

Neonatal end-of-life decisions and ethical perspectives

Madjid Soltani GerdFaramarzi¹, Shabnam Bazmi^{2*}

1.PhD Candidate of Medical Ethics, Medical Ethics Department, School of Traditional Medicine, Shahid Beheshti University of Medical Sciences, Tehran, Iran.

2.Associate professor, Medical Ethics Department, School of Traditional Medicine, Shahid Beheshti University of Medical Sciences, Tehran, Iran.

Abstract

End-of-life decisions are usually required when a neonate is at high risk of disability or death, and such decisions involve many legal and ethical challenges. This article reviewed the processes of ethical decision-making for severely ill or terminal neonates, considering controversial issues including the followings: (i) identifying primary decision makers, (ii) the role of law and guidelines, and (iii) changes in treatment controversy, law and regulations over twenty years in several European countries such as Switzerland, Germany, Italy, United Kingdom, France, the Netherlands, Sweden, and Spain. This review study conducted on accessible articles from PubMed, Google Scholar, Web of Science and Scopus databases. Based on two studies in 2016 and 1996, neonatologists reported that withholding intensive care, withdrawing mechanical ventilation or life-saving drugs, and involvement of parents in decision-makings have become more acceptable as time passes, indicative of trend change. Trend of physicians on how end the life of neonates, at risk of death, varies in different countries, and cultural factors, parents' involvement in decisions and gestational age are factors considered in end-of-life decision-making. Future investigations continuously need to identify upcoming ethical aspects of proper decision-making.

Keywords: Ethics; Neonatal intensive care; End-of-life; Decision-making; Law.

*Corresponding Author

Shabnam Bazmi

No. 8, School of Traditional Medicine, Shams Alley, Across from Shaid Abbaspour St., Vali Asr Ave., Tehran, Iran.

Tel: (+98) 21 88 78 10 36

Email: sh.bazmi@sbm.ac.ir

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Introduction

Over the last twenty years, perinatal technology advances, have raised survival rate of the fragile and premature neonates. However, intensive care remains ineffective for a small number of such neonates that prolongs the death process and results in upsetting them and their families. Despite many advances in diagnosis and treatment of congenital diseases, perinatal death is still widespread in European countries. Most of such deaths occurred in obstetric wards or Neonatal Intensive Care Units (NICUs) and often preceded by end-of-life decisions such as withholding or withdrawing life-sustaining treatments (1, 2). End-of-life decisions are usually considered when a neonate is at high risk of disability or death regardless of treatment approach. Such decisions to save neonates' life are often faced with the dilemma of being unaware of the extent of neonates' suffering involved, and hence various consequences of each decision option need to be considered in decision-making (1, 3). Nevertheless, how and when to discontinue treatment involve several controversial and complex ethical aspects, and thus end-of-life care constantly poses ethical challenges to healthcare professionals. The medical decisions for these neonates may affect the quality of care they receive in the last days or weeks and how parents experience such terrible situation (4-7). Many theories have been published regarding decision-making criteria; however, few studies provided empirical data about decisions before intensive care. Moreover, a few studies focused on the comparison of different cultures of various countries (8), and

majority of studies focused on English-speaking countries or Netherlands where reasoning supporting non-prosecution of euthanasia for eligible adults is similarly applicable to neonatal decision-making (9-14). A research conducted in 1996-1997 in several European countries documented different self-reported practices and attitudes of neonatal nurses and physicians according to different national, cultural and legal frameworks (15, 16). Parents, policy makers, and physicians should be aware of the current medical perspectives, attitudes, practices, and values regarding ethical decision-making as they can over time affect the laws and guidelines and even enhance or prevent their usage. Such awareness is also required to find practical approaches to support parents and healthcare providers regarding end-of-life decision-making and develop appropriate comfort care plans for patients and their families. Investigating how such attitudes and beliefs change over time is necessary (17-19). Hence, this work aimed at studying attitudes, practices, and treatment options of neonatologists regarding the followings: (i) parents' involvement in decision-making about intensive care for neonates at risk of severe disability or death, (ii) processes of ethical decision-making for such neonates considering controversial issues (e.g., identifying primary decision-makers, role of laws and guidelines, treatment controversy in European countries), and (iii) changes in withdrawing or withholding intensive care in NICUs, (iv) changes in parents' participation in decision-making, and (v) changes in guidelines and laws.

Method

All original and review articles on PubMed, Google Scholar, Web of Science and Scopus databases were searched using the following keywords: ethics, neonatal intensive care, end-of-life decision, guideline and laws. After excluding duplicate articles, the titles of the remaining articles were reviewed and the irrelevant were removed. Then, the abstracts of the remaining articles were studied, and the reference lists were also assessed.

Differences in neonatal end-of-life decision management in Europe

This review presents differences in end-of-life care and neonatal decision-making approach in several European countries such as Switzerland, Germany, Italy, United Kingdom, France, the Netherlands, Sweden, and Spain. This article reviews neonatologists' perspectives on decisions that limit intensive, futile, or disproportionate

interventions imposing burden on patients and their parents. Most neonatologists in these countries stated that limiting intensive care to “let nature take its course” can be ethically justifiable in terminal and fatal disease conditions (Fig.1) (17,19). Neonatologists considered continuing treatment with no escalation and prohibiting intensive support from the beginning to restrict intensive care during such conditions (16-19). Treatment prohibition was accepted in United Kingdom, Netherlands, Germany, and Sweden, but not completely in Italy (Table 1). In addition, administering pain-control medication was less admissible in Italy compared to other countries, when the hastening risk of death is possibly involved. Defined as administering medications to end a patient's life, active euthanasia was assumed admissible by many doctors in Netherlands and France (Table 1).

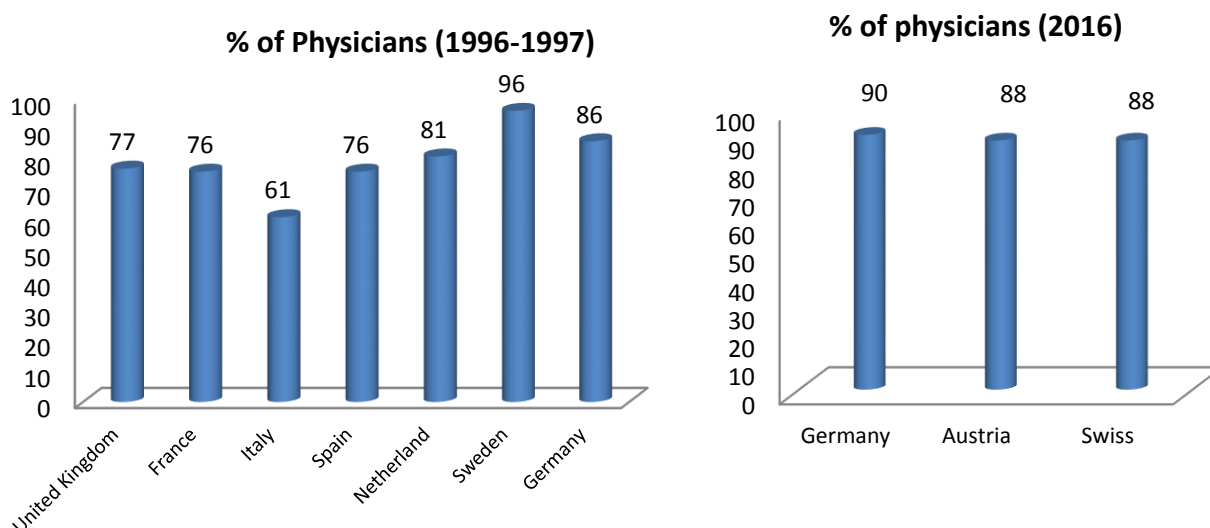


Fig. 1- Proportion of making decision (alone or with others) to set limit to intensive interventions among physicians (*1996-1997 and 2016 charts were extracted from (17) and (19), respectively)

Table 1- Proportions of physicians reporting to have ever decided (alone or with others) to set limits to intensive interventions ** this table is from (16-19)

Decisions	Percentage of physicians (95% ci) who had ever made decisions (1996 – 1997)							Percentage of physicians who had ever made decisions (2016)		
	United Kingdom	France	Spain	Italy	Netherland	Sweden	Germany	Germany (N=71)	Austria (N=8)	Swiss (N=17)
To continue current treatment	86 (78-92)	83 (74 -89)	85 (79-90)	81 (76-85)	89 (84- 92)	95 (90-98)	95 (88-98)	97 (90 -99)	100	100
To withhold intensive care (e.g., resuscitation at birth, mechanical ventilation)	91 (79-96)	67 (58 -89)	74 (67-8)	57 (49-63)	95 (87-98)	82 (69-90)	81 (76-86)	99 (92-100)	100	100
To withdraw life-saving drugs	97 (87-99)	59 (48-69)	50 (38-61)	29 (21-39)	99 (95-100)	94 (85-97)	74 (61-85)	97 (90-99)	100	100
To withhold emergency treatment/maneuvers (e.g., resuscitation for cardiac arrest)	91 (82-95)	66 (59 -73)	66 (55-75)	44 (38-51)	96 (96-98)	68 (53-79)	95 (90-97)	99 (99-100)	100	94
To withdraw mechanic ventilation	92 (80- 97)	82 (76-86)	63 (54-71)	53 (45-60)	95 (90-98)	88 (75-95)	82 (74-88)	96 (88-98)	88	100
To administer sedatives / analgesics to suppress pain even at risk of respiratory depression and death	93 (89- 96)	96 (91-98)	87 (81-91)	64 (56- 71)	98 (89-100)	95 (88-98)	86 (78-91)	97 (90-99)	88	100
To administer drugs with the purpose of ending life	15 (7-28)	73 (64 -80)	6 (3-12)	5 (3- 9)	71 (53-83)	3 (1-9)	8 (4-14)	3 (1-10)	0	6

In a 2016 multi-center, online, anonymous study in NICUs in Switzerland, Germany, and Austria, 198 eligible neonatologists received questionnaires (19), and 96 returned their completed questionnaires. Most

neonatologists in Germany, Austria, and Switzerland answered all items except the one referring to active euthanasia (Table 1). French physicians, however, were against its legalization assuming that this illegality

status would limit abuses. In the Netherlands, more than half of neonatologists agreed to legalization, thinking that public transparency was a better safeguard (20, 21). In Germany, in 2016 (94%) compared to 1996 (69%), the number of physicians who have made the following decisions at least once in their professional life was remarkably high: limit intensive care, withhold resuscitation at birth or emergency interventions, as well as withdraw life-supporting medicines or mechanical ventilation (19,22). In 2016 (97%) compared to 1996 (57%) significantly greater number of German physicians accept the risk of death as an analgesic complication for an infant in pain with a low probability of recovery (19, 22). Shown in Table 1, no significant differences were found in 1996 (22) and in 2016 (19) surveys regarding limiting intensive care for end-stage patients and medicine administration to end patient's life (illegal in Switzerland, Austria, Germany, and several other countries).

Parents' role in neonatal end-life decisions

In all countries except Sweden and France, physicians believed that parents should be involved in ethical decisions (16-19). Almost 80% of participants in France stated that parents' role should not be direct, and instead their opinions should indirectly be considered by physicians. Such attitude was also reported in Netherlands and Sweden. In Italy, however, 13% of participant believed that parents should not be involved in such decision-makings. Several physicians stated

that although parents should seriously consider neonate's prognosis and health, they should not decide whether to prohibit or limit treatment so as not to blame themselves and suffer the consequences of their decision in case of infant's death. Moreover, being involved in end-of-life decisions can put physicians in a difficult position, especially when they need to notify parents of their infant's death. However, openness in ethical decisions vanishes, when physicians report such death condition as an unexpected heart attack, as a convincing white lie (18).

If parents participate in decision-making, conflicts between the physicians and parents could arise about making the most appropriate decision for the infant. However, such conflicts scarcely occur and often can be resolved. According to most physicians, parents' opinions and opinions of parents should be agreed upon when they want to continue severe interventions. A physician said, "We need to consider parents' viewpoints to withhold intensive care when we are those who have asked about it". However, parents' opinions do not receive similar consideration when they reject severe care (19).

Review of ethical and legal framework

In Nuffield Council document, no survival chance was considered for neonates prior to 22 weeks of gestational age; however, at 22 and 23 weeks, they have extremely low weight such that resuscitation and critical care must be experimental and cautioned. At weeks 24–25, critical care must be supplied,

except when both doctors and parents accept that considering baby's general health, no hope for survival due to the baby's general health condition and probably high suffering level. After 25 weeks, intensive care is considered standard treatment approach (22).

The revised Swedish society of medicine's guideline, on discontinuing life-sustaining therapy, in March 2007, supported the competent individual's decision right as well as patient's right to make informed decisions about avoiding treatments such as mechanical ventilation, tube feeding, fluid resuscitation, and medications. However, proper sedative interventions should be prescribed. Sedation at the time of stopping life-sustaining interventions raised challenges as it was regarded physician-assisted suicide (22).

The National Ethics Committee in France published a document for involving parents in decision-making. Leonetti's law on patient rights at the end of life in 2005 and Kouchner's law on patient rights in 2002 addressed overtreatment at birth and neonatal active euthanasia (22). These laws significantly changed the Code of Public Health and restructured the physician-patient relationship guidelines and end-of-life care in France. The Leonetti's law prevents "unreasonably obstinacy" in researches and clinical settings as well as authorizes withholding or withdrawal of useless, disproportionate or artificially life-preserving treatments. However, pain relief and palliative care need to be provided when intensive treatment is stopped; for end-stage critically-ill patients with incurable disease, pain-relief medications are allowed if

necessary, even if death is hastened as a side effect (22).

Recent laws enhanced patients' autonomy to get informed decisions and provide consent to clinical measures. Although parents or guardians make decisions for minors, in emergency and two other situations, medical authorities make decisions: (i) when parents and physicians' disagreement may cause serious consequences for minor's health, and (ii) when decision to relinquish treatment becomes a risk, parents are entitled to be informed and consulted, but their consent is not required. Decisions about any incompetent patient should be made through collegial procedure, including consultation with the healthcare team, external counselor, patient's trustee, and family (22).

In Italy, in 2007 and 2008, resuscitation guidelines were provided for neonates at extremely low gestational age to determine where resuscitation and intensive care should be mandatory and when might such care could be useless or excessively challenging, contrary to patient expediency. These guidelines emphasize treatment in the early stages of pregnancy or regardless of gestational age, and parents should be notified; however, in case of disagreement, medical decision should be followed. Such guidelines support treatment in the delivery room to provide each neonate the best survival chance, but in the event of treatment ineffectiveness, to consider compassionate care (22).

In the Netherlands, active euthanasia was legalized in 2002 for eligible adults and children over 12. Despite general illegality of

neonatal euthanasia, the Groningen Protocol authorizes it in cases of “hopeless and unbearable suffering” under the following conditions: (i) definitive diagnosis and prognosis, (ii) confirmation of diagnosis, prognosis and unbearable suffering by at least one independent physician, (iii) informed consent of mother and father; and, (iv) performing euthanasia according to accepted medical standards. Prior to decision of the public prosecutor, a specific advisory committee by the Health Ministry has assessed all cases since 2007 (22).

The ethicists and physicians’ reactions to the Groningen protocol were negative because they question measure of “hopeless and unbearable suffering” in presence of appropriate pain control and relief medications as well as using involuntary euthanasia instead of palliative care (22). Despite objections, in 2005 Dutch Pediatric Association approved the Groningen protocol as a national guide and reviewed its guidelines for neonates’ resuscitation at early gestational age and suggested more active management at 25-24 weeks (22).

Discussion

The 2016 study explains neonatologists’ practices and perspectives about non-treatment decisions and involvement of parents in taking care of neonates at higher death risk or severe illness (19). Since 1996, many legal regulations and ethical recommendations have modified in European countries including Swiss, German, and Austria. The 2016 study indicated that neonatologists’ opinions, views, and

practiced have changed over 20 years (19). Almost all physicians have decided, at least once, to withhold intensive or emergency interventions, to withdraw life-saving medications and mechanical ventilation, or to use palliative care even at the risk of respiratory despair and death. Moreover, life quality aspects and respect for parent’s opinions have affected the neonatologists’ decision-making (19).

In a study conducted on neonatologists and nurses, most subjects (60%) agreed upon both neonatal end-of-life and parental decisions, although such high acceptance of end-of-life decisions did not fit within the framework of the law in several countries (1). Medication-induced end-of-life with life-shortening purposes was significantly more acceptable in physicians than in nurses.

Discussing non-treatment decisions in the public pediatric community has increased the inclination of neonatologists to limit treatments if it is in patient's best interest (19). Moreover, in many countries courses in medical undergraduate curricula included the followings: clarification of medical treatment goals, discussions of life-sustaining treatment, development of a treatment plan, or implementation of a treatment program in palliative care conditions (19).

In Swiss, German, and Austrian national guidelines, withholding and withdrawing life-sustaining medical treatment in neonates, if not in their best interest, are considered ethically and medically appropriate (19). The majority of 2016 study’s participants stated that the national guideline affected their

decision-making, and considered it useful in changing their perspectives. These national guidelines reduced physicians' fear of legal consequences when withdrawing and withholding life-sustaining treatments were necessary (19).

Neurologists are now more likely to include parents in deciding whether to start, continue, or leave intensive care. Moreover, caring with the support of family including parents or guardians is mandatory in Germany, Switzerland and Austria (19).

In 2016, almost all neonatologists would pursue the parents' desire to resuscitate the preterm neonate with gestational viability limits. However, if parents do not request resuscitation of the premature neonate, less than 20 percent of neonatologists stated that they would resuscitate the neonate despite the national guidelines and parents' decisions; and hence, in practice, personal beliefs and attitudes could be prioritized over national policies and default options in decision-making about severely preterm neonate with viability limits (19). Similarly, withholding treatment for sustaining life in the delivery room, when the pain of the new-born child is not clear and distinct yet, may bring about ethical challenges in physicians. Moreover, predicting best interest of a patient is simpler for a patient with a certain diagnosis who deteriorates despite treatment.

Conclusion

European countries' legal and ethical background is not coherent. Modifications introduced in several countries have followed directions determined by the neonatologists'

attitudes and beliefs documented by the available data. Informing parents or guardians when decisions are made about children is required in almost all countries. While most countries request third-party counseling or intervention in the event of ongoing disputes between medical staff and parents, physicians often make the final decisions.

According to the data of the 1996 and 2016 surveys, withdrawing and withholding intensive care in the NICU as well as involving parents in decision makings have become more accepted, which could be as a result of administration of medical guidelines over the past two decades regarding joint decision-makings and care options for neonates at high risk of severe disability or death.

Nevertheless, for some physicians, personal attitudes take precedence over parental decisions and national policies in resuscitating premature neonates with limited viability.

Guidelines and laws are not the only factors influencing behaviors and opinions, and viewpoints of physicians as well as society may change before reflected in legislations. Future surveys need to explore such hypotheses.

Conflict of Interests

The authors have declared that no competing interest exists.

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