

Families of survivors of ECMO for heart conditions report favorable quality of life

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One of the few large studies to report long-term outcomes in cardiac patients treated in childhood with extracorporeal membrane oxygenation (ECMO) has found overall favorable outcomes among survivors, as reported by families. ECMO provides short-term breathing and heart support for critically ill children while doctors treat the underlying illness.

A research team from Children's Hospital of Philadelphia (CHOP) published the ECMO study in the August 2017 issue of *Pediatric Critical Care Medicine*.

The team analyzed a cohort of 396 [patients](#) with cardiac disease treated with ECMO at CHOP from 1995 to 2012. Overall mortality was 66 percent at a median follow-up of 6 years after ECMO therapy, which remains consistent with outcomes seen in previous decades.

In phone surveys or written surveys among the families of survivors, a majority reported positive outcomes regarding health and [physical limitations](#). Over 90 percent of families reported good or excellent health, and approximately 86 percent reported no or mild physical limitations.

However, the authors noted a discrepancy between [family](#)-reported favorable outcomes and a relatively high rate of medical and behavioral issues revealed by more detailed questioning. Almost 25 percent of patients had below-average school performance and required special

education, and almost 50 percent had parental-reported learning disabilities. These results may help families define realistic expectations regarding long-term outcomes for children supported with ECMO due to an underlying cardiac condition.

Matthew D. Elias, MD, a pediatric cardiologist at CHOP and first author of the study, noted that ECMO use in children with congenital heart disease (CHD) has increased markedly over the past several decades, as increased experience in pediatric cardiology and cardiac surgery has allowed ECMO use to expand to more complex patients. Senior author Matthew J. O'Connor, MD, also a CHOP pediatric cardiologist, added that "several factors have potentially improved long-term outcomes, such as increasing experience with ECMO and CHD in general. But the inclusion of a more medically complex population in the recent era may mitigate these improvements in outcomes, accounting for the fact that overall mortality rates haven't changed much."

Although this single-center study represents one of the largest cohorts of ECMO patients undergoing detailed assessments of outcomes and quality of life, Elias said that further research in larger, multicenter studies should further investigate family experiences and long-term patient outcomes. He added, "In the meantime, our findings should allow for improved family counseling in discussing long-term quality-of-life for children with heart disease."

More information: Matthew D. Elias et al, Long-Term Outcomes of Pediatric Cardiac Patients Supported by Extracorporeal Membrane Oxygenation, *Pediatric Critical Care Medicine* (2017). [DOI: 10.1097/PCC.0000000000001227](https://doi.org/10.1097/PCC.0000000000001227)

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