ABC of preterm birth

Supporting parents in the neonatal unit

Peter W Fowlie, Hazel McHaffie

This is the 10th in a series of 12 articles

Parents find it very stressful when their baby is admitted to the neonatal unit for any reason. Different sources of stress have been identified, and certain occasions (such as discharge from hospital or bereavement) are particularly difficult. These experiences impact on families in positive and negative ways, and people adopt a range of coping mechanisms. Staff should adopt a holistic approach to care that acknowledges the uniqueness of each family and supports them appropriately.

Sources of stress

During pregnancy, most women and their partners do not give serious consideration to the possibility of preterm delivery or illness in their newborn baby. In most cases admission of an infant to the neonatal unit is unexpected and is stressful for the parents.

If a problem is diagnosed antenatally, parents can be forewarned. For most admissions to the neonatal unit, however, there is little or no time to prepare the family. Parents are unfamiliar with the potentially complex problems their infant is facing and they are unsure of the future. Incomprehension and uncertainty are major sources of stress. In addition, maternal health is often compromised at this time.

A degree of separation exists between the mother and baby when the infant is admitted to the neonatal unit, and this may extend over many months. Although in some places a visit to the neonatal unit is a routine part of antenatal care, the neonatal unit is an alien environment to most parents. Units are often noisy, bright, and hot. They can be overcrowded and parts of every unit will be "high tech." Parents rarely know the neonatal unit staff before their baby is admitted, and the language and behaviours they encounter can contribute to an overwhelming feeling of isolation. The sickest preterm infants may be in hospital for many months, and visiting can be difficult, exhausting, and a financial drain for parents, especially as neonatal services become more centralised. All these factors put strain on the parents' relationship: breakdown is more common in couples during the months after preterm delivery. Some couples, however, feel the experience makes their relationship closer, at least initially.

Generally, stress and anxiety are higher in mothers than in fathers, and lessen as time goes by. In some parents stress is similar to that seen in adults diagnosed with post-traumatic stress disorder. High levels of stress may last beyond the first year of their infant's life, and the level and duration of stress may not be directly related to how preterm or how sick their baby is. In addition to high levels of stress and anxiety, these parents are more prone to clinical depression, which may be difficult to recognise.

Coping mechanisms

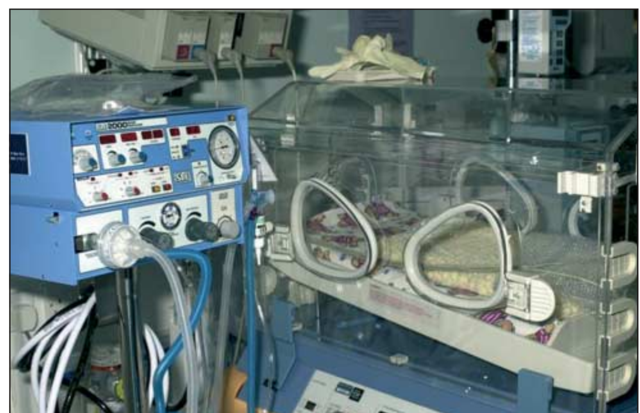
Responses and feelings reminiscent of a classic grief reaction can be identified: shock, denial, anger, guilt, acceptance, and adjustment. Several models explore how parents cope with having their baby in the neonatal unit. A great variety of mechanisms are seen, however, and a single model will probably not fit all parents. Some of the coping strategies

Seeing their baby receive intensive care can be terrifying for parents

Sources of stress experienced by parents

- Maternal ill health
- Separation from their baby
- Strange, "hostile" environment
- Unfamiliar staff
- Appearance and condition of the baby
- Complex medical problems to understand
- Sudden changes
- Uncertainty
- Lack of information
- Physical demands
- Financial hardship

The degree of stress and anxiety experienced by parents varies from individual to individual and with time



The environment of the neonatal intensive care unit, which can be hot, noisy and "high tech," is usually alien to parents

Cultural and religious variations may cause differences in the way experience of having a baby in the neonatal unit and the surrounding circumstances may be perceived and handled. Staff should be aware of this diversity so as not to view different responses by the parents as necessarily "abnormal" or uncaring

include trying to gain a deeper understanding of the problems, establishing a degree of control over the situation, seeking social support from other people, and escaping from or minimising the apparent severity of the situation. These mechanisms are used to varying degrees in individual parents, and there is a systematic difference seen between mothers and fathers. Mothers tend to look for support from others and to search for an explanation for what has happened, whereas fathers are more likely to try to minimise the situation, often by concentrating on supporting their partner.

A welcoming environment is important in the neonatal intensive care unit

Limiting parental stress

A better understanding of the sources of stress and how parents might try to cope allows appropriate care of the family. When designing neonatal units, great emphasis is placed on effective layout, lighting, and noise reduction. Facilities for families to stay close to their baby are usually provided, and parent rooms allow mothers and fathers to relax and meet other parents. Play areas for siblings can be incorporated into some units. This more "family-orientated" approach to care is helped by less restricted visiting policies in neonatal units. Most units will allow parents and siblings open access to their baby if they comply with local infection control measures. Having transitional care areas as an integral part of the neonatal unit or as a separate area (for example, as part of the postnatal ward) minimises the separation of mother and baby.

When time permits, members of the neonatal team will often meet with parents before the birth to discuss any likely admission. Parents may visit the unit before their baby is born to familiarise themselves with the environment and some of the staff. After delivery, it is good practice to discuss medical and nursing issues in detail with parents and to involve them in decision making from an early stage. Parents will often have immediate access to recordings, results, and clinical notes. They can also help care for their preterm baby. This care may extend beyond simple but important measures, such as "skin to skin" contact, to providing skilled care such as tube feeding, oral toileting, and intensive "developmental care" programmes.

Parents of other preterm babies can give personal support through "buddying" programmes or informally. Counselling through organisations, such as the Premature Baby Charity (BLISS) in the United Kingdom, or formal support can be helpful even for families whose babies are not critically ill. Written information about the neonatal unit and, where appropriate, describing specific conditions or procedures may be useful. Routine contact between the neonatal unit and social services may allow financial support to be provided for the parents.

A place to relax as a family in the neonatal unit can help reduce stress and anxiety

Death and decision making

Babies, particularly extremely preterm infants, may die despite continuing intensive treatment and full medical support. In addition, a decision to limit active treatment may be made because of the inevitability of death or a prognosis that indicates a very poor quality of life. Death, however it comes about, is a desperate time for the families who are affected. Parents want to be involved in decision making at these times. They need full and frank information, given in a compassionate manner by experienced staff who know the family and their baby.

In most cases, the decision to stop or limit treatment is made with senior medical and nursing staff. Family, friends, and external bodies (such as religious leaders and support groups)

Fathers and mothers may respond to and deal with the stress of preterm birth differently

do not often have a substantial role in the decision to withdraw treatment but they do contribute to family support afterwards.

Mothers and fathers may differ in the way they grieve and cope with their loss. Mementoes, formal contact with senior staff in the weeks after the death, and contact with a bereavement support worker or group may all help the process. Most families begin to move on in the first year after the death—not forgetting the child but adjusting to life without him or her.

Bereaved parents often need factual information that may help explain why their baby has died. Without autopsy, important information can be missed, and in most neonatal units, postmortem examination will always be considered and offered to the parents if appropriate. High profile cases of procedural inadequacies and anxieties about organ retention have contributed to a fall in the number of autopsies carried out. This drop is increased by a parent's natural reluctance to authorise further "suffering" for their infant and a lack of awareness of the questions that remain unanswered.

Leaflets are another source of support and information for parents and families

Discharge home

Discharge home, although an exciting time for families, can also be a time of extreme anxiety, and so a formal approach to "discharge planning" is often adopted. Mothers "room in" with their baby to promote bonding, establish feeding, and learn practical skills that might be needed. Support for the family in the community once the infant is discharged can also be arranged, including specialist neonatal nurses, primary care health staff (for example, health visitors, general practitioners), social workers, and national or local family support groups (for example, BLISS).

Although managing the immediate stress of discharge home is important, it needs to be recognised that although practical issues may become easier to manage as time passes, for some families considerable levels of stress and anxiety remain long after the discharge itself. Psychological support should be an integral part of neonatal follow up programmes.

A formal approach to discharge planning has allowed infants who might otherwise have stayed in hospital for some time (for example, infants with chronic lung disease) to be discharged sooner to the more natural and stimulating home environment

Conclusion

The parents and families of babies who are admitted to the neonatal unit are exposed to a variety of stressors, and may face extremely difficult decisions in unique situations. Vulnerable families may benefit from specific environmental and personal support. By targeting this support appropriately, staff on neonatal units can provide a more complete package of care.

Hazel McHaffie is deputy director of research, Institute of Medical Ethics, Loanhead, Midlothian.

The ABC of preterm birth is edited by William McGuire, senior lecturer in neonatal medicine, Tayside Institute of Child Health, Ninewells Hospital and Medical School, University of Dundee; and Peter W Fowlie, consultant paediatrician, Perth Royal Infirmary and Ninewells Hospital and Medical School, Dundee. The series will be published as a book in spring 2005.

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Summary points

- Having a preterm baby is stressful
- Parents manage stress and anxiety in many ways that are not necessarily consistent across different families, religions, and cultures
- Men and women differ in how they cope with stress and bereavement
- Appropriate support for parents should be an integral part of neonatal care

Further reading

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