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Identifying parent anxiety and family distress of critically ill children in response to changes in hospital visitation policies during the COVID-19 pandemic

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ABSTRACT

Purpose: This research study describes parent anxiety and family distress among three study groups of varying restrictions in parent presence for children in the PICU during a pandemic.

Design and methods: A retrospective study was conducted to describe differences in parent anxiety and family distress for parents of children hospitalized before and during the COVID-19 pandemic. Participants fell into three study groups based on the dates of the child's hospital stay and the level of parent and family presence or restriction they experienced. Participants were asked to complete a survey that included basic demographic information along with utilization of the GAD-7 and FDI measures. The data were assessed using descriptive statistics, Fisher's exact test, and the Kruskal-Wallis test.

Results: A total of 82 parents of children hospitalized during the specified times in the PICU participated. There was a statistically significant difference among the three cohorts in diagnoses (respiratory, cardiovascular, and medical-surgical), $p \leq 0.001$. A larger percentage of children of the study participants were hospitalized with respiratory illnesses (62.5%) in the unrestricted study group when compared to the other study groups with higher patient acuity. There was also a statistical significance among the three study groups regarding whether the second parent was able to visit the child during the PICU admission ($p = 0.007$).

Conclusions: Our study suggests that restricting parent and visitor presence does not increase parent anxiety or family distress during a child's admission to the PICU. The literature widely supports that having a critically ill child is undoubtedly stressful for parents and families, but the most significant causation for the anxiety and stress remains unknown and is likely multifactorial.

Clinical and research implications: Parents who experienced rigid restrictions in parent and visitor presence did not have increased anxiety. Other impactful variables such as a child's mortality risk and the uncertainty of outcome may have impacted anxiety for parents whose children were critically ill. Further research is needed to understand which stressors are most significant, during a critically ill child's hospitalization, from a parent's perspective. Limiting staff and patient exposure to persons who may have contagious illness (restricting parent and family presence) may not in itself lead to increased anxiety and distress for parents and families. This study may provide context for careful development of hospital visitation policies to ensure balance between patient and family centered care and protection from infectious disease.

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Background

A child's admission to a pediatric intensive care unit (PICU) is one of the most stressful and anxiety-provoking situations that parents, and

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families can endure (Jee et al., 2012). Parents describe the PICU environment as unfamiliar, loud, confusing, unpredictable, and emotional (Alzawad et al., 2020). Parent and family routines are dramatically disrupted during a child's PICU hospitalization, further contributing to parent stress (Kirschbaum, 1990).

Parents of critically ill children report feeling stressed and uncomfortable about the inability to participate in their child's care. This loss of control increases parent anxiety and stress as well as feelings of hopelessness and helplessness (Dahav & Sjostrom-Strand, 2018; Simeone et al., 2018). Additional parent stressors include limited access to medical information, uncertainty of the child's prognosis, and leaving the hospitalized child (Kirschbaum, 1990). Parents report that unrestricted access to their critically ill child helps them better understand the treatment plan and options for care, feel more confident in healthcare staff, and alleviates stress and anxiety (Dahav & Sjostrom-Strand, 2018; Simeone et al., 2018; Sood et al., 2018).

In 2020, healthcare institutions throughout the world struggled to care for unprecedented numbers of patients afflicted with COVID-19. While most children were spared significant illness, pediatric hospitals around the world found themselves adapting to accommodate adult patients or shifting personnel to assist in overwhelmed adult units. The desire to protect vulnerable staff and patients by limiting spread of the virus prompted abrupt changes in visitor policies in both adult and pediatric hospitals (Hugelius et al., 2021). For patients of children admitted to the PICU, the already-stressful circumstances surrounding ICU admission were compounded by checkpoints and restricted parent presence.

In our Midwestern academic medical center, parent and family presence during the initial phases of the pandemic was limited to one parent/guardian per day. Additional parents, siblings, grandparents, extended family members, and close friends were temporarily prohibited. Parents were often forced to navigate their child's illness alone, separated from their core support systems. Shared decision-making was relegated to phone calls or in-person conversations outside the hospital, in many cases forcing parents to choose between emotional support and being present for an ill child.

This study aims to describe parent anxiety and family distress after parents experience restricted presence during the recent pandemic. While previous research has demonstrated negative effects of PICU admission on a child's family (Alzawad et al., 2020; Hugelius et al., 2021), very few studies have examined the impact of restricted parent presence and visitation on parent anxiety and family distress. This study explored differences in parent anxiety and family distress in the context of three different levels of visitor restrictions.

Methods

Design and setting

A retrospective cohort study was conducted using survey methodology to describe differences in parent anxiety and family distress for parents who experienced three different levels of parent and family presence while their child was in the PICU during the COVID-19 pandemic. During an unrestricted period prior to the COVID-19 pandemic, multiple parents/guardians had unlimited access to their child. Parents and their children experienced liberal visitation from family and friends, as well as extensive hospitality support (e.g., Ronald McDonald area, sleeping suite, respite room). This environment was designed to reduce the inherently stressful PICU environment. During the initial period impacted by COVID-19, restricted visitation was implemented, and parent presence was reduced to one parent per day. Additionally, family hospitality services were significantly reduced. As the COVID-19 surge declined to a semi-restricted state, parent presence guidelines were relaxed, and two parents were allowed to be present with their child while in the hospital. However, family hospitality services had not re-commenced. This study was approved by the University of Iowa

institutional review board. Participants in this study were recruited from a PICU in a large academic medical center located in the Midwest region of the United States. The 28-bed unit cares for critically ill patients from newborn to 21 years of age who require advanced therapies and monitoring.

Participants

The study participants were parents or legal guardians of patients aged newborn to 18 years and were consecutively admitted to the PICU from December 1, 2019, through September 2, 2020. The participants were divided into three study groups based on the dates of the child's hospital stay and level of parent and family presence or restriction they experienced (Table 1). The first study group, (pre-COVID-19), experienced unrestricted parent and family presence while their child was admitted to the PICU (between December 1, 2019, and March 1, 2020). The second study group, (strict-COVID-19), were restricted to one parent and no additional family (March 1, 2020 through June 1, 2020). The third study group of participants, (relaxed-COVID-19), were semi-restricted and experienced more moderate restrictions on parent and family presence (June 2, 2020 through September 2, 2020). The PICU daily census records were reviewed to compile a list of potential participants based on inclusion/exclusion criteria. There were 729 eligible, 83 did not meet inclusion, 48 were unreachable; 82 responses of 681 eligible with a 19% response rate. Parent participants representing all three levels of parent/family presence received a survey after their child was discharged from the hospital. If a child was admitted to the PICU multiple times throughout the three study periods, parents were asked to answer the survey using their experience from their child's most recent hospitalization. Parents were excluded from the study if they were younger than 18 years of age, non-English speaking, or actively involved in a suspected child maltreatment case. If there was a death of a child, a discrete, more sympathetic, letter was sent to the parents. The survey remained the same and there was no differentiation in survey responses from parents that experienced the loss of a child.

Measures

The parent email/letter described the study purpose and invited parents to complete a web-based survey activated with an enclosed link. Completion of the survey served as consent for participation in the study. The survey consisted of demographic questions and measures of anxiety and family distress. Demographic data included child's age, diagnosis, and dates of admission and transfer/discharge from the PICU. Measures of anxiety and distress included in the survey were the Generalized Anxiety Disorder-7 (GAD-7) (Spitzer et al., 2006) and items from the Family Distress Index (FDI) (McCubbin et al., 1996).

The GAD-7 assesses generalized anxiety disorder (Spitzer et al., 2006). The scale is comprised of seven items answered using a four-point Likert scale with selections from 0 (not at all) to 3 (nearly every day) and includes questions about nervousness, worry, restlessness, and irritability. The GAD-7 total scores range from 0 to 21. A score of 10 or higher indicates a potential risk for generalized anxiety disorder. The GAD-7 is also useful to assess symptom severity (Spitzer et al., 2006). Scoring 5, 10, and 15 on the tool correlates to mild, moderate, and severe levels of anxiety, respectively. An increase in score on serial evaluations indicates an increase in functional impairment, self-reported disabilities, and healthcare usage. The GAD-7 questionnaire generally takes less than five minutes to complete. The internal consistency of the tool is 0.92 with test-retest reliability of 0.83 (Spitzer et al., 2006).

The FDI is a self-report measure used to detect family distress (McCubbin et al., 1996). The tool assesses family conflict, ability to problem-solve, and presence of environmental triggers that lead to

Table 1
Description of Study Groups.

Cohort Characteristics	Study Groups		
	UNRESTRICTED	RESTRICTED	SEMI-RESTRICTED
Study Period	December 1, 2019, to March 1, 2020	March 19, 2020, to June 1, 2020	June 2, 2020, to September 2, 2020
Parent/Legal Representative (LR)	Two parents or LR allowed unlimited (in room) access to patient	One parent per day allowed unlimited (in room) access to patient	Two parents allowed unlimited (in room) access to patient
Family Members	Visitation between 9:00 am and 9:00 pm	No visitation	No visitation
Visitors ¹	Visitation between 9:00 am and 9:00 pm	No visitation	No visitation
In room parent sleeping accommodations	Two parents	One parent	Two parents
Family Support Services ²	Access to all services	No access to services	Limited access to services ³

¹ In general, the number of people welcomed at the patient's bedside is limited to 4 (The Loop, 2022).

² Family support services located in the PICU include Ronald McDonald room with waiting area, food, and entertainment; sleeping suite; parent respite room; waiting room; sibling activity room; and lactation room (The Loop, 2022).

³ Ronald McDonald staff prepared meals that could be delivered to or picked up by parents (The Loop).

distress. The FDI is an 8-item instrument administered to participants using a four-point Likert scale and is scored by adding the number selected by the family member, 1 = not a problem to 4 = large problem. The FDI internal reliability is 0.87 (McCubbin et al., 1996). In one study of families, the FDI was found to be strongly related to intense family pressures, and was connected to incendiary communication and lack of social support (McCubbin et al., 1996).

Data were collected from participants for a period ending one month from the date of the initial email and letter distribution. Survey data were collected and managed using REDCap (Research Electronic Data Capture), a secure, web-based data collection tool hosted at the University of Iowa Hospitals and Clinics (Harris et al., 2009, 2019).

Data analysis

Descriptive statistics were used to characterize the study participants. Where applicable, the range, means and standard deviations (SD) for continuous variables and absolute numbers for categorical variables were reported. Variable categories were combined for a more effective analysis (elements for race, ethnicity, and perceived stress). Interpretation of the GAD-7 score was used to make categorical variables for analysis instead of using the continuous variable (GAD-7 score). Fisher's Exact test was used to compare parent anxiety among the unrestricted, restricted, and semi-restricted study groups, assessing for nonrandom associations. Both measures, the GAD-7 and FDI, were also analyzed as continuous variables using the Kruskal-Wallis test to determine differences in anxiety and distress scores between the three participant study groups.

During review of the data, it was discovered that one question was left off the FDI survey. Our results will not be comparable to other

research; however, we utilized the data to compare scores among our participant study groups.

Results

Participant characteristics

A total of 82 parents of unique children participated in this study (Table 1). The majority of participants were white, non-Hispanic or Latino. Children of the parents who participated in the study were newborn to 16.8 years of age, with a mean age of 4.9 years and standard deviation of 5.4 years. Children were diagnosed with critical illnesses within the broad categories of respiratory (37%), cardiovascular (30%), and medical-surgical (33%). Patient length of stay ranged from 1 to 81 days with a mean of 8 days, and standard deviation of 11.9 days.

Differences in characteristics among groups

There was no statistically significant difference among the three participant study groups (unrestricted, restricted, and semi-restricted) for parent race and ethnicity (Table 2). There was a statistically significant difference among the three study groups in the child diagnosis ($p \leq 0.0001$, Table 2). A larger percentage of children of the study participants were hospitalized with respiratory illnesses (63%) in the unrestricted study group.

Parent presence experience among groups

There was a statistically significant difference among the three study groups regarding whether a second parent was able to visit the child during the PICU admission ($p = 0.0068$, Table 3). In the restricted

Table 2
Participant Characteristics and Comparison Across Groups, n(%).*

	All participants (n = 82)	Unrestricted (n = 40)	Restricted (n = 15)	Semi-restricted (n = 27)	Fisher's Exact Difference between groups Pr ≤P
Parent Race					0.5103
White	78 (95)	39 (98)	14 (93)	25 (93)	
African American / >1 race	4 (5)	1 (3)	1 (7)	2 (7)	
Parent Ethnicity					0.4903
Hispanic / Latino	3 (4)	1 (3)	0 (0)	2 (7)	
Not Hispanic / Latino	77 (94)	38 (95)	14 (93)	25 (93)	
Unknown / Not reported	2 (2)	1 (3)	1 (7)	0 (0)	
Child's Diagnosis					<0.0001
Cardiovascular	20 (24)	9 (23)	3 (20)	8 (30)	
Respiratory	30 (37)	25 (63)	2 (13)	3 (11)	
Medical / Surgical	32(38)	6(16)	10(67)	16(60)	

* Missing data = 1 participant (McCubbin et al., 1996).

Table 3
Parent Perceptions, Experience and Level of Anxiety Comparison Across Groups, n(%).

	All participants (n = 82)	Unrestricted (n = 40)	Restricted (n = 15)	Semi-restricted (n = 27)	Fisher's Exact Difference between groups Pr ≤P
*Was another parent able to visit?					0.0068
Yes	71 (88)	38 (97)	10 (67)	23 (85)	
No	10 (12)	1(3)	5 (33)	4 (15)	
Level of stress when told child will be admitted to PICU					0.2191
No stress at all / a little stress	10 (12)	2 (5)	4 (27)	4 (15)	
Moderate stress	16 (20)	10 (25)	2(13)	4 (15)	
Large amount of stress	56 (68)	28 (70)	9 (60)	19 (70)	
Level of stress when informed about your ability to stay in PICU?					0.8615
No stress at all / a little stress	28 (34)	12 (30)	5 (33)	11 (41)	
Moderate stress	27 (33)	15 (38)	4 (27)	9 (30)	
Large amount of stress	27 (33)	13 (33)	6 (40)	8 (30)	
*Level of comfort when staying with your child in the PICU					0.1219
Very comfortable	27 (33)	15 (38)	2 (13)	10 (37)	
Mostly comfortable	36 (44)	12 (30)	10 (67)	14 (52)	
Slightly uncomfortable	10 (12)	7 (18)	2 (13)	1 (4)	
Very uncomfortable	9 (11)	6 (15)	1 (7)	2 (7)	
*How often were you able to visit?					0.2001
100% of the time	74 (91)	36 (92)	12(80)	26 (96)	
<100% of the time	7 (9)	3 (8)	3 (20)	1 (4)	
*Severity of anxiety as interpreted by GAD 7 score					0.0236
Mild	27	16 (40)	5 (36)	6 (22)	
Minimal	12	1 (3)	4 (29)	7 (26)	
Moderate	19	9 (23)	4 (29)	6 (22)	
Severe	23	14 (35)	1 (7)	8 (30)	

* Missing data – 1 (McCubbin et al., 1996).

study group, 33% of participants reported another parent was not able to visit their child during the PICU stay compared to 3% in the unrestricted study group (Table 3). During the restricted study group period, 20% of parents reported that they were not able to visit 24 h a day, compared to 8% during the unrestricted period and 4% during the semi-restricted period; however, these differences were not statistically significant (Table 3).

Parent anxiety among the three study groups

There was not a statistically significant difference among the three study groups' average level of stress perceived when informed their child was being admitted to the PICU and when informed about the ability to stay with their child in PICU (Table 3). However, there was a significant difference among the three study groups' interpreted anxiety severity scores (GAD-7) overall. Parents in the unrestricted (35%) and semi-restricted (30%) study groups had a higher number of anxiety scores in the 'severe' range compared to 7% of parents in the restricted study group having anxiety scores in the severe range ($p = 0.024$), Table 4). GAD-7 scores were also analyzed as a continuous variable with the Kruskal-Wallis Test (Table 4). The differences among unrestricted, restricted, and semi-restricted study group in the GAD-7 scores did not reach but approached statistical significance. The highest GAD-7

Table 4.
Parent Anxiety and Family Distress Results

Measure	N	Range	Mean score	Std Dev	Median score	Kruskal-Wallis Pr > Chi-Square
GAD 7						0.073
Unrestricted	40	3–21	11.8	5.7	10.5	
Restricted	14	0–15	7.5	4.9	7	
Semi-restricted	27	0–21	9.8	6.5	10	
FDI*						0.456
Unrestricted	40	0–12.8	2.3	2.9	1.0	
Restricted	15	0–4	1.1	1.5	0	
Semi-restricted	27	0–10	2.2	3.2	1.0	

Kruskal-Wallis Test.

* Missing one question from the original tool. Used for comparison within study groups only (McCubbin et al., 1996).

score for the restricted study group was 15, compared to 21 for both the unrestricted semi-restricted study groups. Other variables such as a child's mortality risk and the uncertainty of outcome may also impact anxiety for parents whose children are critically ill.

Family distress comparisons across the three study groups

The FDI was utilized to measure elements of family distress during the 3 study periods. All participants received the same questions from the FDI, although one question was mistakenly left out of the survey. There were observed differences in FDI scores among the study groups but did not reach statistical significance. (Table 4). Mean and maximum FDI scores in the unrestricted study group and semi-restricted study group were higher than the mean and maximum scores in the restricted study group. FDI scores were lower for participants whose children were hospitalized in the PICU during the restricted study period. (Table 4).

Discussion

In this study, parent anxiety and family distress were studied in relation to different levels of parent and family presence in the PICU. We anticipated that parents of critically ill children hospitalized during the time of restrictions on parent and family presence, would have higher levels of anxiety and family distress, compared to parents of children hospitalized during the period of fewer or no restrictions. In this study, we did not find a significant difference in anxiety and distress levels in parents who had a child admitted to the PICU during the initial phase when parent presence and family visitation were significantly restricted. The study group with the highest levels of anxiety was the unrestricted cohort when there were no restrictions on parent presence and family visitation. There may be possible explanations for our findings.

One explanation may relate to the combination of multiple stressors a parent experiences during their child's hospitalization. When a child is admitted to the PICU, there are many factors that contribute to parental stress and anxiety (Aamir et al., 2014; Abela et al., 2020; Sankar et al., 2014). A significant stressor for parents relates to their child's overall

condition and the uncertainty that surrounds that condition (Dahav & Sjostrom-Strand, 2018; Hagstrom, 2017). Hospitalizations where a child is rapidly deteriorating, has an unknown outcome, or has a high mortality risk becomes a significant stressor for parents (Shudy et al., 2006). In this study, the higher stress levels found in the unrestricted study group may be associated more with the child's condition and ambiguity of their illness than a restriction in parent presence. While we did not measure acuity levels in each study group, anecdotal observations of unit census and acuity levels revealed differences among the study groups. During the unrestricted study period, our PICU daily census was 22 patients, and the anecdotal acuity of patient condition overall was higher. The average daily census of the other two study groups were 12 patients and 19 patients for the restricted and semi-restricted study groups respectively.

Historically, a significant number of admissions to our PICU are comprised of children with respiratory decompensation that require supplemental oxygen, and in severe cases mechanical ventilation. Respiratory decompensation contributes to the increased acuity level of PICU admissions. We examined the admission diagnoses for each of the three study groups. There was a difference in diagnoses among the three study groups with the greatest variance in respiratory illness. Our hospital and many others throughout our region experienced an unprecedented high volume of admissions of children with severe respiratory illness labeled 'non-RSV influenza-like illness' during the unrestricted study period. This was a finding we did not anticipate. Once the pandemic was realized, national guidelines to mitigate the spread of COVID-19, including school and daycare closures, resulted in an early disappearance of seasonal respiratory infections (Haddadin et al., 2021).

Additionally, our hospital postponed complex elective surgeries in children in anticipation of an increased need for PICU beds for COVID-19 patients. As a result, patient census and severe respiratory disease admissions were lower during the restricted and semi-restricted study groups. Our experience is similar to other PICUs in the United States (Haddadin et al., 2021; Pelletier et al., 2021) and worldwide (Shanmugavadivel et al., 2021). Zee-Cheng et al. (2021) found pediatric critical illness admissions in the United States had decreased during the COVID-19 pandemic and the largest decreases were in respiratory conditions. Shanmugavadivel et al. (2021) also reported a 50% reduction in the United Kingdom emergency department visits after the COVID-19 lockdown, noting a significant decline in visits related to breathing difficulties and fever, specifically.

Not surprisingly, the percentage of time of a parent stayed with their child differed among study groups. A larger percentage of parents from the unrestricted and semi-restricted study groups were able to stay with their child compared to parents from the restricted study group. Although one parent was allowed to stay with their child in all three groups, parents in the restricted study group were less likely to have stayed in their child's hospital room overnight. While the exact reason is not known, it is plausible that there may have been pandemic-related challenges that prohibited a parent from staying overnight with their child (e.g., the single parent without home support, career demands).

Last, even during the restricted study period, one parent was allowed 24-h access to their child for each 24-h period. This one parent could be actively involved in their child's care and direct communication between this parent and the interdisciplinary team was maintained. In qualitative studies, parents describe the importance of being involved in their child's care and having consistent and reliable communication with the interdisciplinary team (Dahav & Sjostrom-Strand, 2018; Foster et al., 2019). In our study, communication between the parents and the interdisciplinary team was not intentionally altered among all three study groups.

Additional contributing factors that were not examined include medical procedures the child may have experienced, changes to diet and mobility, and pain and discomfort of the child. These, and many

other causes, can create increased anxiety and distress in parents and families of hospitalized children.

Clinical and research implications

Findings from this study offer insights and recommendations for practice. We found that parents who experienced restrictions in parent and visitor presence did not have increased anxiety. Other variables such as a child's mortality risk and the uncertainty of outcome may also impact anxiety for parents whose children are critically ill. Further research is needed to understand which stressors are most significant from a parent's perspective. From this, we may be able to design interventions to lessen parent anxiety and family distress while concurrently supporting the critically ill child. Hospital leaders must carefully consider all aspects of restricting parent presence and family visitation during a public health crisis. It is vital to balance staff safety with the importance of parent presence for critically ill children. This research provides context for careful development of hospital visitation policies to ensure this balance.

Limitations and strengths

We have identified limitations in this study, including a small sample size as a result of low response rate. The sample sizes for the restricted and semi-restricted study groups were smaller than the unrestricted study group. During the restricted and semi-restricted study periods, elective surgeries were canceled, there were few pediatric COVID-19 PICU admissions, and the daily census was low. This imbalance may have biased the results. Additionally, during the time in which this study was conducted, additional variables such as limited PICU family hospitality services, patient acuity, hospital length of stay, ventilator days and age of the child may have impacted parent anxiety and family distress. Additionally, measuring family distress and parent anxiety in real time would have provided more robust measure of these outcomes. Lastly, the survey tool inadvertently did not include one question from the FDI measure. The missing data disabled the tool for use in comparison to other family distress data, however, we were able to utilize the data to compare family distress levels within this study. Because of the missing question in the FDI questionnaire, we wanted to assess the internal consistency and reliability. We calculated the Cronbach coefficient alpha which was 0.72.

Despite these limitations, this descriptive study utilized reliable and valid measures to collect data efficiently and inexpensively from a broad range of participants. This study contributes new knowledge for children's hospitals as they continuously navigate the challenging subject of parent and family presence during public health emergencies, including information about parent anxiety and family distress during times of restricted presence.

Conclusions

Global pandemics are stressful for hospital staff, as well as patients and families. As we attempt to navigate through continued uncertainty, this research may provide some context of how the restrictions on parent and visitor presence impact the patient and family experience. Our study suggests that the single factor of restricting parent and visitor presence in this single center study of parents' experience under three conditions did not increase parent anxiety and family distress during a child's admission to our hospital's PICU. The literature widely supports that having a critically ill child is undoubtedly stressful for parents and families, but multifactorial elements that exacerbate anxiety and stress remain unknown. Parent and visitor presence is only one factor among many that may affect anxiety and stress levels. The magnitude or individual perception of stress may relate more to the cumulative effects of multiple or varied stressors a parent experiences during a child's PICU stay rather than one stressor that restricts parent and family

presence. Future research is needed to determine factors that affect the severity of parent anxiety and family distress in critically ill children.

CRedit authorship contribution statement

Jodi J. Bloxham: Conceptualization, Methodology, Validation, Investigation, Resources, Data curation, Writing – original draft, Writing – review & editing, Visualization, Project administration, Funding acquisition. **Paula Levett:** Methodology, Resources, Writing – original draft, Writing – review & editing. **Jihye Lee:** Software, Validation, Formal analysis, Data curation. **Chelsea Dvorak:** Methodology, Data curation, Writing – original draft. **Danielle Hodge:** Methodology, Data curation, Resources, Writing – original draft. **Stephanie Stewart:** Conceptualization, Methodology, Software, Validation, Formal analysis, Investigation, Resources, Data curation, Writing – original draft, Writing – review & editing, Supervision.

Conflict of interest

The authors of this research have no conflicts of interest to disclose.

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References

- Aamir, M., Mittal, K., Kaushik, J. S., Kashyap, H., & Kaur, G. (2014). Predictors of stress among parents in pediatric intensive care unit: A prospective observational study. *Indian Journal of Pediatrics*, 81(11), 1167–1170. <https://doi.org/10.1007/s12098-014-1415-6>.
- Abela, K., Wardeell, D., Rozmus, C., & LoBiondo-Wood, G. (2020). Impact of pediatric critical illness and injury on families: An updated systematic review. *Journal of Pediatric Nursing*, 51, 21–31. <https://doi.org/10.1016/j.pedn.2019.10.1013>.
- Alzawad, Z., Lewis, F. M., Kantrowitz-Gordon, I., & Howells, A. J. (2020). A qualitative study of parents' experiences in the pediatric intensive care unit: Riding a roller coaster. *Journal of Pediatric Nursing*, 51, 8–14. <https://doi.org/10.1016/j.pedn.2019.11.015>.
- Dahav, P., & Sjoström-Strand, A. (2018). Parents' experiences of their child being admitted to a paediatric intensive care unit: A qualitative study-like being in another world. *Scandinavian Journal of Caring Sciences*, 32(1), 363–370. <https://doi.org/10.1111/scs.12470>.
- Foster, K., Mitchell, R., Young, A., Van, C., & Curtis, K. (2019). Resilience-promoting factors for parents of severely injured children during the acute hospitalisation period: A qualitative inquiry. *Injury*, 50(5), 1075–1081. <https://doi.org/10.1016/j.injury.2018.12.011>.
- Haddadin, Z., Schuster, J. E., Spieker, A. J., Rahman, H., Blozinski, A., Stewart, L., ... Halasa, N. B. (2021). Acute respiratory illnesses in children in the SARS-CoV-2 pandemic: Prospective multicenter study. *Pediatrics*, 148(2), Article e2021051462. <https://doi.org/10.1542/peds.2021-051462>.
- Hagstrom, S. (2017). Family stress in pediatric critical care. *Journal of Pediatric Nursing*, 32, 32–40. <https://doi.org/10.1016/j.pedn.2016.10.007>.
- Harris, P. A., Taylor, R., Minor, B. L., Elliott, V., Fernandez, M., O'Neal, L., ... Duda, S. N. (2019). The REDCap consortium: Building an international community of software platform partners. *Journal of Biomedical Informatics*, 95, Article 103208. <https://doi.org/10.1016/j.jbi.2019.103208>.
- Harris, P. A., Taylor, R., Thielke, R., Payne, J., Gonzalez, N., & Conde, J. G. (2009). Research electronic data capture (REDCap)—A metadata-driven methodology and workflow process for providing translational research informatics support. *Journal of Biomedical Informatics*, 42(2), 377–381. <https://doi.org/10.1016/j.jbi.2008.08.010>.
- Hugelius, K., Harada, N., & Marutani, M. (2021). Consequences of visiting restrictions during the COVID-19 pandemic: An integrative review. *International Journal of Nursing Studies*, 121, Article 104000. <https://doi.org/10.1016/j.ijnurstu.2021.104000>.
- Jee, R. A., Shepherd, J. R., Boyles, C. E., Marsh, M. J., Thomas, P. W., & Ross, O. C. (2012). Evaluation and comparison of parental needs, stressors, and coping strategies in a pediatric intensive care unit. *Pediatric Critical Care Medicine*, 13(3), 166–172. <https://doi.org/10.1097/PCC.0b013e31823893ad>.
- Kirschbaum, M. S. (1990). Needs of parents of critically ill children. *Dimensions of Critical Care Nursing*, 9(6), 344–352. <https://doi.org/10.1097/00003465-199011000-00009>.
- McCubbin, H. I., Thompson, A. I., & McCubbin, M. A. (1996). *Family assessment: Resiliency, coping and adaptation: Inventories for research and practice*. University of Wisconsin Publishers.
- Pelletier, J., Rakkar, J., Au, A., Fuhrman, D., Clark, R., & Horrat, C. (2021). Trends in pediatric hospital admissions in 2020 compared with the decade before the COVID-19 pandemic. *JAMA Network Open*, 4(2), Article e2037227. <https://doi.org/10.1001/jamanetworkopen.2020.37227>.
- Sankar, J., Lodha, R., & Kabra, S. K. (2014). Parental stress in pediatric intensive care unit: How do we cope with it? *Indian Journal of Pediatrics*, 81(11), 1141–1142. <https://doi.org/10.1007/s12098-014-1599-9>.
- Shanmugavadivel, D., Liu, J. F., Gilhooley, C., Elsaadany, L., & Wood, D. (2021). Changing patterns of emergency paediatric presentations during the first wave of COVID-19: Learning for the second wave from a UK tertiary emergency department. *BMJ Paediatrics Open*, 5(1), Article e000967. <https://doi.org/10.1136/bmjpo-2020-000967>.
- Shudy, M., de Almeida, M. L., Ly, S., Landon, C., Groft, S., Jenkins, T. L., & Nicholson, C. E. (2006). Impact of pediatric critical illness and injury on families: A systematic literature review. *Pediatrics*, 118(Suppl. 3), S203–S218. <https://doi.org/10.1542/peds.2006-0951B>.
- Simeone, S., Pucciarelli, G., Perrone, M., Angelo, G. D., Teresa, R., Guillari, A., ... Palma, G. (2018). The lived experiences of the parents of children admitted to a paediatric cardiac intensive care unit. *Heart & Lung*, 47(6), 631–637. <https://doi.org/10.1016/j.hrtlung.2018.08.002>.
- Sood, E., Karpyn, A., Demianczyk, A. C., Ryan, J., Delaplane, E. A., Neely, T., ... Kazak, A. E. (2018). Mothers and fathers experience stress of congenital heart disease differently: Recommendations for pediatric critical care. *Pediatric Critical Care Medicine*, 19(7), 626–634. <https://doi.org/10.1097/PCC.0000000000001528>.
- Spitzer, R. L., Kroenke, K., Williams, J. B., & Löwe, B. (2006). A brief measure for assessing generalized anxiety disorder: The GAD-7. *Archives of Internal Medicine*, 166(10), 1092–1097. <https://doi.org/10.1001/archinte.166.10.1092>.
- The Loop for the footnotes. Patient & Visitor Resources. (2022, January 7). The Loop. Retrieved October 22, 2022, from <https://www.medcom.uiowa.edu/theloop/patient-visitor-resources>
- Zee-Cheng, J., McCluskey, C., Klein, M., Scanlon, M., Rotta, A., Shein, S., ... Carroll, C. (2021). Changes in pediatric ICU utilization and clinical trends during the coronavirus pandemic. *Chest*, 160(2), 529–537. <https://doi.org/10.1016/j.chest.2021.03.004>.