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RESEARCH ARTICLE (ORIGINAL)

Communicating with the intensive care team: the perspective of hospitalized children's families

Comunicação com a equipa de saúde intensivista: perspetiva da família de crianças hospitalizadas

Comunicación con el equipo sanitario intensivista: perspectiva de la familia de los niños hospitalizados

Jéssica Stragliotto Bazzan [1]
https://orcid.org/0000-0002-8457-134X

Viviane Milbrat Marten [1]
https://orcid.org/0000-0001-5523-3803

Ruth Irmgard Bärtschi Gabatz [1]
https://orcid.org/0000-0001-6075-8516

Milena Munsberg Klumb [1]
https://orcid.org/0000-0002-8318-9499

Eda Schwartz [1]
https://orcid.org/0000-0002-5823-7858

[1]Universidade Federal de Pelotas, School of Nursing and Midwifery, Pelotas, Rio Grande do Sul, Brazil

Corresponding autor
Jéssica Stragliotto Bazzan
E-mail: jessica_bazzan@hotmail.com

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Abstract

Background: Communicating with the health care team is key in the family's process of adapting to child hospitalization.

Objective: To know the families' perspective on their communication with the intensive care team during their children's hospitalization.

Methodology: Qualitative study conducted with 13 family members of children hospitalized in a Pediatric Intensive Care Unit of a University Hospital. Data were collected in 2017 using semi-structured interviews and interpreted following Roy's Adaptation Model.

Results: Two thematic units were identified: "Effective communication between the health team and family within the context of the Pediatric Intensive Care Unit," in which the health team clarifies doubts and transmits clear information on the child's medical condition; and "Poor communication between the health team and family within the context of the Pediatric Intensive Care Unit," in which health professionals use language that hampers families' understanding.

Conclusion: Understanding and adopting effective communication strategies between health teams and families are essential for a good adaptation process during children's hospitalization.

Keywords: family; patient care team; qualitative research; communication; hospitalization

Resumo

Enquadramento: A comunicação com a equipa de saúde é muito importante no processo de adaptação da família à hospitalização infantil.

Objetivo: Conhecer a perspetiva das famílias acerca da comunicação com a equipa de saúde intensivista durante a hospitalização da criança.

Metodologia: Estudo qualitativo, realizado com 13 familiares de crianças internadas numa unidade de terapia intensiva pediátrica de um hospital universitário. Os dados foram colhidos em 2017 através de entrevistas semiestruturadas e interpretaram-se à luz do modelo de adaptação de Roy.

Resultados: Identificaram-se 2 unidades temáticas: Comunicação efetiva entre equipa e família no contexto da unidade de terapia intensiva pediátrica, quando a equipa esclarece dúvidas e transmite informações claras sobre o quadro clínico da criança; Comunicação prejudicada entre equipa e família no contexto da unidade de terapia intensiva pediátrica, quando os profissionais utilizam linguagem que dificulta a compreensão da família.

Conclusão: A compreensão e a adoção de estratégias de comunicação eficaz entre a equipa e a família são indispensáveis para que ocorra um processo de adaptação adequado no internamento infantil.

Palavras-chave: família; equipa de assistência ao paciente; pesquisa qualitativa; comunicação; hospitalização

Resumen

Marco contextual: La comunicación con el equipo sanitario es muy importante en el proceso de adaptación de la familia a la hospitalización infantil.

Objetivo: Conocer la perspectiva de las familias sobre la comunicación con el equipo sanitario intensivista durante la hospitalización del niño.

Metodología: Estudio cualitativo, realizado con 13 familiares de niños hospitalizados en una unidad de cuidados intensivos pediátricos de un hospital universitario. Los datos se recopilaron en 2017 mediante entrevistas semiestructuradas y se interpretaron según el modelo de adaptación de Roy.

Resultados: Se identificaron 2 unidades temáticas, Comunicación eficaz entre el equipo y la familia en el contexto de la unidad de cuidados intensivos pediátricos, cuando el equipo aclara las dudas y transmite información clara sobre el estado clínico del niño; Comunicación deficiente entre el equipo y la familia en el contexto de la unidad de cuidados intensivos pediátricos, cuando los profesionales utilizan un lenguaje que dificulta la comprensión de la familia.

Conclusión: La comprensión y la adopción de estrategias de comunicación eficaces entre el equipo y la familia son esenciales para que tenga lugar un proceso de adaptación adecuado durante la hospitalización infantil.

Palabras clave: familia; equipo de atención al paciente; investigación cualitativa; comunicación; hospitalización

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Introduction

The word "family" involves multiple concepts and structures influenced by sociocultural contexts and their own historical characteristics. Thus, it is impossible to understand the word "family" as a single model of functioning. Nevertheless, the different family configurations are developed through bonds (Milani et al., 2019), clarifying that what forms a family is the bond established and experienced, particularly when facing difficult situations such as the illness of one of its members.
A child's illness and hospitalization are complex situations for all the involved, due to the child and family's removal from their significant contexts, and the loss of autonomy in child care, among other intense experiences that require the mobilization for adaptation (Almeida et al., 2016). To mitigate the suffering caused by children's hospitalization in a Pediatric Intensive Care Unit (PICU), the health team is responsible for using strategies that promote families' adaptation. In this sense, the use of clear and understandable communication constitutes an important tool in this setting.
In health care, communication is a key process, and it is essential to reflect on how information is transmitted to patients and their families. This requires the health team's attention to adapt communication to the level of understanding of those receiving the information (Nardi et al., 2018). The speaker and receiver must use a type of language that both understand. Thus, communication constitutes a differentiating factor for delivering humanized care to family members because health professionals cannot deliver adequate care without effective and clear communication (Luiz et al., 2017).
Given the importance of communication between health teams and the children's families for adapting to the hospitalization in a PICU, this study aims to identify the families' perspective on communication with the intensive care team during the children's hospitalization.

Background

Considering Roy's Adaptation Model, the effectiveness of human beings' adaptation to the moment they are experiencing is verified through their behavior, expressed through their actions and reactions under specific circumstances (Roy, 2009). Thus, when a child is admitted into a PICU, understanding what is happening favors the adaptation process to their experiences during the stay at the unit. The lack of understanding can lead to an ineffective adaptation.
Behavior can then originate an adaptive response that will promote the individuals' integrity and not jeopardize their survival and control over the imposed circumstances. However, behavior can also originate ineffective responses that harm the individuals' integrity and threaten the elements mentioned (Roy, 2009).
To foster the children and families' effective adaptation process, the health team should use communication as a tool to humanize care. This communication needs to anticipate the interaction with the child and family members, aiming to clarify their doubts about the therapeutics and clinical exams and/or procedures, thus reducing the anxiety and fear caused by illness and hospitalization, and bearing in mind that families also participate in the care process (Vasconcelos et al., 2016). The PICU multidisciplinary team (physicians, nurses, physical therapists, psychologists, nutritionists, and nursing technicians) must develop a good relationship and bond with the families to meet their communication needs and develop a satisfactory interaction. This promotes families' trust (Pêgo & Barros, 2017), contributing to their adaptation process.
Effective, regular, and continuous communication regarding the children's clinical condition and treatment ensures that families receive consistent information. Moreover, patient's care plans change regularly after being discussed among the health team. Therefore, families need to be informed about the updates quickly, clearly, and in a way that enables them to understand the changes and prognosis.

Research question

What is the family's perspective on communication with the PICU health care team during the child's hospitalization?

Methodology

This is a descriptive and exploratory study, with a qualitative approach, carried out in the PICU of a University Hospital located in southern Brazil. This unit has 10 beds, eight for users of the Unified Health System and two for private patients and/or patients with health insurance. In this service, families can stay 24 hours per day and count on a multidisciplinary team to care for their children. It is worth mentioning that this unit is a regional reference for care delivery to children with respiratory and neurological diseases. Thus, most of its inpatients present complications in organs such as the lungs and brain.
Given that this is a qualitative study, its design sought to meet the COREQ (COnsolidated criteria for REporting Qualitative research) Checklist. The period of data collection occurred from July to September 2017. Twelve mothers and one father of children hospitalized in the PICU participated in the study in a total of 13 family members. The sample was randomly selected among the family members of hospitalized children. The inclusion criteria were to be a family member of a child discharged from the PICU but who remained hospitalized, and to be a family member of a child hospitalized for at least 7 days in the PICU. Family members under 18 years of age and of children who died or were receiving palliative care were excluded.
The researcher personally invited the family members to participate in the study one day after the child was discharged from the PICU and transferred to the Pediatric Unit or an individual room of the institution.

Data were collected through semi-structured interviews (Cardano, 2017), which included questions on the participants' characterization and the question that allowed achieving this study's objective: What is your perspective about the communication with the health care team from the time of admission into the PICU until your child's discharge? The interviews were conducted individually, in a private setting, with the participant, the child, and the researcher. With a mean duration of 30 minutes, the interviews were recorded on a cell phone and manually transcribed in full. Two different researchers double-checked the transcriptions. The participants signed an informed consent form at the interview, attesting to their agreement and willingness to participate in the study.

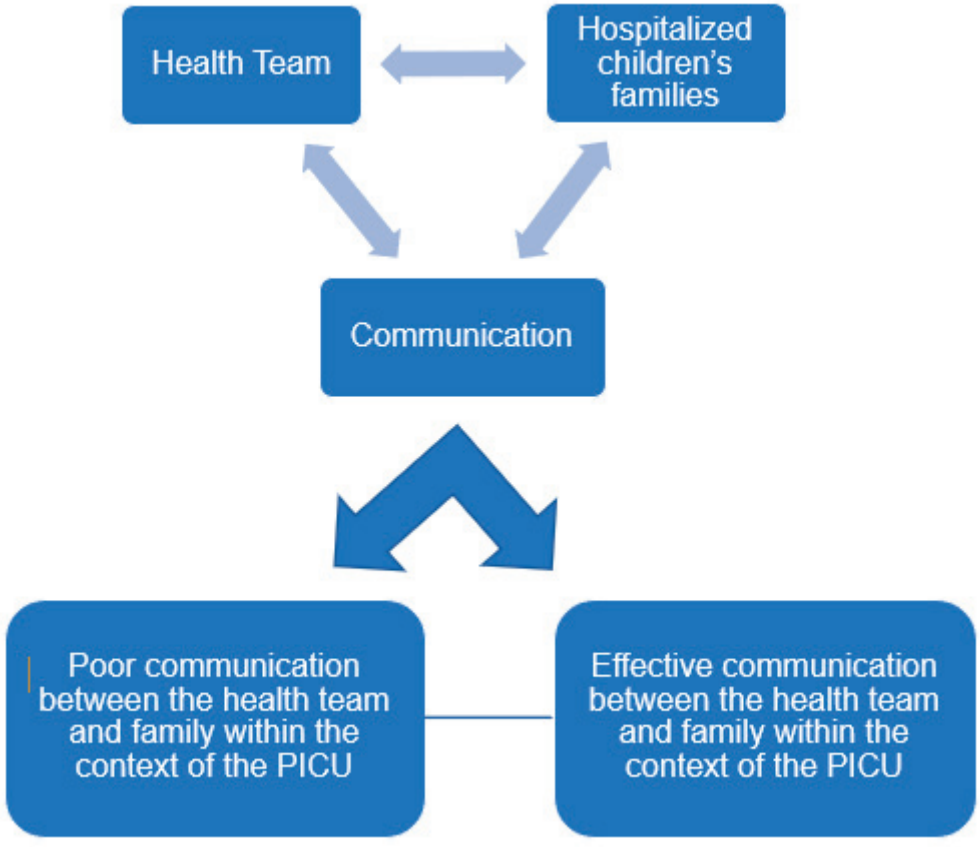
The data saturation criterion was applied to limit the number of participants. Thus, the interviews were first transcribed, and the initial codes were extracted. Next, the codes were categorized according to prevalence and type, and it was observed that each code had sufficient depth and complexity to explain the issue being studied (Hennink et al., 2017). In this study, saturation was reached in the 11th interview.

The anonymity of the family members was ensured by using the letter "F" from "Family," together with a sequential number to identify the participant (F1, F2, and so on). The ethical principles of Resolution 466/12 of the National Health Council of the Ministry of Health were respected regarding the ethical aspects of research involving human beings. The project was approved by the Ethics Committee of the School of Nursing and Midwifery of the Universidade Federal of Pelotas by CAAE 69933617.7.0000.5316, under opinion number 066635/2017. The interviews were not subjected to the participants' feedback because there was no further contact after the data collection.

Data analysis occurred inductively and using thematic analysis to identify, analyze, and report patterns (themes) within the information. The thematic analysis was developed following the six-phase approach: data transcription, reading and re-reading it, and noting down initial ideas; initial systematic data codification; code collating into potential themes; theme review, generating a thematic map of analysis; theme definition; and final analysis of the selected points, producing an academic analysis report (Braun et al., 2019).

Figure 1

Thematic Map of Analysis



Next, the data were interpreted based on the Nursing Theory framework of Callista Roy's Adaptation Model, which aims to understand individuals' adaptation to the different contexts of their life situations, including the adaptive processes of the person/group, adaptive modes, and health-related adaptation (Roy, 2009). The adaptation process is defined by the adaptive responses that promote individuals' integrity, modifying their way of survival, growth, reproduction, and mastery, but also by the ineffective responses that do not promote their integrity or contribute to the goals of adaptation (Roy, 2009). These responses can threaten individuals' survival, growth, reproduction, or mastery.

When faced with a new fact, individuals have new actions defined as behaviors directly linked to the specific circumstances that affect them (Roy, 2009). For example, each new fact about the child's health transmitted to the family will impact it. Thus, to evaluate the adaptation process, it is necessary to pay attention to individuals' behavior, considering the overall goals of adaptation.

After data analysis and interpretation aimed at collating codes into a thematic unit: Communication between the intensive care team and the hospitalized children's families, two themes were selected to be addressed: "Effective communication between the health team and family within the context of the PICU" and "Poor communication between the health team and family within the context of the PICU."

Results

Thirteen family members participated in the study, 12 mothers and one father, aged between 18 and 39 years. Of the total number of participants, five were married, and eight were single. Regarding religion, four participants said they were Catholic, two atheists, one evangelical, and five said they did not follow any religion but believed in God. Four participants were experiencing their child's first hospitalization process, and nine were experiencing readmission, which revealed that most participants were experiencing the adaptation process for the second time.

When asked about their communication with the health professionals' team, the study participants listed the positive and negative aspects of the process. Two themes emerged from the information analysis: "Effective communication between the health team and family within the context of the PICU" and "Poor communication between the health team and family within the context of the PICU."

Theme 1: Effective communication between the health team and family within the context of the PICU

Effective communication is an important tool for children and their family members' adaptation to the context of the PICU. One of the positive aspects listed in the participants' statements was the health team's availability to meet their needs. In this context, communication was referred to as being effective, with the health team clarifying doubts and transmitting information about the child's clinical condition in a way that promoted each family member's understanding.

"I could (understand), and when the doctors said something that I didn't understand, I asked them, and they answered my questions" (F6). "(Communication) was easy, during the morning when they (the doctors) gave the news, the residents always answered the questions when necessary" (F11). "I got nervous when there was news; there was always a lot of information ... I needed to understand everything that was happening; when I didn't understand, I asked them to repeat, I always cleared up all my doubts right away so that nothing would pass" (F13).

The health professionals' explanations to families about what was happening to their children during treatment provided them with the calm to face their adaptation process, generating an adaptive response, as confirmed in their statements:

> I have nothing to complain about; they were always very considerate, they always explained everything to me; when I had questions, I asked the nurses and doctors about the treatment, and they always told me what they were doing and what might happen; even if it didn't happen, they told me in advance. So, this was one of the things that reassured me about leaving him in the hospital again and the freedom I had to go home and come back. . . (F9)
>
> I felt calm because they (nurses) explained everything they were doing, so this process was easy ... when they were going to collect (blood), they said: 'ah! I'm collecting it to do such and such exam'. So, it wasn't difficult. (F8)

Theme 2: Poor communication between the health team and family within the context of the PICU

Communication is key for adapting to the PICU. However, several obstacles in the process hamper it. According to the participants' statements, although the team explained what happened, whether regarding the child's clinical condition, or a procedure that needed to be performed, the family did not understand what was being said, constituting a failure in the communication process. The information was transmitted, but not understood by families, thus originating the receiver's ineffective response.

"They said it was diabetes, but we didn't know what this thing called diabetes was." (F3).

> So, I think that when you ask the doctor something, and he can't explain it to you, it gives you that bad feeling, a tightening in your heart, because sometimes you don't understand things correctly, they explain them to you, but it seems that you don't understand the words ... Then you start to get worried. (F5)

Besides some participants considering communication poor, this study revealed that even when they did not understand the information, they tried to answer their questions by asking health professionals or other family members to clarify them. It was also observed that the lack of understanding sometimes occurred because health professionals used technical language specific to the health area, and the family members, who were mostly lay, found it difficult to understand and assimilate. Moreover, it was noted that these family members felt embarrassed

and preferred to look for information elsewhere (e.g., on the internet) to understand what was being transmitted to them. Such situations are described in the following statements:

"(Communication) was more difficult because we didn't understand a lot ... what they said, until one day the doctor spoke, and I wrote it down on a piece of paper and looked it up on the Internet" (F2). "I get embarrassed to ask all the time; I don't understand what they say, I prefer to look up what he said later to try to understand" (F4).

Technical language became a barrier to communication with different family members, who were forced to ask several times about what was being said and why it was happening. When the message was not properly transmitted, family members also looked for other professionals with whom communication was more effective.

> Yes, they use a lot of difficult words, they don't transmit the information, so you must ask several times... Because some words are not clear, I think they sometimes don't make it clear... they speak in their language, but we don't understand, then I asked several times: 'okay, and why is that?'; then, they would explain; sometimes we got really scared (F10).

"When I didn't understand something, I would ask a more experienced one, who was there ... then, she would come and explain it to me" (F7).

During the child's stay at the PICU, family members receive a lot of information, some of which is difficult to handle. The difficulty to face negative news regarding the child's clinical condition triggers the family members' anxiety, who often disassociate from the information received to remain emotionally balanced. This constitutes one of the adaptation strategies used, even if unintentionally.

> I always had (information), although I didn't accept it, I always had (information about the clinical condition) ... they told me something, and I knew what was happening, but it was like it went in here and came out here ["ears"], and I didn't pay attention. (F12)

Discussion

Considering that the PICU is a setting where sudden transformations occur, this study observed a constant need for adaptation, which each family experiences in a unique way. Therefore, communication between the family and the health team constitutes one of the most important factors in this setting. When communication occurs clearly, using terms that are easy to understand, transmitting the child's real clinical situation, explaining each treatment stage, and answering emerging doubts, it influences family members' effective adaptation, diminishing psychological suffering and promoting trust and the feeling of safety. Communication is one of the key factors in humanizing care, becoming effective when carried out clearly (Luiz et al., 2017).

According to this study's results, communication between the intensive care team and the child's family is effective when it fosters the appropriate behavior for family members to effectively adapt to the moment they are experiencing (Roy, 2009), reducing their anxiety and assisting them in understanding what is happening to their children. This way, family members start to trust the health team and the care they deliver, despite the severity and instability experienced during their child's stay in the PICU.

Therefore, effective communication with the health team facilitates family members' adaptation process. Nursing is responsible for providing adaptive responses and minimizing ineffective ones, prioritizing the individuals' integrity, and allowing their system to remain unaffected while experiencing hospitalization in a way that the feelings of fear and anxiety regarding the lack of communication are minimized (Roy, 2009).

The data revealed that families have difficulty understanding the information transmitted by some health team's professionals due to their use of extremely technical language, with the exception of nursing professionals. These professionals spend longer periods with families, fostering bonding and better communication and allowing families to feel more free to clarify their doubts.

Therapeutic listening promotes the establishment of effective communication, as it creates a reliable link that promotes the daily identification of needs and the necessary conditions for professionals, especially nurses (Ribeiro et al., 2018), to care for the child and family.

The participants' statements demonstrated that communication occurred, at times, softly and clearly, with procedures being explained before being performed on the child. This communication mechanism promotes the family member's recognition, who feels valued as the accompanying adult apart from understanding the situation.

The relevance of consistent communication capable of promoting the well-being between health professionals and family members is undeniable. If communication is not adequate, effective, respectful, and sincere, it can be a misfortune (Luiz et al., 2017). With quality guidance and the existence of a support system, families experience the period of their children's hospitalization with greater calm, sense of safety, and positive thinking, being able to focus on the better days to come (Bazzan et al., 2019). Thus, health teams need to be trained to assume this role, realizing that communication constitutes a commitment that prevents families from feeling helpless during this period. This reduces parents/family members' negative feelings and their better acceptance and commitment to the care process.

Ramos et al. (2016) point out the relevance of health professionals recognizing families' needs as one of the key aspects of care and strengthening and promoting the attention to families' emotional conditions, reinforcing the bond between them. However, health professionals' communication with family members is sometimes inappropriate, compromising families' understanding by using technical language (Biasibetti et al., 2019) and hampering the trust and bond formation between them.

The health professionals' role proves to be even more relevant when there are families who understand what is being transmitted by the team but do not accept that such a situation is happening to them and their children. Human beings adopt different defense mechanisms when facing situations, among which is the denial process, in which the individual considers the experience of a certain process intolerable. Thus, when a child is admitted to the PICU, it is common for family members to develop this mechanism, mentioning they understand what the health team explains but do not accept it (Garboza Junior & Badiou, 2019).

Like in the grieving process, this mechanism emerges from the non-acceptance of the child's health and disease process and is characterized by denial and isolation (Afonso, 2013). Most families who have this attitude try to escape reality and to prove by all means that there was a mistake, needing time to internalize the process.

The process of illness and admission into the PICU and the demand to face the seriously ill condition of their children are so devastating for some families that, in their adaptation process, even if involuntarily, they claim to understand what health professionals transmit, while not paying the necessary attention. Although this may be understood as a form of neglect, this behavior is triggered by family members' non-acceptance of their children's clinical condition.

The family members' lack of understanding about their children's situation or pathology generates concern and distress, being one of the behaviors derived from the stimuli caused by poor or ineffective communication, when the speaker cannot achieve the objective of making the receiver understand the information transmitted, thus undermining the adaptation process (Roy, 2009).

The poor and ineffective communication between families and the intensive care team requires reflection on information transmission. Poerschke et al. (2019) state that adequate communication about patients' clinical conditions during visiting hours should be done clearly, objectively, without technical and difficult terms, and including important information explaining the diagnosis, treatment, procedures, and equipment used.

Thus, health professionals need to consider family members' level of knowledge to enhance their understanding and ensure that their interpretations are correct. This will decrease family members' anxiety and concern (Poerschke et al., 2019) and assist in their decision-making process, making adaptation easier.

Moreover, due to their lack of understanding of their hospitalized children's clinical condition and the health and disease process, the families' sense of abandonment leads them to seek on the internet or with other family members the clarification of terms that they do not know when these should have been clarified by the health professionals or replaced by words simpler to understand. The internet is recognized as a significant source of information within the area of health. It can contribute to patients and families finding information, clarifying, and promoting their understanding about the guidance they received within the health system (Fergie et al., 2016). However, it is important to emphasize the need to seek information on reliable websites, which can be difficult and lead to misunderstandings.

Furthermore, this study observed that family members look for clearer information by questioning health professionals. However, when this clarification is not obtained, it creates a stimulus that contributes to the families' ineffective adaptation process and responses, which hamper the natural process and harm their integrity and well-being in the face of the imposed circumstances (Roy, 2009).

Braga et al. (2020) pointed out a deficit in some health professionals' repertoire of communicative skills, specifically in the nonverbal component, such as talking more than patients and ending discussions, using technical language, interrupting patients or accompanying family members when they speak, ignoring the questions asked by patients or family members, and adopting defensive behaviors, which weaken the communication process, the bond with patients and family members, and their trust. Communication in the PICU needs to be multifaceted and focus on the different communication levels, involving the physicians, nurses, and other professionals who deliver care to children and families. Notably, improving communication between professionals and families in the PICU, through interventions aimed at how communication is performed and received, is an important step in improving the effectiveness outcomes for ill children and families (Yagiela & Meert, 2019).

The limitations of this study include the fact that it only involved family members and assessed verbal communication. The integration of health professionals working in this setting and the assessment of non-verbal communication (gestures, visual contact, and facial expression) would have broadened the perception of the issue and further enhanced the study results.

Conclusion

The perceptions of hospitalized children's families reveal fragility issues in the communication with the health professionals, particularly due to the use of technical language and the lack of clear guidance and information about the treatment. These issues bring fear and concern to families. Therefore, attention is needed to solve the problems arising from ineffective communication and increase families' participation, empowering them to care for their children and minimizing the harm resulting from the difficulties experienced in the adaptation process to the PICU hospitalization.

When participants considered communication effective, having their doubts clarified, they felt calmer, trusting their children's care to the health team and feeling safe to leave them at the PICU while going home. Therefore, the health team should value communication effectiveness, integrating it into the assistance and care being delivered, enhancing families' understanding, and helping them reduce the anxiety caused by their children's hospitalization.

As a contribution to practice, this study aims to encourage discussions about communication between health teams

and families in the context of the PICU, demonstrating the relevance this issue has in care delivery. This will favor the adoption and expansion of strategies promoting effective communication between health teams and families and contributing to the safety and reliability of care delivery in the PICU.

Author contributions

Conceptualization: Bazzan, J. S., Marten, V. M.
Data curation: Bazzan, J. S., Marten, V. M.
Formal analysis: Bazzan, J. S., Marten, V. M., Gabatz, R. I.
Investigation: Bazzan, J. S., Marten, V. M.
Methodology: Bazzan, J. S., Marten, V. M.
Project administration: Marten, V. M.
Supervision: Marten, V. M., Gabatz, R. I.
Visualization: Bazzan, J. S., Marten, V. M., Gabatz, R. I., Klumb, M. M.
Writing – original draft: Bazzan, J. S., Marten, V. M., Gabatz, R. I., Klumb, M. M., Schwartz, E.
Writing – review & editing: Bazzan, J. S., Marten, V. M., Gabatz, R. I., Klumb, M. M., Schwartz, E.

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