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Ethical dilemmas associated with clinicians' decisions about treatment in critically ill infants born in Córdoba, Argentina

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Abstract

The objective of this article is to examine end of life decisions made by neonatologists of Córdoba, Argentina. An anonymous questionnaire was designed to investigate neonatologists' decisions on when to initiate or withdraw treatment in critical neonates. All neonatologists who take care of critically ill neonates in Córdoba participated in the survey. More than 75% of them would initiate treatment in preterm infants with uncertain prognosis based on the viability of the newborn. Because it is common to find that critically ill neonates lack sufficient diagnostic information at birth, this attitude seems to manifest a certain therapeutic activism. However, more than 80% of physicians withdraw futile treatments that do not produce benefits. Cordoban neonatologists initiate medical treatment based on the current clinical conditions of neonates, applying a certain degree of therapeutic activism. Doctors withdraw neonatal treatment when it is considered futile.

Keywords

End of life, ethics, medical decision-making, withdrawing/withholding of life-sustaining medical treatments

Introduction

The birth of premature or disabled infants with neurological damage and with poor future quality of life (QOL) prognosis is a major challenge in the decision-making process of neonatologists, making it an issue that triggers a wide discussion on ethics (Meadow, 2012; Meadow and Lantos,

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2009; Pignotti, 2008). Both doctors and parents have great difficulty acting according to the newborn's best interest (Argent et al., 2014; Committee on Fetus and Newborn, 2007). Reaching an agreement on when to start, deny or withdraw a treatment and to set a limit on the degree of clinical intervention remains complex (Campbell, 1995; Fajardo et al., 2012; Hagen and Hansen 2004; Roy et al., 2004; Wilkinson et al., 2006).

The objective of this article is to describe the attitudes of neonatologists of Córdoba (Argentina) regarding the decision to initiate, deny or withdraw treatment in critically ill neonates, in order to contribute to the ethical debate of modern neonatology. The results of the medical attitude regarding euthanasia were recently published (Silberberg and Gallo, 2013).

Material and methods

The ethical implications of the decisions made by the neonatologists of the city of Córdoba (Argentina) in the treatment of critically ill neonates were explored using the answers to a questionnaire prepared specifically for this investigation. The anonymous survey consisted of two sections. Section one included two clinical cases to inquire about the medical behaviour regarding euthanasia (Silberberg and Gallo, 2013). Section two is reported in this article and included 18 questions that assessed the ethical aspects regarding the initiation, denial and withdrawal of neonatal treatment. The doctors expressed their decisions based on the five-point Likert-type scale (from totally agree to strongly disagree). Some of the questions were derived from the EURONIC study (Cuttini et al, 2006; Saaman et al., 2008). Since our questionnaire was prepared in 2007, there was no change in the neonatal local practice until the recent guide elaborated by Ministry of National Health in 2014.

At the time of data collection, there were 85 specialists in neonatology in Córdoba (14). In 2007, this Argentine city included 3.5% of the country's population (i.e. 1,422,600 inhabitants) and 3.4% of live births (i.e. 25,602 children). The number of preterm infants (<37 weeks gestation) was 2231 (8.7% of live births) (Ministry of Health of Argentina, 2008).

All the neonatologists that care for critically ill newborns in Córdoba were invited to participate. Of the 85 neonatologists who worked in Córdoba at that time, 61 treated children with this level of complexity. All of them participated in the survey. These professionals, belonging to six different medical centres, both public and private, had an average of 13 years of experience in the medical specialty.

Results

All of the 61 neonatologists completed the survey (response rate of 100%). Table 1 shows the 10 questions used to assess decision-making at the beginning of the treatments and their answers. Over 75% of the specialists initiated the treatment in each of the following conditions: viable newborn (≥24 weeks' gestation), presence of chorioamnionitis, lacking prior lung maturation and existence of trisomy 21 (questions 1 to 4). However, less than 20% did so in cases of trisomy 13 or 18 and none in the case of anencephaly (questions 5 to 7). Forty-one percent of physicians considered it important to start treatment as clinical experience for the benefit of another patient (question 8). Over 54% of neonatologists treat all newborns regardless of the economic costs (questions 9 and 10).

Table 2 shows the eight questions that evaluate the denial and the interruption of treatments, with their responses. Eighty-two percent of the doctors, when confronted with futile treatment,

Table 1. Neonatologist's attitude towards making decisions and initiating treatment.

	Agree (%)	Disagree (%)	Doesn't know/doesn't answer (%)
1. On the birth of a premature child (≥24 weeks' gestation) with uncertain prognosis, initially apply all intensive care measures the patient's viability requires.	59 (96)	1 (2)	1 (2)
2. Initiate treatment on a premature infant regardless of the presence of corioamnionitis	46 (75)	15 (25)	0
3. Initiate treatment on a premature infant regardless of the absence of prior pulmonary maturation with corticoids.	46 (75)	15 (25)	0
4. Initiate life support treatment on a child with Down syndrome	60 (98)	1 (2)	0
5. Initiate life support treatment on a child with Edwards syndrome	11 (18)	50 (82)	0
6. Initiate life support treatment on a child with Patau syndrome	8 (13)	53 (87)	0
7. Initiate life support treatment on an anencephalic child	0	61 (100)	0
8. Initiate maximum treatment regardless of the infant's prognosis because the clinical experience acquired will benefit future patients.	25 (41)	30 (49)	6 (10)
9. Due to limited resources, aim at the survival of infants with better prognosis.	23 (38)	33 (54)	5 (8)
10. The economic cost of rehabilitation that the parents of an ill infant will have to face is important in the decision.	9 (15)	47 (77)	5 (8)

Note: Survey results ($n = 61$ doctors).

Table 2. Neonatologist's attitude regarding treatment denial and withdrawal.

	Agree (%)	Disagree (%)	Doesn't know/ doesn't answer (%)
1. In certain medical situations, treatment is futile. In these cases, deny treatment.	50 (82)	11 (18)	0
2. When life support treatment on an infant is denied, hydration and nutrition is mandatory.	60 (98)	1 (2)	0
3. In certain medical situations, treatment becomes futile. In these cases, withdraw treatment.	50 (82)	11 (18)	0
4. When treatment on a newborn is withdrawn, hydration and nutrition are mandatory.	60 (98)	1 (2)	0
5. The burden on the family of a disabled infant leads to the withdrawal of treatment.	17 (28)	42 (69)	2 (3)
6. The newborn's foreseeable future quality of life leads the decision to withdraw treatment.	25 (41)	35 (57)	1 (2)
7. From the ethical point of view, the non-initiation and withdrawal of treatment is the same.	15 (24)	45 (74)	1 (2)
8. From the ethical point of view, treatment withdrawal is equivalent to administering drugs to end a life.	21 (34)	34 (56)	6 (10)

Note: Survey results ($n = 61$ doctors).

denied treatment or withdrew it if it was already initiated. In such cases, 98% of them indicated that hydration and nutrition must be provided (questions 1 to 4). A majority of neonatologists made an ethical distinction between not starting the treatment and withdrawing it. On the other hand, 56% disagreed with the statement that withdrawal of treatment is equal to euthanasia (questions 5 and 8).

Discussion

We have carried out a survey about the attitude of neonatologists of the city of Córdoba (Argentina) regarding the initiation, denial and withdrawal of treatment in high-risk newborn infants. Results show that Cordoban neonatologists begin medical treatment in preterm infants with uncertain prognosis and in neonates with non-life threatening disabilities, according to the viability of the newborn (Table 1).

It is common to find that critically ill neonates lack sufficient diagnostic and prognostic information at birth (Griswold and Fanaroff 2010; Manley et al., 2010; Meadow et al, 2008). Based on this, the fact that 96% of the Cordoban physicians initiate treatment in premature children ($\geq$24 weeks' gestation) with uncertain prognosis seems to indicate a certain therapeutic activism. This same behaviour is also shared by 75% of doctors when they face neonates with chorioamnionitis, with or without prior lung maturation.

The initiation of treatment is also practised in infants with trisomy 21 (98%), determining the same vital support measures used on other newborns. In the case of children with trisomy 13 or 18, which are associated with more significant morbidities and shorter life expectancies, only a small group of neonatologists begins treatment; no doctor applies treatment in anencephalic children. These medical decisions demonstrate that, for the Cordoban specialists, the severity of the disability is what determines the level of therapeutic intervention applied.

Forty-one percent of neonatologists deem the interest of enhancing the clinical experience for the benefit of future patients important during the decision process regardless of the prognosis of the child. Nevertheless, because they practise a certain level of therapeutic activism, it seems reasonable to think that they are not only motivated to gain experience for the benefit of other patients. However, the ultimate justification of the motivation for this behaviour was not analysed, which is a drawback.

Less than 50% of the mothers giving birth to children in the included sanitary area reached their secondary studies; also, between 6.6% lived in homes with their minimal needs unsatisfied, measured by quality of house construction, sanitary conditions, children and parents living in common rooms, deficits in school education and nutritional needs. Scarce medical resources justify that 38% of neonatologists consider the assignment of resources to be relevant. However, only 15% consider the economic cost of rehabilitation to the parents of the infant as an important factor in decision-making. Although the Report of the American Academy of Pediatrics' Committee on the Fetus and Newborn (Committee on Fetus and Newborn, 2007), initially published in 2007 and reaffirmed in 2010 and most recently in June of 2015, notes that the treatment must be based on the best interest of the child, the percentage of Cordoban doctors who give special thought to financial resources may express the economical burden some countries are subjected to, among which Argentina is included.

When the treatment does not change the natural course of the disease towards death, 82% of the physicians in Córdoba avoid starting treatment. However, the approach of the doctors regarding treatment withdrawal is based on the child's clinical condition. When the treatment is futile, 82% remove it (Table 2).

Considering that QOL significantly influences the decision to withdraw treatment and this varies according to cultural contexts (Saugstad, 2011; Verhagen et al., 2009, 2010), it is interesting to note that a substantial number of Cordoban specialists do not consider third party interests such as those of the family and the burdens they will incur looking after a severely disabled child. However, when the QOL refers to the current situation of the newborn in the clinic, it becomes a particularly important parameter in the doctor's decision-making process, which is why 82% of professionals remove treatment when it is futile.

Cordoban neonatologists do not suspend treatment initiated on a viable newborn. This attitude of the physicians is probably similar to that of the disabled child's parents', as outlined by Lam et al.'s study (2009). Saaman et al.'s (2008) study shows somewhat different results, establishing that 73% of the Irish physicians believe that the burden has a greater role in the decision.

Kuhse (1987) and Rachels (1975) have expressed that withdrawing treatment is morally equivalent to euthanasia. In some studies (Cuttini et al., 2006; Saaman et al., 2008) and among the doctors participating in our research study, the ethical distinctions between the two decisions prevail. However, it should be noted that 34% of Cordoban doctors do not make this distinction.

The feeling of a substantial number of Cordoban specialists, precisely due to their behaviour against euthanasia (Silberberg and Gallo, 2013), considered that discontinuing certain treatments is equivalent to choosing the death of the infant. In the ethical analysis, it is necessary to know the decision maker's intent. When a neonatologist chooses to discontinue futile therapy, as do 82% of the Córdoba neonatologists, this decision allows the newborn's disease to follow its natural course. Therefore, the fact that a group of Cordoban doctors do not distinguish between euthanasia and treatment withdrawal could lead to futile therapies. Perhaps, they mistakenly interpret that the withdrawal of a treatment is a deliberate action to end the life of the child.

Conclusions

Prematurity ($\geq$24 weeks' gestation) and prognostic uncertainty do not appear to influence decisions of Córdoba neonatologists regarding the non-provision of intensive care treatment.

Cordoban neonatologists withdraw neonatal treatment when it is considered futile. They distinguish between treatment withdrawal and euthanasia, but it seems that in some cases, the choice to reject the withdrawal of life support could lead to a moderate degree of aggressive medical treatment.

Author contribution

AAS conceptualized and designed the study, and drafted the initial manuscript. JEG carried out the initial analyses, and reviewed and revised the manuscript. Both authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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