Title: DISCHARGE PREPARATION FOR PARENTS OF SINGLE VENTRICLE INFANTS PARTICIPATING IN A HOME MONITORING PROGRAM
First Author: Jena Tanem, RN, MSN, FNP, APNP (262-894-9709, jtanem@chw.org)
Additional Authors: Ann Scott RN, MSN, CPNP, APNP; Jennifer Neubauer, RN, MSN, CPNP, APNP; Nancy Rudd, RN, MS, CPNP
Institution: Children’s Hospital of Wisconsin and The Medical College of Wisconsin, Milwaukee, WI

Background: Infants with Hypoplastic Left Heart Syndrome (HLHS) require a series of three palliative cardiac surgeries. Following the first palliation (S1P) they remain with high-risk physiology until stage 2 palliation (S2P), with mortality reported as high as 20%. Therefore, all S1P infants discharged home from Children’s Hospital of Wisconsin participate in a Home Monitoring Program (HMP). The HMP is highly dependent on parental involvement and requires extensive education. Following discharge, parents are expected to obtain daily oxygen saturations using a pulse oximeter, daily weights using a home infant scale, and record findings in a HMP binder. Breach of criteria necessitating notification to the care team include SpO2 < 75% or >90%, weight loss of 30 grams or failure to gain 20 grams over 3 days, and intake <100cc/kg/day. In addition, the HMP includes weekly phone call from the interstage care team to parents, as well as evaluation every 1-2 weeks in a multi-disciplinary cardiac specialty clinic.

Purpose: The purpose of our study was to assess the discharge readiness and HMP competency of interstage parents.

Sample/Setting: Twelve consecutive infants home-monitored between October 2011 and November 2012.

Methods: Outpatient clinic visits, frequency of unplanned admissions, and outcome of interstage calls were assessed. In addition, at the initial clinic visit following S1P discharge, parents completed a questionnaire evaluating their perceived readiness for discharge.

Results: Interstage survival for this cohort was 100%. On average teaching was initiated 21 days prior to discharge with parents receiving a mean of three, 45 minute teaching sessions (range 15-100 minutes each session). Questionnaire results showed 100% of parents either agreed or strongly agreed to the following: purpose of HMP was adequately explained, content of binder was useful, scale and pulse oximeter teaching was adequate, and felt capable of completing all home monitoring tasks. Furthermore, 100% of parents strongly agreed they knew points of concern and how to contact the interstage team. Only 2 parents reported the HMP to be more challenging than expected. Half of parents reported they would have found it helpful to speak to a parent who had previous HMP experience. Mean frequency of phone contact between parents and care team during the interstage period was 15 (range 5 – 25) and mean number of clinic visits was 4 (range 1-6). Six infants (50%) experienced a breach of criteria identified by a parent; no parent failed to report a recognized breach. Four infants required unplanned clinic evaluation due to a breach or other physiologic concerns identified by parents. Seven infants required inpatient admission related to a breach or other physiologic concern identified by parents. No child presented to clinic or hospital with a serious adverse event.

Conclusions / Implications for Practice: From a parent perspective, current HMP pre-discharge education adequately prepares caregivers for transition to home. With standardized discharge preparation, a HMP can effectively be implemented by parents allowing for potentially life-saving interventions in response to early detection of subtle changes in the infant’s status. Parents are competent in carrying out daily home monitoring tasks but perceive a potential benefit in mentoring from experienced HMP parents.