

PhyMedExp



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MUSE
MONTPELLIER UNIVERSITÉ D'EXCELLENCE



Quality of life in ACHD

M3C Academy

November 22nd, 2018

Pascal AMEDRO

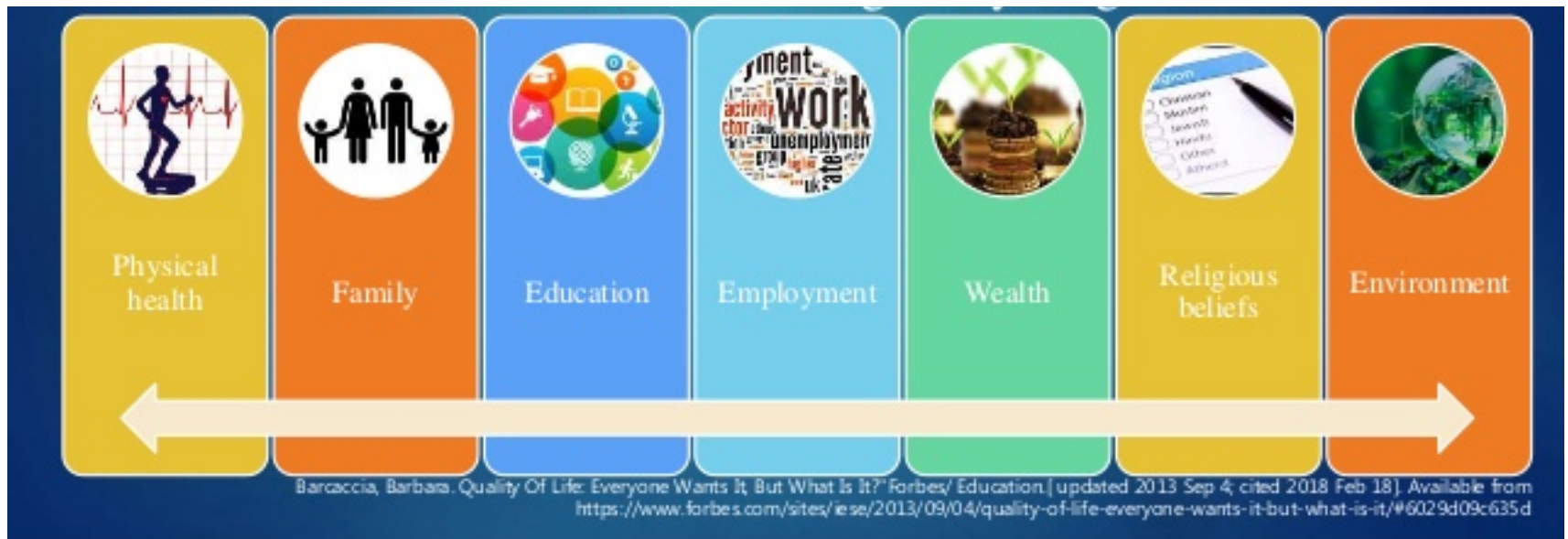
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Quality of life (QoL)

- General well-being of individuals and societies
- Life satisfaction



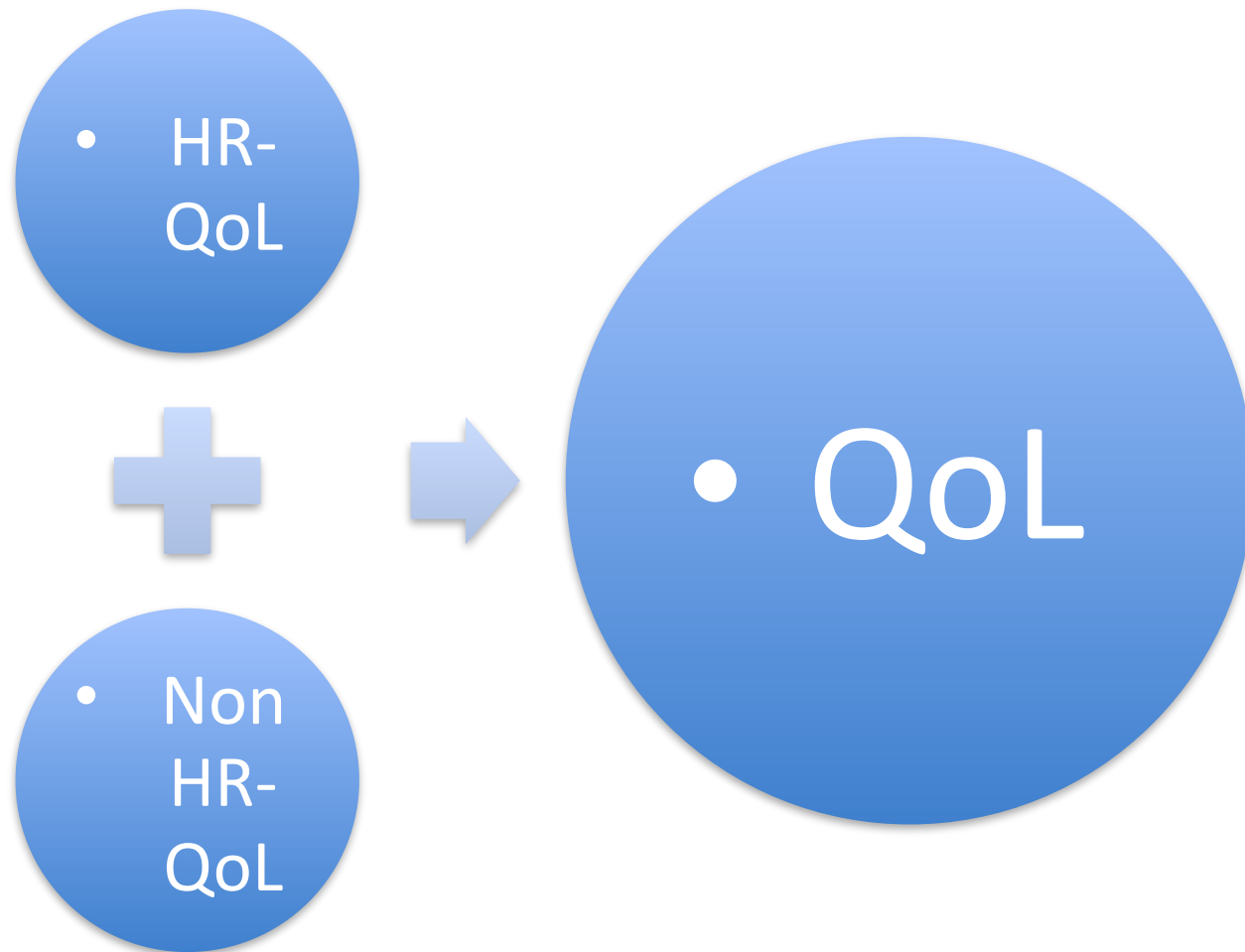
Health-related quality of life (HR-QoL)

- It's part of a person's overall QoL that represents the **functional effect of an illness** and its consequent **therapy** upon a **patient**, as perceived
 - by the patient (self-reported HR-QoL)
 - and/or by his/her family (proxy-reported HR-QoL)

Uses of HR-QoL measurement

- More in clinical research than in medical practice
- Recommended in drug trials (EMA)
- May improve patient-doctor relationship
- Reliable to assess the effectiveness and relative merits of different treatments
- Health service evaluation
- Policy making

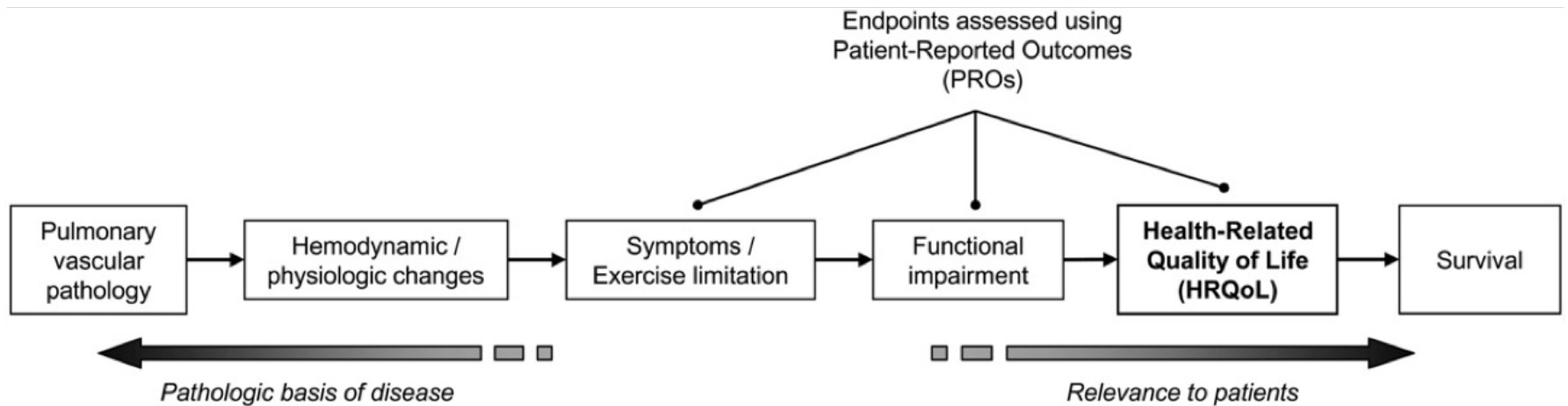
Health-related quality of life (HR-QoL)



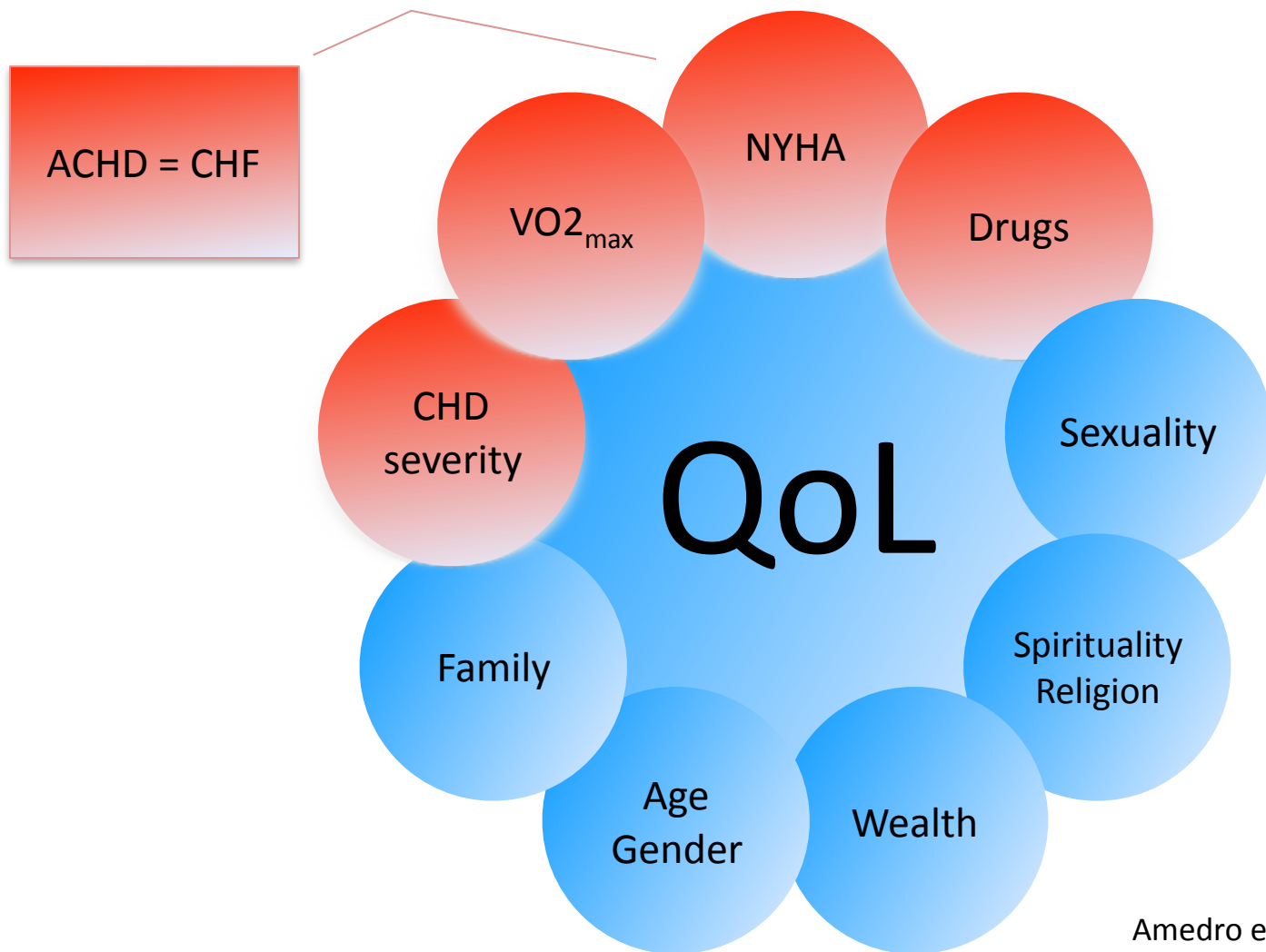
HR-QoL instruments

- Should include at least 4 dimensions:
 - Physical functioning
 - Psychological functioning
 - Social functioning
 - General health perception
- Generic questionnaires
 - SF-36 https://www.rand.org/health/surveys_tools/mos/36-item-short-form/survey-instrument.html
- Specific questionnaires
 - CAMPHOR

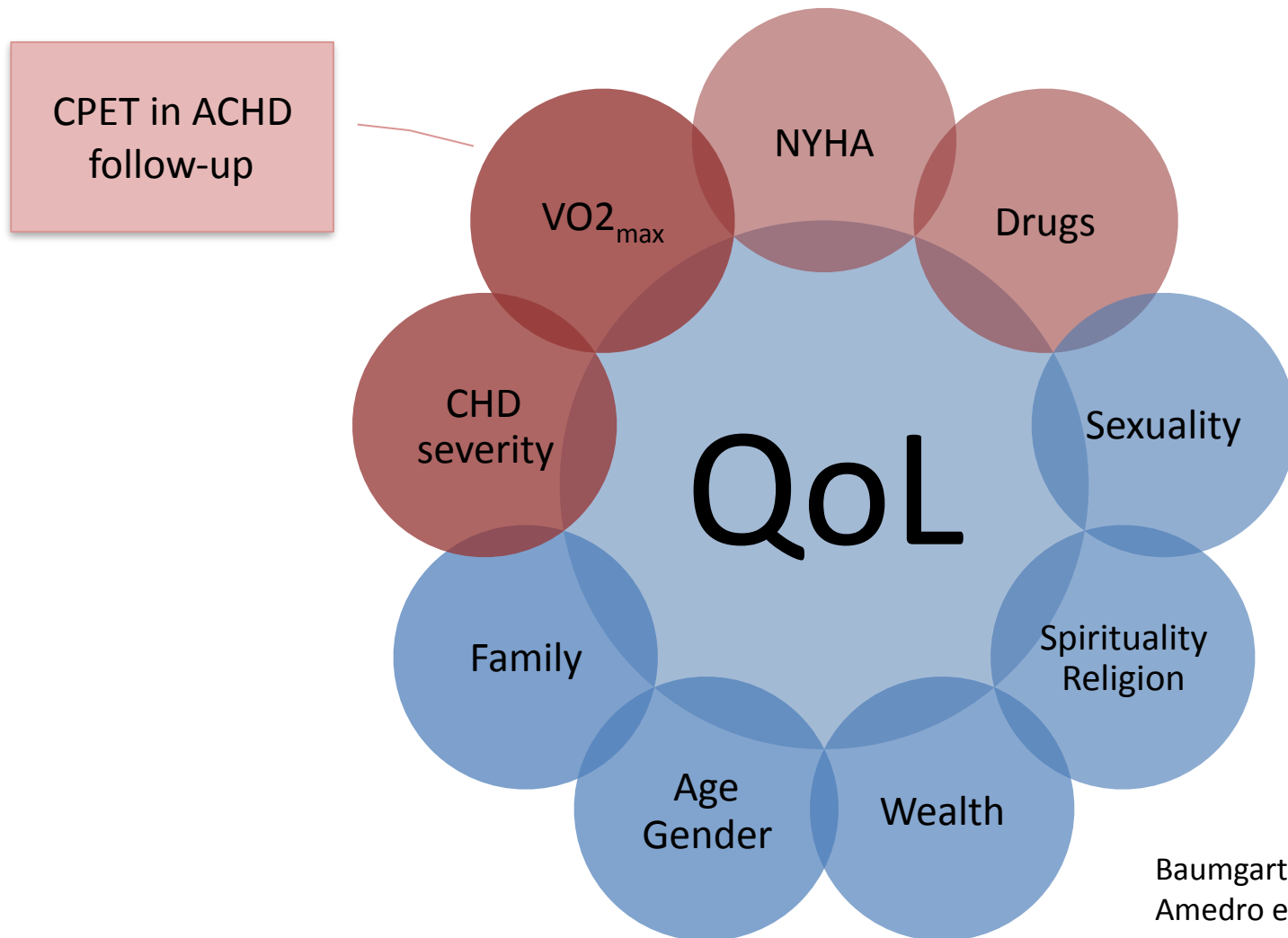
HR-QoL belongs to « patient-related outcomes » (PRO's)



Components of QoL in ACHD

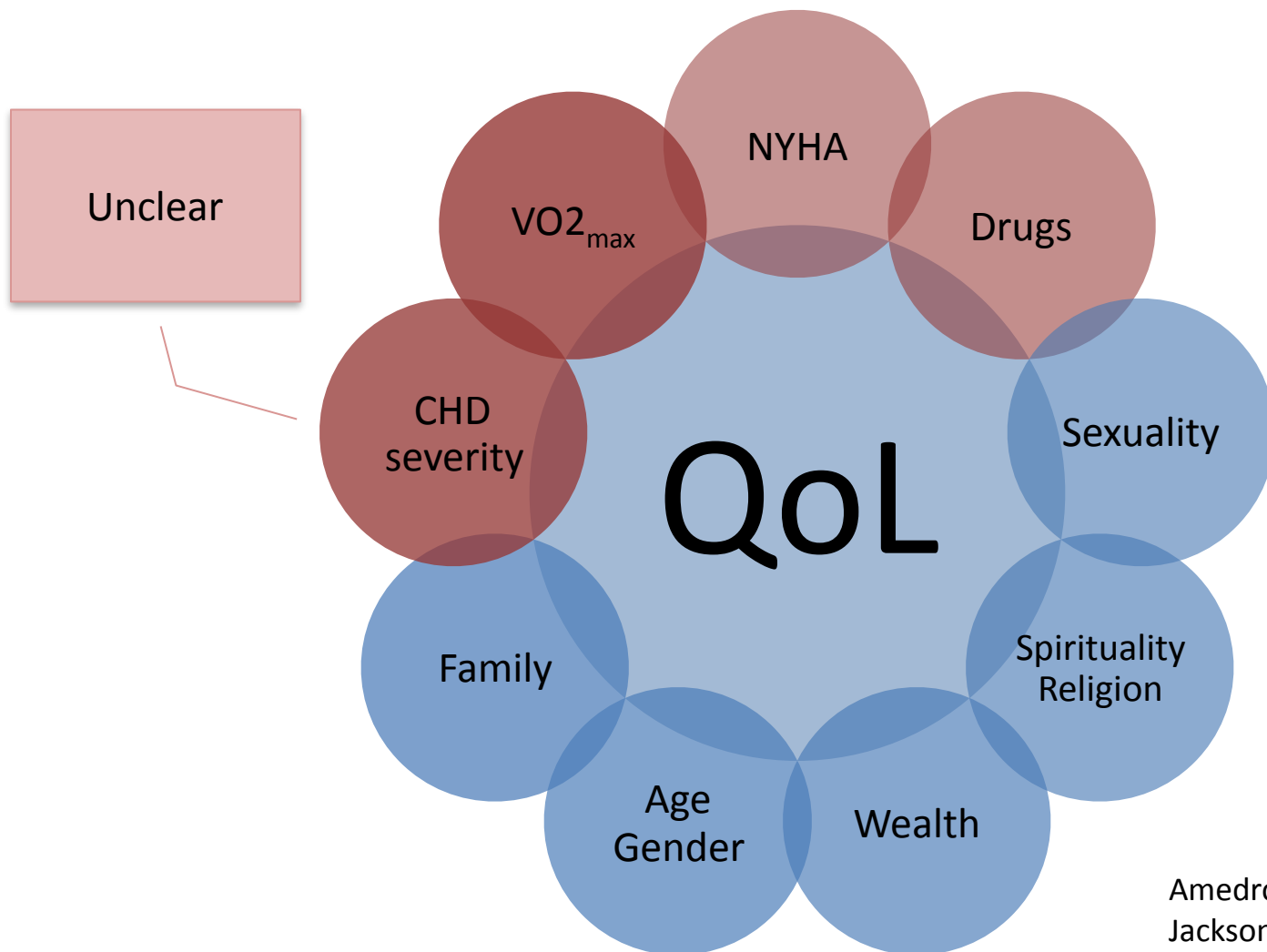


Components of QoL in ACHD

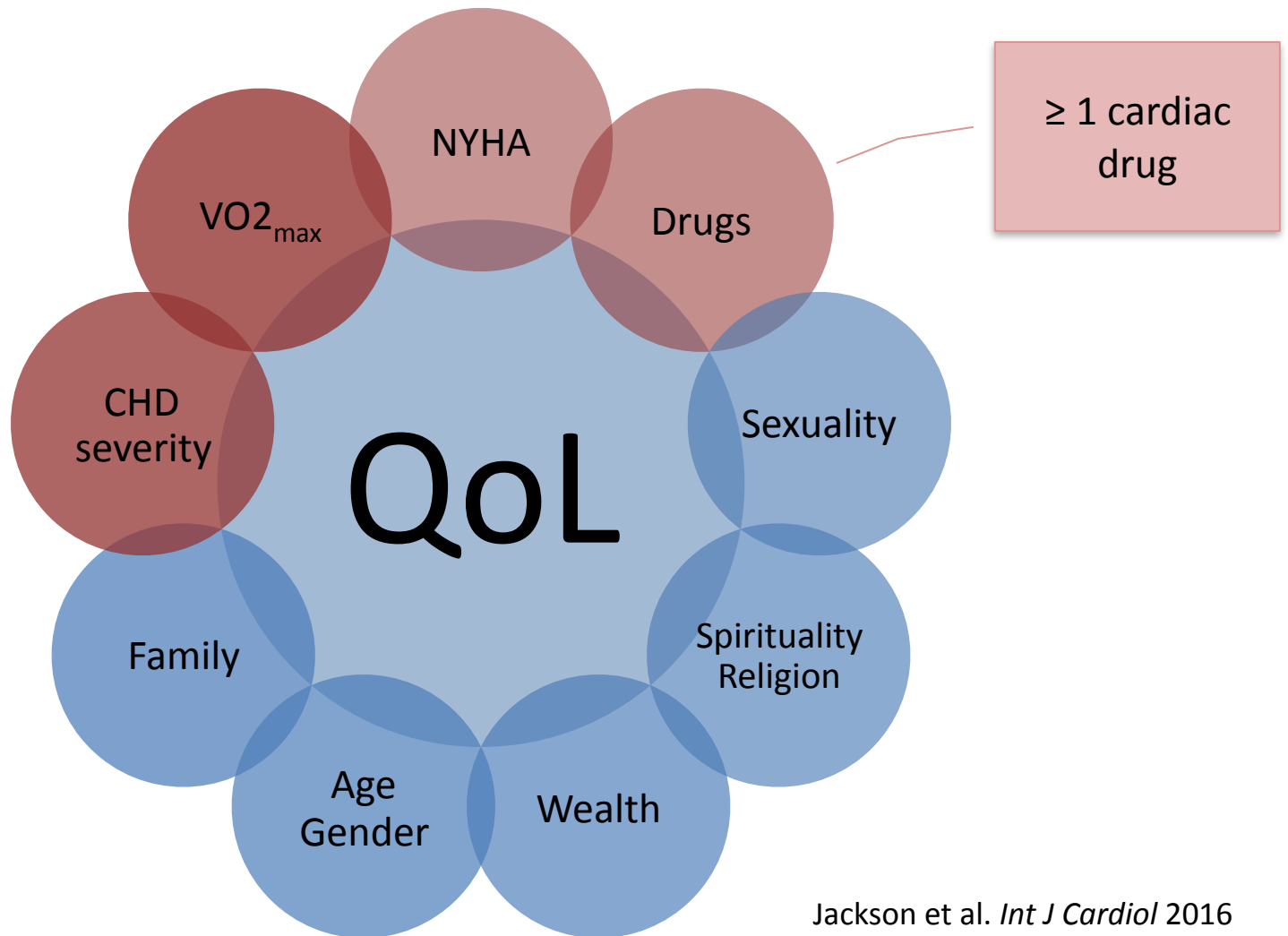


Baumgartner *et al.* Eur Heart J 2010
Amedro *et al.* Int J Cardiol 2017
Marcadet *et al.* ACVD 2018

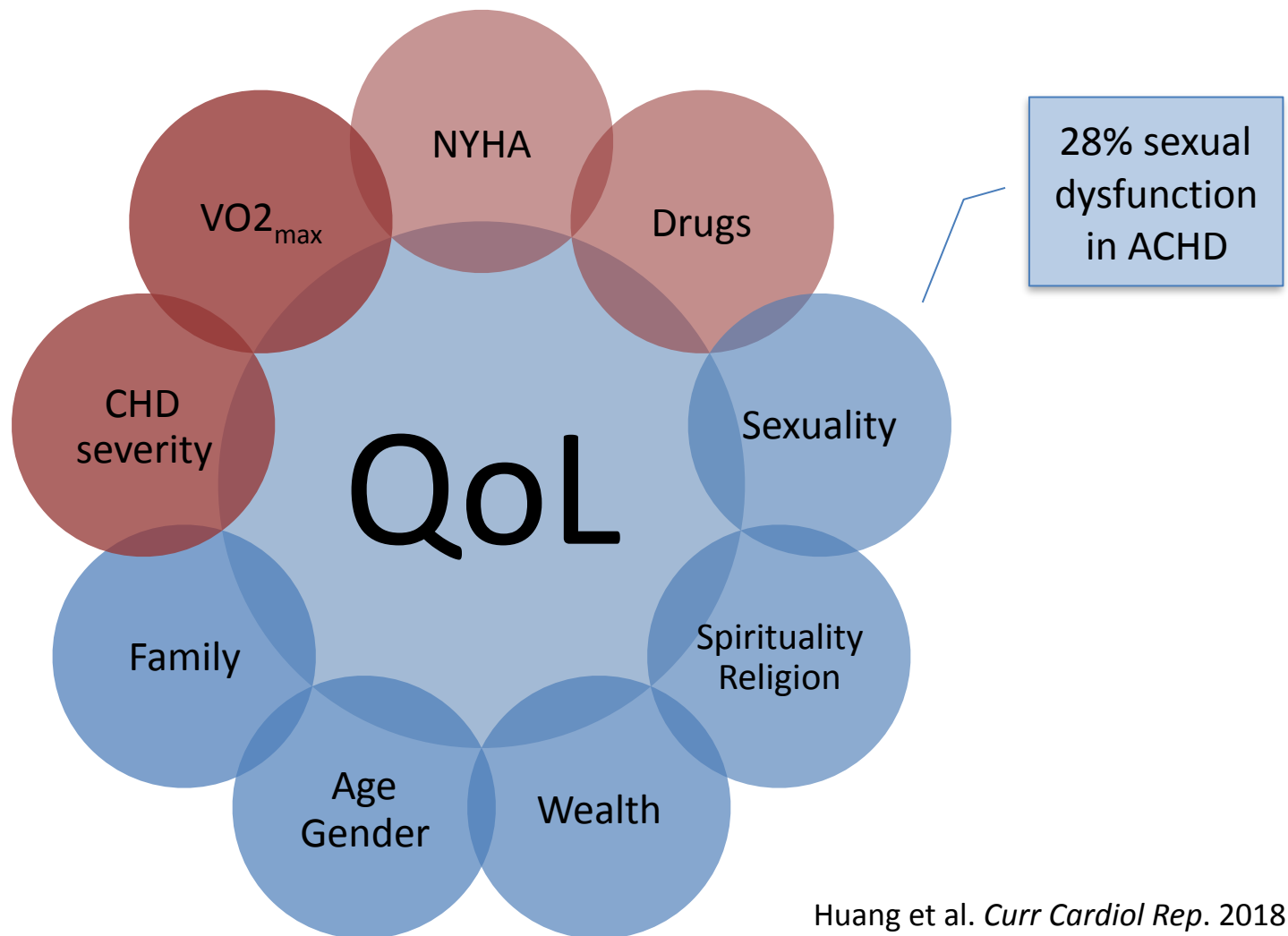
Components of QoL in ACHD



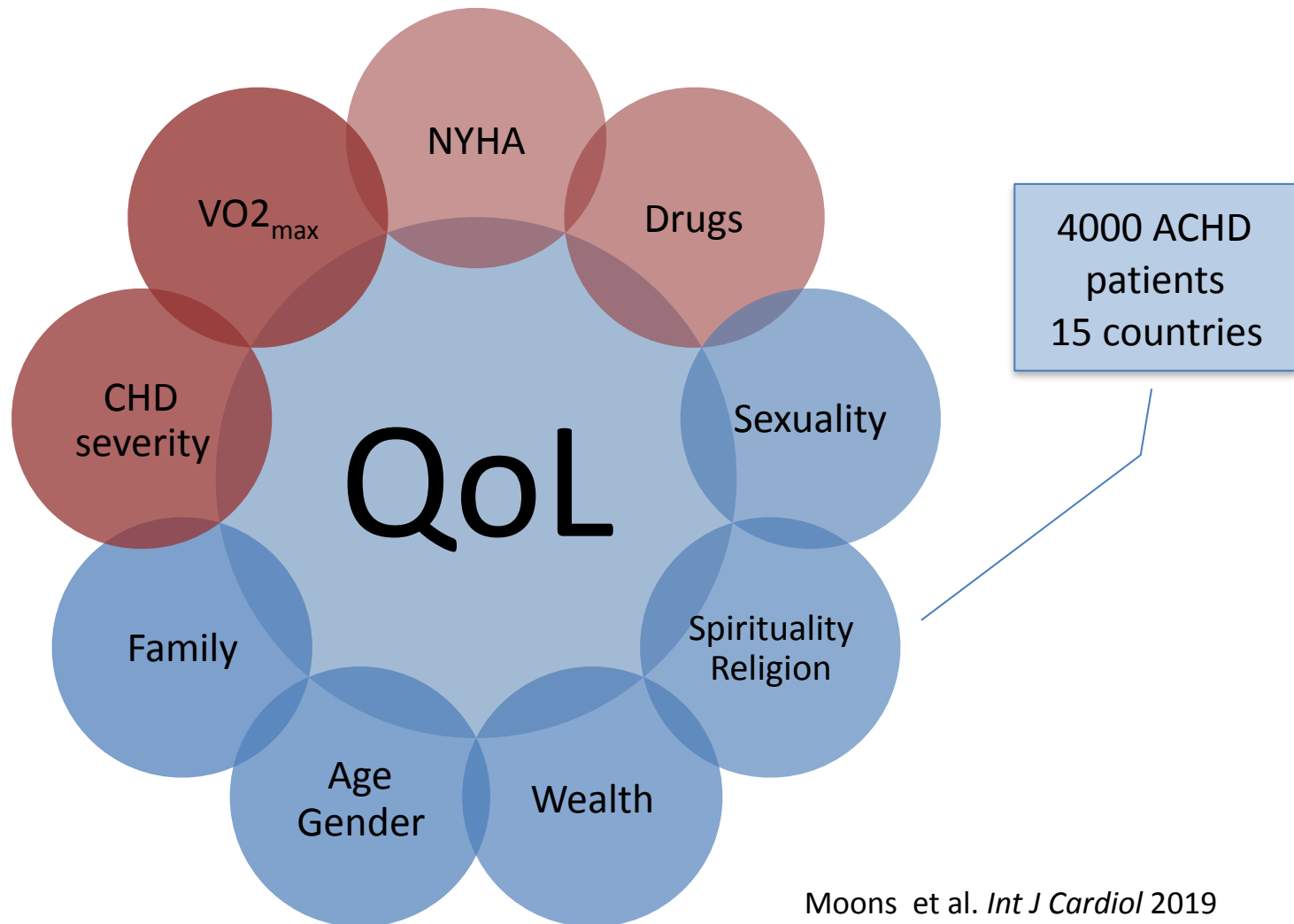
Components of QoL in ACHD



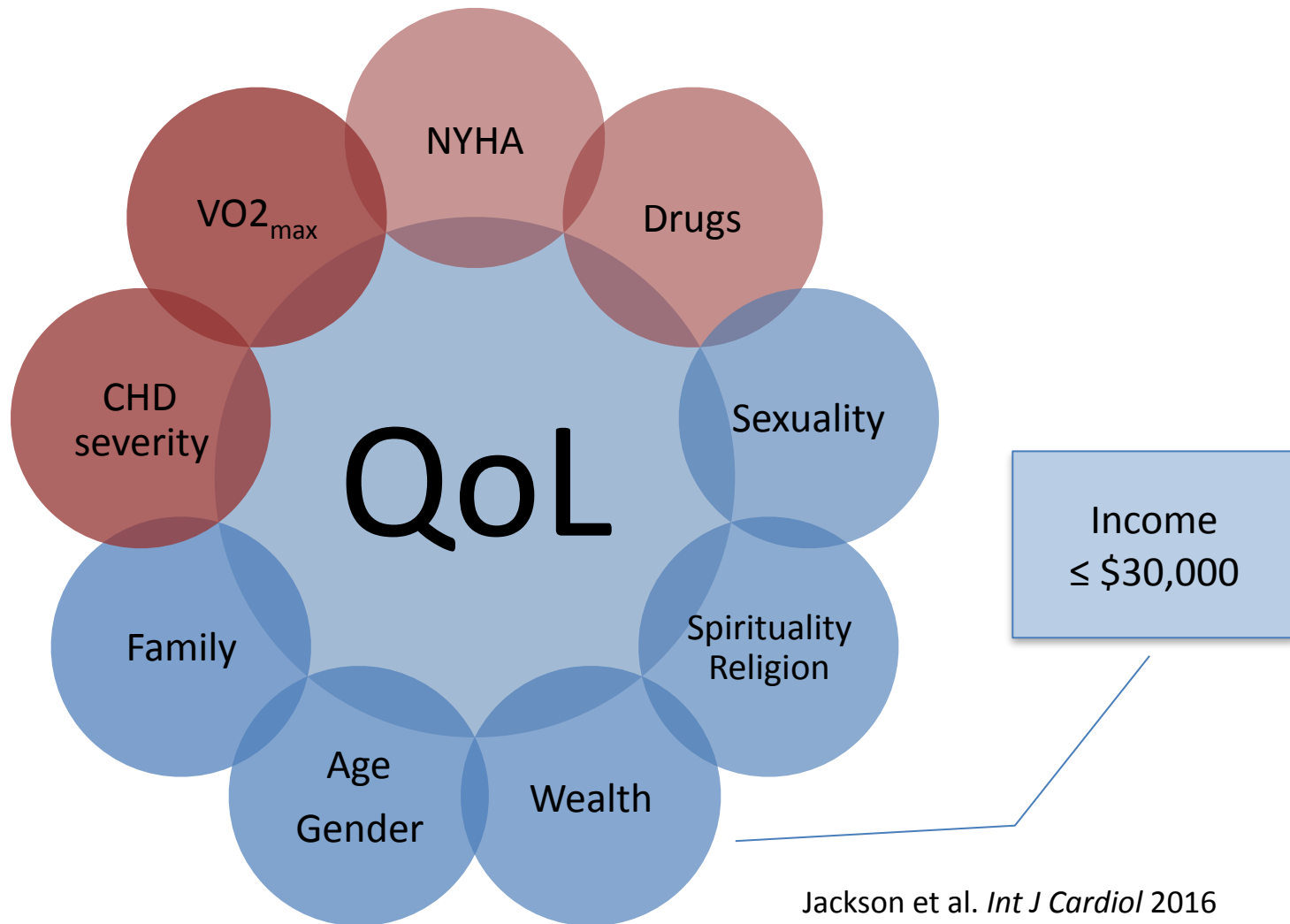
Components of QoL in ACHD



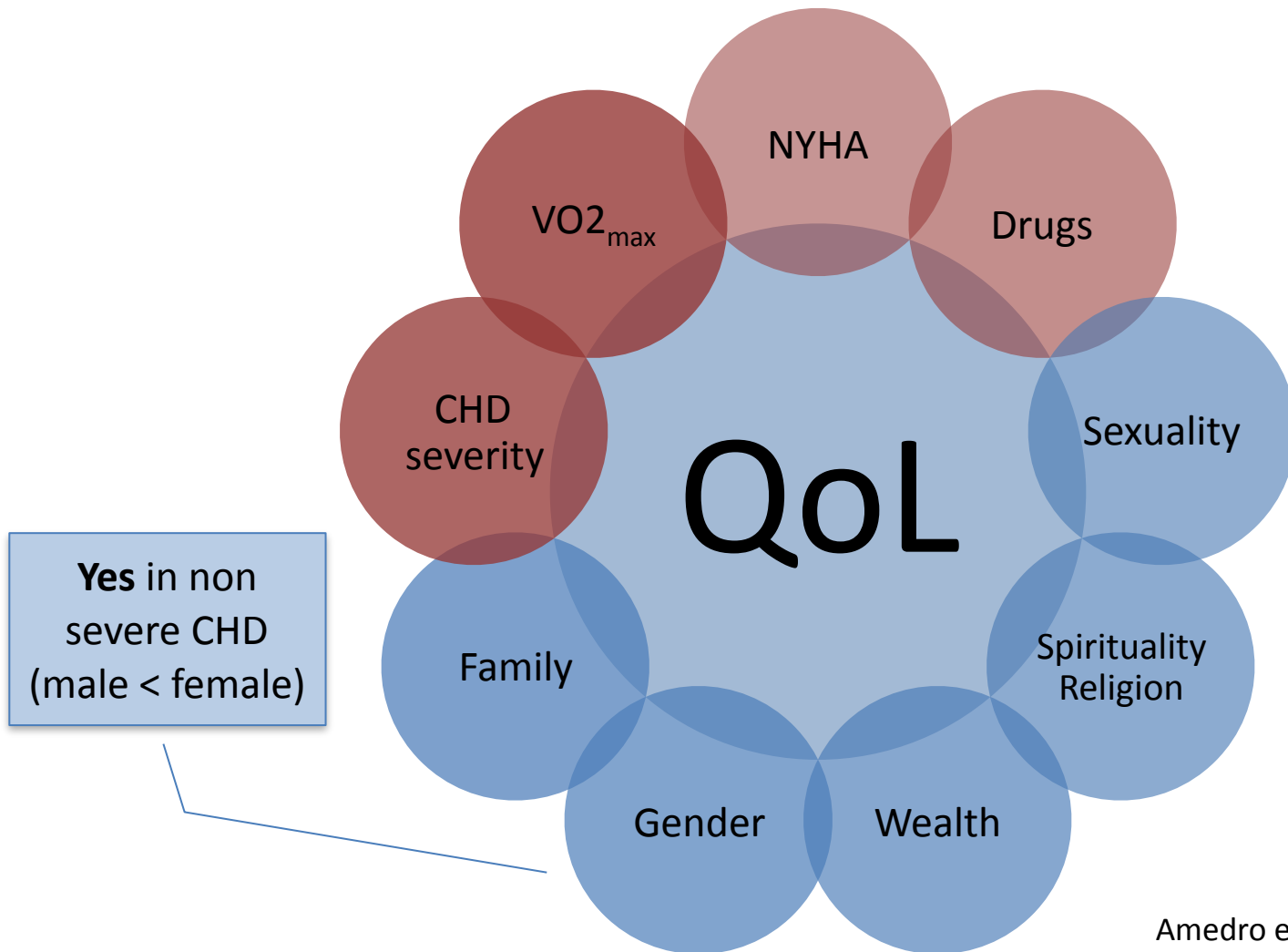
Components of QoL in ACHD



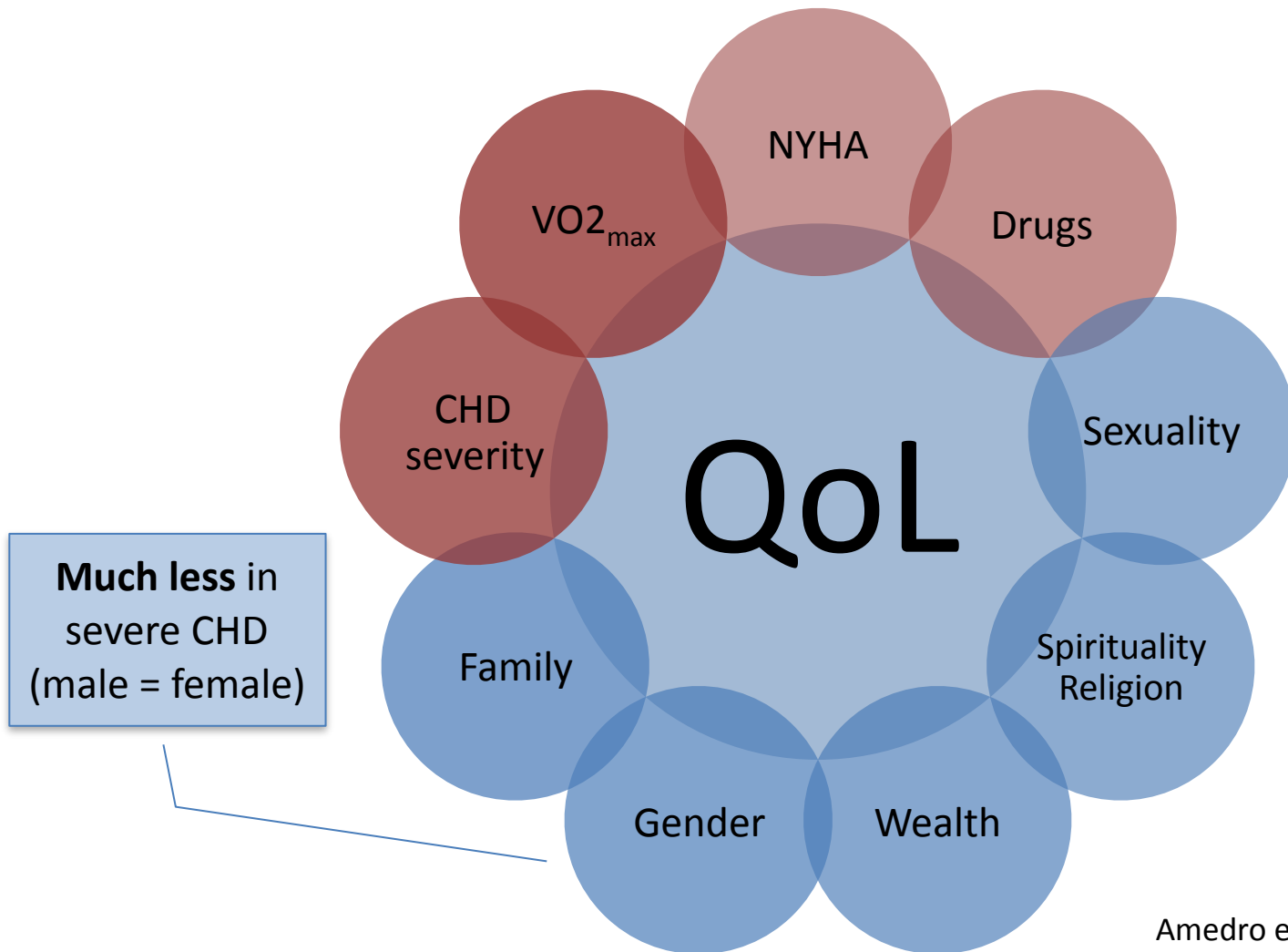
Components of QoL in ACHD



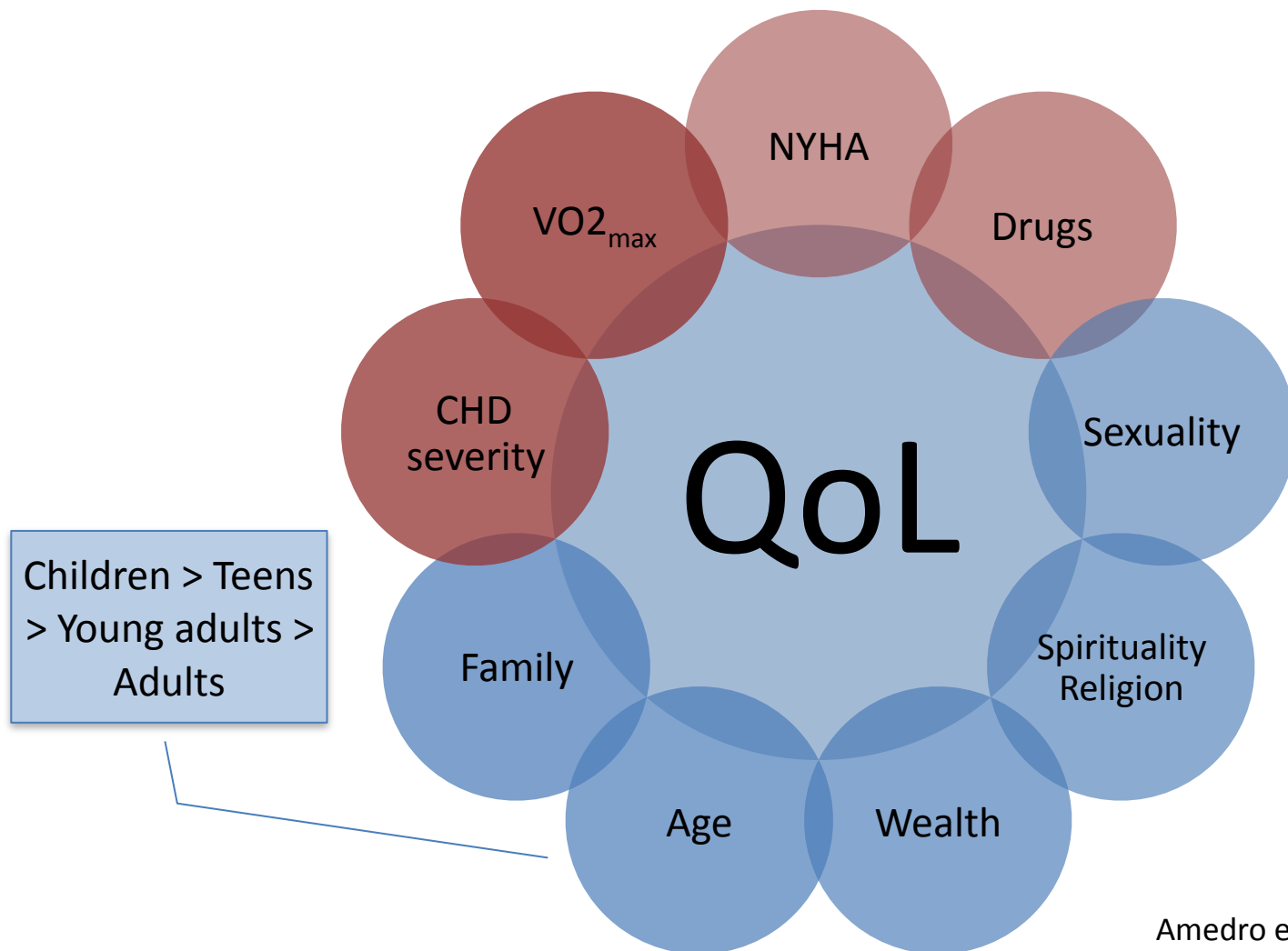
Components of QoL in ACHD



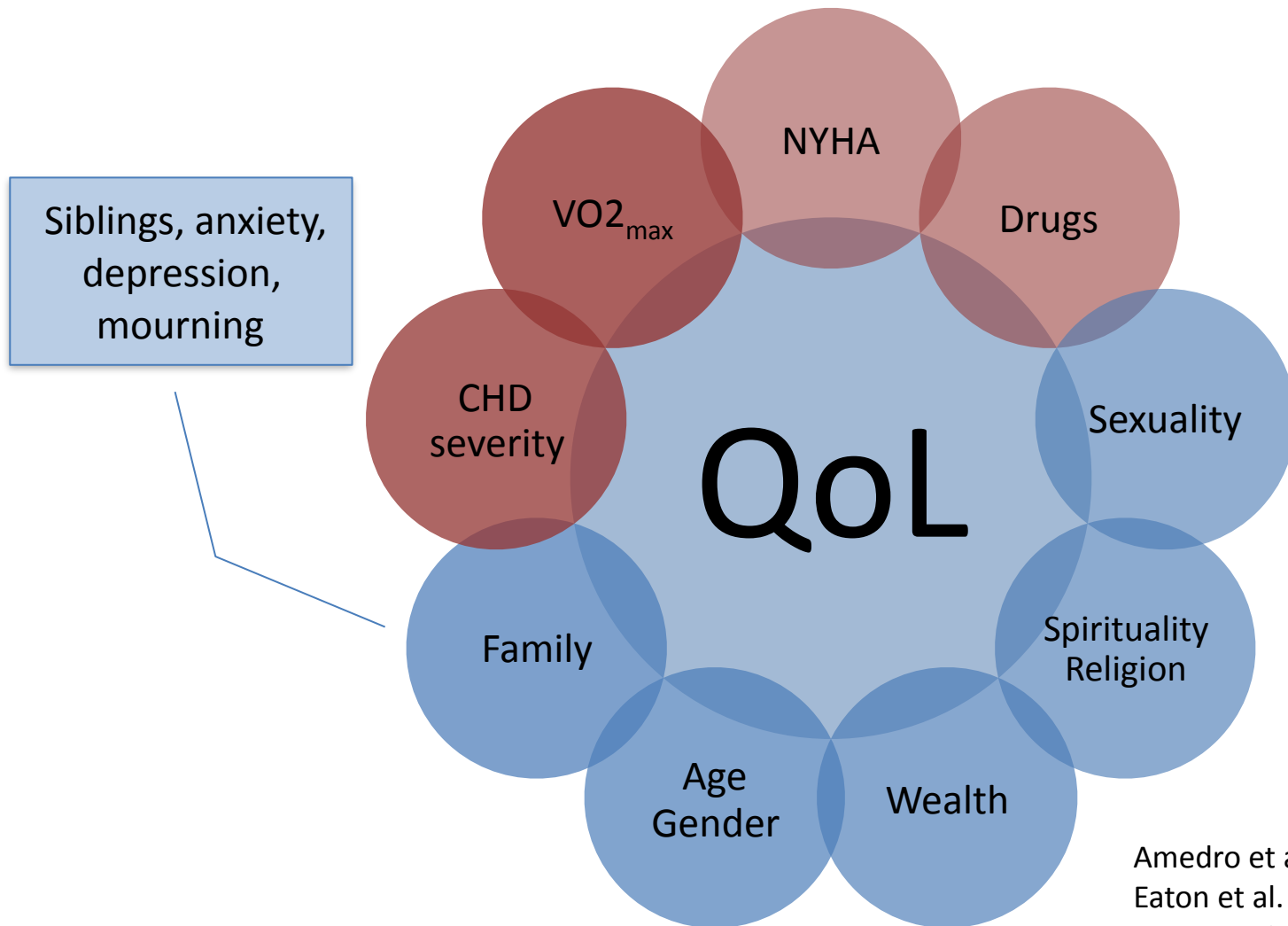
Components of QoL in ACHD



Components of QoL in ACHD



Components of QoL in ACHD

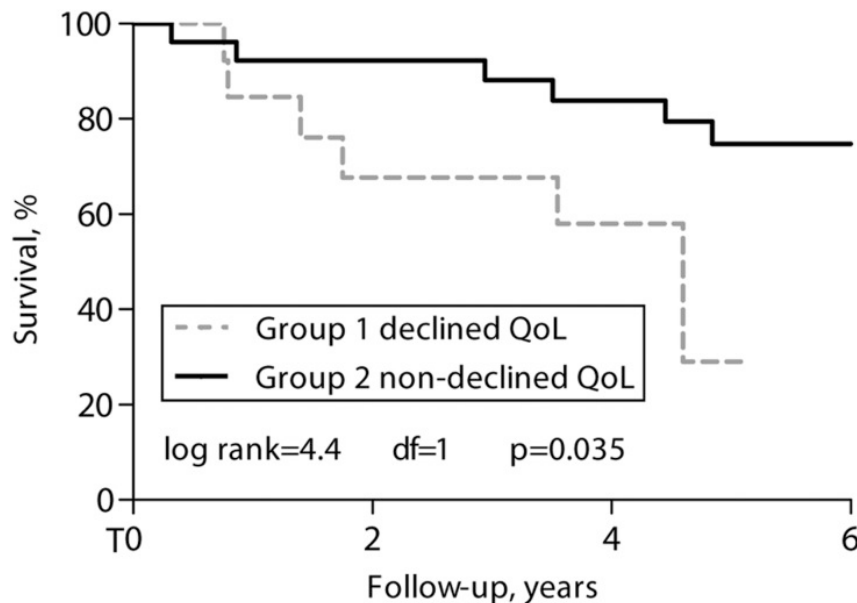


Amedro et al. *Cardiol Young* 2017
Eaton et al. *Cardiol Young* 2017
Yu-mi et al. *Qual Life Outcomes* 2018

Is HR-QoL a predictor of mortality?

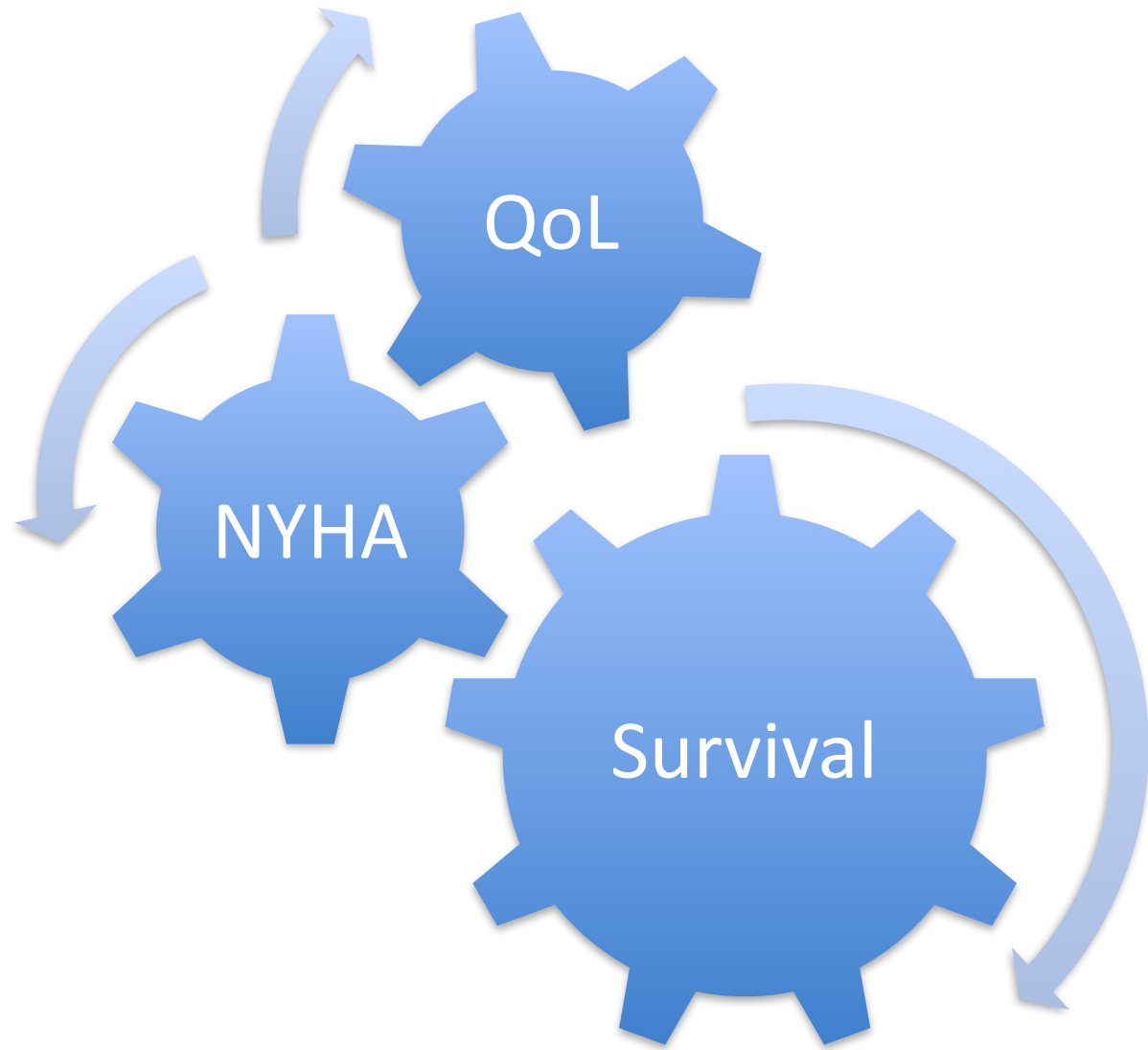
- In PAH-CHD patients: decrease in SF36 initiation of PAH-specific therapy is a predictor of mortality

YES !



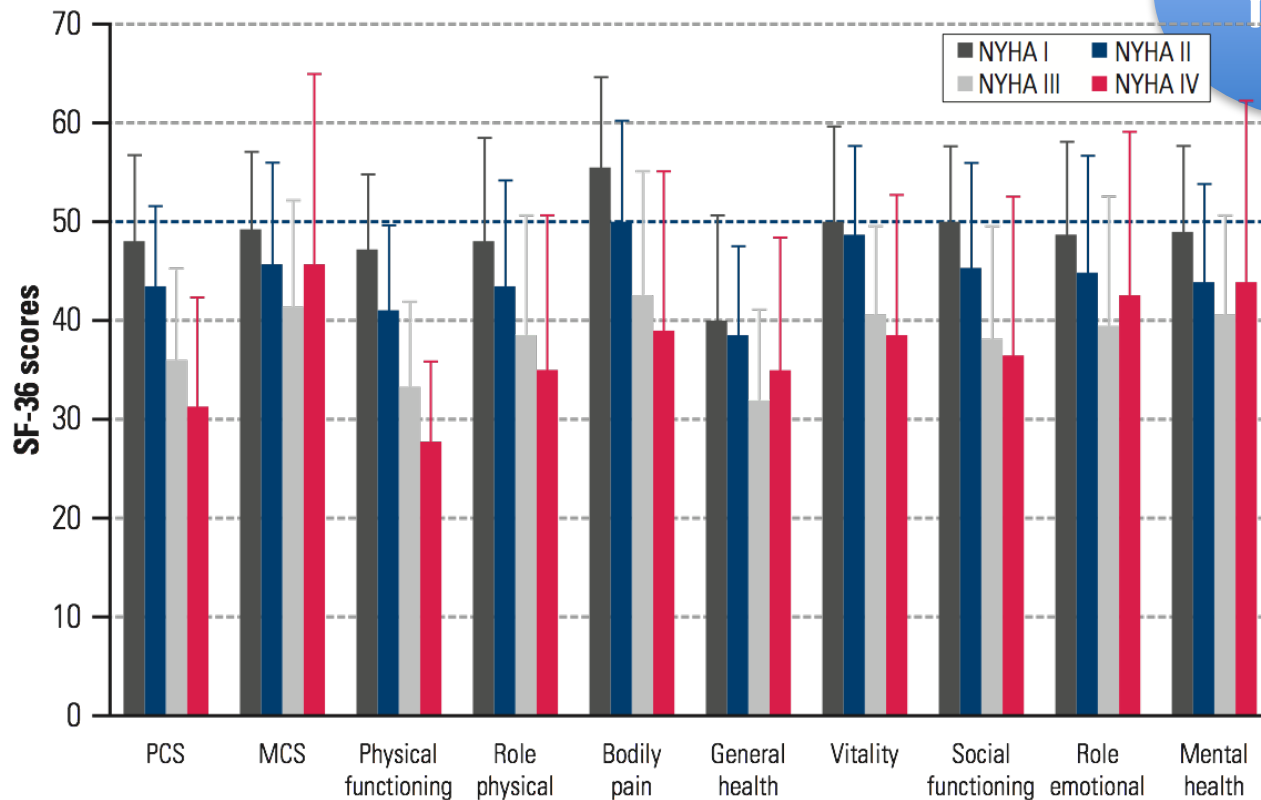
Most important determinants of survival:
- HR decrease SF-36 (PCS) = 3.4
- HR NYHA = 4.5

no at risk:	— 26	23	20	8
	--- 13	9	6	1



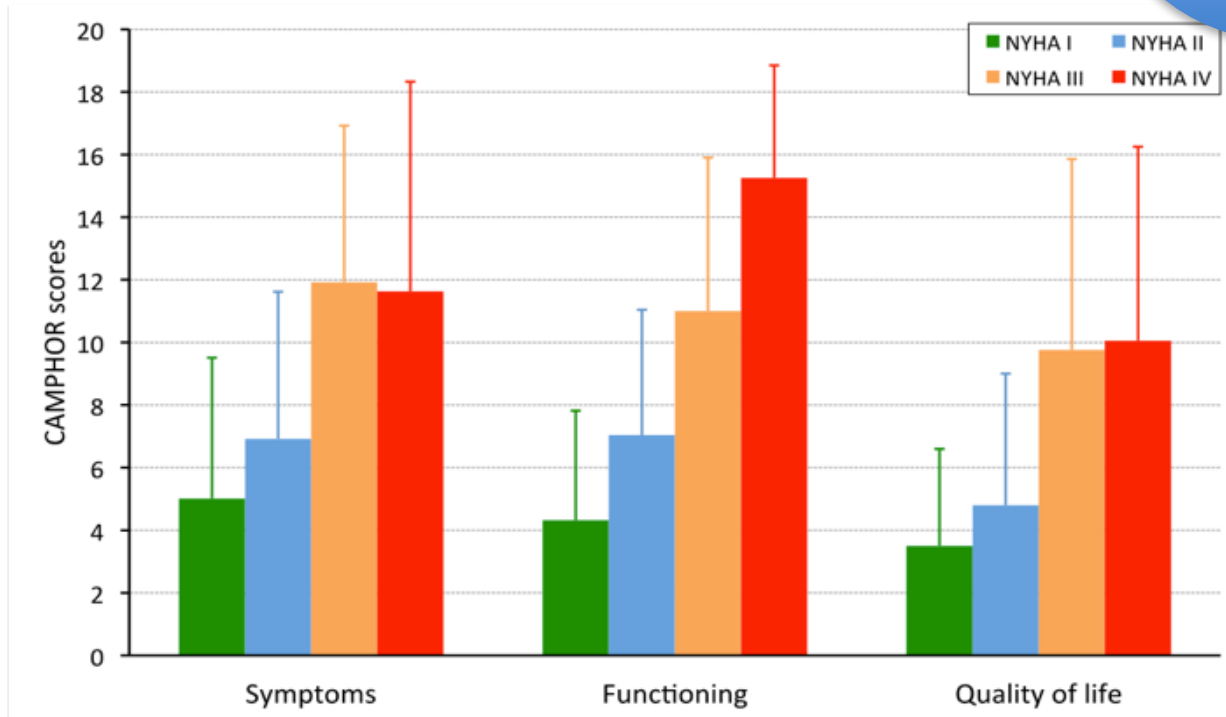
Does HR-QoL correlate with NYHA in ACHD using generic instruments?

YES !



Does HR-QoL correlate with NYHA in ACHD using specific instruments?

YES !



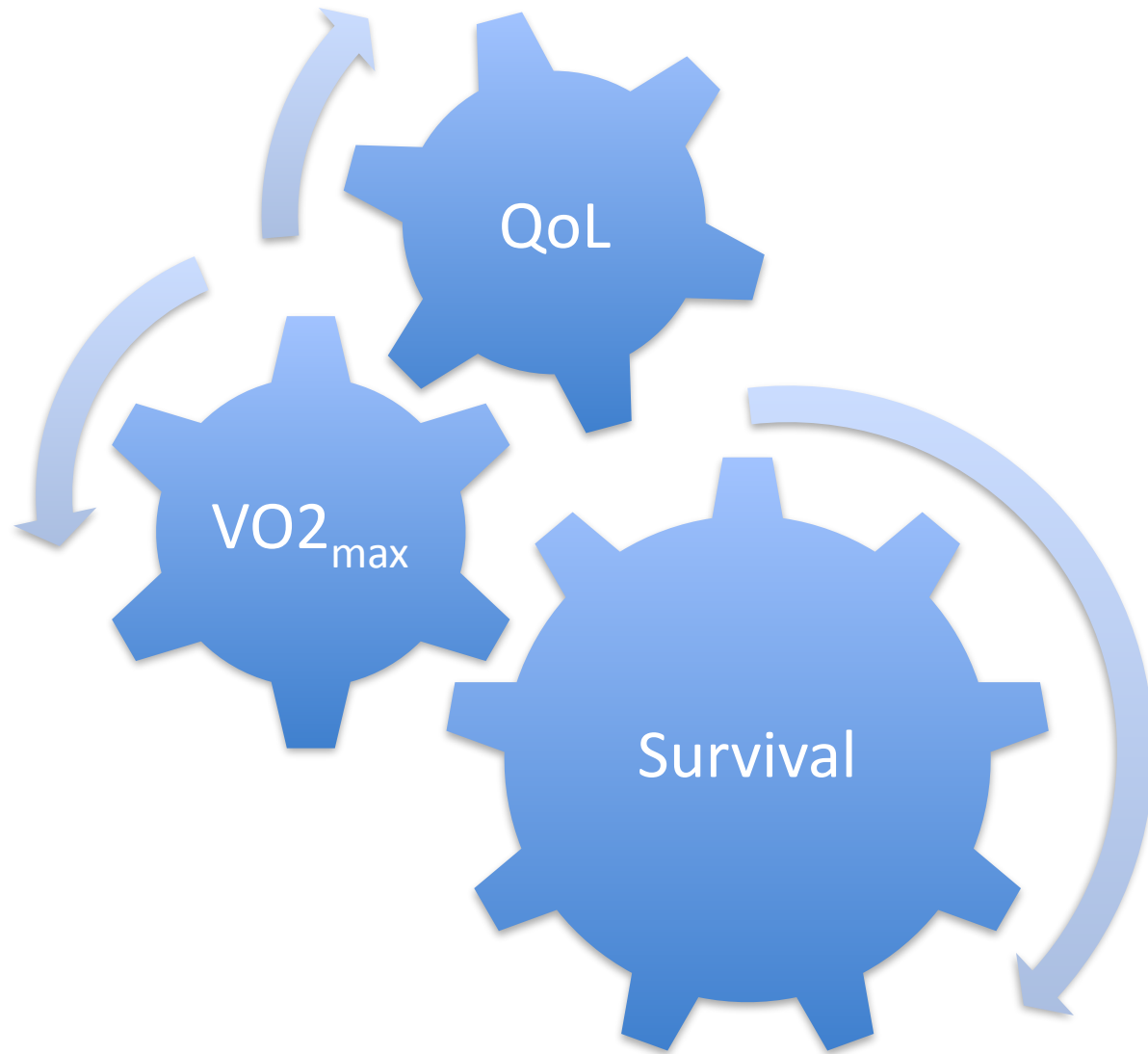
QoL and physical capacity

Concept of WOOD (WHO 1980)

A functional test during exercise better reflects QoL related to a chronic disease than any evaluation at rest

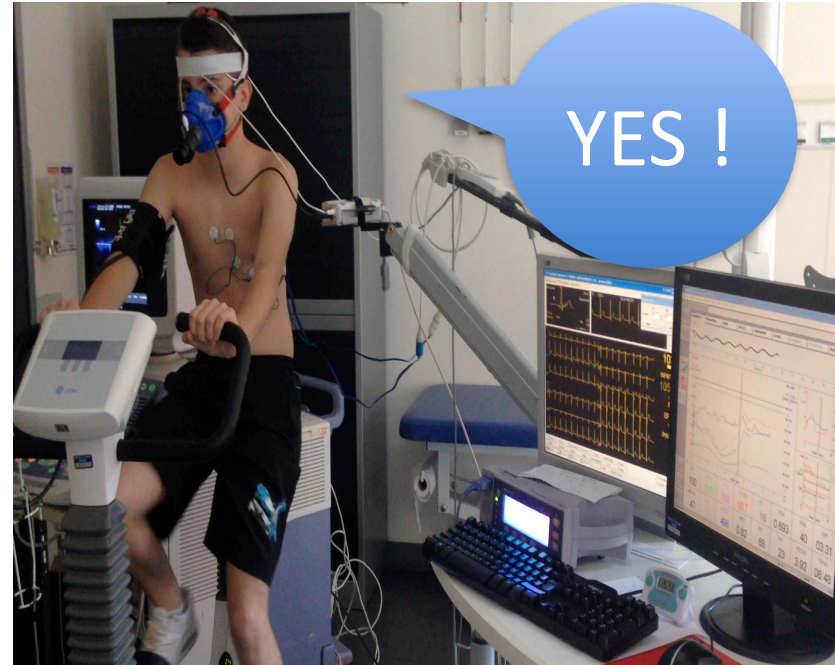


P.H. Wood, Appreciating the consequences of disease: the international classification of impairments, disabilities, and handicaps, *WHO Chronicle*. 34 (1980)



Does QoL correlate with physical capacity in CHD?

- Correlation between QoL and $VO2_{max}$
 - In chronic heart failure ^{1,2}
 - In ACHD patients ^{3,4}
 - In pediatric CHD patients ⁵
- CPET recommended in ACHD follow-up ⁶
 - $VO2_{max}$
 - VE/VCO₂ slope
- And now in pediatric CHD follow-up ^{7,8}



- 1 Myers et al. *Am Heart J* 2008
- 2 Mancini et al. *Circulation* 1991
- 3 Hager et al. *Heart* 2005
- 4 Giardini et al. *Ann Thorac Surg* 2008
- 5 Amedro et al. *Int J Cardiol* 2016
- 6 Baumgartner et al. *Eur Heart J* 2010
- 7 Amedro et al. *Heart* 2017
- 8 Marcadet et al. *Arch Cardiovasc Dis* 2018

QoL and physical activity

- Regular physical activity in ACHD improves QoL ¹
 - In the physical dimension
 - And in the mental well-being
- Regardless ACHD severity, surgery, age, betablockers, pacemaker, SpO₂
- Cardiac rehabilitation in ACHD patients should be promoted ²
 - safe
 - improves VO₂_{max}
 - probably improves QoL ³

¹ Hager et al. *Heart* 2017

² Amedro et al. *Press Med* 2017

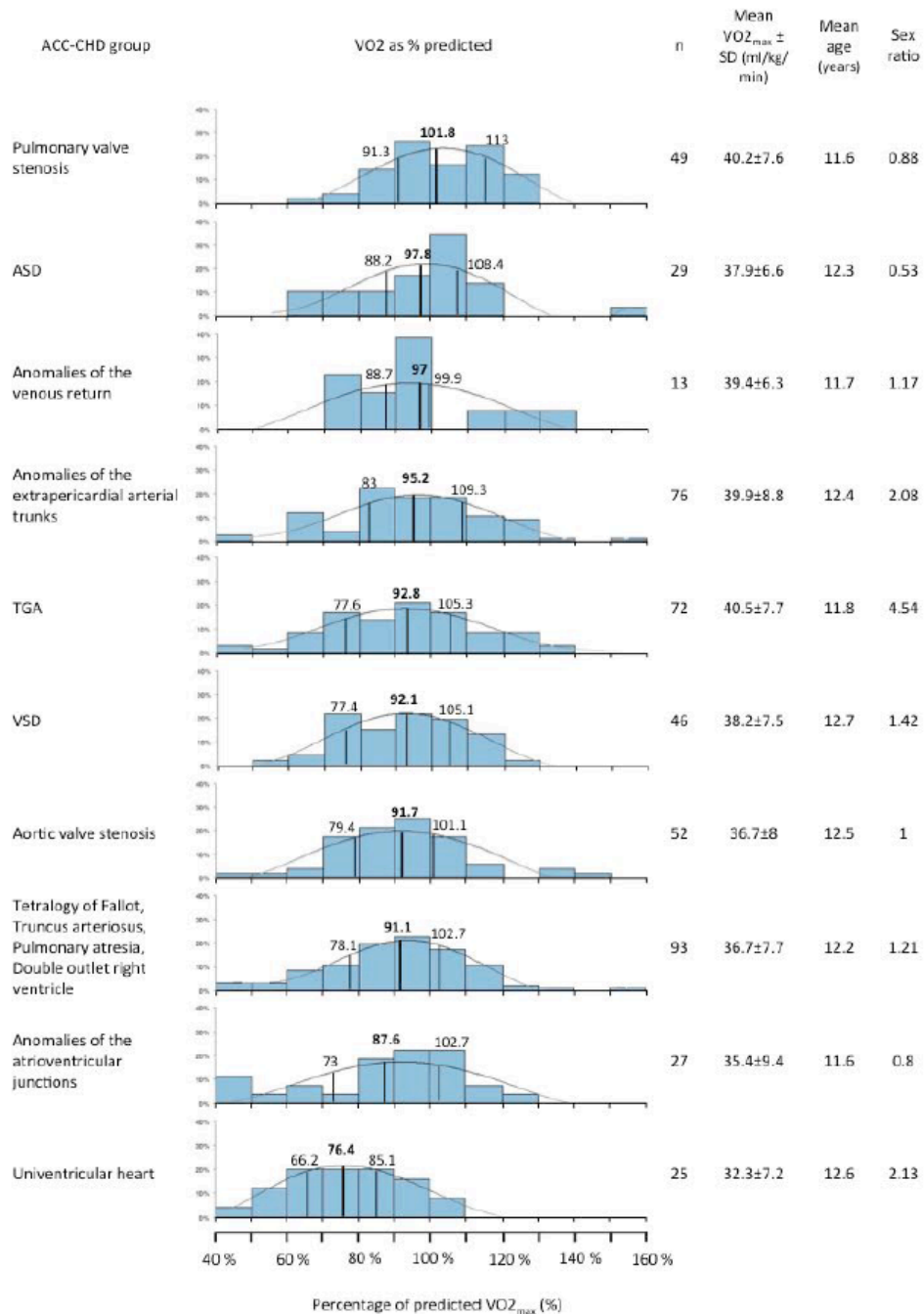
³ Amedro et al. *Int J Cardiol* 2019

QoL and CHD severity

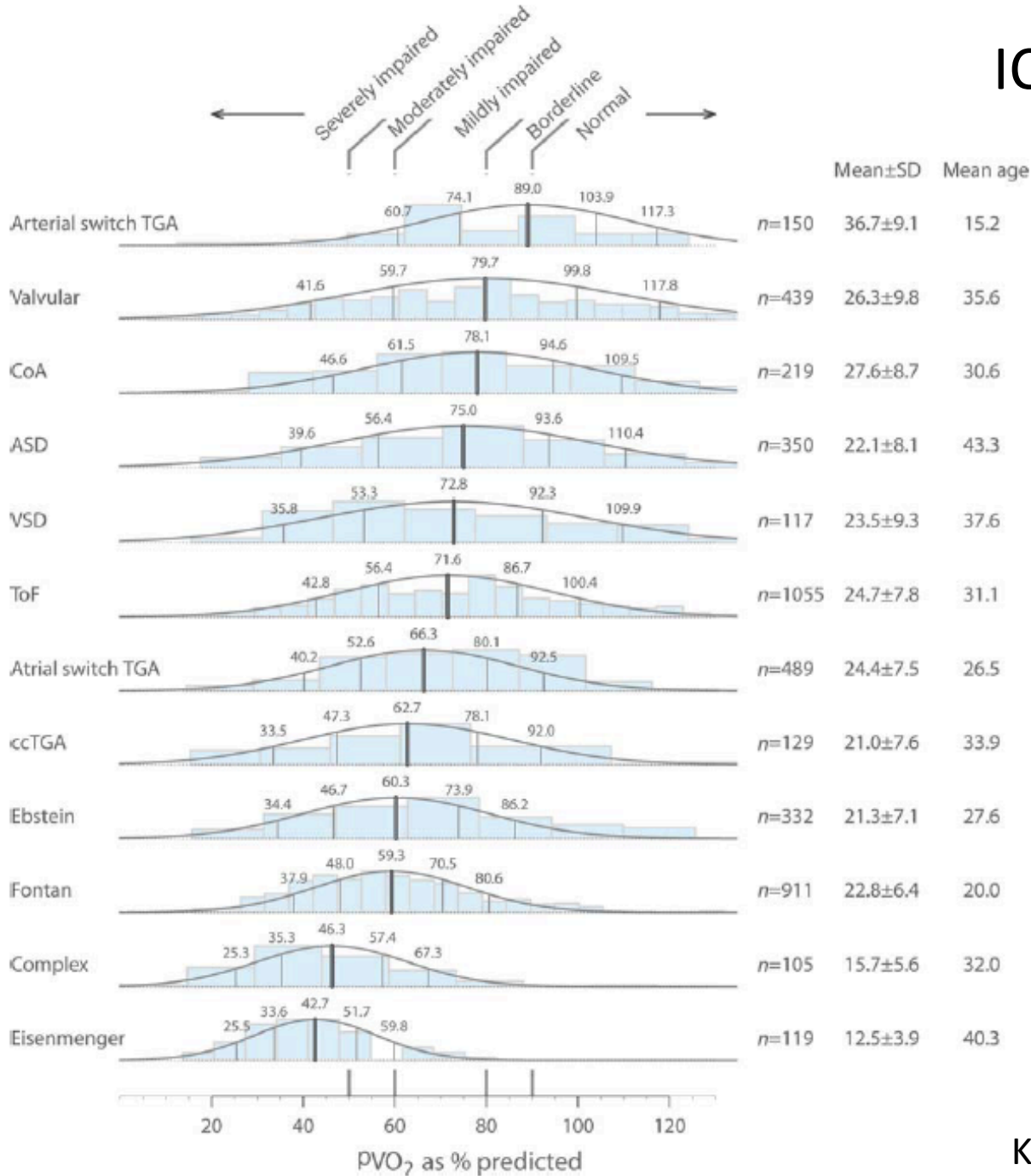
- Depends on the classification of CHD severity
- Mostly yes
 - When using simple classification (Bethesda)
 - And for the physical dimension of HR-QoL
- No data with exhaustive classifications
 - ACC-CHD

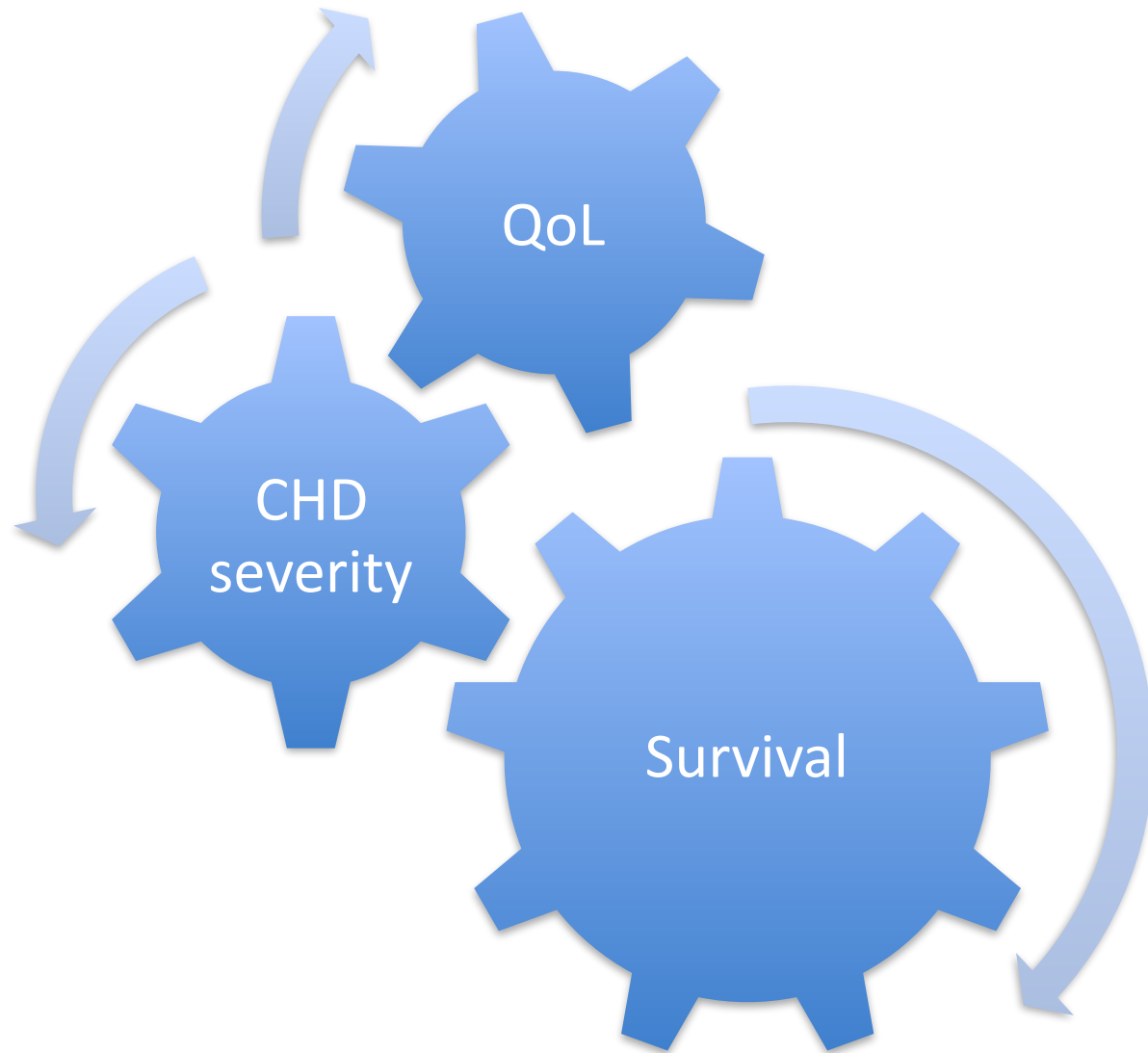
Remains unclear

ACC-CHD Classification



ICD-10 classification





Does QoL correlate with CHD severity?

Mostly YES in the
physical dimension !

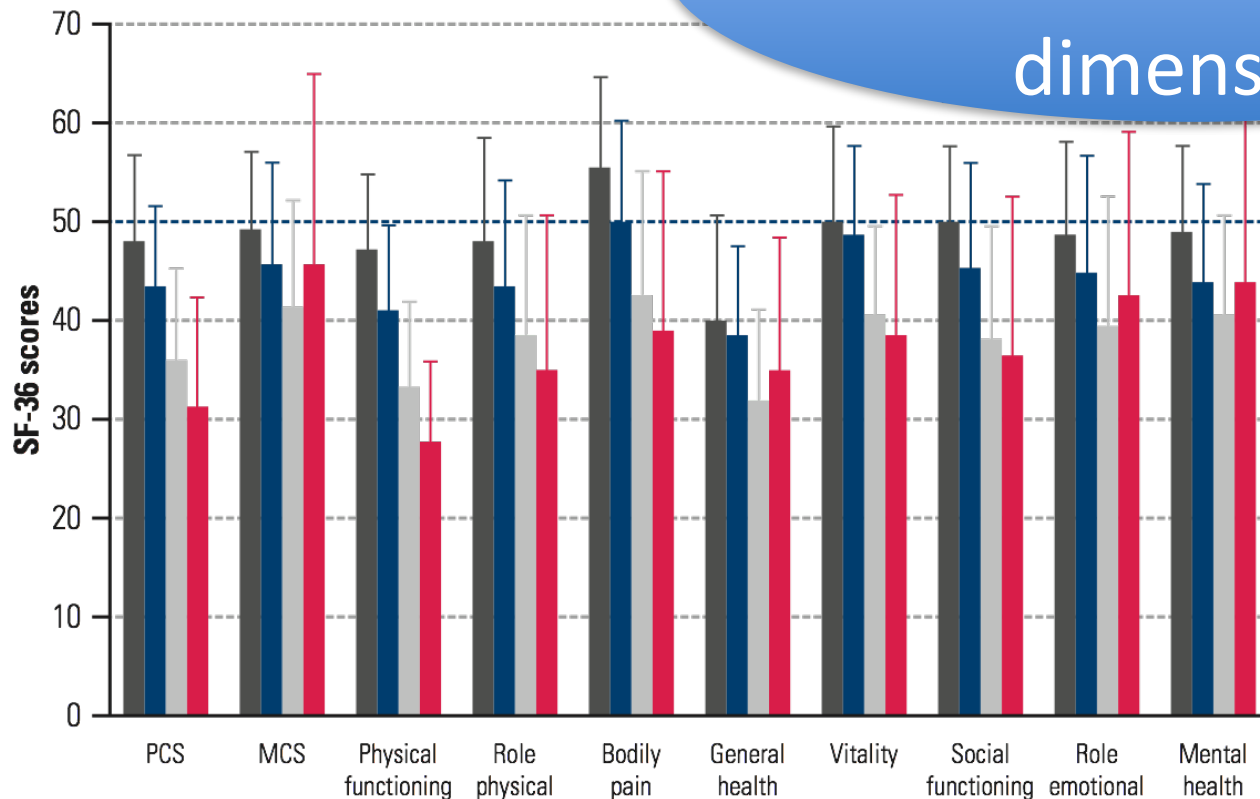
- Physical dimension of HR-QoL impaired in severe CHD (Fontan, Mustard, Senning) ¹
- Physical dimension of HR-QoL more impaired in simple TGA than complex TGV ²

¹ Kamphuis et al. *Heart* 2002

² Culbert et al. *Circulation* 2003

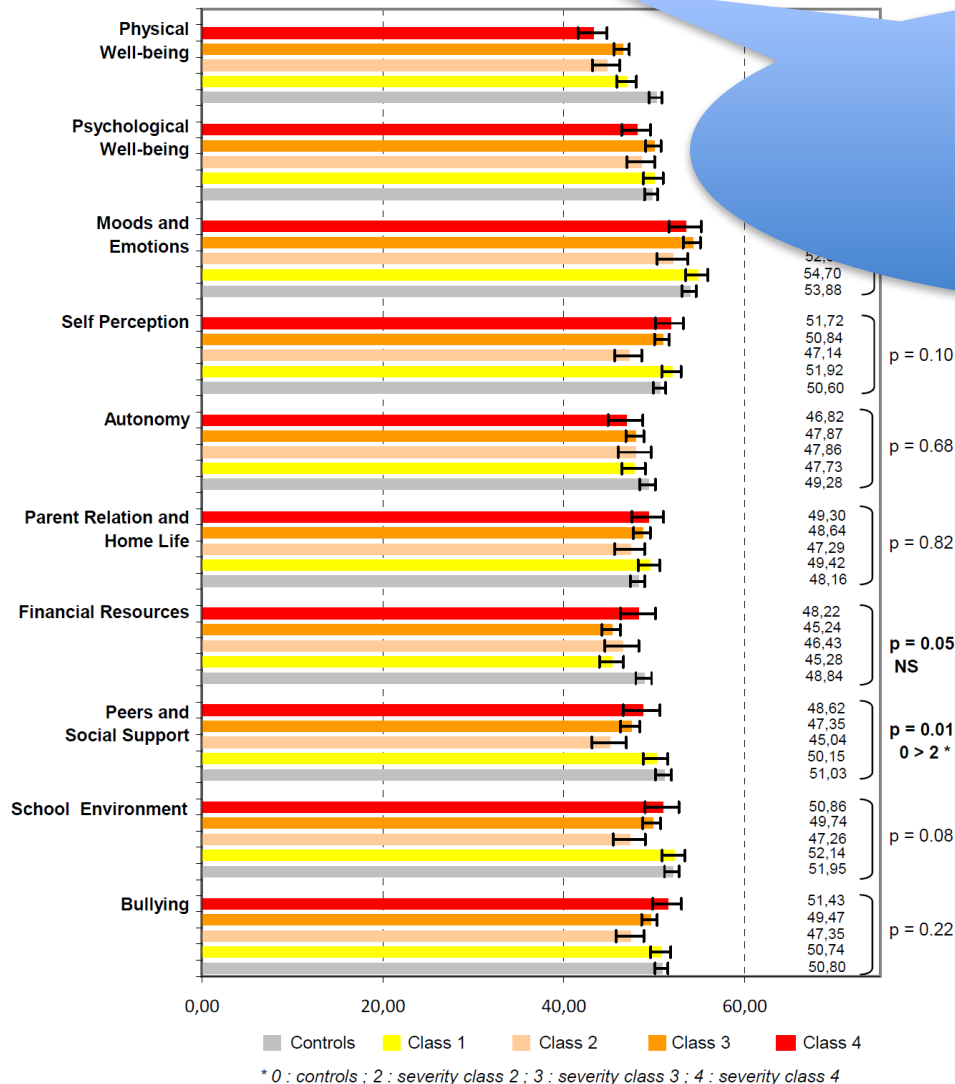
Does QoL correlate with CHD severity?

Not always
in the mental
dimension



In ACHD

Does QoL correlate with CHD severity?



Not always
in the mental
dimension

In children
with CHD

Good QoL levels in severe CHD

- Medical advances
 - New techniques (catheterization)
 - Better patient's global healthcare
 - Patient therapeutic education programs (transition) ¹
- Australian ACHD patients: mean score 90 ²
- Coping in CHD patients ²⁻⁴
 - Disability paradox
 - Response shift
 - Sense of coherence



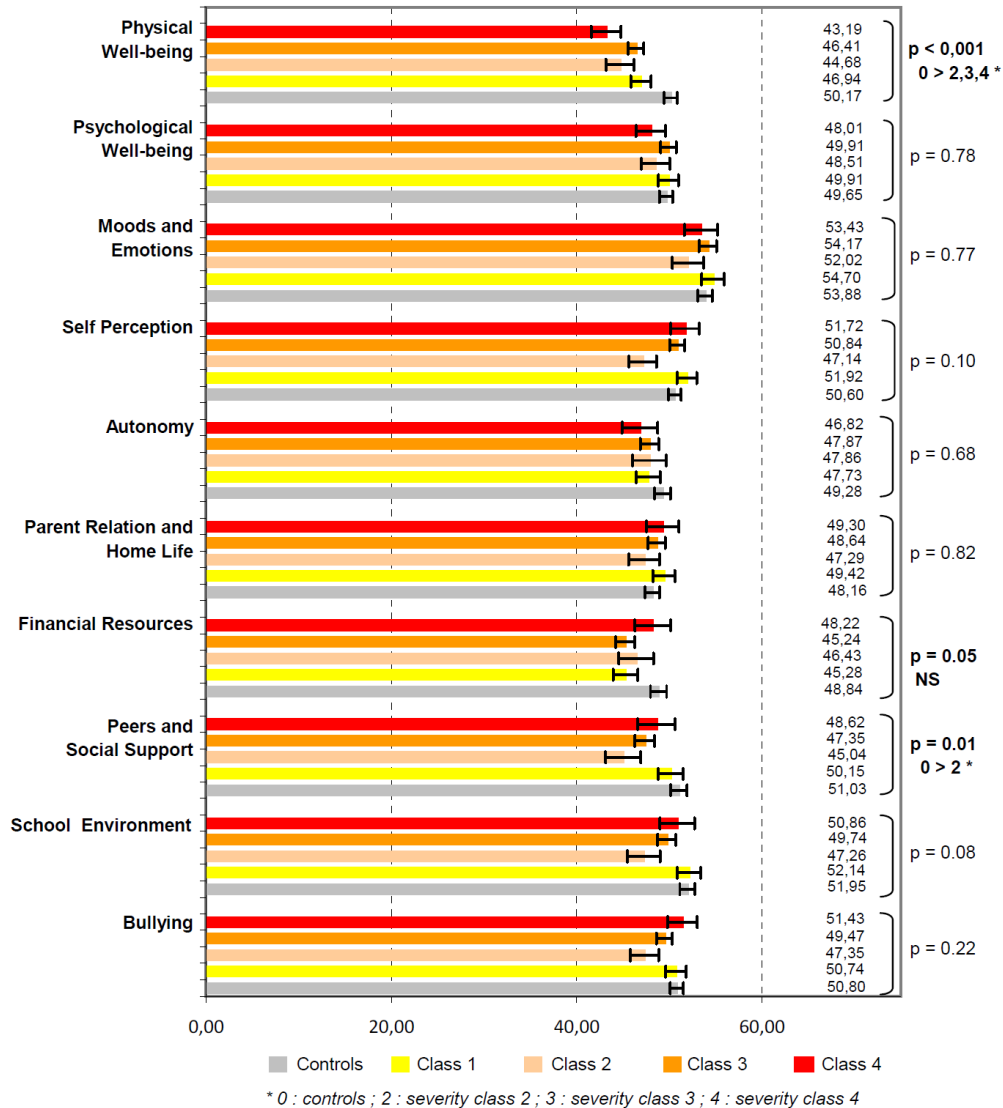
¹ Sable et al. *Circulation* 2011

² Eaton et al. *Cardiol Young* 2017

³ Moons et al. *Eur J Cardiovasc Nurs.* 2013

⁴ Amedro et al. *Ped Cardiol* 2015

Impaired QoL in non-severe CHD



Impaired QoL in non-severe CHD

- Lack of autonomy ¹
- Patients on the « sideline » from childhood ¹
- Parental barriers to physical activity ²
- Muscular deconditioning and impaired $VO2_{max}$ even in simple CHD (ASD, VSD)
 - In ACHD ³
 - In teenagers ⁴

¹ Amedro et al. *Ped Cardiol* 2015

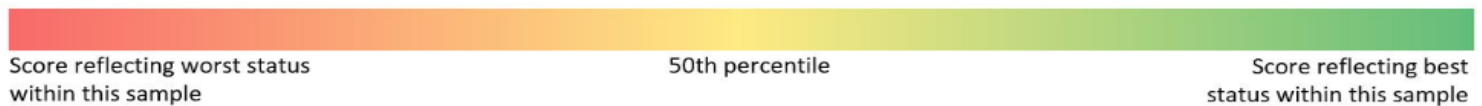
² Moola et al. *Qual Health Res* 2011

³ Kempny et al. *Eur Heart J* 2012

⁴ Amedro et al. *Heart* 2018

QoL inter-country variation in ACHD

	PCS (0-100)	MCS (0-100)	EQ-VAS (0-100)	HADS-A (0-21)	HADS-D (0-21)	Total health risk score (0-100)	LAS QOL (0-100)	SWLS (5-35)	Composite APPROACH-15 PRO score (0-100)
Switzerland (n=278)	80.4 (21.5)	75.7 (17.5)	81.3 (16.4)	4.5 (3.7)	2.9 (3.3)	18.4 (16.7)	81.7 (15.8)	26.9 (6.2)	81.0 (12.3)
Sweden (n=471)	83.0 (20.9)	75.9 (19.1)	79.3 (17.5)	4.9 (4.0)	2.8 (3.1)	16.8 (15.9)	79.5 (17.7)	26.3 (6.2)	80.1 (14.4)
Netherlands (n=256)	77.2 (19.9)	75.7 (17.4)	79.4 (13.7)	4.4 (2.9)	2.4 (2.8)	19.7 (16.9)	80.1 (11.9)	27.0 (5.5)	79.1 (11.0)
Malta (n=119)	84.7 (16.8)	77.3 (17.1)	82.3 (14.3)	5.8 (4.1)	2.5 (3.2)	32.1 (16.4)	80.7 (13.4)	26.1 (5.5)	78.2 (11.4)
Italy (n=66)	77.7 (19.4)	76.2 (17.8)	79.5 (15.4)	4.4 (4.1)	3.0 (2.9)	25.7 (16.5)	79.7 (14.7)	26.0 (6.4)	77.3 (13.4)
Belgium (n=276)	77.4 (21.1)	73.7 (18.7)	78.5 (14.1)	5.8 (4.0)	2.9 (3.4)	23.2 (16.5)	76.9 (14.4)	25.9 (5.9)	76.9 (12.5)
Argentina (n=178)	77.0 (20.0)	70.0 (19.7)	80.1 (16.6)	5.6 (3.9)	3.3 (3.2)	28.8 (16.3)	79.5 (14.5)	26.7 (6.1)	76.5 (11.4)
USA (n=752)	74.6 (23.6)	71.5 (20.6)	76.6 (17.7)	6.2 (4.1)	3.0 (3.4)	21.9 (16.6)	80.5 (17.2)	25.6 (7.1)	76.4 (15.1)
Australia (n=132)	75.9 (19.8)	71.5 (18.0)	77.9 (15.1)	6.0 (3.7)	3.1 (3.0)	26.6 (16.4)	83.0 (14.1)	26.1 (6.7)	76.2 (11.2)
Norway (n=174)	77.3 (20.8)	70.2 (19.9)	72.6 (19.0)	5.4 (4.0)	2.3 (2.9)	18.5 (18.1)	76.6 (17.5)	25.5 (6.8)	75.9 (14.3)
Canada (n=523)	78.5 (18.3)	69.3 (17.3)	74.7 (15.3)	6.6 (3.2)	3.7 (3.1)	18.8 (17.0)	75.9 (15.9)	24.4 (6.7)	75.3 (12.1)
Taiwan (n=250)	70.9 (18.4)	67.0 (16.8)	79.4 (14.8)	4.9 (3.3)	4.2 (3.2)	22.0 (15.2)	75.3 (14.4)	24.8 (6.5)	74.1 (11.0)
Japan (n=257)	80.7 (17.5)	72.5 (18.9)	77.1 (17.0)	5.2 (4.3)	3.9 (4.2)	29.8 (16.6)	70.7 (21.5)	20.7 (6.3)	73.7 (13.4)
France (n=96)	73.0 (21.7)	65.7 (20.8)	79.4 (16.0)	6.8 (4.2)	3.7 (3.4)	29.6 (15.9)	78.8 (14.5)	25.0 (6.7)	73.6 (13.1)
India (n=200)	67.2 (20.7)	68.9 (19.5)	77.6 (18.7)	6.3 (3.8)	4.4 (3.5)	34.5 (13.1)	76.7 (18.5)	25.8 (5.9)	71.3 (12.2)
Total sample (n=4028)	77.2 (20.9)	72.1 (19.0)	77.9 (16.5)	5.6 (3.9)	3.2 (3.3)	22.6 (17.1)	78.3 (16.6)	25.4 (6.6)	76.6 (13.3)



Predictors of QoL in ACHD worldwide

- Independent patient-related factors:
 - **Functional class**
 - **Unemployment status**
- Other factors:
 - **Standard of living** (gross domestic products per capita and human development index)
 - **Healthcare system characteristics** (total health expenditure per capita and overall health system performance)

Remaining questions & projects

- Predictors of HR-QoL during prenatal diagnosis
- QoL and type/severity of CHD
 - Anatomy
 - Physiology
 - Combined CHD lesions
 - Invasive treatment: surgery, cardiac catheterization
- Composite scores including QoL assessment in clinical trials
- Undetermined components of HR-QoL in CHD
- Randomized trials with QoL as primary outcome
 - Qualirehab
 - Transition

**What does my quality
of life correlate with?**



M3C

Academy

