Factors associated with companions' perceptions of family-centered care in pediatric units

Fatores associados à percepção de acompanhantes acerca do cuidado centrado na família em unidades pediátricas

Factores asociados a la percepción de los acompañantes sobre el cuidado centrado en la familia en unidades pediátricas

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Abstract

Objective: To describe the perceptions of companions regarding Patient and Family-Centered Care, and to analyze their association with sociodemographic variables and hospitalization locations during the COVID-19 pandemic.
Methods: This analytical, cross-sectional study was conducted in the neonatal and pediatric units of a public hospital between May and October 2021. Data were collected over a period of 30 days in four units, using the Brazilian version of the Family-Centered Care Perception Instrument for Parents.
Results: Ninety-four companions participated. The perception of Patient and Family-Centered Care was predominantly positive, with an average total score of 3.21. The highest-scoring domain was respect, followed by collaboration and support.
Conclusion: Family members generally perceived the care as family-centered and positive. Identified areas for improvement include professional identification, managing high staff turnover, enhancing team knowledge about family support, and including other family members in the care process.

Keywords
Family; Child, hospitalized; Pediatric nursing; Nursing care; Family nursing

Resumo

Objetivo: Descrever a percepção dos acompanhantes acerca do Cuidado Centrado no Paciente e na Família e analisar sua associação com variáveis sociodemográficas e local de internação durante a pandemia da Covid-19.
Métodos: Estudo transversal analítico, realizado em unidades neonatais e pediátricas de um hospital público entre maio e outubro de 2021. Os dados foram coletados em quatro unidades durante 30 dias por meio do instrumento Percepção do Cuidado Centrado na Família-Pais versão brasileira.
Resultados: Participaram 94 acompanhantes. A percepção em relação ao Cuidado Centrado no Paciente e na Família foi positiva, com média do escore total de 3,21. O domínio com maior média foi respeito, seguido de colaboração e suporte.
Conclusão: Os familiares tiveram percepção positiva em relação ao cuidado centrado na família. A identificação dos profissionais, a alta rotatividade, o conhecimento da equipe sobre o suporte familiar e a inclusão de outros membros da família foram pontos de melhoria.

Descritores
Família; Criança hospitalizada; Enfermagem pediátrica; Cuidados de enfermagem; Enfermagem familiar

Resumen

Objetivo: Describir la percepción de los acompañantes sobre el Cuidado Centrado en el Paciente y la Familia y analizar su asociación con variables sociodemográficas y el lugar de hospitalización durante la pandemia de Covid-19.
Métodos: Estudio transversal analítico, realizado en unidades neonatales y pediátricas de un hospital público entre mayo y octubre de 2021. Los datos se recopilaron en cuatro unidades durante 30 días a través del instrumento Percepción del Cuidado Centrado en la Familia-Padres versión brasileña.
Resultados: Participaron 94 acompañantes. La percepción sobre el Cuidado Centrado en el Paciente y la Familia fue positiva, con un promedio de puntuación total de 3,21. El dominio con el promedio más alto fue respeto, seguido por colaboración y apoyo.
Conclusión: Los familiares tuvieron una percepción positiva sobre el cuidado centrado en la familia. La identificación de los profesionales, la alta rotación, el conocimiento del equipo sobre el apoyo familiar y la inclusión de otros miembros de la familia fueron puntos de mejora.

Descriptores
Familia; Niño hospitalizado; Enfermería pediátrica; Atención de enfermería; Enfermería de la familia

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Introduction

The process of hospitalization imposes adverse conditions due to the disruption of routine home life and can lead to biopsychosocial changes in both the child and their family members. These changes can interfere with their reactions and interactions with the environment, healthcare team, and support network.[1] The presence of the family in the hospital setting is crucial for the child's recovery process. However, with the onset of the COVID-19 pandemic in early 2020 in Brazil, children and their families experienced a new dynamic in hospital environments.[2]

Despite illness and hospitalization altering the lives of the child and family, comprehensive and humanized care, focusing on the needs of the child and family, can mitigate the negative impacts and enhance adaptive mechanisms, making the experience less traumatic.[3] In this context, Patient and Family-Centered Care (PFCC) is a philosophy that emphasizes the importance of family presence during the hospitalization of a sick person. It promotes a space for the involvement of the care unit, consisting of the patient and their family, in decision-making processes related to the care provided during hospitalization, in partnership with the healthcare team.[4]

The restrictive measures adopted during the pandemic should not have compromised the presence of companions in pediatric units, as the constant presence of parents or guardians is a right guaranteed by the Statute of the Child and Adolescent (ECA).[5] However, allowing family members in care spaces does not necessarily mean that the health unit adopts the PFCC model. The attitudes of health professionals and the structuring of an institutional policy capable of facilitating the participation of patients and their families in the planning and execution of care are key elements for implementing this care model in clinical practice.[6]

To identify obstacles and present resources for the implementation of PFCC in different pediatric units, the Brazilian version of the Family-Centered Care Perception Instrument for Parents (FCCP-Parents Brazilian version) was validated and translated into Portuguese by Silva et al. This tool allows for the identification of potential barriers and supports the development of strategies for implementing PFCC in various pediatric contexts.[7]

During hospital care, family members are often minimally included in the care dynamic,[8] playing a peripheral role in planning the care of the children under their responsibility. This situation may have been exacerbated by the measures adopted during the COVID-19 pandemic. Thus, the objective of this study was to describe the companions' perception of PFCC and analyze its association with sociodemographic variables and hospitalization location during the COVID-19 pandemic.

Methods

This study was an analytical, cross-sectional study conducted at a large public hospital in Belo Horizonte (MG), Brazil, which exclusively serves patients through the Brazilian Unified Health System (SUS). The study was carried out in four units: the Pediatric Intensive Care Unit (PICU) with 10 beds, the Neonatal Intensive Care Unit (NICU) with 20 beds, the Conventional Neonatal Intermediate Care Unit (CNIMCU) with 15 beds, and the Pediatric Inpatient Unit (PIU) with 36 beds. The study was conducted during May, June, September, and October of 2021, respectively, with data collected in each unit over a 30-day period.

Regarding the level of dependency, children in the intensive care units (PICU and NICU) required intensive, high-dependency, and semi-intensive care. In the CNIMCU, the care level ranged from semi-intensive to intermediate, while in the PIU, it varied from intermediate to minimal.[9]

The study population consisted of family members of children and adolescents hospitalized in the specified units. Data collection took place during the COVID-19 pandemic, which necessitated the restructuring of norms and routines concerning visits and companion presence.

For clarity, "companions" are defined as family members who spend most of their time with the children and participate in their care alongside the health team. "Visitors" are those family members or individuals connected to the child and family who visit the hospital to provide support.

During the research period, visitor presence was suspended in all the units involved in the study. In terms of companions' stay, parents or legal guardians

were allowed to be with the children full-time in the PIU and CNIMCU. In the PICU, specific visiting hours were designated for parents. In the NICU, only mothers were permitted to stay full-time, while fathers were allowed daily visits to the newborns.

The inclusion criteria were companions aged 18 years or older who had stayed with the child for at least 24 hours at the time of data collection and whose children had been hospitalized for a minimum of 48 hours. Companions identified by researchers or indicated by the care team as being in a fragile emotional state were excluded. Those associated with children in the active process of dying, experiencing acute clinical deterioration, or suffering from depressive conditions were considered clinically fragile. Companions were invited to participate in the study through individual contact, followed by the presentation and explanation of the Informed Consent Form (ICF) by the responsible researcher.

Data were collected using the Brazilian version of the Patient and Family-Centered Care Perception (PFCCP) instrument. The first part of this instrument includes sociodemographic data, such as gender, age group, and education level. The second part comprises 20 closed-ended questions related to patient and family-centered care, which are subdivided into three domains: respect, collaboration, and support. The respect domain includes questions 1 to 6; collaboration encompasses questions 7 to 15; and support consists of questions 16 to 20.[10]

Responses are organized on a Likert scale, with (1) representing 'never,' (2) 'sometimes,' (3) 'usually,' and (4) 'always.' To calculate the overall score and the scores for each domain, the values obtained from each response were summed and then divided by the number of questions. In scoring, questions 5 and 15 were inversely valued.[10]

The final score indicates whether the responses were positive or negative. In the context of PFCC, an average or median score approaching the maximum value (4.0) was interpreted as indicating a positive perception of patient and family-centered care. Conversely, when the total score neared the minimum value (1.0), it was considered that the care provided significantly deviated from the practices of PFCC.[10]

The data collection instrument was completed during interviews with the families. The questions were posed by the interviewer and recorded by a researcher who was not involved in the direct care of the children or their companions. Participants were assured beforehand that the content of their responses would not influence the care provided by the team to their families and children. The estimated average time for completing the instrument was 15 minutes.

For data analysis, Statistical Software for Professionals (Stata), version 14.0, was utilized. Initially, data were entered into Microsoft Excel spreadsheets through double data entry, then compared and corrected using Epi-Info™ version 3.3.2. Following verification, the study's population was described, and estimates were presented as percentages (%). For quantitative variables, normality was assessed using the Shapiro-Wilk test. Data were presented in terms of measures of central tendency (mean) and their corresponding measures of dispersion (standard deviation). The results were organized by the unit of each child's hospitalization. To examine associations between the average scores in the domains of respect, collaboration, support, and the total score in relation to the perception of family-centered care, according to gender, age, education, child's age, and hospitalization location, Student's t-tests (for two groups) or analysis of variance (ANOVA; for two comparison groups) were employed. For variables demonstrating statistical significance in ANOVA, a Bonferroni correction analysis was conducted to mitigate type I errors resulting from multiple comparisons. A 5% significance level was maintained in all analytical procedures.

This study was approved by the Research Ethics Committee of the Federal University of Minas Gerais (4.554.643) under the Certificate of Presentation for Ethical Appreciation (CAAE) 40396520.3.0000.5149.

Results

During the data collection period, 195 children were hospitalized, with 39 in the Pediatric Intensive Care Unit (PICU), 39 in the Neonatal Intensive Care Unit (NICU), 24 in the Conventional Neonatal Intermediate Care Unit (CNIMCU), and 93 in the Pediatric Inpatient Unit (PIU). Out of these, 51 patients did not stay hospitalized for the minimum period of 48 hours, 9 companions were under 18 years of age, 30 children

were unaccompanied, 5 family members refused to participate in the study, and 6 family members were excluded due to emotional fragility. Therefore, the study included 19 companions from the PICU, 18 from the NICU, 17 from the CNIMCU, and 40 from the PIU, totaling 94 research participants. Table 1 presents the demographic characteristics of the 94 family members included in the study.

Regarding the total score of the PFCCP (Patient and Family-Centered Care Perception), the overall average score was 3.21. When analyzing the scores obtained in each domain, the average score for Respect was 3.49; for Collaboration, it was 3.10; and for Support, it was 3.08. No statistically significant difference was observed between the domains. Figures 1, 2, and 3 graphically present the averages of each question of the instrument distributed among the domains in all the units participating in the study. The highlighted line represents the average obtained in each question.

Table 2 presents the scores for the domains of Respect, Collaboration, and Support in relation to gender, age group, educational level, children under the care of the family member, age of the hospitalized child, and location of hospitalization.

According to the data presented, the Respect domain was not influenced by the analyzed variables. The average score in the Collaboration domain was higher among companions with a higher level of edu-

Table 1. Characterization of the Companions of Children Hospitalized in the Pediatric Intensive Care Unit, Neonatal Intensive Care Unit, Conventional Neonatal Intermediate Care Unit, and Pediatric Inpatient Unit

Variables	NICU	CNIMCU	PICU	PIU	Total
Gender					
Female	17(94.44)	17(100)	14(73.68)	35(87.50)	83(88.30)
Male	1(5.56)	-	5(26.32)	5(12.50)	11(11.70)
Age Group (years)					
Up to 25	7(38.89)	6(35.29)	4(21.05)	7(17.50)	24(25.53)
26-30	5(27.78)	2(11.76)	6(31.58)	13(32.50)	26(27.66)
31-45	6(33.33)	9(52.94)	7(36.84)	16(40.00)	38(40.43)
Over 45	-	-	2(10.53)	4(10.00)	6(6.38)
Educational Level					
Incomplete Elementary Education	1(5.56)	-	3(15.79)	6(15.00)	10(10.64)
Complete Elementary Education	4(22.22)	3(17.65)	6(31.58)	15(37.50)	28(29.79)
Complete High School	9(50.00)	11(64.71)	10(52.63)	19(47.50)	49(52.13)
Higher Education	4(22.22)	3(17.65)	-	-	7(7.45)

Results are expressed as n(%); ICU - Intensive Care Unit; CNIMCU - Conventional Neonatal Intermediate Care Unit; PICU - Pediatric Intensive Care Unit; PIU - Pediatric Inpatient Unit

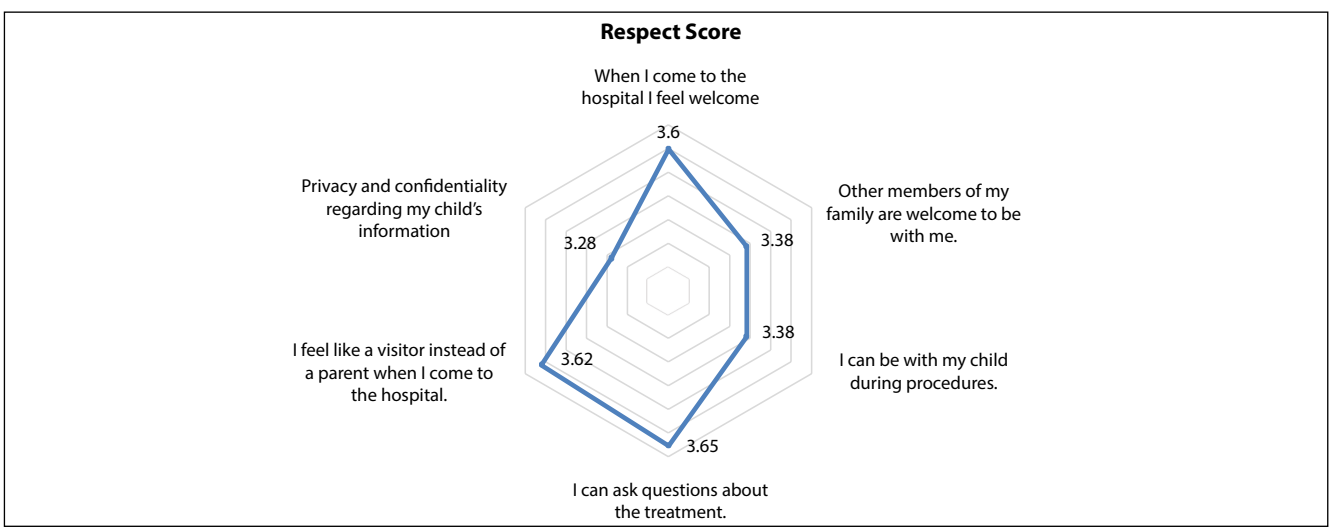

Figure 1. Averages of the variables within the Respect domain of the Brazilian version of the Family-Centered Care Perception-Parents instrument

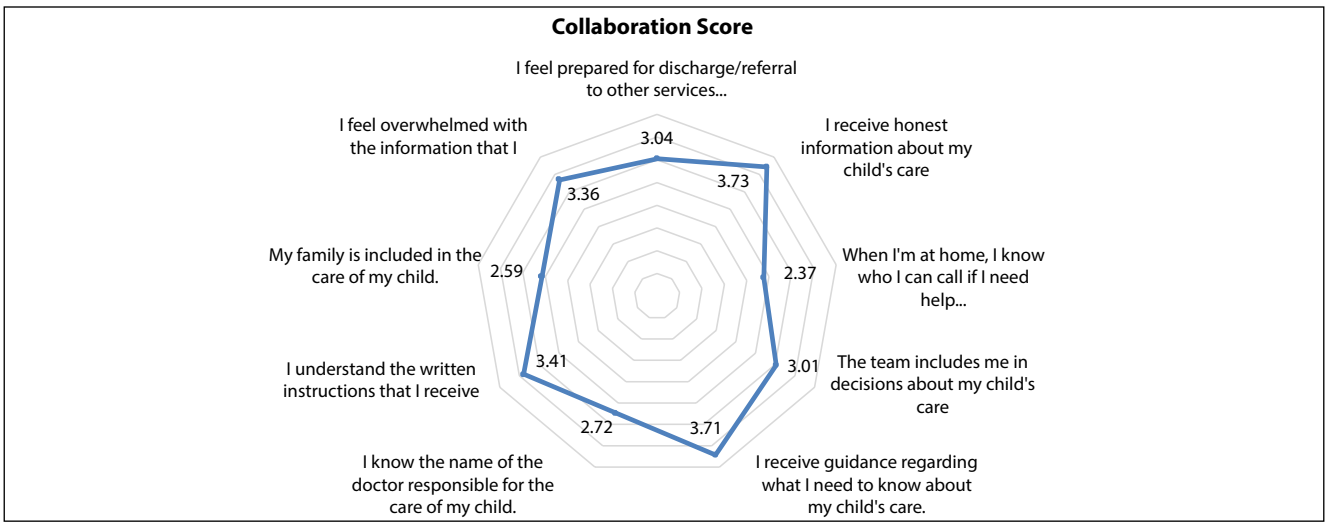

Figure 2. Averages of the variables within the Collaboration domain of the Brazilian version of the Family-Centered Care Perception-Parents instrument

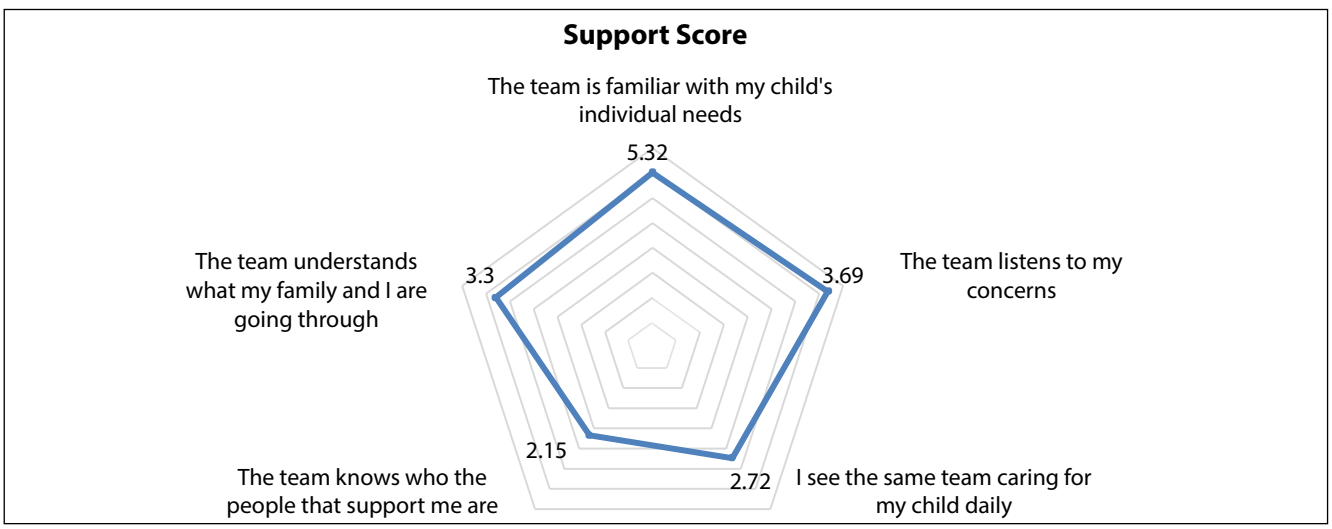

Figure 3. Averages of the variables within the Support domain of the Brazilian version of the Family-Centered Care Perception-Parents instrument

cation, particularly during the care of children under 1 year old who were hospitalized in the PICU. The average score in the Support domain was lower in the PIU compared to the other units.

Discussion

In this study, a positive perception of Patient and Family-Centered Care (PFCC) was observed. Similar results were described in a study conducted in Australia[11] and also in Brazilian studies in the pre-pandemic period.[12-14] The practice of patient and family-centered care is associated with better outcomes in health resource management, a lower incidence of errors, and positive reports regarding the experiences of patients and their families.[15]

Regarding the profile of the companions, most were women aged up to 45 years with a high school education. Historically, the care of children and family members in illness conditions has been predominantly undertaken by women, who largely manage these processes, experiencing the physical, emotional, social, and spiritual impacts resulting from hospitalization.[14]

When analyzing the perception of companions in different child care units, it was observed that the total

Table 2. Influence of Demographic Variables and Location of Hospitalization on the Perception of Patient and Family-Centered Care

Variáveis	Escores							
	Respeito		Colaboração		Suporte		Total	
	Média ±DP	p-value	Média ±DP	p-value	Média ±DP	p-value	Média ±DP	p-value
Gender		0,936		0,260		0,692		0,377
Female	3,48±0,04		3,08±0,05		3,07±0,06		3,20±0,04	
Male	3,5±0,08				3,14±0,12		3,30±0,08	
Age Group (years)		0,248		0,761		0,876		0,578
Up to 25	3,36±0,09		3,10±0,12		3,08±0,13		3,17±0,09	
26-30	3,47±0,07		3,02±0,09		3,00±0,11		3,15±0,06	
31-45	3,56±0,05		3,16±0,07		3,11±0,08		3,27±0,04	
Over 45	3,58±0,13		3,12±0,24		3,16±0,24		3,27±0,19	
Educational Level		0,684		0,015*		0,698		0,059
Incomplete Elementary Education	3,35±0,16		2,68±0,16^{A}		2,96±0,11		2,95±0,10	
Complete Elementary Education	3,49±0,07		3,07±0,08^{AB}		3,10±0,09		3,20±0,05	
Complete High School	3,51±0,05		3,16±0,07^{B}		3,06±0,09		3,24±0,05	
Higher Education	3,5±0,13		3,42±0,18^{B}		3,28±0,23		3,41±0,10	
Idade da criança, anos		0,180		0,035*		0,091		0,050
≤ 1	3,46±0,05		3,18±0,06^{A}		3,15±0,07		3,26±0,04	
1-5	3,40±0,08		2,81±0,11^{B}		2,76±0,12		2,97±0,07	
> 5	3,63±0,06		3,02±0,10^{AB}		3,03±0,11		3,21±0,06	
Location of Hospitalization:		0,970		0,003*		<0,001*		0,001*
PICU	3,45±0,10		3,31±0,11^{A}		3,2±0,09^{A}		3,32±0,07^{A}	
PIU	3,49±0,05		2,88±0,06^{B}		2,78±0,07^{B}		3,04±0,04^{B}	
CNIMCU	3,51±0,10		3,25±0,11^{AB}		3,28±0,16^{A}		3,34±0,10^{A}	
NNICU	3,49±0,10		3,24±0,14^{AB}		3,43±0,12^{A}		3,36±0,09^{A}	

*p-value ≤ 0.05 (analysis of variance and post hoc with Bonferroni correction). Identical letters indicate similarity between the group averages, and different letters denote a statistically significant difference between the group averages. SD - standard deviation; PICU - Pediatric Intensive Care Unit; PIU - Pediatric Inpatient Unit; CNIMCU - Conventional Neonatal Intermediate Care Unit; NNICU - Neonatal Intensive Care Unit

score for the Respect domain was higher compared to the Collaboration and Support domains. The Support domain obtained the lowest score, corroborating findings from other studies where aspects related to the recognition of individualized needs in the context of hospitalization and high turnover of healthcare professionals during care were the lowest-scoring items among the investigated population.[13,16,17]

In this study, the perception of Respect did not vary in relation to the location of hospitalization, gender, age group, caregiver's education level, or the age of the hospitalized child. According to Dall'Oglio et al., respect is a complex concept that involves recognizing the diversity of families in social, economic, racial, and cultural aspects, as well as valuing the individualized needs of the child and their family.[18] In the instrument used, the Respect domain addresses issues related to the dignity and understanding of families' rights in the hospital.[13] The Institute for Patient and Family Centered Care (IPFCC) states that dignity and respect are fundamental concepts that involve listening to and valuing the choices of families, as well as their beliefs and values.[19] Peres et al. described in their study that families felt welcomed in the hospital environment, expressed a desire to stay with their children during care, and perceived themselves as responsible for monitoring the care provided to their children.[20]

Regarding the Collaboration domain, this study showed that the lowest-scoring items were access to the support network at home, inclusion of the family in care, and identification of healthcare professionals during hospitalization. Collaboration is understood as the partnership established between the team and the family/companion.[17] Integrating the family during the provision of care to hospitalized children strengthens the practice of humane and safe assistance.[21] However, in many clinical situations, the family is still perceived as an obstacle to better care, with exclusionary practices and undervaluation of family participation during assistance being common.[8]

Communication is an important element for enabling collaborative practices. Families highlight that the information provided by the team is a supportive element, as it directs intervention needs and promotes

a greater understanding of the child's health context.[22] Family collaboration is so important during hospitalization in pediatric units that early warning scores for risk attribute additional points based on the family's perception of signs of clinical deterioration.[23] Therefore, a hospitalization can become more prolonged when the family is not involved in care, increasing the risk of adverse events and the costs related to assistance, as the risk of complications increases by 6% for each day of hospitalization.[24]

In this study, a positive perception of Patient and Family-Centered Care (PFCC) was observed. Similar results were reported in a study conducted in Australia[11] and in Brazilian studies during the pre-pandemic period.[12-14] The practice of patient and family-centered care is associated with improved health resource management, reduced incidence of errors, and positive reports concerning the experiences of patients and their families.[15]

Regarding the profile of the companions, most were women aged up to 45 years with a high school education. Historically, women have predominantly undertaken the care of children and family members in conditions of illness, bearing the burden of these processes, including the physical, emotional, social, and spiritual impacts resulting from hospitalization.[14]

When analyzing the perception of companions in different child care units, it was noted that the total score for the Respect domain was higher compared to the Collaboration and Support domains. The Support domain scored the lowest, corroborating findings from other studies where aspects like the recognition of individualized needs during hospitalization and high turnover of healthcare professionals during care were the lowest-scoring items among the studied population.[13,16,17]

This study found that the perception of Respect did not vary in relation to hospitalization location, gender, age group, the caregiver's level of education, or the age of the hospitalized child. According to Dall'Oglio et al., respect is a complex concept that involves recognizing the diversity of families in social, economic, racial, and cultural aspects, as well as valuing the individualized needs of the child and their family.[18] In the instrument used, the Respect domain focuses on issues related to dignity and understanding of the families' rights in the hospital.[13] The Institute for Patient and Family Centered Care (IPFCC) states that dignity and respect are fundamental concepts involving listening to and valuing the choices, beliefs, and values of families.[19] Peres et al. reported that families felt welcomed in the hospital environment, expressed a desire to stay with their children during care, and perceived themselves as responsible for overseeing the care provided to their children.[20]

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Communication is essential in enabling collaborative practices. Families emphasize that the information provided by the healthcare team is supportive, as it directs intervention needs and promotes a greater understanding of the child's health context.[22] Family collaboration is so crucial during hospitalization in pediatric units that early warning scores for risk include additional points based on the family's perception of signs of clinical deterioration.[23] Consequently, a hospitalization can become prolonged when the family is not involved in care, increasing the risk of adverse events and costs related to assistance, as the risk of complications increases by 6% for each day of hospitalization.[24]

Despite the significance of the results observed in this study, it is essential to acknowledge that the research was conducted during the COVID-19 pandemic, which undoubtedly had a significant impact on the inclusion and participation of families/companions in the care of hospitalized children.[25]

In this context, understanding how to integrate the child and their family into the social context, identifying the support network, and recognizing what they consider essential to care enables the activation of support resources during hospitalization and optimizes the planning of hospital discharge and follow-up outpatient care.[26,27]

To avoid setbacks in PFCC, as suggested by the IPFCC, institutions must maintain a policy that values respect for the family during the hospitalization of children.[19] In adverse contexts, such as those experienced during the pandemic, certain aspects should be highlighted regarding effective communication: explaining the reason for restrictions, reaffirming that changes are temporary, maintaining an open channel for information and inquiries, and recognizing the family as a partner in ensuring safety and quality of care.[4] Thus, the manner in which support for the family and their involvement in care is provided can either facilitate or hinder the development of the therapeutic plan during hospitalization.

A limitation of the study is its cross-sectional design, which limits the identification of a cause-and-effect relationship. Additionally, data collection during the peak of the COVID-19 pandemic constrained the participation of the support network beyond the primary caregiver, potentially influencing the research results by reducing their rotation among them.

Conclusion

This study's results revealed that companions had a positive perception of family-centered care across all the investigated inpatient units. The Respect domain was rated highest by the families, followed by Collaboration and Support. Despite the positive response regarding the care provided, areas for improvement were identified. These include the identification of professionals, high staff turnover, the team's knowledge about family support, and the inclusion of other family members during the hospitalization of children. Investing in these aspects of care can contribute to achieving participatory and safe care, capable of generating positive experiences during hospitalization for both children and their families. Furthermore, it is important to emphasize that the model of Patient and Family-Centered Care should be sustained even during health crises, such as the COVID-19 pandemic, as strengthening patient and family participation in care can minimize negative impacts and favor clinical recovery, patient safety, and family support.

Contributions

GCP Soares, TPR Silva, JH Amata, DA Almeida, HB Neiva, BF Manzo, DAS Simão, and JO Marcatto contributed to the conception of the project, analysis and interpretation of the data, writing of the article, critical review of the intellectual content, and approval of the final version to be published.

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