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Timing and Causes of Death to 1-Year Among Children Presenting to Emergency Departments

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Abstract

Background and Objectives: A better characterization of deaths in children following emergency care is needed to inform timely interventions. This study aimed to describe the timing, location, and causes of death to 1-year among a cohort of injured and medically ill children.

Methods: We conducted a retrospective cohort study of children < 18 years requiring emergency care in 6 states from 1/1/2012 through 12/31/2017, with follow-up through 12/31/2018 for patients who were not discharged from the ED. In this cohort, 1- year mortality, time-to-death within one year, and causes of death were assessed from ED, inpatient and vital status records.

Results: There were 546,044 children during the 6-year period. The 1-year mortality rate was 2.2% (n=1,356) for injured children and 1.4% (n=6,687) for medically ill children. Matched death certificates were available for 861 (63.5%) of 1,356 deaths in the injury cohort and for 4,712 (70.5%) of 6687 deaths in the medical cohort. Among deaths in the injury cohort, 1,274 (94.0%) occurred in the ED or hospital. The most common causes of death were motor vehicle collisions, firearm injuries, and pedestrian injuries. Among the 6,687 deaths in the medical cohort, 5,081 (76.0%) children died in the ED or hospital (primarily in the ED) and 1,606 (24.0%) occurred after hospital discharge. The most common causes of death were sudden infant death syndrome, suffocation and drowning, and congenital conditions.

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Contributions statements:

SA conceptualized and designed the study, drafted the initial manuscript, and critically reviewed and revised the manuscript.

CN, AL, and AS conceptualized and designed the study, conducted the statistical analysis, and critically reviewed and revised the manuscript.

CM, PJ, MH, LP, SS, and CS conceptualized the study and critically reviewed and revised the manuscript.

All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

Conclusions: The 1-year mortality of children presenting to an ED is 2.2% for injured children and 1.4% for medically ill children with most deaths occurring in the ED. Future interventional trials, quality improvement efforts and health policy focused in the emergency department could have the potential to improve outcomes of pediatric patients.

Keywords

Pediatric Emergency Care; Mortality; Trauma

INTRODUCTION

Children with injury and acute medical illnesses account for 30 million emergency department (ED) visits each year in the US.¹ Prior work has highlighted gaps and variability in the quality of emergency care for children, which have spurred national efforts to improve the quality and consistency of pediatric emergency care.²⁻⁸ The National Pediatric Readiness Project (NPRP) is a national quality improvement initiative to improve ED pediatric readiness,⁹ which has been associated with improved survival among children with critical illness, trauma, and other clinical conditions.¹⁰⁻¹³ Two recent studies of ED readiness have demonstrated that children who die tend to do so early in the clinical course,^{12,14} placing extra emphasis on the quality and effectiveness of care at the initial ED. However, the causes and changing distribution of causes-by-time of pediatric deaths remain incompletely characterized. Research pertaining to the timing and etiologies of death in children after presentation to an ED is sparse because death is an uncommon outcome, few large-scale longitudinal pediatric studies exist, and discerning the causes of death generally requires matched death certificates or autopsy records.

A better understanding of the causes and timing of deaths in children following presentation for emergency care may facilitate improvements in interventions, provider training, ED preparedness, and prevention efforts. Furthermore, this research may inform the NPRP and other efforts to raise ED pediatric readiness across the US. Research on this topic may also inform the NPRP and efforts to raise ED pediatric readiness across the US. Understanding the most common clinical conditions causing early deaths in children may facilitate targeted strategies to address these conditions, particularly for reversible causes.

In this study, we describe the timing, location, and causes of death to 1-year among a cohort of injured and medically-ill children presenting to 596 EDs for care in 6 states, including deaths occurring in the ED, inpatient, and hospital post-discharge settings. We also characterized the types of children presenting for emergency services who subsequently died in the ED, during inpatient admission or after hospital discharge compared to children who survived to 1-year.

METHODS

Study Design:

This study was a secondary, descriptive analysis of a retrospective cohort study that was reviewed and approved by Institutional Review Boards at Oregon Health and Science

University and the University of Utah School of Medicine, which waived the requirement for informed consent. We followed the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) cohort study guidelines.¹⁵

Study Setting:

We included children presenting to 596 EDs in six states over a 6-year period. To be included, EDs had to have a matched 2013 NPRP assessment, as the parent study focused on an outcome-based evaluation of ED pediatric readiness using the 2013 NPRP assessment.¹² Matching was completed by linking the NPRP assessment, a national assessment of adherence to national emergency department pediatric guidelines,² to the index ED record using hospital name, address, and zip code. Next, we included children residing in six states, as determined by having a home zip code listed in one of the study states, which granted approval to match pediatric ED and inpatient records to state death records. The states included Arizona, California, Florida, Iowa, Maryland, and New Jersey. We selected states based on broad geographic representation, availability of the necessary hospital and patient identifiers, and approval to link vital statistics death records.

Patient Population:

We created a patient-level, chronological dataset for consecutive children < 18 years receiving care in 596 EDs, with follow-up to 365 days. We identified the first ED visit for each child (marking time zero) from January 1, 2012 through December 31, 2017, with follow-up through December 31, 2018. Inclusion criteria at the time of the index ED visit were: admission from the ED, transfer to another hospital (to another ED or to an inpatient settings), or death in the ED. We also included matched records for inpatient transfers originating in the ED to ensure the full acute care episode was represented. We tracked mortality for every child to 365 days from the date of the index ED visit. For children transferred to another hospital, we matched available records from the second hospital to capture complete episodes of acute care. While we included all children meeting the above criteria, the primary focus was on children dying within 365 days of the index ED visit. We excluded children who were treated in EDs without a matched NPRP assessment (based on the parent study)¹², missing hospital disposition, transferred from the initial ED without a record from the second hospital, or missing diagnosis codes or other key data (eFigure 1). To evaluate for potential differences in time to death and causes of death among children with different clinical conditions, we divided the sample into children with injuries versus medical illnesses using ED and hospital discharge International Classification of Diseases Clinical Modification (ICD) diagnosis codes from the index ED visit and hospitalization.

Variables:

We included variables available from the initial ED visit and accompanying hospitalization. These variables included: age; sex; complex chronic conditions;¹⁶ Severity Classification System (1–5 acuity scale for children presenting for emergency care, with higher numbers denoting higher clinical severity);¹⁷ ED/hospital diagnoses grouped by standardized ICD categories; hospital procedures; injury severity and mechanism of injury (for injured children); and inter-hospital transfer. For hospital procedures, we used the Agency for Healthcare Research and Quality Clinical Classification System (CCS)¹⁸ and mapped CCS

categories to standardized operative domains. For injured children, we used the Abbreviated Injury Scale (AIS) score¹⁹ and Injury Severity Score (ISS)²⁰ to measure injury severity. Because AIS and ISS are not included in administrative data, we used ICD ISS Map v2.0 (AAAM, Chicago, IL) to convert ICD9-CM and ICD10-CM diagnosis codes into standardized injury severity measures, which we have validated against hand-abstracted values.²¹

Outcomes:

The primary outcome was mortality, measured from the date of initial ED presentation to 365 days. To identify deaths, we used ED, inpatient, and vital statistics death records. To link vital statistics records to the index ED visit, we used probabilistic linkage²² (LinkSolv v9, Strategic Matching) and established linkage routines.^{23,24} Linkage variables included date of birth, home ZIP Code, date of service, sex, race, and ethnicity. We validated the sensitivity and specificity of linkage in the parent study, estimating that these processes identified 92.5% of all deaths among injured children and 85.6% of deaths among medically ill children within one year.¹²

To describe the causes of death, we categorized the ICD-10 diagnosis codes listed on death certificates into standardized disease-based ICD-10 categories.²⁵ Because the category of “Symptoms, signs, and abnormal clinical and laboratory findings, not elsewhere classified” was a common and non-specific category for deaths in the medical cohort, we created subcategories based on the frequency of specific diagnosis codes (e.g., sudden infant death syndrome). Similarly, for deaths in the category “Injury, poisoning and certain other consequences of external causes,” we created subcategories for different mechanisms of injury, poisoning, and drowning/suffocation. To describe and characterize causes of death, we only used information from death certificates. Among children who survived their initial hospitalization, we tracked subsequent ED visits and hospital readmissions to 365 days from the date of initial ED presentation as a secondary outcome.

Statistical Analysis:

We used descriptive statistics to compare children who survived versus died within one year of their initial ED visit. Among children who died within one year, we described the timing, causes, and location of death. Causes of death were limited to children with matched vital statistics death certificates. We measured time-to-death in days, based on the interval between the date of the initial ED visit and the date of death (as extracted from the ED, inpatient and vital statistics records). Among children dying after discharge, we quantified the number of post-discharge ED visits and readmissions, and used death certificates to describe the location of death (ED/hospital, skilled nursing/long-term care, hospice, or home). We performed all analyses separately for the injury and medical cohorts. Based on our data use agreements, cells with sparse data ($n < 30$) are reported as “ $n < 30$ ”, with the accompanying percentage rounded to the nearest whole number. All analyses were performed in SAS 9.4 (Cary, NC).

RESULTS

This study included 546,044 children who presented to an ED during the 6-year period, including 62,710 (11.5%) injured children and 483,293 (88.5%) children with acute medical illness (eFigure 1). The 1-year mortality rate was 2.2% (n=1,356) for injured children and 1.4% (n=6,687) for children with medical illness. Matched death certificates were available for 861 (63.5%) of 1,356 deaths in the injury cohort and for 4,712 (70.5%) of 6687 deaths in the medical cohort. The median time to death was 0 (IQR 0,2) days for injured children and 0 (IQR 0, 8) days for medical children. In Table 1, we compare children who survived versus died within one year of the initial ED presentation. Among the injury cohort, deaths were more common among adolescents, certain injury mechanisms (firearms, motor vehicle, and pedestrian events), high injury severity, and serious traumatic brain injury. For the medical cohort, deaths occurred predominantly among young children (< 1 year), those with chronic medical conditions, children with circulatory and nervous system diseases, and higher clinical acuity.

Characteristics of children who died are detailed in Table 2. Among the 1,356 deaths in the injury cohort, 1,274 (94.0%) died in the ED or hospital, with relatively few deaths after discharge. For the injury cohort, the most common causes of deaths occurring during the index ED/hospital visit were due to motor vehicle crashes, pedestrian events, and firearms, while the majority of deaths after discharge were from medical causes. Among injured children dying after discharge, most deaths occurred weeks after discharge (median time from discharge to death = 45 days [IQR 5 – 160]) and 60% occurred during a subsequent ED visit or readmission. Among the 6,687 deaths in the medical cohort, 5,081 (76.0%) children died during their index hospitalization (primarily in the ED) and 1,606 (24.0%) occurred after hospital discharge. Early (i.e., ED) deaths in the medical cohort were most commonly due to sudden unexplained infant death (SUID), drowning/suffocation, and perinatal/congenital conditions. The causes of inpatient deaths differed from those in the ED, with perinatal/congenital conditions being most common. Among deaths in the medical cohort occurring after discharge, neoplasms/blood/immune diseases and perinatal/congenital conditions were most common and the majority occurred weeks after discharge (median time from discharge to death = 48 days [IQR 13–145]). Repeat ED visits and readmissions were common (54.1%), and 60% of post-discharge deaths occurred during a subsequent ED visit or readmission.

Figure 1 demonstrates the number of deaths in the injury cohort by day, beginning with the date of the index ED visit. The majority of deaths in the injured cohort were on days 0–1 and half of early deaths were due motor vehicle collision (26%) or pedestrian/bicycle related injury (24%). Following the initial ED presentation, injury-related causes of death continued to predominate until 30 days after the initial ED presentation, with medical causes increasing to 56% of all post-discharge deaths.

In Figure 2, we show the number of deaths by day for the medical cohort. The majority of deaths occurred within 0–1 days of the index ED presentation, with the most common causes of death being SUID (20%), drowning or suffocation (17%), and congenital (14%). For children dying from two to 365 days, congenital conditions and neoplasms were the

most common causes. There was a small percentage (7%) of children in the medical cohort who died of injury causes during the 0–1 day and 30–365 day intervals. Particularly among children dying early, these were children coded as having a medical diagnosis in the ED/hospital (including non-specific signs and symptoms), who ultimately had an injury cause of death. Because we considered injuries, poisoning, self-harm, and suffocation/drowning as separate subcategories (all of which are included under “injury” in the ICD-10 framework), injury causes were not related to the other subcategories.

DISCUSSION

In this large, multi-state cohort of 546,044 children presenting to an ED between 2012–2017, we found an overall 1-year mortality rate of 2.2% for injured patients and 1.4% for medical patients. The most common mechanisms associated with death among injured patients were motor vehicle collisions, firearms, and pedestrian injuries. Over 80% of deaths after injury involved a serious traumatic brain injury. For children in the medical cohort, the most common causes of early death were SIDS, drowning or suffocation, and congenital conditions. Importantly, most deaths in both cohorts occurred in the ED (which was most pronounced in the medical cohort), illustrating the importance of early care and a short time window for interventions. Our study is the first to describe the etiology and timing of death in a large multi-state cohort of children. The results of this study have the potential to inform future pediatric interventional trials (e.g., the type and timing of interventions to avert death), investments in education and quality initiatives, and health policy focused on children.

The timing of deaths among children presenting for emergency care highlights a key window of opportunity for life-saving interventions in pediatric healthcare. Although pediatric deaths are rare compared to adult populations, the majority of deaths occurred in the ED, rather than other healthcare settings.²⁶ These findings suggest that the opportunity for rescue is early in presentation and interventions aimed at reduction of mortality should begin in the prehospital and ED settings. Unfortunately, research (e.g. interventional trials) in the prehospital environment and ED settings for life-threatening causes involve many challenges, including identification and enrollment of eligible patients, time required to recruit and consent patients, and loss to follow-up.²⁷ Addressing these concerns through deferred consent, waivers of consent, and improved staffing for 24/7 recruitment may be necessary to conduct high quality emergency care research aimed at reducing pediatric mortality.²⁸

Based on our results, quality improvement and educational efforts to improve early pediatric resuscitation have the potential to substantially impact pediatric mortality, given the high burden of death in the ED. One potential mechanism for improvement is through the NPRP initiative to increase ED pediatric readiness. This national quality improvement effort focuses on ensuring all EDs have the necessary equipment, staffing and policies to provide high quality emergency care for children.² Our data support these essential efforts to raise all EDs to high pediatric readiness in order to reduce mortality in children. Future health policy aimed at ensuring high pediatric readiness of EDs may lead to improved pediatric outcomes and reduced mortality in children requiring ED care.^{10,12–14} Educational efforts, including

simulation training for pediatric resuscitation in the prehospital and ED settings, may also be of benefit.²⁹

In addition to timing of death, our study characterized the most common etiologies of mortality by the time from ED presentation. Among the injury cohort of children, motor vehicle collisions, firearm injuries, and pedestrian/bicycle injuries were the leading mechanisms associated with death. Recent data generally support this finding³⁰, however in recent years firearms have overtaken motor vehicle crashes as the most common cause of death in children.³¹ Among types of injury, serious traumatic brain injury occurred in the majority of children who died within one year, highlighting the importance of TBI prevention and early treatment among children. In the medical cohort, SIDS and drowning/suffocation were the leading causes of death, representing potentially preventable deaths.^{32,33} Knowledge of the most common etiologies of death and high-risk children can be utilized by emergency medical services (EMS) agencies, EDs, and public health organizations to inform future research, targeted interventions, quality improvement efforts, and prevention strategies in specific patient populations. In addition, this information can shape future policy, NPRP efforts, and other national efforts focused on child advocacy related to addressing the leading causes of death in children.

LIMITATIONS

There were limitations in the study. While the data were generally complete for time-to-death, the causes of death were missing for about a third of pediatric deaths due to reliance on matched death certificates. Among early deaths in the medical cohort with a matched death certificate, unknown causes were common – these cases may reflect SIDS cases that did not have an autopsy completed or where there were other reasons to list “unknown” as the cause of death. Also, death certificates do not always provide the desired granularity for cause of death, particularly if an autopsy is not performed. Therefore, the causes of death were limited by the presence of a matched death certificate and the available information included on the document. Also, we used three data sources to identify deaths in the ED and hospital (i.e., statewide emergency department databases, statewide inpatient databases, and statewide vital statistics records), which provided a comprehensive surveillance strategy. However, to identify deaths after discharge, we primarily relied on matched vital statistics records, which may have undercounted such deaths.

We were unable to assess whether ED and hospital diagnoses from the index visit were related to causes of death for children who died after discharge. While we attempted to align the diagnosis codes between ED/hospital versus death certificate data sources for these patients, there were limitations with the detail of diagnosis codes from the different sources and relatively small numbers of patients, which prevented the opportunity to draw conclusions.

CONCLUSIONS

The 1-year mortality of children presenting to an ED was 2.2% for injured children and 1.4% for children with medical illness, with most deaths occurring early in the child’s

clinical course. Among children presenting with injury conditions, the most common causes of death were motor vehicle collisions, firearms, and pedestrian/bicycle events. For children presenting with acute medical illness, the most common causes of death were SUID, drowning/suffocation, and congenital/perinatal conditions, with cancer being a common cause of death following hospital discharge. Future interventional trials, quality improvement efforts, and health policy should consider the timing and etiology of pediatric mortality to target preventable mortality.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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REFERENCES

1. McDermott KW SC, Freeman WJ. Overview of pediatric emergency department visits, 2015. HCUP Statistical Brief #242 2018 (<https://www.hcup-us.ahrq.gov/reports/statbriefs/sb242-Pediatric-ED-Visits-2015.pdf>).
2. Gausche-Hill M, Ely M, Schmuhl P, et al. A national assessment of pediatric readiness of emergency departments. *JAMA Pediatr* 2015;169(6):527–34. DOI: 10.1001/jamapediatrics.2015.138. [PubMed: 25867088]
3. Chime NO, Katznelson J, Gangadharan S, et al. Comparing Practice Patterns Between Pediatric and General Emergency Medicine Physicians: A Scoping Review. *Pediatr Emerg Care* 2017;33(4):278–286. DOI: 10.1097/PEC.0000000000000557. [PubMed: 28355170]
4. Hampers LC, Faries SG. Practice variation in the emergency management of croup. *Pediatrics* 2002;109(3):505–8. DOI: 10.1542/peds.109.3.505. [PubMed: 11875148]
5. Bekmezian A, Hersh AL, Maselli JH, Cabana MD. Pediatric emergency departments are more likely than general emergency departments to treat asthma exacerbation with systemic corticosteroids. *J Asthma* 2011;48(1):69–74. DOI: 10.3109/02770903.2010.535884. [PubMed: 21117877]
6. Abulebda K, Whitfill T, Mustafa M, et al. Improving Pediatric Readiness and Clinical Care in General Emergency Departments: A Multicenter Retrospective Cohort Study. *J Pediatr* 2022;240:241–248 e1. DOI: 10.1016/j.jpeds.2021.08.084. [PubMed: 34499944]
7. Shibata S, Khemani RG, Markovitz B. Patient origin is associated with duration of endotracheal intubation and PICU length of stay for children with status asthmaticus. *J Intensive Care Med* 2014;29(3):154–9. DOI: 10.1177/0885066613476446. [PubMed: 23753230]
8. Brown KM, Ackerman AD, Ruttan TK, et al. Access to Optimal Emergency Care for Children. *Ann Emerg Med* 2021;77(5):523–531. DOI: 10.1016/j.annemergmed.2021.03.034. [PubMed: 33902828]
9. The National Pediatric Readiness Project, Emergency Medical Services for Children (EMSC) National Resource Center. (<https://emscimprovement.center/domains/pediatric-readiness-project/>).
10. Ames SG, Davis BS, Marin JR, et al. Emergency Department Pediatric Readiness and Mortality in Critically Ill Children. *Pediatrics* 2019;144(3). DOI: 10.1542/peds.2019-0568.

11. Newgard CD, Lin A, Goldhaber-Fiebert JD, et al. Association of Emergency Department Pediatric Readiness With Mortality to 1 Year Among Injured Children Treated at Trauma Centers. *JAMA Surg* 2022;157(4):e217419. DOI: 10.1001/jamasurg.2021.7419. [PubMed: 35107579]
12. Newgard CD, Lin A, Malveau S, et al. Emergency Department Pediatric Readiness and Short-term and Long-term Mortality Among Children Receiving Emergency Care. *JAMA Netw Open* 2023;6(1):e2250941. DOI: 10.1001/jamanetworkopen.2022.50941.
13. Newgard CD, Lin A, Olson LM, et al. Evaluation of Emergency Department Pediatric Readiness and Outcomes Among US Trauma Centers. *JAMA Pediatr* 2021. DOI: 10.1001/jamapediatrics.2021.1319.
14. Newgard CD, Lin A, Goldhaber-Fiebert JD, et al. Association of Emergency Department Pediatric Readiness With Mortality to 1 Year Among Injured Children Treated at Trauma Centers. *JAMA Surg* 2022:e217419. DOI: 10.1001/jamasurg.2021.7419. [PubMed: 35107579]
15. von Elm E, Altman DG, Egger M, et al. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: guidelines for reporting observational studies. *Journal of clinical epidemiology* 2008;61(4):344–9. DOI: 10.1016/j.jclinepi.2007.11.008. [PubMed: 18313558]
16. Feudtner C, Feinstein JA, Zhong W, Hall M, Dai D. Pediatric complex chronic conditions classification system version 2: updated for ICD-10 and complex medical technology dependence and transplantation. *BMC Pediatr* 2014;14:199. DOI: 10.1186/1471-2431-14-199. [PubMed: 25102958]
17. Alessandrini EA, Alpern ER, Chamberlain JM, et al. Developing a diagnosis-based severity classification system for use in emergency medical services for children. *Academic emergency medicine : official journal of the Society for Academic Emergency Medicine* 2012;19(1):70–8. DOI: 10.1111/j.1553-2712.2011.01250.x. [PubMed: 22251193]
18. HCUP Clinical Classifications Software (CCS) for ICD-9-CM. Agency for Healthcare Research and Quality. (<https://www.hcup-us.ahrq.gov/toolssoftware/ccs/ccs.jsp>).
19. Abbreviated Injury Scale (AIS) 2005 Manual. Barrington,IL: Association for the Advancement of Automotive Medicine, 2005.
20. Baker SP, O'Neill B, Haddon W Jr., Long WB. The injury severity score: a method for describing patients with multiple injuries and evaluating emergency care. *The Journal of trauma* 1974;14(3):187–96. (<https://www.ncbi.nlm.nih.gov/pubmed/4814394>). [PubMed: 4814394]
21. Fleischman RJ, Mann NC, Dai M, et al. Validating the Use of ICD-9 Code Mapping to Generate Injury Severity Scores. *J Trauma Nurs* 2017;24(1):4–14. DOI: 10.1097/JTN.0000000000000255. [PubMed: 28033134]
22. Jaro MA. Probabilistic linkage of large public health data files. *Statistics in medicine* 1995;14(5–7):491–8. (In eng) (<http://www.ncbi.nlm.nih.gov/pubmed/7792443>). [PubMed: 7792443]
23. Newgard CD. Validation of probabilistic linkage to match de-identified ambulance records to a state trauma registry. *Academic emergency medicine : official journal of the Society for Academic Emergency Medicine* 2006;13(1):69–75. (In eng). DOI: j.aem.2005.07.029 [pii] 10.1197/j.aem.2005.07.029. [PubMed: 16365326]
24. Newgard CD, Malveau S, Zive D, Lupton J, Lin A. Building A Longitudinal Cohort From 9-1-1 to 1-Year Using Existing Data Sources, Probabilistic Linkage, and Multiple Imputation: A Validation Study. *Academic emergency medicine : official journal of the Society for Academic Emergency Medicine* 2018. DOI: 10.1111/acem.13512.
25. Organization WH. International Statistical Classification of Diseases and Related Health Problems (ICD), ICD-10 Version 2019. (<https://icd.who.int/browse10/2019/en>).
26. O'Malley P, Barata I, Snow S, American Academy of Pediatrics Committee on Pediatric Emergency M, American College of Emergency Physicians Pediatric Emergency Medicine C, Emergency Nurses Association Pediatric C. Death of a child in the emergency department. *J Emerg Nurs* 2014;40(4):e83–e101. DOI: 10.1016/j.jen.2014.05.003. [PubMed: 24998719]
27. Brown J, Lane A, Cooper C, Vassar M. The Results of Randomized Controlled Trials in Emergency Medicine Are Frequently Fragile. *Ann Emerg Med* 2019;73(6):565–576. DOI: 10.1016/j.annemergmed.2018.10.037. [PubMed: 30551894]

28. Harron K, Woolfall K, Dwan K, et al. Deferred Consent for Randomized Controlled Trials in Emergency Care Settings. *Pediatrics* 2015;136(5):e1316–22. DOI: 10.1542/peds.2015-0512. [PubMed: 26438711]
29. Whitfill T, Gawel M, Auerbach M. A Simulation-Based Quality Improvement Initiative Improves Pediatric Readiness in Community Hospitals. *Pediatr Emerg Care* 2018;34(6):431–435. DOI: 10.1097/PEC.0000000000001233. [PubMed: 28719479]
30. Cunningham RM, Walton MA, Carter PM. The Major Causes of Death in Children and Adolescents in the United States. *N Engl J Med* 2018;379(25):2468–2475. DOI: 10.1056/NEJMSr1804754. [PubMed: 30575483]
31. Goldstick JE, Cunningham RM, Carter PM. Current Causes of Death in Children and Adolescents in the United States. *N Engl J Med* 2022;386(20):1955–1956. DOI: 10.1056/NEJMc2201761. [PubMed: 35443104]
32. Jullien S Sudden infant death syndrome prevention. *BMC Pediatr* 2021;21(Suppl 1):320. DOI: 10.1186/s12887-021-02536-z. [PubMed: 34496779]
33. Denny SA, Quan L, Gilchrist J, et al. Prevention of Drowning. *Pediatrics* 2021;148(2). DOI: 10.1542/peds.2021-052227.

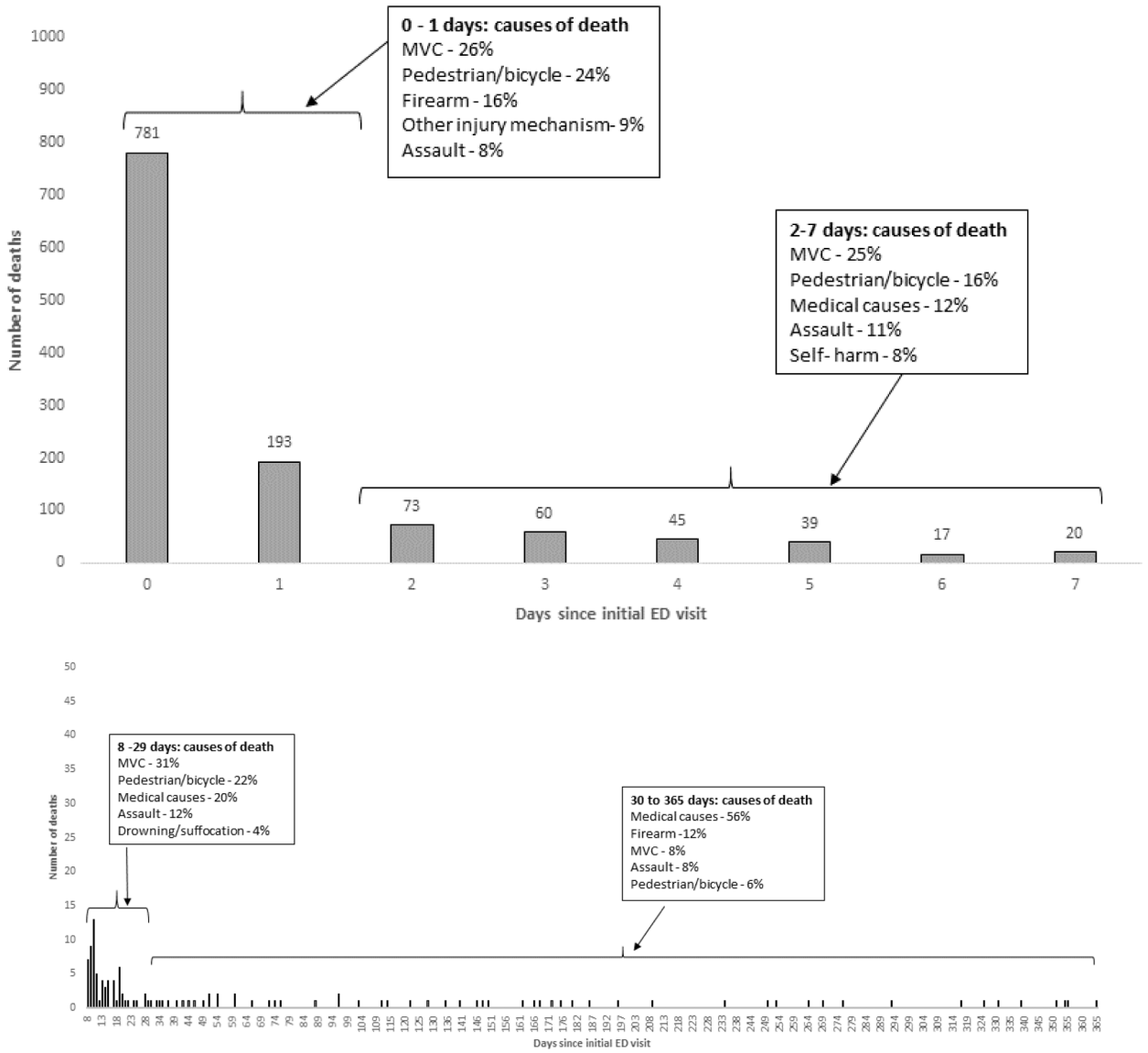


Figure 1. Timing and causes of death* among children presenting to the ED with *injury* (n = 1,351 deaths)

A. Deaths within 0–7 days of ED presentation (n=1,228 deaths).

B. Deaths within 8–365 days of ED presentation (n=123 deaths).

*Deaths from the injury cohort included in the figures are limited to those where time-to-death was known (1,351 of 1,356 deaths). The causes of death are based on patients with matched death certificates (n = 858 of 1356 deaths). Note change in scale of y axis between panels A and B for clarity.

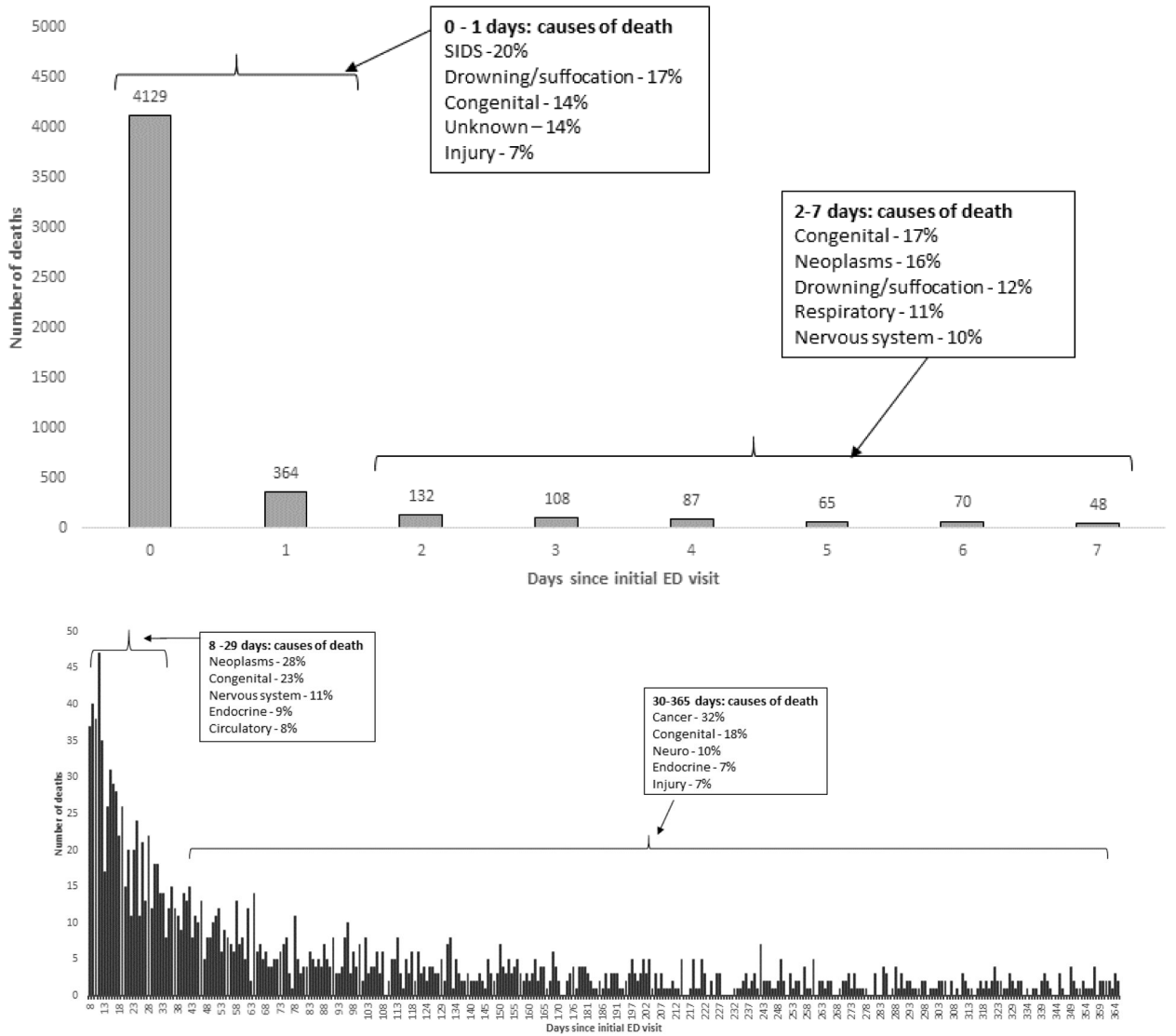


Figure 2.
 Timing and causes of death* among children presenting to the ED with *acute medical illness* (n = 6,676 deaths).
 A. Deaths within 0–7 days of ED presentation (n=5,003 deaths).
 B. Deaths within 8–365 days of ED presentation (n=1,673 deaths).
 *Patient deaths included in the figures are limited to those where time-to-death was known (6,676 of 6,687 deaths). The causes of death are based on patients with matched death certificates (n = 4,712 of 6687 deaths). Note change in scale of y axis between panels A and B for clarity.
 *Causes of death are provided for deaths with a matched death record (X of X deaths, X%). Note change in scale of y axis between panels A and B for clarity.

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Table 1.

Comparison of children who survived versus died within one year of ED presentation, separated by injury versus medical illness presentations.

Injury Cohort (n=62,571)		
	Survival to 1 year	Death within 1 year
	n=61,215 (97.8%)	n=1,356 (2.2%)
Median age (IQR)	10 (4–15)	11(3–16)
Age group:		
< 1 year	5326 (8.7%)	134 (9.9%)
1–4 years	17686 (28.9%)	385 (28.4%)
5–12 years	15054 (24.6%)	221 (16.3%)
13–17 years	23149 (37.8%)	616 (45.4%)
Female	22427 (36.6%)	451 (33.3%)
Chronic complex conditions		
1	2924 (4.8%)	204 (15.0%)
2	831 (1.4%)	163 (12.0%)
Mechanism of injury:		
Fall	23742 (38.8%)	98 (7.2%)
Firearm	1336 (2.2%)	289 (21.3%)
Stab/penetrating	3104 (5.1%)	37 (2.7%)
Assault	6013 (9.8%)	70 (5.2%)
Motor vehicle	7634 (12.5%)	327 (24.1%)
Pedestrian or bicycle	6096 (10.0%)	276 (20.4%)
Other	13290 (21.7%)	259 (19.1%)
Injury severity:		
ISS 0–8	43738 (71.4%)	211 (15.6%)
ISS 9–15	13962 (22.8%)	503 (37.1%)
ISS 16	3515 (5.7%)	642 (47.3%)
AIS head 3	7752 (12.7%)	1102 (81.3%)
AIS chest 3	2509 (4.1%)	793 (58.5%)
AIS abdomen 3	689 (1.1%)	739 (54.5%)
AIS extremity 3	5809 (9.5%)	708 (52.2%)
Severe clinical severity (score 4–5)	29518 (48.2%)	1272 (93.8%)
Major surgery	4324 (7.1%)	652 (48.1%)
Inter-hospital transfer	3776 (6.2%)	47 (3.5%)
Medical cohort (n=483,293)		
	(n=476,606, 98.6%)	(n=6,687, 1.4%)
Mean age	3(0–11)	0(0–7)
Age group:		
< 1 year	167031 (35.0%)	3563 (53.3%)

1–4 years	126964 (26.6%)	1447 (21.6%)
5–12 years	81762 (17.2%)	781 (11.7%)
13–17 years	100849 (21.2%)	896 (13.4%)
Female	221255 (46.4%)	2867 (42.9%)
Chronic complex conditions		
1	42534 (8.9%)	910 (13.6%)
2	20300 (4.3%)	1269 (19.0%)
Top 5 diagnoses at ED presentation:		
Circulatory diseases	36651 (7.7%)	4475 (66.9%)
Respiratory diseases	195606 (41.0%)	2167 (32.4%)
Perinatal and congenital conditions	105618 (22.2%)	1924 (28.8%)
Endocrine, nutritional, digestive, and metabolic diseases	119681 (25.1%)	1590 (23.8%)
Nervous system diseases	55532 (11.7%)	1567 (23.4%)
Severe clinical severity (score 4–5)	247935 (52.0%)	6273 (93.8%)
Major surgery	64648 (13.6%)	1184 (17.7%)
Inter-hospital transfer	24818 (5.2%)	241 (3.6%)

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Table 2.

Timing and etiology of death for children who died within 365 days of the ED visit.

<i>Injury cohort deaths, n=1,356</i>			
	ED deaths	Inpatient deaths	Deaths after discharge
N (%)	693 (51.1%)	581 (42.9%)	82 (6.1%)
Median days to death from ED presentation (IQR)*	0 (0–0)	2 (1–4)	53 (10–172)
Cause of death †(n = 858):	n=395	n=381	n=82
MVC and other transport	107(27.1%)	102 (26.8%)	<30 (11%)
Pedestrian/bicycle	103(26.1%)	76 (19.9%)	<30 (5%)
Firearm	63(15.9%)	42 (11.0%)	<30 (7%)
Assault	<30 (7%)	43 (11.3%)	<30 (6%)
Falls/Mechanical forces	<30 (7%)	<30 (7%)	<30 (2%)
Self-harm	<30 (7%)	34 (8.9%)	<30 (5%)
Neoplasms, blood and immune diseases	0 (0%)	<30 (<1%)	<30 (18%)
Other injury causes	<30 (2%)	<30 (2%)	<30 (2%)
Medical causes	<30 (8%)	45 (11.8%)	35 (42.7%)
Median days from discharge to death (IQR)‡	-	-	45 (5–160)
Repeat ED visits or readmissions after discharge (any)	-	-	<30 (31.7%)
Location of post-discharge death:			
ED	-	-	<30 (20%)
Hospital Inpatient	-	-	33 (40.2%)
Hospice	-	-	<30 (9%)
Home	-	-	<30 (21%)
Other	-	-	<30 (11%)
<i>Medical cohort deaths, n=6,687</i>			
N (%)	4150 (62.1%)	931 (13.9%)	1606 (24%)
Median days to death from ED presentation (IQR) *	0 (0–0)	3 (1–10)	54 (18–147)
Cause of death † (n = 4712):	n=2,474	n=632	n=1606
Sudden infant death syndrome	532 (21.5%)	11 (1.7%)	21 (1.3%)
Suffocation/drowning	442 (17.9%)	64 (10.1%)	55 (3.4%)
Perinatal and congenital conditions	322 (13.0%)	133 (21.0%)	304 (18.9%)
Respiratory diseases	145 (5.9%)	62 (9.8%)	86 (5.4%)
Circulatory diseases	121 (4.9%)	61 (9.7%)	76 (4.7%)
Nervous system diseases	78 (3.2%)	59 (9.3%)	159 (9.9%)
Infectious diseases	53 (2.1%)	53 (8.4%)	70 (4.4%)
Neoplasms, blood and immune diseases	34 (1.4%)	62 (9.8%)	517 (32.3%)
Endocrine, nutritional, digestive, and metabolic diseases	71 (2.9%)	49 (7.8%)	122 (7.6%)
Other medical causes	<30 (<1%)	<30 (<1%)	<30 (2%)
Injury causes, including poisoning and self-harm	294 (11.9%)	47 (7.4%)	130 (8.1%)

Unknown	366 (14.8%)	<30 (3.9%)	39 (2.4%)
Median days from discharge to death (IQR)[‡]	-	-	48(13–145)
Repeat ED visits or readmissions after discharge (any)	-	-	868 (54.1%)
Location of post-discharge death:			
ED	-	-	765 (47.6%)
In-hospital	-	-	191 (11.9%)
Hospice	-	-	80 (5.0%)
Home	-	-	490 (30.5%)
Other	-	-	72 (4.5%)
Unknown			<30 (<1%)

* Days-to-death was based on patients with known dates for the initial ED visit and day of death (1,351 of 1,356 deaths in the injury cohort and 6,676 of 6,687 deaths in the medical cohort).

[†] Cause of death was only available for pediatric deaths with a linked death certificate, representing 858 (63.3%) of 1,356 deaths in the injury cohort and 4,712 (70.5%) of 6,687 deaths in the medical cohort. For cells with less than 30 patients, absolute numbers are not presented and percentages are rounded to whole numbers based on our data use agreements.

[‡] Among patients who died after discharge, days-to-death was based on patients with observed values for date of discharge and date of death (73 of 82 deaths in the injury cohort and 1,527 of 1,696 deaths in the medical cohort).