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EXPERIENCE REPORT

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Life-threatening conditions, family conferences and patient-centered care: the experience of the PEDCONF

Condições ameaçadoras à vida, conferências familiares e cuidado centrado no paciente: a experiência do PEDCONF

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ABSTRACT

Introduction: Communication among healthcare professionals (HCPs), patients, and family members during hospital admission represents a major challenge for everyone involved. Life-threatening conditions or illnesses bring complexity to care and require effective and empathetic communication, one of the core components of patient-centered care. Nevertheless, there is still a lack of structured communication models in Portuguese to support HCPs, patients, and family members during family conferences in critical care units in Brazil.

Experience Report: A structured and proactive communication model that uses the acronym PEDCONF was developed, consisting of four stages: (P) preparation of the conference, (E) early active listening to family members, (D) discussion of the clinical context, and (CONF) convergence between family and HCPs to develop a shared care plan. This model has been applied in the teaching-learning activities with HCPs through simulated conferences.

Discussion: Although the implementation of structured and proactive communication models with family members of critically-ill patients has the potential to improve HCPs confidence in life-threatening illness scenarios, studies evaluating self-perceived outcomes related to confidence and performance during conferences by students in the short and long term are required in a local context.

Conclusion: The PEDCONF model is presented as a promising tool to improve communication between HCPs, patients suffering from life-threatening diseases and their families, providing a shared and harmonized care plan among all those involved.

Keywords: Patient-Centered Care; Pediatric Intensive Care Units; Treatment Plan; Clinical Conference.

RESUMO

Introdução: *A comunicação entre profissionais de saúde (PDS), pacientes e familiares durante a internação hospitalar representa um desafio significativo para todos os envolvidos. Condições ou doenças que ameaçam a vida trazem complexidade ao cuidado e demandam uma comunicação eficaz e empática, um dos componentes centrais do cuidado centrado no paciente. Entretanto, nota-se uma carência de modelos estruturados de comunicação em língua portuguesa que apoiem os PDS, pacientes e familiares durante as conferências familiares em unidades críticas no Brasil.*

Relato de experiência: *Foi desenvolvido um modelo de comunicação estruturado e proativo denominado PEDCONF, composto por quatro etapas: (P) preparo da conferência, (E) escuta ativa dos familiares, (D) discussão do contexto clínico e (CONF) convergência entre a família e os PDS para a elaboração de um plano de cuidados compartilhado. Esse modelo vem sendo aplicado em atividades de ensino-aprendizagem com os PDS por meio de conferências simuladas.*

Discussão: *Embora a implementação de modelos estruturados e proativos de comunicação com familiares de pacientes críticos tenha o potencial de melhorar a confiança dos PDS em cenários de doenças ameaçadoras à vida, são necessários estudos que avaliem desfechos autopercebidos relacionados à confiança e ao desempenho dos estudantes durante as conferências em curto e longo prazos, em contexto local.*

Conclusão: *O modelo PEDCONF apresenta-se como uma ferramenta promissora para aprimorar a comunicação entre os PDS, os pacientes acometidos por doenças ameaçadoras à vida e os familiares destes, promovendo um plano de cuidados compartilhado e harmonizado entre todos os envolvidos.*

Palavras-chave: *Cuidado Centrado no Paciente; Unidades de Terapia Intensiva Pediátrica; Plano de Tratamento; Conferência Clínica.*

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INTRODUCTION

The admission of a child in an Intensive Care Unit (ICU) represents a deeply challenging experience for parents. The critical condition and the threat to a child's life expose family members to feelings of uncertainty, apprehension, powerlessness, hope, confidence and fear. This variety of emotional responses can manifest itself through symptoms such as intrusive memories, nightmares, avoidance behaviors, and alertness[1,2].

Critically-ill pediatric patients admitted to the ICU often experience life-threatening conditions, defined by the Global Overview – Pediatric Palliative Care Standards (*GO*-PPaCS Project)[3] as "a condition with a high probability of premature death due to severe disease, but also with a chance of long-term survival into adulthood." This clinical condition, in general, is associated with isolated or multiple organ dysfunction and often requires life support (technological, drug-related and human) for treatment and recovery support.

In addition to the concern about the child's health condition, family members face the continuous stress imposed by the hospital environment, being confronted with a reality that challenges both their emotional balance and their ability to cope. This context also has the potential to generate significant psychological impacts, which can manifest themselves both during hospitalization and after discharge, affecting not only individual well-being, but also family dynamics[4,5].

The experience lived by family members with the communication of sensitive news in life-threatening circumstances reveal a scenario marked by weaknesses: delayed communication, limited perception of the possibility of death and the still restricted involvement in care-related decisions. These weaknesses limit the active participation of family members and highlight high-quality communication as an essential strategy for the qualification of care[6].

Understanding the experience of these parents and the challenges faced by them can provide relevant support for the development of more effective strategies within ICUs. Effective communication, patient and family engagement in daily care, as well as acceptance of their perspectives, beliefs, needs, and values are central elements of patient- and family-centered care[7-10].

The scenario experienced by these parents imposes significant challenges to healthcare professionals (HCPs), especially during family conferences. In an Australian study, HCPs identified seven relevant topics related to the adequacy of their preparedness to conduct sensitive conferences in pediatric patients with life-threatening diseases. Among the identified topics, trust for communication, professional education and care with listening and delivering information stood out[11].

In another recent study, carried out in Brazil, the perception of 144 HCPs in ICUs of three pediatric hospitals was investigated, regarding their training and level of confidence in conducting end of life conferences in the ICU. Although confidence increased with the length of professional experience, only 12% reported having received adequate training for this practice, while 40% stated they had never had any specific training in the area[12]. These data show a significant gap in communication education for HCPs who work in pediatrics, especially in critical circumstances.

Therefore, since the 1990s, several communication models based on a proactive structure and supported by communication skills have been developed in several countries and different languages. These models seek to prepare HCPs to conduct family conferences at different levels of care and clinical contexts[13–19].

However, with the existing gaps in Portuguese literature for HCPs training for pediatric family conferences in life-threatening scenarios; the specificities inherent to care and family dynamics in the pediatric age group; the evidence that points to the benefits of using proactive and structured models for conferences; and, finally, the linguistic barrier present in internationally developed communication models, the need to develop a communication tool focused in pediatric family meetings and appropriate to the local reality, is identified.

Hence, the proactive and structured communication model PEDCONF for pediatric conferences was developed and is presented in the following experience report.

EXPERIENCE REPORT

PEDCONF model place of development

The model was developed in the Pediatric Cardiovascular Intensive Care Unit (UTICP, *Unidade de Terapia Intensiva Cardiovascular Pediátrica*) of a philanthropic pediatric hospital located in the city of Curitiba (state of Paraná), Brazil, which serves patients from both the public and private health networks. The unit has 26 beds, including 8 new ones added in 2024, and performs approximately 1,000 percutaneous and transthoracic cardiac procedures annually. Furthermore, the UTICP has active heart transplantation and extracorporeal circulatory membrane oxygenation programs.

The UTICP adopts an "open door" policy regarding family presence during the child's hospitalization. This presence is not only allowed, but also encouraged, through the "Participating Family Program", implemented at the institution since the 1980s and aimed at all hospitalized patients. Additionally, daily multidisciplinary discussions are held to review and define the care plan according to each patient's clinical condition.

The development of the PEDCONF model

Based on the abovementioned premises, a structured and proactive tool for communication in life-threatening circumstances was developed, adjusted to the sociocultural context of the UTICP and supported by evidence extracted from the literature regarding patient- and family-centered care[7–10].

This tool was named locally by the acronym PEDCONF. Its objective is to offer support to the HCPs for conducting and participating in pediatric family conferences in the UTICP, favoring the creation of a shared care plan centered on the patient and the family (Figure 1).

The PEDCONF model is structured in four stages: **P** (preparation of the conference), **E** (early listening to the patient and family), **D** (discussion of the patient's clinical context) and **CONF** (family convergence for the creation of the care plan). These stages are permeated by three main skills: exploration of perspectives (exploratory skill), preparation of information (informative skill) and harmonization of the care plan (deliberative skill) (Figure 1).

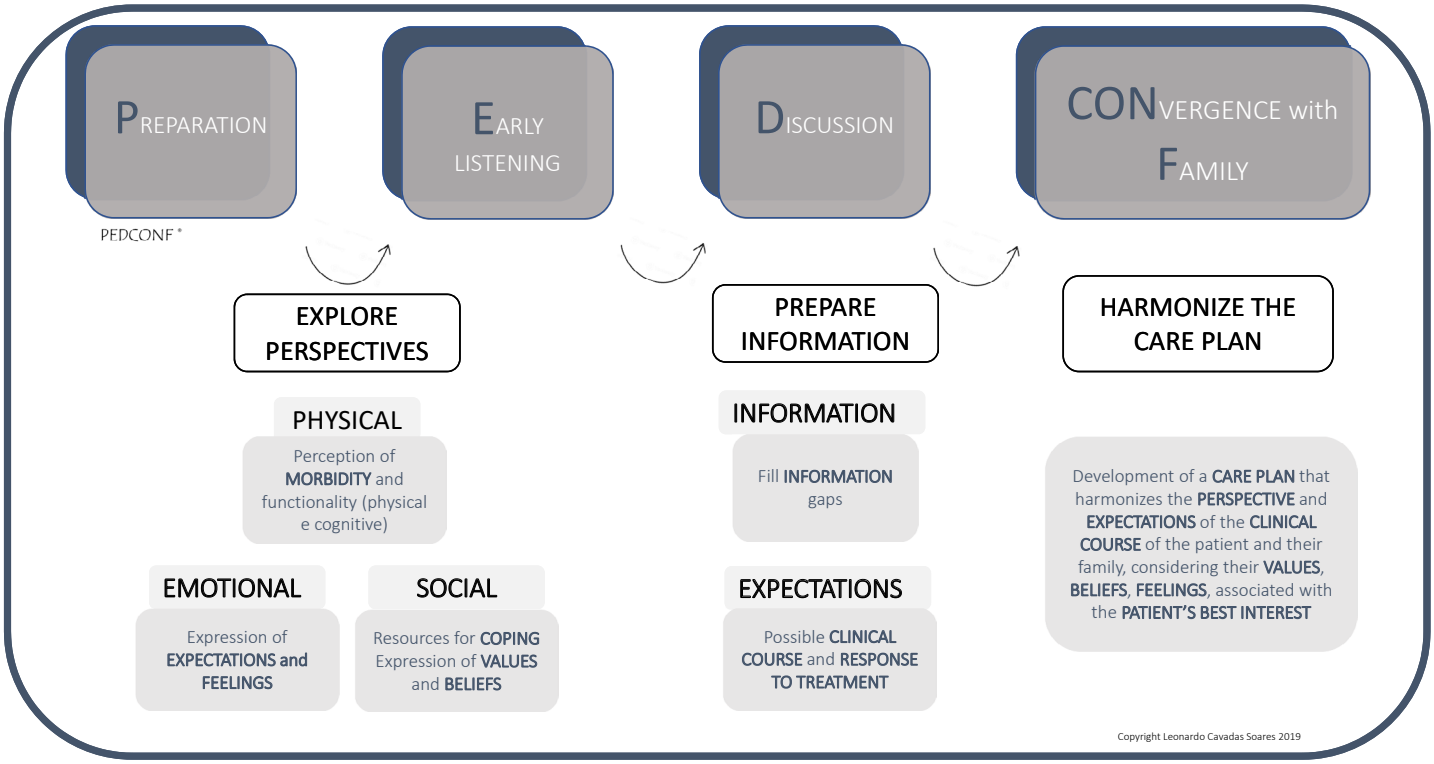
The separation into stages facilitates the conference organization and planning, so that the multiprofessional team follows and actively participates in the process. For family members, the model creates a space for the expression of their perspectives, the obtaining of information and active and shared participation in the construction of their child's care plan. Next, each step of the model is described in detail. The objectives, approach strategies and examples of recommended statements are summarized in Chart 1.

The PEDCONF model

1. Preparation

The first stage, called "**Preparation**", begins before the conference and involves the care team in a previous meeting to establish the clinical objectives to be addressed at the conference. The harmonization of the perception among health professionals about the patient's clinical evolution and possible scenarios is essential for the meeting productivity. Moreover, parents must be prepared by professionals so they can present their perspectives, expectations, beliefs, needs and values. To do this, it is recommended that parents write down their conceptions and understandings on paper or in note-taking apps on their mobile devices. This stage also consists of preparing to deal with intense emotions that may occur during the conference.

Figure 1. Structural model of the PEDCONF. Consisting of 4 stages and supported by 3 core skills.



Source: prepared by the authors.

Chart 1. Objectives, strategies and goals and speech suggestions of the PEDCONF model. Staggered model in (1) guiding objectives, (2) strategies and goals and (3) examples of statements.

PREPARATION	EARLY LISTENING	DISCUSSION	CONVERGENCE with FAMILY
GUIDING OBJECTIVES			
Create a comfortable environment	**Explore perspectives**	**Prepare information**	**Harmonize the care plan**
STRATEGIES AND GOALS			
Define the meeting place and participants Team preparation – perception and harmonization Introductions and embracement Introduce the meeting	Encourage speaking – listen attentively before informing Start with open-ended questions and then move on to targeted ones. Explore understanding (and missing information) in the following dimensions: **Physical** Identify the parents' perception of morbidity and functionality (physical and cognitive). **Emotional** Observe and identify the parents' expectations, hope, feelings, and beliefs. **Social** Identify coping resources (spiritual and social).	**Empathetic attitude** Consider and welcome the family's perspective. Acknowledge expectations regarding their child. Validate the family's values – their wishes, beliefs, and needs. **Sharing of Information** Fill in the information gaps and pause for processing. Use culturally appropriate language. Reassure the comfort measures currently in place (sedation, analgesia, feeding, hydration, hygiene). **Alignment of Expectations** Present the different possible scenarios for evolution. Present possible clinical courses and treatment options.	Clarify each stage of planned care with the expected outcomes (best-case scenario). Clarify how the family can engage in care, aligned with the care plan – hygiene, feeding, distraction for the child, observation of behavior and comfort, sharing of perceptions and understanding. Offer resources for support (psychosocial, social, spiritual). In end-of-life circumstances – align the care plan to encompass the patient's and family's hope and dignity, considering their values and wishes, aligned with the clinical team's expectations and the best interest of the patient.
EXAMPLES OF STATEMENTS			
Are you feeling comfortable for a sensitive conversation about your child? *We are all here to better understand how you are perceiving your child's clinical course and to help in any way we can.*	*How are you perceiving your child's evolution?* *How are you perceiving your child's response to the implemented care plan?* *How do you hope your child will recover?* *How do you perceive the risks involved in the current clinical condition?* *Do both (family members) understand it in the same way?* *What expectations do you have?* *Do you have support from anyone else?*	*We recognize the difficult time you are going through and imagine how this has affected your family.* *Although you have understood, it seems that some information is still missing (in case of perception gaps).* *It is not easy for us to inform you that your child has a serious condition.* *There are uncertainties related to the clinical course (different outcomes) in these circumstances we are facing (introduction to possible clinical courses).* *We believe in and are working toward your child's recovery, while maintaining our commitment to keep you openly informed about the current clinical course.*	*We acknowledge this difficult moment. Is there anything else you would like to be involved in regarding your child's care?* *Questions may arise at any time. Please feel free to ask us whenever you feel the need.* *Are there any family members or friends who can help by being close?* *Are there any aspects of the presented clinical courses that go against your beliefs or what you consider to be dignified? (for difficult decisions)* *Do you participate in any religious community?*

Source: prepared by the authors.

2. Early Listening

The second stage, called "**Early Listening**" takes place right after the presentations of the professionals and parents in order to create closeness and bond between the participants. At this point, we seek to explore the perceptions of family members through open questions, such as: "How have you perceived your child's clinical evolution?".

This stage has a proactive and exploratory feature, focused on listening to and understanding the family's perspectives and expectations. Exploration follows four

fundamental dimensions: physical (functionality), cognitive, emotional (parents' feelings and expectations) and social (support networks, values and beliefs). This segmentation is based on the PICS-p Syndrome (*Post Intensive Care Syndrome in Children*), which describes the morbidities associated with critically-ill patients after ICU admission, facilitating the organization of information at this stage[20,21].

Attentive listening conveys to family members the feeling that they are heard and valued[22], fostering active contribution to patient care. Additionally, encouraging speaking provides HCPs with an opportunity for a detailed analysis of the family's level of understanding of the child's clinical evolution, allowing the identification of possible information gaps. Thus, it becomes possible to evaluate in detail the understanding that parents have of the ongoing treatment for their child, pain and anxiety care, the food offered, wound care and dressings, test results, use of antibiotics, among other topics.

Clinical empathy consists of a process of emotional resonance[23,24] and is an attitude for moral practice[25], permeating the entire conference. It allows the HCPs to take the patient's perspective, through the understanding of the clinical reality impact on the child's life from the parents' perspective, which can be done through open questions, investigating their concerns and exploring the influence of clinical evolution on daily activities[13,17,18].

3. Discussion

The third stage, called "**Discussion",** is informative and aims to contextualize the patient's clinical status and evolution so far. The etiological diagnosis, clinical manifestations, implemented support and therapy, and the expected response to treatment are discussed and updated in detail. It offers the possibility of resolving the identified information gaps and clarifying the remaining doubts. To ensure the adequate assimilation of this information, it is recommended that professionals take intermittent breaks and confirm the family's understanding as the information is being transmitted. This approach is beneficial, since cultural and emotional factors can interfere with the understanding of the clinical information provided.

Once the doubts of the family members are clarified and they understand the current scenario, it is possible to move on to the last stage – the family convergence.

4. Convergence with Family

In the fourth and final stage, called "**Convergence with Family**", the care plan is created, which seeks to share the possibilities of the patient's clinical trajectories.

Although HCPs are trained for accuracy and high efficiency, it is essential that they recognize and welcome the uncertainties inherent to health care[26]. The patient, unique in their biological nature, has uncertainties associated with their response to a life-threatening disease. Thus, different patients go through different journeys, some with rapid improvement, others with slow progression and others, unfortunately, with deterioration of the clinical status, which is not always predictable.

Open discussion about the possible and most likely outcomes is indispensable in clinical settings of all degrees of predictability, whether reasonable (e.g., elective surgical procedures) or more uncertain ones (e.g., severe cases of sepsis). In these, uncertainty increases as organic dysfunctions accumulate. At this stage, the HCP needs to have the sensitivity to balance the transmission of realistic clinical data without afflicting the parents' hopes, which represents one of the greatest challenges during a family conference[16].

The recognition of uncertainties with the clinical circumstance, combined with the explicit desire to offer positive information, should be part of the dialogue, while still disclosing the reality of the situation in a sincere and empathetic way.

In this last stage, the family's perspective, the patient's best interests, and professional ethics converge. In the care plan, the following are shared: the procedures or therapy to be adopted; the expected results, their perceptible manifestations, and the estimated time for clinical response; possible courses of clinical evolution, highlighting the most favorable outcomes.

Moreover, the family engagement points must also be identified, that is, how the family member can actively participate in the care. Some examples of family engagement comprise participation in hygiene care and administration of diets or oral medications. More complex scenarios offer the opportunity for family members to mobilize early in the postoperative period (when possible and according to unit routines) and tracheostomy aspiration, when trained and qualified.

Family members want to closely monitor the response to treatment and understand the clinical signs of recovery, such as: reduction of fever, adjustments in medications, decreased ventilatory support or signs of improvement revealed by complementary tests.

Participation in the comfort and control of their child's pain is another relevant factor for parents. In the context of intensive care, analgesia can be performed with different classes of drugs, routes of administration, clinical potencies, and side effects. It is essential that professionals inform their expected function and implications.

Although the control of analgesic action is monitored by vital signs and pain scales widely validated in the literature,

children with complex chronic conditions often show individual, verbal and non-verbal behaviors, which are more easily identified by parents than by health professionals. Thus, by including family members in the monitoring of the child's pain and well-being, the bond between team and family is strengthened, promoting a more humanized and patient-focused care

DISCUSSION

Communication is the most frequent procedure in medicine and is the basis for the construction of therapy[27]. The establishment of open and quality communication between health professionals and family members of critically-ill pediatric patients strengthens the bond of trust between them[28].

The National Council of Education incorporates empathetic and interested communication into its curricular guidelines[29], considering it a component of health care for users, family members, communities and members of health teams. This structuring element is also present in the attentive listening of the practices for the implementation of the Singular Therapeutic Plan (PTS, *Plano Terapêutico Singular*) in accordance with the National Humanization Policy (PNH, *Política Nacional de Humanização*) [30]. However, there is still a lack of specific models that contemplate the scenario of critically-ill pediatric patients with life-threatening diseases in Brazil.

Although there is a consensus among researchers on the impact of empathy on the construction of interpersonal relationships in the health care context, its incorporation into clinical practice still faces challenges. One of them is its difficult evaluation. A randomized study used the Jefferson Medical Empathy Scale as a teaching-learning metric in the training of students in communication skills. The absence of difference observed between the groups suggests that there remain gaps in the training of this skill[31].

The outcomes related to the teaching of health communication can be both objective and subjective and can be measured based on the perception of the HCPs, patients and their families. Evidence-based framework for health communication are well-documented in English-language with positive impacts on short and long-term outcomes, especially related to the self-perception of confidence and effectiveness of professionals[13,19,27,32]. Professionals who participated in training reported improved self-perceived efficacy and a positive association between effectiveness and performance in simulated conferences, acquisition of communication skills[17,33] and increased confidence in the application of these skills to clinical practice[19].

Recently, Dohms *et al.*[34] performed the cross-cultural translation of the Calgary-Cambridge Observation Guide, allowing the implementation of objective metrics for student and HCPs evaluation in training in Brazil.

In a randomized study published in 2007[14], Lautrette *et al.* evaluated the effects of the application of a proactive and structured communication strategy in 22 French ICUs, aimed at family members of patients at the end of life. The results demonstrated a significant reduction in the scores of anxiety, depression and post-traumatic stress syndrome in these patients' families, when the end-of-life process was conducted using the VALUE methodology. Subsequently, the American College of Critical Care Medicine included the use of the VALUE model in its consensus recommendations for end-of-life care in ICUs[35].

Antunes *et al.* studied the use of the Conflict Scale in Decision-Making (ECTD, *Escala de Conflito na Tomada de Decisão*)[36] in patients with spinal cord injury and decision to use intermittent catheterization. The fragility of information and lack of support were predisposing factors for indecision[37]. These results suggest a path for more studies with outcome measured by patient perception to be carried out in Brazil, in other clinical contexts.

Although the PEDCONF model represents a structured and promising approach, it has limitations, since, so far, its application has occurred in the context of teaching-learning with HCPs. Thus, future studies are needed exploring metrics directed to outcomes in health communication, allowing the evaluation of retention and maintenance of these skills over time.

CONCLUSION

In conclusion, there are still opportunities for the development of more effective strategies in teaching and learning about active, interested and attentive listening to patients and family members during pediatric family conferences. The empathetic exploration of family members' cognitive, emotional, and coping resources contributes to the development of harmonized, convergent, and patient-centered care plans.

The PEDCONF model is expected to be intuitive for the Portuguese language, based on a proactive framework that incorporates evidence-based communication skills. In addition, it is expected that this tool will encourage the harmonization of perceptions between patients, family members, and health professionals in the shared formulation of an individualized care plan.

Long-term local studies are needed to identify metrics capable of assessing outcomes of interest for health professionals, patients, and their families. This is a challenging, but at the same time fascinating field, in the context of the doctor-patient and doctor-family relationship.

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AUTHORS' CONTRIBUTIONS

Leonardo Cavadas da Costa Soares contributed with the study concept, research, methodology, project administration and initial writing of the draft. Guilherme Andrino Sanches contributed with the study concept, research and methodology. Rosiane Guetter Melo and Daniel Garros contributed to the study concept, methodology, supervision and review of the draft, individually.

CONFLICTS OF INTEREST

The authors declare no conflicts of interest.

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The authors declare no sources of funding.

DATA AVAILABILITY

Research data is available in the body of the document.

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