


 **CORE MATHS**

Hurray, we are still alive

Tough Hearts Conference 2014
Noémi de Stoutz
Baar, July 23, 2014

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Hurray, we are still alive !


2005 Research on Psychosocial Issues

we are Introduction
alive The Normal Life
Psychological Adjustment
Quality of Life
still End of Life Issues
Hurray Conclusion

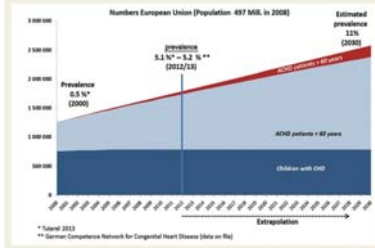
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The GUCH patient population
(new)
growing
special
not so special

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We are ... a growing patient population



Numbers European Union (Population: 487 MIL in 2008)

Prevalence 6.5%* (2000)

Prevalence 5.1%* - 5.2%** (2012/13)


Estimated prevalence 13% (2030)

Childen with CHD

AHD patients > 65 years


* Total 2013
** German Competence Network for Congenital Heart Disease (data on file)

Figure 1 Changing prevalence of congenital heart disease in the European Union by age groups (reproduced from Baumgartner).


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We are difficult to research on

- heterogeneous patient population
- today's adults treated with yesterday's techniques
- no representative samples
- small groups = statistical problems
- statistics obscure significant single experience

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We are to be found everywhere




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The Normal Life


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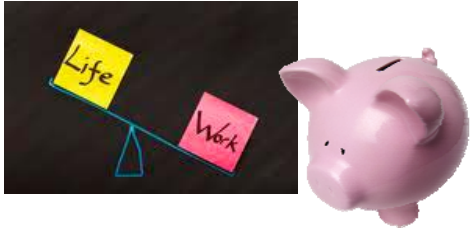
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The Normal Life




 **CORE MOTO**


The Normal Life



 **CORE MOTO**

The Normal Life



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Exercise in GUCH


Advice: Swan, Hills, Healt 2000

- Issue not raised by patients (63%) or physicians (71%)
- Advice too encouraging (14%) or inhibitory (14%)
- Discrepancy Guidelines / advice / current activity level

Self-estimation of exercise capacity:

- Distinction pathologic / physiologic symptoms
- Medical follow-up may increase perception problem
- Discrepancy subjective / objective exercise response
- Congenital problem ⇒ limitations seen as normal


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Training to increase Exercise Tolerance?

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

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Coronary rehabilitation for CHD


Physical aspects of rehabilitation programs

Staff not used to thinking through anatomy/hemodynamics
 ... ok for anatomically corrected CHD
 Evidence-based rehab in palliative situations is lacking
 ⇒ **Staff guided by clichés is dangerous!**

Psychosocial aspects


- Little attention to psychosocial situation **during** rehab
- Individual support and consultations often unavailable
- Previous experience with CHD improves staff attitudes

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- Psychological Adjustment
- Perspectives of GUCHes


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Psychological Adjustment

Van Rijen et al, Eur Heart J 2004

Questionnaires filled by Patients and Parents

- Attention Problems
- Intrusive Behavior
- Aggressive Behavior
- Delinquent Behavior
- Thought Problems
- Anxious/Depressed
- Withdrawn
- Somatic Complaints

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Perception of behavioral problems


Van Rijen et al, Eur Heart J 2004

Perception of loved ones influenced by

- number of hospital stays
- pacemaker
- ugliness of scar
- female gender

Perception of GUCHes influenced by

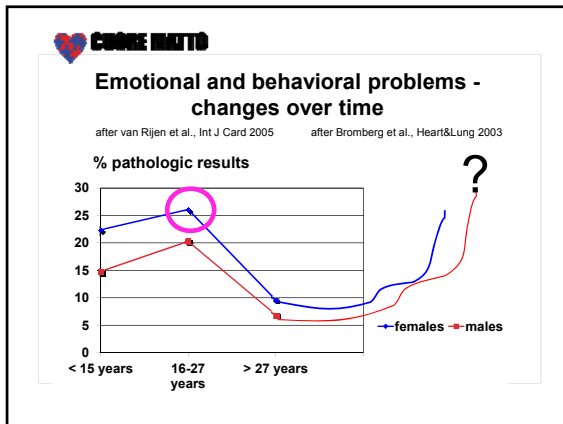
- current physical performance
- painful/bothering scar
- female gender

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To be normal – to be different

Claessens et al., Eur J Cardovasc Nurs 2005
Berghammer et al., Int J Cardiol 2006

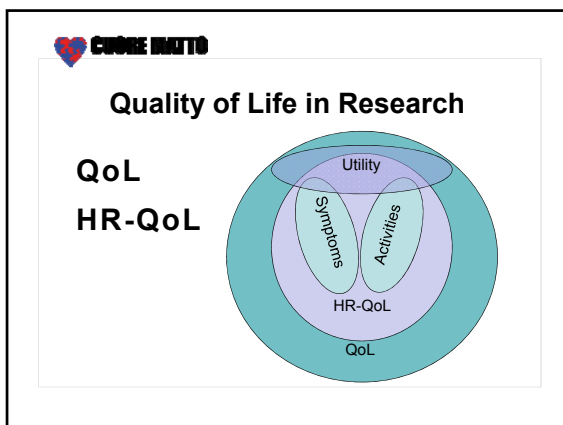
Normal	Different
• dealing with limitations	• handicap
• setting priorities	• life project
• proving oneself	• exclusion / demarcation
• getting ahead of others	• self-responsibility



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Quality of Life:

- General scientific discussions
- Research with GUCHes
- Perspectives of GUCHes



Comparison of GUCH QoL with Normals
Moons et al., Eur J Prev Card 2006

Method: Scales for QoL
Life Satisfaction
Health Status

QoL GUCH > Healthy Peers
Percieved Health no group difference

Problems and concerns very similar

77 items of distress GUCH 16
Healthy Peers 20

Determinants of Quality of Life
et al., J Adolesc Health 2012 et al., Curr Cardiol Rep 2013 Luyckx Appels

Age and gender
 Severity of CHD and residual lesions
 Physical fitness
 Health Worries
 Manageable
 Family Environment and Support
 Education, Professional Position / Perspectives

Sense of Coherence

Biographic perspective

Pediatric Cardiology

Volume I: happy ending
 Volume II: GUCH

... and they lived happily e

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End of Life – a Tough Topic!

- what happens
- what GUCHes want
- what is being discussed

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GUCHes don't take life for granted

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Mode of Death of GUCHes
Oechslin et al, AJC, 2000

GUCHes between 1981-1996

Mode of Death	Percentage
heart failure	21%
perioperative	18%
non-cardiac	17%
other cardiac	18%
sudden death	26%
(unlabeled)	23%

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Circumstances of GUCH Deaths
Toronto 2000-2009
Tobler et al, Pall Med 2011

- 93% moderate to high complexity
- 64% severe chronic heart failure
- 56% prior admission due to CHF
- 90% prior life-threatening event
- 42% assessed for transplantation

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Medical Care for Dying GUCHes
Toronto 2000-2009
Tobler et al, Pall Med 2011

- 50% DNR at time of death
- 67% died in ICU
- 44% mechanical ventilaton
- 15% hemofiltration/dialysis
- 52% attempted resuscitation

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Is that what they hoped for?
Toronto 2000-2009
Tobler et al, Pall Med 2011

Documented End of Life discussions:

- in 26 of 48 patients
- 3 before final admission
- 2 with patients during final admission
- 21 with substitute decision maker during final admission
- time interval EoL discussion to death: 2 days

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Barriers to communication

Greutmann et al., Congenit Heart Dis 2013

Patients

- prefer to concentrate on staying alive
- don't know what kind of care they would want

Doctors

- worry patients aren't ready to discuss End of Life
- don't want to take away hope
- want to be sure about prognosis

Longstanding relationship helps

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Communication about End of Life

Greutmann, Tobler et al. Int J Card 2010

Survey completed by 200 patients:

- Would they wish health care professionals to discuss EoL issues?
- When would be the right time for this?

Survey completed by 46 professionals:

- How often do they discuss EoL with patients?
- When would be the right time for this?

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Communication about End of Life

Greutmann, Tobler et al. Int J Card 2010

EoL planning has been discussed

Patients	1%
Providers	50%

EoL should be discussed

Patients	78%
Providers	... depends on disease severity

Discussion before severe complications

Patients	62%
Providers	38%

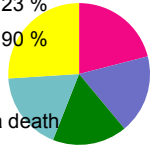
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GUCH Deaths – Psychosocial Context

Tobler et al. Pall 1 1

Family constellation during last hospital stay

- Married / living with a partner 42 %
- At least one child 23 %
- At least one parent still alive 90 %
- Complex bereavement situations ... whatever the circumstances of a death



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Palliative Care

WHO 2002

Palliative care is an approach that improves the quality of life of patients and their families facing life-threatening illness,

prevention and relief of suffering
early identification
impeccable assessment
treatment

of physical, psychosocial and spiritual problems

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Ongoing research

- EoL communication – demand and barriers
- how to train cardiologists for this communication
- palliative care needs / possibilities
- how to better care for us at the end of our lives
- how to care for our bereaved loved ones

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Summary

- ♥ bad news
- ♥ good news

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**Conclusions
The Bad News**

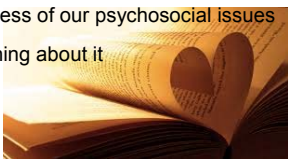
- «Normal» adult life - a bad joke
- Excellent pediatrics
 - healthcare unprepared for GUCH
- Specialized care necessary
 - also by psychsocial disciplines
 - but availability is another question



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**Conclusions
The Good News**

- GUCH care is growing
- Increasing awareness of our psychosocial issues
- We can do something about it



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... and the best news is



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