



## ORIGINALS

### Care and support for families of deceased newborns: descriptive analysis of six years

Cuidados y atención a las familias de recién nacidos fallecidos: análisis descriptivo de seis años

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#### ABSTRACT:

**Introduction:** Several studies have indicated that the quality of professional support received during and after a neonatal death significantly influences the grieving process and mental health of parents. This article aims to describe the characteristics of neonatal mortality at the Hospital Clínico San Carlos, care practices for families, and the variables with which they are associated, as well as maternal depressive symptoms.

**Method:** A retrospective descriptive observational study was conducted from October 2018 to December 2024, analyzing clinical and sociodemographic variables, internal care records, and Montgomery-Asberg Depression Rating Scale (MADRS) scores of mothers the first week after death. **Results:** Since 2018, there have been 60 neonatal deaths, most of them extremely premature. More than half of the mothers were of foreign origin. 98% of families received at least one care intervention; the most frequent was seeing the baby (96%) and receiving a memory box (96%), and the least frequent was dressing the baby in their own clothes (30%). More than 60% were contacted by telephone by clinical psychologists in the first week after death.

**Conclusions:** Prematurity and maternal foreign origin are the most common characteristics. Recommended care practices for neonatal deaths have been successfully integrated into the service.

**Key-words:** Perinatal death; Neonatology; Humanization of Assistance; Bereavement; Hospice Care.

## RESUMEN:

**Introducción:** Diversos estudios han señalado que la calidad del apoyo profesional recibido durante y después del fallecimiento neonatal influye significativamente en el proceso de duelo y en la salud mental de los progenitores. Este artículo tiene como objetivo describir las características de la mortalidad neonatal en el Hospital Clínico San Carlos, las prácticas de cuidado hacia las familias, y las variables con las que se asocian, así como la sintomatología depresiva materna.

**Método:** Se realizó un estudio observacional descriptivo retrospectivo desde octubre de 2018 hasta diciembre de 2024, analizándose variables clínicas y sociodemográficas, registros internos de cuidados y puntuación en Escala de Depresión Montgomery-Asberg (MADRS) de las madres la primera semana tras el fallecimiento.

**Resultados:** Desde 2018 se han producido 60 muertes neonatales, la mayoría prematuros extremos. Más de la mitad de las madres tenían origen extranjero. El 98% de las familias recibió al menos una intervención de cuidado, las más frecuentes ver el bebé (96%) y obtener una caja de recuerdos (96%), la menos frecuente vestir al bebé con su ropa (30%). Más del 60% fue contactada telefónicamente por psicología clínica la primera semana tras el fallecimiento.

**Conclusiones:** La prematuridad y el origen extranjero materno son las características más frecuentes. Las prácticas de cuidados recomendadas en la muerte neonatal se han integrado con éxito en el servicio.

**Palabras clave:** Muerte Perinatal; Neonatología; Humanización de la Atención; Duelo; Cuidados Paliativos al Final de la Vida.

## INTRODUCTION

The loss of a newborn son or daughter is one of the most painful experiences a family can endure, with a deep and lasting emotional impact <sup>(1)</sup>. Despite advances in healthcare, neonatal death—occurring within the first 28 days of life—and postneonatal death—between one month and one year <sup>(2)</sup>—remain major challenges in the field of public health. In Spain, the most recent data estimate a neonatal mortality rate of 1.77 and a postneonatal mortality rate of 0.86 per 1,000 live births, while in the Community of Madrid these figures are 1.55 and 0.68, respectively <sup>(3)</sup>.

In countries with advanced healthcare systems, neonatal mortality rates have decreased due to improvements in perinatal care, such as access to neonatal intensive care units (NICUs)<sup>(4)</sup>. However, beyond biomedical aspects, the humanization of care and the support provided to families are essential components of modern clinical practice. Several studies have highlighted that the quality of emotional and psychological support received during and after neonatal death has a significant influence on the grieving process and on parents' mental health <sup>(5,6,7)</sup>.

The *Hospital Clínico San Carlos* (HCSC) not only provides specialized clinical care for critically ill newborns but has also developed strategies to support and accompany families in cases of neonatal death. These include sensitive communication protocols, memory-making activities, opportunities for contact and farewell with the newborn, and access to psychological assessment and/or treatment both in the hospital and during follow-up. The involvement of clinical psychology teams in this context is crucial for detecting and addressing complex emotional reactions, facilitating a more adaptive grieving process, and reducing the risk of long-term psychological disorders among parents <sup>(7,8)</sup>.

The objectives of this study are: (1) to describe the characteristics and trends of neonatal mortality in the Neonatology Unit of the HCSC; (2) to analyze care practices (degree of adherence to the neonatal end-of-life care protocol); (3) to identify the prevalence of depressive symptoms in mothers during the first week following neonatal death; and (4)

to determine the relationship between selected sociodemographic and obstetric variables and depressive symptoms and care practices. By analyzing these aspects, the study aims to provide relevant information to optimize neonatal care and comprehensive support for bereaved families.

## MATERIAL AND METHOD

### Procedure

A retrospective, descriptive, observational study was conducted in the Neonatal Intensive Care Unit (NICU) of the HCSC in Madrid. The hospital has a level IIIB Neonatology Unit, making it one of the referral centers for the care of critically ill newborns in the Community of Madrid. In 2023, the hospital attended 1,604 deliveries<sup>(3)</sup>.

The service has a *Protocol for the Humanization of Neonatal End-of-Life Care*, introduced in October 2018 and developed by a multidisciplinary team composed of clinical psychology, nursing, and pediatrics professionals. This plan covers both the moment of death and subsequent follow-up stages. The protocol was designed after a review of the scientific literature, an analysis of the service's specific needs, and consideration of the team's prior experiences, with the aim of providing comprehensive support to families during neonatal death.

Nursing care actions are documented in a paper-based checklist, indicating whether each action was performed or not. Condolence letters sent to families are stored in a dedicated folder on the service's intranet. Clinical psychologist follow-up phone calls, the modality of psychological intervention, and depressive symptom scores are recorded in an internal database and in the electronic health record.

Between January and February 2025, study data stored in both paper and electronic formats were collected.

This study was approved by the Research Ethics Committee of the *Hospital Clínico San Carlos* (internal code 25/151-E) and conducted in accordance with the Declaration of Helsinki. Since data were anonymized and obtaining informed consent from individuals in a critical emotional situation posed significant practical challenges, informed consent was not requested. However, all appropriate measures were taken to ensure the privacy and confidentiality of the data collected.

### Participants

The study sample included all neonates who died in the NICU of the *Hospital Clínico San Carlos* between October 2018 and December 2024, and their families. Intrauterine and intrapartum deaths were not included. No exclusion criteria were applied.

### Variables

For this study, the following information was collected:

Sociodemographic variables: Mother's age, mother's nationality, previous children, previous miscarriages, previous neonatal losses, infant's sex, gestational age, and days of life.

Care-related variables: Nursing care actions (yes/no): seeing the baby, holding the baby, dressing the baby, taking the baby's handprints or footprints, keeping vigil with the baby, performing a religious ritual, receiving a memory box containing items used during hospitalization (identification bracelet, pacifier, cord clamp), taking a photograph, and allowing other relatives to say goodbye.

Healthcare team care actions (yes/no): condolence letter sent to the family between 3 and 5 weeks after the death.

Clinical psychology care actions (yes/no): first phone call within the first week after the death, second phone call, and psychological treatment.

Montgomery-Åsberg Depression Rating Scale (MADRS), Spanish adaptation <sup>(9)</sup>, was used to assess maternal depressive symptoms. It is a clinician-administered scale consisting of 10 items evaluating depressive symptoms. Each item is rated on a Likert-type scale from 0 (absence of symptoms) to 6 (maximum symptom severity). The total score is obtained by summing all items. Several cutoff points have been established; according to Gaynes et al., scores of 10–19 indicate mild depressive symptomatology, 20–29 moderate, and  $\geq 30$  severe depressive symptomatology <sup>(10)</sup>.

Sociodemographic, obstetric, and clinical data were extracted from electronic health records. Nursing care actions were obtained from paper-based checklists. Condolence letters and phone calls were retrieved from internal electronic records. The assessment of depressive symptoms, documented both in electronic health records and internal databases, was conducted during routine clinical psychology consultations.

## Statistical Analyses

A descriptive analysis was performed for all variables. Quantitative variables were analyzed by calculating the mean (M), standard deviation (SD), median (Mdn), minimum (Min), and maximum (Max) values. Qualitative variables were described using frequency (n) and percentage (%).

Nonparametric tests were used due to the lack of normality in continuous variables. Spearman's rank correlation was employed to examine relationships between quantitative variables, the Chi-square test to analyze associations between categorical variables, and the Mann-Whitney U test to compare differences between two independent groups.

A significance level of  $p < 0.05$  was considered statistically significant for all analyses. Statistical analyses were performed using the *Statistical Package for the Social Sciences* (SPSS), version 26.0.

## RESULTS

### Descriptive analysis of neonatal deaths and sociodemographic and clinical background of the newborns and their mothers

From October 2018 to December 2024, a total of 60 neonates died in the Neonatology Unit of the *Hospital Clínico San Carlos* (HCSC). Intrauterine and intrapartum deaths were not included. During the same period, 2,435 infants were admitted to the Neonatology Unit, resulting in a mortality proportion of 2.46%. Table 1 presents the number of admissions and neonatal deaths by year.

**Table 1.** Admissions and neonatal deaths in the Neonatology Unit of the *Hospital Clínico San Carlos* (October 2018–December 2024)

	Admissions(n)	Deaths (n)	Proportion (%)
October–December 2018	93	4	4,30%
January–December 2019	373	14	3,75%
January–December 2020	386	8	2,07%
January–December 2021	439	7	1,59%
January–December 2022	470	12	2,55%
January–December 2023	369	7	1,89%
January–December 2024	305	8	2,62%
Total	2435	60	2,46%

The sociodemographic and obstetric background of the mothers, as well as the clinical characteristics of the neonates, are presented in Table 2. Slightly more than half of the mothers were of foreign origin and had previous children. In addition, 30% had experienced previous miscarriages, and 3% had lost a child during the neonatal period.

Regarding the deceased infants, the majority were extremely preterm (less than 28 weeks of gestational age), slightly more than half died within the first week after birth, and most were male.

**Table 2.** Sociodemographic and clinical characteristics of the study sample

Variables	n	%
Mother		
Age (n= 60)		
M=32,98; DT=5,95; Median=34,50; min = 18, máx.= 43		
- 18- 25 years old	8	13,3%
- 26- 35 years old	27	45%
- 36 years and older	25	41,7%
Origin (n=49)		
- Spain	23	46,9%
- Foreign	26	53,1%
• Europe	4	15,38%
• Asia	3	11,54%
• Africa	3	11,54%

<b>Variables</b>	<b>n</b>	<b>%</b>
• America	13	50%
• Central America	3	11,54%
<b>Type of delivery (n=55)</b>		
- Vaginal	32	58,18%
- Cesarean section	23	41,81%
<b>Previous children (n=59)</b>		
- Yes	30	50,8%
- No	29	49,2%
<b>Previous miscarriages (n=59)</b>		
- Yes	18	30,5%
- No	41	69,5%
<b>Previous neonatal deaths (n=59)</b>		
- Yes	2	3,4%
- No	57	96,6%
<b>Neonate</b>		
<b>Sex (n= 60)</b>		
- Male	33	55%
- Female	27	45%
<b>Gestational age (days) (n=59)</b> M=197,12; SD= 38,05; Median=182 min= 162; max= 286		
- 161-196 days (23 - 28 weeks)	43	72,9%
- 197-224 days (28+1- 32 weeks)	3	5,08%
- 225-259 días (32+1 - 37 weeks)	5	8,47%
- 260-287 días (37+1- 41 weeks)	8	13,55%
<b>Days of life (n=60)</b> M=15,52; DT=21,232; Mediana= 7 min= 0; max= 92		
- 0-7 days (early neonatal death)	31	52,5%
- 8-27 days (late neonatal death)	19	32,2%
- 28-365 days (postneonatal death)	10	15,3%
<b>Neonatal diagnosis(n=60)</b>		
- Prematurity	48	80%
- Hipoxic-Isquemic Encephalopathy	8	13,33%
- Others	4	6,66%

## Care actions provided to the families of deceased newborns

Among the care interventions recorded by nursing staff in the context of end-of-life and post-neonatal death care, three main categories can be distinguished:

1. Actions directed specifically toward the baby, such as seeing, holding, or dressing the infant;
2. Actions oriented toward memory preservation, such as providing a memory box or taking photographs; and
3. Actions with a social or religious component, such as keeping vigil with the baby, performing a religious ritual in the unit, or allowing the presence of other family members.

Across the total sample, data loss occurred in seven cases for which no information was available regarding any of these actions. This lack of documentation corresponded to the first months following the protocol's implementation and, in other cases, to the summer period (when new staff are typically present). In addition, one family did not return to the hospital after the baby's death.

Of the families whose data was available, 98% received at least one care intervention, with the most frequent being seeing the baby (96%), followed by receiving a memory box (96%). The least frequently accepted action was dressing the baby (30%). Table 3 provides a detailed overview of the proportion of families who accepted, declined, or did not receive each of these interventions.

**Table 3.** End-of-life care actions provided by the Neonatology Unit team at *Hospital Clínico San Carlos*

<b>End-of-life care actions provided by nurse staff</b>	<b>n</b>	<b>%</b>
<b>Seeing the infant (n=51)</b>		
- Yes	49	96,07 %
- No	2	3,93 %
<b>Holding the infant(n=50)</b>		
- Yes	47	94 %
- No	3	6 %
<b>Dressing the infant (n=37)</b>		
- Yes	11	29,73 %
- No	26	70,27 %
<b>Taking the infant's fingerprints(n=49)</b>		
- Yes	46	93,88 %
- No	3	6,12 %
<b>Memory box (n=49)</b>		
- Yes	47	95,92 %
- No	2	4,08 %
<b>Keeping vigil with the baby (n=47)</b>		
- Yes	39	82,98 %
- No	8	17,02 %
<b>Performing a religious ritual in the unit (n=41)</b>		
- Yes	18	43,90 %
- No	23	56,10 %
<b>Taking a photography (n=38)</b>		
- Yes	16	42,10 %
- No	22	57,90 %

<b>End-of-life care actions provided by nurse staff</b>	<b><i>n</i></b>	<b>%</b>
Presence of other family members (n=46)		
- Yes	36	78,26 %
- No	10	21,74 %
Sending condolence letter to the family (n=57)		
- Yes	45	78,95%
- No	12	21,05%

Various psychological care interventions were provided to families in the context of neonatal end-of-life care. These included a phone call during the first week after the loss, a second follow-up call, and psychological treatment when required, all conducted by a clinical psychologist.

According to the data obtained, 62% of families received a psychological follow-up call during the first week after the infant's death. A second follow-up call was carried out in 41% of cases. Regarding psychological treatment, 26% of families received this type of intervention. See Table 4 for details.

**Table 4.** Care actions provided to parents by the Clinical Psychology team of the Neonatology Unit at Hospital Clínico San Carlos

<b>Care actions provided to parents</b>	<b><i>n</i></b>	<b>%</b>
Follow-up call during the first week after infant's death(n=58)		
- Yes		
- No	36	62,07%
	22	37,93%
Second follow-up call (n=56)		
- Yes	23	41,07%
- No	33	51,78%
Psychological treatment (n=54)		
- Yes	14	25,93%
- No	40	74,07%

### **Differences in care actions according to sociodemographic, clinical, and obstetric characteristics**

When analyzing whether obstetric history, clinical characteristics, and sociodemographic variables were associated with the care actions provided, only one significant association was found: dressing the deceased newborn and receiving a second follow-up call from the clinical psychology staff were both related to the mother's national or foreign origin. See Table 5.

**Table 5.** Associations between care actions and sociodemographic, clinical, and obstetric variables

	Spanish mother's origin/ Foreign mother's origin ( $\chi^2$ )	Previous miscarria ges (yes/no) ( $\chi^2$ )	Previous neonatal losses (yes/no) ( $\chi^2$ )	Mother's ages (3 groups of ages) ( $\chi^2$ )	Babys' days of life (3 groups) ( $\chi^2$ )
Seeing the infant	0,931	0,425	2,165	0,279	2,165
Holding the infant	2,002	1,154	0,238	0,700	0,918
Dressing the infant	<b>6,605*</b>	0,110	0,064	2,574	2,103
Taking infant's fingerprints	2,003	1,225	0,234	0,543	1,565
Memory box	1,026	0,391	0,899	1,379	1,161
Keeping vigil with the infant	0,175	0,408	0,414	0,417	0,491
Taking a photography	0,185	0,002	1,616	3,103	2,798
Performing a religious ritual	1,074	0,307	1,766	1,640	0,864
Presence of other family members	0,040	0,073	0,918	0,018	0,705
Condolence letter	0,101	2,123	0,405	0,254	0,722
First follow-up call	0,031	0,397	0,855	1,563	1,111
Second follow-up call	<b>2,440*</b>	0,075	0,048	0,545	0,805

\*  $p < 0,05$ ;  $\chi^2$ =Chi squared

### Depressive symptomatology in mothers of deceased neonates: relational and comparative analysis according to sociodemographic and obstetric variables

Depressive symptomatology in mothers was assessed using the clinician-administered MADRS scale. The results ( $n = 33$ ) showed a mean score of 15.76 (standard deviation = 6.66) and a median of 18. Thirty-nine percent of mothers scored above the cutoff point of 20, indicating moderate to severe depressive symptomatology.

Associations and differences between depressive symptomatology—measured using the MADRS scale—and various sociodemographic and obstetric variables were also examined. None reached the level of statistical significance. See Table 6.

**Table 6.** Comparative and correlational analysis of depressive symptomatology (MADRS) according to sociodemographic and obstetric variables

Variable	Statistics	p
Spanish/foreign origin	U=61	0,153
Previous children	U=108	0,491
Previous miscarriages	U=90,50	0,424
Type of delivery (eutocic/cesarean section)	77,50	0,091
Days of life	Spearman's r=0,028	0,879
Mother's age	Spearman's r= -0,209	0,244

Note: U= Mann-Whitney U to compare scores on Maternal Depression Rating Scale (MADRS) as a function of dichotomous variables (Origin, Previous children, Previous abortions, Type of delivery); Spearman's r= Spearman's correlation coefficient for the variables Ages and Days of life.

## DISCUSSION

The objective of this study was to describe the characteristics and trends of neonatal mortality at Hospital Clínico San Carlos, the care and support practices provided to families, as well as the most frequent emotional symptomatology in mothers after neonatal loss. To our knowledge, this is the first study published in Spain that examines palliative care and post-neonatal death practices.

The clinical characteristics of the deceased infants in the hospital are consistent with previous data indicating that the main cause of neonatal mortality is prematurity, and that the lower the gestational age, the greater the risk <sup>(11)</sup>. On the other hand, the percentage of males among the deceased is slightly higher than that of females <sup>(11)</sup>. Regarding maternal characteristics, about half were of foreign origin. Considering that only 24.42% of babies born in Spain are to foreign mothers <sup>(3)</sup>, this overrepresentation could be explained by the fact that HCSC serves a high percentage of families of foreign origin. However, maternal origin could also constitute a risk factor; for example, ethnicity in countries such as the United States is associated with perinatal mortality <sup>(12)</sup>. The reasons are multifactorial, but socioeconomic factors may play a role, which indicates the need to adapt prevention and education initiatives with specific approaches aimed at reducing infant mortality rates and eliminating disparities by origin in perinatal outcomes.

Moreover, advanced maternal age among Spanish mothers is associated with more gestational pathology, which affects fetal morbidity and mortality. There is also a higher risk of prematurity at both extremes of maternal age, with double the risk compared to mothers aged 20 to 40 years <sup>(13)</sup>.

With regard to the care actions offered to families of babies who die, these are included in a care protocol implemented in 2018 in the service. This protocol incorporated clinical practice recommendations and family-centered care guidelines in perinatal and neonatal death <sup>(14,15)</sup>. The analysis of practices allows us to affirm that the protocol has been successfully integrated into the service, as most families received such care. Successful team approaches seem to include staff education and the development of protocols on palliative care and perinatal and neonatal end-of-life care <sup>(16)</sup>, and both

strategies have been implemented in our service. At the same time, the analysis made it possible to detect those actions that are still improvable in terms of their generalization, such as condolence letters and, above all, the number of families contacted by clinical psychology after discharge.

It is worth highlighting that the integration of specialized psychological care in supporting families after neonatal death constitutes one of the strengths of the protocol and the service — an integration widespread in Anglo-Saxon countries <sup>(17)</sup> but recent and incomplete in our country <sup>(18)</sup> — and which is justified by the fact that this is a population at higher risk of presenting mental health problems <sup>(19,20)</sup>. Access to psychological treatment during the perinatal period is a challenge noted in several publications <sup>(4,21)</sup>. Furthermore, follow-up after discharge is desired by families and recommended by guidelines <sup>(15)</sup>, although it remains infrequent in most countries <sup>(22)</sup>.

The analysis of these aspects provides relevant information for optimizing neonatal care and comprehensive support for bereaved families. It is an exercise in transparency and a commitment to improving the quality of care. Therefore, it is especially important to note the finding that psychological follow-up (second call) of mothers of non-Spanish origin after the death occurred less frequently than among Spanish mothers. This may be due to difficulties in telephone contact or to biases in assessment, which should be corrected in the future. The fact that it was mostly mothers who participated in the telephone contact may be due to biases and inequities in professional care, but also to gendered differences in coping with grief in our society, through which women are more receptive and seek more professional support <sup>(23)</sup>. With regard to the care action of dressing the baby, the authors attribute it to prematurity who may not have had time to prepare clothing.

Most of the mothers in this study, however, showed mild depressive symptoms, and only about one in four women contacted by telephone after the death received psychological treatment. This is consistent with the perspective that most grief processes are adaptive and that socio-family and personal resources provide sufficient support <sup>(24)</sup>. However, it has also been shown that bereaved mothers are four times more likely to present depressive symptoms and seven times more likely to present post-traumatic stress symptoms compared to those who are not bereaved, highlighting the powerful impact of this loss and the severe distress it can create in the family <sup>(4)</sup>, and therefore the importance of prevention. In addition, undertreatment of people with mental health problems during the perinatal period has been noted, and active assessment of emotional symptoms during this stage is recommended <sup>(25)</sup>, including after perinatal loss <sup>(4)</sup>. The methods described and the routine implementation of these strategies may be beneficial to support mothers and fathers during their grief after the loss of a baby in the NICU <sup>(26)</sup>.

On the other hand, the absence of association between depressive symptomatology during the first week and obstetric or sociodemographic characteristics, although it should be interpreted with caution given the small group, serves to contrast some myths surrounding perinatal death <sup>(27)</sup>. For example, the intensity of emotional pain in mothers during the first week is not significantly lower among those who have previous children.

This descriptive and correlational study, however, has several limitations. The first is that the checklist of care provided to families does not allow us to accurately distinguish those actions that were declined by families from those that were not offered. Moreover,

depressive symptomatology was assessed only in mothers (not fathers), and only in part of them, and this assessment had a clinical character and was limited to the first week. Future studies could focus on examining the evolution of depressive symptoms longitudinally and including post-traumatic stress symptoms. We also consider it highly relevant to continue contributing to transparency in practices by examining possible biases in care.

## CONCLUSIONS

This study provides unprecedented information in the Spanish context on palliative care practices and family support following neonatal death in an university hospital.

The description of neonatal mortality in the Neonatology Unit of Hospital Clínico San Carlos, together with the analysis of the degree of implementation of care interventions, shows that the integration of specific protocols and specialized psychological care is both feasible and well accepted by families. However, areas for improvement were identified, particularly regarding equity in post-discharge follow-up and the generalization of certain care practices.

The results, after identifying the prevalence of depressive symptomatology in mothers and its relationship with certain sociodemographic and obstetric variables and care practices, highlight the importance of a multidisciplinary, culturally sensitive, and family-centered approach, in which both nursing staff and clinical psychology play a key role in mitigating the emotional impact of loss and advancing toward more equitable and humanized neonatal care.

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