



CUORE MATTO

Vereinigung für Jugendliche und Erwachsene
mit angeborenem Herzfehler

Psychosocial Issues in Adults with Congenital Heart Disease ... in Rehabilitation

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Geneva, March 13, 2010



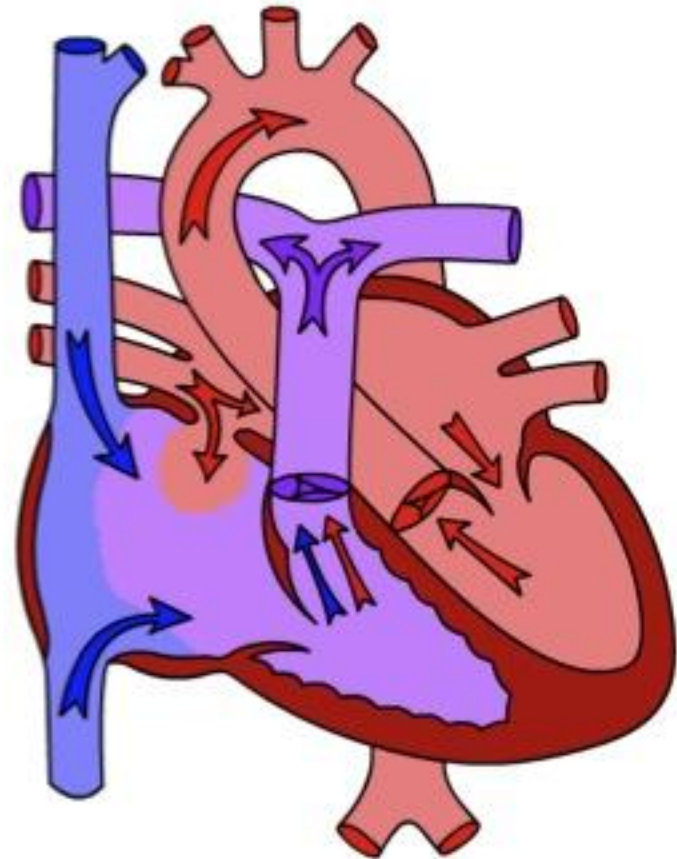
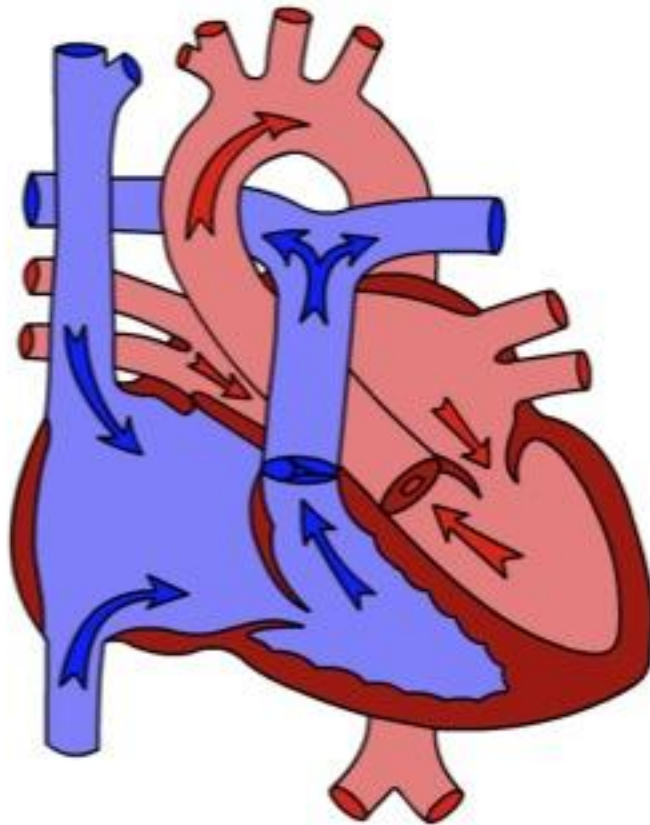
Structure of the presentation

- Introduction: Congenital Heart Disease
- Medical & psychosocial issues in grown-ups
- Exercise tolerance and training
- A study of psychosocial issues in rehabilitation
- Conclusions
- Discussion



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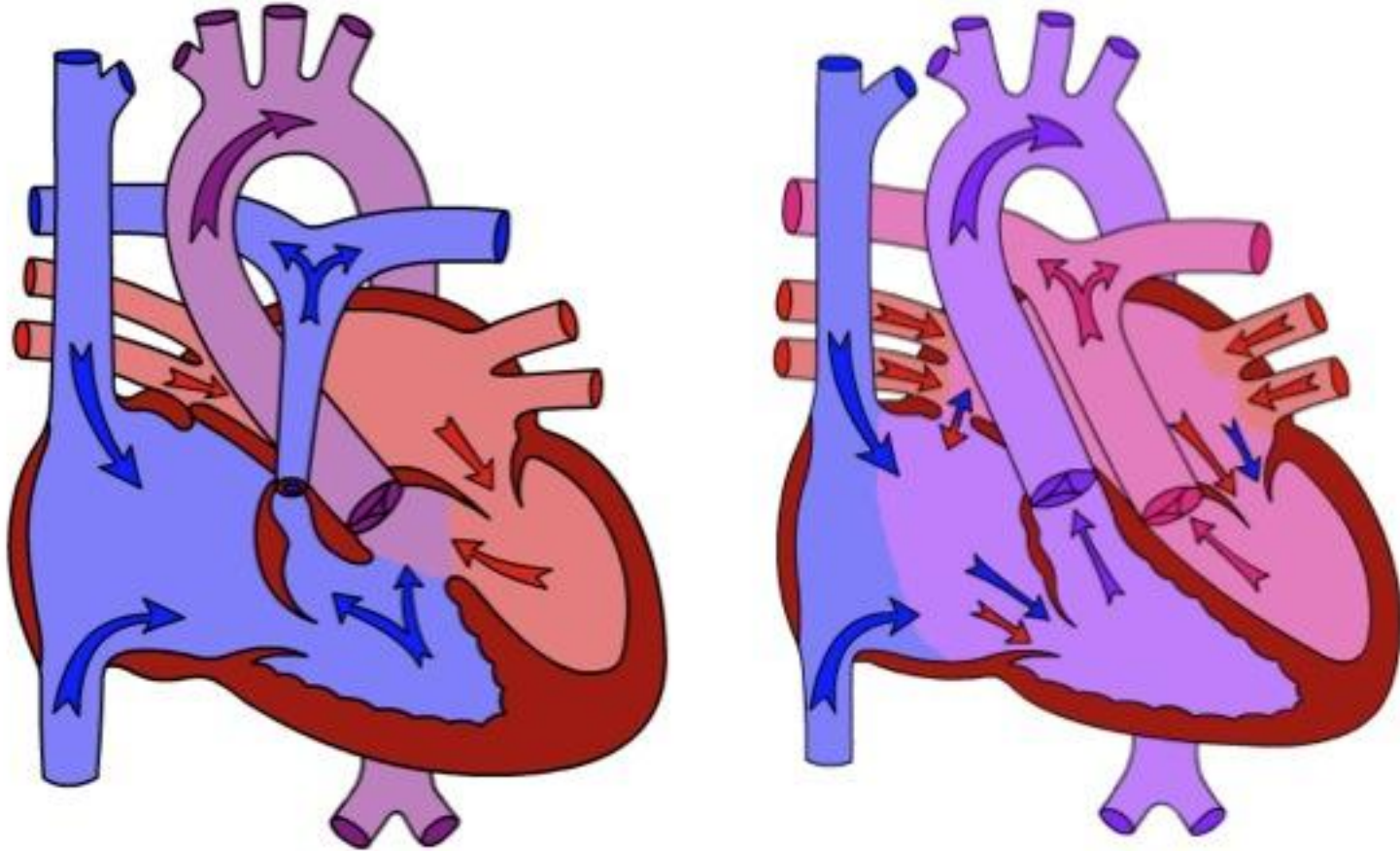
Simple CHD, anatomic correction possible (75%)





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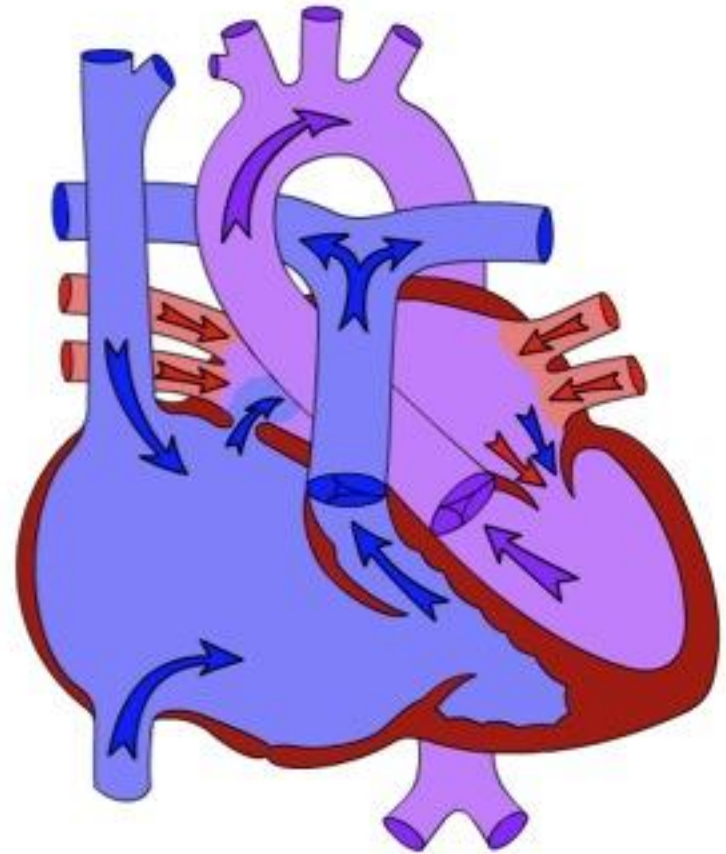
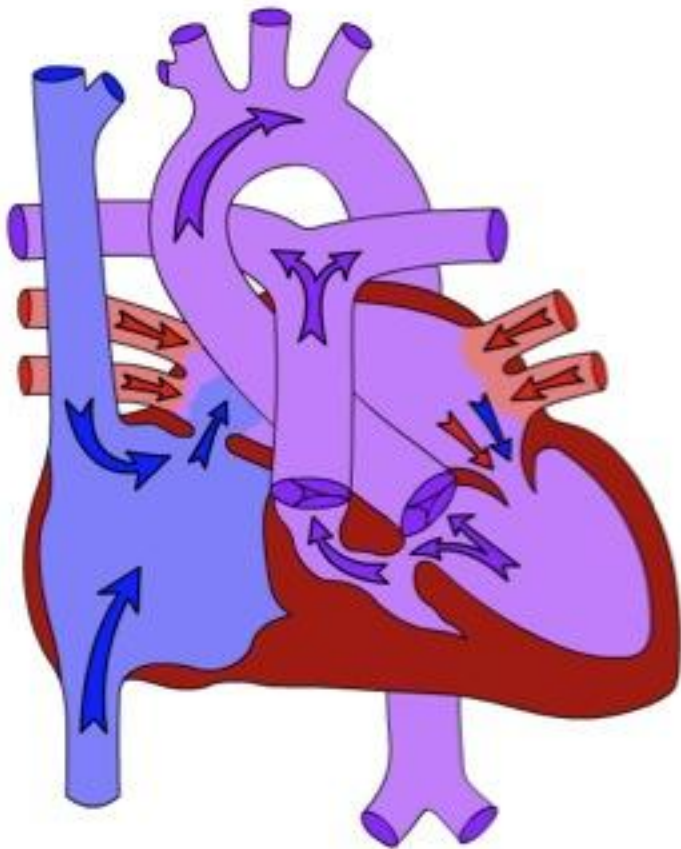
Complex CHD, rough correction possible





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Complex CHD, palliative operations





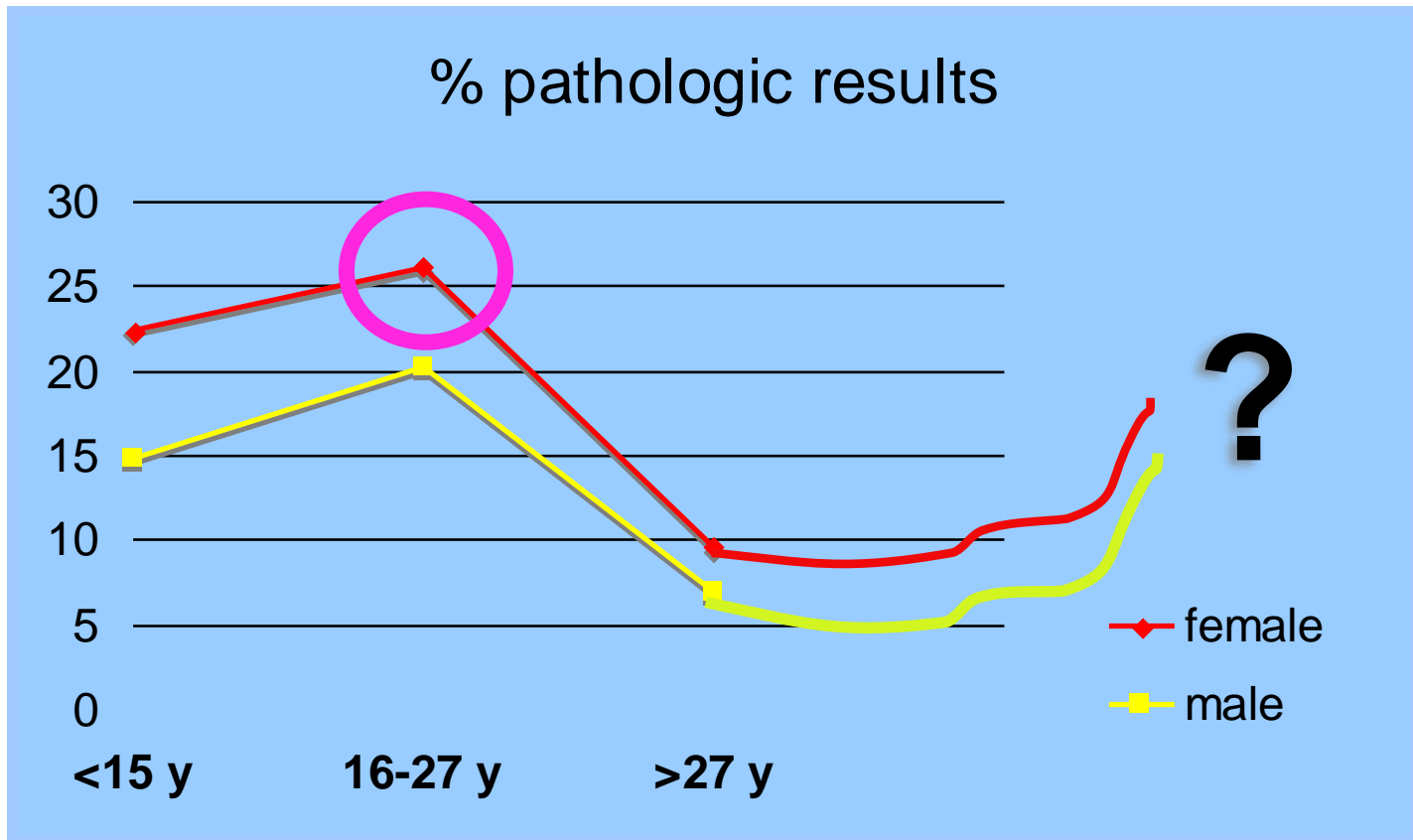
Course in adulthood

- Life expectancy close to normal in anatomically corrected CHD
- Follow-up recommended with GUCH specialists in most
- Arrhythmias
- Endocarditis and other infections
- Cerebral ischemia
- Reoperations necessary:
 - Recurrent stenosis, regurgitation, degeneration of implants
 - residual shunts
- Death: sudden 22%, CHF 40%, postoperative 26%



Chronology of emotional and behavioral problems

Bromberg et al., Heart&Lung 2003





To be or not to be normal

after Claessens et al., Eur J Cardiovasc Nurs 2005
and Berghamer et al., Int J Cardiol 2006

Normalising behavior

- boundaries
- setting priorities
- being ahead of others
- pioneering against advice

Managing difference

- handicap(s)
- coming out
- taking responsibilities
- planning life



Psychosocial issues in adulthood

- Anxiety about heart condition, prognosis
- Social interaction, partnership, sexuality, procreation, parenthood
- Education, employment, career planning, loss of working capacity
- Insurance, pensions, provision for family and (hypothetic) old age
- Lifestyle issues, travelling, **physical activity**



Exercise in Adults with Congenital Heart Disease

Advice: Swan, Hillis, Heart 2000

- Issue not raised by patients (63%) or physicians (71%)
- Advice inappropriately encouraging (14%) or inhibitory (14%)
- Discrepancy between Guidelines, advice and current activity level

Self-estimation of exercise capacity:

- Distinction pathologic / physiologic symptoms during exercise
- Perception of medical problem related to follow-up
- Discrepancy subjective / objective exercise response
- Congenital problem ⇨ limitations experienced as normal



Research on exercise in congenital HD

Exercise tolerance

Many small studies on very specialised questions:

- Outcomes of Fontan modifications
- Serial studies after palliative operations

Exercise training in congenital HD

Few studies, **complex lesions**, small numbers, young patients

⇒ Anaerobic threshold to guide exercise intensity



Any general conclusions?

- **Impact of training in complex congenital HD:**
 - Improvement of skeletal muscle function in all
 - Little improvement of cardiorespiratory adaptation
 - ⇒ training must be individualised, light and prolonged
- **Rhythm often a problem**
- **Comparisons:**
 - with normals ⇒ large differences in ET persist
 - performance before and after training
 - ⇒ **improvement of ET and QoL**



Psychosocial issues in rehabilitation

After operations in GUCH, it is routine to prescribe CV rehabilitation.
In patient organisation CUORE MATTO, informal talk suggests:

Rehabilitation is a psychosocial issue in itself !

Attempt at a qualitative study:

Volunteer members of CUORE MATTO,

unstructured interviews

analysed for recurrent themes

Patients	11
Courses of rehabilitation	13
Inpatient programs	9
Outpatient programs	4



Patient characteristics

1	F	21	Aortic stenosis diagnosed at age 18	Symptomatic	⇒ AC
		33	Recurrent stenosis	Deterioration anticipated	⇒ AC
2	F	40	Aortic stenosis	Symptomatic	⇒ AC
3	F	33	Aortic + pulmonary stenosis 30 y after correction of ToF	Highly symptomatic	⇒ AC
4	M	27	Pulmonary stenosis 25 y after correction of ToF	Deterioration anticipated	⇒ AC
5	F	33	Sinus venosus type ASD, diagnosed due to arrhythmias	Increasing symptoms	⇒ AC
6	F	21	Pulm. stenosis 20 y after correction of endocard cushion defect	Symptomatic	⇒ AC
		22	Implant infection	Symptomatic	⇒ AC
7	F	28	Tricuspid regurgitation 21 y after correction of Ebstein	Highly symptomatic	⇒ PR
8	F	31	Mechanic valve complications 25 y after correction of Ebstein	Symptomatic	⇒ PR
9	M	23	Tricuspid valve regurgitation in univentricular heart	Symptomatic	⇒ PR
10	M	33	Unoperated Ebstein, deconditioning after unrelated disease	No operation	
11	F	35	Corrected TGA, family + profession, deconditioning	No operation	



Recurring themes 1: Age and gender

- **GUCH patients are the youngest in CV rehabilitation**

**« My roommate was twice my age,
and she was the youngest except for me. »**

- **The majority in CV rehabilitation are men**

**« I felt like I was back in gym class... always the weakest!
I'm so glad I was in a pure female pilot group! »**



Recurring themes 2: Staff uncertainty

- **Staff in CV rehabilitation has limited knowledge on GUCH**

**« I knew I was performing better than ever before.
They blamed me for not performing better at my age. »**

- **Staff support is limited**

**« They didn't force me to share a table
with that lady who kept talking about her ailments. »**



Recurring themes 3: Theory sessions

- **CV rehabilitation includes theory on coronary risk factors**

**« It all was directed at elderly men
who didn't have a clue about cholesterol. »**

- **Individual consultation is possible in some institutions**

**« They don't offer any psychological consults.
Later the doctor called and asked me to support his next GUCH patient. »**



Recurring themes 4: Psychosocial support

- **Professional support**

**« It was called occupational therapy,
but we were told to express emotions in our paintings. »**

**« One session about returning to a normal life really depressed me.
I know this operation wasn't much of a success »**

- **Peer support**

**« The group noticed I was holding back tears.
They all hugged me and we went to have a drink together »**



Conclusions 1

Coronary rehabilitation for congenital HD

- **Physical aspects of rehabilitation programs**
 - Staff not used to thinking through anatomy + hemodynamics
... physical aspects adequate for corrected congenital HD
 - Evidence-based rehabilitation in palliative situations is lacking
... **Staff guided by clichés is dangerous!**
- **Psychosocial aspects**
 - Little attention to psychosocial situation **during** rehabilitation
 - Individual support and consultations often unavailable
 - Previous experience with GUCH improves staff attitudes



Conclusions 2

Coronary rehabilitation for congenital HD

- **Age and gender**
 - If patient mix in CV rehabilitation can't be changed
... preparation of staff, GUCH patients and other patients can!
- **Burden on GUCH in rehabilitation**
 - Management of own motivation and group dynamics
 - Deciding about relevance of theory sessions
 - Deciding about exercise intensity
 - ... educating staff !!
- **And yet**
 - **9 would do it again, 2 are not so sure**



Discussion

- **Study limitations**
 - Number and heterogeneity of patients and programs
 - Selection bias
 - Retrospective with variable time lapse
- **Need for education**
 - ... all staff involved in rehabilitation?
 - ... selected and certified rehabilitation programs?
- **Need for truly professional research !**