

## CLINICAL SCIENCE

# End of life in the neonatal intensive care unit

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**PURPOSE:** Death at the beginning of life is tragic but not uncommon in neonatal intensive care units. In Portugal, few studies have examined the circumstances surrounding the final moments of neonates. We evaluated the care given to neonates and their families in terminal situations and the changes that had occurred one decade later.

**DESIGN AND METHODS:** We analyzed 256 charts in a retrospective chart review of neonatal deaths between two periods (1992-1995 and 2002-2005) in a level III neonatal intensive care unit.

**RESULTS:** Our results show differences in the care of dying infants between the two periods. The analysis of the 2002-2005 cohort four years revealed more withholding and withdrawing of therapeutic activities and more effective pain and distress relief; however, on the final day of life, 95.7% of the infants received invasive ventilatory support, 76.3% received antibiotics, 58.1% received inotropics, and 25.8% received no opioid or sedative administration. The 2002-2005 cohort had more spiritual advisor solicitation, a higher number of relatives with permission to freely visit and more clinical meetings with neonatologists. Interventions by parents, healthcare providers and ethics committees during decision-making were not documented in any of the charts. Only eight written orders regarding therapeutic limitations and the adoption of palliative care were documented; seven (87.5%) were from the 2002-2005 cohort. Parental presence during death was more frequent in the latter four years (2002-2005 cohort), but only 21.5% of the parents wanted to be present at that moment.

**CONCLUSION:** Despite an increase in the withholding and withdrawing of therapeutic activities and improvements in pain management and family support, many neonates still receive curative and aggressive practices at the end of life.

**KEYWORDS:** Neonatal death; NICU; End of life; Ethics in neonatology; Intensive care.

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## INTRODUCTION

Recent advances in prenatal and neonatal care have increased the survival of many infants who, in previous decades, would not have been treated because of a presumed lack of viability. A significant number of extremely preterm infants and newborns with lethal congenital malformations or lethal chromosomal anomalies still face terminal illnesses in the neonatal intensive care unit (NICU).<sup>1</sup> More infants die in the first 28 days of life than during any other period of childhood, and neonatal palliative care is rarely offered.<sup>2</sup> When science and technology are insufficient for the rehabilitation and cure of certain neonatal diseases, intensive treatments may be either inappropriate or inhumane. Physicians and nurses frequently are willing to withhold additional treatment and withdraw life support when the infant is severely injured or marginally viable, when death is imminent, or when further medical interventions would only

prolong pain and suffering.<sup>3-9</sup> However, the treatment decisions for children with life-limiting conditions often involve ethical, moral, legal, and emotional conflicts between the parties involved in decision making. Neonatal physiological resilience complicates predicting survival and outcomes, and no one wants to give up fighting for a child's opportunity to live. Caregivers and parents tend to ceaselessly extend the process of dying, with exponential costs in the form of pain, suffering, and loneliness.<sup>10,11</sup>

End-of-life care requires holistic and consistent support of the family. The knowledge and communication skills of the medical caregivers can greatly influence the ability of the parents to effectively cope with their loss around the time of death and after returning to their home.<sup>12</sup> Understanding how these infants and families are treated in the final moments of an infant's short life can provide accurate information that can lead to the development of an action plan for accurate policies, educational practices, and research.

## STUDY DESIGN AND METHODS

In this study, we evaluated the care given to neonates and their families in terminal situations and compared the

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practical attitudes of the staff during two periods: from 1 January 1992 to 31 December 1995 and, one decade later, from 1 January 2002 to 31 December 2005. The charts of the newborns who died in a level III NICU at São João Hospital were retrospectively reviewed. This NICU provides care to all premature neonates and newborns affected by respiratory, cardiac, neurological, metabolic, renal, and gastrointestinal diseases as well as newborns recovering from surgery. It is a reference center for neonatal cardiology and surgery in northern Portugal.

Our goal was to analyze the documented end-of-life care of neonates and their families, with a focus on five areas: 1) therapeutic activities, 2) pain and distress relief, 3) family support, 4) decision-making, and 5) parental presence during death.

A simple data collection methodology was developed and piloted by the researchers, and its reliability was tested. The categories registered in the chart review included the following: the infant's birth weight and gestational age, resuscitation in the delivery room, the cause of death, any prenatal diagnosis, the hospitalization period, any medical interventions in the final 24 hours of life, any decisions to withdraw or withhold medical interventions, any documented orders to limit medical interventions or to initiate palliative care, the use of a neonatal pain scale, opioid and sedative administration, referrals to chaplains or other spiritual advisors, psychosocial support, permission for siblings and other relatives to visit the infant, interdisciplinary meetings between parents and neonatologists, advice from an ethics committee or judicial support during decision-making, and parental presence during the death of the infant.

Each chart was reviewed by two researchers. To identify the mode of death, the researchers used the classifications of Garros, Rosyckuk and Cox<sup>13</sup> to gather the data and allocate the neonatal deaths into three groups: cardiopulmonary resuscitation failure (CPR failure), withholding and/or withdrawal of therapy (W/W), and do-not-resuscitate (DNR).

A total of 313 deaths occurred from 1 January 1992 to 31 December 1995 and from 1 January 2002 to 31 December 2005; of these, 256 (81.8%) charts were examined. Incomplete charts were excluded.

The data were analyzed using Statistical Package for Social Sciences (SPSS) (version 14.0). We used descriptive statistics and a Chi square test to identify any differences between the cohorts;  $p < 0.05$  was required to achieve statistical significance.

## RESULTS

In both cohorts, approximately 50% of the neonates were born after 37 weeks of gestation and weighed more than 2,500 g at birth. Death occurred within the first six days of life in 59.5% of the 1992-1995 cohort and 62.5% of the 2002-2005 cohort.

### Therapeutic activities

In the final four years (2002-2005), W/W was found in 51.6% of the charts, CPR failure was found in 44.1% and DNR was found in 4.3% (Table 1). In the final 24 hours of life, in both cohorts, 93.8% of the infants died with ventilatory support, 75.8% died with antibiotics, 48.8% died with inotropic support, 1.2% died with peritoneal dialysis, 25.4% died with parenteral nutrition, and 16.4% died with enteral nutrition (Table 2). DNR orders were documented in

**Table 1 - Modes of death in the NICU in the two cohorts.**

Modes of death	1992-1995	2002-2005	Total	p-value*
	n (%)	n (%)		
Failed CPR	94 (57.7)	41 (44.1)	135 (52.7)	0.036
Withholding and/or withdrawal of therapy	54 (33.1)	48 (51.6)	102 (39.8)	0.044
Do-not-resuscitate	15 (9.2)	4 (4.3)	19 (7.4)	0.147
Total	163 (100)	93 (100)	256 (100)	

\*Chi-squared test.

only one chart, in 1994. In the eight (7.8%) charts in which the mode of death was W/W, the following was written: "comfort care only", "decided to reduce ventilatory measures", and "decided to withdraw vital support". In the 2002-2005 cohort, there were seven orders to limit therapeutic activities. In 92.6% of the charts, the charts from both cohorts, no specific order was found.

### Pain and distress relief

In the 1992-1995 cohort, the charts of 151 (9.6%) infants mentioned the use of a neonatal pain scale; 123 (75.5%) and 71 (43.6%) infants received opioids and sedatives, respectively. In the 2002-2005 cohort, the charts of 89 (95.7%) infants mentioned the use of a neonatal pain scale; 71 (76.3%) and 54 (58.1%) infants received opioids and sedatives, respectively (Table 3).

### Family support

In the later cohort, 28 (30.1%) charts mentioned a chaplain visiting the NICU. Permission for siblings and other family members to freely visit the infant was documented in 30 (32.3%) charts. There was no referral to psychosocial family support or support groups (Table 4). The reviewed charts focused on the neonate's physical condition and therapeutic procedures; the emotional support provided by the caregivers (physicians and especially nurses) to the neonate, parents, and others family members during the grieving process was not recorded.

### Decision-making

There were no data regarding parental participation during decision-making. However, 56 (60.2%) charts in the 2002-2005 cohort mentioned that the parents had meetings with their neonatologists to discuss the clinical situation of their infants. In the first cohort, 62 (38%) parents communicated with their neonatologists ( $p < 0.001$ ). Regarding the involvement of other entities in the decision-making

**Table 2 - Therapeutic activities in the final 24 hours in the two cohorts.**

Therapeutic activities in the final 24 hours	1992-1995	2002-2005	Total	p-value*
	n (%)	n (%)		
Ventilation	151 (92.6)	89 (95.7%)	240 (93.8%)	0.331
Antibiotics	123 (75.5)	71 (76.3%)	194 (75.8%)	0.563
Inotropics	71 (43.6)	54 (58.1)	125 (48.8)	0.056
Peritoneal dialysis	1 (0.6)	2 (2.2)	3 (1.2)	0.311
Parenteral nutrition	37 (22.7)	28 (30.1)	65 (25.4)	0.256
Enteral nutrition	26 (16)	16 (17.2)	42 (16.4)	0.549

\*Chi-squared test.

process, some of the reviewed charts mentioned interdisciplinary meetings to discuss better intervention plans or the solicitation of an ethics committee. An appeal to the Minor Court was found in one chart in the 1992-1995 cohort.

**Parental presence during infant death**

In 20 (25.1%) of the reviewed charts in the 2002-2005 cohort, one or both parents were with their infant when death occurred, as compared to 3.7% in the first period ( $p < 0.001$ ). Fifty-four (58.1%) parents in the 2002-2005 cohort did not want to be present during the infant's death. In 19 (20.4%) charts, there were no data regarding parental communication concerning the death of their infant.

**DISCUSSION**

In this study, we found that more than half of the newborns died within the first six days of life and that neonatal palliative care was rarely offered in the NICU. However, there appears to be a strong tendency to not hasten the dying process of a child facing imminent death by withholding and withdrawing medical interventions, which causes more harm than benefits to the neonate and family. This tendency is consistent with published European studies, in our opinion.<sup>3-9</sup> Additionally, in 92.6% of the charts, no clear written orders to discontinue life support or withhold resuscitation were found, which has also been previously reported.<sup>13,14</sup> Nevertheless, even as caregivers have more regularly given life-limiting therapeutic orders in the 2002-2005 cohort, it remains crucial to have explicit records and written institutional policies permitting the forgoing of life-supporting treatment of neonates in terminal situations. In this context, the American Academy of Pediatrics<sup>15</sup> has stated that when a life-sustaining medical treatment is to be forgone, the attending physician should write an order in the medical record, and the chart notes must include the following information: the diagnosis, the prognosis, or other decisions, the contents of any meetings with the involved parties, any disagreements or unresolved issues, and the recommendations of the treatment team and any consultants.

Despite recent advances in neurobiology indicating that fetuses and newborns are able to experience acute, persistent or chronic pain and express abnormal biochemistry as well as physical and behavioral changes during pain, neonates in the NICU remain vulnerable to many invasive therapeutic procedures without adequate pain relief.<sup>16</sup> Although we observed the development of a neonatal pain scale assessment tool and a significant increase in the administration of pain and discomfort medication one decade later, 25.8% of the infants under life-limiting conditions did not receive any sedatives or opioids during their dying processes (Table 3). Today, sedation and analgesia are widely used in neonatal procedures and in situations that require comfort or palliative care.<sup>26</sup> Additionally, 95.7% of the infants remained connected to a ventilator until death, 76.3% received antibiotics, and 58.1% received inotropics. These procedures involve repetitive secretion aspiration, tracheal intubation or frequent and potentially painful intravenous punctures. These results show that our NICU urgently needs to develop neonatal palliative care, adopt guidelines and maintain regular staff education to improve the end-of-life care of newborns. Wolfe et al.<sup>11</sup> and McCallum et al.<sup>10</sup> reported the introduction and persistence of submitting children to

**Table 3 - Pain and distress management.**

	1992-1995	2002-2005	Total	p-value*
	n (%)	n (%)		
Neonatal pain scale	151 (9.6)	89 (95.7)	240 (93.8)	<0.001
Administration of opioids	123 (75.5)	71 (76.3)	194 (75.8)	<0.001
Administration of sedatives	71 (43.6)	54 (58.1)	125 (48.8)	0.007

\*Chi-squared test.

aggressive procedures until death. A new attitude toward the concept of total pain as a life-limiting condition in the NICU is needed. Appropriate environmental, behavioral, and pharmacological approaches to prevent, reduce, or eliminate the pain and discomfort of neonates at the end of life should be provided. Educational programs should be promoted to improve caregivers' pain and symptom assessment and management skills. Institutional policies and NICU guidelines for the management of neonatal pain under life-limiting conditions should also be implemented.

Providing compassionate and family-centered end-of-life care to infants and their families in the NICU should be a mandatory component of optimal neonatal palliative care.<sup>12</sup> Honest and complete information, adequate communication, careful coordination, emotional expression and support by the staff, preservation of the integrity of the parent-child relationship and support of religious faith are important priorities that have been identified by grieving parents.<sup>17</sup> When a child dies, the family needs intense and long-term psychosocial support as well as cultural and spiritual comfort. Nevertheless, no charts documented any emotional and social support given to families or referrals to grief counseling groups.<sup>14</sup> A neonatal death in the NICU results in a great deal of spiritual distress and can initiate a serious crisis of meaning and connection, which highlights the need for religious and spiritual support to families and caregivers.<sup>18</sup> Our data support the findings of Robinson et al.<sup>19</sup>, who stated that parents draw on and rely on their spirituality to guide them during end-of-life decision-making, to find meaning in their loss, and to sustain them emotionally. One decade later, we observed a major increase in the number of chaplain interventions in response to families' spiritual needs, which suggests more acceptance and integration of spiritual issues during end-of-life care in the NICU and emphasizes the significance of having access to a clergyperson as an important part of good care. Facilitating sibling visits or asking parents for other relatives to join them in the NICU is an opportunity to evaluate family dynamics, integrate the family into the dying process. In the final four years of the study, we observed a

**Table 4 - Family support.**

	1992- 1995	2002-2005	Total	p-value*
	n (%)	n (%)		
Chaplain/spiritual counselor	16 (9.8)	28 (30.1)	44 (17.2)	<0.001
Psychosocial support	0 (0.0)	0 (0.0)	0.0 (0.0)	
Visitation by siblings or other family members	19 (11.7)	30 (32.3)	49 (19.1)	<0.001

\*Chi-squared test.

higher frequency of visits by siblings and other family members. However, no charts documented how the siblings and other relatives coped with the death, although sibling support is an important component of compassionate and holistic neonatal palliative care.<sup>20</sup>

Access to honest and complete information, appropriate communication, and coordination of care are important priorities that have been identified by parents to achieve quality care under end-of-life conditions.<sup>17,21,22</sup> One decade later, our data revealed a positive evolution in the communication between parents and their neonatologists. Although this issue is critically significant in defining what is in the child's best interest, no charts documented parental involvement in decision-making. Additionally, we found no information concerning interdisciplinary meetings, although it has been found that the parents are critically important to the proper management of the illness.<sup>20</sup> The opinion of an ethics committee was not sought in any of the charts in our study, consistent with a study by Cook and Watchko.<sup>23</sup>

Their physical presence during infant death is a spiritual need felt by grieving parents.<sup>24</sup> Our data showed that in the final four years (more than in the previous decade), 21.5% of the parents were present at the moment of death, which suggests better support and preparation for infant death. Meert, Thurston and Sarnaik showed that more than 50% of parents studied stayed with their child in the PICU at the time of death. Although none regretted being present, 63% of the parents who were not present later wished that they had been present.<sup>25</sup>

## CONCLUSION

Despite an increase in the withholding of therapy and reduction in therapeutic approaches, and improvements in pain management and family support, a large number of neonates in intensive care units still receive curative and aggressive treatments at the end of life. Additionally, psychosocial support for families and bereavement follow-up care, such as interdisciplinary meetings for discussing the best intervention plan to follow, are woefully lacking. A holistic and specialized team approach to care for newborns with life-limiting diseases is suggested to improve the conditions of the infants and families during the dying process. Caregivers should be trained in the basic principles of pediatric palliative care and should be prepared with the skills, confidence and expertise to provide consistent and high-quality end-of-life care. This research concerns only what was documented in neonatal charts; therefore, we cannot know if additional measures were taken during the actual care of the infants and their families. However, it is crucial that consistent and complete documentation be taken during end-of-life care. Research into the care of infants who do not benefit from intensive and life-extending support is needed to develop action plans that ensure that every child receives the best possible care, regardless of the outcome.

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