Ethical issue

Balancing options in neonatal care

JANET GOODALL

Department of Paediatrics, North Staffs Hospital Centre, Stoke on Trent

Because of advances in technology, paediatricians are finding themselves torn between relentless activity for all children under their care and masterly inactivity when treatment seems only likely to protract distress rather than to restore reasonable function. In neonatal care, for example, a common dilemma is to know clearly what *should* be done rather than what *could* be done. To prolong life artificially may be to prolong dying rather than living.¹

Child/parent relationships—normal and threatened

At the same time as these perplexities have arisen, we have been learning very much more about neonatal response to parental contact (and vice versa) and the way in which the child/parent relationship can be cemented or threatened at birth.² Few of the studies have been done on handicapped babies, though they too must have emotional needs. To be mentally or physically handicapped is not to be sentenced to a life devoid of warm relationships, as many of our older patients show us. As yet, the general public knows little of these advances in knowledge about babies' behaviour and some child health workers are still ignorant of a baby's enjoyment of eye to eye contact from birth.

When bereaved of their expected, normal child, parents of a handicapped baby experience great grief and shock that can show itself as denial, one manifestation of which may be rejection, so that a child's mute signals may not be received because they are unwanted as well as unrecognised. Given information and involvement, and thus support, parents' attitudes can be changed, even though anger or anxiety may feature in the slow process of coming to terms with the child's condition. While some marriages break under this, as under other strains,³ most paediatricians will know parents of handicapped children who have achieved a remark-

able degree of acceptance and who can tell us how their own relationship has matured through what at first seemed such pointless tragedy. It is possible for their devoted self sacrifice either to humble us or to appal us and for these reactions to influence (unconsciously) the degree of support that we give. Doctors too may manifest denial by either persisting in forlorn attempts to bring normality or by feeling an urge to bring things to a swift—if unsatisfactory—conclusion.

Child/parent/doctor relationships

Clearly, for each child, we must, with the parents, seek to arrive at a judgement suited to individual need. A common example is whether a child should be put on (or taken off) ventilatory support. Where there is serious doubt as to what is appropriate, it is wise for senior colleagues to confer about proper management. This concern should also hold where therapeutic interventions are likely to threaten the successful establishment of secure, early relationships because baby and parents are unable to interact across the miles or machines interposed between them. (Are all journeys to neonatal surgical units, even if really necessary, so desperately urgent?)

We have been slow to include this area of family need in our decision making, but it is now clear that the child/parent/doctor relationship can be affected for good or ill both by the presence of irreversible handicap itself and also by the practicalities of its management. Efforts to promote bonding should always accompany efforts to preserve life. Even if the child eventually dies, experience now tells us that parental mourning proceeds far better after proper involvement with the baby. For some very sick and unresponsive children the relationship appears to be one way, and such parents will need to draw upon relationships elsewhere while working through their grief.^{4 5}

Technology should serve (not shatter) relationships

It would be good if the advances of technology were to sharpen our focus on what life is all about. Is life of itself sacred, its sanctity only departing with the heartbeat or the flattening of an EEG? Or is human life to be valued primarily because it is given to us as a vehicle for caring relationships? If the latter, does this take priority in shaping these decisions? For most neonates we are slowly becoming more successful in restoring the child and cementing family bonds. Yet sometimes we may spend a lot of energy and skill (not to mention resources) on trying to renovate hopelessly damaged premises while at the same time making the tenant's personal life isolated and insupportable. It is right to respect and to try and preserve other people's property, yet it may even be possible now for an occupant to have left the scene long before we decide to stop our futile attempts at restoration. There is a distinction to be made between revering DNA (or even life itself), which is not essentially a human property alone, and honouring the human person, dependent for success and survival on relationships which are unique to mankind.⁶

Perhaps more than most physicians, paediatricians have been made to take into account the unseen areas of family life, including their patients' emotional wellbeing, even when dealing with physical crises. The debate on priorities will continue both in clinical practice and, no doubt, in law courts. Advances in technology will continue too. In our ethical discussions about neonatal care we have an opportunity to clarify issues for others. The lay public as well as members of our own profession are

being persuaded that there are only two options open in the care of badly handicapped lives—to keep on trying to cure, or to kill.⁷ While still aiming to correct and comfort where we can, there will be many times when the balance between these options is reached neither by one more operation nor by over zealous sedation. We must watch for the point when it is time for a change in emphasis and expectation: when no longer endlessly labouring for a miracle nor secretly harbouring a death wish, we should now simply aim to give the child as good a life as can be offered, short though it may be. Our need is to put a greater value on whatever potential remains for relationships, giving symptomatic relief to the patient and support to the family as we try to keep their interrelationships viable—and growing—to the end.

References

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Correspondence to Dr J Goodall, Department of Paediatrics, North Staffs Hospital Centre, Stoke on Trent ST4 6QC.