Family Practice

Support for parents experiencing perinatal loss

FETUS AND NEWBORN COMMITTEE,*
CANADIAN PAEDIATRIC SOCIETY

Grief following perinatal loss is just as debilitating as that following the death of an older person and may not be completely resolved for years. The physician's role in assisting parents following perinatal loss is one of a sympathetic listener and compassionate informant, but each category of perinatal loss — miscarriage, stillbirth, neonatal death and sudden infant death syndrome — requires a somewhat different approach. To be of assistance, physicians must understand the normal process of grief and the differences between the reactions of mothers, fathers and siblings. The advent of liberal attitudes to family visiting in perinatal units has helped parents better understand perinatal illness, and appropriate management in the event of perinatal death can greatly benefit the family.

Le chagrin consécutif à la perte périnatale d'un enfant est tout aussi affligeant que lorsqu'il s'agit d'une personne plus âgée et peut ne se dissiper complètement qu'après des années. Suite à une mortalité périnatale le rôle du médecin auprès des parents consiste à leur prêter une oreille sympathique et à les informer avec compassion; chaque type de mortalité périnatale, qu'il s'agisse d'une fausse couche, d'une mortinatalité, d'une mortalité néonatale ou de la mort soudaine du nourrisson, exige une approche quelque peu différente. Pour être utile, le médecin doit comprendre le processus normal de la réaction à la perte d'un être cher ou souhaité et les différences qui existent entre la réaction du père, celle de la mère et celle des frères et soeurs. La libéralisation des attitudes face aux visites familiales dans des unités de soins périnatals a contribué à aider les parents à mieux comprendre la maladie périnatale; lorsqu'une mortalité périnatale survient, la conduite prise par le médecin est susceptible de profiter considérablement à la famille.

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Making the decision to be with our son when he died was probably the most difficult thing we will ever have to do in our lives, especially for my husband. He did not change his mind until the day our little one died. At first, I was hesitant, but as his mother I felt my place was with him. I would rather have my child die in my arms than alone. This we will always have. It is like locking our baby away in our hearts and throwing away the key. It is like a book read from beginning to end. Always remembered — never forgotten.

—Extract from letter from a bereaved mother

As a result of advances in perinatal care, perinatal death has become relatively infrequent, affecting only about 12 to 15 families per 1000 births per year in Canada. Attitudes toward newborn babies have changed markedly; as Silverman[1] recently discussed, it is barely 100 years since infanticide was an accepted method of birth control. Nowadays, pregnancies that continue beyond the 20th week are usually very much wanted and the result of a major commitment to parenting. In the hope of guaranteeing a safe yet satisfying birth, hospitals have become accepted as the appropriate place for childbirth. If pregnancy ends in stillbirth or the baby dies soon after birth, the parents, especially the mother, will have to cope with a major tragedy. Further, for many couples the loss of their baby will be their first intimate experience with death, because for at least 20 years hospitals have cared for the sick, especially for those who are critically ill and likely to die. Occurring as it does at a time of anticipated joy, perinatal death may precipitate major psychologic problems for the parents and threaten the integrity of what is often but a formative family.

The death of an older child or an adult is both a family and a community affair. The person was known, had friends and had created a personal and community life. The processes of grief experienced with such deaths have been described in such works as that of Kübler-Ross.[2] But the possible effects on parents of the death of an infant who had had little or no opportunity for life and who was thought not to be "known" to the parents attracted little attention until the work of Kennell and associates[3] in the early 1970s. Since then, there has been considerable literature on perinatal death. It is obvious from some of these accounts and from recent descriptions by parents[4,5] that the care parents receive following perinatal

loss sometimes leaves much to be desired. We have written this article in the hope that it will help health professionals caring for parents who have experienced perinatal loss.

Maternal/infant attachment

It is now well accepted that a bond is formed quite early in pregnancy; it is stimulated by fetal activity, hormonal changes, psychologic preparations and fantasies about the infant-to-be.[3,6] Also usual is "nesting" behaviour, manifested by purchase of a crib and baby clothes, decoration of the nursery, attendance at baby "showers" and so on. The anticipatory joy of the mother heightens through the later stages of pregnancy. The father's attachment process, although definitely recognizable, is less intense during the pregnancy but rapidly intensifies following the birth. For both parents, fantasies of their future with their child are usual. A lovely example is Billy Bigelow's soliloquy in Rogers and Hammerstein's "Carousel". Billy, on learning that Julie is pregnant, is overjoyed and voices his thoughts of what his future son will be like and will achieve: "He'll be the spitting image of his Dad ... [have] more common-sense than his wooden-headed father ever had .... He'll be tall and tough as a tree with his head held high .... Don't give a hang what he does ... from pack peddler to president!" Billy then suddenly realizes "What if she is a girl? ... What would I do for her, a 'bum' with no money .... You can have fun with a son but you gotta be a father to a girl." He goes on to picture his little girl "pink and white as peaches and cream .... I gotta get ready before she comes. I gotta make certain she won't be dragged up in a slum."

Thus, by the time of birth a powerful bond has been established between the baby and parents. Contrary to the commonly held view that only short-lived psychologic trauma will result from the baby's death, both parents will experience profound grief that may not be completely resolved for years. Morbid grief reactions may occur in as many as one third of mothers.[7]

Although this article is concerned primarily with perinatal death, "loss" in perinatology has much wider connotations. A sense of loss occurs not only with perinatal death but also when an infant is born malformed, prematurely or of the "wrong" sex,[8] and in the event of persistent inability to conceive.

Grief

Grief has been defined as the process whereby individuals separate from someone or something that has been lost. It is an instinctive response involving psychologic growth, which stimulates a reassessment of values and philosophies. To be resolved, the grief process cannot occur in isolation. Unfortunately, there is a widespread lack of knowledge and understanding of the process of grief. This often leads to a corresponding lack of understanding for the bereaved by those from whom they could most benefit. Kübler-Ross[2] examined the stages of grief from the viewpoint of the dying, whereas Kavanaugh[9] described seven stages of grief experienced by the survivor: shock, disorganization, anger, guilt, loneliness, relief and re-establishment.

Shock is usually extreme and is often accompanied by denial and disbelief, especially when the parents had expected a normal, healthy child. Sensations of choking, shortness of breath and exhaustion occur, and the emotional reactions vary from impenetrable flatness to hysterical screaming. Mothers describe a "feeling that their world has suddenly stopped". In this phase, after the initial information has been received, further words are not usually heard by the parents.

The parents then pass into a phase of disorganization, accompanied by confusion, anguish and an inability to make decisions or to comprehend what has happened or what to do next. Parents need to talk to others, discuss their feelings and grieve together. Often, because of his self-image or society's image of his masculinity, the father does not enter into this mutual sharing but attempts to "protect" his wife.

Until these two phases pass, the death may appear unreal to the parents. With a return to reality, the loss is fully recognized, and the grieving is accompanied by anger and hostility. This phase may occur suddenly and, especially among fathers, even within a few minutes of being informed of the baby's death. It may take the form of violent behaviour, such as shouting obscenities at the hospital staff or relatives. Guilt often accompanies the anger, particularly among mothers.[10] Most will search through the pregnancy or the period before the baby's death for evidence of their own failure. Their imagined failings may include poor diet, working, smoking or even minor alcohol consumption during the pregnancy. Some parents of premature infants experience guilt about having had coitus, which they may associate with premature rupture of the membranes or premature onset of labour. The guilt may be so severe that the mother may feel she has failed as both a mother and a woman. Toward the end of this phase she begins to isolate herself emotionally, yearning for the baby, with whose image she may be preoccupied. Sleeplessness and nightmares, which may include imagined fetal movements and babies' cries, are common. The appetite is often poor. Overwhelming sadness occurs intermittently, often without warning but not infrequently as a result of thoughtless comments from others. The depression is usually oppressive and debilitating, and many days may be spent in crying. Resentment and jealousy of other mothers and their babies are common. This period of loneliness, sometimes interspersed with guilt, usually lasts several months. It passes slowly, only gradually giving way to relief and restitution. Sadness may persist, but thoughts of the baby can be entertained without crying. The dreams and preoccupation with the baby's image give way to thoughts of the present and plans for the future. The despair lessens. As one mother remarked, "the light begins to appear at the end of the tunnel". Parents can again enjoy activities together and with others. Mothers can enjoy other people's babies. Often the seal is set upon this phase by another pregnancy.

Although this basic sequence of the grief process can be recognized, individual variations must be anticipated. The manifestations of grief vary among individuals, families and

communities and may be influenced by personality traits, religious beliefs and ethnic background. Consequently, both "grief diagnostics" and stereotyped responses by health professionals must be avoided.

Perinatal loss

Miscarriage

Although some mothers may be profoundly affected by early miscarriage and undergo the usual process of grief, others may not. To a great extent this will depend on the mother's desire for the pregnancy. In many instances the father has hardly had an opportunity to appreciate the pregnancy; for him the relationship may therefore not have progressed to attachment. This asynchrony may result in a lack of understanding by the father of the intensity of the mother's grief and thus to incongruous grieving, perhaps leading to marital discord.[11]

Stillbirth

Special problems are associated with stillbirth. The mother may begin the grieving process before the birth of the baby, and the father, in his protective role, may prevent her from making any decisions. For example, he may ask that she be sedated during the birth, when, in fact, she may wish to experience it. He may decide that she should not see or name the infant, and he may control events at home, perhaps emptying the nursery while she is in hospital. While mothers often wish to see the infant, fathers frequently do not — a situation that may well lead to disharmony and misunderstanding. Doctors and hospital staff are often reluctant to discuss the stillbirth with the parents, which may lead to major psychiatric trauma for the parents.[12]

Neonatal death

We have already described the grief of the mother whose baby has died. For the father, life may have become very stressful before the infant's death, especially if the baby was transferred to a neonatal intensive care unit. He will have demanded much of himself — visited the baby, reported to his wife and cared for their children at home, all while attempting to respond to the demands of his work. Following the death, he may adopt a protective role towards his wife and deny himself the normal grief process. He may be perceived as "strong", yet he too needs support and comfort. However, he may not be met with understanding. One father recently told of a work supervisor who told him to "snap out of it — you can soon have another" within 10 days of the death of a premature baby following 2 weeks of extreme anxiety over both his wife and the child.

When a move from aggressive support to one of terminal care is being considered for a baby for whom the prognosis is hopeless, involvement of the parents in the decision-making process is essential and may assist them in their subsequent grief process.[13] Although some are opposed to this view,[14] we and others[5] believe that it is vital for parents to have a complete understanding of the problem and prognosis, and that paternalism be avoided.

Sudden infant death syndrome (SIDS)

Unlike perinatal loss, SIDS nearly always occurs at home, with no warning and no opportunity for the parents to prepare themselves. Thus, they may feel totally responsible for the infant's death. Usually there is no convincing reason for the death, and there is often a coroner's inquiry. No matter how carefully handled, SIDS inevitably results in extreme shock, guilt and bewilderment. The mother's confidence in her mothering ability is often shattered; the father may doubt it too. The despair accompanying these feelings may lead to a major breakdown of the family, since the family members may at times be less than supportive of the grieving couple, resurrecting their own feelings of unresolved guilt relating not to the loss of the child but to the loss of another loved one.[15]

Management of perinatal loss

Until recently bereavement and bereavement counselling was a relatively neglected aspect of medical education. Students generally learned little of the grief process during their training. Most texts that discuss the role of physicians in the management of perinatal loss point to two major weaknesses to which we are vulnerable: the professional self-image of "one who cures" and a common tendency to paternalism.[8,16,17] These features, when combined, may result in major deficiencies in our ability to help bereaved parents, especially if we have not come to terms with our own inevitable mortality. Counselling parents who have experienced perinatal loss is thus "not for all". As Kowalski[8] pointed out, "young professionals are often expected to work with obstetric losses with no help and no role models". Furthermore, as Peppers and Knapp[17] noted, the role model many physicians follow is based upon that quality Osler[18] regarded most highly — imperturbability. Unfortunately, this quality is often interpreted as professional aloofness, an attitude that is unlikely to assist grieving parents.

Parents facing perinatal loss require an honest but compassionate discussion of what can be expected. Anticipatory grief is common among parents of infants born prematurely and therefore needs to be recognized. In the event of stillbirth as well as neonatal death the couple should be given the opportunity to both see and hold their infant. Even though there may be major malformations, the fear of the unknown and the imagined is often much worse than the reality and is usually dissipated when the normal features of the infant are demonstrated. Parents often need support when they wish to see their baby. One should remove as many tubes as possible and clothe and wrap the baby in a cotton blanket so that the abnormal features are covered. The parents can remove the blanket if they wish. If possible, discussion should involve both parents so that they may have the same understanding. Technical terms should be avoided.

Even if the parents do not wish to see their baby at the time of death, most of them will want to have a photograph of the baby later. Therefore, pictures of the suitably wrapped baby should be taken and filed with the chart for this purpose.

If possible, a "quiet room" should be available close to the neonatal intensive care unit for discussions with parents of critically sick neonates and for families to be with their babies at the time of death. The extract at the beginning of our article is taken from a letter from a mother whose infant died of thanatophoric dwarfism following the discontinuation of assisted ventilation. It eloquently expresses the positive aspects of encouraging parents to be with their infant at the time of death. For many parents who have to live with the pain and helplessness of seeing their infant suffer, this period of quiet with their baby before death may be the first and only real opportunity that they have to offer comfort to the baby.

The physicians, nurses and social workers who form the health care team are not the only sources of assistance for the grieving couple. The clergy, bereavement counsellors and parent support groups may also be of great help. The importance of baptism to parents who want it for their baby must not be overlooked. In our modern multicultural society, it is also important to appreciate differences in beliefs and hence in attitudes and reactions to perinatal death.

For parents experiencing perinatal loss it is useful to have a booklet available that describes the grief process, autopsy procedures and funeral arrangements, and gives a list of perinatal loss support groups.

The physician's role

The physician's role during the early phases of grief is one of a sympathetic listener and a compassionate informant. Parents need to know the causes of their baby's death and often require immediate and strong reassurance to relieve their guilt. It is appropriate both to sympathize and to express one's own sadness at their loss.

Anger and frustration may be expressed very early and be directed against those who have cared for the infant. Its cause must be recognized and willingly discussed — parents need sympathetic, not affronted, professionals at this time. A friendly gesture, such as putting an arm around the father's shoulder or holding both parents' hands, may be beneficial to their great need. The shedding of tears by the physician or nurse caring for the baby may cause embarrassment, but it is not a sign of a lack of professionalism. To the parents it may signify the level of concern and compassion for them in their loss.

It is essential to realize that little will be remembered of the first conversation after the death of the baby. Hence, it is inappropriate to attempt to enter into a long discussion at this time. The parents are in a state of shock and grief. Such statements as "Try to get over it" or "You are young enough to have another" are both thoughtless and inappropriate. At this time the parents' desperate need is for the child they have lost.

Follow-up

Parental dissatisfaction with the amount of information and support they receive following perinatal death is common.[16] The first follow-up appointment should therefore be as soon as the gross autopsy results are available. This interview permits careful discussion of the causes of death and will provide an opportunity to reassure the parents of the lack of preventable factors and the inevitability of their baby's death. It is important to again confirm the lack of foundation for their feelings of guilt. At this time it may be wise to briefly introduce the parents to the normal process of grief. It is helpful to indicate to them that others, even close friends and relatives, may not appreciate the depth of their attachment to their baby and hence may not appreciate the intensity of their suffering. They should also be warned that they will go on grieving long after others will expect them to have recovered. At this stage the advice to have another baby is not only thoughtless but also wrong. There is good evidence that another pregnancy should not begin for at least 6 months after a perinatal loss. Pregnancies beginning sooner commonly result in birth before the grief is resolved, and a morbid grief reaction may result.[16] Morbid grief reactions have several causes and are usually not aided by consolation. Indeed, they are an indication for referral for psychiatric evaluation and therapy.[19]

It is a sad reflection upon physicians' ability to care for parents experiencing perinatal death that none of the 26 mothers seen following perinatal loss by Rowe and colleagues[16] mentioned their doctors as a source of emotional support.

The number of meetings with a family following perinatal death will to some extent be affected by time constraints. Kennell and associates[3] recommended three meetings — one at the time of death, one 2 or 3 days later and one 3 to 6 months later. Others have recommended four to eight interviews, pointing out that follow-up interviews are particularly important during the phase of depression, when parents will often be prone to assign blame as they readjust their own values.[20] These later interviews may reveal evidence of pathologic or morbid grief, such as inappropriate hostility or cheerfulness, exacerbation of pre-existing psychosomatic disorders or continuing isolation.[21] The physician's role during these interviews is mainly one of an informed listener, helping parents to appropriately interpret their thoughts, sadness, guilt or anger in terms of the grief process. Parents will often respond to the question "How are you?" with "Fine". Therefore, leading questions may be necessary to initiate a conversation, such as "How are you feeling now?", "How are you sleeping?", "Tell me more about your feelings (or memories etc.)" and "How are the children reacting?"

Although many visits are undoubtedly ideal, they may not be practical for parents who live far from a neonatal unit. Moreover, the staff of a busy newborn unit may simply not have the necessary time for such repeated visits. Under these circumstances just one telephone call during the 3 weeks following the perinatal death has been shown to help parents with their many questions and to prevent problems that otherwise might have developed over the next few months.[22]

Siblings

Siblings of a baby who dies will

also undergo grief reactions. They too will have been involved in the joyous anticipation surrounding the arrival of a new family member and, if they are young, will have difficulty comprehending the "nonarrival". Jealousy may be coupled with the anticipation. For the young child the absence of the mother or repeated visits by the parents to an ailing newborn may lead to resentment of the new baby. The baby's subsequent death may therefore lead the sibling to believe he or she has caused the death and hence may result in severe behavioural disturbances. It is thus essential that siblings understand in simple terms what has happened to their brother or sister. Visits by the siblings to the infant during life will help minimize their difficulties in understanding. As with the parents, the siblings must be able to relate to the infant — for example, by name. Parents may avoid expressing their emotions in front of the children in the belief that it will minimize their psychologic trauma. However, it should be explained to the parents that this is erroneous no matter how well-meaning. The lack of sharing in their parents' sadness over their loss may cause siblings to feel distinctly insecure about their parents' love for them.

Bereavement counsellors and perinatal support groups

Doctors can provide only part of the support families need to adapt to the perinatal loss of an infant. Sensitive understanding from nursing staff, especially those who cared for the mother and her baby, may be enormously beneficial, and social workers will be able to assist not only with emotional support but also with many practical concerns. Moreover, support from those with special training in bereavement counselling or from other parents who have experienced and recovered from perinatal loss is extremely helpful.[23] It is therefore very beneficial to develop a perinatal loss support group in association with the perinatal care unit.

Several books are available that will help parents understand the grief process and adapt to the perinatal loss of an infant (see our list of additional reading material). Of particular benefit to health care professionals are the films "Death of a Newborn", "Discussions with Parents of a Malformed Baby" and "Discussions with Parents of Premature Infants", available from the health sciences communications center, Case Western Reserve University, 2119 Abingdon Rd., Cleveland, OH 44106, USA.

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