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## Next steps in the study of sudden infant death syndrome

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Several important lessons emerge from the paper by Pinho & Nunes<sup>1</sup> that appears elsewhere in this issue. First, by means of a careful case-control study, the authors convincingly show that the epidemiologic features of sudden infant death syndrome (SIDS) in Porto Alegre, Brazil, are similar to those found in other parts of the world, wherever infant deaths have been studied. These features include higher rates of prematurity, low birth weight, teenage pregnancy, dark-skin ethnicity, smoking, and poverty – along with the single most distinctive and puzzling feature of SIDS, a mean age at death of 3 months. The authors point out that because of the relative prosperity and diversity of Porto Alegre's population, the determined incidence of 0.55/1,000 live births may not be representative of other areas of Brazil. In less prosperous areas, the frequency is probably higher, as is infant mortality in general.

Second, the term SIDS is not generally recognized by certifying officials. Only two out of the 33 cases that fit the clinical and pathologic criteria, were classified as SIDS. That is not surprising. Though historical evidence points to "crib death" occurring throughout the ages, even in

ancient times, SIDS as a disease entity only began to be recognized in the last 40 years.<sup>2</sup> Many years usually pass from the time a disease entity is first recognized to when it becomes accepted within the medical community. This is especially true when the cause(s) remain(s) unknown. Some examples are Reye's syndrome, Kawasaki's disease, multiple sclerosis, sarcoidosis, and lupus.

Third, in looking for practical measures that have been shown to lower the incidence of SIDS, the authors identify the two most subject to modification: smoking both during and after pregnancy,<sup>3</sup> and placing the infant to sleep in the supine position.<sup>4</sup> That is not to say that changing long-standing habits is easy.

### Fate of the families

Not described in the paper from Porto Alegre, because it was not the subject of the investigation, is the fate of the families of infants who died suddenly and unexpectedly. I first became acquainted with the emotional devastation caused by SIDS while doing home visits as part of an epidemiological study, when I was invariably asked, "why

See related article  
on page 115

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did my baby die?." Rarely asked, but so obviously felt, were the questions "what did I do to cause my baby's death?," or "what could I have done to prevent it?"<sup>5</sup> Our research team came to believe that though we could hardly bring dead babies back to life, as physicians we might mitigate the guilt of the family members, and hence prevent living deaths. Therefore, as an adjunct to our research study, my pathologist colleague, J. Bruce Beckwith, would review the autopsy findings with the family, and a nurse would follow up with a home visit. At the conclusion of our research project, a model infant death investigation system that was both compassionate and medically sound was instituted in King County, WA, under the aegis of the King County Medical Examiner. That system still exists to this day. The components are: a) autopsies are conducted on all infants dying suddenly and unexpectedly; b) the results of the autopsy are promptly communicated to the family; c) the term SIDS is used on death certificates if the defined criteria are met; and d) a public health nurse makes one or more follow-up visits to provide information and counseling, and the family is referred to local parent support groups.

### Next steps

What are the next steps that should be taken in the battle against SIDS? First and foremost, research must be supported that is directed at finding the cause(s) of SIDS and coming up with a means of prevention. The key, in my view, is identifying the mechanisms controlling breathing and sleeping as they change from a fetal to an adult mode between the 2nd and 4th months of life. Investigation of possible genetic factors<sup>6</sup> and examining brainstem abnormalities connected with serotonin release<sup>7</sup> are ongoing projects that show promise. This type of basic research can only be done in resource-rich countries. The work requires experienced scientists, and sufficient funding to support their labors.

But there is much that can be done in developing countries like Brazil. That would be extending the work done in Porto Alegre – identifying the causes of death in infants dying suddenly and unexpectedly – to other parts of the country. To the extent possible, families deserve the right to know why their babies have died. This requires establishing systems of infant death investigations that are both compassionate and medically sound. Such reforms invariably occur as a result of advocacy by parents who have lost babies: in the U.S., it was not until a group of activist parents, frustrated by the inability of physicians to answer the question "why did my baby die?" took collective action to spur research efforts, educate health care providers, and to bring about reforms in the death investigation system.<sup>8</sup>

Ironically, there is currently a movement in the U.S. led by forensic pathologists and pediatricians who specialize in child abuse to restrict the use of the term SIDS. The

Centers for Disease Control and Prevention (CDC) finds: "the decline in SIDS since 1999 can be explained by increasing sudden unexpected infant death (SUID) rates, (e.g. deaths attributed to overlaying, suffocation, and wedging). This change in reporting or classification of SUID can be explained by changes in how investigations are conducted, and how diagnoses of SUID are made. For example, more deaths may be attributed to accidental suffocation than to SIDS."<sup>9</sup> I think such reasoning is faulty. If suffocation, overlaying and wedging were prominent etiologic factors in sudden infant death, the smallest and weakest infants would be expected to succumb. Instead, the peak incidence is between 2-3 months of age.

It is especially important to counter false accusations of infanticide. Infanticide does indeed exist, and in the U.S. when it does occur, it is a common strategy for attorneys to conjure up SIDS in defense of their clients. However, it is usually not difficult to differentiate between infanticide and SIDS.<sup>10</sup>

Until research provides us with better answers about causation, the advice of Pinho & Nunes<sup>1</sup> to promote the measures we know will reduce risk should be followed.

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