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Correspondence

Results of selective treatment of spina bifida cystica

Sir,

I congratulate Lorber and Salfield on their paper[1] and support its underlying humane philosophy and emphasis on full counselling with the infant's parents. The paper is very timely in the present climate of debate. However, I was disappointed in their policy of dissuading parents from taking home their infants for whom active management was assessed as inappropriate, and in the unconvincing reason given—that they would then receive inappropriate treatment, including antibiotics, presumably from their GP. If, as I believe would be the case, the GP is involved during the initial assessment of the infant and the counselling of its parents then he should also be involved with the plans for subsequent management. Paediatricians are becoming more aware that many infants and children with incurable diseases, or who are dying, can be nursed lovingly and adequately at home. This is possible when parents are fully counselled in the management of existing and anticipated problems before the babies are discharged, and have well informed support from both the GP and his team and the hospital team. Indeed it is likely that the family will cope and find the experience rewarding and even therapeutic in assisting them to come to terms with their grief and bereavement. I have experienced the satisfaction that a paediatrician also can receive by being actively involved in the home care of an infant with severe spina bifida cystica until its death, and found the parents' expression of gratitude that their infant died at home with the family extremely moving. In short, we must not underestimate the parents.

Reference

[1] Lorber J, Salfield S A W. Results of selective treatment of spina bifida cystica. *Arch Dis Child* 1981; **56**: 822–30.

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Professor Lorber and Dr Salfield comment:

Parents were given the choice of looking after their child at home, or having the child cared for in our hospital or in the referring hospital. Very few looked after their baby at home but those who did usually found this a rewarding experience. However, this was not a policy which we encouraged for most families. Many of our patients were referred from far away and it would not have been feasible to maintain the necessary close contact with the general practitioner or repeatedly to discuss the very difficult questions concerned.

Because of these difficulties, we have known patients looked after at home or in other hospitals who received 'intensive' treatment which produced unnecessary and prolonged suffering. We have also seen patients, not initially referred to us, who were sent home without adequate palliative therapy and whose parents complained of the suffering their child experienced, even though the parents and doctors accepted the principle of no active treatment.

It has been our experience that most parents preferred their child to be looked after in hospital and were grateful for the loving nursing care the child received. We feel that this care is usually best provided in a unit in which the medical and nursing staff are fully experienced and conversant with the problems of looking after infants with spina bifida.

Water supplementation in jaundiced babies

Sir,

The futile practice of giving jaundiced babies extra drinks of plain water or 5% dextrose is firmly ingrained in nursery lore, as indeed is the giving of water to newborn infants for all manner of mistaken reasons. I was glad to see that Mathew and Wharton, describing their investigation and management of neonatal jaundice,[1] may review their practice of giving extra water. It is not surprising that the study they cited[2] failed to show any worthwhile difference in serum bilirubin levels or weight loss between babies who received water supplements and those who did not.

The measured concentration of bilirubin in plasma must rise in dehydration although the total bilirubin level remains the same. However, it is a fallacy to believe that water alone can correct dehydration. Water is rapidly excreted, does not satisfy thirst or hunger except momentarily, and serves no useful purpose. Most neonates are effectively managed on low sodium diets.[3] For the fluid loss to be made good it is necessary to provide more sodium. The simplest way to do this is to give more milk, preferably using one of the less drastically sodium-reduced formulae. Alternatively, a commercial dextrose-electrolyte mixture such as Dextrolyte (Cow and Gate) (3·5 mmol per 100 ml), or a sodium bicarbonate supplement of 2 mmol/kg a day can be used. Rehydration is desirable so that inappropriate action is not taken on the basis of a spuriously raised bilirubin concentration, but using ordinary water for the purpose is unphysiological and misleading.

References

[1] Mathew P M, Wharton B A. Investigation and management of neonatal jaundice;a problem-orientated case record. *Arch Dis Child* 1981; **56**: 949–53.