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Parents receiving heart disease diagnosis for infants need better information

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Based on a survey of parents of children with congenital heart disease, physicians delivering the diagnosis need to do a better job of showing compassion, ensuring parents understand all their options and providing easily understandable information, according to a new study published in the February edition of the journal, *Pediatric Cardiology*.

Researchers at Los Angeles Biomedical Research Institute (LA BioMed) worked with the California Heart Connection, a nonprofit organization of parents of children with congenital heart disease, to conduct an online survey of 841 parents of children who were either diagnosed before birth or shortly afterward with congenital heart disease. The researchers said physicians remain the primary source of information for parents at diagnosis. So they analyzed the survey's findings to offer suggestions for how physicians and other health care providers can most effectively tell parents their child has a serious and potentially life-threatening medical condition.

"Parents confronted with a diagnosis of congenital heart disease face very difficult choices – from selecting a treatment to determining whether to continue a pregnancy, if they receive the diagnosis prenatally," said Ruey-Kang Chang, MD, an LA BioMed researcher and the corresponding author of the study. "All of these decisions depend on the information they are given at the time of diagnosis and how well they can understand and retain the information at such a difficult time."

Upon learning of their children's diagnosis, most of the parents surveyed

said they received no information on support groups, Internet resources or success rates at other hospitals. Two-thirds of the parents were told their children's heart conditions were "rare." More than half of them believed that meant fewer than one in a million infants had the condition or there were few people alive with the defect. In reality, congenital heart disease occurs in about eight in 1,000 births in the United States, with approximately one-third of those cases requiring invasive treatment during the first year of life.

Of those surveyed, 13% reported feeling pressured to terminate the pregnancy by their pediatric cardiologist, and 15% felt their physician showed a lack of compassion. More than a fourth of the respondents said they sought a second opinion, and 71% of them chose the second physician for long-term follow-up care. The two most commonly cited stress factors were "uncertainty" about their child's future (87%) and "not knowing about survivors with this defect" (52%).

In the United Kingdom, parents have access to a database of information about the number of procedures and mortality rates among children with congenital heart disease. In the U.S., Dr. Chang said no such database is available to the public so physicians continue to be a vital source of information.

"The information parents receive at diagnosis and the manner in which it is conveyed often determines their assessment of their children's chances for survival and may shape the parents' decisions," said Dr. Chang. "To ensure the parents have the information they need to make these critical decisions about their children's health, physicians should provide context for the parents, including information on success rates at different hospitals, Internet resources and referrals to support networks. Physicians should also be aware of how their demeanor and the words they use will be interpreted by the parents."

Debra Hilton-Kamm of the California Heart Connection, and Mark Sklansky, MD, of the David Geffen School of Medicine at UCLA, co-authored the study. The 82-question survey was distributed to online support groups for parents of children with congenital heart disease. A total of 1,001 responses were received and 160 were excluded because they were incomplete or didn't meet the study's criteria.

Provided by Los Angeles Biomedical Research Institute at Harbor

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