

# 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

The aim was to identify the perception of Family-Centered Care from the perspective of healthcare professionals and parents of newborns hospitalized in a neonatal intensive care unit of a private healthcare hospital. A survey was carried out in a large hospital, under private law, in the city of São Paulo. Two instruments were used to measure the perception of healthcare professionals and parents about family-centered care. 102 parents and 102 professionals participated. The score in the perception of healthcare professionals and parents were low regarding the inclusion and participation of the family in care; permanence of the parents during the procedures; recognition by professionals of the sources of family support, identification of the sources of help in the unit for parents, and parents' perception of the turnover of the multidisciplinary team in caring for the newborn. The correlation of the perception of Patient and Family Centered Care is more positive for parents. In conclusion the barriers identified, referring to the domains of respect, collaboration, and support, must be overcome so that the family can be considered a partner in the care of the newborn in the neonatal intensive care unit.

**Keywords:** Family. Newborn. Intensive Care Units. Neonatal. Nursing.

### Resumo

*Com o objetivo de identificar a percepção do Cuidado Centrado na Família na perspectiva dos profissionais da equipe de saúde e dos pais de recém-nascidos hospitalizados em unidade de terapia intensiva neonatal de um serviço de saúde privado foi conduzido uma pesquisa do tipo survey, em um hospital de grande porte, de direito privado, no município de São Paulo. Utilizaram-se dois instrumentos de medida da percepção de profissionais da equipe de saúde e de pais sobre o cuidado centrado na família. Participaram 102 pais e 102 profissionais. O escore dos itens do instrumento quanto à 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 foram baixos tanto na percepção dos profissionais de saúde como dos pais. Na correlação das percepções de ambos, o Cuidado Centrado no Paciente e Família é mais positivo para os pais. Os autores concluíram que as barreiras identificadas, referentes aos domínios respeito, colaboração e suporte, precisam ser superadas para que a família seja considerada parceira no cuidado ao recém-nascido na unidade de terapia intensiva neonatal.*

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

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## 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<sup>1</sup>.

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 healthcare 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<sup>2</sup>.

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<sup>3-5</sup>. It is based on four core concepts: dignity and respect, information sharing, participation and collaboration.

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, advocated by the Sistema Único de Saúde (SUS), the Brazilian Health System<sup>5</sup> becomes a reality. The public sector has weaknesses caused by excess demand in relation to the provision of services. Whereas the supplementary and private sectors have

better resources disposable for the customer care<sup>6</sup>. 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<sup>7</sup>.

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, Brazil.

The 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 the NB admission, rounds and invasive procedures, all parents present at the NICU are invited to withdraw, waiting outside the unit. It is not allowed for grandparents or other family members to go into the NICU to be with the NB.

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 healthcare 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 healthcare 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,<sup>(8)</sup> which received the denomination Perception of Family-Parents Centered Care (PFCC) 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 healthcare professionals was analyzed using the Kappa test; 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 Kruskal 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.

## Results and Discussion

A total of 35 fathers 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 with no difficulty being in the hospital (41.2%). Most respondents have only one child (65.7%), and count on someone to help them to care for the child (57.8%), have no previous experience with hospital admissions (88.2%) and do not know the child's discharge plan (76.5%).

102 healthcare 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 ( $\pm$  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 question “6.respect to privacy and the confidentiality of information” (3,72); “5.parents considered as parents” (3.59); “1.Parents’ are welcome when they arrive at the hospital” (3.50); and “4. openness to ask questions about the treatment” (3.42). Whereas in questions, “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 question “8. provision of honest information about child care” (3.65); “15. feeling of relief about the information received” (3.57), “13. Parents understand the written informations received” (3.42); “11. Offering information for the family about the child’s care ” (3.35); “12. recognition of the name of the physician responsible for their child” (3,34); “7. Preparation for discharge/referral to other services in the community for follow-up of the child after discharge” (3,19) and “10. Family inclusion in decisions making of child’s care” (3.08). However, in item “14.Family inclusion in decisions making of child’s care” (1.77) opted for the option *never*.

Regarding the support domain, parents answered *generally* to questions “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 questions

“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 healthcare 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’ are welcome when they arrive 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 questions 7 to 13 and 15, the only exception was question “14. Family inclusion in decisions making of child’s care” which had *ever* as an answer.

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

When the perception of parents and healthcare 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 - Correlations of the perceptions of Healthcare Professionals and Parents about PFCC Model**

Variables	Parents					Health team professionals					
	Mean	Median	Min	Max	SD <sup>a</sup>	Mean	Median	Min	Max	SD	p <sup>b</sup> value
<b>Respect</b>	3.15	4	1	4	0.23	2.77	3	1	4	0.04	0.0000
q1. Parents’ are welcomed when arrive at the hospital	3.50	4	1	4	0.68	3.04	3	1	4	0.68	0.0000
q2. Inclusion of other family members	2.73	2	1	4	1.15	1.92	2	1	4	0.80	0.0006
q3. Parents stay with the child during the procedures	2.29	2	1	4	0.97	1.88	2	1	4	0.69	0.0004
q4 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
q5 Parents considered as parents	3.59	4	1	4	0.66	3.20	3	1	4	0.76	0.0002
q6., 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
<b>Collaboration</b>	3.12	4	1	4	0.23	2.65	3	1	4	0.08	0.0000
q7 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
q8 Provision of honest information on child care	3.65	4	2	4	0.53	2.99	3	1	4	0.75	0.0000
q9. Identification of support sources in the unit	2.72	3	1	4	1.27	2.73	3	1	4	0.87	0.9755
q10. Family inclusion in decisions making of child’s care	3.08	3	1	4	0.81	2.45	2	1	4	0.96	0.0000

Variables	Parents					Health team professionals					
	Mean	Median	Min	Max	SD <sup>a</sup>	Mean	Median	Min	Max	SD	p <sup>b</sup> value
q11. Offering information for the family about the child's care	3.35	3.50	1	4	0.74	2.97	3	1	4	0.86	0.0012
q12. 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
q13. Parents understand the written informations received	3.42	4	1	4	0.72	2.52	3	1	4	0.74	0.0000
q14. Inclusion of family on the child's care	1.77	1	1	4	1.08	1.95	2	1	4	0.86	0.1980
q15. Parents relief with the information received about the child's clinical conditions	3.57	4	1	4	0.67	2.50	2	1	4	0.86	0.0000
<b>Support</b>	3.06	3	1	4	0.15	2.82	3	1	4	0.07	0.0007
q16. Staff familiarity with the child's individual needs	3.38	3	2	4	0.63	2.92	3	1	4	0.81	0.0000
q17. Openness of staff to listen to parents' concerns	3.39	4	1	4	0.71	2.92	3	1	4	0.83	0.0001
q18. Identification of the same healthcare professionals caring for the child daily	2.96	3	1	4	0.79	2.87	3	1	4	0.83	0.5167
q19. Team recognition about the parents sources of support	2.50	2	1	4	1.01	2.50	2	1	4	0.79	0.9428
q20. Staff understanding the parents' concerns	3.08	3	1	4	0.90	2.90	3	1	4	0.79	0.1605
<b>General Score</b>	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, questions "4" (p 0.2331); in domain collaboration, questions "9" (p 0.9755) and "14" (p 0.1980) and in domain support, questions "18" (p 0.6167) and "19" (p 0.498) the parents' and professionals' perceptions are similar since the differences were not statistically significant.

It was concluded that there is no agreement between parents' and healthcare 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 version with a pair of variables, indicated that there was an association between age group and the question "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 question "15. Parents relief with the information received about the child's clinical conditions" (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 question "10. Family inclusion in decisions making of child's care" (p 0.0340).

Regarding the number of children under parents' care and the questions of the Brazilian PFCC version, the association is directly proportional, that is, the higher the number of children under their care, the higher the answer score is in item "10. Family inclusion in decisions making of child's care" (0.0107).

According to the significant associations between the sociodemographic data of the healthcare professionals and

their responses in the Brazilian PFCC version, the longer the working time with newborns, the lower the score in question "4. openness for parents to ask about the treatment of their child" (p 0,0015); and question "5. parents are considered as parents" (p 0,0399).

In the association between profession and the question "11 Offering information for the family about the child's care", in the domain respect, nurses answered that they realize that parents receive less orientation 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 us to verify that parents' perception is more positive than that of the healthcare team, in most questions, revealing that the family tends to be less critical than healthcare professionals.

This pattern has been repeated in studies carried out by the author of the instrument<sup>9</sup> with parents whose sociodemographic profile is 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 healthcare professionals. 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<sup>10</sup>.

When comparing the results of the Brazilian study with the Australian<sup>11</sup> observe lower averages in all the domains, revealing that the PFCC practice is not implemented in the Brazilian NICU, in the context of this research, which principles are not perceptible in the care practice by both



parents and professionals.

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<sup>12</sup>.

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<sup>13</sup>.

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 healthcare 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<sup>14,15</sup>, becoming a challenge to its implementation. In a study performed in 20 European countries on the priority of care from pediatric nurses at intensive units, PFCC was the fifth most important source out of the nine existing ones, being behind pain and sedation, clinical practices in nursing, quality and safety, breathing and mechanical ventilation.

Another study<sup>16</sup> which identified the attitudes and beliefs of pediatric residents about family centered rounds, including benefits and barriers, demonstrates the difficulty of professionals in perceiving the family<sup>17</sup> and their satisfaction with care.

To achieve parents' satisfaction with the safety of the care offered by the healthcare team, an important factor to be considered is the PFCC model, because it reduces the level of parents' stress and contributes positively to the parents' experience<sup>18</sup>.

Another aspect that parents did not perceive in the interactions with the healthcare team was their capacity to identify the parents' sources of support in NICU, and who can provide them with information and orientation about the child's care. 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 healthcare team

professionals<sup>19</sup>.

Care for the child should take place jointly, multiprofessional team and parents, integrating the professional'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.

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<sup>20,21</sup>.

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

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.

According to Bell<sup>24</sup>, take care of family is more than family centered care as it advocates knowing their strengths and challenges to deal with the demands caused by the crisis of the child's hospitalization.

#### 4 Conclusion

This study showed that parents' perception of PFCC is more positive than that of healthcare professionals.

The significant correlation between demographic variables and health professionals' perceptions was the longer the working time, the lower the score in questions 4. Openness for parents to ask questions about treatment and 5. Parents considered as parents.

The barriers identified in this study in the perception of parents and professionals can be grouped into non-inclusion of parents in NB care; non-stay during therapeutic procedures with the NB; non-recognition of sources of family support, non-identification of sources of help in the neonatal unit and high turnover of the multidisciplinary team in the NICU.

The main way for the PFCC to be implemented is the collaboration between the healthcare professional and the family with empathic communication, clear and defined roles of each one's participation and function, negotiation and shared decision making.

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