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Using experience-based co-design to explore care experiences and identify practice change priorities for children with medical complexity in the paediatric intensive care unit

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ABSTRACT

Objectives Children with medical complexity (CMC) frequently experience acute deterioration requiring paediatric intensive care unit (PICU) hospitalisation. Collaboration between families and healthcare professionals (HCPs) is vital yet often challenging, suggesting a new care approach is needed. This study explored the PICU care experiences of CMC, parents and HCPs and identified common priorities and practice changes to enhance care.

Design An experience-based co-design (EBCD) approach was used. Semistructured interviews were conducted with CMC and parents (stage 1) and HCPs (stage 2). A co-design event with parents and HCPs followed (stage 3).

Setting Interviews took place in family homes, hospital meeting rooms and virtually. The co-design event took place at the hospital.

Participants Interviews: CMC and parents (n=21, 13 families) within 1 year of their most recent PICU discharge. PICU and complex care service HCPs (n=15). Co-design event: parents and HCPs (n=22). Maximum variation sampling was used.

Results Stage 1: Child and family-related themes included becoming known, becoming a parent caregiver or child care receiver, establishing caregiver relationships, and expecting a responsive and dignified caregiving environment. Stage 2: HCP-related themes included adapting to a different care approach, positioning parents as collaborators, navigating personal connections, and providing continuity of care. Stage 3: Two videos (sharing child and family perspectives, and HCPs' perspectives) were produced to promote discussion at the co-design event. Common care priorities included increase HCPs' awareness of who the child is when they are well; improve interdepartmental communication; enhance HCPs' understanding of families' expertise and needs; enhance parent-HCP partnerships and develop HCP training programmes. Potential practice changes were identified.

Conclusions Participants identified the need for a collaborative approach to care for critically ill CMC, integrating the expertise of children, parents and HCPs. EBCD can help ground the perspectives and needs of HCPs, children and families in future PICU patient and family-centred care interventions.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ This study used experience-based co-design (EBCD) to engage paediatric intensive care unit (PICU) knowledge users including children with medical complexity (CMC), parents and healthcare professionals (HCPs), in exploring their patient and family-centred care experiences in the PICU and identifying care priorities and potential practice changes to ultimately enhance care for CMC.

⇒ Two videos were developed based on key touch points identified in family members' and HCPs' interviews to promote understanding of knowledge users' PICU care experiences, stimulate collaborative discussion and facilitate future dissemination of findings.

⇒ Documenting the voices of CMC was challenging; however, photo elicitation methods and sentence starters were used with verbal children, and non-verbal children contributed via parent-proxy, to address challenges and elicit their perspectives.

⇒ A co-design event brought parents of CMC and HCPs together to view the videos, discuss PICU care experiences and identify common care priorities and potential practice changes to direct future evidence-based practice change initiatives.

INTRODUCTION

Advances in medical technology and post-operative care have dramatically increased the number of children living with complex medical care needs.[1] Children with medical complexity (CMC) have one or more severe chronic lifelong illnesses, medical fragility and functional limitations; they rely on medical technology and have considerable healthcare utilisation and care needs.[2] These children frequently experience acute, life-threatening deterioration in their health status requiring hospital admission, often to the paediatric intensive care unit (PICU) where they constitute an increasing proportion of admissions.[1 3] Between 2001 and 2019, the proportion of children with preadmission medical technology dependence in the USA increased from 16.4% to 23.5%.[3] CMC now account for approximately 50% of PICU days and are at increased risk of recurrent and prolonged stays and PICU mortality.[1 3 4]

The increasing proportion of CMC in the PICU has a profound impact on interactions between parent caregivers and PICU healthcare professionals (HCPs). Parents typically care for CMC at home, becoming expert caregivers with an intimate understanding of their child's conditions and life-sustaining treatments.[5] Close collaboration with HCPs in the PICU is vital to promote best outcomes for all,[6] yet relationships are often complicated and difficult for both families[5 7–9] and staff who may be unprepared to care for this unique population.[8 10 11] Technologically sophisticated parent caregivers challenge the traditional PICU caretaking model in which parents are typically positioned as visitors rather than integral members of the healthcare team.[12] Care is transitory and the focus is on rescuing the child with acute care needs.[1] That model may not be aligned to address the particular needs of children with severe chronic illness and suggests that a different approach for this PICU population would be beneficial.[6 13 14]

Paediatric healthcare institutions typically adopt a patient and family-centred care (PFCC) approach grounded in mutually beneficial partnerships between HCPs, patients and their families.[15] Tensions between HCPs and families can negatively impact those partnerships when they are most needed. The objectives of this study were to (a) explore how knowledge users (CMC, parents, HCPs) experienced PFCC in the PICU and (b) engage them as partners in identifying common care priorities and potential practice changes. This study constitutes the first three stages of a larger mixed-methods study, and findings will be used to direct subsequent practice change initiatives aimed at enhancing PFCC for CMC in the PICU.[16]

METHODS

Experience-based co-design (EBCD), an integrated knowledge translation approach used to capture, understand and enhance healthcare experiences, was used to achieve the study objectives.[17 18] EBCD is a narrative-based approach that draws on participatory action research and user-centred design.[17 19] The study included three stages: (1) gathering family members' experiences and identifying their shared narratives of what it was like to be cared for in the PICU, (2) gathering HCPs' experiences and identifying their shared narratives of what it was like to care for CMC and their families in the PICU and (3) hosting a co-design event to enhance parents' and HCPs' insight into each other's care experiences and initiate momentum for change through the identification of common care priorities and potential practice change initiatives.[20]

Settings and participants

CMC and their parents were recruited within 1 year of the child's most recent PICU discharge from a Canadian quaternary care paediatric hospital. HCPs were recruited in the PICU and complex care service (CCS). CMC <18 years of age who spoke English or French were included with (1) one or more severe, complex chronic medical conditions expected to be lifelong; (2) significant functional limitations with reliance on life-sustaining medical technology; (3) daily home care needs similar to hospital care and (4) high healthcare service utilisation, including one or more PICU visits in the previous year.[2] Definitional criteria for these children were operationalised for eligibility screening using the Standard Operational Definition for Children with Medical Complexity developed by the Provincial Council for Maternal and Child Health in Ontario, Canada.[21] Parents and HCPs who spoke, read and wrote English or French were included.

Maximum variation sampling was used to capture a diverse range of perspectives from families of CMC typically admitted to the PICU and HCPs who cared for them.[17] CMC were purposefully selected who varied in age (also an indicator of parent caregiver experience), medical diagnoses, the number of previous PICU admissions (an indicator of children's and parents' PICU PFCC experience) and home care needs. HCPs were selected who varied in years of seniority and professional role to ensure a broad perspective on PFCC experiences with CMC and their families in the PICU.[16]

Family interviews were conducted in their homes, and in those instances when a child was readmitted to hospital, in a small hospital conference room. Following the outbreak of COVID-19, the study protocol was amended to accommodate virtual interviews. All HCPs and one child were interviewed virtually. The co-design event was held in a hospital conference room after pandemic restrictions were eased.

Procedures

Stage 1: gathering family members' experiences

CMC and their parents were interviewed by an experienced qualitative researcher with no previous connections to or presuppositions regarding the study population. A research nurse collected observational data not necessarily captured on video (ie, distractions, tensions, nonverbal communication) and ensured video equipment worked properly.[22] Following introductions in which the interviewer and research nurse acknowledged their roles and briefly described their prior research experience, informed consent and assent were obtained, and video-recorded data detailing participants' PFCC experiences were gathered. Interview guides were informed by the core dimensions of PFCC[23] (dignity and respect, information sharing, participation in care and decision-making and collaboration).

Rich descriptions of parents' PICU care experiences were gathered using a semistructured interview guide (online supplemental table 2). Team members with PICU experience caring for CMC and with research experience developing tools to interview children post-PICU collaboratively developed a child interview toolkit. The toolkit included photo elicitation techniques using visual props to facilitate engagement and elicit their perspectives,[24 25] and sentence starters providing verbal prompts to facilitate responses to questions.[26] Images of PICU scenes with probing questions such as "What are others in the room saying?" and sentence starters (eg, "I like it best when staff…") evoked relevant information and stimulated communication (online supplemental table 3). The mothers of two non-verbal children participated in online parent-proxy interviews, an effective technique for gathering perspectives of those unable to respond verbally.[27] Sentence starters from the children's toolkit were used to encourage parents to reflect and respond from their children's perspectives. Prolonged engagement, paraphrasing and reflective listening to confirm the interviewer's understanding of participants' perspectives enhanced trustworthiness. In addition, preliminary findings were validated with participants as analysis progressed to verify ongoing interpretation.[28]

Interviews were transcribed to facilitate the identification of patterns and trends difficult to recognise within and across lengthy, complex videos.[22] Two qualitative researchers independently reviewed and analysed the video data and transcripts using constant comparison analysis[29] supported by NVivo V.12 software.[30 31] Analysis was informed by PFCC concepts, data from the literature and debriefings with three team members skilled in qualitative research methods. Data and investigator triangulation further improved trustworthiness.[28] Analysis continued until the essence of child and parent experiences was uncovered and key touchpoints, or themes reflecting the shared narratives of their PICU care experiences were defined.[20]

Three team members, one with previous film development experience, transformed text-based themes into sections of video material using a virtual storyboard. Representative video excerpts were selected to develop key ideas and highlight touch points. The final video was intended to mitigate family-HCP pre-existing power imbalances at the co-design event[32] by providing HCPs with a deeper understanding of families' PFCC experiences[33 34] and stimulating discussion to identify means for enhancing PICU care.[7] The 29 min video was first shown to participating parents and children who validated the findings and identified their top priorities for enhancing PFCC in the PICU. These priorities were synthesised for presentation at the co-design event.

Stage 2: gathering HCPs' experiences

HCPs were interviewed by the same qualitative researcher who, again, had no previous connections to or presuppositions regarding this study population. A semistructured interview guide informed by PFCC's core dimensions was developed and used to gather HCPs' experiences caring for CMC in the PICU (online supplemental table 4). Participants were asked about their caregiving experiences, interactions with CMC and parents, and how PFCC could be improved. Trustworthiness was enhanced through prolonged engagement, paraphrasing and reflective listening, and ongoing validation of preliminary findings with participants.[28] Interviews were audio recorded, verbatim transcriptions of the recordings were prepared and data analysis proceeded as with the family interviews until key touchpoints, or themes reflecting the shared narratives of their experiences caring for CMC and their families in the PICU were defined. Data and investigator triangulation further enhanced trustworthiness. Results were incorporated into a PowerPoint presentation and reviewed and validated by participants who then identified their top priorities for enhancing PFCC in the PICU. HCPs' priorities were synthesised for presentation at the co-design event.

At this point, an adaptation was made to established EBCD methodology. Based on input from the parent partner on the research team and parent participants, a decision was made to develop a second video to share HCPs' experiences caring for CMC and their families. Parents felt it would be easier to appreciate HCPs' perspectives through a video medium and would facilitate engagement at the co-design event. The presentation was transformed into a 15 min video featuring illustrations and professional voiceovers of participant quotes to ensure content accessibility for all co-design event participants.

Stage 3: the co-design event

A moderated, in-person co-design event was held in 2023. Families and HCPs partnered to identify common care priorities and recommend practice changes to enhance PFCC for CMC in the PICU. The event was planned by three team members and an invited expert in integrated knowledge translation. The event design had substantial input from the parent representative on the team who had previous co-design event planning experience. Concerns regarding the parent–HCP power differential were discussed, and the guidance of a skilled moderator was sought to run the event and ensure that all parents would have an equal opportunity to share their perspectives. A team member skilled in qualitative research who was both a nurse and an ethicist agreed to assume this role. To ensure a range of HCP perspectives, the active buy-in of senior PICU and CCS leadership was secured, and attention was paid to recruiting multidisciplinary team members to participate in the co-design event.

Table 1 Baseline characteristics of 13 children with medical complexity whose families participated in interviews

Characteristic	
Hospital and paediatric intensive care unit (PICU) stay	
Age at PICU admission in years, mean (range)	6.0 (0.6–15.9)
PICU length of stay in days, mean (range)	3.9 (0–13)
PRISM III[41] score during first 24 hours, mean (range)	1.8 (0–4)
Hospital length of stay in days, mean (range)	7.4 (1–25)
Previous PICU admissions, mean (range)	6.1 (0–15)
Female sex	9 (69%)
Followed by complex care service (yes)	11 (84%)
Communication	
Verbal	7 (54%)
Non-verbal	6 (46%)
Homecare needs	
Activities of daily living	10 (77%)
Home oxygen	6 (46%)
Suction	10 (77%)
Tracheostomy	2 (15%)
Non-invasive ventilation	6 (46%)
Cough assist	6 (46%)
Enteral feeds	9 (69%)
Ostomy	1 (8%)
Mobilising technology	6 (46%)
Polypharmacy	10 (77%)
Central line	2 (15%)
Other implanted devices	4 (31%)
PICU admission diagnosis	
Neurologic/neuromuscular	2 (15%)
Respiratory/pulmonary	8 (62%)
Ear, nose and throat surgery	1 (8%)
Ortho	1 (8%)
Metabolic	1 (8%)
Primary chronic diagnosis*	
Neurologic/neuromuscular	6 (46%)
Respiratory	3 (23%)
Genetic disease	2 (15%)
Cardiovascular	2 (15%
Comorbidities*	
Neurologic/neuromuscular	5 (38%)
Respiratory	4 (31%)
Genetic disease	2 (15%)
Cardiovascular	1 (8%)
Gastrointestinal	4 (31%)
Haematologic/immunologic	3 (23%)
Renal	2 (15%)
Metabolic	2 (15%)

All data are presented as n (%) unless otherwise stated.
*See online supplemental table 1 for specific medical diagnoses and comorbidities.
PRISM, Pediatric Risk of Mortality Score.

On the day of the event, each video was viewed by all participants and a summary of care priorities arising from previous family and HCP interview validation activities was presented. Participants were asked by the moderator whether the experiences presented in the videos and the PFCC priorities resonated with them and whether they were surprised by, or disagreed with, any ideas. They were then guided through the process of identifying common (family–HCP) care priorities until consensus was achieved. Finally, participants were asked to recommend potential practice changes to address those priorities and enhance PICU care experiences for children, parents and HCPs. The event lasted 4 hours, with a mid-morning break, and was audio recorded in its entirety. Three team members acted as observers, with one providing an ongoing, written summary of participant responses that was projected on a screen so participants could view and comment on it in real time, further enhancing trustworthiness.[28]

Patient and public involvement

The parent partner contributed to the research team and was central to all aspects of study design. They advised throughout the conduct of the study, coauthored this paper and will be active in disseminating findings through social media platforms used by CMC and their parents. Family and HCP participants were actively engaged in all EBCD activities. They validated key touchpoints identified in the interviews and highlighted in the videos and worked together at the

Table 2 Descriptive characteristics of 13 family members interviewed

Descriptive	Mean (range)
Parent age (years)	37.0 (30–43)
	n (%)
Caregivers at home	
Parents	13 (100)
Siblings	2 (15)
Extended family	6 (46)
Homecare (public)	6 (46)
Homecare (private)	2 (15)
Parent level of education	
Community college	4 (31)
Undergraduate	6 (46)
Graduate	3 (23)
Parent employment	
Stay at home	3 (23)
On leave	3 (23)
Part time	5 (38)
Full time	1 (8)

Table 3 Family interview findings

Theme	Quote
Becoming known	A nurse passing by or a respiratory therapist… saying “Ah, what are you doing here,” coming to get news, to see how grown up she is, how old she is, helps me (feel she’s not)just a number in a hospital.” It’s as if they were taking care of a family member. This relationship makes me feel safer for my daughter at the hospital. I’ll take time to eat… because I know she’ll take good care of her because she cares about her; her nurse or the staff know her. I think this relationship is necessary to me, to calm me down.
Becoming a parent caregiver or a child care receiver	I ended up [filling the gastrostomy bag] myself because a lot of the time they're busy or they don't notice, and then it beeps and wakes me up. So, I'm like, I might as well just fill it up myself and deal with it. …My husband, when it’s his turn, he'll do everything. He doesn't like seeing my son be anxious about treatments, so he says, “I'll just do it myself.” Whereas me, I like to teach [my son] that other people can do this stuff, because he’s gonna be older one day and maybe I won't be there, so he has to learn confidence. It’s also a teaching moment for me. I'll participate because it calms him down, but I will let [staff] do Cough Assist or suction and he'll decide, “Mommy you do this, they'll do the other one.”
Establishing caregiver relationships	We were having a hard time weaning and getting on oral Diazepam. It was not going well. My husband and I would have long conversations about how we thought it should be done. Eventually they consulted with(child’s)neurologist, and [she] came to see us and said “You guys are going to set the plan for how the wean is going to go… Because that way if it works, well that’s good. But if it doesn’t work, you will feel like you have done everything that you could.” So, they got everybody on board, and we said exactly how we thought it should be done. This time we give this amount of medication. Then we wait an hour and decrease it by this much. If we feel we can wean after lunch, we do. But if we say no, she’s a bit too jittery, we don’t. And if we want to take a day off from weaning, we do. So, we were the bosses of this wean. …It was a bit scary to be honest. But at the same time, it was very empowering, and we did it. And we got to go home, and it worked.
Expecting a responsive and dignified care environment	The difference this year, as he’s older, is that the doctor came in [and said to him], “Today the objective is for you to do this. Let’s organize ourselves to do [this] exam.” He was involving him [and] explaining what was going on. I found it nice that it didn't happen only between adults and because you're a child, we don't need to tell you. The doctor introduced himself, "I'm your doctor today, my name is(…). And we just made this decision. What do you think of that? Are you okay with that?” It made me feel so good. As parents, we're involved but now that he’s older they take the time to show him the game plan so he can get out [of PICU]. I think it’s very, very good.

co-design event to identify common care priorities to enhance PFCC for CMC.

RESULTS

Stage 1

21 family members (13 mothers, 2 fathers and 6 children) from 13 families of CMC with varying age, diagnoses, age of illness onset, home care needs and the number of PICU admissions were approached and agreed to participate (tables 1 and 2 and online supplemental table 1). Participants from eight families (n=8 mothers, 1 father, 4 children) spoke French as their first language (62%), while those from five families spoke English (38%). Parents’ semistructured interviews lasted 48–100 min (mean=78 min), children’s interviews using the toolkit lasted 40–75 min (mean=53 min), and parent proxy interviews for non-verbal children (n=2) lasted 40–63 min (mean=52 min). Interviews took place in families’ homes (n=10), while a small hospital conference room was used for parents whose child was readmitted to the PICU (n=3). A virtual toolkit interview was successfully conducted during the COVID-19 pandemic with one child who did not participate previously.

Analysis of family interview data revealed four themes that reflected the evolution of families’ care experiences and relationships with staff. (1) Becoming known: As the number and duration of PICU admissions increased, CMC, parents and HCPs gradually became acquainted, built relationships that spanned between hospitalisation events and developed mutual trust regarding decision-making and care delivery. This was reported by families as empowering. (2) Becoming a parent caregiver or a child care receiver: Initial uncertainty and anxiety about their role at their child’s bedside and their place on the team diminished over time, allowing parents to become more confident in their caregiver roles. Children became familiar with PICU staff and routines and were reassured by their parents’ presence and involvement in care. (3) Establishing caregiver relationships: Parents felt they had to demonstrate expertise regarding their child’s medical condition to be respected by PICU HCPs. They described communication challenges with PICU team members and across services, highlighting the importance of establishing relationships with, and being included in, their child’s broader community of care. (4) Expecting a responsive and dignified caregiving environment:

Table 4 Family and healthcare professional care priorities

Family priorities		**Healthcare professional priorities**	
Priority	**Quote**	**Priority**	**Quote**
Increase continuity of care across services	Maybe it's dependent on the hospital to say, "Ok, we have a parent who is asking for a staff person to be involved even if this isn't officially her department." It calms us to know that someone who has known us for so long is with us and accompanying us. And that is to our family's advantage.	Enhance continuity of care within and across services	We want to be able to treat the families as best we can and try to respect the expertise that each individual brings to the table. And sometimes I don't know how to do that. How can one operationalize that, so that we can accentuate the expertise of all the different [stakeholders]? …How much to get involved? How much to express your opinion? There is the balance between knowing the patient and having the expertise.
Recognise and incorporate parent expertise	We become specialists of our children. We know things down to the smallest detail. We have routines that are important. In my opinion the communication should be different. And the approach should be different.	Develop collaborative working relationships with the child and parents	The value of [incorporating the] parents' lived experience in caring for the child… we get that from talking to them at the bedside. But perhaps there needs to be… a mechanism to have structured communication among the family, the child, and the ICU, because all of them have a different experience in caring for that particular child.
Children are integral members of the team	I like it, and my son as well when they ask, "How do you do it at home? How do we put on the mask?" So, when [PICU staff] ask questions like that from the start, that inspires confidence in my son. He collaborates a lot better because that reassures him.	Consistently establish expectations and goals with the family during each admission	Establishing what the goal of care is for that hospitalization. Because often, we're not going to get to a place where the patient is optimized. So, establishing better plans with the families and the health care professionals that this is where we want to be going, so we all have an idea of what the desired outcome is.
Patient-centred and family-centred care must include children and parents	When my daughter was there, I would say "our" doctor. And I realized afterward that was probably some kind of subconscious slip. It was "our" experience because it felt like it was my body that was there in some kind of way… it's your child, who still feels like she's part of you because she is not even 10 years old yet.		When patients arrive and they are very sick, we don't see what they do on the outside when they are not sick. If a nurse has seen [a photograph] of what life is like at home, it can make a big difference. The nurse can be an advocate for intubation, for example.

Families felt that information exchanges with parents and children (verbal and non-verbal) should be approached with respect, optimism and reassurance and that care should extend 'beyond illness', capturing the holistic elements of the child's ongoing health situation. Quotations exemplifying each theme are in table 3.

After validating the interview findings, family members identified four priorities for improving PICU care to be presented at the co-design event: (1) increase continuity of care across services; (2) recognise and actively incorporate parent expertise; (3) recognise CMC as integral members of the team and (4) a PFCC approach must include children and parents. Corresponding quotations are in table 4.

Stage 2

15 HCPs from different disciplines and with varying levels of seniority were approached and agreed to participate in virtual interviews. Interviews lasting 35–90 min (mean=60 min) were conducted. 11 PICU staff (5 nurses, 3 physicians and 3 allied health professionals) and 4 CCS staff (2 nurses and 2 physicians) were included (table 5).

Analysis of the HCP interview data uncovered four themes. (1) Adapting to a different approach to care: Participants described managing chronic illness in the PICU as being outside of their training, HCP preferences, and unit resources. They acknowledged parents' expertise in caring for their children and noted that conflict could occur when seeking to adapt care delivery to include

Table 5 Demographic characteristics of 15 healthcare professionals interviewed

Demographic	Mean (range)
Age	44.20 (range 27–57)
Years in professional role	16.47 (range 2–31)
Years working in PICU/CCS	12.13 (range 1–31)
	n (%)
Female	11 (73)
Male	4 (27)
Professional role	
Nurse	7 (47)
Physician	5 (33)
Child life specialist	1 (7)
Spiritual care	1 (7)
Social worker	1 (7)
Education	
Associate's/college	1 (7)
Undergraduate	5 (33)
Graduate	4 (27)
Postgraduate (physician)	5 (33)

CCS, complex care service; PICU, paediatric intensive care unit.

expert parent caregivers. (2) Positioning parents as collaborators: Participants suggested that open communication promotes collaborative care and decision-making and facilitates positive working relationships with CMC and families. (3) Navigating personal connections: With repeated admissions, challenges can develop in HCP–parent relationships related to accumulated tension and shared histories about treatment decisions. Participants reported that with increasing critical illness admissions, questions and sometimes conflict can be generated about what is in the child's best interests. Long-term relationships with CMC and their parents can strain personal and professional boundaries for HCP. While techniques exist to diminish this risk, they were reported as not often practiced. (4) Establishing continuity of care: Participants acknowledged that continuous multidisciplinary team-based care is important for CMC. While closely followed by the CCS in other care settings, when admitted to the PICU, CMC and their families find their connection with the CCS team is disrupted and communication between teams can be challenging. Quotations exemplifying each theme are in table 6.

After validating the interview findings, three priority areas for improving PFCC for CMC from the HCP perspective were identified to present at the co-design event: (1) enhance continuity of care within and across services by working with HCPs who know the family; (2) establish expectations and goals with the family at admission to improve clarity and transparency regarding treatment plans and goals and (3) develop collaborative working relationships with the child and parents, recognising that family and staff expertise is complementary. Corresponding quotations are in table 4.

Stage 3

22 participants (13 HCPs and 9 parents) participated in the co-design event (table 7, online supplemental table 1). This included five HCPs and three parents who were previously interviewed, and eight HCPs and six parents who met inclusion criteria, allowing us to maintain maximum sample variation. The moderator asked participants at the beginning of the event about language preferences. All were bilingual (French and English), and both languages were spoken without a need for translation.

The research team entered the co-design event with a clear sense of the touchpoints and priorities identified by CMC, parents and HCPs. Presenting family member and HCP interview findings to co-design event participants in video format enhanced their understanding of each other's perspectives and PFCC priorities, and facilitated group discussion. All agreed that a collaborative multidisciplinary care model that integrated the expertise of all knowledge users was the optimal approach to care for CMC in the PICU.

Consensus was reached on five PFCC priorities: (1) Increase HCPs' awareness of who the child is when they are well; (2) develop structured approaches to improve communication between the PICU and CCS teams; (3) enhance HCPs' awareness and understanding of the unique expertise, needs and experience of CMC and their families; (4) enhance HCPs' awareness and understanding of parents' desire to partner with staff in their child's care and the impacts of frequent and lengthy PICU admissions on families and HCPs (caregiver continuity can provide support) and (5) provide training programmes to HCPs to address the increasing numbers of CMC utilising PICU services. Strategies to achieve those priorities were discussed, and participants generated a series of practice recommendations for achieving them that would benefit all knowledge users (table 8). All agreed on the importance of establishing a working group of families and HCPs to design and implement future practice change initiatives.

DISCUSSION

This study used EBCD to explore the PFCC experiences of CMC, parents and HCPs in the PICU and identify common priorities and practice recommendations for enhancing PFCC. While interviews with CMC, family members and HCPs elicited diverse perspectives on care experiences, considerable overlap was found across participant groups' care priorities. There was general agreement that a collaborative, multidisciplinary care model drawing on the expertise of all knowledge users, including CMC, their parents and HCPs, was the optimal approach to care for CMC. This supports earlier suggestions that

Table 6 Healthcare professional interview findings

Themes and subthemes	Quote
Theme 1: Adapting to a different approach to care	
Managing complex chronic illness in a critical care setting	If you're looking after the complex care patients in the PICU long-term … it's not something that's actually taught at university or college or anywhere how to do it. It's not even something that's taught on the unit. It is something you need to learn as you go along. It's different for every patient, but also different for every nurse. (PICU HCP)
Learning to work with medically socialised parent caregivers	Usually, people that take care of a complex care kid run a sort of intensive care unit at home. They know a lot. They take care of this kid. They've been trained for years. (PICU HCP) It becomes difficult… let's say we make a child NPO and then the parent really wants to give the feed. If there's a reason for this child not to have any food and I'm adamant about it, it becomes a conflict. (PICU HCP)
Theme 2: Positioning parents as collaborators	
Getting to know the family and their expectations	It's a collaboration that you probably never had with any other parent, where you invite them to be the expert of their child while also giving your advice and recommendations. (PICU HCP) I think having an idea of the background of these children definitely helps in terms of how fragile they are and what worked in the past. …It's also the wishes of the families [that are] important for them to know. Even though they're in the PICU, the family may have some limitations on what they want done. That's usually documented but [Complex Care] can be helpful in making sure that is honoured. If they are having different ideas [about] the level of care they want(…)for their children, sometimes we can be helpful [in] these discussions. (CCS HCP)
Theme 3: Navigating personal connections	
Struggling with the best interests of the child	I've witnessed those situations where I thought, is this really in this child's best interest? Are we doing the right thing? We as a team, and this family, are we doing the right thing for this child? Or is this causing a lot of suffering? (PICU HCP) Some of the patients I follow will end up in the PICU and [staff] might think "What on earth are we doing? Why is this patient in the ICU? Why are we doing so much for someone who has so little quality of life?" …if they could see them in their home and how they're loved, even though they don't seem to be able to do very much, they do have some quality of life. And how to convey that, it's hard… (CCS HCP)
Maintaining personal and professional boundaries	I think we need to know that we're there to help the parents and to be their support and to help their child, but not to cross the line. … Sometimes that line does get crossed. It becomes personal, and parents are texting nurses and asking for favours or things like that. [It] becomes very difficult. (PICU HCP)
Theme 4: Establishing continuity of care	
Discrepancies in messaging at the bedside	Families have told me one nurse said this, one nurse said that, and while they both mean well it's contradicting information. If there are differing options or opinions, then the multidisciplinary team has to meet without the family to come up with a plan. (PICU HCP)
Limited communication between PICU and CCS teams	In the PICU, we obviously collaborate with everyone. But the Complex Care Service, who probably knows these children the best, aren't as implicated in the PICU. I feel like Complex Care is not as involved in the PICU as I would love them to be. But that's my bias. (PICU HCP)

CCS, complex care service; PICU, paediatric intensive care unit.

a different approach to providing paediatric critical care would benefit this population.[4 12–14]

Parents of CMC voiced their desire to have their expertise as caregivers recognised and described the complex process of establishing working relationships with staff that would ultimately facilitate their integration into the healthcare team. Achieving that relationship occurred with repeated admissions and was central to the evolution of families' PICU care experiences as reflected in their interviews. Parents' efforts to establish relationships with HCPs were often aimed at addressing perceived communication breakdowns, a finding consistent with our own and others' previous work.[5 35] The importance of care coordination and synthesising medical information within and across services is reported elsewhere[36 37] and was identified by participants in this study as a respectful way for HCPs to work alongside family partners. Indeed, the need for respectful information exchanges throughout the child's PICU stay was emphasised and is consistent with other findings.[6 35 38] Also consistent with other reports,

Table 7 Characteristics of the 22 co-design event participants in the study

Healthcare professional participants (n=13)	
	n (%)
Professional role	
Nurse	4 (31)
Nurse educator	1 (8)
Advanced practice nurse	1 (8)
Assistant nurse manager	1 (8)
Nurse manager	1 (8)
Paediatric intensivist	2 (15)
Division head (physician)	1 (8)
Social worker	1 (8)
Spiritual care professional	1 (8)
Division or service	
Paediatric intensive care unit (PICU)	8 (62)
Complex care service (CCS)	4 (31)
Spiritual care service	1 (8)
	Mean (range)
Years in professional role	24 (8–33)
Years working in PICU/CCS	20.5 (6–33)
Parent participants (n=9 parents from seven families)	
	n (%)
Parent attended alone	5 (56)
Parent attended with partner	4 (44)
Child's sex (female)	5 (71)
Child followed by CCS (yes)	6 (86)
Child's communication	
Verbal	6 (86)
Non-verbal	1 (14)
Child's PICU admission diagnosis	
Neurologic/neuromuscular	1 (14)
Respiratory/pulmonary	3 (44)
Ear, nose and throat surgery	1 (14)
Cardiovascular	1 (14)
Ortho	1 (14)
Child's primary chronic diagnosis*	
Neurologic/neuromuscular	2 (29)
Respiratory	1 (14)
Genetic defect	4 (57)
Child's comorbidities*	
Neurologic/neuromuscular	6 (86)
Respiratory	4 (57)
Genetic defect	1 (14)
Cardiovascular	4 (57)
Gastrointestinal	5 (71)
Haematologic or immunologic	3 (43)
Parent participants (n=9 parents from seven families)	
	n (%)
Child's homecare needs	
Activities of daily living	3 (43)
Home oxygen	3 (43)
Suction	4 (57)
Tracheostomy	2 (29)
Ventilator	1 (14)
Cough assist	1 (14)
Enteral feeds	5 (71)
Mobilising technology	3 (43)
Polypharmacy	4 (57)
Other implanted devices	2 (29)
	Mean (range)
Child's age	7.37 (0.6–13 years)
Number of PICU admissions	3.16 (1–5)

*See online supplemental table 1 for specific medical diagnoses and comorbidities.

continuity of care was identified as a challenge at both the bedside and the interdepartmental level.[8]

Family members stressed the importance of treating the child with dignity and respect and including them as integral members of the team. While the voices of CMC are largely absent in the PICU literature, we created an interview toolkit that successfully used photo elicitation techniques to gather the perspectives of verbal and non-verbal children regarding their PFCC experiences. For non-verbal children, parent proxy interviews encouraged participants to reflect and respond to interview questions in their children's words. We recommend similar approaches be integrated into future studies to better capture the voices of CMC, which are of central importance to the development of paediatric critical care practice change initiatives.

HCPs described having to adapt their clinical practice and adopt a different mindset to care for CMC and work alongside medically socialised parents in the PICU. This suggests a broader perspective on these parents' role in the PICU is needed to facilitate collaboration. Indeed, parents' sophisticated understanding of their children's complex care requirements impacts the navigation of care roles with HCPs in a way that not all may feel comfortable with.[10 39 40] Parents of CMC may, for example, wish to be involved in their child's medical management, substantially altering the typical clinician–parent dynamic.[10] We identified apprehension in HCPs concerning their interpersonal connections with families that impacted professional boundaries and strained therapeutic relationships. Conversely, junior staff with less experience expressed feeling intimidated by expert parents and uncertain about

Table 8 Co-design event: parent–healthcare professional consensus priorities and potential practice changes

Priority	
Develop a standardised communication tool	▶ Help staff learn who the child is and how they communicate. ▶ Include videos and photos to provide non-medical information about the child/family. ▶ Keep the tool visible and accessible on the unit. ▶ Build on/coordinate with existing PICU projects.
Improve communication between PICU and CCS	▶ Determine what information is needed and by whom. ▶ Determine best timing for communication with family. ▶ Ensure everyone who needs to know what is happening with the child and family is kept in the loop. ▶ Better bridging of CCS–PICU communication gap during child's PICU stays.
Improve HCP understanding of the uniqueness of CMC and their families	▶ Engage parents who have important information about their child that is often difficult to find or not recorded in the medical chart. ▶ Engage child directly and in team discussions; ensure parent present or bedside communication tool available for non-verbal children.
Enhance understanding of parents' desire to partner with staff in their child's care and the challenges for families and staff of frequent and lengthy PICU admissions to facilitate partnerships	▶ Discuss how parent wants to/can be involved in child's care as not all parents have same level of PICU experience. ▶ Support and encourage parent caregivers to take breaks during stressful and frequent PICU admissions (can become exhausted and risk burnout). Lack of physical space to be alone/sleep in PICU is challenging. ▶ Family–nurse relationship important; nurse continuity promotes establishment of trust. Continuity must be balanced with PICU staffing needs; a challenge for families and HCPs. ▶ Primary physician knows child's unique needs, care 'slows down' when they are absent; care plan must be explicitly shared.
Provide training to PICU HCPs, particularly those new to working with CMC and their families	▶ New nurses do not have knowledge/experience with CMC and can be intimidated. How can they be supported? ▶ Encourage HCPs to share tasks and work with parents ▶ Medical education and training programmes need to address CMC needs during acute deterioration. Would CCS rotations help?

CCS, complex care service; CMC, children with medical complexity; HCP, healthcare professional; PICU, paediatric intensive care unit.

how to establish collaborative relationships, resulting in a shift in the usual parent-HCP power dynamic. Findings strongly support the need to develop multidisciplinary educational initiatives that draw on the expertise of all knowledge users. Potential practice changes identified at the co-design event can be used to direct future evidence-based practice change initiatives to enhance care for CMC in the PICU.

EBCD was founded on the principles of co-design and collaboration; thus, it was crucial that participants felt empowered to genuinely engage in the interviews and in the co-design event. This proved challenging for families who were concerned that HCPs would be offended by their critique and were cognisant that, in some cases, staff who viewed the video may be assigned to care for their child in future. In the final stages of the video's creation, parents were asked to approve the use of video clips in which they or their children appeared. After viewing the video, parents felt reassured that their narratives were part of a larger dialogue to improve PFCC. We were less concerned about HCPs' ability to speak up, yet informal feedback suggested that not all HCPs were comfortable sharing their perspectives directly with parents. This challenge has been highlighted elsewhere by HCPs moving from their 'expert' role to partnering in co-design events,[15] suggesting that while EBCD aims to change power relations in a positive way, the extent to which this is effective in healthcare settings warrants further investigation. Finally, study findings suggest that current models of care in the PICU may not be meeting the needs of and promoting the best outcomes for CMC. The key messages produced by this study may provide a framework for additional competencies to be incorporated into training for all PICU HCPs to better serve the needs of this unique and growing population of children requiring critical care services.

Limitations

Participants from a single PICU were interviewed, potentially limiting the transferability of study findings. To alleviate potential bias, maximum variation sampling was used to capture a range of perspectives. Documenting the voices of CMC proved challenging due to communication barriers, shyness and, for some, difficulty recollecting details of their PICU stay. While this may have impacted data quality, we attempted to address those challenges using photo elicitation and sentence starters with verbal children, and a parent-proxy method with non-verbal children to elicit their perspectives. Finally, this study was conducted in the context of the COVID-19 pandemic and extrapolation to 'non-pandemic' times may be limited.

CONCLUSIONS

EBCD was used to explore how CMC, their parents and HCPs experienced PFCC in the PICU and engage them as partners in identifying common care priorities and potential practice changes to direct future change initiatives and enhance care for CMC. Key touchpoints in participants' PICU care experiences shared at the co-design event revealed how closely aligned family members' and HCPs' priorities for enhancing care were. Findings suggest the traditional focus of paediatric critical care on acute illness does not meet the needs of children with severe chronic illness, and that a collaborative, multidisciplinary care model drawing on the expertise of children, parents and HCPs would provide an optimal approach to caring for CMC in the PICU.

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