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HEALTH GAINS WITH THE CUIDAR+ PROJECT TRAINING OF PARENTS OF PREMATURE OR LOW BIRTH WEIGHT INFANTS

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ABSTRACT

Objectives: To characterize the parents and newborns who participated in the CUIDAR+ Project; Assess the health status of newborns and their adaptation to the family environment; Identify the difficulties in the home care process; Assess parental skills.

Methodology: Descriptive study with a quantitative and qualitative approach. As instruments in data collection, the Observation technique, clinical processes and questionnaire were used. The sample consisted of twelve parents and fourteen newborns. Participants received a home visit from December 2017 to April 2018, between the 3rd-7th day after discharge. The visit took place in conjunction with Primary Health Care, continuing the follow-up in the 2nd and 4th weeks.

Results: During the visit, 83.3% of the parents pointed out the newborn's intestinal functioning as the main difficulty. The most representative category in the narratives was the adaptation to the new family dynamics, referred to as the main difficulty by 9 families.

Conclusions: The Project had an impact on visible organizational result variables in the quality and productivity of the services provided. Consequently, it has achieved gains in client health, in terms of satisfaction, autonomy and safety in care, with a reduction in adverse events and complications, creating health value.

Descriptors: Prematurity; home visit; empowerment; health gains.

INTRODUCTION

The interference of the New Public Management (NPM) in the health sector introduced the idea of a "client" of the public service. The concept, as the center of new policies, came to command decisions, emphasizing competitiveness, economic rationality and enhancing the results obtained[1]. The model brought new values focused on quality, efficiency and productivity, in addition to ethics and proximity to the citizen[2-3].

In a visionary perspective of quality, healthcare organizations align the strategic focus defined by the mission and values. Thus, they meet the expectations of clients[4], as a result of reflection on practices, raising the concern with satisfaction and the final results in health[5].

According to the World Health Organization[6] the babies who were born alive before 37 weeks are called premature. Many of these babies are born with a weight suitable for gestational age (GA). However, if the birth weight is below the ten percentile or two standard

deviations below the average, they are considered Light for the Gestational Age (LGA). Even if they are term, they have a higher risk of developing complications in the neonatal period[7].

Prematurity is currently recognized as a Public Health problem, so assistance to premature infants at home should guarantee access, equity and integration of care, constituting one of the great challenges of NPM. In the Évora district, home visits (HV) are carried out by primary health care nurses (PHC) until the fourteenth day of life. Premature or low-birth weight newborns (NBs) still hospitalized during this period do not have this visit, reflecting on the morbidity rate. Corroborating this fact in the diagnosis phase of the situation, it was found that in the last 5 years the average rate of readmissions of these newborns in the period of 0-3 months after discharge was 66.91%, including episodes of urgency and hospitalizations.

The complex process of premature birth directly affects the family structure, which can lead to a crisis. The term parenting can be defined as a maturation process of psychoaffective restructuring, implying increased responsibilities[8]. Parenting is considered a transition of a developmental nature that implies changing roles, relationships, expectations and skills, so the client has to incorporate new knowledge[9].

Nurses are the key to the identification and understanding of these phenomena, providing for nursing actions within the transition process. They act as "facilitating" agents, assuming decisive roles in supporting parents/family and in post-discharge follow-up. Thus, they influence response patterns, through the mastery of new competences and the reformulation of identities[10].

From this alignment of interests, the CUIDAR+ Project, entitled "Empowerment the parents of premature or low-birth weight newborns", was created. Its purpose is to facilitate the transition from hospital to home. It aims to improve the integration of the newborn in the family, to promote parenting skills and to anticipate risk situations. It contributes to the reduction of morbidity. The implementation of the Project requires the evaluation of its quality in health, using indicators based on the concepts of structure, processes and results as the final product of the care provided, considering value in health, the satisfaction of standards and expectations[5]. The implementation of the visit designed for comprehensive actions involving different levels of care, is intended to be an indicator of quality and simultaneously an indicator of health production, improving the performance of the organization and the satisfaction of its clients[11].

In this segment, the objective of the present study was to: a) Characterize the parents and newborns who participated in the CUIDAR+ Project; b) Assess the health status of newborns and their adaptation to the family environment; c) Identify the difficulties in the home care process; d) Assess parental skills.

METHODOLOGY

This is a descriptive study with a quantitative and qualitative approach.

The Direct Descriptive Observation technique was used, opting for participant observation. This technique allows the qualitative investigation of phenomena in naturally occurring contexts. It makes it possible to collect data on the characteristics of the participants, to identify specific actions and behaviors and to document physiological and psychological processes[12].

The inclusion criteria for conducting the visit were as follows: Parents and newborns with GA <36 weeks or with birth weight <2000gr, admitted to the neonatal intensive care unit (NICU) with residence in the district of Évora.

The sample consisted of 12 parents and 14 newborns (two cases of multiple pregnancies) who were discharged from December 2017 to April 2018. A visit was made to each family between the 3rd and 7th day after discharge, constituting the most critical period, confirmed by data analysis at the stage of diagnosis of the situation.

The visits were scheduled through telephone contact with the Health Center or Family Unit (FU) in the area of residence, where information on the clinical history of the newborns was shared.

Being a planned and structured observation, a matrix with evaluation parameters was created. Regarding the Newborn: Health status and adaptation to the family environment. Regarding parents/family: Emotional assessment; Binding; Autonomy; Adaptation to parental role; Family support.

To the observation technique, two data collection instruments, clinical processes and a questionnaire applied to parents at the end of the visit were added, composed of open and closed answer questions using the Likert scale. The main open questions were: What does it mean for you to be parents of a premature/low weight baby? What are the difficulties/concerns felt in care in a family context? Do you consider this visit important? In your opinion what issues/themes should be addressed? Did the visit take place according to your expectations?

To preserve the anonymity of the participants, mothers were identified by the letter "M" and the fathers by the letter "P" followed by a number that corresponds to the chronological order of the visits. After collecting data related to the opinions of parents/family, an approach to the qualitative method of thematic content analysis, proposed by Bardin[13], was carried out. After reading the answers, they were grouped into specific categories by similarities of meaning. Quantitative data were analyzed and treated using descriptive statistical analysis.

All the Ethical Principles for research contained in the Declaration of Helsinki were complied with, including authorization for the implementation of the Project and the respective study, approved under Opinion no. 47/2017.

PRESENTATION, ANALYSIS AND DISCUSSION OF RESULTS

The values presented in table 1 show that 50% of mothers belong to the age group of 31-35 years old, while the majority of parents (41.8%) were between 36-40 years old. It is the mothers who hold the most academic qualifications, about 67% with secondary education, with a 25% higher education degree and 16.7% with the 2nd cycle (Table 1).

Table 1 – Distribution of Maternal and Paternal Variables.

Groups	Maternal N(%)	Paternal N(%)
Age		
21-25	2(16.7)	1(8.3)
26-30	1(8.3)	1(8.3)
31-35	6(50)	3(25)
36-40	1(8.3)	5(41.8)
41-45	2(16.7)	1(8.3)
>45	0(0)	1(8.3)
Academic qualifications		
≤ 9.º Ano	1(8.3)	6(50)
> 9.º-12.º Ano	8(66.7)	3(25)
Teaching degree	1(8.3)	3(25)
Master degree	2(16.7)	0(0)
Professional situation		
Employed	11(91.7)	12(100)
Unemployed	1(8.3)	0(0)
Total	12(100)	12(100)

It should be noted that 57.1% of mothers are primiparous and need more support in the transition process. Regarding the type of delivery 57.1% was performed by cesarean section, which is justified by the emergency situations at the origin of premature births.

In relation to the newborns, it can be seen that the vast majority (71.4%) was born with GA less than 34 weeks and 35.7% (5) was born weighing less than 1500gr. The length of stay was over 30 days in 28.6% of cases and 14.3% of newborns remained hospitalized for more than 60 days. About 64% of neonates were discharged before the 37 weeks of corrected GA, thus demonstrating the importance of conducting the visit to assess parental skills. Of the 14 newborns who participated in the study, 71.4% (10) needed ventilatory assistance, among which 21.4% (3) were connected to the ventilator, who, due to their vulnerability, were the ones who registered the most complications (table 2).

Table 2 – Distribution of Neonatal Variables.

Groups	Newborn N(%)
Gestational age at birth	
26s-29s+6d	2(14.3)
30s-33s+6d	8(57.1)
34s-36s+6d	4(28.6)
Birth weight	
<1000gr	1(7.1)
1500-1499gr	4(28.6)
1500-1999gr	5(35.7)
2000-2500gr	3(21.4)
>2500gr	1(7.1)
Ventilatory assistance	
Non-invasive (CPAP)	7(50)
Invasive (ventilator)	3(21.4)
No assistance	4(28.6)
Corrected age at discharge	
35s-36s+6d	9(64.3)
≥ a 37s	5(35.7)
Hospitalization Time	
≤ a 30 days	10(71.4)
31-60 days	2(14.3)
>60 days	2(14.3)
Breastfeeding at discharge	
Exclusive breastfeeding (EBF)	1(7.1)
Breastfeeding and artificial milk	5(35.7)
Does not breastfeed	8(57.1)
Total	14(100)

Results of the Observation

In the 12 visits made, 14 newborns, 12 mothers and 8 fathers were observed in a family context (table 3). The 14 NBs were evaluated with health status considered normal, given their clinical history, that is, without severe pathology and with good adaptation to the family environment. On the day of discharge, 57.1% of mothers no longer breastfed, with the EBF rate being only 7.1%, given the fragility of these newborns, this practice was encouraged during visits and we managed to increase the rate to 16.7%.

It was found that mothers are always the main caregivers, corroborating the results with previous studies, reaffirming that caring is still a task culturally delegated to women, especially when it requires specific monitoring[14-23]. All mothers mentioned receiving family support in the care of the Newborn, mainly given by the figure of the maternal parent (*i.e.*, the NB's grandmother) in 75% of the cases. This help as a reference for safety and experience of previous generations, contributed to the maintenance of the emotional balance of the puerperal woman and to the identification of the parental role[15-21].

In the first days after discharge, parents' concerns are focused on the continuity of care the newborn received during hospitalization, protection against infections and the early identification of possible complications[14-15,17,20-22]. During the visit 83.3% of the parents pointed out the newborn's intestinal functioning as the main difficulty/concern. On the other hand, 75% expressed doubts about breastfeeding/feeding, about 67% reported adequate temperature and clothing and 41.6% mentioned changes in the newborn sleep pattern.

After the visit, telephone contacts were established with the FU and a second visit was scheduled for 9 newborns/families. The 12 families were monitored during the 2nd and 4th weeks after discharge through telephone contact (Table 3).

Table 3 – Summary matrix of observed data.

Parameters	Roles	Indicators
Emotional assessment	Mother	• Calm (2);
		• Anxious (8);
		• Tired (4);
		• Afraid (9).
	Father	• Calm (6);
		• Anxious (2);
		• Afraid (3).
Link with the Newborn	Mother	• Good interaction mother-NB (12).
	Father	• Good interaction father-NB (8).
Parents' autonomy about the newborn	Mother & Father	• Care autonomy (12);
		• Understading NB's crying (9).
Difficulties and/or concerns expressed	Mother & Father	• Intestinal fuctioning (10);
		• Feeding (9);
		• Room temperature (8);
		• Clothing (6);
		• Choking (5);
		• Night sleep (5);
		• Skin and oxygen therapy (1).
Lessons taught	Mother & Father	• Alarm signals (12);
		• Sking hygiene and hydration (12);
		• Strategies for intestinal fuctioning (10);
		• Breastfeeding/feeding (9);
		• Infection preventions (8);
		• Adequate temperature and clothing (8);
		• Degassing maneuvers (5);
		• Strategies for a better night sleep of the NB (5).
Adaptation to parental role	Mother & Father	• Mother as the main caregiver (12);
		• Participation of the father in the care (11).
Family support	Mother	• In the NB care and house chores (12);
		• Given by the mother (9);
		• Mother-in-law (2);
		• Sister (1);
		• Aunt (1);
		• Grandmother (1).
Health status	Newborn	• Normal vital signs (14);
		• Weight gain (11);
		• Skin features: flush (11); Slightly flush (1); Pale (2); Hydrated (14);

Table 3 (cont.) – Summary matrix of observed data.

Parameters	Roles	Indicators
Health status	Newborn	• Type of feeding: Exclusive maternal breastfeeding (2); Breast and artificial milk (4); Artificial milk (8);
		• Proper posicioning (14);
		• Adequate clothes (14);
		• Suitable cot and bedding (14);
		• Adequate house conditions (14).
Adaptation to the family environment	Newborn	• Good adaptation in the family environment (14);
		• Good interaction between parents/family (14).

Results related to the Questionnaire

1. Adaptation to parenting in the context of prematurity

It was verified by the analyzed responses that the parents are fully aware of the fragility of the NBs, mostly referring to the perception of the need for special care (10), describing parenting in this context as an adaptation phase, of trust (7), assuming the concern (9), great representativeness, followed by fears (6).

The main difficulties/concerns felt by the parents were organized into 4 categories: NB health; Adaptation to the new family dynamics; Adaptation to the family environment; Risk of infections (Table 4). The category with the most representativeness in the narratives was the adaptation to the new family dynamics, referred to as the main difficulty by 9 families, also mentioned in other studies including, the siblings' adaptation and the change in the newborn's sleep pattern[14-15,17,21].

Table 4 – Difficulties/concerns felt in the family context.

Categories	Sub-categories
Newborn health	• The fact that it is accompanied by oxygen and we cannot hear the alarms (M1,P1)
	• With his health in 1st place (M5,P4)
	• With food and intestinal functioning (M8;M5,P4)
	• With the hernia of the navel (M3,P2)
	• In the control of feeding (M4,P3)
Adaptation to the new family dynamics	• To ensure the conditions for the adaptation to the family environment to be quiet (M6)
	• Reconciling the presence of the sibling, habits and additional care in a family environment (M11,P8)
	• The adaptation of the older sibling to the baby (M1,P1)
	• Concern about doing something wrong (M7,P5)
	• If we can take care of our daughter properly (M10,P7)
	• If we know how to respond properly if something unexpected happens (M9,P6)
	• The biggest difficulties were at night, he gets more agitated and doesn't sleep (M8)
	• The biggest difficulty was nobody sleeps at night (M2)
	• It was the family changes of having a premature baby at home (M12)
Adaptation to the family environment	• Adapting the environment to your baby's specific needs (M7,P5)
	• With room temperature and the right clothes (M2)
	• With bed /cot (M5,P4)
	• With the ambient temperature of the room /house (M1,P1)
	• I was more worried if he was cold, if it was the right temperature (M9,P6)
Infection risk	• Contact limitations, need for prior disinfection (M1,P1)
	• Contact with people who may have health problems (M6)
	• Special cleaning, sanitation and sterilization care (M5,P4)

2. Perception of the need for a *continuum* process in Health Care

In regard to the 12 families that received the visit, 100% totally agreed and considered it important and about 92% (11) said it should be done in the 1st week, reinforcing this period as the most vulnerable. When asked about the degree of satisfaction in relation to the teaching carried out during the visit, 100% (12) responded that they were very satisfied.

In view of table 5 we observe the subjects/themes that, in the opinion of the parents, should be treated in the visits and that were grouped into 2 categories: Baby care and Environment, assuming the first great relevance. Inserted in the care of newborns, the theme of feeding/breastfeeding was the most referenced, followed by the development,

risk situations and sleep pattern of the newborn. The environment is also of concern to families that mentioned the appropriate temperature in the house and bedroom as themes.

Table 5 – Subjects/themes that in the opinion of the parents should be addressed in the visit.

Categories	Sub-categories	Indicators
Babies care	• All issues that are pertinent and that help us to take care of correctly (M8) • Baby general care (M4,P3) • Specific questions of each mother (M6;M12) • It depends on the specific circumstances of each baby and/or household (M3,P2) • They must reconcile with the difficulties of each one without forgetting the "formation of the family" (M5,P4) • Correcting the baby care (M9,P6) • Baby health care (M12) • To maximize baby's well-being (M1,P1) • Baby development (M2;M10)	• Baby schedules (2) • Weight (3) • Hygiene (5) • Sleep standard (5) • Feeding/breastfeeding of NB (9) • Situations of risk/choking (5) • Development (6)
Environment	• To improve home adaptation (M7,P5;M8;M11) • Adequate environment (M3,P2;M4,P3;M9,P6)	• House temperature (6) • Where baby sleeps (4)

3. Expectations and suggestions

The visit was carried out according to expectations for 100% of respondents. Regarding the expectations created 3 categories emerged: Clarification of doubts; Follow-up on continuity of care and Parental Empowerment (Table 6). The interviewed families had created expectations in relation to the visit, that this would clarify their doubts and enable them to be even better caregivers, what was materialized.

Table 6 – Parents' justification for expectations created.

Categories	Sub-categories
Clarification of doubts	• It served to remove all doubts that we had to date (M3,P2)
	• Allowed to answer doubts (M5,P4)
	• It went very well and was very enlightening (M1,P1)
	• It was very helpful in removing several doubts that existed (M2;M6)
	• The visit was very good and made it possible to clarify doubts about babies and care (M4,P3)
	• It was very important because the 1st week is the most difficult in terms of doubts (M10,P7)
Follow-up on continuity of care	• It served as an intermediate follow-up between leaving the unit and the first consultation (M9,P6)
	• Control of baby weight (M7,P5)
Parental Empowerment	• We are able to understand what we are doing well and what we can improve (M3,P2)
	• The nurse has always accompanied and dealt with the baby in neonatology and her visit is comforting (M1,P1;M2)
	• It validates and improves the care provided by parents, meeting the best evolution of the child and the family as a whole (M4,P3)
	• The support of the nurse helps us a lot and reassures us, I was very surprised by the positive with this service (M6;M11)
	• They gave us a lot of important information for the baby's day-to-day (M8;M12)
	• The visit was wonderful, all help is indispensable (M7,P5)

The suggestions for improvement pointed out by the parents are very pertinent when proposing a continuous follow-up over time, with more face-to-face visits or using new technologies, through online platforms (*i.e.*, videoconference, *skype*, *whatsapp*, etc...), being in agreement with other studies[18].

CONCLUSIONS

Actions to investigate health needs led to the production of care, resulting from the monitoring of premature or low-weight newborns and their families, expanding the concept of quality for the home with the operationalization of the Project.

The home visit as an integrality strategy carried out in the vulnerable period is an innovation for the district, as it leverages the specialized human resources of the NICU as links with the PHC, facilitating the transition from care to the family environment.

In view of the results obtained, we can conclude that the objectives were achieved, making the importance of the visit in parental training evident. It should be noted that 57.1% of mothers are primiparous, about 71% of newborns were born with GA less than 34 weeks and 35.7% weighing less than 1500gr, confirming the effectiveness of the intervention. The 14 newborns were evaluated with a health status considered normal and with good adaptation to the family environment. The main difficulties/concerns voiced by the parents are related to the newborn's health, with emphasis on changes in intestinal functioning. Comparing these observed results with those of the written narrative, it was found that the most representative category was adaptation to the new family dynamics.

The Project's result indicators correspond to the parents' carrying out the activities taught, thus constituting indicators of competence or mastery. These indicators related to self-knowledge revealed progress leading parents to assume the condition of caregivers, reflected in the results obtained.

The limitations of the study are related to the lack of human resources and the time to implement the Project. Regarding resources, only 25% of visits were carried out in partnership with the family nurse. Greater involvement of PHC will enhance the final results in the long term and certify this intervention as a good practice in Health. In terms of time, it was not possible to compare values regarding the rate of readmissions before and after the Project. However, using computerized tracking of newborns until June 2018, there were no records of emergency episodes or hospitalizations, only routine consultations.

In short, as a final product, the Project had an impact on visible organizational result variables in the quality and productivity of the services provided. Consequently, it has achieved gains in clients health, in terms of satisfaction, autonomy and safety in care, with a reduction in adverse events and complications, creating health value.

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