Cardiovascular deaths in children: General overview from the National Center for the Review and Prevention of Child Deaths

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Background Cardiovascular conditions rank sixth in causes of death in 1- to 19-year-olds. Our study is the first analysis of the cardiovascular death data set from the National Center for the Review and Prevention of Child Deaths, which provides the only systematic collection of cardiovascular deaths in children.

Methods We developed an analytical data set from the National Center for the Review and Prevention of Child Deaths database for cardiovascular deaths in children 0 to 21 years old, reviewing 1,098 cases from 2005 to 2009 in 16 states who agreed to participate.

Results Cardiovascular cases were aged 4.8 ± 6.6 years; 55.3%, ≤1 year; 24.6%, ≥10 years; male, 58%; white, 70.5%; black, 22.3%; Hispanic, 19.5%. Prior conditions were present in 48.5%: congenital heart disease, 23%; cardiomyopathies, 4.6%; arrhythmia, 1.7%; and congestive heart failure, 1.6%. Deaths occurred most frequently in urban settings, 49.2%; and in the hospital, 40.4%; home, 26.1%; or at school/work/sports, 4.8%. Emergency medical services were not evenly distributed with differences by age, race, ethnicity, and area. Autopsies (40.4%) occurred more often in those >10 years old (odds ratio [OR] 2.9), blacks (OR 1.6), or in those who died at school/work/sports (OR 3.9). The most common cardiovascular causes of death included congenital heart disease, 40.8%; arrhythmias, 27.1%; cardiomyopathy, 11.8%; myocarditis, 4.6%; congestive heart failure, 3.6%; and coronary artery anomalies, 2.2%.

Conclusions Our study identified differences in causes and frequencies of cardiovascular deaths by age, race, and ethnicity. Prevention of death may be impacted by knowledge of prior conditions, emergency plans, automated external defibrillator programs, bystander cardiopulmonary resuscitation education, and by a registry for all cardiovascular deaths in children. (Am Heart J 2015;169:426-437.e23.)

Etiology of childhood cardiovascular death

Cardiovascular deaths in children, which rank sixth in causes of death in 1- to 19-year-olds,[1] are associated with identified congenital heart disease (CHD) or with other structural and electrical cardiac abnormalities including hypertrophic cardiomyopathy, other cardiomyopathies, coronary artery anomalies, or electrical conditions including long QT syndrome as well as other acquired cardiovascular conditions.[2,3] These deaths may be sudden and unexpected.[4]

National Center for the Review and Prevention of Child Deaths

The only systematic collection of cardiovascular death in children resides in the database of the National Center for the Review and Prevention of Child Deaths (NCRPCD) housed at the Michigan Public Health Institute (MPHI) with partial funding from the Maternal and Child Heath Bureau of the Health Resources and Services Administration of the Department of Health and Human Services. The overall development of this database has been previously described in detail.[5] The NCRPCD has developed a standardized reporting system for all states and municipalities reviewing child deaths. In 2005, NCRPCD initiated its Web-based case reporting system (CRS), built initially using MS-ASP.net, and made it available to all local and state review teams with 35 states participating in 2011 and 43 by 2014. Data entered

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into the system are stored on secure servers at MPHI. The system captures data on the child, the circumstances surrounding the death, the death investigation, and services offered to the family. Extensive data elements are included that address risk factors for most major causes of injury-related death and other elements that relate to all categories of deaths, including natural or medical deaths. Access to the system is allowed upon the signing of a data sharing agreement between a state and MPHI. A data dictionary and data code book is available and is linked to every data element in the Web system. There are >1,200 state and local child death review teams in all 50 states and the District of Columbia, 43 of whom use the NCRPCD-CRS, often under the state health departments or other legal organizations within the state with a varying scope from state to state.[6]

Development of a data set of natural cardiovascular deaths from the current NCRPCD database to study cardiovascular deaths in children

In the NCRPCD database report in 2011, 2.4% of the database was categorized as a natural cardiovascular death[5] compared to 3% to 5% of childhood deaths from a cardiovascular cause in the national vital statistics database for the same year.[7]

We have previously described the process that we used to develop an analytical data set to inform our understanding of cardiovascular deaths in children from data in the NCRPCD database on natural cardiovascular deaths.[8] This database was not originally developed to evaluate cardiovascular deaths; thus, substantial manipulation was required to achieve our goals including reclassification, recategorization, and the development of new variables from existing data.[8]

We have identified aspects of this database that could benefit from systematic changes in the CRS and review process including changes in and clarification of questions, fewer free-text choices, requirement to supply answers to critical questions resulting in fewer missing data, additional training and educational information provided to the child death review (CDR) teams regarding cardiovascular deaths and provision of cardiovascular expertise to the CDR teams for cardiovascular case discussion.[8]

The goal of this manuscript is to describe, for the first time, the characteristics of cardiovascular deaths in children from the analytical data set that we developed from the CRS of the NCRPCD. In addition, we aimed to identify modifiable risk factors and uncover potential disparities. The information gleaned from our study could inform the development of the Registry for Sudden Death in the Young by identifying gaps in knowledge and limitations in information gathering about cardiovascular deaths that could be remedied in future data collection efforts.[9] Currently, services and prevention are hindered by a lack of understanding of the potential to prevent these natural cardiovascular deaths. Limited knowledge of the relative contribution of modifiable risk factors within the various fixed demographic groups, including age, gender, race, and ethnicity, hinders our ability to target preventive efforts.

Methods

Cardiovascular analytical data set development overview

After our study was funded by the Maternal and Child Heath Bureau of the Health Resources and Services Administration and approved by the Institutional Review Board of The Children's Hospital of Philadelphia, we partnered with the NCRPCD to review the natural cardiovascular deaths in their database. Twenty-five states reported natural cardiovascular deaths in the NCRPCD system during our study interval and were contacted for participation. Sixteen states signed a data sharing agreement to participate; 12 agreed to provide additional narrative data. An example of the CRS case report is shown in online Appendix A along with the variables of interest for this data set (online Appendix B) and the detailed information regarding these variables (online Appendix C).

Challenges to building a final analytical data set were identified and included reclassification, recategorization, and the development of new variables from existing data with examples of reclassification and recategorization for medical conditions, activity, and place of death shown in Supplementary Tables I, II, and III.

Review interval and target population. We searched all completed cases from 0 to 21 years identified as having a natural death from cardiovascular causes from 2005 to 2009. Some reviews were not completed until 2011 as it can take from <1 to 3 years after a death for certification of completion related to the process within the specific state CDR teams. This includes review of medical records, autopsy data, scene investigations, the CDR meetings, and narrative development as well as actual data entry, cleaning, quality assurance checks, and completion. The sample size consisted of 1,098 cases from the 16 participating states.

Variables of interest in the NCRPCD data set

All of our cases were natural (medical) cardiovascular deaths. The variable list consists of the following broad categories: A. Child information, B. Caregiver information, D. Incident information, E. Investigation information, F. Detailed information by Cause of death, G. Circumstances of incident, J. Services provided, K. Prevention initiatives, and M. Narratives. The variables evaluated are a subset of the 1,895 variables in our original data set from the case report form. Details on these sections can be found in online Appendix C.

Statistical analysis. The analyses were primarily descriptive and were conducted in SAS 9.2 (SAS Institute, Inc, Cary, NC) and Stata 13.0 (StataCorp LP, College Station, TX). Statistical analyses included 2-sided tests of hypotheses with a $P < .05$ as the criterion for statistical significance. Continuous variables were described using means, SDs, medians, and interquartile ranges. Discrete variables were tabulated and cross-tabulated to explore