

Family and community factors associated with infant deaths that might be preventable

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Abstract

A detailed psychosocial study was made of all deaths in babies aged between 8 days and 2 years in Sheffield over two years. An identical assessment was made of a group of control children matched for age. Sixty five children who died and 102 controls were studied. Each index and control child was assessed for 13 potentially adverse social and family factors. The deaths were classified into causal groups. The families of children who died during the course of potentially treatable diseases (those with infections and those who presented as cot deaths but had treatable infection) had a significantly greater number of adverse social factors than the families of children who died from conditions with a poor prognosis, children who presented as completely unexplained cot deaths, and controls. The adverse factors studied, although often related to economic state, appeared to be independent of social class.

Introduction

When a child dies the final diagnosis and certificated cause of death are statements only of disease. The statement that a child has died of pneumonia or gastroenteritis identifies the terminal crisis but provides no explanation of the complex chain of circumstances behind it. The possibility of further reduction in infant deaths lies in the continuing study not only of final disease processes but also of background factors that are associated with the initial development of a disease and that may affect the outcome.

When a child develops an infection a causative organism must be present but other factors—climatic, psychological, social, nutritional, etc—may play an equal part.^{1 2} For the child to be successfully treated the parents must first recognise that he is

ill^{3 4} and must then recognise the need to take action. Next, they must be able adequately to communicate their anxieties to an appropriate member of the health care service, and these services must be able to recognise and respond to the families' needs.^{5 6} Non-infectious diseases also often have a multifactorial origin, and the outcome may be similarly influenced by a wide variety of factors.

In this study of all postperinatal deaths in Sheffield over two years (April 1979 to April 1981) the form of analysis used during the Department of Health and Social Security's postneonatal study⁷ to assess the relative importance of different pathological factors was extended to include family, community, and health care factors (table I).

Subjects and methods

We obtained information about each child who died from obstetric, paediatric, and casualty department records. Questionnaires were completed by the family doctor and the health visitor in all cases, and also by the domiciliary midwife and social worker if appropriate. A home visit was made by appointment, and usually both parents were interviewed. Most home interviews were made by one of us. When all data had been collected and the final necropsy report was available a case conference was arranged. All but one of the conferences on children who died unexpectedly at home were held in the family doctor's surgery, the exception being the conference on a child of a family that was not registered with a general practitioner. Paediatricians were also invited to these conferences if they had previously seen the child. Some of the conferences on hospital deaths were held in the family doctor's surgery and the rest in hospital. We were present at all the case conferences. Using all the information available, we evaluated the factors shown in table I. Each factor was assessed as present or absent, recorded, and then reassessed for its apparent relevance to the infant's death.

Parents' upbringing and home background

An attempt was made to assess the environment in which the parents had spent their childhoods and whether this might have adversely influenced their management of their own children. Any history of family separation, ill health in childhood, or institutional care was recorded. Severe psychic trauma such as the death of a parent in early childhood was also recorded as was any history of a family tendency towards physical violence.

Example—One baby (case 26) was the third child of the mother and

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TABLE I—Form on which conclusions of case conference were scored (scores given in parentheses)

	Not known	Absent (0)	Present but no recognised association with death (1)	Present but not more than minor contributing factor (2)	Present and major contributing factor (3)	A determining cause of death (4)
Mother's upbringing and home background Father's upbringing and home background Domestic and financial problems Housing problem Mother's or father's state of health Mother's intelligence Father's intelligence Mother's competence Father's competence Level of maternal/infant bonding Competence of other non-professional carers Family crisis Failure of communication						

the second child of the father. The mother was one of a family of nine. Her father had been violent towards her. She had always been on poor terms with both her parents, who banned her from the family home when they discovered she was pregnant. The infant's father had also had a difficult childhood. His own father had been regularly violent towards him. The baby died unexpectedly at home after a relatively minor episode of gastroenteritis that had progressed to severe metabolic upset without the parents realising that she was ill. The home background of the parents was assessed as a factor contributing to the parents' inability to respond to their child's illness.

Domestic, financial, and housing problems

If both parents were unemployed they were generally thought to have financial problems; if the house lacked the usual amenities of heating, cooking, etc, they were thought to have domestic problems; and if the house was in poor repair, damp, and overcrowded they were assessed as having a housing problem.

Example—One baby (case 65) was one of twin boys born to a young couple who already had one other child. The father was unemployed and had a drinking problem. As a consequence of this the family were often without enough money to buy food or dried milk for the bottle fed twins. They lived in an unsatisfactory flat in a massive inner city development. The baby died unexpectedly at home in the course of a minor illness. A housing problem was assessed as being present and a possible major contributing factor; financial problems were assessed as being present and a possible major contributing factor; and other adverse social factors were also present.

Health of parents

The health of both parents was assessed. Psychiatric illness, present or past, was included in this section. An attempt was made to determine whether both mother and father were in normal physical and mental health during their baby's life and at the time of death.

Example—One baby (case 45) died unexpectedly at home. She had an aesthetically disturbing congenital abnormality that was not directly responsible for her death. The mother had been under treatment for many years for a prolonged and severe psychiatric illness. From information made available at the case conference it became apparent that this child came into the group of "gently battered children"—that is, an action or inaction on the part of the mother had probably been a major factor in the child's death. In this case the mother's state of mental health was probably a determining cause of death. The surgeons concerned with the care of the child were unaware of the mother's psychiatric history.

Parents' intelligence

Intelligence was assessed separately for each parent. Education at a special school or abnormally low intelligence as assessed by the family doctor or health visitor was scored as an adverse factor if this was accompanied by evidence of poor parenting abilities.

Example—One baby (case 57) was the first child of young parents. He died in hospital at the age of 3 weeks from an intraventricular haemorrhage associated with extreme prematurity. Both parents were of low intelligence and illiterate. They had not understood the implications of the mother's severe pre-eclamptic toxæmia. She had repeatedly taken her own discharge when admitted to hospital for rest during her pregnancy and had tried to refuse emergency lower segment caesarean section at 29 weeks, which had been decided on to save her own life. At the home visit after the infant's death the parents showed that they had no understanding of the risk to the mother's life during her pregnancy or of the necessity for the medical care that had been instituted and said that they had decided on a home confinement "next time." If this mother had understood and cooperated with antenatal care the pregnancy might have been prolonged, giving a greater chance of a viable child. In this case there had been a complete breakdown in communication and understanding.

Parental competence

Parental competence was assessed separately for each parent and an effort made to distinguish problems of competence from problems of intelligence.

Example—One (case 76) died unexpectedly at home during the course of a moderately severe but untreated respiratory tract infection. She had been discharged home from the maternity hospital into a household in which almost everyone had a respiratory infection. Both mother and baby became ill. The parents, both graduates, did not agree with conventional medicine. They ignored the midwife's advice to seek medical help and did not give the baby the antibiotic prescribed by their family doctor, who visited at the midwife's request. Necropsy showed *Haemophilus influenzae* infection, which was considered to be the major contributing factor in death. The parents' intelligence was above average, but their actions were assessed as a contributing factor in the child's death.

Bonding between mother and infant

An attempt was made to assess whether the mother's relationship with her child was such that her ability to recognise possibly important changes in her baby's pattern of behaviour was impaired.

Example—One baby (case 61) was one of twins born to a 19 year old mother who already had two other children. The pregnancy had been unplanned. The twins were delivered prematurely at 34 weeks and were in a special care baby unit for four weeks. The mother had a postpartum haemorrhage that required transfusion, and she was subsequently readmitted twice for treatment of heavy bleeding. Because of her ill health and her two other children she was unable to visit the twins regularly. When the twins came home she found it difficult to love and care for them in the way that she cared for her two older children. She later admitted to injuring both twins. When they were 4 months old both twins became ill. The mother either did not recognise their illness or was unable to respond to it. One twin was found dead in her cot; the other was virtually moribund but eventually recovered in hospital. Failure in maternal infant bonding was assessed as a contributing factor in this child's death. Other social factors were also present.

Competence of other non-professional carers

The availability and quality of help from an extended family or friends was assessed. If the parents were isolated this was regarded as an adverse factor by virtue of the absence of support, which is a basic need of all parents of young babies.

Example—One baby (case 41) was the first child of very young parents. She died unexpectedly at the age of 4 months during an unrecognised respiratory illness while the family were on holiday. Previously almost all the decisions about the care of this infant had been taken by the maternal grandmother, with whom the couple lived. This baby died on the first occasion that the family was away from the grandmother's care. When the baby fell ill the parents did not know how to respond and medical help was not sought until after she died. The absence of the grandmother was as important as the lack of competence of the young parents in the events leading to this child's death.

Family crisis

An assessment was made of whether the family was in a state of chronic or temporary crisis that might interfere with the parents' ability to recognise illness in their child or with their judgment in deciding how to respond to this illness. "Crisis" included recent unemployment or parental illness, moving house, being away from home, or any other change in the pattern of family life that might interfere with the parents' attention to their child.

Example—One baby (case 28) died unexpectedly at home at the age of 10 weeks. He developed gastroenteritis that progressed to a severe electrolyte disturbance unrecognised by his young parents. At the time the baby became ill the father was at home on a short leave from Borstal. The parents did not recognise the baby's worsening condition. The baby died on the day the father returned to Borstal. It seemed certain that this couple had been distracted by their other problems.

Failure of communication

The level of communication between the parents and the health care services was assessed. The parents' impression of the accessibility of their family doctor, health visitor, and midwife was considered,

together with the parents' attitude to the health care services. For example, parents who thought that under no circumstances at all could they "bother" their general practitioner except during surgery hours were considered to have a communication problem. It occasionally became apparent that advice that the family doctor had given had been misinterpreted by the parents.

Health care factors

The provision of health care—that is obstetric care, paediatric care, general practitioner care, and care given by the clinic health visitor or midwife—was assessed in the same way, but we found this to be extremely difficult. There were, however, a few outstanding cases. For example, one baby died unexpectedly more than 12 hours after admission to hospital before he had been seen by any senior member of the medical staff.

CONTROL INFORMATION

Controls matched for age (the 10th babies before and after the index child's entry in the birth register) were selected and information obtained by telephone inquiry to the health visitor, who was asked to assess whether each adverse social factor had been present on the date of the index child's death in such a way as to interfere with the optimal upbringing of the child. When the health visitor was uncertain whether to score a factor as present or absent she was asked to imagine that the child had died and score as she would have done under those circumstances. Although it was possible to obtain information about some of the factors that we assessed, such as the presence of crisis and housing problems, financial state, and family background, it was not possible to assess the challenge of a serious illness in a child in the family; thus only incomplete control data were available. Control data could not of course be rated for relevance, and so each factor was rated only as present or absent. Health visitors could not give any information on 28 control babies.

Results

In the two years under study 65 babies died between the ages of 8 days and 2 years. A total of 102 controls matched for age were studied.

Deaths were divided on a pathological basis into groups related to possible preventability (table II).⁸ Thirty five babies died from

TABLE II—Analysis of adverse social factors by category of death (ranges given in parentheses)

Classification of death	Total No of cases	Mean No of adverse factors present (maximum = 13)	Score of adverse social factors
<i>Infants who died</i>			
Deaths from disease with poor prognosis	35*	2.7 (0-10)	3.6 (0-19)
Deaths from diseases occasionally fatal	20	6.7 (0-11)	13.3 (0-31)
Deaths in the course of minor disease	2	8.5 (7-10)	14.5 (8-21)
No recognisable disease	2	1.0 (0-2)	1.0 (0-2)
Gentle battering	3	6.0 (6-7)	14.3 (12-17)
Non-accidental injury	2	7.5 (7-8)	20 (17-23)
Accident	1	3.0	8.0
	<i>Controls</i> 102	1.2 (0-7)	

* One case not assessed (insufficient information available).

conditions with a very poor prognosis (congenital abnormalities, obstetric problems including prematurity, and tumours). Twenty babies died with potentially treatable infections, five in hospital and 15 at home. Three others fell into the gently battered group. Four unexplained, unexpected deaths occurred: two of the babies had minor illness and two were apparently perfectly healthy. Two deaths were due to non-accidental injury and one to a road traffic accident.

Care was taken to grade the pathology independently of the clinical history and social findings. The amount of pathology was graded according to the results of necropsy, using a system described elsewhere.⁷

The mean number of adverse background factors present in the families of the 102 control infants was 1.2; in families of children who died of diseases with a poor prognosis it was 2.7. Families of children who died during the course of diseases rarely fatal and potentially treatable, however, had a mean of 6.7 adverse factors. Twelve of the 20 children in this category presented as cot deaths. The two children who died in the course of minor illness had seven and 10 adverse factors present, and the two children who were apparently completely healthy had 0 and 2 adverse factors respectively. The three children who were thought to have been gently battered had an average of six adverse factors present, and the two children who died from overt non-accidental injury had seven and eight factors present. These latter groups, with the exception of the completely unexplained cot deaths, had significantly different numbers of adverse factors present compared with the controls and babies who died of diseases with a poor prognosis ($p < 0.001$).

When background factors were given a numerical rating related to their importance in the pathways leading to the child's death the findings were similar but more exaggerated; thus the average score for these factors was 3.6 in the infants who died of diseases with a poor prognosis compared with 13.3 in the infants who died of potentially treatable conditions that are occasionally fatal. When the latter group of infants were considered according to place of death (table III) significantly more adverse background factors were found in the families of babies who died at home compared with the families of babies who died from similar conditions in hospital and with controls ($p < 0.001$).

Table IV shows the number of adverse social factors present in families of babies who died unexpectedly at home during the course of potentially treatable illness compared with the families of babies who died from diseases of poor prognosis and control families (expressed as a percentage of the families in each group). When individual background factors were considered the difference between these same three groups became even more apparent. Table V compares the

TABLE III—Analysis of background factors by place of death in babies who died of diseases that are occasionally fatal

Place of death	Total No of cases	Mean No (range) of adverse background factors present	Mean score (range) of factors when assessed for contribution to death
Hospital	5	1.8 (0-4)	2.0 (0-4)
Home	15	8.3 (5-11)	17 (7-31)
	102	<i>Controls</i> 1.2 (0-7)	

TABLE IV—Number (%) of adverse social factors present in families of children dying from different causes and controls

No of factors	Controls (n = 102)	Children dying of:	
		Conditions with poor prognosis (n = 34)	Potentially treatable infections (n = 15)
0	54 (53)	8 (24)	0
1	21 (21)	8 (24)	0
2 or 3	13 (13)	6 (18)	0
4 or 5	10 (10)	5 (15)	2 (13)
6 or 7	4 (4)	4 (12)	4 (27)
8 or 9	0	1 (3)	3 (20)
10+	0	2 (6)	6 (40)

TABLE V—Number (%) of families in which various adverse social factors were noted

	Controls (n = 102)	Children dying of:	
		Conditions with poor prognosis (n = 23)	Potentially treatable infections (n = 15)
Parents' upbringing and home background	15 (15)	9 (26)	13 (87)
Domestic, financial, and housing problems	28 (27)	9 (26)	13 (87)
Parents' health	10 (10)	9 (26)	9 (60)
Parents' intelligence and competence	24 (24)	5 (15)	14 (93)
Bonding and family crisis	20 (20)	17 (50)	13 (87)
Communication failure	5 (5)	11 (32)	8 (53)

prevalences of various background factors in families in these three groups; they showed a consistent pattern. Families of babies who died at home of potentially treatable illness were appreciably different from families of babies who died of diseases with a poor prognosis and families of control babies. An appreciable difference between families of babies who died of diseases with a poor prognosis and control families was apparent only with respect to failure of bonding and of communication.

Discussion

The relevance of social class to infant mortality is well recognised.⁹ In this study we attempted to look beyond the simple characteristics of social class and to identify significant individual factors. Although an obvious direct association exists between some adverse social factors, such as housing and social problems, and social class, we have been impressed in this and other studies related to unexpected death that the conventional approach to social class has little overall relevance. We found that successful breast feeding is more closely related to education than to social class.¹⁰ Educational attainment is not always reflected by conventional choice of employment—for example, in this study the parents of one infant who died unexpectedly at home were both university graduates but the father had, of his own choice, been working for several years as an unskilled labourer. We therefore attempted to identify and assess adverse background factors as they related to individual families rather than to social classes.

Controlled information is a considerable problem in a study of this type. Most of the background factors presented in table V can be reasonably adequately assessed in control families, but failure of communication and of bonding cannot be. These factors may only become apparent under conditions of stress and are therefore bound to be relatively underreported in control children; in children who die of diseases with a poor prognosis, in whom terminal illness will usually have been present throughout the child's life and separation from the parents is inevitable, failures of communication are likely to become obvious and adequate bonding may be impossible or even undesirable.

Many of these factors are interdependent and rarely occur in isolation; thus a woman with a psychiatric disorder will probably have difficulty in communication and in general competence, but this is by no means invariable. One of the reasons why we attempted to assess each factor separately was to avoid a tendency to label family units—for example, the history of a psychiatric disorder in a mother does not necessarily imply incompetence, an inability to bond with her children, or an inability to be a completely adequate parent.

Of the adverse background factors assessed in table V, some are more obviously open to intervention than others. The effects of parents' upbringing and home background are probably open only to long term intervention, but domestic, financial, and housing problems, parents' health, and family crisis may be open to intervention. Problems of intelligence and competence indi-

cate a need for a compensatory increase in professional health care. Domestic, financial, and housing problems, although politically important, do not appear to be more prevalent than other less obvious factors such as poor parental health, problems of parental competence, intelligence, and family crisis.

Infant mortality is higher in the United Kingdom than in some other European countries. One possibly preventable group of deaths are those that occur at home during the course of illness for which conventional paediatric treatment is potentially life saving.⁴ In this study most babies (12 of 15) in this group presented as unexpected deaths. In a previous study symptoms in such children who died did not differ substantially from symptoms that resulted in admission to hospital and successful treatment in a control group matched for age and symptoms.¹¹ In this study this group of children who died had the highest mean number of adverse background factors; failure of identification of the presence of illness and inadequate response were the most important in the pathways leading to death.

The factors that determine whether a child with a potentially treatable illness receives successful health care are complex and not immediately susceptible to purely economic intervention or necessarily to an unselective increase in primary health care. Perhaps we should be more conscious of the differing needs of individual families.

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SPLEENWORT, CETERACH, OR HEART'S TONGUE. The smooth Spleenwort, from a black, thready and bushy root, sends forth many long single leaves, cut in on both sides into round dents almost to the middle, which is not so hard as that of polypody, each division being not always set opposite unto the other, cut between each, smooth, and of a light green on the upper side, and a dark yellowish roughness on the back, folding or rolling itself inward at the first springing up. It grows as well upon stone walls, as moist and shadowy places, about Bristol, and other the west parts plentifully; as also on Framlingham Castle, on Beaconsfield church in Berkshire, at Stroud in Kent, and elsewhere, and abides green all the Winter.

Saturn owns it. It is generally used against infirmities of the Spleen: It helps the stranguary, and wasteth the stone in the bladder,

and is good against the yellow jaundice and the hiccough; but the juice of it in women hinders conception. Matthiolus saith, That if a dram of the dust that is on the back-side of the leaves be mixed with half a dram of amber in powder, and taken with the juice of purslain or plantain, it helps the gonorrhoea speedily, and that the herb and root being boiled and taken, helps all melancholy diseases, and those especially that arise from the French diseases. Camerarius saith, That the distilled water thereof being drank, is very effectual against the stone in the reins and bladder; and that the lye that is made of the ashes thereof being drank for some time together, helps splenetic persons. It is used in outward remedies for the same purpose. (Nicholas Culpeper (1616-54) *The Complete Herbal*, 1850.)