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RESEARCH ARTICLE (ORIGINAL)

Strengths and Constraints of Family Involvement in Pediatric Critical Care: A Qualitative Study

Potencialidades e Constrangimentos do Envolvimento da Família no Cuidado à Criança em Situação Crítica: Estudo Qualitativo

Potencialidades y Limitaciones de la Participación Familiar en la Cuidado a Niños en Situaciones Críticas: Un Estudio Cualitativo

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Abstract
Background: The hospitalization of a child in a pediatric intensive care unit is a traumatic event for the family, making it essential that they feel involved in the environment and in the care process.
Objective: Identify the strengths and constraints of family involvement in the care of critically ill children as perceived by nurses.
Methodology: An exploratory, descriptive, qualitative study was conducted with 26 nurses from a pediatric intensive care unit at a hospital center, organized into four focus groups. Data were analyzed using Flick's content analysis approach.
Results: Several constraints were identified, related to family members and parents, the child's clinical situation, healthcare professionals, and institutional factors. Strengths were reported in areas such as the team's communication skills, the child's comfort and safety, the usefulness of family participation, and the possibility of reducing hospitalization time.
Conclusion: Involving the family in care is essential to promoting feelings of usefulness, calm, and safety. However, nurses encounter constraints, which they attempt to mitigate through strategies that enhance family participation.

Keywords: critical care; family; child; nurses; strengths; constraints

Resumo
Enquadramento: A hospitalização da criança em cuidados intensivos pediátricos é um evento traumático para a família, sendo fundamental que estes se sintam envolvidos no ambiente e nos cuidados.
Objetivo: Identificar as potencialidades e constrangimentos, na perceção dos enfermeiros, do envolvimento da família no cuidado à criança em situação crítica.
Metodologia: Estudo exploratório descritivo, de natureza qualitativa, com participação de 26 enfermeiros, em três *focus group*, de uma Unidade de Cuidados Intensivos Pediátricos, de um Centro Hospitalar. Recorreu-se à análise de conteúdo para tratamento dos dados, de acordo com Flick.
Resultados: Identificaram-se diversos constrangimentos associados aos familiares/pais, à situação clínica, aos profissionais e à instituição. As competências comunicacionais da equipa, o conforto e segurança da criança, o sentimento de utilidade dos familiares e a possibilidade de minimização do tempo de internamento foram potencialidades relatadas.
Conclusão: Envolver a família nos cuidados é primordial, promovendo sentimentos de utilidade, tranquilidade e segurança. No entanto, os enfermeiros experienciam constrangimentos, os quais tentam minimizar com estratégias de envolvimento, de forma a potenciar a participação da família.

Palavras-chave: cuidados críticos; família; criança; enfermeiros e enfermeiras; potencialidades; constrangimentos

Resumen
Marco contextual: La hospitalización de un niño en cuidados intensivos pediátricos es un acontecimiento traumático para la familia, por lo que es fundamental que se sientan involucrados en el entorno y en los cuidados.
Objetivo: Identificar las posibilidades y las limitaciones de la participación de la familia en el cuidado de niños en situación crítica, según la percepción de los enfermeros.
Metodología: Estudio exploratorio-descriptivo, de naturaleza cualitativa, con la participación de 26 enfermeros, en cuatro grupos focales, de una unidad de cuidados intensivos pediátricos de un centro hospitalario. Se recurrió al análisis de contenido para el tratamiento de los datos, de acuerdo con Flick.
Resultados: Se identificaron diversas limitaciones relacionadas con los familiares/padres, la situación clínica, los profesionales y la institución. Las competencias comunicativas del equipo, la comodidad y la seguridad del niño, el sentimiento de utilidad de los familiares y la posibilidad de minimizar el tiempo de hospitalización fueron algunas de las potencialidades señaladas.
Conclusión: Implicar a la familia en los cuidados es fundamental, ya que promueve sentimientos de utilidad, tranquilidad y seguridad. Sin embargo, los enfermeros experimentan limitaciones que intentan minimizar con estrategias de implicación, con el fin de potenciar la participación de la familia.

Palabras clave: cuidados críticos; familia; niño; enfermeras y enfermeros; potencialidades; restricciones

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Introduction

Family involvement during hospitalization has evolved significantly. When conditions allow, according to Melo (2020) and Sá (2023), families should participate in caregiving by performing simple tasks, always under the supervision of a nurse, and by providing information about the patient's habits and needs, thereby minimizing the disruption and changes to the family unit caused by hospitalization in intensive care. Given the importance of this involvement for both the child and the family, nurses focus on integrating families into care. However, according to Melo (2020), this integration must be effectively embedded into care practice. In this context, nursing focuses on personalized and holistic care, centered on the needs of patients and family members, integrating them into the environment and, consequently, into the care provided. The emphasis on nursing work and competencies requires an evolution in thinking and practice, with a paradigm shift being crucial−one that views patient care as inherently inclusive of the family. This shift promotes family involvement in the care of critically ill children through a care partnership centered on the child and their family. This approach should not be viewed as an obstacle to practice but rather as benefiting the quality, safety, and humanization of care. Nurses thus emerge as a vital link between the family and the critically ill patient (Melo, 2020; Waddington et al., 2021; Weber et al., 2021), identifying possible constraints to involvement and acting as key agents in promoting behaviors that foster engagement.

Therefore, it is important to identify, from nurses' perspectives, the strengths and constraints of family involvement in the care of critically ill children, in order to generate scientific knowledge applicable to clinical practice. This, in turn, will improve the care provided, leading to health gains and contributing to a qualitatively differentiated practice.

Background

Involving the family in care within the context of pediatric intensive care, a setting often perceived as hostile, unfamiliar, and complex, allows families to feel useful and connected to their child, maintaining both the emotional bond and parental role. However, the participation of all stakeholders (family, nurses, and the child) is not always effective or easy to implement due to a range of constraints related to the unit, the institutional culture, healthcare professionals, and even the parents or family members (Melo, 2020; Weber et al., 2021; Sá, 2023).

Families should be prepared early on to participate in care, should they wish to do so and feel ready for it (Jaffa & Hwang, 2021; Melo, 2020), as involvement allows them to feel useful and secure, while preserving the parental bond (Melo, 2020). Insufficient involvement, on the other hand, can lead to anxiety, depression, and feelings of guilt (Bennett & LeBaron, 2019; Jaffa & Hwang, 2021; Wool et al., 2021; Wubben et al., 2021).

A partnership between the healthcare team and the family is essential in pediatric intensive care units (UCIP) (Sánchez-Rubio et al., 2021). For this partnership to develop, family members must feel integrated into, and prepared for, the environment.

Family involvement in care is therefore a relevant and necessary component of clinical practice, and when effectively implemented, it promotes a qualitatively differentiated model of care.

Research question

What strengths and constraints do nurses identify regarding family involvement in the care of critically ill children in a UCIP?

Methodology

Taking into account the COnsolidated criteria for REporting Qualitative studies (COREQ) guidelines and in accordance with the defined research question, a descriptive and exploratory qualitative study was conducted using focus groups for data collection.

The study took place in a level III, multi-purpose UCIP that admits patients under 18 years of age with serious yet potentially reversible conditions. The target population consisted of nurses working in a UCIP within a hospital center. Although the intention was to include the entire nursing team, inclusion criteria were defined to ensure relevance to the phenomenon under study: having worked in the unit for at least six months, providing daily care to critically ill children, welcoming family members into the unit, and agreeing to participate voluntarily (Melo, 2020). Consequently, nurses who were in the integration process, completing internships, or occupying management and leadership positions without regular contact with families were excluded. Of the 32 nurses on the team, 26 nurses met the criteria and participated in the study.

Four focus groups were conducted − coded A, B, C, and D − with participants aged between 31 and 63 years. In terms of academic and professional training, each group included both registered nurses and nurse specialists. The participants had between eight and 38 years of professional experience and more than three years of experience in intensive care. The focus group method was selected as the data collection strategy, using a semi-structured and flexible interview guide. Four groups of nurses were formed: two comprising six nurses each, and the remaining two groups consisted of seven nurses each. Sessions lasted between 40 and 50 minutes. Group composition followed heterogeneity criteria regarding professional experience, communication style, demographic characteristics, training, and experience in the unit in order to foster a rich, diverse discussion based on different opinions and perspectives. Sessions were held between May 9 and June 8, 2019. All data were audio-recorded in full to minimize information loss. Each session was facilitated by an interviewer (the researcher) and supported by an

observer, enabling comprehensive documentation of non-verbal information and the development of field notes. The researcher also reflected on their position. Systematic analysis followed, with transcription of the interviews and subsequent content analysis based on the stages described by Flick (2013). This included inductive and interactive coding, comparison of meaning units, and the development of groups and categories to ensure interpretative coherence. Data collection and analysis were conducted in accordance with COREQ guidelines, also incorporating triangulation of researchers and sources. Regarding ethical and legal considerations, approval was obtained from the hospital center's board of directors and ethics committee in April 2019 (code 135-18). Participants were informed about all phases of the research and the study's purpose. Informed consent was obtained, ensuring anonymization of data, confidentiality, respect for privacy and human dignity, and the right to withdraw from the study at any time without consequences.

Results

The in-depth analysis of the focus groups revealed a central theme of the study: Family involvement in care. This theme comprises two overarching categories—Constraints and Strengths—each consisting of several subcategories that helped clarify both the challenges and the added value perceived by nurses when involving families in the care of critically ill children.

The Constraints category includes subcategories related to factors associated with family members, the clinical condition of the child, healthcare professionals, and the institution. In contrast, the Strengths category is organized into subcategories that reflect the benefits of family involvement, namely the facilitation of professionals' activities and the advantages for family members, patients, and the institution.

All subcategories emerged from meaning units drawn from participants' narratives, providing relevant and coherent insights into nurses' experiences and perceptions regarding this topic.

The findings allowed for a deeper understanding of how nurses perceive family involvement in the care of critically ill patients, particularly within an adverse context marked by multiple challenges and constraints. This knowledge strengthens nursing practice by supporting a more informed, individualized, and family-centered approach, aligned with the daily demands of UCIPs and focused on promoting effective family involvement in care.

Constraints

During the focus groups, participants repeatedly mentioned that effective family involvement in care is conditioned by a set of constraints arising from different types of difficulties. These may be associated with family members, the patient's clinical situation, or even with healthcare professionals and institutional factors.

These multifactorial constraints gave rise to the subcategories analyzed below.

Participants noted that family involvement in care can be hindered by factors related to family members, particularly when they do not wish to participate due to feelings of fear or insecurity, when they refuse to engage, or when they are rarely present, or even absent, from the UCIP. Nurses also attributed these constraints to family members' increased level of demand and need for information, which may manifest as excessive questioning or, at times, as more aggressive behavior. Additionally, reduced receptiveness to guidance, failure to comply with institutional rules, insufficient preparation for caregiving, and a lack of emotional and psychological support were identified as further barriers to effective participation in the care of their hospitalized child. Some of these difficulties are illustrated in the following statements:

"Only if they don't want to, because I've also had parents who said they didn't feel comfortable and didn't want to . . ." (B2).

"It's difficult to get them involved in care when they're absent. And no matter how much you show that their presence benefits the child, it is often not easy" (A1).

"Another thing that I think can also be an impediment is those family members who try to impose their own way of caring. They do not follow the instructions of the healthcare team treating the child" (D2).

Other constraints identified across all focus groups were associated with the patient's clinical condition. Participants reported that the complexity and/or deterioration of the child's clinical condition can limit family participation, even when family members are willing and available to be involved. This idea is reflected in the following statement: "Sometimes, too, if the situation is very complicated and they can't do anything at all, or almost nothing, they can't participate or almost don't" (A1).

On the other hand, insufficient emotional and psychological support, as well as the lack of adequate professional training to deal with these situations and with family members themselves, were identified as difficulties associated with healthcare professionals. According to the participants, the prioritization of care interventions, the individual work models adopted by each nurse, the recognition of family members' skills, and the possibility of delegating tasks also constitute barriers to effective family involvement.

These difficulties arising from professional practice are evident in the following statements:

> But we have to involve parents, and we also need group strategies for dealing with them. I don't have the tools to help me deal with these parents, and I think we should have them. Here, I don't see any psychologists available either. (A4)

"Family participation does not reduce the workload" (D3).

Family involvement in care also faces constraints arising from institutional aspects, namely insufficient human resources, the need for team coordination, and limited time to balance communication, involvement, and care provision. In addition, inadequate infrastructure to meet the daily demands of the unit, existing needs, and the need to ensure privacy were identified as institutional factors that hinder family involvement.

"The ratio is something that hinders this involvement . . . Perhaps if, instead of having 'x' nurses in the morning, there were more, the quality of care would increase" (C5).

> Sometimes, the most difficult thing is also coordinating our schedules. We are a team, aren't we? The work, all the team members, who are not always coordinated with each other. And sometimes it becomes more difficult. (B1)

"And when I say welcome, I don't just mean welcoming them into the unit, I mean welcoming them into everyday life, into the daily context" (A4).

Strengths

According to the data obtained from the focus groups, family involvement in care has significant potential, as it facilitates the work of healthcare professionals and benefits family members, patients, and the institution. This potential is also linked to the team's communication skills, which are recognized as central to establishing therapeutic relationships and building trust.

"I think we are a good team and communicate very well, and we all know how to talk to parents, listen to them, hear their doubts and anxieties" (A4).

Participants considered family involvement in care to be an asset, as it eases professional work both by providing greater peace of mind when family members are present and by allowing nurses to better understand the work, responsibilities, and challenges they face daily:

"It is an advantage for us . . . knowing that the parents are present also facilitates all our monitoring work" (A6).

"And they value our work, they understand how difficult it is in terms of the amount of work. They understand that we are there giving our all for the best for their child" (C4).

Furthermore, participants reported that family involvement fosters feelings of usefulness, trust, and emotional reassurance, helping to maintain family bonds. They also highlighted that participating in care promotes a better understanding of the patient's clinical condition and facilitates coping with clinical worsening and deterioration: ". . . parents feel useful in participating in care, and I think that gives them a lot of peace of mind" (B7).

"When the patient's condition worsens, the closer and more involved the parents are, the easier it is to manage these situations later" (C7).

For the patient, the primary benefits of family involvement are related to feelings of security and comfort resulting from the presence of their relatives, which in some situations may even reduce the need for pharmacological interventions.

Nurses also perceived that family involvement in care represents added value for the institution, notably by potentially reducing hospitalization time and associated costs, as well as serving as an indicator of the quality of care provided. This is evidenced by the following statements: "They can minimize hospitalization time in some situations . . . ." (D1). "It is an indicator of quality and parental satisfaction" (B3).

Discussion

Family involvement in care presents both constraints and strengths, making it essential to identify and critically analyze these factors. According to nurses, family involvement is often hindered by characteristics of the family members, including infrequent presence in the unit, feelings of insecurity, and insufficient preparation to cope with the UCIP environment. Even when encouraged to participate, some family members remain unwilling to engage in care. These findings are consistent with studies indicating that absence, low participation, and limited understanding of the clinical situation compromise the implementation of family-centered care (Boyamian et al., 2021; Burns et al., 2018).

Easier access to information, facilitated by new technologies, has resulted in families who are better informed but also more demanding and assertive and, in some cases, may adopt aggressive stances toward healthcare professionals. Nurses reported that some family members consider themselves sufficiently knowledgeable to intervene in care, which can negatively affect their inclusion in the process. Non-compliance with institutional rules and difficulty accepting the need for highly specialized care in the UCIP context were also identified as relevant constraints, as documented in previous literature (Alshahrani et al., 2018; Boyamian et al., 2021; Kiwanuka et al., 2019).

The lack of structured emotional and psychological support, as well as insufficient nurse training to manage complex situations involving the family, were identified as limiting factors. These findings reinforce the importance of multidisciplinary intervention, incorporating psychologists and social workers to support family members in understanding and accepting the clinical situation and actively participating in care (Melo, 2020; Mirlashari et al., 2019; Waddington et al., 2021). The complexity or deterioration of the patient's clinical condition was also highlighted as a factor inhibiting family inclusion, due to concerns about clinical instability or increased anxiety among family members, in line with previous studies (Alshahrani et al., 2018; Coats et al., 2018).

Other constraints identified include the fear that encouraging participation may be interpreted as delegating tasks, failure to recognize the skills of family members, shortages of human resources, work overload, and insufficient time for more humanized interventions. Inadequate coordination within the multidisciplinary team and limited infrastructure in the unit, particularly with regard to monitoring and privacy conditions, were reported as factors that compromise family involvement.

Despite these constraints, nurses acknowledged the multiple benefits associated with family involvement, which positively impact healthcare professionals, family members, patients, and the institution. Family involvement enhances and facilitates the work of nurses, promotes feelings of security, trust, and usefulness among family members, and contributes to maintaining emotional

bonds. For patients, the presence of family is associated with greater comfort, reassurance, and security, and may even reduce the need for pharmacological interventions. At the institutional level, effective family involvement is perceived as promoting quality of care, reducing hospitalization time and associated costs, consistent with the literature (Sá et al., 2023).

Identifying both the constraints and strengths of family involvement highlights the need to adapt nursing practices and develop strategies that promote a more family-centered approach. Although this study contributes to the understanding of nurses' perceptions, its limitations include the analysis of a single UCIP and the absence of the family members' perspective, issues that should be addressed in future research.

Conclusion

Understanding nurses' perceptions regarding family involvement in the care of critically ill children—within an adverse and often challenging context marked by multiple constraints—is essential for improving nursing practice. Despite the relevance of this topic for health and nursing practice, there remains a notable scarcity of publications focusing on nurses' roles in engaging families in the care of critically ill patients, particularly in UCIPs, with emphasis on perceptions of experiences, benefits, and barriers.

The study showed that intensive care nurses attribute great importance to family involvement in care and recognize its potential benefits. However, this process is often hindered by multiple constraints related to healthcare professionals, family members, the institution, and the patient's clinical situation. Nurses attempt to address these constraints by implementing practices and strategies developed within the care context.

It was also concluded that fear of delegating tasks to family members, inadequate infrastructure to meet existing needs, work overload, prioritization of interventions due to limited time and human resources, the complexity of the care environment, the diversity of patients' clinical situations, and lack of team training and coordination are significant constraints limiting family involvement in the care of critically ill children.

Despite these obstacles, family involvement in care is widely recognized as beneficial. It facilitates healthcare professionals' work by helping family members appreciate nurses' efforts; promotes feelings of usefulness, calm, trust, safety, and well-being among family members; supports acceptance of the patient's illness; and provides the patient with greater security and confidence, potentially reducing therapeutic needs and length of hospital stay.

This critical understanding of nurses' perceptions regarding a topic central to the quality and satisfaction of care enables units to adjust practices toward more individualized approaches grounded in both human and scientific competence. Furthermore, it encourages family involvement through practices capable of overcoming existing constraints, fostering a humanized, participatory, and partnership-based model of care that prioritizes the well-being of the child, the family, and the healthcare professionals. Consequently, it promotes satisfaction within the nurse–child–family triad and generates health gains, contributing to a differentiated care practice oriented toward continuous quality improvement.

Author contributions

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