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RESEARCH ARTICLE (ORIGINAL)

Nurses' perceptions of family involvement in the care of critically ill children

Perceção dos enfermeiros relativamente ao envolvimento da família nos cuidados à criança em situação crítica

Percepción del personal de enfermería sobre la participación de la familia en los cuidados de niños en estado crítico

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Abstract
Background: Family involvement in the care of critically ill children benefits the child-family-nurse triad by promoting closeness, security, and emotional support.
Objective: To explore nurses' perceptions of family involvement in the care of critically ill children.
Methodology: This descriptive, exploratory, and qualitative study was conducted with 26 nurses from a pediatric intensive care unit in a hospital center. The nurses were organized into four focus groups, and content analysis was used to examine and process the data.
Results: The following three categories emerged – Procedures Used, Involvement Strategies, and Type of Care. Participants reported using skills assessment and family training as family involvement procedures, based on a set of pre-established criteria, as well as strategies such as activity supervision, information for decision-making, negotiation, and unit personalization. It was also determined that these strategies were not applicable to all types of care.
Conclusion: Family involvement in care is essential. However, nurses experience multiple limitations that they attempt to minimize through procedures that require the involvement of family members in care delivery.

Keywords: pediatric intensive care; involvement; family; nursing; critical situation

Resumo
Enquadramento: Envolver a família no cuidado à criança em situação crítica, apresenta potencialidades na tríade criança, família e enfermeiro, fomentando a proximidade, segurança e suporte emocional.
Objetivo: Analisar a perceção dos enfermeiros relativamente ao envolvimento da família nos cuidados à criança em situação crítica.
Metodologia: Estudo exploratório descritivo, natureza qualitativa, tendo participado 26 enfermeiros, em quatro grupos focais, de uma Unidade de Cuidados Intensivos Pediátricos, de um Centro Hospitalar. Para a análise e tratamento de dados recorreu-se à análise de conteúdo.
Resultados: Emergiram três categorias – Práticas utilizadas; Estratégias de envolvimento; Tipologia de cuidados. Os participantes utilizam a avaliação das competências e capacitação dos familiares como práticas, subjacentes a um conjunto de requisitos. A supervisão das atividades, informar para a tomada de decisão, a negociação e a personalização da unidade são estratégias utilizadas, mas nem sempre aplicáveis em toda a tipologia de cuidados.
Conclusão: Envolver a família nos cuidados é essencial, no entanto os enfermeiros experienciam múltiplos constrangimentos, que tentam minimizar através de práticas, as quais ditam o envolvimento no cuidado.

Palavras-chave: cuidados intensivos pediátricos; envolvimento; família; enfermagem; situação crítica

Resumen
Marco contextual: Implicar a la familia en el cuidado de los niños en situaciones críticas presenta un potencial en la tríada niño, familia y enfermero, y fomenta la cercanía, la seguridad y el apoyo emocional.
Objetivo: Analizar las percepciones de los enfermeros sobre la implicación de la familia en el cuidado de niños en situación crítica.
Metodología: Estudio exploratorio descriptivo de carácter cualitativo, 26 enfermeros participaron en cuatro grupos focales en una Unidad de Cuidados Intensivos Pediátricos de un centro hospitalario. Se utilizó el análisis de contenido para analizar y procesar los datos.
Resultados: Surgieron tres categorías – Prácticas utilizadas; Estrategias de participación; Tipología de cuidados. Los participantes utilizan la evaluación de competencias y la capacitación de los familiares como prácticas, respaldadas por una serie de requisitos. Supervisar las actividades, informar sobre la toma de decisiones, negociar y personalizar la unidad son estrategias utilizadas, pero no siempre aplicables a todos los tipos de cuidados.
Conclusión: Implicar a la familia en los cuidados es esencial. Sin embargo, los enfermeros experimentan múltiples limitaciones, que intentan minimizar mediante prácticas que determinan la implicación en los cuidados.

Palabras clave: cuidados intensivos pediátricos; implicación; familia; enfermería; situación crítica

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Introduction

Sudden illness enters people's lives unexpectedly and without preparation and can lead to hospitalization without warning. Intensive care is essential to sustain life and involves complex interventions and the use of sophisticated technical skills (Melo, 2020; Mirlashari et al., 2019; Sá, 2023; Walter et al., 2019). When hospitalization takes place in a pediatric intensive care unit (PICU), it constitutes a stressful and anxiety-inducing experience, which is shared by health professionals, patients, and their families. In this context, the presence and active involvement of families plays a fundamental role, producing a calming effect and providing valuable help and support during children's hospitalization (Melo, 2020; Waddington et al., 2021; Weber et al., 2021).

Family involvement during a patient's hospitalization has evolved significantly and, whenever possible, families should participate in care delivery and provide information about the sick children's habits and needs. This helps to mitigate the disruption caused to the family unit by hospitalization (Waddington et al., 2021; Weber et al., 2021). However, despite the recognition of the importance of family involvement, studies suggest a gap between theory and practice (Melo, 2020; Walter et al., 2019; Waddington et al., 2021).

Therefore, it is essential to explore the importance of hospitalization and family involvement in the context of PICUs and examine nurses' perceptions of family involvement in the care of critically ill children.

Background

Given the hostile, unfamiliar, and complex environment of intensive care units, family involvement in pediatric intensive care allows families to feel useful and closer to their children, thus maintaining their emotional bonds and performing their parental roles. However, it is not always easy to encourage effective participation that engages all stakeholders (families, nurses, and patients) due to multiple limitations associated with the environment, the people involved, and the institutional culture (Melo, 2020). Although nurses express their interest in providing comfort and information and being closer to families, few actively invite families to participate in patient care (Melo, 2020; Walter et al., 2019). However, families should be prepared as soon as possible in order to be involved in decision-making and care, whenever clinically safe and appropriate, as well as according to their level of comfort (Jaffa & Hwang, 2021). Lack of appropriate family involvement can lead to feelings of anxiety, depression, and guilt (Bennett & LeBaron, 2019; Jaffa & Hwang, 2021; Wool et al., 2020; Wubben et al., 2021). In PICUs, partnerships between health care professionals and families are essential (Sánchez-Rubio et al., 2021; Rennick et al., 2019). Nevertheless, for these partnerships to be effective, teams must develop professional procedures and interventions based on collaboration and sharing, which effectively recognize the importance of families (Rennick et al., 2019; Walter et al., 2019).

Family involvement in care is a pertinent and urgent topic that needs to be addressed and researched, as it is a frequently reported need. Furthermore, when encouraged, it provides health benefits and promotes a qualitatively differentiated care practice.

Research question

What procedures do nurses implement to promote family involvement in the care of critically ill children in pediatric intensive care?

Methodology

To answer the defined research question, an exploratory-descriptive qualitative study was conducted using focus groups as the data collection method. When a qualitative approach is adopted, investigators typically collect information in the environment where the participants involved in the investigation experience the problem under study. This implies working in close proximity (Polit & Beck, 2019). In addition, this research approach, in which the phenomenon is experienced *in situ*, allows for obtaining data that reflect both reality and practice.

The study was conducted in a level III multipurpose PICU, which is indicated for the hospitalization of patients under 18 years of age with serious and potentially reversible medical conditions.

The target population consisted of nurses working in the PICU of a hospital center, and the selection process of participants considered all nurses of the PICU nursing team. Considering the phenomenon under study, participants had to meet the following inclusion criteria: to work in the PICU for at least 6 months, to provide daily care to critically ill children, to welcome family members in the PICU, and to agree to participate voluntarily in the study (Melo, 2020). Nurses were excluded if they were newly admitted to the service or doing an internship, if they held a management or leadership position, or if they did not welcome family members to the PICU as part of their daily functions. Thus, after applying the defined exclusion criteria, only 26 of the 32 nurses on the PICU nursing team participated in our study.

Four focus groups, designated as A, B, C, and D, were conducted. The participants ranged in age from 31 to 63 years and the majority were women. Male participants were divided into two different groups. In terms of academic and professional training, each group included generalist nurses and nurse specialists. The study participants had between 8 and 38 years of work experience. Although some participants had worked in the PICU for 28 years, most had worked there for more than 3 years. The focus groups were organized with the intention of being heterogeneous. However, it is worth noting that focus group A had a higher mean length of professional experience and PICU experience than the other groups. Focus group interviews were selected as the data collection

method, and four focus groups of nurses were formed: two with six nurses each and the other two with seven nurses each. The mean duration of the focus group sessions was between 40 and 50 minutes. To be heterogeneous, the groups were organized considering the nurses' professional experience, communication characteristics, demographic characteristics, education, and length of service. This organization enriched the focus group discussions, which were based on different opinions and perspectives. The sessions took place between May 9 and June 8, 2019. The data collected were audio-recorded to minimize loss of information and guided by an interviewer (the investigator) and an observer, who made the detailed collection of nonverbal communication. The interviews were transcribed, and their content was analyzed according to Flick's (2013) specifications. The approval of the study's methodology and ethical-legal principles was requested to the board of directors and the ethics committee of the hospital center where the study was conducted. The positive opinion (code 135-18) was obtained in April 2019. The participants were informed about the phases and aim of the study and asked to sign informed consent forms. The participants were also assured of the study's respect for anonymity, confidentiality, intimacy, and human dignity, as well as their right to withdraw from the study at any time without consequences.

Results

After the detailed analysis of the focus group interviews, the results allowed identifying the main theme of the study as "Family Involvement in Care". This theme included the following categories: "Procedures Used," "Involvement Strategies," and "Type of Care."

The results also provided a deeper understanding of nurses' perceptions of family involvement in care for critically ill patients, particularly in an adverse context with multiple challenges and limitations. This understanding is essential for improving care procedures and strengthening collaboration between care teams and patients' families. Assessing family members' capabilities is a key procedure that must underpin family involvement in care, as it allows for understanding the skills of family members and whether they are capable or have previous experience. In other words, it allows health professionals to assess family members' level of training and their availability and/or willingness to play a collaborative role. The following recording units illustrate this assessment:

"Assess their abilities. Then . . . try to, regardless of their abilities, [assess] whether they're capable or not. Some don't really want to do that, because they [the children] are all wired up and it's very difficult" (A2).

"I think one of the things we do with that in mind is to ask them a little bit about how it is... what they like, what their habits are... to involve them a little bit in the process" (A3).

The participants in all focus groups frequently mentioned the procedure of training family members. Nurses stressed the importance of informing, educating and training family members so that they can actively participate in care, always considering the environment in which they are. This training process includes not only the transmission of information, but also practical training to provide specific care, bearing in mind future dependencies and needs.

Participants mentioned that the aim of this training is the gradual involvement of family members, "after assessing the abilities, to try to eventually teach them some things, or instruct them, or teach them, or . . . and try to get them to become autonomous in some things, in some care interventions, in some partnership care interventions" (A2); " We are training them for the new reality . . . training them and adapting them. That's our role, to enable them to do that" (B2).

The procedures used to involve families can be conditioned and vary according to the patient's state of health, as participants considered that the patient's clinical condition must be taken into account. In addition, family involvement is not considered essential when patients' condition is reversible. However, in the case of chronically ill patients who will continue to need care, or when family members already play the role of caregivers, the involvement procedures adopted need to be different, as illustrated by the following statements:

"And we have bad situations, serious situations, chronic situations where they already have basic training . . . in these cases the involvement has to be different" (B1).

"If it's a hospital situation that will be solved in the hospital, no. But there are other situations that can't be resolved and go to the nursing ward, [such as] polytraumatized [patients] and so on . . . But at that moment I'm not going to teach feeding either" (B2).

All four focus groups agreed that there are certain requirements to be considered when involving the family. The participants perceived family involvement as a gradual process that requires nurses' availability, and the establishment of a relationship based on trust and respect for the patient's wishes. It is also important that health professionals show consistency in their daily practice and performance, respecting the patient's preferences and consent to the possibility of involving a family member in their care. The following statements illustrate these requirements: "Because then they begin to feel comfortable... day by day they are able to participate in more care interventions" (C1).

> The partnership must be voluntary; the nurse can't impose the negotiation... the parents must show initiative, willingness, and availability. Although they're here for several days, if they never show availability and willingness, this must be respected". (C5)

In the focus groups, the participants mentioned the use of the following strategies for family involvement: supervising family activities, providing information for decision-making, negotiating with family members, and personalizing the PICU.

These strategies aim to increase family involvement in care. Considering the discussion in one of the focus groups, the participants recognized that one of the involvement strategies was the supervision of family members' activi-

ties. After assessing the family members' capabilities, the nurses guide and supervise their actions, thus promoting the family members' confidence. This is evident in the following statement: "But there are things they can do as they did at home. We supervise and guide them" (A5).

Another strategy for involving the family is to provide information for decision-making. Nurses explain to family members what activities can or cannot be done and provide information in a timely manner. This allows family members to act and make informed decisions that are aware of and responsive to their children's needs.

"Keeping to the rule that we are the ones who decide but giving them space in chronic situations... sometimes it is necessary to give them a different space" (B1).

"At the beginning, when everything is scary, they are even afraid to touch them, and we need to go and tell them what they can and can't do... or if it's appropriate... if it's the moment when they can stimulate or not" (C3).

"They participate, but we have to give them some rules to follow" (B2).

Participants also mentioned positive reinforcement as a strategy for involving family members in care. Positive reinforcement is a fundamental tool for encouraging and motivating family members and acts as a resource for subsequent family member interventions. This is illustrated in the following recording unit: "And another very important thing is to always praise at the end. Always give positive reinforcement, I think that's fundamental" (C3).

As frequently mentioned in the focus groups, negotiating with family members is essential to promote their involvement in the PICU environment. This approach promotes trust and mutual respect and establishes effective collaboration between nurses and families. Negotiation allows for the definition of which care interventions need to be provided and when, so that they can be timed according to family members' capabilities and availability as well as the daily activities of the PICU. Dialogue is fundamental and must be maintained throughout the process, as illustrated in the following statement: "Overall, we manage to find a way to reach an agreement, through dialogue, talking to them, involving them in the care" (A1).

The participants also perceive and mention the personalization of the unit as a strategy they use to involve the family. The personalization of the unit allows for making the environment more familiar and welcoming through the introduction of some personal objects that are meaningful to the patients or that correspond to their personal preferences:

> To make it more theirs, with their doll, their blanket, their clothes. Little things that allow parents to really have a way of . . . okay . . . participating and trying to make that space their child's space and not the hospital's space. (C1)

Regarding the type of care, the different focus groups explained that family members are involved (or attempts are made to involve them) in specific types of care, depending on the patient's needs and level of dependency, as well as the family member's skills. The analysis of this information allowed determining that this type of involvement focuses on the delivery of basic care (physiological interventions), emotional and affective care, and specialized care with a certain degree of differentiation (differentiated care).

Participants reported that there is an attempt to involve family members in the provision of basic (physiological) care, such as hygiene, feeding and assistance with patient positioning. Involving family members in this type of care is justified as something that family members already know how to do at home or need to learn in order to ensure continuity of care after discharge from hospital.

"Hygiene care. Sometimes temperature assessment... feeding, in situations where they can give the food" (A1).

"Help with positioning or covering or applying cream at the end of the bath, when everything is stabilized . . ." (C7).

Participants also mentioned that they involve family members in the provision of emotional and/or affective care. By doing so, they provide opportunities for family members to touch their child, be affectionate, and, whenever possible, provide comfort.

"The first thing I suggest is that they touch their child. If it's possible, I think the least they can do is to touch their child . . . the same with comforting, cuddling, being affectionate..." (D2).

In addition to basic and emotional care, all the focus groups reported the involvement of family members in specialized and/or differentiated care. This situation is more frequent when family members have already experience prior to the child's admission to the PICU or in specific situations in which the patient is expected to be permanently affected or require specialized care at home.

"It's a very special situation, ostomies, whether it's a tracheostomy or something else, if it's a child going home with it, you have to involve the parents and teach them how to provide care at home" (B7).

> With chronically ill patients, they are already used to . . . they already come with the experience of feeding through the gastrostomy tube, the nasogastric tube, even suctioning secretions from tracheostomized children who are at home. [Teaching how] To do the dressings, colostomy care, so we involve them in that [type of] care. (D2)

Discussion

Nurses assess the family's capacity to participate in the care process, looking at their knowledge and skills, and whether they are sufficiently ready and integrated to participate and be with their child in the PICU environment. In this assessment, nurses try to understand whether family members are willing to actively participate in care provision, because regardless of the level of integration and call for participation, they may not be willing to do so. This is directly related to the context, which makes it difficult for family members to intervene because they are afraid of harming the patient or damaging the equipment. In addition, failure to accept the seriousness of their loved one's clinical situation can make it difficult for them to be actively involved in care. Therefore, an assessment of

family members' capabilities is essential and should be conducted in the PICU environment, allowing nurses to define family members' interventions considering the reality and individuality of each family. Hetland et al. (2018) concluded in their study that nurses assess family members' capabilities by considering aspects such as physical strength, willingness to participate, emotional stability, knowledge of the disease process, pre-existing knowledge, and the relationship between the family member and the patient to determine whether they are able or have the skills to provide care. Waddington et al. (2021) and Boyamian et al. (2021) also emphasize the importance of assessing the needs and potential of families before involving them in the care process, while highlighting the beneficial effects of involvement. Family training is essential because family members must learn about the types of care they can provide and be alerted to special situations. However, this training depends on the patient's clinical condition. In cases where the patient's condition is reversible or when the hospital stay is expected to be short, the educational process may not be implemented since it is only relevant for family members of patients who are likely to undergo changes requiring support or substitution by a family member. In the literature reviewed, no data were found that contradicted or clarified the results of our study, which addressed family involvement taking into account whether or not the patient's clinical condition is reversible. Therefore, this is an important research finding.

The review by Burns et al. (2018) highlights that nurses tend to involve family members when patients are in intensive care for longer periods but does not specifically mention that there is no involvement when the patient's condition is reversible. However, when family members are engaged in care, this involvement is mostly related to physiological/basic care and emotional/affective care interventions, as these types of care are perceived to provide the most benefits to both the patient and the family. These benefits include a sense of safety, comfort, calm, and the maintenance of the affective bond. Hygiene care, taking body temperature, feeding, applying body lotion, and positioning are examples of basic care interventions in which nurses involve family members. The opportunity to touch the patient, provide affection and attention, and, when possible, hold the patient are also emotional and/or affective care interventions that include family members. However, when it comes to specialized care, such as ostomy care, administering treatments, suctioning secretions, and feeding through a nasogastric or gastrostomy tube, family members are involved only if they have previous experience or if it will be necessary for them to provide this type of care. The provision of specialized care requires training focused on the specific needs involved. Similarly, in the study by Hetland et al. (2018), nurses reported that they found it difficult to involve family members in complex and specialized care, especially in the removal of secretions through tracheostomy suctioning or in respiratory kinesiotherapy, due to safety concerns for the patient and the family member as well as possible legal repercussions. Our study is also consistent with the conclusions of these authors, as it shows that nurses tend to involve family members primarily in the provision of basic care, such as body and oral hygiene and body massage (Hetland et al., 2018; Waddington et al., 2021). Nurses follow a set of pre-established criteria when assessing the skills and training of family members. Thus, the involvement of family members in the care of critically ill patients is a gradual process based on a relationship of trust between nurses and family members, which develops based on the assessment of family members' skills and the patient's clinical condition.

Nurses' respect for family members' choices and consistency in the information provided throughout the process are also prerequisites for effective family involvement. Nurses must be consistent in their actions so as not to jeopardize the trust that has been established, which could hinder the future involvement of family members. The analysis of strategies for family involvement in the care of critically ill patients revealed that encouraging family presence and participation in care, with appropriate guidance and supervision, provides both parties with a sense of trust and security. Moreover, during the process of supervision and guidance in/for care, giving praise for participation provides the family member with positive reinforcement.

Informing the family for decision-making is also considered fundamental because providing clear information about the activities they can carry out and the limits that must be respected, taking into account the patient's clinical situation, the context or the constraints that this involvement may create, allows the family to make informed, contextualized and conscious decisions. This is supported by the work of Mirlashari et al. (2019), Waddington et al. (2021), and Weber et al. (2021).

Family participation and involvement occurs through negotiation and dialogue with family members from the moment of admission to the PICU. However, this process can be hindered by parents' anxiety, the professionals involved, communication, and the type of relationship established (Araújo et al., 2021; Sá, 2023). In order to make the PICU environment more welcoming, humanized, familiar and less frightening, personalizing the surrounding space with personal objects of symbolic value, as well as catering to personal preferences, becomes a strategy to facilitate involvement. However, this result was not found in any of the other studies consulted.

Discussion of the results allows for an understanding of nurses' procedures regarding family involvement in the care of critically ill children in the PICU, providing new findings on the topic and confirming that the results are consistent with what has already been studied and presented in the literature.

Conclusion

The importance of family involvement in the care of critically ill children has emerged as a fundamental element of care, in terms of providing emotional support to the child as well as overall support to family members. In

this sense, it is crucial to highlight the importance of the strategies developed by nurses in their daily activities to frame the involvement of families in the care of critically ill children and the appropriateness of the different strategies to the type of care intended. The humanization of care, the provision of holistic and personalized care, and the consequent involvement of families in this care setting have become a priority for both professionals and health institutions. However, despite the relevance of this topic to health and nursing practice, there is a lack of publications focusing on the role of nurses in family involvement in the care of critically ill patients, especially in the context of pediatric intensive care. Our study found that PICU nurses value family involvement in care. However, this process encounters limitations related to health professionals, family members, institutions, and the children's clinical condition. Nevertheless, nurses have developed procedures and strategies to overcome these limitations. In conclusion, involving families in the care of critically ill children provides added value in several areas and can be implemented through strategies aimed at assessing, training, negotiating and informing family members in order to ensure that they feel safe and confident in the PICU environment. This process helps families cope with the difficulties and experiences of hospitalization. However, it is also crucial to minimize limitations, through the preparation and effective integration of families into the context, the availability of sufficient human resources, and the provision of specific training that enables health professionals to involve families in care, thus promoting a qualitatively differentiated care practice.

Author contributions

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