Int. J. Prenatal and Perinatal Studies (1991) 55–62

Psycho-social Problems Associated with Increased Risk of Unexpected Infant Death

R.G. Carpenter, E.M. Taylor, and J.L. Emery*

*London School of Hygiene and Tropical Medicine, London, WC1E 7HT, Child Development Study, Department of Paediatrics, University of Sheffield

Abstract

Postnatal factors account for 50% of unexpected deaths. Preventive resources can be effectively targeted by risk scoring. Home visiting with naked weighing reduces high risk mortality by 50% and total mortality by 25%. Maternal history of psychological illness is an important risk factor as is discussion of termination of pregnancy. 33% of high risk families have multiple problems. Naked weighing focusses attention on the infant.

Introduction by Hans von Lüpke

The following paper by Carpenter, Taylor and Emery continues the integrative approach on Sudden Infant Death Syndrome (SIDS), that started in the ISPPM during a symposium at the International Congress in Jerusalem, March 1989. The papers are found in Vol. 1, No. 3 of this journal.

Among the immense amount of research about SIDS, the authors and coworkers, usually connected with Sheffield, are virtually the only ones that by their intervention could reduce the total infant mortality (by 25%) and the mortality of a high risk group (by 50%). This intervention seems to be rather simple: they initiate additional home visits by health visitors who 'discuss the health and development' of the infant as well as weighing it undressed. This is by far more than a pure routine health control: the procedure gives fundamental information about the interaction between mother and child and the opportunity for intervention in a psychological understatement.

In this paper, the additional impact of maternal history of psychological illness and the discussion of termination of pregnancy as risk factors is of special interest for those professionals who are in contact with the family prior to birth. The authors speak about 'unexpected death', SIDS being only a subgroup. This

Correspondence to: R.G. Carpenter, London School of Hygiene and Tropical Medicine, London WC1E 7HT.

is an additional aspect in the discussion about the usefulness of confining studies and interventions to SIDS in the strict and specific sense.

Finally, the concluding statement about the impact of multiple problem families, the question 'how we can begin to reduce the pressures and problems, both psychological and social, which surround many of the infants at greatest risk of unexpected death', is a challenge for interdisciplinary cooperation which the preceding papers and this journal in general strive to meet.

Review

Post neonatal mortality in England has declined little in the last ten years [1] and the situation is similar in most other developed countries [2]. Deaths in this age group may be broadly defined as inevitable or possibly preventable [3]. The latter group which comprise over 50% of the total are almost all unexpected and 70% are certified as due to SIDS or respiratory causes associated with SIDS. Unexpected infant deaths also include deaths due to acute infections. The distinction between these deaths and SIDS is not precise and from the public health point of view these deaths are often the most preventable [4].

Figure 1 shows the four age groups, the seasonal distribution of unexpected deaths attributed to SIDS or respiratory causes based on deaths in England and Wales over a ten year period [5]. In each age group the death rates are highest in December, January and February and lowest in the summer months. If seasonal variation were due to exposure of the fetus to some prenatal factor, e.g. maternal infection, the seasonal distribution of mortality would peak at different months of the year in different age groups. The synchronization of seasonal variation of the death rates for different age groups in Fig. 1 demonstrates that seasonal variation in unexpected infant deaths is essentially due to a *postnatal* factor associated with winter possibly affecting infants at a vulnerable stage of development. The two most obvious factors are temperature and infection. Improved health care could in principle reduce the impact of these factors. This analysis therefore suggests that a substantial proportion of unexpected deaths may be preventable by improved *postnatal* health care.

Many studies have shown that infants at increased risk of unexpected death can be identified by score systems similar to that used in Sheffield [6,11]. There is, however, some controversy as to the value of such score systems because the mortality rate of high risk infants is seldom greater than 2% and sensitivity, i.e. the proportion of deaths identified as high risk, may be less than 60%. In ordinary clinical terms these risk predictors are not very useful, although most people would seek and expect extra health surveillance if they were told that they had a 1 in 50 chance of unexpected death in the next six months.

The theory of risk related intervention [6,12,13] shows that even a comparatively weak risk predictor can substantially enhance the effectiveness of an intervention programme by focussing care on high risk infants. Thus, by using a risk predictor which identifies a high risk group comprising 23% of the population and which is expected to pick up only 60% of cases, an intervention programme can be

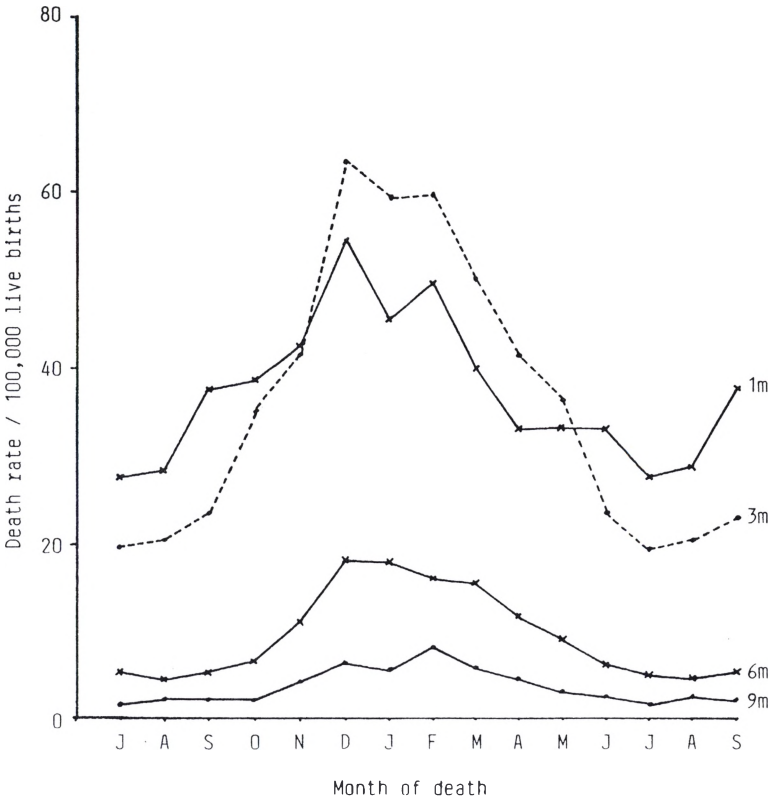

Fig. 1. Death rates by month of death and age.

focussed sufficiently to increase its effectiveness by 27% without increasing the resouces required[6].

Carpenter et al.[6] evaluated 10 years of risk-related intervention in Sheffield and studies in five other districts. The study concluded that intervention, comprising five extra home visits by health visitors, when the infant was weighed naked and the weights were charted, reduced mortality in the high risk group by 50% and overall mortality by 25%. A progressive reduction in post neonatal mortality has also been reported in West Virginia following the introduction of a risk-related intervention project along these lines[14]. Miller (personal communication) has also reported an abrupt 38% reduction in post neonatal mortality in infants of families of British Forces serving in Germany coincidental with the start of a similar intervention programme, $p = 0.07$. The small numbers of deaths do, however, make it extremely difficult to establish the magnitude of the effect of intervention. A formal randomized controlled trial, if it were ethical, would involve at least 100 000 infants to be reasonably certain of not missing a 25% reduction in overall mortality, i.e., power > 70%.

The results described above, turn on regression discontinuity analyses. Two approaches are possible. The first is to examine the relation of log (risk) to risk

score. If all children receive similar care, log (risk) usually increases linearly with score. When children with scores above a critical score, s, receive extra care the effect is to produce a step down in the relationship at s [6,12]. Analysis then compares the mortality at the bottom end of the treated high risk group with that observed at the top end of the untreated low risk group after making some adjustment for the difference in risk scores. The methodology has been advocated for social science research [15] and the validity of such comparison has been theoretically established by Rubin [16].

An effective intervention programme targeted at the high scoring infants will reduce the proportion of high scoring infants. Without fitting a logistic regression with a parameter representing the regression discontinuity, it is impossible to distinguish between an effective risk score coupled with an effective intervention, which corresponds to a steep slope and step down, and a less effective predictor plus an ineffective intervention, represented by a lesser slope and no step down.

A reduction in overall mortality is, however, the ultimate goal of intervention. So the second approach is to look for a discontinuity in the time trend in mortality for the district at the time the intervention programme begins. Such an analysis is beset with all the usual uncertainties associated with comparing the period before the study with the period when the study is in progress. Are the changes due to the intervention programme or to some other social changes which occurred at about the same time? Another problem is that in a district with around 6000 births per year, random variation in death rates makes it almost impossible to differentiate a downward trend from a step down, unless the study includes a substantial number of years before and after the start of the study. The impression of a downward trend rather than a step down is likely to be enhanced because 38% of deaths one year will have been born in the previous year. Consequently the effect of an intervention programme will only partially appear in the first year.

Failure to recognize these problems appear to have led Madeley and his colleagues [17] to conclude that intervention was not effective in Nottingham because the reduction in mortality could be described by a steep linear downward trend over the six years before and the five years after the intervention started. Simulation studies show that, had there been no underlying downward trend, but an abrupt 40% reduction in mortality following the start of intervention the resulting pattern of mortality could be described by a simple linear trend 85 times out of 100, i.e., the power of Madeley's analysis to detect an effect of intervention is only 15%. Extending the analysis to 13 years before and 18 years after the start of the programme increases power to around 75%. When 'possible preventable' post neonatal mortality in Nottingham was examined between 1965 and 1985, it was found that a model in which mortality before intervention was consistently 79% above the rate for England and Wales before intervention started and was then abruptly reduced by 38%, describes the observed pattern of mortality accurately. Furthermore, it fits the data significantly better than a simple downward trend $p < 0.05$. It therefore appears that Madeley et al. may have been misled in their conclusion that their intervention programme was ineffective. Further-

more, their attempts to explain the downward trend in mortality that they observed as being due to a reduction in the birth rate is demographically highly improbable and not supported by a study of trends in infant mortality and birth rates over an 8 year period in 98 districts in England and Wales. This showed that on average there was no correlation or lagged correlation between the two.

Two New Risk Factors

A case control study of 77 unexpected infant deaths that occurred in Sheffield between July 1979 and March 1987 and 129 randomly selected controls selected four previously undetected risk factors. Two of specific interest to the present discussion were found in the maternity records, namely a history of emotional or psychiatric illness including suicide attempt. 16 (20.8%) of cases; 1 (0.8%) of controls and second, termination of pregnancy discussed, 10 (13.0%) of cases compared with 1 (0.8%) of controls. Analysis showed that both these factors were highly significant after taking account of the risk scores and other factors.

Accordingly, data on both these factors has been routinely reported for all births since 1st June 1988. As a check, the prevalence of these risk factors in the first 1733 returns has been compared with the prevalence in the 23 unexpected deaths which occurred between March 1977 and September 1988. In these data there were 3, 11.1% of deaths in which there was a history of psychiatric illness compared with 2.5% of the population. Termination of pregnancy was discussed in 4, 14.8% of the cases and 1.8% of the population. So although the risk associated with a psychiatric history appears somewhat less in the new data than in the case control study, both data sets are in general agreement and taken together, indicate that both maternal history of emotional or psychiatric illness and a discussion of whether the pregnancy should be terinated are important new independent risk factors. When present, both have important implications for the mother/child relationship and probably affect the psychological development of the child.

Psycho-social Background

The risk factors, maternal age, parity, birthweight, etc, which together make up the Sheffield Month Score[6], do not in themselves give much indication of the psycho-social background of high risk infants. To do so, data on 321 high risk infants born in Sheffield since 1st June 1988 has been compared with a 13% random sample of 347 low risk infants. Table 1 shows the variables abstracted and the characteristics of the high and low risk groups. With the sole exception of weight gain in the first month, differences between the groups in respect of every variable, considered singly, is statistically very high $p < 0.001$.

The anxiety depression score, shown, is the Leeds anxiety depression score modified to make it appropriate to mothers with a new infant. It includes 13 items related to anxiety/depression, each rated on a 4 point scale. Further analysis indicates that the differences between the groups primarily lies in the level of anxiety rather than depression.

Table 1. Differences between 321 high risk infants and 347 low risk controls reported by questionnaire applied to all parents one month after the birth (s.e. in brackets where appropriate).

Variable	Cases		Controls	
Father unemployed %	35.8%		17.0%	
No. of children under 5 yrs	0.76%	(0.044)	0.52%	(0.038)
Weight at 1 month	3.85 kg	(0.036)	4.18 kg	(0.032)
Weight gain birth to 1 month	783 g	(22)	795 g	(20)
Bottle fed at 1 month	84.4%		55.5%	
Mothers' standard of hygiene	2.8	(0.04)	2.1	(0.04)
Mothers' ability to recognize illness	2.5	(0.04)	2.1	(0.04)
Mothers' general care of baby	2.3	(0.04)	1.9	(0.04)
Mother completing full-time education at 16 yrs	35.6%		22.9%	
Unstable marital relationship	19.0%		7.5%	
Concern mother/child relationship	8.3%		0.6%	
Mother suffered from psychiatric illness, depression or suicide attempt since birth	11.9%		3.4%	
Anxiety/Depression Score	23.1	(0.39)	20.6	(0.28)

These variables are correlated. Discriminant analysis shows that differences primarily lie in weight at 1 month, percentage bottle feeding at 1 month and standard of hygiene $p < 0.0001$. Anxiety/depression score, $p < 0.0001$. Three other variables, number of children under 5, marital instability and unemployed fathers add to the discrimination at a less significant level, $p < 0.025$.

While this analysis shows that there are very real differences between high and low risk infants, it does not show to what extent high risk infants are in multiple problem families. We therefore designated problems as father unemployed, two or more children under 5, weight at 1 month < 3 kg – the 3rd centile – hygiene, care and ability to recognize illness, poor or worse, marital instability, mother psychologically ill since the birth and bonding failure. Using these criteria it emerges that 68% of low risk families have no problems and only 9% have two or more. In contrast, only 29% of high risk families have no problems under these headings, while 16% have 2, 9% have 3, 5% have 4 and 2.7% have 5 or more, i.e. a third of high risk infants have multiple problems of some kind.

Discussion

A survey of health visitors shows that, when visiting low risk families, they usually discuss the health and development of the child. In contrast, when visiting high risk infants, mothers want to discuss all the family's problems (Powell, J. personal communication). The limited analysis described in the previous section shows that at least a third of the high risk families are indeed families with multiple problems.

It is in this context we see naked weighing of the infant as so important. This simple procedure ensures that the child is the focus of attention for a substantial

part of the interview and demonstrates the health visitor's concern for the child to the mother. In addition, the mother will be seen handling the child while it is undressed and dressed again, which can provide vital clues as to the mother/child relationship. Charting the weights using the Sheffield Weight Charts [18] can also provide a clear warning of illness. Experience shows that there is seldom a significant fall off in weight gain without good reason.

However, while home visiting and weighing may reduce mortality, the question arises as to how we can begin to reduce the pressures and problems, both psychological and social, which surround many of the infants at greatest risk of unexpected death. Discussion of these issues is needed urgently.

References

1. Office of Population Censuses and Surveys (1988). *Sudden Infant Deaths 1985–87.* OPCS Monitor. DH3 88/3
2. Pharoah, P. O. D. and Morris, J. N. (1979). Postneonatal mortality. *Epidemiological Reviews* **1**, 170–83
3. Taylor, E. M. and Emery, J. L. (1982). Two-year study of the causes of post perinatal deaths classified in terms of preventability. *Arch. Dis. Child.* **3**, 191–6
4. McWeeny, P. M. and Emery, J. L. (1975). Unexpected postneonatal deaths (cot deaths) due to recognizable disease. *Arch. Dis. Child* **3**, 191–6
5. Carpenter, R. G. and Gardner, A. (1982). *Variations in unexpected infant death rates relating to age, sex and season.* OPCS Studies in Medical Population Subjects. No. 45, 23–32. (London, HMSO)
6. Carpenter, R. G., Gardner, A., Harris, J. et al. (1988). Prevention of Unexpected Infant Death. A review of risk-related intervention in six centres. *Ann. N. Y. Acad. Sci.* **533**, 96–105
7. Peters, T. J. and Golding, J. (1986). Prediction of sudden infant death syndrome: an independent evaluation of four scoring methods. *Stat. Med.* **5**, 113–26
8. Cameron, M. H. and Williams, A. L. (1986). Development and testing of scoring systems for predicting infants with high-risk of sudden infant death syndrome in Melbourne . *Paediatr. J.* (suppl.) 37–45
9. Madeley, R. J. (1978). Relating child health services to needs by the use of simple epidemioloy. *Public health* **92**, 224–30
10. Knowelden, J., Keeling, J. and Nicholl, J. P. (1984). *A Multicentre Study of Postneonatal mortality.* (London: HMSO)
11. Smith, R. W. I. (1978). *Dead babies in BAOR.* MFCM Thesis. Dept. of Community Medicine, London School of Hygiene and Tropical Medicine, London
12. Carpenter, R. G. (1983). Scoring to provide risk-related primary health care: evaluation and up-dating during use. *J. Roy. Statist. Soc., Ser. A* **146**, 1–32
13. Alberman, A. and Goldstein, H. (1970). The 'At Risk' register: a statistical evaluation. *Brit. J. Prev. Soc. Med.* **24**, 129-35
14. Myerberg, D. Z., Britton, C. M., Frey-McChung, V. et al. (1988). Predicting and preventing postneonatal mortality. *Proc. Am. Paediatr. Soc.*
15. Judd, C. M. and Kenny, D. A. (1981). *Estimating effects of Social Interventions.* (Cambridge, Cambridge University Press)
16. Rubin, D. B. (1978). Bayesian inferences for causal effects: the role of randomization. *Ann. Statist.* **6**, 34–58
17. Madeley, R. J., Hull, D. and Elwood, J. M. (1988). Evaluation of the Nottingham birth scoring system. *Ann. N.Y. Acad. Sci.* **533**, 106–18

18. Carpenter, R. G. and Gardner, A. (1985). *Sheffield Weight Charts* (London, Foundation for the Study of Infant Deaths)