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REDUCING THE RISK OF COT DEATHS: OUTLINE OF A REGIONAL AND NATIONAL CAMPAIGN*

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During the 1970s and early 1980s attempts by health care professionals to reduce the incidence of cot deaths were broadly divided into two main areas:

- 1) Attempts to define a group of infants at increased risk of sudden death and then focusing the attention of health care professionals upon that group.
- 2) The provision of respiratory or cardiac monitoring devices for infants deemed to be at increased risk (eg, siblings of victims, babies born prematurely and those who had suffered an apparent life-threatening event).

Both attempts had only limited success. Both focused attention on infants deemed to be at high risk, and thus provided no additional support to the great majority of infants. Whilst the former approach was shown to lead to a reduction in the incidence of the sudden infant death syndrome (SIDS) within the high risk group in some geographical locations, this was not universally true, and the overall incidence in the population was little changed. The second approach was very expensive in resources and staff time and has not been shown to have any significant impact upon the overall incidence.

In the late 1980s information began to accumulate that, apart from the innate inborn risk identified in some infants (which was therefore not amenable to change), there were a number of environmental factors and child care practices which were associated with the increased risk and which might be amenable to change.

The concept that by altering child care practices within a community the incidence of SIDS might be reduced originated in Holland and South Australia, where publicity campaigns to dissuade parents from sleeping babies in the prone position was followed by a reduction in the incidence.^{3,4}.

RISK REDUCTION CAMPAIGN IN AVON

The County of Avon is in the south-west of England. The Infant Mortality Study was set up in 1983 as a means of collecting detailed information on every infant death from birth to 1 year occurring to a resident of the County of Avon. A detailed account of the study and its results have been reported.⁵ (Fig 1).

By the Autumn of 1989 it had become clear that a number of environmental and infant care practices were significantly associated with an increased risk for SIDS. These factors included the prone sleeping position, heavy wrapping particularly in a warm environment, parental smoking, and failure to recognise significant illness (in particular, continued heavy wrapping in the presence of acute viral infection).

^{*}Based upon a lecture delivered at the Symposium on *Preventive Medicine* held in the College on 9–10 November 1994.

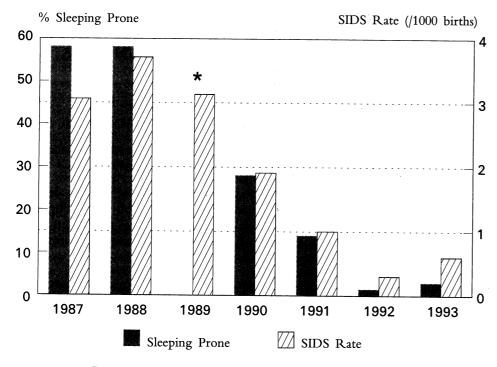


FIGURE 1

Infant sleeping position and SIDS rate in Avon County (UK) 1987–1993. (*=start of public information campaign to reduce prevalence of infants sleeping prone in Autumn 1989. The figure for prone sleeping in 1989 was similar to 1988 for the first half of the year, and fell rapidly with the campaign in the second half of the year. It is not therefore possible to give a representative figure for the year.)

Ethical issues

Before attempting to change parental practice, a number of ethical issues had to be considered:

- a) Would the proposed interventions increase parental anxiety? Whilst raising public consciousness of SIDS might temporarily increase people's anxiety, the balance of professional opinion was that a positive message informing parents of the simple choices they can make and the potential value of those choices in reducing the risk of cot death, might reduce their (previously unvoiced) fears.
- b) Was there sufficient evidence to justify the proposed interventions? While there was considerable supporting information for the importance of the identified risk factors, no randomised control study had been undertaken. A proposal that one group of parents would be given information and another group would act as controls, was seen to be impractical and probably unethical in that the proposed new child care practices, which would be recommended to some parents, were not known to carry any identifiable risks.
- c) Would the changes in recommendations increase guilt feelings in parents whose babies had died of SIDS? This question was discussed extensively

with members of the local SIDS parents support groups, families from whom the information had been gathered in order to identify the risk factors. A strong feeling was that, whilst there might be some increase in guilt feelings amongst some families, the benefits to the general population would easily outweigh them and that potentially beneficial information for others might come from studies of their own tragic bereavements.

A further point was the possibility of increasing feelings of guilt amongst health care professionals who had, for many years, been giving advice about sleeping position and wrapping which was in direct conflict with present views. The great majority of health care professionals having been given the detailed information upon which the new recommendations were based, were comfortable with giving the new advice and felt an ethical obligation to do so.

TARGET MESSAGES

The evidence for the association of prone sleeping, smoking and SIDS is strong. That on the importance of thermal care was less strong and the message more complicated. The advice to seek medical help if the baby is unwell is sound though the presence of infection in itself did not seem to be a major factor in the aetiology of SIDS.⁵ Reduction of the amount of bedding and wrapping in the presence of viral infection was in line with standard recommendations in slightly older infants as part of the strategy for prevention of febrile convulsions. This information was therefore also included in the campaign. The evidence for a protective effect of breast feeding against SIDS was considered insufficiently strong to justify a campaign to increase breast feeding rates.

Four simple messages for parents emerged from the discussions.

- (1) Put your baby to sleep on the back or side (with the lower arm well forward),
- (2) Stop smoking during pregnancy, if you can. Minimise exposure of your baby to cigarette smoke before and after birth. Create a smoke free zone around your baby after birth.
- (3) Do not let your baby get too warm or too cold. Do not cover your baby's head indoors and check your baby frequently to see whether he or she is comfortably warm, rather than hot or cold.
- (4) Seek medical attention early if your baby is unwell. Be aware of the fact that at the time of a viral infection your baby may need less bedding and clothing rather than more.

TARGET POPULATION

A number of key targets were identified; health care professionals, parents and parents-to-be the general public (especially grandparents), and school children. The needs of these 4 target populations were seen to be different and information to each of the groups was introduced at a different stage of the campaign.

STAGES OF CAMPAIGN

The campaign was planned in 4 stages:

(1) the information and involvement of professionals, (2) the information and involvement of parent support groups and previously bereaved parents, (3) public launch, and (4) sustained public information and feedback.

Health care professionals

The content of the campaign and the results of the Avon Infant Mortality Studies were passed on to all groups of health care professionals involved in the care of pregnant women and young children at regular postgraduate meetings, seminars, lectures and by means of a six-monthly newsletter. A detailed information pack was produced in 1991 and a helpline set up to answer the queries of health care professionals about childcare practices and environmental factors related to SIDS.

Parent support groups and bereaved parents

All families in Avon who had lost a baby due to SIDS in the previous 4 years were contacted by mail. The professional staff involved in the campaign attended meetings of the parent support groups to provide full information. A telephone helpline was set up for confidential discussion with bereaved parents.

Public launch of the campaign

By the time the public campaign was launched in October 1991, childcare practices throughout the county had already changed to a very great extent because of communication of new information by midwives, health visitors, general practitioners and paediatricians.6 Information for parents was made available in all hospitals, health centres, general practitioner surgeries, public libraries and citizen advice bureaux. The local television, radio, newspapers and magazines were actively involved in publicising the nature, purpose and content of the campaign. A public telephone helpline was established, which was manned by a research health visitor. In the first 4 weeks of the campaign over 100,000 leaflets were sent out, both locally and nationally. Two hundred and eighty phone calls and 150 letters were received requesting information, advice and comment.⁷

Sustained public information

Feedback to health care professionals was maintained by means of the twice yearly newsletter. Information about the campaign was circulated to all hospitals and health centres in the county, and public interest was maintained by regular updates on the progress of the campaign broadcast by local television and radio stations. Regular articles also appeared in local newspapers and magazines.

PRELIMINARY RESULTS

By October 1991 evidence on the effectiveness of the campaign which up to that time had only directly involved health care professionals became available through the continuation of the Avon Infant Mortality Study, and the collection of control data. These results showed there had been a 50% reduction in the incidence of prone sleeping in infants in the county and that this had been accompanied by a 50% reduction in the SIDS rate.6 This encouraging information was incorporated into the high profile public launch of the campaign in October 1991. These results, together with preliminary results of similar intervention in New Zealand at the beginning of 1991,8 were instrumental in persuading the UK Department of Health to mount a national risk reduction campaign from the end of 1991.

THE UK NATIONAL CAMPAIGN

The first stage which was organised by the foundation for the Study of Infant Deaths, commenced at the end of October 1991, and was timed to coincide with a television documentary shown nationwide which reported the preliminary results of the studies in Avon and New Zealand. This was given considerable publicity by the media as it involved a well known media personality who had herself lost a baby of SIDS some three months earlier.

The second phase of the national campaign was organised and funded by the

UK Department of Health and commenced in December 1991.

Many health care professionals felt confused by the speed with which the campaign was implemented and the rapidity with which previously recognised and widely held values were challenged and changed. The national campaign, having arisen largely as a consequence of media involvement, was a media event. Multiple news items and brief documentaries examined the background and facts behind the campaign, and high intensity television exposure occurred through the 3 week period leading up to and including Christmas and New Year. There were full page advertisements in all national newspapers and wide and rapid distribution of very simply worded leaflets for parents. A telephone helpline was established which dealt with many thousands of calls over this 3 week period. A total of 2 million parents leaflets were distributed during this period.

MONITORING THE EFFECTS OF THE NATIONAL CAMPAIGN9

Methods

Each month interviews are conducted by the Office of Population Census and Surveys (OPCS) with approximately 2,000 adult individuals aged 16 or over in private households in Great Britain. The sampling frame uses the post code address of all 'small users', which includes all private household addresses. A new sample of 100 postal sectors is selected each month with stratification by region, the proportion of households renting from local authorities and the proportion in which the head of the household is in each socio-economic group. The postal sectors are selected with probability proportionate to size and 30 addresses are selected randomly within each sector. If an address contains more than 1 household, the interviewer uses a standard OPCS procedure to select 1 household randomly. Within households with more than 1 adult member, just 1 person aged 16 or over is selected with the use of random number tables. The interviewer endeavours to interview that person and no proxies are taken.

This survey was used in March and November 1992 to assess public awareness of the messages of the 'Back To Sleep' campaign. Detailed information was sought on the knowledge and understanding of each of the factors which had been publicised in the national campaign. Further information was sought on the

source of that information.

In March 1992 among women in child bearing age groups (16-24 and 25-44 years) 82% and 86% were aware of the advice to put a baby to sleep on its back or side and not on its front, 48% and 50% were aware of the advice not to let a baby get too hot and 13% and 15% were aware of advice not to expose a baby to cigarette smoke. In November 1992 the respective figures were 60% and 77%, 50% and 62% and 13% and 20%.

Also in March 1992, among women in child bearing age groups (16-24 and 25-44 years) 73% and 87% had heard or seen the message on reducing the risk, 82% and 87% had received the message from television, 36% and 45% from newspapers or magazines, 12% and 6% from health professionals, 20% and 13% from the Department of Health leaflet, 5% and 5% from other sources. In

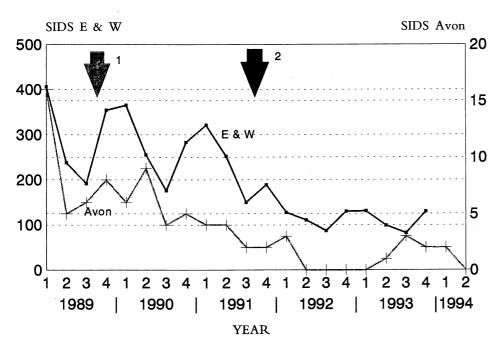


FIGURE 2

Number of SIDS deaths in England and Wales and in Avon in each 3 month period, 1989–1993. The time of the start of the 'risk reduction' intervention campaigns in Avon (1) and the UK (2) are shown. The data for England and Wales for 1993 are provisional, and 1994 figures are not yet available.

November 1992 78% and 86% had heard or seen the message reducing the risk overall, 88% and 86% had received this message from television, 41% and 61% from newspapers or magazines, 18% and 27% from health professionals, 18% and 22% from the Department of Health leaflet, and other sources 15% and 18%.

During the period March to November 1992 increasing numbers of women in these target groups heard the messages on reducing the risk of cot death from health professionals and through private conversation.

Changes in child care practice

No national data were available prior to the television campaign on the incidence of prone sleeping, heavy wrapping or exposure to cigarette smoke. Data collected from Avon is shown in Fig 1. The incidence of prone sleeping in the general infant population in Avon fell from 57% in 1987–1989 to 3% in 1992 and less than 1% by 1993.

RESULTS OF THE RISK REDUCTION CAMPAIGN

SIDS rates in the UK and Avon

The changes in SIDS rates in the UK and Avon are shown in Fig 2. In Avon there was a dramatic fall from a mean rate of 3·2/1000 in period 1985–1989 to 0·27/1000 in 1992. From February 1992 until May 1993 there was a 15 month period during which no infants died of SIDS in Avon. The change in national SIDS incidence was equally dramatic: there was a fall in SIDS rate from 1·4/1000

live births in 1991 to 0.7/1000 live births in 1992. Provisional figures for 1993 for the UK show that the incidence of SIDS remained at this low level. A further striking feature has been the marked reduction in the winter peak of SIDS deaths which followed the campaigns, initially in Avon, and subsequently in the UK as a whole.

Whilst it has been correctly pointed out that SIDS rates began to fall nationally in the UK from 1990, two studies have shown evidence that this fall may have been due to health care professionals throughout the country picking up the risk reduction message from publicity of the Australian and Dutch reports and changing their childcare practice. The results of the Avon studies on sleeping position and heavy wrapping were published nationally in 1990 and received considerable media attention. Information from the Isle of Man¹⁰ and Scotland¹¹ showed that health care professionals incorporated this information into their recommendations to parents.

Changes in risk factors

Continued collection of information in Avon suggests that the relative importance of some factors may have changed with the effect of the campaign. The reduction in incidence of prone sleeping has been accompanied by an apparent reduction in the relative risk attributable to heavy wrapping and continuous overnight heating. The risk attributable to parental smoking has, however, risen over this same period. Breast feeding, which in the initial studies in Avon, was not shown to be a significant protective factor has now emerged as having potentially significant protective effects. This may be related to the fact that breast feeding mothers are more amenable to health care advice and, whilst that advice was firmly of the opinion that prone sleeping was the safest position for babies, there was a strong association between infants sleeping prone and breast feeding mothers. Conversely, the advice on health care matters generally is less well received amongst individuals who smoke. Acceptance of the message on risk reduction was thus less in families in which one or other parent smoked, and the relative risk associated with parental smoking thus apparently rose. 12

THE IMPORTANCE OF CONTINUED MONITORING

Experience from the Avon and the UK risk reduction campaigns has shown that it is possible to achieve a major change in child care practices within a large population in a very short period of time. It appears that these changes have been associated with a considerable reduction in SIDS and, to date, no identifiable adverse effects have been recognised. It is, however, important to emphasise that changes in child care practice of this magnitude and short time scale are unprecedented and it is of the utmost importance that any potential adverse effects of these changes in practice are recognised as quickly as possible. It should, therefore, be an integral part of any planned risk reduction campaign to collect detailed information on all aspects of the impact of the campaign. This monitoring should include: The knowledge and understanding of the risk factors in the target population, changes in child care practice which have resulted, changes in SIDS rate and overall infant mortality rates, information of adverse effects which may have occurred, and the relative importance of the established risk factors after intervention and whether other risk factors begin to emerge.

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NOTES FROM A SYMPOSIUM ON PREVENTIVE MEDICINE* HELD IN THE COLLEGE ON 9–10 NOVEMBER 1994

DIET AND HEALTH

Dr P. James, Rowett Institute, Aberdeen, spoke on The scope for prevention and the Scottish diet. In Scotland the leading cause of premature death between 40–69 years is coronary heart disease (CHD). International comparisons of CHD mortality rates suggest a reduction of 80–90% is possible. Diet has an important role to play as it affects both atherosclerosis and thrombosis. Diets high in fruit and vegetable are protective against DNA damage and micronutrients modulate the immune response. In Scotland only 7% of the population have an adequate fruit and vegetable intake although 69% believe they do.

Are there benefits to health by lowering blood cholesterol? was addressed by Dr G. Davey-Smith, University of Bristol. Large epidemiological studies have shown that individuals with raised cholesterol levels have higher cardiovascular disease (CVD) mortality rates. There is no conclusive evidence to suggest a causal relationship between low cholesterol and a higher non-CVD mortality. A meta-analysis has shown that lowering cholesterol levels with drugs is associated with a 21% excess in non-CVD mortality (95% CI 7–37%). A significant excess is not associated with dietary therapy. At an individual level the effect of diet is disappointing and most patients progress to drug therapy. Drugs are only of proven benefit in individuals whose risk of dying from CHD is greater than 3%/year.

Dr A. Robertson, Safeway Stores plc, gave an overview on Shopping for a healthy diet—a retailer's perspective. The main role of retailers is to satisfy customers. Increasing the range, quality and accessibility of particular types of food promotes purchasing as do promotional offers. Retailers can assist better nutrition by manufacturing healthier products and providing in-store education. However to change the long term dietary patterns of a population governmental commitment is required so that a co-ordinated approach can be achieved. Lower socioeconomic groups must be specifically targeted.

PREVENTION AND THE ENVIRONMENT

The talk by Dr P. J. Fleming, University of Bristol, on Preventing cot death is published on page 213.

Dr D. P. Strachan, St George's Hospital Medical School, London, spoke on The impact of traffic pollution on the development of asthma. Population-based data is only available for school aged children. Studies suggest an increase in prevalence rates for wheeze in children since the 1970s and a rise in hospital admission rates but the severity of wheezing episodes has declined. These changes may be attributable to differences in diagnostic patterns and in changes in health care. There is no

*A full list of speakers and titles of their papers presented at this symposium is recorded in *Proceedings*, Vol. 25, p. 180.