- 14 Roberts AH, Reinhardt L. The behavioural management of chronic pain: long term follow up with comparison groups. *Pain* 1980;8:151-62.
- 15 Cinciripini PM, Floreen A. An evaluation of a behavioural program for chronic pain. *J Behav Med* 1982;5:375-89.
- 16 Keefe FJ, Block AR, Williams RB, Surwit RJ. Behavioral treatment outcome of chronic low back pain: clinical outcome and individual differences in pain relief. *Pain* 1981;11:221-31.
- 17 Ignelzi R, Sternbach R, Timmermans G. The pain ward follow up analysis. *Pain* 1977;3: 277-80.
- 18 Gottlieb HJ, Koller R, Alpersen BR. Low back pain comprehensive rehabilitation program: a follow up study. *Arch Phys Med Rehabil* 1982;63:458-60.
- 19 Painter JR, Seres JL, Newman RI. Assessing benefits of the pain centre: why some patients regress. *Pain* 1980;8:101-13.

- 20 Cairns R, Thomas L, Mooney Y, Pace J. A comprehensive treatment approach to chronic low back pain. *Pain* 1976;2:301-8.
- 21 Maruta T, Yatterot MK, McHardy MJ. Pain management as an antidepressant: long term resolution of pain associated depression. *Pain* 1989;36:335-7.
- 22 Guck TP, Skultety FM, Meilman PW, Dowd ET. Multidisciplinary pain centre follow up with a no-treatment control group. *Pain* 1985;21:295-306.
- 23 Linton SJ. Behavioural remediation of chronic pain: a status report. *Pain* 1986;24:125-41.
- 24 Fisher K. Early experience of a multidisciplinary pain management programme. *Holistic Med* 1988;3:47-56.
- 25 Skinner J, Pearce SJ, Erskine A, Robinson I. An outpatient pain management programme. *J Psychosom Res* (in press).

Is sudden infant death syndrome a diagnosis?

Or is it just a diagnostic dustbin?

As infant mortality diminished in the first half of this century more attention was given to those babies dying unexpectedly and with less florid disease. The skills required to study such deaths had not, however, been developed, and the result was that diagnoses ranged from "pneumonitis" to "suffocation." The latter label led to parents being interrogated by the police and to social stigma. In 1969 a group in Seattle, believing that all of these were natural deaths, recommended that they should be registered as the sudden infant death syndrome.¹ This approach was rapidly copied throughout the world.

The diagnosis was seductive for five reasons. First of all, it enabled doctors to tell parents that their child had died of natural causes and that no one could have prevented it. It excused all concerned from any defect in care, diagnosis, and treatment. Pathologists welcomed the diagnosis: the less they found, the more certain they could be. Because the syndrome was of unknown origin health authorities had no basis for prevention. And finally, this diagnosis facilitated the development of parent support groups and the raising of money for research. Those concerned in research and support became media sensitive, and all concerned looked for the day when a genius would find "the cause."

This, then, is the setting in which armchair theories surface monthly. Yet, as the diagnosis is open, parents relate every new theory to themselves. If it concerns some obscure reflex, brain enzyme, or organism they are content, but any theory that reflects on the care of their child makes them feel threatened. They react, and they are supported by doctors who have developed an interest in their welfare.

At the XIX International Congress of Paediatrics in Paris in 1989 we were told that these deaths are increasing in Sweden (S G Norvenius) and Finland (P Rintahaka). The same has been occurring in New Zealand² and in some districts in Britain.³ One British group (E M Taylor) reported that only 17% of deaths diagnosed as the sudden infant death syndrome were completely unexplained. A Paris group concurred, describing seven of 45 as unexplained.⁴ The diagnosis depends on necropsy findings, but in Holland only half the infants so described have necropsies (J Huber,

personal communication) and in France the proportion is only a third (C Nezelof, personal communication). In Britain it is over 90%.

Questions are now beginning to be asked, including: Is there such an entity as the sudden infant death syndrome or is it a convenient diagnostic dustbin? If, as has been alleged, 5-10% of sudden infant deaths are infanticide is the label the sudden infant death syndrome facilitating infanticide? The justification for retaining the sudden infant death syndrome is the supposed benefit to parents, but who is benefiting—the doctors or the parents? The "no cause, no guilt" approach has never been subjected to any controlled trial; nor is there any evidence that a parent of a victim of cot death has greater need for help than one given a diagnosis of meningitis or of "cause unknown." To abolish the sudden infant death syndrome as a registerable cause of death would simply put the clock back to 1960. Among research workers there is much vested interest against change. Lip service is paid to possible multiple causes, but each acts as if his or her own theory is universal.

The speakers in Paris concluded that all postperinatal deaths should be examined in very great depth in a few centres that have the time and skill to do so; epidemiological studies should be based only on data from these centres; and journals should be encouraged to accept only those studies on the sudden infant death syndrome in which every child has been examined by a paediatric pathologist and been subject to a neutral confidential inquiry. What else can we do?

JOHN L EMERY

Emeritus Professor of Paediatric Pathology,
University of Sheffield,
Sheffield S10 3BN

- 1 Bergman AB, Beckwith JB, Ray CC. *Sudden infant death syndrome*. Seattle: University of Washington Press, 1970.
- 2 Hassall IB. Sudden infant death syndrome—a serious New Zealand health problem. *N Z Med J* 1986;99:233-4.
- 3 Taylor EM, Emery JL. Trends in unexpected infant deaths in Sheffield. *Lancet* 1988;ii:1121-3.
- 4 Dehan M, Imbert MC, Gautier JP, et al. Clinical and pathological analysis of 59 consecutive cases of sudden unexpected deaths in infants. *Arch Fr Pediatr* 1988;45:541-8.