

SPECIFIC MEDICAL AND ETHICAL ASPECTS IN THE CARE OF LIFE – THREATENING ILLNESSES IN NEWBORN

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Abstract

Neonatology practice deals with many and complex situations, all derived from life-threatening problems in neonatal care, especially in severe asphyxia and extreme prematurity. The neonatologists' problems derive not only from the duration of the resuscitation which is to be established while having in mind his interests and the quality of babies future life but also whom to resuscitate at the limits of viability taking into account the complexity and severity of future complications and the unfavourable prognosis.. Authors of this article comment upon some specific bioethical aspects of neonatal practice from the large field of such aspects and give some clinical examples from real practice that suggests that bioethical decisions must be taken into account in the daily practice.

Keywords: ethical decisions, newborn, limits of viability, severe perinatal asphyxia.

Neonatology is one of medical specialities that has been recently recognized as being important and which has been developing rapidly and constantly in the last 12 years. Due to quick progresses we could recover some of most difficult cases and situations at the limits of viability or with severe asphyxia at birth that in former conditions were lost. These achievements were possible not only because of the new and modern

equipment, new technologies in medical neonatal practice, but also because of medical training and teaching among medical staff, with higher professionalism and dedication. Together with this progress, we had to deal with new ethical difficulties in approaching and managing critical situations. According to this we identified some specific situations. that neonatological practice is dealing with.

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Impossibility of a direct dialog with the patient

The newborn is not able to speak and clinical symptoms are often little and unspecific, represented mainly by respiratory distress symptoms, which is an unspecific set of symptoms present in a large group of illnesses, most with vital risk (3). A good and correct follow-up of the pregnancy, a real dialogue among obstetrician, perinatologist, neonatologist and general practitioner focused on the main player – the pregnant woman – may lead to a better knowledge of neonatal risk factors. Critical situations are determined either by the complications and the pregnancy pathology in spite of the precise monitoring, either by no addressability of pregnant woman to any physician. In this situation the problems of fetus and newborn remain a surprise to deal with at birth, which demands a rapid and sustained management in the best interest of the baby. The newborn belongs to the category of vulnerable patients (as stated in the „International ethic guide of biomedical research” that includes human subjects from 2002 – as „persons absolutely unable to protect their own interests”). So, decisions are transferred to legal parents or bioethical committees of the hospital.

Difficulties in getting a rapid and accurate informed consent of the parents, regarding the vital risk problems and poor outcome of the newborn

Most of times the mother herself is in a poor condition in deliverance and postpartum or after cesarean section, and this affects the accurate perception of the provided information. Vital risk conditions needs for explanation and understanding a minimum of specialized medical information, which is hard to be

understood by the non-specialists. Many times the father is not present in order to be immediately informed. The communication of the unpleasant news has to be done by the neonatologist, with a lot of diplomacy and patience, but also rapidly and in a concise way on the other side, a difficult thing to be accomplished in emergency, because the first obligation of the doctor is to provide correct and rapid care to the patient, that demands his active and sustained presence and action. On the other side, it is well known that information about patients' status should be communicated rapidly, as soon as possible, and eventually in the presence of a third person, from the family or medical care staff, who is able to provide affective support. In severe cases, beside the medical emergency, the need of informing the family about the unfavourable evolution of the disease appears. The news of a potential death should not come like a „bad surprise” and „thunder hit” that could raise suspicions about the quality, on time or professionalism of medical care. The parents must be updated both with the therapeutic procedures administrated, and with the illness progress. The necessity of confidentiality is not only a part of Hipocrat's Oath, but is also a legal stipulation and it is frequently asked by the family. Sometimes we even refuse to give information to a third person, even if they declare they are siblings with the patient and physicians. These situations must, of course, be cautiously evaluated, as many times parents can be so serious depressed by the bad news so that that deny, reject them, refuse to accept reality and are looking for reconfirmation or other opinion from other members of the family that are also doctors. An advantage for us is that in Romania, unlike other countries, there are no significant difficulties in communication

due to language differences, the population being mostly Romanian, and the language is easy and fluent (6). The only exceptions are the cases of deafness or psychiatric illnesses when there is no power of judgement and when some difficulties in getting informational contact with the mother may appear but fortunately these cases are rare.

The difficulty of obtaining parents' informed consent regarding therapeutic options

Patients' Rights Act (Law nr. 46 of January, 2003) guarantees the patient or his legal guardians the right to be informed about available or necessary therapies, health status, progress of the disease, hospital policies, the identity and professional status of the medical personnel but also guarantees the right to refuse certain therapeutic measures. Informed patient consent regarding the commencement or continuation of life-support therapy is therefore obligatory. There are situations when parents do not agree among them or are not available immediately. The hospital ethics committee is required in such a situation, but this too is impossible to assemble in due time, especially when deterioration is quick and there is an urgent need to make a peremptory decision. That is why, in neonatology, more than anywhere, the physician must deal with the pressure of making emergency ethical decisions by himself, with no legal protection and with some important professional, psychological and social implications (2, 7).

The lack of a long experience which could allow a highly accurate statistics from which we could predict survival chances and the future quality of life deters from a realistic briefing to the parents. Lately, the international sta-

tistics results have been used, acknowledged by important bodies in the field of neonatology (4). These results cannot be superimposed on our existing care and monitoring backgrounds. Moreover, parents often require guarantees and certainties, percents and timely prognosis, which are in fact impossible to provide. Hazardous personal opinions, based on personal experience or subjective intuition from some doctors can provide false hopes to which parents can cling to. Deception can therefore be more overwhelming and accusal can affect in an even more negative way the medical staff.

The lack of a clear legislation regarding the viability of a newborn and the opportunity of commencement of resuscitation manoeuvres in decreasing gestational ages

The existing legislation stipulates that any fetus that is presenting minimum signs of life in the immediate postnatal period regardless of his gestational age is considered to be a newborn. This means that resuscitation manoeuvres must be initiated in case of any newborn with minimum cardiac activity, even if his degree of immaturity will lead to the exhaustion of organic response in the following hours, days or weeks. Only neonates diagnosed during pregnancy with anencephaly, trisomy 13 or 18 as well as those with gestational ages under 23 weeks or weighing under 400 grams are excluded from resuscitation manoeuvres (1).

The decision whether not to resuscitate or to stop intensive care when survival chances are minimal or, in spite of survival, the neurologic future of the infant is definitively compromised is a difficult one (5). Not few are the cases

of neonates with extremely low birth weights, under 800 grams and low gestational ages, under 28 weeks, which were recovered and cared for intensively during weeks or months using medication which implied enormous costs and later developed long-term complications requiring repeated surgery and prolonged hospital stays, to finally die after years of sustained medical and human efforts. Another category which requires ethical decision-making at some point is that of newborns with severe perinatal asphyxia. After attaining cardiac and pulmonary stability, some of them present irrecoverable neurologic deterioration, with no degree of consciousness and motor, physic and cognitive impairment which are extremely difficult to care for and discouraging for the parents. The presence of such a case can be not only depressing for the whole family but can also represent an important destabilizing factor for a couple, can strongly influence the psycho-emotional development of the brothers, not to consider the financial issues to be dealt with by the family and even by the entire society.

The quality of life of the survivors should be an important element to be considered in decision-making, especially in the case of a newborn. The right to life is certainly inalienable and doctors should commit their entire capabilities in order to save each and every life. The continuation of a prolonged resuscitation at any cost, despite severe hypoxia followed by neuronal destruction, will eventually lead to different stages of encephalopathy, an entirely vegetative existence, with no identifiable conscious human component. The most frequent scenario is as follows: the newborn premature or at term with severe, prolonged asphyxia as

defined by current criteria, resuscitated at birth is then set on mechanic ventilation, with cardiac support medication, parenteral nutrition, with no signs of stabilizing or EEG activity. Following briefing, his parents require that life maintenance efforts should continue, regardless of the consequences. After a variable time span in intensive care, some degree of cardiac and respiratory stability is acquired which allows enteral nutrition, with no signs of improvement or neurological progress. After prolonged hospitalization, during which the mother is also taught how to take care of the child, this one is discharged, with compulsory visits to the follow-up neonatologist and the kinetic therapist who indicate the possible useful methods during the recovery. Following disabling outcome, parents' enthusiasm progressively decreases and deception is overwhelming. The longer the situation the more, parents tend to blame the medical staff and frequently declare: „If only I knew it to be this hard, I wouldn't have insisted you kept it alive at any cost”.

Next, some cases resulted from different clinical situations with different ethical and social consequences are presented.

Case 1

Baby S.E.: severe asphyxia with permanent devastating consequences and forensic implications

S.E., term female newborn baby, from natural delivery, breech presentation, birth weight 3600 grams, Apgar score 4 at 1 minute, 7 at 5 minutes and 8 at 10 minutes, was born in a level II maternity hospital and transferred in the regional neonatal intensive care centre after 24 hours, for perinatal asphyxia. Following complex

investigations, diagnoses were issued: second stage hypoxic-ischemic encephalopathy, seizures, severe respiratory distress, subgaleal hemorrhage, brachial plexus paralysis, posthypoxic hypertrophic cardiomyopathy, posthypoxic renal and liver failure. Five days of mechanic ventilation, blood transfusions, total parenteral nutrition, antibioprophyllaxis, anticonvulsivants were necessary with apparent improvement during the first 12 days. She is then enrolled in a neurologic follow-up program but despite kinetic therapy she presents at 18 months of age with motor and psycho-affective retard and no verbal acquirement. She no longer develops seizures, but her only acquisitions is vegetative. Her family had great difficulty of coping with this result and started legal procedures of investigation regarding the causes leading to her impairment and of blaming medical staff involved in the delivery and postnatal care of their infant.

Case 2

Baby C.T.: prolonged resuscitation followed by death during the tardive perinatal period

C.T., term male newborn baby, delivered by cesarean section, birth weight 2500 grams, Apgar score 1 at 1 minute, 3 at 5 minutes, 4 at 10 and 20 minutes. He needed prolonged and complex resuscitation in the delivery room, (one hour) followed by delayed appearance of respiratory movements and early seizures. He needed 8 days of mechanic ventilation, 6 large doses of bicarbonate necessary for the correction of severe metabolic acidosis, dopamine and dobutamine for three days and promptly and aggressive treatment with two anticonvulsivants. Severe perinatal asphyxia was accompanied by renal

failure, bronchoplegia, lack of primitive reflexes and difficult nutrition. The EEG shows distinctive spike/wave traces and low amplitude traces and the CT exam showed cerebral diffuse edema with poor differentiation between white and gray matter. The boy was transferred after 40 days of life in a Pediatric Neurology facility, then later discharged with no signs of progress or neurologic acquisitions. died at home at 2 months of life.

Case 3

Baby D.R.: stage III hypoxic-ischemic encephalopathy, with unforeseeable implications

D.R., term newborn baby, birth weight 4000 grams, was delivered by cesarean section (due to decreased fetal movements) in a level II maternity hospital, with Apgar score 8 at 1 minute, 7 at 5 and 10 minutes. Following birth, the infant rapidly deteriorated, developing hypotonia, cyanosis, cardiac murmur, bradycardia, respiratory distress and transfer was decided upon to the regional neonatal intensive care centre, after intubation and initiation of ventilatory support. Findings are as follows: hypoxic-ischemic encephalopathy, severe respiratory distress of neurologic etiology, which needed mechanic ventilation for 10 days. After 13 days, seizures emerge, resistant to usual anticonvulsivants. The CT scan showed posthypoxic cerebral atrophy. EEG showed flat, isoelectric traces. Echocardiography showed posthypoxic hypertrophic cardiomyopathy. Muscle biopsy showed posthypoxic muscle atrophy. After 52 days of no clinical neurological improvement, the infant is transferred to Pediatrics department, where it dies at 3 months of age, in spite of all intensive care efforts.

Case 4

Baby M.I.: stage III hypoxic-ischemic encephalopathy, with no apparent explanation, with severe outcome and social and family implications

Term female newborn baby, from natural delivery, birth weight 3600 grams, Apgar score 1 at 1 minute, 4 at 5 and 10 minutes and 5 at 20 minutes developed severe perinatal asphyxia in need of prolonged and complex resuscitation. 30 minutes following resuscitation, she presented with gasps, and 10 minutes later, her breaths became spontaneous and effective. 4 hours later she presented with continuous generalized seizures, resistant up to 48 hours to sustained double anticonvulsant therapy. Her biochemical investigations showed renal and liver failure, metabolic acidosis, following the hypoxic event. After 14 days doctors decided upon her transfer to a level III centre. Continuous 24-hour EEG showed normal amplitude trace alternated with flat, isoelectric trace on both cerebral hemispheres and distinctive spike/wave trances, typical for seizures. Cranial ultrasound could not determine the presence of hemorrhage and CT scan shows hypodensity in both hemispheres of possible hypoxic or metabolic cause. The girl was discharged from the hospital at 45 days of age with severe neurologic impairment, hyperexcitability and poor reflexes, especially the suckling reflex, which makes feedings difficult and prolonged. At home, under continuous anticonvulsant treatment she no longer had seizures, but her neurologic acquisitions are null, she maintains cognitive and motor impairment and a vegetative status under kinetic therapy at 7 months of age. Socially, she comes from an illegitimate family, a 21-year old mother and a 38-

year old father who does not express any compassion for their offspring and they can not provide proper and safe care. Therefore the maternal grandmother took the charge of the infant. The difficult ethical issues arise from the lack of understanding by the parents of the causes and of the poor outcome of a child derived from an apparently normal pregnancy.

Case 5

Baby B.A.: severe complication of extreme prematurity with inauspicious outcome

Preterm baby girl, birth weight 930 grams, 28 weeks gestational age, born from natural delivery in a level II maternity hospital and transferred in a level III centre, initially presented severe respiratory distress in need of mechanic ventilation, surfactant therapy, three antibiotics for positive tests of infection. After an apparently favorable outcome, in the 15th day of life, intraventricular stage III hemorrhage occurred, evolving next to hydrocephaly and periventricular leukomalacia. In spite of the neurosurgical treatment, ventriculo-peritoneal shunt required repeated desobstruction. The outcome was poor the hydrocephaly progressed. Severe complications occurred, such as stage II retinopathy of prematurity, not correctable due to anesthetic risks. At 10 months of age, her outcome is extremely precarious as she is in terminal coma, with severe muscular dystrophy, anemia, impressive hydrocephaly and encephalopathy. She has always had emotional support and care from her devoted mother, of a medium social condition and a strong family with a healthy older child, who may be morally and emotionally influenced and who might be in need of psychological counseling and support in future.

Case 6

Baby M.M.: severe complications of prematurity and special social implications

M.M., preterm baby girl, birth weight 1250 grams, 29 weeks gestational age, was born through cesarean section, by a 30-year old mother with advanced stage Hodgkin's disease. The parental couple decided to keep this pregnancy at any cost (the mother previously had 2 miscarriages), although properly informed of the effect of the pregnancy on maternal pathology and of the possibility of a premature birth with all its consequences. Apgar score was 4 at 1 minute, 5 at 5 minutes and 6 at 10 minutes, the neonate was resuscitated and admitted in neonatal intensive care with hyaline membranes disease, stage III intraventricular hemorrhage followed by tetra-ventricular active hydrocephaly, PDA, necrotizing enterocolitis. She needed intensive care for 40 days, was then transferred to neurosurgery for ventriculo-peritoneal drainage and was subdued to multiple surgical procedures. During her hospital stay, her mother's condition worsened progressively and she died. Her father was forced to move out of their home and at a long distance

of the hospital where at present, at the age of 2 years and half his daughter is artificially maintained alive.

Conclusions

The cases presented can be subdued to multiple comments and observations. Each has its own particularity which emphasizes the important ethical, moral involvement of the neonatologists, issues which are hardly to be perceived, are unexpected or even unknown. Enhanced attention must be paid and consistent psychological support must be granted to the family of the severely affected neonate, but also to its caregivers, witnesses to such tragedies, which impact on human, moral and professional attitude of each individual. The lack of legal guidelines to help implementing medical standardized practice leaves enough room to interpretations and errors. A more sustained concern for neonatological bioethics is necessary and the present article is intended to be a starting point for discussion among physicians, but also decision-makers, discussions which may contribute to the prevention and decrease of such tragedies.

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