Creating a lesion-specific "roadmap" for ambulatory care following surgery for complex congenital cardiac disease.

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Abstract

Over the past 20 years, the successes of neonatal and infant surgery have resulted in dramatically changed demographics in ambulatory cardiology. These school-aged children and young adults have complex and, in some cases, previously unexpected cardiac and non-cardiac consequences of their surgical and/or transcatheter procedures. There is a growing need for additional cardiac and non-cardiac subspecialists, and coordination of care may be quite challenging. In contrast to hospital-based care, where inpatient care protocols are common, and perioperative expectations are more or less predictable for most children, ambulatory cardiologists have evolved strategies of care more or less independently, based on their education, training, experience, and individual styles, resulting in highly variable follow-up strategies. We have proposed a combination proactive-reactive collaborative model with a patient's primary cardiologist, primary-care provider, and subspecialists, along with the patient and their family. The goal is to help standardise data collection in the ambulatory setting, reduce patient and family anxiety, increase health literacy, measure and address the non-cardiac consequences of complex cardiac disease, and aid in the transition to self-care as an adult. PMID:27373527 DOI:10.1017/S1047951116000974