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Knowledge Base of Adolescents with Congenital Heart Disease

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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 responsible for decision-making. The adolescent assumes this role in preparation for transition to an adult congenital heart program. We studied the knowledge base of our adolescent CHD patients and their parents.

Methods

Established CHD patients, ≥ 11 y.o. and their parents, were independently surveyed in the outpatient clinic. Participation was voluntary. Cardiomyopathy, electrophysiology and transplant patients were excluded. Scores were assessed as full, partial or incomplete.

Results

Most (98% parents; 83% adolescents) reported that their cardiologist had provided education. Adolescents provided a full (49%) and partial (15%) medical name and full (32%) and partial (35%) description of their condition. Older adolescents performed better ($p < 0.005$). Parents scored better, regardless of patient age ($p < 0.005$) [Table I]. Presence of prior surgery/intervention made no difference. Patients undergoing last surgery ≥ 11 y.o. scored better than those with surgery only when younger or without surgery ($p < 0.05$) [data not shown]. Patients with mild unrepaired or surgically repaired shunt lesions (ASD, VSD, PDA), and their parents, were much less able to name their lesion than those with left heart lesions (aortic stenosis, coarctation, mitral valve disease), tetralogy of Fallot, TGA/TAPVR or palliated single ventricles, but similar in ability to at least partially describe the defect ($p < 0.005$) [Table II]. In this more affected population, the ability to fully name the defect (81/134; 60%) far exceeded the ability to fully describe it (37/134; 28%; $p < 0.005$).

Table I: Patient knowledge by age

Age (yrs)	Name (n=522)		Describe (n=521)	
	Full	Partial	Full	Partial
11-14	40%	13%	23%	35%
15-17	51%	17%	35%	37%
≥ 18	68%	16%	54%	31%
Total	49%	15%	32%	35%
Parents (n=402)	78%	11%	61%	29%

Table II: Patient knowledge by defect type

Type of CHD	Name (n=470)		Describe (470)	
	Full	Partial	Full	Partial
Mild (n=153)	37%	18%	24%	46%
LV (n=183)	48%	17%	33%	32%
TOF (n=63)	60%	8%	19%	40%
TGA (n=25)	64%	8%	40%	32%
SV (n=46)	59%	4%	33%	22%
Total	49%	15%	30%	36%
	(n=238)	(n=73)	(n=149)	(n=175)

Conclusion

Only one-half of adolescents are able to name their cardiac defect, and one-third are able to adequately describe the anatomy. Older adolescents, those with a more recent history of surgery and those with more complex defects perform better. Parents are much more knowledgeable than their children. A strong emphasis should be made on educating adolescents with CHD as they transition to adulthood.