

Adolescents, young adults with advanced heart disease show desire to take active role in medical care decisions

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Adolescents and young adults with advanced heart disease are at high risk of dying in the hospital, often require invasive treatment and

experience significant symptoms that impact their quality of life.

And while most of their parents prefer that decision making about their treatment and care options remain between parents and physicians, many [young people](#) want to be actively involved in medical decisions affecting them, a new study suggests.

"As a pediatric psychologist, I have found that health care communication is one of the most critical—yet most underappreciated aspects of care," said lead author Melissa Cousino, Ph.D., director of the U-M Congenital Heart Center Psychosocial and Educational Program (M-COPE) at University of Michigan Health C.S. Mott Children's Hospital.

"How we communicate about diagnosis, prognosis, treatment options and more impacts coping, medical adherence, and health outcomes. In pediatric health care, it is critical that we better understand the communication and medical decision-making preferences of the young people we care for."

Researchers surveyed 53 young adults ages 12–24 with advanced heart diseases, including [heart failure](#)—a lifelong condition in which the [heart muscle](#) can't pump enough blood to meet the body's needs—along with 51 of their parents at Mott.

"In our sample of patients with serious heart disease, we found that the majority of teens and young adults want to be aware of their [treatment options](#), risks and prognosis information and desire active involvement in their medical decision making," Cousino said.

But there was a notable gap between the preferences of young patients and their parents, according to the research published in *JAMA Network Open*.

Nearly 45% of patients desired active, patient-led decision making specific to their heart disease management with a considerable majority wanting to discuss adverse effects or risks of treatment, surgical details, quality of life and life expectancy.

Many youth surveyed agreed with the statement "I should make the decision but strongly consider the physician's and my parents' opinions." More than half wanted to be involved in their end-of-life care decision making if critically ill.

Meanwhile, parents and guardians preferred an approach involving shared decision making between them and their child's doctors.

"The largest proportion of parents felt they should make [medical decisions](#) for their teen or young adult in partnership with the medical team," Cousino said. "Even though half of our patient sample were adults themselves, only six parents felt medical decision-making should be patient-led."

"I often find that parents, as well as pediatric health care clinicians, are understandably trying to protect young people from the bad, sad, or difficult news," she added. "Yet, for a large number of young people, keeping them from fully understanding or engaging in their health care, even when information is related to death or dying, can be more isolating and anxiety-provoking."

Cousino says research on patient communication and medical decision making was recently identified as a top priority in the field of palliative care in pediatric cardiology.

"There is not a one-size-fits all approach to medical communication and decision making. Each child, teen, young adult and family system has different needs and preferences," she said.

"It is on us to better understand youth needs and preferences to best incorporate their voice into medical care decisions in a way that is aligned with their needs. Ultimately, this will inform the development of interventions to support parents and health care clinicians working with young people facing serious illnesses and arduous medical courses."

Senior author, Kurt Schumacher, M.D., a pediatric cardiologist at Mott, says the study has important implications for clinicians caring for children and young adults with serious heart disease.

"The study should get the attention of all clinicians who care for children with significant heart disease. We all communicate with families, but not everyone is aware of the information that our patients would like to receive and discuss," he said. "Both parents and providers may be underestimating how actively involved adolescents and [young adults](#) want to be when it comes to decisions about their heart disease."

"These findings underscore the importance of understanding each individual's preferences and personalizing communication methods with each young patient regardless of their diagnosis, disease severity or symptoms," Schumacher added.

"We need to continue to pursue individualized conversation tools and decision-making interventions with young patients with advanced [heart](#) disease. And we need to help providers be comfortable and open with these discussions as well."

More information: Melissa Cousino et al, Medical and end-of-life decision-making preferences in adolescents and young adults with advanced heart disease and their parents, *JAMA Network Open* (2023). [DOI: 10.1001/jamanetworkopen.2023.11957](https://doi.org/10.1001/jamanetworkopen.2023.11957)

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