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Illness perceptions, health literacy and health related quality of life: the patient's perspective of preventive care

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EAPC
European Association
of Preventive Cardiology

ACNAP
Association of Cardiovascular
Nursing & Allied Professions

Why is patients' perspective important?

- Engagement with preventive care

- Making and sustaining Lifestyle changes

- Taking and adhering to prescribed cardio-protective medications

- Cost to healthcare system

- Increased mortality

Health Related Quality of Life (HRQoL)

"the value assigned to the duration of life as modified by the impairments, functional states, perceptions and social opportunities that are influenced by disease, injury, treatment or policy."

Patrick DL & Erickson P. *Health status and health policy. Quality of life in health care evaluation and resource allocation.* New York: Oxford University Press, 1993.

Health Related Quality of Life (HRQoL)

- Multidimensional concept that can be viewed as a latent construct which describes the physical, role functioning, social, and psychological aspects of well-being and functioning

- Includes objective and subjective perspectives in each domain

de Wit M., Hajos T. (2013) Health-Related Quality of Life. In: Gellman M.D., Turner J.R. (eds) Encyclopedia of Behavioral Medicine. Springer, New York, NY

Dimensions of HRQoL

- Physical and occupational functioning
  - E.g. ability to care for one self, washing, doing house work etc

- Psychological State
  - E.g. Mood, anxiety, depression

- Social interaction
  - E.g. social isolation, family support, friends

- Somatic sensation (symptoms)
  - E.g. angina, breathlessness

Origins of Health Related Quality of Life measurement

- People living longer with chronic diseases

- HRQoL has become an important outcome in evaluations of health interventions

- Reflects a biopsychosocial perspective in modern healthcare

Health Literacy

"The degree to which individuals have the capacity to obtain, process and understand health information and services needed to make appropriate health decisions"

Illness Perceptions

Activated by symptoms, diagnosis, risk perception	Misconceptions can lead to:
• Identity	• Non-adherence to treatment, adoption of health protective behaviours
• Cause	
• Timeline	• Emotional distress
• Consequences	• Guilt, low self esteem, poor psychological adjustment
• Cure	
• Control	• Passive coping strategies (avoidance) and dependence on health professionals

Leventhal 'Self Regulatory Model' 1984   Petrie et al 1996, 2002

Overall Study Aim

- Develop an understanding of cardiovascular patients' perceptions of their condition and engagement with treatment (lifestyle change and medication management).

- To understand more about barriers and levers to effective secondary prevention from the patient's perspective.

Objectives

- Assess patients' self-reported:
    1. Illness perceptions regarding their coronary disease
    2. Health literacy
    3. Health related quality of life
    4. Perceived barriers to life-style changes
    5. Adherence to secondary prevention medications
- Identify associations between demographic and socio-economic variables, and above .

EUROASPIRE V

- Pan-European cross-sectional survey in patients with coronary heart disease (CABG, PTCA, AMI, Ischaemia, Unstable Angina)

- Patients were recruited from centres in defined geographical areas in **12 countries**: Egypt, Ireland, Kazakhstan, Lithuania, Netherlands, Poland, Portugal, Russian Federation, Sweden, Turkey, Ukraine, United Kingdom.

2016 European Guidelines on cardiovascular disease prevention in clinical practice

The Sixth Joint Task Force of the European Society of Cardiology and Other Societies on Cardiovascular Disease Prevention in Clinical Practice (constituted by representatives of 10 societies and by invited experts).

Developed with the special contribution of the European Association for Cardiovascular Prevention & Rehabilitation (EACPR).

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Councils: Council on Cardiovascular Nursing and Allied Professions, Council for Cardiology Practice, Council on Cardiovascular Primary Care.
Working Groups: Cardiovascular Pharmacotherapy

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Eligible study population

- Retrospective identification of eligible patients from hospital records

- Elective revascularisation with CABG or PCTA

- Acute STEMI or NSTEMI or acute myocardial ischaemia with or without emergency revascularisation

- > 6 months but not > 2 years post coronary event

- < 80 years of age and at least 18 years old

Methods

- EUROASPIRE V case record form, physical measurements and validated questionnaires:
    - Adherence to cardio-protective medications
    - HADS
    - HeartQoL
    - EQ-5D

Additional questionnaires
    - Health Literacy Questionnaire (Scale 9)
    - Brief Illness Perceptions Questionnaire (B-IPQ)
    - Behaviour change questions

B-IPQ instrument

1. **Consequences**
   How much does your illness affect your life? (no affect at all - severely affects my life)

2. **Timeline**
   How long do you think your illness will continue? (very short time - forever)

3. **Personal control**
   How much control do you feel you have over your illness? (extreme amount of control - absolutely no control)

4. **Treatment control**
   How much do you think your treatment can help your illness? (extremely helpful - not at all)

5. **Identity**
   How much do you experience symptoms from your illness? (no symptoms at all - many severe symptoms)

6. **Illness concern**
   How concerned are you about your illness? (not at all concerned - extremely concerned)

7. **Coherence**
   How well do you feel you understand your illness? (understand very clearly - don't understand at all)

8. **Emotional representation**
   How much does your illness affect you emotionally? (not at all - extremely affected emotionally)

The B-IPQ instrument

- Score range 0 – 10 for each item
- Overall score is arithmetic mean of the 8 scores
- Represents the degree to which the illness is perceived as threatening or benign. Higher score reflects a more threatening view of the illness.
- "Cognitive illness representations" score - arithmetic mean of the scores 1, 2, 3, 4 and 5.
- "Emotional representations" - arithmetic mean of the scores 6 and 8.
- "Illness comprehensibility" score - score 7.
- B-IPQ reliable with a **Cronbach's alpha of 0.71**

The Brief IPQ (Broadbent, Petrie, Main, & Weinman 2006)

Health Literacy Questionnaire - HLQ SCALE 9 (9 separate scales relating to health literacy)

- Scale 9: "Understanding health information well enough to know what to do"
  - Confidently fill medical forms in the correct way
  - Accurately follow the instructions from healthcare providers
  - Read and understand written health information
  - Read and understand all the information on medication labels
  - Understand what healthcare providers are asking you to do

- Response categories: 'cannot', 'very difficult', 'difficult', 'easy' and 'very easy'.

- Score range 0 – 4 for each question – higher the score, better the HL

HLQ-9 was shown to be very reliable with a **Cronbach's alpha of 0.89**

EQ-5D (and EQ-VAS) Utility and Generic measure of HRQoL

Figure 1: EQ-5D-5L (UK English sample version)

Under each heading, please tick the **ONE** box that best describes your health **TODAY**

MOBILITY

I have no problems in walking about	☐
I have slight problems in walking about	☐
I have moderate problems in walking about	☐
I have severe problems in walking about	☐
I am unable to walk about	☐

SELF-CARE

I have no problems washing or dressing myself	☐
I have slight problems washing or dressing myself	☐
I have moderate problems washing or dressing myself	☐
I have severe problems washing or dressing myself	☐
I am unable to wash or dress myself	☐

USUAL ACTIVITIES *(e.g. work, study, housework, family or leisure activities)*

I have no problems doing my usual activities	☐
I have slight problems doing my usual activities	☐
I have moderate problems doing my usual activities	☐
I have severe problems doing my usual activities	☐
I am unable to do my usual activities	☐

PAIN / DISCOMFORT

|	
I have no pain or discomfort	☐
I have slight pain or discomfort	☐
I have moderate pain or discomfort	☐
I have severe pain or discomfort	☐
I have extreme pain or discomfort	☐

ANXIETY / DEPRESSION

I am not anxious or depressed	☐
I am slightly anxious or depressed	☐
I am moderately anxious or depressed	☐
I am severely anxious or depressed	☐
I am extremely anxious or depressed	☐

- We would like to know how good or bad your health is **TODAY**.
- This scale is numbered from **0** to **100**.
- **100** means the <u>best</u> health you can imagine.
  0 means the <u>worst</u> health you can imagine.
- Mark an **X** on the scale to indicate how your health is **TODAY**.
- Now, please write the number you marked on the scale in the box below.
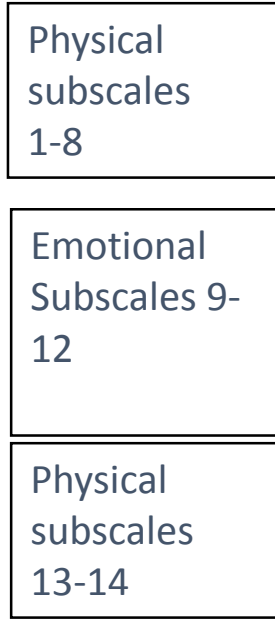
YOUR HEALTH TODAY = ☐

The best health you can imagine

100
95
90
85
80
75
70
65
60
55
50
45
40
35
30
25
20
15
10
5
0
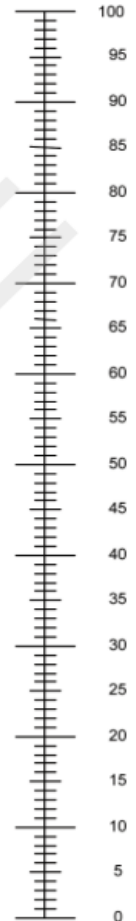
The worst health you can imagine

HeartQoL – Disease Specific Measure of HRQoL

- Each answer has a numerical value

- Range: 0 (low)-3 (high)

Physical subscales 1-8

Emotional Subscales 9-12

Physical subscales 13-14

HeartQoL

Thank you for addressing these questions that will give us an understanding of how your heart problem has affected you.

We would like to know how your heart problem has bothered you and how you have been feeling **DURING THE LAST 4 WEEKS**.

Please circle one number

First, in the last 4 weeks, have you been bothered by having to:	No	A little	Some	A lot
1. Walk indoors on level ground?	3	2	1	0
2. Garden, vacuum, or carry groceries?	3	2	1	0
3. Climb a hill or a flight of stairs without stopping?	3	2	1	0
4. Walk more than 100 yards at a brisk pace?	3	2	1	0
5. Lift or move heavy objects?	3	2	1	0

Now, in the last 4 weeks, have you been bothered by:	No	A little	Some	A lot
6. Feeling short of breath?	3	2	1	0
7. Being physically restricted?	3	2	1	0
8. Feeling tired, fatigued, low on energy?	3	2	1	0
9. Not feeling relaxed and free of tension?	3	2	1	0
10. Feeling depressed?	3	2	1	0
11. Being frustrated?	3	2	1	0
12. Being worried?	3	2	1	0
13. Being limited in doing sports or exercise?	3	2	1	0
14. Working around the house or yard?	3	2	1	0

The Hospital Anxiety and Depression Scale – dimension specific HRQoL measure

- One questionnaire, comprising of 14 questions – 7 on depression and 7 on anxiety.

Hospital Anxiety and Depression Scale (HADS)

Tick the box beside the reply that is closest to how you have been feeling in the past week.
Don't take too long over you replies: your immediate is best.

D	A		D	A	
		I feel tense or 'wound up':			**I feel as if I am slowed down:**
	3	Most of the time	3		Nearly all the time
	2	A lot of the time	2		Very often
	1	From time to time, occasionally	1		Sometimes
	0	Not at all	0		Not at all
		I still enjoy the things I used to enjoy:			**I get a sort of frightened feeling like 'butterflies' in the stomach:**
0		Definitely as much		0	Not at all
1		Not quite so much		1	Occasionally
2		Only a little		2	Quite Often
3		Hardly at all		3	Very Often
		I get a sort of frightened feeling as if something awful is about to happen:			**I have lost interest in my appearance:**
	3	Very definitely and quite badly	3		Definitely
	2	Yes, but not too badly	2		I don't take as much care as I should
	1	A little, but it doesn't worry me	1		I may not take quite as much care
	0	Not at all	0		I take just as much care as ever
		I can laugh and see the funny side of things:			**I feel restless as I have to be on the move:**
0		As much as I always could		3	Very much indeed
1		Not quite so much now		2	Quite a lot
2		Definitely not so much now		1	Not very much
3		Not at all		0	Not at all
		Worrying thoughts go through my mind:			**I look forward with enjoyment to things:**
	3	A great deal of the time	0		As much as I ever did
	2	A lot of the time	1		Rather less than I used to
	1	From time to time, but not too often	2		Definitely less than I used to
	0	Only occasionally	3		Hardly at all
		I feel cheerful:			**I get sudden feelings of panic:**
3		Not at all		3	Very often indeed
2		Not often		2	Quite often
1		Sometimes		1	Not very often
0		Most of the time		0	Not at all
		I can sit at ease and feel relaxed:			**I can enjoy a good book or radio or TV program:**
	0	Definitely	0		Often
	1	Usually	1		Sometimes
	2	Not Often	2		Not often
	3	Not at all	3		Very seldom

Please check you have answered all the questions

Table 1. Characteristics of the patients included in the analyses

	Men N=2543 **(74.6%)**	Women N=865 **(25.4%)**	All N=3408
Country*			
High income			
Ireland	244	49	293
Lithuania	176	74	250
Netherlands	24	8	32
Poland	288	115	403
Portugal	40	7	47
Sweden	186	55	241
Turkey	161	43	204
United Kingdom	804	251	1055
Middle income			
Egypt	138	68	206
Kazakhstan	131	68	199
Russian Federation	289	107	396
Ukraine	62	20	82
Age at interview			
< 50 yrs	9.7% (246/2543)	6.5% (56/865)	8.9% (302/3408)
50-59 yrs	25.8% (655/2543)	17.3% (150/865)	23.6% (805/3408)
60-69 yrs	37.4% (951/2543)	39.3% (340/865)	37.9% (1291/3408)
≥ 70 yrs	27.2% (691/2543)	36.9% (319/865)	29.6% (1010/3408)
Mean (SD)	63.2 (9.6)	65.7 (9.1)	63.9 (9.6)
Educational level**			
Low	13.2% (334/2521)	13.8% (118/858)	13.4% (452/3379)
Intermediate	54.0% (1362/2521)	55.9% (480/858)	54.5% (1842/3379)
High	32.7% (825/2521)	30.3% (260/858)	32.1% (1085/3379)

*Grouping of countries by income level according to World Bank (2018-2019): High-income countries: Ireland, Lithuania, Netherlands, Poland, Portugal, Sweden, United Kingdom; Upper Middle-income countries: Kazakhstan, Russian Federation, Turkey; Lower Middle-income countries: Egypt, Ukraine. Here, upper middle- and lower middle-income countries were pooled.
**Low educational level = Primary school education or less; High educational level = University or Postgraduate degree

Table 4. Spearman correlation coefficients, partialized for age and educational level

	HADS Questionnaire		HeartQoL Questionnaire			EQ-5D
	Anxiety	Depression	Physical	Emotional	Global	VAS
MEN						
B-IPQ Overall score	+0.42	+0.48	-0.55	-0.47	-0.55	-0.54
Cognitive illness representations	+0.32	+0.43	-0.53	-0.44	-0.52	-0.54
Emotional representations	+0.43	+0.41	-0.44	-0.41	-0.45	-0.39
Illness comprehensibility	+0.13	+0.17	-0.09	-0.10	-0.09	-0.15
HLQ-9 Overall score	-0.22	-0.33	+0.21	+0.14	+0.20	+0.19
WOMEN						
B-IPQ Overall score	+0.42	+0.48	-0.49	-0.45	-0.50	-0.56
Cognitive illness representations	+0.36	+0.46	-0.48	-0.43	-0.49	-0.56
Emotional representations	+0.39	+0.40	-0.39	-0.37	-0.40	-0.40
Illness comprehensibility	+0.15	+0.14	-0.07	-0.09	-0.08	-0.16
HLQ-9 Overall score	-0.27	-0.41	+0.26	+0.18	+0.25	+0.23

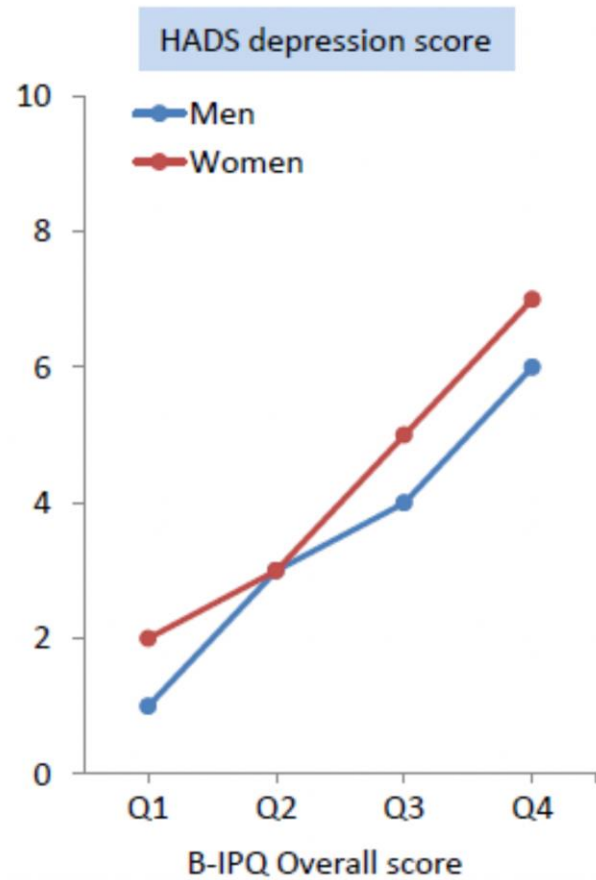All correlation coefficients are statistically significant

Figure 1a. Median HRQoL scores according to quartiles of the B-IPQ overall score distribution
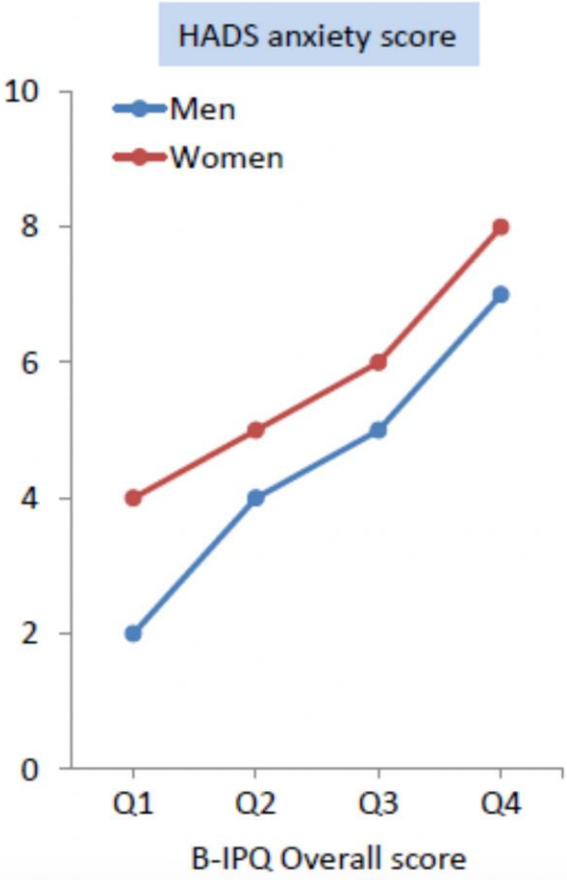
Figure 1a. Median HRQoL scores according to quartiles of the B-IPQ overall score distribution
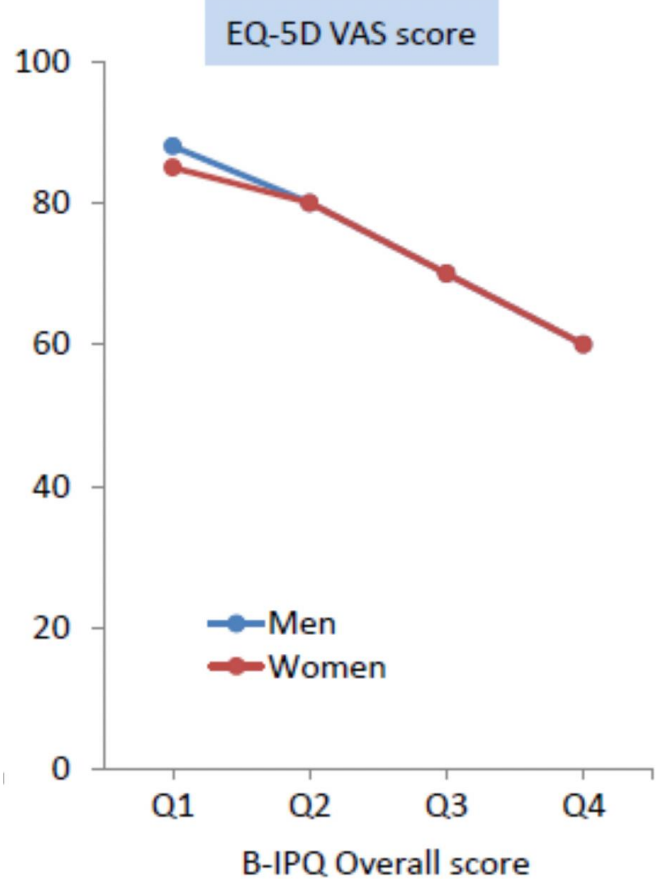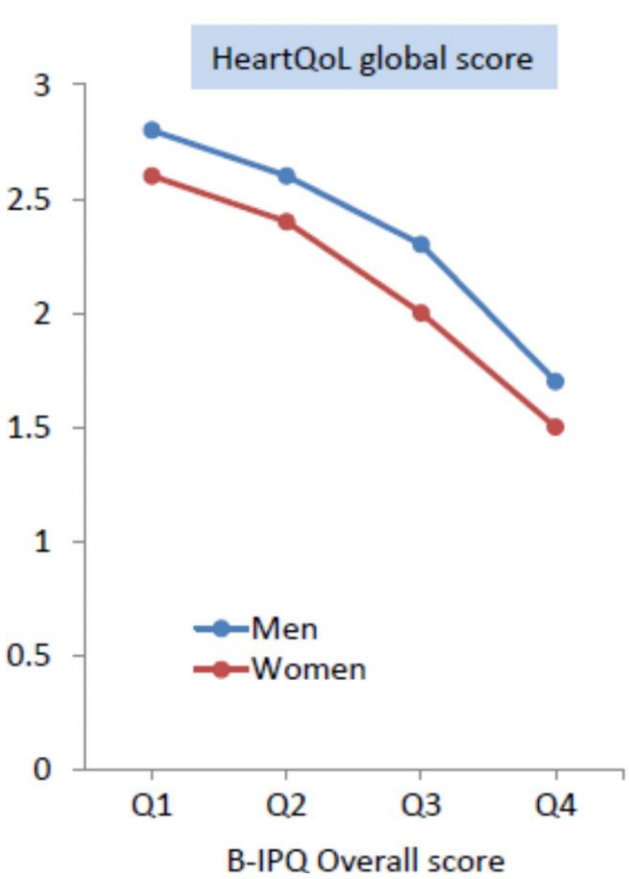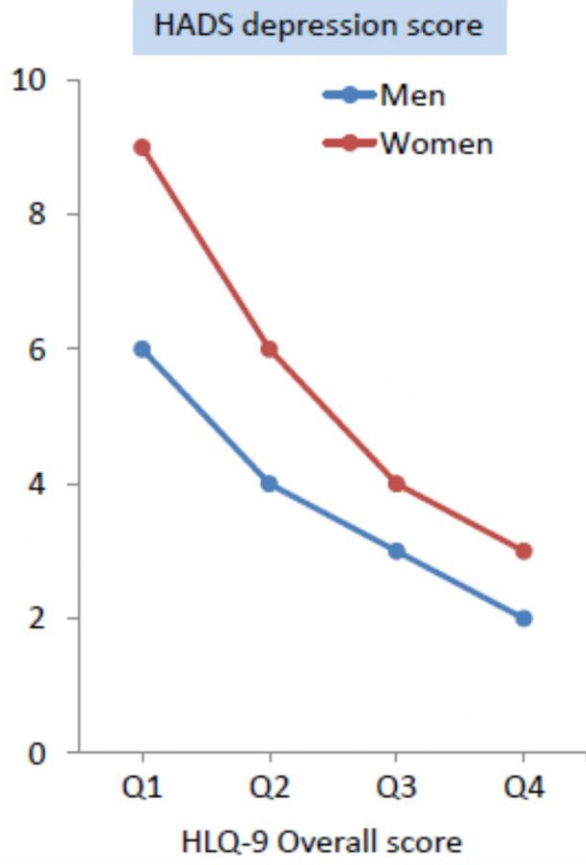
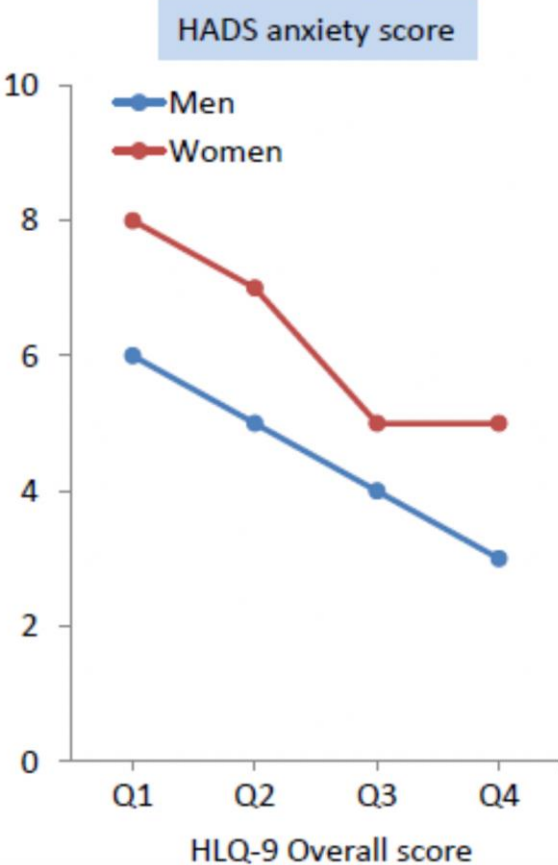# Figure 1b. Median HRQoL scores according to quartiles of the HLQ-9 score distribution

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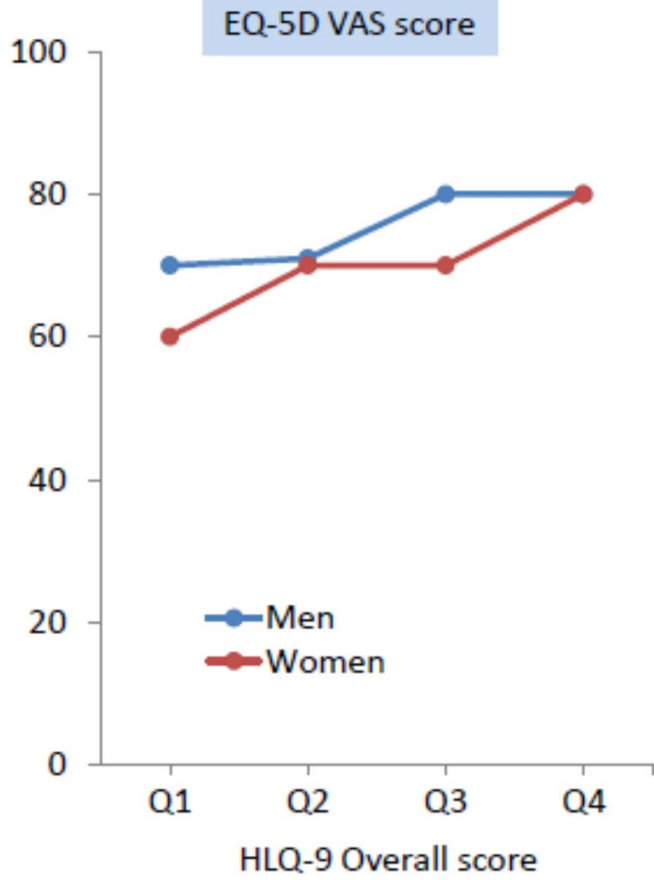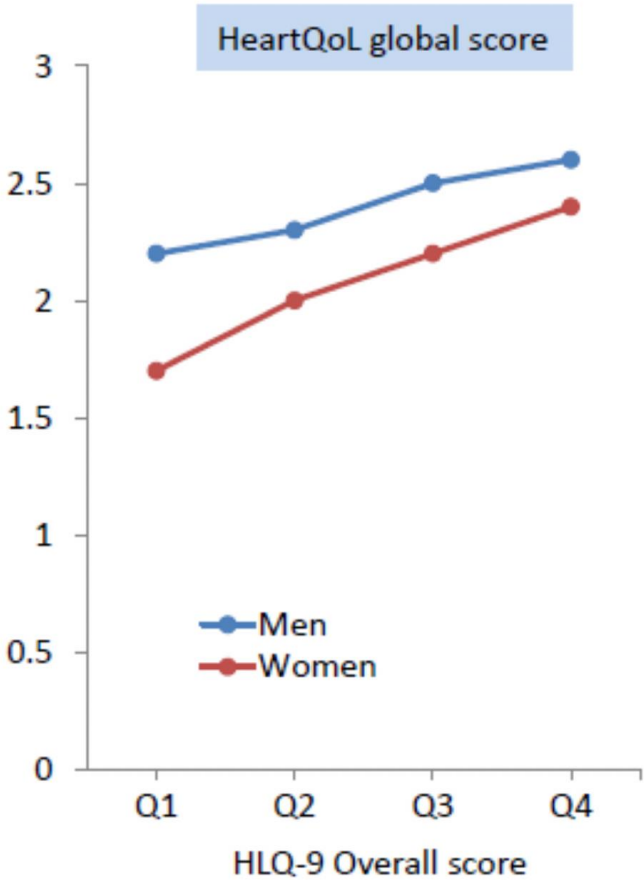
Table 5. Independent impact of illness perception and health literacy on HRQoL scores

OUTCOME	Explanatory variable					
	B-IPQ Overall score			**HLQ-9 Overall score**		
	β (SE)*	T-statistic, P-value*		β (SE)*	T-statistic, P-value*	
MEN						
HADS Questionnaire						
Anxiety scale	+1.1378 (0.0450)	+25.31	P<0.0001	-1.0748 (0.1245)	-8.64	P<0.0001
Depression scale	+1.0580 (0.0429)	+24.66	P<0.0001	-1.2969 (0.1167)	-11.11	P<0.0001
HeartQoL Questionnaire						
Global scale	-0.2349 (0.0079)	-29.56	P<0.0001	+0.1517 (0.0231)	+6.56	P<0.0001
EQ-5D Questionnaire						
VAS scale	-5.5283 (0.2387)	-23.16	P<0.0001	+3.2994 (0.7041)	+4.69	P<0.0001
WOMEN						
HADS Questionnaire						
Anxiety scale	+1.2077 (0.0812)	+14.87	P<0.0001	-1.4867 (0.2362)	-6.29	P<0.0001
Depression scale	+1.0280 (0.0702)	+14.65	P<0.0001	-1.6470 (0.2017)	-8.16	P<0.0001
HeartQoL Questionnaire						
Global scale	-0.2402 (0.0148)	-16.22	P<0.0001	+0.2700 (0.0430)	+6.28	P<0.0001
EQ-5D Questionnaire						
VAS scale	-5.6581 (0.4061)	-13.93	P<0.0001	+6.7505 (1.2831)	+5.26	P<0.0001

*according to mixed model analyses taking clustering of patients within countries into account with additional adjustment for age and educational level

Conclusions and Implications

- Healthy illness perceptions and good health literacy improves health related quality of life in coronary patients

- Health professionals should aim to assess and improve Health Literacy and Illness Perceptions in order to favourably impact HRQoL

- Patients may then be more able to make and sustain healthy changes and adhere to their medications