Fatigue and Sleep Experiences at Home in Children and Adolescents With Cancer

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Purpose/Objectives: To (a) investigate fatigue and sleep patterns of children and adolescents at home and (b) examine factors associated with fatigue and sleep.

Design: Descriptive with repeated measures.

Setting: Homes of study participants in Los Angeles and Orange, California.

Sample: 35 children and adolescents with cancer.

Methods: Data were collected using the PedsQL™ Multidimensional Fatigue Scale, which was completed once at home by each participant, and sleep actigraphs, which were worn for five days at home following discharge from hospitalization.

Main Research Variables: General fatigue, cognitive fatigue, sleep-rest fatigue, sleep duration, sleep quantity, sleep efficiency, and wake after sleep onset.

Findings: More than half of the participants had problems with fatigue at home. Significant correlations were found between sleep/rest fatigue and sleep duration. Factors that affected fatigue were age, gender, and cancer diagnosis. Adolescents had more problems with fatigue than children, and female patients had more problems with fatigue than male patients. Patients with sarcoma had more problems with fatigue than those with leukemia, lymphoma, and other cancer diagnoses. Adolescents slept less than children.

Conclusions: Children and adolescents with cancer have fatigue and sleep problems at home that vary by age, gender, and cancer diagnosis.

Implications for Nursing: Data from the current study support the need for nurses to provide teaching about fatigue and sleep at home in children and adolescents with cancer. Future studies are needed to examine interventions that may alleviate fatigue and improve sleep at home.

Key Words: child; adolescent; fatigue; sleep

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Children and adolescents undergoing cancer treatment frequently experience distressing symptoms, such as fatigue and sleep disturbance (Edwards, Gibson, Richardson, Sepion, & Ream, 2003; Miller, Jacob, & Hockenberry, 2011; Walker, Gedaly-Duff, Miaskowski, & Nail, 2010; Walker, Johnson, Miaskowski, Lee, & Gedaly-Duff, 2010). Fatigue is often characterized by physical symptoms, including lack of energy, decreased physical ability, and feelings of tiredness. It may be experienced before the initiation of experience (Goedendorp, Gielissen, Verhagen, Peters, & Bleijenberg, 2008), during cancer treatment (Hinds, Hockenberry, Gattuso, et al., 2007; Perdikaris et al., 2009; Purcell et al., 2010), in disease-free survivors (Andrykowski, Donovan, Laronga, & Jacobsen, 2010; Bower et al., 2006), and at the end of life (Murphy, Alexander, & Stone, 2006; Teunissen et al., 2007; Ullrich et al., 2010).

Although the severity and frequency of fatigue have frequently been reported, many studies have not examined the multiple dimensions of fatigue—namely general, cognitive, and sleep/rest fatigue. The strategies for minimizing cancer-related fatigue in previous studies were predominantly physical exercise training interventions that primarily addressed the physical dimension and had documented benefits regarding fat mass, muscles, bones, flexibility, and endurance (Baumann, Bloch, & Beulertz, 2013; Braam et al., 2013; Chang, Mu, Jou, Wong, & Chen, 2013; Cramp & Daniel, 2008; Huang & Ness, 2011; Keats & Culos-Reed, 2008). However, other nonpharmacologic interventions (e.g., cognitive behavioral therapy, mind-body relaxation therapy, music therapy, sleep hygiene) may be useful in addressing other dimensions of fatigue, such as cognitive and sleep/rest fatigue, particularly in children who may not be able to perform physical exercise.

Multidimensional fatigue measures define the physical dimensions of fatigue with items such as feeling tired or experiencing physical weakness (Hinds, Hockenberry, Tong, et al., 2007; Varni, Burwinkle, Katz, Meeske, & Dickinson, 2002; Varni, Burwinkle, & Szer, 2004). Cognitive fatigue is defined by items such as having difficulty with paying attention to things or remembering what people say (Varni et al., 2002). Sleep/rest fatigue is