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Article Title: Do we Need a New Definition for SIDS? Commentary on 'Sudden Unexpected Death in Infancy and the Dilemma of Defining the Sudden Infant Death Syndrome' by Henry Krous

Year of publication: 2010

Link to published article:

<http://dx.doi.org/10.2174/157339610791317287>

Publisher statement: None

Do we need a new definition for SIDS?

Commentary on 'Sudden Unexpected Death in Infancy And The Dilemma of Defining The Sudden Infant Death Syndrome' by Henry Krous

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'When I use a word,' Humpty Dumpty said, in a rather scornful tone, 'it means just what I choose it to mean, neither more nor less.'

When faced with the multitude of definitions surrounding the infant who dies suddenly and unexpectedly, a paediatrician may feel as bewildered as Lewis Carroll's Alice before her ovoid friend. In the accompanying discussion paper, Henry Krous, a well respected leader in the field of SIDS research presents a useful discussion of some of the issues raised by different definitions of SIDS.

As Krous points out, definitions serve a number of purposes. In the context of unexpected infant deaths, first and foremost should be the needs of the bereaved family for understanding how and why their child died. There are the needs of practitioners for a framework within which to approach the investigation of an infant death and for supporting the family; the needs of forensic and law enforcement services to either exclude or pursue the investigation of any suspicious circumstances; and wider needs for research and development ultimately aimed at preventing future infant deaths.

Krous suggests that the way forward, given the ever-evolving field of SIDS understanding, is to strive for ever more precise definitions and to strive to achieve universal acceptance of these. Over 20 years of research and clinical practice however have demonstrated that a) there is not, and probably never will be, any uniform acceptance of a definition; b) standards for investigation will necessarily vary between and within countries; and c) the complexity of understanding SIDS has the potential to increase rather than decrease as other genetic, biomedical and environmental factors are identified. I would argue that the more definitions are developed, the more will be used, and the more complex any definition becomes, the harder it will be to apply, and therefore the more variability there will be in its application.

Given the changing nature of the field, three approaches could be adopted in relation to SIDS definitions:

- a) To constantly refine and develop new definitions, incorporating new knowledge, techniques and understanding;
- b) To stick with a simple definition;
- c) To acknowledge the validity of a range of definitions.

All have their advantages and disadvantages. Perhaps what is most important is that practitioners and researchers alike are clear in how they are defining and categorizing sudden infant deaths, and that beyond the use of any definition, there is a need to document what factors have been considered in assigning any diagnosis. A final important issue in relation to the use of definitions, is the way in which such definitions influence our understanding of SIDS itself. Retaining a simple, broad definition acknowledges that the term SIDS is an admission that we do not know why the child has died, and therefore is likely to include deaths from unrecognized medical causes as well as asphyxia, both intentional and unintentional. The more specific we are in our definition, the more it implies we know what SIDS is and that we are excluding other causes from it. In our current (and foreseeable) state of knowledge, that is inappropriate.

My personal approach, and one that is increasingly adopted across the UK, is to use the term Sudden Unexpected Death in Infancy (SUDI) as a descriptive term, used at the point of presentation to encompass all unexpected infant deaths. We use the CESDI-SUDI definition of “the death of an infant which was not anticipated as a significant possibility 24 hours before the death or where there was a similarly unexpected collapse leading to or precipitating the events which led to the death” (1). At the conclusion of any investigation, these will then divide into those for which a specific cause of death is established (explained SUDI) and those which remain unexplained (SIDS). We use the NICHD definition (2) as being the simplest and most widely used. It encompasses what most researchers and practitioners would consider the minimum requirements for categorizing those sudden infant deaths that remain unexplained, whilst allowing for more detail to be added as needed for research or practice. This provides a pragmatic approach which can be applied by front line professionals, is comprehensible to parents and non-academics alike and allows for future development without the need for constant refining.

References

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2. Willinger M, James L, Catz C. Defining the sudden infant death syndrome (SIDS): deliberations of an expert panel convened by the National Institute of Child Health and Human Development. *Pediatric Pathology* 1991;11:677-84.