

Resilience and quality of life go hand in hand for heart defect survivors

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Melissa Jeng had her first surgery when she was 3 days old—and the

first of four open-heart surgeries at 8. Since then, she's also had over a dozen heart procedures.

"I got to the point where I would call them tune-ups," the 52-year-old from Seattle said. "None of it feels good, but it is what it is, and you have to choose to move through it."

That attitude, and a bit of humor, has helped her build resilience. And resilience, research suggests, can boost quality of life among heart defect survivors.

Nearly 1 in 100 people—about 40,000 newborns per year in the United States—are born with a [congenital heart defect](#), when the heart and surrounding blood vessels don't develop normally in the womb. About 1 million children and 1.4 million adults in the U.S. are living with a heart defect, according to the Centers for Disease Control and Prevention.

Among newborns, about 25% will need surgery or other procedures before their first birthday. Even those with a mild or moderate heart defect may require monitoring and treatments over the course of their life.

Jeng was born with tetralogy of Fallot, a combination of four structural heart defects that prevents blood from being oxygenated properly. It can cause bluish skin tone, fatigue and a dangerous thickening of the heart walls.

Despite the challenges, a study presented late last year at the American Heart Association's Scientific Sessions conference reported that [young adults](#) with congenital heart defects demonstrated good resilience. Higher resiliency scores also were correlated with a better quality of life.

The findings make sense to Jamie L. Jackson, a principal investigator in

the Center for Biobehavioral Health at The Abigail Wexner Research Institute at Nationwide Children's Hospital in Columbus, Ohio.

"The vast majority of the adolescents and young adults in my research are doing well," said Jackson, who also is an assistant professor of pediatrics at Ohio State University College of Medicine in Columbus. "These individuals are survivors, and they may experience life in a sweeter way than the rest of us."

Jeng credits her parents for her resilience. Before every surgery or procedure, her mother would take her shopping for a new robe, followed by lunch at one of her favorite restaurants, where they would talk about her concerns.

In addition, they encouraged her to play sports and do the same kinds of activities as her five older brothers. Today, she hikes, skis, zip lines and participates in charity runs such as the New York City Marathon, which require her to train at least four days per week.

"They never kept me from doing anything, and they never allowed me to use it to get something I wanted," Jeng said. "Life has setbacks, whether you have heart disease or not."

That kind of family and [social support](#) play an important role in building resilience, said Dr. Anushree Agarwal, a cardiologist at the University of California, San Francisco. Good communication between doctors and patients also is crucial.

"The more empowered a patient is about their heart, about what to expect, about what could go wrong, the more resilient they tend to be," she said. "Even if they have multiple setbacks, they understand why that's happening."

According to Jackson, there is wide variability under the congenital heart defect umbrella, which also may explain why some survivors are more resilient than others.

"Some with (a) congenital heart ([defect](#)) have a surgical procedure in the first year or couple of years of life and don't ever need another one," she said. "Others, as they get older, might have three, four or more surgeries."

Indeed, prior studies show people with complex [heart](#) defects fare worse than healthy people or those with mild or moderate defects.

That's why it's important to identify people who are at risk for gaps in care and develop strategies to help them, Jackson said.

"We need to recognize what's working well and how to translate that into interventions," she said. "There is a subgroup of folks who really struggle, but with assistance and the right kind of care, people with CHD can thrive."

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