Sudden unexpected death in infancy – amazing progress but still unanswered questions

EA Mitchell

Address for correspondence
Department of Paediatrics
University of Auckland
Private Bag 92019
Auckland
New Zealand

Phone (+64 9) 923 6431
Fax (+64 9) 373 7486
Email e.mitchell@auckland.ac.nz
The sudden unexpected death of an infant (SUDI) is one of the most tragic events that can occur to their families. The infant is seemingly healthy, probably asleep, and is then found dead. For these families the next hours and days can only be described as a nightmare. The police may investigate the case as a homicide, which causes further anguish. The families have to deal with the pathologist and coronial system (and/or medical examiner in the United States). They have to deal with their partner and the infant’s brothers and sisters, who have their own needs, and with the extended family. To compound the problem many deaths are unexplained, and families are left with the unanswered question “Why did my baby die?” Their grief is overwhelming and there is guilt. It can be compounded by fear that tragedy could strike again making subsequent pregnancies and the experience of parenting fraught with anxiety. Sadly many marriages (partnerships) cannot handle these stresses, so separation and divorce is added to the trauma.

Fortunately much has changed. The dramatic decline in mortality from sudden infant death syndrome (SIDS) and in total infant mortality is one of the most successful public health interventions in child health.

We need to remember the pioneering work of people in the 1970s, people like Bruce Beckwith (US), John Emery (UK), Bob Carpenter (UK), Susan Beal (Australia) and Shirley Tonkin (NZ), who highlighted the problem of cot (crib) death, as it was commonly called, a problem not really recognised by hospital based paediatricians. Furthermore they made many astute clinical observations, which have been confirmed in more formal studies.

The breakthrough came in the 1980s when SIDS case control studies were set up with a focus on infant care practices. The strong association with prone sleeping position was clearly seen in a number of independent studies. This led to the recommendation to avoid placing the infant to sleep in the prone position. The rest is history. Mortality declined rapidly, although some countries were late in implementing the advice and their rates remained high until they too implemented their prevention campaign.
Despite the reduction in the number of babies dying, there are still many infants dying suddenly and unexpectedly. Those who die now are more likely to be from disadvantaged families, some living in poverty and chaos. These were probably always there but now are more visible because the socioeconomically advantaged families have heeded the prevention advice. This has led to deaths being labelled by pathologists as positional asphyxia, unascertained and undetermined etc.

In this series we start with a discussion of the definition of SUDI and SIDS [1, 2]. We then discuss the investigation of a death with contributors describing the multidisciplinary team approach in the UK [3] and Norway [4], the role of the pathologist [5] and the death scene investigation [6]. These are best practice models of care and should be the norm.

The next papers address altered physiological control during sleep [7] and potential mechanisms [8]. This is probably the hardest area of research as it is of course impossible to study living cases.

One of the more exciting developments is the studying the genetics of SUDI and this is discussed in the next issue. A small number of deaths are due to long QT syndrome [9], but many more are likely to be a combination of genetic predisposition and environmental influences [10]. We are still waiting for the first genome wide association studies (GWAS).

This series (February and May issues) has not focussed on the epidemiology of SIDS (and SUDI), as specific aspects have been reported previously. We refer readers specifically to:

- Smoking [11]
- Pacifiers [12, 13]
- Head covering [14]
- Immunisations [15]
- Breastfeeding [16]
However, one of the more contentious areas relates to the increased risk of SUDI with bed sharing. The arguments that this is a valued traditional practice and that it increases breastfeeding is balanced by the increased risk in infant death in certain circumstances. It is unlikely that a consensus would be reached that is acceptable to all. In the next issue three perspectives on bed sharing are given [17-19].

Because SIDS is diagnosed by excluding other conditions, leaving the death unexplained, it is possibly not that surprising that many different theories are advanced to “explain” the cause. Some theories are advanced with little evidence and some warrant detailed investigation. Unfortunately the media attention, which sometimes seems to be inversely proportional to the amount of evidence, causes confusion and draws attention away from established risk factors. Vennemann et al discuss some controversial theories [20].

The success of the intervention, whether called reduce the risk or prevention campaigns, has been stunning with reduction in mortality ranging between 50% and 80% [21]. This intervention was successful because of the important role of the voluntary organisations and the use of sound educational principles [22, 23].

We have not tried to address what should be included in the intervention programmes. The various components differ somewhat in different countries. However, the closest to consensus is the recommendations from the International Society for the Study and Prevention of Perinatal and Infant Death (ISPID). ISPID recommendations for reducing the risk of Sudden Infant Death Syndrome are [24]:

**Always (day and night) place the baby on his/her back when it's time to sleep**

- The most significant proven risk factor is the sleep position. The risk of SIDS is over three times higher for a baby sleeping on the stomach.
- The practice of always placing the baby on his/her back when it’s time to sleep should begin at birth. The baby will become accustomed to sleeping on the back and will have no problems falling asleep.
- Make sure every caregiver uses the "back to sleep" position. A caregiver placing a baby to sleep on his/her stomach or side when the baby is accustomed to sleeping on the back raises the risk of SIDS 18-fold.
- Place the baby on the stomach only when he/she is awake and under adult supervision.

**Always keep the baby's environment smoke-free**

- Do not smoke during pregnancy. The more you smoke, the greater the risk for SIDS.
- Second-hand smoke is also a risk factor: stay in a smoke-free environment when pregnant.
- Always maintain a smoke-free environment for the baby.

**Make the sleeping environment as safe as possible and avoid overheating**

- Place the baby to sleep in its own crib next to the parents' bed for the first six months (room sharing).
- Never share a bed with baby if you or your partner smoke. Babies whose parents smoke are at increased risk of SIDS while co-sleeping.
- Never share a bed with baby when you have had alcohol or drugs. (Don’t use alcohol or drugs when caring for your baby, especially ANY TIME you may fall asleep.) Babies whose parents have recently used alcohol or drugs are at increased risk of SIDS (and accidental suffocation) while co-sleeping.
- There is a slightly increased risk of SIDS with bed sharing for infants less than 3 months even if they were not exposed to cigarettes, particularly if the baby was small (less than 2.5 kg) at birth or born prematurely.
- In some countries there is a recommendation to avoid all bed sharing, although some disagree and advise avoiding bed sharing only if there are other risk factors present such as smoking or alcohol use.
• Never sleep with baby on a couch or sofa. This increases the risk of SIDS and fatal sleep accidents.

• Keep the crib free of soft objects and anything loose or fluffy (bedding, toys, bumpers, pillows, duvets).

• Do not allow the baby's head to be covered with bedding/blankets.

• Keep the room temperature at 18°C to 22°C and avoid over-dressing (i.e. too many layers of clothes; particularly avoid the use of a hat when indoors) when placing the baby to sleep. Overheating has been cited as a risk factor for SIDS in the past, however, it has been shown that thermal factors are less important if the infant sleeps on the back.

• Use a safe, firm mattress that fits the crib properly.

• Use a mattress that is in new or used and in good condition (no tears).

A word about breast feeding and pacifiers

• Breast feeding is always recommended for its numerous benefits for babies and mothers (as a source of multiple necessary nutrients, disease protection and as a contributor to mother-baby bonding). Several studies show that breastfeeding also offers a risk reduction for SIDS.

• Research suggests that using a pacifier may reduce the risk of SIDS. Start using a pacifier after one month of age when breast feeding is usually well established. Give a pacifier when you put the baby to sleep, but do not force it. Some but not all studies have shown that pacifiers may have an adverse effect on breast feeding.

Immunization

• Infants that are immunised have half the risk of SIDS and are protected against diphtheria, tetanus, whooping cough, etc.
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