Personal practice

Neonatal death—the neglected side of neonatal care?

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All maternity units and special care baby units witness neonatal death but this event becomes comparatively more common at high risk regional neonatal referral centres. These centres have sprung up to rescue preterm and sick infants for the benefit of the families concerned and to improve perinatal mortality for the country as a whole. The success of this policy is clearly reflected in the developed world by the steady downward trend in perinatal mortality statistics for all weight groups. Despite these trends, however, an appreciable number of infants arriving in neonatal intensive care units will die, either because of still lethal congenital abnormality or because intensive care has failed. At our own unit the percentage of infants reaching us who later die has been 19%, 12.8%, and 13.5% over the past three years.

With all formal training (medical and nursing) geared to rescue, the death of the patient may be regarded as failure. As an occasional event it can be rapidly forgotten but in a referral unit it is common and can therefore be less easily avoided. The emotional load of guilt and depression after frequent death almost certainly plays a part in the high turnover of nursing staff and the incidence of 'burn out' in physicians in these units. In the arena of neonatal intensive care the unsatisfactory nature of death as an outcome is highlighted locally at the perinatal mortality meetings and more universally in the unit's perinatal statistics which may be seen by all.

Parental grief

The grief of the parents after a neonatal death seems independent of the size of the offspring, being present even when the infant is non-viable or lives for only a very short time.¹ It has also been shown that the parents go through an identical reaction after a stillbirth.² Cullberg showed that the failure of a mother to come to terms with a perinatal death could lead to a very high incidence of emotional

problems; over 30% of mothers in his study had overt psychiatric problems in the two years after such an event.³ It was the recognition by Kennell and Klaus that psychiatric sequelae could be considerably reduced by parents touching their infants before and after death that led to the acknowledgement that the treatment of death is as important as the rescue of life.⁴

A developing approach—the death

The death of a baby in the neonatal unit is a very undignified event for the baby and the family especially when 'rescue therapy' is applied until the last moment. It is difficult for the parents to express their true emotions in the intensive care unit where staff are busy with other critically ill patients. It is difficult for staff to cope on the one hand with the rescue care for some patients and still provide sensitivity for grieving parents in the same nursery, and it is particularly difficult for parents of other babies in a unit with an open visiting policy. Over the past years at St George's Hospital we have shifted our emphasis in neonatal death from that of the medical failure to be forgotten about to an event, tragic indeed, but one in which the parents are, if at all possible, involved. Deaths on our unit now very frequently occur with the parents present and life support is often withdrawn with the baby in the mother's or father's arms. Thus, in many instances, the time of death is itself organised for the benefit of the parents. In this way we hope to allow the death to be a reality and also hope that in retrospect the parents will feel that they have done their best for their infant by allowing death in a dignified way in the presence of love and company.

In an attempt to dissociate death from the urgency of the intensive care unit we have set aside for the parents a room in the unit which can be used for terminal care as has been suggested by Whitfield *et al.*⁵ This room is less coldly clinical than the main nurseries and has wallpaper, curtains, a rug and easy

chairs which have been provided by the parents of babies that have died, the League of Friends, and unit jumble sales. We are still able to give full supportive care but are also able to involve the parents in care more of the hospice type for the infant's last hours or occasionally days. In this way we hope that they will come to terms more easily with the impending death. On occasions we have had extended families involved in culturally important ritual. During the terminal period a senior member of the nursing and medical staff is present to provide continuity and it is made clear to the parents that someone will always be present unless they wish otherwise.

It is difficult, particularly in such a mixed area as ours, to know and respect the cultural and religious background of all families passing through our unit and yet this is crucial in the terminal care. Discussion early on with the parents should elaborate their religious beliefs and standpoints and outside support should be encouraged if indicated. The introduction of this support at an early stage in a critically ill infant is important as it allows more constructive relationships to develop than when the meeting is for the baptism of a terminally ill infant. In the Christian families our clergy or social workers, when appropriate, are actively involved with the family. Our hospital chaplaincy has provided a proper silver christening bowl (rather than a plastic pot which was used previously) to facilitate baptism with meaning and dignity when the parents wish. This simple way of providing more concrete support for the religious ritual also provides a more positive memory of the event later. We suggest to parents that they might like to hold or groom their dead infant. This is usually met with agitation and a certain degree of horror particularly by the European parents but after a short time many mothers will request such involvement. In some instances parents have left the hospital to obtain their own baby clothes in which to dress their infant in the laying out process. Photographs of the infant will usually have been taken during life but if the life span has been short it is suggested that pictures of the dead infant are taken, often in the parents' arms. Frequently the baby can be specially clothed to enable a better photograph for remembrance to be taken than the ones in life with evidence of intensive care support.

A developing approach—aftercare (bereavement counselling)

Kennell and Klaus in 1974 suggested that the aftercare of the parents and siblings was important for subsequent emotional wellbeing⁴ but Rowe *et al.* in a much later study showed that after a perinatal

death 60% of mothers were highly dissatisfied with the information they received after the event and the way they received it.⁶

With this in mind we usually attempt to see each couple two or three times after the death. On the first occasion, usually on the day of death, sympathy is shown for the parents' situation; explanation is inappropriate at this stage and intrudes into the grief. The following day necessary formalities have to be completed and this can be a bewildering time. If the mother is mobile (that is, not just postoperative after a caesarean section) we encourage both parents to complete formalities together if possible. Our social worker (or clergy if indicated) can frequently be involved in a shepherding role to sort through these routines. One of the most distressing parts here is the need to register the baby's birth in the place of birth (frequently many miles from the regional unit) before being able to register the death which must be done in the district of death. It is also at this second interview that permission is asked for necropsy. We do not pressurise parents for this permission but find it is exceptional for them to be unwilling when the reasons are explained unless there are cultural or religious differences, and these can usually be resolved by contact with a local mosque or temple. The final task at this stage is to guide the parents through a few of the reactions and emotions that they will suffer in the ensuing period.

At about two weeks after the death the parents are seen a third time; if possible this interview is with the senior nurse who has been involved in the terminal events and the interview usually lasts between half and one hour. It is important not to see the parents in the neonatal unit or in the middle of a busy outpatient session where other babies and infants intrude too easily into their consciousness. At this meeting the necropsy findings are explained and the cause of the infant's life and death are discussed, frequently in depth. The distress and anxieties of the ensuing weeks are again raised and suggestions made as to how best to deal with them.⁴ Finally at this time an appointment is given for an optional final visit at about three months at which outstanding questions may be clarified and at which pathological grief, if present, should be evident.

We have recently introduced a babies' book of remembrance for infants dying in the neonatal unit, an idea gleaned from the Nottingham Unit. (Hale P, Rutter N, personal communication). This book is kept in the hospital chapel. A full page is allocated to a baby and a personal inscription designed by the parents is made in copper plate writing. The parents can see this book at any time by arrangement with the hospital chapel.

It is difficult to know whether our approach is wholly beneficial without using an intrusive questionnaire. The positive comments that are offered are, however, helpful and it is rare for the parents if there is a subsequent pregnancy not to rebook with us or let us know about the pregnancy if they live a considerable distance away. We have not made use of a local branch of the stillbirth and perinatal death association to provide aftercare which is a useful facility offered by the Nottingham Unit. (Hale P, Rutter N, personal communication). Our approach is still developing. We now feel much more adequate at dealing in a positive way with the death of a white baby but still feel frequently that we have far to go when the death is of one of our many ethnic minorities. We are in the process of meeting with representatives of the local Sikh, Hindu, and Moslem religious communities to obtain a better understanding of their rituals and to set up contacts who can be involved personally when necessary.

A developing approach—staff support

Finally with the realisation that the support and understanding of health professionals can play a vital role in the eventual recovery of the parents, there has also come the realisation that this involvement can itself cause depression and emotional tension in the staff.⁷ After a death we not only analyse in detail traditional physiological and pathological events but also the stress aspects for both the parents and the nursing and medical staff. We have not involved formal psychiatric help in this process

as after an initial trial we found it to be too intrusive for our apparent needs. We also have a more open discussion at bi-weekly meetings on the unit to which all staff are invited. In this way we hope that people involved in a neonatal death and who will inevitably be under considerable stress will not reach the point of physical and emotional exhaustion.

We would like to thank past and present medical nursing staff of our unit, our social workers, and clergy. Without their sensitivity and continuous support we would have kept to a more traditional and remote approach.

References

- ¹ Kennell JH, Slyter H, Klaus MH. The mourning response of parents to the death of a newborn infant. *N Engl J Med* 1970;**283**:344–9.
- ² Lewis E. Mourning by the family after a stillbirth or neonatal death. *Arch Dis Child* 1979;**54**:303–6.
- ³ Cullberg J. Mental reactions of women to perinatal death. In: Morris N, ed. *Psychosomatic medicine in obstetrics and gynaecology*. (3rd International Congress, London, 1971). Basel: Karger, 1972:326–9.
- ⁴ Klaus MH, Kennell JH. Caring for parents of an infant who dies. *Maternal infant bonding*. St. Louis: C. V. Mosby Co, 1976.
- ⁵ Whitfield JM, Siegel RE, Glick AD, Harmon RJ, Powers LK, Goldson EJ. The application of hospice concepts of neonatal care. *Am J Dis Child* 1982;**136**:421–4.
- ⁶ Rowe J, Clyman R, Green C, Mikkelsen C, Haight J, Ataide L. Follow up of families who experienced a perinatal death. *Pediatrics* 1978;**62**:166–70.
- ⁷ Walker CHM. Neonatal intensive care and stress. *Arch Dis Child* 1982;**57**:85–8.

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