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Introduction

The Canadian Disclosure Guidelines give Paediatrics special consideration, stating "in most circumstances, the pediatric patient with the cognitive ability and emotional maturity to understand the information provided should be included." Surveys reveal almost all parents expect full disclosure irrespective of actual vs potential harm. Parents' views on including children in disclosure, and reasons for a different 'severity threshold,' have not been explored.

Methods

Fifteen parents of children admitted to Paediatric Medicine at SickKids participated in semi-structured interviews. They were given three scenarios [adverse event (AE), error without harm, and near miss (NM)], and asked about preferences regarding disclosure to themselves and their children. Interviews were audiotaped, transcribed verbatim, and manually coded for emergent themes.

Results

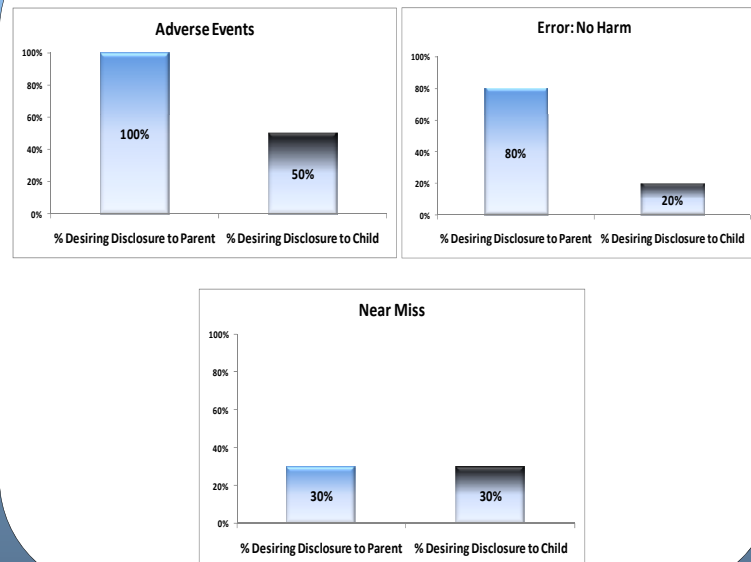
A diverse sample was obtained, with half Canadian-born. Six had previously healthy children, four had children with special healthcare needs, and five had medically complex children.

Parents uniformly wanted to be informed if their child experienced harm, but only a half wanted their child to be informed. Most parents wanted to know about an error with no harm, but few wanted to know about a NM. Very few wanted their children informed of either scenario without harm.

Results

For the AE scenario, disclosure preferences were consistent with the Canadian Guidelines. However, parents strongly emphasized the need for reassurance of a good final outcome. They anticipated difficulty managing emotions such as anger and anxiety. Reasons not to tell the child included fear of 'stressing' the child, compromising their recovery, or compromising their trust in the healthcare system. Parents considered children's cognitive and emotional readiness to cope with disclosure and wished to be a 'buffer' between the healthcare team and the child, dictating what, when, and who would tell the child. Generally, as event severity decreased, they felt the risks of informing the child outweighed benefits.

Results: Desire for Disclosure



Conclusions

Parents in this study had heterogeneous expectations regarding disclosure of errors without harm and near misses, which differs from the results of survey studies indicating a desire for disclosure regardless of degree of harm. They seem to have a greater need for reassurance than adult patients, and consistently wish to be a 'buffer' between the healthcare team and the child.

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Theme	Illustrative Quote
Need for Reassurance	P1: "I would like... the doctor also to be there to reassure us that this is what we're doing to, you know, correct basically what was wrong" P2: "what I expect to hear is that everything is under control and my kid is going to be okay"
Managing Emotions	P8: "I would be really, really upset" P2: "because 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."
Parent as Buffer	P1: "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" P4: "If they're in that situation...it's your kid, you wouldn't want them...you'd rather take it on yourself than give it to them, right?"
Child's Readiness for Disclosure	P7: "And I am thinking, yes, she would understand it... To understand people's different positions and, ... think a little more objectively as well. I think they could put themselves in other people's shoes" P7: "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"
Avoiding Stress on the Child	P2: "when he gets better I'd let him know" P10: "so they need to be, um, focused and, and relaxed on getting healthy. And if we put anything else into the child's head..."
Confidence and Trust	P1: "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" P3: "Because I don't think he should know it because then he will not have any trust. Because they are kids and it is hard for them to understand. They'll be refusing hereafter"
Using Information to Protect from Future Harm	P7: "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" P10: "so, again, I just keep getting back to being an advocate for your, your, your child"