

Perinatal hypoxic-ischaemic encephalopathy: a national survey of end-of-life decisions and palliative care

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ABSTRACT

Objective To explore end-of-life (EoL) decision-making and palliative care in hypoxic-ischaemic encephalopathy (HIE) nationwide.

Methods A cross-sectional national study on moderate-to-severe HIE in newborns ≥ 35 weeks' gestational age in 2015, including all 57 level III units that offered hypothermia. Forty-one questions were included to explore how the prognosis is established, as well as timing of the decision-making process, and also how ongoing palliative care is offered.

Results The main difficulties in EoL decisions lie in the scarce time to make an early, accurate prognosis. Only 20% shared the neurological prognosis with the parents within 72 hours of life, and in only a third of the centres is the nurse present when the prognostic information is given to the family. Almost 50% do not use protocols to order the EoL process. Practically, all centres (91%) reported taking into account the wishes of the parents. However, in 30% the team does not always reach consensus on how the withdrawal process. Specialised psychological support is available in 54% of the hospitals; in more than 50%, interviews are not arranged to examine the grieving process with parents.

Conclusions There are four areas for improvement in the comprehensive, multidisciplinary approach to the EoL decision in the patient with HIE: (1) the need for EoL and interdisciplinary palliative care protocols, (2) participation of nurses in the process and improvement in the nurse-physician communication, (3) psychological support for parents involved in the EoL decisions and (4) implementation of strategies to give support during the grieving process.

INTRODUCTION

Hypoxic-ischaemic encephalopathy (HIE) after birth asphyxia is a major cause of death and disability worldwide. The reported incidence of HIE is imprecise even in developed countries, which hinders understanding of the burden of HIE, with estimates from 1 to 2 per 1000 live births in wealthy countries, but as high as 26 per 1000 live births in underdeveloped countries.^{1,2} Therapeutic hypothermia (TH) is now well established as standard treatment for infants with moderate-to-severe HIE but is only partially effective; up to 25% of infants with neonatal HIE die during the neonatal period.³

The vast majority of deaths in perinatal HIE are preceded by withdrawal of life-sustaining therapies.^{4,5} There are no national data about the process of end-of-life (EoL) decisions in infants with HIE. However, understanding when, how and why these decisions are made nationally is crucial to accurate interpretation of the mortality data in this disorder.

A survey was carried out in Spain using a questionnaire sent to all 57 level III units that offered TH for HIE, exploring (1) the process of EoL decision-making and (2) palliative care.

METHODS

We conducted a cross-sectional national study of moderate-to-severe HIE in newborns ≥ 35 weeks gestational age. All public and private level III neonatal and pediatric-neonatal units were contacted in 2015; each clinical head of neurology was asked to describe the care practice of the team but not personal considerations. All respondents were clinicians involved in the management of infant with HIE.

The questionnaire was divided into two parts: (1) the process of EoL decision-making (questions 1–26) and (2) the process of palliative care (questions 27–41).

In the first part of the questionnaire, in that the EoL decision is often based on a poor prognosis, we explored how this prognosis is established and on what evidence it rests. In addition, we explored the difficulties of the different teams in establishing the prognosis. And finally, we explored the timing of the decision-making process, particularly the window of opportunity.⁶

In the second part of the questionnaire, we explored how ongoing palliative care is offered once the EoL decision is taken, and some questions about postmortem family support and necropsy.

RESULTS

The collected data on the processes of EoL decision-making and palliative care in the setting of HIE are presented in [table 1](#).

Centres used most of the tools with proven prognostic value including neurological exam (100%), conventional or amplitude-integrated electroencephalography (90%), and neuroimaging (MRI 77% and ultrasound-Doppler 80%).

Most hospitals emphasised that the main difficulties in EoL decisions lie in the scarce time allowed to make an early and accurate prognosis. Only 20% shared the neurological prognosis with the parents during the window of opportunity (within 72 hours of life). Importantly, in only about a third of the centres is the nurse always present at the meeting where the prognostic information is given to the family.

Almost half of the centres do not use specific protocols to order the EoL process, and in 80% of them, the opinion of an ethics committee is rarely, if ever, involved. Practically, all centres (91%) reported taking into account the wishes of the parents.

Once the EoL decision has been taken, nearly all centres (95%) look for consensus with the team and the family on how to perform the withdrawal process. However, in one-third of the centres the team does not always reach consensus on how to carry out the withdrawal process.

There are no restrictions on how parents can properly bid farewell to their children in most centres. Specialised psychological support is available in only 54% of the hospitals, and in more than half of the centres, interviews are not arranged to examine the grieving process with parents.

DISCUSSION

In Spain, there is no specific legislation regulating the withdrawal or suspension of treatment in EoL care or in critically ill patients on life support.⁷ However, different scientific societies, including the Spanish Society of Neonatology, have developed guidelines for good medical practice, emphasising that critically ill babies exercise their autonomy through the parents because they cannot make their own medical decisions.⁸

In this context, withdrawing or withholding life support when considered futile is considered a good clinical practice.^{8,9} Accordingly, EoL decisions in infants with HIE in Spain take place in the confidential context of the doctor–patient relationship, and our study has shown that parents are involved in the process.¹⁰ Practically, all centres (91%) reported taking into account the wishes of the parents, and unlike what has been reported for extremely preterm neonates, sociodemographic characteristics of the family are not considered in establishing the EoL decision in infants with HIE.¹¹

Infants with HIE who die following an EoL decision must have clinical findings consistently associated with very poor prognosis.^{5,12} However, considerable uncertainty about the likelihood of survival or severe impairment nearly always exists, and outcome prediction is substantiated by a combination of clinical, neurophysiological and neuroimaging examinations.¹³ This study provides a detailed panorama of complementary studies in infants with HIE to establish what is involved in the consideration of EoL nationwide.

Wilkinson coined the concept of ‘window of opportunity in severe brain injury’ as a period of time during which infants with severe HIE may be able to survive with life-sustaining treatment, and delays in decision-making may result in independence from ventilation or inotropes after a few days. The timing of EoL decision-making in HIE involves a balance between greater prognostic certainty and a perception of ‘urgency’ regarding a short ‘window’ of opportunity when withdrawal of mechanical ventilation due to diminished respiratory effort is still possible.⁶

EoL decision-making is a complex challenge. Accordingly, it is not surprising that most hospitals in this survey emphasised that the main difficulties in EoL decisions lie in the scarce time available to make an early and accurate prognosis; most of the centres reported that they shared the neurological prognosis with the parents after 72 hours.

Centres indicated that the decision-making process was established after a joint session with other members of the unit, although only half of the centres use specific protocols to order the EoL process, and local ethics committees are rarely involved. Given the difficulties inherent in EoL decisions, we believe that a systematic, protocolised approach with the participation of bioethicists and the palliative care service would facilitate EoL decision-making within 72 hours.

An important revelation of this study is that in only about a third of the centres is the nurse almost always present at the moment of giving the prognostic information to the family. This is worrisome because it indicates that in our environment the significant role of the nurse as a fundamental source of information and continued support to families of newborns in TH is underestimated.¹⁴ Furthermore, it suggests that in most centres, there is no open, effective communication among professionals, which can hinder the construction of an interdisciplinary collaborative relationship. A strong doctor–nurse relationship is

Table 1 Questions regarding end-of-life decision-making and palliative care in the infant with hypoxic-ischaemic encephalopathy

	Almost always	Often	Rarely or never
In the decision-making process, do you use the information from			
1. The neurological exam?	54 (96)	2 (4)	0
2. The amplitude-integrated electroencephalogram?	43 (77)	7 (12)	6 (11)
3. The MRI performed within the first week?	28 (50)	15 (27)	13 (23)
4. The brain Doppler-ultrasound?	31 (55)	14 (25)	11 (20)
5. The conventional electroencephalogram?	41 (75)	9 (16)	5 (9)
6. Any neurobiochemical markers of brain damage?	3 (5)	5 (9)	48 (86)
7. The perinatal data (cord blood pH, Apgar score, resuscitation)?	17 (30)	17 (30)	22 (39)
8. An expert opinion (neonatologist or neuropediatrician)?	43 (75)	11 (19)	3 (5)
9. The wishes of the parents or legal guardians?	52 (91)	5 (9)	0
10. The socioeconomic status of the family?	3 (5)	9 (16)	44 (79)
11. Your knowledge of and experience with HIE?	41 (72)	15 (26)	1 (2)
12. Your own personal beliefs and/or moral values?	6 (11)	10 (18)	40 (71)
13. The opinion of an ethics committee?	3 (5)	8 (14)	45 (80)
In the decision-making process do you encounter difficulties due to			
14. The scarce time of life elapsed?	21 (38)	18 (32)	17 (30)
15. Uncertainty about the prognosis?	24 (42)	26 (46)	7 (12)
16. A discrepancy in the information concerning the different tools?	12 (21)	22 (39)	23 (40)
17. Limitations in your knowledge of and experience with HIE?	6 (11)	18 (32)	32 (57)
18. Differing opinions with other colleagues?	6 (11)	16 (28)	35 (61)
19. Disagreement between the two parents?	2 (4)	10 (18)	44 (78)
20. Personal emotional consideration?	2 (4)	9 (16)	45 (80)
21. The lack of communication techniques to improve the empathic relationship with the family.	9 (16)	18 (32)	29 (52)
22. The lack of teamwork techniques.	9 (17)	20 (37)	25 (46)
In the decision-making process, the information			
23. Given to parents is done with the nurse in charge of the child present.	18 (31)	29 (51)	10 (18)
24. Is shared with parents after a joint session with other colleagues.	36 (63)	16 (28)	5 (9)
25. Is shared with the parents between 24 and 72 hours of life.	12 (21)	22 (39)	23 (40)
26. Is shared with the parents after 72 hours of life.	26 (46)	20 (36)	10 (18)
Once the EoL decision is taken and palliative care is offered			
27. Is the process carried out using a specific protocol?	28 (51)	12 (22)	15 (27)
28. Do you use a dedicated location?	25 (44)	9 (16)	23 (40)
29. Is there a consensus in the team on how to perform the process (removal of monitoring, drugs, ...)?	40 (70)	14 (25)	3 (5)
30. Is there a consensus with the family on the process: withdrawal of devices, drugs, monitoring, etc?	35 (62)	19 (33)	3 (5)
31. Are all medications withdrawn except for sedoanalgesia?	42 (74)	13 (23)	2 (3)
32. Can parents take their children in their arms if they wish?	56 (98)	1 (2)	0
33. Are there restrictions on parents staying with their children?	3 (5)	3 (5)	51 (90)
34. Are parents offered religious support?	27 (47)	8 (14)	22 (39)
35. Are parents offered specialised psychological support?	15 (26)	16 (28)	26 (46)
36. Is there a continued presence of the physician during palliative care?	38 (66)	18 (32)	1 (2)
37. Can parents change their minds and take back the EoL decision?	2 (3)	3 (5)	52 (92)
If the infant dies as a result of an EoL decision			
38. Are interviews arranged with parents to examine the mourning process?	14 (25)	12 (21)	30 (54)
39. Is necropsy requested in the newborn who dies?	30 (54)	12 (21)	14 (25)
40. Is the result of the necropsy explained in a meeting with parents?	33 (59)	14 (25)	9 (16)
41. Is the result of the necropsy discussed in a collective session?	19 (34)	19 (34)	18 (32)

EoL, end of life; HIE, hypoxic-ischaemic encephalopathy.

essential to establish therapeutic support for the family, improved application of palliative care and contributes to an appropriate ethical climate that protects professionals from experiencing moral distress.^{8 15}

Once the EoL decision had been taken, nearly all centres looked for a consensus on how to perform the withdrawal process with the team and the family. However, in one-third of the centres the team does not always reach consensus on the withdrawal process, and the decision depends only on the patient's doctor.

Withdrawal is a difficult time for parents and professionals. Interdisciplinary dialogue and trust are the keys to collaboratively addressing this challenge.^{8 9} There are no restrictions regarding how parents can properly bid farewell to their children in most centres, but specialised psychological support is available in only 54% of the hospitals, and postmortem interviews are not arranged to examine the grieving process with parents in more than half of them. Death of an infant is a painful loss, provoking intense, long-lasting grief, and our data indicate that in our environment many families do not receive specialised support during the palliative care nor follow-up support or care during their grieving process, including counselling and psychoeducation for parents, siblings and grandparents.

Despite the intrinsic limitations of a survey, this study has the virtue of including all the hospitals that admit cooled infants with HIE in a Mediterranean region. National studies on EoL decisions and palliative care in patients with HIE may detect areas for improvement in this complex process in a highly emotional context shortly after birth, including how to achieve the best accurate prognosis, continuous discussion in the team and interprofessional collaboration culture and communication with parents.

Our study reveals four important areas for improvement in the comprehensive, multidisciplinary approach to EoL decision-making in the infant with HIE: (1) the need for EoL and palliative care interdisciplinary protocols; (2) participation of nurses in the whole process and improvement of nurse-physician communication; this is particularly relevant in Mediterranean countries with limited interprofessional collaboration traditions; (3) psychological support for all parents of infants with HIE involved in EoL decisions; and (4) the implementation of strategies to provide support during the grieving process.

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