Home monitoring program improves survival between surgeries for babies with certain heart defects

August 11 2020

Interstage Home Monitoring (IHM) programs for infants with single ventricle heart defects help families recognize potential complications early and improve infant survival rates and growth prior to the second of multiple surgeries, according to a new Scientific Statement from the American Heart Association, "Interstage Home Monitoring for Infants With Single Ventricle Heart Disease: Education and Management," published today in the *Journal of the American Heart Association*.

The National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC), a network of pediatric cardiology care centers across the U.S., reported an average 40% decrease (9.5% to 5.3%) in infant mortality and a 28% improvement in infant weight gain (18.6% to 13.1%) across 50 cardiac centers using IHM programs from 2008 to 2016.

Treatment for the single ventricle heart defect hypoplastic left heart syndrome—in which the heart's left side is underdeveloped—involves one surgery shortly after birth with a second surgery planned four to six months later, and a third procedure a year or so after that. IHM programs concentrate on the high-risk time between the first two surgeries, known as the interstage period. The primary focus of IHM programs is to help family caregivers carefully monitor several important health parameters including an infant's oxygen saturation levels, caloric intake and weight gain. Weight gain is an important

marker for an infant to successfully undergo the second surgery.

IHM programs also train caregivers to recognize early "red flag" symptoms such as respiratory changes, sweating, fussiness, diarrhea, fever or changes in skin color that warrant immediate notification of the infant's health care team.

The AHA scientific statement outlines plans for health care professionals when training home caregivers while the infant is still hospitalized, and also addresses caregiver support and education, health care teams and resources, surveillance strategies and practices, national quality improvement efforts, interstage outcomes and future areas for research.

"This is a comprehensive resource for cardiology care professionals and family caregivers, and it also provides a framework and roadmap for cardiac centers looking to establish an IHM program or possibly expand or strengthen one already in place," said chair of the statement writing group Nancy Rudd, M.S., C.P.N.P.-P.C./A.C., FAHA, nurse coordinator for the Interstage Home Monitoring Program at Herma Heart Institute, Children's Wisconsin, and a nurse practitioner in the division of pediatric cardiology at the Medical College of Wisconsin, both in Milwaukee. "The statement is also a much-needed document validating the need for cost coverage for the various parts of IHM programs that lead to improved patient outcomes."

The first IHM program was initiated in 2000 at Children's Wisconsin due to trends indicating mortality rates were as high as 16% during the interstage period. The pediatric quality improvement cooperative was formed in 2008 and has advanced knowledge and best practice guidelines to improve the outcomes and quality of life for children with hypoplastic left heart syndrome during the interstage period.

"Prior to IHM programs, the outpatient management of interstage infants was the same as that of much less complex patients. Unfortunately, the tenuous nature of these infants means they can get very sick very quickly from even minor childhood illness like the common cold," said Rudd.

Statement authors noted other practice and program changes associated with caring for these pediatric patients also contributed to their improved survival and weight gain.

Sarah Robinson's daughter, now two years old, was born with hypoplastic left heart syndrome. As part of an IHM program, Robinson learned how to care for her infant through a rooming-in session during the baby's first post-surgery hospital stay. "Before discharge, we had to provide 24 hours of care, which meant doing everything for our daughter by ourselves with no machines on—all the feedings, administering medications and more—while having medical staff available if needed or if a problem arose," Robinson said in a perspective published with the statement. "Having a program like this in place gave us comfort, knowing we would not be completely alone during a very stressful and anxious time before the second surgery. Interstage home monitoring was our life preserver and safety net."

Many IHM programs have evolved to include telehealth platforms, and expanding technology enables optimized data collection and real-time video visual assessments of patients at home. The authors conclude that together with improved care coordination, discharge planning, and nutritional management bundles, IHM is a key component in optimizing outcomes in these high-risk infants.

More information: *Journal of the American Heart Association* (2020). DOI: 10.1161/JAHA.119.014548

Provided by American Heart Association