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Study of the relationship between caregivers and the family of hospitalized newborns: experience of neonatology Center -Rabat

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Abstract

Background: While in adult medicine, consideration of the patient's entourage is often a choice, it is essential in neonatology since parents are not only our main interlocutors but also often our mediators and obviously an irreplaceable support for our young babies. The objective of our study was to collect the opinions of caregivers in the family's involvement in the different care of their newborns.

Materials and Patients: This is a qualitative prospective observational study that spanned three months between December 2016 to February 2017 which took place at the Rabat Children's Hospital in the Department of Medicine and neonatal resuscitation including nursing staff.

Results: Of the 111 questionnaires distributed, 109 were returned (98%). The median age of caregivers was 26.5 [24-42] years. The female sex was represented in 79.82% of the cases. Residents and pediatricians accounted for 44.95% of the workforce and nurses 31.20%. The median years of nursing practice was 1.5 [1-15] years. Out of a total of 10 treatments, the median number of treatments for which caregivers were favorable was 4 [5-6].

Conclusion: Caregivers in all categories are generally very supportive of family involvement in patient care, but under conditions. They even feel almost unanimously that the participation of families in care is essential for patients such as newborns.

Keywords: Family involvement in care - neonatal medical and resuscitation service.

Introduction

While in adult medicine, the consideration of the patient's entourage is often a choice, it is inevitable in neonatology since the parents are not only our main interlocutors, but also often our mediators and obviously irreplaceable support for our little babies [1].The relationship that professionals develop with parents on behalf of their child is built on trust. It takes time, information, honesty and compassion. Finally, the goal is to ensure that the newborn lives in a family.

The goal is not only survival; it is the well-being and quality of life of the infant. [2]. For every family there should be someone asking, «Is there anything we can do? » As they become accustomed to the routine and environment of the intensive care unit, parents feel the

desire to participate in the care of their child and to get involved in medical decisions.

Several models promoting the presence of parents in neonatal units and their preparation for the intensive care environment have been proposed, such as the NIDCAP and COPE (creating Opportunities for parents Empowerment) programs that incorporate the Family-centered care.

The latter is defined as an innovative approach to organizing, carrying out and evaluating care, developing a partnership and mutual benefit between patients, families and caregivers. Like NIDCAP and COPE, there are other programs that encompass developmental care and behavioral approaches that equip parents by allowing them to know their child's unique characteristics (temperament, potential Development) and by teaching them to correctly interpret the signals it manifests (Mother-Infant Transaction Program, nursing Child Assessment teaching Scale). [3; 4] .

The clinical impacts of family-centered care are the subject of several studies that show the benefit of a decrease in the length of stay. [3; 5]

The objective of our study was to gather the opinions of caregivers regarding the involvement of the family in the different care of their newborns.

Materials and patients

Type and period of study

This is a qualitative prospective observational study that spread over 3 months between December 2016 to February 2017.

Place of study

The study took place at the National Reference Centre for neonatology and Nutrition, which is a center located on the ground floor of the Rabat Child Hospital. Our Centre's current hospital capacity is estimated at 55 beds divided into three units:

-A 12-bed medico-surgical Neonatal resuscitation unit, providing assisted ventilation and the various acts of resuscitation essential for life-saving.

-An intensive care and post-resuscitation unit with 11 beds providing the various urgent care and monitoring outside the mechanical ventilation.

-A standard care and rearing unit of 32 beds equipped with a room to receive the mothers who are breastfeeding their baby, recently arranged.

There are two units in the delivery room of Souissi maternity. In addition to its units, the center provides a day-hospital activity and has an emergency, functional area 7 d/7 and 24h/24.

Study Population

Inclusion criteria: All the service providers present during the study were included: general practitioners, pediatricians, and residents, medical students in internship, childcare students and nursing staff.

Exclusion criteria: All caregivers who refused to participate in the study were excluded from the study

Variables collected: The opinion of the caregivers was assessed by a questionnaire-Information concerning the caregiver: Age, sex, seniority, function.

-care for which the caregiver was favorable to be carried out by a family member,

-Free Opinion with personal remarks on the participation of families in care.

Ethical considerations

The Protocol of the study was submitted to the Ethics Committee of the Faculty of Medicine and Pharmacy of Rabat for approval

Statistical analysis

Statistical analysis was performed using SPSS software version 13.0 .Quantitative variables were expressed in median with quartiles or on average ± standard deviation, and qualitative variables in strength and percentage. The student test and the Chi 2 or the exact Fisher test were

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used respectively for the univariate comparison of quantitative variables and qualitative variables with a degree of significance $p < 0.05$

Results

Of the 111 questionnaires distributed, 109 were returned (98%).

Characteristics of caregivers (table 1)

The median age of caregivers was 26.5 [24-42] years. Female sex was represented in 79.82% of cases. Residents and pediatricians accounted for 44.95% of the staff and paramedics (nurses, caregivers) 31.20%. The median of years of practice of nurses was 1.5 [1-15] years

Care for which caregivers are favorable (table 2).

The treatments for which the caregivers were most favorable were among other things the breast, the feeding with gastric tube or bottle, the stimulation of the orality, the nursing, the accompaniment of newborns for various exams: EEG, magnetic resonance imaging or other additional examination. For technical care, 17.1% of caregivers were favorable for the family to put or remove oxygen goggles, check the position of the gastric probe, take the temperature.

Opinion of caregivers on the different aspects of care provided by the family was generally positive.

The aspects for which there was a quasi-unanimous agreement (96.8%; n = 102) were respectively "the involvement of families in patient care is useful" and "family involvement in Care decreases the anguish of family members".

Free Opinions of Caregivers

Opinions differed according to the categories of caregivers. The opinion that came out most was:

- For medical students and childcare students: there is clearly a complementarity between caregivers and the family, but they insist on the importance of training families in the rules of hygiene
- for Nurses: the participation of families in care is important but under conditions, in particular the fact that it respects the caregivers and that it is educated about the care that it must notachieve.
- for pediatricians and residents: family participation in care is essential and beneficial but must beframed

Comparison of caregivers (table 3)

The comparison between the different categories of caregivers in terms of the number of care provided by the families of patients for whom they are favorable has made it possible to highlight a statistically significant difference between physicians and nurses ($p = 0.001$).

Table1. Caregiver characteristics (N = 109)

Characteristics	Caregiver population N=109
Age (years) [a]	26.5 [24-42]
Sex [b]	
Female	87(79.82)
Male	22(20.18)
Functions [b]	
Doctors*	49(44.95)
Nurses	34(31.20)
Bachelors in Childcare	7(6.42)
Medical students	19(17.43)
Years of practice [a]	
Nurses	1.5 [1-15]
Caregivers	2.3 [2-7]

*:pediatric residents, The values are expressed in median and quartiles (a) or in Number and percentage (b)

Table 2: Care for which caregivers are favorable (N = 109)

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Type of care	Values
Breastfeeding	109 (100)
Bottle feeding	92 (84.44)
Nursing and hygiene	82(75.22)
Feeding to the gastric probe	57 (52.29)
Stimulation of Orality	102(93.58)
Taking the temperature	88 (80.73)
Laying and removing oxygen goggles	75 (68.81)
Urine Collection	55(50.46)
Stimulation of Transit	62 (56.88)
Nebulisations	43 (39.46)

Values are expressed as effective (%)

Table 3. Categories of caregivers and family care for which they are supportive.

caregivers	effective	Favorable activity	*p*
Residents	30	6.8±2.2	0.83
Pediatricians	19	7±1.9	
Doctors*	49	7.8±2.1	**0.001**
Nurses	34	5±3,1	
Doctors	49	7.8±2.1	0.3
Carers	7	8±7	
Nurses	34	5±3.1	0.5
Carers	7	6±2.1	

The values are expressed on average and standard deviation, *: Residents and pediatricians.

Discussion

In our study the majority of caregivers were in favor of the participation of the family members in the care of hygiene and comfort as well as the food. They were more reluctant to perform invasive care such as bronchial aspirations, CPAP manipulation... They want families to do the care in their presence after they have been trained.

Studies of the scientific literature evaluating the opinion of caregivers on the participation of families in the pediatric community in general and neonatal in particular are few. Our work is a first nation- wide experience.

The number of treatments for which the nurses were favored was lower than that of the doctors: out of 10 treatments considered, the doctors were favorable for 7.1 ± 2.1 and the nurses favored 5 ± 2.1 types of care; p = 0.001. This difference is explained by a feeling of mistrust on the part of the nurses who are responsible for the vast majority of the acts and on the other hand by a sense of fear seeing the attribution of certain stains to the family.

Some nurses advanced as a rejection argument: if the family has to take part in the care, it would be better if we stayed at home because it would be impossible to work in their presence.The involvement of parents on the part of medical students and caregivers would relieve the burden of work on the medical nursing side.

In Western countries, qualitative studies with collection of the opinions and beliefs of families and caregivers on this participation in care showed its relevance and importance, and have led to its framed implementation in various units of hospitalization. [2.6.7. 8.9]. But in practice the caregivers leave little room for the families, the arguments advanced are • The risk of increasing the suffering of the relatives • The decrease in the quality of care if not performed by professionals • Families by their presence can cause congestion hindering the proper organization of care.

Conceptually the idea of family participation in care is accepted, it is poorly applied because it seems difficult to achieve in practice and it is not perceived as a substantial help for caregivers

Potential beneficial effects for the patient are evoked but rarely evaluated in an objective manner:

- Establishing a close relationship with care promotes better information about the patient's clinical situation and gives him moments of intimacy with lovedones.
- Basic care such as toilet, touch or development care allows non-verbal communication and provides additionalcomfort.
- Care and decisions are more appropriate to the patient's situation, through closer communication between caregivers and families.

Opinion surveys of caregivers show that this integration of families can lead to problems:

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- Increased workload by a need for family support
- Loss of concentration of caregivers that may be distracted by the presence of visitors.
- The onset of conflicts with certain families who are not listening to caregivers, their duty and needs, or disagreements about therapeutic decisions or procedures to be applied. These negative effects do not appear to be significant in our experience [10].

On the other hand beneficial effects are reported: the presence of families allows the caregivers to better communicate with the relatives and thus to better apprehend the personality and the wishes of the patient. It improves the confidence of families in the team and promotes the work of caregivers in their eyes. It promotes communication between caregivers and improves relationships in the team.

Conclusion

This action seems to us even more important in our countries where there are few human resources in neonatology. It is a question of developing a specific program where parents and caregivers will collaborate for better care of newborns.

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