

Sudden Infant Death¹:
A global problem, local action.
Report to Public Health Agency of Canada
(PHAC)
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¹ Confusion over terminology will be discussed in the text, see p 5.

Executive summary

This is a report on presentations made at the Joint Conference - The International Stillbirth Alliance (ISA) and International Society for the Study and Prevention of Infant Death (ISPID), 8-10 October 2010, in Sydney, Australia. This is not a conference report *per se*. This report is based on notes made at the conference at sessions attended by the author, supplemented by responses to questions made of the presenter, and where possible, the published abstracts. The presenters were not asked to comment on this report, and the author accepts full responsibility for the interpretations given. This report focuses on issues of infant death rather than stillbirths, as it was not possible to attend all sessions of the joint conference.

Attendees at this conference included scientists (basic and applied), physicians, nurses and other health care professionals, administrators, leaders of voluntary organizations and students. Most importantly, parents who had had a stillbirth or infant death were full participants.

The report does not present conference presentations chronologically; it does so thematically. The sections are listed on p5. The report concludes with suggestions, based on information presented at the conference, on the way ahead in reducing infant deaths in Canada.

Conference participants were in wholehearted agreement that infant deaths remain a substantial public health problem, particularly in disadvantaged populations, including aboriginal groups. There was concern that the reduction in the rates of SIDS would reduce the emphasis and funding given by public health agencies for education on safe sleep practices. Some evidence was presented that the reductions in deaths have levelled off, and perhaps increased marginally.

The issue of what to call the phenomenon described as “SIDS” since the late 1960s was discussed in a number of presentation, but consensus was not reached. The point was made that

the starting point for investigation was Sudden Unexpected Death in Infancy (SUDI). When investigations, including an autopsy and inspection of the scene of death were negative, hitherto deaths had been called SIDS. On an individual basis, coroners and medical examiners, and sometimes government bodies, investigating infant deaths were assuming that prone sleep position or finding an infant in bed with an adult were sufficient causes of death. This would have the effect of reducing the number of deaths called “SIDS”, but of course would not reduce the number of infant deaths.

There was also overwhelming agreement that infants should sleep on their backs, should be breast-fed, should never be exposed to tobacco, even *in utero*, and should have an uncluttered sleep environment on a sleeping surface designed for an infant, placed in the same room as the parents. There was some early controversy on whether the practice of infants sharing a bed with adults should always be avoided. As evidence was presented it became clear that while there is a variation in the level of risk of bed sharing, it was never free of risk. Hence infants should never sleep in the same beds as adults. In some populations, traditional practice should be respected. (It has already been established that sharing other sleeping surfaces, such as sofas etc is even more dangerous than bed sharing).

Presentations were made on a variety of ways in which the message about safe sleep could be delivered to vulnerable populations. While this is recognized as an important topic, it is still in the early stages of study. It is essential to deal with the anxieties of parents who hear the safe sleep message but fail to follow it because of specific concerns. Comments were made about the need for funding to see projects through, including evaluation.

There was acceptance of the concept of safe sleep practices, but recognition that most infants, for example, placed prone or exposed to tobacco, in fact survive. Bereaved parents ask the question “why did my infant die and not my friend’s infant, when we both placed infants prone or in our bed?” This question was not answered at the conference, but was addressed by a number of studies dealing with physiological changes in infancy, and variation in genetics in children who

died compared with children who survive. The question is important, both for the peace of mind of the bereaved parents, and more generally to understand more completely the phenomenon of infant deaths. This understanding may lead to different preventive strategies in the future.

Parents whose child dies suffer greatly. Some of their experiences were given, along with various ways of providing support, including online support. Their experiences and comments need to be more widely known to improve society's approach to bereaved parents.

Background to Report and Objectives:

The Public Health Agency of Canada (PHAC) and Health Canada have been involved in measures to reduce infant deaths for decades. They have partnered with other agencies, such as the Canadian Paediatric Society and in 1999, produced a Joint Statement: Reducing the Risk of SIDS in Canada. They produced accompanying pamphlets and spearheaded a publicity campaign. PHAC is in the process of producing a revised statement and devising a strategy to further reduce infant deaths. PHAC recognized that important and relevant information would be presented at the Joint Conference - The International Stillbirth Alliance (ISA) and International Society for the Study and Prevention of Infant Death (ISPID), 8-10 October 2010 in Sydney, Australia. The author of the report was attending and presenting at this conference, and was asked to summarize the presentations he attended, his conclusions, and some suggestions for action. This report is the responsibility of the individual who wrote it, and the opinions expressed are his, not those of PHAC.

This is not the first time that the International Stillbirth Alliance (ISA) and International Society for the Study and Prevention of Infant Death (ISPID) have had a joint meeting. The conference program was much more clearly integrated than in previous conferences. There are some sessions in which there are obvious commonalities, such as “coping with loss” and many of the scientific sessions dealt with topics of interest to both groups. For example issues of genetic factors and vulnerability to infection are of interest to those dealing with stillbirth just as much as they are of interest to those dealing with SUDI/SIDS.

The conference had Plenary Sessions and Parallel Sessions. It was possible to attend all the Plenary Sessions, the topics being: Perinatal and infant deaths-a global perspective, Coping with loss, Priorities in future research directions, Genetic factors, Vulnerability and infection and a concluding session called “Call to action”. Obviously it was not possible to attend all the Parallel Sessions and therefore some selection was made. The complete list was: Physiology, Epidemiology, Safe sleeping environment, Definitions/diagnosis, Bereavement care, International perspectives, Pathology, Research directions, and Safe sleeping education. These

sessions had presentations varying between 10 and 20 minutes long, always with time for discussion. I attended the sessions on: Epidemiology, Safe sleeping environment, Definitions/diagnosis, International perspectives, Research directions, and Safe sleeping education. I was able to participate in discussion, and develop formal and informal contacts with individuals from other countries

The objectives of the report were:

Present an overview and analysis of the current global situation and trends in sudden infant death as described at the Joint Conference - The International Stillbirth Alliance (ISA) and International Society for the Study and Prevention of Infant Death (ISPID), 8-10 October 2010 in Sydney, Australia:

- i. Summarize the main issues identified at the conference,
- ii. Identification of priority issues that impact Canada; in particular indigenous, socio-economically disadvantaged, and newcomer populations. Present recommendations, including any best practices identified at the Conference, for future directions in Canada in terms of understanding and reducing the impact of sudden infant death.

The report is organized in the following fashion:

1. Summary of presentations
 - Terminology used in infant death,
 - Comments on overarching issues in infant death,
 - Non-controversial issues,

- Controversial issues,
- Risk factors and vulnerable populations: Physiological, genetic and behavioural aspects,
- Other issues,
- Do we know how to make our message heard to reduce further infant death rates?,
- Parents' view of their experiences.

2. Implications for Canada of findings presented at conference

Terminology used in infant death

Before discussing the specifics of the conference, it is important to point out that some jurisdictions are now using the label Sudden Unexpected/Unexplained Death in Infancy – SUDI - where previously they might have used SIDS. More commonly speakers and writers are using the composite label SUDI/SIDS. Some also use SUID – Sudden Unexpected Death in Infancy. Throughout this report, the acronym used by whoever is being quoted will be used. However, when there is a choice, SIDS will be used as this is the more familiar term. This use is one of convenience and does not in any way invalidate the justification for the other terminologies. It is acknowledged that change is underway in the labels used and in their definitions. Until international agreement is reached on which acronym to use, and its precise definition, caution should be exercised on use of new terminology. Some of the problems are outlined in publications by Byard et al and Mitchell et al.²

The first Plenary Session of the Conference was entitled “Perinatal and Infant Deaths: A global Perspective”. In a talk by Blair, “SIDS/SUDI an international perspective”, a question was posed: Who and exactly how do infants die suddenly and unexpectedly? The point was made that the studies done were observational but have been a great achievement in science. He made an even stronger point; these studies described association, not causality. The term SIDS had an air of honesty, a statement that we really didn’t know what had happened. In terms of the “when”, this was not in the first week, but peaked around 12 weeks. The “who” were male, had neonatal problems, had lower socioeconomic status, and their mothers were smokers.³

There has clearly been a fall in SIDS rates, and a review by Hauck on international trends was

² Byard RW, Marshall D. An audit of the use of definitions of sudden infant death syndrome (SIDS). *J Forensic Leg Med*. 2007;14(8):453–455; Mitchell E, Krous HF, Donald T, Byard RW. Changing trends in the diagnosis of sudden infant death. *Am J Forensic Med Pathol*. 2000;21(4):311–314

³ These are the usual generalizations of epidemiology, of course females can die suddenly and unexpectedly, and the death can happen to children of any socioeconomic status.

cited.⁴ This particular review pointed out the difficulty of obtaining international statistics and diagnostic confusion over the use of the various terms. There has also been “diagnostic transfer”, deaths which might have been attributed to SIDS now being attributed to some other cause or labelled “undetermined”. Despite this caveat there has been a real fall in the number of SIDS deaths, the main reason being use of supine sleep position. Using different methods of calculation, supine sleep is associated with a drop in SIDS deaths, and in USA is somewhere between 27 and 47% of the deaths.

⁴ Hauck FR, Tanabe KO., International Trends in Sudden Infant Death Syndrome: Stabilization of Rates Requires Further Action *Pediatrics* 2008;122;660-666 DOI: 10.1542/peds.2007-0135

Blair issued a number of warnings:

1. Don't assume that we can easily change all infant care practices. He pointed to the historical pictures, when in the 1950s we encouraged prone position for preterm infants. When the error in this advice was recognised, it was fairly easy to change practice in terms of sleep position; other practices will be more difficult to change.
2. There are many differences in sleep practice and we need to be careful when we deal with issues of culture, SIDS rate and bed sharing.
3. Don't mix association with causation. Placing a child prone is NOT a cause of death. [Editorial comment; warnings about confusing association with causation were not only repeated later, they were echoed by other speakers during the conference.] He reviewed some of the definition of SIDS, and pointed out that in Norway in 1994, the focus was on the term "unexplained". He also quoted the criteria developed by Bradford Hill ⁵about inferring causation from epidemiological data. These are worth quoting.
 - a) **Strength of the association.** How large is the effect?
 - b) **The consistency of the association.** Has the same association been observed by others, in different populations, using a different method?
 - c) **Specificity.** Does altering only the cause alter the effect?
 - d) **Temporal relationship.** Does the cause precede the effect?
 - e) **Biological gradient.** Is there a dose response?

⁵ Bradford-Hill A. The environment and disease: Association or causation? *Proc R Soc Med* 1965;58:295-300.

- f) **Biological plausibility.** Does it make sense?
 - g) **Coherence.** Does the evidence fit with what is known regarding the natural history and biology of the outcome?
 - h) **Experimental evidence.** Are there any clinical studies supporting the association?
 - i) **Reasoning by analogy.** Is the observed association supported by similar associations?
4. We should remember that studies are never about SIDS, always about SUDI. The concept he advanced is that SUDI deaths can be subdivided and some will be considered SIDS. SUDI should be reserved for those that are explained. The groups he described were:

- I – No abnormal findings;
- II - Associated findings;
- III - Fully explained death.

In his view only deaths in group III should be called SUDI. He was clear that this was neither a new definition nor a plea for recognition of SUDI in the International Classification of Diseases. It also was not too prescriptive.

Mitchell⁶ presented information from Alberta Canada about use of the term SIDS, based on a

⁶ Mitchell I. When we say SIDS what do we mean? J Paediatr Child Health, 46 (Suppl. 3) 2010, 13.

database of all SUDIs notified to the Medical Examiner over a period of 30 years. The definition of SIDS was similar to the one used in the Avon study and assumed that an infant sleeping prone or in bed with a parent, with otherwise negative findings was SIDS. Until 1991 there was full agreement between this definition and Medical Examiners' determination. In the period 1992-1999 agreement was 95%, from 2000 -2005 it was 95%, and from 2005-2008 it was 76.3%. The diagnoses used included "SUDI", "unexplained" or "indeterminate".

This is clearly part of a larger international trend and serves to emphasize the care we need when we review statistics between jurisdictions.

On a quite different vein, Mage⁷ addressed the issue of whether SIDS was a distinct disease entity, or a collection of different causes of death. If SIDS is a collection of different causes of death, then it will eventually disappear, as it is a diagnosis of exclusion. He used mathematical processes to demonstrate distinct differences between the age distribution of SIDS, death from neurological causes, deaths from infection and from long QT syndrome. The mathematics seemed to indicate that SIDS is a unique and distinct disease entity. These results require to be verified using statistics where SIDS has been strictly defined, and where there are well accepted control or comparison groups.

⁷ Mage DT Cramer's theorem proves that SIDS is a distinct entity and not a collection of different causes of death. J Paediatr Child Health, 46 (Suppl. 3) 2010, 15.

Comments on overarching issues in infant death

In one of the Plenary Sessions, Fleming dealt with the issue of decreasing the risk of unexpected deaths, the advice we give, and the consequences. He used data from the Avon study that started in 1991 and is ongoing today. He described issues that were non-controversial, and issues with some controversy.

In the non-controversial group he included:

- supine sleep position,
- sharing a room with parents,
- not sharing a sofa as a sleeping surface,
- no exposure to tobacco,
- no pillows,
- no head covering.

Those with some controversy were:

- avoiding heavy wrapping (in any case bedding used is now much lighter),
- using feet to foot (to avoid the infant slipping under covers),

- using a baby sleep bag with sleeves (same reason as feet-to-foot),
- avoid all bed sharing,
- use of dummy,
- benefits of breast feeding in terms of preventing SIDS,
- swaddling.

He spent most of the time dealing with bed sharing, and whether this should be avoided all the time with every infant. He did emphasize the dangers of sleeping with an infant on a sofa, if the infant had ever been exposed to tobacco, including in prenatal life, if the adult sleeping with the infant had any alcohol, or took any drug that might cause drowsiness. He speculated that perhaps it is possible to create a safe environment in bed, and that we need to be careful that we do not get the message to the wrong people. The issue of maternal obesity and sharing a sleeping surface was an infant was also raised, but he felt the evidence wasn't clear cut. Questions were raised about the overall risk of infants sharing a bed with adults, but still not clear evidence when this practice would be safe,

Swaddling is also seen as a risk factor, but this is an area that is very poorly defined. It can vary from a simple sheet covering infants to very thick layer of clothing, restricting infants' movement. In some cultures swaddling is extensively used and any studies of swaddling must look at several different cultures, and be carefully explored in detail before we make widespread recommendations to forbid or encourage this.

In another Plenary Session, Mitchell⁸ presented an "Update on SUDI/SIDS Risk Factors". This

⁸ E A Mitchell, New Zealand, no abstract available.

dealt with some of the issues covered by Fleming; sometimes there were subtle differences of interpretation. The four topics he dealt with were sleep position, smoking, bed sharing and head covering. He was clear at the outset that he would not deal with pacifier use, breast-feeding or room sharing.

A clear statement was made about sleep position - “prone sleeping is a cause of death”. He quoted New Zealand statistics, where prone sleeping now occurs in less than 3% of the deaths, and no longer appears as a risk on review of deaths. However we must continue to remind all caregivers, especially grandparents, of the risk of prone sleeping. When children are unaccustomed to prone sleeping, and then sleep prone, the risk of death seems to be high. He also pointed out that side sleeping was unstable and risky, and the only safe position for infants to sleep was supine.

In regards to maternal smoking and pregnancy, all studies have shown an increased risk. When the father is a smoker, and the mother is a non-smoker, there is an increased risk but the odds ratio (OR) is only 1.5 suggesting the risk is not greatly increased. In other words the risk of smoking is mainly *in utero* exposure.

Co-sleeping, more accurately described as bed sharing, was dealt with in detail. The well known Biblical story of disputed maternity was about a baby who died in his mother’s bed. In one of the early studies⁹ of SIDS/SUDI, the OR was 2.7 and a subsequent study¹⁰ showed an interaction with smoking, an interaction that has been confirmed many times. In issues of bed sharing versus the

⁹ Mitchell EA, et al. Four modifiable and other major risk factors for cot death: the New Zealand study. *J Paediatr Child Health*. 1992;28 Suppl 1:S3-8.

¹⁰ Scragg R, et al. Bed sharing, smoking, and alcohol in the sudden infant death syndrome. New Zealand Cot Death Study Group. *BMJ*. 1993 Nov 20;307(6915):1312-8.

infant using their own crib, bed sharing seems to be the problem. In those not used to bed sharing, and then bed sharing there is an increased risk of death. In alcohol and co-sleeping combined, the OR is increased to 14. Co-sleeping on the sofa also seems to increase the risk.¹¹

The main conclusions about co-sleeping/bed sharing are that the risk of SIDS is increased and when this practice is combined with smoking ± alcohol the risk is increased. There is a small increased risk in infants aged less than 3 months. There is no evidence that co-sleeping/bed sharing is protective for SIDS. In the various interactions described, removal of one factor will make a difference; it seems unlikely that behaviours around alcohol and smoking will change.

There were also some remarks about parents' right to know about the scientific evidence, and whatever one's personal stance on bed sharing, parents should be allowed to make an informed choice. He noted the current push to increase bed sharing on the rationale that it will increase breast-feeding despite a lack of evidence to support the rationale. He also noted that sharing the bed is common in some cultures, and when evidence is presented about risks, it is perceived as an attack on culture. He also noted that many healthcare practitioners do not discuss bed sharing, and that in various surveys less than half parents know that bed sharing is a risk for SIDS. In New Zealand, there are 60,000 births per year, and in the most recent year there were 41 SIDS, 5 "ill-defined", and 12 "accidental suffocation in bed", in other words 58 that would have been called "SIDS" in a previous use of the terminology. The current trend in New Zealand is to stop or reduce bed sharing as the most important way to reduce the number of SIDS. The use of a basket or a bassinet can allow the infant to be close to the bed.

Information on head covering is not clear. Information that head covering was a risk led to the

¹¹ Carpenter RG et al. Sudden unexplained infant death in 20 regions in Europe: case control study. *Lancet*. 2004 Jan 17;363(9404):185-91. And Blair PS Et al. Hazardous cosleeping environments and risk factors amenable to change: case-control study of SIDS in south west England. *BMJ*. 2009 Oct 13;339:b3666. doi: 10.1136/bmj.b3666

idea of sleeping “feet-to-foot.”¹² Some studies have shown some benefit from a sleeping sack. He felt the evidence on these was not so clear.¹³

In conclusion he stated strongly that SIDS was preventable and that we can eliminate SIDS. The question is how we implement the knowledge we already have.

How old does a child need to be to have SIDS? This question is answered in different ways, with definitions only including the post neonatal period (28 days of age), or part of the neonatal period, for example starting to include infants dying after the age of one week, or after three weeks of age. It is unusual for definitions to include infants immediately after birth. Wang¹⁴ reviewed all SUDI deaths in the first 28 days of life from 1996-2008. There were 121 such deaths out of a total of 810 SUDIs (15%). Of the 121 deaths, 14% with preterm and 17% low birthweight. Just under one third (36 deaths) occurred in the first 7 days, and 18 were unexplained. Of the 85 late (after 7 days), neonatal deaths 68 were unexplained. The causes of death and risk factors of these neonatal SUDI deaths were compared with all SUDI deaths, and were shown to be similar, with a slight excess of co-sleeping.

This study suggests that when we study SUDI we should include infants from birth onwards. Also, attempts at prevention should recognize that the neonate is at risk.

¹² Blair PS, et al. Hazardous cosleeping environments and risk factors amenable to change: case-control study of SIDS in south west England. *BMJ*. 2009 Oct 13;339:b3666.

¹³ L'Hoir MP et al Risk and preventive factors for cot death in The Netherlands, a low-incidence country. *European Journal of Pediatrics*, Volume 157, Number 8, 681-688.

¹⁴ Wang L. analysis and prevention of neonatal sudden unexpected deaths in NSW. . *J Paediatr Child Health*, 46 (Suppl. 3) 2010, 15.

Hauck^{15 16}, in common with other speakers, accepted the success of the back to sleep campaign in SIDS/SUDI; her talk focused on “new challenges”. One of the new challenges is that the reduction seems to have stabilized, but there remains variation across countries in the number of infant deaths. She indicated that comparison was not easy because of problems in definition, diagnostic methods and assignment of cause of death.

In terms of specific interventions, 16 studies have looked at back to sleep. No studies have shown aspiration as a consequence. However an increase in the incidence of plagiocephaly has been noted. She cited Hutchison et al¹⁷, who suggested “Early identification of a preferred head orientation, which may indicate the presence of neck muscle dysfunction, may help prevent the development or further development of nonsynostotic plagiocephaly in infants. Plagiocephaly might also be prevented by varying the head position when putting the very young infant down to sleep and by giving supervised tummy time when awake.” It has been difficult to evaluate interventions about avoiding smoking, but at least there is unlikely to be harm in such interventions. There seems to be an increase in the rate of smoking in females, and there is a high rate of smoking in Aboriginal populations. Unfortunately only 25% will stop smoking if they become pregnant. One intervention that does work to reduce tobacco use is an increase in taxes! It is important to encourage breast-feeding, and to have a “baby friendly home”.

Hauck commented on social marketing and the need for positive advertisements about SIDS.

¹⁵ Hauck FR. The success of the back to sleep campaign in SIDS/SUDI and new challenges. *J Paediatr Child Health*, 46 (Suppl. 3) 2010,2.

¹⁶ Hauck FR. The success of the back to sleep campaign in SIDS/SUDI and new challenges. *J Paediatr Child Health*, 46 (Suppl. 3) 2010, 2.

¹⁷ Hutchison BL, Thompson JM, Mitchell EA. Determinants of nonsynostotic plagiocephaly: a case-control study. *Pediatrics*. 2003 Oct;112(4):e316.

SIDS needs to stay in the news.

Non-controversial issues.

Maternal smoking during pregnancy is an important risk factor for SIDS. While some authors have suggested postnatal smoking is also relevant, the evidence for this has been less clear. Liebrechts-Akkerman¹⁸ described the Dutch prevention system, and why the Dutch may be able to provide important information. There is a very low rate of SIDS in Holland which is attributable to a well-developed education system, and the fact that general practitioners, midwives, nurses in well-baby clinics together have been delivering information on risk factors, including birth history, sleep position and smoking, since 1987. Since 1996, all SIDS cases have been well documented. They believe they have enough information to look at under estimated risk factors.

They examined 142 SIDS cases, and compared this with data from 2871 infants in the Netherlands Pediatric Surveillance Unit. The findings were that prone sleeping was strongly associated with SIDS. Postnatal smoking, of one or both parents, and premature birth were also strongly associated with SIDS. The conclusion was that postnatal parental smoking was the second most important risk factor for SIDS in the Netherlands. This came after prone sleeping, but before preterm birth. In other words we need to continue to support parents in their attempt to reduce postnatal infant tobacco exposure.

Breast-feeding is beneficial for children. However it has been difficult to show clearly that breast-feeding is protective for SIDS. Hauck¹⁹ presented a meta-analysis on this topic. She and

¹⁸ Liebrechts-Akkerman G. Postnatal parental smoking is an important risk factors for SIDS. J Paediatr Child Health, 46 (Suppl. 3) 2010, 11.

¹⁹ Hauck F. Breast feeding and reduced risk of Sudden Infant Death Syndrome: A meta-analysis. . J Paediatr Child Health, 46 (Suppl. 3) 2010, 32.

her coworkers reviewed 288 studies reported in Medline from 1966- 2009. There were 24 case control studies. When the study looked at “any breast-feeding”, the Odds Ratio was 0.49, in other words breast-feeding reduces the risk of SIDS. When the study focused on “exclusive breast-feeding”, the Odds Ratio was 0.32.

The conclusions were very clear. Any kind of breast-feeding, and any duration of breast-feeding protects against SIDS. Exclusive breast-feeding gives stronger protection.

Controversial issues

Should infants use soothers? This was called the “dummy debate” by Richardson²⁰. The reference is to the fact that infant soothers are given different names in different parts of English-speaking world, “dummy” being used in Richardson’s home country, Australia. The background is that since the underlying problem leading to death is impaired arousal, and that the various “risk factors” work by decreasing arousability. For example, arousability may be modified by prone position, and maternal smoking may affect cortical aspects of arousability. Some studies have shown that using a dummy seems to be protective for SIDS, perhaps by affecting arousability.

In this study there were 26 healthy infants, 10 who used a dummy and 16 who had never used one. Daytime full sleep studies – polysomnography - were done at 3 months, using an air blast to the nose as a means of arousal. She found that dummy users had fewer cortical arousals during quiet sleep compared with non-users. She also noted that dummy users had increased proportions of active sleep, which is a more arousable state.

Her conclusion was that the protective effect of dummy use may be related to alterations in sleep state rather than the arousal process *per se*.

Moon²¹ accepted that pacifier use is associated with a decreased risk for SIDS. Given that

²⁰ Richardson HL. The dummy debate – does dummy use affect infant arousability from sleep? J Paediatr Child Health, 46 (Suppl. 3) 2010, 4

²¹ Moon R. pacifiers and SIDS risk: would parents change their mind if they knew? J Paediatr Mitchell/PHAC report/January 2011

African-Americans are at higher risk for SIDS, she wondered why African-American parents did or did not use pacifiers, and whether knowledge about the association of pacifiers with decreased risk of SIDS would change their attitude. There were interviews and focus groups with lower and higher socioeconomic status African-American mothers. Of 83 mothers who were interviewed, 75% used pacifiers for their infant. Then the pacifier non-users were asked if the decision would change if they knew that pacifier use decreases SIDS. These moms were sceptical about the pacifier-SIDS link, and their other concerns about pacifiers outweighed concern for SIDS. It was concluded that it would be difficult to convince African-American parents who did not like pacifier use, to use one to prevent SIDS.

Taylor from New Zealand wanted to find out if we could identify when co-sleeping²² was safe. He really provided the background to a study that would start in 2011 in his country. He made some general observations on SIDS, and mentioned the triple risk hypothesis, that is that SIDS results from some interaction of the following factors:

- 1) A vulnerable infant (i.e. some preceding abnormality),
- 2) A critical developmental period in homeostatic control (hence we need to look at normal development),
- 3) An exogenous stressor (perhaps sleep position).

Child Health, 46 (Suppl. 3) 2010, 31.

²² By co-sleeping he means a child and an adult or adults sharing a sleep surface

He also discussed some of the controversies, and also sensitivities, around adults and infants sharing a sleep surface. He said “the evidence based practice of cultural sensitivity risks irrelevancy”. He also showed videos of bed sharing and in some cases when the babies moved the mothers responded, but not always. In any study of sleep environment we need to consider all players, and if all are healthy the risk may be very low. On the other hand any change in any one of those involved will change the risk.

The study he proposed was a randomized control study of a Wakakuri (Maori basket) versus a portable bassinet. During the study he would look at issues of physiology, infant behaviour, community connections, video parental behaviour, and look at issues of parental depression, anxiety and stress. This would seem to be an important study but would not advance our understanding of bed sharing until results are available in several years.

By contrast, Blair reported some of the issues about bed sharing and breast-feeding.²³ He felt the discussion would be better informed if we knew more about what actually happens with breast-feeding over time. In the well-known Avon study, of just over 14,000 births, long-term follow-up occurred and information was available on 5 time points between birth and 4 years old in 7447 infants. In the study, overall there was an 83% response in the first 2 years of life, falling to 54% at age 10 years.

Latent class analysis is a technique to look at patterns over time, described phenotypes and list probabilities. It is limited by the number of time points available. This analysis identified four mutually exclusive groups:

²³ Blair PS. The relationship between bed-sharing and breast feeding: a longitudinal population-based latent class analysis *J Paediatr Child Health*, 46 (Suppl. 3) 2010, 10.

- Non-bed-sharers (66%),
- Early bed-sharers, who shared only in infancy (13%),
- Late bed sharers who started bed sharing after the first year (15%),
- Constant bed sharers who bed-shared through the 4 years (6%).

There was a male preponderance of the bed sharers, and breast feeding duration was greatest in those who always bed-shared and least in those who never bed-shared. In response to a question from the audience, it was confirmed that there was no information on maternal obesity.

There was no real conclusion from the study, merely affirmation of the many factors that affect successful breast-feeding in infancy.

In another contribution to the discussion on bed sharing, Vennemann²⁴ presented the results of a meta-analysis. Data from PubMed and Medline were searched for studies published after January 1, 1970 that contained some combination of the terms “sudden infant death syndrome”, “sudden unexpected death”, and “cot death”, combined with “bed sharing” and “co-sleeping”. 139 studies were identified and 11 met the inclusion criteria. The combined Odds Ratio for SIDS in all bed sharing versus non-bed sharing was 2.86 (95% CI 1.94 and 4.22). This finding was more pronounced in infants younger than 13 weeks (Odds Ratio of 3.47), and very high for infants of smoking mothers (Odds Ratio of 9.0). No studies showed a protective effect of bed sharing.

The conclusion here was clear: bed sharing is a risk factor for SIDS and should be discouraged.

²⁴ Vennemann MM. bed sharing and the risk of SIDS: A discussion document. J Paediatr Child Health, 46 (Suppl. 3) 2010, 32

Risk factors and vulnerable populations: Physiological, genetic and behavioural aspects.

Widdows²⁵ considered whether prenatal factors might play a role in SIDS. She reviewed some of the factors suggesting that SIDS is a developmental disorder, such as the effect of prenatal smoking, of drug use, and of obstetric complications. Also, it has been suggested that SIDS may be associated with fetal hypoxia and incomplete development of some organs. She has access to archived placentas. She retrieved placentas from 18 infants with SIDS and normal birth weight, 14 with SIDS and low birth weight, 19 term control infants, and 7 non-SIDS and low birth weight. Her hypothesis is that changes in the trophoblast will lead to placental hypoxia, then fetal hypoxia, and then SIDS.

She showed that the placentas from SIDS infants with abnormal birth weight or low birth weight, whether or not the mother smoked, had specific changes with increased volumes of gas exchange, villi and cytotrophoblast. She concluded that SIDS was associated with placental abnormalities, and that the changes found in SIDS were different from those found in the placenta of infants with low birth weight who survive.

Other authors also looked at maternal and perinatal risk factors. Highet²⁶ obtained data from 118 SIDS cases and 227 matched controls. SIDS was more common when the infant's mother was not in a relationship, was not the first born, and when the mother lived in a socio-

²⁵ Widdows KL. Hypoxia-related morphological abnormalities in villous trophoblast turnover in placentas from victims of SIDS. *J Paediatr Child Health*, 46 (Suppl. 3) 2010, 3

²⁶ Highet A. Maternal and perinatal risk factors in a south Australian SIDS cohort. *J Paediatr Child Health*, 46 (Suppl. 3) 2010, 16.

economically disadvantaged area. Obstetric complications did not seem to be an issue. The author was clear that this information was in keeping with findings from other regions.

Yiallourou²⁷ is interested in why prone sleeping is a risk factor for SIDS. Speculation on the mechanism of this known risk factor might be autonomic dysfunction, with failure of blood pressure control. It is notable that blood pressure is lowest in the age range 2-3 months, and this nadir may be more marked when infants are prone, especially while asleep. Baroflex sensitivity is a function of the relationship between blood pressure change and heart rate. The hypothesis of this study is that infants in the prone position will have reduced blood pressure control. 31 term infants had daytime sleep studies with continuous blood pressure monitoring at 2-4 weeks, 2-3 months and 5-6 months of age. Studies were done during quiet and active sleep in supine and prone positions. At each age and sleep state the maneuver of head up tilt was performed 3 times. The main finding was at 2-3 months Baroflex sensitivity was lower during quiet sleep in prone versus supine position, and lower in quiet sleep compared to active sleep.

The conclusion was that dampened baroflex function may increase vulnerability to SIDS.

Concern has been expressed about the relationship of car seats and SIDS. McIntosh²⁸ explored how car seats were used, and their effect on the infants. Unfortunately the latter part of the study is ongoing, and information at the time of the conference was limited. However they confirmed that oxygen saturation fell, the longer the child was in the car seat. In terms of use age of car

²⁷ Yiallourou SR. Does sleeping position affect baroflex sensitivity in infants? Implications for Sudden Infant Death Syndrome. *J Paediatr Child Health*, 46 (Suppl. 3) 2010, 4.

²⁸ McIntosh CG. Car safety seat use in the first 6 weeks of life in full term infants. *J Paediatr Child Health*, 46 (Suppl. 3) 2010, 9

seats, 81 full-term infants were followed and the parents used a diary of car seat use over the next 6 weeks. Information was available on 67 infants. These infants spent a mean $\pm$ SD of 3.9 ± 0.6 hours/week in their car seats. One infant spent 23.3 hours in their seat in one week. A mean of 19.5 infants had at least one period of an hour or more during car travel. A mean of 25.5 infants were left in the car seat for at least one hour over the car each day.

Clearly many infants spent long periods of time in a car seat. This study can only partly address the issue of risk. However, given that infants sitting have compromised airways and impaired respiratory mechanics, this information is concerning.

At one moment in time, apnea was considered the basis for SIDS. Interest developed in using electronic cardio-respiratory monitors at home to prevent SIDS. However, over time it has become clear that SIDS is a very complicated phenomenon, and that its incidence can be reduced by changing child care practice. Despite the lack of evidence of benefit, monitors continue to be used at home. The Collaborative Home Infant Monitoring Evaluation (CHIME) study is well known, and investigators have published a number of studies. This particular component of the study reports on changes in oxygen saturation over time in preterm and full-term infants²⁹. The study included 103 infants who were preterm and 99 healthy full term infants. This study showed that drops in oxygen were frequent, and did not disturb the infant. These drops were down to 82% in the full-term group. It was speculated that intermittent hypoxia may be associated with neuro-cognitive impairment, but no evidence of this is as yet available from the study.

Another physiological area that was examined was the development of circadian (day/night)

²⁹ Hunt CE. Longitudinal home assessment of oxygen saturation in preterm and full-term infants during the first 6 months of life. *J Paediatr Child Health*, 46 (Suppl. 3) 2010, 9.

rhythm development. Joseph³⁰ studied 35 infant and mother pairs seen several times every 2 weeks. Monitoring included overnight deep body temperature, actigraphy as a measure of sleep state for infants and mothers, melatonin and cortisol secretion by overnight urine collection and peripheral gene expression (“clock” gene) using swabs from the mother. The so-called “clock” gene is related to diurnal variation, and its expression seems to coincide with the drop in core temperature, maximum level of melatonin by night and highest level of cortisol by day. These changes are occurring when infants are most vulnerable to illnesses and particularly to sudden and unexpected death.

It is well-recognized that SIDS varies by geography and by ethnic group. In Bradford, England there is a substantial South Asian population which has a relatively low rate of SIDS. Infant care practices in families of South Asian and European origin in the area may differ. The Born in Bradford Project consists of telephone questionnaires to a cohort of 4174 families. 3089 questionnaires have been completed so far. Fernandez Moya³¹ presented data on the first 1519 completed questionnaires. The questionnaire domains included questions about sleep surface, sleep location, sleep position, cot safety, bed sharing, sofa sharing, breast-feeding, dummy use, over heating, smoking and alcohol consumption.

European origin infants were more likely to sleep alone, sofa share with mother or other adult, have a mother who smokes, or have a mother or father who consumes alcohol.

³⁰ Joseph D. Circadian rhythm development related to sleeping patterns in human infants. *J Paediatr Child Health*, 46 (Suppl. 3) 2010, 10.

³¹ Fernandez Moya E. Bradford infant care study (BRADICS): Infant care and SIDS prevention in a bi-ethnic population. *J Paediatr Child Health*, 46 (Suppl. 3) 2010, 13.

South Asian origin infants more often slept on their side, slept with a pillow, do not use a dummy and bed share regularly with parents (about 70%).

It was noted that the non-responders had multiple risk factors.

This is an ongoing study, which over time will provide useful information and understanding appearance of different ethnic backgrounds care for their children. It is too early to know how much of information is relevant to SIDS.

In infants dying of SIDS, a common, but not well explained finding, is that many have mild viral infection in the few days before death. Blackwell³² is an investigator who has explored the issue of infection and toxin production as a cause or contributing factor in sudden death, whether SIDS/SUDI or stillbirth. She accepts the important role of risk factors but insists that we continue to ask the question “why”. She has previously identified toxins in SIDS, and points out that the pro-inflammatory response to toxin is to produce cytokines, especially IL6. Again IL6 has been identified in CSF of SIDS infants on many occasions. Blackwell points out that many of the “risk factors” for SUDI might affect control of cytokines; these include ethnicity, gender, cigarette smoke and viral infection.

In terms of ethnicity, this will affect genotype, and hence the type of inflammatory response. Specifically, the genotype for IL6 is overrepresented in Australian aboriginals. Gender may be relevant; males have a decreased pro-inflammatory response. Cigarette smoke increases susceptibility to viral infection and bacterial colonization, and an increase in IL8 and a decrease

³² Blackwell C. Infection and SUDI/SIDS: possible links to stillbirth. J Paediatr Child Health, 46 (Suppl. 3) 2010, 2.

in IL 10. Viral infection themselves increased pro-inflammatory response, increase Staphylococcus aureus receptors and decrease IL 10.

She links the high risk of SIDS and stillbirth as situations sharing genetic profiles in which the immune system may develop “shock like responses” to toxins. The cytokine levels in amniotic fluid are higher than those the maternal serum, the cytokine IL-1Ra is higher in the amniotic fluid of female infants. She suggests further studies to provide at least a partial explanation for the excess of males among SIDS and stillborn infants.

The issue of genetics is a particular interest for many. Weese-Mayer has explored genetics in SIDS and in disorders of control of breathing. One of the rationales she gives for exploring genetics is the marked ethnic differences that occur in SIDS. She has looked at cardiac channelopathies, metabolic disorders and a variety of other conditions. In terms of candidate genes, she has considered the 5HTT gene which is involved in serotonin transport and hence the autonomic response to homeostatic stress. The 5HTR gene may also be involved. In terms of SIDS, the association of sweat, pallor, decreased heart rate variability and increased temperature are all suggestive that there may be an issue with autonomic network genes. The PHOX2B gene is a major role in Congenital Central Hypoventilation Syndrome, which has autonomic dysfunction as part of its spectrum of disease.

She pointed out the genetic studies have been mainly done in Caucasians. In American studies African Americans have been under represented. Indeed the high risk groups overall have been under represented. There is a strong need for an ethnically diverse study, particular when there is a three generation history of SIDS.

Other issues

While the conference focused on death related to pregnancy or infancy, other aspects were covered. For example, McGarvey³³ presented information on Sudden Unexplained Death in Children (SUDC) in Ireland. He had information on 26 SUDC deaths from 1994-2003, and compared this with information on 319 SIDS deaths in the same time period.

80% of the SUDC deaths were unexplained, and the numbers seemed to be increasing. Children in the SUDC group normal allow it to be prone on controls, more let led to visit their physician because of illness in the week before death and more likely that controls to have illness during lifetime. Low birth weight and prematurity were also had increased prevalence in SUDC, but bed sharing and maternal smoking were lower

The conclusion was that while SUDC shares some features with SIDS, there are important differences. Over time it may be possible to determine whether or not SUDC and SIDS represent the same pathophysiological entity.

³³ McGarvey C. Sudden unexplained deaths in childhood: An epidemiological profile. *J Paediatr Child Health*, 46 (Suppl. 3) 2010, 12.

Do we know how to make our message heard to reduce further infant death rates?

As is already clear, there is a great deal of consensus on how we might further reduce the number of infants dying of SIDS/SUDI. There is also consensus that we have problems in delivering the message clearly to many populations. So why do some parents not hear us?

Colson³⁴ and coworkers conducted 3172 interviews with mothers of infants at Women Infants and Children Centers in 8 cities in the US from 2005-2008. These were low-income African-American mothers, whose infants are more likely to die from SIDS than infants of other parents, and who seemed to be less likely to follow SIDS related recommendations. There was wide the variation between sites, for example supine use varied from 50% to 73%, not-bed sharing from 56% to 88% and pacifier use from 50% to 41%. The variation seemed to be specific to local sites, rather than to wider regions. In other words when trying to improve adherence to safe sleep practice, we need to identify local factors when we design interventions.

Health professionals are key in delivering safe sleeping messages, but they need help and support as they develop ways of communicating effectively. Young³⁵ has been involved in this topic, particularly as Queensland has one of the highest rates of SIDS in Australia, and 30% are not placed to sleep on their backs. Therefore a state-wide policy on safe – sleep was developed

³⁴ Colson ER. Infant' sleep position, bed sharing and pacifier use in a population at high risk for SIDS in the United States. *J Paediatr Child Health*, 46 (Suppl. 3) 2010, 32.

³⁵ Young J. sustainable support for health professionals delivering evidence-based safe sleeping messages to families: A multiagency approach. *J Paediatr Child Health*, 46 (Suppl. 3) 2010, 26.

supported by education for health care professionals. The team developed new collaborators, and also worked with existing collaborators including SIDS and Kids (an Australian support group), SIDS and Kids National Scientific Advisory Group, expert clinicians, indigenous representatives, and educational experts

Education was provided via a training package and culturally appropriate messages. The training package had 4 sessions:

- Introduction and listing of risk factors;
- Safe sleep recommendation;
- Clinical practice and parent education;
- Frequently asked questions.

There were many questions about reflux and aspiration, and these were explicitly addressed. The training package was delivered in person but also as an e- learning resource.

Williams³⁶ as part of the same group as Young, did an assessment of the teaching tools that had been developed. There were responses for some of the common questions. Examples were: “why not prone?”, anxieties over choking, what to do with an infant who was not settling, and dealing

³⁶ Williams A (presenting author). Improving uptake of safe infant sleeping recommendations: Teaching tools for parents and health professionals. J Paediatr Child Health, 46 (Suppl. 3) 2010, 26

with concerns about head shape. She also told the conference some individuals who told her “SIDS it is so rare we shouldn’t worry parents about it”. On the other hand other professionals said “back to sleep from birth”.

This study involved a pre-test/post-test intervention, evaluating knowledge and practices about 55 recommendations in the teaching module. The intervention was applied to nurses and midwives caring for families with infants. There were 102 paired responses, and investigators showed that the intervention improved documentation and practice and achieved positive changes and knowledge of risk factors and parental advice related to recommended position particularly for infants with reflux. The resources developed included a lariat card, poster, a cot card and an online resource to facilitate health professional and parent understanding of the importance of supine sleep.

Another important topic is engaging teenage parents with information about child care and risk factors. Mullan³⁷ described a program in the UK. This used current social media and was developed following focus groups of pregnant teenagers and young parents, that is those aged less than 20. It is known that infants cared for by this group of mothers have approximately a three-fold increased risk of death in infancy. These young women use Face Book, often become isolated as friends desert them, have a lack of trust of authorities, and in general seek advice from “mates or moms”. A website was developed in consultation with the teenage parents- <http://www.bubbalicious.co.uk/>-and also in consultation with experts on child exploitation, and experts on the Internet. The site is not picked up by Google, and is monitored daily. They are also able to use outreach to “hot spot” boroughs within London.

³⁷ Mullan L. “Better Beginnings”- communicating the reduce the risk message to teenage parents. . J Paediatr Child Health, 46 (Suppl. 3) 2010, 27.

This would seem to be an important program, but has not yet been evaluated.

Another way to deliver a message about safe sleep to “hard to reach” populations is to engage communicators on the inside of these groups. Bennett³⁸ described a process in New Zealand involving peer to peer communication. This of course is an everyday event, and it was used here to pass on a message.

The “six” refers to:

- Face-up,
- Face clear,
- Smoke free,
- Breast fed,
- Close to parents,
- Handle gently.

They had identified clusters of parents from priority groups, and helped them in communicating safe sleep principles to family members and friends. They were supported with simple resources, and had access to a dedicated webpage with more information. Some initial evaluation of the

³⁸ Bennett SM. Six plus one: communicators on the inside of priority groups. . J Paediatr Child Health, 46 (Suppl. 3) 2010, 28.

program had been done. Seven priority communicators were engaged, and they had achieved 92 recorded information sessions about safe sleep over a four-week period. The evidence showed that those involved were from different cultures, genders, professions and generations. The project is being extended, but Bennett was enthusiastic that this may be a way to improve survival for those children most at risk of sudden unexpected death in infancy.

Another study started with the premise that many mothers in “at risk” groups fail to follow safe sleep practice either because they did not know all about safe sleep, or because they did not believe the messages. This study was sponsored by the Foundation for the Study of Infant Deaths in England, and presented by Jolly³⁹. 506 mothers with children aged between 6 months and 3 years were asked about infant care, what they did and why. The group was oversampled to ensure that vulnerable families were included. 19% did not believe that tobacco smoke was a risk, 29% did not believe that prone sleeping was a risk, and 50% did not believe that sleeping on the side was a risk. The families knew these were stated to be risks but did not believe they really were. The presentation included core statements such as “as our baby is fine lying on his front”, which then gets integrated into family mythology and beliefs, is related then to credibility of difference sources of information, related to how information from different sources is used, and translated also into disbelief of professionals. There is no doubt that with present-day communications research is accessible to the families but is confusing, and media images often compounded confusion rather than lead to clarity.

Jolly pointed out that the major implications of this study are that we need to do things differently, not just do things more intensely. We need to make sure that we don’t provide information that “changes parents at risk to anxious parents at risk”, and instead truly communicate risk information to families. We need to make health promotion fun. For example, young people enjoyed “teaching granny to text”, and we should set up “baby clubs”, rather than

³⁹ Jolly CI. Influencing parents beliefs about reducing the risks of cot death. *J Paediatr Child Health*, 46 (Suppl. 3) 2010, 28.

“clinics”.

Moon⁴⁰ looked at another way in which a common child care practice might interact positively with a risk reduction method. She was interested in whether the use of swaddling improved adherence to supine placement of infants. 100 were then enrolled in the Women Infants and Children’s Clinic in Washington DC for a 5 minute interview. 92% of them swaddled an infant at least once and 40% did this for the infant’s comfort. Those who swaddled mainly placed the infant on the back. Thus it was suggested that swaddling might be used to comfort infants, and the parents who use this method for comfort usually uses the supine position when swaddled even if they would otherwise place the infants prone.

Faichney⁴¹ also acknowledged that while the safe sleeping campaign had had a dramatic effect on the mainstream population it was not reaching high-risk or vulnerable families. She is based in Australia and developed a “low literacy” resource in stages. Options were reviewed, designed and focus tested, brochures were printed then tested again, then finally distributed. The “low literacy” resource is in use, but problems continue, particularly with very limited budget. There were insufficient details in the presentation or the abstract to fully assess the materials⁴², but the point is well taken that if this is regarded as important (and of course it is) the budget must be adequate for development testing and using and practice.

⁴⁰ Moon R. Knowledge, attitudes and practices with regards to swaddling among a low income US population. . J Paediatr Child Health, 46 (Suppl. 3) 2010, 28.

⁴¹ Faichney K. Effecting behavioural change in high-risk populations - development of a low literacy safe sleeping resource. J Paediatr Child Health, 46 (Suppl. 3) 2010, 33.

⁴² The materials can be accessed at: http://www.sidsandkids.org/wp-content/uploads/SIDS8pp_low-lit_red-a.pdf (checked January 14, 2011)

One important source of information is industry! By this is meant the baby product manufacturers, who of course design products to appeal to parents. Clarke⁴³ pointed out that many of the products respond to parents' worries such as choking, flat heads, covered faces, short sleeps, crying and so on. Information on the packages, the imagery used, and direct advice from sales staff can be highly influential. Clarke described a project in New Zealand to include the baby product marketing and retail industry in a wider strategy to support rather than weaken recommended safe sleep practices. When new parents are given advice by health care professionals, then see contradictory images in magazines they are unlikely to follow safe sleep practices. The presenter has participation from a national retail baby product store, but it is too early to know whether or not this venture will be successful. Nevertheless this is an area that needs to be explored as we deliver the safe sleep message.

Moon⁴⁴ reviewed the whole topic of getting the safe sleep message to disadvantaged groups. She has worked extensively with African American populations, and speculates that there may be both biological and behavioural differences. She also cited Canadian data about Inuit and North American Indian women, both high risk groups for SIDS⁴⁵. A biological difference might be variation in how nicotine is metabolized. Behavioural differences can be encompassed in the observation that many parents have received the message about safe sleep, but have not embraced the message. Parents may regard placing infant prone as an important practice to avoid aspiration. They may use alcohol and tobacco as coping mechanisms in disadvantaged lives, and may have little perception of SIDS risk. We may give advice to buy a crib, but the parent may

⁴³ Clarke JA. Industry cleanup: Aligning product promotion with safe sleep advice. *J Paediatr Child Health*, 46 (Suppl. 3) 2010, 33

⁴⁴ Moon RY. Getting the safe sleeping message to disadvantaged groups. . *J Paediatr Child Health*, 46 (Suppl. 3) 2010, 33

⁴⁵ Luo ZC, Wilkins R, Platt RW, Kramer MS Risks of adverse pregnancy outcomes among Inuit and North American Indian women in Quebec, 1985-97. *Paediatr Perinat Epidemiol.* 2004 Jan;18(1):40-50.

have no money to finance such a purchase.

She felt we should be smart, not work harder, as we encourage positive safe sleep behaviours. She looked at various concepts, such as diffusion innovation, and Health Belief Models. Under the Health Belief Model, if we insert SIDS, the first question is: What are we talking about? If we use the term “SIDS” we deal with something unknown. If we use “suffocation” we have something parents can visualize. Perhaps we should talk about Sudden Unexpected Infant Deaths (SUID).

Recommendations only work if we answer two questions: How does this work? Will it make a difference? We also need to answer the question: is my baby susceptible? We need to convey how common the phenomenon is. Also we need to ensure people parents trust – paediatricians, nurses, family physicians - talk to them.

Consistency in messaging is essential. If a mother notices a health care practitioner putting a baby on the stomach, it is unlikely she will hear a message about placing her infant on the back. We need to use Media to keep infant death in the news. One challenging aspect is advertising of products that do not contribute to safe sleep. Parents will conclude “if they are selling it, it must be safe”.

Thus we need to emphasise the positives in our message. For example if the baby is close to the mother, but not in the adult bed, there is no longer a need to worry about pillows in the bed. We also need to defuse perceived disadvantages in the safe sleep message, the commonest of which is anxiety re aspiration.

What are the barriers to safe sleep? Some might be financial; does the mother have enough

money to buy a crib? Some might be availability of space in disadvantaged groups – is there space for a crib next to the mother’s bed in a small bedroom in a small apartment? Is it possible to bed share safely? We may need to discuss these issues in detail and compromise “bad” with “good”.

Moon’s closing statement is worth quoting:

“The safe sleep message should be one that makes sense to parents, is consistent, explains the positive aspects of the behaviour change, and addresses misconceptions.”

Parents' view of their experiences.

Richardson⁴⁶ presented the results of an on-line survey. 214 responded; 94% were female, and 90% were married. The limitations were obvious and were acknowledged at the outset; this was not a random sample. All respondents had access to the Internet and likely were more highly educated than most SIDS parents,

Listed as the four most helpful were

- Time,
- Support,
- Normalizing and purpose,
- Honouring and making memories.

The least helpful were:

- Platitudes and careless comments,
- Community ignorance (inability to say "I'm sorry for your loss"),

⁴⁶ Richardson R. The voices of bereaved parents. J Paediatr Child Health, 46 (Suppl. 3) 2010, 2

- Isolation,
- Lack of support and compassion.

For the question, what would you need? – Responses were:

- Honest clear information,
- Understand the nature of the loss (there is no such thing as “closure”),
- Offer options,
- Sensitivity (use child’s name).

They wanted to tell others:

- About grieving (the experience of others who survived),
- About trusting instincts,
- About keeping the memory alive,
- About hope (“a new normal”).

The impact of death was described as:

- Life changing,
- Changed priorities,
- Life is richer (“I watch the news different now”),
- Legacy (“I honour my daughter the way I lead my life”).

In a presentation about pregnancy loss, Gold addressed the issue of Internet support groups.⁴⁷ Internet support has value for a rare event such as SIDS as parents whose infant has died often feel stigmatized. There is a need to address the issue of ensuring personal information is kept secure. Of course we cannot assess or prove absolutely that such groups are effective, as we cannot perform randomized studies. On the groups she surveyed, about 8% disclosed thoughts of self-harm. Her conclusion was that there were several advantages of Internet groups. These were:

- Knowing you are not alone,
- Convenient and available 24/7, can use at home and don’t need to dress up,
- Validate grief,
- Access when there are no local groups,
- Easier to communicate by typing than by talking for some individuals.

⁴⁷ Gold K. Bereaved mothers using internet peer-support message boards for pregnancy loss: an internet survey of user characteristics and depressive symptoms. *J Paediatr Child Health*, 46 (Suppl. 3) 2010, 3

Suggested actions in Canada based on evidence and concerns presented at the conference.

- 1 Affirm the importance of infant death to Canadian Society, and the need for adequate funding to further reduce the number of deaths. PHAC clearly has a leadership role, but also has a role in encouraging other agencies to participate. The funding may come directly from government departments, or indirectly from Federal agencies such as the Canadian Institutes for Health Research (for example to fund research).
- 2 Develop a series of strategies to disseminate information to the mainstream population, high risk groups, including Aboriginal groups and health care professionals. Ensure that anxieties of all these groups about the current agreed upon safe-sleep measures are addressed.
- 3 Clarify the name given to the phenomenon currently described as SIDS/SUDI. While discussions will be led by Medical Examiners and Coroners, researchers in the area and parents affected should be included in discussions.
- 4 Funded basic research, including genetic research, to ensure we increase our detailed understanding of the phenomenon of unexpected death in infancy. Such scientific knowledge will help us now as we refine our understanding of “safe sleep”, and will help us in the future as parental childcare practices evolve and new challenges are presented.
- 5 Ensure resources are available for bereaved parents including provision of effective support and avoiding increasing the pain by using neutral terminology to describe the cause of death. Ensure that there is recognition that this particular grief is lifelong, and

will affect all future interaction parents may with health care professionals about their own health and that of family members, and indeed with society in general.