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Evaluating quality of life after correction of a cardiac defect

Eva Goossens, Silke Apers, Marc Gewillig, Werner Budts, Philip Moons

Fallot 2013
Marseille June 11, 2013


What is quality of life?
What is the caliber of studies?
What is the QoI of ToF patients?
Better than expected?!

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Background

- Improved long-term survival in patients with Tetralogy of Fallot
  - 78% survival to age 18y
  - after total correction, 90% expected to become >40y
- Residua and complications often result in
  - impaired clinical status
  - need for re-operation
  - decreased exercise tolerance,...

→ToF transformed from lethal condition to manageable lifelong condition

→Little is understood about the impact of this condition

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Hickey E.J. et al., 2009; Gatzoulis M.A. et al., 2000; Moons P. et al., 2010; Loup O. et al, 2009; Garson A. Jr. Et al., 1985; Geva T. et al., 2000

Background

- Goal of surgery changed from a “therapy for survival” to allowing a normal life in terms of “expectancy and quality”

Improved life expectancy ? good quality of life

- Mortality and morbidity are too limited to evaluate benefit of therapies
- Importance of assessing impact of disease and treatment on patient-reported health status and quality of life

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Geva T. et al., 2004; Rumsfeld J.S. et al., 2013

Patient-reported health status

AHA scientific statement on patient-reported health status (2013)

Circulation
JOURNAL OF THE AMERICAN HEART ASSOCIATION

American Heart Association®

Cardiovascular Health: The Importance of Measuring Patient-Reported Health Status : A Scientific Statement From the American Heart Association

John S. Rumsfeld, Karen P. Alexander, David C. Goff, Jr, Michelle M. Graham, P. Michael Ho, Frederick A. Masoudi, Debra K. Moser, Véronique L. Roger, Mark S. Slaughter, Kim G. Smolderen, John A. Spertus, Mark D. Sullivan, Diane Treat-Jacobson and Julie J. Zerwic

Circulation. published online May 6, 2013;
Circulation is published by the American Heart Association, 7272 Greenville Avenue, Dallas, TX 75231

Print ISSN: 0009-7322. Online ISSN: 1524-4539

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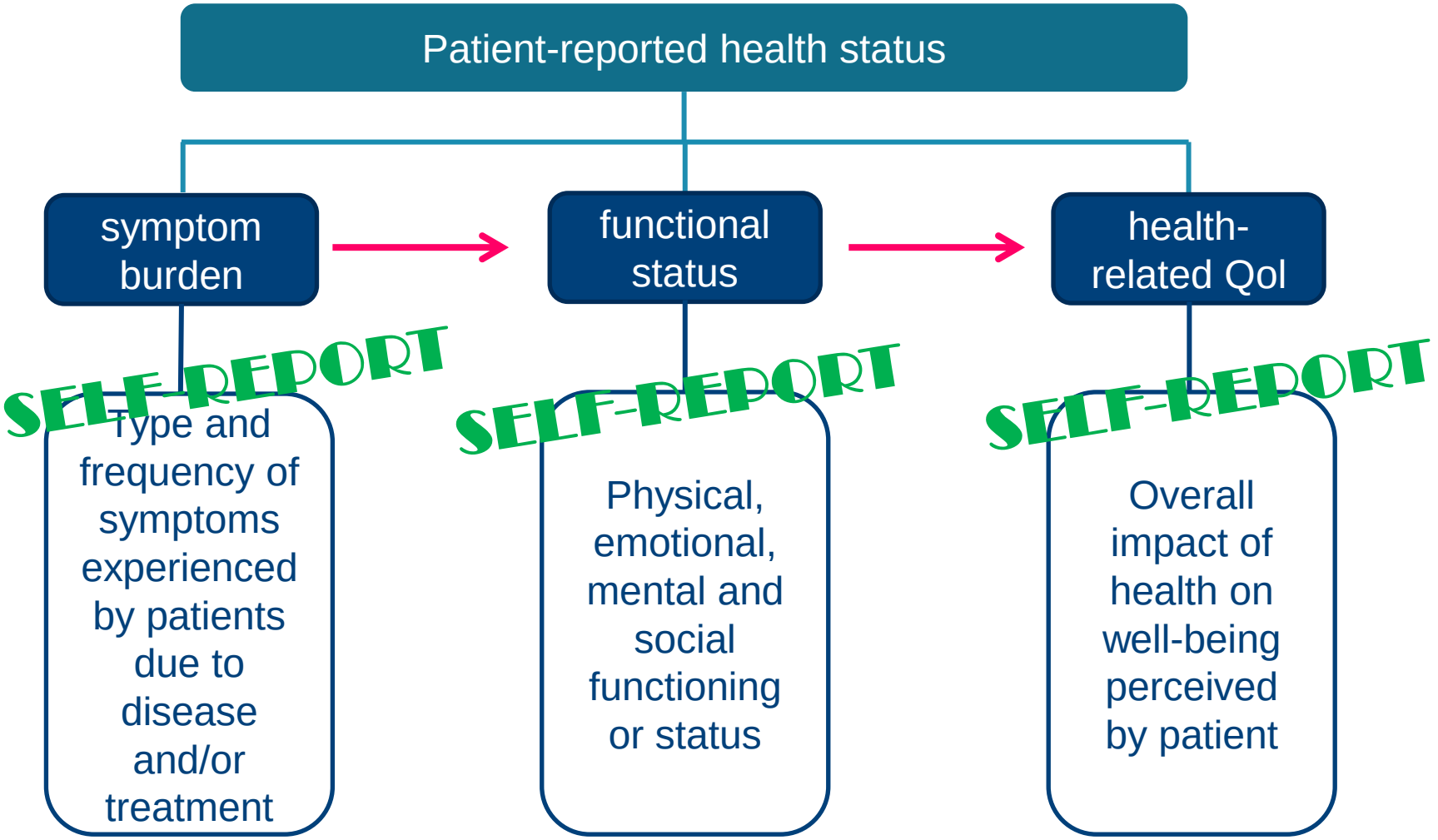
Patient-reported health status



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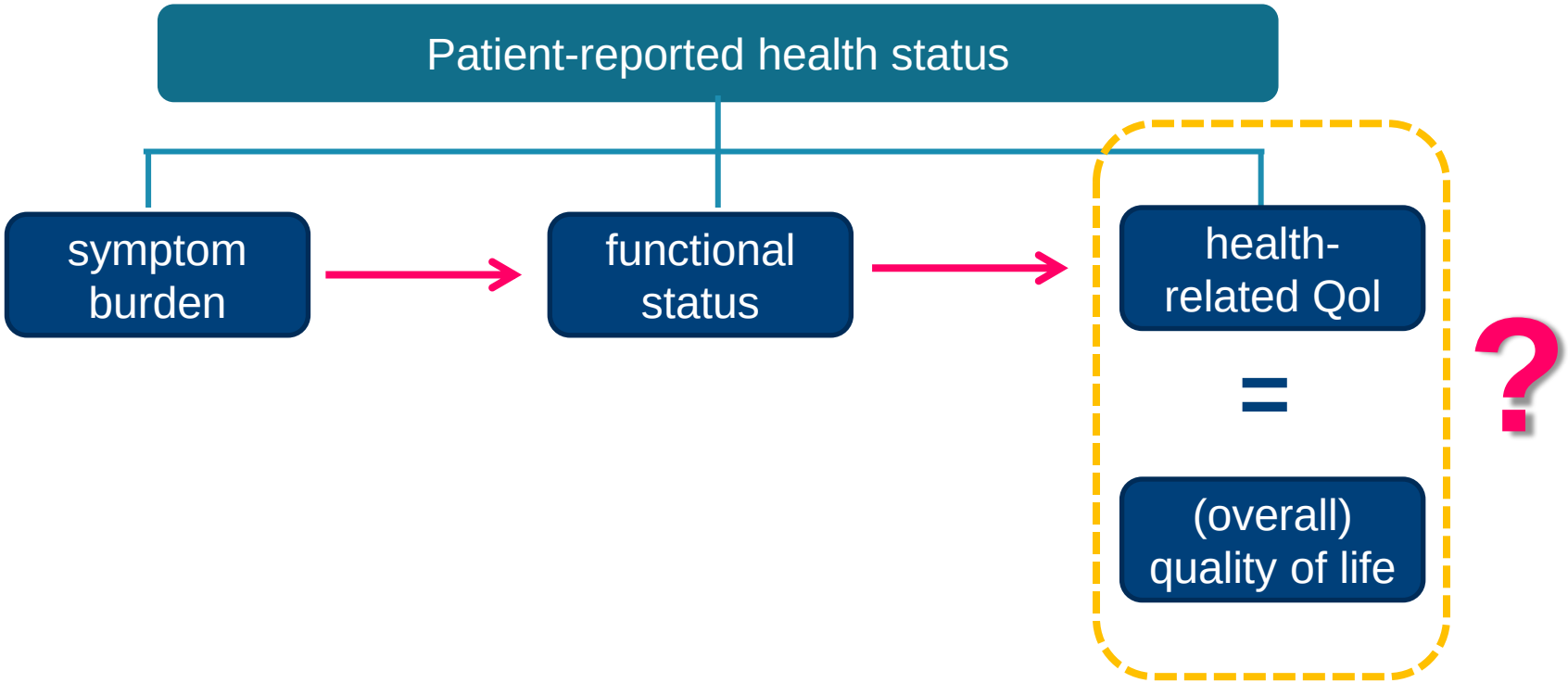
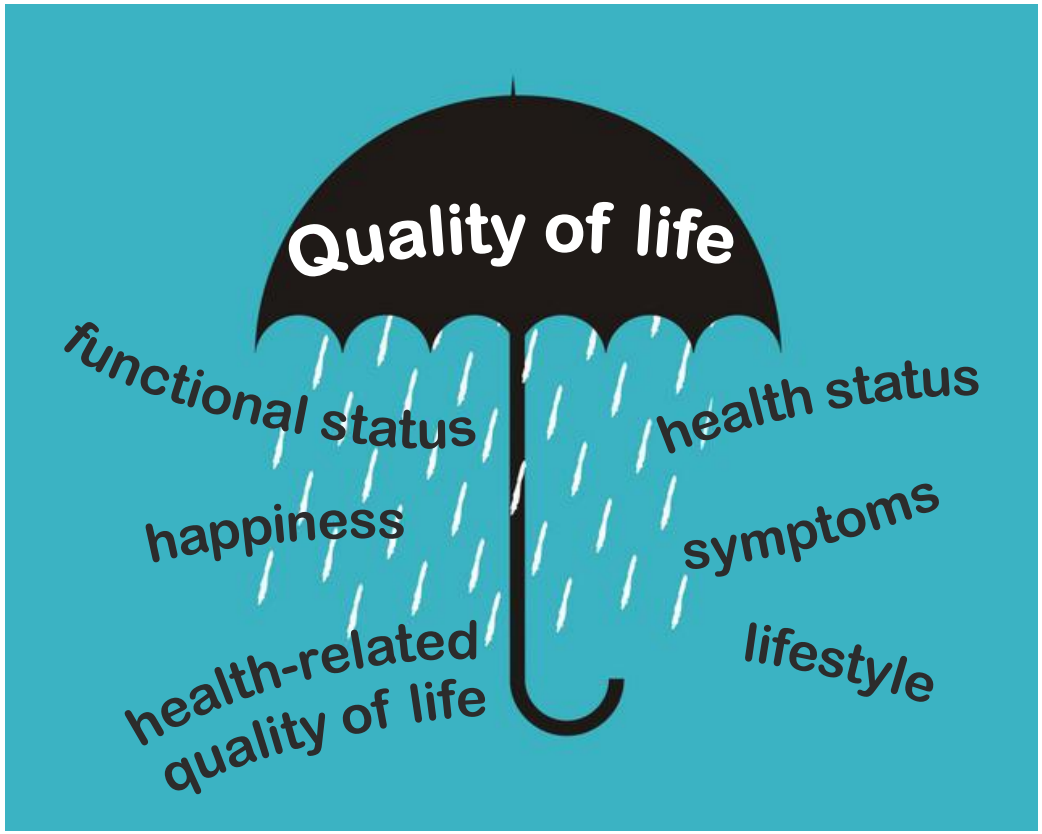
Rumsfeld J.S. et al., Circulation, 2013

Patient-reported health status

= the impact of disease and medical treatments on function and well-being as reported by the patient *(Rumsfeld J.S., 2002)*



Quality of life is often used as an ‘umbrella’ term



Lack of a uniform definition results in conceptual vagueness and obscurity

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Health-related quality of life

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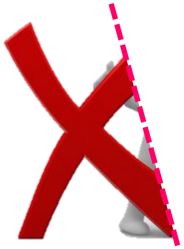

concept of HRQol is subject to debate!

d factors

edical phenomena

- ope   essing physical, mental, cognitive, emo   ocial functioning
- often researchers actually measure perceived health status

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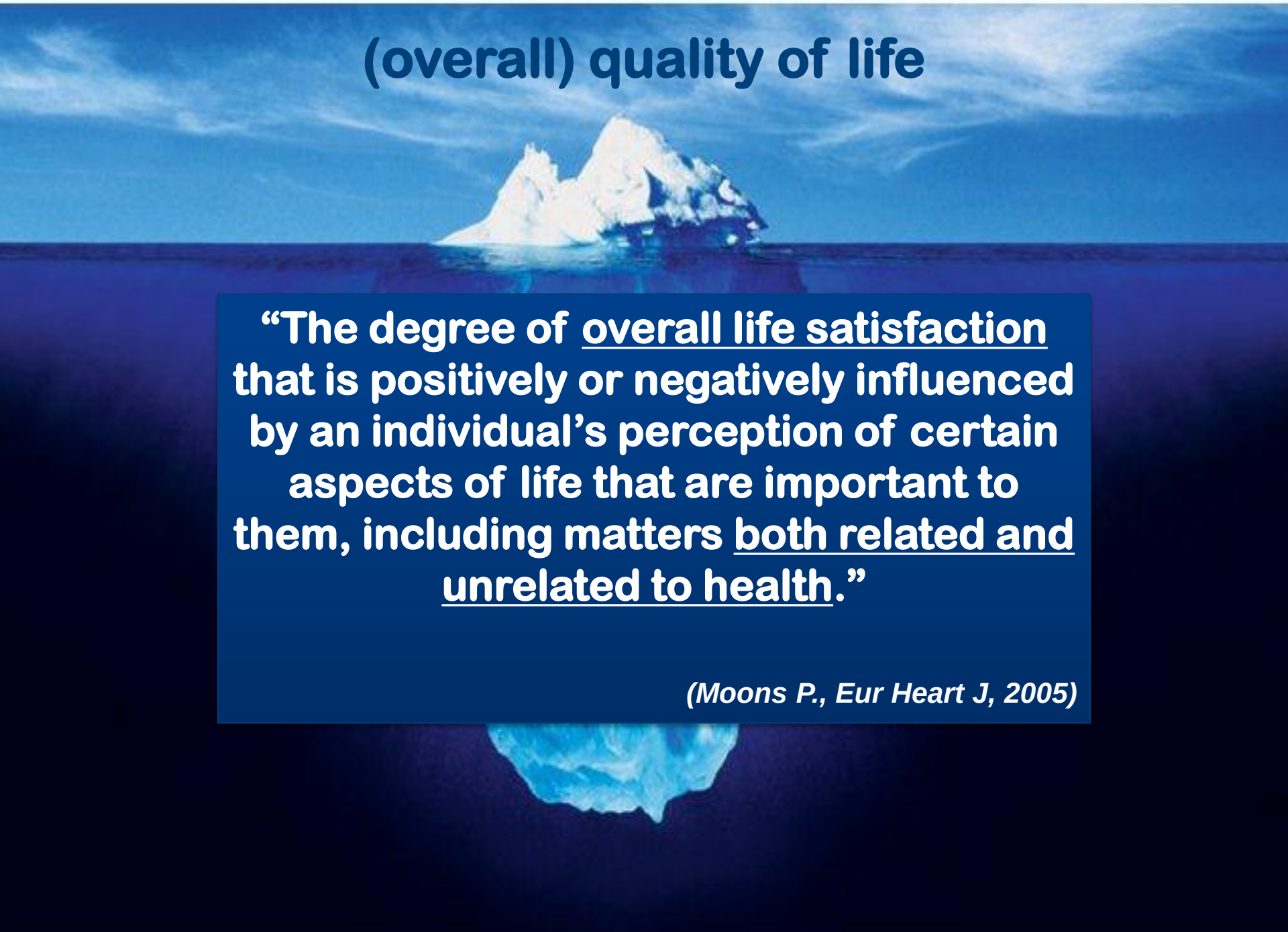
Moons P. et al., 2006

(overall) quality of life



"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 P., Eur Heart J, 2005)

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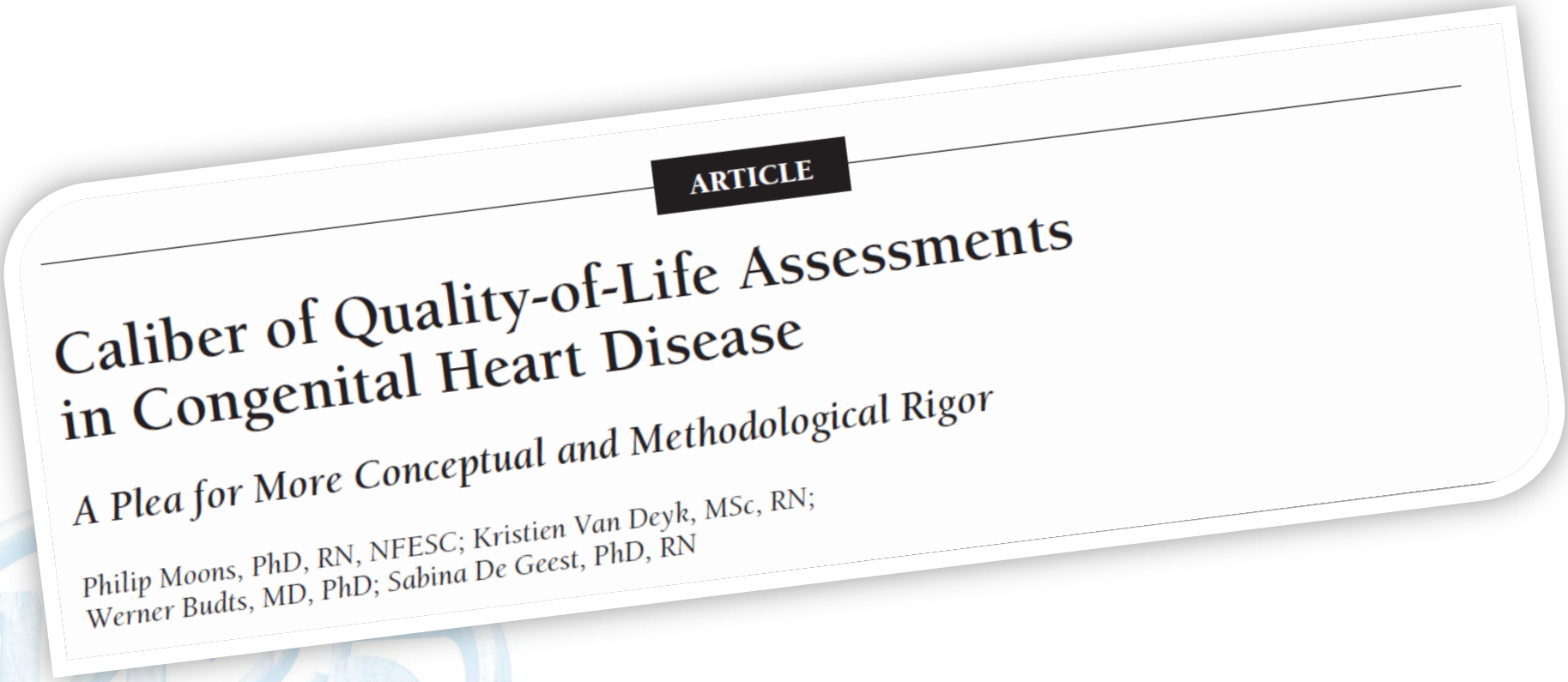
Quality of life in CHD: methodological rigor



ARTICLE

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

A Plea for More Conceptual and Methodological Rigor

Philip Moons, PhD, RN, NFESC; Kristien Van Deyk, MSc, RN;
Werner Budts, MD, PhD; Sabina De Geest, PhD, RN

Assessment of the methodological rigor of 70 publications on quality of life in patients with CHD

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Quality of life in CHD: methodological rigor

10 criteria to assess caliber of QoI measurements *(Gill & Feinstein,1994)*	
1. Provide a conceptual definition of QoI	1%
2. Explicitly stating domains measured as components of QoI	24%
3. Provide reason(s) for the choice of QoI instruments	3%
4. Aggregation of information into a single composite QoI score	31%
5. Patients could give their own global rating of QoI	1%
6. Distinguishing overall QoI from health-related QoI	1%
7. Patients can supplement items to the instrument(s) used	0%
8. If so, supplemental items are incorporated into final rating	n.a.
9. Patients can indicate personal importance of QoI items	4%
10. If so, rated importance is incorporated into final rating	100%

➡ >50% of papers did not comply with any of these criteria

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Moons P. et al., Arch Pediatr Adolesc Med, 2004

Quality of life in CHD: methodological rigor

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.

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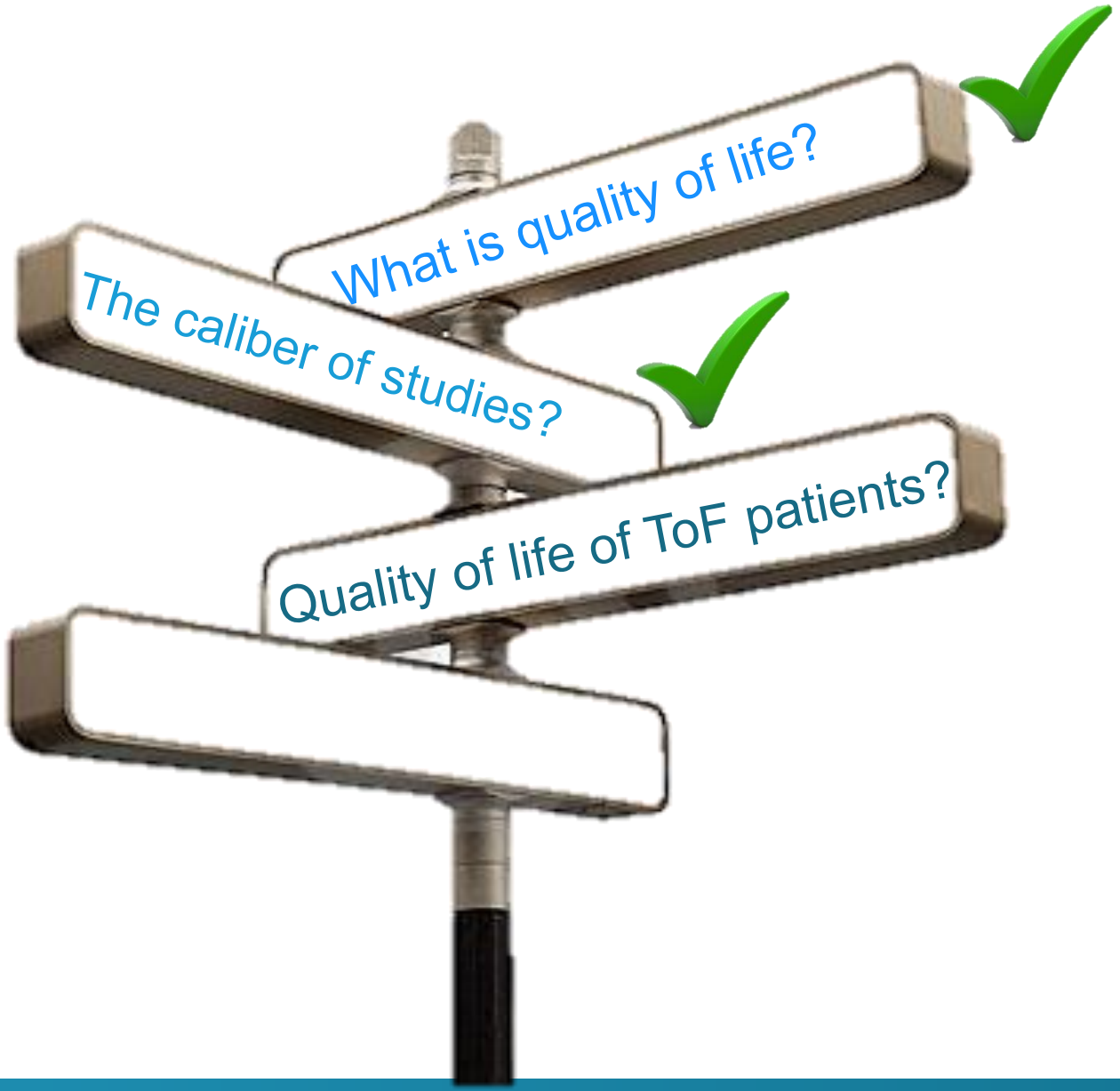
Moons P. et al., Arch Pediatr Adolesc Med, 2004


What is quality of life?
The caliber of studies?
Quality of life of ToF patients?

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Quality of life in adults with CHD

2 recent literature reviews concluded:

- ✓ strong evidence that ACHD pts experience decreased QoL in the physical domains as compared to general population
- ✓ limited to no impact of CHD on psychosocial functioning
- ✓ **BUT** limited comparability of studies due to heterogeneity of samples, methods, assessment tools, ...
- ✓ quality of life is a multifactorial concept, to a limited extent determined by CHD defect

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Apers S. et al., 2013; Fteropouilli T. et al., 2013

Quality of life after surgical correction of ToF

- >10 studies in patients with corrected ToF assessed
- Heterogeneity in terms of methods:
  - concepts being measured: Qol, HRQol, or functional health status
  - either self-reported or proxy-reported
  - assessment tools: SF-36, health utility index, CHQ-PF50, KINDLR, PedsQL generic and cardiac module

Quality of life after surgical correction of ToF

- Comparison of QoI in surgically corrected ToF patients versus healthy controls

Reference	Tool	Sample	Results
Daliento, 2005	SF-36	n=54 32±4y	NS ≠ with normal population
Hövels-Gurich, 2007	KINDLR	n=20 7±2y	SS ↑ self-reported QoI
Pila, 2008	CHQ-PF50	n=22 6y (med)	SS ↓ physical functioning NS ≠ psychosocial functioning
Bygstad, 2011	SF-36	n=55 32y (med)	SS ↓ physical functioning NS ≠ psychosocial functioning
Hickey, 2012	SF-36	n=396 35y (med)	SS ↓ physical functioning NS ≠ psychosocial functioning

Quality of life after surgical correction of ToF

- comparison of QoI between TGA-VSD-ASD-ToF patients

Reference	Tool	Sample	Results
Bygstad, 2011	SF-36	n=55 ♂ vs n=40♀ ToF	NS ≠ ♀ vs ♂, except for pain
Hövels-Gürich, 2007	KINDLR	n=20 ToF vs n=20 **VSD**	NS≠ ToF vs VSD pts
Walker, 2002	Health utility	n=44 ToF vs n=44 **VSD**	NS ≠ between 2 groups
Loup, 2009	SF-36	n=43 ToF vs n=52 **VSD** vs n=59 **TGA**	NS ≠ between 3 groups
Irtel, 2005	SF-36	n=32 ToF vs n=32 **TGA**	SS ↑ psychosocial functioning in ToF vs TGA
Ternestedt, 2001	Sefl-rated Qol	n=12 ToF vs n=14 **ASD**	SS ↑ Qol in ToF vs ASD

Quality of life after surgical correction of ToF

- exploration of relationship between QoI and clinical variables

Reference	Tool	Sample	Results
Kwon, 2011	PedsQL	n=20	SS ↑ QoI in ♂ vs ♀ SS pos correlation with **VO_2max**
Bygstad, 2011	SF-36	n=55	SS ↓ phys functioning ↑ **NYHA**
Hickey, 2012	SF-36	n=396	SS neg correlation with **age, co-morbidity, prior sx, cardiopulm symptoms**
Pilla, 2008	CHQ-PF50	n=22	NS correlation with RV function, demographic and perioperative variables
Loup, 2009	SF-36	n=43	NS correlation with age, SS ↓ QoI if **≥1 reoperation**
Lu, 2010	SF-36	n=62	SS neg correlation with **RV dysfunction** (phys functioning)

Quality of life after surgical correction of ToF

- Overall studies in patients with corrected ToF reported:
  - No significant difference as compared to normative data in overall Qol/health status
  - All psychosocial domains were similar to matched controls
  - All physical domains were compromised in patients with sx ToF

Although significant RV dysfunction, haemodynamic limitations, PR or PS, ToF patients reported good Qol

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Lu et al., 2010; Walker et al., 2002; Loup et al., 2009; Daliento et al., 2005; Pilla et al., 2008; Hövels-Gürich et al., 2007; Ternested et al., 2001; Bygstadt et al., 2011; Hickey et al., 2012

Conclusion: QoL in ToF patients after sx

"Patients who survived ToF surgery are more purposeful, have more willpower, and are less willing to compromise as compared to healthy peers or patients with less complex CHD."

HIGH ACHIEVERS !

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Ternested et al., 2001


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Potential pathways to explain a better quality of life in patients with CHD

1. Disability paradox
2. Response shift
3. Sense of coherence

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Disability paradox

Good quality of life is associated with:

- acknowledgement of their impairment;
- preservation of control over their body, mind, and lives;
- ability to perform expected roles;
- feeling 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.

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Albrecht G.L. et al., Soc Sci Med, 1999

Response shift

Definition:

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

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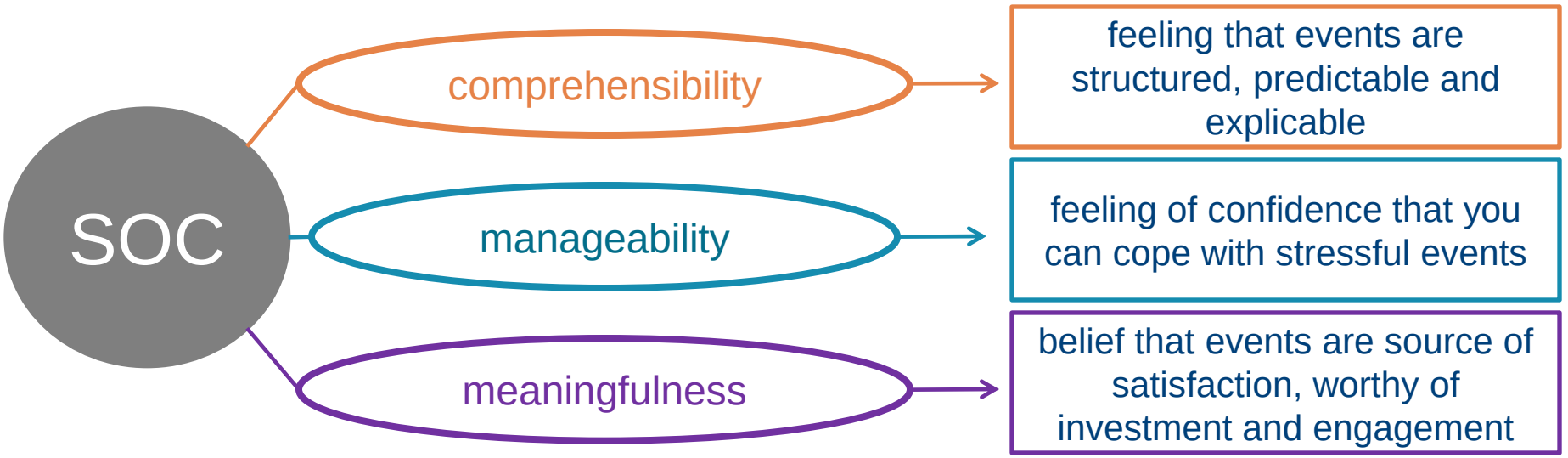
Rapkin B.D. et al., Health Qual Life Outcomes, 2004

Sense of coherence

- a key concept of the salutogenic theory developed by Antonovsky A. (1987) comprising 3 components:



- a global life orientation of a person that expresses the extent to which one deals with stress

Sense of coherence

Hypothesis

- adolescents with CHD have learnt to discuss concerns (comprehensibility)
- have learnt how to cope with a chronic disease since their birth (manageability)
- and their cardiac condition possibly has a high existential meaning (meaningfulness)

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Sense of coherence

Original Article

European Journal of Cardiovascular Nursing

EUROPEAN SOCIETY OF CARDIOLOGY®

Sense of coherence and perceived physical health explain the better quality of life in adolescents with congenital heart disease

European Journal of Cardiovascular Nursing
0(0) 1–9

DOI: 10.1177/1474515113477955
cnu.sagepub.com
SAGE

Silke Apers[1*], Philip Moons[1,2,3*], Eva Goossens[1,4], Koen Luyckx[4,5], Marc Gewillig[6], Kris Bogaerts[7] and Werner Budts[2], on behalf of the i-DETACH investigators

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Apers et al., Eur J Cardiovasc Nurs, 2013

Sense of coherence

Linear mixed modelling showed that the better QoI in patients was explained by:

- a higher SOC (mean=61.4±12.0 vs. 53.6±10.4)
- better perceived physical health (mean=87.0±13.8 vs. 85.3±13.2).

Table 2. Correlates of the difference in quality of life between patients and controls using linear mixed modelling (*n*=806).

Variable	Estimate	Standard error	95% CI	*p* Value
Intercept	49.12	5.61	38.11–60.14	<0.001
Patient vs. control	4.61	1.21	2.23–6.98	0.001
Demographic variables				
Educational level	0.02	0.63	−1.22–1.25	0.979
Romantic relationship	−0.57	1.15	−2.82–1.68	0.618
Patient-reported outcomes				
Sense of coherence	0.15	0.06	0.04–0.26	0.006
Perceived health status: physical health	0.14	0.04	0.06–0.23	0.001
Perceived health status: psychosocial health	0.10	0.06	−0.01–0.21	0.072
Health risk behaviour	−0.02	0.03	−0.08–0.04	0.480
Depressive symptomatology	−0.02	0.07	−0.16–0.12	0.742

95% CI: 95% confidence interval.

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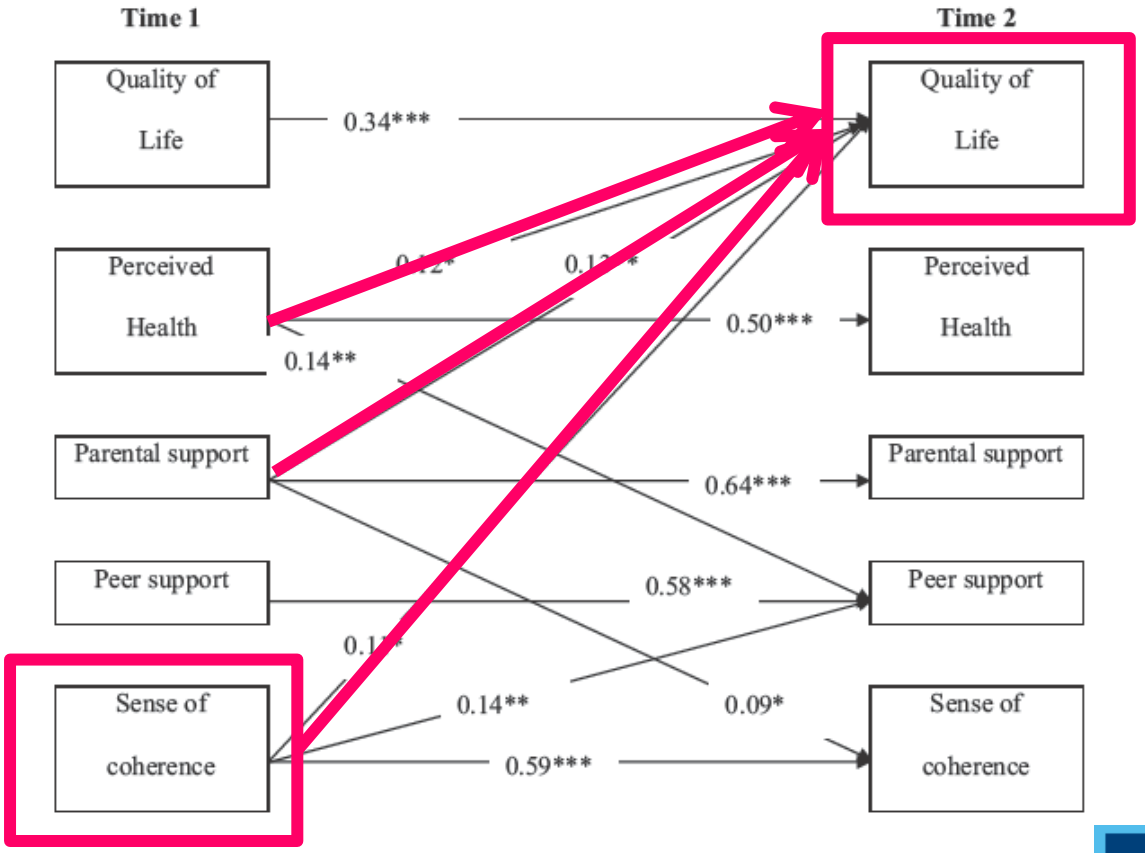
Apers S. et al., Eur J Cardiovasc Nurs, 2013

Sense of coherence: developmental pathways

Longitudinal analysis showed that perceived health status, SOC, and parental support positively predicted quality of life over time



Luyckx K. et al., J Adolesc Health, 2012

Conclusion

- Quality of life – research in CHD:
  - not characterized by scarcity of studies
  - caliber of studies remains poor
  - inconclusive study results
  - arguments are provided to define overall Qol in terms of “satisfaction with life”
  - often perceived health status is measured, but conclusions in terms of Qol are drawn

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Moons P. et al., Arch Pediatr Adolesc Med, 2004; Apers S. Et al., Eur J Cardiovasc Nurs, 2013

Conclusion

- Quality of life of persons with CHD/ToF can be **better** as compared to healthy individuals
  - If Qol is defined in terms of **overall life satisfaction**

- Quality of life of persons with CHD/ToF is likely to be **equal or lower** as compared to healthy individuals
  - If Qol is defined in terms of **functional status**

- **Sense of coherence** is an important factor to explain why persons with CHD/ToF can have a better Qol

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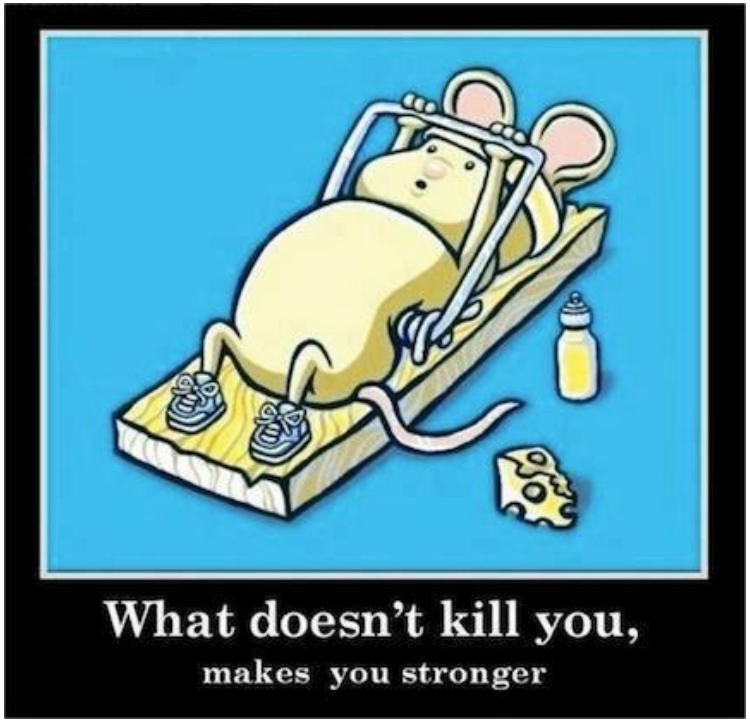
Conclusion

Live longer

Live better

Live stronger?



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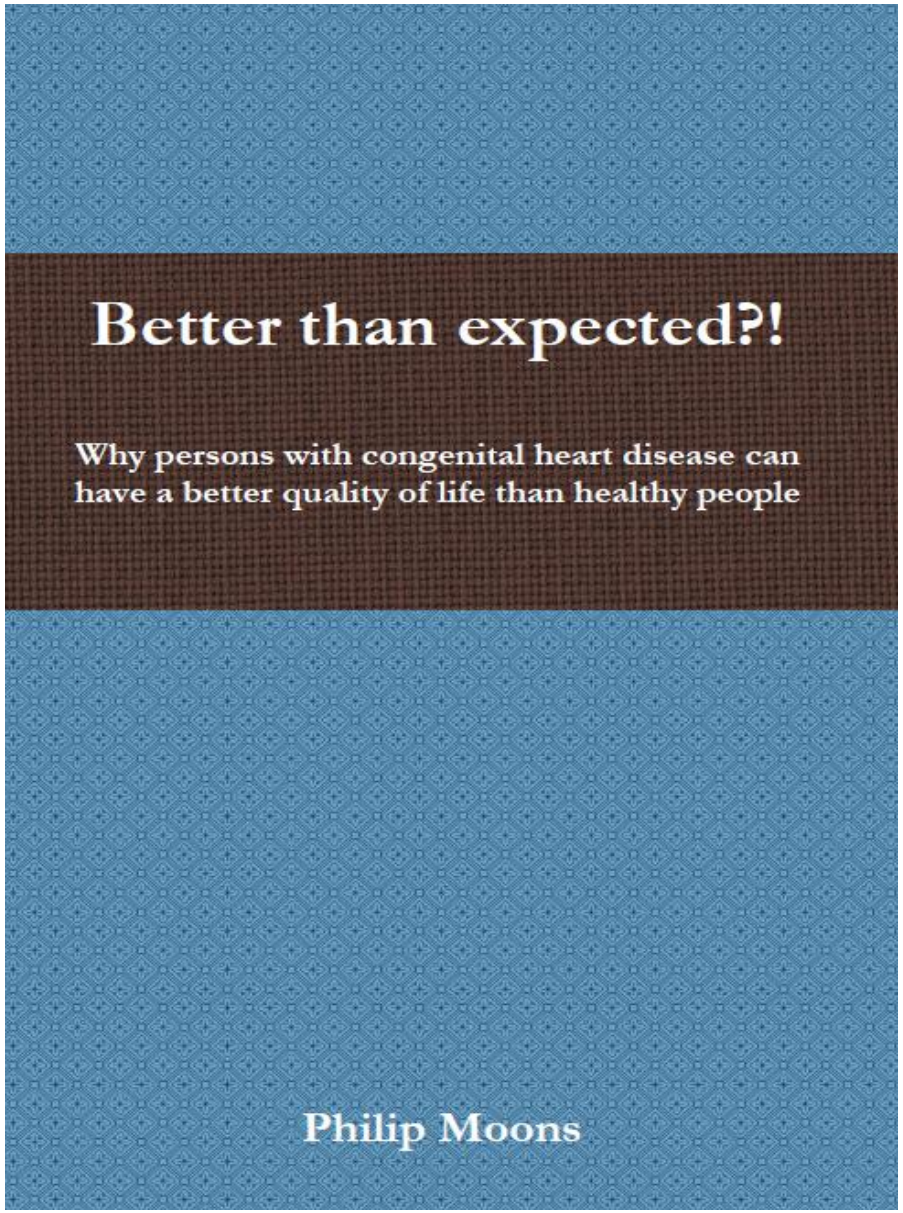

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