Children's Hospital of Wisconsin

Herma Heart Institute

Interstage Home Monitoring Program Overview

Staged single ventricle palliation has become the mainstay of therapy for most cardiac centers who care for infants with hypoplastic left heart syndrome (HLHS) and/or single ventricle physiology. Evolving perioperative surgical techniques, medical management, and postoperative monitoring have dramatically improved operative survival. However, despite improved early survival, mortality before second stage palliation remains a significant concern with some centers reporting the incidence of interstage death at 10% or greater.

Following stage one palliation (S1P), patients remain at risk because of the combination of parallel circulation, volume overload of the single ventricle, and cyanosis. The presence of residual or development of recurrent lesions such as a restrictive atrial septal defect, arch obstruction, shunt stenosis, pulmonary artery distortion, and tricuspid valve insufficiency has been associated with late death after successful S1P. In addition, commonly acquired childhood diseases, such as viral illnesses or gastroenteritis, have also been implicated in interstage morbidity and mortality. Respiratory infections can result in impaired gas exchange that will result in progressive hypoxemia in the cyanotic, shunt dependent patient. Childhood illnesses that decrease fluid consumption, increase insensible loss secondary to fever, or result in gastrointestinal fluid loss may result in hypovolemia and lead to decreased cardiac output, thereby contributing to interstage death even in the absence of residual or recurrent anatomic disease. After successful S1P, any of the pathological processes outlined above can lead to a decrease in oxygen supply-demand relationship, placing the infant with minimal myocardial reserve at even greater risk for mortality. Hence, transitioning infants to home after S1P warrants ongoing vigilance well beyond the initial early postoperative period and requires continued collaboration amongst caregivers, including parents.

For the reasons just outlined, a home monitoring program of tracking daily oxygen saturation, weight, and enteral intake was developed at Children's Hospital of Wisconsin in 2000. The primary goal of the home monitoring program was to develop a simple, reliable strategy to identify inadequate systemic oxygenation and acute dehydration. Besides the usual discharge instructions that include directives to contact a physician for respiratory or gastrointestinal illnesses, respiratory difficulties, or alteration in perfusion, parents are sent home with an infant scale and pulse oximeter. The digital infant scale is sensitive to 10 grams and the infant is weighed daily to identify dehydration as well as growth failure. Pulse oximeters are used to detect declining systemic oxygen saturation. Parents are trained

during the initial hospital stay to use this equipment and properly record the data on provided log sheets. The criteria for contacting a physician before scheduled clinic visits were determined by a consensus of multiple caregivers and are felt to represent the physiologic limits beyond which survival would be in jeopardy. Physicians are to be notified if SpO2 falls to <75% or increase above 90%, if there is acute weight loss of 30 grams of failure to gain 10 grams over 3 days, and if enteral feeding volumes are less than 100cc/kg/day. Patients who breach surveillance criteria undergo physician evaluation within 24 hours.