



# Addressing mortality in mothers of infants with congenital anomalies

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This article, “Associations between the birth of an infant with major congenital anomalies and subsequent risk of mortality in their mothers” (1), adds to the growing literature revealing the adverse health condition of caretakers of children with severe chronic disease (2,3). Using population-based registries in Denmark, the authors have extended the literature to now include mothers of children with major congenital anomalies and have used as the definitive metric of health, the subsequent death of the mother and her cause of death. Their findings demonstrate an increased risk of death of the mother both within the first 10 years and over the first 35 years after the child’s birth, particularly from cardiovascular and respiratory diseases. The authors suggest that the adverse impact on the child’s mother over the long-term may be a response related to the stress of caring for a child with a birth defect/birth defects.

The 1979–2004 birth cohort (n=2,003,850) yielded a final study group (n=455,250) comprised of those with major congenital anomalies (n=41,508; 9.1%) and a matched comparison group (n=413,742) from those without a major congenital anomaly. The up-to 10-fold match was on maternal age, parity, and birth year (but not on birth hospital or birth county of residence). Hazard ratios (HR) were calculated using multiple confounders and mediators including, but not limited to, diabetes, alcohol use, hypertension, depression, smoking, BMI, age, education, income, and pregnancy complications.

Statistically significant HRs were reported for all causes of mother’s death (HR =1.22; 95% CI, 1.15–1.29) and for certain specific causes of death [cardiovascular disease (HR =1.26; 95% CI, 1.04–1.53), respiratory disease (HR =1.45; 95% CI, 1.01–2.08), and other natural causes (HR =1.50; 95% CI, 1.27–1.76)].

The positive findings are not completely unexpected, though it is surprising that the HR was not elevated for endocrine/nutritional/metabolic diseases (including diabetes) [HR =1.02; 95% CI, 0.58–1.79], for nervous system diseases [HR =0.79; 95% CI, 0.48–1.31] or for deaths by unnatural causes (violence, suicide, motor vehicle accident, etc.) [HR =1.12; 95% CI, 0.92–1.36]. Each of these might contribute to stress-related causes of death.

Caring for a child with major birth defects who may have developmental disabilities, physical disabilities, and may require surgeries is likely to be a stressful situation for caregivers. Some children may not become fully-independent adults, depending upon their specific functional and structural birth defects, creating the need for the caregivers to provide life-long care and prolonging the stressful situation. Stress not only affects the functioning of the body, resulting in increased risks of disease, but may result in unhealthy coping mechanisms that also increase the risks for chronic conditions.

The authors comment that there may be explanations other than stress for the increased risk of mortality such

as genetic factors that might have gone unnoticed in the mothers but could have become factors in the birth defects of the child. Behavior was also another possible explanation for the increased risk as children often model the behaviors of their families related to diet, exercise, and substance use, extending the risk through generations that have the same behaviors. Those maternal behaviors have the potential to increase the risks for structural and functional birth defects in obvious ways, related to diabetes and alcoholism, and in yet unknown ways.

Teratogen Information Specialists who review odds ratios and risk ratios to determine if exposures might increase the risks for birth defects generally are not concerned about a less than two-fold risk, but a more than 20% increased early mortality for the mothers of children with birth defects would be of concern. We suggest that Teratogen Information Specialists, researchers with birth defects registries, and primary care clinicians consider the needs of the caregivers to help mitigate any possible increase in early deaths for mothers of children with birth defects.

The study was conducted for births and mothers in Denmark, where “universal access to health care” is provided to all. Families in countries, such as the United States, without universal health care may have other challenges accessing care for mothers and caregivers at risk for chronic conditions. Those families might also face challenges accessing care for their child with a birth defect. That lack of access compounded by higher costs for health care may increase the stress for families theoretically increasing the hazard ratio and risk for early mortality.

The Danish registry provides a rich source of information on the health of the child and mother from which the HR were determined. That type of combined information is not easily available in the United States. Replicating this study in a U.S. population would be challenging. Questions regarding the comparability of the U.S. population are not likely to be answered in the near future and thus, U.S. providers should not wait to offer support and resources for caregivers of children with birth defects.

The authors have used the vast resources of the Danish registries to examine the mortality of mothers of children with birth defects. We would hope that this study design could be extended to examine mothers of children with other stressful health conditions, such as ADHD, autism, and cerebral palsy.

Professionals are encouraged to seek out families with children and youths with special health care needs (CYSHCN) that face challenges in access to care.

Professionals could assist families in finding resources to access care, financial aid, and other community resources to help reduce family stress and meet the health needs of the entire family. The 2004 recommendations from the American Academy of Pediatrics (4) are for more pediatricians and family practices to improve their services for families and develop stronger medical homes. Family partners and care coordinators could help families access medical care, respite care, support groups, and other services that may reduce stress, improve family health, and, hopefully, prolong the life of the mother. As children with birth defects transition into adulthood, families should consider the benefits to the child and family from estate planning, special needs trusts, or in more rare cases, guardianship, depending upon the child’s particular disabilities, as they consider the possibility that the child may outlive the parents. Families may experience crises on and off for years, but helping them plan for the future could help to reduce their stress.

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