Sudden unexpected infant death

**II Home monitoring**

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There are several reports of long term monitoring of respiration and sometimes of heart rate in relation to the possible prevention of the sudden infant death syndrome (SIDS).\(^1\)\(^-\)\(^8\) Clearly, whatever the mechanism of death, at some stage cessation of breathing or slowing of the heart will occur. If prolonged central apnoea\(^4\) (the cessation of respiratory movements), or obstructive apnoea\(^5\) (the continuation of respiratory movements in the absence of airflow at the nostrils and mouth), or bradycardia (with or without apnoea) is the forerunner of death in SIDS, the early detection of any such event might permit successful resuscitative intervention. In the absence of reliable, inexpensive, and convenient methods for monitoring alveolar ventilation and arterial oxygenation in the home the variables monitored have included respiratory movements and the electrocardiogram (ECG). Monitoring of respiration (or its absence) in isolation may be inappropriate\(^6\) as there is no certainty that changes in the rate or pattern of breathing initiate the sequence of events which leads to death. Conceivably, breathing movements may continue until the moment of death. The precise order of events has never been recorded, and perhaps no one sequence is invariably responsible. As monitoring for apnoea is fairly cheap compared with ECG monitoring the use of an apnoea monitor alone has sometimes been dictated by financial rather than theoretical considerations.

Sensitive screening methods for detecting infants at 'high risk' have yet to be devised. Scoring systems\(^7\) based on discriminate analysis of obstetric and perinatal variables have proved helpful in epidemiological studies but are not sufficiently sensitive for clinical use. Risk is increased for certain clinical groups readily identifiable by the paediatrician, but it is not known whether this increased risk is distributed evenly within each group. Subsequent siblings born to families with experience of SIDS,\(^8\) and 'near miss' for SIDS cases\(^9\) have been the risk groups most often included in home monitoring programmes. Infants in the latter category are identified after an episode of pallor or cyanosis associated with limpness and apparent cessation of breathing which had led parents or attendants to believe that but for their intervention death would have occurred. By the time of admission to hospital many such infants appear to have recovered and investigations to exclude infective, neurological, cardiovascular, respiratory, and metabolic causes are negative. Positive results of uncertain relevance include the isolation of a virus from the upper respiratory tract, swallowing incoordination, gastro-oesophageal reflux, or minor electroencephalographic changes. Many investigators\(^1\)\(^-\)\(^3\)\(^10\)\(^11\) reserve the term 'near miss' for infants in whom investigations are negative—an extrapolation from SIDS, which is defined in part by negative necropsy findings. It is likely that had death been caused by the effects of such functional abnormalities, no specific pathological markers

**References**

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would be identifiable at necropsy. Such cases would be designated victims of SIDS. Apart from these categories other groups about whom less information is available—low birthweight infants, neonates discharged from special care baby units, infants with bronchopulmonary dysplasia, and infants of narcotic dependent mothers—have also been shown to be at increased risk for SIDS.

Are the current monitoring methods and alarm systems adequate for the task of long term monitoring in the home? The limitations of apnoea monitors, especially those based on impedance methods, have been widely publicised. There may be failure to detect cessation of breathing so that no alarm is given; conversely alarms may occur when respiratory movements are present. At best such devices would only be expected to detect prolonged central apnoea, and not obstructive apnoea. Combined monitoring of respiration and ECG diminishes the likelihood of failure; even so, none of the published reports of home monitoring includes a thorough validation of the monitoring techniques employed or a statement of the limitations of methods for analysing 24 hour cassette recordings. Until this kind of information is available from studies in the home, lack of confidence in the systems currently in use must remain.

The provision of a comprehensive support system for parents whose infants are being monitored is a formidable undertaking. Positive support for parents and easy access to advice and expertise (medical, nursing, and technical) is difficult to achieve. The financial consequences of providing such a service to infants in these risk categories would probably tax the resources of most large centres in the UK unless funds were made specially available. The 'shoe string' approach of issuing monitors to parents with totally inadequate backup support is to invite failure, 'monitor neurosis' and parental despair, and allow the perpetuation of unfounded practices and opinions about the usefulness of monitors in the home.

With selection criteria far from ideal, the efficacy of monitoring systems in doubt, and the practicability of providing a broadly based support system in question, is there any need for monitoring in the home? Pioneers are convinced that monitoring saves lives and that it is the most effective preventive measure available. Sceptics point out that deaths have been reported in infants being monitored and infer that even a reliable early warning system will not prevent death. Unfortunately there are no reports of prospective controlled investigations which help resolve these conflicting views. The difficulty is made worse by the fact that paediatricians committed to home monitoring feel that controlled trials would be unethical. How then should the paediatrician respond when his advice is sought, for example, after the birth of a subsequent sibling? Many bereaved parents accept the slightly increased risk and regard the arrival of another baby as an opportunity to start afresh without additional external support. Others cannot accept reassurance and remain in constant dread of further tragedy. The misery endured in the past by such parents has not been adequately documented. The paediatrician has to decide whether support for such families should include monitoring in the home. As in other areas of medicine, judgements cannot always be deferred simply because the scientific data are lacking. Personal experience based on monitoring some 60 infants for at least 6 months indicates that this provision is immensely gratifying both to parents and paediatricians; this view is supported by investigations of the psychological and social aspects of home monitoring. Any residual anxiety is perhaps related less to the monitor than to the indication for monitoring. Whether a monitor is an essential component of support might be questioned, but alternative systems which exclude monitoring have yet to be devised and tested. The psychological benefits of monitoring 'near miss' cases are less impressive. In retrospect, parents sometimes wonder whether they had panicked or over reacted and may regard home monitoring as a 'necessary imposition'. They are less reluctant than parents of siblings to return monitors after a period of use. Guidelines for monitoring such infants are unclear partly because of the problem of defining 'near miss' infants, and partly because of conflicting reports on the cardiorespiratory status.

It seems therefore that the scientific basis for home monitoring is imprecise and that the question 'does monitoring save lives?' cannot be answered. However, a support system that includes monitoring may allay parental anxiety and allow families to cope. It may be wise for the paediatrician to avoid polarisation to a pro- or anti-monitoring stance but instead to judge each case individually in the light of the information available, the approach recommended by the Scientific Committee of the Foundation for the Study of Infant Deaths (FSID). He may not escape scientific censure but will almost certainly bring a measure of comfort to many sorely stressed parents.

References


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