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Commentary

More important than guidelines themselves are the principles which underlie them and nowhere is this more true than in the sensitive field of medical ethics. Doyal and Wilsher's paper explores some principles which may govern future guidelines for the provision of life prolonging treatment in neonatal medicine, focusing on moral arguments.

Most would agree that when death is perceived to be inevitable, and when it is felt that the baby has entered the process of dying, then the provision of life support measures is a futile and pointless exercise. In practice these measures will already be in place and their very failure heralds the inevitability of death. The issue is normally one of withdrawal of ventilatory support with the anticipation of death in minutes or several hours. Guidelines for practice would have to include the medical criteria which point to a baby entering the process of dying.

The issue which really tests our moral judgment, and the one which Doyle and Wilsher bravely address, is whether there are circumstances where death is *not* inevitable, yet infants may none the less lose the right to have their lives prolonged. The authors focus on the concept of the 'potential for personhood' and seek to identify conditions in which infants are so disabled that their possession of human rights may legitimately be called into question because they will never develop the potential for self awareness, intentional action, and the ability to act on their own behalf.

Those of us who regularly see in our clinics very severely handicapped children may be aware of a sense of 'correctness' which sometimes drives us, against our better judgment, to complicity with parents and other health workers when we are asked to initiate a range of services that are unlikely to yield any material benefit for the child yet might well satisfy parental needs.

Against this background the idea of infants being 'so disabled that they can never become persons with the rights which accompany this status' will be abhorrent to many paediatricians, especially those who are prominent in championing the rights of children. Yet this must be seen in context – the authors are arguing that there is no moral obligation to keep a newborn baby alive by medical science if the result will be an infant so disabled. Indeed, they wish to prevent this ultimate state of affairs. Of course, given that such disabled children *do* exist then they have the rights of any other person (except the right to life prolonging treatment).

What we have here is a coherent moral argument (even if some might not share their position) but a major problem in translating it into neonatal practice. In essence, by the time it has become clear that an infant has a very high risk of becoming so disabled the opportunity to exercise judgment and choice in the provision of life prolonging treatments has often passed. Probably the most common scenario is the very preterm baby or the perinatally asphyxiated term baby who is receiving assisted ventilation (where there were no reasonable grounds for denying such treatment when it was initiated). As the authors say the prognosis must be determined as accurately as possible, and adequate time must be allowed to achieve consensus. Yet the baby may have been successfully weaned from the ventilator before this point is reached.

While I am comfortable with the idea that withdrawal of assisted ventilation can in some cases present itself as a 'window of opportunity' which is morally acceptable I am uneasy about too broad an interpretation of 'treat for dying'. Assisted ventilation is surely an extraordinary measure of care in so far as we expect babies to breathe without assistance, whereas all newborns require a caregiver for nutrition, hydration, and maintenance of a normal body temperature. I see a real moral difference between hastening death of a newly born baby by withdrawing ventilatory support and doing so by withholding fluids or nutrition.

Examples of withholding or withdrawing treatments other than assisted ventilation *in order to allow a baby to die* are uncommon on neonatal units today. Doyal and Wilsher's paper acknowledges some very difficult issue surrounding surgical treatments of congenital abnormalities and the notion of 'pain and suffering'. Babies with multisystem abnormalities who pose these sort of ethical problems highlight the complex case to case variability of their circumstance. I suspect that their individuality might preclude guideline driven management unless the guidelines were so broad as to be of little material help.

Doyal and Wilsher touch on the question of resources when parents insist on treatment in the face of an extremely poor prognosis. Given the financial constraint that is common to all health services I wonder, especially with respect to the care of exceedingly preterm babies, whether future guidelines on life prolonging treatments can ever reconcile our duty to act in the infant's best interest with our broader responsibilities to ensure a wide provision of service.

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