

“We Aren’t Meant to Go Through the Hardest Parts of Our Lives Alone”: Family Experience With Restricted PICU Presence During the COVID-19 Pandemic

CONTEXT: PICUs across Canada restricted family presence (RFP) in response to the COVID-19 pandemic from allowing two or more family members to often only one family member at the bedside. The objective of this study was to describe the experiences and impact of RFP on families of critically ill children to inform future policy and practice.

HYPOTHESIS: RFP policies negatively impacted families of PICU patients and caused moral distress.

METHODS AND MODELS: National, cross-sectional, online, self-administered survey. Family members of children admitted to a Canadian PICU between March 2020 and February 2021 were invited to complete the survey. RFP-attributable distress was measured with a modified distress thermometer (0–10). Closed-ended questions were reported with descriptive statistics and multivariable linear regression assessed factors associated with RFP-attributable distress. Open-ended questions were analyzed using inductive content analysis.

RESULTS: Of 250 respondents who experienced RFP, 124 (49.6%) were restricted to one family member at the bedside. The median amount of distress that families attributed to RFP policies was 6 (range: 0–10). Families described isolation, removal of supports, and perception of trauma related to RFP. Most families (183, 73.2%) felt that policies were enforced in a way that made them feel valued by PICU clinicians, which was associated with less RFP-attributable distress. Differential impact was seen where families with lower household income indicated higher RFP-attributable distress score (2.35; 95% CI, 0.53–4.17; $p = 0.03$). Most respondents suggested that future policies should allow at least two family members at the bedside.

INTERPRETATIONS AND CONCLUSIONS: Families of children admitted to PICUs during the COVID-19 pandemic described increased distress, trauma, and removal of supports due to RFP policies. Vulnerable families showed an increased odds of higher distress. Healthcare professionals played an important role in mitigating distress. Allowance of at least two family members at the bedside should be considered for future policy.

KEYWORDS: COVID-19; family; intensive care units; organizational policy; pediatrics

Hospitals worldwide restricted family presence (RFP) in response to the rapidly evolving COVID-19 pandemic and to protect patients and healthcare professionals (1). Highly restrictive adult ICU policies resulted in family member stress, post-traumatic distress, impaired communication, and weakened therapeutic relationships (2–4). Most Canadian PICUs restricted to one family member at the bedside, limited trading places between

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KEY POINTS

Questions: How have restricted family presence policies impacted families of critically ill children?

Findings: In this national, cross-sectional, online, self-administrated survey, restricted family presence in Canadian PICUs was associated with family distress, isolation, and loneliness.

Meaning: Although restricted presence policies in Canadian PICUs during COVID-19 pandemic increased family distress and trauma, and removed family support systems, PICU healthcare providers played an important role in mitigating family stress.

family members, and limited movement within hospitals (5). These restrictions raised serious ethical concerns and threatened well established family-centered care (FCC) practices prevalent in most PICUs (6–9). PICU FCC is rooted in evidence that family presence facilitates realization of parental identity as “good parents” allowing empowerment of family members while mitigating some of their trauma and distress (10–16).

Understanding the experiences and impact of RFP policies on families of critically ill children is essential for informing future policies. These policies were rapidly adopted with minimal evidence base and an absence of involvement of patients, families, and frontline clinicians in the decision-making process. This was evident through the evolution of recommendations from national organizations (i.e., Centers for Disease Control and Prevention, Health Canada) as the pandemic progressed and a better understanding of disease transmission and the negative consequences of restricted visitation were appreciated. This rapid uninformed initial decision making, underscores the need for documenting the impacts of these policies on families of critically ill children (5). In two small single-center surveys, PICU parents reported a “lack of support,” a “sense of isolation” (17) and increased stress (18). However, the broader experience of PICU families across multiple centers remains unexplored. The objective of this study was to describe the experiences and impact of RFP on families of children admitted to Canadian PICUs during the first year of the COVID-19 pandemic.

METHODS

Design and Ethical Implications

We conducted an online, self-administered, cross-sectional survey in English and French. The IWK Research Ethics Board (REB) (Study Identification: 1026029) approved the study “Restricted Family Presence in the PICU during the COVID-19 Pandemic: Family Impact” on September 2, 2020. The REBs of each participating PICU approved contact for recruitment. Upon accessing the survey, participants received a letter of information that proceeding constituted consent to participate. Study procedures were followed in accordance with the ethical standards of the REB, and the Helsinki Declaration of 1975. The survey was voluntary, anonymous, and unincentivized. No identifiable information was collected.

Setting and Sample

For this study, voluntary sampling was used. Family members of children admitted to Canadian PICUs from March 2020 to February 2021 were invited to participate through active recruitment from participating PICUs and public advertisement. Active recruitment occurred in 11 PICUs for patients who were admitted during four-month periods: March 2020 to June 2020 (wave 1 of COVID-19 pandemic) and/or November 2020 to February 2021 (wave 2 of COVID-19 pandemic). These time periods were determined based on the local REB approval at each site and times of known restricted visitation. Active recruitment methods included postal, e-mail, text, poster, telephone, and social media invitation templates (**Supplemental File 1**, <http://links.lww.com/CCX/B262>). Each site used the recruitment method most suitable to their site and whether the family was bereaved or not, this is further described by Ryan et al (19). Public advertisement occurred through Twitter feeds of research teams and the website of the Maternal Infant Child and Youth Research Network (Canada) and was publicly available from October 2020 to September 2021 (20).

Measures

Our study team of multiprofessional PICU clinicians, PICU/hospital leaders, and family and patient

partners, developed the questionnaire utilizing the methodology described by Burns et al (21). Items were generated through interviews with a PICU social worker, intensivist, and PICU family member; and brainstorming amongst our study team. Items were grouped into four key domains: 1) understanding and experiences with RFP; 2) distress, impact, and coping; 3) medical information sharing and technology; and 4) recommendations for future policy. We adapted the moral distress thermometer, a validated scale (0–10) measuring situation-specific distress, to assess RFP-attributable distress (22). Initial pretesting was completed by three parents of children previously admitted to one of three Canadian PICUs (each parent from a different PICU), the Family councils at two separate Canadian PICUs, the First Nation's Council (two members affiliated with a Canadian Children's Hospital), and three PICU clinicians each from a different Canadian Children's Hospital (intensivist, nurse, social worker). Written and verbal feedback was obtained both broadly and for specific questions by all pretesters. Following initial pretesting items were generated, revised, and or removed. The survey was then pilot tested for flow and readability by three different family members of children previously admitted to one of two Canadian PICUs as well as a patient and family feedback coordinator. Written and verbal feedback was incorporated resulting in the final instrument. Items were not randomized or alternated. The final instrument, which included a maximum of nine pages, 57 closed- and open-ended questions (1–14 questions per page), and branching logic, was translated into French and administered via QualtricsXM (Qualtrics, Provo, UT) (**Supplemental File 2**, <http://links.lww.com/CCX/B262>) Respondents could change answers using a back button. Completeness checks were not performed, and atypical time stamps were not used to determine eligibility. As multiple family members were invited to complete the survey, and likely used the same device, log file analysis was not used to eliminate multiple entries per device. Unique visitors were defined as each individual who accessed the survey. We followed the CHECKlist for Reporting Results of Internet E-Surveys (CHERRIES) (**Supplemental File 3**, <http://links.lww.com/CCX/B262>) and the Checklist for Reporting of Survey Studies (**Supplemental File 4**, <http://links.lww.com/CCX/B262>) (23, 24).

Data Analysis

Due to minimal missing responses, statistical correction was not used and the denominator represents the number of responses received for each item. While we recognize that the sample might not be representative of all PICU families, we did not use any methods to adjust for the potential nonrepresentativeness of the sample. Nominal variables are reported as frequencies and percentages (n [%]). For infrequently selected responses, grouping was completed by consensus of four team members (L.A.L., J.R.F., D.N., M.J.R.). Ordinal or skewed continuous variables are reported as median (minimum–maximum), and normally distributed variables as mean and SD. We used multivariable linear regression to identify factors associated with RFP-attributable distress. Variables were determined a priori through literature and investigator discussion and grouped into respondent and policy. Variables with greater than 10% missing values were excluded (25). All assumptions of linear regression were met. A two-sided p value of 0.05 was considered statistically significant. Analysis was completed in Stata Statistical Software: Release 16 (StataCorp, LLC, College Station, TX, 2021).

Open-ended questions were analyzed utilizing inductive content analysis by experienced team members (D.N., M.J.R.) (26). Preliminary analysis of open-ended responses began with familiarization through data immersion. Responses were read multiple times and annotated to achieve familiarity with data. The coding framework was developed through data immersion, and regular dialogue between research team members. Discussions within the research team ensured verification and reflexivity of the coding process. All experience-related open-ended questions were analyzed together. Policy recommendation questions were analyzed separately. Frequencies of codes are described in absolute number of respondents (n/N).

RESULTS

The survey was sent directly to the families of 1005 patients admitted to 11 participating Canadian PICUs representing all regions of Canada (**Table 1**). Given online advertising, it is not possible to estimate a response rate. The survey was accessed and completed by 270 individuals. As per CHERRIES, the participation

TABLE 1.
Characteristics of Survey Respondents and the Child's PICU Admission

Respondent Characteristics	<i>n</i> (%)
Respondent age (<i>n</i> = 243), yr, mean (SD)	38.8 (8.43)
Relationship to the child (<i>n</i> = 250)	
Maternal-like role (e.g., mother, grandmother, foster mother)	210 (84.0)
Paternal-like role (e.g., father, step-father)	29 (15.6)
Other	1 (0.4)
Language most often spoken at home (<i>n</i> = 249) ^a	
English	226 (90.8)
French	10 (4.0)
Other	19 (7.6)
Self-identified ethnic/cultural group(s) (<i>n</i> = 245) ^a	
Indigenous (First Nations, Inuit, Metis)	20 (8.2)
Other North American origins	138 (56.3)
British Isles origins	44 (18.0)
European origins	56 (22.9)
South Asian origins	10 (4.1)
East and Southeast Asian origins	18 (7.3)
Other (Latin, Central, and South American origins; Central and West African origins; North African origins; South and East African origins; West Central Asian and Middle Eastern origins; Oceania and Pacific Islands origins)	15 (6.1)
Prefer not to answer	10 (4.1)
Average gross household annual income (<i>n</i> = 249)	
0–50k	40 (16.1)
50–100k	79 (31.7)
More than 100k	97 (39.0)
Prefer not to answer	33 (13.3)
Respondent's highest completed educational level (<i>n</i> = 249)	
High school diploma or less	19 (7.6)
Some college or university courses	35 (14.1)
College, trade school, or undergraduate university degree	149 (59.8)
Post-graduate degree (e.g., Master/Doctoral) or a professional degree (e.g., Medical Doctor)	46 (18.5)
Respondent relationship status (<i>n</i> = 247)	
In a relationship with the other parent	205 (83.0)
In a relationship, not with the other parent	42 (17.0)
Divorced/separated	14 (5.7)
Single	21 (8.5)

(Continued)

TABLE 1. (Continued)
Characteristics of Survey Respondents and the Child's PICU Admission

Admission Characteristics	n (%)
PICU location (n = 250)	
Atlantic Canada	25 (10.0)
Quebec	9 (3.6)
Ontario	76 (30.4)
Prairies	57 (22.8)
British Columbia	83 (33.2)
PICU admission era (n = 249) ^b	
Pre-March 2020	14 (5.6)
March 1, 2020, to June 30, 2020	174 (69.9)
July 1, 2020, to October 31, 2020	15 (6.0)
November 1, 2020, to onward	67 (26.9)
Intubated (n = 249)	115 (46.2)
First admission to the PICU (n = 249)	186 (74.7)
Child suspected to be COVID-19 positive (n = 250)	35 (14.0)
Child COVID-19 positive (n = 250)	3 (1.2)
Age of the child when admitted to the PICU (n = 249)	
Birth to < 1 mo	23 (9.2)
1 mo to < 1 yr	65 (26.1)
1–4 yr	38 (15.3)
5–11 yr	48 (19.3)
12–18 yr	73 (29.3)
More than 18 yr	2 (0.8)
Had to travel more than 100 km (n = 222)	87 (34.9)
Other children < 12 yr old at home (n = 222)	105 (47.3)
Respondents bedside presence (n = 222)	
Spent more time than any other caregiver	172 (68.8)
Evenly shared time with other caregiver	64 (25.6)
Limited presence (was unable to spend time, spent a small amount of time, or spent less time at bedside than other caregiver)	14 (5.6)

^aRespondents were able to select more than one option.

^bTotals may be over 100% due to multiple PICU admissions.

rate was 0.99, and the completion rate was 0.94 (Supplemental File 3, <http://links.lww.com/CCX/B262>) (23). Of 270 respondents, 250 indicated admission during RFP and were included in our analysis. We received responses from all 11 participating PICUs. Most respondents experienced RFP between March 2020 and June 2020 (174, 69.9%), 210 (84%) identified as a maternal like role (i.e., mother, step-mother, foster mother, grandmother, or aunt). Household income

was over \$100,000 Canadian Dollars for 97 (39% of respondents). Further demographics are outlined in Table 1.

Experiences With RFP

Half of respondents (124, 49.8%) experienced restriction to one family member. A requirement to stay in their child's room was experienced by 114 of

233 (48.9%), and 61 of 237 (25.8%) described restrictions to leaving the hospital (**Supplemental File 5**, <http://links.lww.com/CCX/B262>). Most respondents (165, 66.0%) were unsure about processes to request

exceptions (e.g., an increase in number of visitors, or an allowance for siblings) to RFP policies. Ninety-four (37.9%) felt they had needed an exception, 37 (40.7%) of whom had one granted (**Table 2**).

TABLE 2.
Description and Experience of Restricted Family Presence Policies by Respondents

Rules and Application of RFP Policy	n (%)
Number of family members allowed at the PICU bedside at any one time? (n = 249)	
0	9 (3.6)
1	124 (49.8)
2 or more	116 (46.6)
Switching between caregivers was allowed (n = 241)	172 (71.4)
RFP rules were consistent between days, shifts, and patients (n = 250)	197 (78.8)
Hospital or PICU changed the RFP rules during the child's PICU admission (n = 248)	63 (25.4)
Hospital team explained why RFP policies were necessary (n = 237)	
Agree	177 (74.7)
Disagree	28 (11.8)
Neutral	32 (13.5)
Experience With the Rules	n (%)
RFP policies treated me as (n = 250)	
A visitor	45 (18.0)
A member of child's care team	124 (49.6)
A bit of both	81 (32.4)
PICU team treated me as (n = 249)	
A visitor	15 (6.0)
A member of child's care team	155 (62.2)
A bit of both	79 (31.7)
Hospital administrators/managers treated me as (n = 148)	
A visitor	18 (12.2)
A member of child's care team	89 (60.1)
A bit of both	41 (27.7)
The policies were enforced in a way that made me feel respected and valued (n = 243)	183 (75.3)
Exceptions	n (%)
Was there a process for requesting exception to the RFP policies? (n = 250)	
Yes	39 (15.6)
No	46 (18.4)
Unsure	165 (66.0)
Family felt that they needed exception to RFP rules (n = 248)	94 (37.9)
PICU care providers listened to the concerns about exception (n = 91)	60 (65.9)
Caregivers had a chance to talk to a hospital leader/manager about the exception (n = 93)	93 (48.4)
Exception was granted (n = 91)	37 (40.7)

RFP = restricted family presence.

Although 126 respondents (50.4%) felt the RFP policies treated them either fully or partially like a visitor, rather than a member of the care team, most (183, 75.3%) felt valued and respected by the way policies were enforced, and perceived inclusion as a member of the care team by PICU clinicians (155, 62.2%) (Table 2).

Distress, Impact, Coping

Respondents reported a median (minimum–maximum) RFP-attributable distress score of 6 (0–10) (Fig. 1). In multivariable linear regression of respondent factors, having an intubated child and identifying as a paternal-like role were associated with a 0.99 (95% CI, 0.19–1.79;

$p = 0.016$) and 2.07 (95% CI, 0.92–3.23; $p \leq 0.001$) lower score, respectively. Increasing income was also associated with an absolute decrease in RFP-attributable distress with those making greater than \$100,000 having a 2.74 (95% CI, 1.37–4.11; $p = 0.001$) lower score than those making less than \$50,000. Being less present at the bedside was associated with a 2.35 (95% CI, 0.53–4.17; $p = 0.03$) higher RFP-attributable distress score. COVID suspected or confirmed, first PICU admission, child's age, multichild family, and marital status were not significantly associated with RFP attributable distress score. In multivariable regression of policy related factors, inconsistent provision of food (1.63; 95% CI, 0.60–2.66; $p = 0.007$) was associated with higher scores, while agreeing that policies were enforced in a way that made families

feel valued was associated with a lower RFP attributable distress score (–2.52; 95% CI, –4.15 to –0.89; $p = 0.002$). Number allowed at the bedside, allowance for switching, awareness of exceptions, ability to leave the hospital, place to sleep, invitation to rounds, explanation of policy rationale, understandability and consistency of policies, and policy valuing of family were not significantly associated with RFP attributable distress (Supplemental File 6, <http://links.lww.com/CCX/B262>).

When informed about RFP policies, participants ($n = 227$) reported negative emotional responses (113/227) such as feeling “anxious, worried, sad, disappointed” (Fam-012; Q28), neutral responses (61/227) such as “fine with it” (Fam-037; Q28), and acceptance (58/227) that they “...understood the reasoning behind the policies” (Fam-030; Q28).

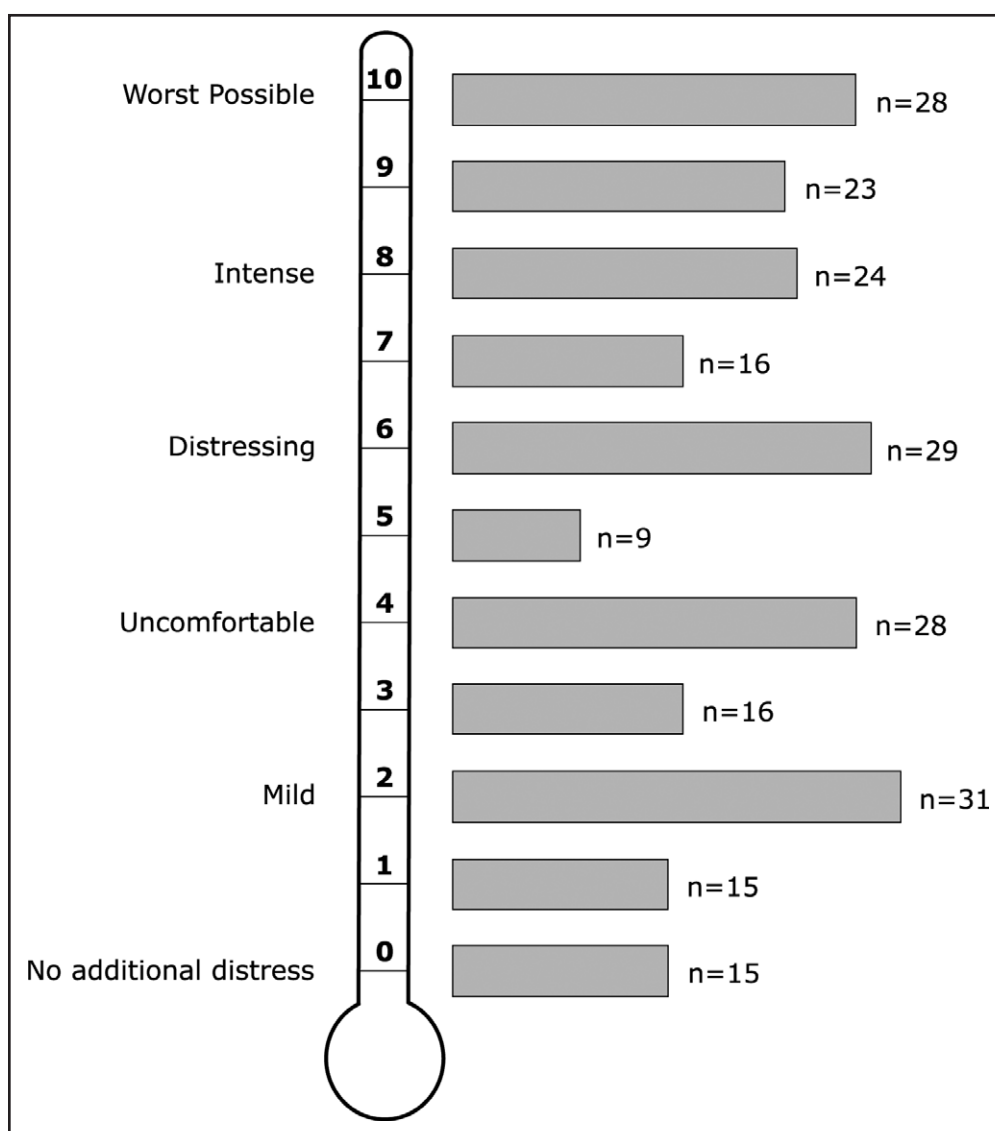


Figure 1. Level of increased distress reported by family members of children admitted to a Canadian PICU experienced due to restricted family presence policies ($n = 234$).

Many respondents (178/238) wanted the presence of someone who was restricted by RFP, including the child's siblings (79/172), grandparents (65/172), other parent (57/172), parent's siblings (22/172), extended family (13/172), or friends (4/172). Respondents described trauma during stressful experiences (e.g., providing consent, receiving medical/diagnostic information, death) both when they were alone at the bedside or restricted from the bedside (**Supplemental File 7**, <http://links.lww.com/CCX/B262>).

Reported impacts of RFP were positive and negative. The most reported negative impacts were lack of support (87/207), and family separation (87/207). Families described this as: "traumatic," "isolating," "sickening," "inhumane," "excruciating," and "unbearable" (**Supplemental File 8**, <http://links.lww.com/CCX/B262>). Five respondents described unique challenges for nontraditional families, such as divorced parents, and families with more than two primary caregivers.

Respondents described short- and long-term consequences: "the restrictions caused her [patient] to miss out on time with her daddy in her final weeks here on earth. I can't put into words what a huge deal this is" (Fam-238; Q50). Frequently, family members neglected their own needs to avoid leaving their child alone (25/207), and some (14/207) felt RFP decreased their ability to support and advocate for their child: "Baby would have had a stronger advocate, a calmer support ... She would likely have a mother with better mental health today who is better prepared to face ongoing medical challenges" (Fam-210; Q50). Positive impacts included not having to deal with stressful visitors or denying visitation (30/207): "We didn't have the distraction of extended family ... and did not have to be the 'bad guys' telling them they couldn't come in" (Fam-078; Q51), feeling safe (23/207): "I felt much safer with a minimum amount of people in regards to germs..." (Fam-225; Q51) and calmer PICU environment (9/207) (**Table 3**; and **Supplemental File 8**, <http://links.lww.com/CCX/B262>).

When asked how RFP affected their children, many (91/207) respondents indicated minimal or no perceived impact. Others (55/207) felt absence of close family and friends negatively affected children, with 20/207 describing their child's experience of RFP as traumatic (**Table 3**; and **Supplemental File 6**, <http://links.lww.com/CCX/B262>).

The most frequently selected coping mechanism was holding/talking with their child (175/244, 71.7%). Respondents also reported substance use: alcohol (5/244, 2.0%), cigarettes (13/244, 5.3%) and marijuana (4/244, 1.6%) (**Supplemental File 9**, <http://links.lww.com/CCX/B262>).

Communication and Medical Information Sharing

When asked how RFP impacted medical information sharing, 194 respondents (84.7%) reported being able to attend medical rounds in person, whereas 58 (26.4%) did not receive medical information unless the parent was present at the bedside. Negative RFP-related interactions with the clinical team were described by 14 of 207, and 13 of 207 found it stressful to manage medical information alone (**Supplemental Files 8 and 9**, <http://links.lww.com/CCX/B262>). Internet was acceptable/good/excellent for 79.4% of respondents.

Future Policy Recommendations

Ten themes emerged from open-ended questions for future family presence policies (**Table 4**). Most respondents addressed the number present at the bedside (145/195), with 91 indicating two family members should always be allowed. In considering implementation, respondents emphasized provisions for meeting basic needs (53/145), adequate family support (52/145), and clear communication (16/145) (**Table 4**).

Respondents identified patient condition (52/206), end of life (43/206), unique family situations (e.g., mental health issues) (31/206), and length of stay (10/206) as criteria for RFP exceptions. Twenty-two respondents felt that exceptions should be granted on a case-by-case basis (**Table 4**).

DISCUSSION

We present the first multicenter description of the experiences and impact of RFP on family members of critically ill children during the COVID-19 pandemic. We found that RFP increased distress associated with a child's PICU admission, primarily through removing supports and separating families. While unsurprising, these results document the important impacts of RFP policies on families of children admitted to Canadian PICUs and are essential in informing future family

TABLE 3.

Qualitative Themes Generated From Open-Ended Questions Where Family Members of Critically Ill Children Described the Impact of Restricted Family Presence Policies on Themselves, Their Family Members and Their Child ($n = 207$)^a

Theme	Code	Frequencies
Negative impacts of RFP policies		
Difficulty coping alone	Lack of support	87
	Being alone	23
	Managing medical information alone	13
	Communication with other caregiver	10
Separating families	Being kept apart	87
	Deciding who will stay with child	7
	Nontraditional families	5
Restricted access to basic needs	Access to food, drinks, or place to eat	31
	Amenities for sleep	11
	Access to toilet, showers, laundry	16
	Unable to take breaks	8
	Financial burden	8
	Family medical and self care	5
	Lack of privacy	4
	Arranging childcare	4
	Challenges to the "good parent" role	Not wanting to leave child alone
Inability to fulfill the parent role due to RFP policies		14
Communication with clinical team	Negative interactions with clinical team	14
	Unclear/inconsistent rules	14
No impact of RFP policies		4
Positive impacts RFP policies		
Decreased stress and distraction by visitors	No stressful visitors	30
	Parent able to focus on child	9
Feeling safe		23
PICU was calmer		9
Provisions made for basic needs	Access to food	7
	Amenities to sleep	1
Personal growth from the challenges of RFP policies		4
Respondents' view on impact of RFP policies on the child		
Minimal or no perceived impact/unable to assess	Minimal or no perceived impact	91
	Unable to assess	5
Negative impact	Missing family members	55
	Traumatic and stressful experience	20
	Slower recovery	2
Positive impact	One on one time with parent	3
	Less pressure on the child	2

RFP = restricted family presence.

^aContent analysis of all open-ended questions together utilizing the question to contextualize the answers.

Supporting quotes available in Supplemental File 3 (<http://links.lww.com/CCX/B262>).

TABLE 4.
Future Policy Recommendations for Restricted Family Presence Policies From Family Members of Children Admitted to a Canadian PICU During a Period of Restricted Family Presence (n = 217)

Important Elements of a Family Presence Policy	Example Quote
1) Allow at least two caregivers minimum to be present at the same time	“[In the future], they should do everything possible to allow two caregivers at all times and the rules should be made to reflect/enable that.” (Fam-011, Translated from French, MR)
2) Instead of a one-size-fits-all approach, design policies with compassion for family’s unique needs and sufficient flexibility to respond to these needs as they arise	“Make sure you address the family’s unique situation before enforcing broad policies for every family.” (Fam-166) “Allow as much flexibility as possible to caregivers.” (Fam-042)
3) Develop evidence-informed policies to keep everyone involved safe. If evidence suggests limiting family presence is necessary, provide clear rationale as to why	“The health and safety of the patients. Parents or legal guardians and the staff. Nothing else matters.” (Fam-242) “Any restrictions on families should be reasonable and evidence based. I can understand the need to restrict large family gatherings at the child’s bedside but I don’t believe restrictions on immediate household family members outside those restrictions that are typical in a PICU are appropriate without an incredibly good reason.” (Fam-065)
4) If limiting bedside presence, allow caregivers to switch in and out of the PICU at a time and frequency that works best for them	“Allowing ‘tag out’ at least once per day was absolutely critical to our physical and mental health during that time and should be the minimum standard.” (Fam-135) “24 hours in between was hard and left our daughter alone some nights. 12 hours would be better.” (Fam-053)
5) Increase use of screening, vaccine requirements, rapid-testing, and Personal protective equipment rather than limiting family presence	“I liked it how it was but would love the addition on rapid testing for family members who want to visit. If I can get a 15-min test to travel to Hawaii. I’d love to have the same luxury for a visit with family during our hospital stay.” (Fam-185) “100% access through better management of visits with supervised entry/exit and hospital supplied and effective Personal protective equipment. Spare no expense. It’s that important.” (Fam-243)
6) Consider impact infection control restrictions may have on caregiver’s ability to access basic needs and have sufficient supports in place to ensure their needs are met in a compassionate, dignified, and efficient manner	“Parents need to have their basic personal needs met (i.e., food and access to shower). It can be dehumanizing enough to have to sleep on a chair in a PICU room with no privacy and staff watching you - not even being able to shower or eat made me feel like a prisoner. The time taken to shower and get dressed is personal care for me. Allow[ed] me to think and process what my child is facing. It made my stress increase +++ to never be alone for 3 days and to not even be able to eat - embarrassing to constantly have to ask for food.” (Fam-074)
7) Need clear, consistent communication of policies at all levels to ensure families are aware of policies, policy changes, and exception processes as early as possible	“Communicate clearly all of the rules as early and as frequent as possible.” (Fam-073) “Having cohesive guidelines for staff to relay families. [It] reflects poorly on the hospital when their own staff doesn’t understand their protocols.” (Fam-208)
8) Exceptions to restricted family presence policies are necessary, especially for end of life	“If the child was fatal - then family should be able to come say their goodbyes” (Fam-076)
9) Exceptions should be granted on a case-by-case basis, primarily based on patient, as well as key moments in time and family needs	“Provide mechanisms for parents to request special allowance on a case-by-case situation rather than a blanket refusal.” (Fam-040) “Any time when decisions need to be made that have to be discussed.” (Fam-109)

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presence policies both during public health emergencies as well as more typical periods.

Our results support those of small, single-center PICU studies of family experiences which identified themes of distress, isolation, and loneliness (17, 18), and the experience of families across pediatric hospitals (27). One small single-center study did not report a difference in distress scores between families pre- and post-RFP; however, only five participants experienced restriction to one family member (27). Our findings were also consistent with the experiences described in the adult and neonatal literature, where more than half experienced restriction to one family member and lack of support and isolation increased distress and trauma for family members. Contrary to adult ICU literature, communication challenges were not a significant issue for our respondents. This is likely related to the presence of at least one family member, and the continued values of FCC employed by PICU clinicians. It is important to note that 26% of respondents did not receive communication when not at the bedside, highlighting reliance on family presence for adequate communication.

Both family members who were alone at, and those restricted from the bedside, perceived traumatic impacts from managing their emotions and fears alone. The risk of post-traumatic stress for family members of children admitted to the PICU is well described (28, 29). Removal of support systems, such as other family members, and resultant isolation potentially exacerbated this already-prevalent PICU morbidity. Separation from a critically ill loved one may have also increased stress and trauma, as it did among family members of adult critically ill patients restricted from the bedside during COVID-19 (3, 30). While family members report many positive coping mechanisms, such as holding their child and talking with family and friends, almost 10% reported substance use to cope, and 16% reported not coping well. Allowance of one family member may be viewed as an improvement over the fully restrictive adult ICU policies; however, we found that restriction to one caregiver left family members alone to cope with the traumatic PICU experience. Families clearly identified the number of individuals allowed at the bedside as a key policy element, as restriction to one caregiver removed support and coping mechanisms. Where bedside presence was limited to a single caregiver, multiple family members

described choosing their child's need for a family member's presence over their own basic needs (including to eat, shower, or take a break). Future policies should carefully weigh the infectious risks of allowing the presence of a second family member, with risks of physically isolating caregivers from their support systems.

Our results highlighted differential impacts of RFP policies. Lower household income was associated with higher distress scores, which is consistent with studies of general PICU stress (31). Several families identified specific difficulties for nontraditional families in which, even when two caregivers were at the bedside, they were not each other's source of support. Particular attention must be given in policy design for nontraditional and vulnerable populations within the PICU, to ensure they do not suffer disproportionate negative impact of such policies.

Despite the distress associated with RFP, most family members felt that the manner of enforcement demonstrated respect for family and valued them as members of the child's care team. Similarly, feeling valued as part of the care team during enforcement of policies was associated with lower RFP-attributable distress. This is consistent with the findings by Wray et al (18) and broader PICU literature highlighting the importance of a supportive relationship with PICU healthcare professionals in managing PICU stress (32–35). Thus supports for frontline staff are a necessary component of future policy.

Families identified not having to manage stressful visitors as a positive effect of RFP. This too should be considered in future policy design. Clear separation of family presence from visitation may ensure that open visitation does not burden the family without restricting family presence. Engagement of family stakeholders in policy development is key in ensuring this balance is achieved.

Finally, consistent with other reports of low rates of understanding of RFP policies (36), we noted important discrepancies between actual and perceived policy. For example, 3.6% of respondents indicated that no family members were permitted at the bedside (all Canadian PICUs enabled at least one parent) (5), and 66% were unaware of the possibility of or process for requesting exceptions (all Canadian PICUs granted exceptions) (5). Misunderstandings may increase distress of family members and create a potential for differential access

to exceptions based on family's ability to understand and advocate. Families in our study identified clear and consistent messages as key to effective operationalization of family presence.

This study is strengthened by the utilization of open- and closed-ended questions, rigorous survey development and national representation with respondents whose children were admitted to 11 of 19 Canadian PICUs, from culturally and geographically diverse regions of Canada. Our study was limited by a low response rate. With 270 respondents of the 1005 who were directly invited, and an unknown amount who viewed the social media advertisements, our response rate is at best 26.8%. However, this is aligned with similar family experience studies, with postdischarge response rates of 15–25% for PICUs, and 20–36% for ICUs (37, 38). Furthermore, the survey was available in French and English only, limiting participation to Canadians fluent in one of the official languages. Survey respondents may not be representative of the general PICU population, as the reported household income was higher than the national median (\$73,000) (39). Similar to the majority of PICU literature (40), most respondents identified as female. Our survey was unlimited within family groups, potentially resulting in more homogeneous representation of experiences, and conformity bias whereby respondent views were influenced by other family members. Finally, we assumed that having a critically ill child in the PICU would be the primary factor contributing to distress and did not feel that broad measures of distress would be valid. Thus, we modified a validated instrument to assess RFP-attributable distress. Although the tool has not been validated for this use, we corroborated the distress thermometer findings with family member reporting and narrative descriptions of attributable trauma and distress, suggesting construct validity.

CONCLUSIONS

Family members described increased distress and trauma related to RFP, largely attributable to the removal of supports, isolation, and separation of families. Future family presence policies must be informed by the adverse effects family members experienced during COVID-19-implemented RFP, and evidence of differential effects on vulnerable families. Our findings

suggest the most important consideration should be allowing at least two family members at the bedside. Given their importance in mitigating the negative effects of RFP, the PICU team must be supported in their essential role in ensuring maintenance of FCC.

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