



TECHNICAL REPORT

Death of a Child in the Emergency Department

Patricia O'Malley, MD, Isabel Barata, MD, Sally Snow, RN, AMERICAN ACADEMY OF PEDIATRICS Committee on Pediatric Emergency Medicine, AMERICAN COLLEGE OF EMERGENCY PHYSICIANS Pediatric Emergency Medicine Committee, and EMERGENCY NURSES ASSOCIATION Pediatric Committee

KEY WORDS

death of a child, emergency department

ABBREVIATIONS

AAP—American Academy of Pediatrics
ACEP—American College of Emergency Physicians
ED—emergency department
EMS—emergency medical services
ENA—Emergency Nurses Association
CFRT—child fatality review team
CPR—cardiopulmonary resuscitation
OPO—organ procurement organization
NRP—Neonatal Resuscitation Program

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abstract

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The death of a child in the emergency department (ED) is one of the most challenging problems facing ED clinicians. This revised technical report and accompanying policy statement reaffirm principles of patient- and family-centered care. Recent literature is examined regarding family presence, termination of resuscitation, bereavement responsibilities of ED clinicians, support of child fatality review efforts, and other issues inherent in caring for the patient, family, and staff when a child dies in the ED. Appendices are provided that offer an approach to bereavement activities in the ED, carrying out forensic responsibilities while providing compassionate care, communicating the news of the death of a child in the acute setting, providing a closing ritual at the time of terminating resuscitation efforts, and managing the child with a terminal condition who presents near death in the ED. *Pediatrics* 2014;134:e313–e330

INTRODUCTION

When emergency clinicians are faced with an imminent child death in the emergency department (ED), they must carry out many complex tasks. They must treat a patient experiencing an acute and evolving medical situation, establish a compassionate relationship with family they have likely never met before, and support and work in team fashion with their colleagues as they acknowledge the human limitations to remedy a medical crisis. Many of the clinical, operational, legal, ethical, and spiritual layers to this complex care are discussed in this report and are listed in Table 1. The infrequency of these events and the magnitude of the tragedy combine to make the death of a child in the ED one of the most challenging problems facing emergency health care providers.

Despite the relative infrequency of these events, there is considerable diversity in the clinical presentation of the death of a child in the ED. In this technical report, child death in the ED is considered broadly, encompassing acute unanticipated trauma or illness, stillbirth or extreme preterm birth at the margin of viability, the child declared dead on arrival, the child who dies shortly after passing through the ED, and even the child with a known life span-limiting condition for whom the ED becomes the location of end-of-life care.

This technical report builds on the original technical report published in *Pediatrics* in 2005¹ in support of the 2002 joint statement of the American Academy of Pediatrics (AAP) and American College of Emergency Physicians (ACEP)² and a companion article published in *Annals of*

TABLE 1 Essential Components of Care in the ED When a Child Dies

Clinical	
Resuscitation best practice	
Termination of resuscitation	Identifying, validating, and respecting advanced care directives
Operational	
Staff training in communication	
Team response (including readily available support staff such as security, child life, chaplaincy, social work)	
Family presence policy	
Dealing with media ^a	
Communication with medical home	
Defusing/debriefing for team	Private location for family to be with deceased, means and location to conduct rituals
Legal and forensic	
Organ donation	
Autopsy	
Working with police and coroner/medical examiner	
Child protective services	
Child fatality review team	
Documentation in medical record	
Preservation of evidence	
Ethical	
Resuscitation: how long is too long?	
Prolongation of resuscitation efforts for family presence/organ donation	
Practice on newly deceased	
Initiation of resuscitation at the border of viability in extreme preterm birth	
Spiritual and emotional	
Needs of family, including saying goodbye, memory making	
Needs of multidisciplinary team	
Envisioning a “good death” in the ED	
Follow-up care for family	
Helping family to know everything was done	
Assisting family in explaining to siblings, family, friends	
Assisting family in locating community support to address grief and bereavement	
Plan for postautopsy meeting to answer questions	
Plan for scheduled follow-ups and marking of meaningful dates	
Follow-up care for team	
Scheduled voluntary defusing/debriefing with all members of the emergency care team who wish to participate	

^a Not covered in this report.

Emergency Medicine in 2003.³ These earlier publications called for a patient- and family-centered and team-oriented approach to the provision of compassionate care while respecting social, spiritual, and cultural diversity. They outlined responsibilities of the ED staff

involved in the care of the child, including the responsibility to facilitate organ procurement and obtain consent for postmortem examinations; to facilitate the identification of medical examiner cases and the reporting of potential maltreatment cases; to assist team members, including emergency medical services (EMS) personnel, with managing critical incident stress; to notify the primary care provider and other clinicians/specialists; and to delineate the responsibility of follow-up of autopsy reports or other medical information. This revised report, as well as the accompanying revised policy statement of the same title,⁴ reaffirms those principles and examines recent literature regarding family presence during attempted resuscitation, recommendations regarding termination of resuscitation efforts, organ donation, benefit of autopsy, practicing procedures on the newly deceased, benefit of continued contact with surviving family members, and working to support state, local, and national child fatality review teams. New observations regarding the need for and the most effective ways to provide communication training, reflections on the effect of patient death on providers, and definitions of a “good death” are also reviewed. Additional existing resources from the emergency care literature are identified. Observations from venues outside the ED but with potential application to the ED setting are considered. Finally, a re-consideration of what can be called success in pediatric resuscitation is offered.

BACKGROUND

Data from the National Center for Health Statistics for the most recent year completed (2009) revealed that there were 73 million children younger than 18 years residing in the United States.⁵ Although the portion of the population younger than 18 years is

roughly 30% of the total population, fewer than 2% (48 000) of deaths occur in this age range. This statistic is strikingly different from a century ago, when 30% of all deaths were in children younger than 5 years. These data reflect progress in child health but also underscore that child death, unlike parental or spousal death, is no longer an expected part of life. In industrialized nations, child death stands out as a singular tragedy and an increasingly uncommon event in the professional lives of clinicians, even those whose practice is exclusively pediatric.

Beginning in 2006, the Health Care Cost and Utilization Project has provided a national database of ED visits with the Nationwide Emergency Department Sample.⁶ Fewer than 3% of all ED patient visits were children younger than 1 year; deaths in that age group accounted for 1.9% of all ED deaths. Patients 1 to 17 years of age accounted for 18% of all ED visits and another 2% of ED deaths. In total, the percentage of ED deaths among patients younger than 18 years is less than 4%, occurring less than 1 per 15 000 ED visits. Because of the relative infrequency of child death in the ED setting, few emergency clinicians have extensive experience with child death.

Beyond the relative infrequency of this event, there are other formidable challenges in managing pediatric deaths, including the following:

- deciding when to terminate resuscitative efforts;
- deciding when not to initiate resuscitative efforts;
- managing painful or distressing symptoms in pediatric patients;
- ascertaining family wishes or identifying existing advance directives;
- managing family presence in the setting of attempted pediatric resuscitation;

- communicating with and caring for the family;
- asking families in crisis about potential organ donation or autopsy (when, how, who asks);
- effectively discharging forensic responsibilities in a child death, especially when it may be the result of intentional injury or neglect, while attempting to respond to the family's loss with compassion;
- withdrawing or withholding no longer beneficial medical interventions for children with chronic life span-limiting conditions;
- balancing respect for the newly deceased and bereaved with the opportunity for needed practical experience for practitioners and trainees to enhance skills to prevent potentially avoidable deaths in the future;
- resuming work after the emotionally difficult episode, needing to “pick up and move on to the next case”; and
- addressing the personal and clinical team emotions of anger, sadness, inadequacy, or blame that often result after caring for a child who dies in the ED.

The health care team's perceived obligation to maintain a calm and proficient demeanor can be at odds with the empathetic behaviors that are valued as most helpful to families facing the loss of their child. Because ED providers are so often exposed to critical events, they may have evolved a protective mechanism that normalizes the abnormal events they see every day, what Truog et al⁷ have called the “routinization of disaster.” And yet what parents, caregivers, and family members who are enmeshed in this uniquely catastrophic experience report as important and beneficial to them is the kindness, empathy, and genuine caring of their child's care

providers. Given that they can anticipate that death will be the most common outcome of cardiac arrest in a child,⁸ ED providers must add care of bereaved family members to their list of skills and responsibilities.

Lack of training in critical health care communication, particularly in the compassionate delivery of difficult news, is pervasive even today throughout the spectrum of health care education, including nursing education, medical school, and residency.⁹ A large national survey published in 2003 indicates that role models and faculty at the medical school level are not equipped to teach these skills.¹⁰ Nurses may also be ineffective in communication.¹¹ In a 2008 AAP statement reviewing communication skills,¹² it was noted that “health care communication is currently learned primarily through trial and error.” There is increasing evidence that communication skills can and should be taught and learned,¹³ and there are a number of strategies specific to the practice of emergency care.¹⁴ Communication skills are now recognized as a required core competency in nursing, medical student, and resident training accreditation criteria.¹² Emergency clinicians should support explicit training and skill building in communicating the difficult news that they may be called to deliver when a child dies in the ED.^{15,16} Results of parent surveys confirm that the delivery of the news of their child's death is extremely important to the long-term well-being of family members. Skill and compassion in conveying bad news may be the most powerful therapeutic tool clinicians can offer affected families.¹⁷ An approach to notifying parents of the death of their child in the ED is provided in Appendix 1. As with other uncommon but critical events, simulations of management of the death of a child can be conducted by ED staff to prepare them for this rare event.

FAMILY PRESENCE

Family presence in the ED has been defined as “the presence of family in the patient care area, in a location that affords visual or physical contact with the patient during invasive procedures or resuscitation events.”¹⁸ Initial resistance to allowing family presence during attempted resuscitation was based on fears of litigation and concerns that the emotional burden for family members of watching resuscitation would create situations that would distract ED personnel, potentially interfere with effective resuscitation efforts, and only add to a family's burden of grief. These fears have been systematically studied and for the most part clarified or eliminated.^{19–21} Mangurten et al²² reported that 95% of the families they surveyed would again wish to be present and felt that it had been helpful to them, and no disruption of care was documented. In a similar study examining pediatric trauma resuscitation efforts, there also was no difference in time to milestones of care in trauma patients with or without family members present.²³ Studies and position statements reflect the increasing ability of emergency clinicians to effectively support family presence during attempted resuscitation in the setting of effective staff preparation, appropriate policy development and implementation, and, when staffing allows, providing designated personnel to attend to family members.

Family presence has received widespread endorsement. Supportive articles have appeared in the ethics literature, the resuscitation literature, and the general and pediatric emergency medicine and nursing literature.^{18–27} The Emergency Nurses Association (ENA), AAP, and ACEP have position statements on family presence.^{24–26} The revised jointly issued policy statement from the AAP, ACEP, and ENA recommends that all EDs

caring for children have a written policy regarding family presence.⁴

As a further indication of the acceptance of family presence during resuscitation attempts, the debate has turned from a goal of family presence during resuscitation to the goal of family presence at time of death pronouncement.²⁷ Strict adherence to this goal may result in the prolongation of otherwise futile resuscitative efforts. An alternative to prolonging an otherwise futile resuscitation attempt when family have not yet arrived may be to designate a family surrogate, a staff member whose job is simply to be with the child. When family members do arrive after their child has died, they should be assured that their child was not alone at the time of death.

NONINITIATION AND TERMINATION OF RESUSCITATION ATTEMPTS

Deciding when to terminate resuscitation efforts or not to initiate them at all ranks among the most difficult tasks facing the emergency health care team caring for a critically ill or injured infant or child.^{28–30} Although these actions are frequently described as ethically indistinguishable, they may feel quite different in the moment of decision. Further complicating these decisions is a lack of objective data on which to base guidelines, a desire to allow for family presence, the hope to increase potential for organ donation, and provider distress with the tragedy of the death of a child, any of which may contribute to initiation of or persistence in likely futile resuscitation efforts. Differences between general and pediatric emergency physicians in time until termination of resuscitation efforts on a child were first described by Scribano et al,³¹ noting that pediatric-trained ED physicians reported being twice as likely to terminate efforts if there was no return of spontaneous circulation after 25 minutes. The authors speculated

that some of the observed differences between general and pediatric emergency physicians were more related to provider distress than to a lack of familiarity with guidelines.

Although improved clinical outcomes have been reported since instituting new Pediatric Advanced Life Support/American Heart Association guidelines for defibrillation and for chest compressions, a 2008 review of advances in pediatric resuscitation states that there is not sufficient evidence to base a recommendation for duration of resuscitation efforts in all situations.⁹ In particular, findings of better-than-anticipated survival from prolonged cardiopulmonary resuscitation (CPR) followed by extracorporeal membrane oxygenation initiated for children who experienced cardiac arrest in the PICU cannot easily be extrapolated to the ED setting.³² Criteria for termination of resuscitation are not discussed in the 2009 review article by Topjian et al,³³ and at this time there are no universal criteria for termination of resuscitation efforts in children. The 2010 Pediatric Advanced Life Support guidelines point out that clinical variables associated with survival include length of CPR, number of doses of epinephrine, age, witnessed versus unwitnessed cardiac arrest, and the first and subsequent rhythm. None of these associations, however, predict outcome. Witnessed collapse, bystander CPR, and a short interval from collapse to arrival of professionals improve the chances of a successful resuscitation.³⁴

Likewise, in the out-of-hospital setting, there are no nationally accepted guidelines for noninitiation of resuscitation or termination of resuscitation that apply to children. The National Association of EMS Physicians has criteria for adults who experience traumatic or nontraumatic cardiac arrest, but these guidelines explicitly were not applied to children. Even with adults, however, the decision to

make an on-scene pronouncement versus transport in settings of probable futility may be driven more by perceived family needs and provider comfort.³⁵ The little evidence that exists, however, speaks to the family benefit of stopping resuscitation; at least 2 studies in adult patients indicate that families may in fact adjust better after pronouncement on scene than with transport to a hospital.^{36,37} No such data exist for children in the United States, but a Swedish study in adolescents with sudden cardiac death is supportive of pronouncement on scene as an option on the basis of parental report.³⁸ However, Hall et al³⁹ noted that paramedics are far more uncomfortable with termination of efforts in the field for a child than for an adult. Therefore, a child or infant may be transported to the hospital even though the resuscitative efforts may be futile, in order to provide a setting with better resources for support of the family and providers.

The situation of unanticipated birth of an extremely preterm infant at the limit of viability presents yet another example of the dilemmas regarding initiation and termination of resuscitation efforts, made more complex by evolving criteria and conflicting opinions about outcomes for increasingly immature live-born fetuses.^{40,41} Although factors such as gender, antenatal steroids, and single or multiple birth all affect outcome, the factors most commonly used to assess viability and to predict outcome are birth weight and estimated gestational age; however, these “simple” data points may, in fact, be difficult to determine with any accuracy in the ED setting. When such information is available, many institutional practices reflect the policy described in Tyson et al,⁴² who suggested that infants born at 22 weeks’ gestation and less not be subjected to resuscitation efforts, that infants born at 24 weeks’ gestation or more should

all receive attempted resuscitation, and infants born at a gestational age between these ages should undergo attempted resuscitation only with parental agreement. The recommendation of parental agreement is consistent with the 2010 AAP/American Heart Association Guidelines for Cardiopulmonary Resuscitation and Emergency Cardiovascular Care for neonatal resuscitation,³⁴ which serves as the basis for the *Neonatal Resuscitation (NRP) Textbook, Sixth Edition*,⁴⁵ and which cautions interpretation within local policy but advises noninitiation of resuscitative efforts for infants born at a gestational age of less than 23 weeks, who are born weighing less than 400 g, or who have visible lethal anomalies, such as trisomy 13 or anencephaly. The Neonatal Resuscitation Program (NRP) guidelines further suggest that efforts be terminated if, after 10 minutes of effective resuscitative efforts, the infant has no spontaneous heartbeat.

In the absence of precise determination of gestational age and weight, the guidelines developed for antenatal counseling by Batton et al⁴⁴ may prove useful in the ED: namely, that if the clinical team believes that there is no chance of survival, resuscitation is not indicated and should not be initiated; if the team believes that a good outcome is very unlikely, then parents should be engaged in the decision-making process and their preferences should be respected; and if the team's assessment is that a good outcome is reasonably likely, resuscitation should be initiated and its benefit should be continually reassessed, in consultation with the parents. Alternatively, if neonatal specialists are readily available to the ED, resuscitation can be attempted until they can participate in the decision to continue. Comfort care should be provided for all infants, regardless of the goals of care; improved neurologic and physiologic outcomes from comfort

care are clear. Comfort care is of particular importance as well for infants for whom resuscitation is not initiated or is not successful as well as for their families; care provided at the end of life is remembered by the bereaved for the rest of their lives. Nursing care of the dying infant includes comfort care for the family. Nursing guidelines from other venues, such as the NICU, can provide tools for ensuring that families have the opportunity to create memories that will not only help them with their immediate pain but also comfort them for a lifetime.⁴⁵ These recommendations are in accord with the most recent NRP guidelines.⁴⁶ In any given ED, policy regarding initiation and termination of resuscitation attempts on the extremely preterm newborn infant should be developed in conjunction with perinatal subspecialists who are most knowledgeable about resources and outcomes in that region and in accordance with NRP recommendations.

REQUESTING ORGAN DONATION

Broaching the subject of organ donation after the death of a child in the ED can be an intimidating task. However, recent studies have indicated that families are more often appreciative than offended or overwhelmed by such requests when they are approached with sensitivity by skilled staff and with attention to the optimal timing.⁴⁷ US federal regulations require that the regional organ procurement organization (OPO) be contacted for all deaths and impending deaths so that their representatives can become involved in a timely manner.⁴⁸

The patient who dies in the ED often is not a candidate for solid organ donation but may still be a candidate for donation of tissue, including corneas, heart valves, skin, bone ligaments, and tendons. There is little published literature regarding tissue donation

requests when a cardiac death occurs.⁴⁹ Therefore, best practices for request of tissue donation have been extrapolated from the organ consent literature. Likewise, there is little information about best practices specific to donation of tissue or organs from a deceased child.^{50,51} Availability of suitable donors continues to be the major limiting factor for growth in organ transplantation, especially in pediatric recipients, because the size of the organs is a critical aspect of the match process. Although studies have shown that family members' decisions about organ donation are influenced by many factors, including whether the deceased's donation intentions are known, parents/caregivers of young children usually must make a donation decision without any direct knowledge about their child's wishes. Donation can be perceived by families and providers alike as a way to salvage some meaning from an acute, unanticipated, and tragic loss, although there is literature that calls that perception into question.^{52,53} Timely referral and the use of trained personnel in organ procurement is critical to ensure that a rushed approach regarding organ donation is avoided with the family. Although the process of organ procurement may start in the ED with the admission of a critically injured child, at present best practice suggests that conversations regarding solid organ donation not be initiated in the ED if a patient is going to be admitted to the hospital and that consent for donation is much more common when an OPO representative is able to assist the care team in presenting this option to the family. Consulting OPO staff while the child is in the ED may provide guidance for the best timing. When a child dies in the ED, any exploration of family wishes regarding tissue donation should follow at some time removed from the news of the child's death but optimally by an OPO staff member who has become familiar to the family during their brief

stay. Ideally, supportive staff, such as a social worker, chaplain, and/or child life specialist, should be present during any request.⁵⁴

AUTOPSY

Autopsy requirements and standards vary by state. Emergency care providers should be aware of the laws that govern postmortem practice in their state and provide information to the family accordingly. The medical examiner or coroner should be notified, because the majority of ED deaths in most states will be under his or her jurisdiction. Hospitals may establish policies and procedures in collaboration with the medical examiner's or coroner's office for handling bodies after death in the ED. In the event that the medical examiner or coroner declines autopsy, the ED physician may recommend autopsy and consult the hospital pathologist. Autopsy is generally valued for its ability to provide additional diagnostic and epidemiologic data; however, Feinstein et al⁵⁵ argued for a family-centered analysis of benefits derived from autopsy. They noted that autopsies also yield information that may inform parents' or siblings' subsequent reproductive or other health choices or other information pertinent about the deceased child, may assist with quality assurance and improvement, and may provide general knowledge that benefits both families and the clinical care teams. Framed in this fashion, parents may be grateful for the request. Emergency clinicians who understand these additional potential benefits of autopsy for families may be more comfortable in discussing it with them.

Medical Documentation and Notification of the Child's Medical Team

It is the responsibility of the emergency health care team to ensure prompt notification of the primary care pro-

vider, child's medical home, and other appropriate members of the child's medical team, including out-of-hospital providers, in the event of a child's impending death or death in the ED. Families expect that their primary care provider will be aware of their child's death, and the task of notifying the medical home and others of a child's team should not fall to the family. Their loss may be further compounded if they do not hear from their child's providers or there is no outreach or acknowledgment from those who have cared for the child over time. If the child's medical team is not aware, for instance, routine reminders for well-child visits or immunizations might continue. If the child had subspecialty providers, the same guidelines may hold true; and in some conditions and cases, the connection between subspecialist and family may be stronger than that between family and medical home.

In addition, such communication is beneficial for the ED team, to provide helpful background information and to know that bereaved families will be followed by caregivers who have known them before the child's death. The medical home may supply the ideal staff to provide a presence at memorial services, sibling support, and follow-up review of any autopsy findings. Routine follow-up meetings happen infrequently for families of children who die in the ICU setting,⁵⁶ and the frequency of routine follow-up meetings with ED staff is unknown. Autopsy review has benefits not only for the family but also for medical personnel as well, and further information is needed about the impact for families and health care team members on providing this practice.

The development of a policy and procedure for handling of the body may include the following:

- a death packet and checklist to ensure that all appropriate notifications are accomplished;
- documentation of release of valuables;
- documentation of release of the body;
- notification of a funeral home;
- completion of the death certificate in accordance with state law, as applicable; and
- notification of the child's primary care provider.

SUPPORTING THE WORK OF CHILD FATALITY REVIEW TEAMS

Death review is a potent tool for understanding and preventing avoidable deaths. Although child fatality review teams (CFRTs) were first established to review suspicious child deaths involving abuse or neglect, CFRTs have expanded toward a public health model of prevention of child fatality through systematic review of child deaths from birth through adolescence. Child fatality review is supported at the federal level by the National Center for Child Death Review, funded by the Maternal and Child Health Bureau since 2002; by 2005, all but 1 state reported providing state or local review of child deaths. In 2009, 27 states were contributing to the national database maintained by the National Center for Child Death Review.⁵⁷

Child fatality review operates on the principles that a child's death is a sentinel event, the review of which can lead to an understanding of risk factors when based on a multidisciplinary and comprehensive review. Emergency clinicians can support this mission at several levels: by notification of their local or state team when a child death occurs; by advocating for access to ED records regarding the case when legislation, regulations,

and policies allow the confidential exchange of information; and by active participation of ED staff on a particular review or as standing members of the review team. Because most ED deaths will be medical examiner/coroner cases, notification of the CFRT will usually be ensured by that mechanism.

The National Center for Child Death Review recommends that local and state CFRT boards include an ED clinician as a standing board member.⁵⁸ When invited to attend a specific case review meeting, emergency clinicians should make every effort to attend, share information on a specific case and/or general information on ED practices and policies, and encourage improvements in systems and prevention. Emergency clinicians are important to CFRTs, because they can supply information on services provided to a particular child or family if seen in the ED as well as general information related to emergency care, including types of injuries and deaths, medical terminology, and concepts and practices specific to emergency care. They can further support team activities by providing the medical information needed for successful prevention campaigns and strategies. Simply documenting, in detail, the circumstances of a child's death allows the emergency clinician to play a powerful role in the prevention of disease and injury. Emergency health care providers should support training in optimal collaboration with CFRTs and in the documentation of circumstances of death, the completion of death certificates, and analysis of findings on physical examination that may shed light on the cause. The use of CFRT data may result in changes to child welfare systems, improvement in training and interagency protocols, and new legislation and regulations. The determination of the leading causes of preventable deaths has resulted in

implementation of prevention procedures (eg, child safety restraints and pool fencing) and prompt public policy discussion and action.

BALANCING FORENSIC RESPONSIBILITIES WITH COMPASSIONATE CARE

In 2009, an estimated 1770 children in the United States died as a result of inflicted injury or neglect. Nearly half of fatal child maltreatment cases occur in infants younger than 1 year, and 80% occur in children younger than 4 years. Any child death presenting to the ED may require consideration of maltreatment as a cause of death, especially when the history does not match the clinical presentation.⁵⁹ Although there is literature to support the need for training and resources for the responsible performance of forensic duties in the ED in situations involving the death of a child,^{60,61} there is little reported that describes the tension between health care providers and law enforcement that can sometimes result when the death is suspected to be the result of neglect or homicide. The emergency clinician is called to balance the needs for accurate forensic information with the compassionate care of the family whose child just died. In the focus on time-sensitive, potentially lifesaving interventions, medical staff may inadvertently destroy crucial evidence, creating the potential for conflict with law enforcement officials. In the acute care setting, it is often impossible to determine whether a potentially lethal condition has resulted from intentional or accidental causes, and the bereaved family should be offered access to their child, in accordance with local policy, while making every effort not to compromise patient and staff safety or evidence. Access to a forensic nurse examiner, who may have developed collaborative working

relationships with law enforcement professionals, may be beneficial.⁶² Forensic nurse examiners have been specially trained in evidence collection and the care of victims and secondary survivors and may provide another option for standardized expert care. They can be notified of a pending arrival of a pediatric patient in extremis, remain exempt from the actual resuscitative care, and provide an additional trained team member whose primary purpose is the preservation of evidence. Appendix 2 of this report offers a sample protocol for collaboration between health care providers and law enforcement in situations in which there is concern for intentional injury resulting in death.

PRACTICE ON THE NEWLY DECEASED

Studies from the previous decade have suggested that 47% to 63% of emergency medical training programs allowed the practice of procedures on the newly deceased to ensure the development and maintenance of skills for trainees and clinicians to benefit future patients; however, in the past, consent was rarely sought.⁶³ With the increasing frequency of family presence during resuscitative efforts, evolving sophistication of alternative methods of training such as simulation, and a growing sense among participants or observers that norms of decency are being breached, this practice is likely to be diminishing in frequency. Interestingly, consent for procedures on the newly deceased is sought and obtained more often in the NICU than in the ED, possibly because of the existence of a longer standing relationship and trust. The Society for Academic Emergency Medicine has taken the position that all emergency medicine training programs should develop a policy regarding practice on the newly deceased and make that

policy available to the institution, educators, trainees, and the public.⁶⁴ The ENA has issued a policy statement affirming the legitimate need to master critical and lifesaving procedures, to obtain consent, and to consider alternative teaching methods such as simulation.⁶⁵

FAMILY BEREAVEMENT

The *Emergency Department Bereavement Resource* manual from the National Association of Social Workers is a practical resource for optimal ED preparation for the death of a child in the ED.⁶⁶ The manual also offers practical suggestions for memory making and bereavement care in the ED after a child has died. Most families not present at the time of death felt that they should have received the news from an attending physician. Similarly, most felt that a follow-up call from providers who were present with them during and after the time of their child's death would be meaningful, although few reported receiving such a call.⁶⁷ Postmortem follow-up communication has been shown to be perceived as very positive by survivors of adult patients who died in an ED¹² and for bereaved parents of children who died in the PICU.⁶⁸ Parents recognize staff with whom they have had only this brief intense encounter as the last people to see their child alive, with whom they shared an overwhelmingly difficult event in their own lives, and therefore as important keepers of the memory of their child. It can be comforting to ED staff, who themselves mourn the death of child patients, to know that even small gestures of condolence such as a card or phone call can have a profound and positive effect on grieving families. A sample bereavement checklist for use in the ED is included in the Appendix 3 of this report.

Parents reported that they valued the care provided by physicians and other members of the emergency care team who were accessible, honest, caring, and able to speak in lay language at a pace that matched the parents' ability to process and comprehend. The pace of this information is necessarily accelerated in the emergency setting, but the family's need for continued access to providers, whether from the ED staff or from more familiar resources, is very likely the same. It is the responsibility of ED clinicians to ensure that families will receive follow-up from the most appropriate source for that family, which may indeed be the ED staff in some cases.

COLLABORATION WITH PEDIATRIC PALLIATIVE CARE SERVICES

Studies in children with known life span-limiting conditions report that between 3% and 20% of deaths in that population will occur in the ED.^{69,70} Because the ED remains part of the safety net of care for many children who are dying at home or who face a known life span-limiting condition, it is therefore sometimes the unanticipated venue for end-of-life care for such children. Increasingly, children with life span-limiting conditions may be cared for by local agencies and clinicians providing pediatric palliative care. Palliative care is a growing subspecialty within pediatrics, as evidenced by the recent creation of a Section on Hospice and Palliative Medicine within the AAP and recognition of the specialty of palliative care through a certificate of added qualification by the American Board of Pediatrics and other American Board of Medical Specialties boards. Palliative care services are not uniformly available, however, even at tertiary care or exclusively pediatric facilities. Nevertheless, as more

children are provided palliative care services, explicit and anticipatory collaboration between pediatric palliative care services and their corresponding EDs will likely improve care for such children. Many children receiving palliative care have had the opportunity to develop advance care plans. It can be very helpful for ED staff to have an understanding, in advance, of the hopes, concerns, and wishes that the child and family may have expressed. The emergency information form template developed by the Emergency Medical Services for Children program, in conjunction with the AAP and ACEP,⁷¹ includes advance directives that can be helpful in critical decision making with the family. Pediatric palliative care specialists can help families by anticipating which ED and EMS services will serve as entry points for their children and by sharing relevant medical history and care plan information with the EMS and ED personnel, with permission of the family. Similarly, when ED clinicians identify a child who might benefit from such a care plan, they may consider contacting pediatric palliative care resources to help develop such a plan for future potential ED visits. Pediatric palliative care teams can be a helpful resource for providing or identifying bereavement follow-up resources for individual families, for assisting to develop a consistent policy for bereavement follow-up from the ED, and for supporting ED caregiver gatherings and debriefings after the death of a child. An innovative project to integrate palliative care principles into emergency medicine practice provides additional resources on the Web site of the Center to Advance Palliative Care (www.capc.org). A guideline for developing a protocol for planned death in the ED of a child with a known terminal condition is included in Appendix 4.

THE CONCEPT OF A GOOD DEATH

The idea of a “good death” is a concept rarely discussed in the emergency medicine literature, and it is difficult to apply paradigms developed outside of the ED, mainly in the realm of adult palliative care, to the acute, unanticipated death of a child in the ED. The Institute of Medicine report on childhood death provides the following definitions for good and bad deaths:

“A decent or good death is one that is: free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients’ and families’ wishes; and reasonably consistent with clinical, cultural, and ethical standards. A bad death, in turn, is characterized by needless suffering, dishonoring of patient or family wishes or values, and a sense among participants or observers that norms of decency have been offended.”⁷²

Modern medicine has cultivated an unspoken belief that death is a failure on the part of the medical system, and the culture of the ED is perhaps most particularly vulnerable to this covert belief. A first step toward developing an understanding of what a “good death” might be in the ED setting is necessarily the acknowledgment that death is not avoidable. The knowledge and application of best resuscitation practices, whether in terms of applying interventions or appropriately withholding them, are required to know that a death was unavoidable. A second aspect of what might constitute a “good death” in the ED is caring for the survivors of the child’s death in a way that affirms their trust, allowing them to understand the events leading up to death, to exert some control in the situation, and to say goodbye to their child in whatever way is meaningful to them. These tasks have been identified as critical to the well-being of a bereaved family and can be supported by the clinical team with practical assistance, information, and compassion.^{73,74}

CARE FOR THE CARE PROVIDER

Finally, how ED staff care for each other as members of an interdisciplinary team of care providers is a third essential aspect of a “good death.” All ED staff benefit from training in communicating bad news, in managing the families’ expected emotional responses, and in understanding and managing the emotional responses in ourselves and our colleagues. It is important to offer voluntary defusing or debriefing to staff after critical incidents, such as the death of a child, although it is often challenging to find a time to gather those who wish to participate. However, Treadway’s⁷⁵ compelling essay, “the Code,” suggests that even a simple acknowledgment at the bedside after the death of a patient may be beneficial to staff. She speculates that there may be a healing potential to closing rituals that are communal rather than private. An example of a brief closing ritual is provided in Appendix 5 of this technical report.

SUMMARY

The death of a child in the ED remains one of the greatest challenges for ED staff. Since the original technical report,² the science of resuscitation has advanced and national organizations have strengthened position papers to facilitate family-centered care, including family presence during resuscitation. Concepts of the medical home, child fatality review, and pediatric palliative care have evolved. Hospitals can adopt policies and practices that provide guidelines for the care of the patient, family members, and care providers. These policies should incorporate family presence, termination of resuscitation efforts, bereavement protocols, and evidence preservation. It is important to address compliance with laws governing jurisdiction after death and the means to support staff when a child dies in the ED.

LEAD AUTHORS

Patricia J. O’Malley, MD, FAAP
Isabel A. Barata, MD, FACEP, FAAP
Sally K. Snow, RN, BSN, CPEN, FAEN

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Joseph L. Wright, MD, MPH, FAAP

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Tamar Magarik Haro – *AAP Department of Federal Affairs*
Angela Mickalide, PhD, MCHES – *Emergency Medical Services for Children National Resource Center*
Cynthia Wright, MSN, RNC – *National Association of State EMS Officials*
Lou E. Romig, MD, FAAP – *National Association of Emergency Medical Technicians*
Sally K. Snow, RN, BSN, CPEN, FAEN – *Emergency Nurses Association*
David W. Tuggle, MD, FAAP – *American College of Surgeons*

STAFF

Sue Tellez

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APPENDIX 1: GUIDELINES WHEN NOTIFYING A FAMILY OF THE DEATH OF THEIR CHILD IN THE ED

Modern medicine has cultivated an unspoken belief that death is a failure on the part of the medical system, and the culture of the ED is perhaps most particularly vulnerable to this covert belief. It is helpful to acknowledge that death is not avoidable in many of the conditions we are called on to treat in the ED. When it feels as if all you have left is the terrible news of a child's death, in fact your presence, empathy, practical assistance, and information enable you to provide a bereaved family with essential assistance that they will need to adjust to their loss. Families who lose a child through an acute and unanticipated event have at least these tasks to address: they need to understand the events leading up to death, to feel that they can exert some control over a universe suddenly completely out of control, to be able to say goodbye to their child in some meaningful way, to be able to make sense of the death, and to be able somehow to carry the child forward in their lives as they negotiate a new and ongoing relationship with the child they have lost. Your role in telling the family about the death of their child can help them toward accomplishing these tasks.

Preparation

First, take a moment for self-reflection, to acknowledge your own feelings (inadequacy, guilt, sadness, anger, fear) and perhaps to find a colleague with whom to share those emotions beforehand. Take note of those emotions, whatever they are, and then, without comment or criticism, allow yourself to put them aside.

Think for a moment how you might act if a dear friend told you that he or she had just received terrible news: what would you do, as one human

being to another? Use that as a model of how best to help this family with the news you have to give them. Strive to be a kind and steadying presence.

Families take it as a mark of respect and an indication of how importantly we view their loved one when the responsible attending physician is the one notifying the family.

Know and use the child's name.

Ensure that the right family members have been gathered and available resources have been assembled (which might include chaplaincy, social work, child life, or outside family supports, such as family chaplain or primary care provider).

Use a skilled medical interpreter, not a family member, for any translation needs. If using a family member is the only recourse, acknowledge to the family interpreter how difficult it is to hear bad news and then have to share that news.

Choose an appropriate setting that is quiet, provides privacy, and has enough places to sit for all who are needed to be present, with water and tissues available. Make yourself available and presentable (turn off beeper; check appearance, be sure to sit down).

Have a written copy of your name and contact information available. You may want to include other staff member names as well, such as the primary nurse, the social worker, child life, etc.

Steps in the Process

Introduce yourself and your role, shake hands or touch family members if appropriate, sit down at eye level.

If appropriate, determine what the patient and family understand about the present situation. "Please tell me what you already know about what has happened to [child's name]."

Prepare them with fair warning: "I am so sorry that I have to give you this bad news." Hold them in your gaze.

Continue to hold them in your gaze and inform them of the death in a direct manner, using the words "die" or "death." For example, "We did everything we possibly could, but [child's name] has died."

Sit quietly and allow the family to respond. The entire range of human emotion is possible at this moment. Resist the temptation to fill this silence and allow the family to be the first to break the silence.

Hear and respond to the family and patient's emotions, and provide additional information at the family's or patient's pace. (Avoid statements that begin with "I know you must be feeling very...") Instead, acknowledge what you see or feel. "I cannot imagine how difficult it must be to hear this news."

Solicit questions, assess understanding, and follow the family's lead. "I have given you such terrible news. Would it help to see [child's name] now, or do you have any questions for me, anything that I can explain better?"

Families may not ask but may be comforted to know that their child did not suffer, so if it is possible to give that reassurance, do so.

Any bad outcome with a child is inextricably linked to parental feelings of guilt. If it is possible to give reassurance about the family role in the event or note any contribution they made that was helpful, do so. "I don't see any way this accident could have been anticipated." Or, "Your information about her medical problems in the past was essential information for us."

Be prepared to repeat information, because it is nearly impossible to take in new information when under the kind of stress that a family member would be feeling at this time. Nevertheless, understanding and sometimes even reconstructing the events that led up to their child's death are often an

essential part of family acceptance and well-being after the loss of a child. Even simple information about what will happen next or what choices they have will be helpful. Your ability to give the information they need and ask for, at the pace they require, can be one of the most therapeutic “procedures” you can perform.

Offer assistance in helping the family to share this news with others, such as siblings or young children. Let them know that you will be notifying the child’s primary care provider and any relevant specialists.

Give your contact information in written form and let the family know of any follow-up arrangements, such as a call from the ED social worker in the next day or so.

Consider writing a condolence note to any family to whom you have had to give the news of their child’s death in the ED. It is an act with remarkable potential for healing.

SELECTED RESOURCES

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APPENDIX 2: SAMPLE PROTOCOL FOR COLLABORATIVE PRACTICE WITH HOMICIDE INVESTIGATION ON SITE IN ED

City Police Department Homicide Division

The following procedures are to be used by city police officers when responding to a death involving a child

age ≤ 6 years at an area hospital. The procedures are designed to maintain the integrity of the police death investigation while permitting the hospital staff the continued use and management of the ED. The procedures also recognize the rights of the family to have access to their child to grieve the loss. Compassion and cooperation are key in handling these situations, and officers should always exercise good judgment in their decisions as it relates to child death investigations. If there are any questions concerning these procedures, please contact your city’s Homicide Division for resolution and guidance. A sample algorithm is provided in Appendix 2A.

Child Death Investigation Procedures

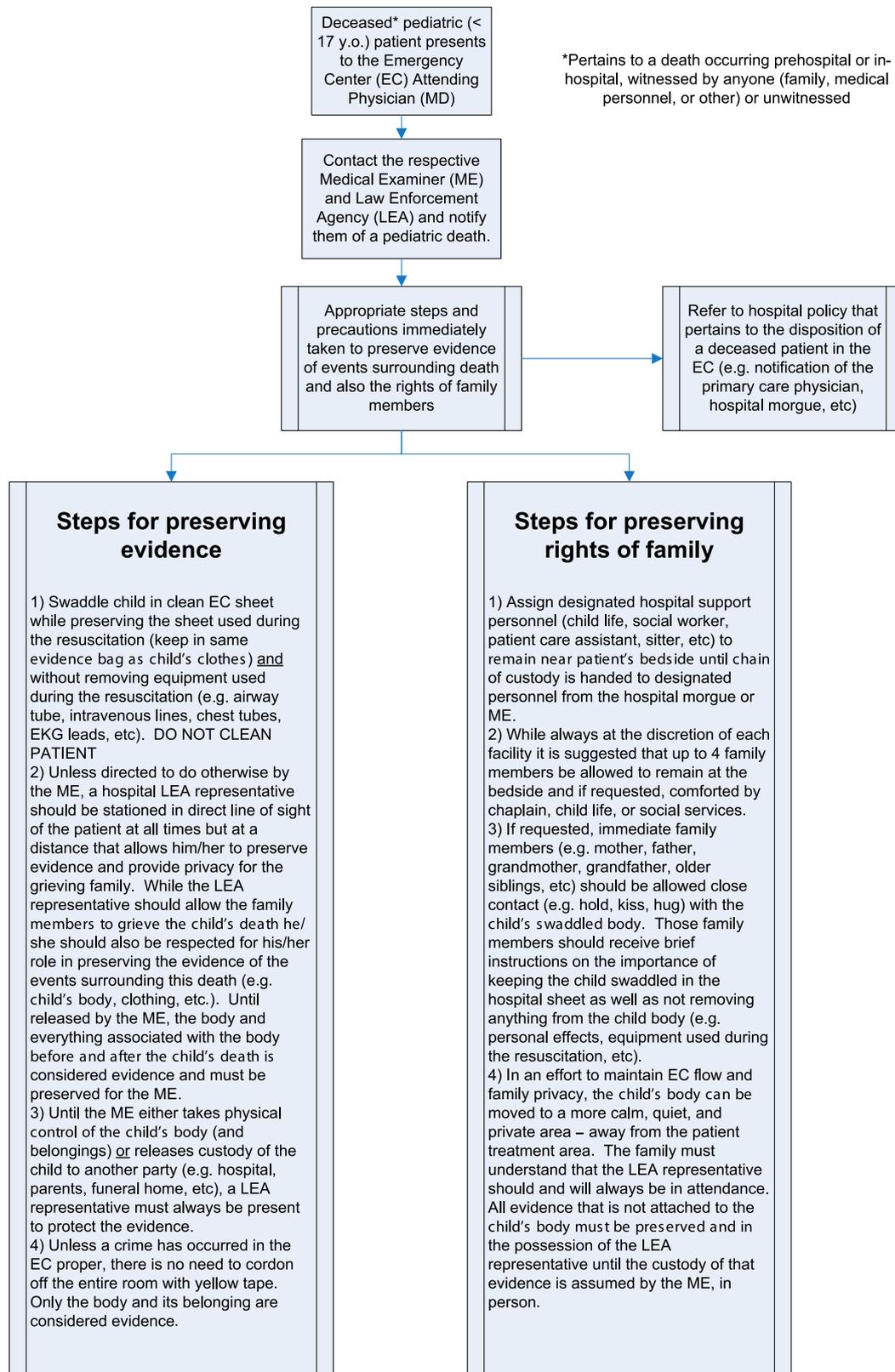
- When notified of a child death at a local hospital, responding officers, whether on-duty or working security, will ensure that the Homicide Division is notified immediately of the death. As many details as possible of the death should be obtained and relayed to the Homicide Division, such as name of the child, location the child was transported from, who transported the child, and any medical history or condition known.
- If the child was transported to the hospital from an outside location, make sure an on-duty unit is dispatched to the location to secure the scene as part of the investigation. In most instances, on-duty units will already be involved. If not, the Homicide Division desk officer can assist in getting a unit sent to the transporting location.
- Allow hospital staff to move the child out of the ED treatment room to another room or morgue. The officer will stay with the child and “observe and record all observations” until the arrival of the homicide

investigators. Remember, the ED room IS NOT a crime scene; the evidence for the investigation is the body of the deceased.

- Immediate family members should be allowed access to grieve the loss of their child. The officers should remain with the child and the family members until the arrival of the homicide investigators. Hospital staff should swaddle the child’s body in a clean sheet while preserving the sheet used during resuscitation efforts and without removing equipment used during the resuscitation efforts.
- If there are “obvious” signs of trauma, such as broken bones, significant bruising, or other injury indicating foul play in the child’s death, the child’s body may be removed from the ED treatment room into a secure room or morgue pending the arrival of homicide investigators. In this instance, there should be no contact with family members and the child’s body should be secured as evidence. Any questions about this should be directed to the Homicide Division.

In cases of child deaths in which the child has a history of medical problems and treatment of a long-term illness that make it clear that the death does not involve foul play or negligence, homicide investigators may elect not to respond or conduct the investigation. In those instances, the officer is responsible for preparing the report and conducting the scene investigation. This decision is made by the Homicide Division duty lieutenant, and all decisions about the homicide response should be directed to him or her.

Any questions about the handling of child death investigative procedures at area hospitals should be directed to the City Police Homicide Division.



APPENDIX 2A

The deceased patient in the emergency center (EC) decision tree: balancing the rights of survivors with the necessary preservation of evidence (courtesy Paul Sirbaugh, MD, personal communication). EKG, electrocardiogram.

APPENDIX 3: SAMPLE RESOURCE GUIDE FOR ED BEREAVEMENT CHECKLIST AND MEMORY BOX

This resource is meant to help guide you in the next stage of your care for a bereaved family.

Your interventions and caring have the potential to bring much comfort and meaning to this family and significantly influence their grieving.

Sections I and II: Demographics/Information

Please complete the Bereavement Checklist, which will help with bereavement follow-up and staff support. Please place the finished checklist *in the designated location/or to the designated personnel*.

Section III: Family Members

Our ED offers the option of family presence during invasive procedures and resuscitation. A family facilitator, nurse, social worker, or physician should assess the family before being with the patient. The family facilitator should accompany the family to provide support and medical explanations.

For many families, this may be their first experience of death, and they will not know what is permissible or expected. They may not know what will be comforting or healing to them now or in the future and will look to us for guidance. You might say something like “Many families have told us that they were comforted by the memory of talking to the patient or holding or touching their loved one—would you like to be able to do that?” Whenever possible, it is desirable to offer family private time (accompanied or unaccompanied as they request) to be with their loved one after death.

Family members may arrive after the child's body has been transported to the morgue and the morgue staff are not available. If appropriate, the resource nurse should notify the nursing

supervisor and police and security to bring the family to the morgue and identify supportive staff (social work, nursing, physician) to accompany family members.

Section IV: Memory Box

The memory box is a legacy gift that can be given to family members after the death of their child. It can include hand and foot molds made out of model magic clay, handprints and footprints using inkless wipes and paper, a lock of hair, photographs if the family so chooses, and any mementos the child came with (clothes, shoes, jewelry, hospital band, hair accessories, etc). The directions for making the clay imprints and inkless prints are in each bereavement box, along with the necessary tools to make them. All of the memory box supplies (including resources and blankets) are kept _____. Sometimes families (including siblings) like to be involved in making the ink prints and clay imprints, so this opportunity should be offered to the family. More than 1 box can be made for families if the parents/caregivers live separately. Extra copies of the ink prints can be made using the copier for additional family members. If the family does not want to take the box home with them at this time, please let them know it will be kept at the hospital in case they change their mind over the next several months. Please lock the box in the valuables cabinet if the family does not want to take it home at this time.

Section V

Notification

Most ED deaths are considered a mandatory autopsy by the medical examiner. If the medical examiner decides to accept the case while the family is still in the ED, the family should be told, because it can affect funeral arrangements. Please note that the OPO will automatically be notified by

the hospital when the death certificate is completed. Studies have shown that professional OPO staff members are more skilled (even more than seasoned ED staff) at discussing potential organ donation with families, so you should defer all discussion of organ donation to OPO staff. In pediatric deaths of uncertain etiology, such as suspected sudden unexpected infant death or abuse, it is sometimes helpful to arrange with the medical examiner that the autopsy be performed at a facility with specific pediatric expertise.

Aftercare of the Deceased

To the extent possible, we should respect and support faith-based or cultural traditions around treatment of the deceased after death. For instance, for some traditions, it is not acceptable to leave a deceased person unattended, whereas for others it may not be acceptable for the child's body to be handled by someone of the opposite sex. You might ask “Does your family culture or faith tradition give you guidance about what should happen after someone dies? We would like to support you in that if we can.” For many families, particularly those dealing with the loss of a child, the thought of leaving the deceased child alone in the morgue is very difficult. If a medical examiner autopsy is declined, it is sometimes possible to arrange for the funeral home to pick up the child's body from the ED. This procedure involves the family identifying funeral home, attending physician completing a death certificate, and admitting staff processing the paperwork.

APPENDIX 4: GUIDELINES FOR DEVELOPING A PROTOCOL WHEN THE ED BECOMES THE UNANTICIPATED VENUE FOR END-OF-LIFE CARE FOR A CHILD WITH A TERMINAL CONDITION

Although the ED is not a common venue for end-of-life care of children with

SECTION I:

Patient Name _____

MR# _____ Date _____

Date of Birth _____

Diagnosis _____

Brief history surrounding death _____

Family contact information (name, relationship, contact#) _____

Primary RN _____ Attending MD _____

Section II: NOTIFICATION (please note, organ bank is notified by admitting staff; please defer discussion of organ donation to organ bank staff)

	Phone or Pager #	Name
Charge Coordinator		_____
Psychiatric Nurse Specialist		_____
_____		_____
Social Worker		_____
_____		_____
Child Life Specialist		_____
_____		_____
Chaplaincy		_____
_____		_____

Medical Examiner's Office _____

Section III: FAMILY MEMBERS:

Key: Father=F Mother=M Sibling=S Spouse=SP Child=C Significant Other=SO

Family presence during resuscitation?	F M S SP C SO	
Not offered? Why?	F M S SP C SO	_____
Not accepted? Why?	F M S SP C SO	_____
Present with patient after death?	F M S SP C SO	
Touched child after death?	F M S SP C SO	
Held child after death?	F M S SP C SO	
Assisted with aftercare?	F M S SP C SO	

Section IV: GENERAL INFORMATION FOR PEDIATRIC PATIENTS

MEMORY BOX

Baby blanket
 Box given to _____ or box locked in valuables cabinet
 Instant photo with permission
 Hand mold and/or prints
 Lock of hair in small bag
 Bereavement resources
 Any personal articles/artifacts
 Siblings names/ages _____

Section V: AFTERCARE OF THE DECEASED/DOCUMENTATION

Prepare child's body for morgue/funeral home (if autopsy leave tubes in place)
 Cover with clean blanket (adult or baby bereavement blanket to go with family)
 Nursing note to document date/time of death
 MD note to document date/time of death
 Assist family with information about funeral arrangements
 Informational booklets given to family

***Please place this finished checklist _____.

APPENDIX 3A

Bereavement Checklist. MR, medical record.

known terminal conditions, as many as 10% of children with complex medical conditions will die in the ED setting. Some of those children will have advance care plans and family may have hoped that their child could die at home. However, in many locales, there are not resources to provide hospice or end-of-life care in the home setting for children, and many parents/caregivers report that even when the child's death is anticipated, the presence of medical personnel at the time of active dying is critical to their support and comfort.

In developing individual institutional guidelines for the care of a child with a terminal condition who presents to the ED actively dying, consider input from the following stakeholders if available:

- ED physician, nursing and administrative staff
- Hospital palliative care
- Chaplaincy
- Social services
- Child life services
- Pharmacy (for rapid access to pharmacologic management of symptoms)
- Admitting staff
- Case management
- Hospitalist service (for consideration of rapid/direct admission or transfer to an alternate site)
- Community-based palliative care providers

Consideration should be given to clarification of the means to facilitate the following:

- Assessment of the family's wishes, including resources needed for the child to return home to die

- Expedient symptom management (respiratory distress, delirium, seizures, pain, control of secretions, control of bleeding)
- Provision of a private space in the ED, with the option for family to hold child if feasible and desired
- Contacting all existing care providers on the child's team
- Identification of alternate venues of care, including inpatient service, residential hospice, home
- Memory making by family members
- Ensuring bereavement follow-up, whether by ED staff or other
- Ensuring debriefing mechanism for ED and EMS staff.

In the event that a child with an advance care plan presents to the ED in medical crisis:

- Provide all comfort measures.
- Acknowledge all family members present
- Ask about current goals of care (eg, maximizing comfort versus attempting to prolong life)
- Engage in rapid resolution of severe distress and manage ongoing symptoms such as pain, secretions, seizures, delirium, respiratory distress, bleeding
- Provide private location as possible, with option for family to hold child if feasible and desired
- Ask family regarding their wishes at this time.
- For example: "We will keep [your child] safe and comfortable. If this

is her time to die, what can we do to support you and your family best? Is there anyone (physician, faith community, family, etc) you would like us to contact?"

- Contact primary and specialty care providers
- Notify OPO if indicated
- Assess optimal venue for care if death is not imminent: for example, "If your hope would be that your child could be at home when he/she dies, what resources will you need for your child to be safe and comfortable there? If we cannot secure those in your home setting, we will try to find the best place for you to be as a family. Would you like us to arrange for your child to be admitted to the pediatric floor/residential hospice?"
- Provide opportunity for memory making, any rituals to support faith-tradition or cultural practice, and family leave-taking
- Identify ED and EMS staff involved in care for participation in staff debriefing and in any bereavement follow-up for family.

APPENDIX 5: EXAMPLE OF A CLOSING RITUAL AFTER THE DEATH OF A CHILD IN THE ED

"I thank everyone here for their efforts to save [this child's name] life. Please take a moment in silence with me now to acknowledge our sorrow at his or her passing... In his or her name [touching the child if appropriate] may we each be rededicated to our work."

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