**Neonatal End of Life Decisions and Legal Consensus: A Review**

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***Introduction***

Perinatal technology advances, in the last twenty years, have increased survival among the most fragile and premature neonates. However, intensive care proves ineffective for a small minority, which can prolong the dying process and thus the babies and their families’ suffering. End-of-life decisions are usually considered when a neonate is at high risk of disability or death in spite of treatment. Nevertheless, the ethical debate is both controversial and complex regarding how and when to discontinue treatment. In fact, end-of-life care presents ethical challenges to healthcare experts constantly. The clinical decisions for these children may have a deep impact on the quality of care received during their last days or weeks of life and the way parents experience this terrible time(1-4). Many theories have been published regarding decision-making criteria and the role given to parents. Nevertheless, studies providing empirical data about decisions preceding intensive care are few; especially, data comparing and contrasting different cultures and countries are rare (5). Many of them have examined English-speaking countries or the Netherlands, where the issue ending to non-prosecution of euthanasia for competent adults was accompanied by similar reasoning regarding neonatal decision making(6-13). An international research was carried out during 1996-1997, in some European countries and documented different self-reported practices and attitudes of neonatal nurses and physicians, assuming several national legal and cultural frameworks(14, 15). Policymakers, parents, and fellow physicians should be aware of present medical attitudes, values, and practices about ethical decision making since they may affect the guidelines and laws and boost or impede their use. This knowledge is required to find the best strategies to support parents and healthcare providers regarding end-of-life decision making and develop influential comfort care plans for patients. We should explore how attitudes and beliefs change over time(16-18). We assessed self-reported attitudes, practices, and treatment choices of neonatologists regarding involvement of parents in decision making with respect to the use of intensive care for infants at risk of severe disability or death and the processes of ethical decision making for severely sick or terminal infants, considering controversial issues like identifying primary decision makers, the role of law and guidelines, and the treatment controversy. The current research is a review article which made use of accessible articles from research sites including Pub Med, Google Scholars, and Scopus by key words; Guideline, Neonatal intensive care, Ethics and End of life decision.

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

This review presents differences in the way of neonatal decision-making and end-of-life care in different countries such as Switzerland, Germany, Italy, United Kingdom, France, the Netherlands, Sweden, and Spain. Data are provided on the views of physicians regarding decisions limiting intensive, futile, or disproportioned interventions that impose a burden on the patient and their parents. Most neonatologists in every country agree that limiting intensive interventions to “let nature take its course” may be justifiable ethically with respect to fatal and/or terminal diseases (Fig. 1 and 2). In fact, physicians consider continuing treatment with no escalation and even prohibit intensive care from the very beginning to limit intensive interventions in chosen situations (Table 1). Treatment prohibition was acceptable in UK, Netherlands, Germany, and Sweden, but less in Italy. In addition, administering drugs to control pain was less admissible in Italy compared to other countries, when the hastening death risk could be involved. Active euthanasia that is defined as administrating drugs to end a patient’s life was assumed admissible by many physicians in two countries of Netherlands and France (Table 1)(15-18).

In a study conducted in 2016 as a multicenter and anonymous online survey of tertiary neonatal intensive care units (NICUs) in Switzerland, Germany, and Austria, a questionnaire was administered among 198 eligible physicians. After the distribution of the survey and the reminder notice, 96 questionnaires were studied. Most neonatologists in Austria, Germany, and Switzerland positively answered to all questionnaire items except the last referring to active euthanasia (Table 1). French physicians were, however, against its legalization assuming that the illegal status would limit abuses. In the Netherlands, in contrast, more than half of neonatologists agreed to legalization, thinking that public transparency was a better safeguard(19, 20).

The findings from Germany in 2016 demonstrated that the number of physicians who had decided to limit intensive interventions at least once throughout their professional life was remarkably high (94% vs. 69%). Similar reports were found to prevent resuscitation at emergency interventions or at birth and withdraw life-supporting medicines or mechanical ventilation. Compared with 67% physicians investigated in the study conducted during1996-1997, today 97% of German physicians accept the death risk as a complication of analgesia, in the case of an infant with no recovery chance.

No significant differences were found in the surveys conducted during 1996-1997 and in 2016 with respect to the relatively uncontroversial practice of limiting intensive care for terminal patients and for the extremely scarce administration of medicines to end the patient’s life (Table 1) (while it is still illegal in Switzerland, Austria, Germany, and some other countries).

***Role of parents in Neonatal end of life decisions***

In all countries, except France and Sweden, physicians agree that parents should be involved in ethical decisions; almost 80% of respondents in France believed that parents’ role must be indirect (i.e., their views have to be indirectly taken into consideration by the physician). This belief was also reported in Netherlands and Sweden. In Italy, however, most people (13%) believed that parents should not be involved in this kind of decision making. A physician stated that parents must be aware of the baby’s health and prognosis, but they should not be involved in the decision regarding limitation or prohibition of treatment. They believed parents should not feel sinful for wishing death for their baby. Nevertheless, not being involved in the end-of-life decision may impose a difficult position on the staff when they have to inform the parents about their baby’s death. However, this openness will fade away in the face of ethical decisions, when it is reported as an unexpected heart attack, for example, as a convincing lie reported by a physician.

If the parents participate in decision-making, there may be conflicts between them and the staff on the best decision for a baby. However, this is a scarce event, and most cases may be solved via discussion and giving time to parents to cope with the situation and accept the suggestions. Most physicians, believed that the parents’ opinion should be accepted when they ask for continuation of intensive interventions. According to a doctor: “we take into account the parents’ opinion to stop intensive care when we are the ones who have requested it. The same consideration is not given to the parents’ opinion when they are the ones who expressly reject intensive care measures(14-18, 21).”

***Overview of ethical and legal framework***

According to the survey conducted during1996-1997 in the UK, the guidelines of Royal College of Pediatrics and Child Health were updated in 2004; however, no prominent changes were presented(22, 23). In fact, the patients’ wish and treatment proportionality are the guiding criteria. Withdrawing and withholding treatment for children is allowed in five situations. Three situations may be related to infants and neonates apart from brain death: 1) “no chance”, where survival is not possible; 2) “no purpose”, where there can be survival, but only with intense impairment; and 3) “unbearable” situation, where the treatments needed to sustain life would involve an intolerable burden of suffering. Since the first situation is not controversial, and the third may be a case-by-case discussion, the “no purpose” situation is the most controversial ethically, raising questions of life quality, judgments, and discrimination against the disabled people.

British Association of Perinatal Medicine and the Nuffield Council on Bioethics issued two documents on the management of extreme prematurity, sharing the RCPCH guidelines. On the basis of the available studies, the Nuffield Council document stated that prior to 22 weeks of gestational age, there is no survival chance; however, at 22 and 23 weeks, they are so slim that intensive and resuscitation care should be experimental. Intensive care should be normally provided at 24–25 weeks, unless doctors and parents agree that due to the baby’s general health conditions there is no hope for survival, and the suffering level would be high. Intensive care is the standard treatment after 25 weeks. The documents and guidelines on extreme prematurity enhance the prohibition of active euthanasia(24, 25).

The Society of Neonatology in Spain published (2004) some recommendations for neonatal resuscitation. A short paragraph was allocated to ethical aspects. Resuscitation is not recommended less than 23 weeks of gestational age or birth, weight less than 400 g, nor in case of lethal prognosis(26).

The Society of Medicine in Sweden has recently changed its guidelines that were published in 1991 on stopping life-sustaining treatment. The new guidelines of March 2007 confirm the rights of a decision-maker and inform patient to withdraw from treatments like dialysis, mechanical ventilation, nasogastric feeding, drugs, and fluid therapy. Proper palliative treatment, however, should be proposed. Sedation at the time of stopping life sustaining interventions has raised some challenges as such a procedure is regarded physician-assisted suicide(27, 28).

The National Ethics Committee in France put forward a document for involving parents in decision-making. There was a concern of overtreatment at birth and neonatal active euthanasia. Two laws were passed subsequently: Kouchner's law on patients’ rights in 2002 and Leonetti’s law on the rights of patients at the end of life in 2005. These bring about prominent change of the “Code of Public Health”, which redesigned the patient–physician relationship rules and end-of-life care in France. The Leonetti’s law hinders “unreasonably obstinacy” in researches and treatment and authorizes the withdrawal or withholding of treatments when they have no benefit or no other impact than merely the artificial preservation of life. Pain relief and palliative care must be provided when intensive treatment has stopped. Anti-pain treatment is needed for patients in an advance or last phase of an intense and irremediable ailment though death may be accelerated as a side effect.

New laws improve the patients’ autonomy, who have to be aware of and agree with medical acts. Regarding minor patients, parents (or guardians) can decide for them. In cases other than emergencies, there are two situations in which parental authority may be defeated and replaced by medical authority. When physicians and parents disagree and this disagreement may have unwanted outcomes for the health of the minor, and when a decision preceding treatment is at stake. Parents should be informed and their opinion should be asked for in this latter case, but their consent is not required. Nevertheless, decisions for incompetent patients must be preceded by a collegial procedure, such as consulting with the health care team, a trusted person chosen by the patient, one external consultant, and the family. Active euthanasia, an action taken with the mere purpose of ending a patient’s life, is prohibited. The opinions of Neonatologists are split in this respect(29, 30).

Guidelines about resuscitation in Italy at early gestational age were first suggested by health care professionals, detecting situations where intensive care and resuscitation at birth should be compulsory, and where they may be assumed futile or burdensome, and thus in contrast to the patient’s best interest(31, 32). In 2008, as a reaction, the Italian High Council for Health presented documents on treating babies at early gestational age. The National Committee for Ethics obliged treatment regardless of gestational age. Parents must be informed, and the medical decision should overcome in case of disagreement. Additionally, the High Council for Health supported treatment in the delivery room offering the best survival chance for each child; simultaneously, it appeared to open transition to compassionate care at the time of ineffective treatment.

Meeting the Italian National Association of Professional Orders, preterm infant management issued that: intensive care and resuscitation at borderline viability may lead to overtreatment according to the Italian Code of Medical Deontology, which withdraws obstinacy in therapeutic or diagnostic interventions that do not seem to benefit patients’ health and/or improve their quality of life; therefore, parents’ awareness and concern are needed(33, 34). Generally, there is controversy in these documents and there is no firm piece of advice for neonatologists.

Active euthanasia for competent adults, and even minors from 12 years of age, was legalized in the Netherlands in 2002. Neonatal euthanasia is illegal. However, it was presented by the “Groningen Protocol” as an unbearable and hopeless condition. Other requirements stated by the protocol are that prognosis and diagnosis have to be certain; prognosis, diagnosis, and intolerable ailment must be confirmed by at least one independent physician; parents must sign consent forms; and the procedure must be followed based on medical standards. When these criteria are met, the doctor will not be prosecuted(33-35). A special advisory committee formed by the Ministry of Health has reviewed all cases since 2007, prior to decision of the Public Prosecutor(35).

The physicians’ and ethicists’ reactions to the Groningen protocol have been negative, which questions the occurrence of hopeless and intolerable pain in neonates provided by proper pain treatment and warns that instead of palliative care, involuntary euthanasia may be applied(36-40). In 2005, the Dutch Pediatric Association introduced Groningen protocol as a national procedure; this association assessed its items with respect to neonatal resuscitation at early gestational age, proposing an active management at 24–25 weeks(41, 42).

***Discussion and Conclusion***

The study conducted in 2016 explains neonatologists’ practices and perspectives about non-treatment decisions and involvement of parents in taking care of newborn infants who are at higher risk of death or intense disability. When -1997 study was set, many modifications took place in legal regulations and ethical recommendations in European countries such as Austria, Germany, and Switzerland. This survey indicates that neonatologists’ self-reported opinions, attitudes, and practices have changed. Recently, they have decided to prohibit severe interventions and emergency treatment, withhold mechanical ventilation and life-saving drugs, or to prescribe sedatives/analgesics even at risk of death and respiratory depression(16). Also, the quality of life and respecting parental opinions are the aspects that appear to have a higher influence on decision making by neonatologists than they used to have 20 years ago. Two phenomena could have affected these modifications.

The progressing culture of non-treatment decisions within the pediatric community might have increased neonatologists’ desire to limit treatment when this is considered as the patient’s best interest(43, 44). This moral and medical debate has found its way into many official documents by the medical societies of Switzerland, Germany, and Austria. After 1996-1997 study, there has been a lot of debate regarding the legal basis, indication, and other aspects of withdrawing and withholding life-supporting medical treatment in pediatrics(45-51). Moreover, in many countries teaching contents were presented in the undergraduate medical education curricula, including clarification of medical treatment goals, initiating discussions about life sustaining treatment, defining a care plan, or implementation of a treatment plan in palliative care situations(52-54).

Swiss, German, and Austrian national guidelines declare withdrawing and withholding life sustaining medical treatment in neonates to be medically and ethically appropriate in situations when treatment does not satisfy the interest of the patient. Approximately all respondents in 2016 survey declared that they knew the national guidelines and that these affect their decision making. More than 90% of the respondents stated that the national guidelines were ground breaking or helpful for their decision making. These guidelines might have reduced physicians’ concern of legal outcomes when withdrawing and withholding life-sustaining medical therapy(55-57).

Another finding was neonatologists’ desire to get parents involved in decisions about starting, withdrawing, or continuing severe care and to admit the decision of parents. Today, family care is really valued, and parents’ or guardians’ information is compulsory in Switzerland, Germany, and Austria. Shared decision making is offered by the national pediatric guidelines of these countries. End-of-life decision making should be individualized and shared with the parents and caregiver of the patient(58, 59).

In 2016, almost all neonatologists would pursue the parents’ desire to resuscitate the baby, when exposed with a preterm infant with viability limits. One-fifth declared that they would neglect a parental desire for palliative care and begin resuscitation against parents’ decision and the national guidelines. In the 1996-1997 survey, 21% of German physicians stated that they would begin resuscitation postnatally for a preterm infant and make the same decision even when parents do not want resuscitation(18). Personal attitudes and beliefs may be more robust compared to default options and national policies in decision making at birth of extreme preterm infants at viability limitation(60). Another explanation is that the decision of withholding life sustaining treatment in the delivery room, when the child’s pain is not yet visible and distinct, may bring about ethical challenges in physicians. Moreover, predicting a patient’s best interest is easier for a well-known patient with a specified diagnosis who deteriorates in spite of treatment.

Different sampling methods were applied in the studies conducted during1996-1997 and in 2016. The first conducted a stratified random sampling of NICUs and used weights to gain national estimates at the analysis stage. In every sampled NICU, all doctors working full-time or part-time were asked to participate. For the present web-based survey, in contrast, all tertiary NICUs in Switzerland, Germany, and Austria were invited to take part in the survey; however, only the unit heads were surveyed, resulting in respondents that may not represent the neonatologists’ population in these countries. To compare the 1996-1997 survey and 2016 study, the data obtained from the 1996-1997 reports were employed. The response rate of 2016 study was meaningfully lower than that of1996-1997 study (52% vs. 86%). Nevertheless, this could be a general problem of surveys which are online although lower response rates have been reported by other research studies(61). The small number of participants from Switzerland and Austria hindered an extensive statistical comparison of responses from all countries capable of conducting online surveys.

The ethical and legal background of European countries is not coherent(62). The modifications presented in some countries have proceeded in the direction specified by the neonatologists’ beliefs and attitudes documented by the provided data. France has given permission for practices such as withdrawing and withholding interventions that are life-sustaining for the competent patient and in selected situations as well as for neonates and children. Parents’ or guardians’ information is required when decisions are related to children as is the case in all countries. While most countries ask for the intervention of a third party encountering persistent disagreement between staff and parents, in France the final decision is the physicians’ decision(63).

Neonatal active euthanasia, intentional ending of a life, is unlawful everywhere. In the Netherlands, the Groningen protocol has been accepted by the national Pediatric Association: a development raising criticism, but it was predictable concerning the widespread agreement expressed by Dutch neonatologists to change the law, and active euthanasia for minors and adults remains unlawful in this country.

The legal and ethical debate of the last years in Italy was prevailed by the right of a competent patient to ignore medical therapy and introduction of advanced directives(62). For newborn infants, the National Committee for Ethics emphasizes treatment, with little authority for parents’ autonomy; however, inconsistencies with the guidelines approved by professional organizations provide physicians with no clear advice.

Comparing the data of the 1996-1997 study, withdrawing and withholding intensive care in the NICU and involvement of parents in decision making are possibly more accepted and practiced in 2016, which may be regarded as a transition record from a paternalistic approach to the shared decision-making procedure addressed by the majority of guidelines of the last two decades. Administration of national guidelines about decision-making for newborn infants with higher risk of severe disability or death and treatment options for severe preterm infants at the viability limits are accepted in Switzerland, Germany, and Austria and considered to be contributions to processes of decision-making. Nevertheless, for some doctors, personal attitudes are stronger in comparison with parental decisions and national policies with respect to post-natal resuscitation of preterm infants at the viability limits. One may suppose that so far no prominent changes in beliefs and behaviors should have happened. However, guidelines and laws are not the only factors influencing behaviors(64), and neonatologists’ and people’s opinions may evolve decently prior to this modification in legislation. Nevertheless, a new survey is required to explore other hypotheses.

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**Figure 1.** Proportion of physicians who had ever decided (alone or with others) to set limit to intensive interventions(1996-1997).

**Figure 2.** Proportion of physicians who had ever decided (alone or with others) to set limit to intensive interventions(2016).

**Table 1.** Proportion of physicians who had made specific decisions

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Decisions** | **% of physicians ( 95% cl) who had ever made decisions (1996 – 1997)** | | | | | | | **% 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 (eg. resuscitation at birth, mechanical ventilation)** | **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** | **91 (79-96)** | **67(58 -89)** | **74(67-81)** | **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 withdraw emergence treatment / manoeuvres (eg. 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** |

**Abstract:**

Perinatal technology advances, have increased survival among premature neonates. However, intensive care proves ineffective for a small minority. End-of-life decisions are usually considered when a neonate is at high risk of disability or death in spite of treatment and it has many legal and ethical challenges. Many theories have been published regarding decision-making criteria and the role given to parents.in this article we have assessed self-reported attitudes, practices, and treatment choices of neonatologists regarding involvement of parents in decision making with respect to the use of intensive care for infants at risk of severe disability or death and the processes of ethical decision making for severely sick or terminal infants, considering controversial issues like identifying primary decision makers, the role of law and guidelines, and the treatment controversy. The current research is a review article which made use of accessible articles from research sites including Pub Med, Google Scholars, and Scopus by key words; Guideline, Neonatal intensive care, Ethics and End of life decision.