A framework for ethical decision making in neonatal intensive care

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Abstract
Intensive care for neonates with high risks of severe impairment and the possibility of a prolonged dying process represents a frequent ethical issue in neonatal units. The aim of this paper is to present a framework for structured decision making that has been developed in a neonatal intensive care unit and to demonstrate its impact on the healthcare team and on survival of critically ill neonates. This framework attempts to integrate the best interests of the infants and their parents, the possibilities of high-tech neonatal intensive care interventions, and the perspective of the nurses and doctors. An external evaluation of 84 sessions over 3 y revealed a beneficial effect on the quality of the decision-making process itself and on the quality of the teamwork in the unit. Survival time was shorter (median 2 d, interquartile range 1–7 d) in 26 infants that died after structured decision making compared with 26 controls matched for gestational age, malformation and intracranial haemorrhage (median 7 d, interquartile range 4–15 d).

Conclusion: The introduction of this framework for structured decision making involving doctors and nurses improved the quality of the teamwork. It shortened futile intensive care, and thereby suffering for both infants and parents.

Key Words: End-of-life decisions, ethics, neonatal intensive care, palliative care

New ethical dilemmas
Intensive care for neonates with high risks of severe impairment and the possibility of a prolonged dying process creates an ethical dilemma in neonatal units [1–3]. In the last 20 years, the mortality rate in neonatal intensive care has decreased steadily due to technical developments. Several investigations show an impairment rate negatively correlating with mortality in extremely-low-birthweight infants [4]. Moreover, with prolonged intensive care comes a large increase in cost. Every neonate poses the same difficult question to medical staff: “How can we decide in his or her best interests?” [5].

How can one make an ethical decision?
The following section outlines several different ways in which the decision-making process may be undertaken in neonatal intensive care.
- Traditionally, the head of the neonatal unit decides when to withdraw or to withhold intensive care in neonates [6]. The disadvantage of this approach is that, in a pluralistic and democratic society, surrogate decisions cannot be taken in an authoritarian way [7–9]. Moreover, modern medicine offers several possibilities for acting in each situation. The pros and cons of each choice have to be evaluated against each other and the final choice has to be made transparent, and be openly debated and defended against other opinions [10–15].
- Another option may be to follow strict rules or guidelines [16]. Such an approach does not allow individual evaluation and does not fulfil the requirements for a responsible decision-making process that takes into account the complex situation of individual neonates.
- Ethical decisions can be delegated to special ethical committees or ethical consultants. In this way, action and responsibility become separated, which may lead to a loss of feeling responsible for the individual infant by the healthcare team.
- Ethical decisions can be delegated to the parents. However, they may be overwhelmed by this task and experience feelings of guilt [17,18].
Doctors and nurses working in a neonatal intensive care unit are primarily responsible for the management of the infant. They know the infant and the parents in this situation better than anyone else. Therefore, the healthcare team should adopt the responsibility for ethical decision making. The team should be specially trained for this task and should be able to lead an ethical decision-making process professionally [11–13,19]. This requires ethical competence on the one hand and communication skills on the other. Decision making should follow a standard procedure which minimizes the arbitrary nature of each decision [20].

The last option was chosen at the Clinic of Neonatology at the University Hospital of Zurich, and a framework was developed to structure the decision-making process for the individual neonate within the boundaries of the national guidelines [21,22].

### Development of a framework for the decision-making process for the individual case

In 1994 a “Medical-Ethical Working Group on Neonatology” at the University Hospital of Zurich was founded after a congress on the ethical problems in neonatal intensive care [15]. The group consisted of three doctors and three nurses of different hierarchical levels, a female minister and a female ethicist who lead the group. During the following years they met every 3 wk for one and a half hours. In the first 5 y, there were only three absences. People even participated during free time and vacations. The work was structured in eight phases.

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### Box 1. Setting of the ethical round.

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<th>Role of the parents</th>
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<td>In the overwhelming situation of finding one’s own child in the foreign place of an intensive care unit, parents need guidance through the jungle of information and possibilities. The medical staff’s first goal is to give parents the opportunity to bond with the infant, which is in the best interest of the child and also in the best interest of the parents, both when their child dies or survives. Therefore, parents do not participate in the ethical round but are directly included in the decision-making process, and their way of life and their value system are taken absolutely seriously. The parents are fully informed in a defined setting by the doctor and the nurse who have the closest relationship with them. The parents do not get the necessary information through “any doctor available”. If the parents do not agree with the proposition of the “inner circle”, a new ethical round including the parents must take place. If a final agreement cannot be reached, the parents have the possibility to appeal to the Ethics Forum of the University Hospital of Zurich.</td>
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<th>Role of the head of the clinic</th>
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<td>The head of the clinic or his deputy has to be present at every ethical discussion. If he is not involved in the care of the child and therefore not a member of the “inner circle” he has to participate in the “outer circle”. He or she represents the clinic and is by law responsible for the final decision. If he or she disagrees, a further meeting will have to be organized.</td>
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### Diagram

- **Outer circle**
- **Inner circle**
- **Independent moderator of the discussion**

Every nurse or doctor involved with the care of a critically ill infant can ask for an ethical discussion. This takes place in a separate room at a round table and is announced in advance to the whole staff of the unit. Everyone from the staff who is interested can participate.
Phase I: Analysis of the status quo decision making at the unit

At first, the status quo of the current decision-making process was analysed. This was accomplished by having the ethicist participate in, videotape and analyse various aspects of each discussion. Afterwards, the group was confronted with the results, showing that difficult decisions were poorly articulated and consensus was assumed even when this was not really the case. Moreover, relevant discussions often took place spontaneously in the common room of the unit or during rounds. Confronted with the arbitrary nature of those life and death decisions, the group was ready to plunge into the ethical literature.

Phase II: Review of literature on neonatology and ethics

The group reflected on different models of ethical decision making. The group members were introduced to ethical methodology and terms. They read basic texts on and introductions to ethics, especially the literature on neonatology and ethics. The various publications did not satisfy the group.

Phase III: Clarifying one’s own value system and determination of the core values of the unit

The core ethical focus of the group was the interest and the well-being of the infant, who is respected morally as a person. Even though the group wanted to decide individually for each child and not according to general rules, they were also searching for objective criteria which would remove the arbitrary nature of any final decision.

Phase IV: Development of a framework

The group found the solution for this double task in a framework which structures the decision-making process. They developed a framework that would guide the decision-making process.

Box 2. Seven steps of ethical decision making.

**Step one: Description of the child’s medical information, care and social situation**

The responsible physician and nurse present the medical information, the care and the social situation of the infant. As far as possible, the child’s future perspectives must be thoroughly described.

**Step two: Different aspects of evaluation**

Five main aspects related to the individual child are weighted against one another:

- The infant’s chances of survival
- The infant’s chances of dying if mechanical ventilation and other critical assistance are continued
- The infant’s chances of dying if mechanical ventilation and other critical assistance are withdrawn
- The infant’s actual suffering
- The infant’s possibility to live independently in the future without developing severe handicaps

The infant’s social and emotional background is evaluated in the same way as medical chances and risks.

**Step three: Developing different scenarios**

Based on the evaluation in Step Two, at least three scenarios should be developed and discussed. This step aims to avoid “either/or” decisions and to promote alternatives and step-by-step decisions.

**Step four: Decision**

All members of the “inner circle” have to come to a unanimous decision. If there is disagreement, a further ethical round must take place. The decision is recorded.

**Step five: Planning the discussion with the parents**

After a decision regarding the future care of the infant has been taken, the group plans the discussion with the infant’s parents.

**Step six: Discussion with the parents**

The parents are informed by the doctor and the nurse most familiar to them. The appreciation of the child’s situation and the decision taken by the group are explained. If the parents do not agree with a proposition to withdraw or to limit critical care, critical care is continued and another ethical round including the parents is scheduled.

**Step seven: Evaluation of the decision**

In the event of an abnormally difficult decision-making process, the process itself can be discussed under the supervision of the ethicist. Every 6 mo the entire unit evaluates the decisions that have taken place and discusses again the most difficult cases.
process but does not imply any given mode of action. Moreover, the framework requires a special setting for the discussion.

*Phase V: Presentation of the framework to the intensive care unit*

The framework was presented to the intensive care team. The first presentation led to controversial reactions in the unit.

*Phase VI: Inclusion of an expert on group dynamics*

A psychiatrist who was already supervising in the unit was asked to discuss the psychological problems associated with the introduction of the framework. The ethicist had obtained substantial experience using role-playing models in other units. She received support for her idea from the psychiatrist, and the ethic group decided to introduce the framework using a role-play model involving the entire unit.

*Phase VII: Establishment of the framework in the unit*

The framework was established in the unit and was integrated into treatment decisions.
Phase VIII: Internal evaluation of the framework

After 6 mo, the unit sat together several times to evaluate the framework. The staff of the unit made propositions for improvement. At that time it was decided to have an external evaluation of the impact of the framework.

Impact of the framework on the team

The consequences of the framework on the decision-making process itself and on the doctors and the nurses involved were analysed by the Department of Applied Psychology of the University of Zurich [23].

All doctors and nurses working in the unit answered a validated questionnaire (Q1) at annual intervals during a 3-y period. In addition, immediately after each session, all participants answered a second questionnaire (Q2).

In Q1 the ethical framework was generally assessed positively. Statements about personal usefulness and about the relation between participants received a mean response between 3 and 4 points on a 4-point scale. In the free text section, the following positive aspects were reported repeatedly: the interdisciplinary composition of the group, the inclusion of many different aspects in the decision-making process, the need to formulate different options for action and the need to find a consensus within the inner circle. Of note among comments pertaining to aspects that could be improved were: to try to appreciate the infant’s “will to live”, to scrutinize better the family situation, and to take into account the estimated future quality of life of the infant in case of survival. Some criticisms changed over the years: when the process was newly implemented, participants criticized the scheduling of the group discussions and the selection of the decision criteria. Later on, critiques focused on communication aspects.

The main result of Q2 was a consistently high ranking for the scales “attitude”, “benefit”, “overall judgement of the discussion groups”, “weighting of decision criteria” and “judgement of the final decision”. These scales were generally ranked higher by females than males, by nurses than doctors, and by staff members having participated in fewer discussion groups than by those having participated in more discussions (see Table I).

The most important change documented during the study period was the relation between doctors and nurses, which improved considerably.

The weighting of decision criteria was ranked highest after a session with a unanimous and clear decision-making process ($F=10.12, p<0.001$) and when the withdrawing or withholding of intensive care was decided ($F=3.26, p<0.05$).

Effect of the framework on survival

Twenty-six critically ill newborn infants who died in our unit after a structured decision-making process...
were matched with infants from the Swiss Neonatal Network. Matching criteria were gestational week (median 26 wk, range 24 to 35 wk), severe malformation (three infants) and intracranial haemorrhage (three infants with intraventricular haemorrhage and four infants with intraparenchymatous haemorrhage). Survival was significantly shorter in infants after structured decision making (median 2 d, interquartile range 1–7 d) compared with controls (median 7 d, interquartile range 4–15 d, \( p < 0.01 \)) (Figure 1).

**Discussion**

The presented framework for ethical decision making has been used for almost 10 years. The implementation process took several years, and it has been adapted several times to satisfy multiple claims. External evaluation revealed a high acceptance by both doctors and nurses, but also showed some limitations. The role of the discussion leader is essential. He or she has to guarantee strict commitment to the prefixed rules, must control the group dynamic and attempt not to influence the decision itself. The group has to agree on a proposal that is discussed with the parents. If one member of the inner circle does not agree with a decision to withdraw intensive care, treatment has to be continued until a second session, usually after 24 h, takes place. This happened only three times in more than 120 sessions. In one instance, the infant died in the meantime; in two instances the situation had evolved further and it became obvious for all group members that further treatment would be futile.

In three instances the parents did not agree with the proposal to withdraw mechanical ventilation. In all cases treatment was pursued and two infants died on the respirator. In one case the parents agreed the next day that mechanical ventilation be stopped and the infant died in their arms. Parental disagreement occurred only in parents with different cultural backgrounds or with strong religious bonds not allowing them to agree that medical treatment be stopped in a futile situation.

Another problem is emergency decisions. To avoid these situations, sessions are held before a critically ill infant enters the dying process, and potential situations are discussed in advance. As the inner circle is always present, emergency sessions can be held during the evening and on weekends. Resuscitation in the delivery room is discussed before birth using a similar framework. If there is no time, the senior neonatologist decides if and how to resuscitate based on the national recommendations and the parents’ wishes.

Details of the infants who died in our unit are given in a separate paper [24]. The analysis of survival after structured decision making compared with controls is an attempt to quantify the impact of the framework. The result may be interpreted as shorter suffering in infants destined to die. We must stress, however, that we never had the primary intention to save costs and that this must never be used as an argument for applying the framework.

**Conclusion**

The introduction of this framework for ethical decision making in our intensive care unit had a beneficial effect on the quality of the decision-making process itself, on the team work, and shortened futile intensive care, and thereby suffering for both infants and parents. Improved quality of life for both the families who lost an infant and for those whose infant survived is very likely but has still to be proven.

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