

e24102

Publication Only

Relative and functioning sleep disturbance and fatigue: Impact on patients with ovarian cancer.

Elif Andac-Jones, Abigail Newell, Elizabeth A. Szamreta, Maria Belen Gonzalo, Juliette Hoffman, Matthew Monberg; Cancer Support Community, Washington, DC; Merck & Co., Inc., Rahway, NJ

Background: Sleep disturbance and fatigue are prevalent among ovarian cancer patients and are associated with poor mental health and Health-related quality of life (HRQoL) outcomes; while this has been well-documented, we know less about the factors that may contribute, what cancer patients perceive as contributing to their issues, and how they describe and manage these issues across their treatment trajectory. **Methods:** In this qualitative study, data were collected via semi-structured interviews with 20 stage III/IV ovarian cancer patients diagnosed within three years with varied treatment trajectory, race/ethnicity, and location. A screener included PROMIS Sleep Disturbance and Fatigue measures, sociodemographics, and cancer history. Transcripts were analyzed using deductive codes of sleep and fatigue and inductive codes based on emergent themes. We identify two novel concepts of patients' sleep and fatigue experiences: *relative* and *functioning*. *Relative* fatigue and sleep issues capture how patients self-report relative to different points in their treatment. *Functioning* concept shows how patients reinterpret and self-censor the severity and impact of their sleep and fatigue by emphasizing their ability to overcome exhaustion or insomnia. **Results:** All twenty patients reported persistent, debilitating fatigue, difficulty falling and staying asleep through the course of their disease, which negatively impacted their HRQoL and activities of daily living. The majority of patients struggled to complete daily chores (17/20), keep up with paid work (9/10), and maintain relationships (16/20). Although patients experience fatigue across their trajectories, the majority of patients described their fatigue as more intense during chemotherapy than maintenance therapy. Patients struggled to evaluate their current fatigue and sleep without reflecting on previous treatment experiences (relative), and continuously reinterpreted their levels of fatigue and sleep based on how much of their daily functions they could complete (functioning). Patients self-censor in reporting to meet their perceived expectations of their care provider/data collector. Although fatigue and sleep disturbance significantly impaired their HRQoL, patients framed their experiences positively and minimized their struggles. **Conclusions:** We conclude that PROMIS measures are important in evaluating baseline sleep disturbance and fatigue in patients with ovarian cancer. However, patients' reporting is informed by their previous treatment experiences, subject to continued reinterpretation. Therefore 1) more nuanced and repeated measures including patients' narratives are needed to understand the complexity of patients' experiences; and 2) Patients' self-censorship and filtering need to be considered. Future research will test these new concepts with a 200 patient survey. Research Sponsor: Merck Sharp & Dohme LLC, a subsidiary of Merck & Co., Inc., Rahway, NJ, USA; AstraZeneca UK Ltd.