Electronic Symptom Monitoring in Pediatric Patients Hospitalized for Chemotherapy

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BACKGROUND: Using patient-reported outcomes for symptom monitoring in oncology has resulted in significant benefits for adult patients with cancer. The feasibility of this approach has not been established in the routine care of children with cancer. **METHODS:** The Pediatric Patient-Reported Outcomes version of the Common Terminology Criteria for Adverse Events (Ped-PRO-CTCAE) is an item library that enables children and caregivers to self-report symptoms. Ten symptom items from the Ped-PRO-CTCAE were uploaded to an online platform. Patients at least 7 years old and their caregivers were prompted by text/email message to electronically self-report daily during a planned hospitalization for chemotherapy administration. Symptom reports were emailed to the clinical team caring for the patient, but no instructions were given regarding the use of this information. Rates of patient participation and clinician responses to reports were systematically tracked. **RESULTS:** The median age of the participating patients (n = 52) was 11 years (range, 7-18 years). All patients and caregivers completed an initial login, with 92% of dyads completing at least 1 additional symptom assessment during hospitalization (median, 3 assessments; range, 0-40). Eighty-one percent of participating dyads submitted symptom reports on at least half of hospital days, and 54% submitted reports on all hospital days. Clinical actions were taken in response to symptom reports 21% of the time. Most patients felt that the system was easy (73%) and important (79%). Most clinicians found symptom reports easy to understand and useful (97%). **CONCLUSIONS:** Symptom monitoring using patient-reported outcome measures for hospitalized pediatric oncology patients is feasible and generates data valued by clinicians and patients. ***Cancer* 2021;127:2980-2989**. © *2021 American Cancer Society*.

KEYWORDS: digital health, health services research, patient-reported outcomes (PROs), pediatric oncology, supportive care, symptom monitoring.

INTRODUCTION

The clinical use of patient-reported symptom and toxicity monitoring during chemotherapy improves adult patients' quality of life, decreases hospitalizations, and lengthens their life.[1,2] Patient-reported outcome (PRO) assessments normalize symptom reporting, reassure patients that physicians value their experience, and generate reliable symptom data.[3] Patient- and caregiver-reported psychosocial assessment and distress screening in pediatric oncology have allowed for targeted therapeutic interventions to improve quality of life.[4-7] For adult patients, methods to more accurately capture and act on symptoms presumably result in better control through enhanced supportive care, which leads to fewer sick clinic visits and hospitalizations, the avoidance of medical escalation, and a better experience for the patient.[1]

Although such benefits may also apply to pediatric patients, little research has explored the routine clinical use of longitudinal patient-reported symptom monitoring in pediatric oncology, even though symptoms from pediatric cancer treatment result in poor quality of life, morbidity, and sometimes death.[8] Furthermore, adult data cannot simply be extrapolated to pediatrics because children have different cancers than adults,[9] experience different symptoms, receive more intensive treatment for a longer duration, are more routinely hospitalized, and are likely not the primary drivers of their health care.

The Pediatric Patient-Reported Symptom Tracking in Oncology (Pedi-PReSTO) study evaluated the feasibility of conveying patient- and caregiver-reported symptom information to the treating providers of pediatric patients hospitalized for planned chemotherapy by examining the usage rate as the primary outcome. To our knowledge, this is the

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first study deploying the use of patient-reported symptom monitoring in hospitalized pediatric patients with cancer for routine clinical care.

MATERIALS AND METHODS

Participants

Pedi-PReSTO was approved by the institutional review board of the Children's Hospital of Philadelphia. Eligibility included being 7 to 18 years old, being developmentally and cognitively capable of self-reporting, being English-literate, having a planned chemotherapy admission for the treatment of malignancy or conditioning for hematopoietic stem cell transplantation (HSCT) at the Children's Hospital of Philadelphia, and having an anticipated hospitalization of at least 48 hours. Caregivers were required to read and understand English. Participants also included the patients' inpatient care teams during hospitalization, who received the patient symptom reports and were asked to provide acceptability feedback.

Patient Symptom Report and Electronic Platform

A self-reporting symptom survey for pediatric patients and their caregiver proxy reporters was built with questions from the Pediatric Patient-Reported Outcomes version of the Common Terminology Criteria for Adverse Events (Ped-PRO-CTCAE), a validated symptom item library[10-15] of symptom-based adverse events experienced by children and adolescents undergoing cancer therapy. Patient- and caregiver-specific versions are available to allow for self-report or proxy report. For each symptom in the Ped-PRO-CTCAE, up to 3 individual items are included, and they represent the attribute of frequency, severity, or interference with daily activities.[12] Each question has 4 response options, which are scored from 0 to 3, with 3 representing the highest frequency, severity, or interference. For this study, a 1-day reference period was used. Ten common cross-cutting symptoms were selected for administration from the Ped-PRO-CTCAE on the basis of published reports, patient focus groups, and clinician consensus. These included anorexia, nausea, vomiting, diarrhea, constipation, pain, mucositis, fatigue, headache, and insomnia.[16] The survey was provided in English only because the translation of the Ped-PRO-CTCAE into other languages is currently in progress.

The Ped-PRO-CTCAE was electronically administered via REDCap.[17,18] The survey followed best practices for usability and data visualization and was optimized to the device type. Surveys were accessible from any internet-connected device with a specific link and username and required approximately 5 minutes to complete.

Symptom information electronically elicited from the patient and the caregiver was downloaded from REDCap and processed with a Microsoft Excel macro to generate a standardized report[19] for clinicians (Supporting Fig. 1). The report included a graphical representation of longitudinal data showing baseline and subsequent symptoms. High-grade (rating of 2 or 3), worsening, or improving symptoms were highlighted with graphs that included that day's report as well as the preceding days' available data (up to 2 weeks) to identify trends. Raw symptom data for all symptoms reported in the preceding 2 weeks were also included.

Procedures

Eligible participants were approached within the 14 days before or on the day of the planned admission. Participating caregivers and 18-year-old patients signed consent forms, whereas younger patients provided assent in addition to caregiver consent. On the day of admission, patients and caregivers (as proxy reporters) completed a symptom questionnaire to communicate the baseline symptoms to the care team. Caregivers (and patients, if they had their own device) were offered a choice of receiving daily reminders with a link to the survey via email or text message; the reminders were sent at 8 AM each morning. They could report symptoms when they were prompted by a reminder or at their discretion. A study-provided iPad was available for those who did not possess their own internet-connected mobile device.

Patients and caregivers continued to receive daily electronic reminders until they were discharged, transferred to intensive care, died, or voluntarily withdrew. Participants who did not provide at least 1 symptom report in a 3-day period were verbally reminded by study staff and offered the opportunity to report symptoms with a study-provided iPad. Standardized symptom reports were emailed via encrypted individual emails as PDFs to frontline and attending clinicians by 10 AM each day if the patient or caregiver had completed the survey by that time. If symptom information was provided after 10 AM, it was emailed to the clinical team within 2 hours of submission. No guidance was provided to the clinician regarding the use of patient-reported symptom information in accordance with

work performed in the adult population[1,20,21] and with the pilot nature of this study.

Descriptive and Outcome Measures

Patients/caregivers

At the baseline, caregivers and patients completed basic demographic information. To evaluate factors affecting the feasibility of electronic capture of symptom information, participants provided data about their access to technology at home, cellphone data plans, and internet usage. Hospitalization duration was determined from the electronic health record.

To evaluate patient/caregiver usage of the system, patients and their caregivers received personalized reminders, and the respondent type (patient or caregiver) for a completed report was tracked. The percentage of patients and caregivers who logged in at least once during a hospitalization was tabulated, as was the proportion of hospital days with completed surveys from either participant.

To determine acceptability, patients and caregivers completed a questionnaire within 4 weeks after the hospitalization. Caregivers and patients older than 12 years received 22-item questionnaires, whereas younger patients completed simplified 12-item questionnaires. Questions were patient- or caregiver-specific, were adapted from measures used in prior related research,[22] and had Likert-type scale responses. Patients older than 12 years and caregivers were also asked open-ended questions to elicit their study experience.

Clinicians

Clinicians received 2 types of web-based questionnaires during their patients' participation in the study. The first included 5 questions sent via an emailed link to the frontline clinician within 4 hours of the receipt of each emailed symptom report. This determined what, if any, clinical action was taken in response to receiving the patient symptom report. The second questionnaire, assessing clinician acceptance of the patient symptom self-r eporting system, was distributed 6 months after study initiation to clinicians who had received at least 2 symptom reports. The 8-item anonymous questionnaire included questions with Likert-type scale responses and open-ended questions (Supporting Fig. 4).

Statistical Analysis

Descriptive statistics tabulated the proportion of patients and caregivers who completed symptom surveys after the baseline, the proportion of hospital days with symptom reports completed by patients and caregivers, and the clinical actions taken in response to symptom reports. The usage rate, defined as the proportion of dyads for which a symptom report was submitted on at least half of all hospital days, was calculated and compared with the a priori feasibility threshold of 75% per prior related research in adults.[20] The relationships between the symptom reporting participation rate (ratio of days with a completed symptom survey to hospital days) and baseline patient/caregiver characteristics (age, cancer type, internet usage, caregiver education and employment status, caregiver-reported patient academic performance, and patient internet usage) were assessed via negative binomial regression. The symptom reporting participation ratio by hospital length of stay was compared with χ^2. Patient, caregiver, and clinician acceptability questionnaire responses were tabulated, and free-text entries were coded and categorized with standardized qualitative methods.[23]

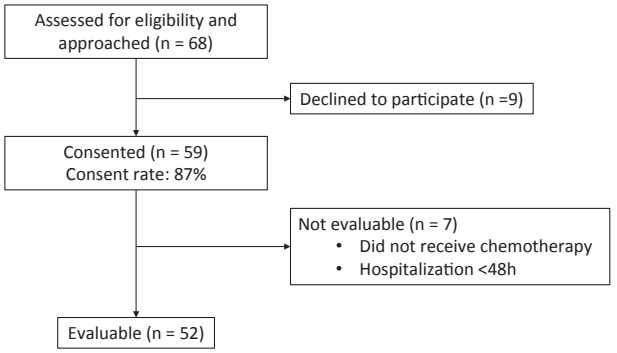

Figure 1. Patient enrollment.

RESULTS

Enrollment and Patient and Caregiver Characteristics

Of 68 patient/caregiver dyads approached over a 12-month period, 59 (87%) agreed to participate. Reasons for nonparticipation included no benefit (n = 3), too much work (n = 3), and not interested in research (n = 1). Of the 59 dyads, 7 (12%) were unevaluable because they did receive chemotherapy during admission or were discharged in less than 48 hours (Fig. 1).

Table 1 lists baseline characteristics. The median patient age was 11 years (range, 7-18 years), the sex distribution was equal, and the majority (70%) had a diagnosis of a hematologic or solid malignancy. Nearly all patients (98%) had access to home internet, and most (90%) possessed their own portable internet-connected device (100% of caregivers possessed a portable internet-connected device). All participants opted to receive study reminders on their own (or their caregiver's) internet-connected devices instead of a study-provided iPad.

TABLE 1. Baseline Characteristics of Patients and Caregivers

Patients (n = 52)		
Age, median (range), y		11 (7-18)
Female sex, No. (%)		26 (50)
Length of stay, median (range), d	Total cohort	4d (2-42)
	Hematologic malignancy	4.5 (2-38)
	Solid malignancy	4 (2-8)
	Neurologic malignancy	3.5 (2-14)
	HSCT	18.5 (7-42)
Race, No. (%)	White	33 (63)
	Black	9 (17)
	Asian	4 (8)
	Other	3 (6)
	Missing	3 (6)
Ethnicity, No. (%)	Hispanic, Latino, or Spanish origin	6 (12)
Cancer type, No. (%)	Hematologic malignancy	18 (35)
	Solid malignancy	18 (35)
	Neurologic malignancy	8 (15)
	Need for HSCT	8 (15)
Patient owns internet-connected device, No. (%)		47 (90)
Caregiver owns internet-connected device, No. (%)		52 (100)
Internet at home, No. (%)		51 (98)
Time patient spends on internet, No. (%)	<1 h/d	1 (2)
	1 to <2 h	18 (35)
	2 to <4 h	12 (23)
	4+ h	20 (38)
Caregivers (n = 52)		Value
Age, median (range), y		46 (34-63)
Female sex, No. (%)		38 (73)
Race, No. (%)	White	35 (67)
	Black	9 (17)
	Asian	4 (8)
	Other	3 (6)
	Missing	1 (2)
Ethnicity, No. (%)	Hispanic, Latino, or Spanish origin	6 (12)
Relationship	Mother	36 (69)
	Father	14 (27)
	Other	1 (2)
Education level, No. (%)	High school graduate	11 (21)
	Some college	15 (29)
	College degree	13 (25)
	Graduate degree	11 (21)
Employment, No. (%)	Full- or part-time	30 (58)
	On leave, unemployed, or retired	20 (38)
Time caregiver spends on internet, No. (%)	<1 h/d	22 (42)
	1 to <2 h	8 (15)
	2 to <4 h	12 (23)
	4+ h	8 (15)

Abbreviation: HSCT, hematopoietic stem cell transplantation.

Nearly all asked to receive text reminders; only 1 participant, a caregiver, opted for email reminders.

Electronic Symptom Reporting During Hospitalization

All 52 evaluable patients and caregivers completed a baseline symptom survey. Patients submitted an average of 4 symptom reports during hospitalization (median, 3; range, 0-40); caregivers submitted an average of 5 (median, 3; range, 0-39). Four of the 52 patient/caregiver dyads (8%) did not complete postbaseline surveys. Among the 48 who logged in during hospitalization, the majority of patients (30 of 48 [63%]) and caregivers (32 of 48 [67%]) submitted symptom surveys on at least half of the days they were hospitalized. Approximately one-third of patients and caregivers (17 of 48 and 15 of 48, respectively) submitted symptom surveys every day of hospitalization. The overall usage rate was 81% (95% CI, 0.67-0.91), and 54% of patient/caregiver dyads (95% CI, 0.39-0.68) submitted a symptom report on every day of hospitalization.

Figure 2 shows the proportions of patients and caregivers who completed symptom surveys at least once during every 3-day period of their hospitalization (for daily results, see Supporting Fig. 2). Early in the admission, survey completion was relatively even among patients and caregivers, whereas later during hospitalization, more surveys were completed by caregivers. When the length of stay was divided into tertiles (2-4 vs 5-6 vs ≥7 days) and the survey completion ratio was examined for each participant type, longer hospitalizations had lower completion ratios. For short admissions, patients completed a total of 52 reports over 83 eligible hospitalization days (63%); for medium-length admissions, the completion ratio was 32/48 (67%); and for long hospitalizations, the completion ratio was 138/317 (44%; $P = .0004$). For caregivers, the completion ratio was 53/83 for short admissions (64%), 34/48 (71%) for medium admissions, and 169/317 (53%) for long admissions ($P = .0287$).

Nearly all surveys (n = 460 [96%]) were completed via the patient's or caregiver's personal device after a text message or email reminder prompt, with less than 5% of reports submitted on a study iPad in response to a verbal reminder (n = 18 [3.8%]). Although not elicited systematically, technological reasons provided to the research staff for not completing reports included not receiving reminders as expected (usually related to phone settings that blocked unknown numbers), forgetting their log-in details, and the system not saving responses despite completion of the symptom questionnaire.

Use by Patient and Caregiver Baseline Characteristics

In a univariate analysis, patients and caregivers were significantly less likely to complete symptom reports if their reason for admission was HSCT (Incidence rate ratio [IRR], 0.009; 95% CI, 0.007-0.096). The modest sample size limited the ability to detect more modest associations,

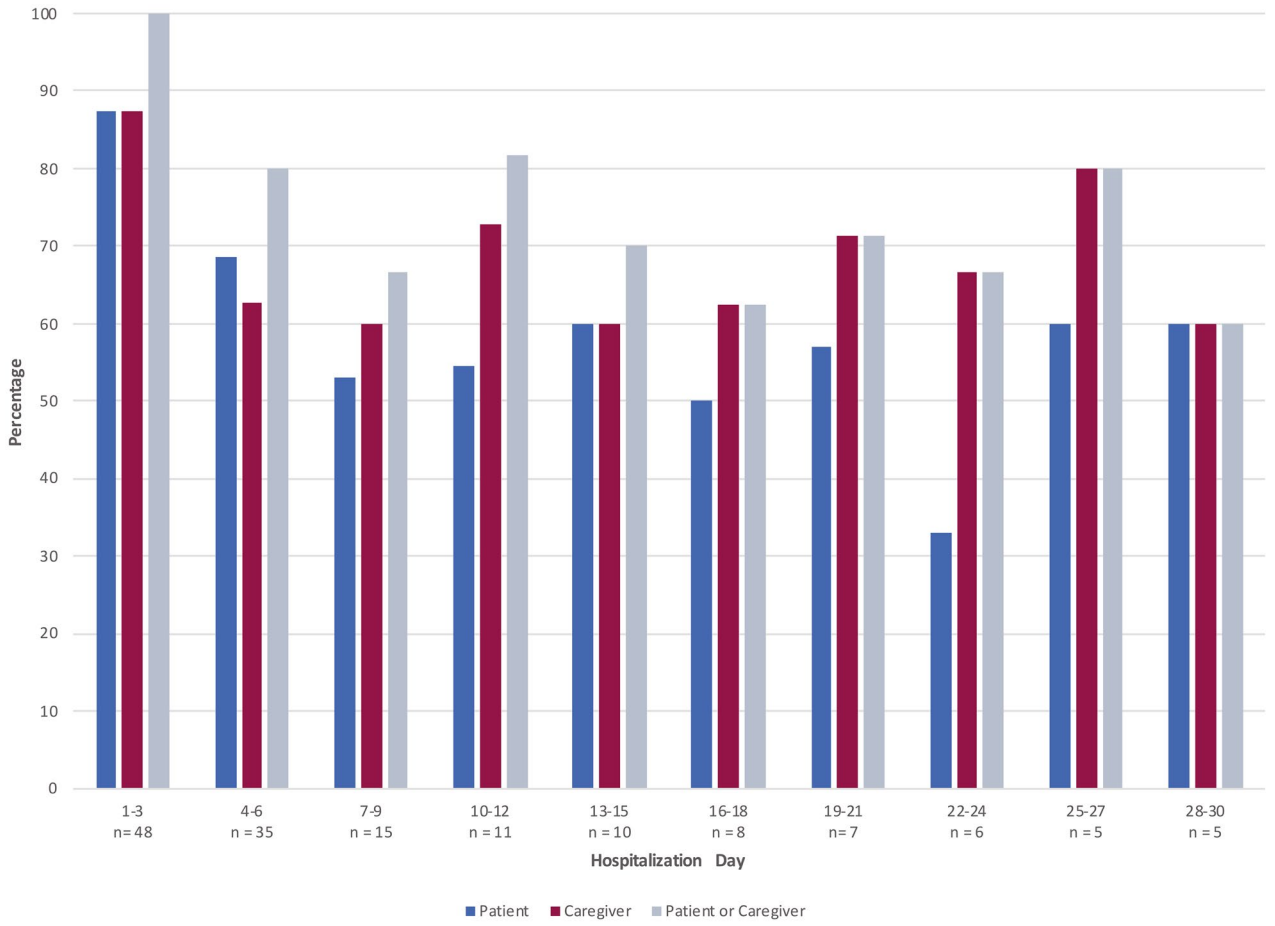

Figure 2. Proportions of patients and caregivers providing at least 1 symptom report per 3-day period of hospitalization. For example, on days 1 to 3, there were 48 available child participants and during that time either a child or a caregiver (or both) completed an assessment for all participants (100%). Five child participants remained hospitalized until day 30; for 60% of these participants (n = 3), either a child or a caregiver (or both) completed an assessment during days 28 to 30.

although IRR estimates suggested some possibilities (Supporting Table 1), including patient race, academic performance, possession of their own internet-connected device, and daily internet usage (IRR, 0.136; 95% CI, 0.0004-42.014), as well as caregiver race, relationship with the patient, and employment status, although none were statistically significant. Patient age and sex and caregiver age, educational status, and cellphone data plan were not associated with log-in frequency.

Clinician Response to Symptom Reports

Treating clinicians received 297 patient symptom reports and returned 130 clinical action questionnaires (44% response rate). Changes in care occurred in response to 62 discrete symptom reports (21%) from 27 patients. Actions taken included the following: counseled use of medications already prescribed (in response to 49 reports [16.5%]), returned to discuss symptoms of interest (39 [13%]), prescribed new medications (27 [9%]), consulted another service (5 [2%]), ordered imaging tests (3 [1%]), ordered laboratory tests (2 [1%]), and performed actions not otherwise specified (2 [1%]). No modifications to chemotherapy were reported.

Patient and Caregiver Acceptability

After hospitalization, 33 patients (63%) and 36 caregivers (69%) completed acceptability questionnaires (2 died, 2 withdrew participation, and the remainder were missing; Fig. 3). On the basis of structured response questions, the majority of patients found the process easy (24 of 33 [73%] agreed a lot/completely) and felt that the questions were important (26 of 33 [79%] agreed a lot/completely). Forty percent (13 of 33) agreed with the statement that electronically reporting their symptoms helped

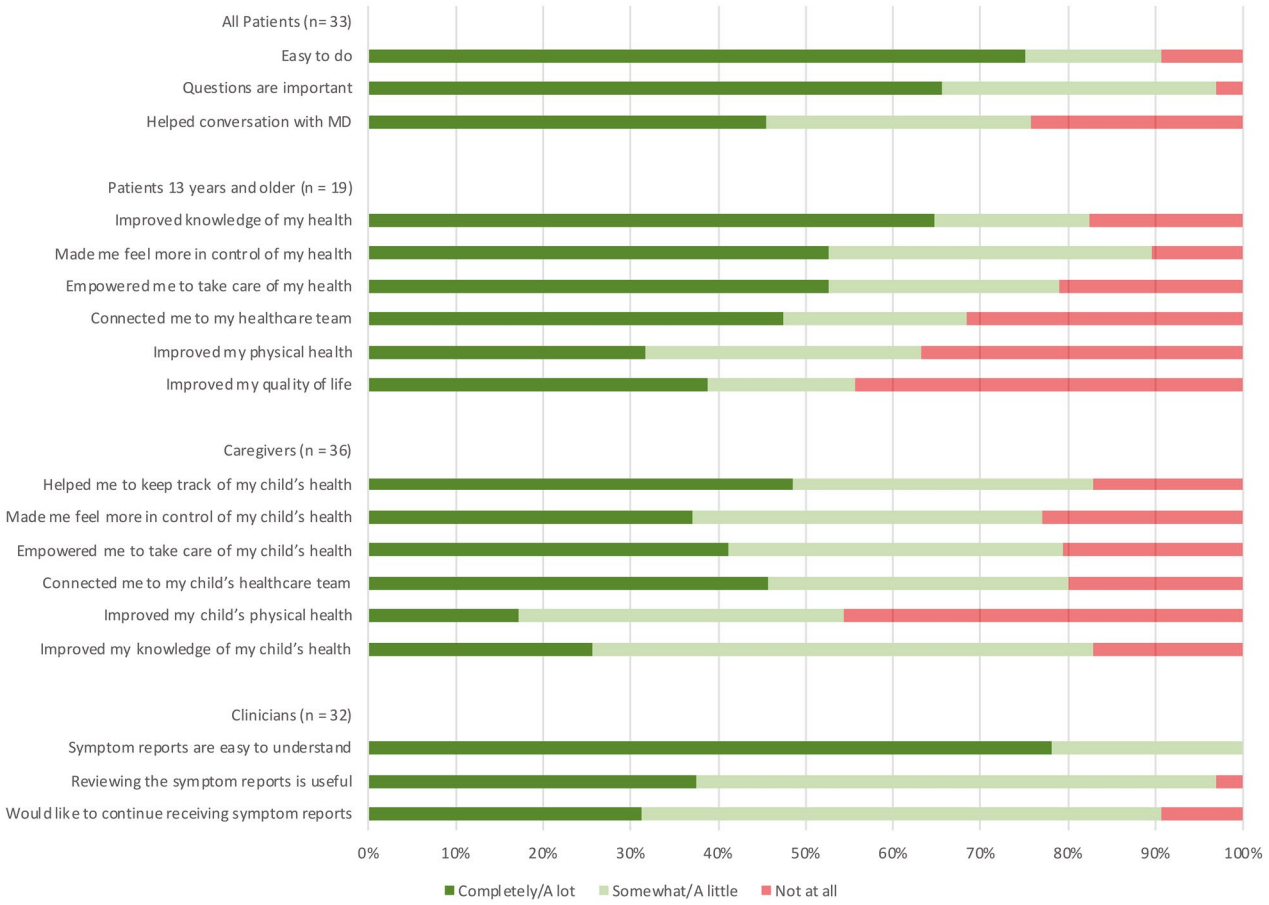

Figure 3. Patient, caregiver, and clinician experience with daily electronic symptom reporting.

conversations with their physicians "a lot" or "completely" (15% [5 of 33] endorsed that it helped "somewhat"). Forty-nine percent of caregivers (17 of 35) reported that symptom reporting helped them to keep track of their child's health, but only 26% (9 of 35) reported that it improved knowledge of their child's health, in contrast to 65% of patients (11 of 17) who strongly agreed that it improved knowledge of their own health. Approximately half of patients reported strong agreement with being more in control of their health (53% [10 of 19]) and empowered in their health (53% [10 of 19]) as well as a feeling of connection to their health care team (47% [9 of 19]). More patients (32% a lot/completely [6 of 19]) than caregivers (17% a lot/completely [6 of 35]) reported feeling that the process improved the patient's physical health, and 46% of caregivers (16 of 35) thought that symptom reporting did not improve their child's physical health at all. Similarly, 42% of patients (8 of 19) reported no improvement in their quality of life. Less than 20% of patients and caregivers (6 of 33 and 7 of 36, respectively) found the questions occasionally upsetting, with 1 patient and 1 caregiver reporting distress with the questions.

When they were stratified by age category, 78% of teenage patients answered that they agreed "a lot" or "completely" with the following question: "The questions asked me about feelings that I thought were important." However, only 47% of 7- to 12-year-old patients expressed that level of agreement ($P = .0386$). There was no difference by age in agreement about any other acceptability parameter.

In optional free-text entries about likes/dislikes of using an electronic system to report symptom information daily (Supporting Fig. 3), 15 patients (80%) responded about their specific likes; 6 of these 15 patients (40%) noted that providing symptom reports enhanced communication with their physicians and made them feel cared for, and 4 (27%) mentioned that it helped them to focus on their health and coping. When asked what they did not like, 8 of 15 (53%) responded positively about the experience: they noted no complaints and reported

TABLE 2. Themes Identified in Clinicians' Free-Text Responses Regarding Their Experience With Symptom Reports

Benefits	Downsides
New information or information pertinent to care (13)	Information already known from other clinical sources (9)
Trend symptom information over time (10)	Unpredictable timing of receiving reports (8)
Graphical presentation of symptoms (2)	Time constraints do not allow review of information (6)
Helps to understand the patient experience (2)	Not integrated with electronic medical record (6)
Enhanced communication (1)	Confusion if disagreement between report and other clinical assessments or proxy reporter (2)

Thirty-four providers responded. A number in parentheses is the number of times that an individual free-text response noted that theme.

that they had liked participating. Three patients (20%) raised concerns about the time involved, needing to report daily, and the fact that it prompted thinking about their experiences. Eighteen caregivers (50%) provided free-text responses; 9 of these 18 caregivers (50%) described the ability to track and better understand or pay attention to symptoms as a positive, with 6 of the 18 (33%) reporting enhanced communication and connectedness with the patient and/or medical team. Negatives included complaints about the clarity or applicability of the questions (4 [22%]), that completion was burdensome or tedious (3 [17%]), that the patient did not like completing symptom assessments (2 [11%]), that they experienced technical difficulty (1 [6%]), and that they did not know if the clinical team was using the information (1 [6%]).

Clinician Impressions

Thirty-four providers, including nurse practitioners (n = 10), physician hospitalists (n = 6), and attending oncologists (n = 18), responded to the acceptability questionnaire (an 81% response rate). The majority of clinicians found the reports easy to understand and useful, with some perceiving value in continuing to receive the reports after the conclusion of the study (Fig. 3). Clinicians noted both positive and negative aspects to receiving and using symptom reports, with themes detailed in Table 2. Clinician opinion varied regarding the pertinence of the information received within the symptom reports: the most commonly reported benefit was learning new information, or highlighting the specific importance of information, about a patient's symptoms; however, the most frequently mentioned downside was that no new information was elicited.

DISCUSSION

This study demonstrates that electronic symptom tracking by pediatric patients and their families during hospitalization for chemotherapy is feasible and that patient-reported information is of added value even in a highly monitored context. The a priori feasibility metric was met, and most participants, both patients and caregivers, self-reported on the majority of hospitalized days. Clinicians found patient-reported information easy to interpret and were willing to use the data in clinical practice to prompt discussions, provide counseling, prescribe medications, and obtain further testing or consultations.

The usage rate, defined as the percentage of patients with a submitted symptom report on at least half of all hospital days, was 81%, which exceeded the 75% feasibility threshold. However, some patients and caregivers demonstrated near daily utilization, whereas others self-reported only occasionally. The optimal frequency for eliciting self-reports in this context is unknown. Previous work[24] suggests that an element of patient adherence is feedback-related: if patients know that their data are actively used by their clinicians, they are more likely to provide it. No such formal feedback to patients existed in this study. Related research suggests that some patients are more amenable to these types of interventions than others.[25]

Patient and clinician feedback reported benefits, including normalizing the patient experience,[26] enhancing communication with the clinical care team,[20,27-29] engendering feelings of empowerment, and helping patients to cope with disease and treatment. This builds on previous work in other pediatric oncology populations in which intermittent symptom or health-related quality of life data were collected[30-36] or conveyed from patients to providers.[29,37] When patients were asked about the experience of electronic symptom reporting, their free-text responses were overwhelmingly positive, but structured response items displayed varying levels of agreement, with no specific benefit rising consistently above the rest. Furthermore, there was a differential noted between teenage patients and younger patients with regard to the importance of the symptom questions that they were asked. These differences highlight that more work must be done to understand how each group (patients vs caregivers, younger patients vs older patients, and individual patient groups) engages with this method of symptom self-reporting and what their expectations are with regard to it, as that will be essential to tailoring the process for maximum uptake, efficiency, and benefit to the patient.

Patients admitted for HSCT and their caregivers were significantly less likely to submit symptom reports than other patients; during longer admissions, there was a lower overall symptom report completion ratio, and there was more patient symptom report submission attrition over time than caregiver attrition. These findings may be driven by similar phenomena: perhaps as patients experience more symptoms, they report less because they are too sick. Alternately, if patients are expected to be more symptomatic during longer (eg, acute myeloid leukemia therapy) or more intense (eg, HSCT conditioning) admissions, the clinical care team may be more active in the surveillance of symptoms, and patients may feel that a self-reporting system is redundant. Identification of these reasons is important because it will inform whether symptom self-report is beneficial for these populations and, if so, how to increase the response rate for symptomatic patients. Future research should include qualitative investigations of the barriers and facilitators of symptom self-reporting in pediatric HSCT patients, as well as others with long hospitalizations, to better understand how to capture the child's voice in these settings.

Similarly to prior findings,[38] patients almost uniformly had access to cellphones, reported at least 1 hour of daily internet use, and had cellphone plans with robust data access. Although participants were from a large, tertiary care institution and may not be generalizable to all pediatric oncology patients, the ubiquity of these devices indicates that access to this type of technology is not a barrier to participation in PRO symptom monitoring.

There are several limitations of this study, including that it is a single-center study with a small sample size and that it is limited to hospitalized patients. Although most clinicians responded that the symptom reports were easy to interpret and were useful, similarly to other PRO utilization studies, they identified logistical challenges that interfered with consistent use.[24,39] These included time constraints, the unpredictability in knowing if (and when) they would receive a symptom report, and the lack of electronic medical record integration. Despite these barriers, changes in clinical care occurred in response to almost a quarter of symptom reports, and this indicates that clinicians will trust patient-reported symptom data sufficiently to act upon them. Because a majority of symptom reports were not associated with a clinical response, future work should focus on what factors determine whether a symptom report warrants a clinical action.

Standards exist for the representation of patient-reported data,[19] and those conventions were used; however, there is no clear guidance for the simultaneous display of pediatric and caregiver data. Also, as identified by participating clinicians (Table 2), 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.[40,41] To effectively integrate this type of information into the clinical workflow, particularly when conflicting patient/proxy data require clinician parsing, further investigation is warranted on methods for displaying and integrating pediatric patient and proxy data.

How patients feel and function is critical to understanding the impact of cancer treatments, and determining how best to incorporate children's voices into their care is essential. Although collection of PROs in children is a priority of the National Academy of Medicine,[42] clinical utilization of this information remains uncommon. This study bridges that gap with a proof of concept demonstrating that pediatric patients and their families are willing and able to provide this information in the hospital environment and that clinicians are receptive to using the data to adjust patient management. Further work should determine appropriate reporting intervals, establish how to use patient and caregiver reports simultaneously, create best practices for electronic medical record integration, evaluate the use of these measures in the outpatient context, correlate these data with resource utilization, and determine ways to optimize engagement for patients, caregivers, and clinicians while measuring this strategy's impact on clinical outcomes.

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CONFLICT OF INTEREST DISCLOSURES

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AUTHOR CONTRIBUTIONS

Allison Barz Leahy: Conceptualization, methodology, investigation, resources, funding acquisition, validation, formal analysis, and

writing–original draft. **Lisa A. Schwartz:** Methodology, formal analysis, and writing–r eview and editing. **Yimei Li:** Methodology, formal analysis, and writing–r eview and editing. **Bryce B. Reeve:** Conceptualization and writing–r eview and editing. **Justin E. Bekelman:** Formal analysis and writing–r eview and editing. **Richard Aplenc:** Conceptualization, funding acquisition, supervision, and writing–review and editing. **Ethan M. Basch:** Conceptualization, methodology, formal analysis, writing–original draft, and writing–review and editing.

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