Sudden Cardiac Death of the Young in Michigan: Development and Implementation of a Novel Mortality Review System

Janice Bach, Ann Annis Emeott, Beth Hanna, Deb Duquette, Velma Theisen, Sarah Lyon-Callo, Kenneth Rosenman

Background and objectives: The Michigan Department of Community Health (MDCH) Genomics Program has identified sudden cardiac or unexplained death of the young (under age 40) as a potentially preventable condition, due to the heritable nature of certain cardiac disorders. Specific causes of sudden cardiac death (SCD) in young people are more likely to have genetic determinants than similar conditions in older persons. These include etiologies such as inherited arrhythmias, hypertrophic cardiomyopathy, undetected congenital heart defects, and early atherosclerotic disease. As much as 40% of families with a young SCD victim have been identified as having heritable disease. In an effort to learn more about the burden of sudden death in Michigan, the Genomics Program initiated a pilot sudden death of the young review system in the early summer 2007. The ultimate goal of this project is to reduce the burden of SCD of the young in Michigan by identifying public health and medical system changes as well as family-based interventions that might be undertaken to increase awareness of opportunities for prevention, as well as appropriate screening and treatment for relatives potentially at risk.

Methods: Over the past few years, several preliminary steps in preparation of implementing the SCD review system have been taken, including partnering with a variety of experts and organizations to learn about the burden of SCD; identifying key stakeholders; becoming familiar with other state mortality review systems; developing a conceptual framework for SCD review in Michigan; administering key informant interviews of the medical community; hosting a symposium on SCD of the young; developing public and provider educational materials; and including family history of SCD questions on a statewide survey. In order to better describe and estimate the number of potential cases the SCD review system would capture, mortality data were obtained from MDCH Division for Vital Records and Health Statistics for all deaths to Michigan residents aged 1-39 years, occurring between January 2006 and May 2007, and occurring out of the hospital or in the emergency room, with specific ICD codes mentioned as a cause of death on the death certificate.

Results: Between January and December 2006, a total of 413 deaths met our initial case criteria, corresponding to an annual incidence rate of 7.66 per 100,000. Among these, the primary cause of death matched our ICD code criteria in 280 cases (67.8%). The majority of cases were male (71.7%). Sixty-five point one percent of the cases were white, whereas 33.4% were black. Incidence increased with age, with 67.1% of the deaths occurring among those aged 30-39 years. Approximately 45.3% of the deaths had taken place in the emergency room (ER) or were dead on arrival to the ER, while 42.6% occurred at home. About 74.3% of cases had undergone autopsy.

Discussion/Conclusion: Our process for developing a novel death review system utilized multiple avenues to gather information. For select cases that died between October 2006 and March 2007, medical records for the day of death and for the year prior to death were requested from providers and health care facilities. Select decedents' next-of-kin were contacted and asked to participate in an interview regarding the events surrounding the death. De-identified case summaries were prepared and an advisory panel of 13 members, with varied genetics, cardiac, and medical expertise, was convened to review the cases and provide feedback on the etiologic nature of the deaths and the mortality review process.

Recommendations made by the advisory panel will be used to modify the case definition, improve the review process, and guide ongoing efforts in developing evidence-based public health recommendations for SCD of the young prevention. This project will result in a more comprehensive understanding of the factors that contribute to SCD and the feasibility of utilizing mortality data to identify family, public, and provider needs regarding these deaths.