



Dr. Karl - Otto Dubowy

Paediatrician, cardiology, pulmology, EMAH, sport with heart and lung

kdubowy@hdz-nrw.de

Psychosocial aspects in congenital heart disease with the focus on adulthood

- Physicians view -

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Prevalence

- 5000 – 6000 patients with congenital heart defect are born in Germany annually.
- Up to day more then 85 % survive – 70% complex defects, 95 % simple defects.
- 277000 ACHD – The number of adults with congenital heart defect increases annually up to about 5000 patients.
- > 60000 highly recommended follow up –

Schmaltz 2008, Marelli, 2007 Kaemmerer 2005 Wren, 2001 Gummert, 2008

What do ACHD expect from the

- **Plain language and information about the disease**
- **Clear information on procedures and treatment options**
- **Practical advice for day-to-day living (partnership, intimacy, pregnancy, family, job,)**
- **Economic support, advocacy and lobbying**
- **Professional psychological support**
- **Encourage patients to get a member of patient organisations**
- **Affected volunteers to visit patients in hospitals**

ACHD or madness is the

Echo, ecg, lungfunction, cath
exercise, pacemaker, anticoagulation,
pregnancy, psyche, social problems,
self-harm,

multiprofessional team and

- ✓ Talk to the patient according to his age.
- ✓ Allow the patients to choose their medical care within your hospital or in a different hospital or medical office.
- ✓ Promote autonomy.
- ✓ >16 years talk to the patient with but also without parents.
- ✓ With female patients address the gynaecologist.

Detachment(parents and

**As juvenile longterm patient with
chylothorax, parenteral nutrition
and pain therapy stationairy / daycare
„ ich komme hierhin
bis tot umfällt “**



Social – emotional development

- contact and separation anxiety
- low self esteem
- low social skills

Hülser K, Kilborn R, Dubowy K O Angeborene Herzfehler: Einflüsse auf die kindliche Entwicklung und psychosoziale Adaptation 2007

Parenting skills

Overprotection

- Balance between care due to illness and essential requests due to development
- ▶ When does necessary care change into overprotection and spoiling?
- ▶ Traumatized parents perceive their child as in need of help, more sadly and social non assertive.
- ▶ Too much parental care and support induces self doubt and low self confidence.

Hülser K, Kilborn R, Dubowy K O Angeborene Herzfehler: Einflüsse auf die kindliche B und psychosoziale Adaptation 2007

How to minimalize these risks in

Use resources

- Families must be flexible in adapting to the needs changing with age, development and actual medical finding of the child.
- Normal educational style with clear behaviour and clear behaviour demands.

Hülser K, Kilborn R, Dubowy K O Angeborene Herzfehler: Einflüsse auf die kindliche E und psychosoziale Adaptation 2007

Sexuality and subjective

- Men under the age of 40 engage less frequently in sexual relationships than their peers from the general population.
- Overall, 9% of women reported increased or altered symptoms related to their heart defect during sexual activity. This proportion increased significantly with worsening functional class (6%, 11%, and 26% in functional class I, II, and III–IV, respectively; $p = 0.001$), increased severity (5%, 8%, and 17% for simple, moderate, and severe heart defects, respectively; $p = 0.005$), and in women with

Vigl et al Heart 2009 Jul; 1127
Vigl et al Am J. Cardiol 2010 Feb 15;105(4):538-41

Many longterm survivors – too little in specialised ambulances

Tabelle 1: Schätzung der Erwachsenen mit angeborenen Herzfehlern (HF) in Deutschland

	Geburtsjahr	Geburten in D	Pt. mit HF	18 J. Überlebensrate	Überlebende mit 18 J.
komplexe HF (Inzidenz 1,5/1000)	1950-59	10 000 000	15 000	10 %	1500
	1960-79	21 180 000	31 770	35 %	11 120
	1980-89	8 860 000	13 290	50 %	6645
	(1990-99)	8 040 000	12 062	70 %	8443
einfache HF (Inzidenz 4,5/1000)	1950-59	10 000 000	45 000	90 %	40 500
	1960-79	21 180 000	95 310	90 %	85 779
	1980-89	8 860 000	39 870	90 %	35 883
	(1990-99)	8 040 000	36 180	95 %	34 371
Gesamt:					181 427

(Gesamt in 2017 ohne Berücksichtigung der Absterberate der älteren Jahrgänge: 224 241)

Extrapolation der empirisch gefundenen Prävalenz von AHD bei Erwachsenen in Quebec, Kanada: 4,09 auf 1000 Einwohner. In Deutschland 2004: 67 672 000 Erwachsene >18 Jahre ergibt 276 778 EMAH-Patienten.

Quellen: Geburtenzahl: Statistisches Bundesamt (www.destatis.de).

Inzidenz und Überlebensquote: 32. Bethesda Konferenz/British Cardiac Society Working Group

About 500000 P. with congenital heart defect.
Since 2005 about one in two > 18 years of age

AChD ambulances / medical offices
? 10.000 patients

Nationales Register / KNAHF 2008

Pregnancy – a controversial reality I

- The number of women treated in GUCH clinics or medical offices is too little.

but

- Maternal death during pregnancy, delivery and confinement in industrial nations is most frequently due to cardiovascular diseases.
- Women of childbearing age with cardiovascular diseases or cardiovascular riskfactors should be treated or counseled by an interdisciplinary team of gynaecologists, cardiologists, cardiac surgeons.
- It is our duty to advice women of childbearing age to join GUCH clinics or specialised medical offices.

V Regitz-Zagrosek Cardiovasvular diseaeses in pregnancy 2011

Pregnancy and peripartal

- Our tailored multiprofessional approach involving early introduction of targeted therapy and early planned delivery with regional anaesthetic techniques has resulted in improved outcomes, although maternal mortality remains significant.
- Consequently, our approach is to counsel women and their partners on the the very high risk of pregnancy, with clear contraceptive advice and, in the eventuality of pregnancy, consideration of termination.

slide courtesy of Kiley D UK

Pregnancy and peripartal management II

**In a better world
it will
be possible to overcome
maladies in the future .**

Great Britain and France are an example of two opposite attitudes.

Pregnancy – a controversial reality II

- There are many different views about pregnancy of women with complex heart diseases.
- The patients must be informed sufficiently about risks to enable them to decide in a good way for themselves.
- Even, when patients´ s decision is doubtful, considering medical view, we have to respect their decision and have to do the best for mother and child.

V Regitz-Zagrosek Cardiovascular diseases in pregnancy 2011

Mental and physical

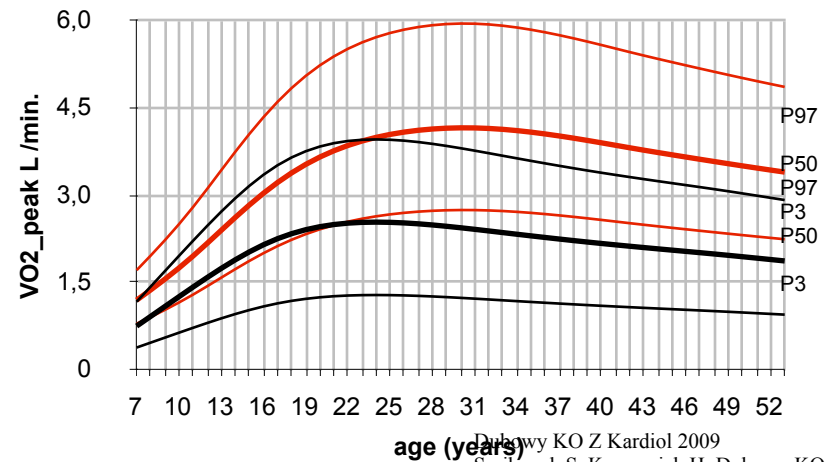
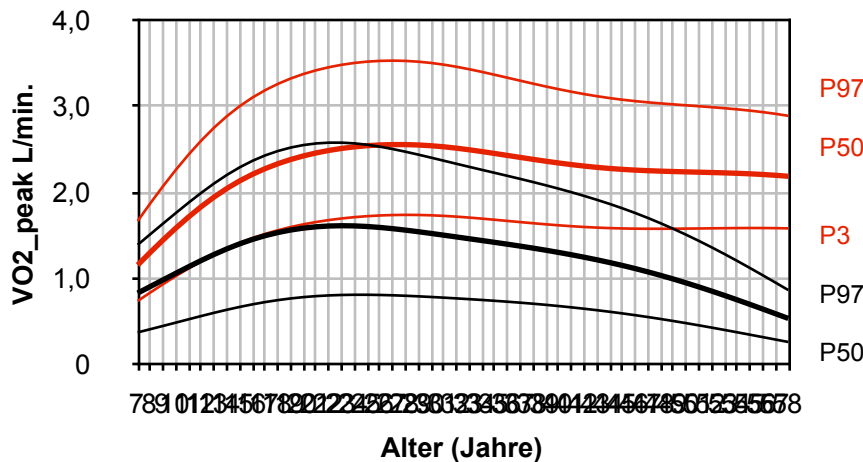
- in / external medical and psychosocial teamwork
- job center
- social integration/including office
- sheltered workshop
- „Landschaftsverband“
- federal patient fund
-

Reduced exercise capacity in GUCH

- **ventricular septal defect 12%**
- **atrial septal defect 20%**
- **Tetralogy of Fallot 20 %**
- **single ventricle 35%**
- **reduced ventilatory threshold in ToF and single ventricle**

J.Fritsch et al 1994, Z.Kardiol.83:Suppl.3, 131-139

Explore and explain exercise

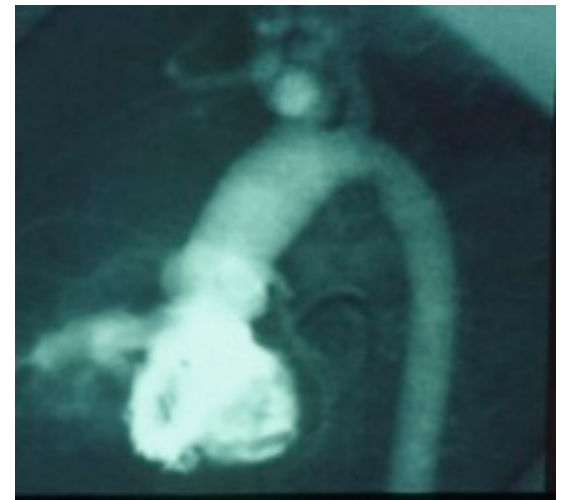


50. percentile of TOF reflects 3. percentile of healthy probands

Dubowy KO Z Kardiol 2009
 Sarikouch S, Koerperich H, Dubowy KO et al
 Impact of Gender and Age on Cardiovascular
 Function Late After Repair of Tetralogy of Fallot
 Dubowy KO, Kardiol 2009
 Circ Cardiovasc Im aging 2011;4;703-711;

ACHD and job limitation

- Cardiovascular disease in common
- Myocardial infarctation
- Congestive heart failure
- Pacemaker
- Arrhythmias
- Hypertension
- Pulmonary hypertension



Arbeitsmedizinische Einschränkungen bei bestimmten Erkrankungen,
Verlag Arzt + Information, 1996/2006/2011

Sociomedical assessment medical fitness / egibility

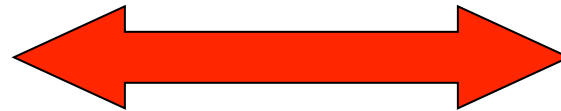
kind of work

characteristics
of the workplace

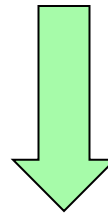


work capacity

job requirement



working time



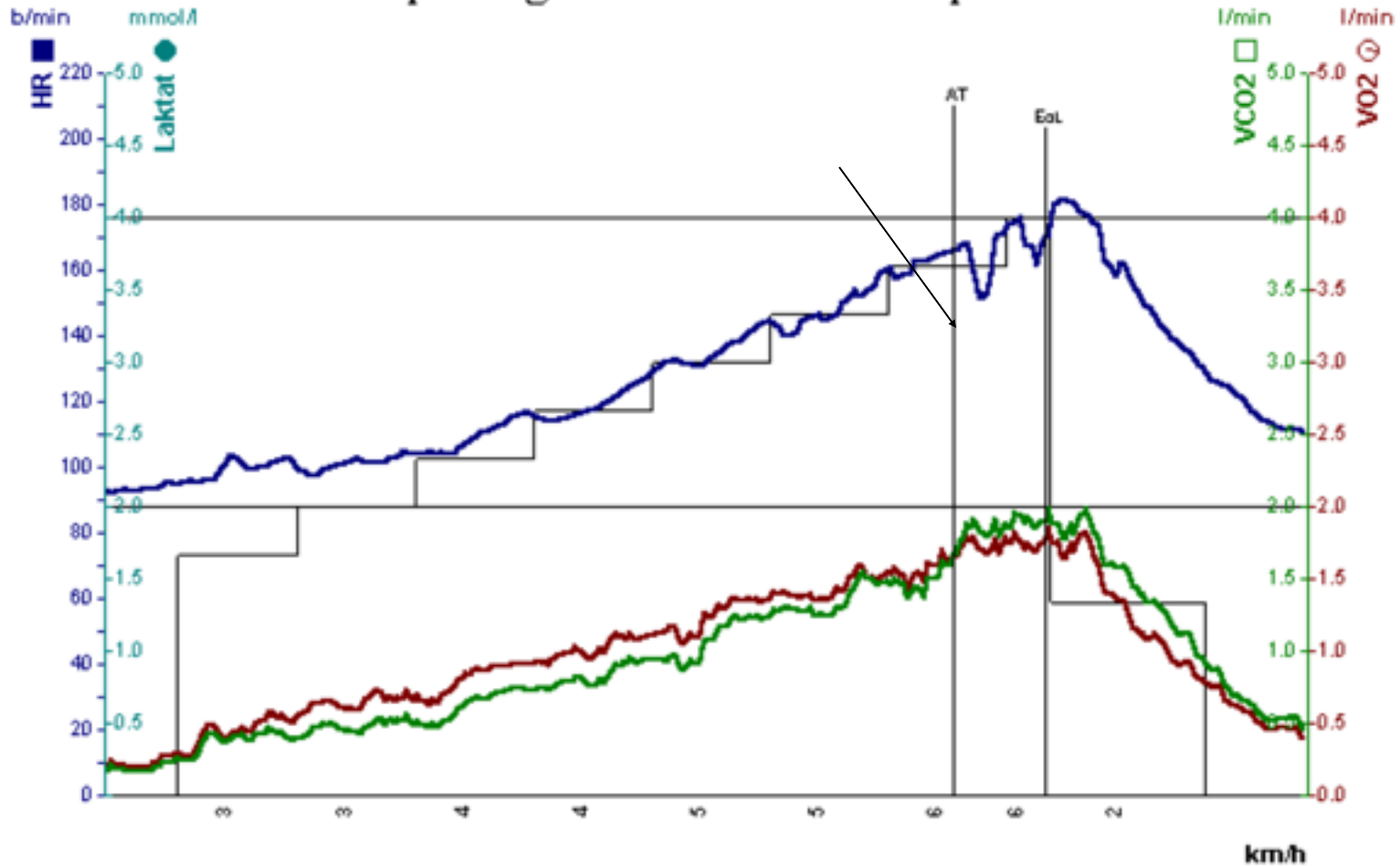
practicable job



AV-Block III° – no pacemaker wanted!

ergospirometry* – aerob

SpiroErgometrie Schwellen-Report



* preferable to stress ECG

Job related oxygen uptake at ventilatory

• sitting	4,25	
• standing	8,75	
• walking	10,5	
• driving a car		4,25
• driving a truck		5,3
• crane operator	8,75	
• pump attendant	9,45	
• work as a cleaner	9,45	
• plumber	10,5	
• storeman	10,5	
• gatekeeper, physician (no surgery)		10,5
• bricklayer, paperer, nurse	14	
• carpenter, surgeon	14–21	
• landscaper	25	

reduced aerobic capacity – rehabilitation

- occupational
- ambulant
- stationary



§ 23 Abs. 2 SGB V

Insurability of ACHD

- Limited statistic on clients with GUCH.
- Public unemployment and annuity insurance are mandatory.
- Statutory health insurance is always given.
- Individual health insurance is usually not possible – except of civil servants in Germany.

Summary

- ACHD have to be treated with detachment as normal adult patients.
- ACHD with mental and physical handicaps have to be included (society, job, peer groups).
- We should encourage all ACHD to join a specialised medical practice or center.
- Especially pregnant women should join a specialised medical practice or center