

PREVENTING SUDDEN INFANT DEATH SYNDROME (SIDS)
(Our experiences in the light of different views)
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Introduction

The past two decades have brought significant results in the field of preventing Sudden Infant Death Syndrome (SIDS). (21.) The success, however, has been partial: even today, there are senseless (because theoretically avoidable) cases of tragic infant death, (in the US, for example, the cause of the sudden death of approximately 2500 infants a year even today is SIDS. (Marc Peterzell: [http:// www.sids.org](http://www.sids.org)), which poses a considerable threat to the infant population. Therefore, learning more about this mysterious phenomenon and rethinking the methods of prevention cannot be neglected even in our days.

In our hospital we have started our preventive programme at the beginning of the nineties and the first steps were issued in 1997. (37.) In the past decade both the practice and the judgement of SIDS prevention have changed in many respects. Thus a critical survey of these changes, taking into account our own experience as well, appears to be most opportune.

Shifts of emphasis concerning the sudden death of infants

As the cause of SIDS has not been found so far, it is understandable that there is an intensive research into the etiological factors. This endeavour itself, however, is contradictory since according to the currently accepted definition SIDS can be presumed when the pathological examinations, taking into account the clinical course and external circumstances, do not present a basis for a diagnosis of the sudden death. (44.) Thus, continuous revealing of the causes presumed makes the clearly defined dividing lines of the "traditional SIDS" grow indistinct, and facilitates separating "transitional cases", "borderline cases" and "unproven cases". This being the case, the validity of a uniform attitude to SIDS seems to be queried and difficulties are thrown in the way of comparing international experience.

As long as the terminology is not unambiguously crystallized, in our own practice, we will consider every sudden and unexpected infant death case SIDS, regardless of their origin, provided that deliberateness can be excluded. (In our preventive programme such use of the term 'SIDS' is admissible – the more so, because we train parents to prevent sudden peril of death in a way the successful execution of which is independent of the origin of the danger.)

To demonstrate the possible traps originating from the erosion of the uniform conception, the following example could be taken. Between 1990-2000 in Norway the rate of sudden infant death cases of non-evident origin – consequently declared SIDS cases – fell to 56% from the 80% of the period 1984-1989. This statistically significant improvement could as well have been regarded as the success of SIDS prevention. However, the fact that during the same period the rate of sudden deaths the cause of which is known – consequently excluded from the concept of SIDS – doubled, cannot be neglected. The increase of the latter cases was mainly due to the increase of the number of criminal cases. (36.)

The criminal attitude has its obvious reasons: true tragedies for innocent parents should be distinguished from criminal acts against life, which have legal consequences. Subsequent

analyses have revealed parental responsibility for several cases previously diagnosed as SIDS (lack of attention, preventable accidents, abuse, negligence or deliberate murder).

Unfortunately, however, the criminal approach is not free from extremes. More and more criminal cases ending in a sentence have been revealed in the past few years, which, on the one hand, have biased the reading public and, on the other hand, have also made some experts become supporters of such extreme principles as “one sudden infant death is a tragedy, two are suspicious, but three are murder”. Although this principle has acquired a bad reputation over the past few years, amongst the diverging and often pointed professional arguments, one can read about groundless molestation of innocent parents who have been overtaken by a tragedy. Such pestering suggests, at the very best, an arbitrary neglect of the presumption of innocence. According to news reports, there have been distortions of the investigating authorities. For example, parents have been prevented from taking their freshly dead child in their arms ‘to avoid hiding clues’. In other cases, the police cordoned off the parental house, or neighbours have been interrogated in public etc. Fortunately, tactful attitude is more typical of our country than the atmosphere of unfounded accusations. (8. 28. 34. 36.)

While carrying on an aetiological research, a clinical approach to the so-called *risk factors* appears to be promising. In certain risk situations (such as exposure to nicotine, prone position, high environmental temperature or cardiac disorders etc.) the insufficiency of the so-called arousal reflex was traceable. However appealing it would be to find a direct connection between the fatal infantile stop of breathing and the latish arousal response, this kind of arousal-deficit theory is not likely to be compatible with certain sleep-physiological characteristics of infancy. Nor does it give an explanation to the mechanism of SIDS occurring in waking state. (2. 11. 12. 17. 19. 31. 41.)

Researchers have always shown great concern about the origin of SIDS as regards the nervous system. Two major approaches could be highlighted: the histo-chemical and the morphological one. The histo-chemical approach is well illustrated by the so-called NICHD study according to which, in the brain-stem of infants who died of SIDS a decreased serotonergic receptor binding was found.(30.) In the field of morphological research, L. Matturi has elaborated a new conception. On the basis of their investigations, a new, coherent theory of the origin of SIDS can be outlined. According to this, pathologically, sudden infant death could be characterised by congenital alteration of the neurotransmitter system of the heart and controlling system of the brain stem, especially by the lack or hypoplasia of the nucleus arcuatus. Owing to the striking likeness of the morphological alterations, L. Matturi conveys the suggestion that SIDS and some kind of foetal death are pathologically identical. (27.) It should also be noted that a Hungarian author was also able to reinforce the above-mentioned view on the basis of his own observation. (4. 5.)

What might also play a role in the central apnoea, is hypoperfusion of the brain stem. On infants who have had ALTE attacks, by turning the head crisply to either side or backwards, partial obstruction of the a. vertebralis and deceleration of circulation in the circulus arteriosus Willisii could be detected. On the cervical vertebrae of these infants (atlas, epistropheus) spontaneously disappearing formations causing obstructions were found, which were not detectable by the end of infancy. (7.)

Such new information takes us closer to clarifying the SIDS problem, but, at the same time, betokens the difficulties of a common approach. Different institutions refer to the diagnosis of SIDS on the basis of different criteria according to their own diagnostic opportunities and professional orientation. At the time being neither an internationally codified autopsy protocol, nor a uniform death scene investigation protocol help comparative statistical

analyses. (35.) As a consequence, results are heterogenous, which makes congener assortment difficult among work-groups. The fact that there is a diverse practice of autopsy country by country is already unfavourable for the demand for comparison. For example, the rate of SIDS mortality in Hungary (according to data published in 2000) is the same as that in Japan (0.3%) whereas the rate of sudden death autopsy in Hungary is 100% while in Japan it is 30%. In this respect, the circumstances of Papua New Guinea are the most clear-cut. According to the data published, there has been no sudden infant death. While there is no autopsy either. (10.)

According to the above-mentioned factors, the pathology of sudden infant death cannot be characterised by uniform criteria. (In the language of logic: the *differentia specifica* of the category SIDS cannot be verbalised.) Even today SIDS can be regarded as a group of multifactor events with unknown causes. Therefore, the fact remains that it is prevention that is of primary importance.

Shifts of emphasis concerning SIDS prevention

Sudden infant death, which has been known since the times of the Old Testament, was regarded as an act of fate at the beginning. It was thought to be something against which it is not possible to fight. Later, tragedies were ascribed to accidental or intended asphyxiation due to the co-sleeping, so laws were made to prohibit the mother from sleeping with her baby. For a while, the so called “status lymphaticus” was believed to count, and thymectomy or irradiation of the thymus was suggested.

In about the middle of the twentieth century the theory of the irreversible stop of breath came to the fore. This theory, although being queried later, brought with it the introduction of home monitoring. At first, a so-called apnoea alarm monitor was recommended. (23.) Then, continuous electrical observation of breathing, circulation and oxygenation as well as the necessity of recording data also became important. Without doubt, the use of more and more sophisticated (and more and more expensive) devices was not causeless. By using such equipment there is a good opportunity to recognise in time a possible collapse of circulation or progressing hypoxia, which might precede the arrest of breath. (33.) Practice, however, has not come up to previous expectations. Enthusiasm, so typical of the early stages, about using such equipment seems to be decreasing nowadays due to several reasons, for example, epidemiological consideration, cost/benefit analysis or the lack of parental collaboration. Today, the international situation shows a very varied picture. Besides several types of monitor to be used under different conditions, a new attitude of mind has been given voice even officially, namely, that home monitoring is no longer part of SIDS prevention, and the only effective way to prevent sudden infant death is to assure optimal sleeping circumstances for infants. (13. 24.)

Attitudes towards the risk factors have changed and refined in the past two decades. Besides premature low birth weight, exposure to nicotine, overheating and prone sleeping position are considered to be the most significant risk factors. The significance of the latter one seems to be born out by the success of the so called ‘back to sleep’ campaigns. Nevertheless, the physiological fact that infants discover the world around them creeping and crawling about cannot be neglected as this is the key to mental and motoric development. In addition, forcing the back position unconditionally deprives the infant of having the chance to learn certain defensive mechanisms. A. Côté showed in the case of 64 SIDS infants having usually slept on their backs, who had turned to prone position right before their death while sleeping, or it had been the parents or supervisors who had changed the accustomed sleeping position. (3. 29.) Nowadays, even for infants who regularly sleep on their backs, prone position is strongly

recommended when they are under the supervision of their parents or when they are not sleeping. (1.)

Laying infants on their sides while sleeping could not abide the test of time either. The side sleeping position, which was allowed a few years ago (and which is still advisable in certain special cases), is regarded as dangerous, so it is not recommended in SIDS prevention. Even the preventive value of breast-feeding is considered controversial today. (14. 39. 40.) Multiple incidence of SIDS in the same family has also been viewed from a different aspect recently. The aspect has not only changed because of criminalistic points of view (as explicated above), but also because persisting external factors (for example, too early maternity, low education, drug consumption or being socially-economically underprivileged etc.) have been given more attention. However, intrinsic (genetic) factors are also assumed. (17.) Even polysomnography, which is considered to be predictive by some, has not proved to be a clean-cut method. (20. 25.)

Our own practice

The elements of our SIDS prevention programme are still *preparing* the parents to recognise and prevent risk factors, *assuring training* of infant-resuscitation, organising *home monitoring*, and *continuous professional control and support*. (37. 39.)

Training and supervision

Preparing the parents in advance and providing continuous professional support are essential conditions of our programme. Upon registration the families are given training. The elements of the training are acquainting the parents with the safe sleeping environment for the infant, demonstrating the functioning and use of the exclusively used apnoea monitor (*Baby Sense, Hisense, Israel*), and thirdly, the practice of infant-resuscitation. During the course we place great emphasis on diminishing uncertainties and worry which are based upon false information. At the same time we find it important to clear up groundless hopes and false self-confidence. (We think that “sudden infant death is in principle no longer an unavoidable fatality. In case of appropriate preparation there are means of defence.” Nevertheless, “no preventive programme can give a one-hundred percent guarantee for survival.”) There is also a record of information gained during the course in the form of a resource booklet. (38.)

Home monitoring

Unlike those who strongly disapprove of home monitoring, we are convinced that there are a few arguments worth considering. On the one hand, a SIDS case-to-be may perhaps be approached from a statistical point of view but it cannot be foretold in reality with absolute certainty either clinically or by means of laboratory methods. On the other hand the division of the two categories ‘at risk’ and ‘not at risk’ is arbitrary to a certain extent and deprives the ‘not at risk’ infants from a discipline-based opportunity. If, on the basis of statistical analysis we reject any kind of home monitoring method what can we offer to the parents in its stead? Would it be only the preventive assurance of the optimal sleeping conditions? If the apnoea alarm monitors can’t sign the hypoxic phase before total cardiac arrest – as some authors argue - would it be better to deprive the parents of any alarm opportunities?

Regarding these considerations our practice may be seen as a compromise. The Israeli made Babysense apnoea monitor (signalling the detection of the sudden immobility of the infant within 14 seconds) used by us works with great accuracy. Its use does present any difficulty even for the not-learned parent and it does not harm the infant in any way. In addition, its comparatively low price facilitates its extensive use. In our experience, which is based on a not inconsiderable number of home monitoring cases, the quality of life of the

parents using the monitor has also improved during the period of monitoring. So far we have not found any counter-arguments which would make us alter our own practice.

All things considered, we regard the home use of *well-chosen* apnoea monitors as a part of SIDS prevention. Along with the risk factors, our practice takes into consideration the demands of worried parents (parental indication). Therefore, we consider home monitoring of clinically healthy infants a true parental demand.

To illustrate the importance of the question, a few examples of our cases worthy of remark could be mentioned.

1, The parents found their 3-month-old infant – after the alarm of the (BS II.) monitor – with his head caught between the bars of its cot suffocating. After freeing the baby's head, the infant recovered, and has been developing without any difficulties since then. According to our judgement afterwards, our method helped to prevent a potential danger of death. It would only be of secondary importance to consider if a possible fatal event would have belonged to the notion of sudden infant death or not. (The parents took part in our training course two weeks before the alarm.)

2, Cs. Zs. is a 36-year-old mother. Seven pregnancies. Three of her children have died in diseases. Two of the remaining three have been killed in a road accident. The parent is asking for home monitoring of her seventh, now the only infant. The infant is at present clinically healthy. The period of home monitoring was eventless.

3, I. F., a 27-year-old mother first came to our office pregnant, 20 days before having her baby. She told us that she would like to protect her baby and that was why she asked for our help. The parent was provided with a monitor, and she took part in our preparatory course. She gave birth to her daughter after her first pregnancy at 37 weeks' gestation without any complications, with an Apgar rate of 10, weighing 3430 grams. One night – when she was two month old - the BS monitor alarmed. The infant, who had been developing steadily so far, was found unconscious, lying faint without breathing in her cot. The parents acted according to what they had been taught in our preparatory course. The ambulance took the infant, already breathing spontaneously but in a toneless condition to hospital. The next day the EEG examination showed some alterations (which disappeared some days later). While in hospital, desaturation with bradycardia was detected twice. ALTE (SIDS) was diagnosed. Today, the child is four and a half years old and is developing steadily. When we asked the mother afterwards why she had found monitoring her infant important without any rational reasons, she said “maternal intuition”.

4, I. K. 36-year-old mother asked for prevention for her 3-day-old infant born with a weight of 2850 grams from her seventh pregnancy. The mother's children born in 1990, 1994 and 1997 are alive and healthy. She, however, lost her infants born in 1989, 1991 and 1995. In all three cases SIDS was diagnosed. (The parent was advised to consult us by the district nurse, who called the attention to the necessity of prevention with regard to the anamnesis.) After six months of monitoring (without any alarm signal) the child is healthy and has no complaints.

Experience

Between January 1995 and September 2002 our programme involved approximately 8000 infants. There were no sudden deaths among them. According to our survey using questionnaires, alarms of technical origin (misuse of monitors by parents) took place in 14%, a “true” alarm involving parental intervention (resuscitation) only took place in 1%. The number of so called “false” alarms (of inexplicable origin) was negligible. So preventing danger of life did not affect most of the families taking part in monitoring. Even so there was

a consensus as regards the fact that our method, which is easy to acquire, could be built in infant-care without difficulties, and home monitoring helped to achieve a tranquil home atmosphere. The shortest feedback said “Thank you for or calm nights.” (In this series only Baby Sense monitors were used)

DISCUSSION

Sudden infant death is one of the leading factors of infant mortality even today. (2.) The assumed reasons vary on a great scale. (26.) Hitherto, no etiological therapy based on uniform principles has seemed to be feasible.

The most recent suggestions say that prevention should be restricted to providing the “optimal environment”. The circumstances being heterogeneous, creating the optimal environment is necessarily beyond the professional setting proper. (Some of the extra-medical tasks of prevention are: reducing smoking and drug consumption, raising the socio-cultural level of society, compensating economical disparity and child-centred family-policy etc.) From among this bulk of tasks related to the whole society our programme has focussed on the “minimal base” on which all the other actions can be built on. That is to prepare the parents for preventing clinical death or reversing it. This minimal base gives an ultimate chance to parents to save their infant. Acquiring the technique of basic resuscitation (BLS) is a great challenge of the new millennium. (32.) Our preventive activity in a circumscribed field of the health of the nation is a humble contribution to raising the level of General Health Culture. Our experiences convince us of the fruitful application of the BabySense monitors in our prevention program.

SUMMARY

This paper looks into the change of approach in terms of SIDS prevention. The author reviews the practice of prevention at Madarász Street Hospital for Sick Infants and Children, Budapest, in the light of these changes. The fact remains that the basis of this programme is preparatory training, home monitoring with a certain apnoea alarm monitor (BabySense by Hisense) and continuous professional supervision. In the past decade there has been no sudden infant death among the 8000 families participating in the program. In addition – taking into account parental feedback –, we have contributed to the improvement of the life quality of the families involved in our project.

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