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Measures and Methods for Symptom and Symptom Cluster Assessment in Adolescents and Young Adults with Cancer

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Objectives: *To provide an overview of resources for measuring symptoms and symptom clusters in adolescents and young adults (AYAs) with cancer and to examine methodological strategies for evaluating symptom clusters.*

Data Sources: *Published research articles and clinical experience.*

Conclusion: *Limited research has addressed symptoms and symptom clusters in AYAs with cancer. Reliable, valid, and developmentally appropriate measures are needed to advance this area of research.*

Implications for Nursing Practice: *Use of mobile technology and mixed qualitative and quantitative methods to understand AYAs' experience of symptoms and symptom clusters could enhance symptom awareness and the evidence base for practice.*

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Adolescents and young adults (AYAs) with cancer experience multiple co-occurring, interrelated symptoms as a result of their disease and treatment.[1] Accurate symptom assessment is vital to provide high-quality supportive care and evaluate therapies. Research that addresses symptoms among individuals with cancer has increased over the past 20 years; however, symptom research among AYAs as a distinct population is limited.

Diversity among the AYA age group with regard to growth, development, and life experiences in general creates challenges in designing studies as well as identifying appropriate symptom assessment measures. AYAs who are ≤ 18 years of age are most commonly treated at pediatric centers and are more likely to be included in study samples with younger children. AYAs older than 18 years are more likely to be included in studies with adults, including older adults. This division of AYAs in research has hindered advancement of symptom science that addresses this distinct group, including attention to developmentally meaningful approaches to symptom measurement.

Validated instruments for measuring symptoms across the full AYA age range (ages 15 to 39) are sparse. Additionally, researchers have used a variety of methodological strategies to evaluate symptoms and symptom clusters, making comparisons and conclusions difficult. This article presents an overview of approaches and resources for measuring symptoms and symptom clusters in AYAs with cancer, and compares and contrasts methodological strategies to evaluate symptoms and symptom clusters. The article also proposes directions to support developmentally meaningful research addressing symptoms and symptom clusters in the AYA population.

DEFINING AND EXPLORING SYMPTOM CLUSTERS

AYAs with cancer, like younger children and older adults, generally do not experience single symptoms in isolation, but rather experience multiple co-occurring, interrelated symptoms.[1,2] Groups of two or more symptoms that occur together and are more strongly related to each other than to other symptoms are referred to as *symptom clusters*.[3] The relationships among symptoms comprising a cluster may potentiate the severity of the individual symptoms and have a synergistic negative impact on distress, functional status, and quality of life.[4,5] Cluster-focused interventions may thus be more potent than single symptom-focused interventions by ameliorating multiple symptoms that potentially share a common biologic mechanism or by influencing a key symptom that additively or interactively exacerbates others.[6,7]

Studies addressing symptom clusters have predominantly focused on either younger children or older adults. These studies emphasize the clinical significance of clusters, with the presence of symptom clusters associated with poorer functional status and quality-of-life outcomes.[8,9] A recent review found that little was known about symptoms and even less about clusters in adolescents with cancer.[1] No studies have focused on symptom clusters in young adults (YAs) with cancer.

RESOURCES FOR MEASURING SYMPTOMS AND SYMPTOM CLUSTERS

Quantitative Self-Report Instruments

To date, no instruments have been developed to measure multiple cancer-related symptoms in AYAs across the age range of 15 to 39 years. Only one instrument exists to measure a single cancer-related symptom in AYAs: body image. A few have been developed and validated to measure symptoms in adolescents with cancer.

Multiple Symptoms. The Memorial Symptom Assessment Scale (MSAS 10-18) adapted from an adult version,[10] is the only instrument that has been developed to measure multiple symptoms in the targeted age group of 10- to 18-year-olds with cancer.[11] This tool has been used in a number of studies with adolescents, where it has demonstrated adequate reliability and validity to measure multiple dimensions (frequency, severity, and distress) of 30 common cancer-related symptoms experienced during the previous week.[12-14]