Apnoea monitors compared with weighing scales for siblings after cot death

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SUMMARY A randomised control trial was carried out on support measures given to parents with a subsequent child after previously suffering a cot death. Apnoea monitors were used in one group and weighing scales in the other. General support measures given to both groups included the keeping of symptom charts and weekly visits by health visitors. Many alarms occurred which were presumed to be false. Eleven per cent fewer symptoms were reported by parents of children on monitors than parents of children being weighed daily. Both systems were acceptable and gave parents confidence. Sixty per cent of parents were reluctant to give up using the monitor compared with 26% of parents using scales. Virtually all parents commented on the great value of the weekly home visit of the health visitor and the symptom diary.

Most parents who have had a cot death will have another child within two or three years, and when they do so the unexpected death of their earlier child is never far from their consciousness. Apnoea monitoring of siblings has been taken up in the USA¹ and this country² but the relevance of apnoea to cot death is still under consideration.³ The situation is more complicated than many realise. No available apnoea monitor suitable for home use is ideal,^{3,4} and infants have died while being monitored.⁵ The increased risk of cot death in a subsequent sibling is only in the order of $\times 4$,⁶⁻⁸ and consequently an effective study to show that any method prevents cot death would require a minimum study population of 4000 children. Paediatricians are under pressure, however, to provide parents with help, and so feasible alternatives to apnoea monitoring are being sought.

There is epidemiological evidence that some cot death infants are below expected weight,^{9,10} and show evidence of recent growth retardation at necropsy,^{11,12} so a close record of weight could be useful in detecting infants at risk. It was therefore decided to carry out a pilot study to answer the following questions:

- (1) Would a controlled study of siblings of cot death victims be practical?
- (2) What are the problems and consequences of using the apparently most suitable apnoea monitors?

- (3) What are the problems and consequences of using scales?

- (4) What can we learn about general support to the families?

Material and methods

After consultation with parent groups, cot death parents associated with the Foundation for the Study of Infant Deaths (FSID) were invited through the FSID newsletter to participate in a randomised controlled study using apnoea monitors or weighing scales with their subsequent babies. The apnoea monitor selected was the Graseby MR10¹³ because it is compact, battery operated, and portable. Seca scales (Seca, Birmingham) were chosen for their size and stability, and specially devised weight charts were used.¹⁴ Overall clinical responsibility for infants remained with the general practitioner, health visitor, and local paediatrician.

An initial study of the use of the forms was carried out in Chelmsford with 10 families. The procedure in the definitive study was as follows. Parents who volunteered for the trial from any part of England and Wales were approached in order of application by the project coordinator (DB later AJW) together with the family's health visitor. It was explained that the apnoea monitor only monitors breathing movements, can give false alarms, and does not necessarily prevent death, but that many parents find

them reassuring. It was also explained that studies have suggested some babies have substandard weight change before death. Parents were also warned that weight gains fluctuate but they would be using a new weight chart designed to detect abnormal weight gain over a shorter period of time than has previously been attempted. With one exception, parents who were approached agreed to enrol, and the envelope containing the random allocation was opened in the presence of the parents and the equipment made available. The general practitioner was asked to nominate a local paediatrician who was contacted by JLE. The mother started to use the apnoea monitor or scales in the maternity hospital during the postnatal period. Parents completed a daily record about their baby on a 'tick chart', which listed 28 symptoms, and also a log of ill health in the family and any disturbances to the baby's daily routine.

The health visitor visited the family once a week. She checked the daily record, discussing it with the mother, and completed a weekly report on the health of the baby and family noting any problems. All parents using apnoea monitors received training in resuscitation, and were given a local telephone number for emergencies, for example paediatric department, GP, or emergency services. Parents were advised that if the alarm sounded they should first observe the baby. If respirations were absent they should stimulate the baby by touch, by picking the child up, and in the last resort by mouth-to-nose and mouth resuscitation. If the child was breathing, they should check the sensor pad, connections, and battery. They also recorded each time the alarm sounded and the action taken. Parents with weighing scales were asked to weigh their naked baby at the same time each day and before a feed. The weights were plotted on to the weight chart by the health visitor each week. Parents were encouraged to seek their health visitor's or local doctor's advice on any problems. The surveillance period covered a minimum of six months, or one month beyond the age at which the previous child had died.

On completion of the trial, a questionnaire was sent, from a department independent of the coordinator, to the parents, health visitors, and general practitioners. This evaluated their experience with the equipment and symptom charts, the effect the trial had had on their relationships with others involved with care of the child, and whether the scheme should continue.

Results

Acceptance. Two sets of parents withdrew immediately when allocated weighing scales and were

excluded from the study. One hundred were admitted—50 were allocated monitors and 50 weighing scales. One infant on a monitor was withdrawn by the parents at 10 weeks, and six others gave up using the monitor after 22 weeks. One family gave up using weighing scales at 19 weeks, and seven after 21 weeks.

Comparison of groups. The two groups were comparable in the following respects: mother's age, number of previous pregnancies, age of previous cot death, infant's sex, birthweight, and gestational age; one family in each group had had two previous cot deaths. The health visitors visited both groups on average once a week. The number of visits to paediatricians was similar in both groups; seven children on monitors and eight of the weighed infants were referred for problems related to alarms or weight. Eleven children on monitors and 12 on scales were admitted to hospital during the survey.

Symptoms. Large numbers of symptoms were reported consistently in some children in both groups. On average, 11% fewer symptoms were reported for infants on monitors than for those on scales. Further analysis shows that the difference is primarily due to a tendency to report fewer upper respiratory tract symptoms in relation to lower respiratory tract symptoms in the monitored group, $P < 0.001$. Gastric symptoms (including colic), named conditions (for example, thrush, otitis media etc), skin conditions, and teething problems were all reported less frequently for infants on monitors than for those on scales but these differences were not statistically significant. Because of the great variation in the rate of reporting of symptoms for different infants, we checked this by comparing the number of symptoms reported in a four week period, starting from the eighth week, for the next 49 infants randomly allocated monitors and the next 50 infants randomly allocated scales, who were part of a continuation of our pilot study. On average 12% fewer symptoms were reported for infants on monitors than on scales, which confirms that our findings are not fortuitous.

Monitors. The 50 children experienced a total of 1986 alarms, varying from 1 to 158 per child; the average rate was 6.7 alarms per child per month. Fifty per cent of the children had more than 31 alarms. There was an average of 3 alarms per week in children under the age of 6 weeks, 1.5 per week from 6 to 12 weeks of age, and 0.9 per week in those aged over 12 weeks. Half of the alarms were thought by parents to be due to technical faults, for example the sensor pad becoming loose. In more than 82% of

all occasions when the alarm sounded the child seemed to be breathing normally when the parents reached the child (Table). On the remaining occasions the parents touched, shook, or handled the child before acknowledging that their baby was breathing. In one child only did a mother carry out mouth-to-nose and mouth resuscitation. Afterwards she was doubtful whether this had been necessary. In only three children was there a significant correlation between alarms and the reported number of symptoms. Alarms were significantly associ-

ated with either the presence or absence of various symptoms in a few other children but no general correlation was found. Inspection of the records shows that most of these associations are due to the tendency for alarms to occur more frequently in the first six weeks or are fortuitous. Two infants, however, had significantly more alarms during respiratory illness, although both had some alarms at other times. After alarms some children were seen by the family doctor and some by the paediatrician. Three children had 24 hour respiratory recording, in one tachycardia was evident. Two children were given theophylline.

Table The number of alarms reported from 50 apnoea monitors, related to the age of the child and the response of the parents

	No of alarms in different age groups			Total
	≤5 wks	6-12 wks	≥13 wks	
Overall	786	430	770	1986
Stimulated by parents	209	45	110	364
(%)	(26)	(10)	(13)	(18)
Resuscitated by parents	1	0	0	1

Weighing. The weight charts used (Figure) were constructed so that a healthy child's weight is not expected to move up or down more than one channel width over a period of two weeks, or two channel widths in eight weeks. Fifteen of the 50 infants' weights crossed down one channel in less than two weeks, and seven crossed two channel widths in less than eight weeks.

Of 15 children showing a one channel fall, six occurred before 6 weeks of age, five immediately

Figure Reproduction of the weight chart designed from prospective Sheffield data by Carpenter and Gardner showing the weights of the child and the weight at death (D). The apnoea monitor was withdrawn at 29 weeks, indicated by the broken vertical line. The arrows identify the period during which the child's weight first crossed 2 channel widths in less than 8 weeks.

after birth, and one was associated with a respiratory tract infection. Between 6 and 12 weeks of age one child showed weight loss, associated with a virus infection and a fever of 101°F. Of the eight children aged 13 weeks or older, one child lost weight before an acute chest infection and a second lost weight before the detection of a urinary tract infection associated with ureteric reflux. One child had thrush and a chest infection, two vomiting and chest infections, two were suffering from colds, and in one child nothing specific was found.

A fall in two channel widths only occurred in children over 6 weeks old. Of the three between the age of 6 and 12 weeks, one breast fed child was referred to a paediatrician and the mother was found to have a thyroid dysfunction: the other two children had colds. Of the four children aged 13 weeks or more all had respiratory tract infections, two with additional feeding problems and one with loose stools.

Thus, if we exclude failure of weight gain in the immediate postnatal period, 16 of the 17 falls picked up by the chart were associated with illness and in three cases the weight loss predates the symptoms and diagnosis.

Relinquishing equipment. Of the parents with scales, 74% were happy to stop using them, but only 40% of those with apnoea monitors were willing to give them up. This difference is statistically significant, $P < 0.01$.

Response to questionnaires.

General practitioners

Ninety three general practitioners returned questionnaires. Some felt their families could have coped without extra care, but only four would not use the scheme again—one because of frequent false alarms. Many were favourably impressed by the monitors, although half were indifferent to whether scales or monitors were used. One with scales would prefer a monitor next time, and one with a monitor would prefer scales! No difference between the anxiety levels in parents using scales or monitors was reported. General practitioners seemed to be more involved with parents on monitors than those with scales, but they felt that neither significantly increased the time they spent with the parents. The weight charts were kept by the health visitors and many general practitioners did not see them.

General practitioners felt that the symptom charts were of more value to the parents than to themselves. They assessed the activity of the health visitor as more important than either the scales, or the monitors, or their own involvement.

Health visitors

Questionnaires were returned by 92 health visitors. They thought the scheme of benefit to the parents. The symptom chart helped their relationship with the parents and formed a focus for their weekly visit. Most felt that these charts helped the parents gain an increased understanding and awareness of their baby's health.

Half the health visitors expressed no initial preference for scales or monitors. Both pieces of equipment were seen to cause some anxiety at first to the parents but increased parental confidence later. The monitors provoked more comments. Health visitors were concerned about the acute parental anxiety when the monitors broke down, if obtaining a replacement from the project coordinator incurred a delay. They felt that some parents became too dependant on the monitor tending to rely on the information given by the monitor rather than on their observation of their child's health.

Health visitors considered that daily weighing did not alarm the parents after they had become accustomed to minor weight variations, and was helpful since it involved the parents closely in their baby's progress. Ninety seven per cent of health visitors would institute a similar procedure again with other parents who wished to participate.

Parents

Questionnaires were returned by 85 families. On the whole parents were happy with the monitor. Most found the ticking reassuring while others found it restrictive since they felt they always had to be within earshot and were worried if they were in a noisy place. Several remarked that they did not get any sleep the night after an alarm sounded. They found it difficult to stop using the monitors, and usually did so by increasing the hours per day when the child was not monitored.

Many of the parents had originally not wanted weighing scales but those who were allocated and used them became pleased with them. Parental confidence grew as they became familiar with daily variation in weight gain. Several commented that they might have become more confident earlier if they had been shown some examples of weight charts from other children. The weighing of babies became increasingly difficult to do as the child became older. Fewer parents reported difficulty in giving up scales. The symptom charts generally received favourable comment. Variability in the way and times they were filled was reported. Parents found them valuable at the weekly meeting with the health visitor.

All but three parents made appreciative comments about their health visitor. Most had never had

such a close relationship with a health visitor before, or realised how helpful health visitors could be. A few parents recorded especial gratitude when their health visitor had given them her home telephone number and had encouraged them to contact her in the evening or at the weekend if necessary. Many parents had no contact with their paediatrician after leaving the maternity unit. Those who had were appreciative, particularly if he offered to see them at any time. Some parents' confidence in the scheme was undermined by doctors who voiced their scepticism as to whether either system could prevent a cot death. Most parents would like to have the same type of support if they had a subsequent child.

Case report. One child died aged 32 weeks, three weeks after the apnoea monitor had been withdrawn. During the time that he was under surveillance the alarm rang 158 times. The parents thought the alarms were false, that is the baby was not found to be apnoeic and was almost always described as breathing shallowly. The monitor was withdrawn at 28 weeks. Three weeks later the baby presented as a cot death. Necropsy carried out by a local general pathologist showed no adequate cause of death and the death was registered as unexpected death in infancy. The child had been weighed in clothes at a clinic, not under the care of the health visitor undertaking the weekly surveillance of the child. We obtained the child's weights after his death and plotted them on one of our charts (Figure). The increment in weight was satisfactory until the 15th week and then remained virtually static. When the baby died at 32 weeks his naked weight at necropsy was equivalent to his recorded dressed weight at 12 weeks.

Discussion

In this study we were dealing with a group of highly motivated parents who had contacted FSID and who felt the need for extra assistance with their next child. The scheme was presented to the health visitors and parents as a package containing two elements—firstly the randomly allocated monitor or scales, and secondly a symptom chart and weekly visits by a health visitor.

The first question asked in this study has been answered. It has been possible to carry out a controlled study of the siblings of cot death victims with satisfaction to parents. This does not imply that it would be possible to carry out a similar study of all subsequent babies after all cot deaths, but it shows that it is possible to provide parents with sufficient support without the use of apnoea monitors.

While the apnoea monitors were acceptable to

parents, the problems associated with their use were greater than we anticipated. Since no child in the weighed group was found collapsed, we must assume that at least most of the 1986 alarms that occurred in the monitor group were not potentially fatal. More sophisticated equipment is required to ascertain the meaning of alarms.

The number of alarms recorded are roughly comparable with the experiences reported by other centres issuing apnoea monitors. Kahn and Blum¹⁵ monitored 50 infants who were considered at risk of sudden infant death syndrome (SIDS), including 10 siblings of SIDS victims at home. The parents were issued with a cardiorespiratory monitor that was set to alarm after 15 seconds apnoea or a heart rate below 50 beats per minute. They recorded a total of 1557 respiratory alarms, 324 in the siblings of SIDS. MacKay *et al*² monitored 64 high risk infants at home using either Eastwood's RE134 monitor or Graseby Dynamics' MR10. This group included 34 siblings of SIDS victims, who were monitored from the first month of life. They had had 573 alarms by 6 months of age. Fifteen infants using the MR10 monitor experienced an average 4.3 alarms per infant per month. This is the same order of magnitude as our average rate. Differences are probably due to how patiently technical alarms were counted and the age at which monitoring started.

Our experience of parents using monitors suggests that in the immediate post-perinatal period the monitor is accepted readily and gives confidence. Later the parents become over reliant on the equipment monitoring the baby's breathing, which is reflected in the reluctance of more than 50% to give the monitor up and a reduction in the comparative frequency with which symptoms were observed.

Weighing did not give the immediate confidence that the apnoea monitor did in the perinatal period, but in the long term, daily weighing and apnoea monitoring seem to be equally satisfactory to parents, and the weighing in some cases usefully detected the presence of unsuspected disease. Both procedures are to some extent self limiting—the child becomes intolerant to both. The scales have advantage in the relative ease with which the tailing off process can take place by reducing daily weighing to weekly weighing at a clinic.

This survey was not expected to reach conclusions on whether apnoea monitors prevent cot death and no child died while under surveillance. The later, unexpected death in our study group might have been prevented had the monitor not been withdrawn. If this child's weight had been correctly plotted on to our chart, however, his failure to gain weight would have been detected long before he died.

The finding that 11% fewer symptoms were reported for infants on monitors than on scales suggests that the former group of infants are less closely observed. This could represent a hazard of using apnoea monitors, especially if they are used without increased general support. Apnoea monitors are available for purchase by the general public. A difference between the monitors and scales was that the monitors produced a large number of crises of short duration compared with a smaller number of longer periods of anxiety associated with unsatisfactory weight gain. The often expressed fear that daily weighing is worrying, was not substantiated by the reaction of the parents.

From the comments in the confidential reports it would seem that the general support to the families given by the health visitors together with the use of the symptom records were the most valuable aspects of the scheme.

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