

Physicians mending broken hearts

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Pediatric surgeons are able to repair complex heart defects with a survival rate of greater than 90 percent, but that doesn't necessarily mean a happy ending for these children and teens. Some may have a great quality of life and others, with the same condition, may not.

A study conducted at seven pediatric medical centers throughout the United States shows that several categories of patients with heart disease, including African-Americans and lower-income families, have a lower quality of life.

"Advanced treatments often result in unintended complications, particularly when combined with the hemodynamic impact of the heart defect itself," says Bradley Marino, MD, a cardiologist from the Heart Institute at Cincinnati Children's Hospital Medical Center and the study's lead author. "The child's neurodevelopmental, psychosocial, and physical functioning are all impacted by these complications, and they may adversely affect the child's quality of life. If we know the predictors, we can put interventions in place to change the outcome for them."

Dr. Marino presents his findings today at the annual meeting of the American College of Cardiology in Orlando, FL.

To measure how much of an effect these factors have on children, Dr. Marino and his team developed the Pediatric Cardiac Quality of Life Inventory (PCQLI), a self-administered questionnaire that quantitatively assesses health-related quality of life in children and adolescents age 8-18 years, and their parents. The questions are designed so that anyone

with a third grade reading level can understand and answer them in fewer than 10 minutes.

Dr. Marino and his colleagues recruited 759 pairs of patients and their parents. The patients were between the ages of 8 and 18 and had at least one prior cardiac surgical procedure. The researchers evaluated the effect of income, socioeconomic status, recent hospitalization, Fontan palliation (a surgical approach to treating hearts with one [ventricle](#)), and a greater number of doctor visits in the past year.

Modifiable factors associated with lower quality of life scores among patients after surgery included recent hospitalizations and greater number of doctor visits. Non-modifiable factors included Fontan palliation and both lower income and socioeconomic status.

In children between the ages of 8 and 12, lower scores were associated with African American race, genetic abnormality, non-thoracic surgery and sternotomy - the usual, vertical incision in the sternum used for heart surgery. Mental health problems in parents of children and teens of all ages in the study predicted lower quality of life scores.

Dr. Marino defines quality of life as "the impact of the specific illness or medical therapy on the child's ability to function in situational contexts, and to draw personal satisfaction from a physical, psychological, and social functioning perspective."

For a young person, the impact could range from not being able to play basketball with friends to being too embarrassed about a surgical scar to wear a bathing suit. Regardless of the factor or complication, it can influence a child's self-image, development, social interactions - all of which make up quality of life.

"Our research will ultimately allow us to use the PCQLI as a screening

tool to determine which patients are at risk for problems that affect their quality of life," says Dr. Marino. "We are trying to figure out how to help children at the point of care. We want to carry out research that's going to change how they carry on in their lives and allow them to grow and develop to their maximum potential."

Source: Cincinnati Children's Hospital Medical Center

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