Parent Perspectives on Pediatric Inpatient OpenNotes

Catherine Arnott Smith, PhD1; Ryan J. Coller, MD, MPH2; Shannon M. Dean, MD2,3; Daniel Sklansky, MD2; Peter L.T. Hoonakker, PhD4; Windy Smith, MSN, RN, CPN3; Anne S. Thurber, MS2; Brad D. Ehlenfeldt, BBA3; Michelle M. Kelly, MD2,4

1The Information School, University of Wisconsin-Madison, Madison, WI; 2Department of Pediatrics, University of Wisconsin School of Medicine and Public Health, Madison, WI; 3UW Health, Madison, WI; 4Center for Quality and Productivity Improvement, University of Wisconsin-Madison, Madison, WI

Abstract

Introduction: 169 U.S. health systems now engage in OpenNotes: a movement to share clinical notes with patients. Few studies have focused on releasing notes during hospitalization, pediatrics, or parents/caregiver perspectives.

Methods: A focus group was conducted with eight parents with experience caring for a hospitalized child at a Midwest children’s hospital. In the 2-hour session, parents were asked about their perspectives of the idea of sharing inpatient doctors’ daily notes with parents during their child’s hospitalization. Qualitative analysis was conducted to elicit themes related to the potential benefits and challenges of sharing inpatient notes. Results: The most mentioned benefits included notes providing information as a reference for improved family education/understanding, communication/continuity, and advocacy/empowerment. Challenges were primarily related to note content, impaired communication and negative impact on families. Conclusion: Participants identified multiple potential benefits of and challenges to sharing notes with parents during their child’s hospitalization but also acknowledged the impact on healthcare professionals who work alongside them.

Introduction

The OpenNotes movement, launched in 2010, advocates “fundamental change in the way visit notes are managed”, by making visit notes available to patients. The objective of this overarching study was to identify stakeholder perspectives on the idea of sharing inpatient doctors’ daily notes with parents during their child’s hospitalization using an inpatient portal, MyChart Bedside (Epic Systems). We conducted five focus groups composed of different stakeholders at a quaternary children’s hospital in the Midwest: (1) parents (Patient and Family Advisory Council members with experience caring for a hospitalized child); (2) nurses (pediatric bedside nurses working on general medical/surgical units); (3) pediatric intern and resident physicians; (4) attending physicians; and (5) representatives from the departments of hospital administration, information services, risk management and patient relations. Findings from this study will be used to inform design requirements for optimally implementing and evaluating OpenNotes for hospitalized patients and caregivers using an inpatient portal. This paper reports on some of the findings from the Parent focus group.

Background

In 1973, the psychiatrists Shenkin and Warner published an editorial in the New England Journal of Medicine proposing that patients should be given complete copies of their medical record and routine issuing of new copies as information changed. This ignited a firestorm of dialogue among healthcare professionals. It has been called the “pioneering” work in the field of patient access. Alan Westin, a pioneering advocate for consumer data privacy, ascribed the patient access initiative to a developing “consumer” theory of health care. This theoretical lens saw patient access as beneficial for patients and the larger healthcare system alike by improving content, patient education, and patient-physician communication. Patient readers could correct erroneous information found in the record, thus ultimately enhancing the quality of care. Record access could also be a part of continual patient self-education, enabling smarter health consumerism and better client-physician relationships. Patients could be “more active partners” if they were allowed more information about their treatment. Further, medical record access could result in a “realignment of power”. Objections to such access by physicians fell into dominant themes, which Westin called
the “doctors’ judgment model.” Opponents located their objections in the nature of the clinical documents themselves. In terms of content, it was argued that reading medical records could result in actual harm to the patient through causing confusion; of education, that the amount required to teach a patient to understand what they read placed a burden on the physician; and that communication between physician and patient would be negatively affected by medical record access.

The question of how much, if any, of their medical records patients and/or their caregivers should be able to see has also been a longstanding debate in healthcare. It is no accident that the first published study of the effects of access, which appeared the same year as Shenkin & Warner’s editorial, was done in a context of Problem-Oriented Medical Record development. Health informatics technologies have the potential to greatly affect the balance of power between physician and patient simply by providing the patient with more information, which requires attention to knowledge representation for new readers as well as re-education of the writers.

In 2010, a movement called OpenNotes began as a collaborative experiment between hospitals in Boston, Pennsylvania and Seattle. Twenty thousand patients were given the opportunity to read their clinical notes—textual summaries of their doctor visits—using their patient portals. In two of the study sites—Pennsylvania and Boston—82% of patients opened the notes, while in Seattle only 47% did. The response from patients was overwhelmingly positive. A very high proportion (77-87%) agreed that the notes helped them feel “more in control of their care”. By self-report, 60-78% reported increased adherence to their medications. As a result of this early success, as of March 10, 2019, 169 health systems in the U.S. “and a couple in Canada” are now engaging in OpenNotes.

Themes consistent with the consumer movements of the 1970s continue to arise in the 21st century research literature of OpenNotes. Benefits include enhanced communication (text supplements to verbal instructions about care plans and appointments), improved patient knowledge and potentially improved self-care (understanding of diagnosis and care plans; patient activation; error correction), and greater patient participation (medication adherence, monitoring and follow-up with physician). Challenges include concerns about security, stress induced by reading notes, information overload, confusion induced by terminology, unintentionally offensive language, and technical issues.

The research literature explicitly referencing the OpenNotes initiative is growing with the movement, but a PubMed search reveals only 20 published studies in which patients were involved and patient feedback sought. Of these, 15 were online surveys or analysis of secondary data from surveys, for example. The remaining five studies used qualitative methods, such as semi-structured interviews or focus groups. Surveys have been done of 13 patients in primary care, 28 patients living with mental health conditions, 20 oncology patients; and 14 patients seen at a university health service. One of the numerous My HealtheVet studies examined the patient experience using focus groups of patients inside and outside the VA. Of note, only two studies have involved caregivers of patients. Bell ET al. reference unpublished studies of focus groups conducted during the early years of OpenNotes that included caregivers. Wolff et al. comment: “Family members and friends are frequently involved in the care of patients who are more vulnerable and may facilitate access and use of a patient portal. However, the longitudinal experiences of patients and families who share formal access to a patient’s portal account has, to our knowledge, not been examined.”

Nowhere is the involvement of caregivers clearer than in the domain of pediatrics. OpenNotes reported that 76 healthcare systems were sharing pediatric notes with patients, parents, or both. However, Sarabu et al. call attention to the complexities posed by pediatric care, “unique because additional caregivers... are almost always involved and generally have legal decision-making capacity for most medical decisions that involve the patient.”

The objective of this study was to identify parent perspectives of the idea of sharing doctors’ notes with parents during their child hospitalization. Qualitative research is required to understand the diverse and nuanced perspectives of stakeholder participants. This is especially important when considering changes within complex healthcare systems, like the implementation of OpenNotes in the pediatric hospital setting. This paper reports the findings from a focus group composed of important pediatric participants: parents.

**Methods**

Setting and participants. In the overarching study, focus groups were conducted with each of the 5 stakeholder groups at an academic children’s hospital in the Midwest during October and November 2018. The study reports on findings from the parent focus group which met once. Eligible parent participants were members of the hospital’s Patient and Family Advisory Council and were invited by email. Respondents were provided an information sheet describing the
study, risks and benefits, and contact information, and informed consent was obtained. Participants were not reimbursed for their participation. The institution’s Institutional Review Board approved this study.

**Study procedures.** The parent focus group was conducted in a private hospital conference room. The facilitator was a research specialist trained in qualitative methods (AT). A semi-structured facilitator guide was developed and refined after piloting with stakeholder representatives. A hybrid approach was used integrating both open-ended and targeted questions. Focus group sessions started with a description and definition of inpatient doctor’s daily progress notes and followed with open-ended probes to explore participant perceptions of the idea of and benefits of and challenges to sharing notes with parents during hospitalization through the inpatient portal. At the end of the session, the facilitator provided a summary, offered an opportunity for revisions or clarifications and administered a short demographic survey to participants. The facilitator guide can be found at: www.hipxchange.org/InpatientPortal.

**Data analysis.** Audio-recordings were transcribed by a professional service. A ‘cleaning’ process was then performed to ensure accuracy, fill in text that the transcriptionist could not discern, and delete any identifying information inadvertently collected. To ensure anonymity, recordings were destroyed after transcription. Transcribed data were transferred to Dedoose© (https://www.dedoose.com), software used to facilitate the organization and coding of qualitative data.

Three researchers trained in qualitative methods participated in thematic content analysis of the focus group transcript (AT, CAS, MK). Data was organized into themes related to benefits and challenges and the analytical approach was based on this framework. Two researchers (AT, CAS) first independently reviewed the transcript, identifying themes and concepts emerging from the data related to benefits and challenges to share inpatient doctors’ notes with parents during hospitalization. With a third researcher (MK), they developed and iteratively refined a codebook of identified themes, their definitions and exemplar quotes. Two researchers (AT, CAS) then independently coded the transcript. During this process, all three researchers continued to meet together to review the coding and reach consensus over any discrepancies, always referring back to the transcript.

**Findings**

The Parent focus group discussed here had 8 participants and lasted 2 hours. All but 1 participant was female, and ranged in age from 35 to over 55 years old. Half had a college degree, 75% (N=6) were White and 25% (N=2) Asian. All reported that they spent time on the Internet, using a computer, a tablet, or smart phone. The majority (N=6, 75%) more than 15 hours a week, 12% (N=1) between 6 and 10 hours a week, and 12% (N=1) between 1 and 5 hours a week.

The most mentioned themes related to potential benefits focused on notes as a means of information provision: serving as reference for improved family education/understanding, communication/continuity and advocacy/empowerment. These themes and examples are shown in Table 1.

<table>
<thead>
<tr>
<th>Benefits</th>
<th>Parent quote</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>REFERENCE FOR IMPROVING FAMILY EDUCATION/UNDERSTANDING</strong></td>
<td></td>
</tr>
<tr>
<td>Provide a recap of information, reinforcement, supplement or reference for family</td>
<td>So I really hope that this kind of comes to being, because it will give, especially patients that have long-term care, more access. And having that at your fingertips is ... so much easier when you have to kind of remember down the line something for the school, or something for a social worker, or something like that that you could can quick go back and look at ... where was he on this scale when he did his neuro test, you know?</td>
</tr>
<tr>
<td>Improve family understanding or knowledge</td>
<td>I've had the good fortune to see some of the doctor's notes, and like you said earlier, I think it allows you to learn a little bit more about what's going on and maybe do a little checks and balances along the way. Did so-and-so understand, or did I understand what was being said?</td>
</tr>
</tbody>
</table>
## Table 1, cont’d.

<table>
<thead>
<tr>
<th>ENHANCE COMMUNICATION/CONTINUITY</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Improve parent-provider and/or team communication</td>
<td>I don't know if it could be used this way, but if it was available, if the doctors’ notes were available on MyChart as an outpatient or outside of the hospital, it’s something that I could have shown to an ER doctor, and, who didn’t want to listen to me. It’s like, okay, here’s the [redacted] system. Here’s the doctors’ notes. Here’s some background on this girl. And it would just be another tool in my toolbox to be an advocate.</td>
</tr>
<tr>
<td>Ensure continuity of information/care between providers</td>
<td>Without a tool or an avenue like that, there are pieces of the puzzle that sometimes get missed. And one of the times we really noticed it was on weekends, when staff maybe had changed over or there weren’t so many of the other ancillary staff, but it was sometimes really hard to get information. And nobody was even sure where to go to get that information, so it seems like it's a really good place to centralize a lot of that.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>PROMOTE ADVOCACY/EMPOWERMENT</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Improve empowerment, engagement, control for parent or child</td>
<td>I personally like it because my son is 11 now, and, you know, he's been treated since birth. So now that he's really learning about his body and learning about his different diagnoses and stuff; it's interesting for, it would be interesting for him to learn like as he's growing and see the trend of his own health. So I think it could be advocating for himself and looking at the things that he's gone through and what's worked for him.</td>
</tr>
<tr>
<td>Parent advocacy for child</td>
<td>I also think that there are parents that might not be so inclined to be involved. But if the tool is present, it might encourage them to do something like that they might otherwise tend to shy away and wait for somebody else to tell them everything.</td>
</tr>
<tr>
<td>Family identify errors/inaccuracies</td>
<td>I’m a parent of an 11-year-old. At one point, he was in the hospital pretty continuously. But we’ve been lucky, and he’s been mostly outpatient but still come in for procedures and surgeries and stuff at least twice a year. So we have a lot of experience with a lot of the different specialties, and I think when he does get admitted, we do like to be able to have the continuity of care. Sometimes, you know, there might be critical pieces of information that may not have been stressed enough or could be missed in that period of rounds, and so it gives you the opportunity to say, hey, this other topic you know, that was really important to me. And only with a second set of eyes would you be able to capture that information, so I think it's really important.</td>
</tr>
</tbody>
</table>

Challenges identified by parent focus group participants constituted 37 distinct themes, with no one theme comprising more than 11% of all comments. Top themes were related to note content and the potential negative effect of sharing notes on communication and family interactions. These themes and examples are illustrated in Table 2.
Table 2. Challenges and exemplary quotes

<table>
<thead>
<tr>
<th>Challenges</th>
<th>Parent quote</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>NOTE CONTENT</strong></td>
<td></td>
</tr>
<tr>
<td>Medical jargon</td>
<td>It's not just the language, there just needs to be somebody that people can ask questions. Because it isn't just medical words. It's like Q4HPRN, you know, every four hours, PRN. Does everybody know what that means? So that's not a word. That's just medical abbreviations. Maybe everybody in this room has had enough experience that they know what that is, but I would venture to guess that there are a lot of people that that would just be a jargon for.</td>
</tr>
<tr>
<td>Discussion of sensitive diagnoses (e.g., eating disorder, mental health, abuse) or private topics (e.g., sexual health, social issues, family dynamics) in notes</td>
<td>The other challenge I was wondering about is if there are certain things a patient wants to keep private...I think this came up several times about use of birth control. Personally, I don't think it's my personal opinion as a parent that if my child is on birth control, I need to know. But I would respect the law, whatever it is. So now does this open the door that like if it goes in the notes, then now someone has access to that?</td>
</tr>
<tr>
<td><strong>IMPAIRED COMMUNICATION</strong></td>
<td></td>
</tr>
<tr>
<td>Release of information (e.g., abnormal tests, diagnosis) before face-to-face communication or without translation by provider</td>
<td>I suspect that notes will also reflect comments between providers that parents are not yet aware of. I'm thinking it may not just be what happened at rounds that we know already, but after rounds, a consultation was had or some discussion was had, and that's going to show up in the notes, and we have not yet become privy to that, so the whole timing issue ... brings that issue up again.</td>
</tr>
<tr>
<td>Physicians inhibited from communication with each other</td>
<td>If I really trusted my kids' doctors, I want them to go in that room without me and to play with their creative, sciency brains and go, “It could be this, it could be that.” I don't want to hear that. ... I want them to figure it out and then say, hey, we're strategizing this. ... I would hate for them to somehow stifle that part of their collegiality, because, oh, mom is going to read it.</td>
</tr>
<tr>
<td><strong>IMPACT ON PATIENT OR FAMILY</strong></td>
<td></td>
</tr>
<tr>
<td>Negative parent emotion induced by information in note (e.g., frustration, confusion)</td>
<td>We got called into a conference room with, what, like four doctors, four nurses, a couple social workers. I mean, we had the whole squad there, you know, and they basically told us we had a 5% chance of survival, and that we could take our daughter home and put her on hospice. If I would have read that in a doctor's note, no matter good I am at absorbing this stuff, I think would have probably freaked out then too, because it was not a good day.</td>
</tr>
<tr>
<td>Parents/families are different</td>
<td>Other parents are going to handle [access to notes] differently. We might be, you know, more professional, or we might be upset but then like keep that poker face on. But some families would probably create quite a bit of static over certain things and stifle that.</td>
</tr>
</tbody>
</table>

Some comments did not fall neatly into the Benefit or Challenge themes. On numerous occasions parent participants seemed concerned about the impact of inpatient OpenNotes on other stakeholders:

“I'd be shocked if the doctors really wanted it.”

The central theme of these comments was concern for healthcare professionals’ time – time that parents wanted to be spent on caring for their children and communicating with other healthcare professionals:

“I don't want to make their jobs more difficult as doctors, and I don't want to burden the nurses and other medical staff with all the questions that this could bring up. I mean, I'm very sensitive to the nurses' time.”

“I don't ever want to interfere with them being able to do their job.”
Discussion

This is the first study to evaluate parent perspectives of the potential for OpenNotes in the pediatric inpatient setting. There is a striking resemblance between these parents’ perceptions of sharing notes and the potential of such sharing enunciated almost 50 years ago at the dawn of the patient access initiative: a focus on content, education, and communication. These themes are echoed in recent studies evaluating patient perspectives of ambulatory OpenNotes and a pilot study assessing inpatient note sharing with 10 hospitalized adults.

These results also highlight multiple potential benefits and challenges that may be unique to sharing doctors’ notes in pediatrics and in the hospital setting. Parents mention characteristics of the child or family that may make note sharing more challenging, such as with hospitalized children approaching adolescence where it is vital to ensure that their information is kept private. Parents’ worry and anxiety may be heightened in the fast-paced, high acuity inpatient setting. Participants suggest this anxiety may be worsened with access to notes, particularly if information is shared prior to face-to-face communication with physicians. On the other hand, note sharing may facilitate parent communication with their child’s inpatient physician. For example, one parent suggests that the information found in notes may support parent engagement in communication with physicians during daily bedside rounds. Another mentions that access to notes may help parents act as “a second set of eyes” to ensure information accuracy and continuity specifically during inpatient care transitions, such as during staff change of shift. These results suggest that there may be differences in the implementation, use and impact of OpenNotes in the inpatient setting, which will be important areas for future research.

The opinions of parent participants in this focus group also reflect parents’ awareness of the potential impact of note sharing on the rest of the healthcare team. They identified potential benefits for parents during their child’s hospitalization, but also acknowledged the potential impact on healthcare professionals. In fact, one of the most frequently expressed ideas during the focus group session by these parents included comments about the potential effects of note sharing for providers. One benefit, for example, was “ensuring continuity of care/information between providers,” and a challenge was the possibility that “physicians [would be] inhibited from communication with each other.”

These results will inform efforts to design, implement and evaluate OpenNotes in pediatric inpatient settings. Potential benefits identified by parent focus group members here will be used to define meaningful outcomes for families. Example outcomes may include improved parent-physician shared understanding upon discharge and family identification of medical errors. Challenges will also be considered proactively and efforts made to mitigate potential negative consequences prior to the wide-scale implementation of inpatient OpenNotes. Parents in this focus group highlight the rapidly changing nature of inpatient care and risk of discordance between the information communicated to parents and updated and shared in notes. Organizations may need to set expectations for parents regarding the fluidity of care plans and who to contact if and when questions arise. Strategies such as these are necessary for hospitals to jointly support the work of patients, caregivers and their healthcare teams.

This study has limitations. Results reflect the perceptions of a small number of parent participants from an academic children’s hospital who may represent a more engaged population of parents. Consistent with the intent of exploratory research, the findings of this qualitative study were not intended to be generalizable, but instead lay the groundwork for future research evaluating the growing use of inpatient portals and expansion of the OpenNotes movement into the inpatient setting.

Conclusion

This is the first study assessing the potential to share inpatient doctors’ daily notes with parents during their child’s hospitalization. Parents anticipated multiple potential benefits and challenges of inpatient note sharing, including the impact of note sharing on healthcare providers who work alongside them. Some themes from this parent focus group are consistent with the benefits and challenges described in the literature on outpatient notes sharing, but others highlight concepts that may be unique to pediatric and inpatient note sharing. Findings from this study will inform the design and implementation of BedsideNotes, an intervention and implementation strategy to share inpatient doctors’ daily notes with families to support their engagement in hospital care.

ACKNOWLEDGMENTS

This project was supported by the NIH CTSA at UW-Madison grant 1UL1TR002373, and the University of Wisconsin-Madison School of Medicine and Public Health’s Wisconsin Partnership Program, WPP-ICTR grant # 3086.
References


about safety-related knowledge, behaviors, and attitudes after reading visit notes. J Patient Saf. 2018 Apr 27. doi:10.1097/PTS.0000000000000494


