
FOREWORD

The health and well-being of children is a primary responsibility of society. Although child death is less common than the morbidity of disease, famine, violence, accidents, and other social concerns, both worldwide and in the United States, the death of children is often a marker of the larger underlying issues. By understanding how and why children die and what contributes to these deaths, it should be possible to apply public health and other approaches to reduce childhood morbidity and mortality.

The problem of child fatalities is enormous, despite the striking gains of the last century. In developing countries, diseases such as diarrhea, malaria, and HIV contribute to epidemics of child deaths. In more industrialized countries, fatal diseases may be seen less often, but underlying social problems emerge more prominently.

For example, youth violence is a serious problem in the United States, both in the form of children being killed by their caregivers (child abuse) and from youths killing youths (homicide). In 2001, a report issued at my direction as the US Surgeon General highlighted youth violence as a major public health problem. This report brought together the Centers for Disease Control and Prevention, the National Institute of Mental Health, the Substance Abuse and Mental Health Services Administration, and a panel of experts to detail the magnitude of the problem, describe its characteristics, and suggest a number of prevention and intervention strategies. Prevention of youth violence would substantially reduce child deaths and morbidity, and a public health approach would add immeasurably to existing social services and legal services.

Within the last several decades, public health approaches to the prevention of unintentional injury (eg, from seat belts, car seats, swimming pools), disease reduction (eg, Hib, polio, and other immunizations), and, most recently, violence have made substantial inroads in preserving the health and well-being of children. By applying scientific processes to such problems, professionals and communities may no longer perceive them as inevitable or impossible to address. Increased investments in the protection and health of children will have a tremendous impact on reducing the social and health costs of both child and adult fatalities.

This is the first major book to address issues of child fatality. An international list of authors puts these problems in perspective in the United States and worldwide. By considering causes of child death and utilizing the multidisciplinary process to address them, specific prevention efforts may be tailored to fit a community's particular needs. These efforts are necessary if we are to preserve our future: our children.

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FOREWORD

The impact of a child's death should be immeasurable, whether it occurs because of an extremely premature birth, ravaging cancer, or a terrible accident. Regardless of the circumstances, a child's demise is catastrophic. However, when a child dies from abuse and/or neglect, a brief surge of public outrage may be the extent of the reaction. Many times, the fact that this type of death tends to be more preventable than any of the previously mentioned is not acknowledged. This text brings the reality of preventable child abuse deaths to the forefront of social consideration and challenges professionals to unify their thought and documentation processes.

The emergence of child fatality review teams throughout the United States compels us to develop protocols and best practices standards, as well as to carefully reflect upon and learn from past lessons. This compendium provides an extremely thought-provoking discussion of the complexity of child fatality and its relevance to many professional disciplines. With an original focus in the criminal justice and child protective services arena, the incorporation of public health and prevention efforts into the tasks of child fatality review teams advances prevention not only at the local and community levels, but also within society as a whole.

Child Fatality Review brings together many great minds that articulate the numerous challenges in the child death review process. We have come to recognize the lack of uniformity from state to state in the documentation of the cause and manner of a child's death. Additionally, not only are deaths misclassified in nearly 1 out of 3 cases, but also these tragic deaths are woefully absent from child abuse tracking systems.

Just as criminal justice research has opened society's eyes to the immediate threat to a child's survival when he or she is abducted by a stranger, so too does this work possess the potential to open eyes as we struggle to decrease childhood fatalities. Community response to the threat of danger and the need for timely action in cases of child abduction has effected state and national legislation such as the American Missing Broadcasting Emergency Response (AMBER) Alert and models how, through increased public awareness and education, child death review team research can move society forward in preventing subsequent mortality in siblings of deceased children, recurrent accidental deaths in communities, and even fatal trauma due to a parent's loss of control when frustrated by a crying baby. These teams can also establish partnerships between state agencies and the private sector to enhance child health and safety.

This excellent text will advance the field of child fatality review by providing a guide for an encompassing network for a multitude of professionals, all of whom must work together and share knowledge, experience, and respect for each other's divergent perspectives in order to ultimately protect our most important and irreplaceable resource, our children.

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INTRODUCTION

Rituals surrounding child death are ancient. Centuries ago, a mother held a still body and screamed. An older woman more experienced with death held the mother, and the chief and the shaman joined them. A small group gathered to chant and appease the gods, support one another, and protect themselves from events they could not understand, like a child's death.

This ancient process continues today, aided by experts from different agencies, modern forensics, data analysis, and computer communications. The behavior appears modern and potentially impersonal, but at the core the ancient purpose remains. The tribal response to the loss of a child has been reborn in the modern process of child death review, in which professionals support one another and work together to understand how these tragedies occur.

THE BEGINNINGS OF CHILD DEATH REVIEW TEAMS

The concept of multiple agencies reviewing child death as a team came to me from an experience I had in medical school with internal and pediatric medicine. Each week, internal medicine faculty, residents, interns, students, nursing staff, social workers, and others gathered to review patient deaths. In my first review session, the patient died of an abdominal tumor that was missed on physical examination. The staff wanted to learn from what went wrong. Death review, it seemed to me, was part of pursuing excellence. The doctors could evaluate their work, successes as well as failures, as they pursued excellence. However, many people found the process out of place in a system that celebrated life.

Pediatric services did not address death so directly, perhaps because of the special status we give to the life of a child. When a child died, staff seemed to behave almost as if it had not happened. Another child arrived to fill the bed in the hospital. Nothing was said. I made note cards on children who might die with the intent of pulling their charts in 6 months to see what happened, but I lost the cards. The task of analyzing child death would eventually require not one doctor, but rather considerable group effort and multiple professions. The work causes pain that, like the ancient tribe, requires a system of peer support.

My work with the precursors of child death review began in Los Angeles County in 1975, where reviews of coroner records created a basis for the first team. The LA County Inter-Agency Council on Child Abuse and Neglect (ICAN) formed in 1977 as one of the first multiagency child abuse forums. This organization provided the agencies for my model in 1978, and we began the first child death review. We shared with other counties and states and the second team formed in San Diego in 1982. I personally contacted all states and met face-to-face with about half of them. We were the center of a rapidly growing peer support network. In 1996, the US Department of Justice was joined by the US Department of Health and Human Services at a press conference to declare ICAN the National Center on Child Fatality Review.

Deaths of children provided the motivation and material for review, one case at a time. Other California counties soon formed review teams, and other states followed suit in the mid 1980s. By 2001, all states had implemented the child death review process with state and/or local teams. The United States had nearly 1000 state and local teams by 2006. International teams began in Sydney, Australia, and British Columbia, Canada, and filed their first team reports in 1994. New Zealand and the Philippines followed. Teams are underway in England and beginning in Scotland and Japan, and professional-assistance requests are arriving from India, Pakistan, Portugal, Estonia, and others. Most of the resources and direction for teams has come from local resources and local child deaths. Some teams begin with a notorious fatal child abuse case and later expand to include all injury deaths. The growing network continues to depend on peer support.

Many agencies are now involved in child death review. The Centers for Disease Control and Prevention sponsors state grants to connect and reconcile data from vital statistics, criminal justice, and social services. The National Association of Medical Examiners has issued death scene protocols. The American Academy of Pediatrics added suspicious child death to growing systems addressing child abuse. The US Department of Defense is beginning review teams for fatalities in military families. The Internet has added resources with Web pages for multiple teams and programs, and international systems exist for medical experts to share cases and Internet training.

WHY TEAMS ARE FORMING AND EXPANDING

Child death review teams form to investigate and prevent child deaths. However, certain factors influence the action of the teams. Child deaths, particularly preventable abusive deaths, create great pain for frontline professionals who have known the children. This pain motivates individuals who, in turn, motivate others. The team provides a forum in which to share that pain. Team intervention is more effective and tempers the sense of helplessness that accompanies the death of a child.

A second factor that affects review teams' effectiveness is technology, including the expansion of the Internet communication and information systems. Computer technology makes the multiagency team process more available to professionals and advocates at all levels. The team review functions as a tool for individuals and agencies trying to work together to be more effective and efficient with multiagency team management of child death. These skills and experiences are passed on to those involved in cases of live children, particularly the very young, and team members learn to work together.

Child death review has grown substantially from its roots in the work of frontline staff serving and suffering with children who die. This is a cultural movement similar to our recognition and fight against child sexual abuse, when we learned to face the obvious facts with technical superstructures and resources that helped us see more clearly. Knowledge of risk factors and possible action for intervention and prevention are important tools, but they are only tools. New interventions, including outcome-oriented data systems, parenting classes, scientific studies, and new criminal sanctions and therapies, may be useful, but the work is not so simple. It is impressive how much effort we make to study children, families, and risk factors and how little we study ourselves. The exception is the multiagency team peer group that makes this work more vigorous and keeps us a bit more accountable and focused on each case.

Bureaucratic, political, legal, and personal barriers to review will persist as this process crosses professional and political lines. Agencies and individuals will build unnecessary walls to protect personal territory. However, the desire to prevent children's deaths will generally overcome the walls. We will learn and relearn to work together and support the review process that existed centuries ago, has been recreated, and thrives because of and despite us. We are learning.

CONCLUSION

Since the first team formed almost 30 years ago, there has been an explosion of child death review teams. The next 30 years will see the formation of even more teams, increased integration between teams, more competent technology, and more appreciation of the need to work with others. Eventually, the spectrum of reviews will include nonfatal and/or severe abuse with reviews of cases of live children with injuries that require hospitalization. Grief support for survivors will improve, and data systems will expand to provide information for prevention programs. The process of an ancient tribe is joining with technology to teach us all.

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PREFACE

While people have always wondered how children die, it is only in the last 30 years that interdisciplinary teams have been created formally to understand deaths and to consider methods of prevention. Previous efforts to address individual causes of child death now are being supplemented by a more systematic approach.

In 1994, I was the guest editor of a special issue of the American Professional Society on the Abuse of Children's newsletter, the *Advisor*. It was titled "Special Issues on Child Fatalities" and had contributions from multiple authors, some of whom are included in this book. In 1995, the US Advisory Board on Child Abuse and Neglect issued an important work titled *A Nation's Shame: Fatal Child Abuse and Neglect in the United States*. Although focusing only on child abuse deaths, its incisive findings and recommendations for child death review are (sadly) just as relevant years later.

In the years that followed, Michael Durfee and I (and others) would periodically meet at conferences and bemoan that no one had ever picked up on these earlier efforts and put together a comprehensive book covering the entire spectrum of child death review. *Child Fatality Review: An Interdisciplinary Guide and Photographic Reference* is the result of this discontent and need from the field, and it is the very first book to systematically include common causes and manners of death, discuss how a child fatality review team functions in response to deaths, and address how deaths might be prevented. This is truly an interdisciplinary text reflecting the work of the numerous professionals needed to gain a more complete understanding of how children die.

In creating this book, certain goals were paramount: determine a comprehensive outline of the fields and issues involved in child deaths and death review, consider more strongly all causes of death beyond what some teams have as their focus, assemble top authors in their respective fields, and include an international perspective.

Any beginning to the problem of child deaths must include some description of how children die. As noted in the chapter titled "Epidemiology of Child Death," the statistics of this topic are not completely certain for a variety of reasons. However, efforts to prevent child deaths eventually need these numbers to assess the efficacy of prevention programs.

The next section of the book includes information about a variety of ways in which children die. The approach is to model child fatality review as looking at all causes of death, not just a narrow subset. There is a strong emphasis on perinatal deaths, sudden infant death syndrome, and child abuse not only because they are among the leading causes of child fatalities, but also because they are among the major topics of discussion for child death review teams. Other chapters address leading causes of death for older children, while still others address less common causes. Lightning is an uncommon cause of child death, but a chapter is included to illustrate what might be done to comprehensively identify a problem and how its understanding may aid in diagnosis and prevention. The photographic chapters depict many of the possible manners of death and allow team members who may have limited experience with actual deaths and autopsies to better understand the findings in such cases.

The third section was designed to look at the process of child death review, spanning how it is approached in multiple ways and using the experience of the world's leading experts in the child death field. International comparisons are important in not only confirming best practices, but also in suggesting new ways in which the problem of children dying may be considered. Native American child fatality review reveals that additional or different steps must be taken compared to the larger population, in which indigenous or culturally distinct groups may exist. The US military has a large number of children as its dependents and has distinctly different issues and approaches to investigating child deaths and determining interventions.

The next section looks further into the details of child death review—health, investigation, treatment, education, and prevention. These chapters provide an overview of the many facets of child death review befitting the challenging and sometimes daunting task that teams face when considering how all children die. As the different team members come together—many of whom otherwise might never have contact with each other in their daily jobs—the creative energy of different perspectives and skills allows the interdisciplinary team to transcend the expertise of any one of its members. This can only work to the benefit of children. Most importantly, prevention is the ultimate goal of all child death review teams and needs an increased emphasis during and after the process.

The final section includes a summary of existing recommendations for child death review teams. Despite the large number of different recommendations by teams around the world, they tend to fall within a limited number of categories. A key observation is that perhaps rather than inventing an increasing number of new recommendations, teams might concentrate on refinement and implementation of recommendations for major categories of child deaths. The final chapter is a look at how teams could review all child deaths, prospectively consider risks to children beyond what occurred in the previous year or two, and frame recommendations for child death prevention with some statement of expected efficacy and fiscal impact statements.

With a wide range of detail about child fatalities, this reference will help professionals working with children, and those involved in child death review in particular, to better understand and prevent the deaths of children.

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