Parental autonomy in the care of premature newborns and experience of a neonatal team.

Salvador Piris-Borregas Sr, Beatriz Bellón-Vaquerizo, Leticia Velasco-Echeburúa, Lidia Niño-Díaz, Susana Sánchez-Aparicio, María López-Maestro, Carmen Rosa Pallás-Alonso

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Salvador Piris-Borregas Sr[1*] MD, PhD; Beatriz Bellón-Vaquerizo[2*]; Leticia Velasco-Echeburúa[2]; Lidia Niño-Díaz[2]; Susana Sánchez-Aparicio[2]; María López-Maestro[2] MD, PhD; Carmen Rosa Pallás-Alonso[2] MD, PhD

[1]12 de Octubre University Hospital. Neonatolgy Department Madrid ES
[*]these authors contributed equally

Corresponding Author:
Salvador Piris-Borregas Sr MD, PhD

Abstract

Introduction. The aim was to study how the time required by families of premature infants to achieve the autonomy in the care of their very low birthweight newborn infants was modified during the implementation of a training program.
Patients and Method. This is an observational prospective study in the context of quality improvement strategy. The Cuídame, what means in English Take care of me program, was aimed at achieving the autonomy of the parents. It was implemented during two periods: period 1, from 1 September 2020 to 15 June 2021, and period 2, from 15 July 2021 to 31 May 2022. The days required by parents to achieve the autonomy in several areas of care were collected from the electronic health system.
Results. A total of 54 and 43 patients were recruited in every period. Less time was required in the period 2 for participation in rounds (10,5 days interquartile range –IQR- 5-20 versus 7 days IQR 4-10,5, p<0,01), feeding (53,5 days IQR 34–68 versus 44,5 days IQR 37–62, p=0,05) and observation of neurobehavior (18 days IQR 9-33 versus 11 days IQR 7-16, p=0,05). More time was required for Kangaroo (14 days IQR 7-23 versus 21 days IQR 10-31, p=0,02), diaper change (9,5 days IQR 4-20 versus 14,5 days IQR 9-32, p=0,04) and infection prevention (1 day IQR 1-2 versus 6 days IQR 3-12, p<0,01).
Conclusion. Families required less time for achieving the autonomy in breastfeeding, observation of neurobehavior and participation in rounds during the implementation. Nevertheless, they required more time for kangaroo, diaper change and infection prevention.

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Original Manuscript

Tittle: **Parental autonomy in the care of premature newborns and experience of a neonatal team.**

Summary

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Keywords. Family-centred care; Neonatal intensive care Unit; Kangaroo Mother Care.

Abbreviations.

EFCNI. European Foundation for the Care of the Newborn Infants.

VLBW. Very low birth weight.

GA. Gestational age.

IQR. Interquartile range.

SARS-CoV2. Severe acute respiratory syndrome coronavirus 2.

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Introduction

The European Foundation for the Care of Newborn Infants (EFCNI) has promoted the importance of parental involvement in the care of their children.[1] It has been expected that family autonomy will result in additional benefits. Some programs have been created[2-4] to achieve such training. However, the time required by parents to become autonomous is unknown, particularly in the case of premature children.

The main objective of this study is to compare the number of days required by parents of very low birth weight (VLBW) newborn infants to be autonomous in different areas of care during the two periods of implementation of a parental training programme.

Methods

This observational prospective study was associated with a quality improvement initiative aimed at increasing the family autonomy in the care of VLBW newborn infants during the implementation of the Cuídame programme in a IIIC level Spanish neonatal unit.

Prior to the implementation of this program, materials and meetings with the most sensitive healthcare providers to neurodevelopmental centred care issues were prepared in 2020. The implementation of the programme was performed over two periods (table 1). Period 1 was from 1 September 2020 to 15 June 2021 and it represents the start of the implementation of the Cuídame programme. Period 2 was from 15 July 2021 to 31 May 2022 which represents complete implementation and greater experience of the neonatal team.

This programme includes several areas of care and a paper called a roadmap where the parents are encouraged to write down the dates when they achieved autonomy under the supervision of the neonatal nurse staff[5]. A responsible professional was assigned to each family to monitor the autonomy of the parents in caring for their babies. In addition, professionals received file books with the criteria and indicators that parents had to meet to advance in every step.

The families who recorded the dates of autonomy in all areas of care on their roadmoaps were included. In the context of clinical management, the families of newborns infants with a severe disease focused on caring for children at the end of their life, those who died during the first month

of life or when important language barriers were excluded.

The autonomy of parents in caring for their VLBW newborn infants during their admission and the dependent variables related to the morbidity of VLBW newborn infants were defined in the scientific literature[5]. Autonomy in Kangaroo Mother Care was achieved when parents transferred newborn infants from the incubator to their chest, placed their children properly in the Kangaroo position and they transferred them to the incubator. With respect to feeding, autonomy was achieved when parents were able to recognize the signs that their infants were hungry and feeding their infants orally. Observation of neurobehaviour was when parents identified their infants's daily achievements and helped them reach the next neurobehavioural step. The parents were considered autonomous in handling, posture and contact when they created the cradle nest, chose the bedding, properly placed the infant properly and executed postural changes in the incubator. Autonomy in diaper change occurred when the infants's diaper were changed by the parents themselves. When they detected their infant's pain or stress signs and applied non-pharmacological analgesic measures were considered autonomous in stress and pain prevention. Autonomy in the prevention of sensory deprivation was achieved when the parents talked to their infants, chose stories to tell them and conveyed the importance of this initiative to other parents. Patient safety involved ensuring that the parents dealt with their babies, were familiar with the monitoring system and alerted the team about any detected incident. It also involved knowing the medication and the type of milk that the infant was receiving. Parents who cleaned their infant properly according to their corrected age were considered autonomous in cleanliness. Prevention of healthcare-associated infections involved the removal of bracelets or watches before they contact with the infant, the use of hand gel before touching them and reminding professionals to use hand gel, as well. Finally, participation in clinical rounds was when the parents provided suggestions to the team during clinical rounds.

Comparisons between the two time periods were performed using the non-parametric U-Mann-Whitney test and the chi-square test or Fisher's exact test. Comparative analyses were adjusted for gestational age (GA) and birth weight. The Ethics Committee of the Biomedical Research Institute of the 12 de Octubre University Hospital approved the project to carry it out.

Results

During the study period, a total of 159 VLBW infants were admitted to the neonatal unit. The parents of 107 of VLVW infants recorded the dates of complete autonomy in the areas of care at discharge on their roadmaps. Four families were excluded because of a significant language barrier and six families because of the death of the newborn in the first month of life. Overall, 54 of 75 (72%)

families were recruited during period 1 and 43 of 84 (51%) families during period 2. No statistical differences were found between the infants in periods 1 and 2.

The median GA and the birthweight were 28.7 weeks (Interquartile range -IQR- 26.8 -31) and 1,080 g (IRQ 850 – 1270) in period 1. In period 2 they were 27.8 weeks (26.7 – 30.4) and 1000 g (800 – 1200). The number of days required by the parents of VLBW newborn infants to be autonomous in the 11 care areas included in this study is described and compared in Table 2. It should be noted that the prevention of healthcare-associated infection was an area of care where healthcare providers and parents required fewer days to be autonomous (6 days with IQR 3-12) and feeding required more days (44,5 days with IQR 37-62). Additionally, different behaviours can be highlighted on the days to be autonomous when they are compared between periods 1 and 2. Thus, a decrease in the days required to be autonomous in the period 2 occurred in participation in clinical rounds (10.5 days with IQR 5-20 versus 7 days with IQR 4-10.5, $p<0.01$). In contrast, a significant increase in the time required in period 2 was observed in three areas of care: Kangaroo Mother Care, diaper change and prevention of healthcare-associated infections.

Discussion

Our study revealed that the implementation of the Cuídame programme changed the culture of care in our neonatal unit resulting in the autonomy of most families in caring for their newborn infants under the supervision of a healthcare professional during their admission. The prevention of the healthcare-associated infections was the first area where parents achieved the autonomy and feeding the last one.

Implementation of a program aimed at achieving autonomy of the family in the care of their newborn infants does not affect every area of care in the same way. In our case, the time required by parents of VLBW newborn infants to be autonomous in kangaroo care, preventing healthcare-associated infections and diaper change increased in the second period. One possible reason for this difference is that healthcare providers became more demanding during the implementation of the programme.

Some limitations should be considered such as the SARS-COV2 epidemic could act as a barrier to the implementation of the Cuídame programme.

Based on our results, it can be concluded that some areas of care could have different behaviours during the implementation of a training program aimed at achieving parental autonomy. The number of days required by parents to obtain autonomy in Kangaroo Mother Care, diaper change and prevention of healthcare-associated infections were increased in our case even though the team was more experienced. This leads us to bellieve that achieving parental autonomy is a complex process

that depends on several factors in the implementation of a training programme.

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CONFLICT OF INTEREST

No authors have no conflicts of interest to declare.

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Table 1. Actions carried out in the Unit aimed at the implementation of the Cuídame programme and its relationship over time, as well as the events that could represent a barrier to the implementation.

Periods	**Prior to the implementation**	**Period 1:** **Start of the implementation of the "take care of me" program** **1 September 2020 -**	**Period 2:** **Complete implementation of the "take care of me" program** **15 July 2021 –**

		15 June 2021	31 May 2022
Actions aimed at developing the implementation of the Cuidame programme at the Unit.	• The use of family rooms has already begun • Design of the "Cuidame" programme • Approval by the Ethics Committee • Selection of professionals responsible for monitoring the programme. • Presentation of the programme to the professionals.	Start of the Cuidame Programme's implementation	Complete implementation of the Cuidame programme.
Events that could act as barriers to the implementation	SARS-COV2 epidemic. Family members are restricted		
			Summer Vacation. Incorporation of new professionals

Table 2. Study of the time required by families of very low birth weight newborns to acquire the highest degree of autonomy in 11 care areas of the Cuídame programme during the implementation.

Days. (Quantitative variables are shown as median and interquartile range)	Period 1: 9 January 2020 – 31 August 2020 N = 54	Period 2: 1 September 2020 – 15 June 2021 N = 43	P value	P value adjusted for birhtweight and gestational age
Kangaroo care	14 (7-23)	21 (10-31)	**0,04**	**0,02**
Feeding and breastfeeding	53,5 (34-68)	44,5 (37-62)	0,39	0,05
Observation of neurobehavior	18 (9-33)	11 (7-16)	**0,04**	0,05
Handling, posture and contact	16,5 (7-36)	22,5 (11-37)	0,24	0,17
Diaper change	9.5 (4-20)	14,5 (9-32)	**0,01**	**0,04**
Stress and pain prevention	13 (6 - 26)	12 (7-26)	**<0,01**	0,61
Prevention of sensory deprivation	6,5 (2,5 – 16)	7 (4,5-9)	0,35	0,82
Patient safety	9 (4-17)	9 (5-19)	0,90	0,90
Cleanliness	15,5 (7,5-39)	23,5 (13-37)	0,25	0,07

Healthcare-associated infections	1 (1-2)	6 (3-12)	**<0,01**	**<0,01**
Participation in clinical rounds	10,5 (5-20)	7 (4-10,5)	0,05	**<0,01**