Symptom Clusters in Children and Adolescents with Cancer

Cheryl Rodgers, Mary C. Hooke, Jessica Ward, and Lauri A. Linder

Objective: *To report evidence regarding assessment methods and management strategies for symptom clusters among children and adolescents with cancer.*

Data Sources: *Published research and clinical guidelines.*

Conclusion: *Although a number of studies have identified multiple co-occurring symptoms in children and adolescents with cancer, only a few have included analyses aimed at identifying symptom clusters. Evidence is limited for symptom cluster management strategies.*

Implications for Nursing Practice: *Researchers and clinicians need to employ mechanisms that support children and adolescents to: 1) fully express multiple, co-occurring symptoms; 2) identify symptom clusters within specific developmental and diagnostic groups; and 3) develop and evaluate interventions targeting symptom clusters.*

Key Words: *symptom cluster, symptom assessment, symptom management, cancer, children, adolescent.*

Cheryl Rodgers, PhD, RN, CPNP, CPON: *Assistant Professor, Duke University School of Nursing, Durham, NC.* Mary C. Hooke, PhD, APRN, PCNS, CPON: *Assistant Professor, School of Nursing, University of Minnesota, Minneapolis, MN.* Jessica Ward, MSN, MPH, RN, CPNP: *Pediatric Nurse Practitioner, Center for Cancer and Blood Disorders, Children's Hospital Los Angeles, Los Angeles, CA.* Lauri A. Linder, PhD, APRN, CPON: *Assistant Professor, University of Utah, College of Nursing, Salt Lake City, UT and Clinical Nurse Specialist, Primary Children's Hospital, Salt Lake City, UT.*

Address correspondence to Cheryl Rodgers, PhD, RN, CPNP, CPON, Duke University School of Nursing, 307 Trent Drive, Durham, NC 27710. e-mail: cheryl .rodgers@duke.edu

Children and adolescents with cancer experience multiple co-occurring physical and psychological symptoms from their disease and its treatment that negatively affect their quality of life.[1,2] Many pediatric oncology studies report symptoms as single entities; however, symptoms rarely occur alone.[3] Symptoms often emerge simultaneously, affecting the intensity of current symptoms and the development of additional symptoms.[4,5] A symptom cluster occurs when two or more symptoms interact with each other, creating a relationship stronger than that with other symptoms.[6] Identification of symptom clusters within pediatric oncology can provide a greater understanding of the patient's symptom experience and support more effective

symptom management strategies. This article reviews symptom cluster assessment methods and management strategies among children and adolescents (age range, birth to 18 years) with a diagnosis of any malignant disease.

Identifying symptom clusters among children and adolescents is contingent on the ability of providers to assess for symptoms and pediatric patients to comprehend and express their symptom experiences. Approaches for symptom assessment vary based on the child or adolescent's developmental level.[7] Clinicians must rely on behavioral cues and parent-proxy reports for young children who are pre-verbal, as well as children and adolescents who are unable to articulate their symptoms.[7] Older children and adolescents may be able to communicate their symptom experiences; however, they may need assistance to convey their experiences and encouragement to express their feelings. Furthermore, most children and adolescents are achieving new cognitive and psychosocial milestones as they undergo treatment. Previous methods to assess and manage symptoms may need to change as they mature. Clinicians must be aware of various methods to assess and manage co-occurring symptoms in children and adolescents undergoing cancer treatment.

An awareness of the potential for the presence of symptom clusters is essential when assessing or managing symptoms in children and adolescents with cancer. When identifying symptom clusters, the strength of the relationships between symptoms should be considered, rather than identifying and merely listing multiple symptoms.[8] The minimum number of symptoms to delineate a symptom cluster varies within the literature.[9-11] To encompass all symptom cluster evidence within pediatric oncology, this review defines symptom clusters as two or more concurrent symptoms that relate to one another. A comprehensive evaluation of symptom assessment and management strategies among children and adolescents with cancer provides an opportunity to advance awareness of symptom clusters.

Symptom Cluster Assessment

Quantitative Assessment

Researchers have used multiple approaches to quantitatively measure symptoms for cluster analysis in children undergoing cancer treatment. The availability of pediatric instruments influences decisions on measuring symptoms of interest. Using a multi-symptom inventory with multivariate statistical analyses is one method to cast a "wide net" to identify clusters of symptoms. The Memorial Symptom Assessment Scale 10–18 (MSAS 10–18)[12] is the most common instrument used in this approach. Yeh and colleagues[10] identified five different symptom clusters in 144 Taiwanese children and adolescents (10 to 18 years of age) using cluster analysis. Participants were heterogeneous with regard to disease type, and included patients who were receiving cancer treatment as well as those who had completed therapy. Sensory concerns and body image were the most prevalent clusters. Baggott and colleagues[11] also used the MSAS 10–18 in 131 children and adolescents ages 10 to 18 undergoing myelosuppressive chemotherapy in the United States (US) for a variety of cancer diseases. Exploratory factor analysis revealed three clusters: chemotherapy sequelae cluster, mood disturbance cluster, and a neuropsychological discomfort cluster. Atay, Conk, and Bahar[13] used the MSAS 10–18 in 54 Turkish children and adolescents age 10 to 18 to measure the trajectory of symptom clusters during the first 3 months of chemotherapy treatment using cluster analysis techniques. They found that symptom clusters changed each month, illustrating the dynamic nature of the symptom experience during cancer treatment. Table 1 describes the symptom clusters.[9-11,13-15]

A second approach to symptom cluster measurement is to hypothesize which symptoms may cluster together and then utilize individual self-report instruments for each symptom in the proposed cluster. Hockenberry and colleagues[9] proposed the symptom cluster of fatigue, nausea and vomiting, and sleep disturbances and then examined their relationship to the clinical outcomes of behavioral changes, depression, and performance status in children ages 7 to 18 who were receiving chemotherapy in the US. The symptoms of fatigue and sleep disturbance clustered together and were predictive of more depressive symptoms and behavioral changes in adolescents. In contrast, only higher fatigue predicted more depressive symptoms in children (Table 1). In a secondary analysis of the same patient group, the researchers categorized the outcome measurements into levels of none, mild, moderate, or severe and used a hierarchical agglomerative cluster analysis approach.[14] Two clusters were identified with the first cluster, including the fatigue subscales of energy, function, mood, and depression, and the second cluster consisting of