

Knowledge base of adolescents with congenital heart disease

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INTRODUCTION: Most congenital heart disease [CHD] is diagnosed and treated in early childhood with parents acting as surrogates for decision-making and recipients of information. The adolescent assumes this role in preparation for transition to an adult congenital heart program. We performed an observational study to evaluate adolescent and parental recognition of their CHD.

METHODS: Established clinic patients, ≥ 11 y.o. and their parents were independently surveyed prior to being seen. Participation was voluntary. Electrophysiology, cardiomyopathy and cardiac transplant patients were excluded. Results were scored as full, partial or incomplete recognition.

RESULTS: Most (98% parents; 83% adolescents) reported that their cardiologist had provided education. Summary results are noted in Table I. Older adolescents performed better. Parents performed better than all patients, including those ≥ 18 y.o. History of prior surgery/intervention had no significance. Patients undergoing last surgery ≥ 11 y.o. scored better than those with surgery at younger age or without surgery ($p < 0.05$). Patients with complex lesions (single ventricle, tetralogy of Fallot, transposition of the great arteries) were better at providing the medical name of their defect ($p < 0.05$) but similar in ability to describe the anatomy when compared to those with repaired shunt lesions and mild unrepaired lesions. Those with more complex disease were better at providing the full name of the defect (81/134; 60%) than in fully describing it (43/134; 32%; $p < 0.005$).

TABLE I.	Name defect (n=522)		Describe defect (n=521)	
	Full	Partial	Full	Partial
11-14 y.o.	40% (n=102)*	13% (n=34)	23% (n=58)*	35% (n=89)
15-17 y.o.	51% (n=87)*	17% (n=29)	35% (n=56)*	37% (n=63)
>18 y.o.	68% (n=65)*	16% (n=15)	54% (n=51)*	31% (n=29)
TOTAL	49% (n=254)*	15% (n= 78)	32 % (n=165)*	35% (n=181)
Parent	78% (402/512)*	11% (n=56)	61% (312/512)*	29% (n=151)

*p < 0.005

CONCLUSIONS: Unlike their parents, only 1/2 of adolescents are able to name their cardiac defect and 1/3 are able to adequately describe their cardiac anatomies. Older adolescents and those with more complex defects are more knowledgeable. A stronger emphasis should be made on educating this population as they transition to adulthood.