EDITORIAL

Developments with Regard to End-of-life Decisions in Newborns

AAE Verhagen

Despite enormous technological advances in neonatology, there are still conditions that cannot be successfully treated. The decision when to start and when to withhold treatment in individual cases remains very difficult. Even more difficult are the decisions regarding end-of-life measures in infants who have no hope for improvement and lead a life of severe suffering that cannot be alleviated. Recently, there was a brief but intense wave of reactions in the international press concerning a supposedly new practice of terminating the life of severely defective newborn babies in The Netherlands. These accounts derived, in particular, from developments in the University Medical Centre of Groningen where a protocol was developed together with the legal authorities, for life-ending measures without ensuing prosecution. Within the Netherlands, the protocol comes as the result of decades of debate both inside and outside the country (1).

Newborns in whom medical end-of-life decisions are considered can be divided into three categories. Those who will die despite the use of continued invasive medical technology comprise the first group. They are infants with underlying diseases, *eg* Potter's Syndrome, in whom death is inevitable. When the futility of treatment becomes apparent, treatment is withheld and the patient dies. There are no ethical or legal dilemmas in this group of patients (2).

The second group are patients who can theoretically survive, but whose expectations regarding the quality of life after the intensive care period are very grim. They are patients with severe congenital intracranial abnormalities or severe neurologic injury. Neonatologists around the world are prepared to withhold or withdraw intensive care treatment in newborns because of the predicted poor quality of life (3, 4). The interest of the infant is paramount, and all treatment decisions are based on the interest of the child. Children in this category are expected to die when intensive treatment is withdrawn. There is difference of opinion about the legitimacy of administering palliative medication to shorten life after treatment is withdrawn (5–7).

The third group consists of patients with a poor prognosis who are not dependent on technology for stability, and whose suffering is severe and sustained, and cannot be alleviated by any means. These are children who remain viable after intensive treatment, but whose condition is one of hopeless suffering without the prospects of any sort of independent life. In these children, in retrospect, one might not have wanted to start treatment if the outcome would have been known. The possible strategies for these infants are to wait for nature 'to take its course' and accept a sometimes long period of suffering, withdrawal of all medical interventions including tube-feeding and hydration, or deliberate ending of life with lethal drugs (qualified as 'newborn euthanasia' in many countries).

Evaluations of the medical practice of end-of-life decisions in different countries in Europe have shown that in very rare situations deliberate ending of life in newborns does take place (4, 8–10). The medical diagnoses reported in these surveys were extreme prematurity, severe asphyxia, cerebral injuries and severe congenital abnormalities. Ending the life of a newborn is against the law in all these countries and, as a consequence, data on the decision making process in these cases have remained scarce. In the Netherlands, efforts have been made to regulate the medical practice of euthanasia (death on request) and deliberate ending of life in newborns. Reports from the medical profession, case reports, court cases and national surveys have all contributed to a long and intense public discussion (11). Finally an approach was chosen with obligatory reporting of life-ending procedures and public review of all cases. The protocol reflects the intentions for transparency and accountability.

With the increased use of technology and advanced drugs, the dilemma of how to deal with sick newborns with untreatable diseases, severe suffering and no hope of improvement becomes more apparent. Also, in the Caribbean, the impact of new technologies and complex treatments are of growing concern (12). Surfactant treatment for respiratory disorders in newborns may serve as an example: following introduction in Curaçao, the mortality of newborns with respiratory distress syndrome has decreased, however complex new morbidities have increased (13). More often physicians will be confronted with newborns from group 3. It is of great importance that physicians anticipate and learn to deal with the new realities of medicine and the law, even if they fall outside the usual medical and legal categories. A standard approach to these new realities that satisfies all social and legal cultures is simply not available. Efforts should be made by the medical profession to openly discuss the dilemmas regarding end-of-life decisions for newborns and to develop a coherent and integrated approach to address them.

From: Beatrix Children Hospital, University Medical Centre Groningen, PO Box 30 001, 9700 RB Groningen, The Netherlands.

Correspondence: AAE Verhagen, Beatrix Children's Hospital, University Medical Centre, Groningen, PO Box 30 001, 9700 RB Groningen, The Netherlands. E-mail: e.verhagen@bkk.umcg.nl.

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