

Evaluating Pediatric Families' Understanding of and Reactions to COVID-19 Visitor Restrictions

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Abstract

The COVID-19 pandemic led to changes in hospital visitor policies and little is known about the impact on patients and their families. This study evaluated families' understanding of and reactions to COVID-19-related visitor restriction policy at an academic children's hospital. We conducted a cross-sectional study with families of patients admitted to the pediatric ICU and general pediatric wards from September 2020 to November 2020. Parents (n = 73) completed a survey assessing communication, understanding of and satisfaction with visitor policies, strategies of coping with illness, and Hospital Anxiety and Depression Scale (HADS) scores. Descriptive analyses were performed to summarize data. Associations between outcomes and participant characteristics were examined. A majority (88%) of respondents reported hospital visitor restrictions were explained, usually in-person (94%), and understood the policy "very well" (68%), but none correctly identified all reasons for visitation restrictions. Eighty-five percent reported other family/friends would have visited, however minority families were more likely to report they would have had fewer visitors if restrictions were not in place ($P = 0.0385$). A majority (69%) were satisfied with how the hospital handled visitor policies, and parents of older children were more satisfied ($P < .0001$). HADS scores were consistent with anxiety or depression in about half of respondents. Forty percent of respondents believed restrictions affected their own and their child's ability to cope during hospitalization. Parents expressed satisfaction with and understanding of visitor policies but did not understand the rationale for visitor restrictions. Visitor restrictions may impact parental and child coping and mental health outcomes.

Keywords

COVID-19, visitor restrictions, communication, patient perspectives/narratives, patient satisfaction, pediatrics

Introduction

Limitation of hospital visitation policies during the COVID-19 pandemic is important for public health protection and safety (1), in order to minimize transmission to patients, staff, visitors, and within the community. Based on broad guidelines provided by the CDC (2), visitor policies have been uniformly implemented by hospitals that limit the number of people allowed to visit patients, with individual hospital policies varying regarding number of visitors, visitors' relationship to patients, and visitor age (3). During the COVID-19 pandemic, the American Academy of Pediatrics recommends pediatric inpatient units limit visitation to two visitors, who have been screened and are wearing face coverings, with exceptions for medically complex and end-of-life pediatric patients (4).

Hospital visitor restrictions pose challenges for healthcare providers, patients and their families, raising potential ethical

dilemmas which require careful risk-benefit analyses (5) to balance public health needs with the known benefits of family-centered care for hospitalized patients and families (6–8). Due to their inherent dependence on surrogate decision makers for their psychosocial and physical wellbeing, pediatric patients are especially vulnerable to abrupt changes in visitation policies.

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Little is known about the impact of pandemic-related visitor restrictions (PRVR) on pediatric inpatient families during the COVID-19 pandemic. However, some unintended negative consequences have begun to be identified. Parents whose infants were hospitalized in the NICU identified limited bonding with infant and role in daily care, including breastfeeding and kangaroo care (9). PRVR also potentially place the burden of decision making on one parent, while also creating the need to provide alternative means of childcare for siblings that otherwise wouldn't be needed. Furthermore, they can limit engagement in family-centered care, exacerbate health inequities of marginalized populations and potentially delay care (10,11). We did not identify any prior study that has evaluated the experiences of families of pediatric inpatients regarding COVID-19 PRVR.

The purpose of this study is to evaluate families' understanding of and reactions to PRVR at an academic children's hospital. Due to conflicting public opinions regarding the reality and importance of the COVID-19 pandemic as well as the rapidity with which the PRVR were instituted, we hypothesized that families would have incomplete understanding of the rationale for PRVR, and that many families would report negative impacts of PRVR, including the disruption of visitation plans and decreased coping mechanisms as they relate to the hospitalization. We further hypothesized that the experiences of families of minority backgrounds would differ from those of non-Hispanic white families.

Methods

Study Design

This was a retrospective cross-sectional study of parents of patients admitted to the pediatric ICU and general pediatric wards of an academic children's hospital between September 2020 and November 2020. At our institution, the COVID-19 PRVR policy limited visitation to two family or support individuals per hospitalization, who were permitted to stay overnight. With the exception of parents, visitors were required to be 18 years or older. English-speaking parents of children 0 to 17 years old who were admitted to the pediatric intensive care unit and general wards at the children's hospital for a minimum of 48 hours with non-COVID-related illnesses were eligible for inclusion. Families were approached in-person by a member of the study team. Families provided written informed consent and completed a one-time paper-based survey asking questions about their experiences during the current admission. Families that were admitted multiple times during the study period were only eligible to answer the survey once. The institutional review board approved the study. Data were managed using REDCap (12).

Survey

A novel survey tool was developed for this study because of the lack of available survey tools designed to evaluate

families' understanding of and reactions to the hospital's PRVR. Surveys were pretested and reviewed for language, length, tone, content, and consistency by study team members. Content validity was obtained by reviewing surveys by a multi-disciplinary group of pediatric providers, resulting in revisions in the language and order of survey items.

The complete survey is available as Supplemental material in the online edition. They include items asking families about their experiences with, understanding of, and reactions to the hospital's PRVR, including the restrictions' potential impact on families' and patients' coping with the hospitalization. Understanding was defined as the ability to identify the rationale for PRVR. Items also explored communication between patients and their families during the hospitalization. The Hospital Anxiety and Depression Scale (HADS) (13) was used to assess parents' psychological distress relating to their child's hospitalization and illness.

Patient data obtained from the electronic medical record included patient demographics, main diagnosis category, type of admission (planned vs unplanned), presence of complex chronic condition (14), location of admission (critical care vs general floor), type of insurance (Medicaid vs other), hospital length of stay, and number of previous admissions. Self-reported family demographic data were obtained from the survey tool and included parents' age, sex, self-identified race/ethnicity, child's race/ethnicity, respondent's role in patient's life, and highest education level achieved.

Statistical Analysis

Descriptive analyses were performed to report frequency of demographic characteristics and clinical variables. Likert responses were either dichotomized (e.g. agree or disagree) or categorized to ordinal variables (e.g. agree, disagree or indifferent) according to the questions of interest. Demographic variables were dichotomized (e.g. age categories: <5 years old, 5 to 17 years old; diagnosis: hematology/oncology, other diagnoses). We used χ^2 test or Fisher exact test to study the association between responses and demographic and categorical variables. Unpaired two sample *t*-test was performed to analyze continuous variables (e.g. HADS score). McNemar's test was used to determine whether one choice is dominantly favored in a multi-choice multi-select question. A *P*-value <.05 was considered statistically significant. All statistical tests were conducted using R version 4.0.0.

Results

Sample Characteristics

Eighty-nine parents were approached for the study and 73 consented to participation and completed a survey (82% response rate). Children were predominantly female, non-Hispanic white, admitted to the general wards for a non-planned admission, and had a complex chronic condition.

Table 1. Patient Characteristics, N = 73

Child's age, mean (SD)	8.4 (6.4)
Gender, No. (%)	
Female	43 (59)
Male	30 (41)
Race/ethnicity, No. (%) ^a	
Non-Hispanic White/Caucasian or Euro-American	53 (73)
Black, Afro-Caribbean or African American	6 (8)
Native American or Alaskan Native	2 (3)
Latino or Hispanic American	15 (21)
Asian	4 (5)
Other	2 (3)
Primary diagnosis, No. (%)	
Hematology/Oncology	12 (16)
Psychiatric	12 (16)
Trauma/surgery	10 (14)
Gastroenterology	7 (10)
Respiratory	6 (8)
Neurologic	6 (8)
Cardiac	5 (7)
Infectious Disease	5 (7)
Other	10 (14)
Hours of admission to survey, median (range)	96 (48-5,063)
Planned admission, No. (%)	21 (29)
Number of previous admissions, median (range)	0 (0-28)
PICU hospitalization, No. (%)	13 (18)
Chronic complex condition, No. (%)	52 (71)
Medicaid insurance, No. (%)	35 (48)

^aStudy participant able to choose more than one answer.

The most common primary diagnosis categories were hematology/oncology, psychiatry, and trauma/surgery (Table 1). Parent/guardian participants were predominantly non-Hispanic white mothers with a high school or college degree (Table 2).

Communication and Understanding of Visitor Restrictions

The majority of parents (88%) reported hospital visitor restrictions had been explained to them. Of those parents, most (94%) were told about the policy in-person. Most parents reported understanding the hospital's PRVR "very well" (68%) or "somewhat" (30%). None of the parents correctly chose all 4 reasons for the visitor restrictions. The most commonly chosen reason was "decrease overall transmission of COVID-19 within the community" (89%), which is more frequent than any other reason ($P = .0001$). Parents reported understanding of PRVR did not differ between those who had the policy explained to them and those who did not.

Communication With Healthcare Team and Patient

The majority (71%) of parents stated they did not have regularly scheduled calls with the healthcare team. To maintain interactions remotely with their child, families utilized phone calls (audio only) (36%), video-based calls (ie, FaceTime, Skype, Zoom) (32%), text messages (30%), and social media (ie, Twitter, Facebook, Instagram) (8%) (Table 2).

Table 2. Parent/Guardian Characteristics, N = 73

Parent's identity in child's life, No. (%)	
Mother	58 (79)
Father	13 (18)
Other legal guardian	2 (3)
Parent's age in years, mean (range)	38 (20-60)
Race/ethnicity, No. (%) ^a	
Non-Hispanic White/Caucasian or Euro-American	52 (71)
Black, Afro-Caribbean or African American	3 (4)
Latino or Hispanic American	14 (19)
Asian	3 (4)
Other	3 (4)
Level of parent education, No. (%)	
Some high school	4 (5)
High school degree or equivalent	29 (40)
Some college	10 (14)
College degree or higher	30 (41)
Modality in which policy was communicated ^a , No. (%)	
Paper form	10 (16)
Online	2 (3)
In-person	59 (94)
Primary reason for visitor restrictions ^a , No. (%)	
Minimize risk of my child from being infected with COVID-19	40 (56)
Protect visitors from being infected with COVID while in hospital	30 (42)
Protect hospital staff from being infected with COVID-19	35 (49)
Decrease overall transmission of COVID with in the community	64 (89)
Level of understanding the hospital visitor restriction policy, No. (%)	
Very well	48 (68)
Somewhat	21 (30)
A little	1 (1)
Not at all/Very little	1 (1)
Maintained interactions remotely with child using ^a , No. (%)	
Phone (audio only) calls	26 (36)
Video-based calls (ex. Facetime, Skype, Zoom)	23 (32)
Text messages	22 (30)
Social media (ex. Twitter, Facebook, Instagram)	6 (8)
Drawings	2 (3)
Other	4 (6)
Does not apply	38 (52)

^aStudy participant able to choose more than one answer.

Perceptions of Visitation

Most parents (83%) said there would be no change in how often they would be able to visit their child if there was no pandemic, but 85% did report other family/friends would have visited their child if there were no visitor restrictions. Parents of racial/ethnic minorities were more likely to report they would have had fewer visitors if the visitor restrictions were not in place (NHW 0% vs minority 14%, $P = .0385$). Parents identified siblings (70%), aunt/uncle (49%), cousins (24%), grandparents (66%), and friends (42%) as those most likely to visit if the restrictions were not in place. There was no difference in perceived change in

visitation based on main diagnosis, Medicaid status, presence of complex chronic condition, and planned admission. Aside from the visitor policy, other circumstances that affected parents' ability to visit their child included childcare for other children (23%), transportation (6%), fear of exposure to COVID-19 (6%), and monetary barriers (4%); the majority (74%) did not define or identify other circumstances not listed as inhibiting their visits.

Coping With Illness

Forty-nine percent of parents reported the COVID-19 pandemic decreased their ability to cope with their child's illness. Thirty-three percent of parents reported the PRVR negatively impacted their child's ability to cope with their illness during the hospitalization and 40% of parents reported the PRVR negatively impacted their own ability to cope with their child's illness. There were no strongly significant differences, nevertheless it was observed that parents of children on Medicaid insurance were more likely to report "a lot" of impact from the visitor restrictions (Medicaid "a lot" of impact 26% vs non-Medicaid "a lot" of impact 8%; $P = .0586$). Patient diagnosis (psychiatric vs non-psychiatric), insurance, parent/guardian race/ethnicity, presence of complex chronic condition, and number of prior admissions were not significantly associated with negative impacts of visitor policy in coping with illness for child and parent/guardian, or the degree of impact of visitor policy. Although not strongly significant, we discerned parents of children with planned hospital admissions more commonly reported a negative impact of the COVID-19 pandemic compared to those with unplanned admission (planned 67% vs unplanned 38%; $P = .0539$).

Thirteen percent of parents reported they had been unable to care for and provide for their family during the pandemic. Age, Medicaid status, parent/guardian race/ethnicity, presence of complex chronic condition, and planned admission did not significantly differ among parents who were able to

care and provide for their family and those who were unable to do so.

HADS Scores

Thirty percent of parents scored within the range of having anxiety and 26% had "borderline" anxiety. Twelve percent scored as having depression and 29% had "borderline" depression. HADS scores did not significantly differ based on whether the policy was explained, insurance type, parent/guardian race/ethnicity, presence of complex chronic condition, planned admission, admission for psychiatric diagnosis, or number of previous admissions.

Satisfaction With PRVR

Most parents (69%) were overall very satisfied/satisfied of the quality of how the hospital handled visitor restrictions. Parents of younger patients were significantly less likely to be satisfied with the PRVR policy (satisfaction 44% patients <5 vs 86% patients >5, $P < .0001$). Other factors including Medicaid status, parent/guardian race/ethnicity, presence of complex chronic condition, and planned admission were not significantly associated with dissatisfaction of the policy (Table 3).

Nineteen percent of parents believed the pandemic interfered with their child's ability to obtain care in a timely fashion. The most common experiences of perceived delays in obtaining care included: delayed time from seeing a provider to receiving medical care (50%), waiting longer to bring their child to receive medical care due to concerns with COVID-19 transmission (7%), and other (57%). There were no significant associations between parental perceived delays in care and patient factors, including psychiatric diagnosis, insurance type, parent/guardian race/ethnicity, complex chronic condition, planned versus unplanned admission, and number of previous admissions.

Table 3. Associations Between Patient Factors and Parental Dissatisfaction of Policy

		Satisfied	Indifference	Dissatisfied	P value
Young age (<5)	Yes	12 (44)	9 (33)	6 (22)	.0001
	No	38 (86)	1 (2)	5 (11)	
Heme/Onc diagnosis	Yes	11 (92)	0 (0)	1 (8)	.257
	No	39 (66)	10 (17)	10 (17)	
Medicaid	Yes	23 (68)	6 (18)	5 (15)	.7071
	No	27 (73)	4 (11)	6 (16)	
Parent/guardian race/ethnicity	NHW	33 (65)	8 (16)	10 (20)	.2076
	Minority	17 (85)	2 (10)	1 (5)	
Complex chronic condition	Yes	36 (72)	6 (12)	8 (16)	.7229
	No	14 (67)	4 (19)	3 (14)	
Admission planned	Yes	15 (71)	2 (10)	4 (19)	.7839
	No	35 (70)	8 (16)	7 (14)	

Associations listed as frequency (percentage).

Discussion

This study evaluated pediatric families' understanding of and reactions to the PRVR policy during the COVID-19 pandemic at an academic children's hospital. As hypothesized, despite most parents reporting they understood the policy "well," none were able to choose all reasons for PRVR, indicating poor understanding of the rationale for this change in policy. There were inconsistencies in how the PRVR policy was communicated to families. At the time of their child's hospitalization, about half of parents had anxiety/borderline anxiety or depression/borderline depression as measured by the HADS scale. Likewise, about half reported decreased ability to cope with their child's illness during the pandemic and one-third reported the restrictions negatively impacted their child's ability to cope while hospitalized.

This is the first study to report on parental experiences with PRVR in hospitalized children. Recommended best practices for hospitalized patients includes prioritizing communication, active engagement with families and patients, and utilizing technology to enhance communication (15). One prior study demonstrated that most adult intensive care units had changed their way of communicating with families, relying mostly on virtual communication (16). The current views of PRVR has raised ethical dilemmas and the need for assessment on how families may be supported through this necessary, albeit challenging to navigate, change in typical hospital policies. Policies should ideally incorporate input from stakeholders other than hospital administration, including providers with diverse clinical training, patients, and families (17). Our study findings suggest there is value in exploring the most efficacious ways of explaining policies to yield the most accurate understanding, as evidenced by the fact that none of our respondents could correctly identify all 4 reasons for the PRVR. The fact that most parents reported receiving information about the policy in person hints at inconsistencies in how the policy was communicated, and the need to more consistently provide written materials.

Our hospital restriction policy of 2 adults per patient was consistent with published recommendations to limit the psychologic and emotional toll on one parent/guardian (17). However, we were concerned to find that a large majority of parents had HADS scores that indicated the presence of anxiety/borderline anxiety or depression/borderline depression. While parents of hospitalized children experience high levels of anxiety and depression at baseline (18–21), there is evidence that their anxiety and depression levels have been significantly higher during the pandemic (22). While we found no association between the HADS score outcomes and parents' and patients' abilities to cope with child's illness, we unfortunately did not have local baseline pre-pandemic HADS measures to compare our results to. However, hospitals should consider extending further psychosocial support to parents, especially during future pandemics, which may aid in managing mental health illnesses rather than promoting poor outcomes (17).

Visitors and more flexible visiting policies are associated with patient satisfaction (23–25). In our study, while most parents reported other family or friends would have visited their child if they were allowed, the majority of parents reported no change in how frequently they themselves would visit without the PRVR. Although many families wished other individuals besides themselves could visit, most appear to be satisfied with the PRVR, which may indicate parental understanding and agreement with the need to restrict visitors during the pandemic. It is interesting to note that minority families differed from non-Hispanic White families regarding projected rate of family and friend visitation if the restrictions were not in place. Racial/ethnic minority families are known to experience different quality of communication in the inpatient setting (26,27). Attention should continue to be paid to how communication challenges may be further exacerbated in the context of changes in policies that affect interactions with families.

Finally, we were interested to find that parents of younger children were significantly less satisfied with the PRVR. This may be due to the differences in needs between the two age cohorts where younger children are more dependent on their parents. Additionally, parents of younger children may be more likely to have other younger children to take care of at home, which may complicate parents' ability to visit, thus negatively impacting the communication they receive from the healthcare team. Given these findings, hospitals should consider providing additional support to families of younger patients.

This study had several limitations. The sample size was smaller than expected due to an abrupt and unexpected cessation of institution-wide research during the pandemic which restricted the ability to enroll families. Nonetheless, we were able to identify points of interest that would be worth further exploring. In order to minimize recall bias, parents were approached in person before discharge or close to anticipated discharge, rather than after discharge; however, limiting our enrollment to parents present in the hospital meant that we did not capture the experiences of families unable to be at the bedside who may be most affected by PRVR. There were no baseline HADS scores to compare levels of anxiety and depression in parents prior to and during their child's hospitalization, limiting our ability to adequately measure impact of PRVR on mental health. Additionally, the survey tool was not reviewed by patient families upon development given the time sensitivity of the study, however this step would have added important value and insight that would have added additional face validity to the survey tool. Finally, the study was conducted at a single pediatric center and participants consisted of mostly white, well-educated, and English-speaking parents, which limits generalizability of results. While we attempted to control for differences in race/ethnicity and socioeconomic status, future studies should focus on obtaining perspectives from a larger sample of a more diverse population, including those with limited English proficiency, to better understand potential disparities in care.

Conclusion

Despite reporting high levels of satisfaction and a good understanding of PRVR, parents of hospitalized children do not completely understand the rationale for the policies. Changes in policies might pose communication challenges among minority families. Limited visitation during a pandemic may interfere with parental and patient ability to cope with illness. Future research should expand on identifying best practices for administering and communicating PRVR.

Authors' Note

Alexis Hyczko conceptualized and designed the study, designed the data collection instruments, coordinated and supervised data collection, carried out initial analysis, drafted the initial manuscript, reviewed and revised the manuscript, and approved the final manuscript as submitted. Chenqi Fu and Dr. Zhou carried out the initial analyses, reviewed and revised the manuscript, and approved the final manuscript as submitted. Zeva Graf collected data, reviewed and revised the manuscript, and approved the final manuscript as submitted. Dr. Perkowski helped design the study and data collection instruments, reviewed and revised the manuscript, and approved the final manuscript as submitted. Dr. Whyte-Nesfield helped design the study and data collection instruments, reviewed and revised the manuscript, and approved the final manuscript as submitted. Dr. Zurca conceptualized and designed the study, helped design data collection instruments, critically reviewed and revised the manuscript, and approved the final manuscript as submitted.

Declaration of Conflicting Interests

The authors declare no potential conflict of interest with respect to the research, authorship, and/or publication of this article.

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Ethical Approval

Ethical approval to report this case was obtained from Pennsylvania State University Institutional Review Board (Study ID: STUDY00015526, Submission ID: CR00017063).

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Statement of Human and Animal Rights

All procedures in this study were conducted in accordance with the Pennsylvania State University Institutional Review Board's (Study

ID: STUDY00015526, Submission ID: CR00017063) approved protocols.

Statement of Informed Consent

Written informed consent was obtained from the study participants for their anonymized information to be published in this article.

Supplemental Material

Supplemental material for this article is available online.

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