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Family-centered care in neonatology: health workers' and families' perceptions

Cuidado centrado na família em neonatologia: percepções dos profissionais e familiares

Atención centrada en la familia en neonatologia: percepciones de los profesionales y familiares

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ABSTRACT

Objective: to examine family-centered care as seen by health personnel working in a neonatal intensive care unit and the parents of children hospitalized there. **Method:** this quantitative, descriptive study was conducted in 2018 with 19 nursing personnel at a teaching hospital in northwest Paraná State and nine family members. Two self-administered questionnaires on the topic were used, and study subjects were approached during their time at the unit. Data were analyzed using descriptive statistics. The study was approved by the institution's research ethics committee. **Results:** the team demonstrated acceptance by the family, and the parents felt that bond, although decision making still centered on the health professional. **Conclusion:** the health personnel's and patient relatives' perceptions converge to family-centered care, although in an incipient manner, and they are unaware of how it can be further developed and put into practice.

Descriptors: Nursing Care; Family; Intensive Care Units, Neonatal; Professional-Family Relations.

RESUMO

Objetivo: analisar, sob a ótica dos profissionais que atuam em unidade de terapia intensiva neonatal e dos pais das crianças internadas, o entendimento do cuidado centrado na família. **Método:** estudo quantitativo de abordagem descritiva, realizado em 2018 com 19 profissionais de enfermagem de um hospital de ensino na região noroeste do Paraná e nove familiares. Utilizaram-se dois questionários autoaplicáveis acerca do tema e os sujeitos foram abordados durante seu período de permanência na unidade. Os dados foram analisados por estatística descritiva. Pesquisa aprovada pelo comitê de ética em pesquisa da instituição. **Resultados**: a equipe demonstra acolhimento pela família, os pais sentem esse vínculo, porém nos momentos de tomada de decisão, esta ainda é centralizada no profissional de saúde. **Conclusão:** a percepção dos profissionais e dos familiares converge para o cuidado centrado na família, porém, de forma incipiente, desconhecendo seus demais desdobramentos e maneiras de colocá-lo em prática.

Descritores: Cuidados de Enfermagem; Família; Unidades de Terapia Intensiva Neonatal; Relações Profissional-Família.

RESUMEN

Objetivo: analizar la atención centrada en la familia como la ve el personal de salud que trabaja en una unidad de cuidados intensivos neonatales y los padres de los niños hospitalizados allí. **Método:** este estudio cuantitativo y descriptivo se realizó en 2018 con 19 miembros del personal de enfermería de un hospital universitario del noroeste del estado de Paraná y nueve familiares. Se utilizaron dos cuestionarios autoadministrados sobre el tema y se abordó a los sujetos de estudio durante su tiempo en la unidad. Los datos fueron analizados utilizando estadística descriptiva. El estudio fue aprobado por el comité de ética en investigación de la institución. **Resultados:** el equipo demostró aceptación por parte de la familia y los padres sintieron ese vínculo, aunque la toma de decisiones aún se centró en el profesional de la salud. **Conclusión:** las percepciones del personal de salud y familiares del paciente convergen hacia la atención centrada en la familia, aunque de manera incipiente, y desconocen cómo se puede desarrollar y poner en práctica.

Descriptores: Atención de Enfermería; Familia; Unidades de Cuidados Intensivos Neonatal; Relaciones Profesional-Família.

INTRODUCTION

Currently, there is a paradigm shift in the context of health care, where the focus, previously centered on curativism, today assumes a much broader role, bringing care centered on the patient and their family into the hospital environment, a moment in which humanization of care and quality of life become a priority, decreasing the specific attention to the illness process. This new approach is translated as Family-Centered Care (FCC), whose characteristic encompasses a philosophy of care provided to the patient and their family, giving voice to both[1].

This model uses assumptions that must be followed throughout the hospitalization, whether in the neonatal, pediatric, or adult contexts. The main ones include the application of: dignity and respect (the health professionals

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respect the choices, values and beliefs of the patient and family); shared information (the professionals communicate and share information completely and impartially with patients and families); participation (patients and families are encouraged and supported to participate in decision-making); and collaboration (patients and families are included and understood as the support base of the institution, assisting in the development of policies and programs, in professional education and in the provision of care)[2].

Specifically in the neonatal context, the benefits of FCC are directly related to reducing parental stress and increasing self-confidence at work, reducing the baby's hospital stay and readmissions, greater adherence to the Kangaroo Method, strengthening the bond between newborns and family members, and increases in breastfeeding rates[3,4].

At the same time, from the parents' perspective, we find little sense of the importance of their real participation in the care of hospitalized children and that they can and should be empowered about their children's health status and clinical situation. The fact that families can express their feelings and fears, when the baby is admitted to the NICU, causes a good part of the FCC assumptions to be applied, even if indirectly[2].

Although it has several advantages, FCC is still little known and applied in our country. This lack of knowledge on the topic negatively influences the care of babies and their families. Most professionals not only do not know about the topic and its assumptions, but also claim several barriers for not doing so in their work environment. In addition, the fact that FCC is not discussed during the academic training of nurses and later in their professional life[5].

Some studies reinforce the need to produce evidence to support the application of FCC in the practice, making it necessary to use measurement instruments that can specifically point out how the professionals perceive the application of this model in their unit[6].

The Shields & Tanner Questionnaires tools[7,8] are some of the instruments developed to measure and compare the perspectives of parents and health professionals about FCC in different pediatric contexts. These are structured and self-administered questionnaires for parents and health professionals and the questions are mutually corresponding, so that comparisons can be made between the two groups. The two questionnaires were called Perceptions of Family-Centered Care-Parent (PFCC-P) and Perceptions of Family-Centered Care-Staff (PFCC-S), translated to Brazil as: *Percepção do Cuidado Centrado na Família-Equipe* (PCCF-E) and *Percepção do Cuidado Centrado na Família-Pais* (PCCF-P)[6].

In this context, some questions arise, such as: What is the real understanding of the nursing team about the participation of the family in the environment of the Neonatal Intensive Care Unit (NICU) and how do they apply FCC even though indirectly? At the same time, How do parents understand their participation in this process and how could they improve their bond and presence within the unit and with other team members?

Given the above, the objective of the study was to analyze, from the perspective of the professionals who work in neonatal intensive care units and of the parents of hospitalized children, the understanding of Family-Centered Care.

METHOD

This is a quantitative study with a descriptive approach, carried out with seven nurses and 12 nursing technicians who work in an NICU of a teaching hospital located in the Northwest region of Paraná, Brazil. At the same time, the instrument was also applied to nine relatives of babies admitted to the unit, these being seven mothers and two fathers.

Regarding the location, it is a University Hospital located in the Northwest of the state of Paraná that exclusively serves the Unified Health System. The NICU has been in existence for 20 years and focuses on the treatment of babies up to 28 days old, premature or not. The unit has 10 neonatal beds, four for intermediate care, and six for intensive care.

The inclusion criteria were being 18 years of age or older. For the professionals, a minimum experience of six months in the area was also required. The exclusion criteria included participants who were on vacation or on leave during the data collection period, or who refused to participate in the study.

The nursing team has 27 employees, 15 of whom are nursing technicians and 12, nurses. Of that total, two refused to participate, three were on vacation and three on leave, totaling 19 participants representing all work shifts. Data was collected between February and May 2018, through the application of questionnaires adapted by the researchers and based on the following instruments: Perception of Family-Centered Care-Staff (PFCC-S) and Perception of Family-Centered Care-Parents (PFCC-P)[3].

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Both the professionals and the family members were approached during their period of stay in the unit, in a place reserved for such activity. At first, the study was explained to the professional and the baby's father or mother, then consent was obtained by signing the Free and Informed Consent Form (FICF) and the subjects filled out the instrument. At the end of the collection, the data were analyzed with the aid of descriptive statistics, using relative and absolute frequencies.

As it is a relatively small unit, with babies that have a long hospital stay and due to the limited time of data collection, it was decided to create two self-applicable instruments based on the PFCC-P and PFCC-S, but that could be analyzed in a descriptive way and not using a Likert scale, which is the one proposed by Shields and Tanner[5].

The study project was assessed by the Standing Committee for Ethics in Research Involving Human Beings, under opinion No. 2,092,136/2017 and Certificate of Presentation for Ethical Appraisal No. 66242617.4.0000.0104. All the ethical precepts of Resolution 466/2012 of the National Health Council were contemplated.

RESULTS

Of the 19 nursing professionals, all were female, with seven nurses and 12 nursing technicians. Their age varied from 30 to 55 years old, with a mean of 42. Their time of experience in the unit ranged from two to 23 years, with seven employees working at the unit for over twenty years. As for specialization courses, 11 had already completed a *latu sensu* graduate course in the field of Neonatology and only one had a *stricto sensu* graduate program, at the master's level in Nursing.

Regarding the family members, of the nine subjects approached, seven were mothers and two were fathers. Their age varied between 30 and 45 years old, with a mean of 37. Only two parents had a college degree and the rest had complete elementary and high school levels. Five lived in the same municipality of the studied unit and the rest lived in neighboring cities less than 30 km away.

Half of the family members reported some difficulty in getting to the unit to visit their baby and the other half did not feel this problem. Five of them spent nearly 30 minutes to come to the hospital and the rest up to an hour. The majority, seven family members, had other children to care for at their homes, whether they were minor children, or children from other relationships of their partners, with ages ranging between six and 12 years old. These same seven participants reported having help at their homes from relatives (husband, mother-in-law, sister-in-law and stepdaughter) to be able to take care of other children and still be able to visit their baby in the unit.

The results related to the team are described in Table 1.

TABLE 1: Family-Centered Care routines performed by the team (n=19). Maringá, Paraná, Brazil, 2018.

Questions	Yes		No	
	n	f(%)	n	f(%)
1) Parents are welcomed when they arrive at the unit	19	100%	0	0
2) Other relatives of the baby are welcome in the institution.	12	63%	7	32%
3) Parents can accompany their baby during the procedures.	7	37%	12	63%
4) Parents have free will to question their baby's treatment.	14	74%	5	26%
5) Parents are prepared for discharge and about the necessary referrals after their baby is discharged.	15	79%	4	21%
6) Parents participate in the decision-making process about care.	7	37%	12	63%
7) The educational folder delivered at the baby's admission is well explained to the family members.	12	63%	7	32%
8) The family is included in the care provided to the baby.	19	100%	0	0
9) The team knows the needs of each baby.	16	84%	3	16%
10) The team has time to listen and welcome the parents' concerns.	16	84%	3	16%

The results found demonstrate that most of the professionals use FCC assumptions in their working hours since, in 19 (100%) cases, parents are welcomed in the unit as well as being included in baby care. At the same time, it is noticed that other family members are not always well received in the environment. The instrument applied did not specify what link these other family members had with the baby; however, this does not justify the fact that 7 (32%) professionals did not receive them adequately, as shown in Table 1.

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It was also identified that 16 employees (84%) know the needs of each baby and have time to listen and welcome the parents' concerns. Regarding decision-making in relation to care, only 7 professionals (32%) claimed that the parents participate in this moment but, when asked about the family's free will to question the treatment offered, 14 (74%) reported that this is a parental right.

The results related to the parents' perception about the application of the instrument, as well as those related to the team are described in Table 2.

TABLE 2: Perception of the parents on Family-Centered Care when they arrive at the unit (n=19). Maringá, Paraná, Brazil, 2018.

Questions	Yes		No	
	n	f(%)	n	f(%)
1) I feel good when I come to the hospital.	9	100%	0	0
2) Other people in my family are well received at the institution.	6	67%	3	33%
3) I manage to be with my baby during the procedures.	4	44%	5	56%
4) I manage to ask questions about my baby's treatment.	7	78%	2	22%
5) I feel prepared for discharge and to take care of my baby at home. I know where to take it when necessary.	8	89%	1	11%
6) The team included me in the decisions to be made about my baby.	7	78%	2	22%
7) I understand the written guidelines I received in the admission folder.	7	78%	2	22%
8) I receive guidelines on the care for my baby.	8	89%	1	11%
9) The team knows the needs of my baby and of the others who are hospitalized.	8	89%	1	11%
10) The team listens to my concerns and understands what my family and I are going through.	9	100%	0	0

All the families approached claimed that the NICU studied is an environment that welcomes them and knows how to listen to their needs and concerns. In most situations, 8 (89%) parents reported that they are included in the care provided, as well as in the decisions made about their child's situation. When asked about participation during the procedures, only 4 (44%) reported that they could accompany their baby.

DISCUSSION

It can be noticed that the team is concerned with pleasantly welcoming family members when they arrive at the unit and this is also a perception of the family. Some authors emphasize the importance of Nursing in welcoming them warmly when they arrive at the unit, in order to soften the impact of being in an unknown place and that, for this reason, it can be provide bad impressions[9].

Regarding decision-making and performance of procedures, a large part of the team (63%) states that the parents have no participation in these moments and this was a reality portrayed by them, reinforcing the curative model and centered on the professional and not on the family.

Ensuring a good understanding of the child's health status, realizing whether the parents are understanding the care provided and striving for them to clarify their doubts helps in reducing anxiety and in building the trust that emerges between the team and the family. When FCC is applied, there is a remarkable decrease in the levels of stress, anxiety and depression in family members, at the same time that satisfaction and good relationships with health professionals increase. For the professionals, the practice can improve their satisfaction and confidence at work and the quality of care, as well as reduce mental exhaustion[10].

The team says that the family can question the care that was provided to their child (74%), but they do not participate in decision-making, which can lead them to believe that the family is informed of the procedure or conduct that was performed, they can ask about it, but it has already happened, so it does not directly interfere with its realization. At the same time, parents report (78%) that they participate in this process, assuming that the family does not understand its role as responsible for the baby and that is free to interfere in these moments. The fact of being informed of what has already happened does not mean participating in decision-making; therefore, it is assumed that there is lack of adequate explanations to the family about their role in these conducts.

The sharing of information and professional knowledge about the babies' clinical condition, their sleep and rest routine, evolution of the breathing pattern, nutritional aspects, eliminations and other situations that happen within the unit are part of the family's wishes. When they have access to such information and about their doubts, parents become more capable of dealing with the situation of prematurity and illness, and begin to better face difficult and fragile moments[9].

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Effective communication is the key to facilitating FCC. The professionals must be available to provide support during the processes and complications that permeate the baby's hospitalization, as well as when welcoming the family from the first moment[11].

Regarding the preparation for hospital discharge and referral for outpatient follow-up of the baby, this was also a concern on the part of the team, and the family felt this care in a positive way; however, we do not know how it actually occurs: if it starts at the time of the baby's hospitalization, or if it is just something focused on when leaving the hospital.

Discharge is a moment surrounded by expectation and emotion, but at the same time that it becomes a happy day, this moment can also be a cause for apprehension, insecurity and fear. Thus, it is essential that the family is prepared to receive this baby at home and that it has a support network which can provide help and encouragement. It is important that parents exercise care for their child during hospitalization so that, when they return home, they are safe and feel able to take care of their baby, knowing where to turn to if necessary[12].

Regarding the explanatory folder delivered on admission to the unit, it is clear that there is a good understanding on both sides. The professionals report that they do it properly and the family reports that they can understand the explanations. During data collection, the researcher did not have direct access to the folder but, talking to the unit's coordination, it was noticed that it is a form with the visiting and operating hours of the NICU, the importance of parents within the unit during the baby's hospitalization, and information about the hospital's Human Milk Bank if necessary.

This is punctual information and should be reinforced during the hospitalization period since, upon admission, the family is usually emotionally shaken, as most pregnant women do not want a premature birth, due to maternal or fetal problems and culminating in NICU admissions. In many cases, the warnings are not absorbed and the family members need a moment to adapt to this new reality that was not in their plans but that, for some specific reason, ended up happening.

A strategy to assist in understanding the information passed on is the delivery of a diary, entitled *Baby Diary*, whose purpose is not based only on informing, but rather to become a record of maternal emotions and feelings during hospitalization. In addition, topics that permeate the NICU are also addressed, such as equipment, main pathologies resulting from prematurity, guidance on breastfeeding, vaccines and preparation for discharge, and provides a space for notes on milk milking, hand and foot stamps of the baby, birth data, and be a supporting space with a record of the daily life experienced to assist in coping with the situation[13].

This reinforces the importance of the team being humanized and working with the FCC assumptions during the process, remembering that the family did not ask to be in that situation: the baby should not have been born prematurely, added to other factors that permeate this moment, such as distance from the hospital, the fact of having other small children at home, financial difficulties that interfere with visiting the newborn, and even mourning for the child that was not expected at that time.

Studies that focus on investigating parents' satisfaction during the hospitalization period are crucial to improve care practices and consequently help to implement the FCC assumptions[14].

In this context, Nursing is of paramount importance, as welcoming the family in the face of their needs, helping to reduce stress, and devising strategies to facilitate coping with their child's hospitalization causes a decrease in anxiety and facilitates bonding[10].

Sometimes the parents were waiting for the baby to be born in two or three months' time, and suddenly they find themselves in a situation like this. It takes a lot of sensitivity and empathy on the part of the team to see the family with these eyes, remembering that they are not there to worsen the situation or to make it more difficult than it already is, but to welcome, listen, and manage to make that moment the least suffering as possible. These aspects were reinforced by the family members, as both the team (84%) and the family (100%) refer to this welcoming and listening.

Pregnancy is a period of great expectation on the part of the family and the parents yearn for a peaceful birth and for the child's birth to occur in the healthiest possible way. However, admission to the NICU brings feelings of uncertainty and helplessness, reinforcing the need to welcome the family at this time[15].

Welcoming must be a way of operationalizing health work, maintaining a listening posture, committed to answering questions and helping to solve the needs expressed by the family, assuming the responsibility of ensuring adequate and Family-Centered Care[16].

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Regarding participation in baby care, both refer that this happens, which becomes something positive during hospitalization because, in some cases, mainly the mother can feel that she is still not responsible for that baby: since it was born, it went to the unit full of wires and tubes and she cannot caress it or feed it for example. The fact of milking breast milk at the bedside and helping to administer it via an orogastric tube, touching her baby, or simply being there for him, makes the family gradually start this process of appropriation of care and, gradually, this becomes stronger and safer. It is up to the team to perceive these difficulties of approximation and to encourage the bond to happen in the best possible way, as it will benefit both parties.

Early family participation with encouragement to touch and small actions as an aid in changing diapers predisposes to a good process of coping with the child's condition and helps to provide confidence when taking the baby home[17]. Interventions centered on FCC may not have a significant impact on mortality, but can help reduce the length of stay in the NICU[18].

It is noticed that there was no discrepancy between the positive answers of the team and of the family, a fact that reinforces the characterization of the unit as humanized and engaged in the process of taking care of the babies and their families. Regarding the family's decision-making and participation in the procedures, it is clear that this is still a path to be taken, as the family is not always psychologically prepared to experience this moment and the team may not know how to deal with them in this process. It is suggested that this starts gradually and in a way that is comfortable for both.

A study that deals with family participation at critical moments shows that the family considers this as something positive, as they were able to clearly see how care for their loved one works and, even when the outcome was death, this moment became less distressing, bringing, in a way, a feeling of comfort in the moment of pain[5].

It is understood that this cannot be generalized and that not all institutions have a profile and qualified professionals to welcome the family at that moment, at the same time that not all parents are prepared to participate. However, it is suggested that the discussion is valid, and that it should somehow be initiated, within the neonatal unit itself.

Study limitations

The number of participants in the study becomes a limitation, and the very characteristic of the unit corroborates that the number is not high. It is suggested to carry out other studies with a longer follow-up time for the family and the team, in order to try to visualize the FCC assumptions in a more practical way.

CONCLUSION

Considering the data from this study, it is concluded that the professionals have little understanding of the real meaning of FCC. For them, its practice involves some of the FCC assumptions; however, this is carried out even if indirectly and not completely. In relation to the family, they were not aware of what the FCC would be, but they feel welcomed and participative in the care provided, even though most of the decisions are made by the professionals and are only communicated to them later.

The need to include the family in this process is emphasized, giving voice to those who are the legal guardians of the child and who, in their vast majority, do not know their rights and importance at that time. At the same time, the need is suggested to include FCC in the professional practice of the team, in order to narrow the gap between what is recommended and what actually happens in the care provided.

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