

End-of-life Decision-Making in Neonatology: The Role of Nurses and Parents

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ABSTRACT

Background: End-of-life decision-making is highly stressful for nurses, faced with ethical dilemmas and great discrepancies between their anticipated and actual role.

Study Aim: To explore the perception of nurses in a neonatal intensive care unit of a tertiary hospital regarding ethical decision-making and the role of the parents involved.

Methods: A prospective, cross-sectional study with a sample of 79 nursing staff using a mixed-method (qualitative and quantitative) approach. Participants completed ad hoc questionnaire.

Results: 75.9% of respondents were caring for infants in the treatment withdrawal process. 84.9% of nurses somewhat, or strongly, agreed that all staff should be involved in the process. Regarding the timing of the treatment withdrawal, 83.5% of respondents believed that the decision is excessively delayed. 91% of nursing professionals believed that their opinion should be considered in the end-of-life decision process. 73.4% believed that the child's welfare is not currently prioritized. For 84.8% of subjects, parents should be actively involved in decision-making processes regarding treatment withdrawal.

Conclusion: Results of this study demonstrate that neonatal intensive care nurses demand a more active role in decision-making during end-of-life and defend the participation of parents. Efforts should be made to improve the participation and communication within these units.

KEYWORDS

Bioethics; End-of-life decision; Humanization of Assistance; Neonatal Nursing, Parental Consent; Treatment Withdrawal.

INTRODUCTION

Scientific and technical advances applied to the field of neonatology have led to the development of improved intensive care treatments for newborns at risk of increasingly complicated health problems, such as congenital malformations, hypoxic-ischemic events and, in particular, extreme prematurity. Therefore, the resuscitation of preterm infants of under 24 weeks gestation age (GA) is no longer considered exceptional

in developed countries. The increase in our ability to intervene has equaled improved survival rates for these children, however the incidence of serious sequelae has not significantly decreased.

In 2012, the Spanish Society of Neonatology (SENeo) published its recommendations on decision-making at the end of life in neonatology, establishing categories of patients susceptible to limitation of therapeutic effort (LTE) [1]. These categories in-

clude: 1. Children born at the limit of viability (gestational age <24 weeks GA). 2. Congenital anomalies incompatible with life. 3. Children with diseases that do not respond to intensive care and who will, therefore, most likely die in a short term. 4. Children who may survive with permanent dependence on invasive life support. This categorization contrasts with the survival and sequelae data of preterm babies available at that time. In the Epicure 2 trial, conducted in England on a cohort of 952 preterm babies less than 26 weeks GA in 2006, an increase in survival in all age groups was observed, compared with the cohort of the first phase this study, collected in 1995 [2, 3]. Thus, survival is exceptional below 23 weeks GA and survivors suffer from the most serious side effects. Between 23 and 24 weeks GA, 10% of those admitted to intensive care survived with moderate or severe disability at 6 years of age. In the 1995 cohort, survival preterm babies between 24 and 25 weeks GA receiving intensive care represented 34%, and half of the survivors had moderate or severe disabilities. In the cohort of 2006, the survival of this group increased by 12%, with no evidence of changes in morbidity. Over 25 weeks GA there has been a significant increase in survival, from 54% to 67%, among the groups studied between 1995 and 2006. The figures for survival and morbidity among different age groups does not allow for the detection of qualitative differences, and thus, gestational age becomes a criterion for establishing one of the assumptions of LTE.

A recent study published by the SEN1500 group on behalf of the Spanish Society of Neonatology (SENeo) has revealed the incidence of serious sequelae in the population of preterm infants in Spain over recent years. According to the results of this population-based study, the survival rate without major morbidity, which includes major brain damage (MBD), bronchopulmonary dysplasia (BPD), retinopathy of prematurity (ROP), necrotizing enterocolitis (NEC) and early or late onset sepsis, is 2.6% at 24 weeks GA, 5.1% at 25 weeks GA and 9.6% in babies born at 26 weeks GA. If we consider only the MBD, BPD and/or ROP, the survival without sequelae is 9.5%, 19% and 29.9% for 24, 25 and 26 weeks GA, respectively. These results show that the chances of healthy survival below 25 weeks of gestation is very low [4]. Thus we find discrepancies between the available evidence and the recommendations on the limit of viability concept.

End-of-life decision-making in the newborn population who are within the limits of viability is highly complex, with medical, ethical, social and cultural implications that impact the balance between survival and quality of life. The changing parental role in neonatal units over the final years presents a challenge to professionals who seek to include them in ethi-

cal and end-of-life decisions. Moreover, the role of the different professionals involved in patient care remains unclear, especially the role of the nurse, who is the professional who spends the most time with both the child and family. In this sense, the SENEo has issued a statement regarding the role of parents: *“Parents are generally the best ‘lawyers’ of their children and in most cases wish to actively participate in end-of-life decisions, however they need information that is accurate, comprehensive, honest and understandable”*. Concerning the role of the nurse, this institution states: *“the importance of the participation of the nurse who is responsible for the patient in the process of deliberation and decision-making is vital, as nurses contribute towards a better understanding of the parents’ values of parents as well as the circumstances and the social and family and social context”* [1].

Because of this incoherence in the definition of the limits of viability and the indefiniteness of the different roles of the stakeholders, we sought to explore the perceptions of the nursing staff in the neonatal intensive care unit (NICU) of the University Hospital La Paz in Madrid, Spain, on the process of end-of-life decision-making, focusing on aspects related to both the role of nurse and the role of parents.

MATERIALS AND METHODS

We conducted a prospective cross-sectional study combining qualitative and quantitative methods, based on an ad hoc questionnaire. The study population comprised the nursing staff (nurses and nursing assistants) of the NICU at the University Hospital La Paz, which is a third level unit with 23 beds. The questionnaire consisted of 3 parts. The first part included 8 demographic questions, exploring sex, age, number of children, work experience and previous involvement in neonatal care at the end of life. The second part consisted of 10 items written in the form of statements, for which subjects were asked to express their degree of agreement or disagreement using a Likert scale. These sought to evaluate two further factors: the decision-making process and the role of parents in end-of-life decisions. The third part of the questionnaire, dealt with qualitative aspects, via two open questions, *“What do you think should be improved in the decision-making process of the LTE?”* and *“What do you think the role of parents should be in decisions on continuing or stopping treatment for their children?”*

Questionnaire responses were tabulated onto a spreadsheet and analyzed using SPSS® program version 18.0. The answers to the open questions were transcribed to a text file and were analyzed by the study authors using qualitative content analysis procedures.

This research study has respected the ethical principles of biomedical research issued in the declaration of Helsinki. Participation in this study was voluntary and confidentiality was ensured at all times based on de-identification of all data.

RESULTS

In total, 79 subjects participated in this study, of which 62 were nurses (78.5%) and 14 were nursing assistants (17.7%). Three participants (3.8%) did not indicate their professional status. In total, 90% of all nurses in the NICU responded to the questionnaire.

The sample consisted of 77 women (97.5%) and 2 males (2.5%). Additional demographic data are shown in Table 1

Table 1: Demographical profile of respondents.

	Nurses	Nurse assistants	Total
Mean Age (SD)[min-max]	34.2 (8.07) [25-61]	37.3 (8.7) [27-60]	34.7 (8.12) [25-61]
Mean work experience (SD)[min-max]	11.9 (7.72) [2-38]	11.7 (5.34) [1.5-20]	11.7 (7.26) [1.5-38]
Mean Experience in neonatology (SD) [Min-Max]	8.8 (7.61) [0.3-38]	9.2 (8.47)[1.5-36]	8.7 (7.61)[38-0.3]
Provided palliative care in neonatology	-	-	-
YES	87.1% (54)	85.7% (12)	86.1% (68)
NO	11.3% (7)	14.3% (2)	12.7% (10)
Lost data	1.6% (1)	-	1.3% (1)
Provided end-of-life care in neonatology	-	-	-
YES	74.2% (46)	85.7% (12)	75.9% (60)
NO	22.6% (14)	14.3% (2)	21.5% (17)
Lost data	3.2% (2)	-	2.5% (2)

Degree of Agreement Regarding Decision-Making among Nursing Staff

In total, 95% of respondents agreed that the decision to continue or to limit treatment should be carried out with the participation of the entire health care team. Up to 81% of nursing staff considered that their opinion concerning end-of-life decisions was not at all valued. When asked whether they would like their opinion to carry more weight in decision-making, 82.3% were in favor. Furthermore, 93.6% of respondents agreed with the statement “not all staff is involved in end-of-life decisions”. Finally, 89.8% of nursing staff agreed that end-of-life decisions regarding severely ill children takes too long. This was met with 83.5% of the total respondents who somewhat or strongly agreed with this statement.

The factor analysis enabled us to group the five questionnaire questions on the decision-making process into three dimensions: the role of parents in end-of-life decisions, the amount of time involved in deciding upon LTE and the value of their opinions. Regarding the first dimension, 84.9% of nurses somewhat, or strongly, agreed that all staff should be involved. Concerning the time factor regarding the LTE, 83.5% of the sample believed that this decision is often delayed too much. Finally, 91% of professionals believed that their opinion should be taken into account in the end-of-life decision-making process.

Role of Parents in Ethical Decision-Making

Up to 59.5% of professionals agreed that the welfare of the child is not taken into account in end-of-life decisions. For 77.2% of respondents, parents are not well informed of the clinical status or the therapeutic options available for their children when end-of-life decisions are raised.

In total, 76% of nurses agreed that parents need to be actively involved in the decision-making process. Also, 69.7% of professionals disagreed on the fact that, because of their personal involvement, parents should not participate in the ethical decision-making process. Only 49.4% of the subjects in our sample agreed that the parents should have the final word regarding either to continue treatment or to limit it.

The factor analysis of the five items related to the role of parents has allowed us to group the results into two dimensions: the clinical status of the newborn and end-of-life decisions, and the parent’s involvement in ethical decisions. In relation to the former, 73.4% of nurses believed that the child’s welfare was not the most highly prioritized aspect in end-of-life decisions. For 84.8% of subjects in the sample, parents should be actively involved in the decision-making process when treatment withdrawal is contemplated.

Qualitative Analysis

In order to perform the qualitative analysis, we divided the sample by experience levels, setting a cut-off at 5 years of experience, so that the sample was divided into junior or senior staff.

Junior Staff and the Global Perception of the Decision-Making Process

Regarding the time it takes to reach the decision of treatment withdrawal, there was a broad consensus that this process currently takes too long: “currently there are delays and it is virtually the children themselves who decide to ‘self-limit’”. The need to reduce the time of decision-making was also raised. Reference was even made to issues such as the wait

for additional studies or tests that delay this decision, *“And above all it should be done at the right time, not waiting for diagnostic studies or tests that could be performed after death”*.

The information provided to parents also appeared as an element of consensus among the subjects in this group, as almost all mentioned in their answers that parents must be provided with appropriate and comprehensive information of the current situation and its consequences: *“[...] sometimes parents are not informed in a clear and understandable way, making it really difficult for them to make a decision”*. Furthermore, some participants commented that such information should be given with the participation of the nursing staff: *“There is a need to inform parents in the presence of the nursing staff, in order to make a multidisciplinary intervention of accompanying and supporting parents during such a crucial time. Planning and developing a communication strategy with parents is important, to enable clear information and feedback”*.

Half of the subjects in this group stated that they felt that it was important that such decisions be taken as a group, whereas all subjects spoke of the importance of nurses participating in this process. In some cases the role of the psychologist is taken into account even if the family is part of the team. *“It is essential that the decision is made by involving both parents and the health team (nursing staff, doctors, etc.)”*.

One important element appearing in the responses of several subjects includes concerns about the child’s comfort, specifically, the suffering experienced due to the deteriorating situation *“[...] there is no need for the child to have to suffer”*, as well as the importance of ensuring that the child does not suffer in the withdrawal process: *“Ensuring at all times the welfare of the child”*.

Senior Staff and the Global Perception of the Decision-Making Process

There was a broad consensus among respondents that withdrawal decisions should be taken as a team, furthermore ideas were shared regarding how specific sessions should be performed. *“Health care team meetings should include parents and a member of the clinical ethics committee who knows our cases. All cases should be treated, not only in one meeting, but in several and with the participation of nurses. Thus the nurse who knows the child the best and other nurses who have had contact with the family should attend, plus any other nurses who wish to attend”*. Parents are also incorporated as active team members; *“Fundamentally, this should take into account all staff that cares for the child on a daily basis, along with the parents”*, *“The team should be diverse, with inter-related people who are well-prepared on the subject. This is in addition to the professionals who directly care for the child, along*

with the parents.”

Within the composition of the multidisciplinary team, according to many of the responses made by the group, it appeared that there was a need for the clinical ethics committee to be involved in this decision. *“Frequent multidisciplinary meetings are required in reaching a decision, together with the contribution of a team of ethical advisors.”*

Another element on which there was broad consensus was the issue of information. Again adjectives were used such as ‘truthful,’ ‘adequate’ and ‘comprehensive’. Parents are positioned as targets of this information, predominantly: *“information to parents [is needed] regarding the real state of their baby and the real consequences that the baby will have in the future if the baby does not die and also regarding the anticipated state of deterioration”*. *“I believe the information given to parents fails from the beginning, not only when death is imminent, I think that, sometimes, they are not aware of the seriousness of their child’s condition until the end, and that makes it more difficult for them to process, understand and cope with”*. There were also comments regarding appropriately informing nurses of the process. *“More information should be provided to the team about the process of the disease and the withdrawal process”*.

Many references to communication between the team appeared, citing that at present this was inadequate. *“The problem is the lack of communication between parents / medical / nursing staff and even among ourselves (failed teamwork) which means that there is no continuity of care. I think in these situations, more than ever a specific team needs to monitor the patient, and thanks to the teamwork, this will allow them to follow the same path”*.

Concerning the time that these decisions are made, there is a general consensus that the total time involved in decision-making must be reduced in order to avoid prolonging the suffering of the children and their families. *“Often, this decision is excessively prolonged over time, thus prolonging the suffering of our patients and their parents”*. The delay is directly associated with greater suffering in the child. *“Withdrawal decisions come with delays, leading to the continued suffering of the baby”*. Several respondents spoke of issues surrounding therapeutic obstinacy: *“I think the decisions are taken too late, so that an great amount of therapeutic obstinacy occurs”*.

In this regard references were made to the emotional costs associated with therapeutic obstinacy: *“Many times nurses don’t agree and do not like to participate in the therapeutic obstinacy, this is overwhelming and ends up affecting us emotionally. We do our job, despite disagreeing. I need the option*

to object and not participate in this therapeutic cruelty”.

The opinion of the majority was that the child’s welfare should guide the process. *“The future quality of life for the child must be taken into account more; the suffering endured by the baby and family [...]”*.

Junior Nurses and Role of Parents

Among the most novice nurses there was a lack of uniformity in their responses, even observing dichotomous stances on the subject; *“I think they must be well informed by the team to take the best decision. They have the last word [...]”* versus *“[...] I think the medical staff should have the last word”*.

Perhaps the unique feature of the reports in this group lies in placing the final decision on the medical team. Thus, we read that: *“It is very hard to decide and even more so if it is about your son. That decision should be only for medical staff”* or *“participatory only up to a certain extent. They [the parents] should not have the last word, They should not carry that responsibility on their conscience. It is a responsibility of health personnel [the doctor]”*. This position was not shared by all the participating nurses; *“The most important thing is that parents are not left with a passive role as ‘spectators’ in which they are only informed of the procedures that are done to their children. They must participate in the decision making concerning the same”*.

Among the reasons to argue that the decision relies primarily upon the medical community, parental subjectivity is underlined: *“I think they should be part of the team right from the start, but in a passive way, as they are not objective enough to take the correct decisions”*.

Senior Nurses and the Role of Parents

Within the group of senior nurses, again, the dispersion in the answers was evident. Ranging from positions that claim that, *“parents should be well informed and have the final decision to accept or reject the proposal made by the health workers [...]”*, to others that are exactly the opposite: *“decisions by the multidisciplinary team, should be objective and based on consensus, where feelings do not affect that final decision”*.

The decision to limit the role of parents in decision-making is focused primarily on eliminating the pressure on parents and to avoid the suffering caused by these decisions, *“[...] for a parent to decide upon the death of his or her son, this is something that is difficult and we shouldn’t burden them with this responsibility for the rest of their life”*.

Among the group of senior professionals two new concepts appeared. First, the quality of life of the newborn: *“[...] de-*

pending on whether they are trained and informed regarding the situation of their children, and always prioritizing above all the welfare and quality of life of the baby, however, I think their role is of great importance, it is their children and we should put ourselves in their place more often so that, if they are not trained in making an important decision, we facilitate as much as possible” and *“offer realistic information options to continue or discontinue [treatment] always considering what is best for the child, [...] parents should express their feelings, expectations and wishes and leave this information for the caregivers to act accordingly”*. Second, the ethical component that always underlies the withdrawal decision was raised by the group, coming to express the need for the ethics committee to become involved, *“[...] active participation of the ethics committee [is needed] who should be informed on each case and make decisions in those cases where it is very painful for the parents”*.

DISCUSSION

To our knowledge, this is the first study performed in Spain to explore the perceptions of neonatal nurses on end-of-life decisions and the role of parents involved. In a similar study conducted in Australia, which also involved neonatal nurses in a tertiary hospital, a similar sample was included (n = 69 vs n = 79) with a similar mean years of experience in neonatology; 8.7 years in our sample versus 9.6 years in the Australian study [5]. The results of our survey demonstrate a high level of involvement of nurses in the care provided at the end of life of the newborn and regarding the family, with a high percentage of professionals reporting caring for children and families in this situation.

Most nurses surveyed stated that the process of decision-making must be carried out with the participation of the entire health care team, while indicating that this situation is not fulfilled in reality and feeling that their opinions are not valued. In the study by Monterosso et al, similar results were found, as over 60% of nurses reported that they were never consulted during decisions to start or withdraw life support in newborns [5].

The ethical environment in which nurses work can be a predictor of the level of moral distress they experience. It is well known that neonatal nurses are an especially sensitive population regarding experiencing moral distress, and that this is directly related to stress and can lead to burn-out syndrome. Interpersonal relationships, especially with other members of the care team, are a major source of distress, especially when differences of opinion occur regarding ethical issues [6].

Sometimes, neonatal nurses conduct care and interventions

against their own ethical position. On occasion the nurse may perceive that the death of a newborn is inevitable, and this may clash with the continuation of care measures, which are often aggressive and painful. In a study of nurses working in pediatric intensive care, the workload was the same whether working with patients with do-not-resuscitate (DNR) orders or others. Also, among nurses who cared for children who died during the study, only 30% reported having actively been involved in the decision-making process [7]. These issues are reflected in the responses to our questionnaire, in which nurse staff reported feeling that the decision-making process takes too long; an aspect which was repeated recurrently in the qualitative analysis.

On the other hand, it is worth highlighting that the experience of moral distress is a very important barrier perceived by nurses for the implementation of neonatal palliative care programs [8].

Regarding the role of parents in decision-making, nurses felt that the information given to parents is often inadequate or insufficient. These findings are similar to those reported by Webb et al. in a study of NICU nurses in the United States in which participants said that parents were not always well informed about the status and prognosis of their child [9]. Concerning the role that the parents must play, the level of agreement is lower, with the majority of nurses agreeing that parents need to be involved in decision-making, albeit disagreeing over the exact type of role they should play. When analyzing the responses a trend is observed among junior nurses who prefer to bear the weight of the final decision upon the medical staff, while the senior nurses entrusted this decision on the health care team in general. Less than half of nurses agreed that the final decision must be taken by the parents. Overall, the emphasis is on information given to parents and the necessity of participation in the decision-making process, however the burden of the final decision is entrusted on the healthcare team or on a part of it.

Indeed, the participation of parents in decision-making is controversial because participation in the final decision has traditionally been associated with complicated grief situations and other adjustment disorders. In a recent study carried out in France with parents of children who died in the hospital setting, models of shared decision-making were associated with fewer complications regarding mourning processes compared to other more paternalistic models where tacit consent is assumed or the model of informed decision-making, in which parents are simply informed, without a discussion on values taking place. Furthermore the perception of the newborn's suffering by the parents is significantly associated with major

complications in their ability to adapt to the situation [10].

A review of the role of parents in decision-making has revealed that parents experience this process individually; thus some parents are satisfied if they are properly informed, compared to others who need to take a more active role; parents generally want to participate in decision-making but not in the final decision. Satisfaction with the process was high when parents felt part of it; however, when the medical team made them feel that they were not being considered or excluded them directly in decision-making, their level of satisfaction was much lower [11]. Regarding this particular aspect, according to the ethical committee of SENeo: *"seeing as the withdrawal decision should be made by mutual agreement between the child's parents and professionals, the former should not feel that they are solely responsible for the decision."* [1].

CONCLUSIONS

The results of our study have the following implications: neonatal nurses do not participate in decision-making at the end of the newborn's life. However they would like their opinion to be taken into account when ethical decisions are made. Moreover, neonatal nurses consider that the decision-making process starts too late and that parents are not always well informed about the options, prognosis and the state of their babies. Finally, neonatal nurses consider that the role of parents should be active, and not limited to being mere receivers of information.

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