



Family involvement in the care of hospitalized newborns: Experience Neonatal Center of Rabat

L. Drame, G. Bouazza, F Z .Laamiri, A. Barkat

¹Neonatology and Neonatal resuscitation reference Center -Rabat child hospital

^{1,2}Maternal-child Couple Health and Nutrition research team

Faculty of Medicine and Pharmacy of Rabat, University of Mohammed V-Rabat

Correspondence Author: L. Drame, Faculty of Medicine and Pharmacy of Rabat, University of Mohammed V-Rabat

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Abstract

Background: Neonatal departments are designed to treat premature infants, low birth weight or presenting pathology during the neonatal period. Parents of babies hospitalized at birth are faced with a difficult situation or they do not feel "really" parents.

The objectives of this work were to make an inventory of the spontaneous participation of the family in the care of neonatal medicine and neonatal resuscitation.

Material and methods: A three-month prospective observational study including the Families of newborn babies hospitalized. The number of care provided by families was.

Results: 421 neonates were collected with a median age during hospitalization of 0 days [0.1], mean weight was $2580 \pm 1065g$, with a median hospital stay of 5 days[3-10]. The main diagnoses were respiratory distress associated with prematurity (36.8%) and neonatal jaundice (20%). Most mothers participated (96.6%) with no difference in educational attainment with an average age of 29.66 ± 7.17 . Breastfeeding and participation in the diet were practiced by 76.4% of mothers. Participation in care as stimulation of transit, regular decompression of the abdomen was made by 8.1% of moms mostly by those who had their newborn hospitalized in the low birth

weight unit ($p = 0.001$). The skin to skin was performed by 68 mothers either (20.5%) but needs to be explained and assisted by professionals.

Conclusion

Several elements supporting the involvement of parents in the care of their child have been clearly identified. They are essentially based on information and education of parents, training and support of healthcare teams, provision of appropriate psychological and social support.

Keyword: Participation-family-care-hospitalized-newborn-babies.

Introduction

The philosophy and environment of care in medical and neonatal resuscitation services have contributed to diminishing the role of families in the care of hospitalized newborns unlike other pediatric services.

A renewed interest in their contribution and involvement is, however, observed with the development of a new approach to family-centered care for mutual benefit between patients, families and caregivers.

The involvement of the family in the care of hospitalized patients is integrated into what is called "patient-centered care and family (SCPF)" or "patient-and family-centered care" of the Saxon, a concept that is multidimensional. [1]

This concept is defined as "An approach to health care planning, execution and evaluation that is based on mutually beneficial partnerships between caregivers, patients and families ". [1] This concept is encouraged by the scientist societies (Adults and Pediatric).

Thus, the families of hospitalized patients, who have long played a passive spectator role of care and whose presence was tolerated or even suffered by caregivers, should no longer be considered as guests but as partners in the Care process [2.3].

CUPE are considered a three-legged stool with one foot representing the caregivers, another representing the patient and the third the family. Each foot must be as important as the other in order to optimize the satisfaction of the three protagonists and the evolution of the patient [4].

Beyond these approaches, aiming not to separate a newborn from his parents, several models were evaluated to promote the presence of parents in neonatology units. One of the most interesting and complex is integrated into the NIDCAP approach (Neonatal individualized developmental care and assessment Program Individualized Neonatal evaluation and Development Care Program) [5], inseparable from the approach of family-centered care. The NIDCAP programmed brings together the concepts of family-centered development and care by considering parents as the principal coregulators of child development [5] the care to be delegated by the families must, however, be Framed and Elementary: food, hygiene, massages, comfort, eye care, distractions [6.7.8]. For more technical care (tracheal aspiration, positioning, handling of equipment...), the recommendations are to propose them to the family members when they enroll in a therapeutic education programmed in order to guarantee the safety of the Patient and to limit the risk of tension with the healthcare team T -The first is respect and dignity. It is the responsibility of caregivers to listen to patients and their

families, and to accompany them in their wishes whenever possible.

-sharing of information is the second component. Caregivers must provide objective and unbiased information that must be delivered at the level of understanding of the patient and the family. For example, effective communication with patients and their families on the expected benefits of prescribed drugs and their potential adverse effects helps to reduce poor therapeutic adherence [9].

-The third is the involvement of the patient and the family in decisions and care. It must be encouraged and supported.

-Finally, collaboration is the last essential component that must be included according to an individual basis and at the institutional level. The Institute for Patient-and family-centered Care considers that establishing a family advisory council with representatives in key institutional committees (such as the Quality Improvement Committee) is an important step in The evolution of the culture of the institution and the acceptance of the concept of SCPF. The Institute for Patient-and Family-centered Care [4] identified four essential components for SCPF:

The concept of SCPF, both in children and adults, is now part of the standards and requirements of international health regulatory agencies that consider its implementation in care structures to be fundamental to ensuring Safety, quality and fairness in patient care [10-11].

Parents are subjected to a stressful situation, so it is difficult for them to get involved in their child's care, especially since their involvement in care has never been explored in a national context. In this regard, we are interested in this issue by proposing this work which is mainly aimed at making a state of place on the participation of parents of children hospitalized in a service of medicine and neonatal resuscitation.

Materials and patients

Type and period of study: This is a prospective observational study that spread over 3 months between December 2016 and 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.

Inclusion criteria: All newborns hospitalized in the service were included.

Exclusion criteria: Excluded were those whose parents refused to participate in the study and patients who had stayed less than 24 hours.

Methods and instruments and data collection in order to identify all aspects related to our research theme, our study consisted, initially, of the recruitment of newborns to their admission, and in a second phase the development of a An operating record that collected information on moms and newborns

The data listed concerned:

-Demographic and socio-economic characteristics (Age, social situation, level of education, provenance, marital status). The woman was considered non-illiterate when

she did not know how to write or read French.

-Health and obstetric characteristics (attendance, parity, medical and surgical history, pregnancy monitoring, delivery pathway). A pregnancy was followed when the woman had observed at least 3 prenatal visits. The history was positive in the face of all clinically apparent symptoms in women and negative in the absence of symptom.

-Neonatal and clinical characteristics at admission (age, sex, reason for hospitalization).

The evolutionary parameters, i.e. the length of hospitalization in the different units, were also collected-the different types of care provided by the family: the setting up, the stimulation of the orality, the stimulation of the transit, The nursing, the temperature taking, the alert of the caregivers, the administration of the medications by oral, the laying and the withdrawal of the oxygen goggles, the contact skin has skin, the duration of the parental presence. For technical care, families have been educated.

Statistical analysis

Statistical analysis was performed using SPSS software version 13.0; Quantitative variables were expressed in median with quartiles or on average \pm standard deviation, and qualitative variables in strength and percentage.

The Student T-Test and Chi 2 or Fisher's exact test were used respectively for the univariate comparison of quantitative variables and qualitative variables with a threshold of significance < 0.005

Ethical Considerations

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

Results

During the study period, 640 newborns were surveyed, 219 of which were less than 24 hours, only 421 newborns meeting our criteria were analyzed.

Maternal characteristics (table I)

The average gestational age was 36.45 ± 3.06 with a positive infectious history in 40.4% of cases. Newborns were born of a pregnancy followed in 47.27% with an urban origin in 67.22%. The most predominant delivery route was the high way (67.5%) with a single pregnancy in 89.55%. The absence of any level of education (illiteracy) among parents was noted in 41.33% of the neonatal and clinical characteristics of admission (table II). The median age was 0day [0-1]. Male sex was represented in 53.4% of cases. The main diagnoses were dominated by respiratory distress associated with prematurity (25.18%) and neonatal jaundice 19.95% (table II). Compared to hospitalization, 147 (34.92) % of newborns were hospitalized in the neonatology unit; 100 (23.75%) in the intensive care unit; 149 (35.39%) in the resuscitation Unit and 25 (5.94)% in the low birth weight unit. The different types of care provided by the family to the newborn (table III). The majority of mothers participated in the care (96.6%) without any difference between education levels with an average age of 29.66 ± 7.17 . Almost 70% were primiparous. They were present mostly in the day (70.55%) with permanent guidance in 6.65% of the cases.

The breastfeeding and participation in food was practised by 72.44% of mothers; 15.91% properly administered the drugs according to the predetermined protocols. 9.03% posed and removed oxygen goggles as needed. One mom out of two was nursing.

The participation in care of type transit stimulation, regular decompression of the abdomen was made by 34 (8.07%) of the mothers skin a skin was realized by 68 moms either (16.15%) but needs to be explained and attended by professionals.

95 Moms or 22.57% alerted caregivers to actions that exceeded their competence especially at the end of Phototherapy sessions.

213 (50.59%) participated in accompanying their babies for the various balance sheets (the realization of the electroencephalogram, Magnetic resonance imaging, routing and recovery of the balance sheets in the laboratory).

Participation in care according to the different Hospitalization units (table IV)

The analysis concerned the area of parental involvement and highlighted the ambivalent emotions of the parents in the first aid to their child and their willingness to participate in care even if they are technical and complex. Breastfeeding and dietary participation was performed by 76.4% of moms without any predominance according to the hospitalization unit ($P = 0.06$). Participation in transit stimulation-type care, regular abdominal decompression was made by 8.1% of moms mainly by those who had their newborns hospitalized in the low birth weight unit ($p = 0.001$). These moms in addition to breastfeeding stimulated orality, did the nursing daily, took the temperature of their babies and subsequently communicated the respective results to the caregiving staff. They properly administered medication per OS according to the prescribed protocols and collected urine for examination cases.

They posed and removed the oxygen goggles as needed. Skin was made by 68 moms either (16.15%) but needs to be explained and attended by professionals. It was mainly carried out in the unit of low birth weights compared to other units ($p = 0.001$).

Table 1: Maternal characteristics

Variables	Mother Population N= 421
Gestationnel Age ^a	36.45±3.06
Maternal Age ^a	29.66±7.17
Martial Status^b (n=421)	
Married	411(97.62)
Single	10(2.38)
Pregnancy follow up^b	
No	222(52.73)
yes	199 (47.27)
Pregnancy Type^b	
Single	377(89.55)
Twin	40(9.50)
Triple	4(0.95)
Delivery route^b (n = 421)	
High Way	137(32.54)
Low Channel	284(67.46)
Infectious history^b (n = 419)	
Positive	170(40.38)
Negative	284(67.46)
Living Environment^b	
Urban	283(67.22)
Rural	168(32.78)
Social coverage^b (n = 421)	
No	187(44.42)
Ramed	163(38.72)
Mutual	71(16.86)
Educational level^b (n = 419)	
Non-Literate	174(41.33)
Primary	105(24.94)
Secondary	121(28.74)
Higher	19(4.51)

Values are expressed on average ± standard deviation (a) or number and percentage (b)

Table 2: Distribution of study population by clinical and neonatal characteristics (N = 421)

Variables	Newborns N=421
Neonatal characteristics	
Newborn Age (Day) ^a	0 [0 – 1]
Birth weight (g) ^b	2580±1065
Hospital Duration (day) ^a	5[3-10]
Sex ^c	
Male	225(53.44)
Female	196(46.56)
Clinical characteristics ^c	
Respiratory distress	57 (13.54)
Prematurity	106(25.18)
Maternal-Fetal Infection	48 (11.40)
Jaundice	84 (19.95)
Intrauterin Growth delay	27(6.41)
Perinatal Asphyxia	37(8.80)
Surgical pathologies	17(4.03)
Other	45(10.69)

a: Mean ± sd, c: number (%), b: median [quartiles].
Others: Macrosomies, Trisomies

Table 3 Distribution of the neonatal population according to the care provided by the family

Characteristics	Newborns N=421
Type of care^a	
Breastfeeding	305 (72.44)
Stimulation of Orality	24 (5.70)
Stimulation of Transit	34 (8.07)
Nursing	218 (51.78)
Temperature taking	61 (14.49)
Caregiver Alert	95 (22.57)
Administration of oral medications	67 (15.91)
Laying and removing oxygen goggles	38 (9.03)
Skin Skin Contact	68 (16.15)
Parental presence ^a	
Day	297(70.55)
Day and night	90 (21.38)
Night	6 (1.42)
Parental accompaniment	28(6.65)

^aThe values are expressed in numbers and percentage

Table 4: Participation in care according to the different hospitalization unit.

Variables	neonatology	USI	REA	UFPN	p
Feeding^a					0.06
Breastfeeding	128(42)	73(23.9)	87(28.5)	17(5.6)	
Bottle	11(45.8)	2(8.3)	11(45.8)	0(0)	
type of care provided by the family^a					
Stimulation of transit	6 (17.6)	4(11.8)	10(29.4)	14(41.2)	0.01
Nursing	82(37.6)	46(22.1)	73(33.5)	17(7.8)	0.01
Temperature taking	16(26.2)	14(23)	16(26.2)	15(24.6)	0.01
Caregiver Alert	34(35.8)	15(15.8)	30(31.6)	16(16.8)	0.01
Laying and removing oxygen glasses	7(18.4)	5(13.2)	18(47.4)	8(21.1)	0.01
Skin to Skin	14 (20.6)	18(26.5)	15(22,1)	21(30.9)	0.01

^a :The values are expressed in terms of strength and percentage. USI: Intensive care Unit, Rea: resuscitation unit, U. NPF:

Low birth weight unit. $p < 0.05$ is considered significant.

Discussion This observational study evaluating the involvement of families in the care of hospitalized newborns represents a first experience in a national medical and neonatal resuscitation service. Analysis of our results revealed that mothers were actively involved in the care of their newborns without any difference in marital status ($p = 0.5$). Almost all moms practiced the breastfeeding and participation in food without any difference depending on the hospital units. In our environment, the refusal of families to participate in care was observed when the patient had severe comorbidities or chronic pathology, this is explained by the clinical condition of the newborn, especially in the resuscitation unit or the most Often these newborns are intubated ventilated. The care provided by the parents is basic care, certainly simple to realize but indispensable to the good development of the baby, they also aim to establish a bond of attachment between the mother, the father and the child and to strengthen the exercise of the parenting role In the neonatology and resuscitation units. The involvement of

the family in Caregiver alert type care, temperature taking, nursing, was practiced more in our low birth weight unit, this difference is due to the fact that are hospitalized in this unit all Premature birth weight less than 1500g stable on all planes with permanent parental guidance while learning and assisting moms on the different care that their newborns should receive. The mothers of these newborns in addition to the breast stimulated orality, did the nursing daily, took the temperature of their babies and subsequently communicated the respective results to the caregivers. They were properly administering medications according to prescribed protocols and collecting urine for examination cases. They posed and removed the oxygen goggles as needed. This explains their greater involvement in care compared to other hospital units in our case. It is also noted that the practice of skin has been made more by her moms; This difference is due on the one hand to the clinical condition of the newborns hospitalized in the other units and on the other hand to the permanent accompaniment of its mothers with their babies. Strategies based on breastfeeding support, skin-to-skin, parenting support allow the baby's environment to be adapted to its neurobehavioural development, which is why it would be necessary to open our services to Parents in order to harmonise the care of our little babies. The presence of parents in neonatology and resuscitation is too often limited. The opening of neonatology services to parents remains variable, in Europe France occupies an intermediate position with just over 50% of the units which allow the presence of the parents 24 hours/24, without any restrictions [5], this is not the case in Our context.

This involvement of parents in the care in our study gave rise to contradictory emotions (joy, stress, anguish). Most often they wanted active participation, even for complex care (feeding by probe...). The parents felt surrounded and encouraged by the health care team but they wanted more

explanations and more implications; Contrary to a French multicentric survey conducted by the Famirea group in patients families Hospitalized [12], the relatives expressed their desire to participate in care only in one-third of the cases; the motivation of parents in our context is a point to be exploited in order to reduce parental stress and to establish the rather possible emotional bonds Babyparents. A study conducted in France showed that 96% of the families reported in a questionnaire that they were volunteers for active participation in care [13], but few spontaneously asked to be able to do so, only 14% of the relatives in this study Spontaneously care or ask the caregivers for permission to do so. The willingness to participate in care increased when the stay extended. In Morocco, this involvement of families in care seems to have always been necessary for hospitalized infants and is naturally part of the mode of operation. However, it has never been evaluated at the national level and deserves to be found in other pediatric units. This difference with the industrialized countries is probably a matter of multiple cultural, financial and organizational factors. Some rare experiences in low-resource countries have been reported as an English nurse in an internship in a pediatric hospital in Sri Lanka where she found, contrary to practices in her country, that all non- Techniques were made by the family. 14 While improving the communication of families with caregivers through specific organizations and tools allows for a reduction in psychological disorders among relatives [12], family participation in care has not been assessed as a Isolated parameter to improve family support. Positive effects are highlighted in many surveys. Participation in care is one of the basic needs of families identified by Motlter [15]. This commitment is one of the items that improve family satisfaction.

Conclusion

This indispensable work, complementary to that of professionals is poorly recognised, little visible, little

valued. Several elements supporting parental involvement in the care of their children have been clearly identified. They are based mainly on the information and education of parents, the training and support of health care teams, the provision of appropriate psychological and social support.

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