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Parental Perceptions of Displayed Patient Data in a Pediatric Intensive Care Unit: An Example of Unintentional Empowerment

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Abstract

Objectives: To explore the perceptions of parents of pediatric patients in a pediatric intensive care unit (PICU) regarding real-time open electronic health record (EHR) data displayed in patient rooms.

Design: Cross-sectional qualitative interview study

Setting: PICU in a large Midwestern tertiary-care children's hospital.

Subjects: Parents of patients in a PICU (n=33).

Measurements and Main Results: Qualitative data were collected through in-person semi-structured, individual and small-group interviews. Data were collected from March to July 2016, with approval from the study hospital's institutional review board. Data were analyzed using inductive thematic analysis. Results included positive effects of accessing real-time open EHR data on family empowerment, situation awareness, potential error detection, understanding of medical data, and facilitating discussions during rounds. Concerns were reported regarding privacy of information as well as potential misinterpretation of displayed data. We identified several ways to improve this collaborative technology to make it more family-centered.

Conclusions: This study suggests that a new health information technology system providing continuous access to open EHR data may be an effective way to empower and engage parents in the PICU, but potential drawbacks were also noted. The results also provide insights into the collaborative use of health information technology in the PICU setting.

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Keywords

Collaborative health information technology; Pediatric Intensive care; Human Computer Interaction; Family engagement; EHR open Data

1. Introduction

Health information technology (IT) can enable patients and families to be more involved in the care process, facilitating care that is more coordinated and patient- and family-centered. (1,2) In particular, in the “new era” of patient and family engagement, health IT can play a role in empowering patients and families to be discriminating consumers and key actors in their health.(3,4) Health IT that promotes open, available data to patients and families enables them to obtain access to and control over their own health data, self-manage and transmit personal health information,self-initiate communication with healthcare professionals,set and monitor personalized health goals, and learn independently.(3–6)

These empowering functions of health IT are particularly welcome in areas with a strong need for family engagement and coordination, such as pediatric hospital units. The Society of Critical Care Medicine presented 43 recommendations, including shared decision making and better communication, to better support families of patients in pediatric intensive care unit (PICU).(7) For their part, parents of patients in ICUs have voiced their desire to be involved in care for their children, including participating in rounds and receiving detailed information at every step rather than the “big picture”. (8–10) Early studies demonstrate that family-oriented health IT have potential to create opportunities for families to be more informed about their child’s care and more involved in the decision-making process. (5,11) For instance, acute care portals help bridge some needs but not generally at the granular level of the ICU. ICUs are unique areas, and prior data show cautious support for portals for families in the ICU. (12)

As new health IT systems are introduced with the potential to support family-centered models of care, it is important to evaluate their impact on families. Just as with health IT for professionals, the availability of technology for families does not guarantee it will be used or perceived to be useful, usable, or satisfactory. (13,14) The objective of the present study was to explore the perceptions of parents of PICU patients when they are provided real-time open EHR data through an in-room health IT system, the Large Customizable Interactive Monitor (LCIM). The LCIM is a flat-panel touchscreen monitor that displays data from the patient’s electronic health record (EHR). Given that the study site is the third hospital in the nation and the first pediatric hospital to implement such technology, we sought to understand early experiences in detail. We interviewed parents of PICU patients about the perceived benefits, concerns, and suggested changes related to the LCIM.

2. Methods

The design was a cross-sectional study of parents’ experiences of having access to open EHR data in the PICU. Qualitative data were collected through in-person semi-structured interviews, some as individual interviews and some as small-group interviews, depending on

parent availability. Data were collected from March to July 2016, with approval from the study hospital's institutional review board.

Setting

The study was conducted at Children's Hospital of Wisconsin, an academic pediatric tertiary care center in Milwaukee. The LCIM was deployed within the PICU, a 72-bed unit with three 24-bed floors. The PICU provides highly specialized care to critically ill children and neonates, including transplant, congenital heart disorders, trauma, sepsis, and oncologic disorders. Participants were parents of patients in the PICU.

LCIM Technology

The LCIM uses a commercially available software called Epic Monitor (v 2010, ©Epic Systems Corporation, Verona, WI) displayed on a large, 42" touchscreen monitor made available at the bedside and implemented in each room. The LCIM is an interactive monitor at the bedside, providing data to patients, families, and professional staff. Data entry occurs through the EHR and interfaces with devices and ancillary information systems. At the time of data collection, viewable data on the LCIM included discrete and trend vital sign information; the patient's early experiential test results; a list of medications and infusions with doses, routes, frequency and last administration time; documented fluid and key actors in their health. Labels and indwelling lines, drains and airways with date/time of placement (Supplemental Figure 1). When the user touches an area, it shows additional details.

The content of the LCIM is customizable by hospital IT management but data must exist in the EHR to be displayed on the LCIM. Unlike a traditional EHR system at the hospital, the LCIM does not require a log-in for each use. It is activated upon the admission of the patient to the room and is always available for view and use. The LCIMs were installed as part of EHR implementation in 2012. There was no formal orientation for physicians or nurses to the LCIM. Similarly, there was no orientation of parents to the monitor by ICU staff; they are neither encouraged nor discouraged from interacting with the LCIM.

Data Collection

We recruited parents by disseminating research flyers in the pediatric ICU every week inviting parents to attend a scheduled meeting time. We only invited English speaking parents since the LCIM was only available in English. Otherwise, any parent was welcome to participate independent of their child's diagnoses, severity, or length of stay. Sessions were held during the day and in the evening to maximize parents' involvement. A well-defined qualitative data saturation concept was used as a guiding principle during data collection. (15) We reviewed the collected data until data saturation was reached, meaning no new information was heard in the prior three interviews. We recruited only one parent per child; participating parents were offered a \$50 gift card. The interview questions, which were informed by the technology acceptance model, (16) covered parents' perceptions, such as perceived usefulness, perceived ease of use, the LCIM's contribution to care and rounds, concerns, and suggestions for improving the LCIM. By design, no patient-level data was collected at any phase of the study.

Data Analysis

We used an inductive thematic analysis approach for the analysis of the qualitative interview data. (15) All interviews were audiotaped and transcribed verbatim for analysis. We developed a codebook to guide the coding process, and uploaded transcripts to NVivo 10 (QSR International) to facilitate data management, coding, and analyses. Two coders conducted the main thematic coding process with a third independent coder serving as a judge to adjudicate any disagreements. The team refined preliminary interpretations throughout this process and added new themes when necessary. Appropriate revisions of the themes and codes were made until consensus was achieved between the coders. Reliability checks were conducted throughout the coding process. The inter-coder reliability was assessed on 6 transcripts in total. The qualitative results were evaluated for validity through member checking.

3. Results

3.1 Demographics

A total of 33 parents participated in 20 sessions. Of the 20 sessions, 10 had only one participant and were treated as individual interviews. The remaining 10 sessions consisted of 2–3 parents interviewed together. Twenty-three parents reported active interaction/using the LCIM, whereas 10 parents stated they only looked at it but never touched it. The interviews lasted 20 to 35 minutes (mean 28 minutes). In qualitative analysis, two main coders achieved acceptable inter-coder reliability of higher than 0.90 (range 0.90–0.96). The demographics of participants are presented in Table 1.

3.2 Themes

(1) Open data can increase parental situational awareness and potential error detection—Multiple parents described how the LCIM facilitates their understanding of their child's overall health problems and helps them understand the situation better. More specifically, it adds visual content/reference to the parents:

“It's a communication tool that keeps everybody up to date so we're not constantly asking something that we could easily find ourselves...”

“As labs come in then you're able to track and see ‘OK, we're making progress the right way or wrong way and it helps you prepare for when a doctor maybe comes in to say [something about the child]”.

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Parents also reported that in some instances, they may find out new information through the LCIM before they had been briefed in person by the care team: “Well, we actually saw that he had another problem before the doctors even said anything to us.” While this could represent a potential source of parental anxiety, the parents in our study indicated how the LCIM allowed them to prepare themselves for discussions with their clinicians. Parents also shared how the LCIM helped them find potential errors in care. One parent noted:

“I have caught errors at rounds because...someone will say...’he’s on vancomycin and cefepime’ when he’s not. ‘It says right there [on the LCIM] he’s not’ and then they’ll say, ‘oh yeah’.”

(2) Open data alters family-provider communication—Parents noted that the LCIM altered communication, either by serving as a conversational or educational aid with clinicians, such as in rounds, or in obviating the need for verbal communication through parental self-service of information.

Parents reported that the LCIM improved the communication with the care team in several ways. One parent reported:

It helps prompt your questions that you might not think about when they’re saying everything really fast. So, it helps for me to process, ‘oh I need to ask about this,’ or ‘maybe I did understand what they were trying to tell me.’ But, I can look at this so I’m not asking again while they’re trying to give care to my daughter to help us with something. So, I think it’s--it works as a really good communication piece for me to them.

Another parent said:

So, when they first pulled it up and showed me where to look and those kind of things and following where they look, now I can use that information to be able to be part of the discussion versus a bystander.

Parents described how some providers used the LCIM as a tool to educate and teach parents about specific cases:

He pulled up the x-ray and then he could show, like, okay here’s, you know, the radiologist said this. That’s what we’re seeing here. That’s what this cloudiness means. Here’s the, he can point out different parts like here’s the ET tube, and here are the pacer. To be able to see them in the x-ray was helpful.

Parents also reported that LCIM improves communication by helping families to formulate an agenda to discuss care topics with nurses.

In some cases, parents wanted to have updates but perceived that they had to interrupt or ‘bother’ a clinician (often a nurse) for information. The LCIM allowed for self-service of data.

Prior to me being able to go that smart board, I felt like I didn’t have a right to that information because I had to pull somebody aside, I had to get them logged in, it was a bother, it was, well, now if I want to know what his x-ray looks like, go look at his x-ray. I don’t need to call on somebody.

(3) Open data facilitates family empowerment, helping with care and advocacy—Twenty one of the 33 participants related the experience of feeling more empowered to proactively help their child. Parents reported using the LCIM to stay up to date on the progress of their child, review lab data or to prompt questions of the team, and advocate for their child. “It gives me a sense of ownership and like I’m doing something,

and that I'm thinking about what's going on with him." Parents, especially those who self-identified as parents of children with complex care needs, often reported doing research and becoming very familiar with the intricacies of their child's care. One parent noted:

My son has a complex health situation. I'm not going to apologize that I need to know what's going on with him, and if you're going to give me this tool and tell me feel free to use it, then you shouldn't be bothered when I say—excuse me, I see that this lab result came back and it's a gram negative cocci. Is that related to something that he's already colonized with?

Parents also show empowerment with statements such as, "The other benefit that it has is it gives you ownership of your child's information." Another parent said:

I'm able to pull up film from a year ago take a look at it, and take a film from yesterday and I can kind of-- I don't know how to read anything, but just by putting them side by side, and being able to look at them I'm able to then go to the doctor, and I think that annoys them but I don't care. And say I noticed this little hitch, and then that puts the onus upon the providers to say oh, that's just shadowing.

One parent noted the importance of the information for promoting parent activation:

[It] is an incredible move for any healthcare facility to be transparent, so I think it's a great tool.. for parents. It really eliminates excuses. People can't say well, I didn't know. You have to educate yourself. It's your child who's on that board.

Importantly, empowerment derived from the use of the LCIM was predicated on the feeling of entitlement or permission to approach and use the tool. Parents noted that there was no training or official instructions made available, which made parents uncertain if they were able to touch and use the screen. "It's not anything that's ever been explained how to use or even if we were allowed to use it, so you kind of look over your shoulders to understand if you can use it or not."

(4) Prior experience and health literacy mediate the usefulness of open data

—Parents noted concerns with the lack of context and explanation and a potential for misinterpretation of the displayed information. Some parents thought that their lack of a health care background made it difficult to understand everything without clinician interpretation or a tutorial. One parent highlighted this concern saying, "You have to be pretty much a healthcare professional to know exactly what you're looking at." Another parent mentioned a desire for interpretation, "it would be nice to have that hovering over interpretation note or whatever it is, so this way we're able to find out what it is, and the very simplistic fifth grade reading level." While the majority of parents stated that the LCIM was not overwhelming, there were some parents who felt overwhelmed due to the absence of explanation on the monitor. In addition, perceived information overload may vary from family to family based on the family's educational background and technological savvy.

Out-of-range test results are displayed using a red font in the LCIM, in contrast to the white font used for results within the normal range. These "red values" were one of the themes discussed by parents. A group of parents admitted that red numbers might be scary or worrisome for them. One parent said, "Especially because you know everything that's not

right is in red and so if you walk in and like especially if you have visitors and they see like ‘why are all of his numbers red?’ that can be really scary.” On the other hand, the majority of parents thought that the red numbers were not a particular concern, especially when they were familiar with the context and typical ranges for their child.

(5) Open data raised potential privacy concerns—Some parents noted potential concerns about privacy with the LCIM, as it is always on and available without need for credentials or login. The two concerns in particular were visibility to people who were passing by the room and friends or family who were invited into the room and were then privy to granular data and problem lists. While parents pointed out these concerns, most noted that they themselves were not bothered by these possibilities. Other families knew of some security or privacy concerns for children, and noted that some form of password protection might be warranted:

I know there’s other parents that have had issues where they’ve had security issues and whatnot with their children where they might want the screen being turned off or something like that. I think that maybe if they had a basic parent password or something like that, that might be appropriate if they have a situation like that. Like give an option to have that. But, I like that there is total access to it, because we came in late last night and I didn’t want to be sitting here worried about trying to do a password or trying to do anything like that.

3.3 Parents’ Suggestions for Improvement

The major suggestions from almost all of the parents were related to helping families interpret or understand the data on the LCIM. Foremost, parents identified the need for some sort of tutorial to better understand how to use the LCIM. The rest of the suggestions for improvement are presented in Table 2.

Discussion

To our knowledge, this is the first study to explore the perception of families on a parent-facing technology that provides real-time EHR data in pediatric ICU. Our findings reveal a range of insights that show granting continuous access to parents might contribute to increased family empowerment and family-centered care. This study also examined parent perceptions regarding early stage benefits and drawbacks of this technology to inform the design and implementation of future collaborative technologies.

Transparency is increasingly a driver for quality and engagement, with efforts such as OpenNotes, acute care portals, and digital applications increasingly offered by health systems to engage patients in meaningful ways to improve patient/family education, co-create care plans, and detect and report errors.(17) LCIM represents another patient engagement tool that empowers families through access to data that have been historically out-of-sight. In similar ways, LCIM provides for transparency, leading participants to find value in improved situational awareness and error detection. Previous studies have also shown that transparency in data sharing improved parents and patients trust in care team. (18,19) In our study, parents acknowledged how the LCIM provided more transparency in

the care of their child, facilitated their understanding of their child's overall situation, and helped them better participate in a shared decision making process with the care team. Past research has demonstrated tension between patients wanting more information and clinicians recommending some barriers to unfiltered information, putatively to reduce anxiety but also because diverging viewpoints or mixed-messages may confuse and alarm families.(20) In some studies, providers preferred "controlled release of information" in ICU environments, claiming that full transparency might violate the "first, do not harm" principle since the information could be too alarming or introduce additional anxiety.(18,21) However, almost eighty percent of families in our study disagreed with this perspective and supported full transparency. The finding that parents of critically ill children support information access despite the potential anxiety from exposure to unexplained laboratory and test results is interesting, and it is consistent with those of studies of patient and parent access to medical records in non-ICU settings which reveal that increased anxiety and/or confusion about test results received prior to physician explanation is outweighed by perceived benefits.(22,23) Additionally, at least one study has found that increased anxiety stemming from a child's admission to ICU is not clearly associated with parental comprehension of medical issues.(24) The findings suggest that rather than hiding results or information from patients, improvements to the technology that provide education and context about the information may best meet parents' needs.

In addition to enabling transparency, LCIM is able to engage patients by serving as a conversational aid. Given the increasing importance of family-centered rounds,(25) the LCIM helped parents "pre-round" or prepare questions for rounds, as well as serving as a shared canvas for conversations with clinical staff. While mobile computers or devices may create a barrier to communication, with clinicians' heads buried in personal screens,(11) the LCIM provides a common (large) interaction space for doctors and parents to look at the same information together. The providers share the same view of the data during discussion with parents. This can improve the communication during the round, consistent with studies of other types of interactive patient technologies which facilitates shared view of data. (26,27) Our findings are in line with prior research that shows that meeting patient and family information needs is a prerequisite to engagement and patient-and family-centered care.(18,28,29)

Finally, several concerns were raised regarding the lack of orientation, context and explanation, and privacy. Parents reported that they had not received any training regarding the LCIM. Some of the parents were not even aware that they were allowed to use it. The LCIM was included as part of a hospital-wide EHR implementation, with no formal or informal orientation of health providers to the LCIM. To date, there continues to be no formal orientation for new providers. Similarly, there has been no attempt to create a standard orientation for parents. This lack of orientation likely accounts for the fact that 10 of the 33 parents never interacted with the LCIM.

The lack of orientation for both providers and parents is an organizational issue that can significantly affect the use of such technologies according to Technology Acceptance Model,(16) meaningful training on such technologies may increase both the use and benefit from this usage.(30) Most parents report that they learned to use the LCIM by experimenting

with it or watching providers use it in the room. Despite the lack of training, most parents thought the LCIM was easy to use and had good usability features. One reason might be that the LCIM is consistent with other pervasive mental models of touch screen and interactive devices. Parents noted privacy concerns to be more hypothetical than real in their cases but suggested some steps organizations can take to obscure data in sensitive situations.

One potential concern identified by some parents was the possibility of misinterpretation of displayed information. The information displayed by the LCIM comes directly from the EHR and was created by healthcare providers with an intended audience of other healthcare providers and workers. Concerns around low health literacy, which has been well described as a barrier to engagement in care, is potentially compounded by the velocity and granularity of data generated in an ICU. At the same time, other literature raises the question of whether issues of health literacy substantively affect parental understanding of aspects of care. (31) This limitation identifies the challenge of providing tools to support multiple audiences such as clinicians and parents.

To address issues related to information interpretation, tools could be built atop the technology to assist parents with understanding the data and keeping abreast of the main issues while enabling drill down into the details. One next step might involve adding features which will give additional information to the parent in lay language regarding that specific displayed value. Another possibility to avoid additional anxiety caused by the data such as red values might be solved by adjusting those ranges based on critical conditions rather than normal values, or deviations from expectations. In order to maximize understanding and engagement, these type of collaborative technologies need to have effective user interface design and accommodate parents' health literacy level, familiarity with technology, mental models, and information processing capabilities.(32,33)

There are several important limitations of this study. First, it is a study at a single site using proprietary technology provided through an EHR vendor. While the vendor had no knowledge of or influence in the design or execution of the study, the findings may be limited to centers using similar technology. At the same time, our findings reveal a potential opportunity for all ICUs to use technology to engage and empower parents. A second limitation of this study is that the technology is created and presented in English, with the LCIM data only currently available in English. While this is understandable considering that the vendor is based in the United States with a market focused on the the U.S., the design of the technology created a third limitation of only studying parents who speak English. It is possible that the perceptions of the LCIM by non-English speaking parents might reflect ambivalence or frustration with the technology. Finally, we did not collect data regarding health literacy of parents and cannot link this to their perception of open data access.

In conclusion, this study suggests that the LCIM, which provides open data to English speaking families and professionals without barriers, may be an effective way to empower and engage parents in the pediatric ICU. The displayed information continuously provided from the LCIM to parents might empower them to be more involved their child's care, improve awareness of their child's condition, be involved in the shared decision making

process, and improve safety by detecting errors. Finally, this study provide insights into the collaborative use of health IT in the pediatric ICU .

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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REFERENCES

1. Blumenthal D, Squires D. Giving Patients Control of Their EHR Data. *J Gen Intern Med*. 2015;30(1):42–43.
2. Finkelstein J, Knight A, Marinopoulos S, et al. Enabling Patient-Centered Care Through Health Information Technology. Evidence Report/Technology Assessment, (206), 1–1531. 2012.
3. Collins S, Dykes P, Bates DW, et al. An informatics research agenda to support patient and family empowerment and engagement in care and recovery during and after hospitalization. *J Am Med Inform Assoc*. 2017;25(2):206–209.
4. Valdez RS, Holden RJ, Novak LL, Veinot TC. Transforming consumer health informatics through a patient work framework: connecting patients to context. *J Am Med Inform Assoc*. 2014;22(1):2–10. [PubMed: 25125685]
5. Kelly MM, Hoonakker PL, Dean SM. Using an inpatient portal to engage families in pediatric hospital care. *J Am Med Inform Assoc*. 2016;24(1):153–161. [PubMed: 27301746]
6. Muething SE, Kotagal UR, Schoettker PJ, et al. Family-centered bedside rounds: a new approach to patient care and teaching. *Pediatrics*. 2007;119(4):829–832. [PubMed: 17403858]
7. Davidson JE, Powers K, Hedayat KM, et al. Clinical practice guidelines for support of the family in the patient-centered intensive care unit: American College of Critical Care Medicine Task Force 2004–2005. *Crit Care Med*. 2007;35(2):605–622. [PubMed: 17205007]
8. Au SS, Roze des Ordon A, Soo A, et al. Family participation in intensive care unit rounds: Comparing family and provider perspectives. *J Crit Care*. 2017;38:132–136. [PubMed: 27888716]
9. Boss RD, Donohue PK, Larson SM, et al. Family Conferences in the Neonatal ICU: Observation of Communication Dynamics and Contributions. *Pediatr Crit Care Med : a journal of the Society of Critical Care Medicine and the World Federation of Pediatric Intensive and Critical Care Societies*. 2016;17(3):223–230.
10. Brown SM, Bell SK, Roche SD, et al. Preferences of Current and Potential Patients and Family Members Regarding Implementation of Electronic Communication Portals in Intensive Care Units. *Ann Am Thorac Soc*. 2016;13(3):391–400. [PubMed: 26700656]
11. Kern J, Bhansali P. Use of Computer Technology During Family-Centered Rounds: A Qualitative Study of Parent Perspectives. *Hospital Ped*. 2018:hpeds. 2017–0127.
12. Bell SK, Roche SD, Johansson AC, et al. Clinician Perspectives on an Electronic Portal to Improve Communication with Patients and Families in the Intensive Care Unit. *Ann Am Thorac Soc*. 2016;13(12):2197–2206. [PubMed: 27700144]

13. Holden RJ, Asan O, Wozniak EM, et al. Nurses' perceptions, acceptance, and use of a novel in-room pediatric ICU technology: testing an expanded technology acceptance model. *BMC Med Inform Decis Mak.* 2016;16(1):145. [PubMed: 27846827]
14. Karsh BT, Weinger MB, Abbott PA, et al. Health information technology: fallacies and sober realities. *J Am Med Inform Assoc.* 2010;17(6):617–623. [PubMed: 20962121]
15. Creswell JW. *Qualitative inquiry & research design: Choosing among five approaches.* Sage Publications, Inc; 2007.
16. Holden RJ, Karsh BT. The technology acceptance model: its past and its future in health care. *J Biomed Inform.* 2010;43(1):159–172. [PubMed: 19615467]
17. Bell SK, Folcarelli PH, Anselmo MK, et al. Connecting Patients and Clinicians: The Anticipated Effects of Open Notes on Patient Safety and Quality of Care. *Joint Commission journal on quality and patient safety / Joint Commission Resources.* 2015;41(8):378–384.
18. Grossman LV, Restaino S, Vawdrey D. Should Hospital Patients Have Bedside Access to Their Complete Medical Records? *J Particip Med.* 2017;9(1):e11.
19. Asan O, Tyszka J, Fletcher KE. Capturing the patients' voices: Planning for patient-centered electronic health record use. *Int J Med Inform.* 2016;95:1–7. [PubMed: 27697228]
20. Feldman HJ, Walker J, Li J, et al. OpenNotes: hospitalists' challenge and opportunity. *J Hosp Med.* 2013;8(7):414–417. [PubMed: 23813756]
21. Bell SK, Roche SD, Johansson AC, et al. Clinician Perspectives on an Electronic Portal to Improve Communication with Patients and Families in the Intensive Care Unit. *Ann Am Thorac Soc.* 2016;13(12):2197–2206. [PubMed: 27700144]
22. Hassol A, Walker JM, Kidder D, et al. Patient Experiences and Attitudes about Access to a Patient Electronic Health Care Record and Linked Web Messaging. *J Am Med Inform Assoc.* 2004; 11(6): 505–513. [PubMed: 15299001]
23. Ferreira A, Correia A, Silva A, et al. Why facilitate patient access to medical records. *Stud Health Technol Inform.* 2007;127:77–90. [PubMed: 17901601]
24. Needle JS, O'riordan M, Smith PG. Parental anxiety and medical comprehension within 24 hrs of a child's admission to the pediatric intensive care unit. *Pediatric Critical Care Medicine.* 2009;10(6): 668–74. [PubMed: 19451843]
25. Xie A, Carayon P, Kelly MM, et al. Managing Different Perspectives in the Redesign of Family-Centered Rounds in a Pediatric Hospital. *Proceedings of the Human Factors and Ergonomics Society Annual Meeting.* 2012;56(1):1733–1737.
26. Kazunas E, Hanauer DA, Ackerman MS, et al. Identifying unmet informational needs in the inpatient setting to increase patient and caregiver engagement in the context of pediatric hematopoietic stem cell transplantation. *J Am Med Inform Assoc.* 2015;23(1): 94–104. [PubMed: 26510878]
27. Patmon FL, Gee PM, Rylee TL, et al. Using Interactive Patient Engagement Technology in Clinical Practice: A Qualitative Assessment of Nurses' Perceptions. *J Med Internet Res.* 2016;18(11).
28. Hefner JL, Sieck CJ, Walker DM, et al. System-Wide Inpatient Portal Implementation: Survey of Health Care Team Perceptions. *JMIR Med Inform.* 2017;5(3).
29. Jackson GP, Robinson JR, Ingram E, et al. A technology-based patient and family engagement consult service for the pediatric hospital setting. *J Am Med Inform Assoc.* 2017; 25(2):167–174.
30. Or CK, Karsh BT. A systematic review of patient acceptance of consumer health information technology. *J Am Med Inform Assoc.* 2009;16(4):550–560. [PubMed: 19390112]
31. Moon RY, Cheng TL, Patel KM, Baumhaft K, & Scheidt PC. Parental literacy level and understanding of medical information. *Pediatrics.* 1998; 102(2), e25–e25. [PubMed: 9685471]
32. Zikmund-Fisher BJ, Scherer AM, Witteman HO, et al. Graphics help patients distinguish between urgent and non-urgent deviations in laboratory test results. *J Am Med Inform Assoc.* 2017;24(3): 520–528. [PubMed: 28040686]
33. Zikmund-Fisher BJ, Scherer AM, Witteman HO, et al. Effect of Harm Anchors in Visual Displays of Test Results on Patient Perceptions of Urgency About Near-Normal Values: Experimental Study. *J Med Internet Res.* 2018;20(3):e98.

Table 1 –

Characteristics of Parent Participants

Variables	n (33)	%
Sex		
Female	21	64%
Male	12	36%
Age		
18–25 years	2	6%
26–35 years	19	58%
36–45 years	9	27%
46–55 years	2	6%
>56 years	1	3%
Race/Ethnicity		
White	23	70%
African American	4	12%
Hispanic	3	9%
Asian	3	9%
Education		
< High School	4	12%
High School diploma / GED	4	12%
Some College	11	33%
Associate Degree	2	6%
Bachelor's Degree	8	24%
Masters Degree	2	6%
Doctorate Degree	2	6%
Past PICU Stay		
Yes	16	48%

Table 2.

Suggestions for improvement of the LCIM

<i><u>Orientation and tutorial need</u></i>
Quick and integrated tutorial to help parents better understand the information on the LCIM
An information page on LCIM so parents feel comfortable explaining the medical situation to visitors or family
Communication from medical team so parents know they can use the LCIM
Including simple definitions when red numbers appear
Hovering over something brings up informational pop out
Having a hyperlink to explain terms that people may not know
Level of information available: start small, in lay terminology and provide an opportunity to learn more by clicking
Inclusion of resource center where parents can look up additional information on procedures
<i><u>Display related</u></i>
Including a screen saver/having a screen that dims after 30 seconds of inactivity
Content can be customizable based on patients' disease
Organization might be system/organ-based like kidney, heart, respiratory, etc.
Sections that are not used could be eliminated
Add special ranges for certain values
Having a feature to see when the medications were scheduled and given to the patient
Different colors for low values and high values (Rather than red for all of the out of range values)
<i><u>Integration related</u></i>
The ability to insert parents' questions/concerns on LCIM (to be responded to on rounds)
Section of LCIM to place the type of information parents are asked repeatedly
Listing the daily goals/plan of the day and progress on them
Integration of parameters chosen by the team for specific children based on their condition(s)