A Phenomenologic Study of Fatigue in Adolescents Receiving Treatment for Cancer

Faith Gibson, MSc (Cancer Nursing), PhD, RSCN, RGN, ONC, Cert Ed RNT, Anne B. Mulhall, BSc, MSc, PhD, Alison Richardson, BN (Hons), MSc, PhD, PGDE, RNT, Jacqueline L. Edwards, BSc (Hons), MSc (Palliative Care), RGN, RSCN, Dip Cancer Nursing, Emma Ream, BSc (Hons), MSc, PhD, RGN, and Beth J. Sepion, B Ed (Hons), MSc (Child Health Nursing), RSCN, RGN, SCM

Key Points . . .

➤ Cancer threatens the life and personhood of adolescents.
➤ Fatigue has been shown to be prevalent in children and adolescents with cancer.
➤ A cyclical relationship exists between fatigue and other factors, such as busy lives, study, and work pressures.

Purpose/Objectives: To generate a detailed description of how adolescents with cancer manage their daily lives and the way in which fatigue affects this.

Design: Phenomenologic.

Setting: A pediatric oncology unit at a regional cancer center in the United Kingdom.

Sample: A convenience sample of adolescents (N = 8), aged 16–19 years and with hematologic or solid tumors, who currently were undergoing primary treatment.

Methods: Semistructured interviews were conducted using 11 open-ended questions.

Main Research Variables: Adolescents’ perceptions of fatigue, well-being, and ability to maintain normal activities.

Findings: Adolescents reported fatigue as overwhelming and embedded in a syndrome of symptoms and emotions associated with the illness itself and with treatment. Fatigue had a significant effect on physical, psychological, and social well-being, placing an extra burden on adolescents who were striving for normality.

Conclusions: Equipped with a rich description of fatigue, clinicians will be better prepared to initiate strategies congruent with their own work settings and particular patients.

Implications for Nursing: The findings should enable healthcare professionals to construct a more accurate and perceptible picture of the needs of particular individuals, highlighting those that may be amenable to intervention.

In the United Kingdom, the annual total incidence of cancer in adolescents aged 13–19 is nearly 150–200 per million (Stillier, 2002). Adolescents have been identified as a distinct and particularly vulnerable group with specific and complex needs (Holliis & Morgan, 2001; Kelly, Mulhall, & Pearce, 2003; Lewis, 1996; Souhami, Whelan, McCarthy, & Kilby, 1996). Developmental theory suggests that adolescence is a crucial stage in the process of building self-esteem, establishing autonomy, forming self-image, and preparing for adulthood (Erikson, 1968). Chronic illness is yet another challenge faced by adolescents. Treatment is known to have physical effects on adolescents (Rechner, 1990), and “being tired” and “unable to get around” causes them significant distress (Hinds, Quargnetin, & Wentz, 1992). Adolescents consider the physical side effects of treatment as the worst aspect of cancer, significantly affecting their quality of life (Enskar, Carlsson, Golsater, & Hamrin, 1997), and “getting on with life” is a primary goal for them (Rechner). Thus, they develop strategies to help manage changes in the social and functional aspects of their lives. But this realignment of life occurs alongside their struggle to meet normal developmental milestones. The overall aim of this exploratory study was to describe fatigue as a phenomenon and to identify whether and how it affects well-being and the ability to maintain normal activities in adolescents undergoing cancer treatment.

Background

Fatigue

Fatigue has been defined as a “subjective, unpleasant symptom that incorporates total body feelings ranging from tiredness to exhaustion creating an unrelenting overall condition” (Cotton, 2000). It has been described as a “syndrome of symptoms and emotions associated with the illness itself and with treatment” (Enskar, Carlsson, Golsater, & Hamrin, 1997). Fatigue can be caused by a variety of factors, including physical, psychological, and social factors. Adolescents with cancer are particularly vulnerable to fatigue, as it can significantly affect their quality of life and ability to maintain normal activities.

Purpose/Objectives:

To generate a detailed description of how adolescents with cancer manage their daily lives and the way in which fatigue affects this. The overall aim of this exploratory study was to describe fatigue as a phenomenon and to identify whether and how it affects well-being and the ability to maintain normal activities in adolescents undergoing cancer treatment.

Methods:

Semistructured interviews were conducted using 11 open-ended questions. Adolescents reported fatigue as overwhelming and embedded in a syndrome of symptoms and emotions associated with the illness itself and with treatment. Fatigue had a significant effect on physical, psychological, and social well-being, placing an extra burden on adolescents who were striving for normality.

Conclusions:

Equipped with a rich description of fatigue, clinicians will be better prepared to initiate strategies congruent with their own work settings and particular patients.

Implications for Nursing:

The findings should enable healthcare professionals to construct a more accurate and perceptible picture of the needs of particular individuals, highlighting those that may be amenable to intervention.