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ORIGINAL ARTICLE

Nurses' perception of the therapeutic relationship with the family and the child with permanent medical complexity in the Pediatric Intensive Care Unit

Percepción de profesionales de enfermería sobre la relación terapéutica con la familia del paciente con complejidad médica permanente en Unidades de Cuidados Intensivos

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What do we know about the subject matter of this study?

PICU nurses take on the role of educators, helping families understand their child's condition and participate in care decisions. However, they face obstacles that prevent them from achieving an ideal therapeutic relationship.

What does this study contribute to what is already known?

Nursing, through the therapeutic relationship, empowers family members, an aspect that contributes to participation in the care process, satisfying the needs of the children and their caregivers. However, it presents challenges related to family grieving and geographic-socioeconomic difficulties that hinder effective communication.

Abstract

Nursing is responsible for care and for involving families in it, fostering and strengthening the bond, as well as managing the use of resources efficiently for the patient's health, through the delivery of continuous, compassionate, and safe care. **Objective:** To know the perception of nurses regarding the therapeutic relationship with the family of the child with medical complexity (CMC) in the Pediatric Intensive Care Units (PICUs). **Patients and Method:** Qualitative research with case study design, involving six nurses working in two PICUs in southern Chile. Data were collected through a semi-structured interview. Thematic analysis was performed, using the Atlas.ti.24 software. The rigor of the study was ensured through qualitative research criteria and the ethical requirements of Ezekiel Emanuel. **Results:** Four main themes emerge: "Nurses' experiences in the care of CMC", "Factors that intervene in the care of pediatric patients", "Nurse-family relationship", and "Elements that influence professional work", where it was observed how the patient's health condition determines

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the type of experience lived, the factors that positively or negatively influence the bond established with the family, and the patient care. **Conclusion:** For the integral development of pediatric CMC, it is recommended that family members be supported and integrated into the healthcare team, allowing the extension of support networks.

Introduction

Children with permanent medical complexity (PMC) are those who present "severe chronic pathologies associated with fragility, multisystem involvement, severe functional limitations, high need for health services and therapies along with a high consumption of health resources"[1]. The percentage of these patients increased in the Pediatric Intensive Care Unit (PICU), posing a challenge for health programs in Chile since they do not have specialized services for their complexity[2].

Since the PICU is a closed service, visiting hours are restricted, causing parents to feel excluded from the care plans, which interferes with the development of a therapeutic relationship between nursing, family, and children[3]. According to Travelbee "care should meet the needs of patients and their families"[4], while García, García, and Martínez, define the therapeutic relationship as "the professional and emotional connection that nurses establish with the family, through communication and emotional support, to reduce caregivers' stress and increase their participation"[5].

It is suggested that family participation in care promotes adaptation and enhances patient care. In contrast, the exclusion of family members generates anguish and increases their insecurity due to the lack of control of the situation and the surrounding environment. In addition, there is a perception that family members are a "nuisance", limiting the attitude of change in nurses, leading to decision-making mostly based on the preferences of the professionals[6].

In the PICU, several physical, regulatory, organizational, and human obstacles interfere with the relationship and communication between nurses and families, generating divided opinions among professionals, as some believe that family members provide emotional support, while others think that they deteriorate the patient's situation[7].

Since they are pediatric patients, the family cannot be set aside; children are emotionally dependent on their caregivers[7], so it is essential to understand, seek, and explore in the experiences of professionals how the therapeutic relationship develops and what are the main challenges in delivering care. The professional explains how and to what degree their role as educator will limit the participation of parents in the care of their children, and what factors hinder/favor the participation of families.

It is emphasized the need to carefully balance the relationship between nursing and the family, considering the different levels of power among users, types of interaction, bonds built, and personal competencies to create a therapeutic bond, differentiating between personal and family behaviors that influence professional work.

The objective of the research is to analyze the perception of nurses regarding the therapeutic relationship they establish with the relatives of children with PMC hospitalized in the PICU in southern Chile during 2023.

Patients and Method

Qualitative descriptive study with a case study design due to the complexity and specificity of the phenomenon addressed, aimed at answering the following assumptions: the work overload of nursing professionals limits the interaction with parents of children with PMC, and the bond created between these PICU professionals and family members influences the care of pediatric patients.

The target population was six nurses working in PICUs in southern Chile, who met the following inclusion criteria: to participate in the clinical care of patients with PMC in a PICU, to interact with the families of these children, to have one year or more of experience in the unit, and to accept that the interview would be recorded. Nurses who did not meet the criteria described were excluded.

The recruitment of the participants was through the snowball method; the participants referred to other professionals who could contribute to the research, as they were familiar with the subject[8]. Nurses were selected through convenience sampling since the phenomenon was explained by professionals caring for patients with PMC in the PICU context. By signing the informed consent form, they authorized the application of a semi-structured interview.

The interview lasted between 45 and 60 minutes and contained questions focused on the therapeutic relationship they maintained with the children and

caregivers, as well as answering assumptions. Its structure allowed the interviewers to adapt to the answers, adding questions to clarify doubts or to explore topics in depth. To ensure the fidelity of the data, the interviews were recorded, transcribed into a Word document, and coded in ATLAS.ti v24 software.

When the repetition of ideas and arguments was observed, the information obtained was considered saturated, therefore concluding the data collection.

Data analysis

The analytical process included the transcription of the interviews, data re-reading, coding, and grouping into categories, sub-dimensions, and dimensions.

The analysis was thematic, and the responses were transcribed in the ATLAS.ti.24 software, where ideas, reflections, and experiences were recorded. Each nurse was assigned the acronym E(n), in order to maintain their confidentiality.

Subsequently, codes were created, and categories were established for their classification, facilitating the analysis by allowing patterns to be recognized. After the formulation of the main categories, the data were distributed among these, resulting in four dimensions in total: "Nurses' experiences in caring for pediatric patients", "Factors involved in the care of pediatric patients", "Nurse-family relationship", and "Elements influencing professional work". Figure 1 presents the process "Dimensions involved in the interpersonal relationship between professionals, patients, and caregivers", showing the data reduction.

Results

Nurses' experiences in caring for patients with PMC

Positive and difficult experiences were identified as well as experiences according to the health condition of the children. The types of patients are identified according to the pathology and severity, care process, and bond created with the professional. Epidemiological changes are mentioned, such as the increase in the number of children and youth with special health care needs (CYSHCN) and how this has led to changes in the units for their care.

[...] Administrative changes have had to be made to assign beds to these children of medium complexity in other services because, many times, we receive more severe patients, and our beds are full of this type of patient who has a long hospital stay [...] (E3, P5).

Regarding the positive experiences of caring for patients with PMC, the valuation of the nurse-patient bond is recognized, highlighting the emotional bond formed between the two. The nurses recognize the integration of the family nucleus in participation and agree that it impacts the care experience, as the more involved they are, the better the patient's progress.

[...] Because, what can we do? Put in invasive devices and… that's it for the treatment. But what about the rest? The patient's comfort? … Who's the expert on that? … Or if they know that the child, a child who doesn't communicate, squeezes their eyes shut… I don't know, or makes a certain face—it's because they're in pain, you know? [...] (E6, P98).

Regarding the difficult experiences, they highlight the complexity of the unit and its repercussions on the physical and mental condition of the professionals, identifying the emotional suffering resulting from the bond created with patients and caregivers.

[...] Emotionally, it is complicated because you end up getting attached to the child, to this child who often goes through many different situations—one moment they're fine, and then their condition worsens and becomes more complex. So you think, shoot, they're not going to make it [...] (E5, P30).

In summary, the nurses value the emotional bond formed with the patients and positively emphasize the presence of the families in the evolution of the children's health. At the same time, the increase in CYSHCN, the unit's difficulties, and the emotional overload represent a challenge for the staff at a personal and administrative level.

Factors involved in the care of pediatric PMC patients and their families

They mentioned the family's commitment to the child's health, the nurse-patient bond, the team's support, and the professional's educational role. The nurses gratifyingly emphasize the attachment they establish with the patients and the bond created with the family members. They recognize the support of the health team and the family, giving importance to the educational role of the professional since the involvement of the caregivers depends on the knowledge they have.

[...] Very committed parents who have helped their children move forward... You see it from the moment they arrive at the unit and see over time, with the family's support—sometimes with the whole team, early stimulation, the exercises given to the parents, working with the "kine" (physical therapist)—you see how that little one goes from zero to moving [...] (E1, P10).

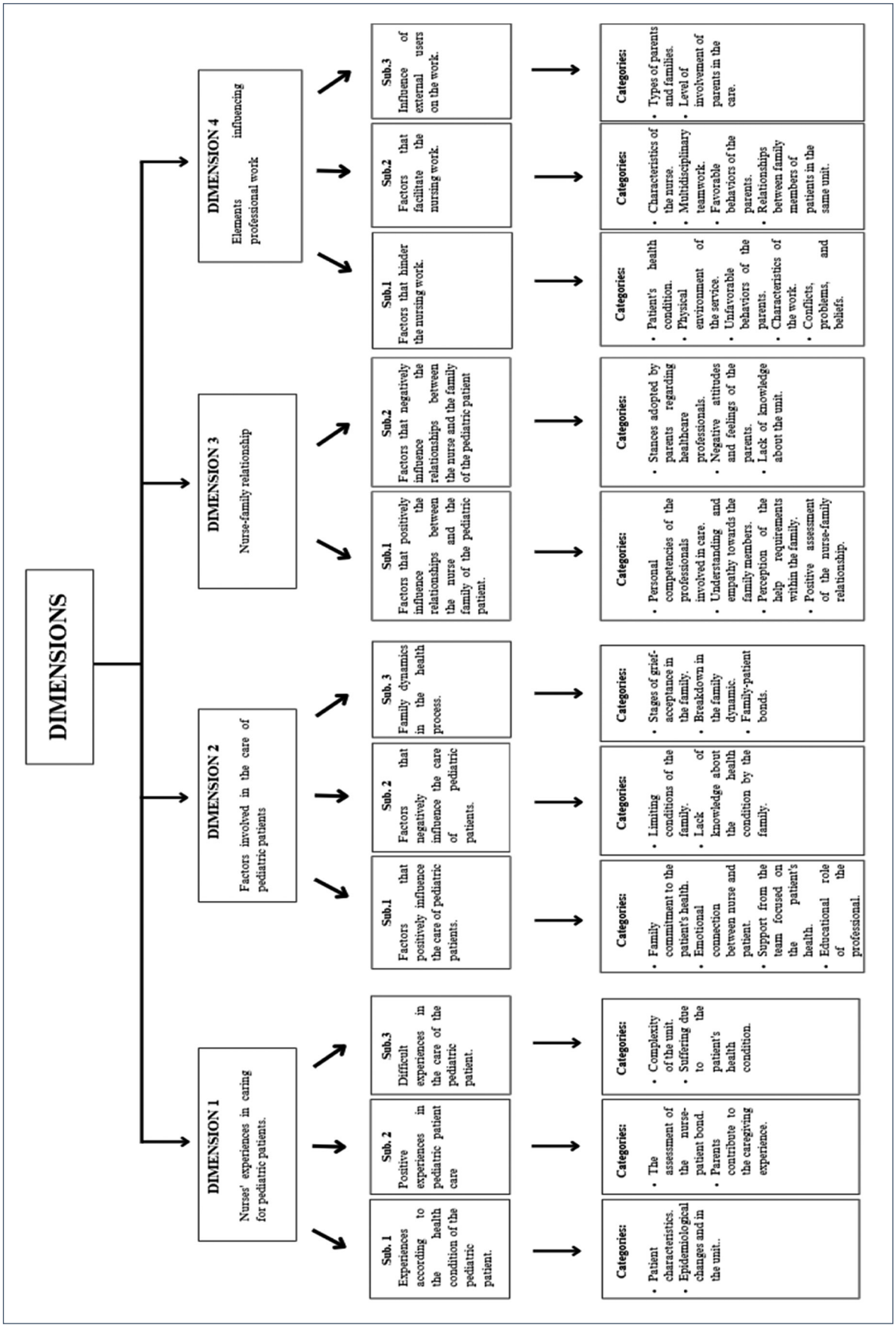

Figure 1. Dimensions involved in the interpersonal relationship between professionals, patients, and caregivers.

The factors that have a negative influence on patient care are the limiting conditions of the family related to their life circumstances, such as rurality and socioeconomic situation. Likewise, the lack of knowledge of the child's health condition generates stress and rejection in the participation of the patient's care, causing distance and mistakes.

[...] Families that don't even have money for bus fare or they live so far away that they can't come on weekends, for example [...] (E5, P40).

They express the complexity of the family dynamics and describe the process of grief-acceptance and the ties with the professionals. The nurses show the difficulty of the caregivers in accepting the health condition of their children, denying the reality and, in some cases, avoiding visits. Subsequently, the family core assimilates and accepts the reality of having a child with other needs, understanding that "it is the child they were given", the gradual acceptance leads to participation in meetings with professionals and commitment to the infant's health.

[...] The denial begins, the process of... oh no, why did this happen to me? And they don't understand much ... and then, they move on to another process where they're calmer, they accept more about what's happening with their child ... and that's when you can talk more to them [...] (E5, P76).

Nurses recognize the breakdown in family dynamics resulting from the unpredictable health of children with PMC. Due to the complicated and slow evolution of the children's state of health, conflicts arise that require a process of change and adaptation within the family. Thus, nurses promote the family-patient bond, allowing caregivers to have contact with their children through exceptions and flexible protocols.

[...] Sometimes we break the rules, because we let in more people than what the visiting protocol says [...] (E3, P11).

To summarize, in the care of pediatric patients, the education of family members is fundamental. It has been shown that knowledge empowers caregivers, strengthening their participation in the care process. This represents a challenge, since family bereavement and geographic-socioeconomic difficulties hinder effective communication with caregivers, causing the need to create plans that favor and facilitate the creation of a bond with the family nucleus, mitigating these limitations.

Relationship between nursing and the family of children with PMC

The emotional, cooperative-rivalry relationships established between nurses and the family were identified, determining factors that positively influence the bonds, such as the personal competencies of the professionals, understanding and comprehension towards the family members, recognizing the needs of the caregivers, and the positive valuation of the nurse-family relationship. Personal competencies and empathy allow for connecting with parents, making them feel listened to and confident in the care, thus strengthening the nurse-family bond.

[...] The idea is to put yourself in their shoes, to be empathetic with their pain, their desperation, their anguish, and their uncertainty about what else is going to happen to their child... to reassure them [...] (E5, P70).

The glimpse of the need for interprofessional care strengthens the bond and trust, activating the roles of the health team to accompany the caregivers, allowing them to cope with the situation they are experiencing. Likewise, the nurses affirm that the relationship formed with the caregivers is special and that the positive valuation of this interaction and bonding is built through patient care, "active" listening, and accompaniment.

[...] Aside from the entire team… We also have a psychologist and a social worker—there's a wide range (of support) in the pediatric area. We strengthen our relationship with the parents because we also understand that some of them need time [...] (E1, P36).

On the other hand, the nurses mention caregiver behaviors that are detrimental to forming a bond. They report that some parents are reluctant to collaborate, uncommunicative, and only see the mistakes, limiting the relationship. In addition, the lack of knowledge and fear of the complexity of the unit has a negative influence on the families.

[...] It's exhausting when parents complain all day long and don't realize that, in the end, we give our all for them at work. And yet, they only seem to see the negative instead of recognizing that we're there for them 24/7, that their children have grown, that we've cared for them, give them love—so it's kind of frustrating when they criticize you [...] (E5, P33).

The interpersonal skills of the nurses are key to strengthening the bond formed with the families. Active listening and empathy from the interprofessional team allow them to connect emotionally with the caregivers, reducing their concerns and fears, and reinforc-

ing the relationship of trust between the two. The assessment of this bond is positive; however, they report that the families' lack of knowledge, overexertion, and fear can deteriorate the relationship and cooperation.

Elements influencing professional work and the relationship with the family

The patient's baseline health status as well as the PICU environment are considered stressors that make the task difficult. Nurses mention that they must deal with intense feelings to cope with day-to-day and maintain good relationships with caregivers. They point out that conflicts, problems, and their own and the families' beliefs are detrimental since they influence the ways of responding-acting, and they also identify demanding attitudes on the part of the caregivers that are perceived as hindering assistance.

[...] Parents, especially those with children who have been here longer, sometimes start taking certain liberties, and you think, whoa, they're pushing the limits. We allowed it once, and now they think it should always be that way [...] (E3, P14).

In relation to the facilitating factors, the most important ones are the skills related to conflict management, the participation and care of the multidisciplinary team, the collaboration of the parents in the care, and the supportive relationship between the professionals of the unit.

[...] Because here, everyone is involved with the patient, from the doctor, physical therapist, nurses, paramedics, nutritionists, the entire team [...] (E1, P35).

Regarding the influence of external users in their work, the nurses highlight various behaviors-attitudes (positive or negative) that they must adapt to according to the requirements and needs of the family. They mention that, depending on how involved the family members are in the care, they receive more responsibility.

[...] Because there's the overprotective parent, the cooperative parent who helps calm their child, the parent who doesn't understand anything, and the detached parent [...] (E6, P59).

Among professionals, there are different personalities and ways of resolving conflicts, and it is essential to establish guidelines that allow the gradual involvement of family members since the positive impact that the family has on the health and development of the child with PMC is evident.

To summarize, the nurses emphasize that the unit causes a high level of stress daily. They point out that the excessive demands of the families hinder the comprehensive care of the children, and that it is necessary for the professionals to manage family participation according to their needs. Through interpersonal skills and interprofessional work, conflict management is achieved, and the collaboration of family members in the care of the children is promoted.

Discussion

Professionals have a history of resistance to the participation of family members in the care of children with PMC in closed units such as the PICU, as they consider that they are not qualified to intervene[7]. In contrast, this research highlights the bonds created between nursing and families as an aspect that influences the progress of the children's health condition, emphasizing family care, as it favors care, facilitates adaptation, and supports childhood development.

Similarly, the Chilean Society of Pediatrics states that the care process must be carried out from a biopsychosocial perspective, providing individualized care focused on the child and the family, which is considered support that provides assurance, containment, stimulation, and maximum development[9].

When it comes to teamwork between nursing and family, there is an "unwritten" agreement that both caregivers and professionals make concessions when working together. On the one hand, the nurses interviewed offer the families their knowledge through education and training in basic care, making it easier for caregivers to better understand their children's needs and, on the other hand, parents take an active-passive stance towards the professionals by handing over control of their children's care to the health team.

However, this loss of control in the family can lead to dependence on the health care team or disconnection with their children[10]. To avoid this, nurses propose the development of the therapeutic bond through active listening, since it favors the involvement of parents by including them in the care of children safely and gradually.

Roberts et al.[11] mention the 6 C's: caring, commitment, compassion, courage, competence, and communication as the basis for maintaining a therapeutic relationship. Personal competencies are fundamental, as empathy and understanding of the family situation allow caregivers to feel heard and understood, making them experience companionship in the process.

As a result of this bond, nurses highlight different behaviors in families, and that, in order to cope with these differences, they must adapt according to the re-

quirements of the family nucleus. Understanding the situation of the family allows the professional to understand the reality of the caregivers and the context where they are.

As noted, depending on the level of involvement of family members in care, they are given greater responsibility. This is supported by Aliberch and Miquel[6], who reaffirm the inclusion of parents, as they see them as a resource in patient care because they are the ones who know them best. Similarly, Rennick et al.[12] indicate that parents can describe physical signs that help to understand their children's needs, in addition to providing information about their medical history, and their responses to care interventions.

However, nurses mention the existence of challenges in their care. First, "over-demanding" parents represent a challenge for effective bonding because although the care given to all patients is the same in quality, the therapeutic bond deteriorates because the professional decreases the interaction time with the children in order to avoid conflicts. In this sense, to prevent the deterioration of the bond, the development of mutual trust through active listening, empathy, and patience is proposed since "when challenges arise and are not addressed, problems can persist and damage the core-patient relationship".

Second, another challenge is work overload, which limits interaction with the parents of children with PMC. To overcome this, the presence of a multidisciplinary team is necessary to help manage actions and time. According to Miró[13], when working collaboratively, it is possible to have clear and shared goals in patient and family care. Likewise, having established roles favors the achievement of objectives and develops shared leadership, which allows the generation of protocols in joint work practices.

Finally, as a last challenge, the bond generated between PICU nursing professionals and family members must be maintained in a balanced way, because it influences the care of pediatric patients since, although the care provided fulfills its therapeutic purpose, the integration of parents in the care influences the holistic development of children.

Ethical Responsibilities

Human Beings and animals protection: Disclosure the authors state that the procedures were followed according to the Declaration of Helsinki and the World Medical Association regarding human experimentation developed for the medical community.

Data confidentiality: The authors state that they have followed the protocols of their Center and Local regulations on the publication of patient data.

Rights to privacy and informed consent: The authors have obtained the informed consent of the patients and/or subjects referred to in the article. This document is in the possession of the correspondence author.

Conflicts of Interest

Authors declare no conflict of interest regarding the present study.

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