

FAMILY-CENTERED CARE IN NEONATAL AND PEDIATRIC INTENSIVE CARE UNIT: NURSE'S VISION

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ABSTRACT

The Family-Centered Care is a philosophy that recognizes the family as a fundamental part of care, with the objective of participation in health planning. The study aimed to meet the nursing vision of a neonatal and pediatric intensive care unit about Family-Centered Care. Qualitative descriptive study, with family-centered care theoretical referential, held in the year 2015 in a Neonatal and Pediatric Intensive Care Unit of a private hospital. Nineteen nurses participated in the study. The reports were submitted to thematic analysis and after, emerged two themes: "the Family-Centered Care in the perception of the nurse that provides intensive care to the child" and "the challenges of incorporating Family-Centered Care in practice daily: gap between theory and practice. The study revealed the persistence of gaps between the theory and practice of Family Centered Care, which is seen as an aim by professionals, but still far from being fully understood and achieved, due to organizational and training obstacles. Conceptual assistance is necessary to promote reflections about the feasibility of this model, evidencing its potential in the qualification of the assistance, making it more holistic and humanized.

Keywords: Nursing Care. Family. Intensive Care Units, Neonatal. Intensive Care Units, Pediatric.

INTRODUCTION

Family-Centered Care (CCF) is a philosophy that recognizes the family as a fundamental part of health care and aims to stimulate the family's bond with the patient, ensuring their participation in the planning of health actions. Patient and family-centered care is an approach to planning, delivering, and evaluating health care that builds on mutually beneficial partnerships between professionals, patients, and families in a way that all involved are recognized as care recipients, regardless of their age, reducing not only the anxiety of family members, but also increasing patient satisfaction with care^(1,2).

The CCF concept also aims to define the quality of care provided according to the patients and their families vision and to promote the discussion of patient autonomy in relation to their health needs. The central assumptions of CCF are dignity and respect, in which professionals should be able to listen to patients and their families, have respect for the knowledge and beliefs of the patient and his/her family, because these assumptions are included in care, shared information, active participation and collaboration⁽³⁾.

This model has been disseminated around the world, presenting elements such as respect for family preferences, flexibility and personalization of care, information sharing in an honest way, to promote participatory decision making, collaboration in all the levels of care provision and an approach based on the strengths of working with patients and families^(4,5).

The opinions of the family members can be incorporated into the care and their participation in the team's decisions contribute to a better management of the hospitalization process, benefiting all those involved^(1,6). In this acquaintanceship, many parents can acquire considerable knowledge about care management and actions in partnership with health professionals⁽⁶⁻⁸⁾. The effective participation of the family during the disease process minimizes social isolation, which may be a risk factor for the patient, especially at the extremes of age, reducing trauma and strengthening the bond between team and family⁽³⁾.

In the field of child health nursing, CCF is a way of caring, not only for the child, but also for the family, identifying it as a care unit⁽³⁾. This model, which values the vital role of the family in ensuring the health and well-being of the child, planning and attending all its

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members as an union of efforts, comes to counter the model that, until the first half of the twentieth century, the children were hospitalized exclusively by health professionals and in which the parents' visits were extremely restricted⁽⁹⁾.

Although nurses recognize the importance of including CCF in their activities, many present difficulties in associating the CCF model with the philosophy of care adopted in care practice. This way, it remains a challenge to minimize the distance between the professional and the child's reality, aiming for comprehensive and humanized care⁽¹⁰⁻¹²⁾.

The research was motivated by the need to investigate nurses working in the Neonatal and Pediatric Intensive Care Unit (UTINP) their understanding of CCF in the care of the child in intensive care, considering the importance of the family as an essential unit of care.

Therefore, the objective of this study was to know the perception of nurses of neonatal and pediatric intensive care unit on Family Centered Care. This way, it is expected that this research can contribute to the use of this care model by the professionals working in the UTINPs, having as motto improving the quality of care/care of the child and the involvement of families in the recovery plan for their children.

METHODS

It is a descriptive and qualitative study that had as a theoretical reference the CCF, which has as a background to support the family, stimulating the effective participation of the parents in the care process, as well as their insertion in the decisions about the behaviors⁽¹³⁾. The target population of this study were nurses (n = 19) who worked in a Pediatric Neonatal Intensive Care Unit of a municipality located in the Northwest of the state of Paraná, Brazil.

The unit has eleven beds of hospitalizations aimed at the care of preterm and/or severely ill neonates and children up to 12 years of age, with a hospitalization rate of approximately 85%. The unit is composed of a head nurse responsible for the unit at each shift (morning/evening/ night 1 and night 2) and four nurses responsible for the care in each period, totaling 20 nurses. The inclusion criterion was to be a nurse working at the UTINP and the exclusion was the absence at the unit on the day of the interview. It is noteworthy that only one nurse refused to participate in the research.

Data were obtained in the second semester of 2015,

during the month of August. The place used to conduct the interview was the institution itself, in the participant's work shift, with an average duration of 40 minutes, in a reserved place in order to allow participants the freedom to answer questions. The interviews were guided by a semi-structured script, composed of two parts, the first focused on the characterization of the participants and the second on the study theme.

The data obtained in this article are the qualitative results of the following open questions contained in the research tool:

- In your words what is the meaning of Family Centered Care?
- How do you perceive the family's participation in the care of the hospitalized child?

The questions were revised and the responses hand-transcribed into a document to allow the qualitative content analysis. During the transcripts, the speeches were highlighted. As the readings were made, the convergent themes were identified and submitted to the thematic content analysis, according to Bardin's assumptions⁽¹⁴⁾. The result obtained after the analysis was presented in descriptive form, divided into categories and subcategories. Initially, the data were divided into units that were significant, using systematic coding and later brought to category integration.

The interviews were recorded with the authorization of the participants, respecting the ethical precepts. To ensure anonymity of the participants and to facilitate the reading and interpretation of the results, the interviewees were identified by the letter "E" for nurses (Enfermeiras), followed by numbers according to the order of the interviews.

The study was developed with the authorization of the institution and approval of the research project by the Standing Committee on Ethics in Research with Human Beings (COPEP) of the State University of Maringá (UEM), according to CAAE: 46851015.3.0000.0104, under the number of opinion 1,166. 668. The participation of the nurses took place after signing the Term of Free and Informed Consent (TCLE).

RESULTS AND DISCUSSION

The study was attended by nineteen professional nurses, all female, with a mean age of 28.7 years. The unit counts on the work of 20 registered nurses, however one nurse refused to participate in the

research. Among the professionals, eight had post-graduation in neonatal nursing already completed or in progress and five were specialists in other nursing fields.

Two main themes were identified from the data analysis: "Family-Centered Care in the perception of nurses who provide intensive care to the child" and "The challenges of incorporating Family-Centered Care into daily practice: a gap between theory and practice".

Family-centered care in the perception of nurses who provide intensive care to the child

In the present study, to conceptualize CCF, nurses diverged in their understanding, showing little knowledge about this philosophy of care, highlighting four aspects: the participation of parents as providers of care to their children during the period of hospitalization at the UTINP; the family as extension of the patient and deserving of care by the team; the family as support in the care process; and the nurse's hosting of the family.

The participation of parents as caregivers of their children during the period of hospitalization at the UTINP

Part of the nurses understands that CCF is related to the ability of family members to provide day-to-day technical care to children, assisting staff in care.

It is the nurse to guide the parents about child care, the doctors also guiding the family and so they make it [...] often, the mother comes in here in fear, insecure and so this care would be better (E4).

Let the mother take care of her baby, change a diaper, clean the eye, the mouth, let that mother pass the milk through gavage. So, I think nursing can provide this for mom (E9).

Parents expect negotiation to enable them to participate in care and become involved in decisions, yet they do not necessarily want to be held responsible for such decisions. The process of developing this experience involves the acquisition of knowledge and skills previously unknown to many, thus necessitating adaptations to the changes for the child's condition⁽⁸⁾. However, in general, the team decides how and when the family will participate in the care, restricting their space with the child⁽¹⁾.

The family as extension of the patient and deserving of care by the team

Participants believed that CCF was related to the emotional support offered by the team, parents who were fragile with the condition of their child's illness and needed attention to go through the uncertainty generated by the hospitalization.

Here we take care not only of babies, we also take care of parents, mothers and grandparents, but especially of fathers and mothers. We handle the excitement, you know? The way of talking, explaining about baby's recovery (E6).

I think not only the child, but the family as a whole. You will take care of the child, but you have to take care of the family too, because if the family is not well, you will not be able to give adequate support to the child (E7).

Nurses and other members of the health care team should develop skilled care plans for all family members, not just infants, as care recipients⁽⁶⁾.

In the CCF conceptualization, in the present study, the approaches did not include more extensive elements about CCF, showing that the professionals still present a knowledge gap on the subject, that allows the implementation of care based on this philosophy for this age group.

Knowing the concept of CCF should be the first step towards recognizing its importance and a crucial step towards its implementation. However, in general, nurses have difficulties to conceptualize this model^(6,12), highlighting only isolated points of this care philosophy.

Because the family is a constant in the child's life⁽¹⁵⁾, its inclusion, from CCF's point of view, must follow its presuppositions based on a partnership, which, consequently, will bring benefits to patients, families and providers. Therefore, the skills and qualification of the professionals are decisive in the implementation of CCF, directly interfering in the efficiency of its application^(1,6).

Although they have not been able to conceptualize the CCF covering all the elements of this model, when asked about what they considered important for a more integrative assistance to be offered, they showed concern for the family, even without conceptualizing the term CCF.

The family as support in the care process

Most nurses agree with the need for the presence of the parents in the ICU during the period in which the patient remains hospitalized. His considerations address the needs of children, but also of family members.

So you have to take care of the emotions of that family [...] and prepare the family for the care the child needs (E7).

I think it is extremely important for the mother's bond with the baby, I also find it extremely important, besides the mother, the father or some other relative, who may have contact with this baby in the ICU (E16).

Studies indicate that the family that feels participative in the treatment ends up getting involved in a much more interested way and understands that their participation is extremely important for recovery of the patient. The family perform care according to its beliefs and values, seeking to be recognized by the team as a participant in care and not an obstacle^(12,13). In this context, it becomes imperative to recognize and understand family needs and their ability to adapt to the hospital environment. It is therefore up to the health professional to identify the moment and the way to intervene and integrate the family with the purpose of improving the quality of care provided to the newborn⁽¹²⁾.

The nurse's hosting of the family

During the speeches, hosting the family was evidenced by the nurses as an element of great importance and part of care.

It's not just the baby who is here as a patient! The family ends up being patient too! We have to welcome parents who have many feelings. So, I think it's up to us to welcome and really insist on humanization. (E9).

Nursing staff can be talking, asking questions, directing [...] on what we can, we are guiding them ... trying to ease the suffering in a certain way is to make them calmer [...] but not only treating the child but trying to treat the family as a whole (E19).

Besides the child, parents also go through a process of assimilation of the effects of hospitalization and adaptation of hospital routines⁽¹⁵⁾. They are significantly affected, being exposed to feelings of impotence, anxiety, fears, frustrations and agony, feeling unable to control the situations imposed by hospitalization^(15,16).

Hosting in this context represents the first step in meeting the needs of family members, humanizing care and promoting ICU integration in order to trace individualized care and according to the specific characteristics of each child^(14,15). Therefore, welcoming becomes the way to be followed, aiming to ensure that the patient and his family have all their rights respected⁽¹⁷⁾.

The challenges of incorporating family-centered care into daily practice: a gap between theory and practice

The search for an inclusive care between the hospitalized child, the family and the team is considered essential according to the CCF. This way, the presence of parents in the process of recovery of hospitalized children, even though it is considered of notable importance, according to the first subcategory, is seen as a result of some challenges as highlighted by nurses in the second subcategory.

The Importance of Parents in the Child Recovery Process

The value of parental presence for the child's well-being is present in nurses' perceptions. They highlight the positive influence that parents exert in the treatment of children, especially regarding the recognition of the psych-emotional contribution and its effects on the recovery and evolution of hospitalized children.

So, we feel that the child realizes that the mother is there [...] the smell, perhaps! The issue of tact [...] I think it is very favorable during the whole treatment (E2)

The family is very important here in the ICU [...] the children are more comfortable, the presence of the parents is very important in their recovery [...] in relation to the vital signs, they improve a lot, I think even they are discharge quickly (E12).

The presence of the parents with the babies is able to reduce the days of hospitalization, the episodes of new hospitalization, besides promoting more periods of sleep, agitation control, reduction of analgesics and relief of pain^(1,6,11,18). The dynamics of care using this model is changed. With the presence of family members, care is no longer focused on the patient as isolated, and everybody is single client, sharing the same information⁽¹⁹⁾.

Discouragement of the relative's stay

The challenges faced by the professionals who work focused so that the care under this perspective is possible are related to the rules and routines of the UTINP, which reflect the type of assistance offered to families in the situation of hospitalization of their children.

The restrictions on visiting hours are related to the persistence of a paradigm that considers parents as

visitors, being one of the limiting factors for the CCF. The following testimonies reflect the actions taken in the unit:

So here we limit the stay[...] in the case of mechanical ventilation, of course, if the mother asks: can I stay? We will not deny it, but we do not offer that possibility to her either, so she understands that she cannot (E9).

I think they could open for visit at night, not overnight because I think it's a very tiring time even for parents [...] but I think they could let them stay here with the kids (E11).

If they had free access, everything would be easier(E13).

Traditional practices of visit restrictions and family exclusion on care planning and their participation in the hospitalization process limit the extent of CCF coverage⁽²⁰⁾. Decisions about treatment are thus restricted to members of the health team, with no family involvement about what should or should not be done. The rules of the unit will often limit a person's full-time presence to the child.

Parents repeatedly find barriers to their participation in the care of their children whether in restrictions on their actions, such as restrictions related to limiting spaces, with respect to the environment, human resources.

In this sense, it can be said that the design of this environment, molded from inflexible norms and routines, further hinders the baby's hospitalization period, while at the same time making it a serious obstacle to the implementation of CCF.

Hostile environment that represses parental involvement

The nurses understood that even in cases where the presence of family members is stimulated by the team, there are blocks by the parents, who consider the UTINP environment to be a difficult place for them.

There are some parents who come here so insecure, so afraid. A difficulty! They do not even want to touch the baby [...] we go on talking, talking and they leave here more relieved. They arrive here scared! (E1).

We have invasive procedures that parents have difficulty understanding and watching [...] they get very worried, until even a puncture for peripheral access, which is basic for us, they get nervous, so they cannot cope and end up making the child even more nervous(E12).

The intensive care unit is characterized by the profusion of high-tech equipment, sophisticated procedures, intermittent monitoring, intense lights, noises, large numbers of circulating professionals. These elements make it difficult for the parents to live with their babies and the team. In this scenario, as a rule, actions are established according to the institution's administrative regulation, aiming at the good development of activities, often triggering the exclusion of the family from the care process.

FINAL CONSIDERATIONS

Nurses' speeches on CCF reveal the lack of knowledge about their conceptual matrix, as well as their purpose, compromising the recognition of its importance in the care scenery in question.

Although nurses use strategies such as the kangaroo method, which favor the humanized approach to health, in line with the precepts of CCF, they still do so instinctively and poorly systematized.

This way, although it is clear from nurses' reports, the attribution of importance to the family as a trigger element of many benefits in the process of recovery of hospitalized children, as well as the recognition of structural and organizational obstacles to a fuller parental participation in care to their children, many still are the challenges for the adoption of CCF as a reference for professional nursing.

The diffusion of this knowledge is therefore a *sinequanom* condition to the assumption of this as a theoretical reference and guiding health practices, which refers to the need to include these discussions in undergraduate and postgraduate courses.

The conceptual collection on the CCF brought through this article intends to promote reflections on the feasibility of this assistance model, evidencing its potential in the qualification of the assistance, making it more holistic and humanized. Nurses in Pediatric Units need to recognize that, in addition to the health needs of children, their emotional needs and those of their parents must be respected in the quest for a complete recovery at the end of the disease process. The education that facilitates the implementation of this care model in the care practice should be systematic and involve all professionals in partnership with the health institution.

CUIDADO CENTRADO NA FAMÍLIA EM UNIDADE DE TERAPIA INTENSIVA NEONATAL E PEDIÁTRICA: VISÃO DO ENFERMEIRO

RESUMO

O Cuidado Centrado na Família é uma filosofia que reconhece a família como parte fundamental do cuidado, com o objetivo de participação no planejamento das ações em saúde. Este estudo teve como objetivo conhecer a visão de enfermeiros de uma unidade de terapia intensiva neonatal e pediátrica a respeito do Cuidado Centrado na Família. Estudo descritivo qualitativo, com referencial teórico do Cuidado Centrado na família, realizado no ano de 2015 em uma Unidade de Terapia Intensiva Neonatal-Pediátrica de um hospital privado. Participaram do estudo dezenove enfermeiras. Os relatos foram submetidos à análise temática e dessa análise emergiram duas categorias temáticas: “O Cuidado Centrado na Família na percepção do enfermeiro que presta cuidados intensivos à criança” e “Os desafios da incorporação do Cuidado Centrado na Família na prática diária: lacuna entre teoria e prática”. O estudo revelou a persistência de lacunas entre a teoria e a prática do Cuidado Centrado na Família, sendo este encarado como um ideal almejado pelos profissionais, mas ainda distante de ser plenamente compreendido e alcançado, em razão de obstáculos organizacionais e formativos. O regaste conceitual é necessário para promover reflexões acerca da viabilidade deste modelo, evidenciando seu potencial na qualificação da assistência, tomando-a mais holística e humanizada.

Palavras-chave: Cuidados de enfermagem. Família. Unidade de terapia intensiva neonatal. Unidade de terapia intensiva pediátrica..

CUIDADO CENTRADO EN LA FAMILIA EN UNIDAD DE CUIDADO INTENSIVO NEONATAL Y PEDIÁTRICO: VISIÓN DEL ENFERMERO

RESUMEN

El Cuidado Centrado en la Familia es una filosofía que reconoce a la familia como parte fundamental del cuidado, con el objetivo de participación en la planificación de las acciones en salud. Este estudio tuvo como objetivo conocer la visión de enfermeros de una unidad de cuidado intensivo neonatal y pediátrico a respecto del Cuidado Centrado en la Familia. Estudio descriptivo cualitativo, con referencial teórico del Cuidado Centrado en la familia, realizado en el año de 2015 en una Unidad de Cuidado Intensivo Neonatal-Pediátrico de un hospital privado. Participaron del estudio diecinueve enfermeras. Los relatos fueron sometidos al análisis temático y de este análisis surgieron dos categorías temáticas: “El Cuidado Centrado en la Familia en la percepción del enfermero que presta cuidados intensivos al niño” y “Los desafíos de la incorporación del Cuidado Centrado en la Familia en la práctica diaria: laguna entre teoría y práctica”. El estudio reveló la persistencia de lagunas entre la teoría y la práctica del Cuidado Centrado en la Familia, siendo este considerado como un ideal deseado por los profesionales, pero aún lejos de ser plenamente comprendido y alcanzado, en razón de obstáculos organizacionales y formativos. El rescate conceptual es necesario para promover reflexiones acerca de la viabilidad de este modelo, evidenciando su potencial en la calificación de la atención, volviéndola más holística y humanizada.

Palabras clave: Atención de enfermería. Familia. Unidad de cuidado intensivo neonatal. Unidad de cuidado intensivo pediátrico.

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