Psychosocial aspects in congenital heart disease with the focus on adulthood

- Physicians view -
Table of contents

- prevalence
- patients expectation
- notes to proper handling
- sexuality / pregnancy
- job situation and integration into the employment market
- insurability
- summary
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 –

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, intimity, 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.
As juvenile long-term patient with chylothorax, parenteral nutrition and pain therapy stationery / daycare

„ ich komme hierhin
bis ...... tot umfällt “
Social – emotional development

- contact and separation anxiety
- low self esteem
- low social skills
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.
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.
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...
Many longterm survivors – too little in specialised ambulances

About 500,000 P. with congenital heart defect. Since 2005 about one in two > 18 years of age

ACHD ambulances / medical offices ? 10,000 patients

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

<table>
<thead>
<tr>
<th>Geburtsjahr</th>
<th>Geburten in D</th>
<th>Pt. mit HF</th>
<th>18 J. Überlebensrate</th>
<th>Überlebende mit 18 J.</th>
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<td>komplexen HF (Inzidenz 1,5/1000)</td>
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<tr>
<td>1950-59</td>
<td>10000000</td>
<td>15000</td>
<td>10 %</td>
<td>1500</td>
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<td>1960-79</td>
<td>21180000</td>
<td>31770</td>
<td>35 %</td>
<td>11120</td>
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<td>1980-89</td>
<td>8860000</td>
<td>13290</td>
<td>50 %</td>
<td>6645</td>
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<tr>
<td>(1990-99)</td>
<td>8040000</td>
<td>12062</td>
<td>70 %</td>
<td>8443</td>
</tr>
<tr>
<td>1950-59</td>
<td>10000000</td>
<td>45000</td>
<td>90 %</td>
<td>40500</td>
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<td>1960-79</td>
<td>21180000</td>
<td>95310</td>
<td>90 %</td>
<td>85779</td>
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<tr>
<td>1980-89</td>
<td>8860000</td>
<td>39870</td>
<td>90 %</td>
<td>35883</td>
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<tr>
<td>(1990-99)</td>
<td>8040000</td>
<td>36180</td>
<td>95 %</td>
<td>34371</td>
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<tr>
<td>Gesamt:</td>
<td>181427</td>
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</table>

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


Quellen: Geburtenzahl: Statistisches Bundesamt (www.destatis.de), Inzidenz und Überlebensquote: 32, Bethesda Konferenz/British Cardiac Society Working Group

Nationales Register / KNAHF 2008

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Ruhr University of Bochum Germany
Pregnancy – a controversial reality

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

- 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 risk factors 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.
Pregnancy and peripartum

- 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 very high risk of pregnancy, with clear contraceptive advice and, in the eventuality of pregnancy, consideration of termination.
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.
Mental and physical

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

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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

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ACHD and job limitation

- Cardiovascular disease in common
- Myocardial infarction
- Congestive heart failure
- Pacemaker
- Arrhythmias
- Hypertension
- Pulmonary hypertension
Sociomedical assessment
medical fitness / eligibility

kind of work

characteristics of the workplace

work capacity

job requirement

working time

practicable job

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AV–Block III° – no pacemaker wanted!
ergospirometry* – aerob

* preferable to stress ECG

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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

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§ 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.

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