battle on, doing less well than they had hoped in exams, attempting to stifle feelings of despair, depression and hopelessness.

Conflicting needs and suppressed grief

As a result of the immense pressures on people in their teens and early twenties, it is often impossible for them to grieve effectively at the time. There may simply not be enough emotional energy or strength to cope with everything. The struggle for many young adults is not only how to cope with the bereavement itself, but how to cope with it in the context of an unaccommodating world. Grief may often be suppressed or denied, not only because of the individual's lack of emotional resources to mourn effectively, but also because of the insensitive and uncaring environment in which young adults are expected to do their grieving.

Perhaps the hardest aspect of a parent's death for young people—and the one most consistently overlooked and misunderstood—is that death, mourning and grief involve feelings of helplessness and lack of control that are exceptionally hard to cope with at precisely the life stage when the individual needs and expects to feel powerful and in control. The bereaved young adult often simply does not possess the emotional resources necessary to handle the conflict between personal need and social expectation. This profound inner conflict frequently finds expression in self-destructive behaviour, such as eating disorders, sexual difficulties, and drug and alcohol abuse.

The expression of unresolved grief in behavioural problems of this kind is a frequent feature in the experiences of young bereaved adults. Less dramatic, but equally expressive of inner anguish, are difficulties with intimacy, surfacing in a tendency to adhere to destructive relationships, an inability to make close emotional bonds with another person, or acute anxiety surrounding the separation from or absence of a partner.

The way ahead

Making the passage from adolescence to adulthood is a slow, demanding and erratic process. So too is the journey through the months and years of grieving. To have to do both at the same time is a considerable undertaking that may require more psychological and emotional resources than the young person has available. Wider recognition of the particular needs of this age group and a greater emphasis on primary and secondary care could go a long way to alleviating this prolonged and unnecessary anguish.

There are a number of ways in which this could be achieved:

- research into the impact of parental death on adolescents
- targeted support of young people through schools and universities
- training of teachers in how to support bereaved pupils
- wider range of teaching aids for raising awareness of the issue in the classroom
- increasing the availability and range of literature on this kind of bereavement in bookshops and libraries
- wider availability and improved access to counselling services and support groups for bereaved young people.

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Parental Responses to Different Types of Infant Death

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The loss of a child through death may engender different feelings and responses from those evoked by the loss of an elderly relative. One possible explanation for this is that there has been a disruption in the normal 'pecking order' of death. This implies that grandparents are expected to die before parents, who should die before their own children. For parents who lose a young infant, such an event may threaten their perceived ability to have control over their own destiny, and those for whom they are responsible[1]. Also although infants die more commonly than older children, even in developed countries, nevertheless infant death is still a relatively rare event. Therefore, within their community, parents may not have been in contact with anyone who has lost a baby.

Another possible explanation for an intense bereavement reaction following infant death applies particularly to women. This reaction in women may be due, in part, to the normal hormonal changes which occur during pregnancy, delivery and in the first few months following birth. Postnatal depression is well recognised as a clinical syndrome during this time. In such cases, the loss of an infant superimposed on an existing depression may precipitate more profound psychological symptoms[2-4].



Back row: John Thearle, Bill Foster, Jake Najman
Front row: Gary Embelton, John Vance

For these reasons it has been suggested that parental responses to the death of a young baby may be more severe or prolonged. From a review of the literature, general trends can be identified[5-11]. The families in most of these studies have been interviewed months or years after the loss. This has the potential to create a recall bias in any evidence presented. In addition, the number of families interviewed was usually small and self-selected. No comparison of symptoms was made with symptoms from control families with live babies, which may be important with respect to postnatal depression. It is hard, therefore, to interpret the data so as to fully understand the grief process which occurs in these families relatively soon after the loss. Furthermore, the potential long-term (more than one year) effects of the loss have not been described.

We have had the opportunity to obtain information from a large sample of bereaved parents who had lost infants from stillbirth, neonatal death or Sudden Infant Death Syndrome. We were also able to compare them with control families, that is, families who had recently experienced the birth of a live baby. It was possible to obtain information over a two year period. All these families were prepared to discuss their feelings with the researchers.

For the purposes of this work, we used the following definitions for each category of loss. Stillbirth (a fetal death) is defined as one in which the baby shows no signs of life and is born after a period of 20 weeks gestation, or has a birth weight of at least 400 grams. Neonatal Death occurs when a child is born live but dies within 28 days of birth. Sudden Infant Death Syndrome (SIDS) is the sudden death of any infant (two weeks to two years of age), which is unexpected by history and in which a thorough postmortem examination fails to demonstrate an adequate cause of death[12]. The last two definitions imply some potential for overlap in the age distributions. In practice, this provides little difficulty. A baby dying in the first 28 days for which an explanation was available was classed as a neonatal death. A baby dying from SIDS at less than four weeks would have had an autopsy which showed no obvious cause.

AIMS AND STUDY DESIGN

The purpose of this research was to define more clearly some aspects of the natural history of the grieving process. Apart from the potential effect of the interviewing process (either positive or negative), no formal counselling was offered to these families by the interviewers. However, this did not mean that these families did not receive support. This was either initiated by families themselves or self-help support groups. We are thus interested in the mental health of bereaved parents in the context of the existing and somewhat 'ad hoc' counselling services which are normally provided.

In describing various aspects of the grieving process, we made assessments of psychological function (anxiety and depression), marital adjustment, membership of social networks, church attendance, alcohol and drug ingestion, subsequent fertility patterns and behaviour of surviving siblings.

Bereaved and control families were recruited over a 20-month period between 1985 and 1988. They were then interviewed four times over a two year period following the loss, or, in the case of control families, following the birth of their baby. We postulated that the emotional distress would be greater in parents who had lost children than in control families who had a live child (matched for age and sex) and that, over a two year period, the degree of emotional distress in parents would be related to the nature of the loss.

The study took place in the most populated part of the state of Queensland, Australia—its south-east corner. The names of all families who experienced stillbirth or neonatal death were supplied by hospitals included in the study and contact was made by telephone or letter. Families who had lost children from SIDS were initially approached by social workers from the State Department of Health and followed up by us. Control families were matched with bereaved families according to the following criteria—sex and birth date, hospital of birth and whether the family had private health insurance or not (a measure of socioeconomic status).

The questionnaires were designed so that they could be administered equally to bereaved or control families. Thus, standardised psychological instruments could be used to obtain information about these symptoms. The Delusions-Symptoms-States-Inventory (DSSI) scale of Foulds and Bedford was chosen to measure the mental state of the parents. It consists of two seven-point scales defining symptoms of anxiety and depression respectively[13-15]. Questions relating to anxiety were asked about excessive worry, somatic symptoms increased acute panic and difficulty with decisions. Those relating to depression included queries about sleeplessness, lack of self-worth, inactivity and intense hopelessness and suicidal thoughts. The response to each question was on a five-point scale—'always; most of the time; some of the time; rarely; never'. Responses to these items were codified and a score generated for each parent. Mean scores of the three different bereavement groups and the controls at each of the four interviews over the two years were then compared. Of course symptoms of anxiety and depression may represent only one consequence of bereavement. Nevertheless, the presence or absence of such symptoms are likely to be important indicators of the generation, intensity and resolution of the grieving process.

Here we seek to describe that aspect of the grieving process which is manifested by the psychological symptoms of anxiety and depression. During the study recruitment time of 20 months, there were 98 babies who died from SIDS, 160 from neonatal death and 157 from stillbirth. An estimated 45,800 babies were born during this period (27,500 per annum) in this geographical area. Families were interviewed in their own homes by experienced social workers. Each parent was asked to respond to the questionnaires separately. We approached all bereaved families in this area and about two-thirds of them agreed to participate. Of these, 52 were SIDS families, 109, neonatal death and 99, stillbirth. This participation rate compares favourably with other studies of families who have been bereaved[16].

It was found that those who participated were more likely to come from stable, middle class backgrounds. It is also known, from other population-based studies of psychological symptoms, that families with less stable relationships are more likely to exhibit psychological disturbance[17-20]. So we believe that the data obtained represent a conservative estimate of the frequency of emotional and psychological problems.

This sample is, to some extent, self-selected. However, in all other studies referred to above, recruitment was based on advertisement, those known to support groups, or clinical contact. The difference with this study is that the names of all who lost children were obtained and contact made with each one of them. The participating sample is therefore based on a known population.

Of those families who initially agreed to participate, 77 per cent were seen two years later for a

fourth interview. The pattern of participation over the four interviews was similar for all three bereavement groups and the controls. Although individual matching was achieved between each bereaved family and its control, examination of group data only is reported here. Furthermore, although each bereaved group was able to be compared individually with a control group, no differences were noted for each of these three control groups. Hence, for the purpose of analysis, the control groups have been considered as a whole.

Biographical data from the participating groups—stillbirth, neonatal death, SIDS and controls—were similar except that statistical comparison showed that the mothers in the SIDS group were significantly younger. This is recognised as part of the known epidemiology of SIDS. Also, control mothers were more likely to be at home than in the work force. This is to be expected as mothers who have lost a child are free to return to the workplace.

RESULTS

The results which follow have been presented in part elsewhere. In particular, a comprehensive analysis of the early responses, two months after the loss, has been published[21], and some of the work was presented at the Third International Conference on Grief and Bereavement in Contemporary Society in 1992[22].

The findings here are based on 512 families who initially participated at the two-month interview. Of these families, 252 were controls and 260 were bereaved (99 stillbirth, 109 neonatal death and 52 SIDS). By the fourth interview at 25 months, 397 families were still participating, (203 controls, 78 stillbirth, 80 neonatal death and 36 SIDS). The presentation takes the form of comparisons at two, six, 15 and 25 months, where the results of each bereaved group are contrasted with the control group. This is a longitudinal comparison of change for a single cohort of parents who have been interviewed on four occasions following the death of their child. Such analysis requires that the size of the cohort be the same for all four interview times. This is possible with the data obtained.

Anxiety

At the two month interview, comparison of mean anxiety scores for mothers and fathers was made between each of the bereaved groups and controls. Comparisons are also presented at each time measurement—crossectional comparison—and over time—longitudinal comparison. At the first interview, the bereaved parents showed significantly more symptoms of anxiety than did the controls. Parents who had lost infants from SIDS experienced more symptoms than those from stillbirth or neonatal death groups; all three were significantly different from controls[21].

When the mean anxiety scores of the bereaved groups and controls measured at each of the four interviews were compared, control mothers showed a lower level of anxiety which remained virtually constant over the two year period (figure 1). In all three bereaved groups, anxiety levels were high soon after the loss, at two months, and gradually approached those of controls over the two years. There was an apparent trend for mothers who lost infants from SIDS to have mean scores indicative of higher levels of anxiety than those who had experienced neonatal death or stillbirth, although the difference between the latter two groups is not statistically significant. Differences in mean scores between the cases and controls were significant at all four interviews.

The anxiety level for control fathers also remained similar over the two-year period (figure 2). For bereaved fathers, the trend was again toward a reduction in anxiety during the two years, with fathers of children who died from SIDS having more symptoms at the first interview than the other two groups. The differences between the bereaved fathers and controls were statistically significant at the two months, six months and 15 months interviews. Comparing the symptom levels for fathers with those of mothers, fathers had less symptoms at all four interviews[22].

Depression

The detailed evaluation performed at the two-month interview[21] showed that bereaved mothers were significantly more likely to be clinically depressed when compared with controls. The patterns of depressive symptoms, as demonstrated by mean scores for the second, third and fourth interviews for both mothers and fathers, were very similar to those obtained for anxiety and are comparable to those shown in figures 1 and 2.

Figure 1
MATERNAL ANXIETY

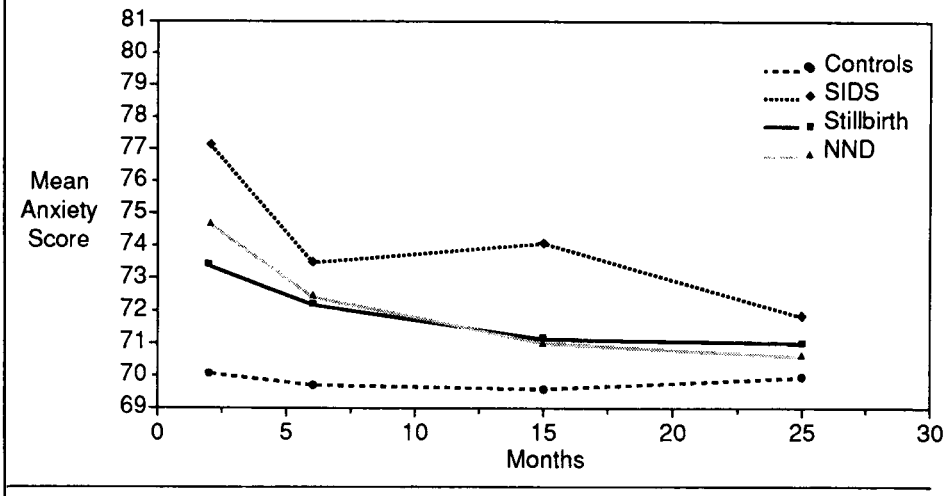
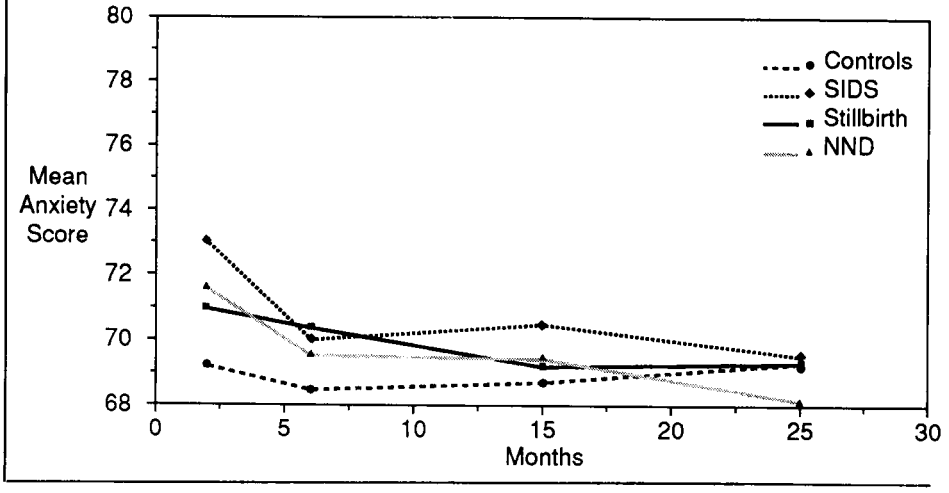


Figure 2
PATERNAL ANXIETY



CONCLUSIONS

The positive features of this investigation were that the samples were larger than in other similar studies, and attempts were made to recruit all who lost a baby[6-11]. Families with a surviving, live-born infant were used to control for many of the normal stresses present in all young families. Information was obtained prospectively to minimise recall bias and standardised questionnaires used to minimise anecdotal descriptions[13-15].

However, some inherent biases were still present. An initial participation rate of about two-thirds is of concern, but compares favourably with other similar studies[16-20]. Participation in the subsequent three interviews was achieved for 77 per cent of families. Those who continued were similar in initial demographic and psychological characteristics to those who dropped out, thus bias due to continued participation is unlikely. However, overall, participants were probably more representative of middle class families. Other population studies have demonstrated that non-participants have more psychological problems. Hence, our data are likely to represent a conservative estimate of what is happening in the population at large[23].

At this stage of our data analysis, no attempt has been made to determine possible differences in symptoms between those who received formal professional counselling and those who did not. Nevertheless, it is our impression that only a small minority received this. Others may have received informal support from families and support groups, but again the effect of this has yet to be analysed.

Further, it would be presumptuous to assume that, by describing changes in anxiety and depression in bereaved parents, we are describing the total grieving process. We believe we are describing only some components of this process. Other aspects, such as marital harmony, response to social support and the individual's own ability to cope with other life stresses, are all important. Although some of our results demonstrate statistically significant differences between affected families and controls, this does not necessarily imply that these families all had psychiatric illness. We have observed differences between mean scores for controls and affected families, and these may represent part of the natural history of the normal grieving process and not psychiatric pathology.

We can however say that families who lose infants show significant psychological symptoms when compared with control families, and that mothers have more symptoms than fathers. The mothers' symptoms persist for longer than the fathers'. For mothers who have lost children from SIDS, these differences persist for two years. These symptoms persist for 15 months for those mothers who have lost infants from neonatal death or stillbirth. Parents who have lost a child from SIDS have more severe symptoms than the other bereaved parents.

These findings highlight the large number of very distressed families which may be present in the community. For example, in Queensland at the time of the study, over 400 families were affected annually, out of an average birth rate of 40,000 infants. The distress can last for a long time following the loss. Although our data highlight the reaction to SIDS, it would be unfortunate if the situation with respect to stillbirth and neonatal death was ignored. These families also experience significant distress for a considerable length of time. The pattern shown by stillbirth and neonatal death families follows fairly closely that found in a small study of families who lost children from stillbirth or neonatal death where psychological symptoms disappeared by 12 months[24]. This occurred both in those families who were offered counselling and those which were not[24]. It is uncertain whether a similar pattern is found in other groups who are bereaved following other losses, such as spouses. Many studies have, however, described symptoms subsiding after about 12 months. For many stillbirths and nearly all neonatal deaths, a conclusive medical explanation for the loss is available. Such concrete knowledge may be vital in the appropriate resolution of grief.

Why families bereaved after SIDS respond differently is unclear. Factors such as type and nature of family support, presence of other children, subsequent pregnancy and religious practices may all be important. However, one attractive explanation relates to the unknown nature of SIDS and the usually devastating scenario which surrounds the death, with police involvement and the need for an autopsy. Such circumstances clearly heighten the possibility of guilt and its associated increased anxiety and depression and the 'loss of control' which these parents often describe[25].

The need for proper support for all these families is clear. This support may include contact with other family members, religious groups, professional counselling and parent support groups. Each of these may be important for different families and at different times. Some may need intensive therapy. The data presented here suggest that such assistance may be required for some considerable time—up to two years after the loss.

We have described the natural progression of some psychological symptoms in a large sample of bereaved parents. These data will improve our understanding of the grieving process in this group of families and help with the design and implementation of possible support for these families.

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