

# New Report Highlights Stress on Families of Babies with Congenital Heart Disease

*Mothers and fathers experience stress differently*



Erica Sood, PhD

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Wilmington, DE -- A study published recently in *Pediatric Critical Care Medicine* highlights the stressors on families and the differences between mothers and fathers in their experience of having a child with congenital heart disease (CHD). CHD is the most common birth defect, affecting 9/1,000 births worldwide. These findings could help healthcare providers to better serve affected families. While most of the research to date has focused on maternal stress, this study emphasizes the importance of understanding the paternal perspective as well, and the need for supportive interventions for fathers. The lead author is Erica Sood, PhD, clinical psychologist with the Nemours Cardiac Center at Alfred I. duPont Hospital for Children, Wilmington, Del. The study involved collaboration with Allison Karpyn, PhD, in the University of Delaware's Center for Research in Education and Social Policy (CRESP).

Participants in the study included 20 mothers and 14 fathers of children who underwent cardiac surgery for CHD at less than 6 months of age. All children were between the ages of 1 and 3 years at the time of study. A cohort of families was selected to represent clinical and demographic diversity, and 84% of invited families chose to participate. Parents took part in one-hour interviews conducted in private by a pediatric psychologist. Consistent themes related to emotional states, stressors and supports emerged.

Parents described feeling unprepared for the emotional impact a CHD diagnosis had on them, siblings and the family unit as a whole.

### Highest stressors for mothers

Insufficient finances

Burden of parenting medically complex child (medical/feeding equipment, insurance denials, etc.)

Changes to role as parent

Insufficient preparation for impact on family

Problems with support network

### Highest stressors for fathers

Changes to role as parent

Insufficient preparation for impact on family

Balancing responsibilities (employment vs. care of child and partner)

Burden of parenting medically complex child

The authors suggest that critical care providers must direct information and questions to both mothers and fathers, even if the mother is more often at the bedside or more vocal about the child's care. An interaction style that doesn't include the father

may intensify feelings of parental role change and helplessness. One father said: “*While mom and baby were [at the hospital] they got support and they got help, but I was pretty much fending for myself.*” Providers must work to increase access to support for fathers, even when they are not physically at the hospital, by accommodating fathers’ schedules and using technology to include fathers virtually, for example.

Both mothers and fathers of children with CHD have high rates of anxiety, depression and post-traumatic stress. Dr. Sood asserts that hospitals should adopt formal standards of psychosocial care and support for all families affected by CHD.

“There are long-term effects on the family of having a critically ill infant with congenital heart disease,” said Dr. Sood. “Hospitals and providers should help parents prepare by informing them about what to expect across a variety of domains, including medical, developmental, and psychosocial.” She is an advocate of structured family meetings with developmental and psychosocial specialists during both the prenatal and postnatal periods. Such meetings not only help prepare families but also help providers understand parental beliefs and concerns and each family’s unique stressors and supports. In addition, prior research has shown that formalized peer-to-peer support can help families feel more prepared and reduce feelings of isolation.

Dr. Sood is Co-Vice Chair of the Cardiac Neurodevelopmental Outcome Collaborative (CNOC), co-leads the Patient/Family Support learning lab within the National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC), and is on the board of Mended *Little* Hearts of Delaware.

“We were challenged with developing an approach designed to engage both parents and capture the unique stresses that mothers and fathers face during a difficult time in their lives,” said Dr. Karpyn. “It was crucial that the study capture the full spectrum of stressors from the time of diagnosis, surgical admission, and discharge to home.”

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