Family Presence and Visitation Practices in Latin American PICUs: An International Survey

Sebastián González-Dambrauskas^{1,2} Cecilia Mislej^{1,3} Pablo Vásquez-Hoyos^{1,4,5,6}
Alexandre Tellechea Rotta⁷

¹ Red Colaborativa Pediátrica de Latinoamérica, Montevideo, Uruguay

² Unidad de Cuidados Intensivos Pediátricos Especializados, Casa de Galicia, Montevideo, Uruguay

³ Unidad de Cuidados Intensivos Pediátricos, Hospital Evangélico, Montevideo, Uruguay

⁴ Departamento de Pediatría, Universidad Nacional de Colombia, Bogotá, Colombia

⁵ Departamento de Pediatría, Fundación Universitaria de Ciencias de la Salud, Bogotá, Colombia

⁶ Unidad de Cuidado intensivo Pediátrico, Sociedad de Cirugía Hospital de San José, Bogotá, Colombia

⁷ Department of Pediatrics, Division of Pediatric Critical Care Medicine, Duke University Medical Center, Durham, North Carolina, United States

Address for correspondence Sebastián González-Dambrauskas, MD, Red Colaborativa Pediátrica de Latinoamérica, Cuidados Intensivos Pediátricos Especializados Casa de Galicia, Aguirre y Lecube 4863, Montevideo, Uruguay (e-mail: sgdambrasukas@gmail.com).

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Abstract

Over the last two decades, there has been a worldwide cultural shift toward family-centered intensive care. In this article, we conducted a survey of 47 pediatric intensive care units (PICUs) across 11 Latin American countries to assess visitation practices and bedside family presence (with a 97.9% response rate). All PICUs had at least some form of parental visitation. The prevalence of unrestricted (24 hours/day) parental visitation was 63%. Sibling visitation was permitted in 23% of PICUs, while 35% allowed family presence during procedures, and 46% during resuscitation. Only 1 PICU allowed pet visitation. Family visitation and bedside presence are still restrictive in Latin American PICUs, with wide practice variation among the various intensive care units.

Keywords

- family
- visiting policy
- pediatric intensive care

Introduction

Admission to a pediatric intensive care unit (PICU) changes the life of a child forever, triggering long-standing effects not only to the patient but also to their families. Among survivors, critical illness can shape the trajectory of a child's physical, cognitive, emotional, and social domains.¹ This conceptual framework is currently known as post-intensive care syndrome, and like the patient, the families also suffer the unintended negative consequences of PICU survivorship.² Giving the unique nature of childhood, and the bond

that ties children to their families, the PICU experience deserves special attention.³

There is currently a global cultural shift toward a more family-centered critical care model, defined as an approach to health care that is respectful of each family individual needs and values.⁴ A growing body of evidence suggests that a family-centered critical care model is mostly beneficial for children, their families, and the medical staff.⁴ Family visitation practices are integral to the concept of family-centered critical care. There is mounting evidence that open policies allowing families at the bedside are beneficial and a crucial

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first step to successfully achieving a family-centered care model.^{5,6}

Restricted visitation policies in critical care have been challenged for over 20 years,⁷ yet most of the available evidence in support of an open model is observational in nature. Current family-centered care guidelines endorsed by key critical care organizations recommend an open, or a more flexible family presence at the bedside in the PICU, including the option of being present during resuscitation efforts.⁴

To our knowledge, there are no published data describing PICU visitation policies or practices across various Latin American countries. Therefore, we sought to describe family access and visitation practices in PICUs across Latin America. We hypothesized that, in the current era, there would be large variability regarding these practices across the Latin American countries.

Materials and Methods

Study Design and Participants

This study consisted of a cross-sectional survey designed to assess current visitation practices and attitude toward family presence in PICUs throughout Latin America. All PICUs belonging to the Latin American Collaborative Network (LAREd Network, $n = 36$) were invited to participate, in addition to a convenience sample of 11 PICUs with which one of the authors had previously collaborated in research activities, including academic ($n = 6$) and private ($n = 5$) units.

Participation was voluntary and consent to participate was implied by completion of the survey. This study was approved by the Institutional Review Board from Hospital de San José (Bogotá DC, Colombia) with waiver of written informed consent.

Measurements and Data Analysis

The survey was distributed during September of 2018 by e-mail messages sent to clinical leaders of each PICU. Clinical leader was defined as someone with deep knowledge of the operational characteristics of their PICU and the point person authors reached out to collaborate with the present survey. This individual could be a lead researcher, a senior attending physician, or a clinical director, to name a few examples. The survey consisted of five open questions that could be answered objectively and with free text: (1) "How many hours each day are the parents allowed at their child's bedside in the PICU?"; (2) "How many hours each day are healthy siblings allowed at the bedside in the PICU?"; (3) "Is family presence allowed at the bedside during invasive procedures (e.g., endotracheal intubation, thoracentesis, insertion of central venous catheter)?"; (4) "Is family presence allowed at the bedside during cardiopulmonary resuscitation?"; and (5) "Is animal visitation allowed in the PICU (family pet or hospital pet therapy)?"

These answers were then abstracted by the investigators, pooled, deidentified, and analyzed using a Microsoft Excel (Microsoft Corporation, United States) datasheet. A quantitative analysis of survey results is presented descriptively.

Fig. 1 Responses by country.

Fig. 2 Responses to the question "How many hours per day are parents allowed to be at the bedside (visit) with their child in your pediatric intensive care unit (PICU)?"

Results

We obtained responses from 11 Latin American countries (→ Fig. 1): Argentina (8.7%), Bolivia (6.5%), Brazil (21.7%), Chile (19.5%), Colombia (6.5%), Costa Rica (2.2%), Ecuador (4.4%), Honduras (2.2%), Puerto Rico (2.2%), Surinam (2.2%), and Uruguay (23.9%), with responses from 46 out of 47 invited PICUs (97.9% response rate). Although the survey consisted of open-ended questions where the respondent could enter free-form text, all responses received were objective, complete, and unambiguous.

Parental and Sibling Visitation at the Bedside

Unrestricted (24 hours per day) parental visitation occurred in 63% of PICUs (→ Fig. 2). The remaining units had some form of restrictive visitation practice, which varied widely among units from 20 hours/day to only 2 hours/day. Only one out of three PICUs allowed sibling visitation with highly restrictive practices since only 2 PICUs (4.4%) permitted sibling access 24 hours/day (→ Fig. 3).

Family Presence during Procedures

Only 35% PICUs allowed family presence at the bedside during invasive procedures (i.e., endotracheal intubation,

Fig. 3 Responses to the question “How many hours per day are healthy siblings allowed to be at the bedside (visit) with their child in your pediatric intensive care unit (PICU)?”

Fig. 4 Responses to the question “Is family presence allowed at the bedside during invasive procedures (e.g., endotracheal intubation, thoracentesis, insertion of central venous catheter)?”

central line placement, chest tube insertion) (►Fig. 4). Conversely, more than half (54%) of PICUs permitted family presence during cardiopulmonary resuscitation, with an additional 11% allowing this practice at the discretion of the attending physician (►Fig. 5).

Fig. 5 Responses to the question: “Is family presence allowed at the bedside during cardiopulmonary resuscitation?”

Pet Visitation

The availability of pet visitation was almost nonexistent in the units sampled, with only 1 PICU allowing patient contact with animals.

Discussion

In this international multicenter study, we found that family access and visitation practices in Latin American PICUs are still restrictive, with a wide variation in existing practices. While there is a paucity of data on visitation and family access in Latin American PICUs, our findings suggest that such practices fall below the optimal standard currently advocated for the care of critically ill children and their families.^{4,5}

Nearly two decades ago, the United States Institute of Medicine put forth its recommendation that health care delivery should be centered on the patient, rather than on the clinician or the disease process, and that treatments and decisions should be tailored to the individual patient's preferences and beliefs.⁸ Shortly thereafter, in recognition of the vital role played by families in the concept of patient-centered care, the American College of Critical Care Medicine (ACCM) of the Society of Critical Care Medicine published its clinical practice guidelines for support of the family in the patient-centered intensive care unit (ICU). These guidelines were developed through an extensive systematic review of the available adult, pediatric, and neonatal literature on family-centered care, including the subject of family presence at the bedside in the ICU.⁴ The ACCM guidelines made strong recommendations for a system of open visitation in the adult intensive care environment that allows for flexibility for patients and families and is determined through shared decision making involving the patient, family, and nursing, thus resulting on a schedule that takes into account the best interest of the patient.⁴ For children, the ACCM guidelines recommended that visitation in the pediatric or neonatal ICU be open to parents and guardians 24 hours a day. In addition, visitation should also be permitted for siblings, provided they complete a previsit education process and have parental approval.⁴ This system of an open PICU with unrestricted visitation affording the family the opportunity to be present at the bedside has since become the standard in North American PICUs.

Family empowerment and engagement in the care of a critically ill relative is an important component of the ICU liberation collaborative effort (it is the “F” in the ABCDEF bundle) that has been shown to improve clinically meaningful outcomes, including survival, mechanical ventilation use, coma and delirium, restraint-free care, ICU readmissions, and post-ICU discharge disposition.⁹ A possible explanation for our findings could be the evidence gap on the salutary effects of open or flexible visitation practices in the ICU environment. Although intuitively positive, there are no robust studies addressing the effect of unrestricted visitation on family-centered outcomes in the pediatric critical care environment. The available body of evidence is largely observational, and derived mainly from the adult ICUs where

visiting policies tend to be more restrictive. Nassar et al performed a systematic review and meta-analysis of observational and randomized studies comparing flexible versus restrictive visitation policies in the adult ICU setting and outcomes; they showed that flexible visiting hours were associated with reduced frequency of delirium, decreased anxiety, and greater family satisfaction, without an increase in mortality, ICU length of stay, or ICU-acquired infections.¹⁰ However, flexible visiting hours were also associated with higher levels of burnout among ICU professionals.¹⁰ More recently, a large randomized trial involving 1,685 patients from 151 Brazilian ICUs sought to answer whether a more flexible visitation practice (up to 12 hours per day) reduced the incidence of delirium compared with standard practice (visitation up to 4.5 hours per day).¹¹ Although this study failed to demonstrate that flexible visitation reduced the incidence of delirium, it led to lower anxiety and depression scores in family members.¹¹ The lack of strong evidence supporting open family visitation policies might explain why current adult ICU visitation practices are still predominantly restrictive. These restrictions range from prohibition of visits up to only a few hours a day, and occur across varied sociocultural contexts, such as in Belgium,¹² Brazil,¹³ France,¹⁴ Iran,¹⁵ Spain,¹⁶ and in the United States,¹⁷ although significant practice variability exists.¹⁸

In pediatric practice, families cannot be simply viewed as “visitors” in the PICU, since they—particularly the parents—are the child’s natural caregivers. Obvious as it might seem, this basic concept is not universally embraced in many PICUs. Italy is the only country for which the prevalence of unrestricted family visitation in PICUs has been described during the last decade. A study of parental presence and visiting policies in 34 Italian PICUs found that only 12% had unrestricted visiting policies, 59% did not allow continuous presence of a parent at the bedside, and 76% did not allow child visitors (i.e., siblings). Parental presence during cardiopulmonary resuscitation (9%) or invasive procedures (3%) was even more rare.¹⁹ Although 48% of PICUs in that study reported at the time that a formal process of revising visitation policies was ongoing, little had changed in the span of 8 years in reappraisal of this topic by the same group.²⁰ Our study has shown that, compared with our Italian counterparts, current family visitation practices in Latin American PICUs are relatively more “open,” with nearly 2 out of 3 PICUs allowing continuous parental presence at the bedside. Unfortunately, much remains to be done toward improving the presence of siblings in the PICU.²¹ It should also be noted that an unrestricted visitation policy does not necessarily translate into continuous parental presence at the bedside. An observational prospective cohort study conducted in a single tertiary PICU in England found that a parent was present at the bedside for only 58% of the time, despite the opportunity for unrestricted visitation in that unit.²² This observation suggests that multiple extrinsic factors beyond visitation policies may influence parental presence at the bedside in PICU.

Animal-assisted interventions, such as pet therapy, are promising adjuncts in the recovery from critical illness and a

tool for “humanization” of the critical care environment,²³ yet such interventions are notably absent and largely anecdotal in our Latin American sample. The fact that only 1 out of 46 PICUs in our sample allowed pet visitation highlights a significant opportunity for improvement.

The concept of family-centered care supports family presence during procedures in the PICU. Family presence during endotracheal intubation has not been associated with a decreased rate of success on first intubation attempt, adverse intubation events, oxygen desaturation, or higher team stress level,²⁴ yet most of our Latin American PICUs do not allow family at the bedside during procedures. Lack of family presence during procedures in the PICU need not be the norm; data from a single PICU in Uruguay that embraces an “open approach” affording continuous bedside access to family reported that a family member was present during invasive procedures (e.g., intubation, central line insertion) 84% of the time, with high rates of family satisfaction.²⁵

Access to a hospitalized loved one is particularly important for Latin American due to certain cultural factors. For Latinos (used here to denote individuals born in a country whose language evolved from Latin), several socioeconomic and cultural factors may affect health care outcomes. For instance, among Latinos, loyalty to the family is viewed as more important than the needs of the individual, a concept known as “familismo.”²⁶ It is common for Latinos to seek input from a large number of family members when making important health decisions. It would be interesting for future studies to explore whether *familismo*, or other similar cultural phenomena, could be associated with the prevalence of unrestricted visitation in our study, and particularly how it compares to those in other parts of the world. Although we attempted to provide a snapshot of visitation practices in our study, we did not explore the impact of more or less restricted visitation practices on the immediate and extended family. We are curious as to whether *familismo* plays a role in family satisfaction and perception of the quality of care delivered to the child, a topic we intend to explore on future studies. It is likely that cultural background and family context will be key drivers in the transformation of Latin American PICUs toward a more open and inclusive environment for patients and their families. Interestingly, these sociocultural needs of Latinos relative to health care features are not be necessarily generalizable. For instance, in Ghana, Yakubu et al reported family skepticism when given the opportunity for unrestricted visitation, with concerns that it could hinder recovery.²⁷

Important additional factors must also be considered when interpreting our findings, namely professional staffing and infrastructure. Open family presence at the bedside can be challenging to ICU staff. For instance, surveys aimed at assessing the beliefs and attitudes of ICU reported skepticism and resistance toward open visiting policies.^{28,29} In one study, over 75% of the surveyed nurses were against liberalizing visitation policies, arguing it would pose a physical and psychological burden for their work, hamper adequate planning of nursing care, and interfere with direct care.²⁸

This potential tension can be aggravated in a PICU environment lacking infrastructure conducive to family-centered care, such as spacious private rooms, designated space where families can visit without interfering with care, and a place for families to rest.⁵

To our knowledge, this is the first multinational survey to explore family visitation practices across a representative number of PICUs in Latin America. Our findings must be interpreted in the context of potentially important limitations that could hinder generalization. First, most of the participating PICUs belong to a collaborative network, many with close relation to academia and research groups and almost two-thirds of responses came from four countries. These could be important biases for external validity that may limit generalization of our findings to the rest of the region. Second, responses were undertaken by PICU leaders on behalf of their units, so answers might represent intent instead of actual practices. It is unclear whether these limitations could have led to an overestimation or underestimation of the real prevalence of unrestricted visitation. Third, we did not explore important determinants of visitation policies, such as PICU type (e.g., academic or nonteaching, public or private) and infrastructure (e.g., number of PICU beds, staffing, patient-to-nurse ratio), attitude of professional staff regarding visitation, institutional policies and procedures, or population sociocultural and ethnographic characteristics. Nevertheless, we believe our study provides a high-level snapshot of visitation practices in the region, and serves as foundation for additional work and interventions. Another timely and important point not addressed in our study but deserving of future attention is how the coronavirus pandemic (COVID-19) and the resultant implementation of extraordinarily restrictive visitation policies and clinical practices have impacted family presence at the bedside and have affected PICU operations around the world. Studies such as ours can help inform the “baseline” for visitations practices that were in place prior to the changes implemented during the coronavirus pandemic.

Conclusion

Our findings indicated that visitation practices and opportunity for family presence at the bedside in Latin American PICUs are still restrictive, although variability exists. Given the global shift toward more open visitation practices and family-centered care, additional research is needed to identify actionable factors to increase family presence and participation in the care of their critically ill children, and potential barriers to its implementation.

What is already known about this topic?

Admission to a pediatric intensive care unit has long-lasting effects for the patients and their family. Family presence at the bedside is a crucial step toward achieving a family-centered care model. There are no published data describing PICU visitation policies (or practices) across various Latin American countries.

What does this article add?

Although there is wide variation in practice, family visitation and bedside presence are still restrictive in Latin American PICUs. Most units do not allow for family presence during invasive procedures. Pet visitation is nearly nonexistent.

Authors' Contributions

S.G.-D. and A.T.R. performed conceptualization and design of the study, secured administrative support, and took part in building of survey data; S.G.-D., P.V.-H., A.T.R. contributed in data analysis and interpretation; provision of study materials or patients were performed by all authors, along with collection and assembly of data; all authors contributed in manuscript writing and the final version of the manuscript is approved by all authors.

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None.

Conflict of Interest

A.T.R. is a scientific advisor for Breas US and Vapotherm, and has received honoraria for development of educational materials and lecturing. The remaining authors declare no conflict of interest.

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