POLICY STATEMENT Organizational Principles to Guide and Define the Child Health Care System and/or Improve the Health of all Children

American Academy of Pediatrics
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Child Fatality Review

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Understanding why children die is necessary to implement strategies to prevent future deaths and improve the health of any community. Child fatality review teams (CFRTs) have existed since the 1970s and provide a necessary framework to ensure that proper questions are asked about a child's death. CFRTs provide a vital function in a community to ensure that preventable causes of deaths are identified. Pediatricians are necessary members of CFRTs because they provide medical expertise and context around a child's death. All CFRTs should have pediatric physician representation, and results from team meetings should inform public policy at all levels of government. Pediatricians should be supported in their efforts to be present on CFRTs, and they should use data from team meetings to help advocate for implementing prevention strategies.

INTRODUCTION

Each year in the United States, more than 40 000 children younger than 19 years die.[1] Approximately two-thirds of these deaths are attributable to injuries, such as motor vehicle crashes, suicides, homicides, drownings, and fires.[1] In addition, approximately 3600 infants die suddenly and unexpectedly each year, usually during sleep.[1] In efforts to more thoroughly investigate and possibly prevent many of these deaths, all 50 states, the District of Columbia, Guam, and the Navajo Nation have child fatality review teams (CFRTs), which systematically collect information on the details of the circumstances of these deaths and formulate policies and procedures to prevent them.[2] In the 1970s, CFRTs initially developed in response to the increased recognition of child abuse and neglect,[3] but in the following 4 decades have grown to include more than 1350 multidisciplinary teams carefully reviewing the circumstances of a wide variety of child deaths with the ultimate goal to prevent future deaths.[2] Pediatricians have an important role in this review process, and a 2010 American Academy of Pediatrics (AAP) policy statement encouraged the nation's pediatricians to be involved in state and local CFRTs.[4] This policy statement provides an update on the status of CFRTs across the country and advocates for continued improvement in the review process to better protect children from preventable deaths.

abstract

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The multidisciplinary review process of child deaths allows for a far more substantial investigation into the circumstances of a child's death than that achieved using death certificate-based vital statistics alone.[5] Vital statistics can provide the total number, age, race/ethnicity, and sex of infants whose deaths would be categorized as sudden unexpected infant deaths, but death certificate-based data provide little information regarding the infant's sleep position, location, or environment at the time the infant died. Review by CFRTs allows for a more complete picture to emerge of the circumstances associated with the death, such as whether a crib or bassinet meeting federal safety standards was used, whether the infant was put to sleep supine but was found with the mouth and nose partially or fully obstructed by an object, or whether there was another person in their sleep environment. This level of careful review allows for the identification of potential preventive measures and the opportunity to make recommendations to prevent future deaths from a wide variety of causes. Data synthesis from CFRT meetings can help in the accurate identification of child maltreatment fatalities and in the design of community and statewide prevention strategies, recognizing that data collection is inconsistent because of differences in resources and access to records. Such a surveillance system is the cornerstone to the public health approach to prevention.

NEED FOR CHILD FATALITY REVIEW

Reducing preventable child deaths requires a systematic and integrated evaluation of fatality causes, which begins with accurate vital statistics data. It is troubling that child welfare data and death certificate reports significantly undercount actual child maltreatment-related deaths. This lack of accurate statistics indicates the need for systemic changes in the way child maltreatment deaths are reported nationwide in the United States.[6] National and state mortality statistics, which rely on the *International Classification of Diseases* coding system to define cause of death in vital statistics, underestimate child fatalities attributable to homicide and unintentional death,[7–9] with the actual number being 2 or 3 times larger.[6,9]

The first CFRT was formed in 1978 in Los Angeles with the intent of investigating deaths from child maltreatment.[3] More teams developed across the country during the 1980s and 1990s. Because the federal Child Abuse Prevention and Treatment Act was updated in 1993, states were required to report on child death review in their program plans, and in 1996, each state had to review child maltreatment deaths.[10] The National Center for Fatality Review and Prevention (NCFRP) was established in 2002, funded by the US Department of Health and Human Services, the Health Resources and Services Administration, and the Maternal and Child Health Bureau.[11,12] A total of 57% of teams are led by state health departments, and others are led by social service agencies, medical examiners' offices, attorneys general, or departments of justice. Seventy-one percent of states mandate a state CFR program, and 35% of states mandate local CFRTs.[2] As CFRTs matured, the focus expanded from reviewing only child maltreatment deaths to reviewing all child deaths, while shifting to a public health prevention model. Information about CFRT programs, examples of data collected from CFR teams, and prevention examples are available at https://ncfrp.org/.

Current Function of CFRTs

CFRTs support the public health approach of using data collection for surveillance to determine major causes of death, identify risk and protective factors and barriers to prevention within individual families and the greater community, develop interventions that are based on analysis, implement interventions at the community level, and use evaluation results to modify and improve the initial interventions. CFRTs have reviewed child deaths from a variety of causes and settings,[13] including sudden unexpected infant deaths,[14,15] automobile collisions,[16] inflicted injuries,[17] drownings,[18] and suicides.[19] In particular, CFRTs represent an effective surveillance tool for identifying victims of fatal maltreatment.[20–23] CFRTs seek to uncover bias and inequities in systems and can recommend strategies that can be used to prevent future deaths. In some jurisdictions, statutes limit what information from CFRTs may be shared, such as feedback to providers who cared for the child who died. Using the findings of CFRTs to change systems to improve prevention can be done while still respecting the privacy of grieving families. The authors are not aware of work that has yet examined the extent of barriers in communicating CFRT findings to community practitioners.

Although some CFRTs restrict their investigation to issues primarily related to injury and maltreatment, others review all child deaths regardless of presumed primary cause. These teams will also review those approximately one-third of all deaths related to medical causes, the majority of which occur during the first year of life, and those primarily in the newborn period (first 28 days). The largest single category of child death is often labeled as "prematurity." Because the goal of the CFRT is to prevent future deaths, data collected from CFRT meetings can help in the design of community and statewide prevention strategies to address these deaths beyond simply describing them as attributable to prematurity and not preventable, but rather as deaths that may have been prevented if systems were better in place to address issues such as access to prenatal health care. These systems are intimately related to the Healthy People 2030 Social Determinants of Health, "conditions in the environments where people are born, live, work, play, worship, and age that affect a wide range of health functioning, and quality-of-life outcomes and risks" (https://health.gov/healthypeople/priority-areas/social-determinants-health). Addressing issues such as the appropriate institution of prenatal care, the number of prenatal visits, and teaching pregnant

persons the signs of premature labor are examples of areas where the examination of system effectiveness may lead to better health outcomes for newborn infants. This public health perspective allows for the understanding of neonatal mortality beyond the confines of the labor and delivery unit and the NICU and includes the larger community, allowing for recommendations to ameliorate deaths that go far beyond the hospital. Throughout the country, many areas use this public health perspective in fetal and infant mortality review (FIMR) programs in which professionals and the community work in concert to address disparities and other issues in infant deaths. Pediatricians should be encouraged to participate in local FIMR programs, which investigate the deaths of the fetuses and newborn infants using a very structured technique, with data shared with the NCFRP. One of the aims of FIMRs is "to use findings to identify and address racial disparities and inequity in pregnancy outcomes."[24] For example, disparities in neonatal mortality present among some racial groups and between neighborhoods can lead to the better understanding of root causes of preterm birth and help focus on the crafting of preventive remedies.

Although CFRTs may struggle with how to prevent these broader "medical" deaths, it does become clear that, with better support of pregnant people or the at-risk, chronically ill child during the early years of life, these presumed "unpreventable" deaths are indeed possibly preventable given better community and legislative support. For the review teams, however, there are often difficulties obtaining the full complement of needed records, which could be because of privacy or legal concerns. In addition, although sometimes not approved for teams to review, the examination of care around stillbirths, as is performed by many FIMRs, can also aid in developing prevention strategies for preterm birth. These issues also reinforce the need of the CFRT to include not only those with pediatric expertise, but also the obstetric/gynecologic community.

One area in which CFRT has played an important role is in the accurate identification of the complex circumstances surrounding sleep-related infant deaths. Although the incidence of sudden infant death syndrome (SIDS) decreased significantly after the 1992 AAP recommendations for safe sleeping positions, the subsequent 2 decades have seen little progress.[25] The more recent declines in SIDS rates in the United States have been associated with a concurrent increase in positional asphyxia; as death scene investigations have become more comprehensive, the diagnosis in some cases has shifted from SIDS (essentially an unknown cause) to asphyxia (one where an etiology may be found).[26] Over the last 20 years, death certifiers have used the term "SIDS" less frequently and are increasingly using 2 other causes: "Unknown" and "accidental strangulation and suffocation in bed." An increase in careful infant death scene investigations with comprehensive reenactments of the circumstances of the death has led to a greater finding of suffocation as a cause for a portion of these deaths. This has changed the relative contribution of the 3 components of sudden unexpected infant death (SUID) (SIDS, unknown, and accidental strangulation and suffocation in bed), but the annual total has remained relatively unchanged.[14] The multidisciplinary child fatality review process has played an important part in our understanding of this "diagnostic shift," and the AAP has published a statement to assist pediatricians in understanding these changes.[27]

Studies have confirmed the need for comprehensive scene investigations and autopsies and the important role of child fatality review.[28] The data collected through fatality review are a rich source that highlights risk factors not available from other data sources. Given that systemic racism and health disparities are affecting Black, Hispanic, and American Indian and Alaska Native children, in-depth multidisciplinary case review through record sharing and deliberation provides more contextual data, family history data, data on underlying health or psychosocial vulnerability, and data on community systems that can better explain these effects and inform prevention planning to address their root causes.[5,8,29,30] This process also allows for greater data sovereignty, which is a group's right to control and maintain their own data, including the collection, storage, and interpretation of data.

Drowning is a leading cause of injury death among children, and there are significant racial and ethnic disparities in drowning death rates.[31] Black children 5 to 9 years old had rates 2.6 times higher than white children, and Black children 10 to 14 years old had rates 3.6 times higher. Disparities are even more pronounced in swimming pool deaths (Black children 10–14 years old drowned at 7.6 times the rate of white children). Child fatality review would provide much-needed information on the circumstances of these drowning deaths to inform drowning prevention strategies.[32] In 2018, 42 states reported that they used their CFR data to identify risk and protective factors in child deaths, inform prevention recommendations, and improve community systems.[2] It is important that CFRTs have a diverse composition of members with the goal to generate culturally safe public health recommendations.

It is also important that deaths without a known or apparent cause be fully investigated using the latest genetics and current scientific advances, as research continues to uncover potential causes in previously unknown deaths. There is also a role for CFRTs to help researchers uncover rare diseases.[33,34] In addition, it is important that teams review deaths of children with neurodevelopmental disabilities or children with chronic health care needs, and make sure that these deaths are fully investigated like all others, and not assumed to be as a result of their disability.[35]

To increase standardization and availability of CFRT review information, the NCFRP initiated its Web-based National Fatality Review Case Reporting System (NFR-CRS) in 2005 and made it available at no cost to all local and state teams. In 2018, 44 states and their local CFR teams contributed to the NFR-CRS, with over 213 000 cases by the end of the year.[2] In April 2018, the NCFRP expanded the NFR-CRS to include fatality review data from FIMR teams, marking the first time the system was changed to collect data from a program other than child death review, which potentiates further data linkage.[2] The long-established, transportation-related Fatality Analysis Reporting System, the National Violent Death Reporting System,[36] and the newer Sudden Death in the Young Case Registry illustrate the power of developing and implementing national standards for data collection in addressing preventable deaths.[37] These systems have potential synergy with CFRTs and the NFR-CRS that will grow over time to provide a more comprehensive database of child deaths, and thus provide better data for prevention activities.

Benefits of CFRT

Many CFRTs use data to make recommendations that can prevent future morbidity and mortality. As teams have matured, prevention recommendations have become more actionable and follow-up on them more straightforward.[38] Understanding what is "preventable" is complex and at times subjective, but teams have helped define what can be done to prevent future deaths.[2] In Washington, state CFRT recommendations led to substantial program and policy recommendations around drowning, and by using data, the CFRT was able to target high-risk populations for prevention.[18] Although policy changes may not be directly traced to a CFRT or a local recommendation, discussions within the CFRT play a role in such changes. In Pennsylvania, discussions at CFRT meetings at a local and state level helped identify the need for better suicide prevention efforts in the school setting. Working with multiple partners, including many CFRT team members and affiliates, the Pennsylvania state Legislature passed Pennsylvania Act 71 in 2014, which mandated professional staff training, student curriculum, and school policy for suicide prevention efforts.[39] CFRTs have had a significant impact on SUID in terms of understanding the scope of problem, its causes, and relevant prevention strategies, with one team citing a decrease in SUID potentially related to a hospital-based education program, using information learned at the CFRT.[40]

Team meetings also bring communities and professionals together for the sole purpose of preventing childhood death.[41] CFRTs are often a catalyst for community organizations and government collaboration. Although some have questioned the advances of CFRT,[42,43] teams have made an impact in their communities, both in the United States and abroad, on multiple areas of prevention, including increasing knowledge, promoting community education, educating providers, changing organizational practices, fostering coalitions and networks, mobilizing neighborhoods and communities, and influencing policy and legislation.[44–47]

Pediatricians and CFRTs

In the 1999 policy statement, "Investigation and Review of Unexpected Infant and Child Deaths," the AAP recommended that pediatricians be involved with the child death review process as a team member or as a consultant.[48] The recommendations were expanded in the 2010 statement, "Child Fatality Review."[4] In 2019, the role of pediatricians in identifying child abuse infant deaths was also clarified.[28] Pediatricians provide medical expertise to help understand the disease process that contributed to the death, the health care systems involved in pediatric care, and the facts around the death. Pediatricians also support the CFRT by facilitating appropriate access to medical records and interpreting medical history while acting as a liaison between the team and the broader medical community. This can also include follow-up to families, when appropriate and allowed by local CFR laws.

Participation on CFRTs requires training to understand team and CFR processes and currently is not formalized or standard across different teams. There is an unknown emotional toll that participation may have on members, including pediatricians. Further study is needed regarding ways to prevent secondary trauma from participation on CFRTs. One study on child abuse pediatrics fellows stated that multidisciplinary team interactions may provide such a protective benefit.[49] Another study of pediatric residents found that burnout may be reduced by engaging in meaningful work; for physicians that engage in CFR, this could be accomplished by having their findings connected to prevention.[50] When more frequent and careful review of deaths leads to true prevention, the work becomes more meaningful and thereby causes less trauma for those involved in the child fatality review process.[50] Finding ways to translate CFRT findings to prevention is one way to protect those who do this work. In addition, although they are generally happy to contribute to improving children's health, most pediatricians who participate on teams are not compensated for their time or expertise.

The AAP acknowledged the value of helping pediatricians who serve on CFRTs by approving the Section on Child Death Review and Prevention in 2016. As a formal Section, AAP members come together to share ideas, provide education at AAP National Conference & Exhibition venues, and help collaborate with other AAP sections/councils/committees to promote child health. Often, CFRT recommendations may include policy changes that require coordination of multiple agencies. As a section of the AAP with all its resources, the Section on Child Death Review and Prevention can help in advancing policies on the federal and state levels. The Scarlett Sunshine Act was passed

by Congress in 2020 and authorizes the investigation and data collection of sudden unexpected deaths of infants and young children, and supports families who have experienced this tragedy. This law is an example of how the AAP contributed to the passage of a significant piece of legislation that will have a major impact on CFRTs across the country.

CONCLUSIONS

The child fatality review process was born out of the need to understand how and why children die, and its goal is to use that information to prevent future morbidity and mortality. In the more than 40 years since the first teams developed, CFRTs have evolved and demonstrated how communities can come together to systematically develop and implement prevention strategies. Pediatricians are vital team members in this process and need to continue to advocate for acquiring high-quality data to drive policy changes that improve children's health.

RECOMMENDATIONS

Given its recognition of the role of child fatality review in improving children's health, the AAP makes the following recommendations to enhance the involvement of pediatricians and the AAP and to improve the child fatality review process.

AAP/Chapters

1. All local, state, and/or tribal CFR teams should have pediatric physician representation. Resources from the AAP and AAP chapters can support such work.
2. Pediatricians, along with AAP chapters, should use recommendations from CFRTs to inform local, state, tribal, and national policies and legislation to reduce preventable child deaths and improve children's health. The AAP has numerous member groups and resources available to assist chapters and members in pursuing policies and activities that support this work.
3. Members of CFRTs, including pediatricians, should receive compensation commensurate with the time and value of their participation. The AAP supports state and federal policy that would enable such financial and other support of CFRT participants.

CFR Process

1. Every child's death should be investigated as appropriate and as resources allow, including a review by a CFRT. This includes a timely autopsy and a report by a certified pediatric forensic pathologist in appropriate cases, when available, especially those that are unexpected (including SUID), suspicious, obscure, or otherwise unexplained.
2. Federal funding should be advocated as necessary to further develop the NFR-CRS, a system for the review of data regarding child deaths for the United States, with high-quality, deidentified, and timely child mortality data that can be easily accessed and queried by researchers and groups interested in prevention.
3. A national surveillance system should be advocated for other deaths, including SUID and sudden death in the young, by building out the current Centers for Disease Control and Prevention SUID Case Registry system. It is recommended that every unexpected infant death have a sudden unexpected infant death investigation reporting form or jurisdictional equivalent filled out by appropriately trained local death investigators.
4. Pediatricians and other interested parties have a role in advocating for timely and consistent reporting on death certification and standardization of the certification process that can lead to improved data on which to base prevention strategies. This is especially important in deaths related to child maltreatment.
5. Where allowed by statute, CFRTs should be encouraged to provide tactful and sensitive feedback to primary care providers and other medical and community agencies that have intersected with the deceased child and family to identify systemic issues that could be improved to prevent future child deaths. Pediatricians who are members of CFRTs would be ideal in this role. Statutes limiting such feedback should be examined, and where appropriate, reconsidered for opportunities to share CFR findings for prevention.
6. Because the work of regularly reviewing the details of child deaths is emotionally draining and personally difficult, support, including comprehensive professional training on secondary trauma, should be provided to pediatricians and other team members to help promote resilience.

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ABBREVIATIONS

AAP: American Academy of Pediatrics
CFRT: child fatality review team
FIMR: fetal and infant mortality review
NCFRP: National Center for Fatality Review and Prevention
NFR-CRS: National Fatality Review Case Reporting System
SIDS: sudden infant death syndrome
SUID: sudden unexplained infant death

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