

RESEARCH BRIEF

Pain, Sleep Disturbance, and Fatigue in Children With Leukemia and Their Parents: A Pilot Study

Vivian Gedaly-Duff, DNSc, RN, Kathryn A. Lee, PhD, RN, FAAN,
Lillian M. Nail, PhD, RN, FAAN, H. Stacy Nicholson, MD, MPH, and Kyle P. Johnson, MD

Purpose/Objectives: To determine the feasibility of collecting symptom data at home from school-age children with acute lymphoblastic leukemia (ALL) and from their fathers and mothers and to obtain initial descriptions of pain, sleep disturbance, and fatigue experienced by the family members at home.

Design: Prospective and descriptive.

Setting: Children's homes in Oregon and southwestern Washington.

Sample: 9 children with ALL (aged 8–16 years), 6 fathers, and 7 mothers. The children received vincristine during the maintenance phase of their outpatient chemotherapy treatments.

Methods: With age-appropriate, paper-and-pencil diaries and wrist actigraphy, data were collected for three days in the families' homes. Families were reminded by telephone to complete their sleep and activity diaries.

Main Research Variables: Pain, sleep disturbance, and fatigue in school-age children and their fathers and mothers.

Findings: Most of the families who were approached indicated willingness to participate in the study. After receiving outpatient chemotherapy, the children reported pain, sleep disturbance, and fatigue data over three days. Fathers and mothers also reported symptoms. Actigraphy showed children waking more often during the night than mothers or fathers.

Conclusions: Children's pain, sleep disturbance, and fatigue suggest that the symptoms are influencing families' quality of life. Larger studies are needed to examine the symptom patterns and health outcomes of children, fathers, and mothers over the course of chemotherapy.

Implications for Nursing: Improving sleep and managing pain and fatigue after chemotherapy treatment for children with ALL may improve health outcomes for children and parents.

Acute lymphoblastic leukemia (ALL) is the most common childhood cancer, accounting for one-third of cancer diagnoses in children younger than 15 and 28% of cancer diagnoses in those younger than 20 (Ries et al., 2005). Children with ALL are treated with six to eight months of intensive chemotherapy, followed by two or more years of maintenance chemotherapy. Pain (Collins et al., 2000; Van Cleve et al., 2004), sleep disturbance (Ljungman, Gordh, Sorensen, & Kreuger, 2000), and fatigue (Collins et al.; Davies, Whitsett, Bruce, & McCarthy, 2002;

Key Points . . .

- ▶ Children being treated for leukemia and their fathers and mothers are willing to participate in research that uses diaries and actigraphy.
- ▶ The number of nighttime awakenings was higher than normal in children over three days after outpatient chemotherapy. The fathers and mothers also had higher than normal awakenings.
- ▶ Symptom reports over the same three days suggest that pain, sleep disturbance, and fatigue cluster together after children's chemotherapy treatments.
- ▶ Parents' symptoms, although different from the children's, also occurred during the three days of caregiving and other family functions, such as work and parenting other children.

Vivian Gedaly-Duff, DNSc, RN, is an associate professor in the School of Nursing at Oregon Health and Science University in Portland; Kathryn A. Lee, PhD, RN, FAAN, is a professor and the Livingston Chair in Nursing in the School of Nursing at the University of California, San Francisco; and Lillian M. Nail, PhD, RN, FAAN, is the Dr. May E. Rawlinson Distinguished Professor and a senior scientist in the School of Nursing. H. Stacy Nicholson, MD, MPH, is the Credit Unions for Kids Professor and Chair of the Department of Pediatrics in the School of Medicine and physician-in-chief at Doernbecher Children's Hospital, and Kyle P. Johnson, MD, is an assistant professor in the Division of Child and Adolescent Psychiatry in the School of Medicine, all at Oregon Health and Science University. This research was supported, in part, by a postdoctoral fellowship awarded to the first author from the National Institutes of Health, National Institute of Nursing Research, 2 T32 NR07088 (K. Lee, principal investigator), and by the National Cancer Institute, K24 CA098442 (L. Nail, principal investigator). Mention of specific products and opinions related to those products do not indicate or imply endorsement by the Oncology Nursing Forum or the Oncology Nursing Society. (Submitted August 2005. Accepted for publication August 9, 2005.)

Digital Object Identifier: 10.1188/06.ONF.641-646