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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 in designated children's hospitals with parents responsible for decision-making and receipt of information. 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 patients with CHD, ≥ 11 y.o. and their parents, were independently surveyed in the outpatient clinic prior to being seen over a one-year period. Participation was voluntary. Cardiomyopathy, transplant and electrophysiology patients were excluded. Scores were assessed as full, partial or incomplete.

Patient Survey

- Has your cardiologist ever described your heart condition in detail to you?
- What is the medical name of your heart condition?
- Describe your heart condition in as great a detail as possible in your own words. If possible, include location in the heart/vessels and nature of abnormality. You may use the diagram as reference, or to draw on, to show the location of the defect(s).
- Have you had any surgery or catheterization for your heart condition? If yes, please describe what was done.
- Are you presently taking any medications for your heart? If yes, please list, and explain how it works.
- Is your cardiologist currently restricting you from exercise/athletics because of the heart condition?
- To what degree is your exercise ability affected by this heart condition?
 - None
 - Mild restriction
 - Moderate restriction
 - Severe restriction
- Will you need any surgery (in addition to any already performed) in the future, even as an adult?
 - No/probably not
 - Maybe/not sure
 - Probably/definitely
- To what degree will your heart condition affect your life as an adult?
 - No effect
 - Some restriction in work/recreation activities
 - Moderate restriction in work choices/recreation
 - Severely restrict my choices for work/recreation

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]. 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%; $p < 0.005$). Patients with complex lesions were more likely to report effect on exercise ability, work and recreation. [data not shown].

Table I: Patient knowledge by age

Age (yrs)	Name defect (n=522)		Describe defect (n=521)	
	Full	Partial	Full	Partial
11-14	40% (n=102)	13% (n=34)	23% (n=58)	35% (n=89)
15-17	51% (n=87)	17% (n=29)	35% (n=56)	37% (n=63)
≥ 18	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)
Parents	78% (n=402)	11% (n=56)	61% (n=312)	29% (n=151)

Table II: Patient knowledge by defect type

	Name defect (n=470)		Describe defect (n=470)	
	Full	Partial	Full	Partial
Mild (n=153)	37% (n=56)	18% (n=27)	24% (n=36)	46% (n=71)
LV (n=183)	48% (n=88)	17% (n=32)	33% (n=61)	32% (n=59)
TOF (n=63)	60% (n=38)	8% (n=5)	19% (n=12)	40% (n=25)
TGA (n=25)	64% (n=16)	8% (n=2)	40% (n=10)	32% (n=8)
SV (n=46)	59% (n=27)	4% (n=2)	33% (n=15)	22% (n=10)
Total	49% (n=238)	15% (n=73)	30% (n=149)	36% (n=175)

Conclusion

Less than 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. A stronger emphasis should be placed on educating and preparing adolescents and young adults earlier and over many years regardless of complexity of CHD.