

# Nurses' experience in caring for families of children on extracorporeal circulation: links and challenges

Experiência do enfermeiro no cuidado à família da criança em circulação extracorpórea: vínculos e desafios

Experiencia de enfermeras en el cuidado de familias de niños en circulación extracorpórea: vínculos y desafíos

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## Abstract

**Objective:** This study aims to understand nurses' perceptions of their role in supporting the families of pediatric patients undergoing Extracorporeal Membrane Oxygenation.

**Methods:** This is a qualitative, descriptive and exploratory research, the participants mostly come from public institutions in the city of São Paulo. Data collection occurred through semi-structured interviews carried out with 14 nurses with a minimum experience of 6 months and completed in the first half of 2024. The data were analyzed using Thematic Content Analysis. The data were analyzed using Thematic Content Analysis.

**Results:** Nurses reported that caring for the child and their family during Extracorporeal Membrane Oxygenation treatment is challenging, requiring a balance between the patient's technical needs and the family's emotional support. Clear communication and empathy are essential to building trust, reducing family members' anxiety, and ensuring their involvement in the care process. However, challenges such as emotional overload, the need for continuous training, and managing conflicts with difficult families were also highlighted.

**Conclusion:** The results indicate that, for effective care, nurses require specialized training not only in technical skills but also in emotional support to manage the complexities of intensive care. Continuous presence and support for families are critical in alleviating suffering and strengthening the bond between them and the healthcare team. The study underscores the importance of the nurse in the ECMO context, not only in patient care but also in providing essential support to families, considering the emotional and technical challenges of this therapy.

## Resumo

**Objetivo:** Este estudo visa compreender a percepção dos enfermeiros sobre seu papel no cuidado da família de pacientes pediátricos submetidos à circulação extracorpórea.

**Métodos:** Trata-se de uma pesquisa qualitativa, descritiva e exploratória, os participantes são oriundos, em sua maioria, de instituições públicas, da cidade de São Paulo. A coleta de dados ocorreu por meio da entrevista semiestruturada realizada com 14 enfermeiros com experiência mínima de 6 meses e concluída no primeiro semestre de 2024. Os dados foram analisados por meio da Análise Temática de Conteúdo.

**Resultados:** Os enfermeiros relataram que o cuidado à criança e à sua família durante o uso da circulação extracorpórea é desafiador, exigindo um equilíbrio entre as necessidades técnicas do paciente e o apoio emocional à família. A comunicação clara e o acolhimento são fundamentais para estabelecer confiança, reduzir a insegurança dos familiares e garantir a participação deles no cuidado. No entanto, desafios como a sobrecarga emocional, a necessidade de treinamento contínuo e a gestão de conflitos com famílias difíceis foram também destacados.

**Conclusão:** Os resultados indicam que, para um cuidado eficaz, os enfermeiros precisam de formação especializada, não só técnica, mas também emocional, para lidar com a complexidade do cuidado intensivo. A presença e o apoio contínuo aos familiares são cruciais para aliviar o sofrimento e fortalecer o vínculo entre eles e a equipe de saúde. O estudo reforça a importância do enfermeiro no contexto circulação extracorpórea, não apenas no cuidado ao paciente, mas também no suporte à família, considerando os desafios emocionais e técnicos dessa terapêutica.

## Resumen

**Objetivo:** Este estudio tiene como objetivo comprender la percepción de los enfermeros sobre su papel en el cuidado de la familia de pacientes pediátricos sometidos a oxigenación por circulación extracorpórea.

**Métodos:** Se trata de una investigación cualitativa, descriptiva y exploratoria, los participantes provienen en su mayoría de instituciones públicas de la ciudad de São Paulo. La recopilación de datos se llevó a cabo mediante entrevistas semiestructuradas con 14 enfermeros con un mínimo de seis meses de experiencia y se completó en el primer semestre de 2024. Los datos fueron analizados mediante Análisis Temático de Contenido.

**Resultados:** Los enfermeros informaron que el cuidado del niño y de su familia durante el uso de ECMO es desafiante, ya que requiere un equilibrio entre las necesidades técnicas del paciente y el apoyo emocional a la

## Keywords

Pediatric nursing; Pediatric Intensive Care Units; Extracorporeal membrane oxygenation; Family

## Descritores

Enfermagem pediátrica; Unidades de Terapia Intensiva Pediátrica; Oxigenação por membrana extracorpórea; Família

## Descriptores

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familia. La comunicación clara y la empatía son esenciales para generar confianza, reducir la ansiedad de los familiares y garantizar su participación en el proceso de cuidado. Sin embargo, también se destacaron desafíos como la sobrecarga emocional, la necesidad de formación continua y la gestión de conflictos con familias difíciles. Conclusión: Los resultados indican que, para un cuidado efectivo, los enfermeros necesitan formación especializada no solo en habilidades técnicas, sino también en apoyo emocional para manejar las complejidades del cuidado intensivo. La presencia continua y el apoyo a las familias son fundamentales para aliviar el sufrimiento y fortalecer el vínculo entre ellas y el equipo de salud. El estudio resalta la importancia del enfermero en el contexto de ECMO, no solo en el cuidado del paciente, sino también en el apoyo esencial a las familias, considerando los desafíos emocionales y técnicos de esta terapia.

## Introduction

Extracorporeal membrane oxygenation (ECMO), introduced in the 1970s, became a common intervention for complex congenital heart disease, with a significant expansion of its clinical applications. In the 1990s, it began to be used more frequently as a life-saving measure during cardiopulmonary resuscitation, contributing to advances in cardiac surgical outcomes.<sup>(1)</sup> ECMO is a mechanical cardiopulmonary support that promotes blood oxygenation, carbon dioxide removal and circulatory support, allowing protective mechanical ventilation.<sup>(2)</sup>

ECMO is a mechanical cardiopulmonary support that promotes blood oxygenation, carbon dioxide removal and circulatory support, allowing protective mechanical ventilation.<sup>(3)</sup> During the COVID-19 pandemic, ECMO's indications have increased, both in adult and pediatric patients.<sup>(4)</sup>

In the last five years, the Extracorporeal Life Support Organization (ELSO) has recorded 115,999 ECMO procedures, 8,665 of which were in infants and 14,915 in pediatric patients.<sup>(5)</sup>

Nurses are crucial professionals in the team caring for patients using ECMO, promoting coordinated and uninterrupted care, allowing constant assessment of individuals' condition through monitoring, observation, prevention of complications and management of care. As this is a high-cost therapy, the procedure requires a trained and specialized team as well as adequate physical resources and material.<sup>(4)</sup>

Furthermore, when considering the care of pediatric and neonatal patients undergoing ECMO treatment, other needs emerge, especially regarding family care in the context of critically ill patients. The presence of families to ensure continuity of care for children and adolescents has been assured since 1990. Studies reinforce the importance of the family of children in intensive care as a link between patient and team as

a source of security and partnership in care. However, some of these studies also reveal that despite this, there are still many barriers and difficulties pointed out by professionals and families in daily care.<sup>(6-11)</sup>

Since this is a procedure considered relatively new within the pediatric therapeutic arsenal, some questions aroused interest regarding nurses' experience in caring for the family: How do nurses perceive the care provided to the family of a child undergoing ECMO? How does the nurse-family relationship occur in this context?

Despite the increase in the volume of research on the role of nurses in the care of patients on ECMO, there is still a gap in literature regarding the specific approach to family care for this type of patient. Therefore, this study aims to understand the role of nurses in the care of the family of pediatric patients undergoing ECMO, from nurses' perspective.

## Methods

This is a descriptive and exploratory study with a qualitative approach. Participants were selected using the snowball technique, in which an initial nurse, called the "seed", indicated the next colleague and so on.<sup>(12)</sup> Thus, research participants came from various healthcare institutions. This sampling strategy was chosen due to the specific nature of the interest group and the characteristics of the context studied, enabling access to a qualified group of professionals.

The inclusion criterion established was to be a nurse with at least six months of experience with ECMO, considering that this period would allow greater familiarity with the area of activity and a more significant participation in the study. No prior exclusion criteria were defined.

Nurses were contacted by telephone and interviewed individually, in single and remote meetings,

held outside of working hours, according to availability. The final sample consisted of 14 nurses, of which 5 refused to participate or did not return the invitation. To preserve participant identity, each of them was assigned a color.

The interviews were audio-recorded, transcribed in full, and lasted an average of 15 to 25 minutes. They followed a semi-structured script, with the following trigger questions: 1. Tell me what it is like for you to care for pediatric patients who require ECMO therapy and their families? 2. For you, how important is a nurse in welcoming a family during ECMO therapy? Data collection was completed in the first half of 2024, and was carried out until sample saturation<sup>(13)</sup>, i.e., when no new topics, categories, or relevant information emerged in authors' perception.

The data were analyzed using thematic content analysis, consisting of four stages: coding, in which the data were fragmented into codes; topic elaboration, grouping similar codes to generate potential topics; topic definition and naming, ensuring clarity in data representation; and, finally, report production, structuring the findings in a scientific manner.<sup>(14)</sup> To ensure analysis reliability and coherence, the authors jointly discussed and refined the coding framework. The first author received specific training and was supervised by the second author, who has experience in conducting qualitative research. Initially, the first author acquired theoretical knowledge about qualitative interviews and data analysis. She then conducted the first interview and began coding the data. This process was monitored and reviewed by the second author to ensure methodological rigor and continuous improvement, repeating this cycle until the research was completed.

The project was approved by the Research Ethics Committee (Certificate of Presentation of Ethical Consideration 72454123.6.0000.0071) of a private educational institution in the city of São Paulo. All participants were informed about the research and signed the Informed Consent Form. The researchers had no prior contact with participants.

## Results

Fourteen nurses participated in the study, 12 (87.5%) of whom were female, with an average age of 33.3

years, and training time between 2 and 20 years, predominantly from public hospitals (87.5%) in the city of São Paulo. All had graduate degrees; 5 had residency degrees; and 4 had professional master's degrees. The content expressed by interviewees allowed the development of two thematic categories, namely:

### **Thematic category I: Proximity, knowledge and challenges: understanding the complexity of child and family care in ECMO**

Nurses consider caring for children and their families to be "challenging." In addition to the complexity of extracorporeal oxygenation therapy, families feel insecure and face doubts throughout the process. Many nurses report initial compassion, seeing themselves as witnesses to a difficult experience, especially when it involves the family's child. They highlight the impact of situations such as cannulation of a child or the use of technological devices due to the severity of the condition. Therefore, they value guidance and good relationships with family members to reduce the impact, promote safety and strengthen them as allies in care.

*"We are very used to it, but I think that at first glance it must be very shocking for parents, poor things. [...] so, the family member doesn't understand what is happening, what all that technological equipment is. As healthcare professionals, we can go there and explain what it is, what it is for..." (Orange Nurse)*

*"Families gave us feedback that the presence of the team there all the time was what made them feel safer [...] there was always someone watching [...] someone paying attention to all the connections. The insecurity that comes with therapy can be reversed with the security of always having a nurse there." (Turquoise Nurse)*

The fact that a nurse is the closest professional during care was also widely cited. They are considered the main translators of information for the family when considering the functioning of equipment, procedures and clinical conditions of an extremely critical patient. Moreover, they are able to manage care and its specificities among the teams that care for a child.

*"I think it's essential, like I told you, we are the team that is most present. So, I am full-time, I am the nurse of this child, only me! So, I will be the point of reference for the mother and the family member who is accompanying this baby. So, I will be the closest person, I will be the person with whom she will have intimacy to ask questions."* (Green Nurse)

*"I think that nurses can translate therapies for families more easily, right? And they can bring the family closer to the patient's care and even to contact with the patient, right?"* (Black Nurse)

*"I usually tell my patients' families that the more we can clarify things for them, the less fear and apprehension they will have, because knowledge brings that, right? It brings that security. And what's more, they will have confidence in our work."* (Magenta Nurse)

Despite being challenging, professionals feel fulfilled when caring for a patient with these characteristics, precisely because it is serious and requires specific preparation.

*"I love it, right? So, it's the type of patient I like to care for the most, which is the most critically ill patient, right? Normally, patients on ECMO are the most critically ill patients in the ICU, right? And it's the type of patient I like to care for the most."* (Red Nurse)

*"I like the patient at the height of their serious condition, because when we manage to take the patient out of this context, it is very gratifying, it gives meaning to what you are doing. [...] saving a child's life gives a very special meaning to the pediatric nurse."* (Burgundy Nurse)

However, despite the satisfaction, for some nurses the need for support and training is pressing. Due to the responsibility and complexity of ECMO therapy, they believe that there should be more investment by institutions. They feel compelled to manage these conditions too early, without having adequate technical preparation time to care for this type of child and family.

*"So, it's a great therapy, but it has this problem that we have to train people [...] continuous, permanent training, right? Because I think it's different... from some, such as private and everything else, that they have, I*

*think, a structure that's a little better than ours. Because our structure really is like this, one day you take the course, the next you're there, it's really the eye of the storm, you know?!"* (Orange Nurse)

However, it is not always possible to complete a shift or planning satisfactorily, which generates frustration or a feeling of unfulfilled duty.

*"And then, sometimes, I find myself taking care of so many machines that I haven't changed a position, you know? I didn't perform proper hygiene, which is basic for nursing, and I can't provide that kind of care. And then, many times, we leave the shift feeling frustrated, right? It's kind of sad. Really sad."* (Red Nurse)

The end-of-life process and termination of ECMO therapy was also highlighted by nurses as something challenging, as it needs to include the family. In this regard, many are concerned about ensuring comfort and humanization, but report discomfort and difficulty when clamping the cannulas, for instance.

*"[...] there came a time when we realized that there was nothing more that could be done. We had a conversation with the family, a multi-member meeting [...] and together with the family we made this decision, and we were able to put the child on the mother's lap and clamp the ECMO on her lap [...] so, we have situations like this, where we are able to make the family a little more present."* (Purple Nurse)

*"Then we called the family, we put the child in the mother's arms, even on ECMO, because [...] the family's greatest anguish was when they held the child in this cold situation, after death. All the families said it was very bad! [...] we did what the family wanted, because it was the last moment!"* (Yellow nurse)

## **Thematic category II: Trust, partnership and conflicts: the nurse building a bond with families of children on ECMO**

Given the challenges of caring for children on ECMO and their families, bonds between nurses and family members are built on a daily basis, based on knowledge and trust. For nurses, welcoming families de-

depends on technical and scientific knowledge and confidence in answering questions. According to the interviewees, a lack of training can compromise the team's credibility and hinder the formation of bonds. Confidence in mastering the challenging scenario is essential for the family to feel safe with a nurse.

*"I think this is fundamental and for that you need knowledge, right? So that we can feel safe, not say stupid things, and be credible, because sometimes a poorly placed statement at an inappropriate time can compromise an entire team, right." (Pink nurse)*

*"So, I think that a nurse who takes care of this type of patient has to be a very qualified, very experienced nurse so that they can instill confidence in the family and can take care of this seriously ill patient and be able to comfort the family, answer questions, calm doubts, which I think is how we can support these family members." (Red Nurse)*

The interviewees highlighted the importance of balancing quality and safety care, including family participation in care. The main difficulty for nurses is to reconcile patients' technical and scientific needs with caregivers' expectations. Recognizing the essential role of the family, even in the face of the complexity of a child's condition, nurses invest in communication as a strategy to support families at this time.

*"There were mothers who wanted their son to stay awake because when he was sleeping, sedated, it felt like he was dead [...] you have to be very patient and flexible, because their participation is very important, obviously, but this threshold, like, to what extent is their participation not important, to what extent is their participation valid, you know? [...] it is an important part of care. Without it, we cannot do the things we need to do, but it is not the mother who will determine the things that need to be done [...] so, it is a very fine line that we have to establish with the family and that requires a lot of communication and a lot of contact." (Green Nurse)*

*"And I think it is extremely important for nurses to have this welcoming attitude, to understand the family's needs and do whatever is possible within what is safe for patients [...] because families bring this up, for instance, "Ah, I want to leave him positioned in a cer-*

*tain way because that's what he likes the most", even though he is sedated, you know? [...] when we are able to provide care [...] it generates comfort, it generates trust." (Gray Nurse)*

Keeping the child presentable, i.e., showing signs that show the family that the child is being cared for and is comfortable, as if the child were providing care, is also considered by the nurse and the team as part of their role, even though this care is different from what is a priority for a healthcare professional.

*"But if the father comes to visit and his mouth is dirty, covered in blood, or his diaper hasn't been changed, he'll think you're the worst professional in the world. Because, for him, that's what care is all about. [...] so, we also have to understand the perception of care that parents have... So, we need to join forces in this sense, to show them that we understand what's going on [...] we also care about their child's well-being." (Blue nurse)*

On the other hand, in some situations, nurses feel challenged to deal with families that they consider difficult, because, in their perceptions, they do not follow rules or do not understand how certain behavior can compromise the routine or safety of children and other patients.

*"So, sometimes, it's a difficult family when I talk about not following the rules, and no matter how much I give them instructions, it goes against what I'm asking for. And sometimes, they still question the things I say and that somehow puts the child or the other children in the ICU at risk. And that bothers me, because I have to keep talking about it several times. Because I have to keep controlling it and I don't like doing that, but I try to deal with it in a light way because I'm going to be taking care of that child and that family for a long time." (Purple Nurse)*

Nurses' perceptions about creating bonds with family members are quite individual. Most believe that closeness can, to some extent, affect their psychological well-being. To deal with this emotional overload, they resort to psychotherapy or try to separate their work experiences from their personal lives. Some

prefer to avoid as much as possible any closeness that goes beyond their limits, keeping their distance, but without compromising the bond necessary for professional care.

*"There are few patients, mothers, families that I will have this contact with. I like to have this contact, but within work, I don't want to have this contact outside. [...] we talk a lot in there, but it's in there. The moment I leave, I stop being a nurse, I become (name) the person. So... I realized that it wasn't healthy [...] so, I set a limit there for myself." (Purple Nurse)*

*"We create strategies. I also go to therapy, to take care of my mental health as well, but we create ways to do this. Because I think the worst thing about healthcare professionals is when they go to the other extreme - to protect themselves, they become an iceberg and become completely indifferent [...] but then, I think we stray from our goal as nurses, which is to be there together." (Blue Nurse)*

## Discussion

The results of this study advanced knowledge about the experience of caring for families of children undergoing ECMO treatment. The interviewees revealed an understanding of the importance of family presence during care and the relevance of being able to guide and clarify doubts of these family members.

The perception of the nurses interviewed validates the vulnerability experienced by these families. It also reinforces the compassionate view of these professionals when recognizing the intensive care environment as frightening due to the presence of unknown equipment and technologies and ECMO as a frightening procedure, in addition to being associated with death.<sup>(15, 16)</sup>

It follows from this analysis that caring for families in this condition requires specific technical and scientific preparation from intensive care nurses. With adequate training, they can meet the family's needs, promote safety, establish bonds and act as a link between the family, the child and the multidisciplinary team. Moreover, nurses contribute to reducing negative perceptions by offering guidance, support, in-

tegrating parents into care and helping to minimize feelings of worry and distress.<sup>(17)</sup>

On the other hand, nurses sometimes face difficulties related to work institutions, such as the lack of adequate training and the lack of the necessary workforce in this context, which jeopardizes their ability to provide care. According to literature, nurses must have fully completed training, such as equipment handling and complications, updates on ECMO therapy, and others.<sup>(18)</sup>

Caring for families in a stressful environment, often when there is a risk of losing a child, generates frustration, conflict, emotional overload and fear of death. Professionals seek to understand the meaning of care for families, establishing safe communication, negotiating partnerships, setting limits and investing in self-care. The literature highlights that many nurses do not feel prepared to deal with death, which can result in guilt, feelings of failure, emotional stress and psychological impact when caring for terminally ill patients.<sup>(19)</sup>

The most challenging aspect seems to be trying to deal with death in a way that does not affect nurses personally, but also in a way that the care does not seem impersonal or insensitive. The literature also describes that when nurses become emotionally involved with patients and their families at the time of care, when they perceive the need for something beyond scientific knowledge, this act is characterized as a demonstration of affection and humanity. However, such involvement can also be a source of suffering.<sup>(20, 21)</sup>

## Conclusion

The professionals interviewed consider the role of nurses as coordinators of ECMO care to be fundamental, highlighting the importance of training to ensure safe and quality care, which also includes care for the family. The bond is built on knowledge, trust and closeness, despite the conflicts generated by the different expectations of those involved. They also recognize that self-care is essential to deal with the stress of intensive care. In addition, they emphasize that the presence of the family is crucial to humanizing care and achieving positive results, regardless of the prognosis.

## Contributions

Rocha MDP and Cunha MLR declare that they contributed to study design, data collection, analysis and interpretation, article writing, relevant critical review of intellectual content and approval of the final version to be published.

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