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Leading article

Parents and end of life decisions in neonatal practice

Many factors over the course of time have influenced the way parents react to the death of their baby, including a less private attitude towards bereavement, unrealistic expectations of survival, perhaps an erosion of spirituality, and more recently mistrust of the medical profession.

In this issue of the journal, the results of a survey carried out in three neonatal referral centres in Scotland are presented that shed light on parents' perceptions of the withdrawal of intensive care¹ and subsequent autopsy.² The strength of these two papers rests not so much with their scientific precision, but with their role in prompting discussion of a sensitive subject.

When neonatal intensive care (presumably assisted ventilation) was withdrawn with parental consent, almost one quarter of the parents were concerned and distressed at the length of time it took for their babies to die, which ranged from three to 36 hours. Parents were not prepared for this, and had anticipated a swifter death. Furthermore, the dying process was particularly stressful for the parents of some babies. There is irony in the idea of withdrawing intensive care in order to avoid prolonging pain and suffering, when it is followed by a variable and unpredictable period of what is perceived as further pain and suffering. Furthermore, the use of drugs primarily to hasten death in this situation probably amounts to euthanasia, which of course is illegal in the United Kingdom and other countries.

Neither of these papers clarifies the precise reasons for withdrawing intensive care. A distinction should be made between withdrawal because a baby has already entered the process of dying, and further intensive care is simply prolonging death rather than saving life, from a decision based on a perception of "quality of life" if the baby survives.³ The likelihood of a lingering death is influenced by the criteria that led to the withdrawal of intensive care.

Whether or not a baby has entered the process of dying is a medical question and not one that is answered by a consideration of ethics. It implies multiorgan system failure resistant to appropriate treatments. When a lingering death occurs, parents understandably question whether the decision to withdraw support was appropriate. It is hard for them to reconcile prior discussions about the inevitability of death with their perception that their baby is "fighting for life" after withdrawal of ventilatory support.

The withdrawal of intensive care on the basis of a "quality of life" decision acknowledges that the baby may well

survive, but only by the further and prolonged discomfiture of intensive care, when it is predicted that substantial neurodevelopmental or physical handicap will radically limit the child's ability to participate in human experience and will render him or her forever dependent on a caregiver for everyday living.⁴ The scenario may be a baby with gross damage to the white matter shown on a brain scan, who has persisting abnormal neurological signs including an impaired level of consciousness, or seizures.

For some babies destined for an intolerable quality of life, their dependence on assisted ventilation may be surprisingly brief. By the time the parents have reflected on the option of withdrawing ventilatory support, reliance on assisted ventilation may no longer be absolute, and extubation may be followed by a prolonged period of dying. Parental anguish follows if it then seems that death is not imminent after all and there is indecision about whether the infant should be reintubated and ventilated.

In the study of McHaffie *et al*,² nearly two thirds of parents consented to autopsy, and only a small minority of these did so in order to confirm the appropriateness of the decision to withdraw intensive care. It would require a larger and more detailed study to determine whether consent is influenced by the indications for withdrawing intensive care.

The most common reason for not consenting to postmortem examination was fear of disfigurement. This has probably always been a major concern for relatives of the deceased, but some parents may have felt awkward to raise this issue in the past. As doctors and nurses reflecting on our patient's necropsy, what comes to mind is examination of their organs. Yet when we are the relatives of a deceased person, we are morbidly preoccupied with the exposure of their organs and the necessary cutting and disruption (mutilation) of the body of someone close to us.

Managing the situation

In their paper on lingering death,¹ the authors conclude with a *crie de coeur*: "Whose interests are we really serving in protracting inevitable deaths?" They invite us to re-examine current practices.

A strategy for helping parents through end of life decisions on neonatal units should embrace a continuum of support extending from discussion about the possibility of withdrawing intensive care, through to the management of the dying baby, the request for necropsy, subsequent

Table 1 Unspoken signals that staff wish to consider withdrawal of intensive care

1.	<i>Standing off on clinical rounds:</i> disgruntled staff turn away as though disinterested in contributing to further management
2.	<i>Exaggeration of clinical signs:</i> overemphasising adverse signs reflects despair that cannot be expressed in another way
3.	<i>Therapeutic nihilism:</i> all suggested treatments are rejected by desperate staff on the basis of their side effects instead of a willingness to consider the balance of risks
4.	<i>The incongruous search for the expert:</i> paradoxically staff may want to call in an “expert” such as a nephrologist or cardiologist to advise on organ system failure (presumably in the hope that a firm lead will be taken to withdraw intensive care)
5.	<i>Group formation among staff:</i> small groups form and discuss among themselves the futility of continuing intensive care
6.	<i>Allegations of parental lack of information:</i> in spite of frequent discussion with parents about their infant’s progress, staff insist that the parents haven’t been informed and don’t know how ill their infant is

explanation of the possible significance of the results, and, when appropriate, bereavement support.

Neonatal staff have their needs too, and it is easier to be caring and compassionate when we are at ease with our own thoughts and feelings surrounding end of life decisions. This is more likely in neonatal units where there is leadership, teamwork, and a forum for discussing ethical issues. In their absence, end of life decisions challenge staff each time as though it was a new experience, and conflicting and unclear advice may be given to parents, reflecting uncertainties and conflicts between staff members.

CARING IN SILENCE

Sometimes intensive care for a critically ill infant is continued because no one, least of all the parents, feel comfortable about questioning whether it is right to continue. Consultants and senior nurses need to engage staff in decision making and recognise those unspoken signals that reflect staff desperation and despair⁵ (table 1).

DECEPTIVE CLINICAL SIGNS

The perception that a baby has “entered the process of dying” is based on clinical judgment, and so is open to error. If the situation is misjudged, it is likely that the baby will suffer a lingering death after extubation, or the decision to withdraw intensive care may need to be reversed when it becomes apparent that the baby’s condition is not terminal. The factors that may give rise to an erroneously pessimistic impression of outcome have previously been discussed⁶ and include: parental and staff despair, adverse appearance of the infant, especially signs of severe malnourishment, cholestatic jaundice, and multiple skin trauma from infusions and blood sampling; biased impression of prognosis based on a superficial comparison with another baby who has recently died (“she’s just like Baby Jones”); and non-visiting parents.

TALKING WITH PARENTS

Parents should not be made to feel that they alone carry the burden of decision making (“these are the facts—what do you want us to do?”). Engaging parents in end of life decisions will normally require a series of meetings during which the futility of continuing intensive care should have become clear. Quality of life decisions are more complicated, and parents should not have to deal with the contradictory concepts of being told that death is inevitable even with intensive care, and that “even if baby survives” it is likely that he or she will be very severely disabled. Counselling on the basis of quality of life acknowledges that the baby does stand a chance of surviving, even if only a small chance, if intensive care is continued.

Most parents who agree to the withdrawal of intensive care want to know how long it will take before their baby will die, but some feel uncomfortable with the question, or

assume that death will be virtually instantaneous. Parents should be prepared for the possibility that their baby may not die within a few hours of ceasing ventilatory support, but we should focus on details of the compassionate care that their baby will receive rather than how long it will take for their baby to die.

A lingering death is not inevitably associated with pain and suffering for the baby. Provided that appropriate arrangements are in place, some parents may wish to use the extended time to know and love their baby in a way that is different from what they have been used to. Withdrawal of intensive care signifies the inevitability of death; whereas, previously, parenting was driven by the hope of survival, it is now driven by the parents’ need to help their baby through death. In this respect, the extra time inherent in a lingering death can be seen as an advantage. For some parents, however, this is too much to bear, and if they are unable to share physically in their baby’s death they should leave the unit confident of the compassionate care that will be offered.

POSTMORTEM EXAMINATION

Raising the question of a postmortem examination is an additional stress for parents, and we should be prepared to sacrifice our drive to understand everything associated with the death of the baby that we cared for. We can’t always dot every “i” and cross every “t” and it is misleading to imply to parents that a postmortem examination will achieve this anyway.

Any request for a postmortem examination must have a coherent reason. If intensive care has been withdrawn, or is being contemplated, it is unhelpful to give the impression that a postmortem examination is needed to determine the cause of death. Parents, in these circumstances, expect us to know the underlying cause; indeed a common reason for declining postmortem examination in the study of McHaffie *et al*⁷ was that the parents had no further questions to be answered.

There will be occasional circumstances in which the proximate medical condition is known (organ system failure), but the underlying cause is unclear. Before withdrawal of intensive care, all reasonable investigations to determine an underlying cause should have been carried out. Additional information from a postmortem examination should be “geared up” to fit the diagnostic needs of the individual baby. This will normally entail prior discussion with the pathologist and other experts in relevant specialties. When the concept of mutilation is so powerful in the parent’s mind, then the notion of the limited organ specific examination should be discussed.⁷

It is, of course, quite inappropriate to use the coroner as a means of obtaining a postmortem examination, even if the underlying cause of death is unclear, unless the death occurred in suspicious circumstances or was thought to be caused by accident, violence, or neglect.

The parents’ graphic descriptions of their babies’ deaths¹ argues for better ways of managing these situations. Many babies with multiorgan failure resistant to treatment, in whom withdrawal of support is a consideration, are receiving opioids to reduce pain and awareness. Having agreed that death is inevitable, it is not in the baby’s best interest, and it serves no purpose, to stop these drugs before ventilation is withdrawn.

Babies who are thought to have entered the process of dying will not normally be receiving muscle relaxants because their use precludes accurate clinical assessment of the terminal state. However, babies in whom withdrawal of assisted ventilation is considered on the grounds of quality of life may well be receiving relaxants to facilitate mechanical ventilation. Here, failure to reverse the effect of

relaxants before withdrawing assisted ventilation may be seen as deliberately hastening death, which is unlawful.

Neonatologists may be treading on a legal tightrope with respect to the introduction of drugs after withdrawing assisted ventilation. If there is reasonable evidence that the baby is in pain, then the use of intravenous analgesics such as morphine is not problematical. However, such babies are often unconscious with prolonged and sometimes frequent gasping. Although it is certainly distressing to all those around, we do not know what the baby is feeling, especially as many are unresponsive. Common sense dictates that it may well be a very unpleasant sensation. The use of intravenous opioids to diminish awareness (not to hasten death) is probably justified. Firstly, the dose used should be conventional; secondly, the reason for starting treatment should be clearly indicated in the medical records; and thirdly, a strategy to support parents and staff must be seen to be operating to deal with lingering deaths. This is important because it reinforces the idea that there is no need to hasten death because systems are already in place to cope with a lingering death, and the use of drugs is solely for the comfort of the baby.

We need to engage and inform the public and the media of the sensitive details surrounding end of life decisions,

which are problematical for parents, doctors, and nurses alike. All too often "education" of the public is based on the reporting of critical incidents by media publicity that is designed to cause public outrage rather than to encourage rational debate and mutual understanding.

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