

Changing the focus of care: from curative to palliative care

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The last ten years, the next ten years in Neonatology

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Abstract

The improvements in the obstetrical and neonatal diagnosis and therapies have resulted into an increase in the survival rate of infants previously considered as non-viable. Debate is focusing on professionals' behaviour about withdrawal or withholding of life sustaining treatment (LST) and administration of palliative care for newborns whose conditions are incompatible with a prolonged life.

Decisions about treatment should be made jointly by the professionals' team and the family, placing the interest of the baby at the very heart of the decision process. It is very important that the environment in which the family has to make the decision is characterized by openness, dialogue and frankness.

A proper and effective communication with parents is always necessary and can resolve any conflict caused by disagreement. Furthermore, parents need time in the decision making process.

Other supports, which could help the family in the final decision are the possibility to ask for a specialist's second opinion and the involvement of religious leaders and of an independent clinical ethics committee.

Withholding or withdrawal of LST does not mean cessation of care for the baby, it means to change the focus of care from curative to palliative care.

Keywords

Palliative care, newborn, parents, empathy, communication, remember box.

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Introduction

Recent advances in prenatal diagnosis and neonatal medicine have led to new scenarios in the area of pediatric palliative care. As a matter of fact, the increase of survival rate of extremely preterm infants and sick newborns has resulted into a significant increase in morbidity and neurodevelopmental impairment with a considerable impact on babies, parents and society [1].

Debate is increasingly focusing on professionals' behaviour when facing the decision about withdrawal or withholding of life sustaining treatment (LST) for newborns whose conditions are incompatible with a prolonged life.

In 2013 our hospital registered 3,124 deliveries with 3,189 newborns: 6 of them were intrauterine fetal death (IFD), and a total number of alive newborns of 3,183.

The main causes of death in infants aged 1 month-17 year in the area of Bologna (2009-2013), other than big traumas, cancer and infectious diseases, were perinatal pathological conditions and congenital malformations.

Furthermore, in Bologna district the number of chronic disease in patients aged below 18 years is increasing (1.7 cases/10,000 in 2009 to 3.9 cases/10,000 in 2013) (courtesy of S. Sandri, general paediatrician of Bologna AUSL district).

With the support of a clinical report about an infant affected by severe chronic lung disease (CLD)/bronchopulmonary dysplasia (BPD) we would like to do some considerations on palliative care in newborn, end of life and withdrawal or withholding of LST.

What is palliative care?

“The verb to palliate means to mitigate, to alleviate, to lessen the severity of pain and disease, or to give temporary relief” [2].

In 1987 palliative care was defined as “the study and management of patients with active, progressive, far-advanced disease from whom the prognosis is limited and the focus of care is the quality of life” [3]. This definition has been more recently summarized by the World Health

Organization (WHO): “...control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families...” [4].

Neonatal palliative care focuses on both infant and family. More specifically, it represents a team approach which embraces many different professional figures (gynaecologists, midwives, neonatologists, neurologists, psychologists, nurses, etc.), whose aim is helping the infant and the family to feel relieved from suffering [5], being the central theme the best interest of the baby [1].

The huge improvements in the obstetrical and neonatal therapies have resulted into early identification of congenital anomalies of the fetus in uterus and, consequently, into an increase in the survival rate of infants previously considered as non-viable [1]. Such improvements allow a pre-natal planning of LST withdrawal or withholding based on the disease and its prognosis and always after a prolonged discussion with the family.

In general, death in neonatal units relates to four different situations [6]:

- withdrawal of LST: death attributable to the elective discontinuation of ongoing life support;
- withholding of LST: death attributable to the non-initiation of treatment necessary for immediate survival after birth including surgical interventions and resuscitation (hand ventilation by bag, endotracheal tube ventilation, external cardiac massage, or administration of adrenaline);
- do not resuscitate (DNR) order: do not initiate any of the procedures outlined in point 2. or further resuscitation for babies already ventilated in the event of clinical deterioration;
- natural: death occurring despite maximal intensive care.

When to consider withholding or withdrawal of life sustaining treatment

The Royal College of Paediatrics and Child Health (RCPCH) in the United Kingdom has provided guidelines describing five situations when it may be ethical and legal to withhold or withdraw LST in the best interest of the infants [1, 7]. The above-mentioned situations are the following: the “Brain Dead” Child, the “Permanent Vegetative” State, the “No Chance”

situation, the “No Purpose” situation and the “Unbearable” situation.

Whereas the first two conditions belong to older children, the latter three can refer to neonatal population. The “no chance” and “no purpose” categories are probably the most frequent applied criteria in neonatal units [1].

The “no chance” situation includes infants with severe anomalies that are incompatible with a prolonged life. In this situation LST simply postpone death as in the case of genetic disorders (e.g. trisomy 13 or 18, triploid syndrome, some lethal cases of osteogenesis imperfecta or thanatophoric dysplasia), kidney diseases (e.g. Potter syndrome), central nervous system (CNS) diseases (e.g. anencephaly, acrania, hydranencephaly) and organ malformations (e.g. congenital diaphragmatic hernia with severe pulmonary hypoplasia, inoperable conjoined twins).

The “no purpose” situation includes babies who may be able to survive with LST, but whose physical or mental disabilities would be so serious that it is unreasonable to expect them to bear them as in the cases of severe condition of hypoxic-ischemic encephalopathy, intraparenchymal haemorrhage and congenital or perinatal infections.

Finally, the “unbearable” situation, includes those cases where LST might sustain infants’ life, but the cost for the baby in terms of suffering is deemed too high (e.g. baby with chronic lung disease with multiple organ failure who do not respond to a maximum ventilatory support) [1, 6, 7].

Chronic lung disease/bronchopulmonary dysplasia

BPD among very low birth weight infants remains one of the most frequent conditions, which affect this fragile population and its prognosis is sometimes poor. In our unit, the rate of CLD defined as oxygen dependency at 36 weeks of post conceptional age is around 18-20% (Vermont-Oxford Network [VON]/ Italian Neonatal Network [INN] data 2007-2012).

Zysman et al. [8] have studied the trend of BPD dysplasia over the past three decades and have noticed a higher incidence of BPD particularly related to multiple gestation, a higher maternal age, a lower gestational age and a lower birth weight. Nevertheless, mortality rate due to BPD is decreased during the last years [8].

Another study [9] shows the long term prognosis in ventilator dependent patients with severe BPD

at home: death can occur not only in the period immediately after birth but also until the age of 14 years, particularly in the population of extreme preterm infants with a birth weight lower than 750 g.

Case report

We report the case of a male infant born at 25 weeks of gestation (birth weight 670 g) by an emergency caesarean section due to premature membrane rupture, retro-placental hematomas and metrorrhagia in central placenta praevia.

The mother’s vaginal swab was positive for ureaplasma urealyticum and the obstetric remote anamnesis showed two miscarriages and an induced abortion.

Since the very first weeks of life, the infant was supported by mechanical ventilation, mainly high frequency oscillatory ventilation (HFVO), with a FiO_2 of 100%. During the hospitalization, the infant contracted several systemic infections, and ureaplasma urealyticum was found on respiratory aspirates. He received a nearly continuous antibiotic and antifungal therapy. Furthermore, due to patent ductus arteriosus a pharmacological closure with Ibuprofen was induced. Additionally, the patient underwent an intestinal resection due to a perforation secondary to meconium ileus and laser therapy due to severe retinopathy of prematurity (ROP).

After four months of hospitalization in our neonatal intensive care unit (NICU) the clinical situation of the baby was extremely severe, the chest X-ray showed a severe BPD and bilateral extended areas of opacity/atelectasis and was still ventilated in HFOV mode, with a mean airway pressure (MAP) of 30 H_2O cm and a FiO_2 100%. The cardiac ultrasound showed an important dilatation of the cardiac chambers, a decreased myocardial contractility, a dilatation of the inferior vena cava, a reduced left-ventricle compliance and a small tricuspid insufficiency. The cerebral ultrasound did not show any parenchymal abnormality. Finally, the infant suffered from a renal insufficiency resistant to diuretics, which caused anasarca.

The patient’s medical conditions led us to ask: “should we consider palliative care?”.

Cooperation and disagreement

As underlined above, for infant with a poor prognosis *quoad vitam* or whose conditions are

incompatible with a prolonged life, decisions should be made jointly by the medical team and the baby's family. All members of the health care team has to take an active part in the decision, placing the interest of the baby at the very heart of the decision process [1].

In clinical practice, there are situations where treatment is either unreasonable (burden outweighs the benefit) or mandatory (benefits clearly outweighs the burden) [1]. However, there is a "grey zone" between these two clear conditions which is characterized by the uncertainty about the patient's survival probability as well as her/his possible future disabilities [1, 10]. In these uncertain cases the role of parents is essential [1, 11].

Furthermore, it is of paramount importance that the environment in which the family has to make this stressing decision is characterized by openness, dialogue and frankness.

There are many factors influencing parents' decisions. In fact, the health care team has to cooperate with the family and to consider parents' worries and desires related to their social, ethnic, religious and educational backgrounds [12]. This means being honest about the baby's condition, without omitting any concrete evidence of poor prognosis or, conversely, without creating any expectation in the family [1].

A Norwegian study by Brinchmann et al. [13] underlines how parents wants to participate to this choice, but at the same time shows that they do not want to make the final decision.

Decision making is indeed a long process rather than an event, where parents have to be guided by the health care team, in full trust [1, 7]. The family needs time to realize which is the best decision for the baby.

Nevertheless, reality is different. Disagreement among professionals, and between professionals and the family have been frequently recorded, as certified – in the case of Netherlands – by Verhagen et al. [14], who reported dissents among professionals in 4% of cases and between professionals and the parents in 12% of cases.

How to resolve disagreement

An open, proper and effective communication is needed both within the professional team and in the relationships with families [1, 7]. In most cases, adequate time and frank exchanges of opinions can smooth disagreements or tensions and resolve conflicts, helping the family and the

health care team to reach a common consensus [1, 14].

Given time to think through the clinicians' recommendations and the baby's condition, almost all parents agree with professionals' team [1, 14]. Giving the opportunity to the family to ask for a second opinion within or outside the hospital is considered as a particularly effective method. Parents have to feel free to arrange the second meeting with the specialist they prefer or with their general practitioner [7]. Moreover, receiving advice from the religious community or calling an outside ethic committee could be helpful to resolve the conflict [1].

Due to endless internal dissents, in our particular case we decided to organize a meeting with all our staff and an expert in palliative care external to our team.

The expert raised two questions, reported below.

- What is the prognosis of the baby? Has he any chances to survive? Additionally, in case he survives, what will be the long-term outcome?
- Does our behaviour follow the bioethical aspects of medical field?

What medical ethics principles can provide is "a common set of moral commitments, a common moral language, and a common set of moral issues. We should consider the so-called *prima facie* principles in each case before coming to our answer using our preferred moral theory" [15].

Three of the *prima facie* principles are beneficence, non-maleficence and justice.

Beneficence refers to actions that is done for the benefit of others; in the medical context, it means to serve the best interest of patients. Non-maleficence means "first, do not harm" (in latin, *primum non nocere*): it is more important not to harm patients than to provide them benefits. Physicians must refrain from providing ineffective treatment; an overtreatment is to avoid. Moreover, we have to consider that what is one patient's benefit could be harmful for another one [15].

Eventually, the principle of justice allow to guarantee the medical right every single patient deserves, without sexual, racial, religious (etc.) discriminations. At the same time, doctors must not exceed the economical budget, except in case of real benefits of the patient.

Therefore, according to these principles, after the meeting we all decided to stop LST (antibiotics, inotropic agents, diuretics..) and provide palliative care (opioids *per os*, in particular eptadone; nasal-

gastric tube feeding) with the common agreement not to intubate the baby again in case of accidental extubation.

In the presented case, the infant passed away at the age of 4 months and ½ due to an accidental extubation. He did not feel any discomfort or pain thanks to an optimal sedation.

The parents received a memory box, which contained handprints and some objects in remembrance of their baby.

Conclusions

Thanks to the improvements in the obstetrical and neonatal diagnosis and therapy, the survival rate of newborns previously considered as non-viable has increased, together with the percentage of the “no chance”, “no purpose” and “unbearable” situations, when it may be appropriate to stop LST and provide palliative care.

The most frequent reasons for withdrawal or withholding of LST among newborns are major congenital abnormalities, severe complications of prematurity and severe perinatal asphyxia.

Decisions about treatment should be made jointly by the professionals’ team and the family, placing the interest of the baby at the very heart of the decision process.

A proper, honest and effective communication with the parents is always necessary and can resolve any conflict caused by disagreement. Time is of paramount importance for parents in the decision making process.

Furthermore, other supports, which could help the family in the final decision are the possibility to ask for a second opinion and the involvement of religious leaders. An independent clinical ethics committee can be helpful too.

In conclusion, a pivotal topic: withholding or withdrawal of LST does not mean cessation of care for the baby, but it means to change the focus of care from curative to palliative care [1, 7].

Decision is a process, not an event [1], and it needs time to consolidate.

Declaration of interest

The Authors declare that there is no conflict of interest.

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