Fatigue in Young Survivors of Extracranial Childhood Cancer: A Finnish Nationwide Survey

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Although an increasing number of young patients with cancer are being successfully treated for their disease (Gatta et al., 2009), demanding treatment regimens may be having a negative impact on this population’s health-related quality of life (HRQOL). The literature has focused on describing the HRQOL of young cancer survivors; however, fatigue usually is overlooked in favor of more obvious late effects of cancer and treatment (Hockenberry-Eaton et al., 1998). Previous reports have shown that fatigue can cause negative changes in HRQOL (Eddy & Cruz, 2007; Meeske, Katz, Palmer, Burwinkle, & Varni, 2004; Meeske, Patel, Palmer, Nelson, & Parow, 2007; Varni, Burwinkle, Katz, Meeske, & Dickinson, 2002). Fatigue is a symptom that may affect a patient’s life, both in the short and long term. Despite the fact that significantly less is known about cancer-related fatigue in children and adolescents than in adults (Whitsett, Gudmundsdottir, Davies, McCarthy, & Friedman, 2008), fatigue is recognized as a significant symptom experienced by children and adolescents with cancer (Gibson, Garnett, Richardson, Edwards, & Sepion, 2005; Meeske et al., 2004; Ruland, Hamilton, & Schjodt-Osmo, 2009; Whitsett et al., 2008). Minimal data are available concerning fatigue in these populations, but Varni et al. (2002) identified that young cancer survivors are more fatigued than their healthy control counterparts.

No shared understanding of the definition and meaning of fatigue exists for these young patients and survivors. As a whole, fatigue is a difficult concept to explain. The first study to evaluate fatigue in children with cancer (Hockenberry-Eaton et al., 1998) reported that the definition of fatigue varies depending on the developmental level of the participants. Another study (Hinds et al., 1999) reported that the patient, parents, and staff each defined fatigue differently. Children reporting fatigue noted increased levels of depressed mood and different physical consequences; adolescents emphasized the dynamic sensation of physical or mental exhaustion. Parents defined fatigue as a state of experience excessive fatigue, which may have an impact on their HRQOL.

Purpose/Objectives: To evaluate self-reports of fatigue by young cancer survivors (aged 11–18 years), to compare young survivors’ fatigue scores with the scores of a healthy control group and of the parent proxy evaluation, and to analyze whether demographic or disease-related factors are associated with young survivors’ fatigue.

Design: Cross-sectional quantitative study.

Setting: An urban hospital in southwestern Finland.

Sample: 384 survivors diagnosed with an extracranial malignancy at age 16 or younger, who have survived four or more years postdiagnosis, and who are free of cancer. General matched population controls were randomly selected from the Finnish Population Registry.

Methods: Demographic data and a self-report written fatigue questionnaire.

Main Research Variables: Total fatigue (TF), general fatigue (GF), sleep or rest fatigue (SF), and cognitive fatigue.

Findings: The control populations reported significantly more issues with TF, GF, and SF than did the survivor population. In survivors, older age, the need for remedial education at school, and a sarcoma diagnosis were associated with increasing fatigue, whereas female gender, better school grades, and greater health-related quality-of-life (HRQOL) scores were associated with lower fatigue. The study variables explained 49%–65% of the variation in fatigue scores.

Conclusions: Although survivors and their matched controls seem to have similar fatigue, subgroups of survivors do experience excessive fatigue, which may have an impact on their HRQOL.

Implications for Nursing: This study increases the knowledge about fatigue levels of young survivors of extracranial malignancies and identifies the need for instruments specifically designed to assess fatigue in this population. The healthcare team should pay attention to the fatigue level of young survivors, particularly SF.