

Barriers in Successful Transition of Care for Patients with Congenital Heart Disease: Providers Perspective

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Background: The majority of patients with congenital heart disease (CHD) require lifelong cardiac surveillance by specialized practitioners. There are several challenges to successful transition of pediatric CHD patients to adult-oriented care, including health insurance, patient education about need for long-term follow-up, availability of local qualified adult congenital specialty physicians, and attachment of patients and families to pediatric cardiology providers. There are growing efforts to improve transition of patients with CHD into adult specialized care, however, whether these efforts and resources are available, utilized, and accepted among cardiology providers is unknown. The aim of this study was to investigate the current perceptions and practice patterns among pediatric and adult cardiology providers regarding transition of patients with CHD.

Methods: A cross sectional internet based survey was distributed through the American College of Cardiology Adult Congenital and Pediatric Cardiology (ACPC) working group of physicians and advanced practice providers who specialize in either (1) pediatric cardiology (PC), (2) adult cardiology (AC), or (3) adult congenital heart disease (ACHD). The survey consisted of a questionnaire tailored to the provider type that inquired about current practice patterns, perceptions, and challenges associated with transition of patients with CHD to adult-oriented care.

Results: A total of 133 survey responses were collected. Survey responders classified themselves as providers primarily in PC (n=91, 68%), ACHD (n=30, 23%), or AC (n=12, 9%). Among PC providers, 5 (5.5%) responded that >50% of their patients are over 18 y/o, and 28 (30.8%) reported that 25-50% of their patients are over 18 y/o. Age that PC providers typically transfer care to an adult specialized provider include < 18 y/o in 0 (0%) respondents, 18-20 y/o in 29 (32%) respondents, 21-24 y/o in 30 (33%), ≥ 25 y/o in 19 (21%), and never transfer in 13 (14%). In contrast, 23 (77%) of ACHD specialists feel the ideal age for transition is < 21 y/o. Among PC providers that transitioned CHD patients, 71% transitioned to ACHD specialists, while the remaining 29% transitioned to either AC or ACHD providers depending on severity of the CHD. Twenty one (23%) of PC find it "difficulty" or "very difficult" to find an ACHD provider in their practice area, and 56 (62%) feel that CHD patients being lost to follow-up during transition is a significant issue. Among PC providers, 47 (52%) begin discussing transition with patients between 16-21 y/o, while 27 (27%) discuss it when patients are < 16 y/o. Out of AC providers, 11 (92%) stated that CHD patients comprise less than 25% of their practice. Eight (67%) of AC providers reported that they received either no CHD training or 1 month rotation during fellowship and 25% report being very uncomfortable or somewhat uncomfortable managing CHD patients. Nine (75%) AC providers will sometimes or most times consult with an ACHD specialist when managing a CHD patient, but 42% find it difficult to find an ACHD specialist in their practice area.

Conclusions: There is wide disparity of practices and opinions in regards to transition of CHD patients to adult specialty care. PC and ACHD providers differ in opinion on ideal age for transition. Both PC and AC providers find it difficult finding an ACHD specialist in their practice area, and majority of PC providers feel that CHD patients getting lost to follow-up is a significant issue in their practice. Further studies and efforts are needed to better understand and address the barriers in transition of the growing population of CHD patients surviving into adulthood.