

## **Parental Knowledge Regarding Life-Long Congenital Cardiac Care**

**Objective:** To assess parental knowledge regarding life-long cardiac care (LLCC) for children with moderate and complex congenital heart disease (CHD).

**Background:** National management guidelines recommend that nearly 50% of the one million US adult survivors with CHD receive LLCC within specialized adult congenital heart disease (ACHD) centers; the number of adults receiving such care appears far less. Inadequate parental knowledge for LLCC may contribute to care interruption.

**Methods:** In this multicenter study, we administered a questionnaire to parents of children age 2 to 18 years, with one of four post operative CHD lesions for which life-long specialty care is recommended: We assessed understanding of a) need for LLCC and b) recommended care providers. Predictors of parental knowledge regarding LLCC were likewise assessed.

**Results:** A total of 419 parents (7 sites) participated. Median age of child was 9 yrs. Diagnoses: s/p aortic coarctation 104 (24.8%); s/p Fontan 125 (29.8%); s/p tetralogy of Fallot 124 (29.5%); s/p arterial switch operation 66 (15.8%). Overall, 55.9% (95% CI: 51.0%, 60.7%) did not know that LLCC would be required and should be provided by an ACHD specialist. Over half (59%) of parents stated that their cardiology team had never addressed LLCC, but the majority (95%) were interested in learning more. Recollections of prior discussions regarding LLCC correlated with a better understanding of this need ( $P=0.0007$ ). Parental knowledge varied by diagnosis, with a higher degree of knowledge in parents of children with tetralogy of Fallot and single ventricles ( $P=0.0007$ ). In addition, ethnicity ( $P=0.003$ ), race ( $P<0.0001$ ) and education ( $P<0.0001$ ) were strong predictors for adequate knowledge. Child's age, relationship to the child, and type of insurance, were not predictive of parental knowledge.

**Conclusion:** A substantial number of parents of children with moderate and complex CHD do not appear to have awareness of current recommendations for LLCC by ACHD specialists. Despite this, most parents are interested in learning more, which provides an opportunity to develop educational programs to address this need.