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“Everybody Makes Mistakes”: Children's Views on Medical Errors and Disclosure

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A R T I C L E I N F O

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A B S T R A C T

Purpose: The aim of this study was to explore the views of chronically-ill pediatric patients on medical errors and disclosure processes.
Design and methods: Semi-structured, qualitative interviews were conducted with twenty pediatric patients. Participants comprised ten children (8–12 years) and ten adolescents (13–18 years). Multiple methods using qualitative approaches were applied to explore and elicit views on medical errors, disclosure and recommendations for patient safety. For the children, art and play-based methods along with visual aids and vignettes were used to facilitate discussion. Older participants predominantly engaged in discussing the issue of medical errors through an examination of vignettes representing levels of harm.
Results: Participants revealed a range of perspectives including a strong desire to be told of errors. While they wanted those responsible for the error to be held accountable, they acknowledged that everyone makes mistakes. Children's rights and participation in patient safety as well as the existence of secret errors emerged spontaneously through the data analysis.
Conclusions: Chronically-ill children want to know about errors, from the person responsible for the error, and consider apologies and genuine remorse to be critical for coping. Children acknowledge that disclosure requires a case-by-case analysis.
Practice implications: The results have implications for how we view disclosure processes with children and how to engage them in patient safety.

Children's understanding of medical errors and preferences for disclosure are largely unknown. In contrast to research with adults, there are no known studies that specifically examine children's knowledge of medical errors and how they should be handled. Given that children have a right to information and participation in health care decision-making (American Academy of Pediatrics, 2010; Canadian Paediatric Society, 2004; United Nations [UN] General Assembly, 1989), the exclusion of children's views on medical errors creates a critical knowledge gap in the delivery of safe and ethically-based care. This gap is particularly disconcerting because children are at high risk for medical errors (Maaskant et al., 2015; Rishoej, Thybo Christesen, Juel Kjeldsen, Almarsdóttir, & Hallas, 2018).

Disclosure of medical errors is a well-established legal obligation grounded in the common law doctrine of informed consent (Health Care Consent Act, S.O., 1996). In North America, the duty to disclose an error is integral to the Canadian and American Medical Associations' codes of ethics (Matlow, Stevens, Harrison, & Laxer, 2006). Internationally, the UK's National Patient Safety Agency policy *Being Open* (2009) devotes a section pertaining to disclosure in pediatrics. The report recommends that health care providers working with children should communicate with the child directly, using language that is both accessible and age-appropriate (p. 28). Similarly, the Australian Open Disclosure Framework (2013) states that “the clinical team should assess the involvement of young people in the open disclosure process on a case-by-case basis, taking account of whether the child is mature enough to receive the information and having regard for the wishes of the young person and the parents, where appropriate” (p. 31.)

Theoretical framework

According to Section 13 of the UN Convention on the Rights of the Child, children have the right to “receive and impart information and ideas of all kinds” (UN General Assembly, 1989: p. 4). Children's rights, however, can often be violated in pediatric settings because patients are frequently excluded from aspects of decision-making surrounding their care (Koller, 2017; Coyne & Gallagher, 2011; Moore & Kirk, 2010). In the case of pediatric medical errors, disclosure processes are complex. Issues

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include the child's desire to know; cognitive and emotional capacities; parental perspectives on disclosure; the responsibilities of health care providers; disparate policies across institutions and regions; and the degree of risk or harm associated with the event (Koller et al., 2016). Despite these considerations, children remain dominant stakeholders and have a right to be informed and consulted when errors occur in their care. Even young children (3–6 years of age) have been shown to have sufficient cognitive and emotional capacities to understand complex medical information (Alderson, 2007; Koller, Khan & Barrett, 2014).

Adverse events are often rooted in systemic issues, such as institutional processes for delivering health care and poor communication practices which can lead to errors (American Academy of Pediatrics, 2016; Reason, 2000). However, the emerging framework of a fair and just culture promotes transparency among health care providers and minimizes the fear of blame and reprimand (Connor et al., 2007; Gallagher & Mazor, 2015). In particular, a fair and just culture is created when all points of view are sought to improve the care environment (Connor et al., 2007). Because error disclosure in pediatrics is multi-faceted and complex, it is imperative that we consider the views of pediatric patients.

Research question

The primary aim of this study was to examine how children[1] understand and define a medical error and how these events should be handled in pediatric settings. A secondary aim was to explore children's desires for disclosure based on different levels of harm as depicted in three vignettes. For example, do children want to know about all errors or just those that cause patient harm?

Methods

Given the exploratory nature of the study, qualitative methods were employed. Through qualitative approaches, critical nuances in children's perspectives can be captured, often revealing how children construe and negotiate experiences across contexts. We chose child-centered, semi-structured interviews as a basis for data collection combined with other methods to represent the mosaic approach (Clark, Flewitt, Hammersley, & Robb, 2014). Other methods included: reading children's books on errors or *mistakes*, examining three vignettes that represented different types of errors, and creating artwork that represented hospital errors (drawing, sculpting, writing, painting) (Diaz-Soto & Swadener, 2005; Hass-Cohen, Chandler-Ziegler, Veeman, & Funk, 2016; Kuhn, 2003). These integrated approaches do not merely duplicate data, but offer complementary insights that may not emerge through a single method of data collection (Darbyshire, MacDougall, & Schiller, 2005). Similar approaches with pediatric populations were implemented by the principal researcher in other studies (Koller, 2017; Koller et al., 2014) and are supported elsewhere in the literature (Christensen & James, 2000; Docherty & Sandelowski, 1999; Epstein, Stevens, McKeever, & Baruchel, 2006; Morrow, 2001; Punch, 2002).

Recruitment

A cross-sectional, purposive sample of twenty chronically-ill children and adolescents were recruited from a medical inpatient unit within a large urban pediatric hospital. Chronically-ill children were chosen for recruitment because of their extensive health care experiences and ability to engage in discussions that involve complex medical events. Inclusion criteria comprised the diagnosis of a chronic condition for at least one year, English language skills and the cognitive and emotional capacity to discuss difficult subject matters. Exclusion criteria precluded patients who had experienced a medical error because of ethical concerns and the risk of inducing trauma.

On a weekly basis, inpatient lists from the medical unit were reviewed to determine patients who met the criteria. The research assistants (child life specialists) followed up with the nurse managers to discuss recruitment and individual capacity to consent. Once potential candidates were identified, families were approached as per ethics board guidelines. For younger participants, assent procedures were administered along with parental consent.

Participants

The study included twenty participants with ten children (8–12 years) and ten adolescents (13–18 years). Five males and 15 females comprised the gender composition with a mean age of 12 years. We strived to obtain a more equitable gender balance, however, this proved challenging as some patients were discharged prior to the scheduled interview. The majority of participants had experienced five or more hospitalizations and a range of diagnoses were represented. Table 1 provides a descriptive breakdown of the sample.

Data collection

Data included: 1) demographic information (age, gender, diagnosis, number of hospitalizations), 2) individual, semi-structured interviews (McCracken, 1988), 3) three case study vignettes along with photographs and drawings of medical situations to support discussions, and 4) participants' artwork (drawing, sculpting).

Interviews ranged from 45 min to 2 h depending on the participant's level of engagement. Each interview was conducted in hospital at the participant's bedside. Due to the sensitive nature of discussing medical errors, senior child life specialists and the principal researcher conducted all the interviews.

Using simple language, the interviewer described the project while playing and building rapport with the child before the interview. By way of introducing the concept of medical errors to younger participants (8–12 years), an array of children's books dealing with *mistakes* was offered. These books were specially selected by a co-investigator on the study, a literacy scholar. Only one child agreed to have a book read aloud. All participants were invited to write, draw or sculpt using a variety of materials to convey what a medical error looked like to them.

During the interview, the term *mistakes* was used to suggest notions of wrongdoings, or harmful events. Probing questions included: “what would be a *mistake* that could happen in a hospital?”, and “if a mistake happened, should doctors tell children or not?” Participants were reminded that discussions regarding errors were for study purposes only. At the end of each interview, parts of the discussion were reiterated as a form of member checking to ensure accuracy.

Case study vignettes were adapted from Matlow et al. (2006) and depicted three levels of harm: 1) a near miss, 2) an error with minimal impact, and 3) an error with serious adverse effects. Vignettes provided an opportunity to examine how children view degrees of harm and their preferences for disclosure. A description of each vignette and associated probes are displayed in Table 2.

Table 1
Demographic summary.

Participants	Children (8–12 years)	Adolescents (13–17 years)
n = 20	n = 10	n = 10
Gender	Male (n = 3)	Male (n = 2)
	Female (n = 7)	Female (n = 8)
Number of hospitalizations	One to five: n = 4	One to five: n = 3
	Five to ten: n = 2	Five to ten: n = 2
	10 or more: n = 4	10 or more: n = 5
Diagnoses	Asthma, cystic fibrosis, kidney failure, Crohn's disease, sickle cell, intestinal motility disorder, organ transplant, and primary ciliary dyskinesia, among others	

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[1] The terms *child* or *children* will refer to pediatric patients between 8 and 18 years of age.

Table 2
Description of vignettes.

Vignette	Description	Probes	Verification
1 Near miss	Before giving out the medicine, the person at the pharmacy sees that it is a lot like the one the child is allergic to, so she tells the nurse and the child does not get the medicine. Instead, he gets another medicine that he is not allergic to, and nothing happens to the child.	1. *Do you think this is a mistake?* 2. *Would you want to know if this happened to you?* 3. *How would you want to find out (who should be there, who should tell, and how)?* 4. *Is there anything the doctor, nurses, or hospital could do to make things better?*	Reiterate your impressions of the child's responses. Ask to confirm/clarify and for a general response to the 3 vignettes: 1. *Would you want to know if a mistake happened?* 2. *How would you want to find out (who should be there, who should tell, and how)?* 3. *Is there anything the doctor, nurses, or hospital could do to make things better?*
2 Minimal harm	The child takes some of the medicine and starts to feel itchy and gets a rash all over his body. The nurse stops giving the medicine and the doctor gives the child another medicine. The rash stops after a few hours.		
3 Serious harm	The child takes some of the medicine and gets very sick and she passes out. She is taken to the critical care (place for emergencies). The child wakes up, but her kidney (the body part that helps you pee) is not working. She will have to use a special machine to go pee for the rest of her life.		

Data analysis

The demographic data for each participant were recorded in an Excel spreadsheet. Interviews were digitally recorded and transcribed. A thematic analysis (Braun & Clarke, 2006) was conducted to identify overarching themes evident across both groups of participants. In the case of exploratory studies, thematic analysis supports a flexible and organic approach to coding and theme development (Holmqvist & Frisén, 2012). This type of analysis is "used to identify patterns within and across data in relation to participants' lived experience, views and perspectives and behaviors and practices…" (Clarke & Braun, 2017, p. 297).

Thematic analysis consists of six steps (Braun & Clarke, 2006). Analysis began with a thorough reading of all transcripts to obtain a general sense of the data. The second step generated initial codes by organizing segments of the text and assigning descriptive labels across the entire data set. The third step entailed a search for potential themes while the fourth step delineated themes by checking them against initial impressions and coding extracts that were determined in step two. A further refining of the codes occurred in step five, where ongoing analysis constructed a story with additional properties and names for each theme. The sixth and final step consisted of writing up the data, in which a flexible and reflective process ensued based on an extraction of compelling data. Additional comparative analyses of themes occurred across and within the participant groups (children and adolescents). Negative case analysis was also applied in order to build and strengthen qualitative rigor (Allen, 2017). This method is used to check for discrepancies between prevalent data and those that appear new or divergent. Unique perspectives are revealed through direct quotes where possible. This process concluded with a final analysis of the selected extracts and an appraisal of how the findings related to the research question and literature. NVivo 12, a data analysis software program, was used at later stages of the process.

The research team comprising of two researchers, one graduate student and two child life specialists met mid-way through the data collection and at various stages of analysis. On two occasions, randomly chosen transcripts were distributed to members of the research team for discussion. All six steps of the analysis were conducted by the principal investigator. Codes were revised as new and spontaneous data emerged. Subsequent to some data refinement, consensus was reached on the categorization of data. A total of 114 codes remained. Table 3 provides an overview of the coding categories and sample responses while Fig. 1 provides a visual representation of the coding scheme.

Data from artwork comprised only five items (three drawings, one list of emotions, and one clay sculpture). It was decided that due to the small amount of artwork elicited from the participants, a merging of the data (interviews and vignettes, artwork) might compromise the quality of the overall analyses. For this reason, artwork was not included in the final analyses.

Findings: themes from the interview data

As a starting point, the presentation of findings begins with an overview of how participants described errors, their causes and levels of harm. These findings are followed by main themes and sub-themes aligned with processes to consider before, during and after disclosure. Therefore, the stages of disclosure are labelled as: 1) pre-disclosure, 2) disclosure, and 3) post-disclosure. For example, sub-themes under the category of disclosure include who discloses and how and what is disclosed. In addition, children's interpretations of the vignettes are integrated in these findings. This review includes children's recommendations for patient safety measures and prevention strategies. Finally,

Table 3
Summary of main coding categories.

Coding category	Sub-theme	Sample responses
Errors	Examples of errors	"Bad and stupid" (C3) "When you do an accident and you don't mean it" (C9)
	Causes	"They should have paid more attention" (C7) "The biggest is miscommunication" (A9)
	Levels of harm	"A minor could be something that is fixable or a larger mistake is when something really bad happens" (A1)
Disclosure process	Pre-disclosure (deciding whether or not to disclose)	"Because maybe if it's serious they'll panic" (A3) "They can't tell babies what the mistake is" (A4)
	Disclosure (who gets told; how and what gets shared; who does the telling)	"I would like them to tell me this right the second they know" (C1) "I would want them to apologize to see if they are sincere" (A8) "Literally what happened" (A4) "I would want to know what is going on… so I know how to help" (A6)
	Post-disclosure (recommendations)	"They should fix it, and tell me what they're going to do to fix it" (C4) "Double check everything" (A2)
Emerging themes	Child rights	"I think the child should know" (C7) "I have a right to know in case something went worse" (A5)
	Secret errors	"I think a mistake happened with me once the first time I was here" (C5) "Hmm, I think some of them just sneak it" (A1)

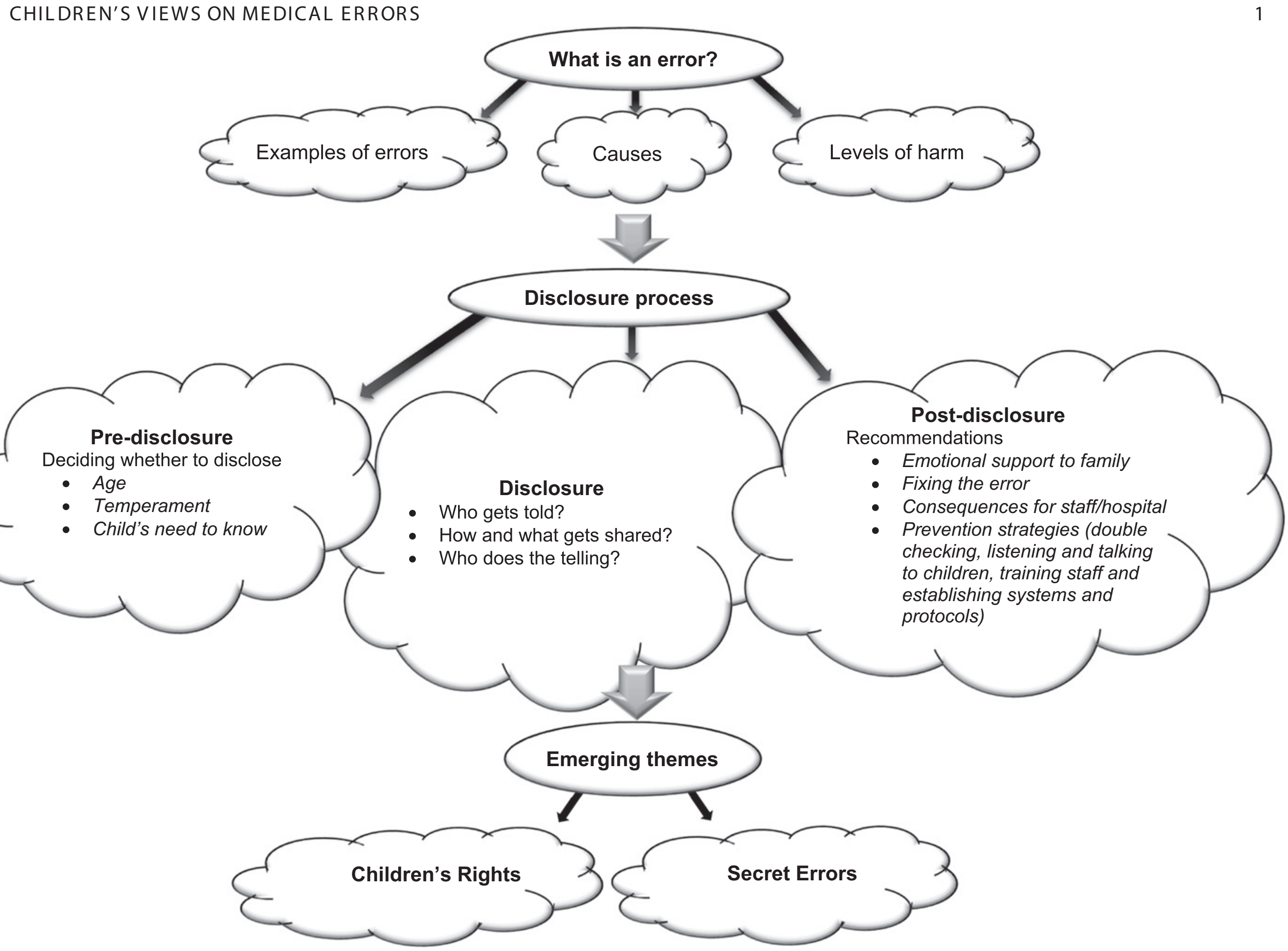

Fig. 1. Views on medical errors and disclosure. Model depicts the coding scheme.

emergent or unexpected themes reveal the importance of children's rights and the presence of secret or hidden errors.

Errors

While discussing errors, half (n = 10) of the participants characterized errors as universal in that “everybody makes mistakes and you shouldn't hold that against a person” (15-year-old female) and “I don't think they have the choice to be perfect cause like everyone makes mistakes and it just happens and you can't really do anything” (13-year-old female). When asked to define an *error*, several participants (n = 8) had difficulty providing specific examples. Some identified errors that occurred outside of health care such as making a mistake on a test in school, or talking back to parents. With further probes and discussion regarding the vignettes, concrete examples of medical errors emerged.

Examples of errors

Participants described errors as “bad and stupid” (12-year-old female), and “something that shouldn't happen” (8-year-old male). Other participants discussed the issue of intentionality by saying “when you do an accident and you don't mean it” (10-year-old female). The majority of participants (n = 16) associated hospital errors with wrong medications or incorrect drug dosages, while some younger participants noted a disregard for hand washing or a surgical mistake. Still others believed that errors could include misinformation shared with patients (i.e. wrong diagnosis, false promises of discharge).

Causes

Almost half of the participants (n = 9) believed that busy and stressful health care environments contributed to errors where “no one's listening and no one's really caring” (10-year-old female). Moreover, “someone that is rushing can make a mistake because they were careless, neglectful or too busy and overloaded” (14-year-old female). Leaving patients and families out of the conversation was a problem because “communication is very important” (14-year-old female) while a ten-year-old female added “It's like you're thinking of that but you're not focusing on something - like what you're supposed to be focusing on”.

Other participants noted that health care providers could be careless in their work. One seventeen-year-old female explained “if they're just being lazy or they're not doing their job properly, it would just kind of bug me. Like if it really harmed me in some way.” Finally, experienced clinicians were less likely to make a “rookie mistake” (15-year-old female) in that “nurses who have more experience probably know to double check it” (12-year-old female).

Levels of harm

Participants understood that errors were associated with varying levels of harm, including no harm (near miss). A big mistake was viewed as something “really bad” (10-year- old female) such as a procedure that resulted in bleeding or an inability for a patient to breathe (8-year- old female). Accordingly, not all errors required the same attention, as some could easily be fixed, while others caused irreparable damage. As described by one thirteen-year-old female, “a minor could be something that is fixable or a larger mistake is when something really bad happens.” Finer distinctions were seen in the case of a near miss when “if they catch themselves before it happens, I don't really consider it a mistake” (16-year-old male). However, one ten-year-old female indicated “like no matter if it's a small mistake, they should have known.”

Pre-disclosure

Deciding whether or not to disclose

Participants identified variables to consider such as the child's age and temperament, as well as factors associated with the family and the degree of harm. Half of the participants (n = 10) explicitly noted that the age of the child was an essential variable because “they can't tell babies what the mistake is” (16-year-old male). Four participants (2 children, 2 adolescents) specifically identified that children from around the age of 7 should be informed.

The temperament and emotional stability of the child denoted important features of disclosure. Justification for non-disclosure involved situations where children would not benefit from truth-telling, such as in the case of serious harm “because maybe if it's serious they'll panic and you won't be able to do something you need to make them better” (13-year-old male). Similarly, another twelve-year-old female stated that “if it's too awful, then don't tell the child”.

Truth-telling was complicated, and there was a need to discern whether a patient wanted to know about an error or not. One eight-year-old female shared “sometimes I don't want to know stuff that happened, sometimes I do, depends on my mood”. While a fourteen-year-old female explained “it's their job to make you healthier. So, technically they would be doing their job by not telling you if it was something that was going to cause you to be sick or stuff like that”. Many suggested that parents should be told first, followed by a determination of whether the child should be told.

Disclosure

Participants were asked to elaborate on specific issues related to disclosure. For example, who gets told of an error (parent, child or both), what is shared during disclosure (saying sorry, telling the truth), and who does the telling? These data were supplemented by examining case study vignettes and associated benefits of disclosure.

Who gets told?

Sixteen of the twenty participants believed that errors should be disclosed to both parents and children where possible. Parental presence would likely benefit the child's ability to cope. About half of the participants (four children, five adolescents) believed they could manage hearing the information alone, declaring “I could probably handle it” (15-year-old female).

Eleven participants discussed the value of telling children about errors because it was beneficial for them. If children were told of an error, they could assist in monitoring their health, sharing emotions and meeting the person who committed the error. Some discussed the need to respect patient rights and provide the best support “so that the kids won't be that worried” (8-year-old female).

Overall, the majority of participants (n = 15) decided that if an error occurred in their care, they wanted to be told regardless of whether it had caused harm or not. In the case of an adverse event, all participants were in favor of being told of the error. Five participants (2 children, 3 adolescents) believed it was unnecessary to disclose a near miss. Table 4 provides an overview of preferences for disclosure based on the levels of harm.

Table 4
Preferences for disclosure based on vignette and risk level.

Participants	Level 1 Near miss No harm		Level 2 Medical error Minimal harm		Level 3 Adverse event Serious harm		All levels	
	Know	Not know	Know	Not know	Know	Not know	Know nothing	Know everything
Children (n = 10)		C6 C8	C6 C8		C6 C8			C1 C2 C3 C4 C5 C7 C9 C10
Adolescents (n = 10)		A2 A4 A8	A2 A4 A8		A2 A4 A8			A1 A3 A5 A6 A7 A9 A10

How and what gets shared?

Sharing news about an error demanded a sense of urgency and expediency. As one ten-year-old male expressed, “I would like them to tell me this right the second they know.” Participants also shared preferences for how errors should be disclosed which included an apology and telling the truth.

Saying sorry. A majority of participants (n = 18) viewed saying sorry as a necessary first step for demonstrating accountability and remorse, particularly when it was deemed genuine. One seventeen-year-old female said “I don't want them to act like it's not their fault. They have to look like they mean it”, while another fourteen-year-old female reiterated “I would want them to apologize to see if they are sincere”.

Benefits associated with an apology included opportunities for greater emotional support. Being accountable meant “taking responsibility for it—that would just make me feel better that they didn't mean to do it” (13-year-old female). A sixteen-year-old female added “It's not going to fix what happened. But it's going to show that they understand and like they sincerely apologize for what they did.” One eight-year-old female agreed that an apology would “make me feel good afterwards.” Negative case analysis revealed that a few participants viewed an apology as insufficient in modifying the impact of a harmful event. Because “depending on the person, it might not be enough” (15-year-old female) and “they could have prevented it” (17-year-old female).

Telling the truth. Participants felt strongly that “sharing information and being honest” (8-year-old female) required disclosing “literally what happened” (16-year-old male). Overall, truth-telling promoted trust between the patient and health care team and was therefore considered an integral component of disclosure.

Who does the telling?

All participants believed that the person who committed the error should be responsible for disclosing the transgression. As one seventeen-year-old female asserted, “the person who did the mistake. I wouldn't expect it from anyone else, just the person who made the mistake.” In cases where serious harm occurred, a few participants believed that disclosure could include any or all of the health care providers who may have contributed to the error.

Post-disclosure

Participants were asked to describe potential emotions after learning of an error. Expectations from health care providers following disclosure included sensitive support to the child and family. Additional recommendations included: fixing the error, consequences for staff/ hospital and prevention strategies (double checking, listening and talking to children, training staff and establishing systems and protocols).

Recommendations following disclosure

Emotional support to family. Participants identified a range of difficult emotions following disclosure. Anger was cited by most participants (n = 15) as a predominant emotion because "I would feel mad but then again I'd feel like it's okay to make mistakes like as long as they fix it" (13-year-old male). Learning about an error could produce disappointment and a loss of trust in the health care team. As one thirteen-year-old female noted "I think that would change my mental state 'cause I'd be really disappointed and just sad that it wasn't my fault what happened", while another seventeen-year- old female added "I'd feel like I lost trust. I'd be upset, but I'd feel more disappointed with the hospital."

Eleven participants said they would feel anxious and unsafe in the hospital following disclosure. In contrast, honesty from the health care team could also alleviate fears. As one fifteen-year-old female claimed, "I would be scared but I would feel comfortable knowing that my care team is completely honest with me." Negative case analysis revealed that some would not express emotion, citing "I would keep it to myself" (8-year-old male) and "I would keep my feelings inside so it doesn't show" (8-year-old female). One participant was unsure of how they would respond.

Because of the emotional impact of an error, thirteen participants recommended ongoing emotional support for the child and family as essential for coping. One ten-year-old male indicated he "would want to be in the most comfortablest spot in the hospital" in order to "keep me relaxed so I don't scream." Another seventeen-year-old female reiterated this stance: "I would be very frustrated and angry if a serious error occurred and would want the hospital to take special care of the patient and family".

Fixing the error. Eighteen participants of twenty viewed fixing the error as the most important function of the health care team. Some stated, "As long as it's just fixed and dealt with good. Letting the family know and just correcting the problem without making more problems and handling it as fast as possible so that they can move on" (13-year-old female) and "they should fix it, and tell me what they're going to do to fix it" (12-year-old female). In contrast, fixing the error was not always an effective solution because "people who work in hospitals can try fixing mistakes, sometimes it works, sometimes it doesn't work" (8-year-old female).

Consequences for staff/hospital. Despite the harmful effects of errors, nine participants discussed forgiveness and compassion for the person who committed the transgression. One twelve-year-old female indicated "I would kind of let go… I don't know, I forgive people a lot." Similarly, a thirteen–year-old male explained "as long as they learn from their mistakes it's alright" while another added "'cause I wouldn't be as angry at the person if it wasn't really their fault. Like, staff have to care, and then it is easier to understand and forgive" (14-year-old female).

Empathy for the transgressors was expressed by five participants. For example, one twelve-year-old female shared "I personally would feel nervous about what would happen to the nurse" and "they should probably see a counselor or something" (15-year-old female). Another twelve-year-old female added "people should also be wondering how the nurse is feeling because she probably didn't want to make the mistake. She probably did it by accident."

Because the causes of errors differed, participants reasoned that the consequences should fit the circumstances. In situations where serious harm occurred, half of the participants (n = 10) discussed having individuals removed from their jobs. One ten-year-old female described "if it is very bad, I think the manager should fire her for that" while another ten-year-old female added "I would like expel her or him for a day or two, and just say 'I think you should practice not being so rushed'".

Participants grappled with whether a hospital should compensate for an error. For some, retribution entailed financial compensation, particularly in the case of a serious error. As one seventeen-year-old female noted "depending on what the mistake was, how big it was, and their reaction, I would consider suing if the situation was a bad one." Younger participants suggested the need to "raise money for the child" (8-year-old female), "pay for medication and everything the child needs" (10-year-old female) and give "candy, not too much but enough" (9-year-old female). Some adolescents considered sharing their story with the media as a way of garnering attention on the issue of patient safety. Finally, three young participants indicated they would demand nothing from the hospital while another six participants were uncertain as to what should happen.

Prevention strategies. Prevention strategies included sub-themes comprised of *double checking*, *listening and talking to children*, *training staff* and *establishing systems and protocols*.

Double checking. All participants emphasized the need to "double check everything" (16-year- old female). Younger participants cautioned "they just rush and they don't think about it so they should double check always" (10-year-old female) and "I think that doctors or nurses should always check the medicine before they give it to the patient just in case it's the wrong medicine. Like say the word again and double check with the doctor who wants the medicine and the doctor will confirm" (8-year-old female).

Listening and talking to children. The majority of participants (n = 18) discussed the relevance of communicating with children as an integral feature of error prevention. One seventeen-year-old female explained "talk to patients, ask about medications, check in with them, not listening is a big problem. They think they know better than kids and this makes it hard", while another thirteen-year-old female added "I'd just know for next time that I have to like warn them".

Moreover, others cited the "importance of having kids speak up and identify when something is wrong" (16-year-old female) and wanting to "be on the help team" (10-year-old female). Finally, seven participants acknowledged that even young patients could be involved in error prevention. In particular, two young participants cited the value of "knowing my life or my body is in danger so I could give them even more information or think of something that could help me" (10-year-old male), "'cause I want to prevent, I could maybe help it" (10-year-old female).

Training staff and establishing systems and protocols. More than half of the participants (n = 13) identified staff training and creating processes for error prevention. Some participants said: "yeah, better training for the workers, that's like number one" (16-year-old female) and "maybe practicing and studying to make sure they never make the mistake again" (12-year-old female).

Participants believed a collaborative approach to patient safety was necessary. They identified the need to monitor the patient, keep records of errors, establish a safety board, along with teams working on safety guidelines as integrated responses to error prevention. Suggestions such as "maybe have like a checklist with you all the time" (9-year-old female) and "getting everyone involved with the situation to talk it over with the whole staff and just say 'okay, this happened, now how can we make sure we completely avoid it next time or try our best to avoid it'" (15-year-old female).

Emerging themes

Unexpected or spontaneously elicited themes emerged from the data and were not prompted by interview questions. These included *children's rights* and *secret errors*. Secret errors were defined as those that may have caused minimal or no harm, but were hidden from patients and their families.

Children's rights

Twelve participants believed that children had a right to receive information about an error and to participate in health care discussions. As one ten-year-old female noted, “they don't always put the kids in the conversation, they just leave them out - because I'm not a ghost, I'm here in real life.” One seventeen-year-old female explained “well they don't really speak to me, they speak to my parents so, yeah that kind of bugs me cause I'm trying to take over my own health now and because I have a right to know in case something went worse.” Even younger children acknowledged themselves as rights bearers in that “they would always leave me out, but I'm the patient who is sick so I should be in the conversation” (10-year-old female). When asked if younger children possessed fewer rights, one sixteen-year-old female replied “Umm, not really. I think everyone should get the same good treatment that they deserve.”

Secret errors

Almost half of the participants (n = 8) described instances in their past where they or a family member suspected an error. In some cases, they described not feeling well, having unexpected reactions to a drug or other occurrences that didn't make sense. One twelve-year-old male described “I think a mistake happened with me once the first time I was here. They gave me a bigger dose of medicine I think, but it was fine and nothing happened to me. So that would be a small mistake.”

As a follow-up, participants were asked about the impact of a hidden error. For some, secret errors could elicit distrust in the hospital. As described by one fourteen-year-old female “well, like I'd feel different ways towards people that didn't tell me for their own reasons”. Although health care providers were trusted professionals, several participants described feelings of anger (n = 15), sadness (n = 10) and disappointment (n = 8) at the prospect of knowing an error had not been disclosed “because I feel like there shouldn't really be secrets between doctors and their patients” (16-year-old male).

Discussion

The aim of this study was to explore the concept of medical errors and disclosure processes with chronically-ill children and adolescents. To our knowledge, there are no studies to date that have explicitly examined children's perspectives on medical errors and disclosure. A lack of research has left clinicians bereft of best practices for disclosure that include the perspectives of pediatric patients.

A noteworthy finding from this study involves the desire for chronically-ill children to know about errors, including near misses. Although the sharing of all errors, particularly near misses, may not be desired in practice, these findings accentuate the *need to know* and, moreover, children's *right to know*. For example, *listening and talking to children* about medications and procedures provides a starting point for fostering participation and collective attention on error prevention. Indeed, research by Haldar et al. (2016) cites the need for inpatient technologies that can enable pediatric patients to identify and prevent undesirable events in the hospital while others suggest incorporating family reports into routine safety surveillance systems (McBride, 2017).

During disclosure, participants wanted to hear from the individual responsible for the error and determined that apologies and showing genuine remorse were critical for coping. Although half of the participants considered strong measures in response to staff errors (e.g., firing), some participants offered a tempered approach characterized by restraint, forgiveness and compassion for health care providers. Recent research exploring forgiveness in young children produced similar evidence. In a study with four-and five-year-olds, Oostenbroek and Vaish (2018) found that children were more forgiving of a remorseful transgressor and more likely to be sympathetic when an apology was offered. The authors claim that humans from an early age are inspired to restore a damaged relationship and uphold cooperation.

Extensive research has shown that children are able to engage in complex medical discussions (Alderson, 2007; Koller, 2017; Koller et al., 2014; Coyne, 2006; Coyne, 2008; Coyne & Gallagher, 2011). Clinicians' perceptions, however, continue to underestimate the competencies of young patients. In a study by physicians Kolaitis, Schinasi, and Ross (2016), members of the American Academy of Pediatrics were surveyed regarding their attitudes toward error disclosure to parents and pediatric patients. Out of 1186 members, 474 responded (40%). Overall, 98% of physicians acknowledged the need to disclose to parents, versus 57% to pediatric patients. The authors recommended that medical errors could be disclosed to developmentally appropriate patients at a mean age of 12.15 years old but not below a mean age of 10.25 years old. The salient quality of the Kolaitis et al. study lies in its delivery of simple and clear directives to pediatricians who must decide whether to disclose an error to a child. These findings are in stark contrast to compelling evidence from research with children and further deny their participation rights in health care and patient safety initiatives.

Limitations and lessons learned

Given the exploratory nature of this qualitative study and the focus on a relatively small sample of chronically-ill children, we are unable to generalize our findings across contexts. As researchers, our biases reflect a framework that underscores the relevance of children's rights and the need for greater collaboration and shared decision-making with pediatric patients. These sentiments are aligned with the emerging stance on patient safety which promotes transparency, inclusion and fair practices. As an outcome, these findings begin to uncover the views of chronically-ill children and adolescents on adverse events and disclosure processes and, in turn, may serve as a catalyst for much-needed research.

This study used various methods to build rapport and elicit data from twenty participants. Reading stories, doing art activities, and discussing vignettes allowed for participant choice and control during the interview process. Many participants were apprehensive or disinterested in creating any artwork. It is unclear whether requests for artwork posed a challenge for them because they were not feeling well or if their intravenous restricted hand and arm movement. Because we obtained only a few pieces of artwork, we chose to remove these data from the final analysis. As recommended by Hass-Cohen et al. (2016) and Kuhn (2003), strong thematic analyses for trustworthy findings are only possible when sufficient amounts of artwork are available. Despite efforts to obtain a balanced sample of male and female participants, this was not achieved.

A note of caution is also relevant here. Conducting studies with pediatric patients requires a high degree of sensitivity that may not be as essential in other settings. In this case, exploring the concept of medical errors with children posed ethical risks in terms of inducing fear or anxiety. While these concerns are real, researchers should remain open to exploring difficult or challenging health care topics with a range of children. In particular, young participants should understand the goals of the research and be offered play-based methods to support research engagement. In turn, this acknowledges critical elements of ethically-based research with pediatric patients. Despite being marginalized due to illness or disability, children have a right to participate in research.

Conclusion

Addressing the disclosure of medical errors demands a coordinated, informed and nuanced approach. Participants in this study recognize that disclosure requires a case-by-case analysis that considers the diverse needs of families and where decisions are not dictated solely by patient age and developmental indicators. This approach reflects those currently applied in Australia (Australian Commission on Safety and Quality in Health Care, 2013). Rather than wait until a point of crisis, health care providers need to understand the ways in which the child and parents communicate, how they cope with challenges, and the degree to which the child can manage adverse information. Information gathering at the outset can promote and respect the child's right to know while acknowledging their evolving capacities to process and contribute to a range of health care experiences. Because hospitalized children are at high risk for medical errors (Maaskant et al., 2015; Rishoej et al., 2018), a reconceptualization of how we view children and engage them in patient safety is essential for advancing best practices.

Declaration of competing interest

None.

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Appendix A. Child interview topics

Introduction

My job today is to ask kids about being in the hospital – the things you like and don't like and different things that can happen in the hospital. These questions are not a test, and there are no right or wrong answers. We just want to know what you think so that grownups working in a hospital can make things better for kids. You can tell me about things that have happened to you in hospital and things that are important to you. We are going to have time to play and draw too, and you can tell me about the things you like to do. I will also show you some pictures and ask you some questions about what you see happening in the pictures.

While we talk, our voices will be taped. I am taping our talk so we don't miss anything important that you say. Everything you say will be kept private and if you don't understand what I am asking, please tell me and I will try to help you understand. Our talk will last about as long as watching a TV show. We can take a break if we need to. You can ask me any questions you want while we are talking and you can tell me when you don't want to answer a question – that's okay too. How does that sound?

A. Rapport building

Test the digital recorder, listen to interviewer and child voices. Allow child to turn on the recorder.

Probe: child's interests, toys, activities, pets at home, friends at school etc.

Introduce various play and drawing materials.

B. Being in the hospital

1. Can you tell me what you like about being in the hospital?
2. Can you tell me what you don't like about being in the hospital?
   Probe: activities, food, gifts, visits, needles, medicine
3. What kinds of things usually happen when you are in hospital?
   Probe: procedures, meds, tests

C. Worries about being in the hospital

4. Have you ever worried about mistakes happening when you are in the hospital?

Probe: what is a mistake?, What does a mistake look like? What happens when a person makes a mistake? Do they get into trouble, or is everything okay?

Differences between mistakes – little mistakes vs. big mistakes, what do they look like?

D. Explore drawing

Provide child time to draw a picture of a medical error. Facilitate by offering a variety of art materials. Ask child open-ended questions regarding their drawing. For example: tell me about what's happening in your picture? How does the child feel in this picture? What is going to happen next in the picture?

E. Introduce vignettes/photos

(Reiterate: this discussion is not about some type of harm that has happened or will happen to them)

I want to show you some pictures and talk about some different kinds of mistakes that can happen in the hospital.

Explain each vignette using simple language, introduce child-friendly visuals where applicable.

Risk Level 1: near miss, Risk Level 2: medical error without harm, Risk Level 3: adverse event with harm.

For each vignette, we will ask the following questions:

- If this happened to another child just like you, what is the most important thing that doctors should do? (Probe: make it better, tell everyone)
- Do you think that kids should be told when mistakes happen? Why or why not? (Probe: reasons for sharing or not sharing)
- What does the child want to know? (Probe: let parents know, extent of information, what do you not want to know about?, should some kids not find out what happened?, too scary, too young, too sick, degree of harm)
- What else should the staff do? (Probe: say sorry, take the blame, make sure it never happens again, try and help family)
- How would you feel if this happened to you? (Probe: loss of trust, anger, change hospitals)
- How would you feel about the doctors or nurses if they kept the mistake a secret and told no one? (Probe: trust, worry)

F. Closing question

Before we finish today, do you have anything else to tell me? Do you have any questions?

Thank you so much for helping us today.

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