1 Introduction

Attitudes towards neonatal illness, childhood impairment, and perinatal death have changed greatly over the past few decades. Improvements in perinatal and infant mortality have been accompanied by ever-increasing expectations by parents that their children will be born safely and will survive. When things do go wrong, it comes as a great shock. Parents may suffer much more than the sense of loss of the healthy baby they had anticipated. They may also lose their faith in modern medicine and doctors, and the belief in their own ability to produce a normal baby. In a similar way it is often shattering for caregivers to witness the apparent failure of their skills.


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To compound the difficulties further, those who live in industrialized societies have lost day to day familiarity with death and bereavement, and the mourning rituals that used to play an important part in dealing with the psychological needs of the bereaved. They have thus become poorly equipped to cope with this tragic situation.

Grieving will follow the birth of an ill or impaired baby, as well as after a baby’s death. The two components of normal grief are the acute symptoms (episodes of restlessness, angry pining, and anxiety), set against a background disturbance consisting of chronic low mood, loss of purpose in life, social withdrawal, impaired memory and concentration, and disturbances of appetite and sleep. These symptoms occur as bereaved people go through the process of coming to terms with the reality of their loss, and of psychologically withdrawing from their relationships with the impaired or dead child. This process, which is necessary to let them continue with their own lives in a positive manner, may take months or years to complete. A successful outcome depends on the personalities and life experiences of the people concerned; on the circumstances of the impairment or death; and on the effectiveness of the supportive network surrounding them.

2 Perinatal loss

2.1 Illness and impairment

The reaction of parents to a newborn baby who is gravely ill or impaired is a form of grief reaction to the loss of the healthy child that they had expected. The initial phase is marked by shock and panic (‘I can’t look after a handicapped child’), denial (‘He’s not my baby’), grief, guilt, and anger. This is followed by a phase of bargaining (‘I will look after him if he can be taught to be clean and dry’); and finally acceptance, when parents cope with the reality of the situation. Some parents remain in a state of chronic sorrow. It is important for caregivers to form an effective alliance with the parents, on which plans for care can be based.

In addition to a grief reaction, most parents of ill or impaired babies suffer high levels of anxiety, which appear to be increased by contact with the baby. This does not mean that separation of mother and baby is to be recommended. On the contrary, close contact between parents and the baby, with support from caregivers, will allow parents to form a relationship with a real child. If the mother planned to breastfeed, she can be encouraged to initiate lactation by expressing her milk.
Providing this milk for her baby may help in the development of her relationship with the child, and demonstrate her own unique role in caring for the baby.

Apart from the emotional stress of the situation, parents have the physical and financial stress of visiting their baby in hospital, particularly if the baby has recurrent medical crises and needs care over a long period of time. Some parents withdraw emotionally and physically from their baby before the medical staff have given up hope of the baby’s survival. This is termed ‘anticipatory mourning’. It can be precipitated by giving an excessively gloomy prognosis, or even by a casual remark indicating a possible bad prognosis. It carries with it a risk of rejection if the baby does eventually survive.

2.2 Perinatal death

Grief after perinatal death is not different from that following the death of any loved person. There are, however, some special features to be considered.

Bereaved parents may feel anxious and angry, and direct blame at their caregivers, other members of the family, or themselves. This may be due in part to the suddenness of the death, and is probably compounded when there is no ‘scientific’ explanation for what has gone wrong. Parents desperately seek for a cause for the baby’s death. It is easier for those who have an explanation, such as malformations or extreme immaturity. ‘Empty arms’ is another common and distressing symptom after the phase of numbness has passed. Mothers are frequently tormented by hearing their dead baby cry. Some bereaved parents experience negative feelings towards other babies and are fearful of losing control, while others long to hold a baby – any baby – however painful this might be. Many mothers do not expect to lactate once the baby has died and find the fact that they do upsetting. Most mothers experience a great loss of self esteem, a sense of having failed, both as a woman and as a wife.

Most parents will not have been bereaved before, and are likely to have difficulty coping with the complicated registration and funeral procedures. Many are unprepared for the emotional turmoil of their grief reaction, and may feel they should be ‘over it’ after a few weeks. This view may be reinforced by well-meaning friends, relatives, and even medical practitioners, who may advise the couple to go ahead with another pregnancy long before they have recovered sufficiently from their loss. There is evidence that fathers recover from their grief more quickly than mothers. This in itself may lead to problems with
their relationship, particularly if the couple are not used to sharing
their feelings, or if one of them is blaming the other for the baby’s
death. Sexual and marital difficulties are common.

Another difficult area is the reaction of other young children in the
family to the loss of the baby. They may be confused about what
has happened to the baby, and even feel responsible for the disap-
pearance. Behavioral changes are common; they may take the form of
over-activity, naughtiness, regression, problems at school, and other
emotional problems. These reactions are usually fairly short-lived
(a few weeks or months) unless the emotional state of the parents is
such that there is an absence of normal warmth in family relationships
for an extended period, or serious difficulties develop in the relation-
ships between the mother and her living children.

It may be particularly difficult to work through one’s grief when a
baby is stillborn. There is no real object to mourn. The baby has never
lived outside the womb and there are no memories to help. The prob-
lems are accentuated if the stillborn baby is rapidly removed from the
delivery room before the parents have a chance to see or hold him or
her, and if the hospital, for whatever reason, takes over the funeral
arrangements without involving the parents.

Long-term follow up studies show that a significant proportion, up
to a fifth of women interviewed, still suffer from serious psychological
symptoms for years after losing a baby. Although it is not possible to
identify with great confidence those most at risk of developing prob-
lems, the most frequently reported markers are not seeing or holding
the baby, having an unsupportive partner or social network, and
embarking immediately on another pregnancy.

There may be problems with parental relationships when babies have
been conceived too quickly after a loss. If the dead child has not been
adequately mourned before the start of a new pregnancy, mourning
may be postponed until after the birth of the next baby, when it can
reappear as ‘postpartum depression’. The new baby’s identity can
become confused with that of the idealized baby, causing great
great emotional problems. The new child may never be able to live up to the
parents’ expectations, and may become the focus of any unresolved
anger that the parents have as a result of their loss. The survivor of a
twin pregnancy may be involved in similar problems if the dead twin
is not properly mourned at the time.
3 Care by hospital staff

The maternity unit staff play a vital role in the care of bereaved parents. A program of care should encourage the parents to see, hold, and name their baby, and to hold a funeral. Arrangements should be made for them to see senior obstetrical, midwifery, and pediatric staff to discuss what went wrong, obtain genetic and obstetrical counseling, and receive the autopsy results. Providing informed, compassionate care will help the recovery process after a perinatal death.

Effective care for most families can and should be provided by the maternity unit staff. These professionals and the family doctor are in a position to help bereaved families by facilitating the establishment of normal grieving from the start. Special bereavement counseling services are not often required.

3.1 Communication

Good care hinges upon good communication. Parents frequently comment on communication failures when describing their experiences. Caregivers must give bereaved parents opportunities to talk about the loss of their baby, and even more importantly, listen sympathetically to their expressions of grief. The senior obstetrical, midwifery, or pediatric staff must help parents with their search for a cause of death and create opportunities for discussing this with them.

Seeing both parents together helps to strengthen their relationship, as they share the experience of their baby’s loss, and prevents misunderstandings and inconsistencies in explanation. Arranging for the same caregivers to attend regularly to the parents also helps this. Any information given in the first few days of the loss will probably need to be repeated later, as the initial shock passes. A follow-up interview a few weeks later seems to be the best way of dealing with this.

Good communication among professionals about the loss of the baby is necessary to prevent painful situations, such as a member of staff being unaware that the baby has died, and asking the mother about the baby. The primary-care team should be informed about the baby’s loss immediately, so that they can make contact with the family as soon as, or even before, the mother is discharged. Parents may want the support of their own religious adviser, and the hospital should check on this and contact him or her if required.
3.2 Immediate and early care when the baby is dead or dying

For mourning to begin, parents must be enabled to face their fear of death and dying, so that they can experience the painful reality of their loss. This involves encouraging them to have as much contact as possible with their baby, both before and after death. It is particularly important for parents of a stillborn baby to see, hold, and name their baby.

When an intra-uterine death is suspected, the fears for the baby’s condition should not be denied, but shared with the parents, together if at all possible. If the mother is at an outpatient clinic or doctor’s office, efforts should be made to contact her partner or a friend or family member, so that she is not left to travel home alone and unsupported. The technicians in the ultrasound scanning room have an important role to play when the confirmatory scan is done. They need to be sympathetic to the situation and allow the mother to be accompanied by anyone she chooses (see Chapter 27).

Most women are frightened at the prospect of delivering a dead baby, as well as shocked by their loss. It helps if caregivers take time to explain carefully what will happen, that adequate pain relief will be available, and what the baby will look like at birth. This is usually successful in overcoming any reluctance that the parents may have about seeing or holding their baby. It may help to show a malformed or macerated baby to the parents wrapped up at first.

A few parents will not be able to cope with seeing and holding the baby at the time of birth. A photograph should be taken and kept in the medical notes for possible use later, and further opportunities for seeing the baby should be offered to parents over the next few days, as they often change their minds. Photographs and other mementoes of the baby, such as a lock of hair, a piece of the umbilical cord, or a print of the baby’s hand or foot are important, as they provide tangible evidence of the reality of the baby’s existence and loss. They should be available for parents as keepsakes, if they wish.

When the baby lives long enough to be transferred to a neonatal unit, it is again important for caregivers to keep parents as fully informed as possible about the baby’s condition, and to encourage them to share in the care. Photographs of the baby are helpful, particularly for fathers to keep at home, or if the mother is too unwell to visit the unit. In a randomized trial of the use of routine photographs of sick neonates in the first week of life, there was a significant increase in visiting by the parents of the photographed babies, compared with the non-photographed group.
When the baby's condition is known to be terminal, it is important to involve the parents in the decision to cease life-support, and then to let them take their dying baby in their arms, if at all possible, free of all equipment that has been necessary until then. In describing this, authors quote parents saying such things as, 'It was all I could do for her to hold her in my arms as she died.' Some parents may wish to take the baby home to die; they should be supported in this decision. Feelings of guilt about removing the baby from the life-support system have not been reported.

Many parents like to help with the laying out of the baby's body, and this should be encouraged. Often they have selected special clothes or toys to be placed in the coffin with the baby. Supporting the parents' contact with the reality of the death of their baby in these ways will facilitate their grief reaction. They will need privacy to express their grief, and this should be provided, however busy the unit happens to be.

The choice of site for the aftercare of the mother is important, as mothers differ in their requirements at this time. Some want to be on their own, far away from the sound of babies crying; others long to return to familiar faces on the ward. It is helpful if as much flexibility as possible is offered to them and if, at least for the first night, partners are allowed to remain with them. Ideally, the hospital should provide a couch in the mother's room so that the parents can share their grief together. Lactation and help with its suppression is an important issue for the mother whose baby has died. If the mother is physically fit to return home immediately and wishes to do so, it is important to ensure that she has a supportive network of family, friends, and professionals before she goes home.

3.3 Autopsy

Consent for an autopsy and chromosome studies should always be requested after a perinatal death. These investigations may provide information about the cause of death, help parents with their grief, and assist the planning of future pregnancies. Most parents agree to an autopsy, although it is often a painful decision for them. Having consented, parents cherish great hopes that the results will provide answers to their questions about why the baby died. It is important that they receive the results in a form that makes sense to them. The best person to do this would be a senior member of staff who can interpret the pathological findings.
3.4 Death registration and funeral arrangements
Knowledge of the legal procedures required when a baby dies or is stillborn is fundamental to good care. It is necessary to be familiar with the registration and funeral arrangements operating in one’s own locality, as these are often complicated and baffling for parents still suffering from the shock of their baby’s death. Religious practices vary greatly as well, and an awareness of these and sensitivity to the wishes of individual parents is crucial. The funeral may involve considerable expense; helping those in financial difficulties, besides encouraging them to attend, are therapeutic aspects of care.

Many units have leaflets outlining their own procedures and giving helpful advice for parents.

3.5 Follow-up
Most mothers will be discharged home within a few days of their baby’s death, still too shocked by it to grasp properly what has happened and why. Careful and supportive follow-up is extremely important. Parents should be able to contact the staff who cared for them by telephone after they leave the hospital. Some units are able to offer home visits by their social worker. An appointment should be made for both parents to see a senior member of staff 2–6 weeks later, as soon as the chromosome studies and autopsy results are available, and some form of perinatal mortality conference has taken place. Caregivers should be aware that returning to the hospital is likely to be traumatic for the parents.

The next pregnancy will inevitably be an extremely anxious time, and the mother will need extra support during pregnancy and in the first few months after the birth.

4 Care in the community

4.1 Health professionals
The general practitioner, health visitor, community midwife, and other primary health-care workers will form the professional supportive network once the mother has returned home. These professionals can help by continuing to support parents in the expression of their grief and putting them in touch with local support groups for parents who have lost a child.

The general practitioner or midwife can watch for signs of pathological grief reactions, and refer the parents for specialist help if
necessary. These pathological reactions can take the form of an inhibited reaction, with no sign of any sense of loss, or a prolonged reaction, with unremitting symptoms of depression, severe anxiety or the appearance of psychosomatic illness. There may be drug or alcohol abuse.

Unremitting anger is another feature of a pathological grief reaction. General practitioners and midwives may need to deal with anger focused on the maternity unit. To do so, they must ensure that the parents have good relationships with the obstetric, midwifery, and pediatric staff, and are fully informed about the course of events that led to the baby’s loss. The parents may blame the general practitioner or midwife, as well as the maternity unit. When this happens, it is essential that he or she meets with the family as soon as possible, so that they can ventilate their feelings and, hopefully, re-establish their relationship. Many parents remain angry simply because they were denied any compassionate response to their situation: no one said, ‘I’m so sorry your baby died’.

The general practitioner or health visitor will probably be the person to whom the family will turn to for help in coping with the reactions of their other children to the baby’s death. Parents may need help to allow their children to express their feelings about so painful a subject. It must be remembered that young children will use play as a vehicle for doing so. Explaining death to children under 5 year of age is difficult because they are not yet able to grasp the concept. Even simple statements like, ‘The baby’s gone’ will be interpreted literally and lead to questions about where the baby has gone and when a visit can be made. The parents will need to add more information as the child’s capacity for understanding develops.

4.2 Self-help groups
Self-help can be effective in providing the right kind of support for parents facing many different kinds of problems, and perinatal bereavement is no exception. It is important though, that the people running the group have recovered sufficiently from their own loss to be able to help others, and that they have access to professionals for help and advice as and when necessary. Parents can benefit from sharing their experiences together, from discovering that they are not alone in their suffering, and from learning that time does help to heal the wounds. Not everyone can cope with group support, and it is unwise to rely on a local self-help group to meet the needs of all bereaved families. While it is invaluable to give parents the telephone number or address of a
local contact, this should not replace follow-up by the hospital staff, general practitioner, and health visitor.

5 The role of specialist counselors

5.1 Routine counseling
Three small trials have been conducted, which evaluated routine counseling for bereaved parents by caregivers trained in grief work, compared to standard care. The studies did not produce conclusive evidence of effectiveness, primarily because the dropout rates of participants were high. More research is needed in this important area.

5.2 Counseling for prolonged grief reactions
Prevention of prolonged grief reactions through appropriate care is not always successful. About one in five families will show reactions that are detrimental to their health and are likely to be accompanied by problems in family relationships. Little is known about the factors that precipitate prolonged grief reactions or the most effective measures of preventing or decreasing their severity. The help of specialist counselors trained in grief work will be needed in these situations, either to advise other colleagues giving care, or to take over responsibility for care themselves. The treatment required is often protracted, and antidepressant drugs and psychiatric surveillance may be necessary for severe depressive symptoms. Child and family psychiatrists may be particularly helpful in dealing with the relationship problems within families.

Specialist counselors can also be useful in supporting the staff of the unit (through regular staff meetings, case discussions, or training sessions) and can offer help and advice to self-help groups. The training of caregivers in the care of families who lose their baby, or who are faced with a baby with a severe impairment, deserves as much emphasis as the development of their technical expertise.

6 Conclusions

Much can be done to help a bereaved family cope with their loss and recover from their grief. The extent to which this is accomplished will depend on the importance that is attached to training in this area, and on the attitudes of individual professionals, both in the maternity unit and in the community. Parents need the opportunity to have contact
with their ill child, and support for the mother to lactate if she wishes. Parents of stillborn or dying babies should similarly be encouraged to touch and hold their baby. Photographs of their baby will provide tangible evidence of the reality of the baby’s existence and loss. Giving photographs to parents of sick babies has also been shown to increase their visits to their babies in the first week of life.

The practical aspects of death registration and funeral arrangements for babies should receive careful attention. Time must be spent, listening as well as talking, with parents whose baby has died or is impaired. The senior members of staff need to play a central role in caring for the parents, sharing their experience and expertise with more junior caregivers. The primary health-care team must accept the role of monitoring and supporting the parents during the ongoing bereavement process.

The provision of adequate support will almost certainly lead to improved rapport with grieving families. It will help professionals to cope better with their own grief, because they feel more able to help. Most importantly, it may help families to emerge from their grief able to resume normal functioning.

Sources

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Other sources

