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## Public Health Approach to Decrease Mortality for Congenital Heart Defects: Dying Too Soon\*

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### Keywords

children's health; congenital heart defects; mortality; outcomes research

With advancements in clinical care, it is unquestionable that survival for both children and adults with congenital heart defects has improved significantly (1). In the United States in 2010, there were an estimated 1.4 million adults and 1 million children living with congenital heart defects (2). Some stakeholders have suggested that survival is no longer a concern, based on improving results in surgical registries. However, in this issue of the *Journal*, the new study by Spector et al. (3) links one of the highest-quality U.S. registries collected for quality improvement to the National Death Index, and demonstrates that despite tremendous advances, people with congenital heart defects are still dying too soon. Even for the most recent time period, the 15-year mortality for those who survived surgery for their congenital heart defects (6.5% had already died before leaving the hospital) was about 10 times higher than for those of the same age and sex in the general population. Surprisingly, the continued excess mortality even among survivors of initial congenital heart surgery was observed not only among those with the most severe defects, like tricuspid atresia or hypoplastic left heart syndrome, but also for those with simple defects, like atrial septal defects, which are frequently viewed as “cured” by surgery (3). To address this early risk for death and improve the health of individuals and families affected by congenital heart defects, a public health approach is essential.

A public health approach focuses on population level rather than individual health, and therefore has the potential to more broadly affect the health of an entire affected population. A public health approach is comprehensive and includes: 1) monitoring or surveillance; 2) epidemiological research; and 3) prevention or intervention. In 2012, the Centers for Disease Control and Prevention convened a meeting of congenital heart disease experts to define

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areas of greatest scientific importance (4). The linkage of the Pediatric Cardiac Care Consortium surgical database cohort to the National Death Index addresses 1 of the key research gaps identified for longer-term outcomes that is part of the Centers for Disease Control and Prevention's Public Health Science Agenda for congenital heart defects, and is a significant accomplishment for which we commend the authors.

Congenital heart defects remain the most common birth defect, with 1 in 110 pregnancies affected, meaning about 40,000 newborns per year in the United States (4). We must use the information provided by Spector et al. (3) as a reminder that a comprehensive public health approach is needed to improve the health of this large and growing population. Although information on selected clinical cohorts is valuable, it is unlikely to be generalizable to the entire population affected by congenital heart defects. Population-based public health surveillance monitors health through an ongoing and systematic collection of data in a defined region and not specific to individuals accessing care at particular institutions, and also includes timely analysis and interpretation of that data to plan for needed services and evaluate the effect of public health interventions. Fortunately, aligned public health efforts on a national scale are already beginning. The Congenital Heart Public Health Consortium (CHPHC) was formed in 2009 as an alliance of stakeholders, including parent and patient groups, professional societies, and federal agencies, to unite efforts and align priorities to improve the lives of those affected by congenital heart defects. The CHPHC has filled critical gaps in facts and figures about the effect of congenital heart defects, and has embarked on educational campaigns, such as the need for lifelong care, care during pregnancy, neurodevelopmental screening, and the importance of early educational intervention. The CHPHC has also developed a framework for a public health agenda for the United States designed to fill critical knowledge gaps and create policies and initiatives to improve health outcomes for people born with congenital heart defects.

Surveillance and research are needed to enhance secondary prevention, as the causes of early mortality among survivors of surgery identified by Spector et al. (3) are not known in detail, nor are ways to improve health care delivery to improve survival, or ways to reduce heart failure, arrhythmias, and associated morbidity to the lungs, kidneys, liver, and brain, all with a major impact on quality of life. A full understanding of the racial or ethnic and socioeconomic disparities in survival among those with congenital heart defects is also lacking, despite the fact that disparities have been documented for many of the leading causes of death in children and adolescents (5); similarly, it is unclear if there are barriers in access to the centers engaged in this quality-improvement initiative described by Spector et al. (3). Only population-based public health surveillance efforts can inform the key question of whether people with congenital heart defects and without access to one of these centers had even poorer survival than the 10-fold excess mortality reported by Spector et al. (3). In addition, there are critical knowledge gaps, such as safety and risks of pregnancy for those with specific types of congenital heart defects, and in particular, information about the overall impact on health and life expectancy, not just limited to complications that occur during and immediately after the pregnancy. The United States is lagging behind some other countries in implementing population-based surveillance networks across the lifespan to understand the health and opportunities for improving health in the population with congenital heart defects (6,7).

A focus on primary prevention of these serious birth defects remains essential. Efforts to reduce the impact of known risk factors for congenital heart defects, such as pre-gestational diabetes and maternal obesity, could reduce the number of newborns affected in the United States (4). There are many initiatives to address the growing public health burden of both obesity and type 2 diabetes. However, the potential impact of the rising number of women with these conditions might increase the number of births affected by congenital heart defects, in addition to other concerns, and efforts to reduce these conditions, especially in pregnant women, are needed. Furthermore, improving newborn screening methods for critical congenital heart defects could minimize the number of children at risk of dying before a diagnosis is established. In addition, early identification of neurodevelopmental issues and early educational interventions can help children with congenital heart defects reach their full potential.

All of these elements are part of a comprehensive public health model: 1) monitoring and surveillance; 2) epidemiological research; and 3) initiatives for prevention or intervention. Uniting and aligning efforts, such as those of the CHPHC, are a beginning; yet, as demonstrated by Spector et al. (3), many gaps remain to reduce the ongoing risk of early death among survivors of congenital heart defect surgery. A sustained commitment to surveillance, research, and prevention across the lifespan is necessary to improve the health of this large and growing population of nearly 2.5 million individuals in the United States to minimize the adverse consequences of these lifelong conditions.

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