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The Politics of Cot Death

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Recent court cases have shown that officials are all too quick to blame the mother in incidents of cot death. AIMS' Research Officer Jean Robinson argues that cot death has its roots in social inequalities and, to be understood, needs to be studied in this light.

In 1971, two paediatricians gave a paper at the International Paediatric Congress in Vienna on the benefits of prone sleeping positions for babies. Their arguments convinced the Dutch paediatricians present and were repeated in the press the following year. Mothers switched from their traditional habit of putting babies to sleep on their backs. By 1986, the cot death rate (very low in Holland) had tripled[1].

Yet, it was the Netherlands that started the first 'back to sleep' campaign in 1987, and their Sudden Infant Death rate fell by 40 per cent. Only after studies had been carried out in England did the UK Department of Health launch their campaign four years later (though many parents were changing before that). The American Academy of Pediatrics did not recommend the change until 1992, but there was no publicity campaign in the USA until 1994.

The lost history

The history of how this well-meant, but ill-founded, advice from doctors, nurses, midwives and health visitors spread so rapidly like a lethal virus, killing thousands - perhaps tens of thousands - of babies throughout the world, and the reasons why some countries took so much longer to change their advice to mothers, has yet to be written. But we won't stop reminding people that it needs to be written - otherwise, how shall we avoid similar mistakes in the future?

Simple advice can kill - you don't necessarily need drugs or technology to do it.

Poverty-the major risk

Eight years ago, we reviewed in the AIMS Journal the large CESDI report on cot death, funded by the Department of Health[2]. It was a wide-ranging study that included 600 questions to parents of dead children and living controls. Smoking and prone sleeping were identified as risk factors, but the researchers also collected a great deal of information about housing and income that clearly and overwhelmingly showed that poverty was the major risk factor.

We know that poorer social groups are more likely to smoke and that smokers, when under stress, smoke more. Being poor enough to receive family-income supplements showed the strongest association with

cot death. There were also powerful associations with having less living space, not having a telephone, having mould on the walls (especially inthe room where the baby slept) and not having a settled home. Some of these families had moved as often as eight times in the previous year.

The babies most at risk came from families who were not merely poor - they were among the most deprived groups in society. From our contacts with mothers, we realised that they would almost certainly suffer more stress - now well known to be a risk factor for poorer growth in the womb, with life-long consequences. Research has shown that even when we compare women on income support, it is those who are more deprived that are more likely to smoke during pregnancy, and find it more difficult to give up or cut down. This group is also probably at greater risk of domestic violence - but no one asked about that.

It is ironic that the underlying association with poverty was at last clearly revealed only because many of the middle-class deaths caused by prone sleeping had now been prevented by the 'back to sleep' campaign. A thought flashed through my mind at the time, which I mentioned to Beverley Beech, our Chair. I knew the way the 'motherblaming' wind was blowing. Would cot deaths of apparently healthy full-term, supine babies in non-smoking affluent families now be suspect? I wish that premonition had not come true.

A large study from Scandinavia (seldom mentioned, but crucial) published the following year showed how the poor can have risks increased. By detailed analysis, these researchers showed that prone sleeping is much more dangerous for babies who already had other risk factors, like prematurity, poor growth in the womb, smoking mothers in pregnancy[3]. All these factors are more common in the poor. And the risks did not simply add together - they multiplied.

It wasn't just medical advice, but medical example that affected mothers' care. A study in the USA found that poor black mothers were more likely to put babies to sleep face down- because that is what they had seen hospital staff do in the nursery[4]. There has been some research suggesting that prone sleeping may be beneficial for premature babies in hospital care, but did they use it for full- term babies too? The Nordic study authors sensibly suggested that premature babies should be put on their backs some days before they were sent home, to reassure the parents.

Missing answers

As CESDI had gathered so much information, we tried to get hold of a copy of the questionnaire, but the researchers refused our request, and claimed that the Department of Health had not given them enough money to make copies.

We were (and are) particularly interested in the birth experiences of the babies in the study, since a possible association with oxytocin inductions has been suggested[5]. We wanted to see what other data had been collected, but not analysed, and to keep an eye on any further information. Only when a further analysis, published by the Stationery Office, appeared four years later[6] did we learn that no association

had been found with induction of labour, oxytocin use or place of birth. Unfortunately, no figures for any of these statements were published. However, significantly more of the dead babies had had a caesarean delivery (13.7 vs 8.3 per cent). No one asked about ultrasound scans, which become ever more powerful and more frequent.

Unbalanced publicity

The CESDI study received surprisingly little publicity. Then, part of it was written up in two articles in the British Medical Journal[7, 8] that dealt only with smoking, drinking, drugs, bedclothes and sleep position - and they got banner headlines. Responsible journalists bitterly criticised the story's unusual early release before the BMJ articles were available for study. The Department of Health's press release did not even mention socioeconomic risk factors. While information on preventable aspects was important, from then on, 'mother-blaming' aspects dominated, and no one wanted to look at the social and economic context.

No one was even warning parents and housing authorities that babies should not be in houses with black mould on the walls, even though studies in Cleveland, Ohio, had shown this to be implicated in some cot deaths when toxins from mould spores were found in the infants' lungs at post mortem. The HMSO report no longer mentioned mould as a separate risk factor-it was lumped together with damp and leaks, and is not mentioned in the index.

However, it does make clear that the more serious these problems were, the more the cot-death risk increased. Overheating the baby is also a risk factor, but since more cot-death families lived in damp homes, mobile homes or bed-and- breakfast accommodation, the fact that they kept the heating on makes sense.

It was also clear from the CESDI reports that there had been suboptimal care from some paediatricians, GPs, midwives, health visitors and social workers, though this has been less well publicised.

The latest study

'Sharing-your-bed-with-your-baby-could-be-lethal' reports of the latest research have dominated news bulletins and newspaper headlines recently, and we rushed off to get a copy[9] It was large and impressive - 745 cot deaths were compared with 2411 live controls in 12 European countries, six of them in Eastern Europe.

As other studies have shown, many of the dead babies were more vulnerable to start with - more likely to have a teenage mother, or to be within a larger family. They were also more likely to be boys, of lower birthweight, to have had lower Apgar scores at birth, to have been in a special-care baby unit and to be one of twins or more.

What the headlines did not say was that whereas 16 per cent of deaths were attributable to bed-sharing, twice as many (35.9 per cent) were attributable to the baby sleeping in a separate room, the same percentage as were related to the baby sleeping face down (also 35.9 per cent). Yet, how many health

visitors are going round telling mothers "you must keep your baby in your room at night" and implying blame if the baby happened to die in a beautifully decorated separate nursery? The study authors report that SIDS babies slept in a separate room from parents 26 days earlier than controls and comment, "Why the baby sleeping in the parents' room reduced the risk is unclear."

This study confirms the increased risk shown in other studies if either the mother or others in the house smoke - whether or not they have the baby in bed with them. But a combination of smoking and bed-sharing was even more dangerous. For non-smoking mothers, there was an increased risk with bed-sharing only if babies were under eight weeks old. Parents who smoke are often more likely to drink. Having a couple of drinks in the last 24 hours did not raise the risk - but having three or more did. However, the actual numbers were small (only 7 per cent of case-mothers and less than 3 per cent of controls).

Sleeping position is confirmed as a major risk factor, and placing the baby prone or on its side greatly increased the risk. Dead babies put to sleep on their side were more likely to have moved on to their front than survivors put to bed in the same position. Those who died were more likely to have heads covered with bedclothes, so the researchers suggest that the safest covering for baby may be a jumper suit, with no additional covers.

Information on economic and social risk factors is sparse. Dead babies were much more likely to have an unemployed father (29.8 per cent vs 11.7 per cent) and their mothers were much more likely to be single.

Time to change direction

Recently, an Australian microbiologist has published swingeing criticism of omissions in past research. While doctors have concentrated on the epidemiology, they have failed to understand, research and learn from pathology findings [10]. The approach he advocates could have been enormously helpful to women who were wrongly convicted of killing their dead children. Further research on bacterial and viral toxins could also help to prevent deaths. Although smoke and prone sleeping can kill, we still do not know how - but it is known that smoke can make bacterial toxins more lethal.

Cot deaths, which had fallen in Sweden after sleep-position advice, have now risen again. Babies sleeping on their backs still die. We still do not know the answers. While we welcome advice which can help us to reduce risk for our babies, as a consumer group, we care about all babies in society. Perhaps we should look beyond potential faults in mothers' care, and look beyond at social, environmental and biological causes.

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