



Family member experience with restricted family presence in Canadian PICUs: an interpretive descriptive study

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Abstract

Purpose We performed this study to explore family member experiences with restrictions to family presence during their child's PICU admission, leveraging the unique context of the COVID-19 pandemic to aid in future ethical and informed decision-making.

Methods Qualitative interpretive descriptive study with family members of Canadian PICU patients admitted from March 2020 to April 2021 who experienced restricted family presence (RFP) policies. Respondents were purposively sampled for demographic-based maximum variation. We generated themes through inductive thematic analysis of open-ended interviews.

Results Fourteen parental figures from five regions across Canada participated. We identified four themes associated with the lived experience and impact of the restrictions on family members of critically ill children: (1) challenges to fulfilling the parent role, (2) isolation from primary supports during a time of crisis, (3) navigating increased logistical difficulties, and (4) seeking compassionate approaches within the healthcare system.

Conclusion: RFP policies created a range of barriers for family members of critically ill children. Healthcare organizations and teams may play a role in removing barriers through consistent and empathetic application of rules with consideration for the duality of the parent role in PICUs, providing important post-pandemic policy and practice implications.

What is known:

- Parental presence with critically ill children may improve health outcomes for patients and their families.
- Restrictions to family presence in PICUs continue to occur internationally and, during COVID-19, resulted in parental isolation, anxiety, and increased stress.

What is new:

- By isolating family members and removing supports, COVID-19-related restrictions in Canadian PICUs challenged family members' ability to fulfil their parent roles while meeting their own needs.
- Families need empathetic, advocacy-based approaches from clinicians and healthcare systems to maintain trust and therapeutic relationships in a family-centered organization.

Keywords Intensive care unit · Pediatric · Family members · Visitors · COVID-19 · Qualitative

Abbreviations

COVID-19	Coronavirus 2019:
ICU	Intensive care unit
PICU	Pediatric intensive care unit
RFP	Restricted family presence

Introduction

Family members of pediatric intensive care unit (PICU) patients experience stress and trauma [1] as they navigate changing roles in a new and frightening environment [2, 3] while fearing for the health of their critically ill child [4]. This frequently results in adverse mental health sequelae [5]. Parent-identified needs and coping strategies include several elements common to a family-centered care framework: readily available access to information [2, 3, 6, 7];

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participation in care [3, 7, 8]; and presence with the child [2, 9]. These elements are necessary pre-requisites for strategies parents use to maintain their self-identity as a “good parent” in the PICU [10]. Family members also cope through self-care [6, 7, 11, 12] and emotional and social supports [11, 13, 14]. Each of these identified needs are potentially threatened when policies and practice limit access of parents and family members to their critically ill child.

Despite widespread recognition of the importance of parental and family presence in hospitalized children and youth [15], many PICUs restrict patient access, including during public health crises [16–20]. Early in the COVID-19 pandemic, all 19 Canadian PICUs, following local hospital policy, restricted family presence (RFP) to one or two primary caregivers, restricted all visitors and minor-aged siblings, provided limitations to movement within the PICU or hospital, and had variable approaches to exceptions [16]. These deviations from non-pandemic practice, in which all PICUs enabled two or more at the bedside without restriction on identity and role [16], were comparable to other North American and Oceania approaches, and likely more enabling than those across the rest of the globe [20, 21]. The COVID-19 context provides opportunities to study and better understand consequences of family presence restrictions for impacted patients, families, staff, and key stakeholders. This is necessary for future policy decisions, in any context, to be proportional and responsive to the impacts of such policies.

Family members of children in the PICU were surveyed about their experiences in two single-center and one national multi-center surveys. They reported that, while they understood the necessity, RFP resulted in isolation, loneliness, and anxiety [22], and increased their distress [23, 24]. Survey data provided important preliminary insights into potential impacts; a deeper understanding of family members’ lived experiences with RFP is needed. The objective of this qualitative study was to explore family members’ experiences with RFP policies during their child’s PICU admission during the first year of the COVID-19 pandemic.

Methods

Study design

Performance and reporting followed the Consolidated Criteria for Reporting Qualitative Research guidelines [25] (Online Resource 1) and was in accordance with the Declaration of Helsinki, with ethical approval from IWK Health (REB#1026029).

To enable the consideration and elaboration of the contextual difference between individuals, families, and centers with different presence policies, as well as the

constructed and subjective nature of the experience for individual family members, we sought to describe the experience for individuals while identifying commonalities in their lived experiences. We approached the inquiry and analysis from an interpretivist position, with an understanding of the operationalization and importance of parental presence supported by clinical experience (JF, LL, DG), pre-pandemic parental presence research experience, and lived experience of being a patient or family member (NM, CS, MW). Thus, we used an interpretive descriptive qualitative study design based on the methods of Thorne [26].

Reflexivity is a core tenet of qualitative research [27]; team members’ reflexivity statement and information are included as Online Resource 2.

Recruitment

Participants were recruited from a survey of family members, defined as any individual who self-identified as such, whose children were admitted to a Canadian PICU during periods of RFP (March 2020 to April 2021) [24]. We purposively sampled those who provided contact details ($n = 108$) for maximum variation along the following characteristics: child age; PICU location; previous experience with baseline family presence policy; planned or unplanned admission; relationship to child (e.g., mother, grandparent); and self-identification as Black, Indigenous, and/or a person of color. Potential participants were approached by telephone or e-mail, at their preference, and provided written informed consent. In keeping with an interpretive descriptive approach [26], we initially sampled purposively, seeking maximum variation. As analysis proceeded, we purposively selected participants who had indicated demographic and PICU-related variables (e.g., child age, hospital of admission) that enabled checking and elaboration of newly identified concepts and themes. Enrolment ended when a sufficiently varied sample had been recruited that included a range of background and PICU-related experiences.

Data collection

We conducted one-time, 30–60-min, open-ended interviews. Participants had no prior relationship with the interviewer (MR), a non-clinician researcher with significant qualitative interviewing and methods experience in health care (non-PICU) contexts. The initial interview guide was based on team members’ knowledge and experience, and the PICU family presence literature [16, 28]. It was reassessed every five interviews and as the analysis progressed with refinement of questions for future interviewees as new areas of inquiry emerged (final interview guide, Online Resource 3).

All interviews took place over Zoom (Version 5.7.3) video-conferencing software or phone per participant preference. Participants confirmed their consent verbally and were provided options for in-the-moment or follow-up crisis support should it be needed. Interviews were audio-recorded and transcribed verbatim by a professional transcriptionist. Participants received a copy of their transcript and were invited to provide additions and changes, which were incorporated into the transcripts directly, and comments, which accompanied the manuscripts as notes for the interpretive analysis. The interviewer completed field notes immediately after each interview as part of an ongoing reflexive practice and to record relevant non-verbal context; these were neither coded nor formally included in the analysis. The study team provided regular interviewer feedback after reviewing transcripts and recordings.

Data analysis

Our interpretive, inductive thematic analysis followed the steps outlined by Braun and Clarke [29] with three important deviations from their reflexive thematic analysis [30]: 1. Two coders sorted the data; 2. Coders used an inductively-generated codebook to support data organization and facilitate team members' immersion in the data; and 3. In keeping with interpretive description, we involved both clinicians and patient partners in the analysis team for the data immersion and development of themes.

We performed independent, inductive coding using NVivo 12 qualitative analysis software and guided by the question: "What was meaningful about RFP for family members of PICU patients?" MR, AA, LL, and JF developed an initial codebook based on open, inductive coding of the first two transcripts. The remaining transcripts were inductively coded by MR and AA who met regularly to discuss consistency, refine code definitions, and define new codes while data collection was ongoing. Every five interviews, the full analysis team (MR, AA, LL, JF, MW, CS, NM) met to discuss potential themes and to adjust the interview guide as needed. Recoding occurred as needed. Changes were documented in an audit trail. Following coding and consensus on the final codebook (Online Resource 4), the team independently interpreted themes and sub-themes and discussed and refined themes together. JF further refined and finalized the themes.

Participants are identified in the text as (P). Quotes are identified as (Q#).

Trustworthiness

Throughout the study process, credibility was sought using peer briefing, reflexive practice, participant transcript review, and by checking possible themes with subsequent

participants. Transferability was sought through purposive sampling, dependability by maintaining an audit trail, and confirmability through reflexive practice.

Results

We interviewed 14 participants (eight mothers, five fathers, one grandmother) with a median age of 40.5 years (range 28 to 63 years). All participants self-identified as parents. Participant characteristics and participant-described hospital rules and practices are provided (Table 1). One participant was divorced, one bereaved of their child, four experienced a prior PICU admission, and four admissions crossed over from unrestricted to RFP at the pandemic outset. Canada's geographic regions except the Territories were represented (Atlantic Canada [$n=2$], Quebec [$n=2$], Ontario [$n=3$], Prairies [$n=4$], and British Columbia [$n=3$]).

Exemplary quotes are listed in Table 2. Participants expressed that they understood the reasons for pandemic-related restrictions: "It's stressful, but we understood" (P14). For some parents, it improved their sense of safety, as their primary goal was for their child to get well (Q1–2). Despite this, restrictions added a new layer of stress to their child's admission and removed or decreased normal mitigating factors. We generated four themes associated with the lived experience and impact of the restrictions.

Theme 1: Challenges to fulfilling the parent role

Most participants self-identified as key members of their child's healthcare team; they needed to be present to help their child and feared leaving (Q3). Restrictions hindered parents' ability to participate in their child's care, typically achieved by tracking their child's medical progress, providing information, and being a continuous presence. This was particularly true for non-present parents (Q4–5). Restrictions expanded parental duties to include explaining RFP to their child (Q6).

Parents who could trade places at the PICU bedside appreciated supporting their child and being able to step away while their child was still receiving care from another loving family member (Q7). Small concessions, like allowing a short bedside handover when trading places, supported fulfillment of self-identified parental roles (Q8).

Participants reported that the rules separated families. Sibling restrictions added to the family's emotional burden, as parents had to choose for which child they would be present, and worried about negative impacts on siblings (Q9). Lost family time was particularly impactful when parents feared it would be the only time they would have together before death (Q10).

Table 1 Participant characteristics and self-reported experiences with family presence rules

Participant	Self-identify as BIPOC*	Child's age ^{‡K}	Planned or emergency admission	Admission timing	Bedside presence rules	Sleep in child's room [†]	Allowed to trade places at bedside with other family?	Notes:
1: Father	No	School-aged	Planned	Spring, 2020	Two primary carers	Yes	No	Isolated in room
2: Mother	Yes	Newborn	Emergency	Spring, 2020	One primary carer	Yes	Yes, with other parent	
3: Father	Yes	School-aged	Emergency	Winter, 2020	One primary carer	Yes	Yes, with other parent every shift	Isolated in room
4: Mother	Yes	Infant	Planned	Winter, 2020	Two primary carers	No	No	
5: Mother	No	School-aged	Planned	Winter, 2021	Two primary carers	Not allowed	No	
6: Grandmother	Yes	School-aged	Emergency	Spring, 2020	One primary carer	Yes	No	Escort to leave room, unable to leave hospital
7: Father	No	Adolescent	Emergency	Summer, 2020	Two family members	Yes	Yes, every four days	Initially parents, liberalized later
8: Mother	No	Infant	Planned	Winter, 2020	Two primary carers	No	No	
9: Mother	No	Newborn	Planned	Spring, 2020	One primary carer	Not allowed	Yes, with other parent once daily	
10: Mother	No	School aged	Emergency	Spring, 2020	One primary carer	On sleep chair	Yes, with other parent infrequently	
11: Mother	No	Adolescent	Planned	Winter, 2021	One primary carer	Not allowed	Yes, with other parent	
12: Mother	No	School aged	Emergency	Spring, 2020	One primary carer	No	Yes, with other parent	
13: Father	No	Toddler	Planned	Spring, 2020	Two primary carers	Yes	No	
14: Father	No	Adolescent	Emergency	Winter + Fall 2020	One primary carer	No	No	Only allowed to leave room when leaving hospital

*BIPOC Black, Indigenous, Person of Color

^KNewborn = < 1 month; infant = 1 month to 1 year; toddler = 1–4 years; school-aged = 5–12 years; adolescent = > 12 years

[†] “No” = parent did not sleep in the room; “Not allowed” = parent prohibited from sleeping in the room

Theme 2: Isolation from primary supports during a time of crisis

Restrictions isolated participants from their primary supports, often the other parent, during a crisis. This forced participants to “experience trauma alone” and required “leveraging alternate supports to cope” including reliance on professional supports.

Experiencing trauma alone RFP exacerbated underlying stress and isolation from having a critically ill child and the

pandemic itself (Q11). One participant described the difficulty of experiencing trauma alone: “Like I was not coping, and I was on the floor hysterically crying. So yeah, having somebody else would have been nice” (P12). The need for emotional and/or psychological support varied by context and individual and was magnified by clinical uncertainty. One participant’s husband (not the typical decisional delegate) was “freaking out” upon realizing the need for an emergency procedure while alone in-person (P9). Another exclaimed the need for emotional support when leading their child to surgery, a moment when “you [parents] don’t know

Table 2 Representative and exemplary quotations

Quote ID	Quote summaries and context	Exemplary quotations	Participant #
General understanding and perception of COVID-19-based restrictions to family presence			
1	<i>Father: RFP rules difficult to experience but understandable in context</i>	You know, if I was to describe them as an individual, you know, one would think that they seemed tough. But, you know, when we look at the pandemic and some of the, I guess, horrible things that it has caused, I feel that it was definitely warranted for the situation that we were dealing with. So it obviously had its trying moments when he was in poorer condition. But it's totally understandable	7
2		I was more concerned about his recovery than anything else	5
Theme 1: Challenges to fulfilling the parent role			
3	<i>Mother has experienced past separation from one of her children, fears this from pandemic policies</i>	That was my biggest fear in this pandemic was that if anything was to go wrong with either of my children, the thought of having to leave the other child is terrifying. And knowing that it's a total real possibility because it happened to me is a real fear for me. And then even other parents knowing like one can get sick, and now you cannot access your other child is kind of cruel	8
4	<i>Father disliked not knowing what was going on, worried about mother being alone for bad news</i>	My partner hated it because he wants to know what's going on as well. Knowing that if we ever got bad information, I'm now there all by myself with this kid... Yeah, it was really hard on him. Because any of that information I got, I was getting by myself. And now he was getting it second-hand from me	8
5	<i>Mother who had to leave for sleep felt like she was abandoning her baby</i>	It was just like the worst feeling ever having to leave [to sleep] because there's no one else who can take your spot. You know, like in a normal scenario, my husband would have been there, or even my mom could have like tagged me off, or someone that I know and love and trust could have been there with her instead. But I just felt like I was abandoning my baby	9
6	<i>Mother had to explain family presence policy to child</i>	Yeah, we would just try to simplify it for [son] And so we would explain that because of the COVID virus and trying to not have it spread to too many people...or to a lot of people, they had to have rules to not have too many people in at a time...	12
7	<i>Taking turns allowed meeting multiple family goals</i>	My husband and I would take turns so I could come home and see my other children and take care of a couple of things here and there. Our son was never alone	5
8	<i>Time for parent-to-parent handover supported family engagement in care</i>	...they gave us enough time [during the switch out] to at least go through the notes that we'd made throughout our time with our son. You know, we were tracking how often he peed and bowel movements and temperatures, and things like that	10
9	<i>Sibling restrictions added logistic burden, caused stress for family including sibling</i>	...yeah, like we couldn't bring her with us. And when we got to the point where we're like, okay, now, we're just going to keep her at a hotel close by just so we could go back and forth during the day. At least she could still see me and see my husband as well. Yeah, so it affected her a lot. She couldn't sleep. She was crying a lot, looking for me, looking for my husband	2
10	<i>Mother expressed regret at lost time with siblings and other family before death</i>	... And [son] passed away that night...or I guess in the morning. He went to sleep, and didn't wake up after that. So I just wish he would have had more time to see his brothers in person and not over Facetime or the window	12

Table 2 (continued)

Quote ID	Quote summaries and context	Exemplary quotations	Participant #
Theme 2: Isolation from primary supports during a time of crisis			
11	<i>Mother's separation from usual supports felt like being in jail</i>	I'm a very fortunate person that I have an extremely supportive family and support system. And like outside of the hospital, people would never leave me like that. It just kind of felt like I was in jail or something, that no one was able to help me. [tearful]	9
12	<i>Father alone in the room experienced emotional trauma from isolation while experiencing fear</i>	And when you look at the PICU room, it's quite ... scary. Like she's right in the middle of the room, machines all around her. And then the only thing you can look at is your daughter. And there's no one to talk to, except when the nurses are exchanging shifts or they come in.... So to me, it was more of like psychological torture having no one to talk to, and then witnessing what my daughter was going through in that room	3
13	<i>Father appreciated offers of support by social worker</i>	There's a social worker there. He stopped by a few times. And he was great as well. You know, offered me support and things like that. So yeah, definitely engaged and definitely awesome	1
14	<i>Father wants hospital-provided supports without compromising medical care</i>	... I don't want to see doctors and nurses pulled away from attending to a child in a critical situation to deal with a parent who's, you know, freaking out	14
15	<i>Hospital design and family creativity used to enhance virtual presence</i>	But those windows allowed [son] to be raised up in his bed and see his family out on the side of the road. Which we then live FaceTimed. And you have basically real-time that you can see them on the side of the road. So it was quite something, actually	7
16	<i>Father notes mitigating impact of access to outdoors</i>	...like it didn't even feel like we were really restricted. Because, you know, we couldn't have the parents, like family or whatever, but we were allowed to take a walk. Like there's a park like at the hospital, you know. So we were allowed outside the building	13
Theme 3: Navigating increased logistical difficulties			
17	<i>Mother described increased responsibility for communications</i>	The only other thing I should highlight is like if there is only one parent there, how challenging it is for that one parent to explain the medical stuff to another parent, and like the importance of taking a moment for medical providers to be like, "Oh, is there anyone else you'd like to call before I give you this information?" Because a lot of times I felt it was up to me	9
18	<i>Mother experienced difficulty navigating virtual relationships and communication</i>	P: We just had our Facetime on for the most part. And even that... Like I get it, we need to get consent from whoever was coming into the room, "Oh, we're taking a video," or, "Oh, we're on Facetime," just to inform them that they'll be in the... Yeah I: And what was that experience like? P: It was hard. Like we could see your family crying over video. They want to be there. They want to see our son, and they couldn't	2
19	<i>Grandmother expressed difficulty accessing hygiene facilities</i>	I didn't have a room with a shower ... So I'd have to make arrangements. I had to have one of the girls, ... Home Life or something, they'd come in and sit with [grandson] and then I'd go take a shower ... You had to be escorted out of that area because we were...locked down.... Sometimes ...I'd ask in the morning, and it wouldn't be until 7:00, 8:00 at night ... if I wanted to go shower	6

Table 2 (continued)

Quote ID	Quote summaries and context	Exemplary quotations	Participant #
20	<i>Mother experienced difficulty accessing appropriate nutrition</i>	...I think it was down to one cafeteria. There were set hours. Life doesn't always work that way... But it was also like there weren't fridges that could store food. So it was not like I could bring stuff	11
21	<i>Lower accessibility of sleep facilities</i>	So I was in an office chair, a raised office chair this past time. In a previous admission, and we're going back to 2006, I think, there was like fold out couch or a recliner. So it was more apt so that you could sleep there, right	11
22	<i>Parents experienced living out of their car in the parking lot</i>	My husband and I had to take turns tag teaming. So I'd stay four hours with my son, you know, and then we'd switch, and then we'd be in the car	10
23	<i>Financial stresses, exacerbated by pandemic, worsened the experience of restrictions</i>	...it requires me to register one additional carer to stay with my daughter. By that time, it was my brother. So we were alternating. When my brother goes to work... I completely switched my schedule. I was working overnight, and my brother was working during the day... [normally] I could take time off. Unfortunately with some financial situations, I couldn't. Because other things also need to move forward at the same time	3
Theme 4: Seeking compassionate approaches within the healthcare system			
24	<i>Although stressful, father expressed that the PICU staff were caring and helpful</i>	So it's very stressful, period. However, the entire PICU staff were absolutely incredible...I cannot thank these people enough for their dedication and their professionalism. They explained things to us very clearly. They answered our questions. They addressed our concerns	14
25	<i>Mother expresses that the healthcare system seemed designed to enact barriers to families and discussion of the rules</i>	[Hospital city]'s smart, they don't actually have any of their own doctors or nurses [tell you "no"]. They just send you on this through this bureaucratic stuff. So like our doctor doesn't have any say into what's going on. And you can't even talk to anybody who does have a say. They kind of just send you through secretaries and people who there's no point getting mad at somebody who makes minimum wage, yelling at them because they're like, "Well, you can't bring your kid, and you can't bring a partner, and you can't do this."	8
26	<i>Parent appreciated being forewarned of changes to rules</i>	When they were changing the policy of two parents at bedside to one, one of the nurses that was taking care of my son, that they came to us and told us, "I don't want you to be surprised. I know you're going through a lot. And this is not official yet, but we are probably going to change from letting both of you into the PICU to just one...." And so by the time it arrived, we were not surprised and we were not upset because it caught us by surprise. But there were other changes that did	4
27	<i>Parent expressed frustration at rules that did not make sense</i>	...if you are saying if I can have my brother to come and stay with my daughter, my brother has his own bubble at work, he goes to totally different places, right. And I go to totally different places. But I can allow /sic/ to go in, and he can also come to the hospital. So to me that somehow lacked sense	3

Table 2 (continued)

Quote ID	Quote summaries and context	Exemplary quotations	Participant #
28	<i>Mother experienced emotional distress from unexpected restriction in her mobility and access to services</i>	R: And they had the name of the patient and who is going to stay with the patient. And they will put like a red magnet, a marker, and then he will go in.... And then in the morning things change I: Right R: So I tried to go out, and I can't. And I'm like, "But I'm telling you my name." They're like, "No, go back to your room and ask the nurse to request an escort." ... And then just having rules that make sense. So, for example, the changeout time for parents, like that should have been a) completely transparent because no one seemed to have an understanding of it. And b) it should be something that is actually designed around working for a family, and not just some obscure "I guess we'll pick midnight because that's the, you know, easiest calendar day that makes sense."	4
29	<i>Parent recommended that rules should be transparent, sensible, and family-centered</i>	Like I've had like 40 or 50 different nurses. So everybody's different, right. But you should have had one. I don't know, like a worker sort of thing, to me. You know, you deal with her. Here's her extension. You can ask questions. Or she comes in and goes through it with all of you And even the simple thing of just, okay, my husband and I are just making a switch just so I can spend time with my daughter. Like I had to leave my son upstairs, go downstairs because my daughter wasn't allowed in. But, you know, there were... I don't know if they'll get in trouble for it, but there were very nice nurses who allowed us to do that switch. Because my daughter was a baby... It showed what kind of nurse they are. [laughs] Because then we could tell which one we could actually, you know, get support from emotionally.... Yeah, the majority of the nurses were ... very empathetic. But at the same time, there were some who, you know, who just didn't want to listen. They just said, "Oh, yes, that's the hospital's rule. We can't do anything about it." We're like, "Okay, thanks for empathizing."	9
30	<i>Parent expressed need for consistent communication of rules</i>	I don't think I even asked because I didn't want to hear the "no". I don't want them to have to say, "No, sorry, these are the rules." Because that was for a specific palliative diagnosis	6
31	<i>Mother experienced compassion from nurses, allowing presence with both children</i>	...somebody's mental health, if that suffering, you know, you've got to...that's not easily weighed...it's the people in the room that have got to make the decisions. So if they think it's reasonable and it needs to be broken because somebody's mental health is at risk, well, who else is to say?	12
32	<i>For mother, degree of nursing empathy enforcing restrictions impacted therapeutic relationship</i>	You know, there was a point in time where, you know, with our son's initial stay, he was in a very critical state that, you know, I am certain that, you know, there was four of us at one time visiting him because we didn't... we weren't quite sure that he was going to survive. So it was important for his siblings to be there, and to spend a little bit of time just in case things didn't go in the right direction	2
33	<i>Mother experienced exceptions to restrictions as rare</i>		12
34	<i>Father expressed importance of healthcare team having rule flexibility</i>		1
35	<i>Father experienced importance of rule flexibility when worried about child's survival</i>		7

Table 2 (continued)

Quote ID	Quote summaries and context	Exemplary quotations	Participant #
36	<i>Healthcare team members built relationships through securing rule exceptions</i>	After we had been there for about three months, [daughter] ended up having like a third open heart surgery ... And then the social worker and the child life worker, they somehow struck a deal with management for us to get to bring our older daughter in once a week for an hour. So we did... And it was like really, really special. So they did go above and beyond to make that happen	9

what's going to happen" (P2). A father, who described staying with his critically ill daughter every day and switching with another family member so that he could continue to work the night shift, referred to being alone in the PICU room as "psychological torture" (Q12). Negative experiences were not universal; one parent appreciated the opportunity to process PICU admission-associated anxieties and emotions separately (P10).

Leveraging alternate supports to cope When deprived of their usual supports, participants appreciated efforts made by hospitals and professionals, particularly when they addressed emotional needs (Q13). Support needed to be spontaneously offered; participants appreciated talking to staff members but were reticent to distract from providing care to their critically ill child (Q14). The sense of isolation was also ameliorated by virtual connections and creative options, such as visits through hospital windows (Q15). To address stress and allow coping, family members noted the importance of mental health breaks and access to the outdoors (Q16), which was not universally granted.

Theme 3: Navigating increased logistical difficulties

Separating families increased the logistical stresses of a PICU admission, particularly as it related to "impaired communication" and "impaired ability to meet basic needs." This created additional challenges to meeting parents' goals, including those related to the admission itself and to maintaining function and relationships within their families.

Impaired communication RFP created novel communication challenges between family members and with healthcare professionals. While bedside participants described opportunities to participate in medical discussions, the opportunities were limited for those whose presence was restricted (Q17). The bedside caregivers often felt overwhelmed with being solely responsible for relaying information and conveying child's status. As one mother described, "...it comes at you quickly. And it's like oh, my God, how am I going to remember all this? Like, you know, how do I communicate it? My husband is like right out the window. Like that I found really frustrating" (P10). Family had to learn and coordinate virtual communication with their family members, and were stressed by managing family members' emotional reactions at a distance (Q18).

Impaired ability to meet basic needs RFP made multiple basic needs more difficult to meet, providing additional logistic challenges to a PICU admission. For example, several participants required escorts when leaving the room, limiting toileting and hygiene opportunities (Q19). Many hospitals implemented free meals for bedside caregivers;

culturally and diet-appropriate food was not always accessible (Q20). Sleep accommodations were variable and less accessible than during normal operations (Q21). One parent, who had to leave their child out of sleep deprivation because COVID-19 protocols mandated removing PICU chairs, reported the “worst feeling ever... because there is no one else who can take your spot” (P9). Three participants identified periods of living out of their car in a hospital parking lot to remain close to their child and enable caregiver switches (Q22). Restrictions, combined with lack of normal operations and resources (Q23), magnified financial stresses as families required alternate accommodations, childcare, and meals.

Participants also noted opportunities for improvement. This included improving sleep facilities, access to video calling technology, and removing requirements for bedside clinician permission for video calls with loved ones (Q18).

Theme 4: Seeking compassionate approaches within the healthcare system

Multiple participants expressed that pandemic-related rules were made bearable by the attitudes and actions of the PICU care team (Q24), particularly through pro-active, empathetic, adaptive, or advocacy-based approaches that improved family health and comfort. For others, restrictions seemed to pit the healthcare system against families (Q25). Through their descriptions we interpreted that “timely communication of restriction policies,” “empathetic approach to rule enforcement,” and using “exceptions as an important relational space with clinicians” were ways in which the rules could be adapted or implemented to support the therapeutic relationships.

Need for timely communication of restriction policies

Knowing what to expect enabled family members to better plan and ensure that their needs were met, allowing them to fulfill parental roles, and improved coping (Q26). Inflexible, rapidly changing, or inconsistent rules increased parents’ stress (Q27). One mother described how she had been coping because she had finally come to understand the rules, but a sudden rule change resulted in an emotional breakdown (Q28). Participants wanted rules that were understood by healthcare professionals, communicated as soon as possible—ideally by one consistent team member—and that made sense from a societal and epidemiologic perspective (Q27, Q29–30).

Need for empathetic approach to rule enforcement Participants valued honesty and wanted the rules enforced empathetically (Q26–27). Actions and adaptations that eased logistic burdens and supported parents in their roles,

including “bending the rules” to support family member needs, made the entire healthcare system seem empathetic. One mother described how nurses bending the rules supported her parent role, allowing her to spend time with both admitted and non-admitted children (Q31). Conversely, strict enforcement and non-empathetic communication negatively impacted therapeutic relationships including participants’ trust in certain clinicians (Q32).

Exceptions as important relational space with clinicians Participants experienced exceptions to the rules as rare, sometimes random (Q33), and an important advocacy opportunity for the healthcare team (Q34–35). One mother valued the significant work clinicians did to secure an exemption for her toddler to meet her critically unwell infant after a long admission (Q36). Participants believed exceptions to be key for PICU families, given the critical nature of their child, and wanted a nuanced approach that would take individual circumstances into consideration (Q34).

Discussion

This interpretive examination improves understanding of the family member experience with RFP implemented in Canadian PICUs, leading to insights with relevance beyond the COVID-19 pandemic. Primarily, we identified that participants encountered increased barriers to engaging in their child’s care and loss of support with heightened feelings of isolation, which was exacerbated by logistical considerations that made meeting even basic needs difficult and placed their mental and physical health at risk. Participants faced challenges to fulfilling their self-defined parental role—balancing competing responsibilities to their child, their entire family, and being part of their child’s healthcare team.

Previous research has identified that parents need unrestricted access to their child to support their primary goals during PICU admission [12, 31]. These are related to ensuring their child feels loved and ensuring their child’s health improvement, which in turn support parental self-identity as a “good parent” [10, 12]. Our results demonstrate that these goals do not change contextually, even in the face of significant restrictions that limited participants’ abilities to meet their own and their extended family’s needs and forced families to make difficult decisions about who would be present.

Parents often cope with the stress of PICU admission by “spending long periods of time at my child’s bedside” [32]. Consistent with the internal drive to be present with their child, our participants indicated significant stress with leaving, even when another family member could take their place. Adult studies during COVID-19-related restrictions demonstrated higher rates and severity of post-traumatic stress disorder in family members who were denied access

to their critically ill loved one [33]. Thus, separation from their child may be expected to worsen the high baseline risk of stress and trauma with PICU admission; future research assessing long-term mental health impacts is warranted.

Participants confirmed unequivocally that family members in PICU need support to enable coping. Forcing a family member to experience the terror of PICU admission alone is not humane (Q12) and violates the principles of family centeredness in PICU, where parents are seen as both members of the child's healthcare team and persons in need of support and care [3, 7]. Pre-pandemic studies of parental needs, stressors, and coping during a PICU admission only minimally address the need for support [9, 32]. Our work corroborates earlier COVID-19 restriction-related findings of isolation and loss of support from Bannerman's single-center [22] and our group's pan-Canadian [24] family member surveys, and provides increased context to Camporesi's findings of higher psychological distress in family members who experienced RFP compared to baseline [34]. While the simple solution would appear to be enabling both parents' bedside presence, thoughtful consideration is needed for diverse family contexts (e.g., two parents are not each other's support system, childcare issues). Further research is needed to define optimal family presence policy and practice in any context, and to explore the impact of suggested strategies to mitigate distress when RFP is necessary.

Participants described family presence-related practices that should be considered for revision in any context. Equity-based approaches included hospital-supplied communications technology [35], in-room or nearby sleep facilities [36]), and comprehensive mental health support for bedside caregivers. Clear and timely policy communication, coupled with empathetic and flexible interpretation and delivery, may demonstrate appreciation of the important role of parents and family members in a child's healthcare journey. Given the burdens imposed by RFP, the impacts of future policy and mitigating strategies should be rigorously assessed.

This work was strengthened through purposive, maximum variation sampling, Canada-wide representation, and engagement of patient and family partners throughout. Use of survey respondents, a group already keen to share their experiences, may have skewed results. Additionally, post-secondary education and high household income were overrepresented in the survey [24, 37] and may have been in this study's participants, impacting how rules were experienced and what supports were needed [38]. Although the study represented a range of experiences and individuals from across Canada, it is not possible to comment specifically on whether the themes are representative for a broad range of language, cultural, ethnic, gender, and sexual backgrounds, or an international context. Finally, the lapse of 4 to 18 months from admission to the study raises the potential for recall bias.

Conclusions

RFP increased the barriers to family members of critically ill children in meeting their goals and needs. While appreciating RFP's attendance to safety, most participants experienced RFP as challenging to their primary caregiving role, basic human needs, and emotional and/or mental wellbeing, and required greater collaboration and thoughtfulness from the healthcare system. Bedside clinicians may remove such barriers through developing an empathetic understanding to allow individualized care and support for families' needs. Policy-makers should consider these findings in the context of diverse family backgrounds and needs to enable strategic decisions around future policies and exceptions. These measures should be a legacy from the diverse and challenging experience of RFP during the COVID-19 pandemic.

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Authors' contributions J.F., L.L., and D.G. conceived the study; all authors designed the study. M.R. acquired the data and, with J.F., managed it. M.R. A.A., J.F., L.L., M.W., C.S., and N.M. were responsible for data analysis and all authors interpreted the data. J.F. wrote the first draft of the manuscript which was edited and revised by M.J. and L.L. All authors provided critical feedback on the manuscript, and then read and approved the final manuscript.

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Data availability The datasets generated and analyzed during the current study are not publicly available to maintain participant anonymity and prevent deductive disclosure. Reasonable requests for specific coding queries may be made of the corresponding author.

Declarations

Ethics approval and consent to participate This study received ethics approval from IWK Health (REB#1026029). All research participants provided informed consent prior to participation in the study. Consent was reconfirmed at each opportunity for participant interfacing.

Consent for publication Informed consent included consent to publish non-identifying and aggregate data, including quotations.

Competing interests Neda Moghadam discloses that she is the co-chair of the Family Leadership Council of IWK Health. All other authors declare that they have no competing interests as defined by Springer, or other interests that might be perceived to influence the results and/or discussion reported in this paper.

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