The Asthma Mortality Review and Sudden Cardiac Death of the Young (SCDY) Mortality Review

Investigators:

Asthma
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Betsy Wasilevich, MPH, PhD

Sudden Cardiac Death of the Young (SCDY)
Beth Anderson, MPH
Janice Bach, MS
Deb Duquette, MS

Ken Rosenman, MD
Beth Hanna, RN
Purpose

- Implement and refine a process to collect and review medical data
- To identify recommendations as a step toward evidence-based medical system changes and public health prevention efforts that will reduce the occurrence of these deaths
- Identify unmet needs for family-based interventions including education, support, medical/genetic resources
2 Death Reviews...
A Common Methodology
Asthma Mortality Review Process

**Notification**
- Death occurs
- Reported to MDCH
- MDCH staff notified
- Obtain death certificate

**Investigation**
- Certificate to MSU
- Next of Kin Interview
- Records Request
- RN summarizes & MD approves

**Panel Review**
- Identify risk factors
- Recommendation
- Reporting
- ACTION
Data Collection

- Structured interview with next-of-kin
- Records request to Medical Examiner
- Request all records for year prior to death from
  - EMS
  - Hospital
  - Pharmacies
  - Primary and specialty care practices
- Medicaid claims history
- If no interview, difficult to obtain records
Blinded Case Summaries

- Death Certificate: age, race, sex, month of death
- Interview: SES, psychosocial issues, symptom & management history, information on fatal attack
- Autopsy/toxicology results & day of death reporting
- Pharmacy records: frequency and type of medications filled
- Chart Abstraction: Frequency of visits, medications prescribed, management plan, referrals, available lab and other procedures
Expert Panel Membership

- **Asthma Death:**
  Specialty, primary care and emergency department doctors, nursing and respiratory staff, social workers

- **Sudden Cardiac Death**
  Cardiac Specialties, primary care and emergency room doctors, nursing, pathologist, geneticist, health plan policy administrator
Expert Review Panel Responsibilities

- Review and discuss each case
- Develop prioritized list of causal factors
- Develop prioritized list of follow-up activities supported
  - Recommend actions to prevent each case
  - Decide if familial risks exist for surviving family members (SCDY only)
- Review year end summary of recommendations
- Provide guidance on implementation of recommendations
Asthma Mortality Review Project

Findings and Activities
Asthma Defined

- Chronic inflammatory disease of the airways
- Causes recurrent episodes of
  - Wheezing
  - Breathlessness
  - Chest tightness
  - Coughing
- Episodes are usually associated with airflow obstruction that is often reversible either spontaneously or with treatment

During an asthma attack...

**Normal Airway**
- Mucus gland
- Airway
- Muscle layer

**Asthma Airway**
- Smaller airway opening
- Mucus fills up airway
- Muscle layer squeezes airway
Triggers of Asthma Attacks

- Narrowing of airways occurs in response to inflammation or hyperresponsiveness to triggers, including:
  - Allergens
  - Infections
  - Diet/Medications
  - Strong Emotions
  - Exercise
  - Cold temperature
  - Exposure to irritants
How is asthma treated?

Expert Panel Report 3
National Asthma Education and Prevention Program
National Heart, Lung, and Blood Institute, 2007

Key Messages:

• Inhaled corticosteroids are the most effective medication for long term management of persistent asthma
• All patients should receive:
  1. Asthma Action Plan
  2. Initial assessment of asthma severity
  3. Review of the level of asthma control at all follow-up visits
  4. Periodic follow-up visits (every 6 months)
  5. Assessment of exposure/sensitivity to allergens and irritants, recommendations to reduce
  6. Asthma education by qualified health professional
  7. Referral to asthma specialist (when appropriate)
  8. Education re: overuse of rescue medication
  9. Education re: risk factors of asthma death
Managing Asthma: Asthma Management Goals

- Prevent chronic and troublesome symptoms
- Maintain normal lung function
- Maintain normal activity levels
- Prevent exacerbations
- Minimize ED visits/hospitalizations
- Provide optimal therapy
- Meet patients’/families’ expectations of care
Case Study

Background

- African-American female pre-teen died from asthma in the fall
- Diagnosis of asthma - infant
- Private health insurance – $10 co-pay
- Parents said that the emergency department and doctor’s office needed to work together.
Case Study

Day of Death
- Woke up in the morning and took a couple breathing treatments
- Called the doctor’s office, but they were at lunch (11:45 am)
- Said happy birthday to her mother and took another breathing treatment
- Brother told her dad that she couldn’t breathe – he drove her to the emergency department
- Lost consciousness on the way to the emergency department
- Died 1:30 pm

Autopsy
- Both lungs were hyperinflated, exuding mucous
- Mucous plugs in the bronchi and deposition of eosinophils
- No evidence of trauma or injury
- Toxicology was negative for drugs and alcohol
Case Study

Medical History

- PCP visits 6 times in year prior to death
- Had not seen a specialist due to some confusion
- ED – 75 times in life, 8 in year prior to death
- Hospitalized – 25 times in life, 4 in year prior to death
- Had been to an asthma clinic 2 weeks prior to death
- Long term control and rescue medicines prescribed
- No smoking, pets, or carpet in her house
- Missed her medications 2-3 times per month
- Had a peak flow meter, occasional use
- Had a written asthma plan and asthma education course
- Had breathing problems almost daily and was awakened at night less than twice per month
- BMI: 95th percentile
<table>
<thead>
<tr>
<th></th>
<th>Children 2-18 yrs 2002-06</th>
<th>Adults 19-34 yrs 2002-05</th>
<th>Adults 45-54 yrs 2006</th>
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</thead>
<tbody>
<tr>
<td>Medicaid Insurance at Time of Death</td>
<td>71%</td>
<td>41%</td>
<td>50%</td>
</tr>
<tr>
<td>Smoker in the Home</td>
<td>46%</td>
<td>57%</td>
<td>64%</td>
</tr>
<tr>
<td>Pets in the Home</td>
<td>47%</td>
<td>60%</td>
<td>67%</td>
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<tr>
<td>Asthma Action Plan</td>
<td>33%</td>
<td>9%</td>
<td>0%</td>
</tr>
<tr>
<td>Prescribed Inhaled Steroids</td>
<td>40%</td>
<td>35%</td>
<td>39%</td>
</tr>
<tr>
<td>Had a Nebulizer</td>
<td>84%</td>
<td>71%</td>
<td>77%</td>
</tr>
<tr>
<td>Pulmonary Function Testing Ever</td>
<td>55%</td>
<td>52%</td>
<td>56%</td>
</tr>
<tr>
<td>Seen by a Specialist during Lifetime</td>
<td>73%</td>
<td>65%</td>
<td>73%</td>
</tr>
<tr>
<td>Previous ED Visit in Year Prior (Avg #)</td>
<td>68% (3.0)</td>
<td>68% (7.3)</td>
<td>73% (3.3)</td>
</tr>
</tbody>
</table>

*Data presented is based on deaths with available information.*
Misclassification of Asthma Deaths

- 2006 special study of all asthma deaths, age 2 years and older (n=118)
- 68% of all asthma deaths had records consistent with that determination
- Inaccuracies increase with age
  - 100% consistency 2-18 years
  - 23% consistency 85+ years
Most Frequent Causal Factors of Asthma Death Identified in Mortality Review

- Compliance issues such as elimination of asthma triggers, follow-up with regular medical care.
- Inadequate use of steroids, and overuse of β-agonists.
- Inadequate prescription of steroids by health care providers.
- Need for specialist referral and pulmonary function testing for high-risk patients.
- Lack of regular medical care with primary care providers.
Asthma Mortality Expert Panel Recommendations

- Case Management
- Timely referral to specialists
- Monitor/Restrict refilling of β-agonists to reduce overuse
- Educate patients and providers (primary and urgent care)
- More comprehensive care in emergency department
Asthma Mortality Review: A Lens

Asthma Management
- Patient
- Provider
- Health Care System

Impact
- Public Health
- Provider
- Policy Development
Impact

- Shared findings with key stakeholders
- Asthma protocol for MI Child Death Review Program
- Provider education module
- ED discharge instructions project (FLARE)
- Informed the Sudden Cardiac Death Review Project
- Informed the Detroit Asthma Mortality Summit
- Informed the Asthma Case Management Program (MATCH)
Acknowledgements

- Health Care providers and Medical Examiners
- Family members and friends of deceased
- Asthma Mortality Review Panel Members
- MDCH Division of Health Statistics and Vital Records
- MPHI Child and Adolescent Health staff

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Sudden Cardiac Death of the Young (SCDY)

Findings and Activities
Sudden Cardiac Death Defined

- Unexpected sudden death due to a cardiac cause and occurring within one hour of the onset of symptoms in an individual who has been in his/her usual state of health, without any known life-threatening condition (Priori et al, 2002)

- An unexpected sudden death due to cardiac cause and occurring out of hospital or in the emergency department (Zheng et al, 1999; MMWR, 2002)
Sudden Cardiac Death of the Young (SCDY) Defined

- Especially tragic event; often high-profile, associated with young athletes
- Variably defined as < 30, < 35, < 40 years of age
- A potentially preventable condition, due to the heritable nature of certain cardiac disorders
  - More likely to have genetic determinants than similar conditions in older persons
  - Immediate family members of SCDY victims may be at increased risk of sudden death
SCDY Risk Factors

- **Dependent of the age**
  - **Over age 40 years**
    - Atherosclerosis
      - typically complex/multifactorial inheritance
      - rare single gene disorders
  - **Under age 40**
    - Depends on country?
    - Congenital heart defects
      - typically complex/multifactorial
      - single gene disorders, teratogens, chromosome abnormalities
    - Long QT syndrome
      - single gene disorder
      - triggers include exercise, swimming, emotional or physical stress, loud noises
    - Hypertrophic cardiomyopathy
      - single gene disorder
      - trigger includes exercise
    - Myocarditis
      - infectious
Family History

Family history is the greatest risk factor for SCDY

As many as 40% of victims have been identified as having a heritable disease

Behavioral Risk Factor Survey (BRFS)

- 2,856 people were asked about SCDY
- 6.3% have a family history of SCDY
- Significantly more blacks (11.2%) than whites (5.4%) reported SCDY

### Table 3

<table>
<thead>
<tr>
<th></th>
<th>%</th>
<th>95% Confidence Interval</th>
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<tbody>
<tr>
<td><strong>Total</strong></td>
<td>6.3</td>
<td>(5.2 - 7.7)</td>
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<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18 – 24</td>
<td>3.8</td>
<td>(1.6 - 8.7)</td>
</tr>
<tr>
<td>25 – 34</td>
<td>8.6</td>
<td>(4.9 - 14.6)</td>
</tr>
<tr>
<td>35 – 44</td>
<td>4.2</td>
<td>(2.4 - 7.1)</td>
</tr>
<tr>
<td>45 – 54</td>
<td>7.7</td>
<td>(5.4 - 10.9)</td>
</tr>
<tr>
<td>55 – 64</td>
<td>5.9</td>
<td>(4.1 - 8.5)</td>
</tr>
<tr>
<td>65 – 74</td>
<td>8.5</td>
<td>(5.4 - 13.3)</td>
</tr>
<tr>
<td>75 +</td>
<td>5.4</td>
<td>(3.5 - 8.2)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>5.4</td>
<td>(3.9 - 7.4)</td>
</tr>
<tr>
<td>Female</td>
<td>7.7</td>
<td>(6.1 - 9.6)</td>
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<tr>
<td><strong>Race/Ethnicity</strong></td>
<td></td>
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</tr>
<tr>
<td>White non-Hispanic</td>
<td>5.4</td>
<td>(4.3 - 6.8)</td>
</tr>
<tr>
<td>Black non-Hispanic</td>
<td>11.2</td>
<td>(7.7 - 16.0)</td>
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<tr>
<td>Other non-Hispanic</td>
<td>9.4</td>
<td>(3.8 - 21.3)</td>
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<tr>
<td>Hispanic</td>
<td>-</td>
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<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than high school</td>
<td>10.8</td>
<td>(5.8 - 19.3)</td>
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<tr>
<td>High school graduate</td>
<td>8.8</td>
<td>(6.6 - 11.7)</td>
</tr>
<tr>
<td>Some college</td>
<td>4.7</td>
<td>(3.3 - 6.8)</td>
</tr>
<tr>
<td>College graduate</td>
<td>4.4</td>
<td>(2.8 - 6.8)</td>
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<tr>
<td><strong>Household Income</strong></td>
<td></td>
<td></td>
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<tr>
<td>&lt; $20,000</td>
<td>7.8</td>
<td>(5.1 - 11.7)</td>
</tr>
<tr>
<td>$20,000 - $34,999</td>
<td>8.4</td>
<td>(5.9 - 11.8)</td>
</tr>
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<td>$35,000 - $49,999</td>
<td>8.8</td>
<td>(5.5 - 13.8)</td>
</tr>
<tr>
<td>$50,000 - $74,999</td>
<td>4.1</td>
<td>(2.1 - 7.9)</td>
</tr>
<tr>
<td>$75,000 +</td>
<td>3.2</td>
<td>(1.9 - 5.2)</td>
</tr>
</tbody>
</table>

* Among all respondents (n = 2,856), the proportion who reported having at least one biological family member that had a sudden cardiac death, or sudden unexplained death, between the ages of 1 and 39.

**Note:** Interviewers were instructed not to include spouses of the respondent, infants less than one year of age, as well as drug-related deaths, traumatic deaths (such as car crashes), suicides, homicides, or individuals who had a long illness.

*b The denominator in this subgroup is less than 50.*
How are the causes of SCDY treated?

- Dependent on the cause
- Examples:
  - Atherosclerosis (pharmacologic, behavior)
  - Long QT syndrome (pharmacologic, ICD)
  - Hypertrophic cardiomyopathy (pharmacologic, ICD, surgery)
  - Congenital heart defects (surgical)
Tentative SCDY Case Definition

- Michigan resident
- Aged 1-39
- Death occurred out of the hospital or in the emergency room
- Underlying cause of death is cardiac-related (ICD-10 codes: I00-I51), congenital cardiac malformations (Q20-Q24), or ill-defined / unexplained (R96-R99)

- Causes of death identified on 1999-2006 death certificates from the Michigan Department of Community Health, Division for Vital Records
ICD Codes (10th Revision)

- I00-I09  Rheumatic heart disease
- I11       Hypertensive heart disease -
- I20-I25  Atherosclerotic heart disease - 3
- I26       Pulmonary embolism
- I30-I31  Pericardium disease
- I33       Endocardium disease
- I34-I38  Valve disorders
- I40       Myocarditis - 2
- I42       Cardiomyopathy - 7
- I44-I45  Conduction disorders
- I46       Cardiac arrest - 2
- I47-I49  Cardiac dysrhythmias - 6
- I50       Heart failure
- I51       Complications and ill-defined heart disease
- Q20-Q24  Congenital abnormalities of the heart
- R96-R99  Ill-defined causes of death - 3

- Died out of hospital, en route, in emergency room
Cases Reviewed

- 23 deaths
- 26.1% were females; 56.5% were African Americans
- 39% were students
- 73.9% had a possible heritable cause
Michigan Case

- African American teenage male
- Student, basketball player
- Reported feeling ‘skipped beats and fluttering’ for 4 months, especially while playing basketball; felt dizzy when rising from chair; felt tired all the time; legs; legs hurt all the time; often asked mom often to place her hand on his chest to feel his ‘rapid heart beat’; he thought symptoms meant he was out of shape so he would practice harder
- Private health insurance coverage
- Family History - mother had “stroke “ as teen; maternal uncle had heart attack at 40 years old
- Sports physical 4.5 months prior
- Never referred to cardiologist of other specialists
Michigan Case Continued

- Playing basketball, collapsed
- No CPR prior EMS
- Locked AED at site, coach no training on AED
- When EMS arrived, large crowd gathered outside swearing and yelling so police called to allow EMS access
- EMS documented no pulse/not breathing; CPR immediately started
- Pronounced dead in ED
- Autopsy performed: hypertrophic cardiomyopathy listed as cause of death
- Toxicology – negative for alcohol, illicit drugs, positive for caffeine
- No family members tested after the death
Sudden Cardiac Death of the Young
Expert Panel: Prevention
Recommendations for this Case

Educate Health Providers
- Quality of pre-participation sports physical

Educate Patients
- None

System-Level Change
- CPR training for sport coaches
- If AED present on-site, require training and availability
- Improvement of pre-participation sports screening
- Mechanism to notify relative of need for screening
Hypertrophic Cardiomyopathy

- Autosomal dominant
  - 50% risk to first degree relatives
  - All first degree relatives should be screened
- Myocardial hypertrophy (wall thickness greater or equal to 13 mm) in the absence of hemodynamic stress
  - Family history is critical!
  - Decrease in exercise tolerance in young
  - Syncope
  - Abnormal ECG and echo
  - Genetic mutations- 11 common identifies 50-60% of patients (genotype-phenotype correlations known)
  - Treatment dependent on severity (pharmacological, ICD, surgical)
Limitations

- Case definition
  - Sensitivity / specificity
- Accuracy / reliability
  - Cause of death (ICD codes)
  - Death certificates
- Novel approach with no defined protocol for state health departments
- Lack of evidence based guidance for population and high risk family screening
- Funding!
A Call to Action

- Advocacy & Support Groups: AHA, SADS, KAYLA, Gillary
- EMS Personnel
- Governor’s Council on Physical Fitness
- Medical: cardiology, primary care, genetics, emergency, sports medicine
- Medical examiners
- MI High School Athletic Association
- Professional organizations: MSMS, ACC
- Public health
- Vendors (AED)

**Sudden Cardiac Death of the Young in Michigan:**

A Call to Action

Thursday, September 18, 2008
Michigan Department of Community Health (MDCH)
Capitol View Conference Center
1:00 p.m. — 5:00 p.m.

**AGENDA**

1:00 Welcome and Overview of Michigan Sudden Cardiac Death of the Young (SCDY) Surveillance Project
   — Gregory Holzman, MD, MPH
   MDCH Chief Medical Executive

1:15 Epidemiology of SCDY in Michigan
   — Beth Anderson, MPH, MDCH Cardiovascular Health Epidemiologist

1:30 Findings from the SCDY Mortality Review
   — Kenneth Rosenman, MD
   Chief, Division of Occupational and Environmental Medicine, Michigan State University

2:05 Introduction to Action Team breakout groups
   — Rochelle Hurst, BSN, MA
   Acting Director, MDCH Division of Chronic Disease and Injury Control

2:15 Networking Break with display tables

2:45 Action Team breakout groups with brief reports on current status/initiatives
   - Pre-participation sports physicals and screenings
     — Gregory Holzman, MD, MPH, MDCH
   - Medical examiner protocols
     — Stephen G. Cole, MD, Spectrum Health
   - Emergency response protocols
     — Robert Swar, M.D., Beaumont Hospital
   - Provider education and public awareness of SCDY risk factors
     — Shariene Mary Day, MD, University of Michigan
   - Public awareness of cardiac symptoms and CPR/AED training
     — John Spina, Life EMS Ambulance

3:30 Break for convience to large group

4:30 Team presentations and review of action agenda
   — Gregory Holzman, MDCH Chief Medical Executive
   — Jean Chabot, MDCH Deputy Director of Public Health Administration

5:00 Adjourn
Action Steps to Address:

- **Pre-participation Sports Screening/Physical and Follow-up**
  - Recommend revisions to MHSAA sports participation form

- **Provider Education and Public Awareness of SCDY Risk Factors**
  - Focus on increasing public awareness through school curricula; create standardized educational presentations for health care provider training

- **Public Awareness of Cardiac Symptoms and CPR/AED Training**
  - Identify gaps in existing CPR/AED training mandates or professional guidelines for specific groups and settings
Action Steps to Address:

- **Emergency Response Protocols**
  - Explore policies and investigate availability of AEDs for volunteer and other non-EMS responders

- **Medical Examiner Protocols**
  - Develop protocols to cover DNA banking for SCDY cases; mechanisms for follow-up with families; and standardized coding for negative autopsy findings
Summary

- Sudden cardiac deaths in young are not common but dramatic
- Investigations of individual deaths highlight problems that may be overlooked or not evident in compiled statistics
- Individual case stories are important for effecting policy change
“I thought we were forgotten....
I thought no one cared...”

- Mother of 18 year old victim, upon being asked for a next-of-kin interview
Sudden Cardiac Death of the Young
Expert Review Committee

Cardiology Adult
Arthur L. Riba, MD
Oakwood Hospital and Medical Center
Sharlene Mary Day, MD
U of Michigan Cardiovascular Center

Cardiology Pediatric
Arnold L. Fenrich, Jr., MD
Helen DeVos Children’s Hospital

Emergency Medicine
Robert Swor, DO
William Beaumont Hospital

Health Plan
Karen Lewis, MS, MM, CGC*
Priority Health

Primary Care
Henry Barry, MD, MS
Michigan State University

Local Public Health
Sugandha Lowhim, MD, MPH
Ingham County Health Department

Medical Examiner
Stephen D. Cohle, MD
Spectrum Health Blodgett Campus

Medical Genetics
Xia Wang, MD, PhD
Henry Ford Health System

Pediatrics
Melissa Hamp, M.D., M.P.H.
Hurley Medical Center

Pharmacology
Lynette Moser, PharmD
Wayne State University

Sports Medicine
Steven Keteyian, PhD
Henry Ford Hospital

Arrhythmia
David J. Bradley, MD
C. S. Mott Children’s Hospital
SCDY Call to Action Report
Available at:

www.michigan.gov/genomics
Discussion Questions

- How might this same process work in your area of expertise? Are there other diseases or risk factors that could use this same approach?
- Who are the audiences that need to hear this information to help move us toward public health action?
- How do we present this information so that it is compelling?