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VIEWPOINT ARTICLE

Flaws in the assessment of the best interests of the newborn

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Abstract

We examined the literature on ethical decisions regarding neonates, to assess whether personal beliefs and prejudices influence end-of-life decisions taken by caregivers. Studies show that religion and familiarity with disability influence caregivers’ decisions, whereas the influx of already being a parent, age, sex and professional experience is controverse. Caregivers’ attitudes towards end-of-life decisions are also affected by personal concerns about litigation, prejudices and their view of disability. The concept of ‘poor quality of life’ is widely used as a reference in end-of-life decisions, but this can be interpreted differently, leaving room for a wide range of personal viewpoints. In most cases, parents’ opinions are considered important and are sometimes the main determinant in decision making. However, it is unclear whether parents’ decisions are based on their own wishes or on the best interests of the newborn.

Conclusion: In neonatal end-of-life decisions, patients may not receive cures based only on their best interests.

In neonatology, ethical decisions about the end of life are hard to make: in the case of patients who cannot speak for themselves, one needs to put oneself in their shoes to decide on their behalf, feeling their feelings and desires and even imagining their psychological reactions to a possible illness. This means that misinterpretation is possible, because what is unbearable for one person might be acceptable to another and vice versa. Prejudices or personal fears might interfere with this process, leading to choices based on criteria other than the patient’s best interests.

We examined the scientific literature to assess the extent of this problem. We performed a search using PubMed and Medscape databases from 1995 onwards. We used as keywords the following: newborn, premature baby, end-of-life decisions, withholding/withdrawing treatment and quality of life. We included studies dealing with the personal, psychological, social and cultural factors that led to an end-of-life decision; we excluded reviews and those papers that reported only the authors’ opinions. Unpublished studies were not included, but language restrictions were not imposed. In total, 34 studies fulfilled the selection criteria and were used for this review.

INFLUENCES ON CAREGIVERS’ DECISIONS

Caregivers can be influenced in end-of-life decisions by personal, psychological and cultural factors. A multicentre study showed that some features (sex of the physician, having had a child, work in a teaching hospital and the number of cots in the neonatal intensive care unit) had no significant association with withholding or withdrawal of intensive care (1), whereas other authors show that being female, having no children and working with a high number of premature babies is correlated with a quality-of-life view (2). Both age and length of professional experience showed a significant effect, with older and more experienced doctors being more likely than juniors to have made these decisions (1). The importance a physician attributed to religion in his or her life was also consistently associated with decision-making: being Protestant or having no religious background is consistent with a lower tendency to actively resuscitate premature neonates (1–3). In France and the Netherlands, daily work in the neonatal intensive care unit (as opposed to rotating for night/day shifts or supervision only) was associated with increased probability of reporting a decision of active euthanasia (1). Being male and having regular involvement in research, less than six years professional experience and prior participation in a decision of active euthanasia were positively associated with an opinion favouring relaxation of legal constraints about euthanasia, whereas being a parent showed a negative association (4). Parental whishes may influence decisions (5,6). One-quarter of neonatologists considered parental parity/fertility history in their medical decision making for infants born at 23- to 24-week gestation (7). A Canadian study showed that decisions also appear to be significantly related to personal experience with a disabled close friend or relative (8).

The influence of fear of litigation (6) also influences decisions. A recent study showed that most neonatologists deferred to parental requests rather than adhering to their best judgment, whether or not parents requested treatment and whether or not parents were described as litigious (9).

Personal prejudices

In 2000, the EURONIC study group investigated caregivers' attitudes towards end-of-life decisions (2). They determined the physician's agreement with 12 statements related to attitudes about the value of life. They included two questions to reveal personal attitudes about handicap. It is significant that only in two countries (Germany and Hungary) more than 50% thought that life is worth living with a severe physical disability, and less than 25% in all countries declared that life with a severe neurological handicap is worth living. Their attitudes correlate with the acceptance of withholding or withdrawing treatment to severely ill newborns in those countries.

In another study (10), a group of neonatologists were asked to complete three questionnaires anonymously. First, they were asked to provide demographic information, including their sex, age, parental status and number of years in neonatal practice. The second questionnaire concerned ethical practices. Finally, they were asked to complete the Multidimensional Fear of Death Scale (11,12). The authors of the study concluded that their 'personal fear of death and their attitude to hastening death when further treatment is considered futile are significantly related.'

Janvier and colleagues (13) recently performed an interesting study on 279 caregivers involved in perinatal care. First they were asked whether they would resuscitate an infant born at 24-week gestation with depressed ventilation. They were then asked whether they would resuscitate a depressed preterm infant with a 50% chance of survival, knowing that of those who survived, 50% would develop 'within normal limits', 20–25% would have a serious handicap and 40% would have behavioural and/or learning disabilities. In the first scenario, which only presented gestational age, 21% of respondents would resuscitate. In the second scenario, which presented prognostic statistics, 51% of respondents would resuscitate. The authors of this study conclude that 'the relative unwillingness to resuscitate a baby of 24-week gestation is surprising since outcomes for such babies are the same or better than those we described in the scenario that provided only outcome data without specifying gestational age'.

It is worth highlighting that children's self-perceived quality of life is often different (i.e. higher) from that perceived by caregivers or from objective measurements (14). For instance, when asked to rate the health-related quality of life in hypothetical situations, health care professionals tend to provide lower utility scores than adolescents and their parents (15). This is another sign of the influence of personal prejudices in assessing the best interest of the baby.

An anonymous questionnaire, describing eight patients with potential neurological sequelae who required resuscitation, was administered to groups of physicians and students (16). Survival and morbidity rates were explicitly described: four patients had a predicted 50% survival and a 50% chance of impairment; they were a preterm and a full-term neonate, and a 2-month-old and a 50-year-old patient. Two already disabled patients, one 7 years old and the other 80 years old, had 50% predicted survival. A 14-year old and a 35-year old had 5% survival. Respondents were asked if they would resuscitate these patients. The proportion stating they would always resuscitate was smallest for the 80-year-old patient (18%), then the preterm neonate (35%), the full-term infant and the 50-year-old patient (53% and 58%). The 2-month-old and the 7-year-old patients would be resuscitated most frequently (74% and 77%), followed by the patients with 5% survival (64% and 68%). This study shows that whether resuscitation is considered in a patient's best interests is not closely related to survival rates or disability and that newborn infants – and particularly preterm infants – are systematically devalued, in comparison with older patients whose outcomes are the same or worse.

INFLUENCES ON PARENTS' DECISIONS

Parents consider it important that their wishes may influence the doctors' decisions (17), but studies show that when there is a risk that a baby may die at birth, fathers feel a lack of control (18), whereas mothers experience a lack of knowledge about long-term outcome, a state of shock and lack of sufficient time to deliberate (19). Cultural background, as well as the current psychological state, can influence parents in their decisions. Families of white infants agreed to limit life-saving medical treatments 80% of the time compared with 62% of the families of African–American infants (20). Parents' religious affiliation may influence the outcome of premature infants with severe brain damage (21); for instance, Muslim parents rarely consent to an end-of-life decision (22).

VARIABILITY OF END-OF-LIFE DECISION CRITERIA

Quality of life

Though irreversible death was a common consideration in end-of-life decisions (23,24), and decisions may be based upon the vitality of the babies in situations of ambiguity (25), most studies agree that future quality of life plays a role in the decision to treat. Poor quality of life was predicted on the basis of suffering and expected inability of verbal and nonverbal communication (26), on long-term neurologic complications (27), or on having self-consciousness, capacity of relationship and of deriving some pleasure from existence (2), though some say that it is hard to define (28) even because the perceived quality of life of children with cerebral palsy is similar to that of the general population (29).

End-of-life decisions and parents' wishes

Studies show that end-of-life decisions based on quality-of-life assessment are seldom performed on the basis of parents' wishes (7,9). The results of a questionnaire study on the treatment of infants with myelomeningocele (30), showed strong consensus (more than 75% agreement) that life-prolonging treatment should be provided when the parents were in favour of treatment. Situations in which an end-of-life decision was not made because parents did not consent predominantly involved infants with complications of pre-maturity (24%) or perinatal asphyxia (40%), whereas situations in which parents requested an end-of-life decision that was not agreed to by the paediatrician involved Down's syndrome either as the main diagnosis (43%) or a concurrent diagnosis (21%) (31). Peerzada et al. reported that neonatologists in general envision little parental role in delivery room decision making for extremely preterm infants (32), whereas most Canadian neonatologists would support a parental request not to initiate resuscitation of an infant at 23- and 24-week gestation (98% and 80%, respectively) (8). When caregivers consider treatment to be clearly beneficial (33) 91% reported that they would resuscitate in the delivery room despite parental requests to withhold treatment, but 33% reported that they would provide what they consider futile treatment at parental request. When respondents considered treatment to be of uncertain benefit, all reported that they would resuscitate when parents request it, 98% reported that they would resuscitate when parents are unsure and 76% that they would follow parental requests to withhold.

FUTURE PERSPECTIVES

Subjectivity in end-of-life decisions calls for some decision criteria. Here we report some recently proposed attempts. The Nuffield council of bioethics (34) advanced a widely established criterion based on gestational age at birth: under 23 weeks, resuscitation would not normally be considered or proposed; after 24 weeks, intensive care should be given; between 24 weeks, 0 days and 24 weeks, six days of gestation, normal practice should be that a baby will be offered full invasive intensive care, unless the parents and the clinicians are agreed that in the light of the baby's condition (or likely condition) it is not in his or her best interests to start intensive care. Between 23 weeks, 0 days and 23 weeks, six days of gestation, precedence should be given to the wishes of the parents regarding resuscitation and treatment of their baby with invasive intensive care. In any case, the authors of the statement admitted that 'between 23 weeks, 0 days and 23 weeks, six days of gestation, it is very difficult to predict the future outcome for an individual baby based on current clinical evidence' (34).

Emergence of consciousness (35) is another criterion proposed to define the beginning of a right to assistance. This approach touches the heart of the matter, because it bypasses the limits posed by the definition of fetal viability based solely on the possibility of oxygen exchange in the lungs: 'To use air breathing as a hall-mark will be as old-fashioned in the near future as to define death only as definitive heart arrest' (35). For this approach, babies' entitlement to care does not depend on external circumstances, such as entrance of air into the lungs, but are somehow intrinsic to the subject, namely to his/her consciousness, which may appear well before the full development of the cortex, though babies below 23 weeks, anencephalic infants and some severely brain damaged infants are less likely to be conscious (35). The Italian National Ethics Committee recently stated that at birth the newborn automatically becomes a citizen with full rights, and that 'uncertain viability' or potential disability do not annul the Hippocratic oath to preserve life (36). The committee stated that baby is entitled to care as any other citizen, when he/she has the possibility of autonomous life, defined as 'the possibility of surviving outside its mother's body' (36).

CONCLUSIONS

A review of the literature showed that caregivers are influenced in their decisions by some aspects of their social or professional background, but also by their own fears and their opinions of the value of life. It is important to be aware of the influence that fears and personal views have on caregivers and parents, because this highlights the difficulty in considering only the patient's best interest as the leading criterion for decision making.

Prejudices can interfere with end-of-life decisions: for instance, it has been shown (31) that conditions (e.g. future learning difficulties) that many people consider as acceptable and bearable, may be considered as a case for withholding treatment by others; other conditions (e.g. spina bifida) considered as a reason for withholding treatment have recently been described as neither awfully painful nor incompatible with an acceptable life (37). It is worth noting that even the impossibility of communication, one of the cases for which end-of-life decisions are considered, does not necessarily mean an actual state of suffering for the patient or his/her perception of a low quality of life. The fact that caregivers' fears (e.g. litigation or illness) have an influence on their decisions shows how far we are from removing personal bias from end-of-life decisions.

An important result of our analysis is that decisions regarding neonates are not made with the same criteria as for older ages. This is well summarized by Janvier's study (16). This means that newborns still have a different moral status compared with older patients, and this prejudice should be overcome in an era in which studies on the competences and psychology of newborns have made huge progress.

Parents' wishes influence physicians (6,9) and the literature analysis raises concern regarding two aspects of this. First the competence and the psychological state of the parents who make the decisions are often sub-optimal. Second, sometimes it is unclear whether end-of-life decisions are taken in the babies' best interest rather than that of a third party, as in some cases a conflict of interests can exist between the parents' wishes and the newborn's right to treatment. In an analysis of international practices, Michael

Gross wrote that there is a general endorsement in end-of-life decisions 'subject to a parent's assessment of the newborn's interest', but this interest is 'broadly defined to consider physical harm as well as social, psychological and/or financial harm to related third parties' (38).

Quality of life is perceived in different ways by different people. This is clear when we consider that quality-of-life perception of paediatricians and parents corresponds only partially with the perception of children both at diagnosis and after initial treatment (39,40). Thus, it is hard to foresee whether a certain life will have an acceptable quality for the newborn.

In conclusion, end-of-life decisions remain a challenging topic. Further discussion and analysis based on the acknowledgement of the dignity of newborns, on the cooperation of parents and on the awareness of advances in neonatology is required to avoid personal interpretations and make decisions based on the best interests of the neonate.

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