This material is protected by U.S. copyright law. Unauthorized reproduction or online display is prohibited. To purchase quantity reprints, e-mail reprints@ons.org. For permission to reproduce multiple copies, e-mail pubpermissions@ons.org.

Patients' Experiences With Cancer-Related Fatigue: A Review and Synthesis of Qualitative Research

Jane A. Scott, MA, PhD, Kathryn E. Lasch, PhD, MA, MSSW, Andrea M. Barsevick, PhD, RN, FAAN, and Elisabeth Piault-Louis, PharmD, MA

ancer-related fatigue (CF) is documented to be a highly prevalent condition among patients with cancer and exacts substantial personal and societal costs (Bruera et al., 2006; Cella, Davis, Breitbart, & Curt, 2001; Curt et al., 2000; Iop, Manfredi, & Bonura, 2004; Irvine, Vincent, Graydon, & Bubela, 1998; Minton & Stone, 2009; Stasi, Abriani, Beccaglia, Terzoli, & Amadori, 2003; Stone & Minton, 2008; Wu & McSweeney, 2004). Several studies have reported that patients view CF as the most common and distressing cancer- or therapy-related symptom (Cella et al., 2001; Fulton & Knowles, 2000). Many publications have documented CF's enormous toll on health-related quality of life (HRQOL) (Bower et al., 2000; Bruera et al., 2006; Cella et al., 2001; Fulton & Knowles, 2000; National Comprehensive Cancer Network [NCCN], 2005; Stone et al., 2000). Patients with CF have found the condition incapacitating, as it directly interferes with their ability to function physically and mentally, and it leads to rapid HRQOL deterioration. The deleterious effect of CF on HRQOL includes dramatic effects on patients' relationships, ability to work and enjoy life, and hopes of fighting the illness (Stone et al., 2000).

However, CF remains an underreported and untreated diagnosis, in part because of differences in its measurement and definition (Minton & Stone, 2009; Piper et al., 2008). Several professional societies (e.g., Oncology Nursing Society, European Association of Palliative Care) have attempted to clarify its characteristics (NCCN, 2005, 2007; Radbruch et al., 2008). In addition, the Fatigue Coalition, a multidisciplinary group of medical practitioners, researchers, and patient advocates, proposed diagnostic criteria in 1998 for CF for inclusion in the *International Statistical Classification of Diseases and Related Health Problems*, 10th Revision, Clinical Modification; however, these criteria were not retained in the final published version (Portenoy & Itri, 1999). **Purpose/Objectives:** To systematically review published qualitative reports of descriptions of fatigue by patients with cancer and how cancer-related fatigue (CF) affects their lives.

Data Sources: MEDLINE[®], CANCERLIT[®], Cochrane Database of Systematic Reviews, and the Cumulative Index to Nursing and Allied Health Literature.

Data Synthesis: Two researchers conducted independent reviews of 667 patient quotes found in 154 articles published from 1996–2009 to identify concepts and language used to describe CF.

Conclusions: CF is more intense than the tiredness patients recalled from before diagnosis or treatment. Published patient quotes fail to adjudicate whether CF should be approached as a single symptom or a more complex symptom cluster.

Implications for Nursing: Systematic study of patients with different cancer types and stages is needed to identify effective, valid, and reliable self-reported assessments of CF for clinical practice and trials.

Measurement experts do not agree as to whether CF is a single, unidimensional concept that can be summarized by a single score or a multidimensional construct that requires a score for each essential concept of importance to patients (Lai, Crane, & Cella, 2006). Most definitions and measures acknowledge that CF is a subjective phenomenon; however, they each focus on certain aspects of fatigue while excluding others. To add to the lack of clinical consensus, many existing instruments that purport to evaluate CF were developed without direct input from patients with cancer and, therefore, whether all the concepts of importance to patients and central to CF are captured by these instruments is questionable. Given the referenced measurement debates, the numerous instruments purporting to measure CF, and the many definitions of CF, regulators have struggled to interpret clinical trials using existing CF instruments.