Danish Registry of Adult Congenital Heart Disease.

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Danish Registry of Adult Congenital Heart Disease.

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We have no disclosures.
Danish Registry of Adult Congenital Heart Disease.

- It is a registry of:
  - childhood and adult - structural - congenital heart disease.
  - "acquired" heart disease up to the age of 26 years.
Danish Registry of Adult Congenital Heart Disease.

- It is build on the basis of the following public registries:
  - Personal identification number (CPR-number) (1968)
  - The Danish Registry of Causes of Death (1900)
  - The National Registry of Hospital Admission, including registry of operation/procedures (1977)
  - The Danish Birth Registry (1964)
  - Database for Labour Market Research for socioeconomic variables. (1985)
  - The Danish Medicines Registry (1995)
  - Survey of all CHD in Denmark 1963 -1974 performed by Henning Bækgaard Laursen
Shouldn’t there be some sort of recognition perhaps—perhaps a prize—for the way the Danes keep producing interesting and useful population research?

How have the Danes done all this? Identity cards, a reliable population database, and a national registry of all prescriptions. The rest of the world should express some appreciation.

It’s just like pressing a button—as they say, and then, the Great Danes can go to sleep.

That’s not reality.
Danish Registry of Congenital Heart Disease


- Inaccurate or omitted diagnosis 11,977 ≈ 35%

- Prevalent CHD patients Jan.1st. 2010 22,359 ptt.

- Prevalent GUCH patients (> 15 years of age) 13,923 ptt.

- (Danish population: all age 5,4 mio inhabitants)

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Main reason for omissions or incorrect diagnoses.

Bicuspid aortic valve and cardiomyopathies, fibroelastosis.

Ductus and PFO (sometimes mistanken for ASD or VSD) in newborn < 2 m. Particularly in premature babies, unless treated invasively.

Non-specific or stand alone diagnosis of CHD and all rule-out cases.

Mothers’ diagnosis of a new CHD, at the same time as a foetal echo.

First diagnosis of cong. LVOTO or mitral disease in subjects > 40 years.

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Living CHD patients in registry

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Living GUCH patients (> 15 years) in registry

- 46% of GUCH 15 to 30 years
- 32% of GUCH 31 – 45 years
- 22% 46 +

GUCH patients 13,923
All GUCH patient in registry

Gender

Gender ratio F/M = 1.12

Men 6,562 = 47%  Women 7,361 = 53%

median age men, 36 years
median age women, 38 years

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Interventions
Surgery or catheter procedure

• GUCH patient 13,336
• Intervention yes 5,361 (39,8%)
• Intervention > 15 year 2,809 (52,4%) of interventions
• Re-intervention > 15 year 273 (5,1%) of interventions

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Annual change in number of GUCH patients. (1990-2009)

- Not operated GUCH
- Operated GUCH
- All GUCH patients

3% increase/year
# DK GUCH patients

## International comparison

<table>
<thead>
<tr>
<th>GUCH patients</th>
<th>GUCH No. – (%)</th>
<th>per mio. inhabitants' &gt; 15 year</th>
<th>per. mio. EU standard population</th>
</tr>
</thead>
<tbody>
<tr>
<td>GUCH &gt; 15 years</td>
<td><strong>13.923</strong> (62 % all CHD)</td>
<td><strong>3.141</strong></td>
<td><strong>3.162</strong></td>
</tr>
<tr>
<td>GUCH &gt; 18 years</td>
<td>10.855 (53% all CHD)</td>
<td>2.976</td>
<td>3.104</td>
</tr>
</tbody>
</table>
Possibilities of stratifying GUCH patient

• Structural (anatomical) diagnoses and combinations of diagnoses. A general accepted hierarchic diagnostic system is necessary, and an association between structural diagnoses and late outcome is a prerequisite.

• Guided by interventions – RACHS-1 or Aristotle Complexity Score, but there are missing scores in some procedures.

• Cardiac co-morbidity in a hierarchic order. (MACE*)

• Extra cardiac co-morbidity, either alone or in combination with one of the possibilities above

* major adverse cardiac events
RACHS-1 scores in operated GUCH patients

- Of the 5,351 patients operated, the following RACHS-1 scores were registered:
  - RACHS-1 grp. 1  2,451  (46%)
  - RACHS-1 grp. 2  874   (16%)
  - RACHS-1 grp. 3  1,263  (24%)
  - RACHS-1 grp. 4+6 249   (4,7%)
  - RACHS-1 no classification 514  (9,6%)
Stratifying GUCH patients. The RACHS-1 system

- **Group 1:** not-operated ptt: 7.062 (60%)
- **Group 2:** RACHS-1 grp. 1 + 2 ptt. 3.381 (27%)
- **Group 3:** RACHS-1 grp. 3-6 ptt* 1.512 (13%)  
  
* (not operated pulm. hypertension & Ebstein in group 3)
Stratifying GUCH patients.
Hierarchic cardiac co-morbidity (MACE)

- Patients with MACE 1.851 (15%)
  - Heart transplant 14
  - Pulm. Hypertension 122
  - Endocarditis 178
  - Heart failure 238
  - Re-operation (1 – 20) 389
  - Arrhythmias 910

- No MACE 10.929 (85%)

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Stratifying GUCH patients, extra-cardiac co-morbidity

- no co-morbidity 5.661 (41%)
- co-morbidity (ex.car.) 8.262 (59%)
  - moderate* Co-morbidity 5.872 (42%)
  - medium* Co-morbidity 1.426 (10%)
  - significant* Co-morbidity 957 (6.8%)

* Evaluated with Charlsons’ co-morbidity index
Conclusions

• Prevalence of GUCH in Denmark is pr. Jan. 1st 2010: 13.923 patients, corresponding to ≈ 3.100 per mio. inhabitans > 15 years.

• Gender ratio F/M = 1,12

• $\frac{3}{4}$ of the patients are ≤ 45 years

• Estimated increase in 10 year ≈ 30 %, especially operated cases.

• Currently, 40% of patients have had an intervention.
Conclusion 2

• There are no universally accepted system of stratifying the well-being and prognosis of the GUCH patient.

• The options tested here do not give a clear answer to the clinical need of risk stratifications.

• An “EURO-GUCH index” including both well-being and prognosis could be an interesting development.
Thank you for your attention.