PAPERS AND ORIGINALS

Terminal symptoms in children dying suddenly and unexpectedly at home

Preliminary report of the DHSS multicentre study of postneonatal mortality

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British Medical Journal, 1978, **2**, 1249-1251

Summary and conclusions

Terminal symptoms in 145 children who died suddenly and unexpectedly at home were investigated and compared with symptoms in 154 control children. Eighty-five (59%) of the children who died had had terminal symptoms, which in 69 cases (48%) appeared to have been major. Non-specific symptoms were especially common among the children who died. Symptoms were often present for several days before death. Only 12 of the 69 children who died with major symptoms had been seen by a doctor within 24 hours before death.

We conclude that many deaths in young children might be prevented if doctors and parents were more aware of the importance of non-specific symptoms as markers of life-threatening illness.

Introduction

Classification of sudden, unexpected death in infancy is generally based on pathological findings because the children are investigated by pathologists, not clinicians. As minor illnesses are common in normal children, some who die unexpectedly at home are bound to have had symptoms immediately before their death, whatever its mechanism. The problem is to distinguish between children whose symptoms were not severe enough to have made sudden death predictable and severely ill children who might not have died had they received earlier or more expert medical attention. Pathology alone cannot solve this problem because, in our experience, some children who have clearly had severe terminal symptoms die without a satisfactory pathological explanation.

Many studies have shown that symptoms frequently occur in the last days before death.[1-4] Assessing the severity and details of these symptoms retrospectively, however, is extremely difficult. None of the previous studies has convincingly defined the ways in which children who die suddenly and unexpectedly at home differ clinically from normal children. The Sheffield study[3] did not describe the symptoms of children with less than definite pathological evidence of illness. The Newcastle study[4] included an assessment shared between clinical doctors, community nurses, and pathologists but, as in Sheffield or at any single centre, the number of deaths was small.

The DHSS multicentre survey of deaths among children aged from 1 week to 2 years is expected to have included over 1000 deaths from all causes by mid-1979, of which nearly half will probably have occurred unexpectedly at home. This paper describes the preliminary clinical findings of the survey relating to children dying unexpectedly at home.

Methods

The DHSS study began in April 1976, based on Sheffield, Newcastle, and Oxfordshire. By October 1977 it had expanded to cover Edinburgh and the Lothians, Gateshead, Leeds, Liverpool, Manchester, and South Yorkshire, with an overall population of over five million. All deaths of children aged between 1 week and 2 years occurring in these administrative areas are notified to the study. Whenever possible there is a standardised interview with the parents soon after the child's funeral. This interview includes detailed inquiries about the family's socioeconomic circumstances, health, antenatal problems, and feeding practices; the early development and previous health of the child; and symptoms during the last days of life. The information thus obtained is compared with that elicited from interviews with the family doctor and health visitor and from the child's medical records. A conference about each death is held, at which all

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those concerned with the family, together with the interviewer and a paediatrician, discuss the clinical findings in detail.

A control child is identified from a local chronological list of birth notifications by counting a predetermined number of names below that of the child who died, so that ages are matched to within two days. In Oxfordshire two controls are found for each case. The same detailed interviews are sought from parents, family doctors, and health visitors, and medical records are examined. Symptoms present at the time of the home interview are used for comparison with the terminal symptoms of the child who died.

The severity of each child's illness is categorised, without reference to pathological findings, according to whether the symptoms are major or minor. Major symptoms are those usually needing a medical opinion on the same day and continuing close supervision but not necessarily treatment or hospital referral. These include wheezing or noisy or altered breathing; cough; diarrhoea or vomiting; unusual drowsiness; irritability or excessive crying; an altered character to the cry; being off feeds or having difficulty with feeding; and fever or excessive sweating. Minor symptoms do not usually need a medical consultation on the same day. They include cold, snuffles, and sneezing; single vomit, loose motion, or missed feed; constipation; rash (excluding nappy rash).

Results

In the first 19 months of the study, until 31 October 1977, 414 deaths were notified. Table I shows the causes of these deaths and where they occurred. One hundred and fifteen infants died without leaving hospital after birth, generally as the result of complications of prematurity or severe congenital abnormalities. A further 101 children died in hospital, having already been home. Most of these had major congenital abnormalities, but 29 had previously been healthy and developed acute illnesses, generally infective. The remaining 198 children died at home, 159 unexpectedly. Of these 159 deaths, six were late notifications and were not investigated. Eight families refused to be interviewed, and there were therefore 145 cases for analysis at this stage of the study.

There were 175 possible controls for the 153 deaths that were notified early, as 22 deaths occurred in Oxfordshire and so had two controls each. Interviews were refused in the case of 17 controls. One family had moved and two provided insuperable language problems. One mother had a puerperal psychosis. Thus 154 controls were available.

TABLE I—*Cause and place of 414 deaths in children aged 1 week to 2 years*

Cause of death	Place of death		
	Home	Hospital	
		Never discharged	Readmitted
Prematurity or birth trauma	1	43	2
Neural tube defect		36	7
Congenital heart disease	12	26	29
Other congenital defects	9	10	22
Trauma	17		5
Tumours			7
Unexpected deaths (including acute infective illnesses)	159		29
Total	198	115	101

TABLE II—*Common symptoms in 145 children who died unexpectedly at home and 154 control children. Figures are numbers of children (some had more than one symptom)*

Symptoms	Children who died	Controls
Respiratory:		
Snuffles	26	21
Cold	19	5
Cough	31	8
Rapid breathing	6	
Wheeze	6	1
Noisy breathing	7	1
Gastrointestinal:		
One loose stool	4	1
Diarrhoea	12	1
One vomit	9	2
Vomiting	14	2
Non-specific:		
Unusual drowsiness	36	3
Irritability and excessive crying	37	8
Altered character of cry	14	
Missed one feed	3	
Off feeds	26	5
Fever	13	2
Excessive sweating	10	
Rash (excluding nappy rash)	10	6

TABLE III—*Type of illness and classification of symptoms in 145 children who died unexpectedly at home (no symptoms present in 60 children)*

Type of illness	Symptoms		Total
	Major	Minor	
Respiratory	42	10	52
Gastrointestinal	12	3	15
Cerebral and non-specific	15	3	18
Total	69	16	85

TABLE IV—*Type of illness and classification of symptoms in 154 control children (no symptoms present in 114)*

Type of illness	Symptoms		Total
	Major	Minor	
Respiratory	14	12	26
Gastrointestinal	1	2	3
Cerebral and non-specific	4	7	11
Total	19	21	40

TABLE V—*Duration of terminal illness according to severity in 145 children who died unexpectedly at home (no symptoms present in 60)*

Duration (in hours)	Symptoms		Total
	Major	Minor	
0-24	20	5	25
25-48	15	1	16
49-72	7	5	12
>73	27	5	32
Total	69	16	85

TABLE VI—*Relation between age and presence or absence of terminal symptoms in 145 children dying unexpectedly at home*

Age in weeks:	1-12	13-24	>25
No with symptoms	28	35	22
No without symptoms	22	26	12

Table II lists the symptoms commonly reported by parents as having occurred in the last week of life or, for controls, in the week before interview. Any child may have had more than one symptom. Eighty-five (59%) of the children who died unexpectedly at home had symptoms in the last 48 hours of life. The corresponding figure for the controls was 40 (26%). The classification of these symptoms as major or minor is shown in table III for the children who died and in table IV for the controls. Minor symptoms were as common in controls as in index cases. Only 19 of the controls (12%) had major symptoms, however, compared with 69 (48%) of those who died.

Table V shows the duration of the terminal symptoms of the children who died. Major symptoms had been present for less than 24 hours in only 20 cases; in 27 cases they had been present for over three days. Only 12 of the 69 children who died with major terminal symptoms had seen a doctor within 24 hours before death. Fourteen had seen a doctor earlier in the terminal illness. Thus 57 were not receiving close medical supervision for major symptoms. Four of the 19 control children with major symptoms had been seen in the previous 24 hours, and a further four had been seen earlier.

Table VI shows the presence or absence of symptoms at different ages. The incidence of symptoms did not change significantly with increasing age. Similar negative results are found if different categories of severity of symptoms are compared for age distribution.

Discussion

This continuing study already clearly shows that an important minority of the children who die at home have major symptoms during their terminal illness, which are often present for a considerable time—for days rather than hours. Many children have

non-specific symptoms rather than the physical signs of life-threatening illness that are traditionally taught in medical schools. Recognition of these non-specific symptoms by doctors depends more on obtaining a careful history from the parents than on physical examination. Few parents, too, seem to have appreciated the importance of unusual drowsiness, irritability, excessive crying, an altered character to the cry, or being off feeds, either in isolation or as markers of deterioration in children with respiratory or gastrointestinal illnesses.

We are not suggesting that all the children who had major symptoms should have been referred to hospital or that they would have benefited from the earlier prescription of drugs. Indeed, as drug treatment is rarely indicated for respiratory illnesses and gastroenteritis at this age, it might be counter-productive, giving false reassurance to parents so that they might delay recalling the doctor despite the child's evident deterioration. It seems essential, however, that any child with non-specific symptoms—which may be the only evidence of developing meningitis or septicaemia—should be kept under close review. If home circumstances are satisfactory, if the parents can be relied on to call for further help at the first sign of deterioration (such signs having been clearly explained to them), and if the primary care team can undertake close supervision then continued observation of the child at home will often be appropriate. We are still investigating how far these conditions are not being fulfilled and which are the crucial deficiencies in the use and provision of health services for acutely ill young children. A definition of which children would be safer under observation in hospital is needed but not yet clear. Closer analysis of the data and comparisons between the histories given by the parents, family doctor, and health visitor may establish that non-specific symptoms should determine when hospital referral becomes appropriate, especially if there is already evidence of respiratory illness or gastroenteritis.

The construction and use of a clinical classification of deaths occurring unexpectedly at home is only one step towards understanding a complex medical and social problem that almost certainly needs several different solutions. A later stage of the study will be to try to match the histories with the histology, so that we can interpret more precisely the importance of minor pathological changes, especially when the fatal process may have proceeded too rapidly for major tissue changes to have developed. Comparing pathological findings with the symptoms elicited may also help to indicate cases in which the observation or history was inadequate.

Once those children dying of inadequately recognised illness have been identified it should be possible to define the epidemiological characteristics of children who die unexpectedly despite appearing to be well. This is a crucial step before prospective investigations of cardiac, respiratory, neurological, and other physiological mechanisms of death can be undertaken in manageable numbers of children.

Such fundamental research is a long-term commitment. The preliminary results of this study show that a large proportion of deaths might be prevented now if existing knowledge were better applied. There is an urgent need to improve the recognition by both doctors and parents of non-specific symptoms as markers of severe illness in young children and their understanding of the necessity for rapid and appropriate action.

This work has been supported by grants from the DHSS. We are grateful to the families, doctors, health visitors, and interviewers for co-operating with the study.

References

[1] Froggatt, P, Lynas, M A, and Marshall, T K, *Ulster Medical Journal*, 1971, **40**, 116.
[2] Cameron, J M, and Watson, E, *Journal of Pathology*, 1975, **117**, 55.
[3] McWeeny, P M, and Emery, J L, *Archives of Disease in Childhood*, 1975, **50**, 191.
[4] Working Party for Early Childhood Deaths in Newcastle, *Archives of Disease in Childhood*, 1977, **52**, 828.

(*Accepted 11 September 1978*)

Severe hyponatraemia in hospital inpatients

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British Medical Journal, 1978, **2**, 1251-1253

Summary and conclusions

A prospective study of severe hyponatraemia in adult hospital inpatients showed that 44 patients had plasma sodium concentrations below 125 mmol(mEq)/l. Eighteen cases (41%) were iatrogenic, caused by diuretic treatment or postoperative administration of intravenous 5% dextrose, or both. Chest infection, a seldom-recognised and ill-understood cause of hyponatraemia, proved more common than carcinoma of the bronchus. Thirty-one patients had symptoms attributable to the hyponatraemia, but these were severe in only five cases. Analysis of blood and urine was of no value in distinguishing the different diagnostic groups in an emergency.

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Introduction

Many studies of cases of hyponatraemia have been reported, some of which have been concerned with the so-called syndrome of inappropriate antidiuretic hormone secretion.[1-4] We report here an investigation into the incidence of severe hyponatraemia in an adult hospital population, the relative frequency of different causes, and the clinical importance of the condition. We have also assessed the clinical value of analyses of urine and blood in distinguishing the causes.

Methods

We were informed by the laboratory of all patients aged over 14 years with a plasma sodium concentration of under 125 mmol(mEq)/l. Patients were assessed clinically by one of us (PK or DM), with particular reference to the state of hydration, possible symptoms attributable to hyponatraemia, and the probable cause of the condition.