

Ethical dilemmas in the vital sustaining therapy for the premature newborns

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Abstract

The paper represents a review of the ethical aspects in the process of care of the premature newborns. It is discussed the decision to support the life of a premature newborn. There are also reviewed the factors that need to be evaluated in the case of a premature neonate and the prognosis that can be made at delivery. The quality of life in the case of a premature neonate and basing the decision on the best interests of the neonate are also reviewed. A separate chapter is represented by the recommendations regarding the parent-doctor conflicts in these delicate situations. The ethical decisions regarding the premature neonates cared in the neonatal intensive care units involve three steps: establishing a correct clinical indications for the intensive care, the most accurate determination of the survival prognosis of the neonate; the estimation of the final result regarding the neurological handicap and the quality of life of the neonate in the future. In conclusion, the studies show that neither the birth weight, nor the gestational age are predictors for the appearance of the neurological sequelae and this is why a clinical strategy based exclusively on the gestational age or birth weight cannot be sustained though.

Keywords: premature, ethic, neurologic, intensive care

Introduction

The essential difference between the maternal-fetal pathology and the other medical clinical specialties is the fact that the purpose of the obstetrics and neonatology medicine is to conserve and protect the health rather than diagnose and treat the disease, thus the existence of prevention dominant when comparing to the pathogenic orientated therapy. Despite the above, the methods that facilitate the main objective of prevention have significantly increased in number and have become more and more invasive and sophisticated, which confers them with a risk potential, imposing a revision of the classical theory of the measures that are exclusively intended to sustain life and health for this category of patients.

When a pregnant woman behaves in a manner that may be harmful for the fetus or refuses a diagnosed or therapeutic measure that is intended to improve the fetus' state of health, ethical dilemmas may appear for the obstetrician, which is obliged to respect the mother's decisions and autonomy as well as to protect the fetus²⁰.

These dilemmas are described as maternal-fetal conflicts (Hornstra 1998; Oduncu et al., 2003; Wallace et al., 1997) and are based upon a supposed opposition between the maternal rights and the fetal rights, when there is a conflict between the woman's autonomy and the best interest of the fetus²⁵.

There are many countries where the courts of law have admitted that fact that the fetus has no legal rights until it is born alive and becomes independent of the maternal body (R v. Sullivan, 1991; Rodgers, 1993; Martin and Coleman, 1995)⁹.

Because the fetus has no legal rights until the time of birth, the child's rights' protection legislation (which, under certain circumstances, authorizes the intervention of the state in the case of a child with high risk) does not apply.

Moreover, a series of international legislative measures clearly state that the fetus has no legal rights which could overcome the right of the pregnant woman to decide upon her own medical assistance (European Council, Paton v. UK-1980; Cook et al., 2003; Copelon et al., 2005)^{3,8,9}.

The decision to sustain the life of a premature newborn

The viable newborn is defined as that that has the capacity, after birth, to survive (taking into consideration the modern possibilities of the neonatal intensive care) up to the point when he can sustain on his own his respiratory and cardiac activities.

In the case of extreme premature newborns, they present a high level of incertitude regarding the long term prognosis, the result could not be known, fact which raises important ethical issues.

Three ethical perspectives continue to have a major role in the decisions of selective non-treatment, with dominants that vary upon country, hospital, medic or even the mother:

- **the principle of sustaining the life of conscious children**, which are not about to die and for whom the treatment is not inutile and inhuman. This perspective offers the simplest way to approach the ethical issues, minimizing the factor of medical incertitude, the role of parents in making decisions, as well as any other dilemmas that may appear during an extended treatment for these newborns;
- **the perspective of the parents' dominant role in the decisions of non-treatment**; which is reasoned by the fact that the parents are the ones who will fight for sustaining their children until the later shall have a family and a "career";
- **the best interest of the patient** (of the newborn), where the focal point in decision making is represented by the relationship between **life** (sustained by medical treatment) and **patient** (centered on patient's life quality)²².

In the clinical cases the evaluations from this perspective are based on more than one variable:

- the gravity of the patient's medical condition, determined both by diagnosed evaluation, as well as comparatively with his newborn status and with the evolution of other newborns in the same medical condition;
- the possibility of application of a curative or corrective treatment within the effort to determine what treatment is benefic for a certain case;
- the main medical objectives of the particular case (i.e. extending life, reducing pain etc.);
- the presence of severe neurological deficiencies;
- the increase of the child's sufferance level (manifested by the increase of the arterial tension, tachycardia, agitation and crying);
- the existence of multiple associated pathologies (neurological, pulmonary, renal, cardiac etc.);
- the child's life expectancy;
- the ration between the benefits offered by the treatment and the level of child's sufferance, which defines the level from which the continuation of the life extension treatment is still into the child's best interest²⁷.

The factors that must be determined for a premature newborn and the prognosis at birth

The decisions involving life sustaining treatment applied to a premature newborn in a severe state must be determined upon what is best for him. The factors that contribute to this decision are:

- the chance of therapy to be successful;
- the risks of the treatment and the risks induced by non-treatment;
- the level by which the child's life may be extended, in the case of a successful treatment;
- the levels of pain and sufferance determined by the treatment;
- the anticipated quality of life of the newborn with and without the treatment²⁰.

When the prognosis is totally uncertain, as it is often happening in the cases of extremely premature newborns, all treating and intensive care measures intended to sustain their life must be applied.

The decision regarding the life sustaining treatment may be taken at the time when prognosis becomes certain.

The neonatology medic must provide the parents with information on the applied treatment, at a reasonable level of understanding, on the therapeutic options and on the estimated prognosis with and without vital functions sustaining treatment, so that they make an informed decision for their child.

The technological and chirurgical acquisitions of the last years and the evolution of the medicamentary therapies for these children have determined a tendency for supra-treating prematures and disabled newborns, tendency that sometimes seems to be in contradiction with the best interest of these children^{7,22}.

The relationship between the weight at birth and the survival prognosis is difficult to estimate, especially in the case of premature newborns with weights between 500g and 875g, thus in a gestation age of between 23 and 26 weeks (month 5 and 6 of pregnancy).

Starting with the '90s, the most controversial cases where those of extremely premature newborns, with weights at births lower than 600g and a gestational age of approximately 24 weeks, which have a high chance of developing severe neurological, pulmonary and cardiac lesions, and the cases of newborns weighting very little at birth and presenting neonatal retard, determined by maternal factors (smoking, alcoholism, malnutrition, infections etc.)^{26,22}.

The majority of these children die within their first days of life, which is why a three day survival determines a significant increase of child's survival chances. The only solution to part the group of children with real chances from the ones that have no chance in constituted by the initiation of treatment for all, and the ulterior clinical evolution shall indicate which of them progress favorably and which have no chance.

The decision to interrupt the sustaining of a premature newborn's life

The high frequency of neurological sequelae of the premature newborns in comparison to the children born on due time is well known, the prognosis of the future neurological pathology of prematures being even more difficult to anticipate than their survival prognosis.

The international perspectives regarding the neonatology medic's and the parents' role in the decisions regarding the health care for prematures and disabled newborns significantly vary from country to country. Whereas in democratic countries these decisions also tend to be democratic, there are countries where the neonatology medic exclusively makes the decision, with little participation from parents or other medics²².

There are only these situations that permit the interruption of these children's treatment in the USA:

- when the child in into an profound and extended coma;
- when the treatment may not extend the child's life for a long period of time;
- when the treatment is inhuman and virtually inutil regarding its capacity of saving the child's life.

The distinction between the incapacity of saving life (second situation) and the "virtual inutilty" (third situation) is given by the "level of probability or incertitude in determining the inutilty of a treatment"⁴.

As a consequence, the prevalent standard for a child's treating or non-treating decision is based on the "child's best interest" in the USA.

The child's life sustaining treatment may be interrupted only when death is inevitable or in the case of very severe organic lesions^{19,22}.

Many pediatricians prefer to provide the prematures with life sustaining treatment for a period of time, to give the treatment a chance to influence the evolution of the child, even when there is a high probability that the child will remain with sequelae in the future. This strategy of "individualized prognosis" reflects, from an ethical point of view, the inherent incertitude in medicine, permits the discreet intervention of the parents in decision making and prepares for making a decision of non-treatment in the case when the prognosis become unfavorable for the child^{19,20,22}.

Life quality of the premature newborns

In the case of newborns in severe state, the decision of maintaining the life sustaining treatment may be taken on the basis of a number of factors:

- the chance of the applied treatment to be successful;
- the risk determined by applying the treatment or by the non-treatment;
- the level by which the treatment, if successful, will extend life;
- the pain and discomfort associated to the treatment;
- the anticipated quality of child's life with and without the treatment.

The child's best interest

From the ethical perspective of the child's best interest the question if the life sustaining treatment offers the child more benefits than disadvantages is an important one.

The main accent, in some case, is placed on long term and it refers to the life quality of the survival prematures, especially when the treatment is partially successful, due to some severe complications that determine definitive sequelae, when the main accent is places on the "quality of life" of the child, even in the case of a favorable diagnosis regarding the sustaining.

In these cases the decisions are not mainly driven by the medical treating indications, but by the question if the final result of the treatment will be an acceptable one.

The components of life quality include:

- the anticipated level of cognitive and neurological functions;
- psychical disorders that may be predicted;
- pain and sufferance associated to illness;
- the disadvantages and difficulties of the treatments that the child that will follow in the future²².

For example, the "quality of life" of children suffering of Down syndrome is seen as above level, thus all these children are considered for treatment. On the other hand, the "quality of life" of the anencephaly suffering children is seen as under level, thus they are not considered for treatment.

The cases found at these extremes are further difficult and controversial, but, generally, the physical handicaps must be approached differently than the neuropsychic ones.

The majority of voices are saying nowadays that a certain minimum level of neurological and psychic functions is necessary for a life to be worth living, for the life of the child to have a "minimum acceptable" level of quality^{13,14,23}.

The criterion of life quality represented by the pain and sufferance associated to illness includes both the treatment addressed to the illness in itself, as well as the future treatments addressed to the definitive sequelae.

From this perspective, the prematurity represents an acute crisis as well as a chronic condition, the prognosis for these children being totally uncertain in many cases.

In the very difficult cases in the USA the prudence procedure in decision making is getting a consensual decision from a multidisciplinary commission, which is fully knowledgeable of the situation, impartial, emotionally stable and coherent^{22,23}.

The practice of the neonatologists in USA is to initiate aggressive life sustaining treatments as precocious as possible, in the same time with running specific tests for diagnosis and asking other pediatric specialists to consult the patients, discussions with the parents taking place either initiated by parents or when the prognosis becomes unfavorable.

This approach, called "waiting until certitude appears" involves a clear ethical choice: saving a child that will have a severe handicap is preferred to the death of a child that might have a reasonable life.

The life sustaining treatment for these children shall be interrupted only if death emerges or if the appearance of severe sequelae that will strongly affect the life of the child is inevitable^{19,22}.

These ethics committees are not as often used in Great Britain and Australia, the decisions being mainly made by the medics and the children's parents.

Another approach, which is frequently used in Sweden, aims to reduce to minimum the number of children that will slowly but predictably die and of those with severe handicaps.

It is called the "statistical prognosis" strategy and it uses statistical data as: weight at birth, gestational age and the results of the precocious diagnosis tests when making a non-treatment decision²².

Medics-parents conflicts

The ethics committees also have the role of mediators in the eventual conflicts that may appear between the medics and the parents in the cases of non-treatment decisions, because the birth of an extremely premature child or of one with a congenial handicap has an enormous emotional impact over the parents, these cases rising extremely complex ethical issues^{22,23}.

In these situations, within a few days from the child's births, the parents usually react in one of the three ways below:

- the parents decide that they do not wish for the treatment to be interrupted and they will not reconsider their decision in the future;
- the parents and the medic commonly agree upon a period of time, time after which they will reevaluate the decision based on the certain data that has appeared and on the evolution of the newborn under treatment; this freely chosen interval usually being between three and seven days;

- the parents immediately decide for the life sustaining treatment to be interrupted for their child.

Conclusions

The decisions involving the prematurely newborns in the neonatology sections imply three stages:

- appraising a correct clinical indication for intensive care;
- determining as exactly as possible the survival prognosis of the newborn;
- estimating the final result regarding the neurological handicap and the quality of the child's life in the future.

The ethical decision that must be taken will be in most cases an evident one if these stages are followed.

The main criterion in the determination of the life quality minimum required level is constituted by the sustenance of the human dignity.

When the prognosis remains uncertain, an unjustified risk to extend and aggravate the child's suffering may lead to a decision of interruption of the vital supporting treatment.

The studies show that neither the child's weight at birth nor the gestational age constitute predicting factors for appearance of neurological sequelae at preterm, thus the existence of a clinical strategy exclusively based on gestation or weight at birth may not be sustained in the decisions involving intensive therapy of the extreme prematures. ■

References

1. American College of Obstetricians and Gynecologists (2006). Maternal decision making, ethics, and the law; In Compendium of Selected Publications; Washington, DC: American College of Obstetricians and Gynecologists, pp. 111–20.
2. American Hospital Association (2007); The 2007 State of America's Hospitals: Taking the Pulse; Findings from the 2007 AHA Survey of Hospital Leaders (ppt); Washington, DC: American Hospital Association www.aha.org/aha/research-and-trends/.
3. Boso v. Italy (2002). App. No. 50490/99, European Commission on Human Rights (September 2002); American Declaration, OAS Off. Rec. OEA/Ser.L/V/II.82, Doc. 6, Rev. 1.
4. Boyd, Diane E., and Thompson, Peter J. 1990. „United States Commission on Civil Rights - Medical Discrimination against Children with Disabilities: An Abstract” *Journal of Contemporary Health Law and Policy* 6: 379–410.
5. Bewley S. (2002); Restricting the freedom of pregnant women; In *Ethical Issues in Maternal - Fetal Medicine*, ed. D. Dickenson, Cambridge University Press, Cambridge, pp. 131–46.
6. Cantor, Norman L. 2001. „Twenty-five Years after Quinlan: A Review of the Jurisprudence of Death and Dying” *Journal of Law, Medicine, and Ethics* 29(2): 182–196.
7. Caplan, Arthur L., Blank, Robert H., and Merrick, Janna C., eds. 1992. *Compelled Compassion: Government Intervention in the Treatment of Critically Ill Newborns*. Totowa, NJ: Humana.
8. Copelon R., Zampas C., Brusie E., and de Vore, J. (2005). Human rights begin at birth: international law and the claim of fetal rights. *Reprod. Health Matt.* 13: 120–9.
9. Council of Europe (1989). *The European Convention for the Protection of Human Rights and Fundamental Freedoms*, 312 UNTS 221 (entered into force on 3 September 1953), as amended by protocols 4, 6, 7, 12, and 13. Strasbourg: Council of Europe.
10. Cook R. J., Dickens B. M., and Fathalla, M. F. (2003); *Reproductive Health and Human Rights*. Oxford: Oxford University Press.
11. D'Angio, Carl T., Sinkin, Robert A., Stevens, Timothy P., et al. 2002. „Longitudinal, Fifteen-Year Follow-Up of Children Born at Less Than Twenty-Nine Weeks Gestation after Introduction of Surfactant Therapy into a Region: Neurologic, Cognitive, and Educational Outcomes.” *Pediatrics* 110(6): 1094–1102.
12. Gibson J., Godkin M. D., Tracy C. S., and MacRae S. K. (2007); *Innovative Strategies to Improve Effectiveness in Clinical Ethics. Bioethics for Clinicians*; Cambridge, UK: Cambridge University Press.
13. Infant Doe, In re. No. GU 8204–004A (Monroe County, Ind., Cir. Ct. 1982); writ of mandamus dismissed subnom. State ex. rel. Infant Doe v. Baker. 1982. No. 482 140 (Sup. Ct. Ind.); cert. denied *Infant Doe v. Bloomington Hospital*; 464 U.S. 961; 104 Sup. Ct. 394 (1983).
14. Jane Doe, In re. 418 S.E.2d 3 (Ga. 1992).
15. JCAHO (2007); *Overview of 2007 Leadership Standards*; Oakbrook Terrace, IL: Joint Commission on Accreditation of Healthcare Organizations, p.20; (http://www.jointcommission.org/NR/rdonlyres/A55ACE4-E027-4FE0-8532-C023E8817A30/0/07_bhc_ld_stds.pdf).
16. Lantos, John D. 1987. „Baby Doe Five Years Later: Implications for Child Health” *New England Journal of Medicine* 317(7): 444–447.
17. MBBNet (2007); <http://mbbnet.lumdn.edu/scmap.html>.
18. Meadow, William, Reimshisel, Tom; and Lantos, John. 1996. „Birth Weight—Specific Mortality for Extremely Low Birth Weight Infants Vanishes by Four Days of Life: Epidemiology and Ethics in the Neonatal Intensive Care Unit”; *Pediatrics* 97(5): 636–643.
19. Rhoden, Nancy K. 1986. „Treating Baby Doe: The Ethics of Uncertainty” *Hastings Center Report* 16(4): 34–42.
20. Singer P. and Viens A. M. (2008). *The Cambridge Textbook of Bioethics*. Cambridge University Press: Hertford College, Oxford, UK.
21. Sperling D. (2006). *Management of Post-mortem Pregnancy: Legal and Philosophical Aspects*. Aldershot: Ashgate.
22. Stephen G. Post (2004). *Encyclopedia of Bioethics*, 3rd edn, New York: Macmillan Reference USA, pp. 1244–51; 1255–63; 1277–80; 1401–02; 2676–79.
23. U.S. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1983; *Deciding to Forego Life-Sustaining Treatment: A Report of the Ethical, Medical, and Legal Issues in Treatment Decisions*, Washington, D.C.: U.S. Government Printing Office.
24. Vohr, Betty R., Wright, Linda L., Dusick Anna M., et al. 2000. „Neurodevelopmental and Functional Outcomes of Extremely Low Birth Weight Infants in the National Institute of Child Health and Human Development Neonatal Research Network, 1993–1994” *Pediatrics* 105(6): 1216–1226.
25. Vo v. France [2004] 2 FCR 577, European Court of Human Rights; Wallace R., Wiegand E., and Warren C. (1997); *Beneficence toward whom? Ethical decision-making in a maternal–fetal conflict*. *AACN Clin Issues* 8: 586–94. *Winnipeg Child and Family Services (Northwest Area) v. G. (D.F.)* [1997] 3 SCR 925.
26. Walters James W. 1991. „Report from North America: Anencephalic Infants as Organ Sources” *Bioethics* 5(4): 326–341.
27. Weir Robert F., and Bale, James F., Jr. 1989. „Selective Nontreatment of Neurologically Impaired Neonates” *Neurologic Clinics* 7(4): 807–822.
28. Wood Nicholas S., Marlow Neil, Costeloe Kate; et al. 2000. „Neurologic and Developmental Disability after Extremely Preterm Birth” *New England Journal of Medicine* 343(6): 378–384.