

The parent perspective on paediatric delirium and an associated care bundle: A qualitative study

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Abstract

Aims: To explore how parents experienced their child with delirium and how parents viewed our delirium management bundle.

Design: We conducted a qualitative exploratory descriptive study using semi-structured individual or dyad interviews.

Methods: Twelve semi-structured interviews with 16 parents of 12 critically ill children diagnosed with delirium in a paediatric intensive care unit were conducted from October 2022 to January 2023 and analysed through a reflexive thematic analysis.

Findings: We generated five themes: (1) knowing that something is very wrong, (2) observing manifest changes in the child, (3) experiencing fear of long-term consequences, (4) adding insight to the bundle, and (5) family engagement.

Conclusion: The parents in our study were able to observe subtle and manifest changes in their child with delirium. This caused fear of lasting impact. The parents regarded most of the interventions in the delirium management bundle as relevant but needed individualization in the application. The parents requested more information regarding delirium and a higher level of parent engagement in the care of their child during delirium.

Impact: This paper contributes to understanding how parents might experience delirium in their critically ill child, how our delirium management bundle was received by the parents, and their suggestions for improvement. Our study deals with critically ill children with delirium, their parents, and staff working to prevent and manage paediatric delirium (PD) in the paediatric intensive care unit.

Reporting Method: The consolidated criteria for reporting qualitative research guidelines were used to ensure the transparency of our reporting.

Patient or Public Contribution: No patient or public contribution to the research design.

What does this Paper Contribute to the Wider Global Community?

- It increases awareness of the parent's perspective on PD in critically ill children.

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- It shows how PD might affect parents, causing negative emotions such as distress, frustration, and fear of permanent damage.
- It shows that the parents in our study, in addition to the care bundle, requested more information on delirium and more involvement in the care of their delirious child.

KEYWORDS

critically ill children, delirium, experiences, management, non-pharmacologic intervention, paediatric delirium, paediatric intensive care unit, parent perspectives, PICU, qualitative study

1 | INTRODUCTION

Paediatric delirium (PD) is a common disorder in critically ill children, with a prevalence ranging from 7% to 66% (Semple et al., 2022; Smith et al., 2022). Delirium is a serious condition involving severe confusion and changes in behaviour. The condition has been investigated in adult patients in the intensive care unit (ICU), and recently, research on PD has been increasing. Several validated PD-screening tools are available and are increasingly implemented in paediatric intensive care units (PICUs), albeit the performance varies (Paterson et al., 2021). While screening tools enable nurses to identify PD, the question of optimal PD management remains. The benefits of pharmacological interventions for delirium are uncertain (Liviskie et al., 2023). Recent studies suggest that non-pharmacological interventions can prevent and reduce delirium in critically ill children (Liviskie et al., 2023; Smith et al., 2022). For this reason, we developed a non-pharmacologic delirium management bundle for PICUs to be tested in a clinical trial. The bundle is proposed for all children and was aimed at three age groups: (1) 0–2 years (preverbal), (2) 3–5 years (preschool age), and (3) 6–18 years (school age) (Stenkjaer et al., 2022). In our recent study, international experts agreed that parents should be included in delirium management when appropriate (Stenkjaer et al., 2022).

2 | BACKGROUND

Parental experiences of delirium in their critically ill child are sparsely investigated, but studies show that parents often feel helpless and ill-prepared to support their child (Moradi et al., 2022). The parents' input and suggestions for improvement are important as they have firsthand experience of the distress and the disturbance in the ICU (Alzawad et al., 2020). Family presence and active involvement at the bedside can provide family satisfaction by alleviating parental distress and increasing satisfaction with professional care (Davidson et al., 2017). Consequently, the Society of Critical Care Medicine suggests facilitating parental presence in the PICU during routine care and interventions (Smith et al., 2022). This is akin to family-centred care (FCC), which is an approach that is respectful of and responsive to individual families' needs and values (Davidson et al., 2017). A key element in FCC is partnership characterized

by complex interpersonal relationships and interactions between nurses and parents (Brødsgaard et al., 2019). Our theoretical approach was FCC where the basic concepts are collaboration, dignity, participation, information sharing, and decision-making.

Evidence of the effect of pharmacological agents for the prevention and treatment of PD is sparse (Capino et al., 2020). There are few reports on the pharmacologic management of PD using anti-psychotic drugs, but studies show that side effects such as extrapyramidal symptoms and prolonged QT interval are common (Joyce et al., 2015). Non-pharmacologic interventions in adult ICU patients may be efficacious in reducing the incidence and duration of delirium (Sahawneh & Boss, 2021), but little research has been conducted in the paediatric setting (Silver et al., 2019). Using a two-round Delphi method with an international multidisciplinary panel of PICU experts, we developed a non-pharmacologic delirium management bundle to help healthcare professionals and parents care for the delirious child (Stenkjaer et al., 2022). Care bundles are defined as a set of three to five evidence-informed practices performed collectively and reliably to improve the quality of care (Lavallée et al., 2017). The non-pharmacologic delirium management bundle is regarded as a complex intervention according to the Medical Research Council (Skivington et al., 2021), that published guidance for the development and evaluation of such interventions. A Cochrane review has recommended consumer involvement in the development of clinical guidelines and patient information to improve the quality (Nilsen et al., 2006). To meet this end, we have involved parents as stakeholders in the development of the delirium bundle.

3 | THE STUDY

3.1 | Aims

The study aimed to explore how parents experienced their child with delirium and how parents viewed the delirium management bundle.

Our research questions were as follows:

1. What were the parents' observations and emotional responses to their child with delirium?
2. What were the parents' comments and suggestions regarding the delirium management bundle?

4 | METHODS

4.1 | Design

We conducted a qualitative exploratory descriptive study using semi-structured individual or dyad interviews analysed through reflexive thematic analysis (Braun & Clarke, 2019).

4.2 | Participants

The participants in this study were parents of children who had experienced delirium in the PICU and who had indicated willingness to participate in this interview-based study. The parents had participated in our previous study validating a PD scale (Stenkjaer et al., 2023). The children of the participating parents had been admitted to a PICU at the Copenhagen University Hospital, Denmark. We contacted the parents of 17 children diagnosed with delirium.

The parents were invited via regular mail, with information on the aim of the present study and the expected time investment. Parents were contacted by telephone a week later. We wished to recruit parents who were present when their child was diagnosed with delirium. If both parents were present at the time, we wished to interview both parents in a dyadic interview. When the parents consented to participate, they received information on the delirium management bundle via e-mail, providing them with time to familiarize themselves with the bundle prior to the interview (Table 1). Parents of 12 children consented to participate, while parents of five children declined participation due to a lack of strength to revisit the children's delirium experience.

4.3 | Data collection

The interviews were conducted in Danish language at 5–21 months after PICU discharge from October 2022 to January 2023 either at

TABLE 1 Non-pharmacologic delirium management bundle—pediatric intensive care unit by age group.^a

Age group	Age group	Age group
0 to 2 years	3 to 5 years	6 to 18 years
Support cognition	Support cognition	Support cognition
Speak calmly and clearly	Explain who you are when you approach the child. Tell your name to the child	Explain who you are when you approach the child. Tell your name to the child
Develop a day structure in collaboration with parents		
Provide appropriate lighting according to the time of day		
Ensure that the child uses eyeglasses and hearing aids if appropriate when awake, and ensure that the glasses are clean, and batteries are working		
Encourage the parents to be present		
Encourage presence of familiar objects around the bed	Encourage presence of familiar objects around the bed	Encourage the child to do activities that they liked to do at home (e.g., watch television, use iPad)
Support sleep	Support sleep	Support sleep
Schedule time for sleep. Ask the parents about the usual sleep rhythm		
Provide sleep objects from home such as teddy bear, sleeping pillow, or cuddle cloth	Provide sleep objects from home such as teddy bear, sleeping pillow, or cuddle cloth	Play music according to the child's preferences. Consult parents
Avoid loud talking in the child's room	Avoid loud talking in the child's room	Close the door if the staff is near to reduce noise
Dim light by using curtains or blinds	Dim or turn off the artificial light around the child	Dim or turn off the artificial light around the child
Support physical activity	Support physical activity	Support physical activity
Document and evaluate daily mobilization goals	Document and evaluate daily mobilization goals	Make activity goals visible in the child's room

Note: Interventions highlighted with grey are similar between all age groups.

^aInterventions with the highest rank from all the strategies.

the home of the family ($n=4$), at the hospital ($n=1$), or video-based online ($n=7$) according to the parents' preferences. The parents were geographically located in all five administrative regions of Denmark, providing good representation. The first interview was intended as a pilot but was included in the study as it contained rich data, and no changes were made to the interview guide. We included a convenience sample of 11 additional interviews. All interviews were moderated by the primary investigator (PI), a nurse not working in the unit. A child psychiatrist who was a member of the research team was present as a co-interviewer. The PI and the co-interviewer were already known to the parents from the validation study during the child's admission. We attempted to create a safe atmosphere that encouraged the parents to share their perceptions and experiences, and we explicitly addressed role boundaries with the parents and clarified our interest in the parents' experiences expressed in their own words (Hewitt, 2007). If the parents had questions regarding the child's condition or care, these were answered at the end of the interview (Eide & Kahn, 2008). A semi-structured interview guide was constructed by the research team based on existing literature and the results of our previous study identifying the elements of the delirium management bundle (Stenkjaer et al., 2022) (Table 2). The parent's statements were verified throughout the interviews by iterative questioning. The interviews were recorded digitally and transcribed verbatim according to a transcription protocol. Two research assistants transcribed the interviews, and the PI validated them by ensuring the transcription was aligned with the audio file. After each interview, the PI and the co-interviewer evaluated the interview and wrote individual field notes with initial reflections and non-verbal communication of the interview to provide an audit trail. The field notes served to elicit observations, supplement the dialogue, enhance reflection, and facilitate the initial coding to support the narrative during the initial analysis (Phillippi & Lauderdale, 2018).

4.4 | Data analysis

The interviews were analysed inductively with the two research questions according to the aim of the study. We used reflexive

TABLE 2 Interview guide.

Interview guide

How did you discover that your child had delirium?
What symptoms did you notice?
Please describe your child during the days with delirium.
How were you affected when your child had delirium?
Which items on the list [bundle] do you think could have helped your child?
Which items on the list [bundle] could be difficult to complete?
How can we make it easier for you and your child?
Would you like to be involved in the treatment when the child is critically ill?
What needs did you have as a parent when your child had delirium?
Do you have any suggestions as to what might have helped your child?

thematic analysis as outlined by Braun and Clarke who describe six phases: (1) familiarizing yourself with your data, (2) generating initial codes, (3) searching for themes, (4) reviewing the themes, (5) defining and naming the themes, and (6) producing the report (Braun & Clarke, 2012). Reflexive thematic analysis acknowledges the role of the researcher during analysis, which means that the themes do not just emerge from data but are generated by the research team. The PI and the co-interviewer generated the initial codes and discussed codes and themes with the research team, who were all experienced in qualitative research. Table 3 provides an example of the analytical process. The coding and organization of data were assisted by computer software NVivo version 12 (QIP Ltd, n.d.). We pursued credibility by investigator triangulation, transferability by a description of participants and context, dependability by providing quotes, and confirmability by describing the process of sampling, data collection, and analysis. The consolidated criteria for reporting qualitative research guidelines were used to ensure the transparency of our reporting (Tong et al., 2007).

4.5 | Ethical considerations

This study was approved by the Danish Data Protection Agency (j.no.: P-2019-548) and reported to the National Committee on Health Research Ethics (reference number: 19076015). Participating parents were informed verbally and in writing about the aims of the study, and they were also informed of the results from the previous study validating the delirium assessment. We were sensitive to the fact that the parents might not be aware that their child had experienced delirium in the PICU (Stenkjaer et al., 2023). Therefore, we reinforced the written information and clarified uncertainties by phone after a week and subsequently obtained written consent. As the topic could be sensitive to the parents, we paused during the interview if the parents' showed any signs of distress. We provided contact details of researchers if they needed further debriefing after the interview (Sque et al., 2014). We realize the potential of bias as the interviewers had previous knowledge of the children's medical history and episodes of delirium. On the other hand, the knowledge of the families might have influenced the parents positively to accept an invitation to the interview. We were particularly attentive to the perspective of the informants.

5 | FINDINGS

We conducted 12 semi-structured interviews with 16 parents of 12 critically ill children diagnosed with delirium in PICU: four couples, one father, and seven mothers. The median duration of the interviews was 56 min (range 41–77). Children in all three age groups were represented with the fewest in the middle age group. The parents were interviewed, and the children's demographics and clinical data are shown in Table 4. The findings are presented according to our two research questions.

TABLE 3 Example of the analytical process.

Quote	Codes	Sub-theme	Theme
M6: We were worried that he had become severely brain damaged. This was our first reaction, because for one, our boy was gone, and then his brain was so damaged that he couldn't recognize us. (Boy, 14 years)	Delirium has a lasting effect on the child The child does not recognize their parents The parents do not recognize their child's behaviour	Fear of brain damage	Experiencing fear of long-term consequences
M1: Well, it's behind us now, it's OK, but of course, it's still in me. They offered more surgery and I don't know if we'll accept it because it still bothers us, although it's been a year now. (Boy, 9 years)	Delirium has a lasting effect on the parents Emotional impact Delirium has consequences	Lasting emotional impact	

TABLE 4 Parents interviewed and the children's demographics.

Parent number	Children's demographics				
	Sex	Age at the time of admission	Reason for PICU admission	Number of PICU days	Type of delirium
M1	Boy	9 years	Epilepsy and recurrent seizures	7	Hyperactive
M2	Girl	13 years	Retropharyngeal abscess	17	Mixed
M3+F3	Girl	12 years	Facial surgery	46	Hypoactive
M4	Boy	15 years	Meningitis	19	Hypoactive
M5+F5	Girl	6 months	Cardiac surgery	19	Hypoactive
M6	Boy	14 years	Facial surgery	21	Hyperactive
M7+F7	Girl	18 months	Leukaemia	38	Mixed
M8	Boy	12 months	Liver transplantation	26	Mixed
M9	Boy	6 months	Cardiac surgery	18	Mixed
F10	Boy	5 years	Multisystem inflammatory syndrome	5	Hypoactive
M11	Boy	14 years	Respiratory syncytial virus	163	Hypoactive
M12+F12	Boy	2 years	Diaphragmatic hernia	4	Mixed

Abbreviations: F, father; M, mother; PICU, paediatric intensive care unit.

5.1 | Research question 1: What were the parents' observations and emotional responses to their child with delirium?

The question addresses the parents' response to seeing their child with delirium, as most parents were unfamiliar with the condition. We generated three themes describing the parent experience: (1) Knowing that something is very wrong, (2) observing manifest changes in the child, and (3) experiencing fear of long-term consequences, Table 5. The general narrative is that the parents without warning experience something wrong with the personality of their child. It starts gradually as subtle changes and progresses to manifest changes, leading to fear of permanent changes in their child.

5.1.1 | Theme 1: Knowing that something is very wrong

The parents sensed subtle changes before they recognized what was happening. Small signs of change in their child were registered by the parents, giving them a feeling that something was wrong.

Sub-theme 1.1: Sensing subtle and ominous changes

The parents noticed mental and physical changes in their child and knew that something was wrong but were unable to explain what it was. They often noticed changes before the staff did because they were more familiar with their child.

M1: I could see that something was wrong, but I couldn't express what it was. Only that he hadn't eaten or slept for 2 days. So I thought the boy was very tired or something, you know. (Boy, 9 years)

M2: And then I get antsy and say that I can see that something is wrong, I know that it's bad, that something's very wrong. (Girl, 13 years)

Sub-theme 1.2: Feelings of inadequacy

The parents were emotionally overwhelmed and felt powerless when they experienced these changes. They felt unable to comfort their child, which led to a feeling of failure as parents. They wanted action to be taken by the professionals.

M6: ...and the powerlessness makes you want to grab the first nurse that comes by and shake her and say 'do something!' Knowing

TABLE 5 Themes and sub-themes.

Themes	Sub-themes
Research question 1: What were the parents' observations and emotional responses to their child with delirium?	
Theme 1: Knowing that something is very wrong	1.1: Sensing subtle and ominous changes 1.2: Feelings of inadequacy
Theme 2: Observing manifest changes in the child	2.1: Behavioural changes 2.2: Disturbed sleep 2.3: Altered communication 2.4: Altered reality 2.5: Absence of mutual recognition 2.6: Signs of mental fluctuation
Theme 3: Experiencing fear of long-term consequences	3.1: Fear of brain damage 3.2: Lasting emotional impact
Research question 2: What were the parents' comments and suggestions regarding the delirium management bundle?	
Theme 4: Adding insight to the bundle	4.1: Individualizing the sleep pattern 4.2: Individualizing music preferences 4.3: Ensuring physical proximity 4.4: Anticipating delirium
Theme 5: Family engagement	5.1: Ensuring relevant information 5.2: Ensuring family involvement

that it isn't her fault and that she can't do more than she is doing, but because you get so emotional and worried, it's just... It's so overwhelming! (Boy, 14 years)

5.1.2 | Theme 2: Observing manifest changes in the child

This theme describes visible changes in the child observed by the parents. The changes impacted the parents' emotional state, leading to the inability to comfort the child as usual. This was again experienced as deficient parenting skills and led to frustration.

Sub-theme 2.1: Behavioural changes

The parents observed changes in the physical behaviour and mental condition of their child, which were easier to describe. They observed motor disturbances, manifested as agitation or apathy, both of which were unfamiliar to the parents.

M6: ...finally I lay with him and held him, and still he was wound up like a bedspring. He sat in bed and babbled weird things and pulled at everything. He picked at cords, tubes, bandages—anything he could get his hands on—even things that weren't there. (Boy, 14 years)

M9: I don't know what you can say about a baby, but there was something apathetic about the way he lay there. (Boy, 6 months)

M11: And [the child's fear] was usually that he wouldn't survive [the PICU stay]. He imagined that it was almost over. He would only live to be 14 years old. (Boy, 14 years)

Sub-theme 2.2: Disturbed sleep

Several parents stated that their child lacked sleep. When the child only had short naps, the parents were distressed as they recognized the importance of getting enough sleep. This led to frustration because they were unable to help their child go to sleep.

M9: He didn't sleep all day. It was distressing for me. I was afraid he wouldn't recover if he didn't sleep—so how do we stop this cycle? (Boy, 6 months)

Sub-theme 2.3: Altered communication

The parents experienced that their contact with their child had changed. Their attempts at interacting with the child failed. Normal eye contact was replaced by a blank stare. Both verbal and nonverbal communication were affected by the child's absence of voice, tears, or facial expression. The child's verbal expression regressed to silence, unintelligible speech, or relapsed into baby language, adding to the parents' concerns.

M9: I see his position in bed—he is too quiet—and it looks like he looks right through you. (Boy, 6 months)

M7: I think when she makes [sound] and cries like this [sound]. She couldn't really make these sounds, you know. She cried without tears. Or with tears but without sound. Quiet tears. This was terrible because I couldn't comfort her. (Girl, 18 months)

F10: ...but also his language changed from normal talk, you know? But then he changed from saying I want water to me water me water, you know? And me play and things about me, very short and baby-like. (Boy, 5 years)

Sub-theme 2.4: Altered reality

The parents described their child as showing signs of delusions and hallucinations. They had the feeling that their child was in a different world, in another reality, where the parents were unable to comfort them. Initially they doubted whether they had missed something the child was experiencing. The hallucinations reflected the child's imagination, everyday life, and interests. The parents realized that they should not try to reorient the child but accept it for the time-being.

M7: She was looking at something that wasn't there. You know, where you are in doubt? I was almost in doubt, but there wasn't anything. (Girl, 18 months)

M6: He didn't have externalizing behavior towards us, but he lay there and punched holes in the air because someone was after him and we couldn't tell him that nobody was there and that he was safe. Dad and I are here, we are taking care of you and all that. We couldn't convince him because—he was somewhere else. (Boy, 14 years)

Sub-theme 2.5: Absence of mutual recognition

During delirium, the parents were unable to recognize their child, and they experienced that their child was also unable to recognize them. The parents experienced that their child did not respond to the parents' inquiries and contact like they were used to and expected. These experiences occurred across age groups.

M9: But this was my first impression when I saw him—the way he looked at me and his position in bed were unfamiliar to me. (Boy, 6 months)

M11: He was very different. Especially his facial expression and lack of expression—this was overwhelming—it just wasn't him [name], I thought. (Boy, 14 years)

Sub-theme 2.6: Signs of mental fluctuation

The children's mental status fluctuated, and these mental swings appeared without warning. It was not only emotional but also behavioural fluctuation. The parents described these variations like waves that were worst at night.

M8: He was generally insecure with mood swings. He could change from smiling 1 min to screaming the next. (Boy, 12 months)

M6: Yes, it was definitely worst at night. Where on some days we could actually have a really nice contact. (Boy, 14 years)

5.1.3 | Theme 3: Experiencing fear of long-term consequences

This theme describes some of the parents' worst fears when experiencing their child with delirium. They feared long-term consequences such as brain damage and a lasting impact of other symptoms.

Sub-theme 3.1: Fear of brain damage

During delirium, the child behaved differently than usual. The parents experienced altered contact, communication, and collaboration patterns and signs of delusions. They feared the behavioural changes in their child would be permanent, and their worst fear was that the child would become insane or have permanent brain damage.

M6: We were worried that he had become severely brain damaged. This was our first reaction, because for one, our boy was gone, and then his brain was so damaged that he couldn't recognize us. (Boy, 14 years)

Sub-theme 3.2: Lasting emotional impact

The fear of long-term consequences had an impact on the parents long after the hospital stay. Some parents feared that delirium would reoccur and considered declining future planned hospitalizations to avoid the horrifying experience of delirium.

M1: Well, it's behind us now, it's OK, but of course, it's still in me. They offered more surgery and I don't know if we'll accept it because it still bothers us, although it's been a year now. (Boy, 9 years)

The parents also experienced that their child's memory of delirium left an emotional impression long after discharge. The oldest children were able to describe their experiences but preferred not to talk about them. The pre-verbal children, however, displayed their memories through behaviour and preferences.

M2: It was distressing and she still doesn't want to talk about it [the delirium experience] today. She even won't, if I tell her we have something else to do here [at the hospital], she still doesn't want to be here [at the hospital] or talk about her admission. (Girl, 13 years)

M7: They [the children's songs] are stuck in her head. She gets hysterical if I sing them. Hysterical. The songs I sang when she was admitted ... she can't stand them. (Girl, 18 months)

5.2 | Research question 2: What were the parents' comments and suggestions regarding the delirium management bundle?

Although the parents were asked to comment on the content of the delirium bundle, rather than its application, their main impression was that the bundle was too rigid and needed room for individualization. We generated two themes describing the parents' responses: (4) adding insight to the bundle and (5) family engagement, [Table 5](#). The general narrative is that the items in the delirium bundle are all potentially suited to alleviate delirium, but the application of interventions should be individualized to each child. When the bundle is individualized and parents are engaged in the care of their child, the bundle supports FCC.

5.2.1 | Theme 4: Adding insight to the bundle

The parents agreed that the interventions in the delirium bundle were all potentially suited to alleviate delirium if tailored to the individual child.

Sub-theme 4.1 individualizing the sleep pattern

The bundle recommends scheduling sleep time, which was interpreted by some parents as fixed scheduling. The parents preferred to follow the child's daily needs rather than following a pre-planned daily structure.

F7: I think it's silly to plan the day and night rhythm, as you suggest.

M7: Yes.

F7: Yes, it's almost impossible I would say. Let the child and parents follow their own rhythm. (Girl, 18 months)

M8: But they [nurses] tried to guide us to maintain a day and night rhythm, but I failed to see the logic in it—if he hadn't slept all night—he had to sleep in the daytime, although I know it went against the recommendations. (Boy, 12 months)

Sub-theme 4.2: Individualizing music preferences

The bundle only suggests music intervention for the oldest age-group. The parents, however, had varying views on interventions with music. While music might generally have a calming effect, some parents worried about how some types of music could potentially interfere with delirium. Some parents missed explicit references to music and singing to younger children.

M8: ...we didn't want music or anything else because he couldn't take it. (Boy, 12 months)

M7: Yes, so sounds and music are lacking from the list.

F7: Yes, I agree [music is lacking from the list]. For the youngest.

M7: Relaxing music [is missing]. (Girl, 18 months)

Sub-theme 4.3: Ensuring physical proximity

The parents wished to be near when the child experienced delirium. They preferred to be present as much as possible to ensure their child's safety, although they knew that their usual way of comforting the child was insufficient. In this new situation, they needed advice from the staff. The parents offered practical suggestions such as using pillows, weight quilts, and sharing a bed with their child. They still experienced that their presence reassured the child.

M8: I remember it was easier to lie down with him. He didn't want me to lift him up or hold him. Normally he likes it, but then I just lay down. I remember I asked for an adult bed for [name of child] so we could put two beds together, like a double bed. I made the bed so we could lie there all three. (Boy, 12 months)

M6: We talked a lot about our chickens and cats and all the daily things to get him back to reality. I think this held him in "my" world, I almost said the "real" world. (Boy, 14 years)

Sub-theme 4.4: Anticipating delirium

Parents and children needed to prepare themselves for the risk of delirium during future hospitalizations. One mother had previously experienced her child with delirium and tried to anticipate what to do if it happened again. She planned strategies with her child that could prevent or alleviate delirium.

M6: Well, [child's name] and I had planned what we could do ... it was things like bringing some games and books, some music ... some movies ... and activities that were planned ahead. But then he remembered that when he awoke, he couldn't speak [due to delirium], and he didn't know if he could next time he awoke. So, we made hand signals that he could use (Boy, 14 years)

5.2.2 | Theme 5: Family engagement

This theme shows that parents needed to be involved in the care of their child and to collaborate with the healthcare professionals. They also requested more information regarding delirium.

Sub-theme 5.1: Ensuring relevant information

According to the parents, the bundle should include ways to keep the parents informed. They needed knowledge regarding delirium, risks, expected duration, diagnosis, and prognosis in order to anticipate and understand the child's behaviour. Information could be a way of alleviating the concerns of the parents.

M7: When I understood that she had delirium it was easier to accept it somehow. You know? (Girl, 18 months)

M1: But perhaps in such cases. I don't know, but could you make a pamphlet? On the other hand, you should not scare people in advance (Boy, 9 years)

Sub-theme 5.2: Ensuring family involvement

The parents wished to be involved in the care of their child, also during delirium. Interventions needed to be tailored to the individual child, and parents wished to collaborate with the staff when possible.

M6: ...but I think the parents should be involved and they should know that this is a part of the treatment, not just entertainment. It's a step on the way to recovery. It is very important to involve and enquire because all families are different. They need a voice and a task to focus on. (Boy, 14 years)

M8: Yes, I still believe our collaboration is good, but I would like more. It's because in my experience it's important for mom and dad to participate. (Boy, 12 months)

The parents wanted to participate when possible, and one mother wished to contribute to the delirium assessments.

M8: I'm not a nurse, so I can't do the assessments alone. I'm just his mother, but I think my opinion counts ... some of the things

that are assessed, I told a nurse, but I understand, it makes sense because we know him. So in my opinion, I don't know your rules, but it is logical that nurses describe how they assess him but our experience also counts. (Boy, 12 months)

6 | DISCUSSION

Our main findings were that the parents were able to observe subtle and manifest changes in their child during delirium and that the child's condition instilled negative emotions such as distress, frustration, and fear of permanent damage. The general view of the delirium management bundle was that most interventions were relevant, but the bundle was too rigid and needed individualization. The parents needed more information regarding delirium and a higher level of engagement in the care of their child during delirium.

Parenting under ordinary conditions promotes and supports the physical, emotional, social, and cognitive development of their child from infancy to adulthood (Brooks, 2012). Conversely, it is shown that parents of critically ill children feel inexperienced and uncertain while still wishing to be attentive and vigilant (Hall, 2005). We assume that when delirium is superimposed on severe disturbances in consciousness, perception, and cognition, the parents may not be able to recognize their child, which is an additional burden. The parents in our study experienced that they were unable to comfort their child during episodes of delirium. The child's lack of recognition of the parents, paired with the parents' inability to offer comfort with eye contact and verbalization, instilled feelings of anxiety and powerlessness. The role of parents has changed over the past 50 years. Contemporary parenting includes keeping informed about ways to help the child to develop normally by stimulating the cognitive and physical development (Furedi, 2002). Nursing practice should be in tune with current parenting by enabling parents to maintain and strengthen their family roles. As such, FCC is a way to help maintain the parents' relationship with their child and for healthcare professionals to be respectful and responsive to the individual family needs and values by information-sharing and involvement in decision-making (Davidson et al., 2017).

The parents in our study described child behaviours consistent with delirium. These symptoms are known as motor disturbance, altered speech and communication, fluctuation of mental status, and hallucinations, which all are core criteria in the diagnosis of delirium (American Psychiatric Association, 2013). These symptoms were reported by the parents, although they were unaware that their child was delirious. Similarly, relatives of adult ICU patients observe symptoms of delirium without knowing that the patient was delirious (Bohart & Møller, 2019). This emphasizes the relatives' alertness and their special knowledge of their family members as they are able to describe even subtle symptoms.

An important finding in our study was the parents' recommendation to individualize interventions in the care bundle. This was directed towards the use of the bundle rather than the content.

Evidence-based practice relies on three perspectives: the scientific knowledge, the experience of the clinician, and the patient preferences (Rycroft-Malone et al., 2004). As such, the bundle should be viewed as an evidence-based intervention that should be tailored to the parent and child and the situation. It should be taken into consideration that parents are distressed when their child is admitted to the PICU, which emphasizes the importance of individualization (Upadhyay & Parashar, 2022).

Guidelines are by nature often interpreted too literally. In a busy hospital unit, there might not be time to include the parent/child preferences as intended. Some parents misinterpreted the bundle and believed that the child should sleep at night only. This was not the intention, but even 'scheduling sleep' was misunderstood. The intention was to reserve undisturbed sleep time (day or night), not to limit sleep to nighttime. This observation shows that the wording of the bundle is important if the parents are to be included in the care of the child.

Another important finding was the parents' wish to be involved in the care of their child. Family engagement is a central goal in contemporary patient care and should, as such, be articulated in the care bundle (Brown et al., 2015). A particular kind of family engagement was suggested by a mother who offered to participate in delirium assessment. Although the delirium assessment instrument was validated for nurses, the parents' observations could support the assessment. Moreover, participating in assessment could help the parents to accept and understand delirium, while also making them useful as parents. Conversely, parent participation in delirium detection might cause a feeling of responsibility and concern for the accuracy of their assessments (Craske et al., 2018). Therefore, parent participation should be voluntary. It is shown in the adult ICU that collaboration with family members to detect delirium is feasible and acceptable (Parsons Leigh et al., 2021). Family participation in delirium assessment increases their knowledge, leading to family satisfaction (Parsons Leigh et al., 2021).

Many parents in our study were distressed by their ignorance of delirium. They voiced a need to anticipate the condition so that they could brace themselves and the child for the event. We assume that early information reduces parental anxiety and other emotional responses. The need for more information can be generalized from other studies and health conditions (Craske et al., 2018). This emphasizes the importance of healthcare professionals having the knowledge of delirium to inform and engage the parents. Continuous staff training is therefore a prerequisite.

The strengths of this study are the inclusion of children of all ages, with a wide range of diagnoses and living in different parts of the country. All interviews were conducted inter-professionally with a nurse and a child psychiatrist, which provided a broader perspective during inquiry and initial analysis. A potential weakness of this small sample study was that the parents were a convenience sample from an earlier study, which precluded purposive sampling. We assume that the most resourceful parents accepted the invitation to participate in the study. As such, we missed the parents with most concerns. Secondly, the interviews were conducted relatively long after

the experience of delirium, increasing the risk of recall bias. Thirdly, the bundle was developed by international PICU experts, and in our study, we only have perspectives from Danish parents and thereby, we lack parent perspectives from other countries and cultures. The delirium management bundle should be adjusted to the parent's suggestions and individualized to each child and the family needs.

7 | CONCLUSION

The parents in our study were able to observe subtle and manifest changes in their child with delirium. The condition caused fear of a lasting impact. The parents regarded most of the interventions in the delirium management bundle as relevant but needed individualization. The parents requested more information regarding delirium and a higher level of engagement in the care of their child during delirium. Further studies are needed to test the feasibility of the bundle, including the parental perspectives from this study in clinical practice.

AUTHOR CONTRIBUTIONS

Made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data: RLS, IE, MM, MOC, JW, EI, GG, and SFH. Involved in drafting the manuscript or revising it critically for important intellectual content: RLS, IE, MM, MOC, JW, EI, GG, and SFH. Given final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content: RLS, IE, MM, MOC, JW, EI, GG, and SFH. Agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved: RLS, IE, MM, MOC, JW, EI, GG, and SFH.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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