Cardiology in the Young

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Original Article

Cite this article: Gal DB, Rodts M, Hills BK, Kipps AK, Char DS, Pater C, and Madsen NL (2024) Caregiver and provider attitudes toward family-centred rounding in paediatric acute care cardiology. *Cardiology in the Young* **34**: 67–72. doi: 10.1017/S104795112300118X

Received: 2 March 2023
Revised: 19 April 2023
Accepted: 26 April 2023
First published online: 18 May 2023

Keywords:
Family-centered rounds; acute care cardiology; provider perspective; caregiver perspective

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Caregiver and provider attitudes toward family-centred rounding in paediatric acute care cardiology

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Abstract

Family-centered rounding has emerged as the gold standard for inpatient paediatrics rounds due to its association with improved family and staff satisfaction and reduction of harmful errors. Little is known about family-centered rounding in subspecialty paediatric settings, including paediatric acute care cardiology.

In this qualitative, single centre study, we conducted semi-structured interviews with providers and caregivers eliciting their attitudes toward family-centered rounding. An a priori recruitment approach was used to optimise diversity in reflected opinions. A brief demographic survey was completed by participants. We completed thematic analysis of transcribed interviews using grounded theory.

In total, 38 interviews representing the views of 48 individuals (11 providers, 37 caregivers) were completed. Three themes emerged: rounds as a moment of mutual accountability, caregivers' empathy for providers, and providers' objections to family-centered rounding. Providers' objections were further categorised into themes of assumptions about caregivers, caregiver choices during rounds, and risk for exacerbation of bias and inequity.

Caregivers and providers in the paediatric acute care cardiology setting echoed some previously described attitudes toward family-centered rounding. Many of the challenges surrounding family-centered rounding might be addressed through access to training for caregivers and providers alike. Hospitals should invest in systems to facilitate family-centered rounding if they choose to implement this model of care as the current state risks erosion of provider–caregiver relationship.

Family-centred rounding is the gold standard for daily inpatient rounds in general paediatrics due to its association with improved patient and staff satisfaction, increased nursing engagement, and reduction of harmful errors.[1] Based on this experience in general paediatrics, family-centred rounding has been widely adopted in subspecialty settings, including paediatric cardiology, although its efficacy remains understudied within these patient populations.[2] Notably, differences exist between general paediatrics wards and acute care cardiology units including team composition, staffing ratios, patient acuity and chronicity, use of high acuity therapies, patient census, and hospital length of stay.[3,4] Due to these differences, it is possible daily rounds may also function differently and may be perceived differently by stakeholders. As such, we sought to describe caregiver and provider attitudes toward family-centred rounding within the acute care cardiology setting.

Methods

Study recruitment and participation occurred at a quaternary care children's hospital in Cincinnati, Ohio with a dedicated acute care cardiology units that utilises family-centred rounding for daily rounds. Patients are rounded on in an order created daily by the charge nurse based on a combination of nursing assignments, anticipated discharges, and patient acuity. Family-centred rounding occurs at the doorway of patient rooms and parents at the bedside are invited to join. Family-centred rounding are initiated by the bedside nurse and a frontline provider, either a paediatrics resident or nurse practitioner, provides a subjective–objective–assessment and plan-style presentation after which there is open discussion among other family-centred rounding attendees — the attending cardiologist, cardiology fellow, dietician, pharmacist, case manager, patient and/or family, and other healthcare professionals on an as needed basis. Paediatrics residents receive formal training in family-centred rounding in the general paediatrics context, but the remainder of the staff do not have family-centred rounding training. This practice of family-centred rounding has been in place since July 2014, about 9 years.

Families of children receiving care in the acute care cardiology unit and acute care cardiology unit staff were approached for participation. To achieve a broad representation of patient/family experiences and opinions, we developed an a priori approach to recruitment rather than using a convenience sample. We attempted to balance long-term versus short-term admission (> or < 7 days), caregivers of non-verbal children/infants versus caregivers of older children who might participate in rounds, caregivers regularly at bedside/opt to participate in rounds versus those away from bedside/not participating in rounds regularly (defined as interacting directly with the medical team during rounds at least half the days hospitalised in the acute care cardiology unit), and caregivers living locally versus living > 1 hour drive from the hospital. For medical providers, we balanced recruitment by role within the medical team (bedside nurse, advanced practice provider, and attending physician). Trainees were not included as they are not dedicated unit providers, and therefore, their participation in family-centred rounding is transient and intermittent. Interviews in English, lasting approximately 15–30 minutes were conducted in-person to provide an intimate, private context for discussing sensitive topics. Interviews were one-on-one or, if multiple members of a family wanted to participate together (e.g. mother and father), all desiring family members were included. Interviews were conducted by one of the researchers (DG) who was a clinician at the study site. This approach has proven beneficial for exploratory research attempting to find a range of perspectives, for discussing sensitive topics, and has been previously used to explore perceptions of family-centred rounding.[5–7] Recruitment continued until thematic saturation was met.

We developed a semi-structured interview guide of open-ended questions intended to elicit caregivers' and providers' views on (1) understanding, challenges, and benefits of family-centred rounding (2) alignment between medical team and caregivers and impact of family-centred rounding, and (3) impact of family-centred rounding on caregivers' ability to assume care of child (Table 1). Semi-structured interviews were used not only to ensure inquiry surrounding specific topics but also to allow further exploration of comments made by interviewees. Interviews were audio-recorded and transcribed. Transcripts were analysed incorporating grounded theory, a method for generating hypotheses or theory based on data that is systematically analysed through coding,[8–10] using the qualitative analysis software Dedoose (www.dedoose.com). Grounded theory allows for simultaneous data collection and analysis during which researchers use theoretical sensitivity based on knowledge of literature, personal and professional experience, and coding of the data to generate theory. Our use of grounded theory was modified slightly in two ways: (1) by using semi-structured interviews to guarantee discussion of certain topics rather than broad, neutral exploration of family-centred rounding and (2) in our a priori sampling of participants to guarantee diverse perspectives. By the 38th interview, the primary coders agreed that no new themes were emerging.

Three initial transcripts were inductively analysed by two researchers (authors DG and MR) to develop preliminary and intermediate codebooks. Four additional transcripts were blindly coded with the intermediate codebook. These transcripts were adjudicated and discussed to create the final codebook. An inter-rater reliability score for coding was 0.86. The primary coders each coded half of the remaining transcripts. The team collaboratively reviewed each code and discussed the interpretation of themes in a series of consultations.[11] Emerging themes were identified, described, and discussed by the research group. Participants also completed a brief survey with demographic data to facilitate our a priori recruitment approach as well as to assess health literacy among caregivers.[12] The Cincinnati Children's Hospital Institutional Review Board reviewed the study protocol and deemed it exempt.

Results

In total, 38 interviews were completed (11 one-on-one with providers, 17 one-on-one with caregiver, 10 two-on-one with caregivers) representing viewpoints of 48 individuals. All interviews were conducted between 3/21/22 and 5/27/22. Among providers, there were four nurse practitioners, three bedside nurses, and four attendings. Among caregivers, 25/27 (93%) completed the survey. From completed surveys, 13 (52%) reported this was their child's first admission, 3 (12%) reported they had 2–4 lifetime admissions, and 9 (36%) reported > 4 admissions. Of the caregivers, seven reported having had a prior admission at a different hospital where rounds were conducted differently. Furthermore, 72% of caregivers regularly attended rounds and 67% had children who were infants or non-verbal. All reported that the mother (or foster mother) would be the primary caregiver for the child after discharge, and 60% had a child whose LOS was > 7 days. The majority (17/25, 68%) lived more than 50 miles from the hospital. Most had completed education beyond the high school level (16/25, 64%) (Table 2). Participants reported high levels of health literacy with 15 (60%) stating they were extremely confident filling out medical forms by themselves, though 10 (40%) answered they always, often, or sometimes need help reading hospital materials.

Three themes emerged from the interviews. (1) Rounds as a moment of mutual accountability; (2) Caregivers' empathy for providers; (3) Providers' objections to family-centred rounding.

Rounds as a moment of mutual accountability

Caregivers and providers frequently alluded to family-centred rounding as a moment of mutual accountability during the day, enabling them to hold each other responsible for different aspects of care. Caregivers noted that rounds are a different type of communication, distinct from one-on-one updates with frontline providers or attendings, and that they benefitted from hearing multidisciplinary discussion and appreciated knowing there was agreement among the team with a given plan.

> "It helps me to see each and every individual and be able to make eye contact with them because it's like 'oh, I'm really a part of this' and learning about my child's health and what we're going to do going forward to treat them and make them better so we can go home." C20

> "It's nice to hear that open discourse during rounds. When we only hear from one person at a time, it's just their outlook. When we have questions, it's nice to hear what the group has to say in total. It's more informative than just talking to the nurse that's in the room at the time or the attending by themselves." C17

Even when asked about disagreement among team members related to the plan, many caregivers felt comforted knowing there

Table 1. Interview questions

Understanding, challenges, and benefits of FCR	
Caregivers: • What is your experience of rounds on this unit? • What challenges and benefits have you experienced with rounds on this unit? • Have you seen other models of rounds on other units? What were benefits and challenges of those? • What barriers prevent you from joining rounds?	Providers: • Describe your understanding of and experience with FCR • What are the benefits and challenges of FCR? • What other models of rounds have you experienced and what are the benefits and challenges of those models?
Alignment between medical team and caregivers and impact of FCR	
Caregivers: • What are the goals of rounds? • What are your goals for rounds? • If you could design rounds yourself, how would they function? • How do rounds impact your interaction with members of your child's care team? • What has contributed to you feeling empowered or not empowered to speak up during rounds? • What has been the impact of seeing disagreement or uncertainty in decisions among members of your child's medical team?	Providers: • What are the goals of rounds? • What do you think families' goals are for rounds? • What is the impact of family participation in rounds on how aligned you feel with families? • How do you feel when families ask questions or speak up during rounds? • How does family presence impact discussion around topics on rounds where you are uncertain or disagree with other team members?
Impact of family-centred rounding on caregivers' ability to assume care of child	
Caregivers: • How do you like to learn new information? • How do rounds impact your understanding of your child's medical problems? • How do rounds impact your feelings about discharge and caring for your child at home?	Providers: • How does family participation in rounds impact their ability to provide care for their child?

Table 2. Caregiver demographics

Relationship of participant(s) to patient	Motder or foster motder alone	15
	Father alone	2
	Mother and father together	10
Location of primary residence of participant/patient	< 50 miles from recruitment centre	8
	50–99 miles	2
	> 100–149	15
Highest level of education completed by primary caregiver	High school	9
	Some college, no degree	4
	Associates degree	6
	Masters degree	4
	Doctoral degree	2
Self-identified race	Black or African American	4
	White	21
	Multiple races	1

were thoughtful debates surrounding care decisions and hearing the rounds discussion increased their confidence in the care being delivered.

> "You know they're trying to take the best care of [child's name] they can. It happens that there are disagreements. As long as it remains civil then it's actually helpful to know that everyone's voicing their opinion and trying to take the best care of [child's name]" C15

In seeing team discussions surrounding care decisions and being "able to make eye contact" with each member of the medical team, caregivers had a sense of holding the medical team responsible. Indeed, the accountability derived from family-centred rounding empowered caregivers to hold providers responsible, even after rounds. One mother noted that she prevented the wrong type of formula from being administered because she had heard the team discuss a specific decision during rounds, "I had been on rounds so I knew what the plan was" C27.

Providers, too, described rounds as a moment of accountability of the families and caregivers.

> "I think [caregiver participation in rounds] gives a great picture on how they will do going home. When they ask questions, it shows how much they're understanding versus what they're not understanding. Maybe they don't recognize how sick their child is or they don't understand what education is expected of them or they don't know about what is to come." P9

> "Having a family ask questions during rounds tells me that they're engaged, that they care, that they are hearing me, that they feel safe enough to ask their questions. Maybe there's a lot of benefit to be had when a family asks questions?" P10

Overall, providers and caregivers alike viewed rounds as a unique moment in the day to come together, to "get on the same page", and to hold accountable all parties involved in care.

> "I think what is most effective for rounds is when at least the nurse, a family member, and a primary team member are there to have a conversation about the plan for the day because when all of those parties aren't on the same page, it leads to confusion, a lot of questions, and just unnecessary work." P1

Caregivers' empathy for providers

Caregivers were consistently forgiving of providers and frequently expressed empathetic statements for providers. There was commonly awareness of the medical team having competing interests such as "sicker patients" or "other things to do" during rounds but rather than expressing negative reactions, caregivers were typically understanding:

> "I understand that the more serious cases probably get rounded on first, so it's just whenever during the morning you guys come our way, we have to be ready. It's useful and helpful for us to join rounds and we try to be respectful of your guys' time too to be here and hear the plan and that way it doesn't have to get repeated multiple times and we're on the same page." C11

Among interviewed caregivers, all but one expressed empathy for providers in some way. Additionally, there were only two who had negative comments related to awareness of the medical team managing multiple demands on their time. One mother who had stopped attending rounds regularly commented,

> "I feel like even though they include me, like let me listen in, a lot of it seemed like they're closed off, like they're just reading off a paper, just reading their notes, and they're ready to move onto the next room. They'll ask if I have any questions, but they're ready to move on and then a lot of times they say medical terms that they know I don't really understand, like I just found out that room air means no oxygen. The whole time I thought it meant switching to a different type of oxygen. So, a lot of times they have to translate for me but they're ready to move on, but it would be nice if they could translate knowing that I'm listening in and a lot of the terms they use I don't know." C27
>
> Another mother who attends rounds stated, "I've had people say that they didn't have time for my son and it's like 'I got this patient down the hall that's worse off' well that still don't make [my son's] care any less important." C24

Overall, there was an indication that families embark on medical journeys with trust and empathy toward the medical team, though this is at risk for erosion over time, often due to poor communication. This was evident among families who had experienced multiple hospitalisations. One caregiver whose child had > 4 admissions commented:

> "Surgeons are not infallible, doctors are not infallible. They're doctors, but they're human too, and parents need to realise that because they feel so beneath [doctors] they don't want to question them, but communication is key because if you don't have communication, you're going to miss something. We've asked questions that led them to discover other things about him and [doctors] tried to play it off. It's a full-time job for a parent of a kid this sick to stay on top of everything and the more help that a parent can get from the medical team through rounds, the better it is. We've been dealing with hospitals all his life, you can't sit back." C25

Providers' objections to family-centred rounding

While caregivers reported many benefits of participating in family-centred rounding, providers raised multiple concerns about family-centred rounding. These surrounded provider assumptions about caregivers, provider frustration with family behaviour on rounds, and the role of family-centred rounding in creating inequity or perpetuating bias. Providers made assumptions regarding caregivers' ability to handle new information, their reactions to medical uncertainty, how caregivers view the goals of rounds, how rounds should function, and what caregivers hope to get out of joining rounds.

> "I think for families having 20 people staring at you in the hallway or 20 people staring at you in your room is probably a bit intimidating. They probably don't like it." P3
>
> "I think there's a small percentage of families that are medically knowledgeable and can give useful information, but sometimes we lose things by presenting in front of families as well, we don't talk shop completely, we don't say certain things around families, probably 10% of families actually add useful information, but I don't think there's a huge role [for families] for our decision-making during rounds. I think it's important for them to know what's going on, but I don't think most families add a lot to what we're discussing." P4

In addition to provider assumptions about how caregivers view rounds, providers also frequently expressed frustration regarding caregiver choices during rounds.

> "I don't understand parents who are in the room and don't come out and participate in rounds. I don't understand what that barrier to participation is. We do have a lot of families who are just in the room and choose not to come out and be a part of it. I would like to hear from the parents. I would like for them to be a part of it and asking questions, and I think that it's important they hear all the information of rounds." P7
>
> "I find it really helpful to have family input. Now, it can be the exact opposite of that too. Some families can completely overtake rounds and we can spend 20 or 30 minutes at one patient's door, which is not helpful." P6
>
> Additionally, providers' assumptions about caregivers impact their candour and content of rounds discussions. This was particularly true surrounding medical uncertainty.
>
> "I think the family wants to have this reassurance that the medical team is well-versed in what's going on with their child and when there are three or four people having a differing opinion on the best plan, I think that is probably very alarming to the family." P6
>
> "I think the providers feel somewhat limited in talking about concerns because parents may not handle it well or understand, if there's uncertainty around medical decision making or social issues and the family is present." P11

While many assumptions providers made about caregivers were paternalistic or unsympathetic, some providers did acknowledge the culpability of the medical team in creating challenges for caregivers.

> "I think sometimes parents have a hard time articulating things they want for their child. We see this happen where one attending comes on and they're going X direction, the next attending comes on and they're going Y direction, and we wonder why families get all kooky. But we've switched management plans, sometimes it's changed completely when a new attending comes on. 'This wasn't important last week, but it's important this week', these types of things are hard and it causes confusion for families." P8

Building on the culpability of the medical team, several providers expressed concern that family-centred rounding can perpetuate inequity and contribute to bias.

> "We do a disservice to the non-English speaking families because we don't have an interpreter there on rounds most of the time and they don't get the complete discussion. The frontline provider goes and talks to them but they don't get to see all the players, so that that is something that really needs to be worked on. There's definitely disparity there. I do see other bias. It feels terrible to say, but there are certain families that we'll coddle during rounds and then other families that we'll just be like da-da-da and off we go. Is it that the family's socio-economic status is different? Or their home life is terrible? I don't know, but I think there's bias." P8

One provider's concerns about family-centred rounding mirrored the negative experiences of C27 (quoted above):

> "There isn't always an opportunity for [caregivers] to speak up. It could be comfort level versus actual opportunity. So many times rounds happen, the provider asks parents 'any questions?', parents say 'no', I then immediately go into the room to do my tasks and the first thing that happens is a parent asks me a question. Well, 'why didn't you ask a question when we were rounding? This was the perfect avenue for you to be able to ask' so there are barriers, whether they truly feel a part of the rounds conversation or if they're intimidated by the group, intimidated by the language we use, or if we appear to be rushed, if they perceive that we have to be moving from patient to patient and they sense that and don't want to take up our time." P2

Additional quotations supporting each theme are in the supplemental table.

Discussion

This is the first study exploring caregiver and provider perspectives on family-centered rounds specifically in the paediatric acute care cardiology setting.[3] In our interviews, themes emerged related to family-centred rounding providing mutual accountability as well as caregivers' demonstrating their empathetic perspectives regarding the healthcare team. While caregivers pointed out aspects of family-centred rounding that could be changed to improve their experience, their overall impression was very positive. A contrasting theme was that of providers expressing objections to family-centred rounding surrounding sharing information with families, family choices during rounds, and how family-centred rounding may contribute to health inequity and bias. Despite the differences between acute care cardiology and general paediatrics units, some of these objections are consistent with previously reported findings.[3] In particular, our findings are consistent with reports from the paediatric intensive care setting where it has been shown that many providers believe family presence can hinder conversation and that families do not meaningfully contribute to rounds. [13,14] While family-centred rounding in subspecialty settings has not been thoroughly evaluated, this suggests the provider experience of family-centred rounding may be consistent across different care settings, especially among patient populations with a heightened risk of need for critical care and with difficult care decisions.[5]

In the context of these interviews, providers' objections to family-centred rounding seem reflective of deeper moral distress surrounding how to best provide care to patients while feeling overburdened on busy clinical services. Dedicated training in family-centred rounding is now endorsed by the American Academy of Pediatrics and the American College of Graduate Medical Education.[15] Checklists have been developed to assess current trainees' skills in family-centred rounding and reports indicate that family-centered care depends on adequately trained staff.[15,16] Family-centred rounding is a challenging communication model which requires adjustment for individual patients and stages within a hospitalisation and continues to have no universally agreed upon definition.[1,3,16] However, currently practising providers may have never had training in this type of communication. Further, providers may be unaware or undervalue the benefits that caregivers and providers themselves derive from family-centred rounding, such as mutual accountability. Among otherwise compassionate and hardworking healthcare providers, the disconnect between wanting to do the right thing and lacking training and resources to execute effective family-centred rounding might drive objections, discontent, and burnout.[17]

Similarly, caregivers are not trained in family-centred rounding, creating an arguably unfair setup in which healthcare providers have expectations for caregiver engagement and interaction that are not communicated to caregivers until conflict arises.[17] The doctor–patient relationship has been described as a social contract with implicit notions and mutual expectations[17], but family-centered care is a relatively new facet of the doctor–patient relationship and does not yet have clear expectations and definitions.[1] To that end, recent efforts to develop family-centered rounding toolkits include the concept of "orientation" for families, but this is far from implemented on a universal scale and requires personnel and resources.[18] Interestingly, despite the lack of mutual expectations and resultant risk for frustration among providers, there is evidence that family-centred rounding may increase humanistic measures including caregiver empathy for providers.[19] It is notable that most caregivers in our study held empathetic viewpoints toward providers despite the challenges of hospitalisation, an experience which inherently restricts autonomy, including a lack of orientation to rounds.[17] Indeed, all but one caregiver expressed empathy for providers at some point during the interview. Factors such as these might, in part, explain those caregivers who expressed unempathetic viewpoints towards providers and also had experienced multiple hospitalisations. Providers require awareness that patients may enter the healthcare system trusting and poor communication may erode that trust, but well executed family-centred rounding may help preserve or even repair it among families who have had negative experiences.[17,19,20]

In our interviews and in previously published work, healthcare providers express reticence to discuss certain topics candidly during family-centred rounding with patients and caregivers.[13,14] Despite this, transparency and information sharing in healthcare is increasing as evidenced by the 21st Century Cures Act Final Ruling mandating the sharing of notes with patients. It has been proposed that increased shared-decision making will positively impact outcomes.[21] Though not designed to test family-centred rounding's impact on outcomes, our findings suggest that family-centred rounding can facilitate error prevention (as in the case of the mother who prevented the administration of incorrect formula to her child) through mutual accountability, enhanced bedside education, and caregiver engagement. While family satisfaction has repeatedly been shown to be improved with family-centred rounding, a recent systematic review found that there is limited high-quality evidence that family-centred rounding actually improves patient outcomes.[22] As hospitals invest in systems to support transparent, family-centered care, there is reason to reconsider the best structure to facilitate patient satisfaction, improved outcomes, and clinician and staff feelings of efficacy.

Overall, providers' objections to family-centred rounding might be addressed by increased training for providers and orientation and education for caregivers. If hospitals choose to adopt family-centred rounding — because they are the stated gold standard, because they increase patient and family experience scores which are increasingly linked to hospital rankings and payments, or because they are invested in providing humanistic care[1,19,23,24] — perhaps they need to invest in training existing providers as well. Further, our interviews and growing evidence on the challenges and required resources for providing high quality, equitable family-centred rounding[25,26] suggest there is need for greater coordination of rounds, possibly provided by a dedicated rounds coordinator.[27,28] Such a professional could orient caregivers to family-centred rounding, keep the team on track with timing and managing conflicting demands, and improve equity through coordination interpretation and telehealth services. The ability to deliver efficient and equitable care could address many of the objections providers in this study expressed. Patient trust in physicians and satisfaction with overall healthcare correlates with physician career satisfaction.[29] For inpatient rounding teams, satisfaction with rounds likely drives a significant portion of their overall career satisfaction making this an essential area for investment.

As with all single centre, qualitative studies, there are limitations to our work. Interviewees' perspectives on rounds represent their experiences primarily at a singular institution, though many caregivers and providers had experienced other models of rounds elsewhere. Additionally, despite efforts to recruit participants with diverse backgrounds and experiences, all interviews were conducted in English and therefore may not reflect the experiences of non-English speaking caregivers. Other factors which may limit the generalizability of the experiences of caregivers in this study include that most identified as white and most attended rounds regularly. The interviewer was a clinician at the study site and interacted with some interviewees in other contexts. This may have hindered some exchanges, particularly if there was a perceived power differential between caregivers the interviewer, but the existing relationship with other interviewees, particularly the providers, may have increased comfort and candour in disclosing opinions.

Though the study, we report here was not a quality improvement project, this was coupled with other work which has aimed to improve our family-centred rounding. Unit leadership has been invested in expanding understanding of family-centred rounding among staff, adjusting the content of presentations to be as relevant as possible to the medical team making the daily plan of care while remaining accessible to families, improving the inclusion of families at bedside, and implementing means of including those not at bedside, as well as standardising systems for the use of interpreters for non-English-speaking families. We also aim to use the themes we identified here to study the experience of family-centred rounding within acute care cardiology units more broadly so we can generate more generalised knowledge.

Conclusions

Our interviews revealed that family-centred rounding hold promise for improving outcomes and caregiver/provider collaboration through mutual accountability and increasing empathy. Yet, provider objections remain. The experience of family-centred rounding among providers in this study was similar to provider experiences reported in paediatric intensive care settings. We suggest providers' objections and current challenges with family-centred rounding could be addressed through increased provider training and caregiver education and creation of dedicated rounds coordinator roles to facilitate the delivery of efficient and equitable rounds. These investments could further improve family-centred rounding and thereby yield multiple downstream benefits.

Supplementary material. To view supplementary material for this article, please visit https://doi.org/10.1017/S104795112300118X.

Conflicts of Interest. None.

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