Sudden Cardiac Death of the Young in Michigan: Development and Implementation of an Innovative Mortality Review System

Janice Bach, MS, CGC,[1] Ann Annis Emeott, MPH, RN,[1] Beth Hanna, RN,[2] Deb Duquette, MS, CGC,[1]
Velma Theisen, MSN, RN,[3] Sarah Lyon-Callo, MA, MS,[1] Kenneth Rosenman, MD[2]

BACKGROUND

- Sudden Cardiac Death (SCD) is an unexpected sudden death due to a cardiac cause and occurring out of hospital or in the emergency department (ED)[1]
- SCD of the young (<30 years, SCDY) is a potentially preventable condition, due to the heritable nature of certain cardiac disorders
  - Causes of SCDY are more likely to have genetic determinants than similar conditions in older persons[2]
  - Heritable etiologies of SCDY include hypertrophic cardiomyopathy,[3] inherited arrhythmias,[3] and early atherosclerotic heart disease[4]
  - Immediate family members of SCDY victims may be at increased risk of sudden death
- To learn more about the burden of SCDY in Michigan, a pilot mortality review system was implemented in 2007

OBJECTIVES

- The pilot mortality review project aims to: 1) conduct an epidemiological assessment of the burden of SCDY in Michigan; and 2) develop an expert review process to identify public health and medical system changes, and family-based interventions that might lead to prevention opportunities, including appropriate follow-up for relatives potentially at risk.

METHODS

- SCDY was defined as a death to a Michigan resident, aged 1-29, occurring out of hospital or in the ED, and having one of the following underlying causes of death: cardiac causes (ICD-10 codes: I00-I51), congenital cardiac malformations (Q20-Q24), or ill-defined (R96-R99)
- Causes of death identified on 1999-2006 death certificates from the Michigan Department of Community Health Division for Vital Records were ascertained
- In-depth case investigation, including medical records review and next-of-kin interview, was completed for select SCDY cases
- De-identified case summaries were discussed by the SCDY Expert Review Panel

RESULTS

SCDY Epidemiology

- SCDY in Michigan exhibited health disparities in sex, age, and race. (Graphs A & B)
- **Approximately 65% of cases were male**, whereas 35% were female. Incidence decreased from age 1-4 years to age 5-9 years, then substantially increased thereafter. (Graph A)
- Only 18% of Michigan's population of 1-29 year olds is black, whereas 79% is white. However, **SCDY appeared to affect blacks disproportionately.** (Graph B)
- The distribution of cardiac, congenital, and ill-defined causes of death differed among the age groups (Graph C), with the proportion of SCDY due to congenital causes higher among those aged 14 and younger, and **the proportion due to cardiac causes higher among those aged 15 and older**. The proportion of SCDY due to ill-defined causes was highest among 1-4 year olds.
- **Cardiomyopathies were the most frequently reported causes of SCDY.** (Table 1)

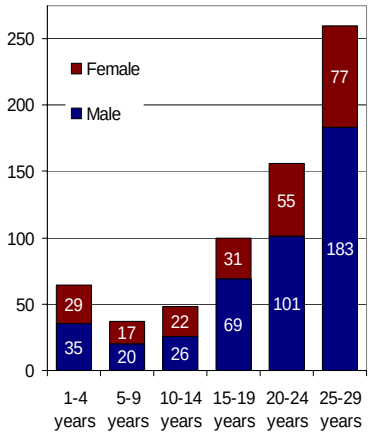
Expert Review Panel Meeting

- The SCDY Expert Review Panel, consisting of 14 experts representing adolescent medicine, cardiology clinical genetics, emergency medicine, health plan, medical examiner, pharmacology, primary care, public health, and sports medicine met in October 2007.
- Four deaths that occurred in late 2006 were reviewed and discussed. (see example below)
- Causal factors implicated in these deaths were categorized as *patient-related*, *provider-related*, or *system-related*. They included: **a lack of provider/insurance, failure to seek medical care for symptoms, delay in seeking emergency services, and potential unrecognized familial cardiac disorders, which presented implications for immediate family members.**

A Case Study Example

A black male in his early 20's complained of not feeling well after spending the evening with friends. He drove home, where later a witness saw him begin to shake, then collapse and become unconscious. His mother initiated CPR, and EMS arrived to find him unresponsive and pulseless. He was pronounced dead on the scene. Cause of death was undetermined by autopsy. He was a non-smoker, with a BMI of 23. Previous history included syncope, shortness of breath with exertion, fatigue, and family history of hypertension.

Graph A: SCDY in Michigan, by age and sex, 1999-2006



Graph B: SCDY in Michigan, by race, 1999-2006

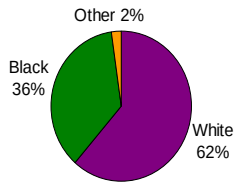
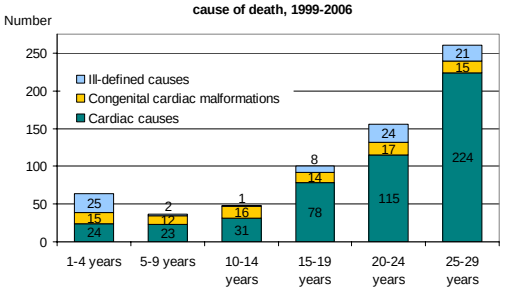


Table 1: Ten most frequent underlying causes of death of Michigan SCDY victims, 1999-2006 (n=665)

Underlying cause of death	Number	Percent
Dilated cardiomyopathy	86	12.93
Other hypertrophic cardiomyopathy	62	9.32
Other ill-defined and unspecified causes of mortality	49	7.37
Cardiac arrhythmia	44	6.62
Congenital malformation of the heart	44	6.62
Cardiomyopathy	35	5.26
Myocarditis	34	5.11
Acute myocardial infarction	30	4.51
Atherosclerotic cardiovascular disease	27	4.06
Instantaneous death	21	3.16

Graph C: SCDY in Michigan, by age group and underlying cause of death, 1999-2006



DISCUSSION

- The Michigan Department of Community Health, Genomics Program, in collaboration with the Cardiovascular Health, Nutrition and Physical Activity Section and Michigan State University has begun to implement a mortality review system for sudden cardiac death of the young. Components include epidemiological analysis of death records and a pilot process to investigate selected cases more thoroughly. Experts have begun to identify contributing factors and possible interventions. Additional deaths are currently being investigated, for later review by the panel. Recommendations from the panel will be used to improve the review process, and guide ongoing development of evidence-based public health recommendations for prevention.
- We expect this mortality review system to result in a more comprehensive understanding of the factors that contribute to SCDY, and to identify family, public, and provider needs. Future plans include development of a follow-up component for contacting next-of-kin in families who appear to be at increased risk; preparation of a summary document describing the SCDY burden in Michigan; convening a stakeholder meeting to discuss consensus recommendations; provider education and a public awareness campaign.
- The SCDY review system is just one example of a successful model for the application of genomics and family history to public health practice and surveillance in the State of Michigan.

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AFFILIATIONS

1. Michigan Department of Community Health (MDCH) Division of Genomics, Perinatal Health, and Chronic Disease Epidemiology
2. Michigan State University, Division of Occupational and Environmental Medicine
3. MDCH Division of Chronic Disease and Injury Control, Cardiovascular Health Nutrition and Physical Activity Section