Family Perception of OpenNotes in the Neonatal Intensive Care Unit

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Abstract

Background   OpenNotes, or sharing of medical notes via a patient portal, has been studied extensively in the adult population, but less in pediatric populations, and even more rarely in inpatient pediatric or intensive care settings.

Objectives   This study aimed to understand families' interaction with and perception of inpatient hospital notes shared via patient portal in a community Neonatal Intensive Care Unit (NICU).

Methods   At the end of the NICU discharge education, completed in the patient portal before discharge, families were offered an anonymous survey on OpenNotes.

Results   Out of 446 NICU patients from March 16, 2022 to March 16, 2023, there were 59 respondents (13%). Race was primarily Asian (48%), and English was the predominant language (93%). Most families indicated that the notes were "very or somewhat easy to understand" (93%). Seventy-three percent of respondents felt much better about the doctor(s) after reading the notes, and 53% contacted the physicians about something in the notes. Six (16%) felt that OpenNotes were more confusing than helpful.

Conclusion   To the authors' knowledge, this is the first study on NICU families' perceptions of OpenNotes, which indicated positive interactions with the doctors' daily progress notes and gave important suggestions for improvement.

Keywords
► clinical documentation and communications
► notes
► patient–provider
► internet portal
► neonatology
► inpatient
► intensive and critical care
► 21st Century Cures Act

Background and Significance

Compliance with the information blocking provisions of the 21st Century Cures Act final rule[1] (Cures Act) has led to sharing of clinical notes electronically to patients (and their caregivers, or proxies). OpenNotes, or sharing of medical notes via a patient portal, has been studied extensively in the adult population,[2] but less in pediatric populations,[3,4] very rarely in inpatient pediatric settings,[4] and not at all in the Neonatal Intensive Care Unit (NICU). Leaders in neonatology state that, "Access and input from the most invested parties in a baby's life is typically healthy," but have also acknowledged that transparency should be balanced with careful privacy consideration of the release of the birth parent's health information within the babies' records.[5] One NICU has assessed the impact of compliance with the Cures Act, especially test result release, on clinicians in the NICU.[6] However, the literature does not include, to the authors'

knowledge, any description of families' experience with OpenNotes in the NICU.

Objectives

This study aimed to understand families' interaction with and perception of the inpatient hospital notes shared via the hospital's patient portal using an anonymous survey in a community NICU.

Methods

El Camino Health (Mountain View, CA) has a 20-bed, community level 3 NICU[7] with approximately 4,500 newborn deliveries and 400 NICU admissions per year. This NICU provides care to infants less than 1,000 g at birth, less than 28 weeks' gestational age, and those with severe or complex illnesses, including the need for high-frequency ventilation or nitric oxide. This unit is staffed by board-certified neonatologists and does not utilize advanced practice providers but does have pediatric trainees. Patient characteristics and demographics were extracted from electronic health record (EHR) administrative data.

The doctors' daily progress notes, as well as the Admission History and Physical, and all nursing and ancillary notes are available in the EHR patient portal, MyChart®/MyChart® Bedside (Epic Systems, Verona, WI), starting at hospital admission. In anticipation of and preparation for the patients' eventual discharge, all NICU patients are assigned discharge education in the patient portal on admission, in English or Spanish by preferred language documented in the EHR. All families are provided a tablet to use in the hospital while their baby is in the NICU, or they may use the patient portal on their own device(s). Parents have access to all of the notes in the portal starting on admission, and they complete the discharge education in the portal prior to discharge. At the end of the NICU discharge education in the patient portal, parents were offered a voluntary, anonymous survey on OpenNotes, with a link to a Qualtrics survey (Qualtrics, Provo, UT) in English or Spanish per preferred language. Patients with a preferred language other than Spanish were assigned the discharge education and survey in English. The survey questions were taken from prior studies of OpenNotes in outpatient[3] and inpatient[4] pediatrics and were modified to fit this NICU's context (for example, "I feel better prepared for rounds" was adapted to "I feel more prepared to explain my child's care to their pediatrician once we leave the NICU and see them in the office" in this nonacademic NICU without a formal rounding structure).

Two free-text questions were included in the survey: "Did anything (good or bad) happen as a result of your reading the doctors' daily progress notes? Please describe your experience." and "Is there anything you would change about how you receive notes about your child?" Respondents who answered the first survey question, "I didn't know I could or I have never read the doctors' daily progress notes" skipped the rest of the survey and were automatically taken to the last two survey questions: "Is there anything you would change about how you receive notes about your child?" followed by, "How old is your NICU baby on the day you are filling out this survey?" The full text of the survey is available in the ►**Supplementary Material** (available in the online version only).

This hospital was not part of the OpenNotes movement prior to coming into compliance with the information blocking provisions of the Cures Act. When the hospital began releasing all clinical notes electronically in the patient portal, the neonatologist group met to discuss implications for NICU notes. Consensus was reached to limit the documented history from the birth parent to only what was relevant to the baby's care due to potential privacy concerns.[8,9] Additionally, the neonatologists switched to problem-oriented notes, which contained briefer daily assessments and plans for each diagnosis, rather than a running history or overview of the baby's entire course for each diagnosis, to make the daily notes simpler and less repetitive for families.

This project was approved by the El Camino Health Institutional Review Board per their policies. Surveys were anonymous and not connected to patient level data.

Results

Out of 446 NICU patients in a 12-month period from March 16, 2022 to March 16, 2023, there were 59 survey respondents (13%). Eight (14%) of the respondents did not know they could or had never read the doctors' daily progress notes, with three commenting in the free-text questions "Let us know earlier about it," "Email doctors comments to parents email," and "(The thing I would change is) to be notified I can read doctors notes." Of the 51 respondents who indicated they had read the notes, 11 answered only the question about how frequently they read the notes and did not complete the rest of the survey, including leaving no qualitative comments. Forty respondents completed the entire survey, and 21 of the 40 left qualitative comments in the free-text questions.

The characteristics and demographics of the NICU patients are described in ►**Table 1**. The Asian group included 20% Indian, 13% Chinese, 3.1% Vietnamese, 2.5% Japanese, and 2% Filipino. The Hispanic/Latinx/Spanish group included 3.4% Mexican American. Two of the 59 respondents (3.4%) answered the Spanish version of the survey. The hospital is located in Santa Clara County, California, where the racial and ethnic background is 41.4% Asian, 0.5% Native Hawaiian or Other Pacific Islander, 49.7% White, 2.9% Black or African American, 1.4% American Indian or Alaska Native, and 2.4% two or more races, with 24.7% Hispanic or Latinx (may be of any race, so also included in applicable race categories).[10]

Most families indicated the notes were "very or somewhat easy to understand" (93%). Seventy-three percent of respondents felt much better about the doctor(s) after reading the notes, and 53% contacted the physicians about something in the notes. Six (16%) felt that OpenNotes were more confusing than helpful. ►**Table 2** and ►**Fig. 1** show the survey results.

Free-text responses indicated satisfaction with NICU OpenNotes, for example: "Helped reinforce the verbal

Table 1 Neonatal intensive care unit patient characteristics and demographics (March 16, 2022–March 16, 2023)

Patients ($N = 446$)	Number (%) or average (SD[a])
Gestational age (weeks)	Average 36.7 weeks (SD 3.4 weeks)
< 28	13 (2.9%)
28 to $30^{6/7}$	14 (3.1%)
31 to $33^{6/7}$	47 (11%)
34 to $36^{6/7}$	120 (27%)
≥ 37	252 (57%)
Birth weight (grams)	Average 2,722 g (SD 832 g)
$< 1,000$	15 (3.4%)
1,000 to 1,500	24 (5.4%)
1,501 to 2,000	51 (11%)
2,001 to 2,500	83 (19%)
$\geq 2,501$	273 (61%)
Male (#)	254 (57%)
C-section delivery (#)	217 (49%)
Length of stay (days)	Average 11.5 days (SD 18 days)
Public insurance[b] (#)	44 (10%)
Race and ethnicity (%)	
Asian	48.4%
Pacific Islander/Native Hawaiian	0.2%
White or Caucasian	23.5%
Hispanic/Latinx/Spanish	5.2%
Black or African American	0.7%
American Indian or Alaska Native	0.4%
Other (includes Mixed)	21.3%
Patient refused	0.2%
Preferred language (%)	
English	92.8%
Spanish	2%
Chinese	2%
Other	1.1%
Unknown	1.4%
Hindi	0.7%

Abbreviation: C-section, cesarean section.
[a]SD, standard deviation.
[b]Public insurance: Medi-Cal, Medicaid, California Child Services.

explanations of progress. Great memory aid when tired," and "We were able to read what the doctors and nurses were thinking and doing while we were away from our baby and could discuss when we visited." But there were also suggestions for improvement, for example: "It can be very jargon-y," and "I was able to figure out what abbreviations and short-hand meant but some people might not know… A glossary

would help." These and other qualitative responses to the free-text questions are found in ►**Table 3**.

Discussion

To the authors' knowledge, this is the first study to document families' perceptions of OpenNotes in the NICU. Families overall indicated positive interactions with the doctors' daily progress notes. They read the notes frequently, understood them, and felt they were accurate and helpful. About half of them contacted the physician about something in the notes, and nearly three-quarters felt much better about the physicians after reading the notes.

Some of the unique nuances to the NICU experience versus other areas in which OpenNotes have been studied include (1) daily progress notes with subtle changes over a longer period of time, (2) a significant amount of specific jargon that is not common in other areas of medicine, and (3) a time when parents and caregivers are usually under significant stress during an initially traumatic experience.

However, our responses were similar to prior surveys of parents and caregivers in outpatient and inpatient pediatric settings. Our results followed the broad themes discovered in prior focus groups with families of inpatients on a hospitalist service at a children's hospital, in which OpenNotes provided written reinforcement of the care plan, enhanced family understanding and knowledge, and improved parent–care team communication and trust.[11,12]

The primary reasons for reading the notes in the NICU were "to know about my child's health" (98% of respondents), or knowledge enhancement, and "to be sure I understood what the doctor said" (68%), or reinforcement of care plan. These were the same top two reasons in a survey of OpenNotes in outpatient specialty pediatrics.[3] In addition, 90% of NICU respondents "better remembered my child's care plan with OpenNotes." Free-text responses confirmed these benefits with statements like: "It really helped to understand the progress and all details about the treatment and progress"; "I felt better informed about my child's progress, stability and growth"; "I have better understanding of my baby's health and progress"; "If I couldn't go… and my spouse went instead it was nice to see notes in case he forgot something"; and "Clarified what providers said verbally."

Clinicians have expressed concern that OpenNotes could harm the patient–provider relationship.[4,6] However, our results showed that 100% of survey respondents felt the same or better about the doctors after reading the progress notes, with 73% feeling "much better." This is significantly more than with surveys in outpatient specialty pediatrics, where only 40% felt much better about their child's doctor.[3] Free-text responses were also reassuring that OpenNotes would not replace conversations with the care team: "The combination of verbal conversations coupled with the written notes worked well for us…"; and "It is practical, but feel more comfortable with hearing update directly from doctor."

In another similarity to prior pediatric OpenNotes surveys, 93% of NICU families rated OpenNotes "very or somewhat easy to understand," consistent with 89% of outpatient

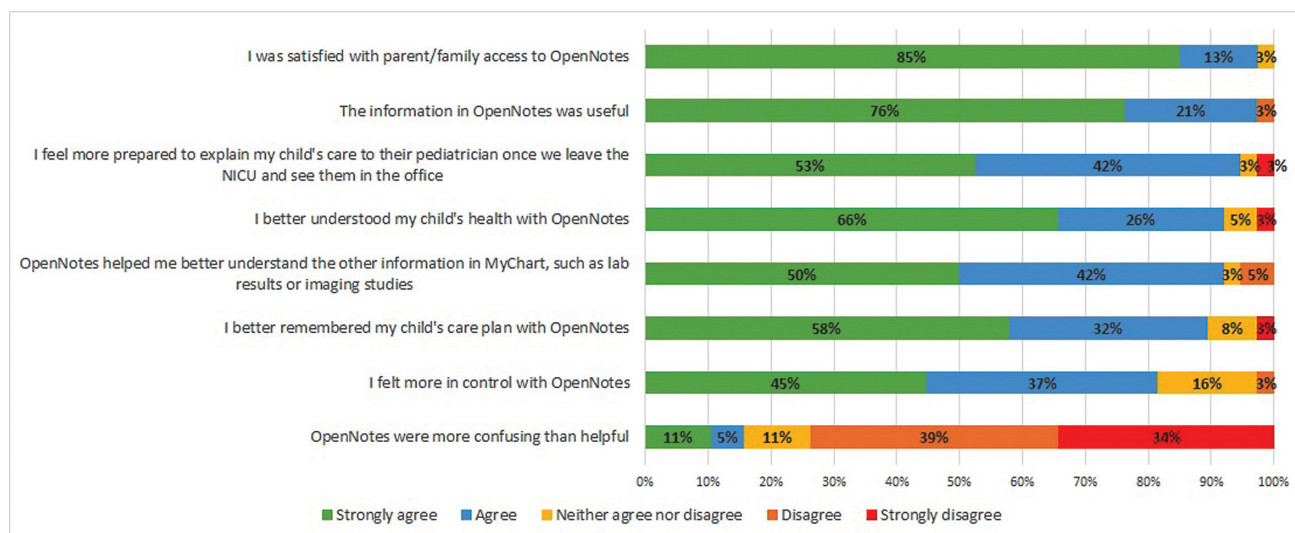**Table 2** Neonatal intensive care unit OpenNotes survey results

Question	Number of responses (%)
How often have you read the doctors' daily progress notes during your child's hospitalization?	
Every day	39 (66%)
A few days a week	12 (20%)
Once a week	–
Less than once a week	–
I didn't know I could or I have never read	8 (14%)
In addition to notes from your child's doctors, there are also notes from nurses and other health team members. Was it clear to you that these notes were from different team members?	
Very clear	33 (83%)
Somewhat clear	6 (15%)
Somewhat unclear	–
Very unclear	1 (2.5%)
What are/were your reasons for reading the doctor's daily progress notes from your child's hospitalization? (select all that apply)	
To know about my child's health	39 (98%)
To be sure I understood what the doctor said	27 (68%)
I was curious	24 (60%)
To remember the plan of care	18 (45%)
To know what the doctor was thinking	16 (40%)
I have a right to see my child's record	11 (28%)
To check that the notes were right	2 (5%)
No particular reason	2 (5%)
How often were the doctors' daily progress notes accurate?	
Always	35 (90%)
Usually	1 (2.6%)
Sometimes	1 (2.6%)
Never	–
Do not know	2 (5.1%)
How easy was it to understand the doctors' daily progress notes?	
Very easy	22 (55%)
Somewhat easy	15 (38%)
Somewhat difficult	2 (5%)
Very difficult	1 (2.5%)
Do not know	–
Did reading the notes change the way you felt about your child's doctor(s)?	
I felt much better about the doctor(s)	29 (73%)
I felt somewhat better about the doctor(s)	4 (10%)
I did not feel better or worse about the doctor(s)	7 (18%)
I felt somewhat worse about the doctor(s)	–
I felt much worse about the doctor(s)	–
Did you ever contact the doctor about something you read in the doctors' daily progress notes?	
Yes	21 (53%)
No	16 (40%)

(Continued)

Table 2 (*Continued*)

Question	Number of responses (%)
Considered but did not	–
Do not know/Do not remember	3 (7.5%)
How old is your NICU baby on the day you are filling out this survey?	
Less than 7 days old	17 (37%)
7–30 days old	24 (52%)
31–60 days old	2 (4.3%)
Greater than 60 days old	3 (6.5%)

Abbreviation: NICU, neonatal intensive care unit.

Fig. 1 NICU OpenNotes Likert scale survey results. NICU, neonatal intensive care unit.

specialty pediatrics families.[3] However, compared with no parents of pediatric inpatients[4] (admitted to a non-intensive care unit floor on a hospitalist service) agreeing that "OpenNotes were more confusing than helpful," 16% of (or six) NICU respondents reported more confusion. This may be due to the difference in patient acuity and more seasoned parents in the inpatient floor setting, as opposed to brand new parents or parents who are unaccustomed to the hospital, especially the initial trauma of the NICU.

In prior studies, both clinicians and parents have worried about the amount of jargon in medical notes and about the added workload that might be required of clinicians in answering questions and altering documentation with OpenNotes.[11–13] NICU families also mentioned that the notes were "jargon-y" and that "A glossary would help." However, while physicians in the inpatient setting reported little or no feedback from parents about the notes,[4] 53% of NICU respondents had talked to the doctor about something in the notes. This was also higher than parents in the outpatient pediatric specialty surveys where only 15% contacted the clinician,[3] which is likely because NICU families have more access to the doctors during daily updates or rounds. While NICU respondents reported contacting the doctors more frequently, 92%

agreed that "OpenNotes helped me better understand the other information in MyChart®, such as lab results or imaging studies." Therefore, it is possible that increased time spent answering questions about the notes was balanced by fewer questions about other information in the portal.

Another difference with this NICU survey compared with other pediatric OpenNotes studies is that we asked a question about the other notes present in the patient portal, that is, nursing and ancillary staff notes. Eighty-three percent of NICU respondents indicated that it was "very clear" and 15% "somewhat clear" which notes were the doctors' and which were from other team members. Their free-text responses indicated that they would like more of the information generally present in nursing documentation: "I would like to see more of the nurse's notes since they are with my baby 24 hours a day. Specifically, weight gain, weight loss and bottlefeeding measurements." They made clear suggestions for elements (daily weight change, growth curve, percent of oral intake, apnea episodes, etc.) that could be added to the patient portal for families to see outside of notes. Respondents also expressed dissatisfaction with the templated nursing plan-of-care notes that do not change from shift to shift: "Notes were updated by nurses and not doctors. Most

Table 3 Qualitative responses to free-text survey questions (quoted directly without correcting grammar or spelling)

Question: Did anything (good or bad) happen as a result of your reading the doctors' daily progress notes? Please describe your experience.
Check my baby's progress
Clarified what providers said verbally
Conocer el progreso diario de mi hija (To know the daily progress of my daughter)
Good experience overall
Helped reinforce the verbal explanations of progress. Great memory aid when tired.
I didn't do anything differently as a result of reading notes but I liked that they were available.
I felt better informed about my child's progress, stability and growth.
I have better understanding of my baby's health and progress.
I was able to understand things more clearly.
If I couldn't go to the appointment and my spouse went instead it was nice to see notes in case he forgot something.
It is practical, but feel more comfortable with hearing update directly from doctor.
It really helped to understand the progress and all details about the treatment and progress.
It was a nice way to get clarity and get consistent answers.
Nothing bad specifically, in fact we were more informed.
We were able to read what the doctors and nurses were thinking and doing while we were away from our baby and could discuss when we visited.
No, everything is ok.
No or n/a (three responses)
Question: Is there anything you would change about how you receive notes about your child?
Notes were updated by nurses and not doctors. Most updates were either very basic or repetitive.
A way to have the notes in digital format after discharge would be nice.
Even more info if possible
The combination of verbal conversations coupled with the written notes worked well for us. No changes recommended.
I was able to figure out what abbreviations and shorthand meant but some people might not know what mob means for example. A glossary would help.
I would like to see more of the nurse's notes since they are with my baby 24 hours a day. Specifically, weight gain, weight loss and bottlefeeding measurements.
It can be very jargon-y.
The current model is perfect as it should be.
Receive notes are great but the app kept logging out most of the times and hard to access it from home.
No there isn't.
No, it's clear.
No or n/a or nope (10 responses)

updates were either very basic or repetitive." The many templated nursing plan-of-care notes and the single doctor's daily progress note, as well as all of the other ancillary notes (from the social worker, dietician, occupational therapist, physical therapist, and respiratory therapists), are lumped together in the patient portal notes section in chronologic order. A filter function in the portal notes section may help to distinguish the different authors for families.

This single-center study has limitations, including low survey response rate of 13%. But, this is comparable to the response rate from the OpenNotes study in outpatient specialty pediatrics which had a 20% survey response,[3] as well as the national average 16% response rate to NICU postdi-scharge surveys like Press Ganey. In addition, the high percentage of English as preferred language means the results may not be generalizable to other NICUs. Given this NICU's location in Silicon Valley, it seems not surprising that technology-savvy parents (such as those who would respond to an online survey) may bias to those who read notes daily. However, all families are provided a tablet to use in the hospital while their baby is in the NICU, so all had access to MyChart® Bedside with the notes and the survey.

We did not ask any questions about caregiver education level, health literacy, or technology (internet and portal) use, which would be important in future studies. Also, having the OpenNotes survey results linked to patient-level data in the

future would lead to more robust analysis of the different interactions with or perceptions of OpenNotes in different patient populations (e.g., families of preterm infants vs. term infants). Though, half of our respondents indicated their baby was 7 to 30 days of age when answering the survey, so there were some longer stay families included in our results. In the future, we hope to improve the generalizability of the results by collecting parent demographics and patient-specific information to compare the survey respondent population to nonrespondents. Future studies would also benefit from having the perspectives and suggestions of the NICU care team (physicians, advanced practice providers, nurses, ancillary staff, etc.) regarding OpenNotes as well.

Conclusion

Though limited by low survey response rate, NICU families overwhelmingly indicated positive interactions with the doctors' daily progress notes. Their responses give important insights into how to improve patient information shared via patient portals and via OpenNotes.

Clinical Relevance Statement

To the authors' knowledge, this is the first study to survey and document families' perceptions of OpenNotes in the NICU. This study is important for NICU providers or other pediatric inpatient or intensive care providers to understand families' perception of and interaction with clinicians' notes. It can help to dispel some of the concerns that inpatient pediatric care providers, including NICU or other intensive care providers, may have about families reading their notes. It also gives lessons learned to the EHR companies to improve data sharing in inpatient pediatric and neonatal contexts.

Multiple Choice Questions

1. With access to doctors' daily progress notes via patient portal (aka OpenNotes), what percent of NICU families reported not being able to understand the notes?
   a) No families found clinical notes difficult to understand.
   b) A total of 7.5% of families found clinical notes difficult to understand.
   c) Thirty-eight percent of families found clinical notes difficult to understand.
   d) Ninety-three percent of families found clinical notes difficult to understand.

   Correct answer: b. Though NICU families commented on lots of jargon in the doctors' daily progress notes, 93% of survey respondents reported that the notes were "very" or "somewhat easy to understand."

2. A common concern raised by pediatric clinicians is that their relationship with their patients' families might be negatively affected if families read their notes. What percentage of NICU families reported feeling worse about their child's doctor after reading their notes?

   a) No families felt worse about their child's doctor after reading their notes.
   b) Ten percent of families felt worse about their child's doctor after reading their notes.
   c) Eighteen percent of families felt worse about their child's doctor after reading their notes.
   d) Seventy-three percent of families felt worse about their child's doctor after reading their notes.

   Correct answer: a. In this study, all NICU family respondents felt the same or better about their child's doctor after reading the notes. And, 73% felt much better about their child's doctor, significantly more than with surveys in outpatient specialty pediatrics, where only 40% felt much better about their child's doctor.[3]

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