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Quality of life in grown-ups with congenital heart defects

Philip Moons, PhD, RN

Quality of life in ACHD: literature review

ARTICLE

**Caliber of Quality-of-Life Assessments in Congenital Heart Disease**

A Plea for More Conceptual and Methodological Rigor

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*Arch Pediatr Adolesc Med, 2004*

Quality of life in ACHD: literature review

**Conclusions:** A poor conceptual and methodological basis for quality of life implies that many results from quality-of-life studies performed in patients with congenital heart disease contribute little to the scientific knowledge base of quality of life in this patient population. Future quality-of-life studies need to invest in a rigorous conceptualization, an adequate operational definition, and a sound measurement of quality of life.

*Arch Pediatr Adolesc Med, 2004*

Quality of life in ACHD: literature review

- Review criteria (Gill & Feinstein, 1994)

1. Conceptual definition of QoL	1%
2. Stating explicitly the domains measured as components of QoL	24%
3. Reason for choosing the instruments used	3%
4. Aggregation of information into a single index	31%
5. Could patients give their own rating for global QoL	1%
6. Was overall QoL distinguished from health-related QoL	1%
7. Could patients supplement items listed in instruments	0%
8. If so, were supplemental items incorporated in final rating	n.a.
9. Could patients indicate personal importance of items	4%
10. If so, was rated importance incorporated into final rating	100%

*Arch Pediatr Adolesc Med, 2004*

Some quality-of-life studies in ACHD

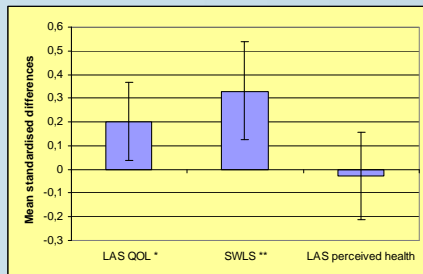
1st Author	Year	Severity	n	Results
Fekkes	2000	mild	94	with social restrictions = without social restrictions ↗
Meijboom	1993	mild	104	=
Meijboom	1994	mild	109	=
Gersony	1993	moderate	1681	=
Meijboom	1995	moderate	77	=
Meijboom	1996	severe	58	=
Saliba	2001	severe	67	=
Kamphuis	2002	severe	78	↘ phys. funct. & gen. health
Simko	2000	mix	124	=
Greenwood	2000	mix	80	functional status ↘ life satisfaction =
Lane	2002	mix	276	surg. palliated + medical = surg. cured + corrected + inoperable ↘

Some quality-of-life studies in ACHD

- Quality of life is most frequently defined in terms of functional status

## Some quality-of-life studies in ACHD

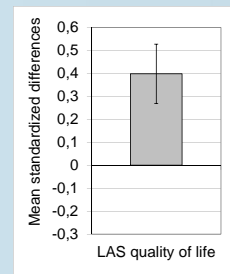
- To compare the quality of life and health status with those of matched, healthy control persons (n=404).



Moons et al., Eur J Cardiovasc Prev Rehabil, 2006

## Some quality-of-life studies in ACHD

- To compare the quality of life with that of matched, healthy control persons (n=403).



Apers et al., Eur J Cardiovasc Nurs, 2013

## Conceptual definition

Quality of life is “the degree of overall life satisfaction that is positively or negatively influenced by an individual’s perception of certain aspects of life that are important to them, including matters both related and unrelated to health.”

Moons, Eur Heart J, 2005

## Quality of life as life satisfaction

- Concept analyses
  - Quality of life ought to be defined in terms of 'life satisfaction' (Meeberg, 1993; Zhan, 1992; Ferrans, 1990)
- Structural equation modelling
  - Quality of life is a global, yet unidimensional, subjective assessment of one's satisfaction with life (Beckie & Hayduk, 1997)

## Potential reasons for better quality of life in ACHD

- Disability paradox
- Response shift
- Sense of coherence

## Disability paradox

### Good quality of life is associated with:

- if they acknowledge their impairment;
- if they preserve control over their body, mind, and lives;
- if they remain able to perform expected roles;
- if they feel satisfied when comparing their self and capabilities with the conditions of others in similar situations.

### Poor quality of life is associated with:

- having pain;
- experiencing frequent or continued fatigue;
- losing control over one's body functions

## Response shift

### Definition:

- The change in the meaning of one's self-evaluation of a target construct as a result of a change in internal standards and values, or a redefinition of the target construct.

### Explanation

- It is possible that patients who grew up with congenital heart disease have developed internal values that are substantially different from those of healthy persons.

## Sense of coherence

### Definition:

- A measure of an individual's world view, which is enhanced by a feeling of high comprehensibility, manageability, and meaningfulness.

### Explanation

- Growing up with congenital heart disease and its consequences may have positively influenced the development of sense of coherence, because patients have learnt to cope with their disease (manageability) and having had a heart operation often has a high existential meaning (meaningfulness).
- Because sense of coherence is strongly, positively associated with life satisfaction and quality of life, this may explain the better quality of life in our patients.

## Sense of coherence



Nio, Cardiol Young, 2010

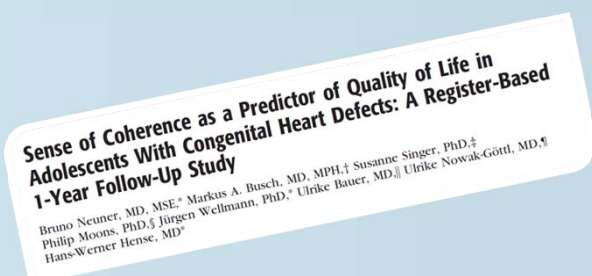
## Sense of coherence

### Conclusion:

- Sense of coherence was higher in students with congenital heart disease than in healthy students.

Nio, Cardiol Young, 2010

## Sense of coherence



Neuner et al., J Dev Behav Pediatr, 2011

## Sense of coherence

### Conclusion:

- Sense of coherence is an independent predictor of QOL in adolescents with CHD

Neuner et al., J Dev Behav Pediatr, 2011

## Sense of coherence



Wang et al., Cardiol Young, 2013

## Sense of coherence

### Conclusion:

- Multiple linear regressions showed that health-related QOL was significantly associated with:
  - Adolescent's knowledge and understanding of the disease
  - Social support
  - **Sense of coherence**
  - Optimism
  - Anxiety and depression

Wang et al., Cardiol Young, 2013

## Sense of coherence



Apers et al., Eur J Cardiovasc Nurs, 2013

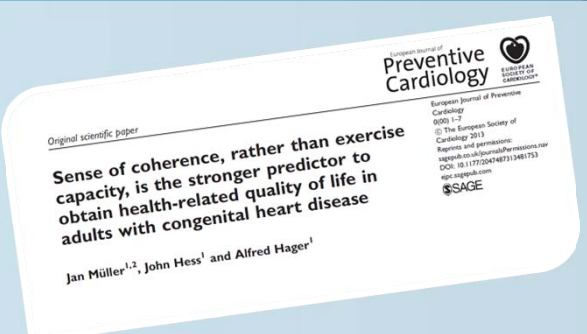
## Sense of coherence

### Conclusions

- These adolescents have a good QOL, one that was slightly better than that of control subjects from the general population. The better QOL in patients was explained in part by a higher sense of coherence.

Apers et al., Eur J Cardiovasc Nurs, 2013

## Sense of coherence



Muller et al., Eur J Prevent Cardiol, 2013

## Sense of coherence

### Conclusions

- Adults with congenital heart disease have an enhanced SOC.
- SOC is moderately correlated with quality of life, and seems to be a stronger predictor of health-related life quality than exercise capacity.
- SOC might explain the rather good quality of life in patients with CHD despite their reduction in exercise capacity

Muller et al., Eur J Prevent Cardiol, 2013

## Conclusions

- Quality of life of persons with CHD can be better than that of healthy individuals  
If QOL is defined in terms of life satisfaction

## Conclusions

- Quality of life of persons with CHD can be better than that of healthy individuals  
If QOL is defined in terms of life satisfaction
- Quality of life of persons with CHD is likely to be equal or lower than that of healthy individuals  
If QOL is defined in terms of functional status

## Conclusions

- Quality of life of persons with CHD can be better than that of healthy individuals  
If QOL is defined in terms of life satisfaction
- Quality of life of persons with CHD is likely to be equal or lower than that of healthy individuals  
If QOL is defined in terms of functional status
- Sense of coherence is an important factor to explain why persons with CHD can have a better quality of life

## New project



## APPROACH-IS

**Assessment of Patterns of Patient-Reported Outcomes in Adults with Congenital Heart disease - International Study**

## Better than expected?!

Why persons with congenital heart disease can have a better quality of life than healthy people

Philip Moons

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