Developing a Sudden Cardiac Death Review System: Approaches and Collaborations

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Introduction
The Michigan Department of Community Health (MDCH) Genomics Unit has identified sudden cardiac death (SCD) of the young (age 1-39 years) as a potentially preventable condition, due to the heritable nature of certain cardiac disorders, and has begun to explore development of a SCD review system.

SCD is a death due to cardiac disease that occurred out of hospital or in an emergency department, or one in which the decedent was reported dead on arrival.

In Michigan, SCD represents about 67.8% of all cardiac deaths.

Specific causes of SCD of the young are more likely to have genetic determinants than similar conditions in older persons. As much as 40% of families with a young SCD victim have been identified as having heritable disease.

Future Directions
To develop a more comprehensive understanding of the factors that contribute to SCD of the young in Michigan.

Objectives
- Increase public and professional awareness of the burden of SCD of the young in Michigan.
- Develop a process to facilitate collection and review of demographic and medical data, as well as other information regarding the circumstances of SCDs in Michigan residents aged 1-39 years.
- Develop evidenced-based public health recommendations for prevention of SCD of the young.
- Identify family members of deceased young SCD victims who may potentially be at increased risk of SCD, and refer for medical and/or genetic evaluation.

Methods & Results: Historical Timeline

CDC Genomics Cooperative Agreement
- Provides funding for the integration of genomics and family health history in chronic disease prevention programs
- Increases genomics leadership capacity at MDCH
- Reviews existing mortality review systems
- Identities external SCD experts and relevant stakeholders
- Develops conceptual framework (logic model) for SCD review process

Cardiovascular Health Advisory Committee
- Group of invited internal and external cardiovascular disease experts
- Genomics staff presents overview of SCD and associated genetic factors
- Solicits interest and discussion of public health implications of SCD of the young
- Key informant interviews
- Medical professionals describe:
  - Variability in amount and completeness of information collected for death certificates
  - Often dependent on level of expertise of medical examiner, and on person completing certificate
  - Benefits of SCD expert review team
  - Promotion of collaborations and communication links among professionals
  - May lead to creation of standardized protocol for autopsy analysis
  - Barriers to SCD review process
  - Time and commitment level of key medical professionals

National and statewide SCD experts and key stakeholders share knowledge and experience
- Breakout groups prioritize goals for SCD review process and identify need for:
  - Mortality review system
  - Public awareness campaign
  - Diverse expert advisory groups for educational and mortality review initiatives

Review of MDCH Vital Records data identified about 300 potential cases of young-onset SCD in Michigan in 2003 that may require further investigation
- The MDCH Genomics Unit and SCD internal work group will continue to review progress and identify next steps for implementing a SCD review system
- Additional funding opportunities to implement a formal SCD review process will be explored in 2006-2007

References

Discussion
Our approach to development of a public health SCD review system has been described. Progress has been made in:
- Statewide Genetics Symposium features presentations on chronic disease, genomics and public health, including:
  - Long QT Syndrome
  - Genetic primary arrhythmogenic disorders
  - University-based expert raises concerns about SCD with genomics and chronic disease staff members at MDCH

Public Health Implications
- A thorough investigation of SCD of the young in Michigan is crucial to the development of preventive measures.
- Since young-onset SCD may have a heritable component, identifying at-risk family members of a young SCD victim for referral to medical and/or genetic services should be a priority in prevention efforts. Additionally, this highlights the importance of family health history and inclusion of family history of SCD of the young in routine health care practices.
- A limitation of the SCD review process is the variability and inconsistency of coding cause of death (ICD codes) on death certificates. There is a need to standardize medical examiner reports and databases for data completeness and comparability across the state of Michigan and nationally.

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