MEDICAL PRACTICE

*Contemporary Themes***Handling of death in special care nurseries and parental grief**

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Abstract

The handling of death in a special care nursery and the needs of bereaved parents were studied in 12 families. Communication was good before death but less satisfactory thereafter, particularly with regard to post-mortem results and advice concerning recurrence risk. Parents needed a lasting memory of their child and attached great importance to a tangible memento. Half had an abnormally high grief and Leeds scale score six months after the death, which seemed to be associated with poor marital support. All in the high scoring group favoured bereavement counselling. Communication with general practitioners needed improvement. As a result of this study a protocol for the handling of death was designed.

Introduction

The death of a child is now an uncommon event but the newborn period remains the most dangerous, and death at that time tends to occur in a hospital intensive care unit. In such an environment parents may feel bewildered and experience a sense of helplessness, faced with their inability to do anything practical to help their child. Often they are unable to hold their baby. If such a baby dies these factors might impede the establishment of normal grieving and make pathological grief more likely.

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In a study of 40 bereaved women Giles¹ found the emotional and physical reactions to be similar to the classical descriptions of grief,²⁻⁵ which include somatic distress, preoccupation with image of the deceased, guilt, hostility, inability to work, and depression. Every mother mourns even if her baby was non-viable and lived for a very short time.⁶⁻⁷ Pathological grief may develop.⁴⁻⁸ In Culberg's study 19 out of 56 mothers showed psychiatric disorders one to two years after their baby's death.⁹

To establish normal grieving the bereaved must accept the reality of the person who has died. To do this bereaved parents should be encouraged to see and hold their dead baby, receive mementos, and hold a proper funeral.¹⁰⁻¹² Opportunity for discussion with medical staff and, when indicated, genetic counselling should be available. Early communication with general practitioners should ensure community support. Bereavement counselling in the home by a trained professional who encourages the expression of grief, reassures on the normality of these feelings, and provides a sympathetic ear might be helpful, particularly when family support is deficient.¹³⁻¹⁴

We decided to see whether we were achieving these objectives and if they accorded with parents' wishes. We also asked parents to complete the Leeds scales,¹⁵ which assess anxiety and depression.

Patients

There were 18 deaths (including one set of twins), and 12 of the 17 families agreed to the study. One of the mothers was separated and one single; seven were in social class V. Two mothers had experienced a previous miscarriage but none a neonatal death or stillbirth. Table I gives the details of the babies.

Results

Parents were interviewed two to 13 months (mean 6.3) after the death of their baby.

TABLE I—Details of babies who died whose families agreed to the study

No of boys	..	..	..	..	8
No of girls	..	..	..	..	4
Birth weight (mean)	..	..	..	..	670-4300 g (1680 g)
Gestation (mean)	..	..	..	..	25-41 weeks (32 weeks)
Survival time (mean)	..	..	..	..	1.5 hours to 7.5 months (7.6 weeks)
No with:					
Congenital abnormalities	..	..	..	..	5
Extreme prematurity	..	..	..	..	4
Necrotising enterocolitis	..	..	..	..	1
Bronchopulmonary dysplasia	..	..	..	..	1
Birth asphyxia	..	..	..	..	1

HANDLING

Ten of the families were satisfied with the general handling of the death in the nursery. The two who were dissatisfied complained of poor communication. All parents saw their baby before death, but in three cases of congenital abnormality the obstetric staff's description frightened the mothers and made them reluctant to look. Ten parents had been invited to touch their live baby, and seven accepted. Eleven parents wanted to participate more in the care of their baby—"anything to make me part of it."

After the death 10 parents were invited to touch or hold their baby. Only four accepted. One parent "wanted to remember her alive as she was at the baptism."

MEMENTOS AND FUNERAL

Five families were offered and accepted a memento (nameband, clothing, etc), two took something secretly, and three regretted not having a memento. Two babies were buried in unmarked graves.

COMMUNICATION WITH PARENTS

All parents thought that the prognosis was adequately given, but one mother complained of insufficient information. After the death communication was less satisfactory and described as good in two thirds. Consent for necropsy was given in 10 cases, but only four mothers had received the result at the time of interview. All had wanted the result—"once I knew the postmortem result I stopped blaming myself."

RECURRENCE RISK

Eight families received some advice about the risk of recurrence. This was provided haphazardly—for example, of the four families whose child had died of extreme prematurity, only two had been counselled by an obstetrician. Of the parents of the five infants with congenital malformations, two were given adequate counselling, one had no discussion, and the others had a brief discussion at the time of death. In two of these cases the general practitioner had not received enough information to provide counselling himself.

Four of the mothers expressed anxiety about future pregnancies. A further two had undergone sterilisation.

SUPPORT

Support by a spouse or extended family was described as good in 10 cases. General practitioners made home visits to eight families, of whom five described these as helpful. Other professional visits were by health visitors to seven families (helpful in two), religious minister to five families (all helpful), and social workers to two families (both helpful). One mother was not visited by any member of the caring professions.

COUNSELLING

Ten families wanted to review the death with a paediatrician. Of these, nine thought that the optimum time for this one hospital visit was about five weeks after the death. Six families thought that

bereavement counselling in their homes would be beneficial. One father thought this more important for men because society did not allow them to grieve openly. Four other families thought counselling valuable for some parents but not necessary for themselves. Seven thought that a self help group would be useful, while six had obtained support from a similarly bereaved relative or friend. No parents were aware of self help groups—for example, compassionate friends.

GENERAL PRACTITIONERS

Notification of all 18 deaths was received by 17 general practitioners, 11 within 24 hours. Twelve general practitioners favoured hospital based bereavement counselling.

REFUSERS

Five of the 17 mothers refused to participate. There was no difference between time of death and request for interview. Table II gives the details of their babies. Three of the mothers were single, of whom one took heroin and one was pregnant again. Three received visits from a general practitioner and the remainder from health visitors.

TABLE II—Details of babies who died whose families refused the study

No of boys	..	..	..	..	3
No of girls	..	..	..	..	3*
Birth weight (mean)	..	..	..	..	800-3740 g (1860 g)
Gestation (mean)	..	..	..	..	25-41 weeks (30 weeks)
Survival time (mean)	..	..	..	..	7.5 hours to 17 days (5.9 days)
No with:					
Extreme prematurity and related complications	..	..	..	..	4
Birth asphyxia	..	..	..	..	2

*One set of twins.

SCORES

Scores of greater than 4 and 6 for the grief and Leeds scales (general), respectively, were considered significant. All mothers and 10 fathers completed the Leeds scales. Grief scores were obtained for all mothers and seven fathers. No significant difference between mean maternal and paternal scores was noticed. Scores did not appear to correlate with the length of the mourning period, high scores being obtained three to 13 months after the death.

Grief scores—Six mothers scored over 4 (range 0-8, mean 3.8); one father scored over 4 (range 0-13, mean 3.2).

Leeds scales—Six mothers scored over 6 (range 0-19, mean 7.5); five fathers scored over 6 (range 0-27, mean 6.7).

High scores

Six families scored 8 or more on the Leeds scales, of whom five also had high grief scores. All six mothers were married, one separated. Only two had good support from a spouse (one wife dead, one husband in prison, one severe marital problems). Four were in social class V. Three of the babies were under 28 weeks of gestation, weighed less than 1000 g, and lived less than 16 hours. There were two congenital malformations. One pregnancy was unwanted. In two cases the parents had never touched the baby. The four who gave consent for necropsy had not received the result, and all wanted one. One baby was buried in an unmarked grave, which contributed to the mother's distress. Three mothers were afraid of future pregnancies. Only these six high scoring families wanted bereavement counselling.

Three of these parents were visited twice to complete the questionnaire. One was taking antidepressants seven months after the death, one at 13 months remained very depressed, and the other at 16 months still required a hypnotic.

One set of parents scored zero in both assessments. Their baby was born at 25 weeks' gestation, required prolonged ventilation, and lived for 7.5 months. Major neurological handicap was apparent, and the parents visited rarely over the last two months.

Discussion

We were pleased to hear parents describe our care as "genuine" and "not cold," but once death occurred our communication and support were less satisfactory. Parents emphasised the importance of the postmortem examination in alleviating questioning and guilt, but only 40% had obtained the results. Two thirds received advice concerning recurrence risk but this was not always given by the most appropriate person. Whatever the cause of death parents were concerned to know if this was likely to recur in subsequent pregnancies.

It was vital for parents to have a lasting memory of their child as a real person. Touch was important, and the lack of this led to a sense of unreality. Only some parents wanted to hold their baby after death, others preferring to remember him alive. Parents attached great importance to a tangible memento. Most favoured participation in their baby's care. This too would provide a memory and lessen their sense of helplessness.

High Leeds and grief scores were obtained in half of the mothers. This appeared to be associated with poor marital support. Interestingly, the two parents who complained of poor communication were in this group, as were the two who had never touched their baby. Half of our patients with high scores were still having problems seven to 16 months after the death. Bereavement reactions are highly individual and the value of grief and self rating scores of health is unknown. We do not know how they correlate with the long term and more serious consequences of bereavement such as marital problems, mothering difficulties, and puerperal psychosis in subsequent pregnancies. A low grief score six months after the death might be a more serious prognostic sign than a high score. Hence it is hard to draw firm conclusions in a small study such as this. What we can say is that a group of patients exist who require extra help after the death of their baby. How do we identify this group? The socially isolated particularly within a marriage, seem more at risk—compared, for example, with the refusal group—but many factors are operating and not all are amenable to our intervention. We can improve our communication and offer bereavement counselling to all parents. We need also to improve the speed and quality of our communication with general practitioners.

PRACTICAL IMPLICATIONS

As a consequence of this study we have designed a protocol for the handling of death. We recognise that the needs of the bereaved are highly individual but we think that without a plan of action and a check list (see appendix) we may overlook details of special importance to some. This is particularly true in a busy nursery. The check list would be completed by the junior doctor certifying the death and any omissions rectified later by the hospital social worker, who will also offer and carry out bereavement counselling. Particularly at risk of oversight are babies dying shortly after birth, who may fall between obstetric and paediatric action. In these circumstances the obstetrician might be more appropriate to provide hospital follow up, as he is known to the parents and will be responsible for the management of future pregnancies.

We will never remove the sting of death, and this is not our aim, but we can try to handle death more appropriately. In all this there is no substitute for real compassion, and this cannot be taught.

APPENDIX

Check list to be completed on death of a baby

Tick boxes:	Mother	Father
Spoken to parents	☐ M	☐ F
Offered time to be with and hold baby	☐ M	☐ F
Offered memento	☐ M	☐ F
Consent for necropsy	☐ M	☐ F
Informed general practitioner by telephone	☐ M	☐ F
Informed obstetrician	☐ M	☐ F
Funeral advice	☐ M	☐ F
Grief reaction advice	☐ M	☐ F
Leaflets given	☐ M	☐ F
Bereavement counselling required	☐ M	☐ F
Follow up arranged	☐ Paediatric	☐ Obstetric

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Clinical curio: hiccuping and lacrimation with brain stem lesions

In more than 20 years of clinical practice I have observed that hiccuping and lacrimation in patients with primary or secondary damage to the brain stem indicate a poor prognosis unless there is a space occupying lesion that can be evacuated or hydrocephalus that allows treatment to be started immediately. Hiccuping sometimes appears in patients who are slightly lethargic; it may represent an early warning symptom and is often followed within a short time by rapid deterioration of the neurological state. In patients thought to

have an intracranial lesion a treatable cause should be found as soon as possible. Lacrimation in patients who do not otherwise respond to painful stimuli may be encountered in cases of primary or secondary lesions to the brain stem. It is usually seen within the terminal stages of illness, and a treatable cause can usually be found. I have not been able to find any previous reports of these phenomena and would be interested to hear of any.—ROY SELBY, neurosurgeon, La Crosse, Wisconsin.