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A Two-Year Study of Sudden Death in Infancy in Inner North London

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Introduction

The Inner North London Project represents a two-year study of the problem of sudden death in infancy undertaken between January 1972 and January 1974 in four London boroughs. The areas covered in the surveys were Camden, Hackney, Tower Hamlets and Islington.

It was intended as a pilot scheme to see whether the format adopted was suitable as the basis of a national scheme for the notification and investigation of sudden unexpected death in infancy. In addition it was desired to provide some supportive advice for the bereaved parents to help prevent them experiencing guilt feelings "based on prevalent but now discounted theories of parental carelessness" (Emery, 1972).

The method adopted depended on the voluntary co-operation of health departments, the coroner and hospital staff.

In the investigation the names, addresses and cause of death of all babies between the ages of 2 weeks and 2 years reported to the coroner, and excluding the obviously battered babies, were given to the appropriate principal medical officer and she, together with a health visitor, arranged a visit to the stricken family as soon as was practicable after the death. (The medical officer and the health visitor having first met and entered on the questionnaire all appropriate details from clinic records and hospital discharge forms.)

As much information as possible was gathered at this first very important interview and all key questions were asked and then, at a much shorter interview three weeks later, any history of infection in the family was carefully noted and any gaps filled in which had been left on the original form.

The interviewers found that a useful therapeutic document had been provided for "talking through" a harrowing experience which most parents appreciated and also a comprehensive "in depth" interview which was needed for research. To establish the credibility of the witness it was important that the parents had a compassionate but dispassionate listener who could assess factors such as hostility to medical attendants or other members of the family, or attempts to either deny or exaggerate symptoms present in the child. As a further aid to credibility it was aimed to make the questionnaire a "self-checking" document. It was intended to verify the correctness of the mother's recollections and to see whether her account of her baby's last weeks tied in with the actual medical history and in several cases discrepancies were found, e.g. one mother in the cot death group said in answer to the question "What illness did your child have in the three weeks before its death?" that her child had only suffered from a runny nose and yet, later on, in answering the question "Did your child see a doctor in the last three weeks before its death?" she recalled that an emergency doctor had been called in two days before the child's death because it had a chest infection, and their own family doctor had visited the child on the

day before it died. This obviously raised the question was this in fact a very sick child not recognized and not in fact a classical cot death?

The interviewers noted that very often the second interview seemed set and rehearsed and that the really valuable visit was the initial one when the parents tended to speak more spontaneously.

Scientific Results

At the end of two years 67 questionnaires were examined, 36 of which fell into the category of unexplained or cot death and 31 who died as evident at autopsy from some specific disease (the number of interviews was actually 56; 11 parents were not interviewed but the information was filled in as far as possible from health visitor's or medical records). The definition of cot death was taken from Dr Beckwith's declaration given in 1969 at the 2nd International Conference in Seattle, Washington on causes of sudden death in infancy, i.e. "The sudden death of any infant or young child which is unexpected by history and in which a thorough post-mortem fails to demonstrate an adequate cause of death".

It was found, as expected, that there were many similarities with previous studies. The baby who succumbed was a child, usually in a low socio-economic situation, with an average, fair, or below standard of mothering, as assessed by our criteria, often of below average birth weight, dying in its sleep, usually at night and in the winter months. The age patterns also corresponded to previous studies.

When a comparison was made between the two groups of babies, i.e. the cot death babies and those with disease evident at autopsy, which had been accepted as a control group, it was found that there was virtually no difference between the two groups of children. Both sets of children who died had had symptoms of illness of varying severity during the three weeks before death except for six of the cot death babies and three of the controls (one other case was subsequently found to have been strangled and in three other cases there was inadequate information on their history of infection).

The picture did not fit what was expected of a typical cot death baby. Some examples of the unexplained or cot death babies' histories are as follows:

(1) An 8-week baby with a cough was taken to the clinic for a check-up 4 days before its death. There they had been dissatisfied with its progress. For the last 2 days of its life the baby suffered from a cold, cough, vomiting and diarrhoea, and apparently had "screamed and howled" continuously and yet had not been taken to the doctor for treatment.

(2) A 10-weeks child had a respiratory infection, vomiting and diarrhoea 8 days before its death. Having taken the child to hospital the parents were told the baby had "gastric troubles" and that they should dilute the feeds. The child continued to vomit so a deputy doctor was called the following day; he suggested glucose feeds. Four days before death the parents returned to the hospital with the child and were told that its progress was satisfactory as it was no longer vomiting. The mother found that the child was now so weak that it could no longer suck and so she fed it from a spoon until it died.

(3) Two weeks prior to death a 30-week-old baby had been taken to the doctor with a respiratory infection, yet the medicine prescribed had only been given intermittently. Two days before death the baby was feverish and restless. The mother took it *in extremis* into hospital where it died during the night.

(4) An 18-week-old baby had been discharged from hospital a month earlier where it had been admitted suffering from tonsillitis. According to the mother it had been unwell ever since with a respiratory infection although a chest X-ray the day before the child's death had not revealed anything of significance.

All these and many others which could be quoted were obviously sick children who were not recognized, as such, quickly enough, sometimes by their parents and occasionally by their medical attendants.

Meanwhile Professor Cameron was examining the histology of all the babies in detail. Working blind, and without taking into account the clinical history, he found that with this detailed histo-pathological examination he could only find five babies out of his group of 62 children (five autopsies were undertaken at other hospitals) who showed no evidence of obvious significant disease. In other words 57 out of 62 babies showed pathological lesions sufficient to account for their death.

His figures closely agreed with the sociological evidence which had been collected from the questionnaires. In fact there was a surprising unanimity by two separate investigators—a sociologist and a pathologist. This obviously raised the question whether the incidence of cot death as defined by Dr Beckwith was, on the Inner North London project's findings less than had been thought before. This study of two years' consecutive deaths of this nature in a typical urban area suggest that the percentage without pathology sufficient to account for their death, and, more surprisingly, without clinical evidence of illness in the child is much *lower* than generally supposed.

Nevertheless sudden death in infancy is still a very real medical and sociological problem. The dramatic and unexpected death of these babies regardless of pathological findings and clinical history still poses a major medical problem. In particular some babies may be especially susceptible by virtue of allergy, immuno-deficiency, over-sensitive respiratory reflexes or other factors currently being researched.

The association of infection with sudden infant death should be too well known to need stressing. However these findings do suggest that everyone caring for small infants, whether as parents or as medical attendants, should be alerted to the dangers of infection and minor illnesses in children of this age group.

In view of the speed with which these babies die this advice may seem useless. However, results are trickling in from various corners of the world which suggest that the incidence of sudden infant death can be reduced, perhaps dramatically, by really close attention to the babies most "at risk". It would be foolish therefore to suppose such measures might not be effective in our own community.

The steps which could be adopted are a matter for discussion but may well emerge from the prospective study of cot death being undertaken in Sheffield by Professor J. Emery and Mr R. G. Carpenter.

The final impression to emerge is the key role which those concerned with community health, health visitors, community physicians, general practitioners and social workers to name but a few, will inevitably play in the final control of the problem of sudden death in infancy.

Reference

Emery, J. (1972). *British Medical Journal* **1**, 612.