Institutional and visitation policies for family participation in pediatric intensive care care

Políticas institucionais e de visitação para participação da família no cuidado em terapia intensiva pediátrica

Políticas institucionales y de visitas para la participación familiar en cuidados intensivos pediátricos

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Resumo

Objetivo: Analisar políticas institucionais das Unidades de Terapia Intensiva Pediátricas (UTIPs) para a participação da família nos cuidados à criança internada.
Métodos: Tratou-se de pesquisa qualitativa, descritiva e exploratória, a partir de análise documental pautada na análise de conteúdo e no modelo do Cuidado Centrado na Criança e na Família (CCCF). Foram realizadas buscas de leis, resoluções e políticas brasileiras relacionadas à participação da família no contexto da internação em UTIPs, levantamento de todas as UTIPs do município de São Paulo, para análise das políticas de cuidado e visitação, em seus sites institucionais de acesso livre.
Resultados: O estudo mostrou a existência de respaldo na legislação brasileira no que diz respeito à importância da participação da família no cuidado da criança em UTIPs e uma distribuição desproporcional da disponibilidade de leitos entre as regiões da cidade de São Paulo. Os dados foram organizados em duas categorias: (1) Conceitos e ações que favorecem a participação no cuidado da criança grave, que apresenta as práticas alinhadas ao CCCF; (2) Restrições das políticas institucionais e de visitação para a participação da família, que está relacionada às barreiras e/ou impeditivos da operacionalização do CCCF.
Conclusão: A legislação brasileira assegura o direito à presença familiar com condições adequadas e visitas ampliadas, mas ainda carece de políticas para a participação de menores, como os irmãos. Em São Paulo, a distribuição desigual de leitos de UTIPs contrasta com a concentração de crianças, evidenciando a necessidade de fortalecer políticas institucionais e cuidados de enfermagem que promovam a ampla participação familiar durante a hospitalização.

Descriptors
Pediatric Intensive Care Unit; Organizational Policy; Family Nursing; Hospitalized Children; Family

Abstract

Objective: To analyze institutional policies of Pediatric Intensive Care Units (PICUs) for family participation in the care of hospitalized children.
Methods: This was a qualitative, descriptive and exploratory study, based on documentary analysis guided by content analysis and the Child and Family Centered Care (CFCC) model. Searches were made for Brazilian laws, resolutions and policies related to family participation in the context of PICU hospitalization, and a survey of all PICUs in the city of São Paulo was conducted to analyze care and visitation policies on their freely accessible institutional websites.
Results: The study showed that Brazilian legislation supports the importance of family participation in the care of children in PICUs and that there is a disproportionate distribution of bed availability among the regions of the city of São Paulo. The data were organized into two categories: (1) Concepts and actions that favor participation in the care of critically ill children, which present practices aligned with CFCC; (2) Restrictions of institutional and visitation policies for family participation, which are related to barriers and/or impediments to the operationalization of CFCC.
Conclusion: Brazilian legislation ensures the right to family presence with adequate conditions and expanded visits, but it still lacks policies for the participation of minors, such as siblings. In São Paulo, the unequal distribution of PICU beds contrasts with the concentration of children, highlighting the need to strengthen institutional policies and nursing care that promote broad family participation during hospitalization.

Descritores
Unidade de Terapia Intensiva Pediátrica; Política Organizacional; Enfermagem Familiar; Crianças Hospitalizadas; Família

Resumen

Objetivo: Analizar las políticas institucionales de las Unidades de Cuidados Intensivos Pediátricos (UCIPs) para la participación familiar en el cuidado del niño hospitalizado.

Descriptores
Unidad de Cuidados Intensivos Pediátricos; Política Organizacional; Enfermería Familiar; Niños Hospitalizados; Familia

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Métodos: Se trató de una investigación cualitativa, descriptiva y exploratoria, basada en el análisis documental orientado por el análisis de contenido y el modelo de Atención Centrada en el Niño y la Familia (ACNF). Se realizaron búsquedas de leyes, resoluciones y políticas brasileñas relacionadas a la participación familiar en el contexto de la hospitalización en UCIP, una encuesta en todas las UCIP de la ciudad de São Paulo, para analizar las políticas de atención y visitas, en sus sitios web institucionales de libre acceso.
Resultados: El estudio mostró la existencia de apoyo en la legislación brasileña respecto a la importancia de la participación familiar en el cuidado de los niños en UCIP y una distribución desproporcionada de la disponibilidad de camas entre las regiones de la ciudad de São Paulo. Los datos se organizaron en dos categorías: (1) Conceptos y acciones que favorecen la participación en el cuidado del niño gravemente enfermo, que presenta prácticas alineadas al ACNF; (2) Restricciones a las políticas institucionales y de visitas para la participación familiar, lo que se relaciona con barreras y/o impedimentos para la operacionalización de la ACNF.
Conclusión: La legislación brasileña garantiza el derecho a la presencia familiar con condiciones adecuadas y visitas prolongadas, pero aún carece de políticas para la participación de menores, como los hermanos. En São Paulo, la distribución desigual de camas de UCIP contrasta con la concentración de niños, lo que destaca la necesidad de fortalecer políticas institucionales y cuidados de enfermería que promuevan una amplia participación familiar durante la hospitalización.

Introduction

The admission of a child to a Pediatric Intensive Care Unit (PICU) can cause stress for the family, impacting on their experience of care. It is therefore essential to implement policies that encourage family participation, with clear guidelines and strategies to meet the needs of children and families.[1] The literature brings together a body of evidence on the importance of taking a close look at visitation and participation policies with regard to the time and stay of the family at the bedside as well as the physical structure, human resources and technical-scientific knowledge needed to welcome these families and promote their participation in a PICU.[2,3]

In this regard, Child and Family Centered Care (CFCC) has emerged as a health care model applicable to institutional policies and which recognizes the family as an essential element in child care. It is known that a family-centered approach helps to reduce the stress of children and their families, and the length of hospital stays promotes better comprehensive care for children and fosters meaningful relationships between children, staff and families, improving their physical and emotional recovery process.[1,4]

Despite the existence of the CFCC model, what we see in hospital practice are institutional policies that, for the most part, restrict and control family members' actions, limiting visits and schedules, lacking flexibility and adequate spaces.[5,6] Thus, there are gaps in the implementation of CFCC and its articulation with institutional policies, limiting the practice of best evidence in the context of care for children in a PICU.

This study reinforces the need for active family participation in a PICU, as this condition provides emotional support and helps to reduce the anxiety and stress associated with children's hospitalization - a desired goal in pediatric nursing practice. [7,8] There is a body of evidence on how family participation in decisions and in the care process results in increased satisfaction with health services by fostering an environment of trust and reciprocal cooperation between health team and family members, strengthening bonds. [9 - 11]

The overview of institutional policies presented in this study favors public policies insofar as it indicates the potential, barriers and limitations of the current actions operationalized in institutions to provide family participation in a PICU. In view of this, the research question of this study was "How do institutional policies support family participation in the care of children in a PICU?", and the objective was to analyze institutional policies for family participation in the care of children admitted to a PICU.

Methods

This was a qualitative, exploratory and descriptive study about institutional policies for family participation in the care of children hospitalized in a PICU, using documentary analysis. Documentary analysis is a technical and scientific process that extracts the conceptual essence of various sources of information, such as laws, photos, videos and newspapers, including social media.[12,13] For this purpose, public sources of information and access to free digital repositories were used, which did not require approval from the Research Ethics Committee.

The data for this study was collected from May to July 2024, using search engines to identify laws,

Table 1. Search strategy for official documents and institutional policies

Source of information	Terms and keywords	Materials selected
Google, Google Scholar, Federal Government Legislation Portal	"law", "resolution", "family", "visitation policy", "child", "companion", "Intensive Care Unit", "ICU" and "pediatric".	Law 8,069/90 of the Statute of the Child and Adolescent, Resolution 41/1995, Companion Law 10,689/2000, Brazilian Health System (In Portuguese, *Sistema Único de Saúde* - SUS) National Humanization Policy (In Portuguese, *Política Nacional de Humanização* - PNH), Ordinance 895/2017 of the Ministry of Health, Bill 622/2020 and Law 14.950/2024
Google	"family", "relatives", "parents", "pediatrics", "care", "visit", "visitation", "schedules" and "mission, vision and values".	Information about visitation policies, care models and perspectives on children and families on the 52 PICU institutional websites found in the municipality of São Paulo.

resolutions, ordinances and public policies related to family participation in a PICU as well as collecting information on institutional and visitation policies in PICUs in the city of São Paulo.

The documents were selected using the search engines Google and Google Scholar, as well as the Federal Government's Legislation Portal, using the free terms "law", "resolution", "visitation policy", "family", "child", "companion", "Intensive Care Unit", "ICU" and "pediatric", as shown in Table 1. National documents that addressed health care policies for children and their families were included.

In order to collect data on institutional and visitation policies, we opted for PICUs in the city of São Paulo. To this end, sociodemographic and epidemiological data was mapped using the Brazilian National Register of Health Establishments (In Portuguese, *Cadastro Nacional de Estabelecimentos de Saúde* - CNES) of the Health Care Department of the Brazilian Ministry of Health (BR-MoH) with a base year of 2024, considering all hospitals in the capital of São Paulo that have PICUs. [14] Based on the addresses of the hospitals in the sample, a classification was made considering the regions of the health surveillance territories of the Health Surveillance Units (HSUs), located in the six regions of the municipality (North, South, East, Central, West and Southeast) under the coordination of the Health Surveillance Coordination (In Portuguese, *Coordenadoria de Vigilância em Saúde* - COVISA).[15]

After identifying the PICUs in São Paulo, a search was carried out on the hospitals' institutional websites to analyze the availability of information related to the CFCC-based care model. Terms such as "family", "familiar", "parents", "pediatrics", "care", "visit", "schedules" and "mission, vision and values" were used on Google® and the websites' internal mechanisms to gather data on visitation policies and other aspects relevant to the research. The research team designed a collection tool to organize the data, taking into account variables such as type of family policy, participation, CFCC concepts, visiting times and duration, number of visitors, presence of accompanying persons and permission for children under 12.

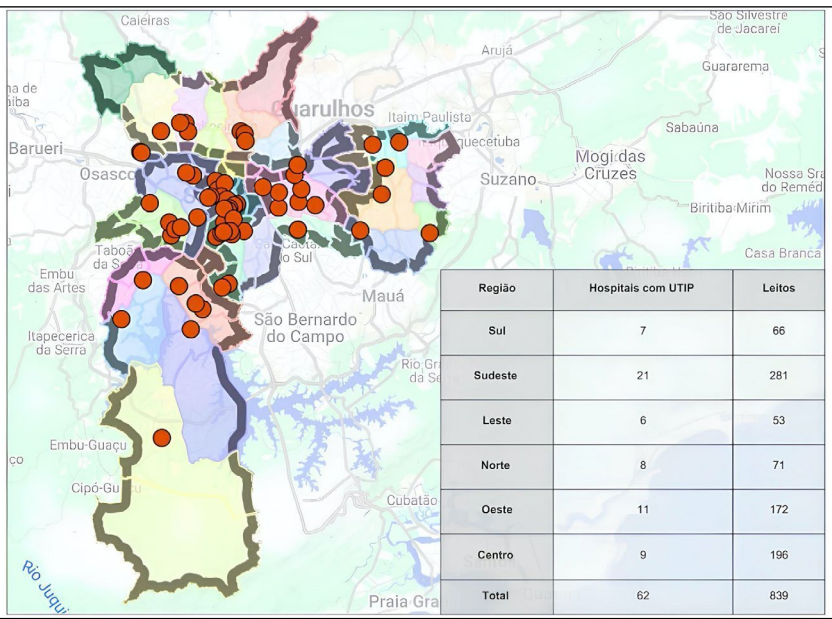
For data analysis, a content analysis was carried out, following three stages: (1) familiarization with the data through careful reading; (2) identification of units of analysis, such as central words or phrases; and (3) categorization, with naming of categories and connections of ideas. The units were grouped by similarities and frequency, with peer checking.[16,17] In order to substantiate the categories, we also sought connections with the CFCC concepts: family participation and collaboration in the care process; guarantees of respect and dignity for the child and their family; and the exchange of information between health team and family.[16]

Results

The results of this study considered seven official documents dealing with family participation and 62 hospital websites in the city of São Paulo. The seven official documents identified in this study involved laws and draft laws, policies and resolutions that dealt with the presence and encourage family participation, including aspects for the development of humanization strategies, particularly in a PICU, as shown in Table 2. The analysis identified essential dimensions in child and family care, such as extending visits, adapting spaces and facilitating access to health information. However, policies for visits to minors, such as siblings, are still limited, with a recent law for visits to hospitalized parents and a bill in progress for visits to hospitalized children.

Table 2. Main legal instruments supporting family participation in a Pediatric Intensive Care Unit environment

Statute of the Child and Adolescent - Article 12 of Law 8,069/90	Provides for the right to full-time family presence in healthcare facilities, including Intensive Care Units, and the need for conditions so that parents or guardians can be provided with this presence.
Resolution 41/1995 of the Brazilian National Council for the Rights of Children and Adolescents (In Portuguese, Conselho Nacional de Direitos da Criança e do Adolescente - CONANDA)	Approves the rights of hospitalized children and adolescents, including the presence of a parent or guardian as a companion during the entire period of hospitalization, as well as their participation in children's prognosis and treatment, receiving information about the procedures they will undergo.
Companion Law 10,689/2000	Ensures that the family member or person responsible, under the State's responsibility, has the right to enter and stay with the person hospitalized in the health service. Subsections 2 and 4 of Article 1 also emphasize that facilities must provide adequate conditions to make this stay possible, and that children must receive preferential attention in this care.
Brazilian Health System PNH - 2003	Plans to expand visits with so-called "open visits" because it understands that mobilizing a network of social and family support for patients is fundamental for their full recovery and for maintaining their life project, given the bond that is established between patients, their families and the health network.
Ordinance 895/2017 of the Ministry of Health	Establishes guidelines and specifications for the physical space of PICUs in order to increase access and improve care, and guarantees daily and scheduled visits by family members as well as free access for mothers and fathers to health information. It also mandates that new healthcare establishments must include support rooms in their PICUs that are equipped to guarantee compliance with children's right to a full-time companion.
Law 14,950/2024	Guarantees the right of children and adolescents to visit their mother or father in a health institution.
Bill 622/2020 (still in analysis)	Seeks to guarantee legal bases so that children can also visit other hospitalized minors in any health care unit, even Intensive Care Units.



Região	Hospitais com UTIP	Leitos
Sul	7	66
Sudeste	21	281
Leste	6	53
Norte	8	71
Oeste	11	172
Centro	9	196
Total	62	839

Figure 1. Distribution of Pediatric Intensive Care Units according to their Health Surveillance Units

Based on the data collected from CNES, 62 health institutions with PICUs were identified in the municipality of São Paulo, 29 of which were private and 33 public, geographically distributed as shown in Figure 1. The PICUs were grouped according to their HSUs in the six political regions of the territory and their areas of coverage, with the southeast region having the highest number of beds (281), distributed in 21 PICUs, which accounts for 33.5% of the total capacity of PICU beds, while the east region has the lowest number of beds (53), available distributed in six PICUs, corresponding to 6.3% of the total capacity of beds.

After identifying the 62 health institutions with PICUs in the city of São Paulo, an analysis of their websites revealed that most of the health institutions considered in the study have institutional websites (n=52, 84%). The ten hospitals that did not have a website were public and municipally run. Of the 52

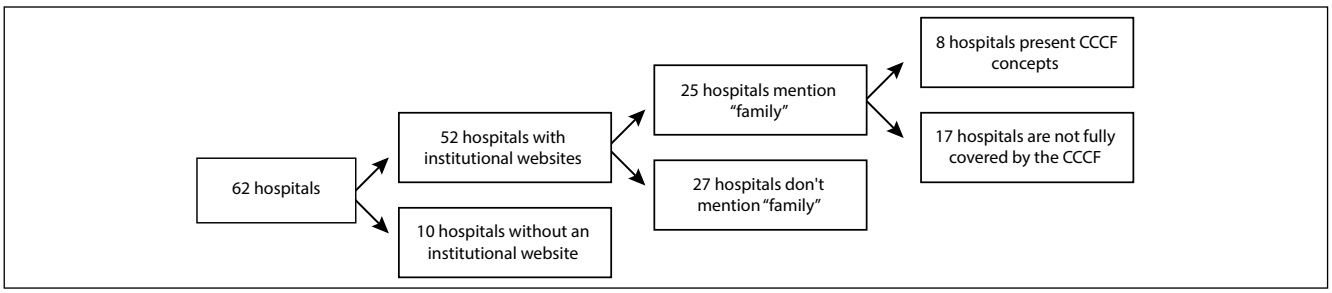


Figure 2. Institutional websites according to availability, mention of the family and relationship with Child and Family Centered Care concepts

institutional websites analyzed, only 25 found direct information related to the family and their participation in the care of hospitalized children. Of these, eight presented the concepts related to CFCC in integrality, and pointed to the family as one of their care priorities, while 17 hospitals did not relate aspects of the CFCC model to their care practices. Figure 2 shows the flow of information analyzed from the 62 hospitals with PICUs.

Table 3 shows the relationship between the care philosophies of the eight hospitals that presented CFCC concepts and the normative policies for visiting hospitalized children in their PICUs. In this way, we were able to analyze institutional policies in relation to family visitation policies.

The analysis of the materials identified two categories that explore institutional policies for family participation in the care of children hospitalized in a PICU: (1) "Concepts and actions that favor family participation", which brought together the practices instituted in hospitals aligned with the CFCC model; (2) "Restrictions of institutional and visitation policies for family participation", which demonstrated barriers in the rigid regulations regarding the presence and participation of the family in a PICU.

The category "Concepts and actions that favor family participation" brings together common perspectives on CFCC. These concepts and actions involved the promotion of humanized care aimed at ensuring respect and dignity for families, communication between families and professional staff to exchange information about children's health, taking a leading role in care and decision-making.

> *"Patient- and Family-Centered Care won't always meet all your wishes and desires, but the big difference lies in transparent communication, in the reasons for what is or isn't possible, in everyone's efforts to offer alternatives within their means. This makes all the difference. The patient and family feel respected as unique and special individuals." (H4)*

Actions that promote respect for the family, reduction of tension and support during hospitalization stand out, including nuclei, programs and committees that give voice to family needs, as well as play environments, rest rooms and hospital psychology services. In this regard, actions aimed at family participation highlighted policies that guarantee CFCC in a PICU, promoting humanized care, respect and clear communication. These strategies seek to strengthen family collaboration and make them leading stars in care and decision-making.

The category "Restrictions in institutional and visitation policies for family participation" represents the set of practices in these hospitals that make it difficult for family members to be present in the child's hospitalization process: lack of access and clarity of information on institutional websites, inflexible schedules and restricted durations of visits, limitations on companions and visitors (visitation policies for children under 12 - not mentioned in the regulations or authorized by staff decision; number of visitors per variable time slot without clear criteria).

> *"Only one person is allowed per bed, i.e. during visiting hours, it is necessary to change the companion and visitor at the entrance." (H1)*
>
> *"Duration of visiting hours: 30 minutes. 2 visitors allowed - 1 at a time. At 3 p.m. Children under the age of 12 are not allowed to visit or be accompanied." (H8)*

Table 3. Hospitals that present Child and Family Centered Care concepts on their websites according to their characterization, visitation policies and presence of a companion

	Characterization	Child and Family Centered Care perspectives	Visiting hours	Visit by children under 12	Number of visitors per hour	Presence of companions
H1	State-run public general hospital in the western region	It values patients and their families. It has a program developed by its humanization unit that gives patients a voice to ensure a more patient-centered approach, holding meetings to discuss the needs and concerns expressed by the patient group.	One hour, twice a day, 3 p.m. and 8 p.m.	Not mentioned	Two visitors per time slot, one at a time	One companion (at the time of the visit, the companion must be at the gate for the visitor to enter)
H2	Private general hospital in the west	It seeks to meet children's personal needs as well as those of their parents and relatives. Family participation is seen as important and encouraged throughout hospitalization. There are conditions for parents to remain close to children, providing emotional support. It highlights the importance of parents knowing the routine of the service so that multidisciplinary work can be fully developed. It has a Hospital Humanization Program.	Visitors are allowed 24 hours a day	Not mentioned	Not mentioned	There are no restrictions
H3	State-run general hospital in the western region	Guided by CFCC. Encourages and values family participation. Presents a space equipped to provide humanized care for children and their families. They include the family through practices and programs in partnership with the team. Groups are offered for families to discuss their experiences and topics of interest as well as recreational workshops. The family is encouraged to participate and accompany professionals in their care.	One hour, three times a day, 11 a.m., 4 p.m. and 8 p.m.	Not mentioned	One visitor per hour	One companion
H4	Private specialized hospital with SUS beds in the central region	Guided by CFCC. It points out that CFCC will not always fulfill every wish and desire, but its differential lies in transparent communication about all the possibilities and alternatives for patients. It values the patient and family feeling respected as unique and individual beings, and considers them active agents in making and carrying out decisions. There is joint action with the multidisciplinary team.	One hour, twice a day 12 p.m. and 8 p.m.	Not mentioned	Two visitors	One companion with a change every 12 hours (at 6 a.m. and 6 p.m.)
H5	Private general hospital with SUS beds in the central region	They have support and humanization actions for families and patients, in order to minimize the tensions and challenges of hospitalization. These include parent committees with the multidisciplinary team, psychology services, entertainment and cultural activities).	Visitors are allowed 24 hours a day	Yes, previously agreed and accompanied by a psychologist	Not mentioned	Not mentioned
H6	Private general hospital in the central region	Patient-centered care is one of the hospital's care models. It is essential that patients and companions are involved in their treatment, informed of important information and feel respected. It establishes the involvement and integrated sharing of actions by the multidisciplinary team. Patients and their families are targets throughout the care process.	Two hours twice a day, 3 p.m. and 9 p.m.	Not mentioned	Two visitors, one at a time	Two companions allowed. Change at intervals of at least four hours
H7	Private children's hospital in the central region	They establish a partnership with parents through active participation. There are multidisciplinary meetings between parents and hospital staff. Companions are included in the care and decision-making process. Spaces and procedures are designed according to children's needs. They understand that no one knows children better than their own parents.	30 minutes, twice a day, 4 p.m. and 9 p.m.	Not allowed	Two visitors, one at a time	During the day, two companions are allowed. At night, only one
H8	Private general hospital in the central region	Pediatric patient-centered work. They offer humanized care. The family is seen as a participatory and collaborative element in care. Together with a multidisciplinary team, the therapeutic plan is discussed with the family.	30 minutes a day, at 3 p.m.	Not allowed	Two visitors	One at a time, with changes allowed every 12 hours

These restrictions are at odds with the CFCC model, as they do not encourage family participation in the process of caring for children in PICUs. The rigid rules demonstrate the lack of actions that promote the family's leading role in care and decision-making as a result of physical and symbolic distancing.

Discussion

This study supports the importance of integrating CFCC principles into hospitals, especially PICUs, in accordance with institutional and visitation policies.[6,18,19] Active family participation is crucial to children's recovery process, as it strengthens emotional bonds and contributes to their physical and emotional recovery. On the other hand, barriers to this participation can have a negative impact on children's experience in hospital and their recovery.[3,20,21]

Furthermore, there was a heterogeneous distribution of PICUs between the regions of the city of São Paulo. The southern and eastern regions, despite having the highest proportion of children among their inhabitants, 583,823 children (20.3% of the total population) and 520,512 children (20.4% of the total population), respectively, have the lowest number of PICU beds available. In contrast, the southeast region, with a similar population of 452,471 children (16.6% of the total population), has three times as many PICU beds available in its catchment area, reflecting inequalities in access to healthcare.[22] It is essential to reflect on the impact of geographical distances on family functioning during a child's hospitalization, seeking to adapt the support network to reduce conflicting feelings and better meet family needs.[23]

The category "Concepts and actions that favor family participation" focuses on humanization that transcends the family's physical presence, favoring the establishment of genuine bonds between health professionals, patients and their families. Effective communication between them is a fundamental pillar in this process, enabling the exchange of relevant information about children's health and fostering an environment of trust and collaboration.[24,25]

For families to be able to play a leading role in actions and decisions related to their children's health, it is essential that they are involved and respected, through spaces where they can express their needs and concerns and participate in decision-making processes. This not only empowers family members, but also contributes to a more complete understanding of children's health conditions, boosting family engagement.[24,,25]

Humanized care requires health professionals to be empathetic, recognizing the uniqueness of families and the complexity of situations in the ICU. By validating emotions and experiences, professionals not only help children's recovery, but also promote emotional well-being, contributing to integrated care. Implementing CFCC in clinical practice requires institutional policies that underpin family support actions, in addition to the commitment expressed in the hospital's mission and values.[26]

Furthermore, in the category "Restrictions in institutional and visitation policies for family participation", we see practical actions in health institutions that contradict family perspectives that are publicized on the websites accessed. For instance, the same institution that claims to "value patients and their families" has restrictive visitation policies on its website, such as not allowing a companion to be present when a visitor enters, which would leave a child unaccompanied for a period of time.

Data analysis shows that although the institutions guide their assistance by CFCC, or by perspectives of its model, all of them have aspects in their visitation policies that restrict the active family participation, supporting the literature that points to multiple barriers to the implementation of CFCC over the years.[27-30]

This study highlights shortcomings in a PICU, such as: (1) the lack of collaborative processes and flexible care, evidenced by limits on the number of companions and fixed visiting hours; (2) restrictions on sharing public information useful to the family; (3) the family's limited view as a physical presence, without considering their active participation and the cultural, ethical and social aspects in a child's life.

Study limitations are related to access to information, due to restricted data sources, considering the public and virtual materials on web pages, and the absence of institutional websites of ten public hospitals considered in the initial sample for analysis.

Conclusion

Brazilian legislation establishes the relationship between hospital policies and family participation in PICUs, guaranteeing, through documents such as the Statute of the Child and Adolescent and the Accompanying Person Law, the right to family presence and extended access to visits. These instruments recognize the importance of the family for child's recovery. However, policies for minor participation, such as siblings, are still incipient. Inequality in access to PICUs in São Paulo is related to the unequal distribution of beds, requiring families to travel long distances, which exacerbates vulnerabilities and makes it difficult to participate in care. Moreover, the analysis of institutional websites revealed that the CFCC model is approached in an inconsistent or absent manner, making it difficult for families to participate and access information about the support available. Although some hospitals follow the CFCC model on their websites, policies focus on visits, without promoting effective family participation in a PICU. Visits are limited by rigid schedules, short duration and restrictions, such as the exclusion of children under 12, making it difficult for siblings to have access. This study highlighted the need to operationalize the CFCC model based on the best evidence and to apply public policies to guarantee the rights of children and families. In addition, it identifies gaps in institutional policies, suggesting improvements in the inclusion of families in PICU care and in nursing practices, with a focus on family participation and strengthening visitation policies.

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Contributions

Lima PL, Silva LTP, Di Gregorio AC, Saraiva CV, Oliveira JA, Silva LAB, Szylit R and Santos MR declare that they contributed to study conception, data collection, analysis and interpretation, article writing, relevant critical review of intellectual content and approval of the final version to be published.

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