experiences with Sleep and Fatigue: "It was a whole different experience with fatigue."

Participants reported that their sleep and fatigue experiences were qualitatively distinct when receiving different treatments and evaluated their current symptom burden by comparing it to prior experiences that dated back to their diagnosis. Chemotherapy was often used as a benchmark for evaluating participants' current symptom burden because it was a period of acute, intense fatigue and cyclical sleep disturbance, and their first treatment experience post-diagnosis. Naomi, who had completed treatment at the time of interview, described her sleep disturbance as most intense during chemotherapy:

> "Even now, I'm having difficulty sleeping... but after the hysterectomy and then the three subsequent rounds of chemotherapy, they put me on this stuff that made me real jittery and made it so I couldn't sleep well, so it was really hard to sleep then." Naomi, a

Table 2
Interview Coding Structure.

Theme	Subtheme	Code	Definition	Prevalence*	Exemplar Quote
HRQoL	Impact of sleep issues	Emotional distress	Describes the emotional distress associated with sleep disturbance, including frustration, anxiety, worry, depression, or other psychological response to issues with sleep	65 %	It's just so taxing mentally, too, because you're so tired. All you want to do is lay down and go to sleep, and you lay down, and you sit there with your eyes open until you fall asleep, and then you finally get to sleep, and you wake up and it's like 5 min later. You're like, "Oh, my God! Why am I awake?!" Angie, 52-year-old, White woman, Stage IV
HRQoL	Impact of sleep issues	Social isolation	Describes the social isolation associated with sleep disturbance, including avoiding other people, cancelling plans, minimizing time with others, or otherwise avoiding social contact related to sleep disturbance	55 %	"It's extremely hard, especially for someone who is so active. I made up a story for my hiking buddy. I said I was doing something else, and I wasn't. I just couldn't get up.. I knew I wouldn't be good company for going for a… I was right here on the couch with the remote and taking naps because I was so out of it." Deborah, 62-year-old Black woman, Stage III
HRQoL	Impacts of fatigue issues	Limited ADLs	Describes the decreased ability to carry out activities of daily life associated with fatigue, including household chores, hygiene routine, caregiving, or other essential activities for daily function	95 %	I can't spend a lot of time on my feet like going grocery shopping. It's just too exhausting for me. It just - I just can't stand up for too long and walk around for too long. I need to sit down… I come home and I'm wiped out." Anita, 59-year-old, Hispanic woman, Stage III
HRQoL	Impacts of fatigue issues	Loss of Productivity	Describes the decreased productivity in paid labor associated with fatigue, including reduced work hours, difficulty starting and completing tasks, difficulty staying focused, or overall dissatisfaction with workplace performance due to fatigue	90 %	"It was hard because we have these deadlines we have to meet. It was a little stressful because of the way I was feeling. I did want to just kind of go lay down and go to sleep instead of work… I would try to work… I'm just gonna go take a nap for an hour. So, that's the reason why I was struggling with work." Melissa, 49-year-old, Hispanic woman, Stage IV
Sleep experiences	Aggravants of sleep disturbance	Concurrent treatment	Describes when patients attribute their sleep disturbance to the treatment they were receiving at the time, such as surgery, chemotherapy, hormone therapy, PARPi therapy, VEGF inhibitor therapy, immunotherapy, or other targeted therapies	75 %	"They put me on the 2 maintenance drugs… At first I was on 300 mg of [PARP inhibitor], and I couldn't sleep. And I was exhausted, but I couldn't sleep. I'd wake up for 3 h during the middle of the night and read and then sleep for 3-h increments." Robin, 54-year-old, Stage III
Fatigue experience	Aggravants of fatigue	Concurrent treatment	Describes when patients attribute their fatigue to the treatment they were receiving at the time, such as surgery, chemotherapy, hormone therapy, PARPi therapy, VEGF inhibitor therapy, immunotherapy, or other targeted therapies	80 %	"Originally, when I was on [chemotherapy], I would go on Friday and get my treatments, and by Monday or Tuesday. I was just wiped out for like a day or two… But then it would slowly wear off, and I'd get more energy, and then I go in again, so that had its own sort of cyclical thing." Jennifer, 51-year-old, White woman, Stage IV
Fatigue experience	Perceived level of fatigue	Relative fatigue	Describes when patients compare their current levels of fatigue to other points in their treatment trajectory, rating their current fatigue relative to other fatigue experiences during prior treatment	80 %	"I had more energy when I was going through chemo… and even after the surgery, I was up and walking 2 days after the surgery… But it's the [VEGF inhibitor] and the [PARP inhibitor] that have created the fatigue that have created the weakness… The biggest side effect would be fatigue. I've never had fatigue like that before." Brenda, 59-year-old, White woman, Stage IV
Sleep experiences	Perceived level of sleep disturbance	Relative sleep disturbance	Describes when patients compare their current level of sleep disturbance to other points in their treatment trajectory, rating their current sleep disturbance relative to other sleep disturbance experiences during prior treatment	75 %	"I was really, really struggling with sleep a lot. Then, actually, when I started chemo for the recurrence, I think the chemo kind of reset my system. And now I'm actually able to sleep better. Which has been really great, because I was pretty miserable." Amy, 49-year-old, White woman, Stage IV

* Prevalence is calculated as the percentage of interview participants coded with the reference code.

65-year-old Black woman with Stage IV OC, completed treatment; previously received surgery, chemotherapy, and PARPi maintenance therapy.

Like Naomi, most (15/20) participants described their sleep disturbance as cyclic when receiving chemotherapy: i.e., their sleep quality was poor immediately following chemotherapy but gradually improved in the weeks between rounds of therapy.

Among the seven participants who had received PARPi maintenance therapy, six described their sleep disturbance as persistent, compared with the cyclical sleep disturbance they experienced during chemotherapy. For example, one participant had occasional difficulty sleeping following chemotherapy, but experienced more persistent sleep disturbance during PARPi maintenance therapy:

> "After [chemotherapy] treatment, I was feeling a lot better. But then they put me on a [PARPi maintenance] drug, and I couldn't sleep. I would wake up for 3 hours during the middle of night and then sleep in. I would just sleep in 2 and 3 hours increments." - Robin, a 54-year-old White woman with Stage III OC, receiving PARPi and VEGF inhibitor maintenance therapy at the time of interview; previously received surgery, chemotherapy, and other targeted therapies.

Like Naomi, Robin described her current sleep disturbance as persistent while on maintenance therapy relative to the cyclic sleep disturbance during chemotherapy.

Participants also described their fatigue experiences as distinct during different treatments. Most participants (16/20) reported that their most intense fatigue occurred immediately after chemotherapy infusions. This fatigue was cyclical and seemed to abate in the days following infusions:

> "When I was in my frontline treatment, I was trying to do as much work as I could in between treatments, but I ended up taking leave because I was so weak and brain foggy... But now [while receiving PARPi maintenance therapy], I don't feel sleepy as much during the day, and it's not all day long." - Amy, a 49-year-old White woman with Stage IV OC, receiving chemotherapy at the time of interview; previously received surgery, chemotherapy, and PARPi maintenance therapy.

In contrast, participants described the fatigue that accompanied radiation and maintenance therapy differently:

> "Every now and then, I might get tired, but when I first started going through the chemo, the fatigue was major. It would last for hours. Then, as my body got accustomed to the chemo, it decreased. But the radiation [therapy] took it to another level... Then, once I started taking the [VEGF inhibitor] and the [PARPi maintenance therapy], it was a whole different experience of fatigue... all of the sudden, I would basically be doing something and have to sit down and just wait until it passed. It's been a roller coaster experience with fatigue." - Cheryl, a 60-year-old Black woman with Stage IV OC, receiving PARPi maintenance therapy at the time of interview; previously received surgery, chemotherapy, VEGF inhibitor therapy, and other targeted therapies.

Cheryl's experience demonstrates how the nature of fatigue varied by treatment type, with the most intense, cyclic fatigue occurring during chemotherapy.

3.5. "It's not going to get any better. You just have to do your best": Managing symptom burden

Given the debilitating nature of sleep disturbance and fatigue, most participants (18/20) engaged in a variety of strategies to manage their symptom burden. The most common strategies participants used to mitigate sleep disturbance included trying to improve their sleep hygiene (13/20), e.g. using black out curtains or noise machine; engaging in mindfulness exercises (11/20), such as guided meditation; increasing physical activity and exercise (7/20), such as walking or yoga; or taking prescription medications (8/20), such as sleep aids or antidepressants, Most (10/11) of the participants who used meditation and mindfulness exercises rated this as the most effective strategy to fall asleep, but still reported struggles with early waking.

Participants reported dissatisfaction with how few support options existed and the lack of provider communication around sleep and fatigue. Most physicians recommended sleep aids or antidepressants for sleep disturbance. However, six participants were reluctant to take sleep aids because of concerns about dependence and diminished HRQoL. Participants expressed frustration when the only solution providers offered was a prescription sleep aid:

> "They'll [providers] be quick to write a prescription for something. But then, you're totally sedated with some sort of sleep medication that takes away from your quality of life." Susan, a 65-year-old White woman with Stage III OC, receiving chemotherapy at the time of interview; previously received surgery, chemotherapy, VEGF inhibitor, PARPi therapy, and other targeted therapies.

Susan's frustration with the lack of support options beyond prescription medications was shared by nine other participants.

Participants employed a variety of strategies to mitigate fatigue, including resting or taking naps (7/20), engaging in light exercise (2/20), taking supplements, or using caffeine (2/20), but most (13/20) participants reported persistent severe fatigue. Fatigue was perceived as less manageable than sleep disturbance, as exhaustion made it difficult to even consider engaging in regular physical activity to combat fatigue. This unrelenting fatigue was exasperating, even for patients who had completed treatment:

> "I don't know what to do to try and get energy. I take vitamins, I go get massages. I try all of these things to get my energy up, and nothing works. But I have nothing to quiet my mind also. It's a double-edged sword. I don't know what to do." Angie, a 51-year-old White woman with stage IV OC, completed treatment; received surgery and chemotherapy.

Half of participants shared Angie's sense of helplessness mitigating their persistent fatigue and this, combined with a sensation of persistent exhaustion, made their fatigue more unmanageable. Only five participants talked to their care team about fatigue because they assumed providers would be unable to help them to manage fatigue, especially given limited time at appointments.

> "There is no one to talk about sleep... It's kind of sad." Beth, a 58-year-old White woman with Stage III OC, completed treatment; received surgery and chemotherapy.

Among the few participants who had discussed their fatigue with their care teams, providers' primary suggestion was to push through their fatigue. Anita, a Hispanic woman with Stage III OC receiving VEGF & PARPi maintenance therapy, who previously received surgery and chemotherapy, asked her doctor how to manage the fatigue she had struggled with for two years since diagnosis. She recounted her primary care doctor saying, "You just need to learn how to deal with your fatigue, it's part of cancer. It's not gonna get better. Just try to do your best." The sense of disempowerment further frustrated participants already struggling with debilitating fatigue and sleep issues, and the distress associated with their intense symptom burden was compounded by both the lack of communication about their symptoms that restricted their lives and sparse supportive care options available.

4. Discussion and conclusion

In this study, we found that sleep disturbance and fatigue were prevalent among patients with advanced OC, and these symptoms had a debilitating impact on their HRQoL. While many patients recalled severe fatigue and sleep disturbance during initial chemotherapy, they also characterized symptom severity as cyclical, with most intense symptoms immediately following treatment and periods of improvement between treatments. In contrast, patients receiving maintenance therapy noted milder, yet unremitting fatigue and sleep disturbance, and several others continued to grapple with fatigue despite having completed treatment. Despite the prevalence of symptoms, few patients sought help from their providers or felt that there was adequate support to address them, revealing an ongoing gap in care.

Our results confirm previous findings that sleep disturbance and fatigue are prevalent among advanced OC patients and limit their HRQoL [1,15,29–31]. Like findings from Sandadi and colleagues [30], sleep disturbance was associated with emotional distress and social toxicity [32], as exhaustion and irritability limited participants' social interactions. Persistent fatigue also contributed to cognitive and physical exhaustion that inhibited patients' abilities to complete ADLs and minimized productivity in the workplace, in line with evidence that fatigue decreases physical and functional well-being [29].

Our findings extend prior research by documenting how patients perceived distinct symptom burdens associated with their different treatment milestones [9,13]. We found that patients re-evaluated their current symptom burden based on their prior treatment experiences, using chemotherapy as a benchmark. These findings reflect OC patients' experiences with fatigue in Poort and colleague's [15] qualitative study, as well as clinical data illustrating the variation in sleep disturbance and fatigue levels during PARPi maintenance therapy and among PARPi drugs [33]. In addition to being an intense period of sleep disturbance and fatigue, chemotherapy was the first treatment that patients experienced following surgery, so this initial symptom burden may be most memorable and subsequently informed how they assessed symptom burden later in the treatment process.

Patients' dissatisfaction with providers' communication about sleep and fatigue underscores the need for increased screening, additional education for providers and patients on effective interventions for fatigue and sleep disturbance, and the development of and referrals for effective interventions to manage symptoms. Although screening for fatigue and sleep disturbance is recommended by National Comprehensive Cancer Network Guidelines and the American Cancer Society, routine screening is not consistently implemented [34]. Given patients' self-reported intense experiences with sleep and fatigue, disease-specific screeners and routine screening may help identify patients in need of support. Education on symptom management strategies for patients and survivors is also essential, so they are prepared to navigate symptoms during and after treatment. In this study, ten of the 11 patients who tried mindfulness exercises reported that mindfulness was the most effective strategy at mitigating sleep disturbance. Mindfulness has been shown to be effective at reducing insomnia among breast cancer patients [35], and a pilot study of an acceptance and commitment therapy-based intervention demonstrated preliminary efficacy in reducing fatigue interference in with patients with OC on PARPi compared to other existing treatments for fatigue [36]. A phase III study is currently testing whether an acceptance and commitment therapy-based intervention reduces fatigue interference and improves medication adherence in patients with OC on PARPi compared with best supportive care (NCT06710548). Healthcare providers should consider referring patients to social workers, psychologists, counselors, and advocacy groups who provide supportive care, especially during treatment. Supportive care to manage fatigue can include mindfulness, acceptance and commitment therapy [4,31] and exercise programs [37]. Cognitive behavioral therapy and pharmacological interventions can also be effective at managing sleep disturbance [38].

Our study had a few limitations. Although qualitative interviews offer unique and important insights, the small number of participants limits the generalizability of our findings. Recruiting participants from patient advocacy groups may present sampling bias, as participants may be more educated about their treatment plans and symptom experiences compared to those who do not engage with advocacy groups, which limits the generalizability of this study to patients with fewer supportive resources and access to information. However, we used multiple methods to increase the diversity of our sample, including multiple recruitment methods and purposive sampling to maximize variability in experiences by race/ethnicity, socioeconomic status, and treatment history. Similarly, individuals interested in participating in a study about fatigue and sleep disturbance may be more likely to report symptoms, compared with other patients with OC, although prior studies have identified high symptom burden as well (7 28). Finally, recall bias may limit the accuracy of patient reports. Despite these limitations, our results are consistent with prior studies documenting high rates of fatigue and sleep disturbance in survivors of and patients with OC [9,13,14], including a recent observational study of patients with OC who reported similar mild-to-moderate fatigue levels using PROMIS short forms to participants in this study [39]. Moreover, our use of semi-structured interviews enabled us to obtain insight into the complex, relational ways that patients with OC assessed their current symptom burden, including the intensity and variability of symptoms, as well as exacerbating factors.

The next steps of this study will examine the intensity and variability of symptoms among larger samples of OC patients and identify the symptoms that most strongly predict poor HRQoL to improve screening for sleep and fatigue symptom burden. Future research should evaluate the efficacy of qualitative patient-reported outcome data collection methods in assessing symptom burden compared to quantitative methods. In clinical settings, open-ended questionnaires may better capture the breadth and complexity of patient-reported outcomes compared to closed-ended questionnaires, and, in turn, facilitate early intervention to ameliorate debilitating symptoms. Future studies should also evaluate treatment-specific screening methods to help better identify patients in need of support at each stage in their treatment trajectory.

CRediT authorship contribution statement

Abigail Newell: Writing – review & editing, Writing – original draft, Visualization, Validation, Software, Methodology, Investigation, Formal analysis, Data curation. **Elif Andac-Jones:** Writing – review & editing, Visualization, Supervision, Software, Methodology, Investigation, Funding acquisition, Formal analysis, Conceptualization. **Maria Gonzalo:** Software, Resources, Project administration, Funding acquisition, Data curation, Conceptualization. **Alexi A. Wright:** Writing – review & editing, Visualization, Methodology, Conceptualization. **Oxana Palesh:** Writing – review & editing, Visualization, Methodology, Conceptualization. **Erica E. Fortune:** Writing – review & editing, Supervision. **Elizabeth Szamreta:** Writing – review & editing, Visualization, Supervision, Methodology, Funding acquisition, Conceptualization.

Ethics approval and consent to participate

Ethics approval for this study was obtained through WCG IRB (Protocol # 20224718). All procedures involving human subjects in this study were performed in accordance with the IRB protocol and applicable laws, regulations, and guidance regarding ethical protections of human subjects. Study staff are certified in the protection of human subjects. Participants consented prior to participating in this study.

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Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests:

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