# Newcastle survey of deaths in early childhood 1974/76, with special reference to sudden unexpected deaths

# WORKING PARTY FOR EARLY CHILDHOOD DEATHS IN NEWCASTLE\*

SUMMARY All early childhood deaths within a total population of 297 000 were studied by prospective methods. 70 deaths of children aged 1 week to 5 years occurred during a 27-month period; 36 died at home, 29 suddenly and unexpectedly. An extensive standardized necropsy showed a disease process clearly or probably related to death in half the sudden unexpected deaths; in the remainder no recognized disease process was identified.

The events preceding sudden unexpected death, and the child's environment, were investigated by a controlled parental interview. Symptoms of serious illness within 24 hours of death were identified in 9 of the 29 children, but in the majority symptoms were thought to have been absent or no more severe than those of the control children. Most children with major symptoms had been seen by a doctor within a few days of death. The two most striking social findings were that 16 of the 29 sudden unexpected deaths occurred at a weekend or bank holiday, and that 45% occurred in three adjacent city wards which contain only 13% of the under-five study population. The additional support and explanation provided during the home visits was greatly appreciated by the bereaved families.

Postneonatal mortality remains unacceptably high. The rate for Newcastle upon Tyne in 1971 was  $11 \cdot 1$  per 1000 live births, the highest since 1953. A major component of this mortality is the sudden infant death syndrome (SIDS). A number of studies have suggested that the common factor in these deaths is an acute terminal disease process, such as respiratory virus infection, which may have progressed too rapidly or been recognized too slowly for effective treatment to be instituted (McWeeny and Emery, 1975; Cameron and Watson, 1975; Downham *et al.*, 1975). Most of these studies however can be criti-

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cized; some have been selective, dealing for example only with deaths at home, or only with deaths referred for necropsy; others have not included special necropsy investigations such as virology and vitreous humour chemistry. Inquiry into the events preceding death, and home conditions, has sometimes been inadequate and uncontrolled.

We therefore embarked in January 1974 on a prospective attempt to study all deaths of children aged 1 week to 5 years within the Newcastle Metropolitan District (total population in 1974, 297 000). We report here our results up to 1 April 1976. The study has included a full standardized necropsy, with virology, bacteriology, and vitreous humour chemistry, and a controlled parental interview for deaths at home. A further objective was to provide additional support for the bereaved families.

#### Methods

A working party set up in 1973 with representatives from both hospital and community planned the survey and thereafter met at regular intervals to review the findings for each death. The working party is composed of a paediatrician (convener), paediatric pathologist, two nursing officers (health visiting), general practitioner, area medical officer, professor of child health, professor of virology, specialist in community medicine (child health), area nurse (child health), and the community divisional nursing officer.

Surveillance. Extensive efforts were made to obtain early notification of all deaths within the survey definition, so that necropsy could be expedited, and the events leading up to the death investigated without delay. Approaches were made to general practitioners through the Local Medical Committee, health visitors, hospital paediatricians, paediatric ward sisters, surgeons in charge of casualty departments, pathologists, and Her Majesty's Coroner. All were asked to notify by telephone either the survey paediatrician or the survey pathologist as a matter of urgency whenever the death of a child aged 1 week to 5 years, with a home address in the Newcastle Metropolitan District, came to their notice. Paediatricians and general practitioners were requested to obtain consent for a necropsy whenever possible. The survey paediatrician and pathologist were in close co-operation and were responsible jointly for ensuring that the various aspects of the investigation were carried out. Surveillance was checked for completeness by studying the weekly extract from the Registrar of Deaths.

Necropsy. Once a death was notified and permission for necropsy granted, a necropsy was performed as early as possible by the paediatric pathologist, or in a small number of cases by his deputy. The necropsy was standardized, according to a written protocol, and extensive, with histological examination of all major organs. The following special investigations were included: *virology* on tracheal and bronchial swabs and lung tissue; *bacteriology* of blood, urine, cerebrospinal fluid, laryngeal swabs, and faeces; *vitreous humour* osmolality, sodium, potassium, and urea estimations; and skeletal *radiological* survey.

Home deaths. Once notified of a home death the survey paediatrician contacted the general practitioner by telephone and after a brief discussion about the family background and the child's medical history and any terminal illness, obtained his consent for further investigation.

One of the two community nursing officers associated with the study then visited the bereaved family. The optimum time for this visit was found to be 5-7 days after the death. The primary purpose of the visit was to complete a standardized home interview, which included questions on the terminal illness, action taken, previous medical history, feeding history, family history, household and social organization, and the use and availability of medical services. At the end of the interview the nursing officer made an appointment for the survey paediatrician to visit the family.

The purposes of the paediatrician's visit were to clarify any clinical symptoms revealed in the first interview and to offer additional support and counselling to the bereaved family. One or more further visits were usually made to continue the support, and the families were encouraged to contact the paediatrician if they felt he could be of help.

Hospital deaths. Once notified of a hospital death the survey paediatrician contacted the paediatrician who had been caring for the child during the terminal illness, and discussed with him the child's history and death. A summary was then made with the help of the hospital records.

**Case conference.** The working party met at approximately monthly intervals to review the findings for each death. The home interviews were described by the nursing officer and the survey paediatrician, the necropsy findings by the pathologist, and special investigations by the pathologist and virologist. Each person presented his findings without previous knowledge of the other results. The general practitioner and health visitor, and if involved the paediatrician and any social agencies, were invited to attend this meeting and encouraged to comment and take an active part in the discussion. After consideration of the evidence presented, the working party collectively arrived at the best available clinical and pathological diagnosis.

Controls. For every sudden unexpected death at home, irrespective of pathological diagnosis, a control child with a home address in the Metropolitan District of Newcastle, matched by age and sex, was identified from the birth lists of the maternity units. As soon as possible after the death, usually within 3 weeks, the same home interview was completed for the control child by the same nursing officer. Date of interview was taken as equivalent to date of death for questions relating to recent illnesses and events. For 3 deaths these arrangements failed, and control families were not interviewed. All families approached agreed to co-operate. Statistical comparisons between deaths and controls were made by the  $\chi^2$  test, with Yates's correction for small numbers.

## Results

Between January 1974 and March 1976 (27 months) there were 70 deaths of children aged 1 week to 5 years. 36 of these children were aged 1 month to

12 months, giving a postneonatal mortality rate of 6.0 per 1000 livebirths for 1974, and 4.8 for 1975.

Clinical diagnosis and place of death. The 70 deaths are categorized by clinical presentation and place of death in Table 1. 36 of the 70 deaths occurred at home, and 29 of these were sudden and unexpected. although one was of a child with known but not yet severe cystic fibrosis, and one had poorly controlled epilepsy. One sudden unexpected death occurred in hospital: this baby had failed to thrive, and was thought to be suffering from acrodermatitis enteropathica. 5 children died with acute illness in or on the way to hospital; of these, 2 had a clinical diagnosis of meningococcal septicaemia, 1 gastroenteritis, 1 bronchiolitis, and 1 septic pericarditis. 6 children died as a result of injuries, 2 from drowning (1 in the river and 1 in the bath at home), 2 from fires in the home, 1 from a fall in the home, and 1 from nonaccidental injuries. 29 children died with chronic or congenital disorders, where a fatal outcome was inevitable.

Table 1Deaths of Newcastle children, aged 1 weekto 5 years, January 1974-March 1976, clinical presentationand place of death

	Place a	f death		
Clinical presentation	Home	Hospital	Other	Total
Sudden unexpected death	29	1	_	30
Acute illness		4	1*	5
Injury	3	2	1†	6
Chronic or congenital illness	4	25		29
Total	36	32	2	70

\*Ambulance; †River.

Necropsy findings. The necropsy findings for the 29 children who died suddenly and unexpectedly at home are summarized in Table 2. The extent to which a pathological finding can be interpreted as a primary or precipitating 'cause of death' remains a fundamental problem. However an attempt, inevitably arbitrary, has been made to assign the pathological findings to three categories: those with major findings which in our opinion were sufficient to account for death (3), a group with evidence of a recognized disease process but in which we felt there was uncertainty about the relationship of these findings to the death (11), and those in whom no evidence of a recognized disease process was found (14). The second group is made up largely of children with histological and virological evidence of respiratory tract infection. The histological changes were patchy, and not extensive enough to suggest a clear explanation for the death, though the possibility remains that virus infection may kill too rapidly to

allow extensive histological changes to develop. Interpretation is particularly difficult in this area, and a more detailed analysis of respiratory tract histology and virus findings for a larger series of deaths will be presented elsewhere. Similarly doubt remains about the significance of vitreous humour osmolality and electrolyte findings after death. The reasons for including 1 child in the first group, and 2 children in the second group, on account of their vitreous humour chemistry, will be argued in a separate paper. In the third group, many of the 14 children showed a variety of histological changes in thymus, liver, costochondral junctions, and respiratory tract, the significance of which is not known but which suggest a period of ill health before death.

 Table 2
 29 sudden unexpected deaths at home, necropsy findings

nyperosmolar 1
caemia and adrenal
la and aurenai
ronchopneumonia 1
piratory syncytial virus 2
us) 1
and adenovirus 1
no virus) 3
1 tracheobronchitis 1
1
and tracheobronchitis 1
1
14
1

\*Tracheobronchitis as defined by Tapp et al. (1975).

Of the remaining 42 children, 24 had necropsies, which in all cases confirmed or extended the clinical diagnosis. The necropsy findings of the 7-month-old baby with acrodermatitis enteropathica, who died unexpectedly in hospital, gave no explanation for his sudden death.

Sudden unexpected deaths at home. The incidence of sudden unexpected deaths at home was 3.76 per 1000 live births for the 2-year period 1974–1975. The age distribution for these deaths is shown in Fig. 1, and the distribution by month of death in Fig. 2. 21 of these 29 children were boys.

Day of death and time at which the baby was found dead are shown in Figs. 3 and 4 respectively. 16 of the 29 children were found dead at the weekend or on a bank holiday, and in 21 cases the death was discovered between 6.00 a.m. and 12 noon. 8 of the children were found dead in their cots, 10 in prams, 7 in carry-cots, and 4 in the parents' bed.



Fig. 1 Age distribution of sudden unexpected deaths at home.



Fig. 2 Sudden unexpected deaths at home—distribution by month (1974 and 1975 only).



Fig. 3 Sudden unexpected deaths at home-day of death.

Symptoms and action taken. Symptoms observed in the 24 hours before death and the action taken by the parents are shown in Table 3, with equivalent data for the control children relating to the 24 hours before interview. There is a significant difference between the two groups if all symptoms are categorized together, but if an attempt is made to divide symptoms into 'major' and 'minor', the difference holds only for major symptoms. Major symptoms were defined as those which, in the retrospective view of the working party, indicated a need for medical intervention and probably hospital admis-



Fig. 4 Sudden unexpected deaths at home—time of day found dead.

Table 3	Sudden	unexpected	deat	hs at	home	and
controls-	-sympton	ms observed	l in th	ie 24	hours	before
death/inte	rview an	nd action tai	ken			

	Deaths $(n = 29)$		Controls (	n == 26)
	Major symptoms	Minor symptoms	Major symptoms	Minor symptoms
No action	2	5	_	3
Home remedies	1	-		1
Seen by doctor within				
1 week	2	6	1	3
Seen by doctor within		-		
24 hours	4	1		
No symptoms	. 8		16	
Not known	-		2	

Note: In Tables 3, 5, 6, and 7, 29 sudden unexpected deaths are compared with 26 controls; controls were not obtained for 3 deaths (see text).

sion. They included a marked change in feeding habit, repeated vomiting or diarrhoea, obvious fever, and rapid or difficult breathing. The assessment of symptoms was made without reference to necropsy findings. The majority of the children with symptoms who died were seen by a doctor within a few days of death. Of the 5 children with major symptoms who were not seen by a doctor within 24 hours of death, 4 died during a weekend or bank holiday.

Table 4 shows the relationship between clinical and pathological evidence of illness. All 3 children with major pathological findings had had major symptoms observed, but there were also 3 children with major symptoms in the 'probably significant' pathological group, and 2 among those with findings of unknown significance. 20 of the 29 children who died had not been observed for at least 5 hours before the time discovered dead, including 5 of the 8 in whom no symptoms had been noted.

Social factors. Parents' age, social class by father's occupation, and type of housing are shown for the

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Significance of necropsy findings*	Observed	symptoms	
	Major	Minor	None
Clearly related to death	3		
Probably related to death	3	6	2
Unknown significance	2	6	6
No necropsy	1		

Table 429 sudden unexpected deaths at home—relationship between necropsy findings and symptomsobserved before death

\*See Table 2.

children who died and the control children in Tables 5–7 respectively. There is a significant excess, for the children who died, of mothers under the age of 21 (P < 0.05), and fathers under the age of 25 (P < 0.05). In the social class comparison there are more unemployed fathers among the families where children died, and no fathers whose occupations were in social class I and II; only the second of these two differences from the control group is significant (P < 0.05). There was a marked difference in the type of housing occupied by the two groups of families; none of the 29 families whose children died owned their houses, and 23 lived in houses rented from the city housing department.

The distribution of home deaths by city ward is shown in Fig. 5, with estimated under-five populations for each ward (Urban Trends, 1975). There was a marked clustering of deaths in three adjacent riverside wards, where 45% of the deaths occurred among an under-five population which makes up only 13% of the city total.



 Table 5
 Sudden unexpected deaths at home and controls—parental age

Age (yrs)	Deaths		Controls	
	Father	Mother	Father	Mother
≪17		3	_	1
18-21	4	10	2	3
22–25	12	13	5	10
≥25	11	3	18	12
Not known (unn	arried			
mother)	2		1	-

Table 6	Sudden unexpected deaths at home an	nd
controls-	-social class by father's occupation	

	Deaths	Controls	
 Unemployed	7	2	
v	8	7	
IV	2	0	
III M	7	7	
III NM	3	4	
I & II		5	
Unmarried mother	2	1	

 Table 7
 Sudden unexpected deaths at home and controls—housing

	Deaths	Controls
Own house		10
Privately rented	6	12
City housing department	23	4

Use of medical services. The families were asked about the frequency of their contact with health visitor and general practitioner ('frequent', 'occa-

Fig. 5 Sudden unexpected deaths at home by city ward, with estimated 1975 under-5 population for each ward in parentheses.

sional', 'rare or none'). There were no significant differences between the two groups of families, but there was a trend towards greater reported contact with both health visitor and general practitioner among the families in which a death had occurred. 5 of the 29 children who died at home, and 2 of the 26 control children, had a history of previous hospital admission.

Counselling. Without exception the families whose babies died suddenly and unexpectedly at home welcomed the opportunity to talk to the nursing officer and then the paediatrician. Four lines of discussion seemed particularly helpful. The families found comfort in the understanding that 'cot death', despite its uncertain aetiology, is a well-defined syndrome, and that a very similar tragedy is experienced by 10-15 families in Newcastle annually. It was also helpful, in the majority of cases, for parents to know that after a thorough search we had been unable to identify anything in their management of the baby which might have been responsible for the death. Thirdly, we were able to tell the parents that the necropsy investigation had shown nothing to suggest an increased risk for future pregnancies. Several of the families have subsequently produced new babies and sought further reassurance during pregnancy and the months after delivery. Fourthly, nearly all families welcomed the opportunity to contribute to an investigation aimed at understanding the causes of 'cot deaths', with the hope of preventing similar experiences for others.

We came to realize that it is often difficult for the family doctor and health visitor to provide as much support as they would like for this kind of bereavement. 'Cot death' occurs too infrequently within any one practice for an individual practitioner or health visitor to gain much experience of the problem. Furthermore the relationship with the family may be strained by resentment on the part of the parents or guilt on the part of the family doctor or health visitor, especially if a consultation took place shortly before death. General practitioners and health visitors therefore welcomed the survey visits, and saw them as a contribution to their continuing relationship with the family.

# Discussion

By studying continuously an unselected series of deaths we are attempting to describe the contemporary pattern of early childhood mortality for an urban population. The outstanding feature is the high proportion of deaths which occur at home, most of them suddenly and unexpectedly.

The postneonatal mortality rates, 6.0 and 4.8 per

1000 live births for the 2 complete years of the survey, were unexpectedly low but parallel the national trend—the figure for England and Wales was 5.0 for both years. The reasons for this improvement are not clear, but we note that in 1971, when the rate in Newcastle was 11.1, 50% of the deaths occurred at home, whereas during our present study the proportion was 64%. This suggests that a fall in hospital deaths is largely responsible for the overall trend. As deaths in Newcastle in 1971 were not studied in detail, we are unable to say whether hospital mortality at this age is falling because of improvements in hospital paediatric services or because fewer ill children are reaching hospital to die. The former however seems more likely, since our incidence of 3.76 per 1000 live births for sudden unexpected death at home in 1974 and 1975 is similar to or slightly greater than that reported from other urban centres over the past decade.

We experienced a number of difficulties in the study. Despite careful plans to encourage early notification of deaths, we have found that the mortuary attendant is usually our earliest source of information for home deaths, and even for hospital deaths it has taken a long time to sensitize paediatricians and nursing staff to the survey, especially as Newcastle children may be admitted to any of 7 hospitals. On two occasions, one sudden death at home and one in the ambulance, the general practitioner issued a death certificate without reference to the coroner, so that no necropsy was carried out, and it was only several weeks later that the death became known to us. The timing of the home visit after sudden unexpected deaths was the subject of much thought and experiment; we found that it was difficult and unfruitful to go into the home before the funeral but that after this the sooner we visited the better, both for the collection of information and for support. The nursing officer did not find it necessary to announce her arrival by letter, and was only sometimes introduced by the family doctor or health visitor.

We hope that by describing these difficulties we will encourage other centres to carry out similar and perhaps less incomplete surveys of their mortality patterns. No special funds or posts were made available for our study, and we believe that all paediatric departments and community services in major centres would quickly recognize the advantages of a co-operative investigation of this kind. As well as the knowledge gained about mortality factors, which may vary for different centres, and the benefit to bereaved families, the exercise provides one much-needed bridge between the local hospital and community child health services.

The results of our investigations, clinical and

pathological, into the causes of sudden unexpected deaths at this age suggest that a minority (3 out of 28 in our series) are clearly preventable. In this group the causes are well known treatable conditions, with major symptoms before death, whose urgent significance was not adequately recognized. These children are part of a continuous spectrum with those who die from the same conditions in or on the way to hospital, usually because they have arrived at hospital too late in the illness for treatment to be effective, and with those who arrive at hospital earlier and survive. There is also a larger group of sudden unexpected deaths (11 out of 28 in our series) which may be preventable in the same sense, when the significance of histological and virus findings in the respiratory tract, and of biochemical findings in vitreous humour, are better understood. We are currently trying to define significant abnormality in both these areas, by a wider study of deaths not restricted to Newcastle children. However, even if we can strengthen the evidence that respiratory infection or hyperosmolality are significant factors in this group, we are left with the difficulty that in the majority of cases warning symptoms seem relatively trivial, and are not apparently different from those frequently experienced by control children. These minor symptoms were usually snuffles, or a cough, or a single vomit, or slight restlessness, in a baby whose feeding and behaviour seemed otherwise to be normal.

There also appears to be a large third group of sudden unexpected deaths (14 out of 28 in our series), in whom there is no pathological evidence of a recognizable disease process, and whose symptoms, if any, are usually minor. In this respect our conclusions differ from those arrived at in Sheffield, where Emery and his colleagues claim to have found necropsy evidence of a recognizable disease process in every one of a series of 40 sudden unexpected deaths (Emery et al., 1974). They also suggest that most children dying in this way have warning symptoms, though they have not attempted to assess the severity of symptoms (McWeeny and Emery, 1975). Our findings are at variance too with those of the Inner North London study, where an adequate pathological explanation for death was found in 57 of 62 (92%) babies dying suddenly and unexpectedly, and major warning symptoms were traced in a similarly high proportion (Cameron and Watson, 1975).

Such marked differences from other studies demand an explanation. Part of the discrepancy almost certainly lies in variable interpretation by different pathologists of histological findings, especially in the respiratory tract. We are currently attempting to improve standardization by a quantitative approach to respiratory tract histology. There is also inadequate information on which to base agreement about the normal range of vitreous humour chemistry at necropsy. Emery and his colleagues found that estimation of vitreous humour sodium and urea helped to explain death in nearly half those cases of sudden unexpected death which otherwise would have remained largely unexplained (Emery et al., 1974); our evidence does not suggest that this is so in Newcastle (Warnasuriya et al., 1977). These difficulties are not only a matter of standardization; there is also the problem of how extensive a given lesion must be to constitute a 'cause of death', a question which will remain philosophical until much more is known about pathogenic mechanisms of death.

Symptoms are also subject to interpretation. We have concluded that in the majority of cases (20 out of 29) there were no symptoms of such severity that different action on the part of the parents or health services would have been more appropriate. Symptoms were assessed at two home visits in our study, first by the nursing officer and then by the paediatrician, and their nature and severity was further debated by the nursing and paediatric members of the working party. It is possible that this approach may explain the discrepancy with other studies, in which we gather that a joint assessment by nurses and paediatricians was not involved.

Can we learn for the future from the 9 sudden deaths which might have been prevented, in that major symptoms were judged to be present? In 6 out of 9 cases the baby had been seen by the general practitioner within a few days of death, in 4 cases within 24 hours (Table 3). Contact with general practitioner and health visitor was not less for families whose children died than for control families, at least according to the parents' view. We therefore suggest that success in preventing postneonatal deaths is likely to come from improvements in health services for young babies, as well as from changes in parental attitudes. Our emphasis here is in agreement with the conclusions of the Inner North London study, but differs from the Sheffield view, which puts more weight on parental attitudes.

Are there ways, apart from the recognition of terminal symptoms, by which babies at risk of sudden death can be identified? Much work has been done in Sheffield in an attempt to define a high risk group by perinatal factors (Protestos *et al.*, 1973), refined recently by data obtained at 6-week examination (Carpenter *et al.*, 1977). Our findings for age and sex of the baby, parental age, father's occupation, and type of housing are not new. Similarly the increased incidence of sudden death in winter months—20 out of 29 between November and March (Fig. 2)—has

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often been described before, though the implications for any preventive effort have perhaps not been adequately emphasized. Two lines of inquiry and analysis however produced results which may indicate new approaches to prevention. The first concerns the timing of the death; we noted that 16 of the 29 deaths occurred at weekends or on bank holidays, that 21 out of 29 babies were found dead between 6.00 a.m. and 12 noon, and that 20 of the 29 had not been observed for at least 5 hours before death was discovered. These findings may be partly explained by the known fact that sudden death occurs most often during sleep; but they also suggest a special need at nights, weekends, and bank holidays for more regular parental observation and better availability of health services. Secondly, we found marked clustering of sudden deaths in certain city wards, particularly three adjacent wards (Fig. 5). These wards are among those recognized as 'stress areas' by the Newcastle Metropolitan District Council, because they contain a high proportion of households suffering socioeconomic deprivation (Urban Trends, 1975). These areas therefore receive preferential allocation of resources from the social services and education departments. We suggest that careful consideration should be given to similar preferential allocation of health services for families and young children living in such areas, especially with regard to numbers of health visitors and open clinics for mothers and children.

## Conclusions

We feel able to draw the following main conclusions at this stage of our investigation.

(1) Some early childhood deaths are preventable by more rapid application of existing methods of treatment of known childhood illnesses. The size of this group, the distribution of illnesses within it, and the ways in which access to appropriate treatment can be improved need further study on a multicentre standardized basis. (2) It seems that symptoms before cot death often consist of only minor disturbances similar to those seen in many babies who do not die. The decision when to intervene, for example by hospital admission, may therefore be difficult to judge, even for a well-defined group at risk.

(3) Some early childhood deaths, probably not as small a number as has been indicated in the recent past, have unknown causes, and will not become preventable without continued intensive research into pathogenic mechanisms.

(4) There is a growing urgency to consider ways of improving health services for families with young children, and for increasing the allocation of health resources to priority areas.

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