Psychological disturbance and service provision in parentally bereaved children: prospective case-control study

Linda Dowdney, Richard Wilson, B Maughan, M Allerton, P Schofield, D Skuse

Sutton Hospital, Sutton, Surrey SM5 2NF
Linda Dowdney, *head of child psychology services*
Department of Child Psychology, Sutton Hospital
M Allerton, *research worker*
P Schofield, *research worker*
Kingston Hospital, Kingston, Surrey KT2 7QB
Richard Wilson, *consultant paediatrician*
Medical Research Council Child Psychiatry Unit, Institute of Psychiatry, De Crespigny Park, London SE5 8AF
B Maughan, *career scientist*
Behavioural Sciences Unit, Institute of Child Health, London WC1N 1EH
D Skuse, *consultant psychiatrist*
Correspondence to: L Dowdney, Department of Psychology, University of Surrey, Guildford, Surrey GU2 5XH
L.Dowdney@surrey.ac.uk

BMJ 1999;319:354–7

Abstract

Objectives To identify whether psychiatric disturbance in parentally bereaved children and surviving parents is related to service provision.
Design Prospective case-control study.
Setting Two adjacent outer London health authorities.
Participants 45 bereaved families with children aged 2 to 16 years.
Main outcome measures Psychological disturbance in parentally bereaved children and surviving parents, and statistical associations between sample characteristics and service provision.
Results Parentally bereaved children and surviving parents showed higher than expected levels of psychiatric difficulties. Boys were more affected than girls, and bereaved mothers had more mental health difficulties than bereaved fathers. Levels of psychiatric disturbance in children were higher when parents showed probable psychiatric disorder. Service provision related to the age of the children and the manner of parental death. Children under 5 years of age were less likely to be offered services than older children even though their parents desired it. Children were significantly more likely to be offered services when the parent had committed suicide or when the death was expected. Children least likely to receive service support were those who were not in touch with services before parental death.
Conclusions Service provision was not significantly related to parental wishes or to level of psychiatric disturbance in parents or children. There is a role for general practitioners and primary care workers in identifying psychologically distressed surviving parents whose children may be psychiatrically disturbed, and referring them to appropriate services.

Introduction

The few empirical studies of parentally bereaved children report increased psychological disturbance, with a wide range of symptoms including anxiety, depression, withdrawal, sleep disturbance, and aggression.[1–10] The risk of psychiatric disorders in children is greater when surviving parents have mental health difficulties.[4] When impaired parenting results, bereaved children are at risk of psychiatric disturbance in adult life.[11]

Despite this risk, bereaved children are not routinely offered support services. Mental health professionals disagree about service provision. Although counselling after parental death could be an important preventive mental health measure,[12] limited resources, coupled with a lack of specificity in identifying children at greatest risk, militate against service provision in the absence of overt disorder.[13] Yet surviving parents, who may themselves be experiencing mental health difficulties, may want support for their children.

Methodological shortcomings in previous research include a lack of standardised measures or control groups[1 6 8]; the use of referred samples[1 4] or community samples identified through obituaries or undertakers,[2 5 7 10] a method that fails to identify up to 30% of bereaved families.[3] Our study is novel for two reasons: it is the first British study of childhood bereavement using a representative community sample, and it is the first study to ascertain whether surviving parents wanted service support for their children and whether service provision is related to parental or child mental health. We obtained ethical approval for our study from the ethics committees of the health authorities in which the study families lived.

Participants and methods

Sample

We identified deceased adults aged 18-55 years from the death records of public health offices for two adjacent health authorities over an 18 month period. General practitioners were asked to provide the age and sex of the deceased's children. Cooperation of general practitioners was exceptionally high. Of the 542 recorded deaths, 476 were registered with general practitioners. Only four general practitioners refused access to families. Of the remaining 472 (99%) patients, 94 had children aged 2-18 years. We included all children (81 families) whose parent had died 3-12 months previously and who lived with both parents when the death occurred. We excluded children (two families) not living with the surviving parent, and two families where one parent had murdered the other. Of the remaining 77 families, 73 were still living in the health authorities concerned. We traced and contacted 71

Table 1 Parental report (40 parents) of emotional and behavioural problems in bereaved children using child behaviour checklist

Rating	Median (interquartile range)
Internalising	55 (46-61)
Externalising	53 (42-58)
Total problems	54.5 (46.25-61.5)

families (97%): 45 families (63%) agreed to be interviewed, and 40 (56%) completed all standardised questionnaires. The final sample consisted of 32 surviving mothers and 13 surviving fathers. We chose one child at random from each family for our study, giving 16 boys and 29 girls. Eight children were aged 2-5 years, 15 were aged 5-11 years, and 22 were aged 12-16 years. The median length of time since parental death was 7 months. The 45 participating families did not differ from non-participants in manner of death (expected or unexpected), sex of surviving parent, sex of index child, age of child, or family size (one or more children).

Measures

We conducted a semistructured interview in each family's home, gathering information on the death, familial grieving activities, and adjustment of the child and family after the death. We also obtained information on whether parents had desired, sought, or been offered bereavement support from public or voluntary services for themselves or their children, and their uptake of bereavement services.

Parental mental health measures

Parental mental health was assessed with the general health questionnaire. This was scored using the conventional method to identify adults with probable psychiatric disorder.[14]

Child mental health measures

Child emotional and behavioural disturbances were measured with standardised checklists completed by the parents (child behaviour checklist),[15 16] and, for school aged children, by teachers (teachers' report form).[17] These instruments measure a broad range of symptoms including behaviour that is withdrawn, anxious, and depressed (internalising scale), and behaviours that are disruptive, aggressive, or delinquent (externalising scale). To reflect appropriate expressions of child disturbance for age, separate checklists were used for 2-3 year olds[16] and 4-18 year olds.[15] All subscales are summed to give a total problem score. For each scale the normative sample mean T (standardised) score is 50. For both parent and teacher checklists, T scores of 67 and above on the internalising and externalising scales and 60 or more on the total problem scale are expected to be obtained by only 5% of the general population, and indicate problems of probable clinical severity.

Each teacher also completed a checklist on a randomly chosen classroom control matched with the bereaved child for age and sex. Teacher checklists on cases and controls were available for 28 of the 32 school age children.

Statistics

Not all measurement scales were distributed continuously or according to an interval scale. Therefore we used non-parametric statistics. Significance values were two tailed, and χ^2 significance values were corrected for continuity. When expected cell values were less than 5, we used the Fisher exact probability test. We used the Wilcoxon matched pairs signed rank test for analyses of matched pairs and the logistic regression and the Pearson product moment correlation when appropriate. Confidence intervals were calculated for median values with confidence interval analysis.[18 19]

Results

Parental mental health

Parental mental health scores ranged from 0 (6 cases) to 21 (2 cases), the median being 8 (interquartile range 3-14). Twenty nine (64%) parents scored 5 or more, a level indicating probable psychiatric disorder.[14] Twenty one mothers (78%) showed probable psychiatric disturbance compared with only four fathers (31%) ($P = 0.05$). Parents with more than one child living at home had significantly higher scores ($P = 0.03$). No significant associations were found between parental mental health scores and time since death, age of the surviving parent, age or sex of the child, or whether the death was expected or unexpected.

Children's emotional and behavioural problems: parental report

Problem scores reported by parents showed a wide range (table 1). Median scores were above the population mean for 25 (63%) children on the internalising scale, 23 (58%) children on the externalising scale, and 24 (60%) children on total problem scores. Eleven children (28%) had total problem scores above the 95th centile. Bereaved boys had significantly higher externalising and total problem scores than bereaved girls (table 2). Total problem scores were not significantly influenced by age, ordinal position, sex of the deceased parent, whether the death was expected or unexpected, length of time since the death, or the number of children living at home. Parental mental health scores were significantly correlated with parents' reports of emotional and behavioural distress in their children on the internalising scale ($r = 0.55$, $P = 0.001$) and total problem scores ($r = 0.53$, $P = 0.001$) but not on the externalising scale.

Children's emotional and behavioural problems: teachers' report

Bereaved children had significantly higher internalising and total problem scores than controls (table 3). Teachers considered them to be significantly more withdrawn, anxious, depressed, aggressive, and delinquent and to show more attention and thinking difficulties. Ten bereaved children had total problem

Table 2 Parental report of emotional and behavioural problems in boys and girls using child behaviour checklist. Values are median (interquartile range) unless stated otherwise

Rating	Boys (n=14)	Girls (n=26)	Difference (95% CI)*	P value†
Internalising	56.5 (46.75-66.50)	55 (46-60.25)	1.5 (–6 to 11)	0.45
Externalising	57.5 (54.25-63)	48.5 (41.25-54.50)	9 (3 to 16)	<0.01
Total problems	58.5 (54.50-67.50)	51 (46-57.25)	7.5 (2 to 15)	0.02

*Calculated with Wilcoxon based method.
†Mann-Whitney U, two tailed.

Table 3 Teachers' report of emotional and behavioural problems in bereaved children using teachers' report form. Values are median (interquartile range) unless stated otherwise

Rating	Cases (n=28)	Controls (n=28)	Difference (95% CI)*	P value†
Internalising	56 (51-59.25)	51 (43.5-54.75)	5 (2.5 to 10)	<0.01
Externalising	52.5 (42-60)	49 (42-53.5)	3.5 (0.5 to 8.5)	0.10
Total problems	54.5 (51-61)	49.5 (45-53)	5 (2 to 9.5)	<0.01
Internalising subscales:				
Withdrawn	57 (51-60)	51 (50-55)	6 (2 to 6.5)	<0.01
Somatic	50 (50-59.25)	50 (50-50)	0 (0 to 7)	0.10
Anxious or depressed	55 (50-59.25)	51 (50-55.75)	4 (0 to 3.5)	0.05
Externalising subscales:				
Delinquency‡	50 (50-59)	50 (50-53.75)	0 (0 to 6)	0.05
Aggression	53.5 (50-59.25)	51 (50-53.75)	2.5 (0 to 5.5)	0.04
Other problems subscales:				
Attention	54.5 (51-60.5)	50 (50-52)	4.5 (1 to 6.5)	0.01
Social problems	52 (50-59.5)	50 (50-54.75)	2 (0 to 4)	0.23
Thought difficulties‡	50 (50-58)	50 (50-50)	0 (0 to 4.5)	<0.01

*Calculated using Wilcoxon based method.
†Wilcoxon matched pairs test, two tailed.
‡Although median scores are identical on this scale, significant differences between groups arise from greater variation in scores of bereaved children as exemplified in interquartile ranges.

scores above the 95th centile compared with none of the controls (P = 0.002).

Parent and teacher agreement

Parents and teachers agreed whether a child was above or below the 95th centile on their total problem scores in 79% of the paired sample ($\kappa = 0.51$, P = 0.003).

Service support for bereaved children

Most parents (27/45, 60%) wanted service support for their children. The only significant influence on this desire was the mental state of the child, specifically externalising behaviour (above or below the median: P = 0.03) and total problem scores (above or below the median: P = 0.05). Of those parents whose children were probably psychiatrically disturbed, 82% (9 of 11) would have liked support compared with 53% (18 of 34) of parents whose children were not psychiatrically disturbed (P = 0.07). Similarly, 90% (9 of 10) of parents whose children were rated by teachers as probably psychiatrically disturbed desired support compared with only 55%[11] of those not so rated (P = 0.06). The manner of parental death did not influence whether surviving parents wanted support for their children (P = 0.7), neither did parental mental health scores when forced into a logistic regression before child total problem scores (P = 0.1).

Overall, 22 parents (49%) were offered support for their children. Of those wanting support, only 44% (12 of 27) were offered it compared with 56% (10 of 18) of those who did not want support (P = 0.4). Only one child received support from a trained bereavement counsellor. Offers of support were unrelated to the child's level of disturbance (total problem score above the 95th centile: P = 0.9) or probable parental psychiatric disturbance (scores above or below the median: P = 0.9).

Only the manner of death and the child's age significantly influenced offers of support. In families where the death was expected, 54% (13 of 24) received offers of support as did all parents whose partners had committed suicide (4 families). This contrasted with 29% (5 of 17) of families where the death was unexpected (P = 0.03). Parents of preschool children were less likely to be offered support than parents of school age children (P = 0.04).

Key messages

- Parentally bereaved children show high levels of psychological disturbance, with boys being more vulnerable than girls
- Surviving mothers show more psychiatric morbidity than surviving fathers
- Psychological distress in bereaved parents is associated with psychological difficulties in their children
- Service provision for bereaved children is not determined by mental health difficulties in either parents or children, or by parental wishes; it is influenced only by the manner of parental death and the age of the child
- The mismatch between need and service provision indicates a role for general practitioners and primary care workers in identifying distressed or disturbed families in need of public or voluntary service help

Discussion

We found high levels of psychological morbidity in a representative sample of parentally bereaved children and the surviving parents 3 to 12 months after the death. Mothers were more disturbed than fathers. Boys were more symptomatic than girls, particularly in acting out or aggressive behaviour. Parents with high levels of psychiatric disturbance reported more symptoms in their child. Independent teacher ratings indicated that bereaved children were significantly more likely than matched controls to show widespread psychological difficulties. Teacher and parental ratings of probable child psychiatric disturbance showed good agreement.

Service provision for bereaved children was unrelated to probable psychiatric disturbance in children or parents or to parental desire for support. Given resource limitations, service provision should be targeted at psychologically disturbed children or psychiatrically disturbed parents wanting parenting support, or both. It was only the child's level of disturbance that significantly influenced parental desire for service support. Yet those most likely to be offered service provision were families in touch with services before the death, particularly services such as hospices with existing child provision. We found no association between the children's age and outcome. None the less, preschool children were less likely than older children to be offered services even though their parents were no less likely to want them. These findings indicate a serious mismatch between service need and provision.

The literature offers little guidance on the duration of childhood grieving. Our clinical experience suggests that where childhood disturbance persists beyond 3 months after death and results in family disturbance or affects performance or relationships at school, primary care practitioners should consider referral to specialist services. Practitioners should also be aware that child disturbance may reflect undetected psychological distress in the surviving parent.

Limitations

Bereaved children are neither easily identifiable nor accessible. We overcame the first difficulty by searching

death records. Researchers followed ethical guidelines[20] and did not unduly pressurise general practitioners or bereaved patients who declined to participate. Our response rate of 63% was lower than we wanted but better than in other community studies (26%-54%).[6 9]

The small sample size precluded analyses of interactions in the data. We cannot, therefore, determine whether service provision was influenced by one variable independently or in conjunction with others. What remains clear is that service provision was not determined by child need or parental wishes.

Our sample was small but seems representative. Participants did not differ from non-participants on key personal variables or the manner of death. Our findings replicate previous research including high levels of mental health difficulties in surviving parents,[21] an association between parental and child mental health, and boys showing more disturbance than girls.[4] We also found widespread psychological disturbance in bereaved children[1–10] and higher levels of disturbance than in classroom controls.[4] It is possible that participants were those most concerned about their children's behaviour. However, the exclusion of particularly vulnerable children—those in care, and those whose parents were murdered—may mean that we underestimated the full extent of disturbance.[22]

Conclusion

Our findings indicate a gap in support for bereaved families at the primary care level. The supportive role of paediatricians and their function as gatekeepers for the referral of bereaved children to specialised services are well specified.[23] We agree with Black[24] that general practitioners and primary care workers are ideally placed to identify families in need of help, particularly when levels of parental distress are high and when parents report persistent child disturbance at home or at school.

We thank the families who participated at a very difficult time in their lives. We hope their efforts and the information they provided will result in an improvement in the match between service provision and need. We also thank the general practitioners who cooperated with this study and gave us access to their patients. Their understanding and desire to help was important for the project.

Contributors: LD and RW initiated the research and with BM and DS designed the study and generated primary study hypotheses. LD, RW, BM, MA, and PS developed interview measures. LD supervised data collection, took the primary role in data analysis and interpretation, and took responsibility for writing the paper. RW and BM discussed core ideas and interpretation of findings and, with DS, contributed to the paper. MA and PS conducted piloting of instruments, sensitively interviewed the families, participated in discussion of core ideas, and undertook preliminary analyses. LD will act as guarantor for the paper.

Funding: South Thames Regional Health Authority (PGA 105/D).

Competing interests: None declared.

1 Cheifetz PN, Stavrakakis G, Lester EP. Studies of the affective state in bereaved children. *Can J Psychiatry* 1989;34:688-92.
2 Fristad MA, Jedel R, Weller RA, Weller EB. Psychosocial functioning in children after the death of a parent. *Am J Psychiatry* 1993;150:511-3.
3 Gersten JC, Beals J, Kallgren CA. Epidemiology and preventive interventions: parental death in childhood as a case example. *Am J Community Psychol* 1991;19:481-500.
4 Kranzler EM, Shaffer D, Wasserman G, Davies MA. Early childhood bereavement. *J Am Acad Child Adolesc Psychiatry* 1990;29:513-9.
5 Sanchez L, Fristad M, Weller R, Weller EB, Moye J. Anxiety in acutely bereaved prepubertal children. *Ann Clin Psychiatry* 1994;6:39-43.
6 Silverman PR, Worden JW. Children's reactions in the early months after the death of a parent. *Am J Orthopsychiatry* 1992;62:93-104.
7 Sood B, Weller EB, Weller RA, Fristad MA, Bowe JM. Somatic complaints in grieving children. *Compr Ment Health Care* 1992;2:17-25.
8 Van Eerdewegh MM, Bieri MD, Parrilla RH, Clayton PJ. The bereaved child. *Br J Psychiatry* 1982;140:23-9.
9 Weller RA, Weller EB, Fristad MA, Bowes JM. Depression in recently bereaved prepubertal children. *Am J Psychiatry* 1991;148:1536-40.
10 Worden JW, Silverman PR. Parental death and the adjustment of school-age children. *Omega J Death Dying* 1996;33:91-102.
11 Harris T, Brown GW, Bifulco A. Loss of parent in childhood and adult psychiatric disorder: the role of lack of adequate parental care. *Psychol Med* 1986;16:641-59.
12 Black D. Childhood bereavement: distress and long term sequelae can be lessened by early intervention. *BMJ* 1996;312:1496.
13 Harrington R. Childhood bereavement: bereavement is painful but does not necessarily make children ill. *BMJ* 1996;313:822.
14 Goldberg D, Williams P. *A user's guide to the general health questionnaire*. Windsor: NFER-Nelson, 1988.
15 Achenbach TM. *Manual for the child behavior checklist/4-18 and 1991 profile*. Burlington, VT: University of Vermont, 1991.
16 Achenbach TM. *Manual for the child behavior checklist/2-3 and 1992 profile*. Burlington, VT: University of Vermont, 1992.
17 Achenbach TM. *Manual for the teachers' report form and 1991 profile*. Burlington, VT: University of Vermont, 1991.
18 Gardner MJ, Altman DG. *Statistics with confidence—confidence intervals and statistical guidelines*. London: BMJ, 1989.
19 Gardner MJ, Gardner SB, Winter PD. *Confidence interval analysis (CIA) microcomputer program manual*. Version 1.1. London: BMJ, 1991.
20 Parkes CM. Guidelines for conducting ethical bereavement research. Special issue: ethics and bereavement research. *Death Studies* 1995;19:171-81.
21 Worden JW, Silverman PS. Grief and depression in newly widowed parents with school-age children. *Omega J Death Dying* 1993;27:251-61.
22 Black D, Harris-Hendriks KT. Father kills mother: post-traumatic disorder in the children. *Psychother Psychosom* 1992;57:152-7.
23 Committee on Psychosocial Aspects of Child and Family Health. The pediatrician and childhood bereavement. *Pediatrics* 1992;89:516-8.
24 Black D. Coping with loss: bereavement in childhood. *BMJ* 1998;316:931-3.

(Accepted 28 April 1999)