

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

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 perceptive picture of the needs of particular individuals, highlighting those that may be amenable to intervention.

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.

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

In the United Kingdom, the annual total incidence of cancer in adolescents aged 13–19 is nearly 150–200 per million (Stiller, 2002). Adolescents have been identified as a distinct and particularly vulnerable group with specific and complex needs (Hollis & 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

Faith Gibson, MSc (Cancer Nursing), PhD, RSCN, RGN, ONC, Cert Ed RNT, is a lecturer in the Children's Nursing Research Institute of Child Health at Great Ormond Street Hospital for Children in London, United Kingdom; Anne B. Mulhall, BSc, MSc, PhD, is an independent training and research consultant at the Coach House in Ashmanhaugh, Norfolk, United Kingdom; Alison Richardson, BN (Hons), MSc, PhD, PGDE, RNT, is a professor of cancer and palliative nursing care at the Florence Nightingale School of Nursing and Midwifery at King's College in London; Jacqueline L. Edwards, BSc (Hons), MSc (Palliative Care), RGN, RSCN, Dip Cancer Nursing, is a clinical nurse specialist in pediatric oncology outreach on the Children's Unit at the John Radcliffe Hospitals in Headington, Oxford, United Kingdom; Emma Ream, BSc (Hons), MSc, PhD, RGN, is a senior lecturer at the Florence Nightingale School of Nursing and Midwifery at King's College; and Beth J. Sepion, B Ed (Hons), MSc (Child Health Nursing), RSCN, RGN, SCM, is a lecturer in pediatric oncology at the School of Nursing and Midwifery in the University of Southampton, United Kingdom. This study was supported by the Lisa Thaxter Trust. (Submitted March 2004. Accepted for publication September 12, 2004.)

Digital Object Identifier: 10.1188/05.ONF.651-660