

Money matters and bereavement support



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Money plays a central role in everybody's life. However, the financial impact of a death in the family appears to have received little attention in literature and research on bereavement support. This recent study of the financial implications for parents of the death of their child shows that links between money and death represent an area of considerable importance for policy and practice. Some bereaved parents would have liked more help in thinking about money matters and dealing with financial problems.

The Social Policy Research Unit at the University of York, UK, was approached in 1999 by staff at a local children's hospice, which by then had experience of supporting 400 bereaved families. Staff said that for a variety of reasons some families faced significant financial problems after the death of their child. They believed financial problems might be widespread, and sometimes serious, with implications for the healing and adjustment process for the surviving families. Staff found it hard to know how to approach such aspects in the support service they offered and how much attention to pay to such issues in staff training.

An exploratory study was funded by the Joseph Rowntree Foundation to throw more light on these issues. A preliminary literature search found almost no previous research on this topic. There is a small literature on the cost of UK funerals¹ but little reference to children's funerals. There is a substantial and influential body of knowledge on the costs of caring for a

disabled child or a child with a life limiting illness^{2,3,4}, but most studies do not consider the time after a child's death.

THE STUDY

There were three elements to the empirical work:

- Interviews with parents in 17 families who had been in touch with the children's hospice and whose child had died during the previous two years. This group included both lone parents and two-parent families, and parents with different levels

EDITOR'S NOTE

Although this article focuses on the economic problems of parents who lost a child in the UK, many of the issues raised are relevant to other types of bereavement and countries. Because it is the emotional aspects of grief which have been the focus of most research, the influences of economic issues may have been underrated. Such issues take on added impact in poorer countries. CMP

and sources of income, living in different locations served by the hospice. The ages of the children who had died ranged from one to seventeen years.

- Individual interviews and group discussions with key staff in health and social services, and in the hospice. Included here were local authority social workers, staff in a regional child development centre and the paediatric oncology unit, and support workers in the hospice.

- A postal survey of all UK children's hospices, and a number of bereavement and support services for UK parents. This provided a more general view of the significance of financial matters for bereaved parents.

- An additional element in the research design was building in some support for the three researchers working in a sensitive and so far unexplored area, using a psychotherapeutic group model of support⁵.

The overall finding from interviews with parents was that financial issues associated with their child's death did matter to most bereaved parents in the study group, and to some they mattered very much and were closely linked to their grieving and moving forwards. This finding was confirmed by the national postal survey of children's hospices and support organisations^{6,7}.

The cost of care preceding death

The study provided further evidence about the costs of caring for a child with a life-limiting illness. Some parents had already faced considerable reduction in or interruption of earnings by taking on a caring role, or problems in trying to combine paid work and care. Some fathers, for example, had already taken a drop in earnings of more than half when they moved to part-time work, and none of the lone parents in the group had done paid work while they cared for their child.

At the same time as reduction in earnings there was a need to spend more, for example on high fuel bills, heavy use of the telephone, expensive transport arrangements, extra clothing or bedding for the child, equipment or house adaptations, and costs associated with treatment or hospital stays.

Parents made spending decisions knowing that their child's life was limited, and some took all possible opportunities for family outings or holidays, which could

be expensive. People have different levels of income and different aptitudes for managing their money, and some parents felt this was not problematic. However, some parents had already lived through several years of financial constraint, built up substantial debt and felt that financial matters were out of control by the time their child died.

The immediate cost of death

All parents felt the financial impact of funeral expenses, and the end of the benefits and allowances paid to them as parents. Parents made different choices about the funeral. It was not always possible to keep costs low, and some parents did not want a simple funeral for their child. A means-tested funeral grant is available to the very poorest families in the UK, but some of those who were eligible did not apply, and some of those who did apply felt humiliated. Costs of headstones can be high, and are not covered by the grant. Grandparents and other relatives sometimes helped here, but for some parents a headstone of their choice meant borrowing or applying to a charity.

When their child died, families experienced immediate loss of or reduction in social security income with the end of benefits and allowances previously paid in respect of the child or the parents' caring role. The impact of this could be unexpected and a great shock. As an example, a two-parent family with a working father in the middle-income range saw an immediate drop of 25% of net monthly family income. Such big drops in income meant a need for rapid adjustment in household budgeting, for which some parents were not well equipped emotionally at that time, leading to housing arrears and debt.

Long-term effects

The kinds of situations described were often not just short-term problems, and the financial impact could go on for a long time. Parents had different employment opportunities and expectations in the months following their child's death. Those who had maintained a strong breadwinner role during their child's final illness and returned to work soon after the funeral felt, in retrospect, they had made the right decision for them, and believed it helped to maintain financial stability. Those whose return to work had been driven by financial necessity felt they had gone back to work too soon, and some did not get on well at work, even in jobs they had previously enjoyed. This meant, for some, new sources of stress if they lost their job and had periods of unemployment.

Finding a new job after time away from paid work to care for a child could be hard. Some employers saw the time which fathers had spent at home as a gap in a CV and questioned their reliability.

Some parents felt they needed considerable time before they were ready to think about future employment. The rules governing social assistance in the UK require people who are able to do paid work to register their availability for employment and look for jobs. Parents whose last or only child had died had to register for work eight weeks after the death in order to continue receiving out-of-work benefits. This could be a shock, and led some parents to seek medical certification for sickness to achieve entitlement to further benefits without a requirement to seek work. Some felt this had been unhelpful in taking them down the path to categorisation as 'long-term sick', with medical labels of 'depression' and 'anxiety'.

Longer-term financial adjustments could be hard for other reasons. Patterns of expenditure established during a child's illness took time to change, especially if other children had become used to particular ways of household management, for example buying a lot of convenience meals. Large adapted vehicles were expensive to run but hard to sell. Debts previously incurred now had to be paid, and trying to find new ways for families to spend time had meant heavy expense for some.

Financial matters could have emotional impact as well as practical effects. The immediate withdrawal of the child's benefits and allowances could seem like society's formal acknowledgment that the child's life was over. The withdrawal of parents' benefits could seem like a message that their caring or parenting role was ended. The pain of such feelings could be intense, especially if parents felt that administrative arrangements had not been handled well. Parents who had not been able to pay for the child's funeral themselves sometimes continued to feel deep regret.

IMPLICATIONS OF THE FINDINGS

This exploratory study provided pointers for consideration by policy makers at various levels.

The UK Department for Work and Pensions has recognised the need to soften the impact of withdrawal of benefits when a child dies, and has extended the payment period after the child's death for some important benefits, allowances and tax credits. Attention has also been paid to the wording of the standard letters and forms

issued at this time, in consultation with parents whose child has died. The special circumstances of bereaved parents are also receiving some attention in UK employment programmes, such as the various New Deal programmes in which personal advisers offer support and help to people who want to move back to or try paid work.

Developments at this level will go some way to help families maintain financial stability, and avoid some of the problems experienced by families in this study.

Findings also raise questions for bereavement services about the relationship between practical support...and the mainly emotional and psychological support that is currently the focus of many services and support groups

However, the implications of the findings go far wider than this. They raise questions about what kind of help and support with financial matters is appropriate for bereaved parents, and indeed other groups of bereaved people, and where responsibility lies for providing such a service. Parents in this study said that they wished they had been helped to think about some of the financial issues in advance of their child's death. This might have helped some to deal with things differently and avoid some of the problems which arose, while those who would not have chosen to do things differently could have been better prepared for the emotional impact of the practical financial issues. Parents felt that it would not have been easy to help them focus on such matters, especially if they were dealing with things by 'taking a day at a time' but, in retrospect, some wished that some of the professionals and support services with whom they were in touch had at least tried. This raises questions for those professionals and volunteers working in hospices and community nursing, and other services in touch with families who are caring for members near to the end of life.

Findings also raise questions for bereavement services about the relationship between practical support and help with employment and money matters, and the mainly emotional and psychological support that is currently the focus of many services and support groups for bereaved people. Practical and financial issues can be critical in how people experience the impact of death and move on in their lives. For parents in this study, feelings about

practical issues and day-to-day managing were often deeply embedded in their experience of grief. Moving forward emotionally required both resolution of practicalities and dealing with the emotional impact of the effects. This may be important in thinking about and designing the kinds of services which are most helpful for bereaved people, and in training and equipping professionals and volunteers for working in such services. **BC**

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W E B W A T C H

Multiple birth loss

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Any pregnancy carries a certain amount of risk but for parents conceiving twins or higher multiples, the risks are even greater. Advances in fertility treatment have increased the number of multiple conceptions but with this often comes the reality of multiple losses.

Although there are several websites on multiple birth, coverage of bereavement issues is fairly brief. For anyone wanting to access the best information on multiple birth loss, the website of **The Centre for Loss in Multiple Birth (CLIMB)** at www.climb-support.org provides all the information, links and articles worth viewing. Founded in 1987 by Jean Kollantai, a bereaved mother, this voluntary organisation offers support worldwide to anyone who has experienced the death of one or more of their twins or higher multiples at any time from conception to childhood. The support is provided by a quarterly, postal **newsletter**, a parent-to-parent **contact list** that enables members to contact each other by post, telephone or email, **gatherings** where possible and by several **contact registries**. CLIMB also seeks to inform the public, health care professionals and bereavement support groups by raising awareness of the many complex issues surrounding multiple birth loss.

The **FAQ section** provides several interesting articles, such as that by Deborah Davis exploring feelings of failure, guilt and anger. The need to access and understand the medical aspects of the loss, often so essential to the healing process, is also discussed here, with a link to an article by a doctor, Elizabeth Pector, 'The Search For Why'. Group organisers wishing to improve support for bereaved parents will find an excellent article under **Support groups/Counseling**.

The **Loss of Both or All** section lists specific internet resources (see Other Resources) including a link to **LAMBS**, a unique email support group for those who have experienced the loss of all babies in a multiple birth. Also included are two informative articles by Jean Kollantai, giving practical suggestions to help parents

immediately following their bereavement in hospital and during the days and months following the death (see 'The death of your twin or triplet babies' and 'If your loss has just occurred').

Delayed grief can be a factor in any bereavement but it can be even more common for parents experiencing a multiple birth as, quite often, they have to channel their energy into coping with surviving babies who may themselves be seriously ill. CLIMB member Brenda Noble has written an article, 'Dealing with delayed grief', offering helpful suggestions for coping (see the Loss of a Supertwin(s) section).

'How we deal with **labelling our surviving children**' explores how bereaved parents and society refer to survivors from a multiple birth. If only two triplets survive, for example, are parents comfortable with referring to them as twins? One member of CLIMB has carried out email interviews looking at parental attitudes, including whether there should be a universal term for bereaved parents, recognised by society, as are 'widow' and 'divorcée'. Examples of birth announcements submitted by parents are also included here. These can serve as an inspiration for any parent struggling with how to announce the birth of their child/children while wishing to acknowledge the death of a baby.

Because of the high number of babies conceived or because of congenital problems, parents are often asked to consider selective reduction through **Multifetal Pregnancy Reduction (MFPR)** and **selective termination**. CLIMB has started a contact registry for parents who have been involved in making these very difficult decisions. Internal links provide greater insight into the issues surrounding both procedures, together with some interesting articles including a questionnaire completed by CLIMB members and conducted by Deborah Davis, 'Emotional impacts of assisted reproductive technology' (see the section on Selective Reduction).

The Loss to **SIDS** section highlights the

need for more research into **sudden infant death syndrome** in relation to multiple birth survivors, and also includes external links for those who have experienced the unexplained death of an older child (**SUDC**). One of the articles here, 'SIDS in twins', incorporates some interesting statistical information.

Certain unique aspects of multiple pregnancies can make a **father's experiences** extremely complicated when bereavement occurs. In addition, denial, anger and feelings of failure to protect his partner and children can be magnified in the case of a complicated multiple birth. Lack of emotional support and the impact on relationships can also be major issues. These difficulties are explored in the **Dads** section, with many personal accounts submitted by fathers.

Sections of the site specifically for **grandparents, siblings, survivors, friends and multiples groups** are **still in progress** and, judging from the standard of the rest of the site, should provide some excellent material. The section for **professionals** is also being developed, although there is already an excellent four-page document giving detailed suggestions for best practice for hospital caregivers. The latest addition to this rapidly evolving site is the translation of some articles into **French** and **Spanish**.

An extensive **bibliography** gives brief descriptions of relevant books and links to **external articles, websites and email support groups** dealing with multiple birth loss in general (click on About CLIMB on the main menu). Of particular note here are links to articles on 'The death of twin babies: some comments for grief counselors' and 'Bereavement in multiple birth', written by two doctors and aimed at caregivers. The links to sites in Other Resources include the UK peer support group organisation for bereaved parents affiliated to **TAMBA (Twins and Multiple Birth Association)**.

Together with the large number of personal experiences submitted by CLIMB members throughout, this is an extensive and extremely informative site. **BC**