

Disparate Barriers to Care among Ovarian Cancer Patients in Managing their Sleep Disturbance and Fatigue

Authors: Elif Andac-Jones, PhD¹, Abigail Newell, PhD¹, Maria Gonzalo, MS¹, Elizabeth Szamreta, PhD²

¹Cancer Support Community, Washington, DC; ²Merck & Co., Inc., Rahway, NJ

Abstract

Sleep disturbance and fatigue prevalent among advanced stage ovarian cancer (OC) patients; yet few studies examine patients' experiences seeking support. This qualitative study conducted 20 semi-structured interviews with stage III and IV OC patients to assess their experiences seeking support for sleep disturbance and fatigue, including any barriers to and unmet needs with care. Although most participants reported significant barriers to care, the barriers were more prevalent among racial and ethnic minority patients and those with lower socioeconomic status. These barriers to care may have implications for patients' health-related quality of life and exacerbate extant racial and socioeconomic disparities in OC health outcomes.

BACKGROUND

- Sleep disturbance and fatigue are prevalent among people with ovarian cancer (OC) and associated with poor health-related quality of life outcomes (Pozzar et al., 2021).
- Despite the prevalence of these symptoms, few studies have assessed experiences from the patients' perspective and incorporated their in-depth narratives (Beesley et al., 2020).
- Moreover, patients' experiences managing symptoms and seeking support are underexplored. There is a significant need for in-depth, qualitative research on the lived experiences of OC patients in managing these debilitating symptoms.

INTERVIEW DATA AND METHODS

20 semi-structured interviews were conducted with III and IV OC patients from diverse racial and socioeconomic backgrounds to assess their experiences of sleep disturbance and fatigue, the strategies they employed to manage symptom burden, and any related unmet needs.

Participant Characteristics

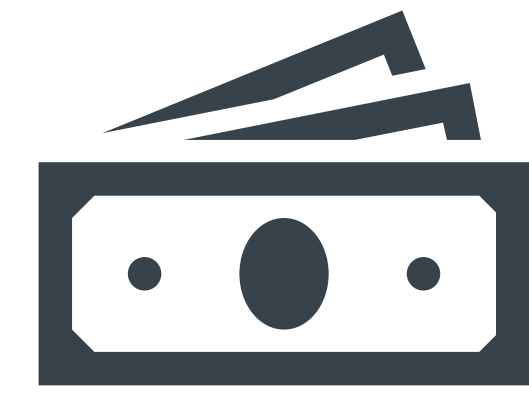
	n (%)		n (%)
Stage		Treatment Status	
III	10 (50)	Currently in treatment	10 (50)
IV	8 (40)	Maintenance therapy	7 (35)
Don't know / Unsure	2 (10)	Completed treatment	3 (15)
Household income		Race & Ethnicity	
<\$20k-\$59k	7 (35)	Black or African American	2 (10)
\$60k-\$99k	4 (20)	Latino or Hispanic	3 (15)
\$100k to \$139k	2 (10)	Multiple races	1 (05)
>\$140k	5 (20)	White	14 (70)
Prefer not to share	2 (10)		
Education		Age	57.1
Less than a college degree	6 (30)		
College degree	6 (30)		
Graduate degree	8 (40)		

N=20

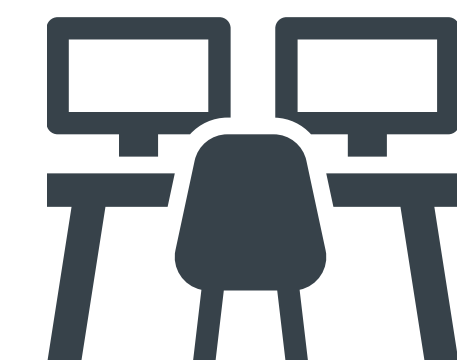
FINDINGS

Barriers to care

Cost concerns



Work-related distress



Medical distrust



Discrimination



Reluctance to medication and therapy



"The first oncologist they sent me to, he was pretty much all about the money... He was like, 'You can come to my office, and I'll do the first visit for free'...He had no compassion at all. All he was worried about was cost because I don't have insurance. It was just so bad." – *Elena, Hispanic, high school degree, <20k a year.*

"I'm not a big pill-taker. I don't want to take anything... I didn't want to go on [sleep aid] because it's so strong. I don't want to rely on pills to live my life... They say that therapy is good. It's just not my thing... I'm just dealing with it by myself." – *Angie, White, some college, no degree, <\$40k a year*

"Of course I can't sleep with my finances. I have bills to pay, and I can't work! ...Sometimes, I take Benadryl... But I can't afford it or [other medications]. CBD was the best, but I can't afford it..." – *Tammy, White, high school degree, <\$20k a year*

- Most participants expressed unmet needs in managing their sleep disturbance and fatigue issues. However, **racial minorities**, those with **fewer years of education**, and **lower income** reported more **intense** and **frequent** barriers to care.
- The tables below show the prevalence of barriers to care by race, education, and income level. The cells indicate the **frequency of the barriers** that participants discussed during interviews divided by the **number of participants** in each group.

Prevalence of Barriers to Care by Race

	Latino/Hispanic	Multi-racial	Black	White
Barriers to care for sleep disturbance and fatigue				
Cost concerns	3.33	4.00	2.00	0.40
Work distress	6.33	3.00	1.50	0.40
Medical distrust	1.33	3.00	1.00	0.27
Discrimination	1.00	1.00	0.50	0.00
Reluctance for therapy	1.00	2.00	1.00	0.07
n (N=20)	3	1	2	15

Prevalence of Barriers to Care by Education

	Less than college	College degree	Graduate or advanced
Barriers to care for sleep disturbance and fatigue			
Cost concerns	2.67	0.50	0.38
Work distress	1.50	1.00	0.75
Medical distrust	1.67	0.17	0.13
Discrimination	0.33	0.00	0.13
Reluctance for therapy	0.50	0.00	0.25
n (N=20)	6	6	8

Prevalence of Barriers to Care by Income

	<\$20k – \$59k	\$60k-\$99k	\$100k-\$139k	>\$140k	Not shared
Barriers to care for sleep disturbance and fatigue					
Cost concerns	2.14	1.25	0.00	1.00	0.00
Work distress	1.86	2.00	2.00	0.80	0.50
Medical distrust	1.14	1.25	0.00	0.00	0.00
Discrimination	0.43	0.25	0.00	0.20	0.00
Reluctance for therapy	0.57	1.00	0.00	0.20	0.50
n (N=20)	7	4	2	5	2

CONCLUSION

Findings suggest that advanced OC patients experience **significant unmet needs** when managing sleep disturbance and fatigue symptoms. OC patients needed increased **provider communication** around fatigue and access to **broad psychosocial support** to manage distress around sleep disturbance.

However, **racial minorities**, those with **fewer years of education**, **less income** experienced more significant, frequent barriers to care compared to White and highly-educated participants. **Cost of care**, **distrust**, **discrimination**, and **reluctance towards medication and therapy** were most frequently cited by racial minorities and those with lower socioeconomic status.

These barriers may **compound patients' symptom burden** and **exacerbate existing racial and socioeconomic disparities** in health outcomes.

1. Beesley, V. L., Staneva, A., Nehill, C., Milch, V., Hughes, F., & Webb, P. M. (2020). Patterns of, and barriers to supportive care needs assessment and provision for Australian women with gynecological cancer and their caregivers: a mixed-methods study of clinical practice. *Palliative and Supportive Care*, 18(2), 170-177. <https://doi.org/10.1017/S147895151900052X>
 2. Pozzar, R. A., Hammer, M. J., Paul, S. M., Cooper, B. A., Kober, K. M., Conley, Y. P., Levine, J. D., & Miaskowski, C. (2021). Distinct sleep disturbance profiles among patients with gynecologic cancer receiving chemotherapy. *Gynecologic Oncology*, 163(2), 419-426. <https://doi.org/https://doi.org/10.1016/j.ygyno.2021.09.002>

