

The prevention of psychological morbidity following perinatal death

LOUISE HAMMERSLEY

CHRIS DRINKWATER

SUMMARY

In recent years, a significant volume of hospital-based literature has been produced about the management of women and their families after a perinatal death. There has also been a considerable amount of work in the voluntary sector which has recognized this as an area of unmet need. The introduction of regional neonatal intensive care units and the shift from secondary to primary care make the development of a structured community-based approach for this group of vulnerable patients increasingly important. This article documents the evidence for high levels of psychological morbidity following perinatal death, reviews a variety of interventions designed to reduce morbidity, and makes some tentative proposals about the key elements of an effective community-based support programme.

Keywords: psychological morbidity, perinatal death, prevention.

Introduction

PERINATAL mortality declined from over 50 people per 1000 population in 1940 to 8.8 people per 1000 population in 1994.¹ For a general practitioner (GP) with an average list of 1700 patients, a perinatal death is now an uncommon event, occurring approximately once every 4 years. The rarity of the event sometimes means that its significance is not always appreciated and that appropriate management skills are not always mobilized. Bereavement in other contexts has a well-developed literature,² and many of the lessons of this literature have been incorporated into everyday practice;³ it is now important to achieve the same level of practice for perinatal bereavement.

Kennell *et al*⁴ were among the first to recognize the classic symptoms of grief following perinatal death; their findings have since been confirmed by many others.⁵⁻¹⁰ However, bereavement through perinatal death differs from 'conventional' bereavement because of the unusual attributes of the lost subject and socio-cultural attitudes surrounding pregnancy and its perceived 'failure'. Ultimately, it is the personal significance of the loss — not the gestational age of the baby — that determines the extent of the parents' grief. Most parents will pass through the phases known to characterize grief; while sympathy and minor intervention might be appropriate, well-supported individuals should not develop long-term or serious sequelae. However, pathological bereavement reactions become all-consuming for some people, and major medical intervention is required to address the situation. Identifying those most at risk and the level of intervention required is not easy.

At present, the voluntary sector and secondary care are taking the lead in stimulating service development in this area.¹¹ The

Cumberledge recommendations¹² for regional intensive care units for neonates in combination with moves to provide services closer to patients will make secondary care outreach an increasingly problematic option. Therefore, it is timely to review the evidence from the literature and to explore how this might be used to develop community-based comprehensive management policies and programmes for this vulnerable group of people.

Pathological grief reactions

The actual amount of psychiatric morbidity following perinatal death remains controversial. Rates of morbidity varying from 13% to 34% have been observed in groups of mothers suffering perinatal bereavement.¹³⁻¹⁶ Whatever the precise scale of the problem, the typical manifestations of pathological grief have been well documented, but, as well as the effects on the mother, the effects on the mother's existing partner and children also need to be considered.

Effects on the mother

Failure to display grief in the first two weeks is unusual and can signify a repression of reality,¹⁷ and later problems are common.¹⁸ Manifestations include phobias (especially agoraphobia), compulsive disorders (especially house cleaning), somatoform disorders (particularly involving the genitourinary system), and psychosexual dysfunctions.¹⁷ Immediate puerperal psychosis is uncommon,⁴ but breakdown and depression may be precipitated by anniversaries, next pregnancy, divorce, the menopause, or other significant losses.¹⁹ In the longer term, what constitutes a normal period for adjustment in bereavement is controversial; many authorities quote two years for resolution, but earlier persistence of very intrusive symptoms, such as phobic avoidance of pregnant women, may be considered pathological.

Effects on marital relationships

Benfield *et al*⁸ reported that one-third of marriages have difficulties after a neonatal death. Incongruent mourning between mothers and fathers can create particular strain.^{9,20-22} Mothers report significantly more crying episodes and depression, while fathers often immerse themselves in work and avoid expressions of feeling in order to be strong for the mother. Fathers are more likely to make funeral arrangements, which may accelerate the affirmation of death and subsequent grieving.^{8,21,23}

Effects on other children

Over-anxiety about and over-protection of surviving children are obvious risks,¹⁸ but child abuse has also been documented.²⁴ One of the surviving children may be used as a scapegoat, preserving family peace by accepting the guilt felt by the whole family.²⁵ There is a particular problem with the treatment of a surviving child from twins; the survivor may experience nameless guilt and a life-long sense of impossible destinies to fulfill.^{18,20} The next child, when conceived before grief is resolved, can be seen as a replacement child; replacing the lost child with another allows parents partially to deny the death, prematurely arresting the mourning process but acting as a continuing vehicle for parental grief. Idealization of the dead child is common and the role of

L Hammersley, MBBS; C Drinkwater, BA, FRCGP, Department of Primary Health Care, Medical School, Newcastle upon Tyne.
Submitted: 20 September 1996; accepted 4 February 1997.

© *British Journal of General Practice* 1997, **47**, 583-586.

the replacement child is a peculiarly defeating one;²² if of a different sex, gender distortion pressures may build up, possibly leading to personality disorders in adult life.

Aetiology of pathological grief

A mixture of psychological and social factors related to individual circumstances can be implicated in pathological grief. Common problems are feelings of guilt and inferiority, which can result in lowered self-esteem.^{14,19,26,27} This is particularly likely to be an issue where there are high expectations of the pregnancy in terms of individual fulfilment or changed circumstances.^{27,28} Equally, if there was a high degree of ambivalence to the pregnancy, this may result in the fulfilment of a forbidden wish, causing guilt and emotional conflict.

These responses may then be compounded if the delivery or memory of the delivery is distressing, particularly if there is an association with insensitive comments or actions. In this context, false optimism and empty reassurance may be particularly problematic, as it may either give rise to a heightened sense of the unreality which devalues the child and dismisses the experience of the mother, or to concerns about staff conspiracies to conceal possible negligence with resulting anger and recourse to litigation.²⁶ Both of these responses will impede grieving, and are more likely to happen if the opportunity to view the baby after birth is not provided.

Internalized anger may result in self-accusation for real or imagined failures or offences (e.g. drugs, nicotine, or alcohol) during pregnancy. This will tend to delay the resolution of grief. Other factors that may have a similar effect include unresolved losses reactivated by this death, other significant losses such as another bereavement, and the adoption of the role of the 'strong' one which may be imposed by the self or the family.

A powerful factor mitigating against pathological reactions is the extent to which the interpersonal network recognizes the emotional significance of the loss and empathizes with — and therefore validates — the reactions of the bereaved parents. There is often a wall of silence based on the assumption that the parents would wish to be alone; this can be misinterpreted as proof of unworthiness.²⁹ Parents are left feeling abandoned: stigma and shame lead to social withdrawal and the suppression of grieving.^{8,9,20,22} If professional support is also withdrawn at this point, anxiety and insecurity can reach a peak.³⁰

Management strategies to reduce psychological morbidity

In response to adverse experiences suffered by parents, a range of practical approaches aimed at reducing psychological morbidity have been devised by perinatal units and the voluntary sector. Taken in chronological sequence, the areas covered by this approach include the provision of honest and comprehensible information from the first suspicion of problems, emotional support rather than sedation at birth, and the involvement of parents in the care of the dying infant. Immediately following the death, the most important task is to facilitate affirmation of the child's existence and the reality of its death.^{7,8,27,30} Lewis advocated this to 'make history, to make memories that can be thought about and talked about, which fill the emptiness that impedes the mourning.'³¹ Parents should see, touch and name their baby, thereby conveying personality and familial characteristics, defining a time and space for the infant in the life-cycle of the family.¹⁹ Photographs, hair, hand and footprints all act as reminders to diminish fear and avoidance, the cornerstones of pathological grief. An autopsy can be medically helpful in determining the

cause of death and recurrence risk; it can also be psychologically helpful as the presence of normal anatomy can be reassuring.

Health care professionals can also discuss the normal manifestations of grief with parents, as this may be their first experience of death. Full funerals should be encouraged as funeral rituals can be powerful facilitators of griefwork. Siblings and grandparents are often forgotten mourners. Parents often want to protect their other children,³² but children can develop fantasies regarding separation and death, guilt for bad thoughts, and anger at depressed parents which can affect behaviour and later life adjustments.³³ Parents can also begin to recover self-esteem through helping surviving children. Bereavement counselling must be available throughout this process.^{33,34,35}

Subsequent pregnancies can be difficult. Forest *et al*²² found that a high number of women who became pregnant within six months of a loss had negative feelings towards their infant, and a period of a year is now often advised before trying to become pregnant again.³⁶ Throughout the new pregnancy, health carers must be aware of the past history, providing support and encouragement. Discussing how this baby may not mitigate feelings of loss and how it could provoke memories of the previous baby can allow preparation for such events.^{37,38} After delivery of a healthy baby, many parents need reassurance regarding both the infant's chances of survival and their parenting skills.³⁸

The primary care response

At the time of bereavement, the patient will probably be in a specialist centre. It has traditionally been the remit of these units to provide both immediate support, often including counselling and follow-up to discuss the results of the autopsy. If primary care is to provide good continuing care, it is essential that effective processes exist for sharing this information. Lack of this information will undermine the ability of the primary care team, both to establish a supportive framework for all individuals at risk, and to specify the methods and criteria for identifying those at high risk who require more intensive intervention.

Supportive framework

The evidence from other work presented in this paper shows that a structured pro-active approach is beneficial. This should involve identification of a key worker who is both appropriate and acceptable to the patient. It does not necessarily have to be a doctor and could equally well be a midwife or a health visitor. However, it is important that this individual is identified in the medical records and that the key worker communicates where necessary with other members of the team. The key worker would be responsible for an early visit — within the first week — to offer sympathy and support. This would then be followed by a second visit at 2–4 weeks to ensure that the findings and implications of the post-mortem results have been understood. At this second visit, a simple information pack with details and contact numbers for local voluntary groups would also be provided. A further visit at 6–8 weeks would include the postnatal visit which allows a natural opportunity to summarize, to assess emotional progress, and, through a discussion of contraception, to explore possible problems in marital or sexual relationships. This is also the point at which the key worker, in association with other members of the team, would try and identify those at high risk.

Identification of those at high risk

Factors that increase the risk of adverse outcome can be divided into those associated with previous experience and those associated with the current circumstances of the mother.

Previous experience. Previous stillbirths or multiple miscarriages can be perceived as confirmation of failure in the roles of reproduction or even femininity. Other types of unresolved bereavements can result in feelings being reactivated by the current loss. Difficulties in coping with existing children and excessive anxiety about the demands of motherhood can precipitate feelings of failure. A history of prior problematic personal circumstances will predispose a bereaved mother towards psychological morbidity; obsessional personality traits, physical disabilities, or perceptions of the mother's own mother as inadequate can focus on failures in the 'skills' of child-bearing in different ways. Problems can also arise from the displacement of anger and grief; for example, when it is towards medical staff. Avoidance and suppression of grief can follow a family-induced or self-induced perception of being strong enough to cope in all circumstances. A stillbirth following interruption of a successful career can be viewed as being 'cheated', especially if there was ambivalence towards the pregnancy.

Current circumstances. A wealth of marital, family, and other social understanding and support is likely to assist in successful resolution of psychological problems, whereas lack of such support can result in feelings of isolation and unworthiness. Similarly, in adolescence, the bereaved mother may not have yet developed a mature coping strategy. Clearly, antipathy from family members will confirm feelings of failure and guilt, hold back the grieving process, and increase the propensity towards morbidity. Concurrent other bereavements may exert too great a pressure with cumulative effects, while unexpected stillbirth following a normal pregnancy takes away the chance of preparatory grief.

The advantage of the above list of factors is that it allows a therapeutic exploration of some of the issues. It can also be used to set the level of further follow-up, and to decide whether or not more specialized or intensive intervention is required.

Specialist intervention and further follow-up

The most common specialist intervention is likely to be referral for psychiatric or psychotherapeutic support, if there is clear evidence of a pathological reaction or if the individual is thought to be at high risk of psychological decompensation. A possible advantage of a structured proactive approach is that decompensation may be prevented by early supportive interventions that encourage expressions of grief, facilitate and acknowledge feelings of guilt and anger, and enhance social support. There is also a potential added benefit for patients and their families through the primary health care team being identified as a source of help and support.

There are at least two other occasions where it is likely that continuing care will be important: around anniversaries of the death and when subsequent pregnancies are planned or undertaken.^{37,38} The offer of an appointment at the time of the anniversary will facilitate the expression of sadness and acknowledgement of the loss. Involvement in the original experience of the shared loss will also enhance the quality of the care provided when individuals have to cope with the complexity of fears, anxieties and emotions that accompany a subsequent pregnancy.³⁷

Conclusions

Although perinatal death and stillbirth is an infrequent experience, there is a need for the GP to be aware of the demands of the situation. The prevention of long-term psychological morbidity requires a management process involving the transfer of care

from the hospital to the community, where a structured proactive approach is required which takes advantage of the skills and resources available within primary care and the voluntary sector. This review suggests that the process should have four key components:

- Effective shared care between the specialist unit caring for the patient at the time of bereavement and the primary care team which has continuing responsibility
- The establishment of a supportive framework of carers, coordinated by a key worker
- A structured process, which might include check lists, for identifying those at high risk through the recognition of predisposing factors, and
- An agreed follow-up schedule with intervention, where necessary, to address problems.

Because it is fortunately rare, one of the best ways of improving care for bereaved parents and their families may be for practice teams to examine the management of individuals following perinatal deaths by using case discussion as a mechanism of significant event auditing.³⁹ This process would help practices to establish their own protocols in the light of the available evidence about psychological needs following perinatal death.

References

1. Department of Health. *On the state of the public health 1994. The annual report of the Chief Medical Officer of the Department of Health for the year 1994.* London: HMSO, 1995.
2. Parkes CM. *Bereavement. Studies of grief in adult life.* Harmondsworth: Penguin Books, 1986.
3. Charlton R, Dolman E. Bereavement: a protocol for primary care. *Br J Gen Pract* 1995; **45**: 427-430.
4. Kennell JH, Slyter H, Klaus MH. The mourning response of parents to the death of a newborn. *N Eng J Med* 1970; **283**: 344-349.
5. Wolff J, Nelson P, Schiller P. The emotional reaction to a stillbirth. *Am J Obstet Gynecol* 1970; **108**: 73-76.
6. Giles PFH. Reactions of women to perinatal death. *Aust NZ Obstet Gynaecol* 1970; **10**: 207-210.
7. Lewis E. Mourning by the family after stillbirth or neonatal death. *Archives of Disease in Childhood* 1979; **54**: 303-306.
8. Benfield DG, Leib SA, Vollman JH. Grief responses of parents to neonatal death and parents' participation in deciding care. *Pediatrics* 1978; **62**: 171-177.
9. Clyman RI, Green C, Rowe J, *et al.* Issues concerning parents after the death of their newborn. *Crit Care Med* 1980; **8**: 215-218.
10. Peppers LG, Knapp RJ. Maternal reactions to involuntary fetal/infant death. *Psychiatry* 1980; **43**: 155-159.
11. Stillbirth and Neonatal Death Society (SANDS). *Stillbirth and neonatal death — guidelines for professionals.* London: Stillbirth and Neonatal Death Society, 1991.
12. Cumberledge J (chair). *Report of the Nursing Review Committee. Neighbourhood nursing: a focus for care.* London: DHSS, HMSO, 1986.
13. Kirkley-Best E, Kellner KR. The forgotten grief — a review of the psychology of stillbirth. *Am J Ortho-Psychiatry* 1982; **52**: 420-429.
14. Clarke M, Williams AJ. Depression in women after perinatal death. *Lancet* 1979; **i**: 915-917.
15. Cullberg J. Mental reactions of women to perinatal death. In: Morris N (ed.). *Proceedings of the Third International Conference of Psychosomatic Medicine, Obstetrics and Gynaecology.* London: Karger, Basel, 1972.
16. Nichol HT, Tompkins JR, Campbell NA, Syme GJ. Maternal grieving response after perinatal death. *Med J Aust* 1986; **144**: 287-289.
17. Condon JT. Management of established pathological grief reaction after stillbirth. *Am J Psychiatry* 1986; **143**: 987-992.
18. Bourne S. Psychological impact of stillbirth. *The Practitioner* 1983; **277**: 53-60.
19. Krone C, Harris CC. The importance of infant gender and family resemblance within parents' perinatal process — establishing parenthood. *J Perinat Neonat Nurs* 1988; **2**: 1-11.
20. Wilson AL, Fenton LJ, Stevens DC, Soole DJ. The death of a newborn twin — an analysis of parental bereavement. *Pediatrics* 1982; **70**: 587-591.

21. Henke JA, McCleod RF. Perinatal grief and mourning. *Advanced Paediatrics* 1990; **37**: 261-283.
22. Forrest GC, Standish E, Baum JD. Support after perinatal death — a study of support and counselling after perinatal bereavement. *BMJ* 1982; **285**: 1474-1479.
23. Cordell A, Thomas N. Fathers and grieving — coping with infant death. *J Perinatol* 1990; **10**: 75-80.
24. Lewis E. Untitled. *Int J Child Abuse* 1979; **3**: 327.
25. Tooley K. The choice of a surviving sibling as a 'scapegoat' in some cases of maternal bereavement. *J Child Psychol Psychiat* 1975; **16**: 331-339.
26. Lovell A. A question of identity — late miscarriage, stillbirth and perinatal loss. *Soc Sci Med* 1983; **17**: 755-761.
27. Lewis E, Bourne S. Perinatal death. *Baillière's Clinical Obstetrics and Gynaecology* 1989; **13**: 935-953.
28. Hoffman L, Morris J. The value of children. In: Carthage F (ed). *Family relationships*. Beverley Hills: Sage, 1982.
29. Stierman ED. Emotional aspects of perinatal death. *Clinical Obstetrics and Gynaecology* 1987; **30**: 352-362.
30. Helmrath RA, Steinitz EH. Death of an infant — parental grieving and failures of social support. *J Fam Pract* 1978; **6**: 785-790.
31. Lewis E. The management of stillbirth — coping with an unreality. *Lancet* 1976; **ii**: 619-620.
32. Weiss L, Fischer L, Richman J. Parental adjustment to intrapartum and delivery room loss — the role of a hospital-based support program. *Clinics in Perinatology* 1989; **16**: 1009-1019.
33. Bibring G. Some considerations of the psychological processes in pregnancy. *Psychoanal Study Child* 1989; **14**: 113-121.
34. Murray J, Callan VJ. Predicting adjustments to perinatal death. *Br J Med Psychol* 1988; **61**: 237-244.
35. Hodge DS, Graham PL. A hospital based neonatal intensive care unit bereavement follow-up program — an evaluation of its effectiveness. *J Perinatol* 1988; **8**: 247-252.
36. Row J, Clyman R, Green C, *et al*. Follow-up of families who experienced a perinatal death. *Pediatrics* 1978; **62**: 166-170.
37. Wilson AL, Soule DJ, Fenton LJ. The next baby — parents' responses to perinatal experiences subsequent to a stillbirth. *J Perinatol* 1988; **8**: 188-192.
38. Bourne S, Lewis E. Pregnancy after stillbirth or neonatal death — psychological risk and management. *Lancet* 1984; **ii**: 31-33.
39. Robinson LA, Stacy R, Spencer JA, Bhopal RS. Use facilitated case discussions for significant event auditing. *BMJ* 1995; **311**: 315-318.

Address for correspondence

Dr Chris Drinkwater, Department of Primary Health Care, Medical School, Framlington Place, Newcastle upon Tyne NE2 4HH.