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Parent and Staff Perception about the Family-Centered Care in Private Service

Percepções de Pais e Equipe Sobre o Cuidado Centrado na Família em um Serviço Privado

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Abstract

Having a newborn hospitalized in the Neonatal Intensive Care Unit can be an extremely stressful and desperate situation for families who end up needing assistance and support to stay by their child's side. To evaluate the perception of family-centered care from the perspective of the healthcare team and parents of newborns hospitalized in the neonatal intensive care unit of a private health service. Descriptive survey, carried out in private a neonatal intensive care unit of a large hospital. Two instruments were applied to measure the professional of healthcare team and parent's perceptions of family-centered care. The study involved 102 parents and 102 professionals of the healthcare team. The barriers identified for the implementation of patient and family-centered care were related to the items family inclusion and participation in the care of newborns; presence of parents during procedures; recognition by professionals of the support sources for the family, identification of resources in the unit by parents and perception of the multiprofessional care team turnover regarding the care to the newborn by the newborn's parents. It is necessary to invest in continuing education programs to make the healthcare team aware for the Patient and Family-centered Care and written protocols to implement this model of care on practice.

Keywords: Infant, Newborn. Family. Intensive Care Units, Neonatal. Nursing.

Resumo

Ter um recém-nascido internado na Unidade de Terapia Intensiva Neonatal pode ser uma situação extremamente estressante e desesperadora para as famílias que acabem necessitando de apoio e suporte para permanecer ao lado do filho. Avaliar a percepção do Cuidado Centrado na Família na perspectiva da equipe de saúde e dos pais de recém-nascidos hospitalizados na unidade de terapia intensiva neonatal de um serviço de saúde privado. Pesquisa do tipo survey descritivo, realizada em uma unidade de terapia intensiva neonatal de um hospital de grande porte, de direito privado. Utilizaram-se dois instrumentos de medida da percepção de profissionais da equipe de saúde e de pais sobre o cuidado centrado na família. Participaram do estudo 102 pais e 102 profissionais da equipe de saúde. As barreiras identificadas para a implementação do cuidado centrado no paciente e família foram relacionadas aos itens inclusão e participação da família nos cuidados; permanência dos pais durante os procedimentos; reconhecimento pelos profissionais das fontes de suporte da família, identificação das fontes de ajuda na unidade pelos pais e percepção da rotatividade da equipe multiprofissional no cuidado ao recém-nascido pelos pais. Há necessidade de programas de educação permanente para sensibilizar os profissionais para o Cuidado Centrado no Paciente e Família e a elaboração de protocolos para sua implementação na prática.

Palavras-chave: *Recém-Nascido. Família. Unidades de Terapia Intensiva Neonatal. Enfermagem.*

1 Introduction

Families of newborns hospitalized in a Neonatal Intensive Care Unit (NICU) reveal the need to stay with their children, receive assistance and support, have information, be received by the team, be able to participate in care and have leisure activities[1].

The Patient-and- Family-Centered-Care Model (PFCC) has been recommended as ideal for neonatal practice, since it fosters a truly collaborative relationship between family and health team. Thus, the family needs can be fulfilled and the family can become empowered to take care of the child and make a shared decision[2].

This care model considers that the family is the primary source of patient strength and support, in addition to being central and constant in his or her life. The individuality and diversity of each family are recognized, as well as their competences[3-5]. It is based on four central assumptions: dignity and respect, collaboration, information and family participation.

In Brazil, despite efforts to promote the inclusion and reception of the family in health institutions, guaranteed in public policies such as the humanization of prenatal care, delivery and birth, *mãe canguru, HumanizaSus, Rede cegonha*, its implementation is not effective in practice yet.

The organization of health services in Brazil consists of the integration of public, supplementary and private services. This diversity in the provision of services contributes to barriers so that equity, integrality and universality, as

advocated by the Single Health System becomes a reality[5]. The public sector has weaknesses caused by excess demand in relation to the provision of services, such as difficulties in scheduling appointments and surgeries, as well as precarious hospital staying service. Whereas the supplementary and private sectors have better technologies, state-of-the-art physical resources, as well as a number of human resources prepared for care with a focus on the quality of customer care[6].

However, the public and private institutions have been moving toward quality certificates, which include patient and family rights care, through collaborative and inclusive policies and procedures to achieve the user satisfaction with the care provided, guaranteeing their rights[7].

In this sense, it is relevant to carry out studies evaluating the user perception and the multiprofessional team regarding family-centered care, in order to identify the barriers to their inclusion and to direct the implementation of interventions that are capable of causing change in organizational culture, according to the PFCC model.

It is questioned how parents and professionals, in a private health care service for newborns, perceive the family-centered care.

The objective of this study was to evaluate the perception of family-centered care from the perspective of health team professionals and parents of newborns hospitalized in the neonatal intensive care unit of a private health service.

2 Material and Method

A descriptive survey conducted at the neonatal intensive care unit (NICU) of a large, private-law hospital located in the south of the city of São Paulo.

NICU has 57 intensive care beds and five semi-intensive care beds, attended by a multidisciplinary team composed of physicians, nurses, nursing technicians, physiotherapists, speech pathologists and psychologists. The parents of the hospitalized NB have free access to the neonatal unit and can remain in the sector during 24 hours a day, but only one of the parents at a time. During admission, on-duty transition and invasive procedures, all parents present are invited to withdraw, waiting outside the unit. There is no visitation time for the other family members.

The sample consisted of 102 parents of newborns hospitalized at NICU and 102 health professionals that compose the NICU multidisciplinary team. Considering a confidence level of 95% and sample error of 10%, the true proportion of concordance among the groups with at least 97 individuals in each group (family, team) was estimated.

The criterion for inclusion of the family was to be one of the parents of newborns admitted to NICU for more than 72 hours; and of the professionals of the health team was to have an employment bond with the hospital for at least six months.

The exclusion criterion adopted for the family was parents presenting verbal communication barriers; and for health team professionals to be on vacation or medical leave at the time of data collection.

Data collection was performed using two family-centered perception tools(*Perceptions of Family Centred Care – Parent - PFCC-P e Perceptions of Family Centred Care – Staff - PFCC-S),* formerly called *Shields & Tanner Questionnaire,* adapted and validated for use in the Brazilian Portuguese language, [8] which received the denomination Perception of Family-Parents Centered Care (PFFCC) Brazilian version and Perception of Family-Staff Centered Care (PFSCC) Brazilian version.

The questionnaires, both from parents and professionals, are composed of 20 Likert-type questions (never, sometimes, usually and always) and differ little from one another. They have clear and direct statements about the perspective regarding the reception, information and support received and provided during admission.

Data analysis for categorical variables was performed using absolute (n) and relative (%) frequencies; and numerical variables were analyzed by mean, median, and standard deviation. The concordance between the PFCC perception of the family and the health team professionals was analyzed using Kappa test; and Wilcoxon's test was used for the correlation. The associations between demographic variables and the perspectives of parents and health professionals were analyzed by Spearman's coefficient and by multivariate analysis using Kruskall Wallis and Mann Whitney tests. Cronbach's Alpha was used to analyze the reliability of the instruments.

The study development fulfilled the national and international standards of ethics in research with human beings, approved by the Ethics Committee of the Federal University of São Paulo number 226.71.

3 Results and Discussion

A total of 35 parents and 67 mothers participated in the study, totaling 102 family representatives. Most of them were female (65.7%), aged 31 to 45 years (70.6%), with a higher education level (45.1%), residing in distant neighborhoods of the hospital (33.3%), but with time of arrival between half and one hour (40.2%) and little difficulty being in the hospital (41.2%). Most respondents have only one child (65.7%), have help to care for the child (57.8%), have no previous experience with hospital admissions (88.2%) and do not know the child's discharge forecast (76.5%).

102 health team professionals participated, most of them female (94.1%), aged between 31 and 45 years (43.1%), and with nursing undergraduate degree (69.6%), medicine (14,7%), physiotherapy (10.8%), speech-language therapy (4,9%) and *lato sensu* graduate degree (59.8%), being 94.1% in the pediatric area. The average working time was 12 (± 8) years.

The most frequent diagnoses of newborns were:

prematurity (65.7%), followed by respiratory tract diseases (14.7%). The age of newborns at the time of the instrument application ranged from 3 to 121 days, with a mean of 22.7 days and a median of 14.5 days.

The reliability of the instruments used, measured by Cronbach's Alpha, was 0.8026 in the Brazilian PCCF-P version and 0.8250 in the Brazilian PCCF-E version, showing good internal consistency in both instruments.

Upon analyzing the average perception of parents by domains, it was verified that in the respect domain there was a predominance of the response *generally* regarding item "6.respect to privacy and the confidentiality of information" (3,72); "5.parents considered as parents" (3.59); "1.reception on arrival at hospital" (3.50); and "4. openness to ask questions about the treatment" (3.42). Whereas in items, "2. Inclusion of other family members in the hospital" (2.37) and "3. stay with the child during the" procedures (2.29) the predominance of parents' responses was *sometimes*.

In the domain collaboration, parents answered *generally* to items "8. provision of honest information about child care" (3.65); "15. feeling of relief about the information received" (3.57), "13. they understand the information received in writing" (3.42); "11. provision of guidance on care" (3.35); "12. recognition of the name of the physician responsible for their child" (3,34); "7. preparation for outpatient discharge or referrals" (3,19) and "10. inclusion of the family in decisions on child care" (3.08). However, in item "14. family inclusion in child care" (1.77) opted for the option *never*.

Regarding the support domain, parents answered *generally* to items "17. openness of the team to listen to their concerns (3.39); "16. staff familiarity with the child's individual needs" (3.38); and "20. Staff understanding of the parents' experience" (3.08). Regarding the items "18. identification of the same team caring for the child daily" (2,96); and "19. recognition of the team about the parents' sources of support " (2.50) parents noticed the PFCC *sometimes* .

In the perception of health team professionals about the PFCCC in the domain respect, the answer *usually* occurred in items "6. respect for privacy and confidentiality regarding the child's information" (3.30), "4. openness for parents to ask questions about the treatment" (3.28); "5. parents considered as parents" (3.20) and "1. parents' reception upon arrival at the hospital" (3.04). and the answer *never* in questions "2 inclusion of other family members in the hospital" (1.92) and "3 parents' stay with the child during procedures" (1.88).

As for the collaboration domain, the response was *sometimes* marked in items 7 to 13 and 15, the only exception was item "14. inclusion of the family in child care" which had *ever* as an answer.

In domain support (questions from 16 to 20), in all items, health team professionals perceive the PFCC occurring *sometimes*.

When the perception of parents and health team professionals was correlated, parents showed a more positive perception (mean overall score of 3.12) than health team professionals (mean overall score of 2.73). Parents' perception of the PFCC was referred to as *generally* practiced in NICU, whereas for professionals, perception is referred *sometimes* practiced (Table 1). This difference was statistically significant (p= 0.000), indicating that health team professionals and parents think differently.

Table 1 - Perception of Health Professionals X Parents

Variables	Parents					Health team professionals					
	Mean	Median	Min	Max	SD[a]	Mean	Median	Min	Max	SD	p [b] value
Respect	3.15	4	1	4	0.23	2.77	3	1	4	0.04	0.0000
Parents' reception parents upon arrival at the hospital	3.50	4	1	4	0.68	3.04	3	1	4	0.68	0.0000
Inclusion of other family members	2.73	2	1	4	1.15	1.92	2	1	4	0.80	0.0006
Parents'stay with the child during the procedures	2.29	2	1	4	0.97	1.88	2	1	4	0.69	0.0004
Openness for parents to ask questions about the treatment	3.42	4	1	4	0.70	3.28	3	1	4	0.76	0.2331
Parents considered as parents	3.59	4	1	4	0.66	3.20	3	1	4	0.76	0.0002
Respect the privacy and confidentiality of the child's information	3.72	4	2	4	0.51	3.30	3	2	4	0.71	0.0000
Collaboration	3.12	4	1	4	0.23	2.65	3	1	4	0.08	0.0000
Preparation for discharge/referral to other services in the community for follow-up of the child after discharge	3.19	4	1	4	1.03	2.78	3	1	4	0.94	0.0033
Provision of honest information on child care	3.65	4	2	4	0.53	2.99	3	1	4	0.75	0.0000
Identification of support sources in the unit	2.72	3	1	4	1.27	2.73	3	1	4	0.87	0.9755
Family inclusion in decisions on child care	3.08	3	1	4	0.81	2.45	2	1	4	0.96	0.0000

To be continued...

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Variables	Parents					Health team professionals					
	Mean	Median	Min	Max	SD[a]	Mean	Median	Min	Max	SD	p [b] value
Provision of guidance on child care	3.35	3.50	1	4	0.74	2.97	3	1	4	0.86	0.0012
Recognition by parents of the physician's name in charge of the child care	3.34	4	1	4	0.90	2.95	3	1	4	0.76	0.0026
Understanding the guidelines received in writing	3.42	4	1	4	0.72	2.52	3	1	4	0.74	0.0000
Inclusion of family on the child care	1.77	1	1	4	1.08	1.95	2	1	4	0.86	0.1980
Relief feeling of parents with the information received about the child	3.57	4	1	4	0.67	2.50	2	1	4	0.86	0.0000
Support	3.06	3	1	4	0.15	2.82	3	1	4	0.07	0.0007
Staff familiarity with the child's individual needs	3.38	3	2	4	0.63	2.92	3	1	4	0.81	0.0000
Openness of staff to listen to parents' concerns	3.39	4	1	4	0.71	2.92	3	1	4	0.83	0.0001
Identification of the same team caring for the child daily	2.96	3	1	4	0.79	2.87	3	1	4	0.83	0.5167
Team recognition of about the support sources to parents	2.50	2	1	4	1.01	2.50	2	1	4	0.79	0.9428
Staff understanding to listen to parents' concerns	3.08	3	1	4	0.90	2.90	3	1	4	0.79	0.1605
General Score	3.12	3.75	1	4	0.21	2.73	3	1	4	0.07	0.0000

Source: Research data.

When analyzing by domains it was found that, in the domain respect, item "4" (p 0.2331); in domain collaboration, items "9" (p 0.9755) and "14" (p 0.1980) and in domain support, items "18" (p 0.6167) and "19" (p 0.498) the parents' and professionals' perceptions and professionals, since the differences were not statistically significant.

It was concluded that there is no agreement between parents' and health professionals' responses in any of the questions of both instruments, since the highest *K* was 0.114 regarding the family inclusion on the child care. Data shown in Table 1.

The associations between parents' sociodemographic data and their responses in the Brazilian PFCC questionnaire, with a pair of variables, indicated that there was an association between age group and item "5. parents considered as parents" (p 0.0242), in parents under 45 years of age (p 0.0078). There was also an association between age group and item "15. parents' feeling of relief with information received about the child" (p 0.0069), in parents under 45 years of age (p 0.0031).

It was evidenced that the longer the time spent for parents to reach the hospital, the lower the score assigned in item "10. Family inclusion in the decisions on child care" (p 0.0340).

Regarding the number of children under the parents care and the items of the Brazilian PFCC version, the association is directly proportional, that is, the higher the number of children under their care, the higher the answers score is in item "10. Family inclusion in the care of the admitted child" (0.0107).

According to the significant associations between the sociodemographic data of the health team professionals and their responses in the Brazilian PFCC version, the longer the working time with newborns, the lower the score in item "4 openness for parents to ask about the treatment of their child" (p 0,0015); and the longer the working time with newborns, the lower the score on item "5 parents are considered as parents" (p 0,0399).

In the association between profession and item "11 offering guidance on child care", in the domain respect, nurses answered that they realize that parents receive less guidance than those reported by the physicians (p 0.0308) and physiotherapists (0.0151).

In this study, it was aimed to identify the parents' and professionals' perception about the PFCC. Data analysis allowed to verify that parents' perception is more positive than that of the health team, in most items, revealing that the family tends to be less critical than health professionals.

This pattern has been repeated in studies carried out by the author of the instrument[9] with parents with sociodemographic profile, similar to that of this study, which was performed in a private health service, revealing a tendency that needs to be better understood. It can be inferred that the family is at a time of extreme vulnerability due to the NB clinical condition, becoming frightened to reveal their perception perhaps because of fear of reprisals from the team. In addition, one might also think that parents are under impact from the situation they are experiencing and cannot even assess the care being given to their child[10].

In the study by Shields[11], as in this study, the parents' follows the same pattern of answers regarding the domains, but the average is a little lower. However, when comparing the results of the Brazilian study with the Australian one concerning the health team professionals, the Brazilian ones presented lower averages in all the domains, revealing that only sometimes they perceive the PFCC in the NICU. This fact can be explained due to the differences in the care model

provided in both units, because in this Brazilian NICU, the PFCC is not implemented yet, in a way that its principles are not perceptible in the care practice by both parents and professionals.

The barriers identified in this study in the parents' and professionals' perception can be grouped into: inclusion in care; stay during the procedures; recognition of family support sources, identification of support sources in the neonatal unit and turnover of the multiprofessional team in NICU.

In a reflection on the PFCC concept, the author ponders that the family needs to be welcomed and supported by its support network at the critical moment of illness, since one member's disease affects the whole family, intensifying their suffering because they cannot be together in the same physical space[12].

It is observed in the study that the family does not realize that professionals recognize their support sources, in a way that the principle of dignity and respect is partially practiced in this environment.

Nurses want to provide the NB with the best care and tend to perform family inclusion actions, but often work in units with policies that are restrictive to the family presence.

The care that involves technologies such as infusion pump management is practiced systematically, with courses and training. This same practice could be implemented for patient and family-centered care policy. While changes in technical care have been rapidly incorporated, the adoption of PFCC philosophy may be less desirable for other members of the multiprofessional team[13].

Strict rules that prevent parents from taking part in child care and their stay during invasive procedures do not respect parents' need to remain with their children, nor do they give them the opportunity to make a shared decision. Perhaps health professionals ask parents to withdraw from the rooms for procedures because they feel uncomfortable with their protective presence.

PFCC is pointed out as the best care model for practice[14,15], becoming a challenge to its implementation. The fact that the parents in this study do not realize that they are included in the care of the hospitalized newborn child is not characteristic of this private service. In a study performed in 20 European countries on the priority of nurses from pediatric intensive units, PFCC was the fifth

most important sources out the nine existing ones, being behind pain and sedation, clinical practices in nursing, quality and safety, breathing and mechanical ventilation.

Another study[16] which identified the attitudes and beliefs of pediatric residents about the on-duty transition of the family centered, including benefits and barriers, demonstrates the difficulty of professionals in perceiving the family[17] and their satisfaction with care, because communication with the family obtained the fifth place and parents' satisfaction with care in seventh, out of ten positions.

To satisfy parents with care and above all offering safety, the continuity of care by health team professionals is an important factor to be considered in PFCC model, because it reduces the level of parents' stress and contributes positively to the parents' experience[18].

Another aspect that parents have failed to understand about PFCC is the identification of support sources in NICU, which is to whom they can resort when they need guidance and information. A full care planning, from the moment of admission to discharge, would facilitate this aspect mainly with quality in communication, honesty, respect and availability, in order to contribute to the synergy between parents and health team professionals[19].

Care for the child should take place jointly, multiprofessional team and parents, integrating the team's knowledge with that of the parents. However, the opportunity for truly collaborative care does not happen, because the team itself realizes that the family is not included in decisions about child care. There must be greater integration among the teams, discussing care to translate them properly to the family.

A study performed with the objective of identifying strategies to improve on-duty transitions demonstrates that nurses believe that they collaborate less than physicians in their working environment, so they feel that they contribute less in case discussions[20].

Sharing information is not just talking to parents about exams and prognoses, that is to inform, share clearly and openly is to give parents voice, listen to their perceptions about the information transmitted, discuss the advantages and disadvantages of each of the actions that will be performed with the child[20,21].

When parents are included in child care decisions, these discussions promote the parents' view development, offer the opportunity for truly collaborative care, demonstrate respect for the parents' needs[17,22,23].

The evaluation of the parents 'and professionals' perception regarding the PFCC allowed us to identify the barriers that prevent or hinder the practice of this care model. Measuring care offered a notion about how the site is in question and what aspects need to be improved.

However, scholars on the theme reflect that measuring care is not enough to fulfill the family 'demands, it is necessary to deepen the knowledge of the reality experienced by each of them, giving voice to their experience[12,24].

4 Conclusion

Even in private healthcare environments there is family vulnerability, there are needs to be fulfilled and improvements to be implemented with a focus on the patient and family.

This study has brought implications for clinical practice, highlighting the need for permanent education programs in effective family care to enable professionals who already work in the area of health for the PFCC practice.

It is also necessary to invest in undergraduate courses, with the insertion of the theme in all disciplines, maintaining the focus on the patient and family.

The main path for the PFCC to happen is the collaboration between the health team and the family with empathic communication, clear and defined roles of the participation of each and the shared function, negotiation and decision.

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