Health-Related Quality of Life Assessment as an Indicator of Quality of Care

Ron D. Hays, Ph.D.
HS249F

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Contact Information

Ron D. Hays, Ph.D.

UCLA Department of Medicine/Division of General Internal Medicine & Health Services Research
911 Broxton Avenue, Room 110
Los Angeles, Ca 90095-1736
310-393-0411, ext. 7581

hays@rand.org or drhays@ucla.edu

http://gim.med.ucla.edu/FacultyPages/Hays/

How do you know how the patient is doing?

Temperature
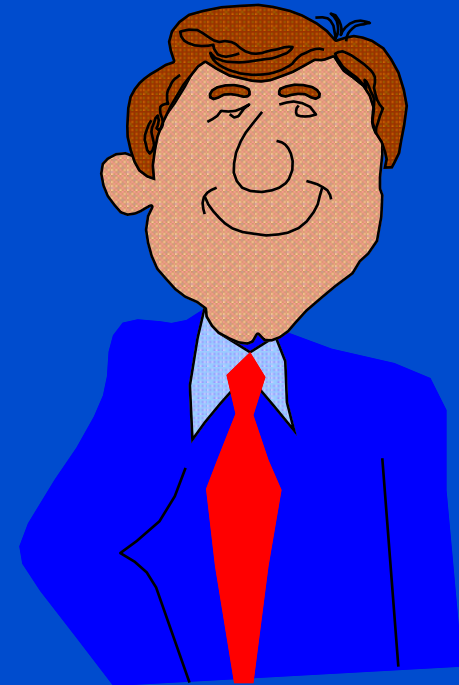
Respiration

Pulse

Weight

Blood pressure

Also, by talking to her or him about ...

Symptoms

What they are able to do

And how they feel about their life

Have you had any of the following symptoms in the last 4 weeks?

Fever?

Loss of appetite?

Unintentional weight loss?

Dizziness?

Trouble sleeping?

Headache?

Trouble swallowing?

First RCT of Treatment for Newly Diagnosed Prostate Cancer (NEJM, 2002)

Radical prostatectomy vs. watchful waiting

   - Trend to reduction in all-cause mortality

   (18% versus 15%; RR 0.83, 0.57 to 1.2, p = 0.31)

Impact on Symptoms

Urinary obstruction (weak stream)

- 44% waiting, <u>28% prostatectomy</u>

Sexual dysfunction

- <u>80% prostatectomy</u> vs. 45% waiting

Urinary leakage

- <u>49% prostatectomy</u> vs. 21% waiting

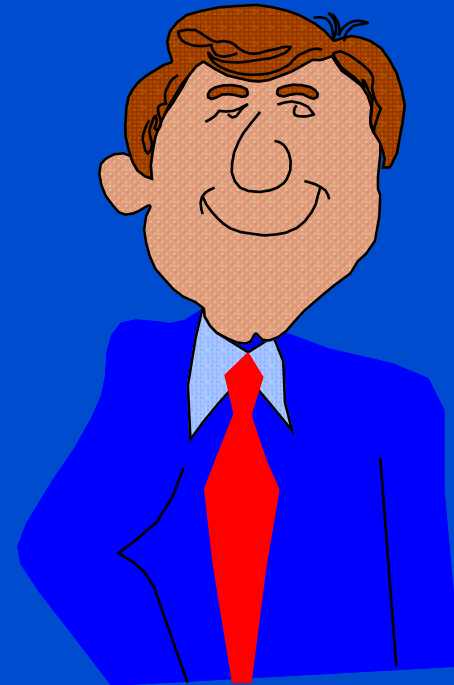# "Outcomes"--How is the Patient Doing?

Physiological

- Vital signs (pulse, BP, temperature, respiration)

- Hematocrit

- Albumin

Physician observation

- Physical performance

Self-report indicators

- Functioning and well-being
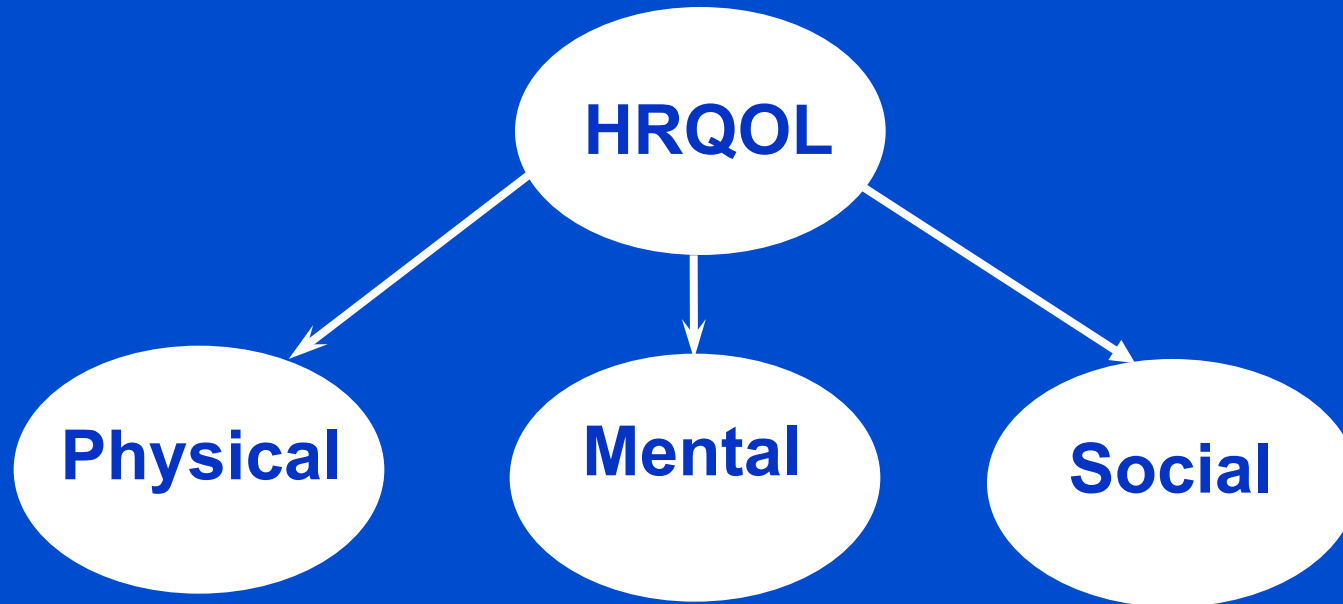
Health-Related Quality of Life (HRQOL) is:

What the person can DO (functioning)

- **Self-care**

- **Role**

- **Social**

How the person FEELs (well-being)

- **Emotional well-being**

- **Pain**

- **Energy**

HRQOL is Multi-Dimensional

Does your health now limit you in walking more than a mile?

(If so, how much?)

Yes, limited a lot

Yes, limited a little
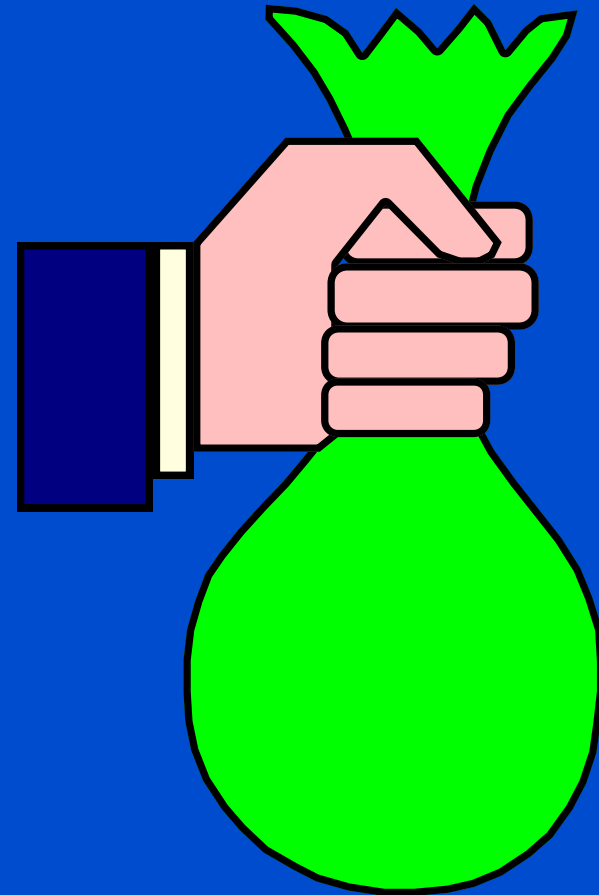
No, not limited at all
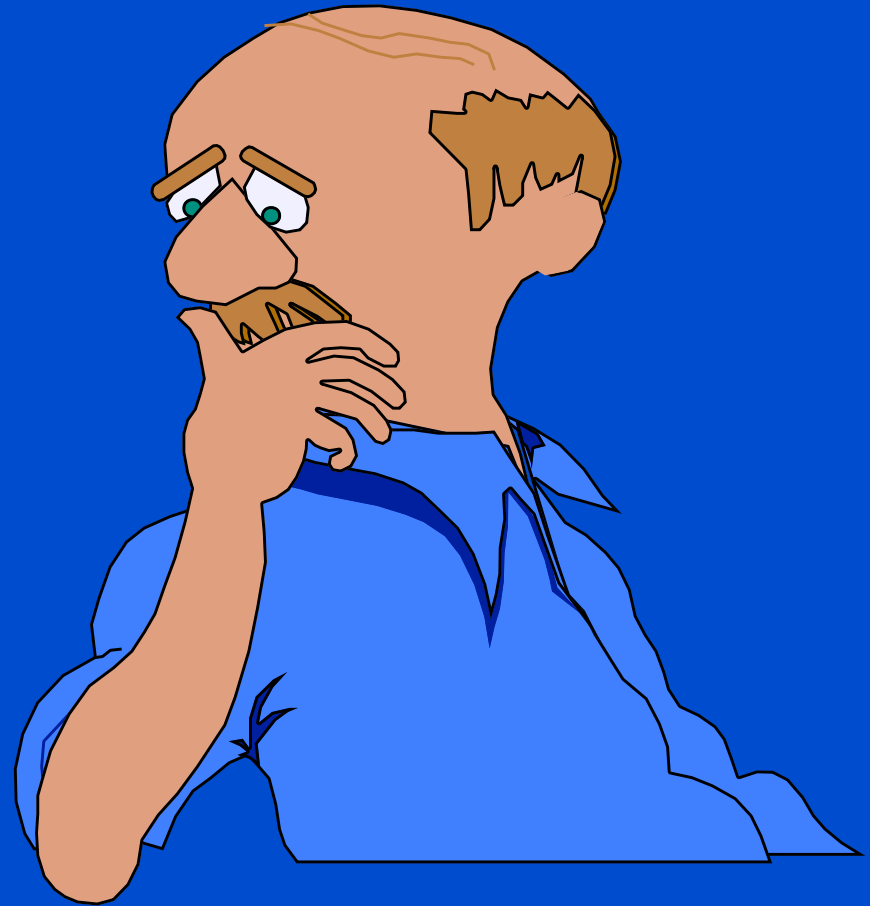
HRQOL is Not

- Quality of environment

- Type of housing

- Level of income

- Social Support

Are self-reports about HRQOL reliable?

Reliability—extent to which you get the same score on repeated assessments

• Do not place the blood pressure cuff over clothing or roll a tight fitting sleeve above the biceps when determining blood pressure as either can cause elevated readings.

• Make sure the patient has had an opportunity to rest before measuring their BP.*

• If the reading is surprisingly high or low, repeat the measurement towards the end of your exam.

•Try the following experiment to assess the impact that this can have. Take a patient's BP after they've rested. Then repeat after they've walked briskly in place for several minutes. Patients who are not too physically active (i.e., relatively deconditioned) will develop an elevation in both their SBP and DBP. Also, see what effect raising or lowering the arm, and thus the position of the brachial artery relative to the heart, has on BP. If you have a chance, obtain measurements on the same patient with both a large and small cuff. These exercises should give you an appreciation for the magnitude of error that can be introduced when improper technique is utilized

Range of reliability estimates

0.80-0.90 for blood pressure

0.70-0.90 for multi-item self-report scales

Are self-reports about HRQOL valid?

Validity—score represents what you are trying to measure rather than something else

• Instruct your patients to avoid coffee, smoking or any other unprescribed drug with sympathomimetic activity on the day of the measurement.

• If possible, measure the blood pressure of a patient who has an indwelling arterial catheter (these patients can be found in the ICU with the help of a preceptor). Arterial transducers are an extremely accurate tool for assessing blood pressure and therefore provide a method for checking your non-invasive technique.

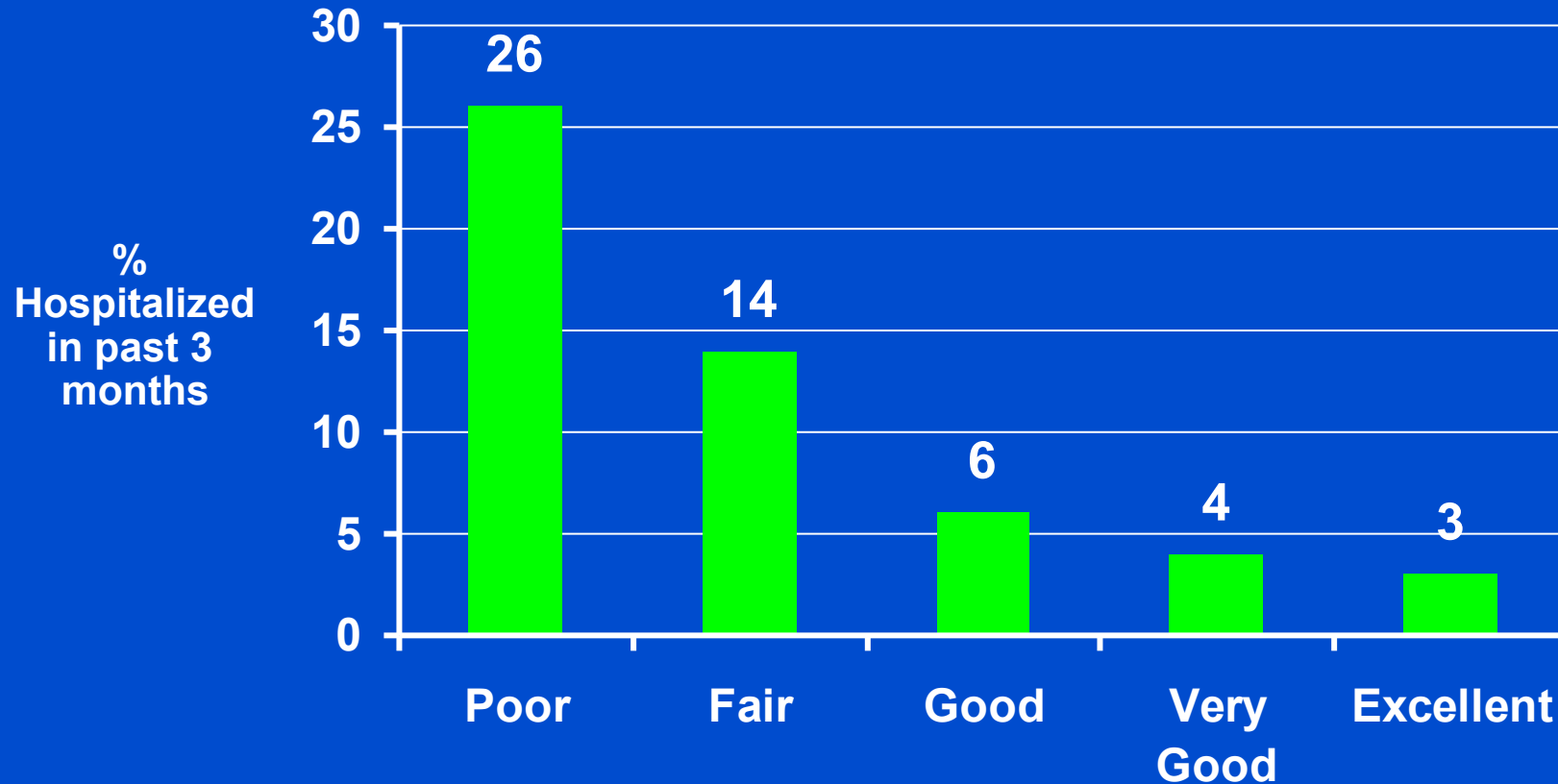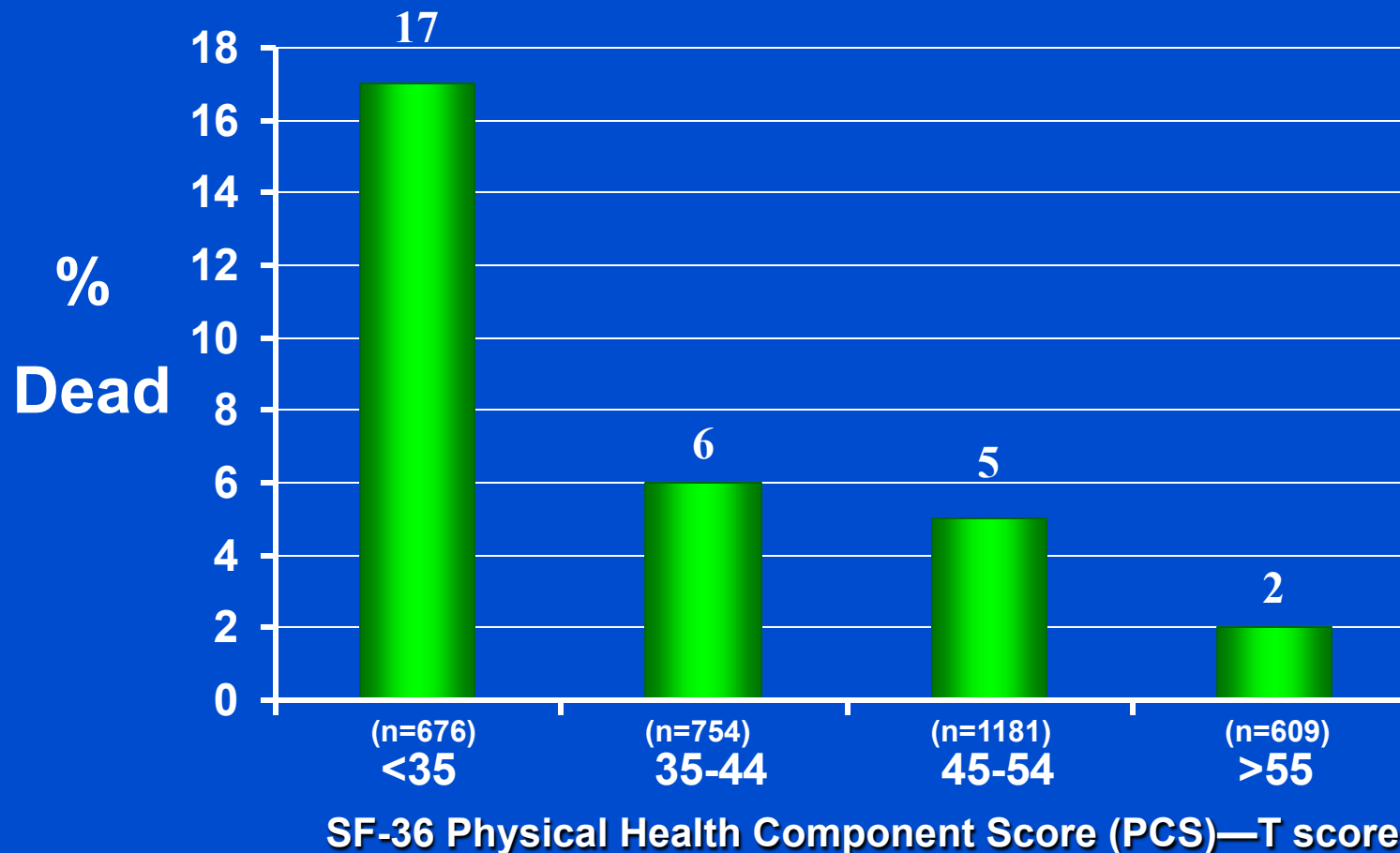# In general, how would you rate your health?

Excellent

Very Good

Good

Fair

Poor

Hospitalized Patients Report Worse General Health (n = 20,158)

% Hospitalized in past 3 months

|	Poor	Fair	Good	Very Good	Excellent
Value	26	14	6	4	3

Y-axis: 0, 5, 10, 15, 20, 25, 30

Kravitz, R. et al. (1992). Differences in the mix of patients among medical specialties and systems of care: Results from the Medical Outcomes Study. JAMA, 267, 1617-1623.

Self-Reports of Physical Health Predictive of Five-Year Mortality Rates

% Dead

17 (n=676) <35
6 (n=754) 35-44
5 (n=1181) 45-54
2 (n=609) >55

SF-36 Physical Health Component Score (PCS)—T score

Ware et al. (1994). <u>SF-36 Physical and Mental Health Summary Scales: A User's Manual</u>.

Types of HRQOL Measures
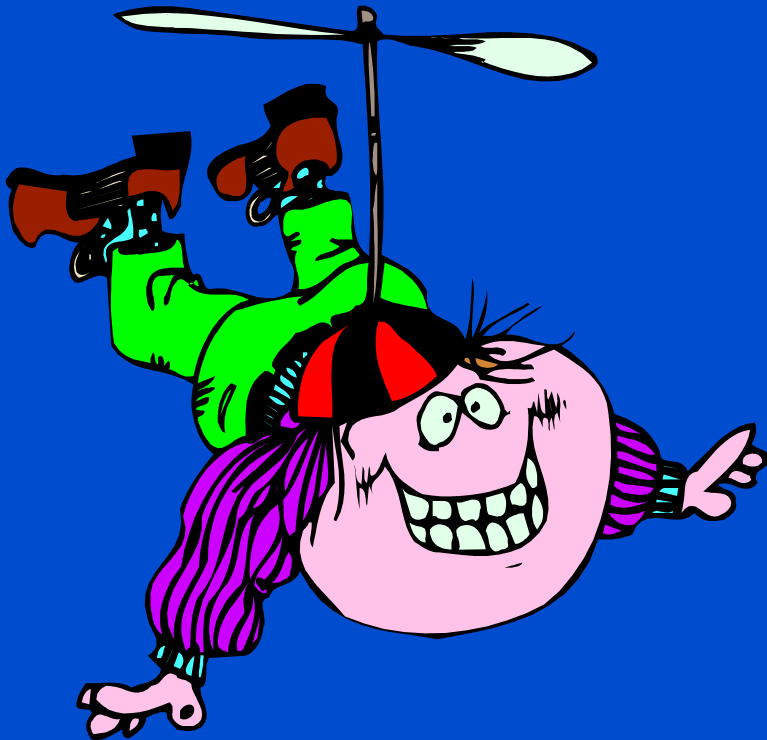
Generic Profile

Targeted Profile

Preference Measure

SF-36 Generic Profile Measure

- **Physical functioning (10 items)**

- **Role limitations/physical (4 items)**

- **Role limitations/emotional (3 items)**

- **Social functioning (2 items)**

- **Emotional well-being (5 items)**

- **Energy/fatigue (4 items)**

- **Pain (2 items)**

- **General health perceptions (5 items)**

Persons with mobility impairments object to SF-36 physical functioning items:

Does your health now limit you in (if so, how much) …

climbing several flights of stairs

climbing one flight of stairs

walking more than a mile

walking several hundred yards

walking one hundred yards

Andresen & Meyers (2000, Archives of Physical Medicine and Rehabilitation)
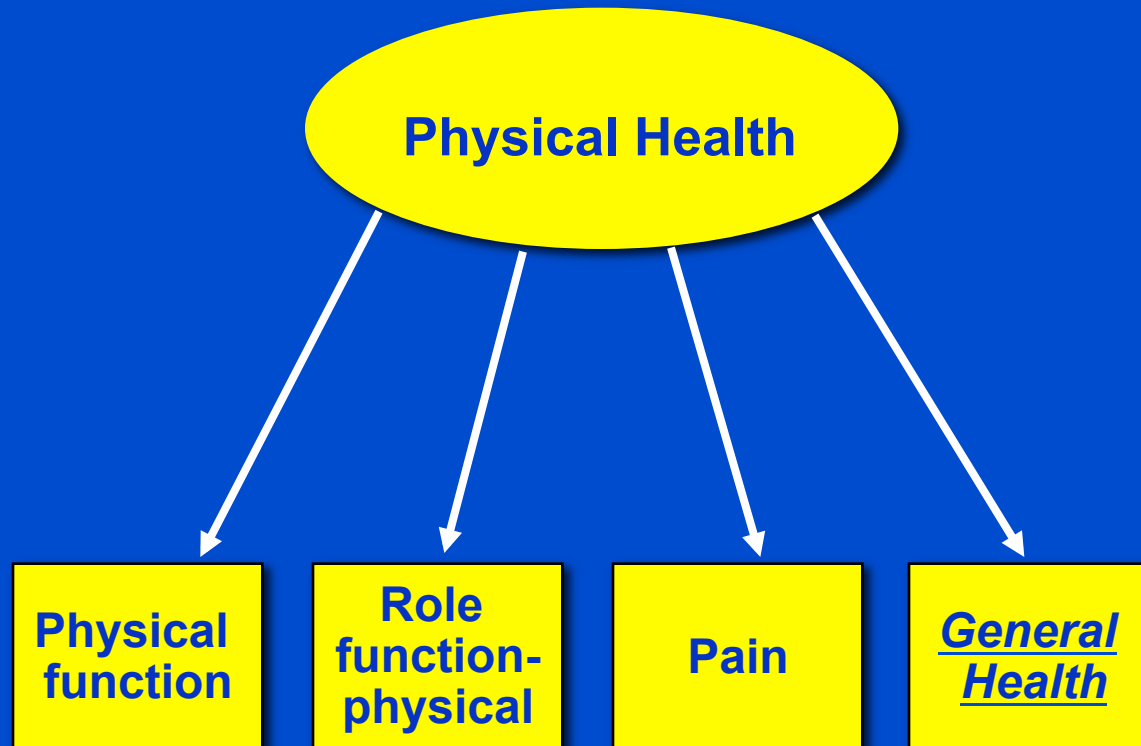
Scoring Generic HRQOL Scales

Average or sum all items in the same scale.
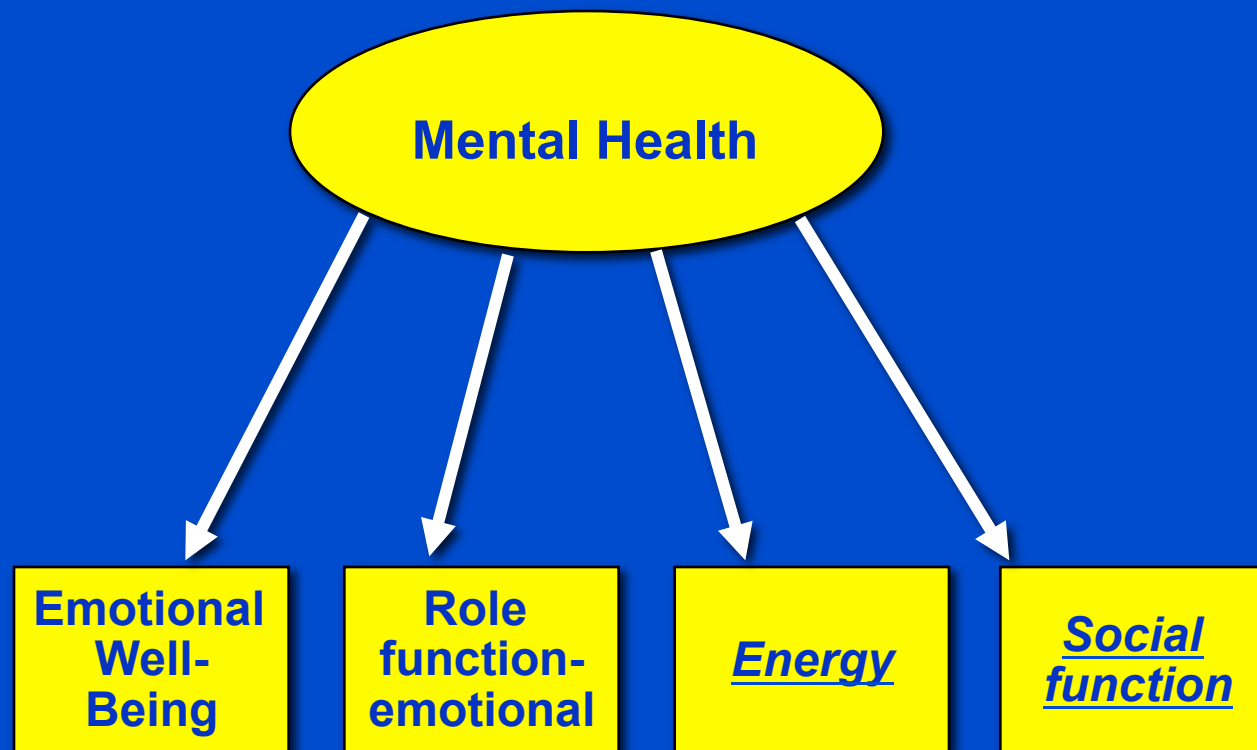
Transform average or sum to

- 0 (worse) to 100 (best) possible range

- z-score (mean = 0, SD = 1)

- T-score (mean = 50, SD = 10)

Physical Health

Physical Health
- Physical function
- Role function-physical
- Pain
- *General Health*

Mental Health

Mental Health

| Emotional Well-Being | Role function-emotional | *Energy* | *Social function* |

Example Uses of Generic HRQOL Measures
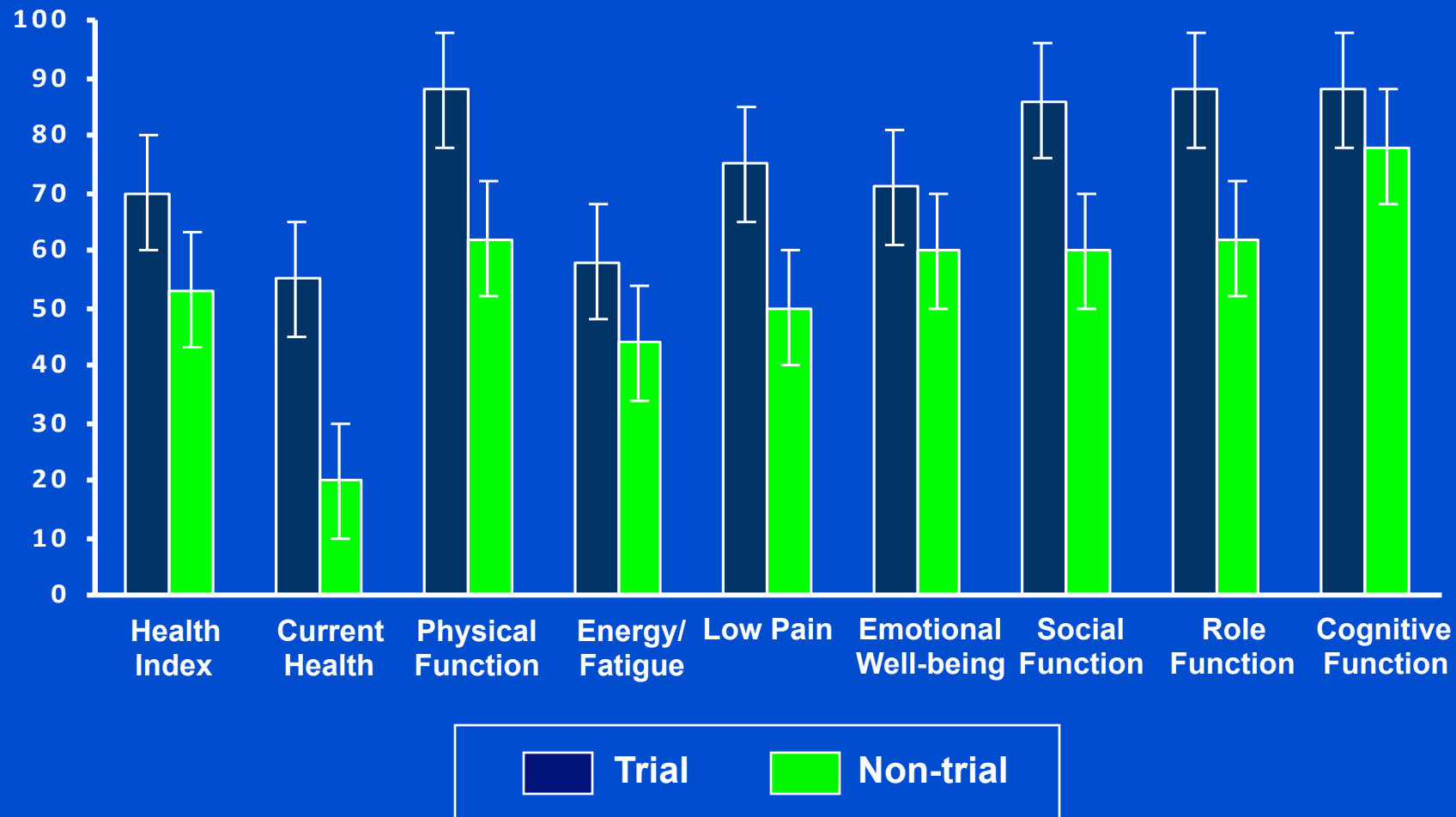
Cross-Sectional

- **Comparison of Same Disease in Different Samples**

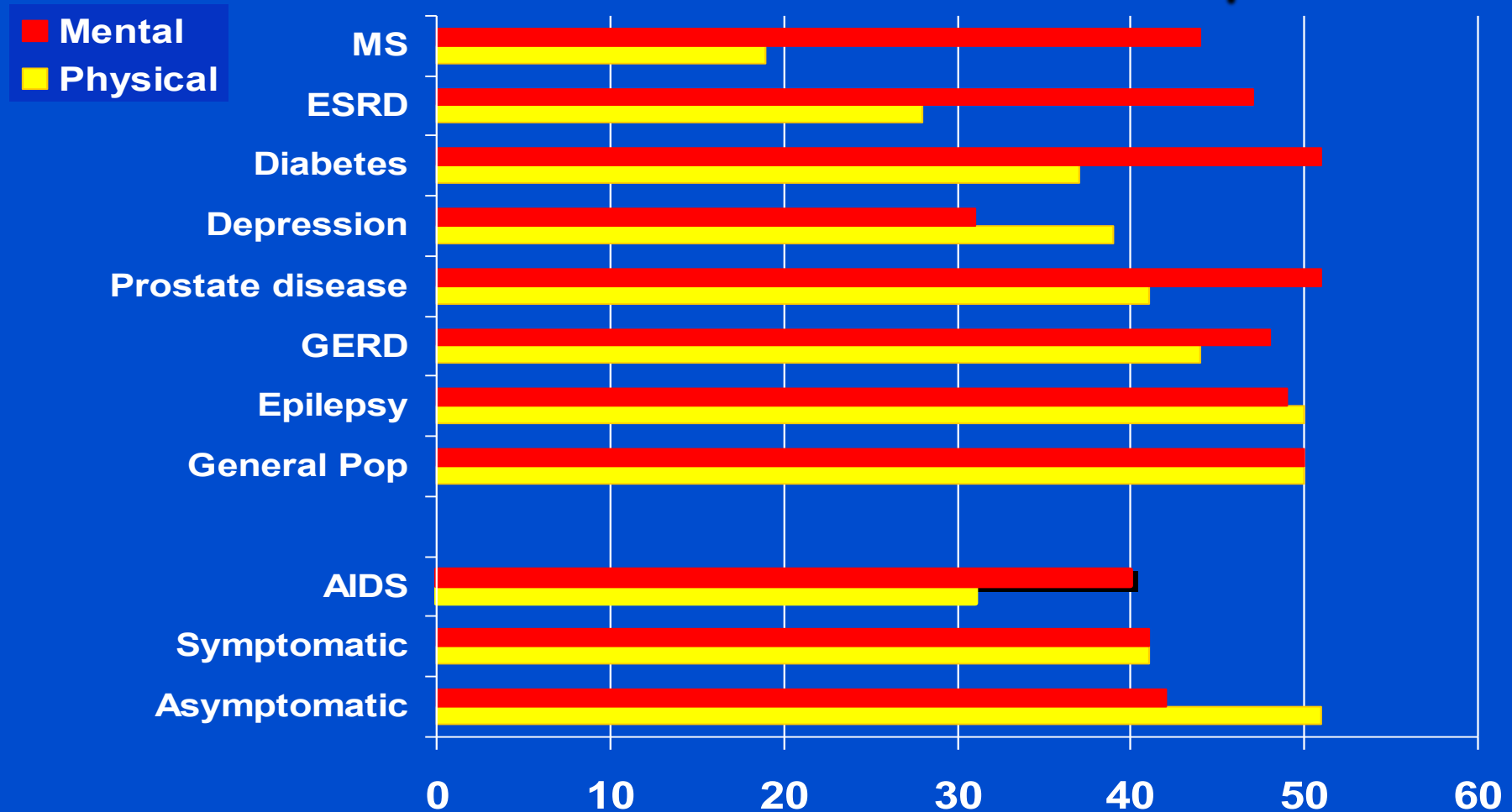- **Profiles of Different Diseases**

Longitudinal

- **Profiles of Different Disease**

- **Identifying Antecedents/Causes of HRQOL**

HRQOL of Patients in ACTG versus Public Hospital Samples
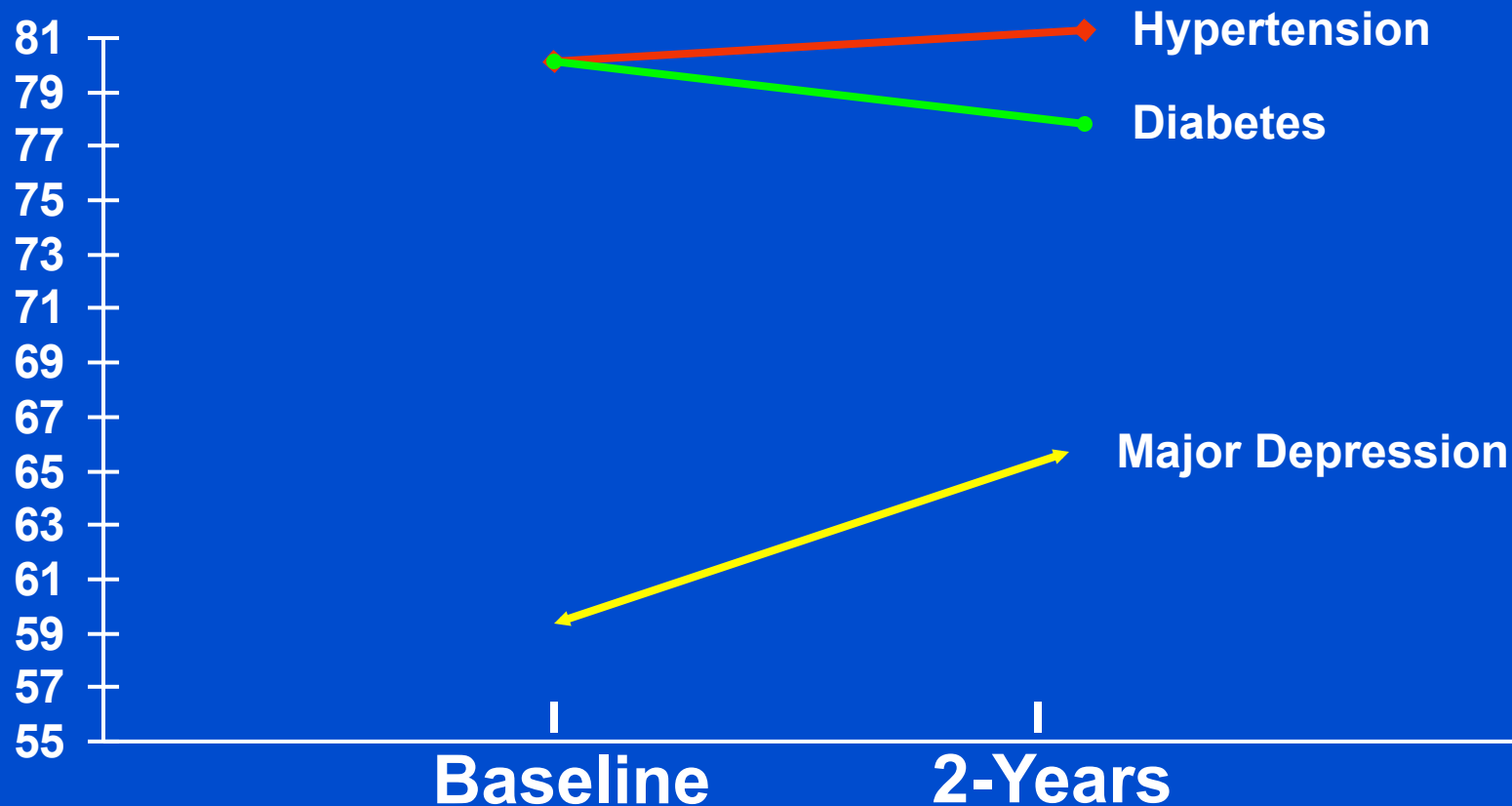
Adjusted Scale Scores (Cunningham et al., 1995)

Legend: Trial / Non-trial

Categories: Health Index, Current Health, Physical Function, Energy/Fatigue, Low Pain, Emotional Well-being, Social Function, Role Function, Cognitive Function

HRQOL for HIV Compared to other Chronic Illnesses and General Population

Legend:
- Mental (red)
- Physical (yellow)

Categories (top to bottom): MS, ESRD, Diabetes, Depression, Prostate disease, GERD, Epilepsy, General Pop, AIDS, Symptomatic, Asymptomatic

X-axis: 0, 10, 20, 30, 40, 50, 60

Hays et al. (2000), American Journal of Medicine

Course of Emotional Well-being Over 2-years for Patients in the MOS General Medical Sector

Hypertension

Diabetes

Major Depression

Baseline

2-Years

81
79
77
75
73
71
69
67
65
63
61
59
57
55

Hays, R.D., Wells, K.B., Sherbourne, C.D., Rogers, W., & Spritzer, K. (1995). Functioning and well-being outcomes of patients with depression compared to chronic medical illnesses. Archives of General Psychiatry, 52, 11-19.

Physical Functioning in Relation to Time Spent Exercising 2-years Before
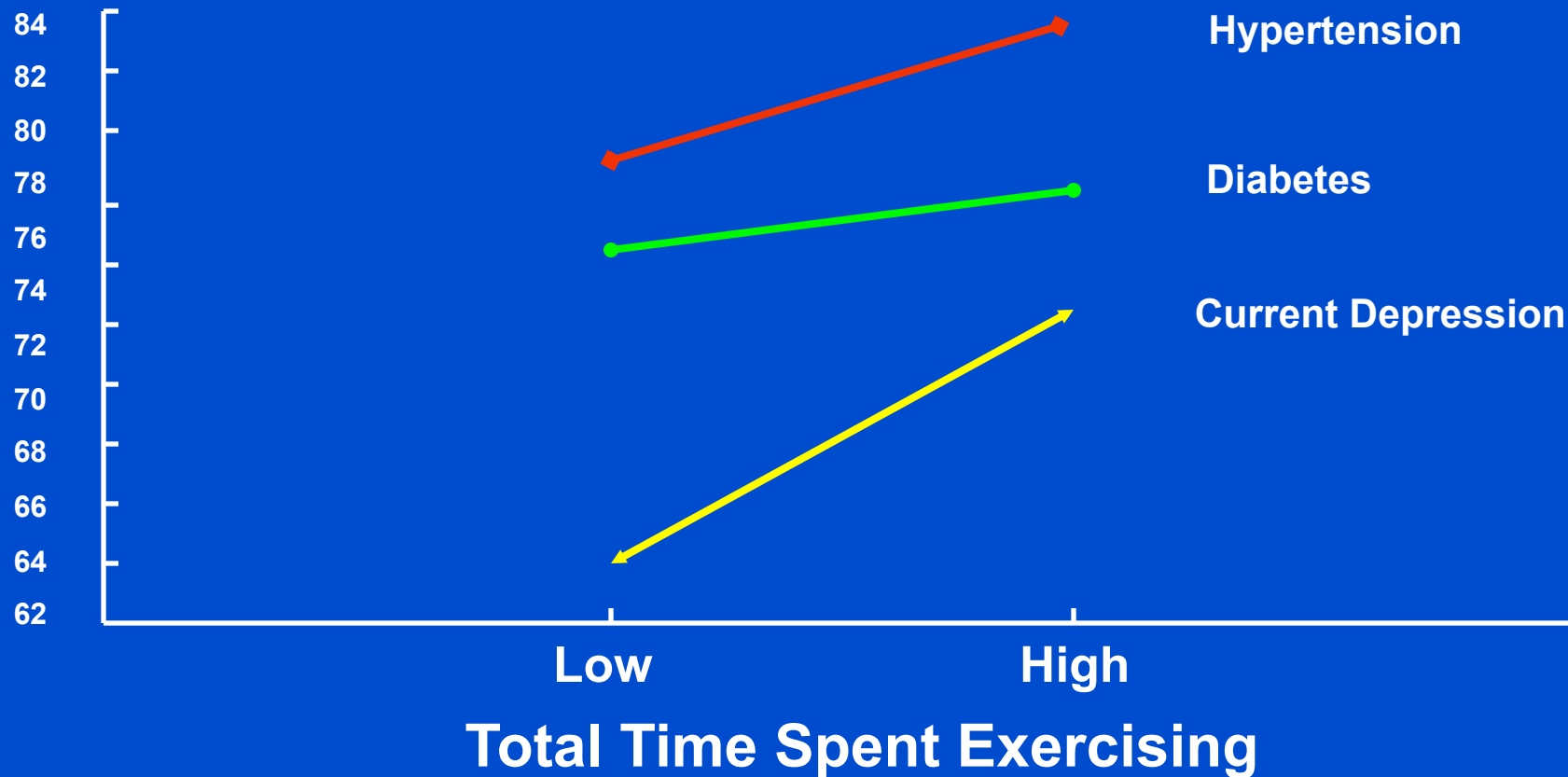
Stewart, A.L., Hays, R.D., Wells, K.B., Rogers, W.H., Spritzer, K.L., & Greenfield, S. (1994). Long-term functioning and well-being outcomes associated with physical activity and exercise in patients with chronic conditions in the Medical Outcomes Study. Journal of Clinical Epidemiology, 47, 719-730.

Targeted HRQOL Measures

- Designed to be relevant to particular group.

- Sensitive to small, clinically-important changes.

- Important for respondent cooperation.

- More familiar and actionable.

Kidney-Disease Targeted Items

During the last 30 days, to what extent were you bothered by each of the following?

- – **Cramps during dialysis**
- – **Washed out or drained**

Not at all bothered

Somewhat bothered

Moderately bothered

Very much bothered

Extremely bothered

IBS-Targeted Item

During the last 4 weeks, how often were you angry about your irritable bowel syndrome?

None of the time

A little of the time

Some of the time

Most of the time

All of the time

HRQOL in Men Treated for Localized Prostate Cancer
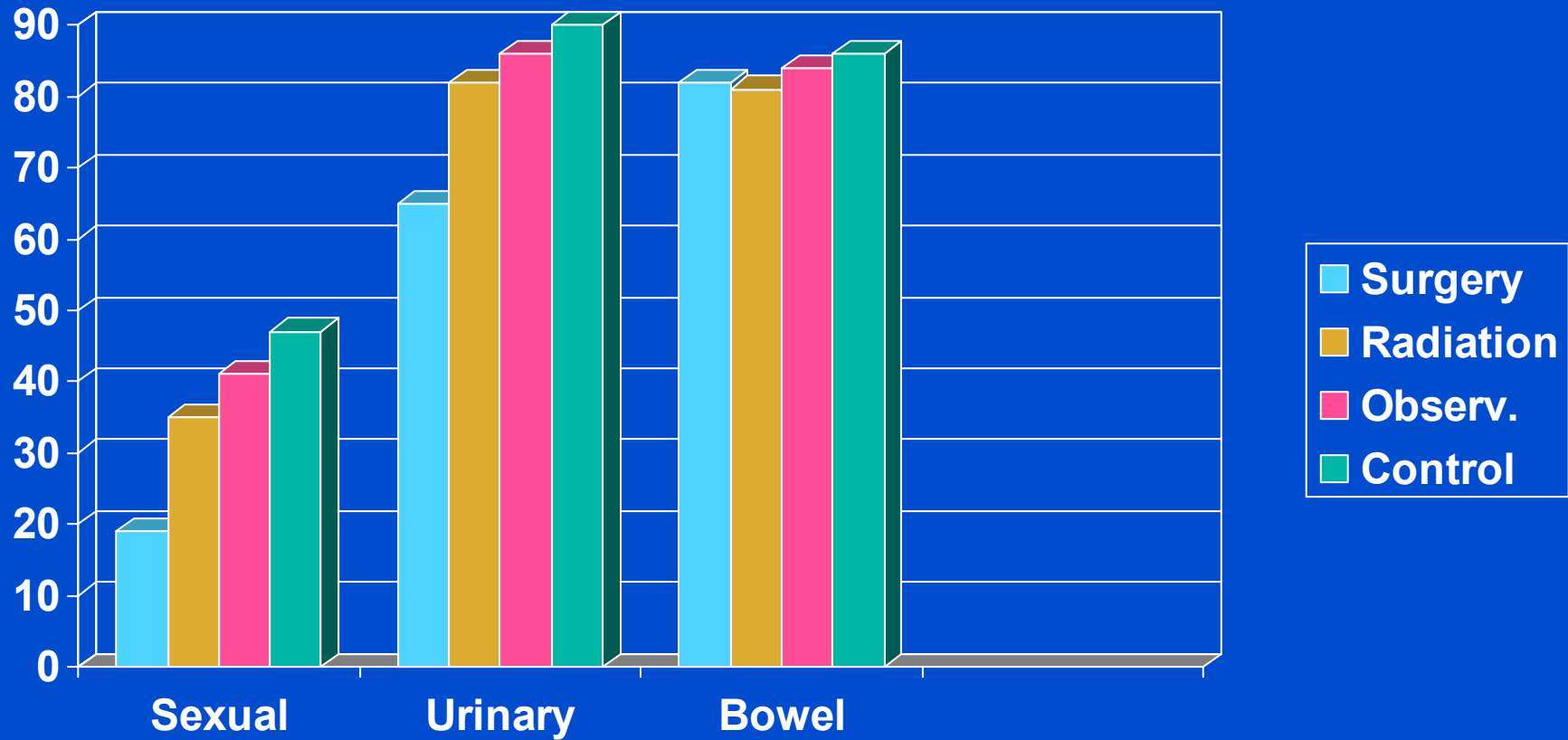
Cross-sectional study of managed care pop.

214 men with prostate cancer

- **98 radical prostatectomy**

- **56 primary pelvic irradiation**

- **60 observation alone**

273 age/zip matched pts. without cancer

Litwin et al. (1995, <u>JAMA</u>)

Sexual, Urinary and Bowel Function

HRQOL Measures Helpful in Ensuring Access to Cost-Effective Care

Cost ?

— — — — — — — — — — —

Effectiveness ?

HRQOL Outcomes

Summarize overall results of health care:

Cost

_____

△ HRQOL

SF-36 PCS and MCS

PCS = (PF_Z * .42402) + (RP_Z * .35119) + (BP_Z * .31754) + (GH_Z * .24954) +   (EF_Z * .02877) + (SF_Z * -.00753) +   (RE_Z * -.19206) + (EW_Z * -.22069)

MCS = (PF_Z * -.22999) + (RP_Z * -.12329) + (BP_Z * -.09731) + (GH_Z * -.01571) + (EF_Z * .23534) + (SF_Z * .26876) + (RE_Z * .43407) + (EW_Z * .48581)

T-score Transformation

$$PCS = (PCS\_z * 10) + 50$$

$$MCS = (MCS\_z * 10) + 50$$

Debate About Summary Scores

- Taft, C., Karlsson, J., & Sullivan, M. (2001). Do SF-36 component score accurately summarize subscale scores? Quality of Life Research, 10, 395-404.

- Ware, J. E., & Kosinski, M. (2001). Interpreting SF-36 summary health measures: A response. Quality of Life Research, 10, 405-413.
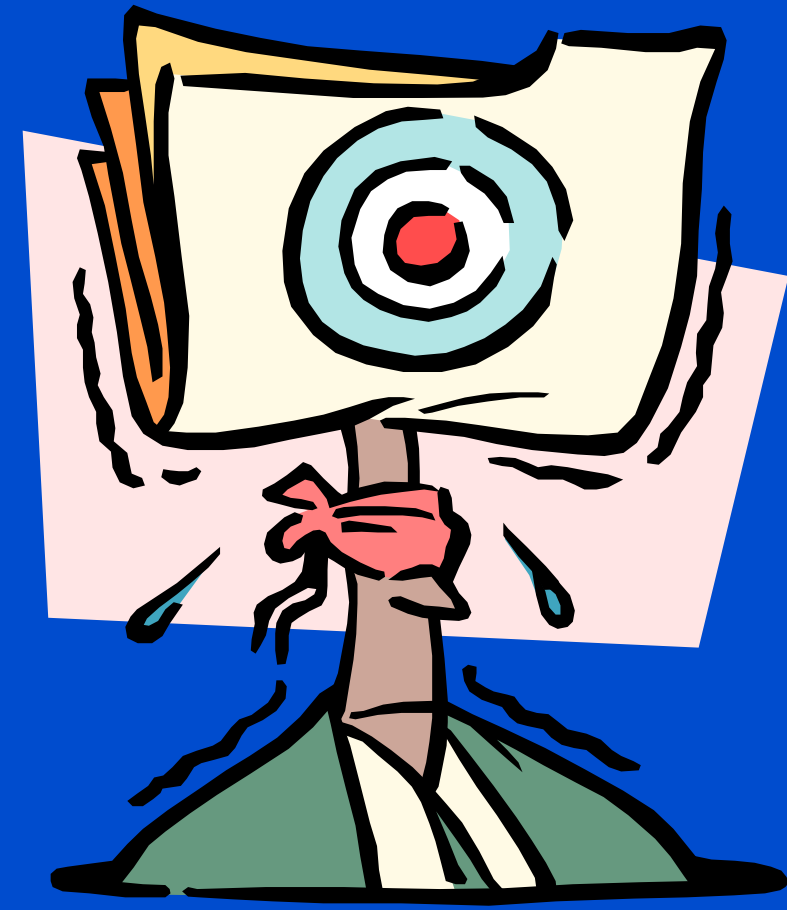
- Taft, C., Karlsson, J., & Sullivan, M. (2001). Reply to Drs Ware and Kosinski. Quality of Life Research, 10, 415-420.

# 536 Primary Care Patients Initiating Antidepressant Tx

◈ 3-month improvements in physical functioning, role—physical, pain, and general health perceptions ranging from 0.28 to 0.49 SDs.

◈ Yet SF-36 PCS did <u>not</u> improve.

◈ *Simon et al. (<u>Med Care</u>, 1998)*

Four scales improve 0.28-0.49 SD, but physical health summary score doesn't change

Physical Health

Physical function

Role function-physical

Pain
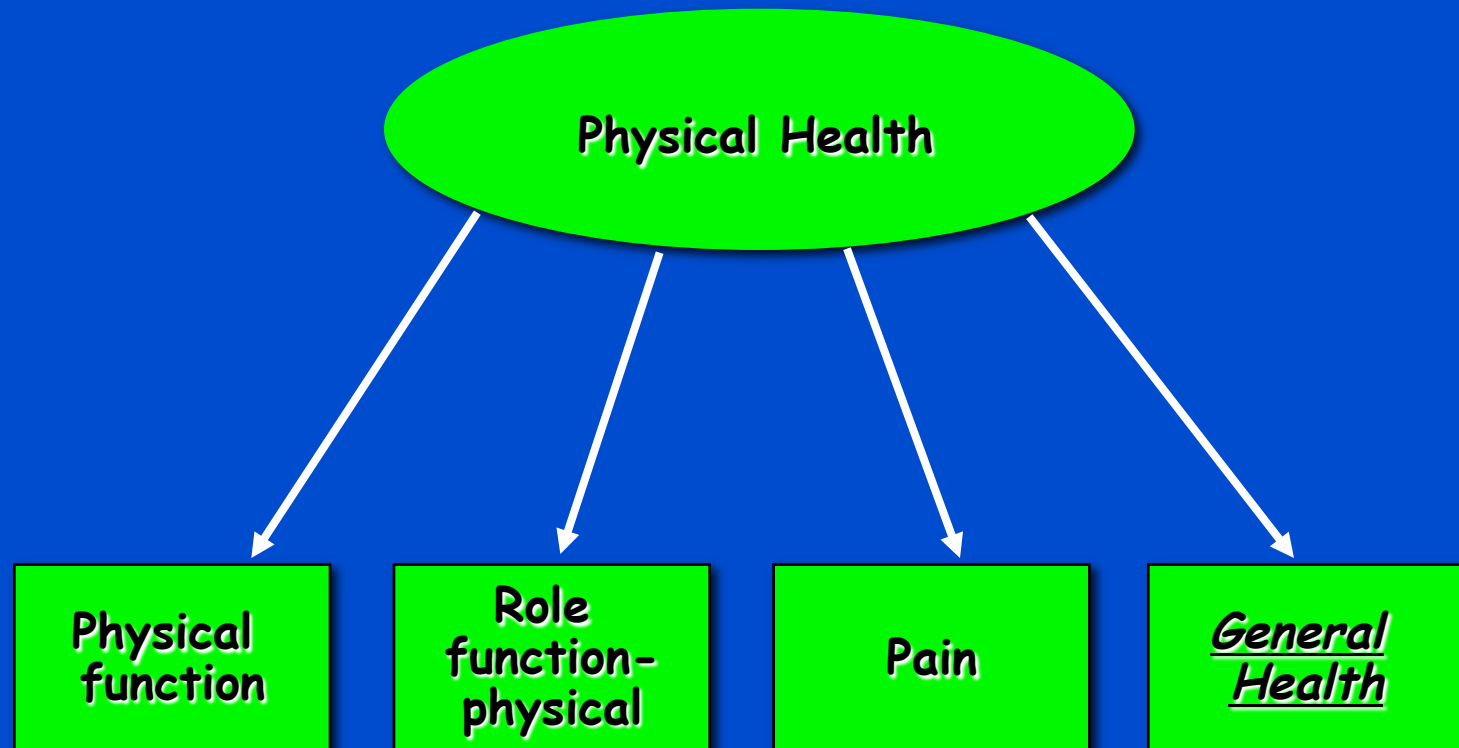
General Health

n = 194 with Multiple Sclerosis

- Lower scores than general population on
  - Emotional well-being (↓ 0.3 SD)
  - Role—emotional (↓ 0.7 SD)
  - Energy (↓1.0 SD)
  - Social functioning (↓1.0 SD)
- Yet SF-36 MCS was only <u>0.2</u> SD lower.
- RAND-36 mental health was <u>0.9</u> SD lower.

Nortvedt et al. (<u>Med Care,</u> 2000)

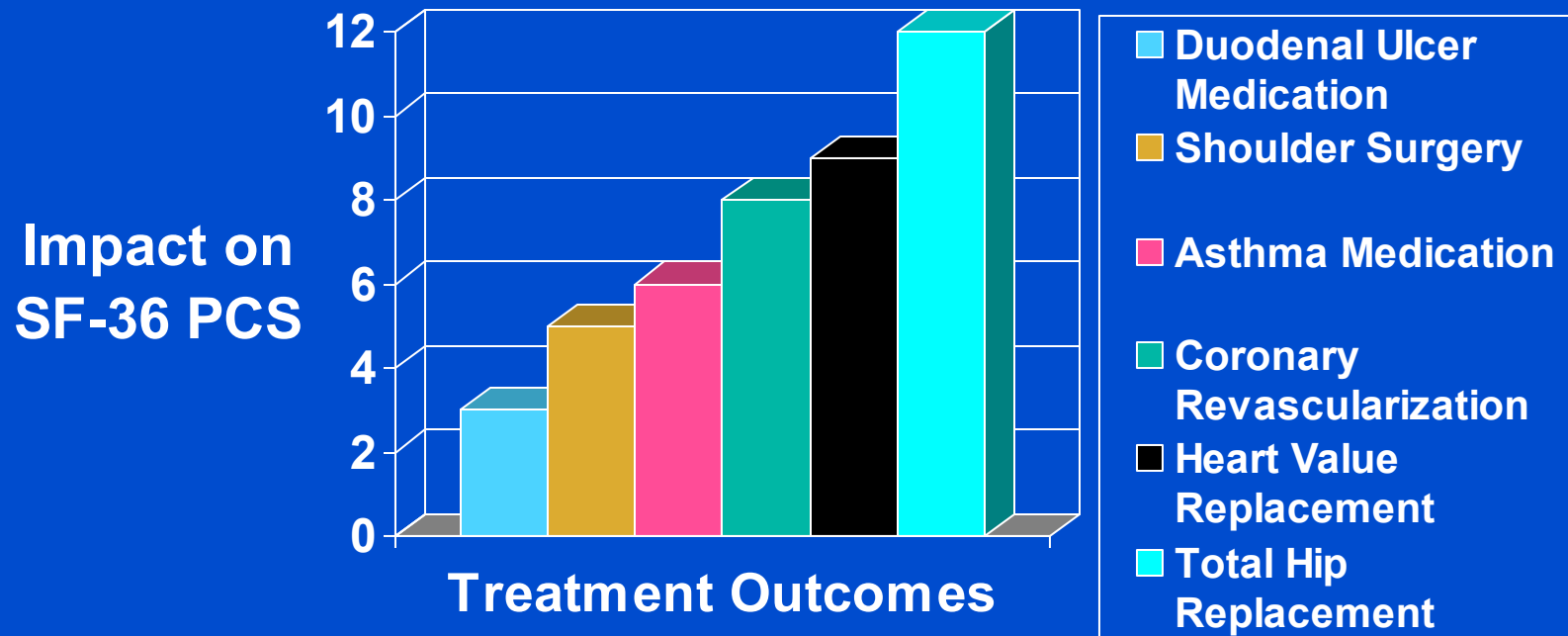# Four scales 0.3-1.0 SD lower, but mental health summary score only 0.2 SD lower

Mental Health

- Emotional Well-Being
- Role function-emotional
- *Energy*
- *Social function*
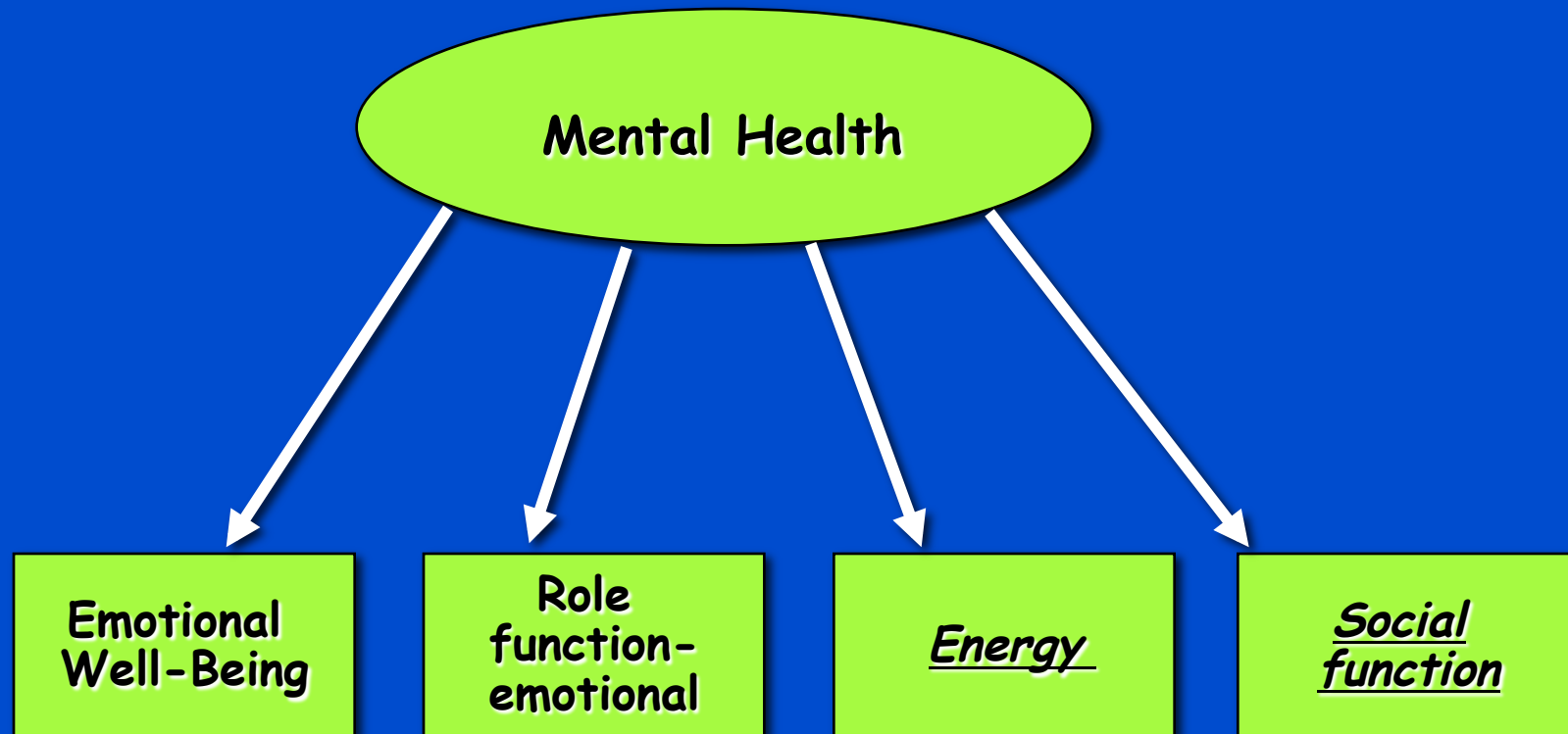
Alternative Weights for SF-36 PCS and MCS

$PCS\_z = (PF\_z * .20) + (RP\_z * .31) + (BP\_z * .23) + (GH\_z * .20) + (EF\_z * .13) + (SF\_z * .11) + (RE\_z * .03) + (EW\_z * -.03)$

$MCS\_z = (PF\_z * -.02) + (RP\_z * .03) + (BP\_z * .04) + (GH\_z * .10) + (EF\_z * .29) + (SF\_z * .14) + (RE\_z * .20) + (EW\_z * .35)$

Treatment Impact on Physical Health

Treatment Impact on Mental Health
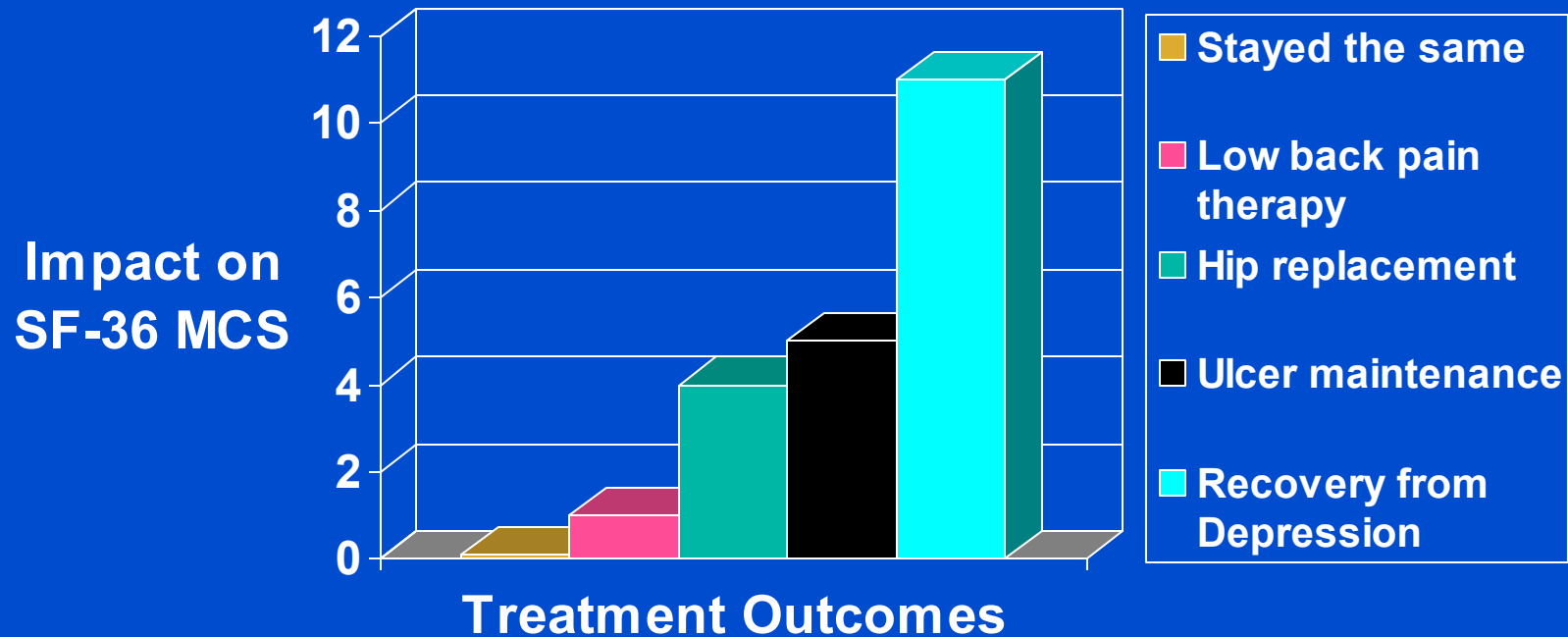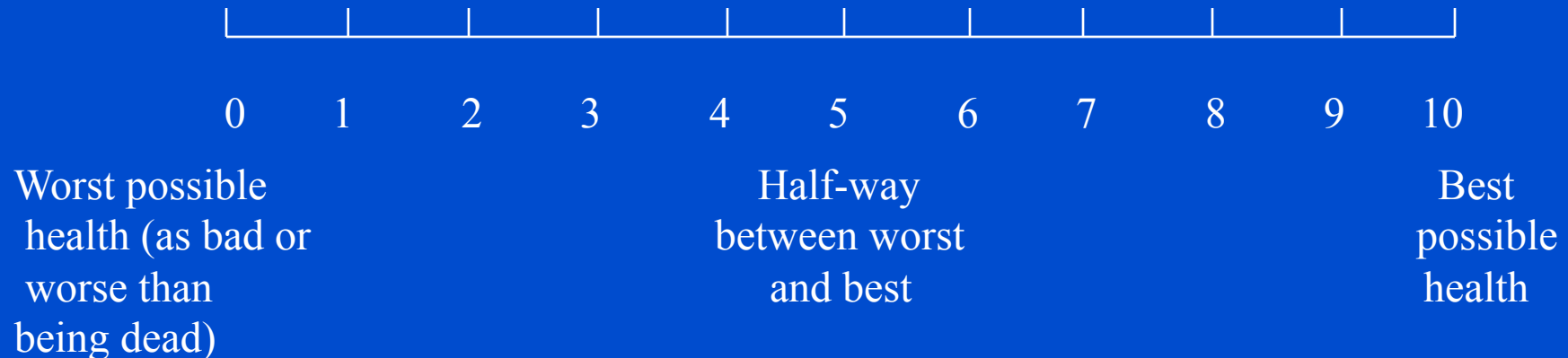
Is New Treatment (X) Better Than Standard Care (O)?
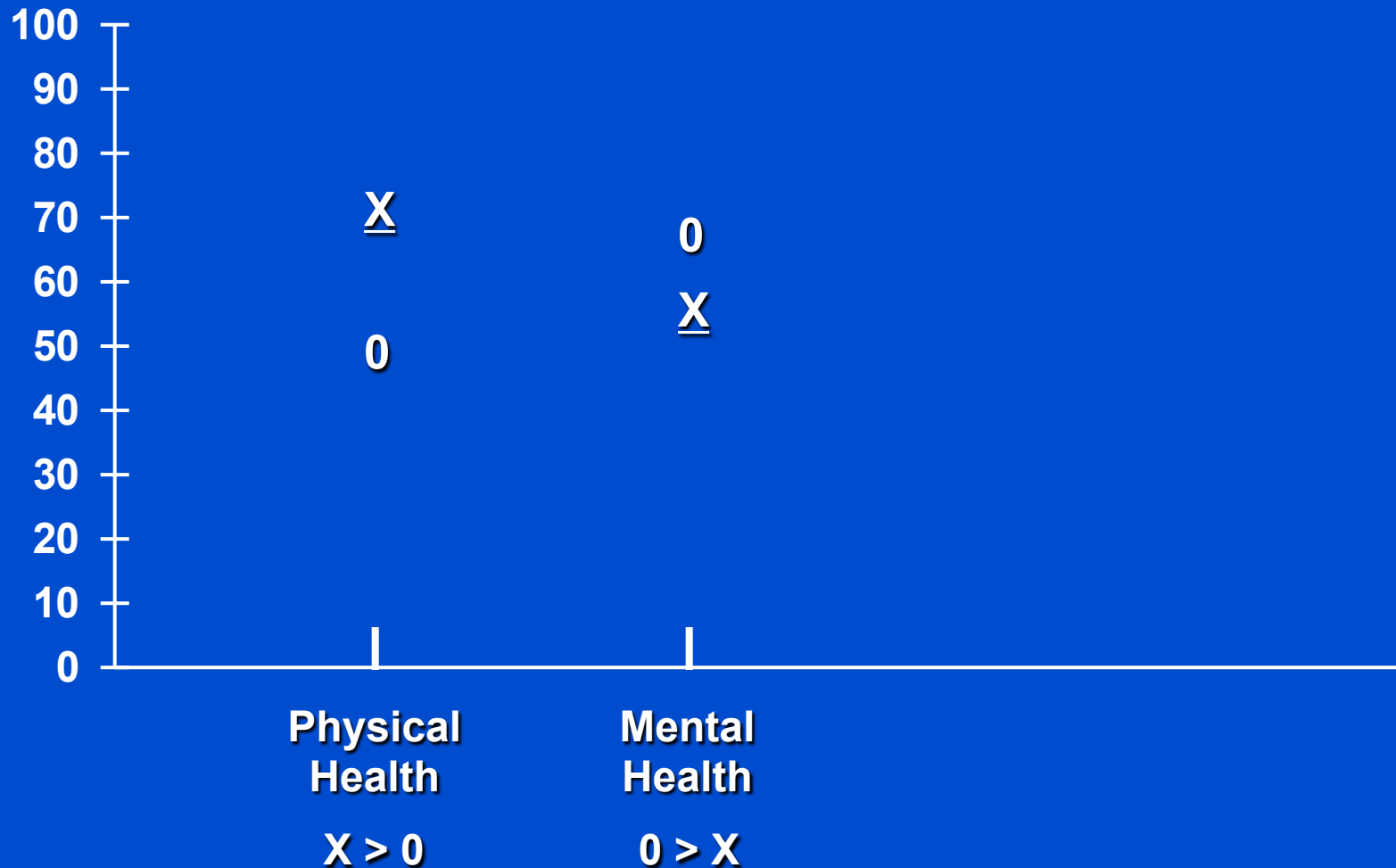
Overall Health Rating Item

Overall, how would you rate your <u>current health</u>?

(Circle One Number)

0	1	2	3	4	5	6	7	8	9	10

Worst possible
health (as bad or
worse than
being dead)

Half-way
between worst
and best

Best
possible
health

Overall Quality of Life Item

Overall, how would you rate your quality of life?

```
|____|____|____|____|____|____|____|____|____|____|
0    1    2    3    4    5    6    7    8    9    10
```

Worst possible
quality of life
(as bad or worse
than being dead)

Half-way
between worst
and best

Best possible
quality of life

Single Weighted Combination of Scores

Perceived Health Index (n = 1,862; reliability = 0.94)

Highest	Lowest	Quartile on Index
35%	84%	at least 1 moderate symptom
7%	70%	at least 1 disability day
1%	11%	hospital admission
2%	14%	performance of invasive diagnostic procedure

Perceived Health Index = 0.20 Physical functioning + 0.15 Pain + 0.41 Energy + 0.10 Emotional well-being + 0.05 Social functioning + 0.09 Role functioning.

Bozzette, S.A., Hays, R.D., Berry, S.H., & Kanouse, D.E. (1994). A perceived health index for use in persons with advanced HIV disease: Derivation, reliability, and validity. Medical Care, 32, 716-731.

Is Use of Medicine Related to Worse HRQOL?

Person	Medication Use	HRQOL (0-100 scale)
1	No	dead
2	No	dead
3	No	50
4	No	75
5	No	100
6	Yes	0
7	Yes	25
8	Yes	50
9	Yes	75
10	Yes	100

Group	n	HRQOL
No Medicine	3	75
Yes Medicine	5	50

Do a Survival Analysis?

Marathoner and person in coma = 1.0

Brazier et al. SF-6D

- Brazier et al. (1998, 2002)
  - 6-dimensional classification
    - Collapsed role scales, dropped general health
    - Uses 11 SF-36 items (8 SF-12 and 3 additional physical functioning items)
  - 18,000 possible states
  - 249 states rated by sample of 836 from UK general population

Health State 111111

Health state 111111

Your health does not limit you in **vigorous activities** (e.g. running, lifting heavy objects, participating in strenuous sports).

You have <u>no</u> problems with your work or other regular daily activities as a result of your **physical health or any emotional problems.**
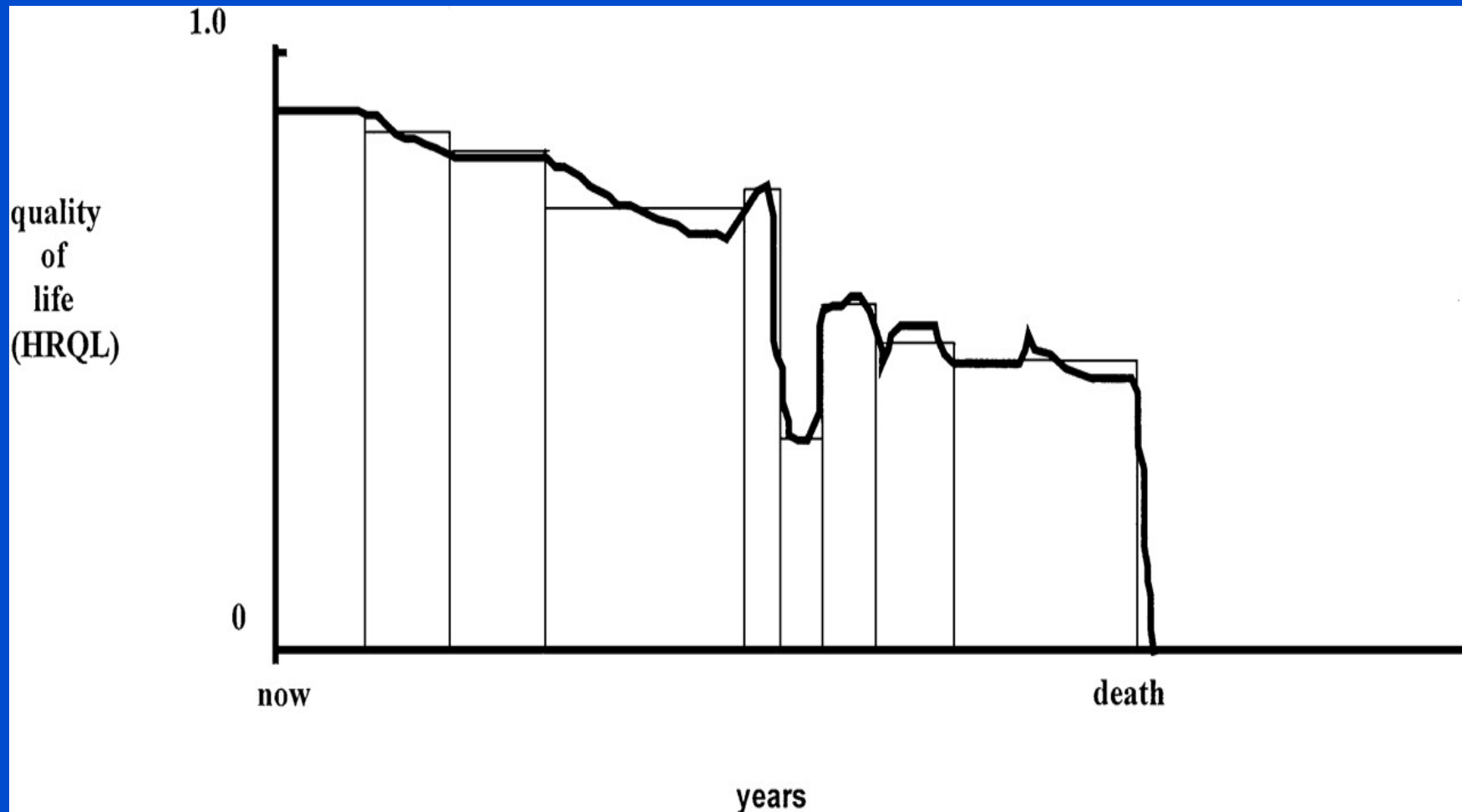
Your health limits your **social activities** (like visiting friends or close relatives) <u>a little or none of the time</u>
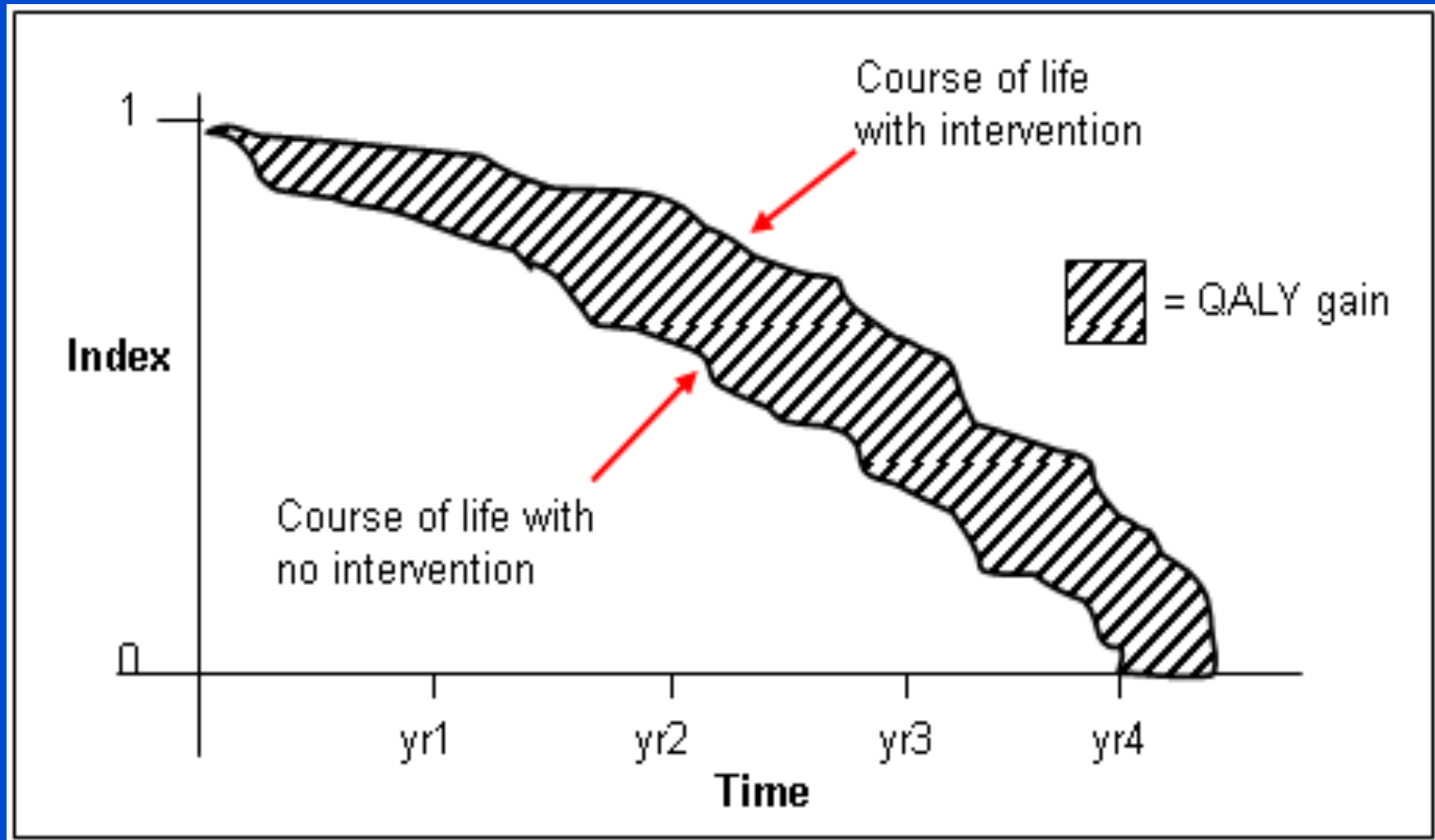
You have <u>no</u> **pain**

You feel **tense or downhearted and low** <u>a little or none of the time.</u>

You have a lot of **energy** <u>all of the time</u>

Quality of Life for Individual Over Time

Questions?

For further information

http://www.rand.org/health/surveys.html

http://www.chime.ucla.edu/measurement/measurement.htm

www.isoqol.org

www.sf-36.com

http://www.proqolid.org/