Parent Preferences for Medical Error Disclosure: A Qualitative Study

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A B S T R A C T

OBJECTIVE: According to disclosure guidelines, patients experiencing adverse events due to medical errors should be offered full disclosure, whereas disclosure of near misses is not traditionally expected. This may conflict with parental expectations; surveys reveal most parents expect full disclosure whether errors resulted in harm or not. Protocols regarding whether to include children in these discussions have not been established. This study explores parent preferences around disclosure and views on including children.

METHODS: Fifteen parents of hospitalized children participated in semistructured interviews. Three hypothetical scenarios of different severity were used to initiate discussion. Interviews were audiotaped, transcribed, and coded for emergent themes.

RESULTS: Parents uniformly wanted disclosure if harm occurred, although fewer wanted their child informed. For nonharmful errors, most parents wanted disclosure for themselves but few for their children.

With respect to including children in disclosure, parents preferred to assess their children's cognitive and emotional readiness to cope with disclosure, wishing to act as a "buffer" between the health care team and their children. Generally, as event severity decreased, they felt that risks of informing children outweighed benefits. Parents strongly emphasized needing reassurance of a good final outcome and anticipated difficulty managing their emotions.

CONCLUSIONS: Parents have mixed expectations regarding disclosure. Although survey studies indicate a stronger desire for disclosure of nonharmful events than for adult patients, this qualitative study revealed a greater degree of hesitation and complexity. Parents have a great need for reassurance and consistently wish to act as a buffer between the health care team and their children.

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The duty to disclose harmful medical errors is a recognized professional imperative.[1] Most patients prefer to be informed when such events occur.[2–5] Even with a near-fatal consequence, trust can be maintained with sincere disclosure.[6] Disclosure is legislated by many jurisdictions, with local policies further directed by accrediting bodies and patient safety organizations.[7–9] Although open disclosure of harmful medical errors is an accepted mandate, there is less consensus around the disclosure of nonharmful errors or near misses.[9–11]

The literature on parents' responses to medical errors in their children's care suggests that parents prefer to be told of all errors, even those without associated harm. In 2 survey studies, parents wanted full disclosure regardless of the event severity; that is, even if no actual harm occurred.[12,13] This difference may be reflected in different attitudes among providers as well. Compared with internal or family medicine faculty and residents, their pediatric counterparts were more likely to disclose a hypothetical error resulting in no harm.[14]

In pediatric practice, a parent or substitute decision maker is usually the primary participant in a disclosure conversation.[15] However, disclosure guidelines suggest that "the pediatric patient with the cognitive ability and emotional maturity to understand the information provided should be included."[9] A recent study showed many pediatricians support disclosure to children, with that decision primarily influenced by the degree of harm and the child's age.[16] Matlow and colleagues[13] found that parents tended to agree with full disclosure, including having children informed of events resulting in potential harm. However, a richer and more nuanced understanding of parental needs and expectations around disclosure and their children's involvement is lacking, according to a recent systematic review.[17] Knowledge of this kind is especially important given that studies of physicians and medical trainees indicate variable attitudes and behaviors, that may not meet patient needs.[18–23] A study by Mazor and colleagues[22] explored the experiences of parents whose children had encountered

perceived errors and found that persistent negative feelings were common, which were strongly influenced by the communication or lack thereof from providers after an event.

Using a qualitative descriptive approach, this study seeks to understand parents' expectations with respect to disclosure of medical errors in the care of their children, and how severity of harm influences these expectations.

METHODS

From May to August 2010, 15 parents of hospitalized children were recruited from the medical inpatient unit at 1 freestanding tertiary children's hospital in Ontario, Canada. Parents of a child admitted for at least 24 hours were considered for eligibility. Purposive sampling was used to generate a heterogeneous sample, including parents of previously healthy children and children with special health care needs[24] or medical complexity.[25] Efforts were made to recruit participants across a diverse sociodemographic spectrum. All inclusion and exclusion decisions were based on the judgment of the attending physician, nurse, and research assistant. Parents were excluded if they were acutely stressed (over and above the general stress of hospitalization), were known to have experienced a significant medical error during the current hospitalization (institutional risk management guidance precluded recruitment of participants known to have experienced actual medical errors), or lacked sufficient English proficiency to participate. Parents were asked the same questions regardless of patient age; thus, for questions regarding inclusion of children in disclosure, parents of younger children drew on their knowledge of older children (either spontaneously, or with prompting by the interviewer).

Participants were asked to reflect on a series of hypothetical scenarios and accompanying questions outlined in a semistructured interview guide (Supplemental Information) that was carefully constructed with input from the entire study team. Initial questions covered demographic data. The next set of questions used 3 scenarios to anchor responses to a particular type of error with varied severity. These included (1) an error

with clear harm (patient given antibiotic, to which she or he is known to be allergic, resulting in severe reaction necessitating transfer to critical care), (2) an error without harm (patient given antibiotic, to which she or he is known to be allergic, but error noticed and infusion stopped before any allergic reaction observed), and (3) a near miss (patient ordered antibiotic, to which she or he is allergic, but error caught and corrected by pharmacist). Using the same 3 scenarios, the next set of questions explored parents' preferences around involving their children. Being mindful that scenario ordering may affect responses,[13] half of the interviews were done in each order (ascending and descending). All interviews were conducted by 1 experienced interviewer (T.H.) and an interviewer in training (H.C.) in a private space away from the bedside. All interviews were recorded, transcribed verbatim, and de-identified. The protocol was approved by the hospital research ethics board and all participants provided written informed consent.

Transcripts were reviewed by using a constant comparison approach. Three investigators (principal investigator and both interviewers) met after each interview to revise the interview guide, recruitment, and scheduling process toward facilitating participant engagement. After 3 interviews, transcripts were reviewed independently by all investigators and the research team met and developed a preliminary coding schema. The emergent codes were informed by the content analysis and iterative focus of the interview process. For example, dominant codes deemed to require another level of subprobes were explored in greater depth in subsequent interviews. Focused coding of all transcripts was led by 1 investigator (T.H.) with close involvement of the principal investigator (M.C.). Coding meetings were then held with the research team at regular intervals to review selected segments of transcripts and to refine the coding schema. Involvement of the research team in the exploration of emerging themes ensured methodological rigor in the focused coding process. The final coding schema was refined and verified, with all team members reaching consensus

through the iterative process of document review and analysis.

RESULTS

A total of 15 parents, mostly mothers, were interviewed. Demographic data are provided in Table 1.

Involving Children in Disclosure: A Complex Assessment With Parent as "Buffer"

Participating parents had specific desires regarding involving children in disclosure. Whereas all parents wanted to be informed of an error causing harm, only half wanted their children made aware. Parents gave careful consideration to the upsides and downsides of disclosing to children and emphasized their own role in protecting their children's health and well-being.

"If they're in that situation …you'd rather take it on yourself than give it to them, right?"

TABLE 1 Participant Demographics

Characteristic	n	%
Parent sex, n = 15		
Men	3	20
Women	12	80
Parent region of birth, n = 15		
North America	7	47
Asia	2	13
Central and South America	1	7
Europe	3	20
Africa	1	7
Middle East	1	7
Hospitalized child sex, n = 15		
Boys	9	60
Girls	6	40
Hospitalized child age, y, n = 15		
<1	3	20
1–5	4	27
6–10	2	13
11–15	3	20
>15	3	20
Hospitalized child health status, n = 15		
Previously healthy	6	40
Special health care needs	4	27
Medically complex	5	33

Those who did not want children informed felt that telling a child would cause a loss of confidence in the health care team and resistance to further care.

"I wouldn't want her to worry about what else is going to happen to her if they're making a mistake. They made a mistake on her, 'Are they going to hurt me anymore?' …So I don't think I would tell her."

For those who would desire disclosure to children, a motivating factor was to keep their children informed of events affecting their health. Many parents noted that even young children may question the situation, and that secrecy would increase their fear or mistrust. Some saw an opportunity for a "life lesson": mistakes happen and health care professionals are not immune to this. Furthermore, some parents identified that this situation provided an opportunity for themselves and their children to become more involved in helping to prevent errors.

"We are going to be more vigilant. We are going to be checking things more (laughs). Um, and we are gonna try to read the labels maybe ourselves and try to ask questions more. You know, both her and myself."

Parents who wanted children informed would use specific strategies to mitigate any stress on the child, such as considering who, when, and how much to disclose. Participants requested that the parent be allowed to decide who should broach the topic, what should be said and when this discussion should take place. That is, they wanted to act as a "buffer" between their children and the health care team in keeping with their role as the children's guardians, caregivers, and advocates.

"I'd want to be there too, just in case she was upset or had any question for me or…or if she had any…if she wasn't comfortable or scared to say anything"

Furthermore, they asserted that they know their children better than anyone else, so they would need to be informed first and allowed to decide disclosure details. They preferred that children be told only as much information as they could handle based on their emotional maturity, developmental

level, and personality. In addition to these intrinsic qualities, parents asserted they would need to assess the children's current state, such as mood and degree of illness, before deciding what to disclose.

"It would really depend on the moment and the kind of mood she is in. If she is in a mood where she…doesn't really want to be there … I might not tell her. Um, but, you know…if I think she could handle it then it would really depend on her condition at that point. You know, emotionally."

Few parents wanted their children exposed to a complete disclosure discussion, instead insisting that children should be given few details to avoid undue concern or stress. Ultimately, parents felt their knowledge and assessment of the child's readiness would take priority over the judgment of health care providers in most cases.

Parents agreed that consideration should be given to the timing of disclosure to children; it would be best to tell them when they were in better health, either in hospital or at home.

"[S]o they need to be, um, focused and, and relaxed on getting healthy. And if we put anything else into the child's head…"

"When he gets better I'd let him know."

Telling their children an error occurred that caused harm or inconvenience would not be easy. Some felt this information would elicit an emotional reaction and their children would resist continued care. They realized they would have to manage their emotions in light of their children's reaction, which would be taxing.

Mechanics of Disclosure: Who, When, and What

Parents were unanimous in their desire to be told about any event that caused their children harm, but when it came to disclosure to their children, they had different expectations (Table 2). Parents wanted someone "in charge" to perform disclosure and for most this meant the physician in charge of their children's care. Some parents suggested that higher-level officials also should be involved, such as

TABLE 2 Comparison of Parents' Preferences for Disclosure of Adverse Events for Themselves Versus Their Children

Parents' Preferences for Themselves		Parents' Preferences for Their Children	
Theme	Illustrative Quote	Theme	Illustrative Quote
Whether to disclose: complete transparency	"…I just feel that I want to be informed of everything because I'm his main caregiver. And I feel like I'm the only one who can advocate for him because he can't speak for himself."	Whether to disclose: a complex assessment	"… I think it should be the parent's choice 'cause kids are all different…. You know your kids better than the doctors know the kids as far as mentally, right? If it's something that you (the parent) think they could deal with, then you (the parent) can divulge it."
Who to disclose: person in charge	"Somebody of authority coming in and speaking to you because…you would feel… the importance of somebody to come in and speak to you."	Who to disclose: parent, with health care provider support	"It depends. Like maybe if the child had questions that I couldn't answer then maybe I would ask the nurse or the doctor to be there. Otherwise I think I would probably be able to answer."
When to disclose: immediately	"So, if you make a mistake, why'd you make the mistake and just tell me about it. I just, it's my daughter, I want to know what's going on at all times."	When to disclose: when the child is ready	"it would really depend on the moment and the kind of mood she is in. If she is in a mood where she … doesn't really want to be there … I might not tell her. Um, but, you know…if I think she could handle it then it would really depend on her condition at that point. You know, emotionally"
What to disclose: full details	"…human error… this is what happened… this is how it came to pass, this is what, this is actually how it came… A never told B, shifts change, like…however it actually happened…."	What to disclose: partial details	"…And say, you know, there was an error with your medication, but now you are here and they're going to rectify it and you're going to get better…I don't think I would like to go into it so deeply and say this is what happened and they screwed up here and now you're here."

the department head, safety personnel, an administrator, head nurse, or even the hospital chief executive officer. These parents felt that having more individuals involved would enhance transparency, accountability, and awareness to ensure prevention of future errors. It should be noted that an even smaller subsample would seek legal counsel.

Parents would want to be told about an event as soon as it is discovered. For example, in the scenario involving a severe allergic reaction, parents would want to be told on transfer to the critical care unit or shortly afterward when the child had been stabilized. They also emphasized the importance of being informed in a timely manner to avoid emotional discomfort resulting from uncertainty about their children's health.

Parents were clear about desiring full and detailed disclosure, including how the mistake happened and what steps would be taken to fix it. However, parents understood that there were drawbacks to knowing. Full disclosure could cause emotional discomfort and an initial feeling of mistrust, but it would also help in rebuilding trust via transparency. Transparency would include details of any actual and/or potential harm and whether the error was attributable to an individual and/or to the larger "system." Parents were divided on whether they wanted to know which individuals were responsible. Some felt that knowing would not be helpful to them and may even cause additional stress. Most thought that only the medical staff needed to know who was responsible.

Parents' Needs After Disclosure

Parents indicated they would be emotionally affected by a medical error involving their children and explained they would have both emotional and pragmatic needs. Additionally, they wanted to be informed of details of any ongoing investigation regarding the event.

Emotional Needs: Reassurance Regarding Final Outcome

Although we used hypothetical scenarios, parents could readily imagine and anticipate their emotional needs after disclosure. They knew they would be upset and concerned over their children's well-being.

"[B]ecause if I see let's say this nurse who made a mistake, oh my gosh.

I want to kill her, so, I don't want to be in that situation, so I'd rather not to know… I just don't want to have like hard feelings to no one."

A pronounced theme was concern about the final outcome after an error and the need for reassurance for their children's well-being. Parents wanted to be told that the situation was under control and their children would be fine.

"I think the doctor just coming to me, calling me to the side and say 'you know what? I'm so sorry, we made a really, really bad mistake, this is going on.' But what I expect to hear is that everything is under control and my kid is going to be okay. Because you know mistakes can happen, accidents can happen, so I understand that but it's really scary, especially if it's your kid."

When probed, some parents said they would be angry if a child was harmed and a few would direct this toward the person responsible for the error. Disappointment with medical staff was another emotion parents discussed, although many acknowledged that mistakes happen. Others spoke of their trust and confidence being

eroded by such an event. Medical staff could alleviate some stress or anxiety by assuring that the mistake was caught and safeguards were being implemented to prevent this from recurring.

Complete transparency was expected by parents and any divergence from this would cause them great emotional discomfort and anger, especially if they uncovered hidden details. In fact, many indicated that being told full details, even regarding errors, would make them feel comforted rather than concerned about staff competency.

Transparency, according to parents, requires extra time with medical staff and most importantly the attending physician, who they expect to provide attention and reassurance. Interviews uncovered general disappointment with the amount of time physicians devote to parents. If a harmful medical error were to transpire, parents would insist physicians give them and their children greater attention and be sensitive to their emotional needs. They felt this attentiveness would help build a unified relationship with medical staff to improve the child's well-being. Parents did not see a need for emotional support from a counselor; instead they would draw on their own support networks.

Pragmatic Needs

When asked about their pragmatic needs in the wake of a medical error, parents were reluctant to request anything other than optimal care for their children. When probed, however, they did explain that the hospital could help in certain ways if they had to prolong their stay. This could include parking vouchers, meals, toiletries, and a place to sleep beside their child. The costs of staying at the hospital weighed heavily on them. Although there would be other personal costs to staying longer, such as time away from work or children at home, parents thought assisting with pragmatic needs would be a show of good faith on the part of the hospital.

> "There's not a lot they can do but they are doing what they can and trying to make it a little easier on us if we do have to stay a little longer...It would

be them admitting that they made the mistake and that they are doing what they can to make it a little easier for us...That they know what they did and...they are doing all they can to make it right."

A minority of participants explained that they did not need this type of help, because they would be well supported by their ethnic or cultural communities.

Postdisclosure Follow-Up

Most respondents wanted to know if an investigation was taking place so this type of event could be prevented in the future. If an ongoing investigation were to take place, all parents wanted to be updated when new information became available. Although some wanted more direct contact than others, a few parents wanted correspondence to be in letter or e-mail format. Most parents wanted a phone call or in-person meeting partly because they wanted to be able to ask questions, but most importantly to discern if the person discussing the unfolding details did so with honesty and emotion. Parents wanted an apologetic delivery of news, which would be evident through facial expression, body language, eye contact, words, and a tone expressing sincere regret.

> "[I want to meet with the medical staff] in person. You have to see the face and the eyes...it tells you a lot. Yeah, if they're just trying to, um humor you or... or they don't care, or...you know, you can, you can tell by body language, face, eyes, everything."

DISCUSSION

This study demonstrates that parents are unanimous in their preferences regarding certain aspects of disclosure, but are heterogeneous in their preferences regarding disclosure of nonharmful events and involvement of children. These qualitative data revealed more complex decision-making processes compared with what could be interpreted from quantitative (survey) data.

Parents were consistent in their desire for physician presence, transparency, accountability, and prompt disclosure. They

anticipated an emotional reaction to this information and wanted medical staff to be attuned to their emotional needs, particularly to their desire for reassurance about their children's well-being. Contrary to the suggestion of some guidelines to refer parents to counseling,[11] parents did not express interest in counseling and instead said they would draw on their personal networks for emotional support. Consistent with guidelines, they did want an apology and an opportunity to communicate with a person in a position of authority. Parents in this study were not typically interested in litigation, but some indicated they would be if they detected a lack of honesty and forthrightness from the medical team.

With respect to children's involvement in disclosure, survey studies indicate parents' wish to have children involved, and guidelines support this.[9] However, this study found that parents are not unanimous in their desire for children to be told, most wanting children informed about errors causing harm but fewer about nonharmful errors. For those who do want children told, they want to act as a buffer between the child and the health care team. Although providers might be disposed to look for a particular age or developmental level that universally indicates appropriateness for disclosure, parents in this study conveyed a set of complex, dynamic, and context-driven considerations. What came across strongly was that parents feel they are best equipped to decide if a child is ready to be told based on their knowledge of the child's personality, maturity, and developmental and emotional readiness in addition to a set of dynamic situational factors, such as illness severity, stage, and trajectory; emotional state; as well as how apparent the error is to the child such that delaying disclosure would cause mistrust. Thus, the process of deliberation is more nuanced than previously described. This strong preference on the part of parents to make decisions regarding disclosure to children could conflict with the ethical imperatives of truth telling and autonomy.

Many of the findings confirm existing knowledge on the disclosure needs and preferences of parents. However, findings from this study bring additional insights with implications for clinical practice. First, medical practitioners should be prepared to meet the needs of parents, who vary in their disclosure preferences. That is, disclosing after a nonharmful event may comfort some parents, but may trigger unease in others. Second, medical practitioners should take into consideration parents' strong desire to act as a buffer between their children and the health care team. In most cases, parents expect to participate in the decision-making and processes around disclosure, so that they can draw on their unique understanding of their children's static qualities, such as personality, and dynamic qualities, such as wellness and emotional state.

This study has several limitations. Most notably, it represents a small sample of parents from a single center. Although some parents had experienced an error in their child's care in a previous hospitalization, most lacked this direct experience and were asked to predict their reactions and needs. Many of the participants had very young children, which may have limited their insight into inclusion of children in disclosure. Last, the significant lag between data collection and publication of these results is relevant given the rapid change of professional norms in the area of disclosure in health care.

CONCLUSIONS

This research highlights the multifaceted disclosure needs of parents of hospitalized children, and the variability in their preferences regarding less severe events. Although parents wish to act as a buffer and feel that children should be told only as much information as they deem appropriate, this needs to be assessed against the legal and ethical rights of children and youth. Education and training in disclosure skills for pediatric health care providers should be tailored to address these considerations.

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