

Acute Care Nurse Practitioner Managed Home Monitoring Program for Patients With Complex Congenital Heart Disease: A Case Study

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KEY WORDS

Home monitoring program, HLHS, continuity, medical home, nurse practitioner role

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Although patients with univentricular physiology, the most common manifestation of which is hypoplastic left heart syndrome (HLHS), account for only approximately 3% of all patients with congenital heart disease and only two to three per 10,000 live births in the United States annually, if left untreated, they represent up to 40% of neonatal cardiac deaths (Reller, Strickland, Riehle-Colarusso, Mahle, & Correa, 2008). Just 20 years ago, these patients often were managed with comfort care. With new surgical techniques and improved postoperative management, patients with HLHS today undergo a three-stage surgical palliation during the first 3 to 4 years of life, with an estimated 70% rate of survival to adulthood (Feinstein et al., 2012). The time from first surgical repair at birth to the second stage (the Glenn procedure), which occurs between 3 and 6 months of age, is referred to as the inter-stage period and carries the highest risk of mortality, with historic rates estimated as high as 20%.

The Heart Center at the Lucile Packard Children's Hospital at Stanford has been at the forefront of innovative care for these patients, including early initiation of a nurse practitioner (NP) administered home monitoring program (HMP) to shepherd these infants through the highly vulnerable inter-stage period. In this unique program, the acute care NP role extends beyond inpatient management and includes providing ongoing telephonic surveillance, directing outpatient nutritional

interventions, responding to subtle changes in clinical status (thus allowing early identification and intervention for patients at risk of acute decompensation), and providing key care coordination across the care continuum. A primary HMP NP makes weekly telephone calls to the family to follow up on patient growth, heart rate, and oxygen saturations and makes changes to the feeding plan to optimize calories to a minimum goal of greater than 150 Kcal/kg/day. Additionally, the NP serves as a resource to families to triage concerns and facilitate appropriate evaluation if they are unable to reach the primary cardiologist or pediatrician. Initiation of HMPs has resulted in marked improvement in survival across the country, with our institutional inter-stage mortality rate for these patients dropping from 7% to zero since the implementation of our program.

This case study demonstrates how the benefits of the HMP extend beyond early detection of growth failure or decreased oxygen saturations, foreshadowing the need for cardiac intervention. In this and many other cases, the NP provides invaluable continuity for these fragile patients, who in years past would not have survived. Many community providers who are unfamiliar with the risks these patients face during the inter-stage period welcome the support of the acute care specialist NP.

CASE PRESENTATION

During a weekly HMP phone call with the mother of a 3-month-old infant with HLHS who resides out of state, the mother reported that 3 days ago the infant began vomiting halfway through her feedings. Nonbilious emesis occurred at almost every feeding and was described as close to the full volume of the feed itself. In response, the mother had already decreased the calorie concentration from 28 Kcal/oz to 20 Kcal/oz and changed from 8 bolus feeds of 55 ml over 2 hours, with an hour off between, to 35 mL/hour continuous. Although the mother reported no further emesis in the 24 hours since making this change, she did note a mildly increased respiratory rate.

Medical History

The infant was diagnosed prenatally with HLHS (mitral stenosis/aortic stenosis with mildly restrictive atrial septum) and at birth underwent a Norwood procedure with a 5-mm valved right ventricle to pulmonary artery (RV-PA) conduit, atrial septectomy, patent ductus arteriosus ligation, and aortic arch reconstruction with delayed sternal closure on postoperative day 5. In the immediate postoperative period, a re-entrant tachycardia developed that was well tolerated and broke with the administration of adenosine. As a result, treatment with propranolol was initiated before the transition to digoxin was made for long-term management of her tachycardia.

During postoperative recovery, an infection developed that resulted in respiratory failure and shock, and methicillin-resistant *Staphylococcus aureus* (MRSA)—positive cultures were obtained from her chest tube insertion site. At the time of her initial hospital discharge, she was dependent on a nasogastric (NG) tube and was below the third percentile for weight. The infant required the following medications: digoxin twice daily, furosemide (Lasix) twice daily, spironolactone (Aldactone) twice daily, clopidogrel (Plavix) daily, aspirin daily, and ferrous sulfate twice daily.

At 2½ months of age, the infant underwent cardiac catheterization for placement of a stent in the RV-PA conduit and an electrophysiology study. No accessory conduction pathways were identified during the electrophysiology study.

Personal/Social/Developmental History

The infant resides with mother, father, and 3-year-old brother in a small urban center 350 miles from the surgical Heart Center. Her parents were trained by Heart Center nurses to place an NG feeding tube and administer tube feedings. The parents also learned to monitor daily weight, heart rates, and oxygen saturation values. In addition to at least weekly telephone contact with the HMP NP, the patient saw her community cardiologist every other week, as well as her primary care provider (PCP). In an effort to minimize exposure to infection, the family avoided large crowded places and engaged in diligent hand washing. To further protect the infant, the brother did not attend preschool during the patient's inter-stage period.

Review of Systems

Through HMP telephone follow-up, the infant's mother reported a mildly increased respiratory rate during the previous 24 hours but denied increased fatigue, retractions, nasal flaring, or markedly decreased oxygen saturations, which, in the setting of emesis, she had been checking more frequently. The infant was reported as being generally fussier in the previous 48 hours. Although she was mildly tachycardic, her heart rate remained within her baseline range. No cough, diarrhea, or other subjective symptoms were reported at that time. The infant's second-stage surgical palliation was planned at the Heart Center 1 week from the phone call.

Pertinent Physical Examination Findings

Because of the unique nature of the HMP, NPs often verbally guide parents through a modified physical examination, gathering additional information to enable triage of care. As this conversation progressed, the mother noted a "purplish red" area around the infant's left nipple with what she described as a "pimplelike" pustule. The mother denied warmth to the touch but reported that it was firm, with swelling and redness

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