

# Qualitative Analysis of the Experience of Mental Fatigue of Family Caregivers of Patients With Cancer in Phase I Trials

Denise M. Weiss, PhD, FNP, BC, AOCNP®, Laurel L. Northouse, PhD, RN, FAAN, Sonia A. Duffy, PhD, RN, FAAN, Berit Ingersoll-Dayton, PhD, Maria C. Katapodi, PhD, RN, FAAN, and Patricia M. LoRusso, DO

Weiss is a nurse practitioner at the Barbara Ann Karmanos Cancer Institute in Detroit, MI; Northouse is a professor emerita in the College of Nursing at the University of Michigan in Ann Arbor; Duffy is a professor in the College of Nursing at Ohio State University in Columbus; Ingersoll-Dayton is the director of the Joint PhD Program and a professor in the School of Social Work at the University of Michigan; Katapodi is a professor in the Institute of Nursing Science at the University of Basel in Switzerland; and LoRusso is the associate director of innovative medicine and a professor of medicine at the Yale Cancer Center in New Haven, CT.

No financial relationships to disclose.

Weiss, Northouse, Duffy, Ingersoll-Dayton, and Katapodi contributed to the conceptualization, design, and analysis. Weiss completed the data collection. All authors contributed to the statistical support and manuscript preparation.

Weiss can be reached at [weisssd@karmanos.org](mailto:weisssd@karmanos.org), with copy to editor at [ONFEditor@ons.org](mailto:ONFEditor@ons.org).

Submitted March 2014. Accepted for publication August 31, 2015.

**Key words:** mental fatigue; caregivers; quality of life

*ONF*, 43(4), E153–E160.

doi: 10.1188/16.ONF.E153-E160

**Purpose/Objectives:** To examine family caregivers' experience of mental fatigue, identify strategies they use to manage it, and ascertain the kind of help they would like from healthcare professionals.

**Research Approach:** Descriptive, qualitative study that was part of a larger mixed-methods study.

**Setting:** Metropolitan comprehensive cancer center in the midwestern United States.

**Participants:** 79 family caregivers of patients with advanced cancer who were participating in phase I clinical trials.

**Methodologic Approach:** Caregivers completed a semistructured, open-ended questionnaire and demographic and health history forms.

**Findings:** Caregivers were able to define mental fatigue and give many examples of it. They reported that mental fatigue did not interfere with patient care, but that it did have a negative effect on their own self-care. They identified strategies to manage mental fatigue. They wanted more information and support from professionals.

**Conclusions:** The majority of caregivers experienced mental fatigue, which manifested as trouble concentrating, difficulty remembering things, and irritability. The majority worked outside of the home and had health problems of their own.

**Interpretation:** Healthcare professionals need to assess caregivers for mental fatigue and find ways to help them reduce mental fatigue and restore their attention. Nurses are in a prime position to mobilize resources for caregivers to effectively manage burden and reduce mental fatigue.

Despite the many advances in treating cancer, metastatic cancer remains an incurable disease and a major threat to the life of patients and the well-being of their family caregivers. For metastatic cancers, few treatment options exist. Some patients with advanced cancer seek phase I clinical trials as a means of finding hope. Phase I clinical trials are the initial step in the translation of research from the laboratory to the clinical arena. Patient benefit is not the intent of these studies, and they are typically offered to patients whose disease is refractory to standard therapies and who have few, if any, remaining treatment options (LoRusso, Boerner, & Seymour, 2010). Patients with cancer participating in phase I clinical trials are generally heavily pretreated, have a poorer prognosis, and undergo treatments that may cause serious side effects. However, many patients remain optimistic about tumor response.

The stress associated with providing care to seriously ill patients with advanced cancer can negatively affect family caregivers' quality of life (Given et al., 2004; Northouse et al., 2007). In addition, caregivers may also face a great