

TECHNICAL REPORT

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Committee on Pediatric Emergency Medicine

Death of a Child in the Emergency Department

ABSTRACT. Of the estimated 40 000 American children ≤ 14 years old who die each year, approximately 20% die or are pronounced dead in outpatient sites, primarily the emergency department (ED). The ED is distinguishable from other sites at which children die, because the death is often sudden, unexpected, and without a previously established physician-patient care relationship. Despite these difficult circumstances and potentially limited professional experience with the death of a child, the emergency physician must be prepared to respond to the emotional, cultural, procedural, and legal issues that are an inevitable part of caring for ill and injured children who die. All of this must be accomplished while supporting a grieving family. There is also a responsibility to inform the child's pediatrician of the death, who in turn also must be prepared to counsel and support bereaved families. The American Academy of Pediatrics and American College of Emergency Physicians collaborated on the joint policy statement, "Death of a Child in the Emergency Department," agreeing on recommendations on the principles of care after the death of a child in the ED. This technical report provides the background information, consensus opinion, and evidence, where available, used to support the recommendations found in the policy statement. Important among these are the pediatrician's role as an advocate to advise in the formulation of ED policy and procedure that facilitate identification and management of medical examiners' cases, identification and reporting of child maltreatment, requests for postmortem examinations, and procurement of organ donations. *Pediatrics* 2005;115:1432-1437; death, child, postmortem examination, family-centered care.

ABBREVIATIONS. ED, emergency department; EMS, emergency medical services; EP, emergency physician; AAP, American Academy of Pediatrics; ACEP, American College of Emergency Physicians; IOM, Institute of Medicine; EMS-C, emergency medical services for children; CPR, cardiopulmonary resuscitation.

INTRODUCTION

Background Information

The death of a child under any circumstances is tragic and devastating. It changes the lives of all those involved who grieve for a life that has ended prematurely. In the immediate aftermath of death there is a great deal of confusion and disbelief.

The guidance in this report does not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

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Parents are left struggling with overwhelming emotions and searching for explanations for such a tragedy. Because it is so charged with emotion, this is a time when the skill of caring professionals in the emergency department (ED) can make a difference. This technical report provides support for professionals when they are faced with the difficult task of performing professionally and with compassion at the time of the death of a child.

Children who die and their families are a diverse group. No single policy, plan, or approach can address all the situations and circumstances of death. However, based on the fact that injury is the leading cause of death in children, it is inevitable that many deaths will involve emergency medical services (EMS) systems. An analysis of 1997 national mortality data showed that 16% of deaths in children < 19 years old occurred in outpatient hospital sites, primarily the ED, and another 5% were declared dead on arrival at a hospital.¹ The frequently sudden, unexpected nature of a child's death in the ED is an important confounding factor, because even the relatively brief nature of the family's interaction with health care providers can have a profound and enduring impact.

A child's death involves family members, including siblings, and health care providers. Members of the involved health care team potentially include out-of-hospital providers, day care or school personnel, nurses, social workers, child-life workers, mental health professionals, chaplains, and physicians. When a child's death occurs in the ED, it involves both the emergency physician (EP) who cared for the child at the end of his or her life, the pediatrician who has cared for the child before death, and possibly other subspecialty physicians.

Establishing policy in areas of common interest and shared care is one focus of collaborative efforts between the Committees on Pediatric Emergency Medicine of the American Academy of Pediatrics (AAP) and American College of Emergency Physicians (ACEP). Our committees believe that this collaboration between professional organizations to establish consensus policy promotes the highest-quality emergency care for children. This collaboration led to the jointly published "Death of a Child in the Emergency Department" policy.^{2,3} This is the technical report to support those policy recommendations.

Statement of the Problem

Forty thousand American children ≤ 14 years old died during the year 2000.⁴ Providing and organizing child- and family-centered care at the time of death is the subject of the Institute of Medicine (IOM) report *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families*.⁵ In this report, the IOM's Committee on Palliative and End-of-Life Care for Children and Their Families describes current practice and the numerous challenges to providing palliative and end-of-life care for children and families. Perhaps the foremost challenge is the inadequate amount of research on which to base policy. Faced with this recognized scarcity of data, this technical report relies on the available research, expert consensus opinion, and published experience to formulate recommendations.

Overall, the occurrence of a death of a child in the ED is an uncommon event. Thus, few physicians in emergency medicine or pediatrics have a great depth of experience on which to base their practice. Additionally, physicians lack training in palliative, end-of-life, and bereavement care.⁶ Only 26% of primary care residency-training programs report education in end-of-life care.⁷ Sixty-two percent of pediatric residency program directors who responded to a survey reported that their residents were involved in end-of-life situations, but only 42% indicated that their residents received direct education in palliative care.⁸ In a survey of EPs, only 14% recalled having training in notifying parents of a child's death.⁹

Although the IOM has noted that, in general, research on palliative and end-of-life care for all children who die and their surviving families is very limited, there are even less data specific to the death of a child who has received EMS care. With only a modest amount of published EMS for children (EMS-C) research to direct practice, EDs must rely on principles of palliative care and other information such as consensus reports and clinical guidelines in the areas of mental health needs and bereavement practices for guidance.¹⁰⁻¹³

Clearly there are similarities between the needs of children and families in palliative care and those

who die in the ED. Most applicable among these similarities are appropriate attention to pain relief; facility design; timely provision of information that is accurate, consistent, and expressed in language that families can understand; provision of immediate and long-term bereavement support; identification of community-based resources; and family involvement in decision-making. Other epidemiologic and medical considerations create unique needs specific to EMS-C for end-of-life care, which are described in "End-of-Life Care in Emergency Medical Services for Children," Appendix F of *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families*¹⁴ and include the number and diversity of personnel involved, unique parental needs when a child dies suddenly and unexpectedly, and medical care issues in the context of sudden death. The areas of EMS-C end-of-life care in need of research investigation and evaluation are summarized in Table 1.

NEW INFORMATION

Education and Training

Education of health care professionals to provide palliative, end-of-life, and bereavement care to children and families is one of the major recommendations from *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families*. This education should include scientific and clinical knowledge and skills, interpersonal skills and attitudes, ethical professional principles, and organizational knowledge skills. A physician who is a skilled communicator with parents and able to convey empathy and compassion can minimize any misunderstandings that might arise during these difficult situations. Education should also consider the bereavement care of siblings and other child acquaintances.¹⁵ These learning objectives are summarized in Table 2.

The understanding that the death of a child is an important, underaddressed issue in EMS-C has initiated efforts to fill gaps in education and training for emergency health care providers through established courses. The AAP Pediatric Education for Prehospital Professionals course contains a child and family

TABLE 1. Research Directions for End-of-Life Care in EMS-C

Issue	Research Questions
Bereavement	What is the association of acute, sudden, or unexpected loss with the development of posttraumatic stress disorder? What is the impact on the bereavement process of parental presence during the attempted resuscitation of a dying child?
Critical incident stress management	How does critical incident stress management affect emergency care providers in the short and long term? What are the important outcomes to evaluate?
Clinical research on resuscitation	What are the predictors of mortality during resuscitation in the prehospital and ED arenas? Is it beneficial to exercise extraordinary intervention in the resuscitation of children who have experienced prolonged hypoxic-ischemic injury?

Adapted from Wright JL, Johns CMS, Joseph JG. Appendix F: end-of-life care in emergency medical services for children. In: Field MJ, Behrman RE, eds. *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families*. Washington, DC: National Academy Press; 2003:332-333. Available at: <http://books.nap.edu/books/0309084377/html/580.html>.

TABLE 2. Educational Needs of Health Professionals to Provide Palliative, End-of-Life, and Bereavement Care to Children and Families

Learning Domain	Learning Objective
Cognitive knowledge and skills	<ul style="list-style-type: none"> Learning biological mechanisms of end-stage conditions Understanding the pathophysiology of pain and other physical and emotional symptoms Developing appropriate expertise and skill in the pharmacology of symptom management Acquiring appropriate knowledge and skill in nonpharmacological symptom management Understanding the tools for assessing patient symptoms, quality, and prognosis Recognizing when consultation with palliative care specialists is appropriate Understanding the epidemiology of death in childhood Learning clinical indications for and limits of life-sustaining treatments
Interpersonal skills and attitudes	<ul style="list-style-type: none"> Listening to child patient and families Conveying difficult news to children and their families Understanding and managing child and family responses to life-threatening illness Sharing goal setting and decision-making with the care team Developing skills in avoiding and resolving conflicts Cultivating empathy, compassion, humility, and altruism Developing sensitivity to religious and cultural differences Recognizing and understanding one's own feelings and anxieties about the death of a child
Ethical and professional principles	<ul style="list-style-type: none"> Acting as a role model of clinical proficiency, integrity, and compassion Determining and respecting child and family preferences Learning principles of end-of-life care Understanding societal and population interests and resources Balancing competing objectives or principles Being alert to personal and organizational conflicts of interests
Organization knowledge and skills	<ul style="list-style-type: none"> Developing and sustaining effective teamwork Identifying and mobilizing supportive resources Understanding and managing relevant rules and procedures Protecting children and their families from harmful rules and procedures Assessing and managing care options, settings, and transitions Making effective use of existing financial resources

Adapted from Institute of Medicine, Committee on Palliative and End-of-Life Care for Children and Their Families. Educating health care professionals. In: Field MJ, Behrman RE, eds. *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families*. Washington, DC: National Academy Press; 2003:332–333.

interaction module that addresses sudden infant death syndrome, family responses to the death of a child, and community resources for support.¹⁶ The current AAP/American Heart Association Pediatric Advanced Life Support course contains an optional module on coping with death and dying that discusses the priorities for family support.¹⁷ *APLS: The Pediatric Emergency Medicine Resource*¹⁸ has sections on family presence during procedures and resuscitation attempts including CPR, termination of CPR, and the approach to the deceased child and family.

Family-Centered Care

Family-centered care is an approach to health care that shapes health care policies, programs, facility design, and day-to-day interactions among patients, families, physicians, and other health care professionals. The AAP outlined the core principles of family-centered care in the policy statement “Family-Centered Care and the Pediatrician’s Role.”¹⁹ This statement recommends that parents and guardians should be offered the option to be present with their child during medical procedures and offered support before, during, and after the procedure. The statement does not make recommendations regarding family presence during situations of resuscitation or CPR. Both the Emergency Nurses Association and the American Heart Association recommend that health care providers should offer family members the opportunity to be present during CPR whenever possible.^{20,21} The *APLS: The Pediatric Emergency Medicine Resource*,¹⁸ developed jointly by the AAP and

ACEP, notes that the family’s presence during CPR can help in the acceptance of the child’s death.

Additional evidence shows that most family members favor having the choice to be present during resuscitation attempts and that they tend to feel that being present was helpful.^{22–27} Results from psychological examinations suggest that family members present during resuscitation attempts have more positive grieving behavior than family members not present during resuscitation attempts.²⁸ Despite these facts, parents and family members often do not ask if they can be present.

The presence of family members during resuscitation attempts prompts consideration of many additional issues including medicolegal issues. For this reason the Emergency Nurses Association has recommended that multidisciplinary consensus guidelines be developed to help organizations and institutions formulate policy regarding family presence during procedures and CPR. If multidisciplinary consensus can be achieved, these guidelines will be helpful in defining when and how to offer the option of family presence and thus in establishing ED policy.

There is a need for additional research regarding the effects of family presence. The IOM Committee on Palliative and End-of-Life Care for Children and Their Families cautions that most studies on family presence during resuscitation attempts are small, often retrospective, and limited in scope. Because this is such a critical experience for parents and care providers, they recommend that additional system-

atic research on the bereavement outcomes and other consequences of family-presence policies be conducted.

Team-Oriented Approach

The care team can include out-of-hospital providers such as emergency medical technicians and paramedics, social workers, child-life workers, mental health professionals, chaplains (including the families religious or spiritual leader), nurses, and physicians; each team member must understand his or her role. It is essential that team members work together to ensure that the occurrence of a death of a child is managed smoothly and with sensitivity.

Sensitive care includes awareness and respect for varied beliefs and cultural backgrounds. In a country as diverse as the United States, there can be profound differences between families and health care providers in beliefs and practices concerning the end of life. Additionally, open communication may be hampered by language barriers. Because cultural issues are most acute if language barriers are present, it is important that EDs and hospitals have rapid, efficient access to translators. In all cases, the health care team must remain sensitive to issues such as family methods for decision-making, the care of the body after death, and culturally appropriate expressions of grief. This is a daunting task. Appendix D of *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families*, titled "Cultural Dimensions of Care at Life's End for Children and Their Families,"²⁹ is a complete discussion of the relevance of cultural difference at the end of life.

Effective counseling, especially at the time of death, has a dramatic, positive impact on the family's grieving process, ultimate recovery, and ability to cope.³⁰⁻³² When possible, it is helpful to let the family know that the child was not in pain or did not suffer. One team member should be assigned to be with the family continuously during the resuscitation attempt. The purpose of this individual is to answer questions, explain procedures, and/or prepare the family and bring them to the resuscitation area.³³

The EP has the responsibility of notifying the family of the child's death. The EP also has the responsibility of speaking with the family regarding the circumstances of death and notifying the family if there are concerns of child maltreatment that must be reported and investigated.

Care for the child does not stop with death. Family members should be encouraged to be with their child after death. Many authors have emphasized that being with the child after death is an integral part of bereavement.^{34,35} Some families may wish to bathe the child themselves. Many will want to hold and rock their child. Providing the space to do this can be a challenge for creative administrators. However, the benefits to the families in these devastating situations are tremendously positive and enduring. The exact nature of aftercare will be determined and sometimes limited by the circumstances of the child's death, cultural practices, religious beliefs, and practical issues of facilities within the ED. Legal and medical examiner requirements may limit what is

done in terms of removing resuscitation tubes and lines. The ED team can be sensitive and supportive by cleaning the resuscitation area and the body, covering disfiguring injuries and wounds as much as possible with clean sheets, and carefully explaining the purpose of remaining tubes or lines.

Kits with plastic molds for an imprint or three dimensional mold of the child's hands and/or feet and Ziploc bags to store a lock of the child's hair can be stored in the ED. Parents surveyed after their child's death have found these small mementos helpful in easing the bereavement after the tragic event.³⁶

In addition, a chaplain, social worker, child-life therapist, and/or psychologist should be made available to the family. Families will have immediate and long-term mental health needs. Attention must be paid to the siblings (who are often overlooked in such overwhelming situations), grandparents, and classmates. The pediatrician has a role in monitoring the siblings for signs of emotional and somatic complaints that could be secondary to the death. Also, primary care physicians should take the lead in directly asking families how they are doing. At the very least, a condolence card should be signed by the direct care providers and sent to the family home, along with a list of community resources for grief and loss.

NOTIFYING THE PEDIATRICIAN AND SUBSPECIALISTS OF THE CHILD'S DEATH

The process of bereavement begins in the ED and continues over time. Many children who die have had an established medical home, and others have had complex medical problems for which they may have received care and established relationships with several providers. These pediatricians and/or subspecialists should be notified at the time of such a child's death. They can be a vital source of counsel and support for the bereaved family.

ASSISTING ED STAFF, OUT-OF-HOSPITAL PROVIDERS, AND OTHERS WHO ARE EXPERIENCING CRITICAL INCIDENT STRESS

The professionals who care for children who die after receiving care in the EMS system are also at risk for emotional distress including posttraumatic stress disorder. Access to appropriate mental health services should be available to provide immediate counseling for members of the ED health care team.

POSTMORTEM EXAMINATIONS AND TISSUE AND ORGAN DONATION

In most jurisdictions, the sudden and unexpected death of a child occurring in the field or ED is considered a medical examiner's case requiring an autopsy. These legal requirements must be explained to the family.

It is important to explain to families that the extent of an autopsy is often limited to the relevant injury and that there will be no additional disfigurement that would interfere with an open-casket ceremony. Additionally, if it is desired, the medical examiner will often honor requests to restore all organs to the original location.

The AAP Committee on Child Abuse and Neglect has published several policy statements to aid professionals by providing information and guidelines that are helpful in situations in which sudden infant death syndrome and other unexpected infant and child deaths must be distinguished from child abuse. These policies and statements include "Investigation and Review of Unexpected Infant and Children Deaths,"³⁷ "Distinguishing Sudden Infant Death Syndrome From Child Abuse Fatalities,"³⁸ and "Addendum: Distinguishing Sudden Infant Death Syndrome from Child Abuse Fatalities."³⁹ These difficult situations require the collaboration of health professionals to ensure the appropriate utilization of available medical specialists and the preservation of evidence and the performance of additional studies such as an appropriately performed skeletal survey or toxicologic screens. Many child-fatality-review teams have established guidelines for evidence preservation and suggestions for documentation for cases of sudden pediatric death.

Cases that are not referred to the medical examiner should also be considered for autopsy. A forthcoming report from the American College of Medical Genetics on newborn screening notes that we may gain a better understanding of the incidence and spectrum of diseases associated with perinatal and early childhood mortality by implementing uniform child autopsy policies and procedures which ensure availability of appropriate studies (including metabolic and genetic studies for all perinatal deaths, including stillbirths) and early unexpected childhood deaths. Currently, autopsy can provide additional information in more than one third of pediatric deaths,⁴⁰ including previously undiagnosed findings, complications, and unsuspected contributors to death.⁴¹⁻⁴³ This information may be of importance to parents and other relatives in future family planning and to physicians in helping to educate and improve the quality of care in medicine. Providing this information can help parents to make an informed decision when they are asked about permission for post-mortem examination. This must be implemented with sensitivity and respect for the family beliefs and values.

Hospitals are required by federal and state laws to have a mechanism for requesting organ donation from the appropriate family members or surrogates.

SUMMARY/CONCLUSIONS

Of the estimated 40 000 American children who die each year, approximately 20% die or are pronounced dead in outpatient sites, primarily the ED. The processes and protocols surrounding the death of a child in the ED are underaddressed and understudied issues related to end-of-life care. Because death in the ED is usually sudden and unexpected, the traditional patient-physician relationship has not been established, the family has not been counseled and advised, and the EP is expected to provide an environment for grieving parents that addresses their emotional, spiritual, and cultural needs while also providing support in responding to legal and procedural demands.

It is unfortunate that, currently, there are few evidence-based data to guide policy in responding to the unique needs of parents and families when a child's death occurs. The recommendations set forth by the AAP, ACEP, and the IOM are vital in solving this problem. Improving the education of physicians in end-of-life care is extremely important. Meeting objectives such as improving and developing clinical knowledge and skills, interpersonal skills and attitudes, ethical principles, and organizational skills can and will help EPs and other team members provide exemplary palliative, end-of-life, and bereavement care to children and families. In addition, creating a family-centered environment in the ED that involves them in the care process can have a positive bereavement effect.

For many families, the process of bereavement after the loss of a child begins in the ED. When a sensitive and understanding environment is provided, the family will truly be in the presence of a system of "care."

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