Childhood Cancer Symptom Cluster: Leukemia and Health-Related Quality of Life

Cheryl C. Rodgers, PhD, RN, CPNP, CPON®, Mary C. Hooke, PhD, APRN, PCNS, CPON®, FAAN, Olga A. Taylor, MPH, Kari M. Koemer, MPH, CHES, Pauline A. Mitby, MPH, Ida M. Moore, PhD, RN, FAAN, Michael E. Scheurer, PhD, MPH, Marilyn J. Hockenberry, PhD, RN, FAAN, and Wei Pan, PhD

About 80% of children with cancer endure at least one symptom during treatment; more commonly, these children experience multiple symptoms throughout treatment (Buckner et al., 2014; Hockenberry et al., 2017). Symptoms of fatigue, nausea, pain, sleep disturbances, and depression commonly occur among children undergoing cancer treatment (Daniel, Li, Kloss, Reilly, & Barakat, 2016; Kestler & LoBiondo-Wood, 2012; Rodgers, Hooke, Ward, & Linder, 2016). A study by Hockenberry et al. (2017) evaluating the trajectory of symptoms among children with acute lymphoblastic leukemia (ALL) confirmed that sleep disturbance and nausea persisted during postinduction chemotherapy treatment, and fatigue, pain, and depression decreased but never completely resolved during this time. ALL is the most common type of childhood cancer and requires about three years of chemotherapy treatment (Scheurer, Lupo, & Bondy, 2016). ALL treatment is divided into three phases: induction therapy that starts urgently after the cancer diagnosis and lasts about one month; postinduction therapy (also referred to as consolidation or intensification therapy) that begins after induction therapy and includes at least eight months of intensified treatment; and maintenance therapy that starts after postinduction therapy and consists of less intensive treatment for about two years (Margolin, Rabin, Steuber, & Poplack, 2016). During postinduction therapy, children receive intensive treatment with several courses of chemotherapy that are associated with numerous symptoms (Hockenberry et al., 2014; Margolin et al., 2016). Children describe symptoms as the worst part of cancer treatment, noting that symptoms cause distress and increase suffering (Ameringer, Elswick, Shockey, & Dillon, 2013; Woodgate, 2008).

Children with ALL have low health-related quality of life (HRQOL) during their cancer treatment

OBJECTIVES: To examine the relationship of the Childhood Cancer Symptom Cluster–Leukemia (CCSC-L) with health-related quality of life (HRQOL).

SAMPLE & SETTING: 327 children receiving treatment for acute lymphoblastic leukemia from four pediatric oncology programs across the United States.

METHODS & VARIABLES: Participants completed fatigue, sleep disturbance, pain, nausea, and depression symptom questionnaires at four time points; these symptoms comprised the CCSC-L. HRQOL was measured at the start of postinduction therapy and then at the start of maintenance therapy. Relationships between the CCSC-L and HRQOL scores were examined with longitudinal parallel-process modeling.

RESULTS: The mean HRQOL significantly increased over time (p < 0.001). The CCSC-L had a significant negative association with HRQOL scores at the start of postinduction therapy (β = -0.53, p < 0.005) and the start of maintenance therapy (β = -0.33, p < 0.015). Participants with more severe symptoms in the CCSC-L over time had significantly lower HRQOL at the start of maintenance therapy (β = -0.42, p < 0.005).

IMPLICATIONS FOR NURSING: Nurses are pivotal in providing management strategies to minimize symptom severity that may improve HRQOL.

KEYWORDS pediatric oncology; symptom cluster; health-related quality of life

ONF, 46(2), 228–237.
DOI 10.1188/19.ONF.228-237