

AHRQ Grant Final Progress Report

Title of Project: Getting on the Same Page: Leveraging an inpatient portal to engage families of hospitalized children

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Abstract

Purpose and scope

Federal regulations require that patients and caregivers have immediate access to notes written by their inpatient clinicians. Our aim was to describe the use of and parent and clinician experiences with sharing notes during pediatric oncology hospitalization.

Methods

This pilot study was conducted with parents of children <12 years and clinicians on an oncology service from 8/2022-6/2023. Parents were provided all inpatient notes and an orientation video on a bedside tablet. EHR data captured note use and surveys and interviews in-depth information about experiences. Quantitative data were summarized descriptively; interviews were analyzed using thematic analysis.

Results

Of the 25 enrolled parents, all viewed at least one note with an average accessing 32 notes during their child's stay. A majority were satisfied with notes and reported understanding their content (both 92%). Most agreed that notes helped them understand their child's reason for admission (84%) and remember their discharge goals (80%). One in five parents reported a potential safety concern in notes, of which 60% were confirmed safety issues. Eight themes described parent experiences, including notes: improved understanding of diagnosis/plan, increased situational awareness, enhanced communication, empowered parents as advocates, and decreased parental anxiety. Parents also described managing medical terminology and excess information, which drove some to seek information online and incited worry. Future efforts should focus on improving note clarity and accessibility and developing systematic ways to capture and address parent-identified safety issues in oncology and beyond.

Keywords: Electronic medical records; patient portals; pediatrics; hospitals; oncology

Purpose

Medical errors occur in up to 55% of pediatric hospitalizations and children suffer harm from errors at a rate 3 times that of adults.¹ Children are particularly vulnerable due, in part, to reliance on their doctors and parents to exchange information about their care and work together to identify and intercept errors.² While sharing honest, unbiased health information with parents is endorsed by the American Academy of Pediatrics as critical to improving pediatric patient safety,³ hospitalizations present unique challenges for parents to engage. Often sleep deprived and meeting their child's inpatient doctor for the first time, parents are bombarded with information during morning rounds, seldom supplemented with written materials, and expected to make quick, informed, high-stakes decisions. As a result, substantial information gaps exist. For example, in one study, up to 45% of parents had a different understanding of their child's care plan than their child's inpatient doctor.⁴

To improve information transparency, our hospital was the first pediatric center to implement an inpatient portal (MyChart Bedside, Epic Systems) – a bedside tablet application that gives parents' real-time access to clinical information from their child's inpatient health record.⁵ Among the findings of a series of studies conducted by our research team to evaluate its implementation,⁶⁻⁸ we found that parents wanted the portal expanded to include access to their child's notes written by their child's clinicians,⁸ which detail their child's diagnoses, treatment, contingency and discharge plans. Studies suggest adult outpatients reading their clinic visit notes had improved understanding of their health condition⁹ and identified safety concerns, with 57% resulting in changes in care.¹⁰ Whether sharing inpatient notes would provide similar benefits for parents during their child hospitalization is unknown. As these portals rapidly become standard of care,⁵ there is a critical need to evaluate whether expanding them to include clinical notes will translate to benefits for children and their parents or instead lead to unintended negative effects, such as heightened parent anxiety and increased clinician workload.^{11,12}

The purpose of this project was to pilot test Bedside Notes – a new capability that we turned on within the preexisting inpatient portal to share all inpatient notes with parents during their child's hospitalization. Based on our preliminary data^{8,13} and promising findings of adult outpatient studies,^{9,10} our central hypothesis was that sharing the information within inpatient notes would improve parent understanding of their child's diagnosis and treatment plan and their ability to identify and intercept medical errors. Our objective was to measure the use of and parent and clinician experiences with Bedside Notes.

Scope

In this self-contained pilot study, we aimed to share inpatient notes with up to 40 parents of children <12 years old admitted to an oncology service at a quaternary children's hospital. We used mixed methods (electronic health record audit reports, surveys, interviews) to assess use of and experiences with notes.

Methods

Study design, setting and recruitment

In this single-center pilot study, we recruited clinicians and parents of children <12 years old admitted to an oncology service at a quaternary children's hospital from August 2022 to June

2023. A researcher screened for eligible parent participants through the EHR. Upon consent, a research coordinator administered an enrollment survey and gave the parent an iPad tablet with access to the MyChart Bedside application with the notes functionality turned on. The researcher reviewed the notes orientation video and how to access inpatient notes once they became available on the tablet. On the day of discharge, the research coordinator interviewed and surveyed enrolled parent participants about their experiences using Bedside Notes. Parent participants were given \$40 upon completion. We recruited clinicians assigned to the oncology service during the study period. Clinicians were surveyed in June 2023. Survey completion was voluntary; clinician respondents were not compensated for survey completion.

Intervention

We employed user-centered design to develop the Bedside Notes intervention (AHRQ K08; PI: Dr. Kelly), which includes: (1) inpatient notes shared in real-time through an inpatient portal application on a hospital-owned bedside tablet and (2) a notes orientation video for parents. Note-sharing on the tablets was enabled specifically for this study. Enrolled parent participants could view notes immediately after signature on the bedside tablets.

Measures and data collection

EHR audit reports were used to assess note use by parents. Surveys were used to collect basic demographic and clinical information along with parent and clinician experiences. Survey includes validated SEIPS survey items¹⁴ assessing the usefulness and acceptance of Bedside Notes and ambulatory OpenNotes items⁹ assessing parent and clinician experience with Bedside Notes (e.g., satisfaction with access and perceptions of the impact of notes on parent understanding of their child's health, care quality, documentation, workload, worry/anxiety). The ambulatory OpenNotes safety concern reporting tool¹⁰ was also included and modified for parent (vs. patient) reporting of safety concerns.

Researchers trained in qualitative methods conducted interviews with parents upon discharge. We utilized open-ended questions within a semi-structured interview guide to generate rich, contextual information from parents about their experience accessing inpatient notes, including benefits and challenges.

Data Analysis

We used descriptive statistics to describe notes use and survey data. Interview recordings were transcribed by a professional transcription service. A researcher deidentified the transcripts and uploaded them to Dedoose for data management. To corroborate the data during analysis and minimize disciplinary biases, three research group members contributed to data analysis. We conducted an inductive and deductive thematic analysis¹⁵ of transcript data. Two researchers independently reviewed the transcripts, noting benefits and challenges of accessing notes. They then coded each transcript individually and reached consensus over any discrepancies, always referring to the data.

Results

Principal Findings and Outcomes

Of 78 unique patients admitted during the study period, 74 were screened, and 36 were eligible and approached. 30 parents or caregivers were enrolled, 5 were lost to follow-up, and 25 were included in analysis. Characteristics of included parents and children are shown in Table 1.

Table 1. Parent and child characteristics, n=25

Characteristic	n	%
Age, years		
18-34	12	48
35-54	13	52
Role		
Mother	23	92
Father	2	8
Race and ethnicity		
Asian	1	4
Black or African American	2	8
Hispanic or Latino	3	12
White	19	76
Primary language		
English	23	92
Other	2	8
Education		
8th grade, high school or GED	14	56
4-year college or more	10	40
Do not wish to answer	1	4
Household income		
Less than \$49,000	7	28
\$50,000-99,999	10	40
\$100,000 or more	7	28
Do not wish to answer	1	4
Read clinical notes before		
Yes	9	36
Health literacy (BRIEF) Score		
Inadequate/Marginal	6	24
Adequate	19	76
Child overall health		
Excellent/very good	8	32
Good	8	32
Fair/poor	9	36
Number of prior hospitalizations		
1-2	9	36
3-6	9	36
>6	7	28

All parent participants viewed at least one note and 96% accessed 2 or more notes during their child's hospital stay, a 14-fold increase from 9% prior to intervention implementation. An average accessed 32 notes during their child's stay. A majority were satisfied with notes and reported understanding their content (both 92%). Most agreed that notes helped them understand their child's reason for admission (84%) and remember the daily plan and discharge goals (both 80%). In all, 20% of parents reported possible inaccuracies in notes, of which 60% were confirmed safety issues (e.g., inaccurate medication, exam findings, discharge instructions).

Parents described eight themes regarding their experience, including note access: improving their understanding of their child's diagnosis and plan, increasing situational awareness, enhancing communication with family and care team, empowering parents as advocates, decreasing anxiety, managing medical terms and excess information, driving information seeking online, and inciting worry. Themes and illustrative quotes are shown in Table 2.

Table 2. Themes and illustrative quotes from parent participants

Theme	Illustrative quote
1. Improving understanding of their child's diagnosis and care plan	<i>"Being able to see [information] written down, that was immensely helpful in helping us understand it" (13).</i>
2. Increasing situational awareness	<i>"I like having the notes because then I know everything that's going on and what every [clinician] thinks of the situation that we're in ... it's good because then I know how everybody else is feeling and then, you know, I'm kind of on the same page with everything that's going on" (7).</i>
3. Enhancing communication with family members and the care team	<i>"Being able to look through the notes when we hand off from one parent to the next, who's staying the night, it helped out immensely. It answered 90% of all my questions that I had, and it also helped me formulate questions to ask the doctors when I see them next" (5).</i>
4. Empowering parents as advocates for their child	<i>"[Note access] helps the parents feel like they're more involved. It also gives us a way of making sure that everything is accurate. I'm not trying to say that people are neglectful on purpose, but we are all human, and mistakes do happen. So, it's okay for parents to be able to look at [notes] and be able to make their, you know, their voices heard as well and then be able to keep up [with the care team]" (19).</i>
5. Decreasing anxiety	<i>"Being able to have these notes is definitely helpful, because my mind has not calmed down at all ... And it won't for a while. So, you know, as many notes, as many summaries, information that can be easily and quickly accessed is like super helpful, especially for</i>

Theme	Illustrative quote
	<i>someone like me, who forgets things easily, especially in a time of chaos” (16).</i>
6. Managing medical terminology and excess information	<p><i>“I think the only downside to [notes] is that, not being a medical person ... you don’t always understand what you’re reading, so just having to keep that in mind, like write my questions down ... Because I don’t know all that lingo and jargon” (12).</i></p> <p><i>“There’s always a fine line between communicating enough and then over communicating like all the extra details ... especially when you’re here longer for your hospital stay, it’s just flooded then with like all the nursing shift progress notes that have been going on ... So, if you’re like looking for what you want, you have to just get past all of that” (9).</i></p>
7. Driving information seeking online	<i>“If there was a specific word that I didn’t know, I would just Google it then on my phone just because I didn’t know what it meant. And then I would understand what it meant in that context” (22).</i>
8. Inciting worry	<i>“[Reading information in notes] makes you worry even worse, puts thoughts in your mind that a parent shouldn’t ... or anybody should never have to go through cancer, let alone have it be your [child] going through it at six months old. So just reading more about the tumor doesn’t ease your thoughts when you don’t have a doctor, or [the patient’s] doctor, in front of you to put, you know, the correct thoughts there” (3).</i>

Of 51 clinician surveys administered, 48 were completed (response rate 94%). Clinician respondent roles are shown in Table 3. Fewer were satisfied with sharing notes (33%). Clinician acceptance of sharing their notes was moderate (mean=5.91 [SD= 2.16], 1-Dislike very much, don’t want to continue sharing at our hospital, 10-Like very much, eager to continue sharing at our hospital). Half of clinician could not estimate the proportion of parents who had read notes because no or very few parents ever mentioned them. Some reported spending more time answering parent questions (27%) and writing, dictating or editing their note (31%); however, few felt that parent access to notes increase the time spent on rounds (8%). Almost 40% were less candid in their documentation and 25% reported that it made their job more difficult. In total, 35% agreed that notes should continue to be available on the bedside tablets, 42% were neutral, and 23% disagreed.

Table 3. Clinician job position, n=48

Job position	n	%
Attending physician	6	12
Fellow physician	2	4

Job position	<i>n</i>	%
PGY 1 (intern physician)	11	23
PGY 2 (2nd year resident physician)	7	15
PGY 3 (3rd year resident physician)	7	15
Nurse practitioner	2	4
Staff RN	12	25
Pharmacist	1	2

Discussion

The implementation of Bedside Notes within the inpatient portal aimed to bridge existing information gaps by providing parents with real-time access to their child's inpatient notes. Parents accessing Bedside Notes reported improved understanding of their child's diagnosis and care plan, increased situational awareness, and enhanced communication with the care team. Some parents identified inaccuracies in notes of which over half were confirmed patient safety issues. The identification of safety issues by parents emphasizes their potential role as active contributors to patient safety in the inpatient setting. However, clinician perspectives revealed challenges, including increased time spent on writing notes and answering questions and concerns about the quality of documentation. Striking a balance between enhanced transparency and addressing clinician concerns will be crucial in the continued implementation of Bedside Notes.

Limitations

This single-center pilot study focused on a small population of English-speaking parents of children <12 years old admitted to an oncology service, which limits generalizability and may impact the broader applicability of the findings. The study was limited to experiences accessing notes during hospitalization. The longer-term effects and sustainability of the intervention were not assessed and are important areas for future investigation.

Conclusions

The initial study of the Bedside Notes intervention demonstrated its potential to positively impact parent engagement and understanding in pediatric inpatient care. While acknowledging limitations, the findings suggest that sharing inpatient notes can empower parents and may contribute to safer and more transparent care. Further research and thoughtful policy implementation may enhance the broader adoption and effectiveness of similar interventions in pediatric settings.

Significance and implications

Findings suggest that sharing inpatient notes with parents may have positive effects on parent engagement, understanding, and communication in the inpatient oncology setting. Bedside Notes may also empower parents as advocates for their children, potentially contributing to improved patient safety. Despite the positive outcomes, careful consideration should be given to managing medical terminology and addressing potential sources of anxiety induced by accessing complex medical information.

Further research should explore the impact of Bedside Notes in different pediatric populations and medical specialties to understand its generalizability. Long-term studies are

needed to assess sustained effects and any evolving challenges or benefits. These preliminary data will be used to conduct a comparative effectiveness study evaluating the effect of Bedside Notes on equitable access to notes, parent engagement and patient outcomes. Our results will also inform the design, implementation, and evaluation of future note sharing interventions and learning health system activities involving patients and families. As health IT meaningful use requirements evolve, this work will also inform organizational leaders, industry stakeholders and policy makers in the (re)design of new health IT solutions to leverage patient and family engagement to improve care quality and patient safety.

List of Publications and Products

Presentations

“Leveraging the voices of families to improve pediatric health systems” Presented at Cincinnati Children’s Division of Hospital Medicine’s Research Meeting. Dec 9, 2021. Cincinnati, OH.

“Help! Parents can read my notes: Pearls and pitfalls of note sharing” Presented at Maimonides Children’s Hospital’s Grand Rounds. Mar 15, 2022. Brooklyn, NY.

“Sharing clinical notes with families during pediatric hospitalization” Presented at the Wisconsin Health Literacy Summit. Apr 6, 2022. Madison, WI.

“Sharing inpatient clinical notes with patients and caregivers: Too early or long overdue?” Payne TH, Rosenbloom ST, Vawdrey DK, Kelly MM. Invited Panel, AMIA Clinical Informatics Conference. May 25, 2022. Houston, TX.

“Help! Parents can read my notes: Pearls and pitfalls of note sharing.” Plenary, Pediatric Hospital Medicine Conference. Jul 30, 2022. Lake Buena Vista, FL.

“Help! Parents can read my notes: Pearls and pitfalls of note sharing.” Visiting Professorship, Children’s Hospital of Philadelphia. Oct 18, 2022. Philadelphia, PA.

Posters

McCallie K, Sabaru C, Kelly M. Pediatric perspectives on OpenNotes from inpatient, outpatient, and neonatal intensive care families. American Academy of Pediatrics National Conference and Exhibition. Oct. 22, 2023. Washington, DC.

Kieren MQ, Smith CA, Brown R, Ehlenfeldt B, Lee-Miller C, Limjoco J, McArdle K, Redalen J, Uhing A, Veit A, Velazquez R, Kelly MM. Parent experiences accessing inpatient clinical notes on a pediatric oncology service. Pediatric Academic Societies’ Annual Conference. Toronto, Canada. *Under review*

Manuscripts

Golden BP, Kelly MM, Olson APJ. Defining the Gold Standard: What is Success in Electronic Health Record Documentation? *J Hosp Med.* 2022 Jan;17(1):71-72. doi: 10.1002/jhm.2737.

Kelly MM, Kieren MQ, Coller RJ, Pitt MB, Smith CA. Pediatric Open Notes: Caregiver Experiences Since the 21(st) Century Cures Act. *Acad Pediatr*. 2023 Oct 2;. doi: 10.1016/j.acap.2023.10.001.

Sprackling CM, Kieren MQ, Nacht CL, Moreno MA, Wooldridge A, Kelly MM. Adolescent Access to Clinicians' Notes: Adolescent, Parent, and Clinician Perspectives. *J Adolesc Health*. 2024 Jan;74(1):155-160. doi: 10.1016/j.jadohealth.2023.08.008.

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Velazquez R, Kieren MQ, Smith CA, Brown R, Ehlenfeldt B, Lee-Miller C, Limjoco J, McArdle K, Redalen J, Uhing A, Veit A, Kelly MM. Dual Narratives: Parent and Clinician Reflections on Sharing Inpatient Clinical Notes in Pediatric Oncology. In preparation.

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