Early Parental Mortality Associated with Children with Major Congenital Anomalies
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Parents and other caregivers of children with complex health care needs can experience high levels of stress. But did you know that that stress may be associated with worsening parental health and a higher risk of mortality? This has been recognized for mothers but what about fathers?

To answer that question Fuller et al (10.1542/peds.2020-028571) studied the long-term health of both fathers and mothers of infants with a major congenital anomaly. The authors analyzed data gathered from a prospective population-based cohort between 1986 and 2015 in Denmark. More than 20,000 fathers and mothers were identified from a cohort of over 950,000 parents as having a child with a major congenital anomaly, who were then followed for three decades. The study found that both mothers and fathers had increased risks of mortality compared to parents of children without anomalies, with fathers having a greater risk than mothers. Many of the parental deaths were related to cardiovascular, endocrine, and metabolic causes, which are associated with stress.

So, what are the implications of these findings for clinicians? We asked experts in complex care, Drs. Richard Antonelli and Olaf Bodamer to weigh in with an accompanying commentary to this study (10.1542/peds.2020-048249). They note the strengths of this study and identify some important limitations. They also ask us to consider a more holistic family-centered approach to these complex patients by checking in on the health of the caregivers as well as of the children themselves when they come to see us. Drs. Antonelli and Bodamer recognize that while this might be an easier thing for someone trained in medicine/pediatrics or family medicine to do, they insist we all must do this. Rather than not ask about the caregiver because a pediatrician feels ill-equipped to care for adult physical and mental health issues, Drs. Antonelli and Bodamer suggest making the time to learn where to refer adult caregivers with medical or psychological concerns if these caregivers don't already have a place for such care. Doing this may result in reducing the stressors that contribute to chronic illness and even death. These two articles will have you even more focused on a family-centered care model for all the children in your practice-complex or not-so-complex so link to these articles and learn more.