Home monitoring for central apnoea

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SUMMARY Between July 1978 and December 1981, 64 infants thought to be at increased risk from sudden infant death syndrome (SIDS) were monitored at home for central apnoea. Twenty four of the infants had had a 'near miss' episode at age, median (range), 6 (1 to 33) weeks, and of these infants 22 had had 335 alarms for apnoea by age 6 months. Stimulation by shaking was carried out on 38 occasions and bag and mask resuscitation on one. The remaining 40 infants were siblings of SIDS victims and of these, 35 were monitored from age 1 week (usually after discharge home). Thirty four of the SIDS siblings had had 573 alarms for apnoea by age 6 months: stimulation by shaking was carried out on 32 occasions and bag and mask resuscitation on one. The duration of home monitoring was, median (range), 34 (8 to 87) weeks for 'near miss' infants and 45 (12 to 70) weeks for SIDS siblings. All infants survived. As part of an over all support system monitors were accepted and greatly appreciated by most parents, especially those with previous experience of SIDS. Home monitoring was practicable but the commitment in time and expertise was great and objective benefits to the infant remain unproved.

Apnoea after the newborn period may occur for many different reasons which may be elucidated by appropriate investigations. When no definite cause is found, for example after a 'near miss' for sudden infant death syndrome (SIDS) episode, the question of recurrence, possibly lethal, arises. Apnoeic episodes exceeding 15 seconds have not been detected in normal infants studied in the home during the early months of life,^{1 2} and it has therefore been assumed that prolonged central apnoea (≥ 20 seconds), though relatively rare, is potentially life threatening. An increased risk for prolonged central apnoea has been ascribed to subsequent siblings born to families with previous experience of SIDS—a group considered to be at increased risk for SIDS.³ 'Near miss' for SIDS infants and subsequent siblings of SIDS victims have been the main groups of infants included in programmes of home monitoring for apnoea,^{4–7} although a relation between spells of apnoea and SIDS remains speculative.⁸

We report observations on the use of home apnoea monitors in the management of 'near miss' infants and subsequent siblings of SIDS victims based on three and a half years' experience. The service provided evolved gradually in response to a growing awareness of the need to support families with previous experience of SIDS and the suspicion that the 'near miss' infant is at increased risk after discharge from hospital.

Patients and methods

Sixty four infants were monitored for apnoea in the home between July 1978 and December 1981. The group comprised 40 siblings of previous SIDS cases referred from family doctors, obstetricians, paediatricians, and parent groups and 24 'near miss' for SIDS infants referred to the Royal Hospital for Sick Children in Edinburgh during the same period. One infant in the SIDS sibling group had a 'near miss' episode at the age of 5 weeks, and two who presented as 'near misses' were siblings of SIDS cases. An additional 9 SIDS siblings and four 'near miss' infants seen during this period did not receive home monitors. Thirty five SIDS siblings were monitored from the first month of life, usually after discharge from hospital and the remaining five from the fourth month or later. Monitoring was started on average between age 5 and 6 weeks. The mean age for 'near miss' episodes was 8.6 weeks (range 1 to 33 weeks; median 6 weeks). Home monitoring began when hospital investigations had been completed, on average between age 10 and 11 weeks.

Siblings of SIDS victims were apparently healthy when monitoring began. 'Near miss' infants were first investigated in hospital to exclude an identifiable cause for the episode. The clinical characteristics of this group and the results of investigations have been reported previously.⁹ The monitors were

used in hospital before the infants' discharge from the neonatal unit (most SIDS siblings) or hospital ('near misses'). Parents were instructed in the use of monitors and were given an instruction manual. They were made fully aware that monitoring for central apnoea was of unproved value and the use of home monitors did not remove all risk. The monitors supplied depended on availability and were the capacitance pad type (RE134 Eastwood Ltd) and the 'volume' capsule (MR10 Graseby Dynamics Ltd). The monitors were set to sound an alarm 15 or 20 seconds after breathing movements stopped. Parents were taught to use an Ambu bag and mask system. On hearing an alarm they were asked to flick the soles of the infant's feet or to shake the infant gently while cradling the head. If there was still no response more vigorous shaking or bag and mask assistance could be used. At the time of hospital discharge parents were given suction catheters and Ambu bags and printed sheets on which to record the times of alarms, the infant's appearance, and any action they took. They were encouraged to write details of minor illnesses or symptoms preceding alarms, family doctor calls, and any medication that the baby received. After hospital discharge they were visited by a member of the home nurse visiting team—weekly at first and on a monthly basis later. Whenever possible the nurse liaised with the health visitor working with the family's general practitioner and both helped provide support for the family. Parents had access to medical attention by telephone, and open access to hospital without contacting the family doctor in the event of subsequent 'near miss' episodes or other problems causing concern. Infants were monitored until they were at least 7 months old and had been free of alarms for more than a month. Sometimes, however, monitors were retained by parents for a longer period until they felt confident without them. Throughout the monitoring period 'near miss' infants were followed up regularly as hospital outpatients, but SIDS siblings were not seen routinely at hospital unless this was requested by general practitioners or parents.

Results

Table 1 gives clinical details of the infants. 'Near miss' infants were of slightly lower birthweight (not significant) than SIDS siblings and fewer were breast fed from the outset ($P<0.05$). On average, 'near miss' infants had two hospital admissions (range 0 to 7) during the first 6 months of life and siblings one (range 0 to 3). This difference, and the difference in duration of stay in hospital of mean 18 and 4 days for the 'near miss' and SIDS siblings

Table 1 Clinical characteristics of 'near miss' infants ($n=24$) and SIDS siblings ($n=40$, except for birthweight and gestation where $n=39^*$)

	'Near miss'	SIDS siblings	P
Birthweight (g) [†]			
Mean (SD)	3148 (682)	3434 (612)	
Median	3366	3540	NS
Range	1380–4364	1820–4430	
Gestation (weeks)			
Mean	38.3 (3.4)	39.2 (2.0)	
Median	39.5	40.0	NS
Range	27–42	32–42	
Boys:girls	2:1	23:17	NS
Birth asphyxia or respiratory distress (no (%))	3 (13)	1 (3)	NS
Feeding (no (%))			
Breast from outset	9 (38)	27 (67)	
Bottle from outset	15 (62)	13 (33)	$P<0.05$

*Remaining infant of 'normal' birthweight and gestation.

[†]'Near miss' group includes four and the SIDS siblings group three low birthweight infants ($<2,500$ g).

Statistical analysis: Student's *t* test (unpaired) and χ^2 .

groups respectively, is explained by the initial admission of 'near miss' infants (mean duration 13 days). Table 2 gives the social and family characteristics of the infants monitored and shows that there was a significant social class difference ($P<0.05$). 'Near miss' families were comparatively larger and their housing less favourable than SIDS siblings' families. These latter observations were not statistically significant. The remaining data are derived

Table 2 Social and family characteristics

	'Near miss' ($n=24$) No %	SIDS siblings ($n=40$) No %	P
Social class			
I and II	3 (13)	14 (35)	
III	8 (33)	17 (43)	$P<0.05$
IV and V	13 (54)	9 (22)	
Head of household			
Mother	2 (8)	2 (5)	NS
Father	22 (92)	38 (95)	
Both parents resident	22 (92)	38 (95)	NS
Number of adults in home			
1	0 (0)	1 (3)	
2	22 (92)	37 (92)	NS
3	2 (8)	2 (5)	
Number of children in home			
1	10 (42)	17 (42)	
2	8 (33)	18 (45)	NS
3	6 (25)	5 (13)	
Housing			
Tenement/flat	5 (21)	6 (15)	
Terrace/maisonette	11 (46)	13 (32)	NS
Semidetached or detached	8 (33)	21 (53)	

Statistical analysis: χ^2 .

from an analysis of parental and nursing records between months 1 and 6 of life. We considered that subsequent data would be less comprehensive as the use of monitors during the day was sometimes erratic after 6 months. Two 'near miss' infants and five SIDS siblings monitored from month 4 of life or later have been excluded from some analyses. Details of minor illnesses and medications given in the home between months 1 and 6 of life were available for 55 infants (33 SIDS siblings and 22 'near miss' infants). Of 99 minor illnesses, 51 (52%) were respiratory—'colds' (20), 'upper respiratory tract infections' (17), 'snuffles' (14); and 33 (33%) were alimentary—'teething' (16), 'vomiting' (9), and 'loose stools' (8). Eighty five courses of treatment were given—principally antibiotics (31), nose drops (18), dicyclamine (9), aspirin (7), and nestargel (7). No differences were observed between the subgroups studied.

Table 3 gives details of monitors, duration of use, alarms, and the action taken in response to alarms for each subgroup. The RE134 was the monitor most commonly used. Monitoring was started earlier and continued for a longer period in the SIDS siblings group. Parents usually retained monitors for at least 6 months; variability thereafter depended on the age of death of a previous sibling, the continuance of alarms, and partly on the

reluctance of some parents to stop monitoring at night after months without alarms.

The number of alarms/infant/month was similar for 'near miss' infants and SIDS siblings. Fig. 1 gives the frequency distribution of alarms for the combined groups. More than half had fewer than 15 alarms. The range was exceedingly wide, however, as five infants had no alarms and two had over 80. The same broad spectrum was seen when the 7 low birthweight infants in the series were considered separately.

The response to alarms (Table 3) was similar in 'near miss' and siblings groups. Overall there were 908 alarms, and parental response to 72 (8%) was vigorous. Figs. 2 and 3 give the ages at which these alarms occurred in 11 'near miss' infants and 9 SIDS siblings. There is broad similarity between the 'near miss' and siblings groups.

Relatively few alarms between 3 and 4 months of age were thought to require active intervention. The time of day when these alarms occurred is shown in Fig. 4. Sixty percent of alarms occurred between 10.00 pm and 6.00 am. There was no relation between the number of alarms to which there was a vigorous parental response and the total number of alarms computed for individual infants.

Table 4 summarises parental impressions of infants' appearance before 'resuscitation'. Often there was considerable uncertainty. Pallor was the most common sign, and cyanosis relatively rare. Limp-

Table 3 Details of home monitoring

	'Near miss'	SIDS siblings	P
Type of monitor			
RE134	20 (83)	24 (60)	
MR10	4 (17)	13 (33)	
Both	0 (0)	3 (7)	
No in group	24	40	
Age monitor issued (weeks)			
Mean (SD)	10.8±7.5	5.5±8.7	
Median	8.5	1.0	
Range	3-34	0-35	
No in group	24	40	
Duration of monitoring (weeks)			
Mean (±SD)	34.7±10.0	43.7±14.4	
Median	34.0	45.5	
Range	8-87	12-70	
No in group	24	40	
Alarms per patient per month	4.2	3.6	NS
No in group	22	34	
Action in response to alarms			
Number of alarms:			
None	252 (75)	498 (87)	
Flick toes	44 (13)	42 (7)	NS
Shaking	38 (11)	32 (6)	
Bag and mask resuscitation	1 (<1)	1 (<1)	
Total	335	573	
No in group	22	34	
Monitor problems	5 (23)	15 (44)	NS
No in group	22	34

Fig. 1 Distribution of alarms in 56 infants aged between 1 and 6 months.

Fig. 2 Alarms/infant/month in 'near miss' infants and SIDS siblings.

Fig. 3 Frequency distribution of alarms followed by 'resuscitation' in 'near miss' infants and SIDS siblings, in relation to age.

ness, sweating, and 'choking' were the other signs observed. For 25 of the 72 alarms requiring parental action the infant was thought to be of a normal colour or no comment was made. Nineteen of the 20 infants 'resuscitated' had minor symptoms preceding

Fig. 4 Distribution of alarms followed by 'resuscitation' in 'near miss' infants and SIDS siblings, in relation to time of occurrence.

Table 4 Physical appearance of 'near-miss' infants (n=11) and SIDS siblings (n=9) before resuscitation*

	'Near miss' (39 alarms)	SIDS siblings (33 alarms)
Pallor	17	16
Limpness	2	5
Sweating	3	0
'Choking'	3	0
Blue	1	0

*From parental records.

alarm episodes, and 15 showed clustering of alarms (usually within a day). Three were admitted to hospital after alarms with suspected 'near miss' episodes. Within the 'near miss' group three infants had prolonged central apnoea (low birthweight infants, during the course of upper respiratory infections) and three had obstructive apnoea (≥ 6 seconds), observed during polygraphic sleep studies. The active intervention group contained all but one (with obstructive apnoea) of those infants. None of the SIDS siblings monitored showed prolonged central apnoea or obstructive apnoea (≥ 6 seconds) during sleep. Nine of the 'near miss' group (38%) had 'high risk' scores (> 500) at birth, by the criteria of Carpenter *et al.*¹⁰ which compares with a prevalence of 30% in the local community. The number of infants with 'high risk' scores was not significantly increased in either the 'near miss' or SIDS siblings active intervention subgroups.

Monitor problems necessitating their return to manufacturers were not uncommon (Table 3). Faults usually came to light because of frequent alarms at times when breathing movements were obvious on observation. The MR10 was preferred by most parents because of its practical advantages outside the home (in the pram or car). Using this monitor 15 infants experienced 174 alarms during 64 months of monitoring (average 4.3 alarms/patient/month) and 38 infants monitored using the RE134 gave 576 alarms in 159 months (4.2 alarms/patient/month). Neither monitor was problem free. When doubt existed whether a monitor was faulty, a change of monitor or admission to hospital for observation helped resolve the dilemma. Variable sensors and changing monitor sensitivity were the main problems encountered with the MR10; 'faulty' sensor pads, inappropriate mattress thickness, condensation on sensors and mattresses, and occasional monitor faults were the difficulties associated with the RE134.

Finally we investigated the relation between alarms and upper respiratory tract infection in 13 'near miss' infants and 22 siblings in whom both alarms and upper respiratory tract infections were recorded. Data obtained between age 1 and 7 months were analysed for each child. When alarms occurred during or within three days of the start or finish of a respiratory tract infection (average duration 6 days) alarms were deemed to coincide with infection. Conversely when respiratory infection occurred within five days of an alarm or group of alarms (usually within a two day period) infection coincided with alarms. Thus 12 day periods were arbitrarily selected for analysis of the infection/ alarm relation, and vice versa. Periods when infections and alarms were absent were not included in the statistical analysis. For both SIDS siblings and 'near miss' groups the likelihood of alarms was significantly increased when respiratory infections were present ($P < 0.01$); an increased likelihood of infection when alarms were present was not found.

The pilot investigation was not designed to assess parental response to home monitoring. The spontaneous verbal and written comments of parents of infants in the siblings group impressed us, however, that the support available, including monitoring, helped considerably to relieve anxiety and restore confidence during a very stressful period. Anxiety was greatest as the age approached at which a previous sibling had died, and support at such times was sorely needed. This unanimity of opinion may reflect the fact that monitors were issued to parents who felt that they could not manage without such support; the experience of others who did not receive or wish home monitoring is not known. Most

parents of 'near miss' infants took a similar view, though some wondered whether monitoring was really necessary and were less willing to accept the constraints that home monitoring imposed.

Discussion

These results present an opportunity to comment on our experience of home monitoring for central apnoea in infants thought to be at increased risk for SIDS. The precise risks for the groups studied is not known, and the difficulty is compounded in the 'near miss' group by the lack of an agreed definition of a 'near miss' episode. Assuming a fivefold increase in risk for SIDS siblings³ and a 10 fold increase for 'near miss' infants¹¹ the likelihood of death in the present series would have been exceedingly small without monitoring, given a prevalence of one sudden and unexpected infant death in every 500 live births in the United Kingdom.¹²

Although the clinical characteristics of the two groups of infants studied were broadly comparable, the 'near miss' group had less favourable social characteristics than the siblings of SIDS victims. It is likely that this was due, in part at least, to the selection of SIDS siblings for home monitoring. The more articulate and better informed parents would have been more likely than others who had suffered previous bereavement to have sought information on the availability of support, including monitoring, when subsequent infants were expected. The social class distribution of the community in question was weighted towards social class III,¹³ and was not significantly different from that of the groups being studied.

The lack of a control group renders our findings on minor illnesses and medication difficult to interpret. Contemporary information on 'normal' infants in the community concerned is lacking. The effects of medicines prescribed or purchased by parents for the treatment of minor symptoms merits further study in the light of suggestions that certain agents, for example phenothiazine derivatives,¹⁴ may be implicated in some cases of SIDS. Our data, almost certainly an underestimate of total medication, serve to highlight the fact that few controlled studies of the efficacy of commonly prescribed preparations have been undertaken.

The monitors used in our study have not been fully validated for home use. Thus the prevalence of alarms in the absence of prolonged central apnoea (<20 seconds) or the failure rate when prolonged central apnoea was present cannot be stated. Any inference that alarms coincided with episodes of prolonged central apnoea is based on assumption. We recognised the inherent inability of the monitor/

alarm systems to detect 'obstructive' apnoea,¹⁵ that is cessation of air flow at the mouth and nostrils with continuing movements of the chest and abdomen. A combined facility for detecting cessation of breathing movements and heart rate changes would have had potential advantages. These systems are costly, but where they have been used extensively provision has been made to minimise the cost to parents.⁷

The wide variation among infants in the number of alarm episodes has been observed previously. Remarkably, parents accepted a large number of alarm episodes without complaint; the occurrence of alarms tended to reinforce the 'need' for monitoring and the fact that babies were sleeping peacefully and breathing normally when observed after many such alarms in no way diminished faith in the system. Had death occurred during monitoring, however, it is conceivable that suffering in the family might have been increased.¹⁶

Where vigorous action was taken many parents felt that this had been life saving. As 20 infants experienced these episodes the likelihood that parental intervention had been decisive seems remote. Parents' descriptions of infants' appearance at the time of these events does not resolve this question. Pallor, described as more severe than hitherto observed during sleep, could have been an exaggeration of the pallor sometimes observed during active sleep.¹⁷ The infrequency of cyanosis suggests that severe hypoxaemia did not occur, but its absence does not preclude a hypoxic episode, as semi-darkness or the spectral qualities of artificial light may have rendered detection difficult even in the presence of severe hypoxaemia. Two infants became apnoeic, blue, and limp and were slow to recover after bag and mask resuscitation. Although parents were convinced that the outcome would have been different had they not been alerted by alarms, we cannot be certain that a fatal outcome was averted. The claims of other investigators⁴ that home monitoring saves lives can neither be confirmed nor refuted. The fact that death has been reported¹⁶ during monitoring for apnoea indicates that this possible means of prevention is, at best, limited.

Neither the monitor was problem free, necessitating the availability of spare monitors that could be issued as the need arose. The dilemma whether repeated alarms at short intervals were due to recurrent apnoea or to defects in apparatus or its use was usually solved by admitting the infant to hospital for detailed observation and monitoring. Usually the fault lay with the monitoring devices. Parental anxiety was often intense when these problems arose, which serves to underline the need to provide as comprehensive a support system as

possible.¹⁸ Our service fell short of ideal but it gradually improved as unforeseen difficulties were remedied. Parents accepted a host of service shortcomings which at times must have added to their concern. Their strongly favourable impressions of home monitoring were therefore the more surprising, and do not conflict with the findings of investigators who have critically examined the impact of home monitoring on the family.^{19 20}

Our observations that alarms were significantly increased when upper respiratory infections were present could mean that apnoeic episodes were increased. An alternative explanation could be that respiration during respiratory tract infections was unusually shallow and that this resulted in occasional failure to trigger the monitoring device.

What do we conclude from this experience? Many parents of siblings of SIDS victims and 'near miss' infants need support. The guidelines for providing support to recently bereaved parents are becoming more clearly defined¹² and continuing support when a subsequent sibling is born is an extension of these. Whether monitoring should be part of such a support system is a separate question to which there is no clear answer.²¹

Monitoring for apnoea is practicable but demands considerable commitment in time and expertise to approach the ideal described by Kelly and Shannon.¹⁸ Infants at increased risk for SIDS cannot be selected precisely at present, and any objective benefit of home monitoring to the infant remains unproved. It is therefore by no means clear which infants should be monitored. We continue to make judgements on an individual basis which take into account estimated risk for the infant; parental anxieties and attitudes; the availability of monitors, including a back up service; and the degree of support that can be provided in the home by a health visitor or a specially trained nurse. Few centres have facilities to combine this kind of approach with physiological assessments during sleep to detect abnormalities of breathing or heart rate that might be potentially lethal. In Belgium, Kahn and Blum⁸ select infants for home monitoring (respiration and heart rate) on the basis of abnormalities detected during sleep polygraphic studies. Whether their approach, with its enormous commitment to 'screening' at risk infants can reduce the prevalence of SIDS in that country, remains to be seen.

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