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Symptom Screening via Screen: Real-Time Electronic Tracking of Pediatric Patient-Reported Outcomes

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The study by Barz Leahy et al[1] leverages the real-time clinical use of technology for efficient, effective symptom reporting by patients and family caregivers during chemotherapy admissions. This innovative study has revealed the feasibility and acceptability of using electronic symptom monitoring from the perspectives of the child, parent, and provider. The study upholds patient-reported outcomes (PROs) as gold-standard communication as revealed in the collection of real-time symptom reporting directly from the child during hospitalization.[2] Importantly, the study design included integration into the electronic medical record, a known barrier to the usefulness of PROs for informing cancer care. Moreover, easier accessibility was shown to enhance the utility of PROs, as 21% of symptom reports led to a change in clinical care.

The validity, responsiveness, and stability of the Patient-Reported Outcomes version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE) instrument offer a new and proven way for children to report how they are feeling and for proxy caregivers to parallel-report on children’s symptoms.[3,4] It is worth recognizing that children with cancer participated as codevelopers in the PRO-CTCAE instrument through extensive cognitive interviews.[5] Now, reading of the instrument’s application in real-time feedback for medical teams harkens to the progressing state of PRO science as true translational research from development to implementation.

Because of the amount of time that oncology teams already spend in front of computer screens instead of face to face with patients, there may be initial skepticism at the concept of electronic data reporting resulting in improved human communication. Clinicians experienced the data reporting as accessible and understandable. Importantly, receipt of the electronic patient-reported symptom data resulted in real-time changes in care, including two main communication interventions: counseling patients on medications and returning to a patient’s room to further discuss symptoms and/or the prescribing of new medications. The

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real-time data translated into opportunities to re-address patient symptoms and to intervene instead of waiting until rounds the next morning.

Because of the circadian rhythm of most adolescents waking later and the known interrupted sleep cycles of young children during hospitalizations, in-person morning rounds may dwell on yesterday’s recall or overnight chart review rather than the actual current experience of the patient. Receiving comprehensive symptom updates with comparative trends allowed the study team to receive real-time knowledge in a personalized and timely manner. Although we would hope that there would be ongoing interactions between the patient, the bedside nursing staff, and the treatment team, the practicalities and pace of inpatient medical care limit the number of moment-by-moment updates for symptoms that may be quite bothersome to a child but underappreciated by busy teams. The use of technology for data reporting fostered real-time clinical awareness with the potential for prompt responses.

With the goal of obtaining direct patient reporting, medical teams do need to be creative in not just the time of day when pediatric patients are approached but also the modality of approach. Anecdotally, an increasing number of children and adolescents are noted to use screens (whether iPads or cellphones) for distraction or social engagement or even virtual schooling during hospital stays. The ready presence of screens may hint at the comfort that younger generations have with expressing experiences and sharing feedback through technology. Conversely, at this time, when children are spending so much of their school days behind a computer screen, they may be hesitant to complete what may be perceived as one more electronically administered assignment. Parents who are attentive to limiting screen time may prefer a nonelectronic reporting modality.

Parents appreciated the reporting process as easy and the symptom content as important. Patients (65%) found that the symptom reporting improved their knowledge of their own health, and more than half of the surveyed pediatric patients experienced an increased sense of control and empowerment. Nearly half perceived that the technology improved their sense of connection to the health care team. Because children are known to underreport their symptoms or minimize side effects out of concern about worrying their parents, “bothering” others, or “interrupting” their clinicians,[6] the finding that children experienced this intervention as connecting is a highly relevant finding for obtaining the child’s voice and sustaining pediatric trust in team responsiveness.

The study occurred within an inpatient setting with hospitalized patient participants. The authors appropriately noted study limitations such as a relatively small sample (52 patients) from a single-institution and concerns about reduced reporting for those undergoing stem cell transplantation (with intense symptoms expected) and longer hospitalizations. Patient reporting notably decreased over time for longer admissions, and this warrants exploration for reasons (if increased or ongoing symptoms were the reason, then it would be all the more important to access the symptom burden for supportive care). With almost three-fourths of the caregivers being female, the inclusion of male caregiver or paternal perspectives may provide a more complete picture.

A consideration is whether, without direct observation, there may have been parental “assistance” in helping the child complete the form or even the risk that the parent may have completed the form on the child’s behalf if the child was not engaged or felt too sick. The extent to which the parent and the child may have discussed or corroborated on responses is unclear. The pressure for some parents to avoid appearing as though their child had not completed an assigned task or to appear adherent to care team requests may warrant consideration of direct observation for assurance of the child’s independent engagement in self-report.

This hospital-based study raises consideration of the ways in which this important work could translate into outpatient care to further connect patients and teams longitudinally. This is an important consideration because an increased symptom burden that is not being observed in an inpatient setting may be associated with a higher level of psychological distress. Increased understanding of the symptom experience can potentially effectively link pediatric patients to timely mental health supports. Recent preliminary work in the outpatient pediatric setting found that more than half of medical providers changed their care for patients on the basis of children’s self-reporting of distressing symptoms when the information was provided in a real-time summary report.[7]

The authors thoughtfully considered what to do with discordant child and parent reports, and they noted that “there is no clear guidance for the simultaneous display of pediatric and caregiver data. Also, as identified by participating clinicians … there is no standard approach to resolving conflicting information when both patient and proxy sources exist in the pediatric setting, although the argument has been made that the child’s voice should be considered paramount”[1] In prior work, caregivers consistently overestimated symptoms and found the “caregiver’s own self-reported HRQOL [health-related quality of life] was associated with the magnitude of difference between child and caregiver scores for all domains except mobility.”[8] In another recent study, investigators found moderate interrater reliability between patient, caregiver, and medical provider ratings, and the strength of this association increased with patient age. More specifically, 42.7% of the caregivers placed the child’s distress in a different risk category then the child did; 28.1% rated their child as more distressed than the child did; and 14.6% rated their child as less distressed than the child.[9] In end-of-life care for children with cancer, the self and proxy symptom reporting gap further widens.[10] Although the child’s voice should take precedent, we should not ignore caregiver observations, especially in the inpatient setting because the family caregiver is often with the child 24/7.

The majority of the study participants identified as non-Hispanic White. Being English-speaking was an eligibility requirement. Replication in more diverse racial and ethnic populations will be important to ensure that the measures and data are culturally relevant to the patient/caregiver experience, especially because the PRO-CTCAE instrument now has certified translations in more than 30 languages. Additional attentiveness is warranted to ensure that the use of technology for symptom reporting does not widen inequities or care gaps based on technology access.

The word *screen* carries 2 meanings: to show/present for viewing and to conceal/hide. Although we celebrate the creativity of the study team in fostering PROs through a technology interface with direct reporting to clinicians, we caution that in the uptake of electronic symptom reporting, we must continue to keep human-to-human interaction central to ensure that this modality results in positive responses. The goal is for technology's connectivity to support and not supplant the actual human interactions so essential to medicine. This study has revealed the potential for technology to obtain child report, to foster pediatric patients' sense of connection with the care team, and to enhance supportive care.

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