Commentary

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A Time to Be Born and a Time to Die: Ethical Challenges in the Neonatal Intensive Care Unit

Commentary on C. Dageville et al.: The French Society of Neonatology's Proposals for Neonatal End-of-Life Decision-Making (Neonatology 2011;100:206–214)

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To live or let die is an issue probably discussed more thoroughly in perinatal medicine than in most other fields of medicine. The ethical dimensions of periviability are huge for several reasons. First of all, the ability to survive has been steadily pushed to lower gestational ages. Second, it has been increasingly clear that many immature newborns survive with serious sequels.

When in 1973 Duff and Campbell [1] for the first time described withholding and withdrawing of treatment of sick newborn babies, it included 14% of neonatal deaths. More recent studies have demonstrated that this now represents close to 90% of the deaths [2]. So what has happened during these 30–40 years? Could it be that doctors working with premature newborns have become more liberal in ending treatment and let die than before, or does this development rather reflect the development of more complex medicine due to the saving of more immature lives to a greater human cost?

Recently, the World Association of Perinatal Medicine issued new guidelines concerning the ethical challenges of periviability [3]. These guidelines underlined that (1) perinatal physicians have beneficence-based obligations toward the pregnant woman, the fetal patient, and the neonatal patient, and (2) that the physicians have autonomy-based obligations toward the pregnant woman. This means that the doctor is obliged to provide the pregnant woman with information regarding the expected clinical benefits and risks of various treatments which may be relevant to the fetus/newborn child. In order to do this properly, the use of neonatal outcome data to predict survival and morbidity of the newborn is mandatory. An ethically based decision must therefore be based on as thorough as possible knowledge of the outcome.

In this issue of *Neonatology*, Dageville et al. [4] on behalf of the French Society of Neonatology propose principles of end-of-life decisions in neonatal medicine. The French recommendations emphasize that the child's best interests must always be a central consideration. The autonomy of the parents has been given increased weight; still, the ultimate responsibility of the doctor for the final decisions regarding the patient's life is underlined. A former paternalistic attitude has thus been substituted by more respect of the parents' autonomy and their viewpoints. The focus of the French recommendations is the child's best interest. Futile treatment is not supported. According to the French, decisions regarding withholding or withdrawing of treatment must be based on analysis of survival in qualitative terms instead of only focus-

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ing on the survival chances. What will life be like for the baby if he/she survives is the key question. In this respect, the French recommendations are in line with a number of other national and international guidelines [3, 5, 6].

The primary goal of palliative care is alleviation of suffering and protection of the dignity of the dying child. Still, not all difficult questions can be answered easily. A consensus was not reached for instance regarding the question of withdrawal of artificial feeding. Although palliative care may hasten death, the French attitude is that as long as its aim is to increase the quality of life it is justifiable. The French oppose euthanasia as practiced in the Netherlands and described in the Groningen protocol [7]. In my opinion, the Dutch practice is not based on medical evidence. When listening to its proponents, they often base their arguments on one single case, a child with epidermolysis bullosa. Every clinician knows that extreme situations may arise, but these are exceptions and should not be the basis for general laws. I fear that Dutch neonatology and the Dutch society are moving in a wrong direction with negative implications for their culture at large. Fortunately, the Dutch attitude in these matters does not seem to have many followers [8].

The French proposals for neonatal end-of-life decisions represent a humanistic approach to protect the infant's dignity at the end of life that also gives support to the family.

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