

# The Diagnostic Shift of SIDS to Undetermined: Are There Unintended Consequences?

Laura Gould Crandall, Laura Reno, Barbara Himes, Deborah Robinson

## ABSTRACT

Over the last two decades, a diagnostic shift in regards to the certification of sudden deaths in infancy has emerged with reassignment of deaths previously certified as sudden infant death syndrome (SIDS) to a trend utilizing the classification of undetermined or asphyxia. The consequences of this shift outside the medicolegal death investigation (MDI) community is unknown. We surveyed US organizations working in the field of sudden infant death as well as bereaved parents to understand their perceptions of the current diagnostic trends. Two online anonymous surveys were utilized. Sixty-seven organizations and 55 parents with an infant death diagnosis of SIDS, sudden unexplained infant death (SUID), undetermined, or asphyxia participated. Just over 50% (34/67) of the organizations perceived the shift had an effect on their organization including barriers to bereavement support and education. Forty percent (22/55) of parent respondents stated they did not understand the final diagnosis of their infant's death. The highest frequency of themes elicited from parents were frustration that the diagnosis (regardless of terminology) did not fully explain the death, detrimental mental health effects, and negative perceptions towards the medical and public health communities. However, parents of children whose death was classified as SIDS were spared from negative perceptions towards the medical field, described the least amount of confusion, and reported the most instances of positives effects. Legal implications, perceived social stigmas, and research obstacles were also described. Recommendations from this study include the integration of collaborative efforts to combat sudden infant death with all stakeholders, in and outside of MDI, to achieve better understanding and eradication of these tragedies, improved public education, and effective care of all bereaved. *Acad Forensic Pathol.* 2017 7(2): 212-220

## AUTHORS

**Laura Gould Crandall MA**, NYU Langone Medical Center - Neurology Comprehensive Epilepsy Center and SUDC Foundation

*Roles: Project conception and/or design, data acquisition, analysis and/or interpretation, manuscript creation and/or revision, approved final version for publication, accountable for all aspects of the work.*

**Laura Reno, C.J.** First Candle

*Roles: Project conception and/or design, data acquisition, analysis and/or interpretation, manuscript creation and/or revision, approved final version for publication, accountable for all aspects of the work.*

**Barbara Himes, C.J.** First Candle

*Roles: Project conception and/or design, data acquisition, analysis and/or interpretation, manuscript creation and/or revision, approved final version for publication, accountable for all aspects of the work.*

**Deborah Robinson**, Washington State Criminal Justice Training Commission

*Roles: Project conception and/or design, data acquisition, analysis and/or interpretation, manuscript creation and/or revision, approved final version for publication, accountable for all aspects of the work.*

## CORRESPONDENCE

**Laura Gould Crandall MA**, 223 East 34 St, Ground Floor, New York NY 10016, [laura.crandall@nyumc.org](mailto:laura.crandall@nyumc.org)

## FINANCIAL DISCLOSURE

The authors have indicated that they do not have financial relationships to disclose that are relevant to this manuscript

## DISCLOSURES

The authors, reviewers, editors, and publication staff do not report any relevant conflicts of interest

## FUNDING

None

## KEYWORDS

Forensic pathology, Sudden infant death syndrome, Sudden unexpected infant death, Asphyxia, Medicolegal death investigation

## INFORMATION

ACADEMIC FORENSIC PATHOLOGY: THE OFFICIAL PUBLICATION OF THE NATIONAL ASSOCIATION OF MEDICAL EXAMINERS (ISSN: 1925-3621)

©2017 Academic Forensic Pathology International

<https://doi.org/10.23907/2017.022>

Submitted for consideration on 15 Mar 2017. Accepted for publication on 13 Apr 2017

## INTRODUCTION

Our understanding of sudden unexpected and unexplained infant deaths continues to evolve through advances in medicolegal death investigation (MDI) practices, research, and public health advocacy. In 2015, the Centers for Disease Control and Prevention (CDC) reported that 3700 infants less than 12 months of age suffered a sudden and unexpected death whose cause was not readily identifiable prior to investigation (1). While specific death certification varies, cases were predominantly reported as either sudden infant death syndrome (SIDS) (n=1200, 43%), undetermined (n=1200, 32%), or asphyxia (of varying types) (n=900, 25%) (1). This significant public health problem, the leading cause of postneonatal infant deaths in the US, requires the cooperative and coordinated efforts of multiple agencies outside of the medicolegal death investigation system in our pursuit of understanding and prevention (2).

Since it was first defined in 1969, SIDS has received targeted attention related to medical research (>\$500 million), public health advocacy, and public support services for the bereaved (3). The National SIDS Act of 1974 resourced SIDS programs in every state to provide information and support to those bereaved, and education regarding SIDS to emergency response workers and the community (4). The American Academy of Pediatrics published safe sleep recommendations in 1992 and the “Back to Sleep” campaign was launched in 1994 to reduce the incidence of prone sleep – a risk factor associated with infant death. Guidelines for SUID scene investigations were first developed by the CDC in 1996 and updated in 2006. Terminology has also evolved and can be confusing by acronym alone. For example, SUID is used to describe the three most frequent types of sudden unexpected infant deaths (SIDS, undetermined, and accidental suffocation and strangulation in bed) and also as a specific final death certification for a sudden unexplained infant death (5). Two acronyms used in very different ways. Death certification and MDI practices have continued to evolve with an ongoing debate regarding standardized certification of such deaths within and outside of the MDI community. Debates

abound not only in regards to the accurate certification of cause of death for an unexplained infant death, but intrinsically important to the role of MDI’s mandate – to also determine the manner of death (6).

Significant published research has reported the increasing trend of certifying unexplained infant deaths as undetermined rather than SIDS as well as the improved recognition of deaths due to asphyxia and certified as ICD W75 (accidental suffocation or strangulation in bed). However, despite popular media reports, this research has focused on the reduction of SIDS rates alone independent of other rates of death. There has not been an overall sustained decrease in the number of sudden unexpected infant deaths in the US since the late 1990’s.

The overall rate of SUID is described as the rate of infant deaths due to SIDS, undetermined, and accidental asphyxia and strangulation in bed combined. In 1990, the overall rate of SUID was 154.6 deaths per 100 000 live births and, in parallel with the interventions previously described, fell over 50 points to 100.7 deaths per 100 000 live births by the year 2000 (7). Unfortunately, the SUID rate has not fluctuated greatly since and has measured between 85.1 and 100.7, with the most recent SUID rate of 92.6 in 2015 representing a slight increase from 88.4 in 2014. However, the diagnostic shifts among SIDS (66.3 to 39.4 deaths per 100 000 live births), undetermined (27.4 to 30.1 deaths per 100 000 live births), and asphyxia (7 to 23.1 deaths per 100 000 live births) are the most dramatic within this same timeframe since 2000 (7).

Improvements in MDI have uncovered crucial information for increased recognition of deaths due to asphyxia, and thereby greatly assist our public health efforts to focus campaigns to these preventable deaths and support the importance of, and access to, safe sleep environments for all infants. However, specific diagnostic criteria to accurately differentiate types of SUID (sudden unexpected infant deaths), such as SIDS/SUID (sudden unexplained infant death), undetermined, and asphyxia is lacking. A common example is whether the final mechanism of death was due to primary asphyxia or another underlying mechanism

that may or may not have been affected by the presence of asphyxial risk factors. The certifying pathologist considers the death by the preponderance of evidence but is invariably affected by his/her own bias on what they opine is reasonably explained by asphyxial factors, and other diagnostic findings, or lack thereof, that prevent them from accurately determining cause and manner of death. Certification of the cause and manner of death as undetermined by the forensic pathologist clearly conveys their admission of “I don’t know” but obscures vital statistics analysis for understanding why it was undetermined by death certificate data alone. The current US death certificate does not lend itself to providing significant information about a death whose cause is not fully understood.

In 2015, 75% of all SUID were certified as SIDS/SUID or undetermined. Sudden infant death syndrome and SUID are both assigned the ICD code of R95 and deaths certified as “undetermined” are assigned the ICD code R99. Deaths with an incomplete investigation, those that are highly suspicious, or those that present medical findings that are inconsistent with an unexplained death (with/without asphyxial risk factors identified) may also be assigned R99. By definition, forensic pathologists do not clearly understand the cause or manner of death in either of these types of cases (8). The preference, or reluctance, to using SIDS/SUID or undetermined for cause of death appears to be multifactorial – personal preference, local/jurisdictional practice, formal training, lack of specific diagnostic criteria, and improved death scene investigation findings identifying environmental risks (including asphyxia) that may be recognized but not considered responsible for the death (8-10).

Has the diagnostic trend toward undetermined certification of cause and manner of death led to unintended consequences for research, public health and education, and the personal families affected? All authors have worked in the field of sudden infant/child death for at least the last two decades and have personally observed the diagnostic shift trends. But how pervasive are the effects? This study sought to describe the perceived effect(s) this shift has had among bereaved families as well as organizations working in

the area of sudden infant death advocacy, support, and research. Change is difficult, even when it is a result of scientific progress; however, are there unintended consequences of this diagnostic shift that can be mitigated to better support and improve the coordination of overarching goals towards the better understanding and prevention of sudden infant deaths? We hypothesize that organizations and families have been affected by the diagnostic shift creating legal, social, bereavement, financial, educational, and research ramifications.

## METHODS

Two online surveys were created. They were administered by the organization CJ First Candle (formerly First Candle and the CJ Foundation for SIDS), whose mail list has access to more than 300 sudden unexpected infant death-related organizations and an online forum of 1300 members consisting of bereaved parents affected by infant deaths of all causes. Individual survey announcements requesting volunteers for a brief survey were emailed by CJ First Candle to the organization’s email list and posted to the online family forum for a period of two weeks in late February to early March 2017. Both surveys asked seven questions (**Table 1**). Survey #1 collected information from US organizations that directly support families after the sudden death of an infant and Survey #2 collected information from bereaved parents who have experienced the unexpected death of an infant since 2002. Submissions were anonymous.

Data collected were descriptive. The researchers used qualitative inquiry to further inform data. Themes were identified and weighted according to their frequency (i.e., social stigma = yellow,  $f = 6$ ), with the authors blinded to the specific infant diagnosis given for each comment.

## RESULTS

Sixty-seven US based organizations who work directly with families affected by the sudden death of an infant submitted complete surveys. Of these, 40.3% (27/67) provided direct support services to families

after the sudden death of an infant, 25.4% (17/67) were professional organizations, 41.8% (28/67) were health departments, 34.3% (23/67) were community based organizations, 22.2% (15/67) were family support organizations, 44.8% (30/67) provided advocacy and education, 3% (2/67) performed research, 1.5% (1/67) was a hospital, and 49.2% (33/67) were 501c3 non-profit organizations.

Leadership roles were held by 59.7% (40/67) of the respondents at their organizations and 77.6% (52/67) were aware of the shift in terminology used in regards to cases of sudden infant death since 2002. Just over half, 50.7% (34/67), perceived the shift has had an effect on their organization, including 28.6% (6/21) of 501c3 organizations that stated they have expanded their services or mission to accommodate, and another that is considering a mission change. An increase in educational resources was reported by 47% (16/34), while one organization reported safe sleep education was less prioritized due to the decrease in SIDS rates reported. An increase in advocacy services was stated

by 8.8% (3/34) and 5.8% (2/34) stated greater difficulty in acquiring funding due to the reported decreased rate of SIDS, regardless of the plateau of SUID in general.

Comments on the scientific merit of the diagnostic shift were offered by 20.6% (7/34) of organizations, conveying hope in its success to provide better data that helps reduce infant death, frustration that the “*shift further confuses an already confusing subject,*” and frustration regarding the lack of standards within the MDI community to provide diagnostic criteria for consistent death certification.

Fifty-five parents who had experienced the sudden unexpected death of their infant since 2002, and whose death investigation was closed, submitted completed reviews. Causes of death included SIDS (n=12, 21.8%), SUID (n=13, 23.6%), undetermined (n=21, 38.2%), and asphyxia (n=9, 16.4%). The majority (34/55, 61.8%) were affected by an infant death since 2013.

**Table 1: Descriptions of Surveys**

Survey #1 Organizational Survey	Survey #2 Bereaved Parent Survey
Are you a US organization who work directly with families affected by the sudden death of an infant?	Are you a parent who has suffered the sudden unexpected death of an infant (under 12 months of age) between 2002 and 2017?
Which of the following categories helps describes your organization? (Check all that apply) Provides direct support to families after sudden infant death Professional organization Health department Community based Faith based organization Family support organization Provides advocacy/education Performs research Research funding agency 501c3 Non-profit organization Other (please specify)	What year did your infant die?
Are you in a leadership role at the organization?	What was the specific wording used to describe your infant's cause of death on the death certificate and/or autopsy report?
Are you/your organization aware of a shift in terminology used in regards to cases of sudden infant death since 2002?	Did you clearly understand what this diagnosis meant for your child and your family?
If yes, please describe your understanding of the shift that has occurred.	If you did not clearly understand the terminology used on the death certificate and/or autopsy report, who (if anyone) helped you better understand its meaning and implications for your family?
Do you perceive the shift has affected your organization? If yes, please describe.	Please describe any effect this particular cause of death description had on your family's experience (your grief, understanding the cause of death, life benefits, employment, legal issues etc.).
Please provide any additional comments you have in this regard.	Please provide any other comments you may have in regards to your child's cause of death.

Forty percent (22/55) of respondents stated they did not clearly understand the final diagnosis assigned to their infant’s death (Table 2). This lack of understanding was predominantly among cases certified as SUID (53.8%) and undetermined (66.7%). Parents of children whose deaths were certified as asphyxia reported confusion (33.3%), specifically when parents perceived that evidence of asphyxia was speculative. Parents of SIDS cases reported the least amount of confusion with the diagnosis (16.7%). Individuals who assisted the parents with an improved understanding of the cause of death and its implications for their family differed by diagnosis. Parents of SIDS and SUID cases more often reported that the medical examiner or coroner assisted them with a better understanding of the diagnosis and the terminology used.

However, parents of children whose deaths were certified as undetermined reported they were more likely not to receive clarity from anyone.

Parents were asked how their child’s specific cause of death impacted them. Answers were open ended. Categories emerged based on themes, with those cited most frequently listed in Table 3.

The certified cause of death left 41.8% (23/55) of respondents frustrated, angry, and/or anxious about the lack of understanding about the “true” cause of their infant’s death. This was the most frequent theme volunteered and most notable among SIDS parents (6/12, 50%) and those of SUID (8/13, 61.5%), while less noted by those with an undetermined certification (6/21, 28.6%).

**Table 2: Frequency of Parents With Confusion Around the Diagnosis and Who Assisted Them With Greater Clarity**

	Did Not Understand Diagnosis	Who helped provide clarity?
Total N=55	22 (40%)	ME/C (11), No one (7), Web (3), Pediatrician (2), Friend (3), Nonmedical professional (1)
SIDS (n=12)	2 (16.7%)	ME/C (1), Web (1)
SUID (n=13)	7 (53.8%)	ME/C (6), No one (1)
Undetermined (n=21)	14 (66.7%)	No one (6), ME/C (4), Pediatrician (2), Web (2), Friend (2)
Asphyxia/ Accident (n=9)	3 (33.3%)	Friend (1), Nonmedical health professional (1), No one (1)

SIDS - Sudden infant death syndrome  
 SUID - Sudden unexplained infant death  
 ME/C - Medical examiner/coroner

**Table 3: Frequency of Themes Described By Parents in Relation to Diagnosis Assigned**

	Frustration Due to Lack of Accurate Cause of Death	Guilt/ Anxiety/ Depression/ Isolation	Negative Perceptions of Medical and/or Public Health Fields	Legal Implications	Social Stigma	Provided Community or Inspired Action, Lessened Guilt, Gave Closure
Total (N=55)	23 (41.8%)	21 (38.2%)	11 (20%)	7 (12.7%)	6 (10.9%)	6 (10.9%)
SIDS (n=12)	6 (50%)	4 (33.4%)	0	1 (8.3%)	1 (8.3%)	5 (41.7%)
SUID (n=13)	8 (61.5%)	4 (30.8%)	5 (38.5%)	0	2 (15.4%)	0
Undetermined (n=21)	6 (28.6%)	5 (23.8%)	3 (14.3%)	4 (19%)	2 (9.5%)	1 (4.7%)
Asphyxia/ Accident (n=9)	3 (33.3%)	8 (88.9%)	3 (33.3%)	2 (22.2%)	1 (11.1%)	0

SIDS - Sudden infant death syndrome  
 SUID - Sudden unexpected infant death

The second most frequent theme uncovered by the survey was the perceived mental health effects due to the diagnosis. Overall, 38.2% (21/55) respondents reported that the diagnosis increased their feelings of guilt, anxiety (especially related to other children), depression, and isolation. Among the four diagnosis groups, SIDS (4/12, 33.4%), SUID (4/13, 30.8%), and undetermined (5/21, 23.8%) were relatively similar for reported mental health effects, but the accidental asphyxia cases were markedly higher (8/9, 88.9%) in the frequency of reported feelings of guilt. However, 41% (5/12) of parents of SIDS stated the diagnosis provided them positive effects by either giving them closure, lessening their guilt, or providing a supportive community. Only one parent among the SUID, undetermined, and asphyxia groups overall reported any positive effects of the diagnosis. The parent of one undetermined case stated that the diagnosis “inspired action” in them to help others.

Negative perceptions towards the MDI community and public health were described by parents in our study as the third most frequent theme. Distrust, frustration, and loss of respect were most significant for the SUID group (38.5%), while parents of SIDS were spared. Dissatisfaction was most often related to their awareness of the inconsistency of death certification practices (“*I know others in my same situation who were given SIDS – not undetermined*”), their opinion that the diagnosis was inaccurate (“*my baby died of SIDS and they won’t admit it*”), the inconsistent information they received from medical professionals (“*the ER [emergency room] doctor told me it was SIDS and the ME [medical examiner] says they died of asphyxia*”), and their shocked frustration at a lack of identifiable cause of death (“*I don’t think they tried hard enough – healthy babies don’t just die!*”).

Legal implications were described by parents of SIDS, undetermined and asphyxia. One SIDS parent relayed the SIDS diagnosis limited their ability to pursue litigation against medical care providers due to the natural manner of death determination. Undetermined and asphyxia cases cited examples of false accusations, ongoing child protective services investigations, and “*being treated as a criminal.*”

Stigma associated with the diagnoses, as described by some of the organization responses, were also reported by parents. While one SIDS parent stated the diagnosis gave them “*comfort*,” two SUID parents said they tell others their infant died of SIDS because “*the public doesn’t understand SUID and there is less blame.*” Parents of two undetermined cases stated that SIDS parents were not as supportive of them and another stated she was accused by others of “*rolling over on her baby.*”

## DISCUSSION

Our understanding and prevention of sudden infant deaths will be maximized by the collaborative efforts of public and private entities dedicated to these tragedies. The diagnostic shift that has occurred over the last ten plus years within the MDI community has resulted in unintentional effects upon this greater system. Our study sought to better understand some of the effects by surveying organizations and families affected.

Our study limitations include using the mail list of one organization only, offering survey participation for a limited two-week timeframe, recall bias among families, and utilizing only open ended descriptive questions. The incidence of each theme must be evaluated in this context – as a failure to volunteer a theme does not rule out its existence. The number of family respondents is also small; therefore, findings may not be statistically significant but offer a sense to possible perceptions among affected families. Further research that questions a large cohort of participants to specifically measure each theme recognized by our study would be valuable for a greater overall understanding of their significance. Additionally, we did not specifically investigate the effects of the shift of manner of death from natural to undetermined, which deserves focused attention in further research.

Organizations provided thoughtful feedback on their understanding of the diagnostic shift and how it has affected their work. Additional resources for education was the most often stated effect, but additional comments related to the difficulty of providing quality

bereavement care, social stigma issues, reduced funding sources, concern that the shift is creating more confusion and less clarity in diagnoses, as well as the lack of consistency and bias among certifiers. These significant issues can provide a basis for how the medicolegal death investigation system can improve communication with outside agencies to address these concerns and improve efforts.

It is undeniable that the shift from SIDS to undetermined creates further barriers to evaluating trends by death certificates alone and its current effect on research efforts cannot be ignored. Standards and consistency within the MDI community must be developed and overwhelmingly adopted to overcome this steep obstacle of identifying cases appropriate for further research and evaluating trends.

The confusion and lack of clarity around diagnoses is not limited to research needs. Forty percent of all family respondents stated that regardless of the diagnosis given they did not clearly understand what the diagnosis meant. Parents of SIDS stated the least confusion, followed by parents given a diagnosis of asphyxia. The authors assume, but cannot confirm, that this is due to the decades of public education on SIDS. The majority of parents given a diagnosis of SUID or undetermined reported the most confusion. Also, while parents of SIDS and SUID attained more clarity by communication with the medical examiner or coroner, the parents of undetermined cases were more likely to not attain further clarity from anyone. The effects of the diagnostic shift reported by our surveys further outline the vitally important role that MDI professionals, and specifically forensic pathologists, play in supporting bereaved parents in understanding the facts surrounding the cause of their child's death. Parents who stated they were not confused by their child's final diagnosis of SUID included one who commented that *"our medical examiner explained things to us from day 1 so we weren't surprised."*

Nashelsky and Pinckard described the *"unintended consequences"* of the SIDS definition of 1969, including, among other things, that the definition evolved from describing a category of deaths to a diagnosis

of exclusion, and that clinical physicians associated the SIDS death with an *"unidentified disease process"* (6). Our parent survey results, although small, did address these issues. Our leading theme for all groups combined, with 50% SIDS cases and 61% of all SUID cases, stated the diagnosis left them feeling very frustrated that the cause of death did not identify a specific cause of death and left them *"without any answers."* However, misinformation by medical professionals was a source of hardship for families in their grief and calls for consistency, not only among the MDI community, but consistency among the medical professional and sudden infant death community overall (11).

Social stigma issues associated with the diagnostic shift, subjectively known to all authors, were reported by both surveys. One organization commented, *"I think parents are more willing to tell their friends/family that their infant died from SIDS rather than asphyxia – there is less blame involved with SIDS."* Another stated, *"Some parents deny the 'Undetermined' diagnosis, and believe/tell others that the cause of death was SIDS."* While some parents of SUID and undetermined deaths conveyed they tell others their child died of SIDS, they get accused of *"rolling over their baby"* and lament that SIDS parents are not as supportive to them. It is unclear to know how pervasive these issues are based on our limited data, but if supported by further research, they represent difficult obstacles to providing essential support to the bereaved. Organizations working in the realm of sudden infant death must investigate ways to reduce stigma and isolation, and improve support to engage all bereaved families regardless of cause of death.

The identification and certification of sudden deaths in infancy due to asphyxia by the medicolegal death investigation has contributed to the development and prioritization of safe sleep campaigns that continue to evolve. As recent as October 2016, the American Academy of Pediatrics issued an update on recommendations for safe infant sleep environments to further address asphyxia risk factors identified by sudden infant death investigation trends (12).

However, as some organizations in our study highlighted, the effective communication and mental health care of the affected parent population may be suffering as a result of the diagnostic shift and must be addressed. Confusion around a diagnosis should not be the lasting result of a MDI for family members. Medicolegal death investigation is a public service. In September 2016, the National Commission on Forensic Sciences issued Views of the Commission – Communication with Next of Kin and Other Family Members, which stated that providing information in a “*clear, sensitive and effective manner to the surviving family members is a critical aspect of the medicolegal death investigation system*” (13). Services that have created strong support for families of SIDS may not be as effective for families who have suffered a preventable accidental death. Parents of SIDS were the only diagnostic group in our study to not report any negative perceptions towards the medical field, described the least amount of confusion and reported the most instances of positive effects regarding their diagnosis. Our data suggest there are perceived social stigmas among some bereaved families that were created by a diagnostic shift that organizations caring for them did not anticipate.

## CONCLUSION

The current death certificate is not designed to adequately address the surveillance and research needs of deaths without a clear cause of death, and it is not sufficient to educate the affected family, or their clinicians, regarding the findings or ramifications of a MDI. As practitioners of medicine, forensic pathologists, and all physicians, are responsible for the accurate interpretation of their findings and a duty to “do no harm.” Whether it be themselves, or the designee of the forensic pathologist, the next of kin deserves the right to be provided with accurate information regarding their child’s death in a format they can comprehend, the opportunity to ask questions, and to be provided with information about the risk to living family members and appropriate referrals as medically appropriate. Due to the recognized effects of traumatic grief on memory, this information must be conveyed in writing, as well as verbally, to the family and their clinicians to carry out appropriate screening measures and follow-up care.

The diagnostic shift that has occurred within the medicolegal death investigation system in regards to SIDS and other infant deaths emerged due to scientific merit, but unanticipated ramifications have resulted in regards to surveillance, research, education, societal views, and care of the bereaved. While the MDI community strives to be impartial in their independent investigations, in cases of sudden infant death they are intrinsically part of a bigger system to help eliminate this public health crisis. Tragically, efforts in reducing sudden infant deaths have seen a plateau for more than 15 years. Frustration abounds.

Consensus on terminology and certification is vital for progress. Early and consistent MDI engagement and education for primary care physicians, public health officials and other infant death-related organizations to adopt such consensus will improve implementation, the care of the bereaved, our vital health statistics, and support research efforts.

Our survey to organizations was open for a short two-week period, but 67 organizations participated to share their views on this important topic. The future success of these willing and dedicated entities, within and outside the resource strapped MDI community, is critically reliant on all parties working in collaboration to attain a clear understanding of these deaths, identify prevention measures, minimize negative ramifications, and provide sensitive and effective care of all those bereaved.

## REFERENCES

- 1) Centers for Disease Control and Prevention [Internet]. Atlanta: Centers for Disease Control and Prevention; c2017. About SUID and SIDS [modified 2017 Feb 1; cited 2017 Mar 15]. Available from: <https://www.cdc.gov/sids/aboutsuidandsids.htm>.
- 2) Centers for Disease Control and Prevention [Internet]. Atlanta: Centers for Disease Control and Prevention; c2017. Infant mortality [modified 2016 Sep 28; cited 2017 Mar 15]. Available from: <https://www.cdc.gov/reproductivehealth/maternalinfanthealth/infantmortality.htm>.
- 3) NIH Research Portfolio Online Reporting Tools [Internet]. Bethesda (MD): National Institutes of Health; c2017. Estimates of funding for various research, condition, and disease categories (RCDC); 2016 Feb 10 [updated 2016 Jul 22; cited 2017 Mar 15]. Available from: [https://report.nih.gov/categorical\\_spending.aspx](https://report.nih.gov/categorical_spending.aspx).
- 4) Sudden Infant and Child Death Resource Center [Internet]. New York: Sudden Infant and Child Death Resource Center; 2017 [cited 2017 Mar 15]. Available from: <http://216.248.198.60/SIDS/history.cfm?s=5>.

- 5) Shapiro-Mendoza CK, Tomashek KM, Anderson RN, Wingo J. Recent national trends in sudden, unexpected infant deaths: more evidence supporting a change in classification or reporting. *Am J Epidemiol*. 2006 Apr 15; 163(8):762-9. PMID:16582034. <https://doi.org/10.1093/aje/kwj117>.
- 6) Nashelsky MB, Pinckard JK. The death of SIDS. *Acad Forensic Pathol*. 2011 Jun; 1(1):92-8. <https://doi.org/10.23907/2011.010>.
- 7) CDC WONDER [Internet]. Atlanta: Centers for Disease Control and Prevention; c2017. About compressed mortality, 1999-2015; [cited 2017 Mar 14]. Available from: <http://wonder.cdc.gov/cmfi-icd10.html>.
- 8) Byard RW, Lee V. A re-audit of the use of definitions of sudden infant death syndrome (SIDS) in peer-reviewed literature. *J Forensic Leg Med*. 2012 Nov; 19(8):455-6. PMID: 23084308. <https://doi.org/10.1016/j.jflm.2012.04.004>.
- 9) Malloy MH, MacDorman M. Changes in the classification of sudden unexpected infant deaths: United States, 1992-2001. *Pediatrics*. 2005 May; 115(5):1247-53. PMID: 15867031. <https://doi.org/10.1542/peds.2004-2188>.
- 10) Byard RW, Beal SM. Has changing diagnostic preference been responsible for the recent fall in incidence of sudden infant death syndrome in South Australia? *J Paediatr Child Health*. 1995 Jun; 31(3):197-9. PMID: 7669379. <https://doi.org/10.1111/j.1440-1754.1995.tb00785.x>.
- 11) Rudd RA, Marain LC, Crandall L. To hold or not to hold: medico-legal death investigation practices during unexpected child death investigations and the experiences of next of kin. *Am J Forensic Med Pathol*. 2014 Jun; 35(2):132-9. PMID: 24781400. <https://doi.org/10.1097/PAF.0000000000000089>.
- 12) Task Force on Sudden Infant Death Syndrome. SIDS and other sleep-related infant deaths: updated 2016 recommendations for a safe infant sleeping environment. *Pediatrics*. 2016 Nov; 138(5). pii: e20162938. PMID: 27940804. <https://doi.org/10.1542/peds.2016-2938>.
- 13) National Commission on Forensic Science [Internet]. Washington: U.S. Department of Justice; Views of the commission: communication with next of kin and other family members; 2016 Aug 24 [cited 2017 Mar 15]. 3 p. Available from: <https://www.justice.gov/ncfs/page/file/905546/download>.