Consensus Recommendations From the Children's Oncology Group Nursing Discipline's State of the Science Symposium: Symptom Assessment During Childhood Cancer Treatment

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Abstract

Background: Recognizing and addressing illness-related distress has long been a priority for pediatric oncology nurses and the Children's Oncology Group. Although symptoms are known to be highly prevalent during treatment for childhood cancer, there is currently no guidance for how often symptoms should be assessed, which symptoms should be prioritized for assessment, and how the data should be collected. **Methods:** The Nursing Discipline, within Children's Oncology Group, hosted a one-day Interprofessional seminar titled "Symptom Assessment During Childhood Cancer Treatment: State of the Science Symposium." Following the symposium, an expert panel was assembled to review all available evidence, including information presented and collected during the symposium. Consensus-building discussions were held to identify common themes and to produce recommendations for clinical practice. **Results:** Four recommendations emerged including (1) the identification of priority "core" symptoms for assessment; (2) inclusion of the child's voice through self-report, when possible; (3) consistent documentation and communication of symptom assessment results; and (4) implementation of patient/family education related to symptoms. **Discussion:** Symptom recognition, through appropriate assessment, is the first step in symptom management. The goal for developing and sharing these recommendations is to promote consistent and comparable clinical practice across institutions in regard to symptom assessment during childhood cancer therapy. Integration of these recommendations will set the stage for future studies related to the frequency of symptoms across disease groups, projection of anticipated symptom trajectories, development of evidence-based teaching tools for common symptoms, and evaluation of patient outcomes with enhanced symptom assessment and management.

Keywords

symptom science, pediatric oncology, consensus, Children's Oncology Group

Introduction

The Children's Oncology Group (COG) is the largest organization in the world devoted solely to cancer research in children and adolescents, and the only pediatric cooperative group funded by the National Cancer Institute's National Clinical Trials Network (Withycombe et al., 2019). Within the United States, there are nearly 200 COG member institutions (Withycombe et al., 2019) which care for the majority of the estimated 16,000 new children and adolescents diagnosed annually with cancer

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(Siegel, Miller, & Jemal, 2018). Each COG institution is represented by individuals from multiple disciplines, with registered nurses comprising 27% of the group's overall membership (Withycombe et al., 2019). Research arising from the COG Nursing Discipline is organized by a conceptual framework (Kelly, Hooke, Ruccione, Landier, & Haase, 2014), guided by a blueprint (Landier, Leonard, & Ruccione, 2013) and has a dual focus of (1) understanding the effective delivery of patient/family education and (2) reducing illness-related distress.

Recognizing and addressing illness-related distress (physiological and/or emotional) has long been a priority for pediatric oncology nurses (Nelson & Guelcher, 2014) and remains a key focus of research for COG Nursing. Symptom science research is also a high priority nationally, and an area of focus for the National Institute of Nursing Research (Miaskowski et al., 2017). Continued attention to symptom science research is warranted within pediatric oncology as 80% of children experience multiple symptoms during treatment, many of which are severe in nature and negatively affect a child's quality of life (Baggott et al., 2010; Buckner et al., 2014; Hockenberry et al., 2010).

Although symptoms are known to be highly prevalent during treatment for childhood cancer, there is currently no evidence-based guidance for how often symptoms should be assessed, which symptoms should be prioritized for assessment, and how the data should be collected (i.e., measurement instruments). In the setting of pediatric oncology clinical trials nursing, standardizing the quality and consistency of symptom assessment for children undergoing cancer treatment has the potential to significantly influence clinical practice and clinical trial outcomes. The purpose of this article is to report expert consensus recommendations developed by the COG Nursing Discipline regarding (1) the major symptoms experienced during treatment for childhood cancer, (2) best practices for assessment of these symptoms, and (3) identification of key knowledge gaps and opportunities for future research focusing on symptom science in pediatric oncology.

Methods

In October 2018, the COG Nursing Discipline hosted a one-day interactive interprofessional seminar titled "Symptom Assessment During Childhood Cancer Treatment: State of the Science Symposium." Speakers for the symposium were selected by the planning committee to include experts representing several aspects of the field of symptom science. Selected topics for symposium presentations/discussions (and subsequent publication) included a review of the existing literature related to common symptoms among children undergoing cancer

treatment (Hooke & Linder, 2019; Linder & Hooke, 2019), symptom biomarkers (Mandrell & Withycombe, 2019), and participant perceptions regarding symptom distress, assessment, and intervention for children undergoing treatment for cancer on clinical trials (Skeens, Cullen, Stanek, & Hockenberry, 2019).

As part of the symposium, a five-member panel composed of four advanced practice pediatric oncology nurses and one parent of a childhood cancer survivor, convened to discuss symptom-related distress in the context of pediatric oncology clinical trials, with a focus on specific disease groups. To begin the discussion, one panel member was asked to respond to the following statement "From your perspective, list the five most distressing symptoms experienced by children receiving cancer-directed treatment on clinical trials." Next, nursing experts, each representing a distinct disease group (leukemia/lymphoma, solid tumor, or central nervous system tumor), responded to the following prompt: "Are there unique symptoms that are related to the child's diagnosis and its related treatment? List the top three unique symptoms that are observed [in your specialty area of practice]." The parent representative on the panel was asked to answer the following question "What was the one most distressing symptom that your child experienced?" Following the panel presentation, the discussion was opened to the audience.

Workshop attendees were then divided into small groups and asked to discuss their thoughts regarding the panel's presentation and to additionally answer two questions: (1) "How is symptom distress assessed in your clinical setting?" (2) "What are the most common interventions used for symptom distress in your clinical setting?" After 20 minutes of discussion, small groups were asked to verbally share their responses to the stated questions with the larger audience.

Two members of the symposium's planning committee took real-time, detailed notes without participant identifiers, related to the topics and findings presented during both the panel discussion and the shared small group reports from the audience. Audience members were also invited to participate in an anonymous written survey pertaining to symptoms; these results have been published separately (Skeens et al., 2019). As data collection was a planned part of the symposium, the project was reviewed and deemed exempt by Duke University's Institutional Review Board prior to data collection.

Following the symposium, the authors of this article (i.e., expert panel members) were charged with summarizing the expert recommendations stemming from the symposium proceedings. After reviewing available evidence, collected and/or presented during the symposium (and subsequently published), all expert panel members participated in consensus-building discussions, conducted through conference calls.

Table 1. Key Recommendations for Symptom Assessment.

Recommendation	Details
1. In pediatric oncology, there are identifiable “core” high-priority symptoms that are common across diagnoses and treatments.	<ul style="list-style-type: none"> • Symptom assessment should occur at regular intervals in conjunction with patient care and in response to patient/family concerns. • Core symptoms (Table 2) should be included in assessments followed by an open-ended question such as “What other things have been bothering you/your child?” • Symptom assessment should be interdisciplinary in nature.
2. Self-report of symptoms from the child is the gold standard, if child is able (based on developmental age, cognitive status, and severity of illness).	<ul style="list-style-type: none"> • Many symptoms are subjective in nature and therefore are best expressed by the child. • Proxy (parent or caregiver) report of symptoms is acceptable when self-report from child is not feasible. • Adverse event reporting on clinical trials should always reflect input from child and/or parent for subjective symptoms, especially in relationship to symptom interference with normal daily activities.
3. Symptom assessment should always be documented and communicated to relevant members of the health care team.	<ul style="list-style-type: none"> • Written documentation of symptom assessment and findings should occur in conjunction with verbal exchange of information. • Findings from symptom assessment should be communicated proficiently between team members, to minimize unnecessary duplication of symptom assessments and reduce assessment burden to the patient and family. • Identified symptoms should trigger appropriate referrals (MD, Nursing, Psychologists, Child Life, etc.) for interventions.
4. Patients and families should receive education related to symptom assessment.	<ul style="list-style-type: none"> • Anticipatory guidance should be provided to patients and families related to common symptoms associated with the therapy that they are receiving. • Consistent messaging is needed when communicating with families regarding symptom assessment, reporting, and management.

Although current evidence from published studies reports the presence and severity of symptoms during specific time points of childhood cancer therapy, the expert panel agreed that symptoms have not been *consistently* assessed across treatment trajectories or across disease groups. Secondary to inconsistent assessments, limitations exist with current research evidence with regard to identifying the most frequent symptoms (overall and by disease type) experienced by pediatric oncology patients, symptom trajectories during treatment, and best practices for symptom assessment in pediatric oncology. Recognizing these limitations, the expert panel agreed to use existing evidence, supplemented by expert consensus, to develop recommendations related to symptom assessment, including (1) which symptoms should be assessed, (2) when symptom assessment should occur, and (3) how symptom assessment should be captured (i.e., symptom measurements). The goal for developing and sharing these recommendations is to promote consistent and comparable clinical practice across institutions with regard to symptom assessment during childhood cancer therapy.

Results

There were 90 attendees reporting affiliations with 56 different COG institutions and representing a variety of disciplines including nursing, medicine, pharmacy, patient advocates, and clinical research assistants. The largest

representation, 78 individuals (87%), identified with the discipline of nursing, with role diversity that included direct patient care, care coordination, research, education, and administration.

Key recommendations related to symptom assessment were generated from information provided during the symposium and from expert consensus (Table 1). Strong agreement was present among the conference attendees that children undergoing treatment for cancer experience multiple symptoms, many of which are severe in nature and potentially interfere with treatment and/or quality of life. This statement was confirmed by the literature reviews presented during the symposium, outlining recent research related to common symptoms, including fatigue, sleep disturbance, nausea and vomiting, pain, and sadness (Hooke & Linder, 2019; Linder & Hooke, 2019) and biomarkers associated with symptoms (Mandrell & Withycombe, 2019). During the symposium discussions, common themes regarding frequently occurring symptoms arose, and were confirmed by responses submitted to the symposium survey (Skeens et al., 2019). *The overarching theme was that symptoms are common, individualized, and may change over time; however, many symptoms can be predicted/anticipated based on the child's diagnosis and treatment plan.* Across all diagnoses, consensus was reached, through symposium findings and expert agreement, regarding the core symptoms for priority assessment in children undergoing cancer treatment, identified as nausea and vomiting, fatigue, pain, sleep disturbance, anxiety, and

Table 2. Core Symptoms for Priority Assessment During Childhood Cancer Therapy.

Anxiety
Fatigue
Nausea and vomiting
Pain
Sadness/depression
Sleep disturbance

sadness/depression (Table 2). Of note, similar concepts such as sadness and depression could not be clearly separated from the symposium results.

Currently, there is significant variability among COG institutions regarding how and when symptoms are assessed and documented. It was noted that institutional requirements and data collection tools often drive symptom assessment practices, as responses to specific data fields may be required within medical record systems (i.e., Review of Systems). Within the United States, it was noted that accrediting organizations such as the Joint Commission (2017) dictate the assessment and documentation of pain in all patients. Other common methods of “assessing symptoms” were reported to occur through direct observation (i.e., observing ambulation or facial expressions) and by information offered by children and/or parents regarding the presence or absence of symptoms. Patient Reported Outcome (PRO) instruments were also mentioned as being used to collect symptom data, but this is currently being done only in the context of research and not as a routine part of clinical care. Assessment of symptoms was also reported to be driven, in part, by clinician experience. Some practitioners reported knowing intuitively to assess specific symptoms based on their experience in pediatric oncology, which allowed them to identify that certain symptoms occur with higher frequency in relation to specific treatments or diagnoses (i.e., headaches in children with brain tumors, or neuropathy in children receiving Vincristine).

Communication of information related to symptom assessment was noted to be inconsistent and often insufficient across institutions (also not tracked over time, no clear documentation of either worsening or resolution of symptoms). Documentation within the medical record was not always reviewed in “real-time,” resulting in children and parents being asked the same questions by multiple clinicians. It was also noted that electronic medical records may have discipline-specific documentation not readily accessible to health care team members outside of specific disciplines, making it difficult to evaluate symptoms using an interdisciplinary approach. During the symposium discussions, it was also noted that communication was hindered when information was not consistently shared in written format in one designated location

within the medical record. Sharing of verbal information between clinicians regarding patient symptoms was noted to be effective in the short term (i.e., helpful for clinicians seeing the patient on the same day), but did not allow for later review or use of the information by other members of the health care team.

Discussion

Based on the information presented at the COG Nursing Discipline’s Symptom Assessment during Childhood Cancer Treatment: State of the Science Symposium, our expert panel identified key issues related to symptoms and symptom assessment in pediatric oncology. Symptom recognition is the first step in treating or managing symptoms, and therefore is of substantial clinical importance. There are “core” symptoms (fatigue, nausea and vomiting, pain, anxiety, sleep disturbance, and sadness/depression) which occur with sufficient frequency to be labeled as high-priority symptoms and recommend for inclusion in all routine symptom assessments. The core symptoms identified during the generation of this consensus statement have also been recognized, among other pediatric oncology experts, as frequently occurring symptoms across cancer types (Reeve et al., 2013). With the exception of vomiting, all of the identified core symptoms are subjective in nature; thus, reports of symptom presence, frequency, and severity are best captured directly from the child. When child report is not feasible secondary to age, developmental status, or severity of illness, parent or proxy report of symptoms are acceptable, as they can approximate the child’s report (Hockenberry et al., 2003; Hyslop et al., 2018).

There are currently no standard guidelines for symptom assessment and/or documentation outside of the mandated adverse event reporting for participants on clinical trials. There is a recognized need for the collection of standardized patient-reported symptom assessments embedded within clinical care. The standardized collection of PROs could also enhance and inform clinician reporting of adverse events for those participating in clinical trials. Assessment of PROs in adult oncology patients resulted in symptoms being identified earlier and with greater frequency than clinician reports (Basch et al., 2009). Additionally, the National Institute of Nursing Research (n.d.) has called for the collection of Common Data Elements to advance science and improve patient care. The availability of a core symptom database, which includes PROs, would allow for the identification of patient profiles across diagnoses and treatment protocols, and better prediction of future symptom burden and individualized symptom trajectories. More accurate assessment and reporting of patient symptoms, such as by using PROs, also holds implications for drug labeling and marketing (U.S. Food & Drug Administration, 2009).

The ideal frequency and best method for symptom assessment during childhood cancer treatment is still unknown. There are multiple validated tools useful for PRO or proxy-reported symptom assessments within pediatric oncology (Pinheiro et al., 2018). Many of these measurement instruments, however, produce symptom scores either for individual symptoms or a global score, for multiple symptoms, which may be difficult for clinicians and families to interpret. The Pediatric PRO–Common Terminology Criteria for Adverse Events, is a newly developed library of questions for children and adolescents to self-report adverse events (symptoms) experienced during cancer treatment. Each symptom is assessed using up to three attributes including the presence, frequency, severity, and/or interference with daily activities (Reeve, McFatrach, Pinheiro, Freyer, et al., 2017; Reeve, McFatrach, Pinheiro, Weaver, et al., 2017). Currently, the measure is available for use as an exploratory measure in pediatric oncology; publications documenting the reliability and validity of the measure are currently in process. In the future, this measure may provide a consistent way to assess and report patient symptoms across time points and treatment settings. In the absence of a universal symptom assessment measure, the expert panel recommend that “core” symptoms (fatigue, nausea and vomiting, pain, sleep disturbance, anxiety, and sadness/depress) be routinely assessed and documented during clinical care.

Although it is beyond the scope of this consensus statement to discuss symptom management, there was agreement that symptom assessment should lead to appropriate symptom intervention and referrals to other professionals when indicated. It is possible that improved symptom assessment and management in pediatric oncology could lead to increased medication adherence (Graetz et al., 2018) and improved quality of life and/or improved overall survival, as demonstrated in adult oncology trials (Basch et al., 2017).

Dissemination and integration of these consensus recommendations will pave the way for future studies that allow for the generation of new knowledge in pediatric oncology related to the frequency of symptoms across disease groups, projection of anticipated symptom trajectories across various ages and treatment protocols, development of evidence-based teaching tools for common symptoms, and evaluation of patient outcomes with enhanced symptom assessment and related management. Collaboration across institutions and electronic medical record systems will be needed in order to generate the data needed to address many of the identified knowledge gaps. Ultimately, we envision that improved symptom assessment will lead to better anticipation and management of symptoms, which in turn may contribute to improved quality of life and/or treatment outcomes for the thousands of children treated for cancer each year.

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