

Quality of Life Measurement

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NIH RCT Summer Training Course

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Where This is Going

- Profile Approach

- SF-36

- Utility Approach

- QWB

- Preference Assessment

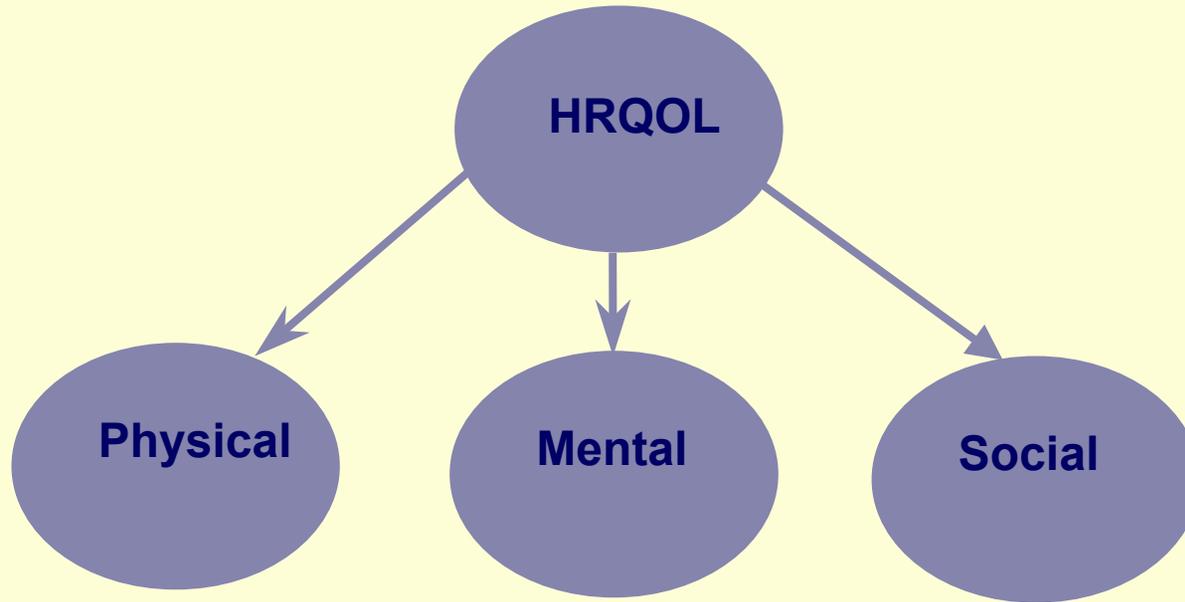




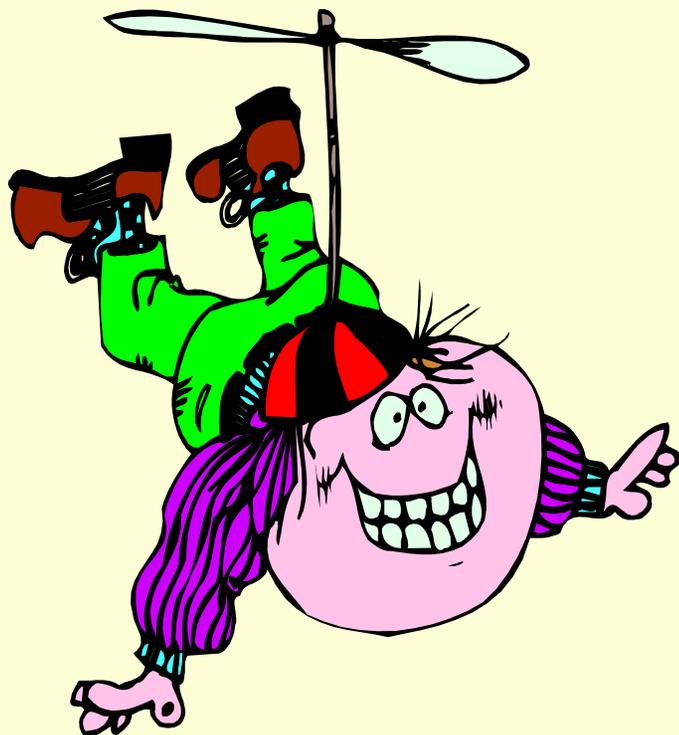
Health-Related Quality of Life is:

- **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



Types of HRQOL Measures

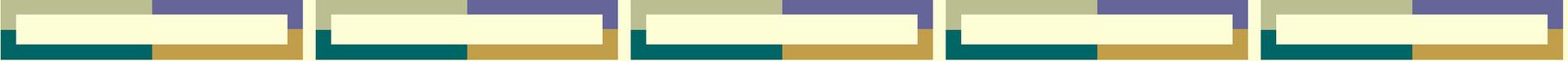


Profile

Generic 

Targeted

Preference-based



RAND-36 Scales (Items)

- **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)**
- 

Physical Functioning Item



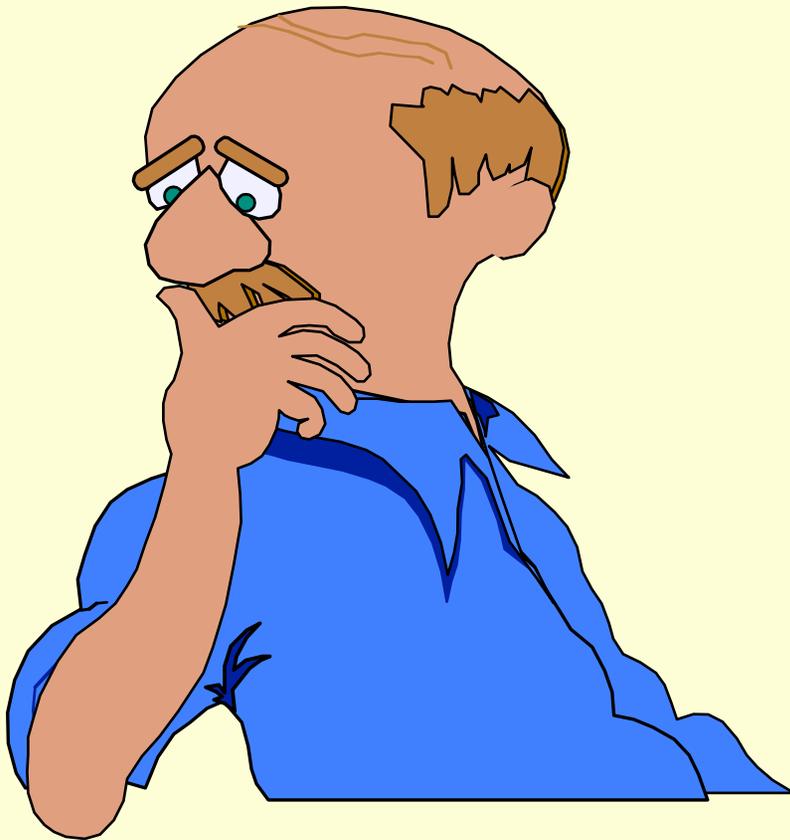
**Does your health
now limit you in
bathing or
dressing yourself?**

Yes, limited a lot

Yes, limited a little

No, not limited at all

Emotional Well-Being Item



How much of the time during the past 4 weeks have you been a very nervous person?

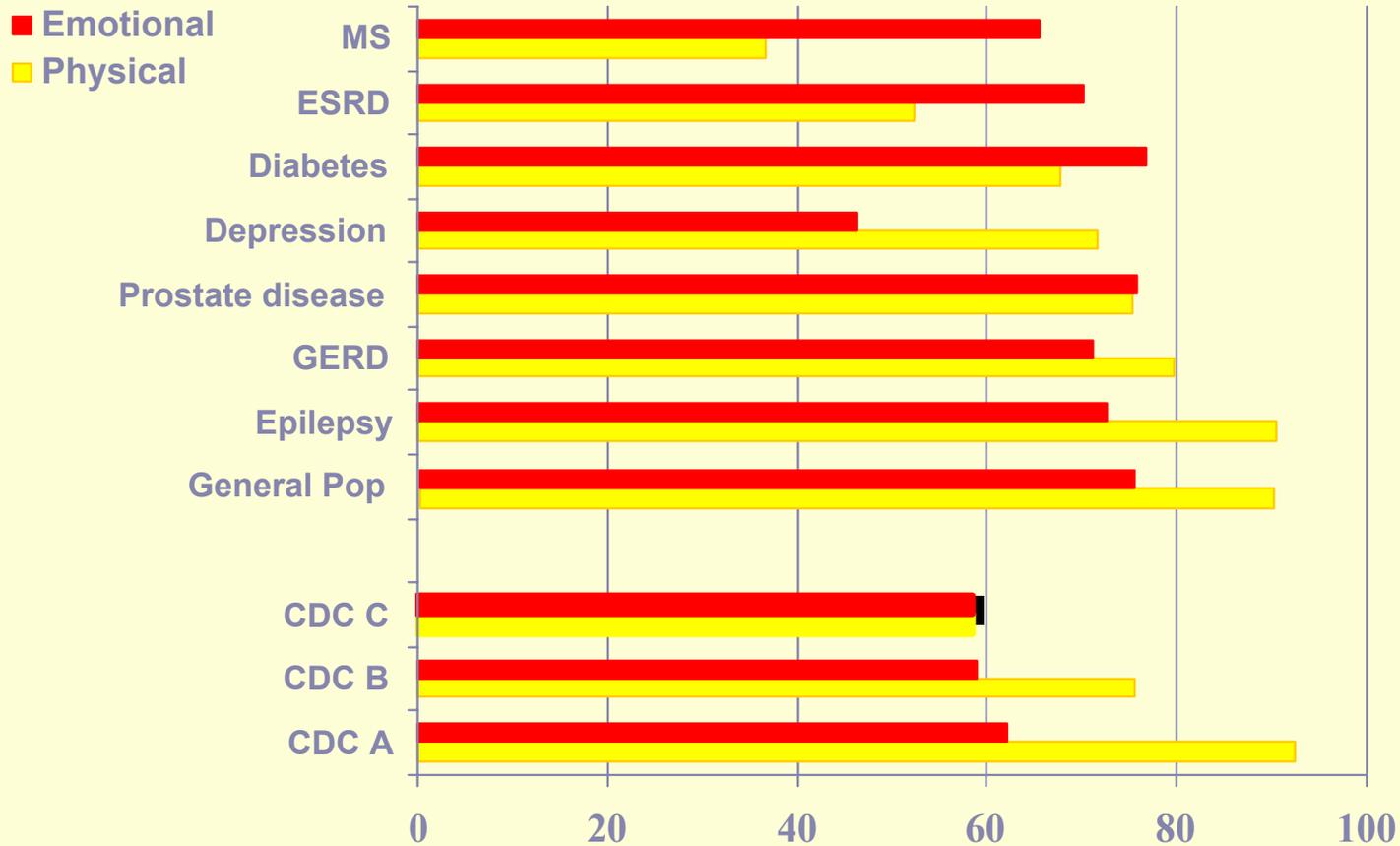
None of the time; A little of the time; Some of the time; A good bit of the time; Most of the time; All of the time



Scoring RAND-36 Scales

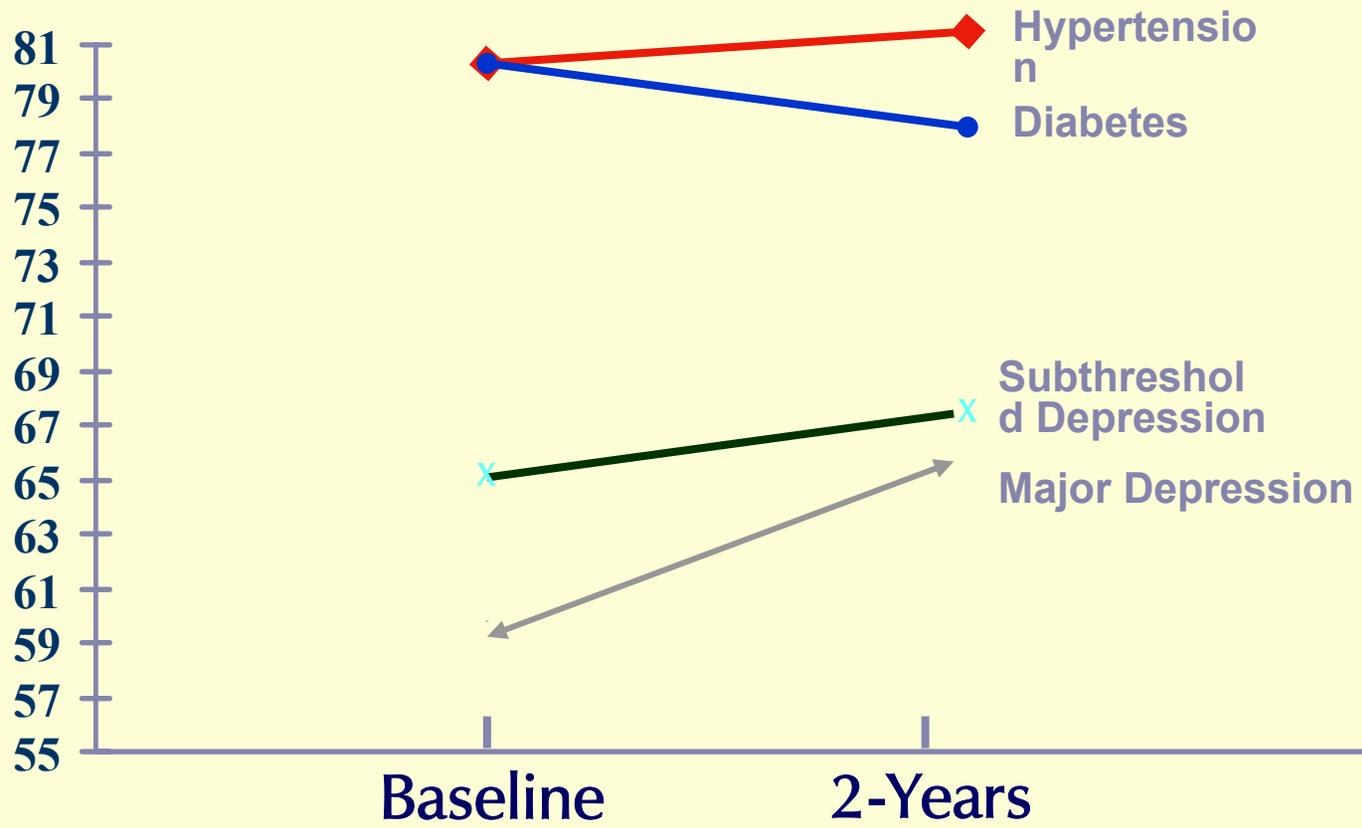
- **Average or sum all items in the same scale.**
 - **Transform raw average or sum to 0-100 possible range (linear transformation)**
 - $(\text{raw score} - \text{minimum}) * 100 / (\text{max} - \text{min})$
-

HRQOL of HIV Infected Adults



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

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



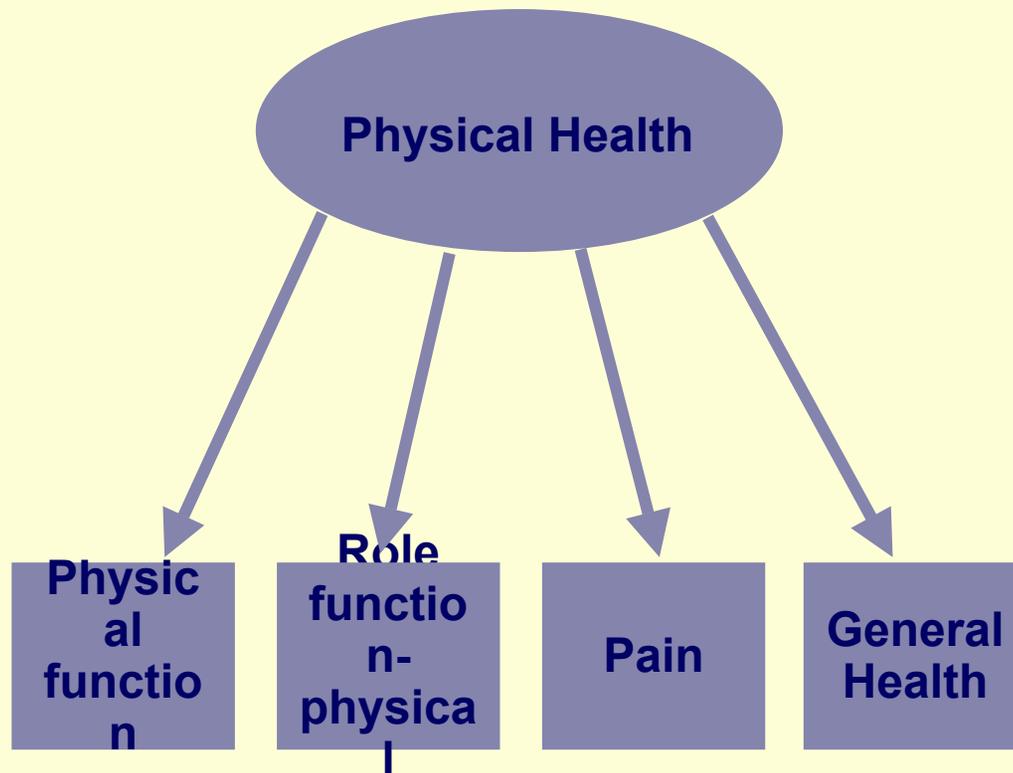
. (1995).
Functioning and well-being outcomes of patients with depression compared
to chronic medical illnesses. [Archives of General Psychiatry](#), 52, 11-19.



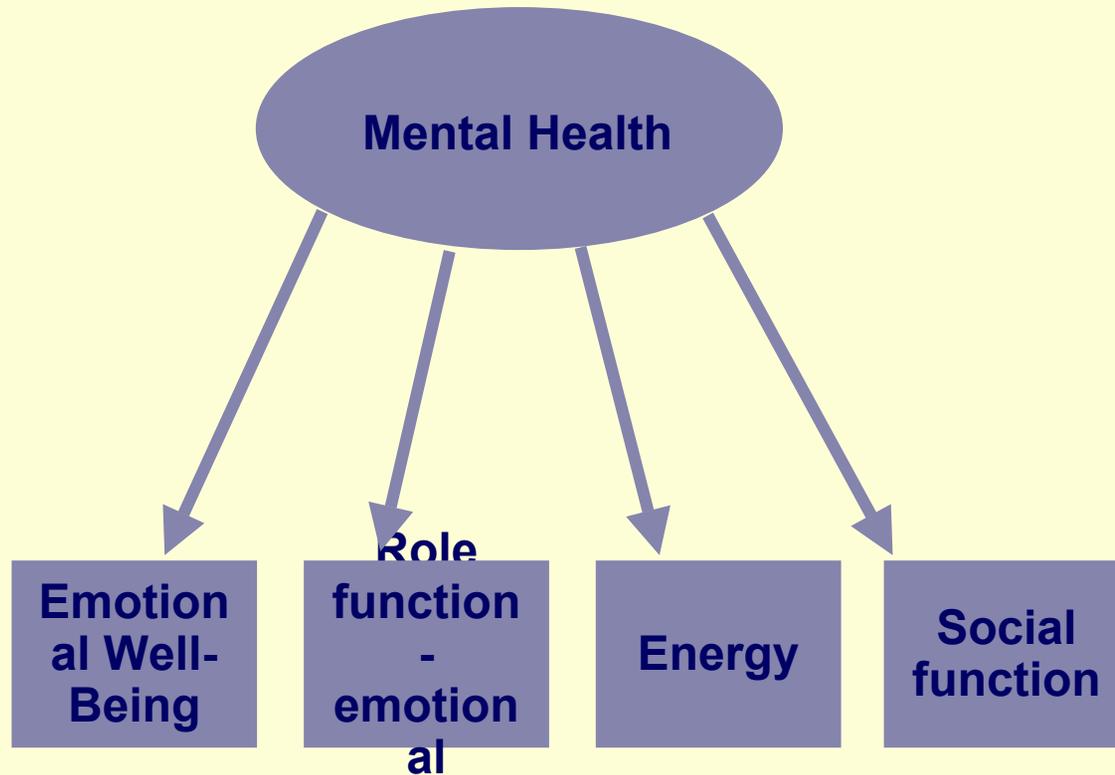
Two Underlying RAND-36 Dimensions

- **Hays, R.D., and Stewart, A.L. (1990).** The structure of self-reported health in chronic disease patients. [Psychological Assessment](#), 2, 22-30.
 - **Hays, R. D., Marshall, G. N. et al. (1994).** Four-year cross-lagged associations between physical and mental health in the Medical Outcomes Study. [Journal of Clinical Psychology](#), 62, 441-449.
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Indicators of Physical Health



Indicators of Mental Health





RAND-36 Summary Scores

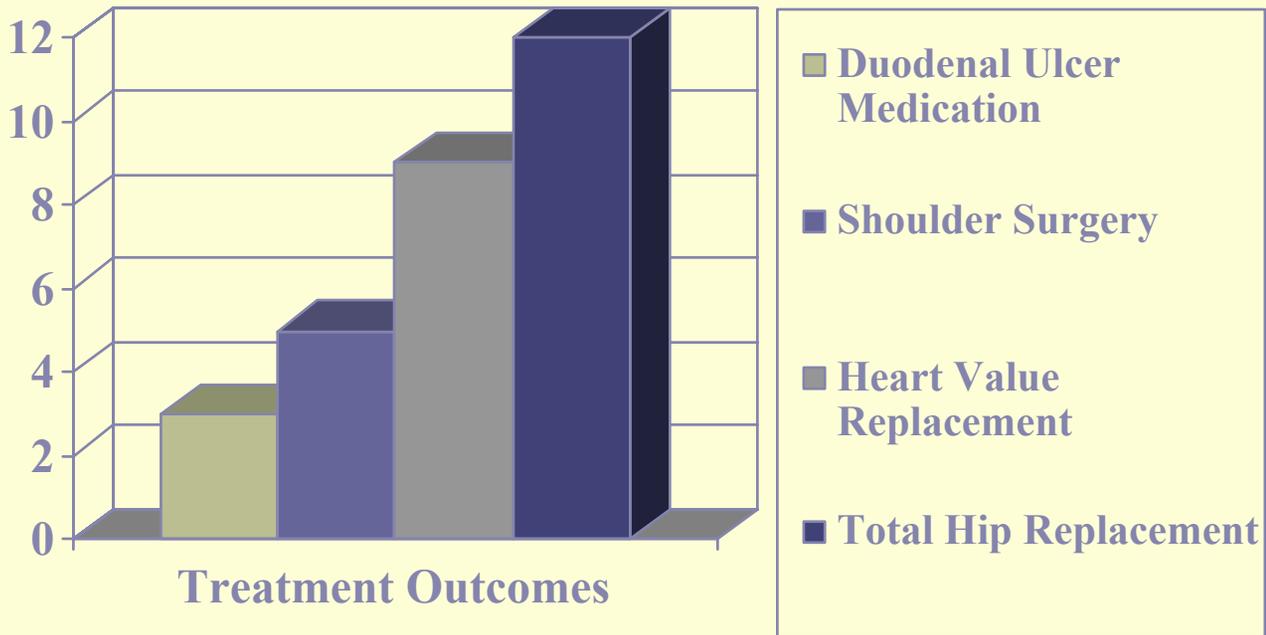
- Physical Health Composite
 - ◆ Physical functioning, role—physical, pain, general health perceptions
- ◆ Mental Health Composite
 - ◆ Emotional well-being, role—emotional, social functioning, energy/fatigue
- ◆ Intercorrelation = 0.66; reliability \geq 0.91

Hays, R. D., Embury, S. & Chen, H. (1998). RAND-36 Health Status Inventory. San Antonio: The Psychological Corporation.

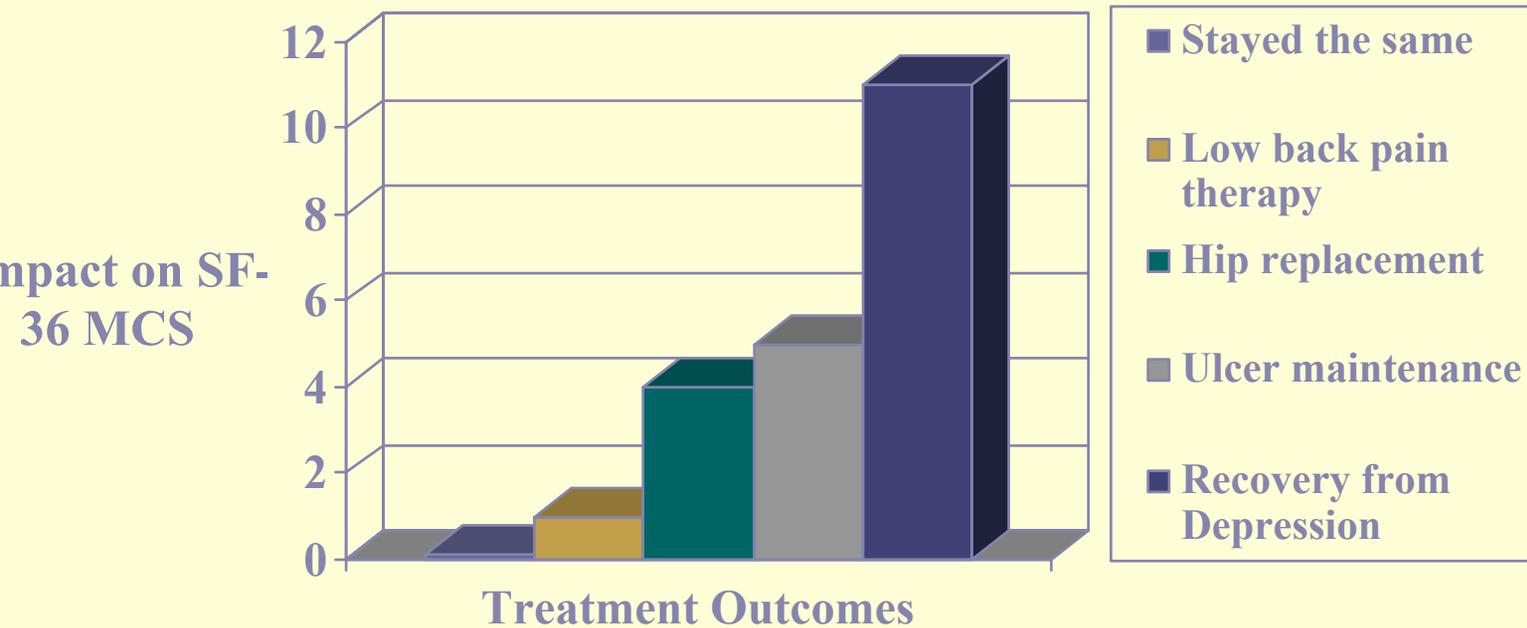


Range of Treatment Impacts on PCS

Impact on SF-36 PCS

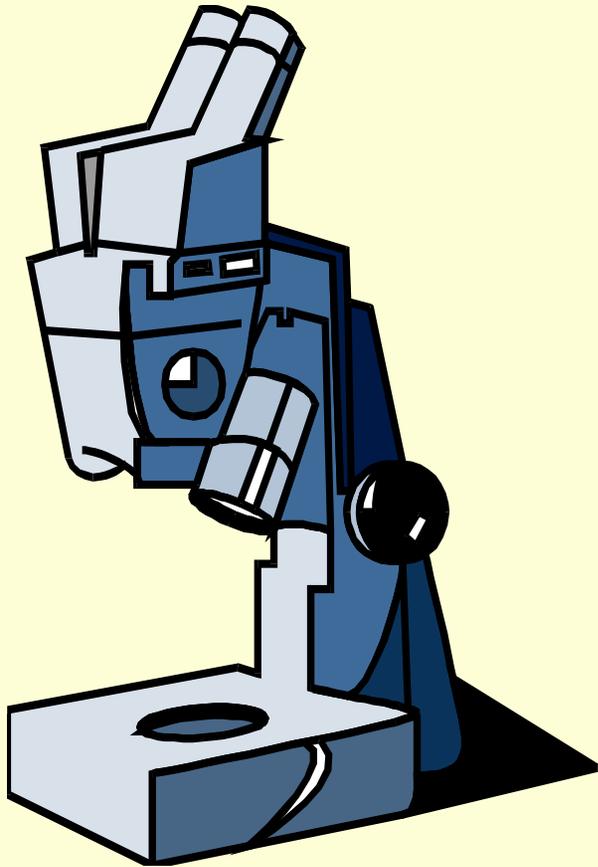


Range of Treatment Impacts on MCS



Samsa et al. (1999).

Pharmacoeconomics



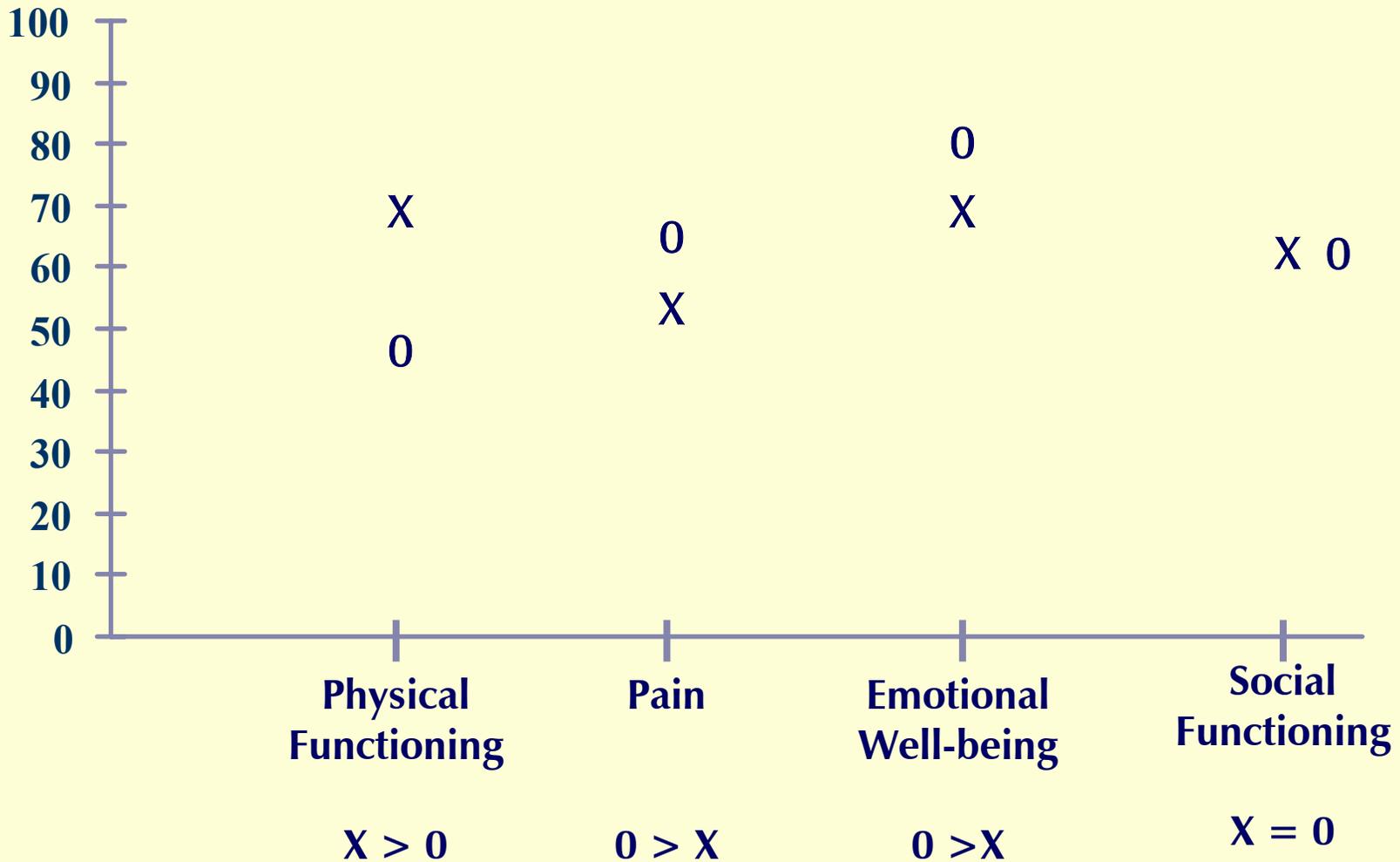
- MCID for SF-36 is “typically in the range of 3 to 5 points” (p. 149).
- .09->0.28 ES



Caution in Using SF-36 PCS and MCS

- Simon et al. (1998, Med Care); 536 primary care patients initiating antidepressant tx.
 - Physical functioning, Role—physical, pain, and general health perceptions improved significantly and by 0.28 to 0.49 SDs, but PCS did not change!
 - Nortvedt et al. (2000, Med Care); 194 MS patients
 - Emotional well-being was 0.3 SD lower, role-emotional 0.7 SD lower, energy/fatigue 1.0 SD lower, and social functioning 1.0 SD lower than general US population, but MCS was only 0.20 SD lower.
-

Limitation of RAND-36: Is New Treatment (X) Better Than Standard Care (O)?





Fryback et al. Prediction of QWB from SF-36

- 56.9% of the observed QWB variance;
49.5% on on cross-validation

$QWB \sim = 0.59196$

+ (PF * 0.0012588)

- (EWB * 0.0011709)

- (BP * 0.0014261)

+ (RP x GH * 0.00000705)

+ (PF x BP * 0.00001140)

+ (BP x EWB * 0.00001931)



Summary of RAND-36

- Generic profile measure
- Single integrated score
 - Preference-based measure
 - Estimate of preference-based measure



QWB Approach



Outcomes Measurement

- Does the health care you give, affect patient health status?
- How do you know?
- How do you distinguish between + and - effects on health status?
- **OVERALL**, does the patient benefit from the health care they are given?



Traditional

- **Life Expectancy**
 - **Infant Mortality**
 - **Disability Days**
- 



Survival Analysis

- Alive 1.0
 - Dead 0.0
- 

Problem with Survival Analysis

- Tennis player 1.0
- Man in coma 1.0





Purpose of Quality Adjusted Survival Analysis

- **To summarize life expectancy with adjustments for quality of life**





Quality of Well-being Scale

- Currently two versions
 - Interviewer
 - Self-Report
 - Takes about 10 minutes
 - Automated scoring, low cost
 - About 200 published papers describe use
- 



QWB Components

● Functional Scales

- Mobility (MOB□□□)
- Physical Activity (PAC)
- Social Activity (SAC)

● Symptom/Problem Complexes (CPX)





Purpose of Quality Adjusted Survival Analysis

- **To summarize life expectancy with adjustments for quality of life**



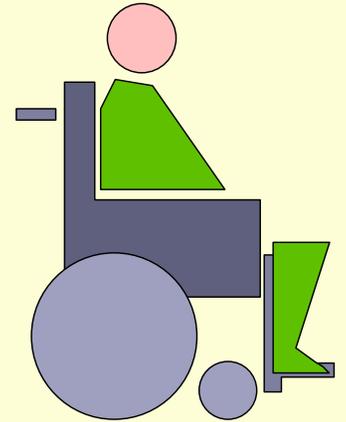
Mobility Scale

- No limitations in travel
- Did not drive or use public transportation



Physical Activity Scale

- Walked without physical problems
- Walked with limitations
- Moved own wheelchair without help
- Confined to bed or chair



Social Activity Scale

- Did work, school or housework and other activities
- Did work, school or housework, but limited in other activities
- Limited in amount or kind of work, school, or housework
- Performed self-care, but not work, school, or housework
- Had help with self care





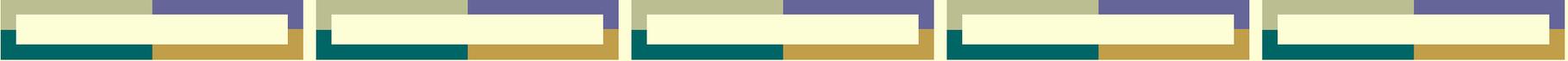
Symptoms or Problems (selected)

- coma
 - trouble learning, remembering, or thinking clearly
 - pain in back or neck
 - sick or upset stomach
 - coughing wheezing of breath
 - spells of feeling upset, depressed or of crying
 - overweight
 - runny nose
 - problems with sexual interest or performance
- 



Quality-Adjusted Life Year

- Combines morbidity and mortality into a single index
 - Represents life expectancy with adjustments for quality of life
 - Is defined as a year of life free of all disabilities and symptoms
- 



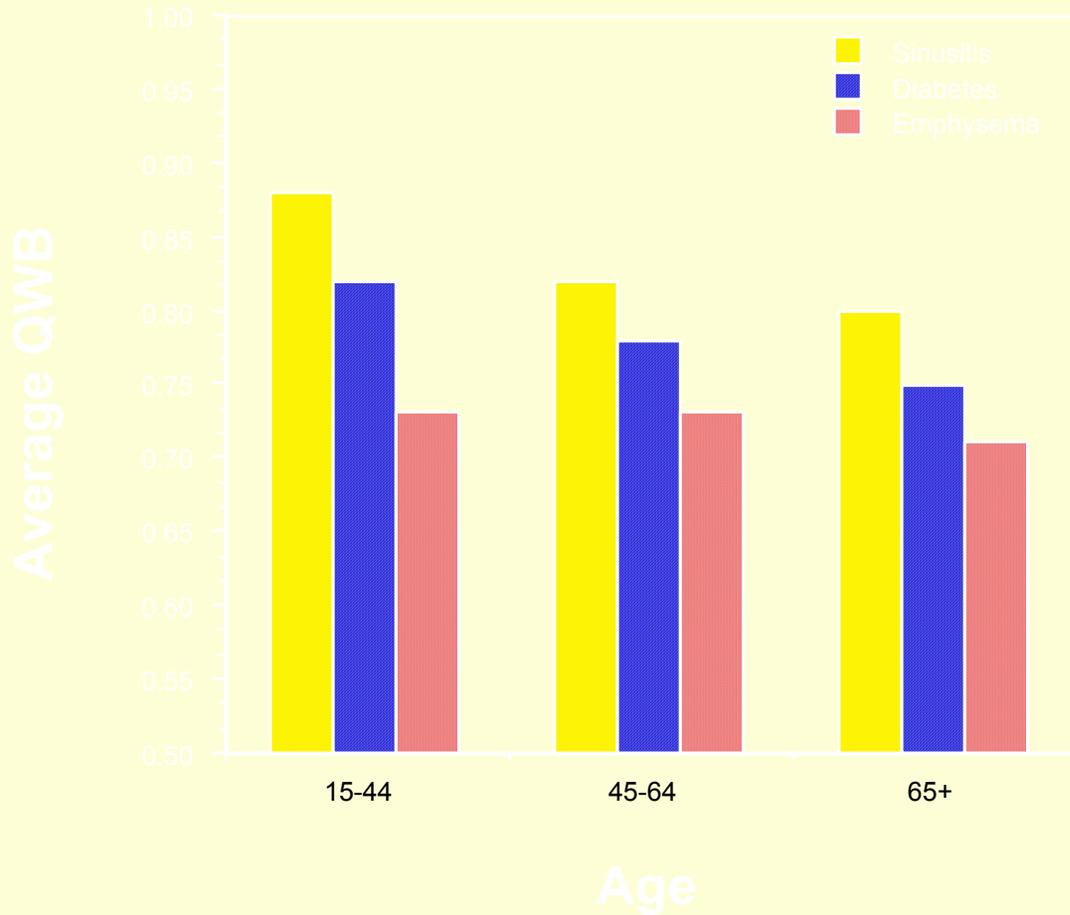
Example Case: 68 year old COPD patient

Description

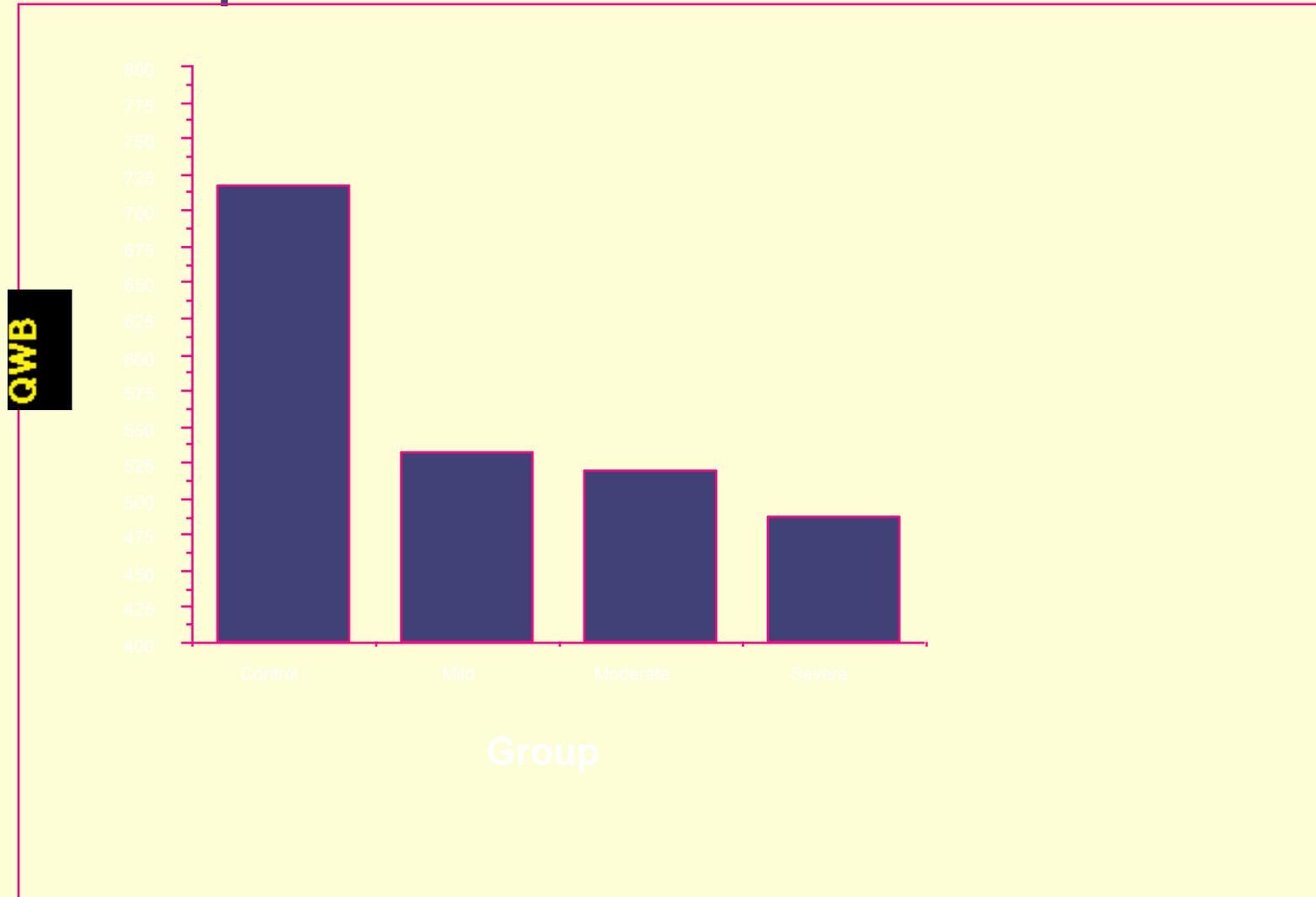
- Shortness of breath
 - Drove Car
 - In Bed or Chair for Most of Day
 - Performed No Major Role Activity, but did perform self-care
-
-
- Weight
 - Peer Rating equals .605
 - For each year in this state, the patient loses $1 - .605 = .395$ well years
- 

Sinus Disease and Diabetes in the General Population

Source: Erickson, 1980 NHIS, Preliminary

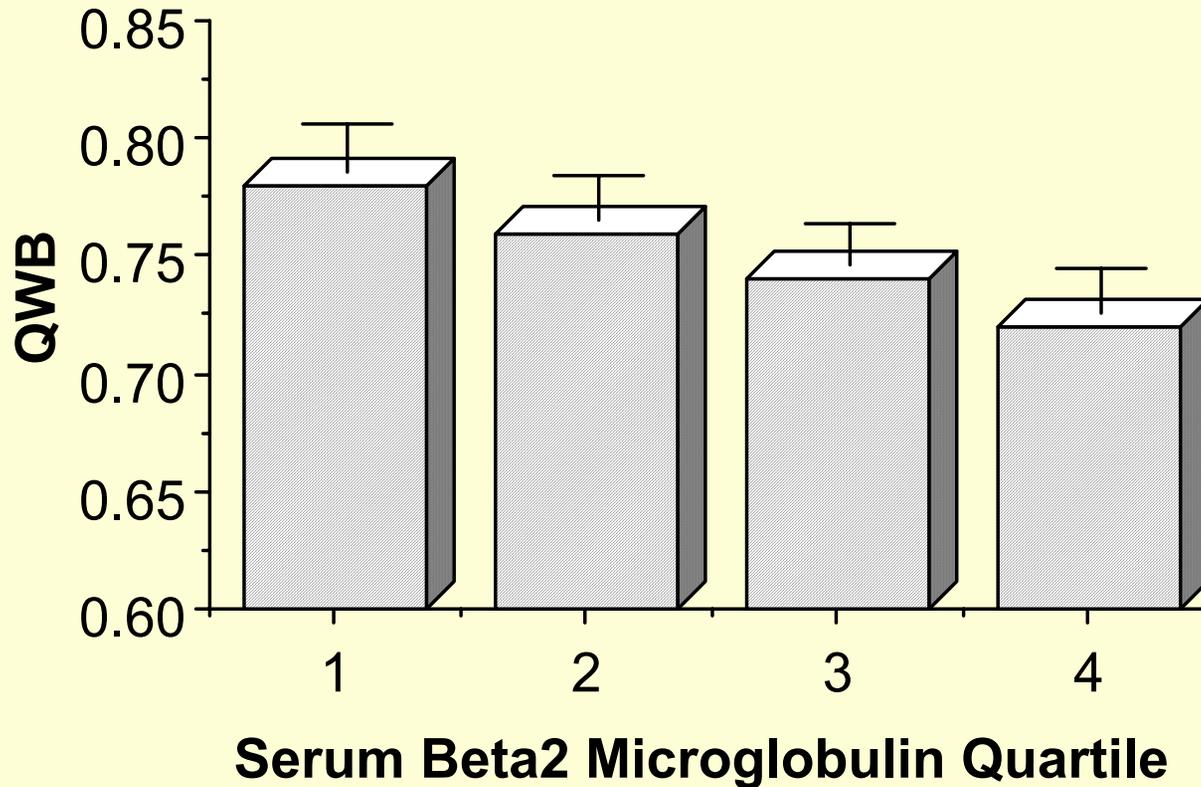


QWB by Level of Cognitive Impairment in Alzheimer's



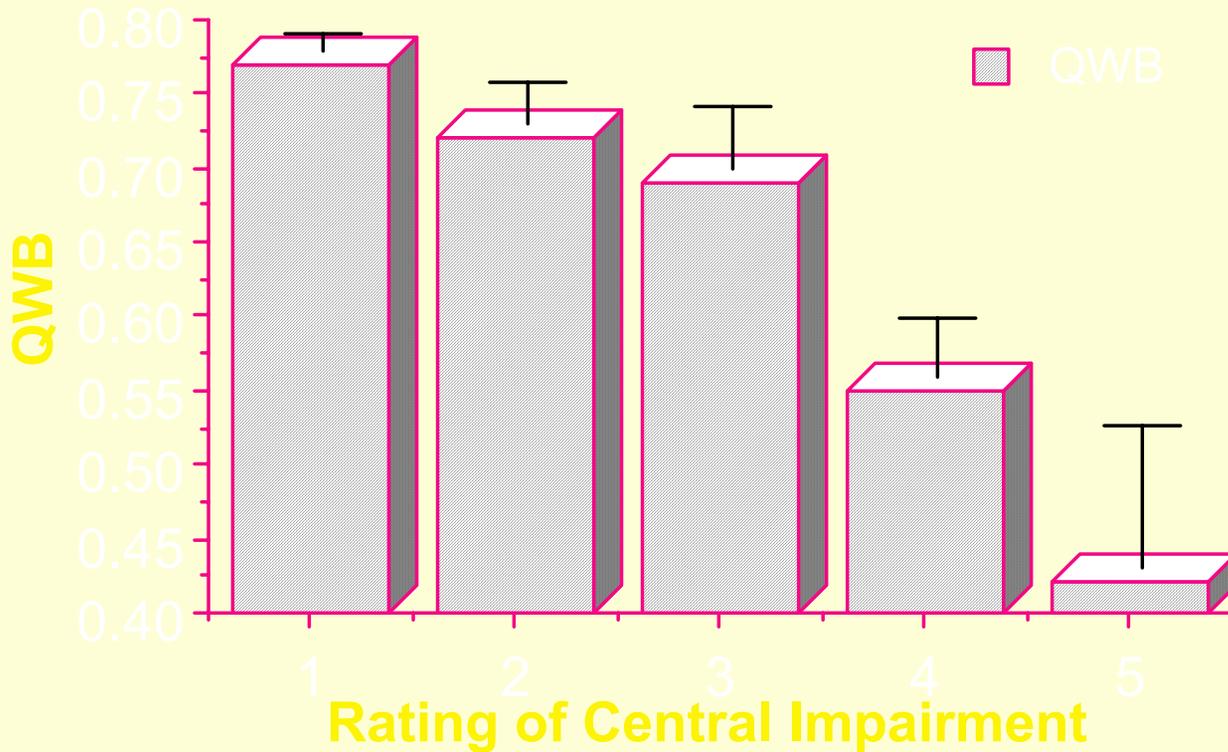
QWB and Serum Beta 2 Microglobulin in HIV

QWB by Serum Beta2 Microglobulin

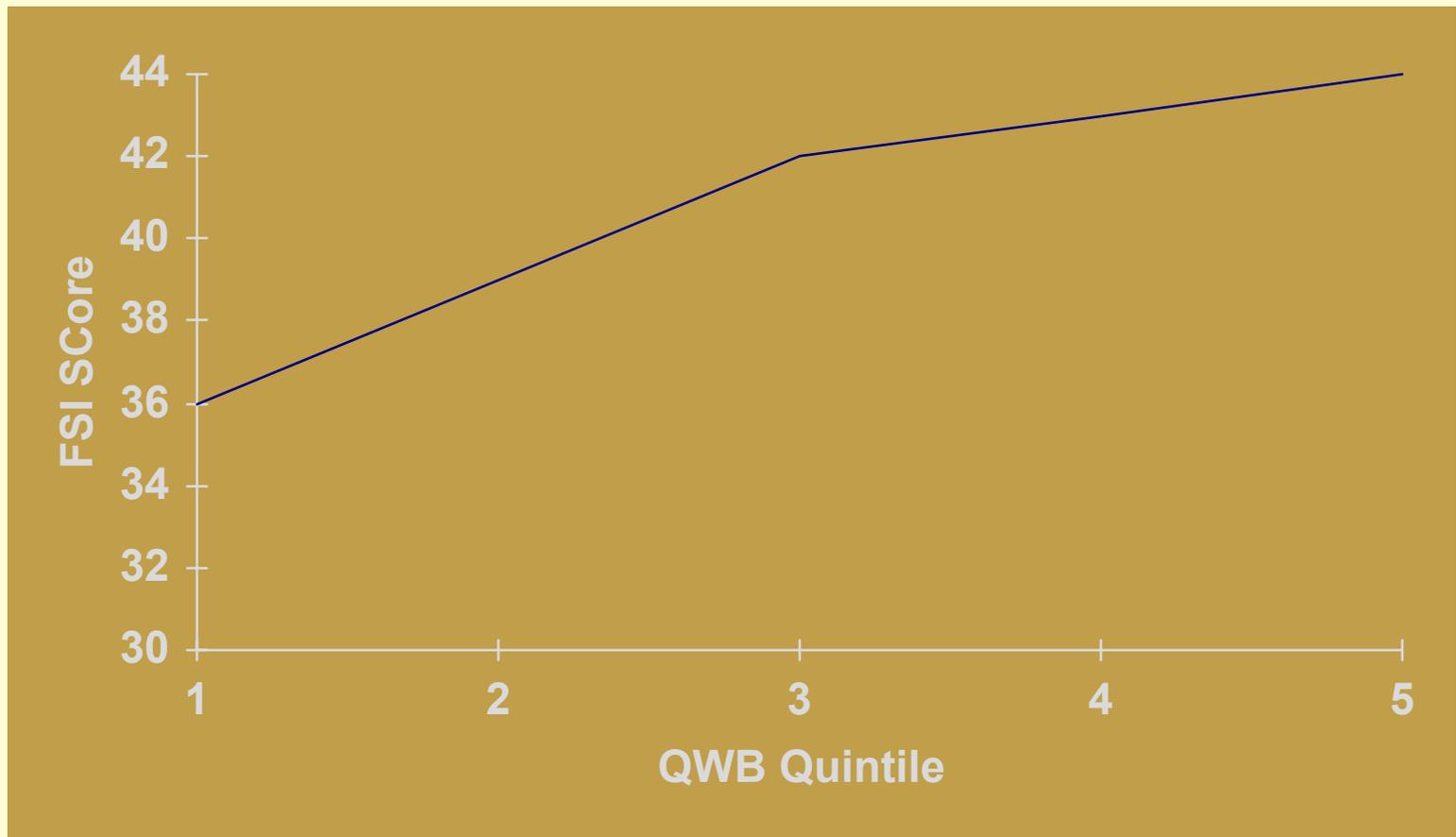


QWB and Neurological Evaluation in HIV

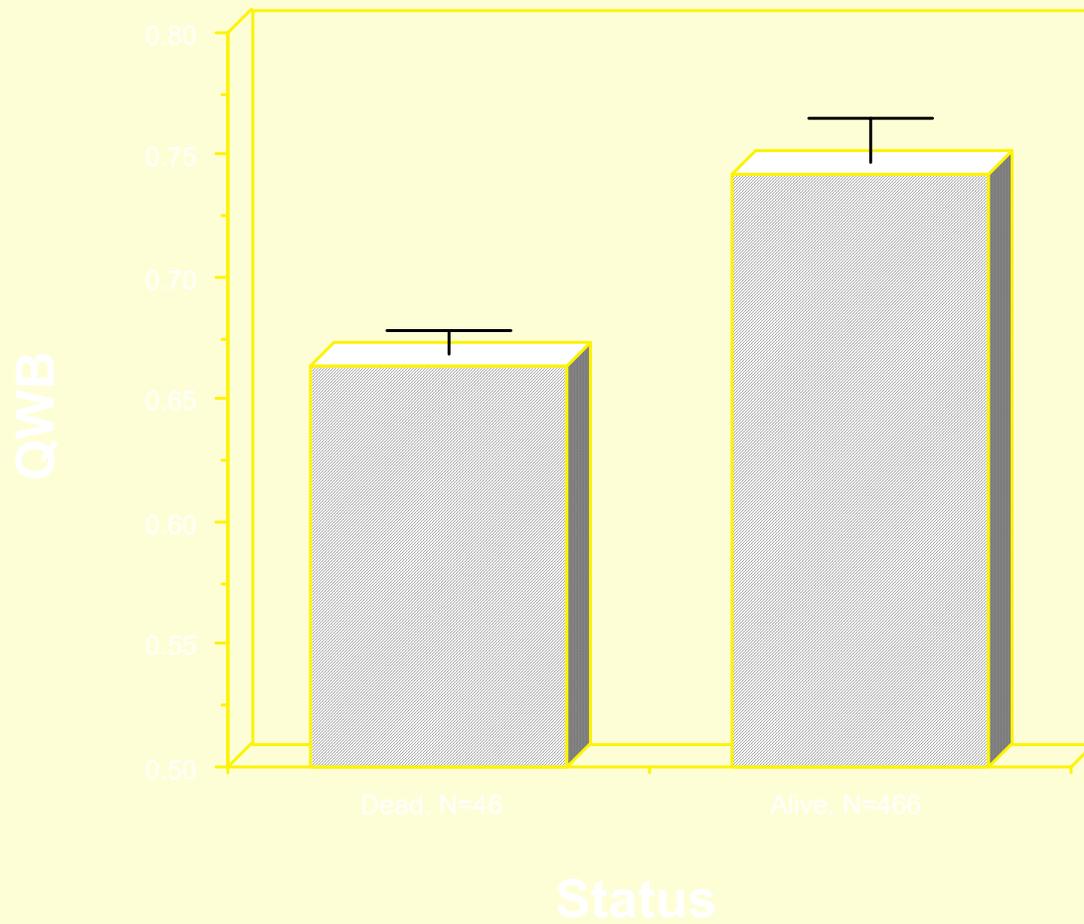
QWB by neurologist rating of central impairment



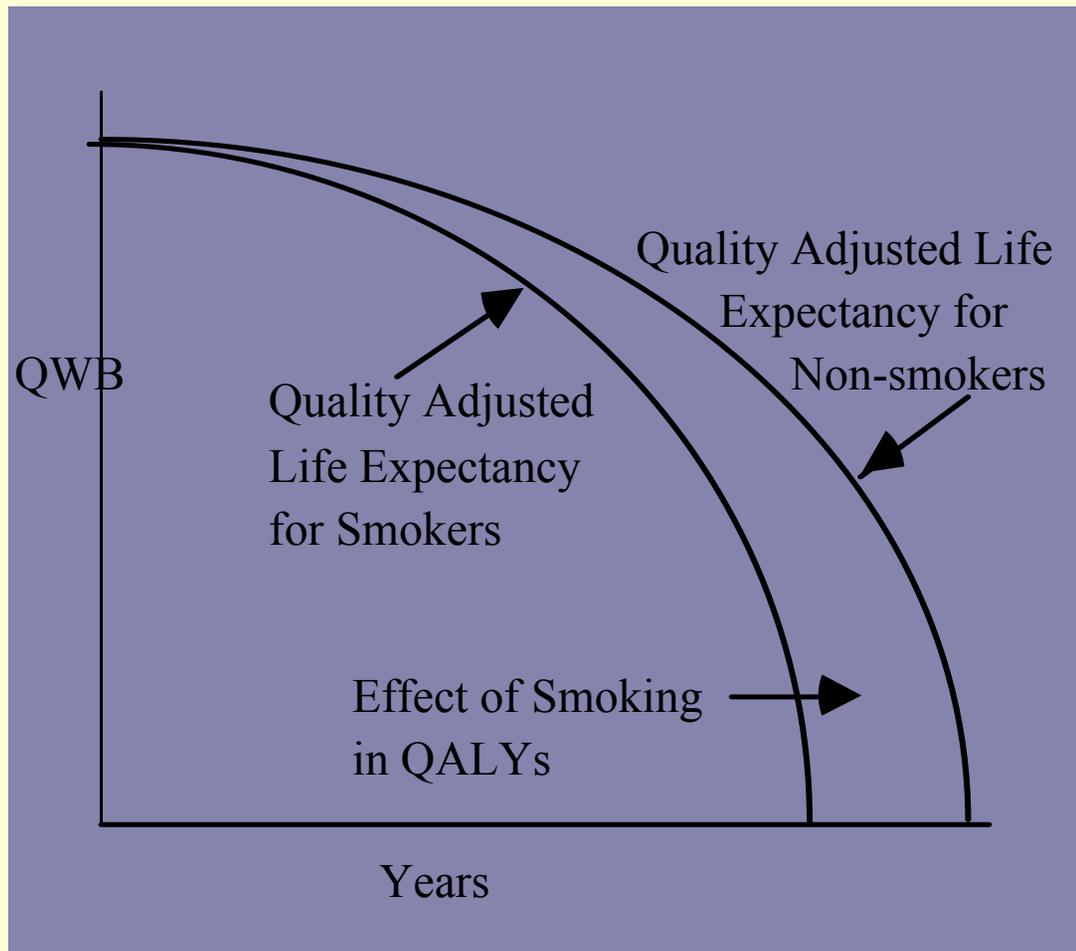
Atrial Fibrillation (Ganiats et al, 1992)



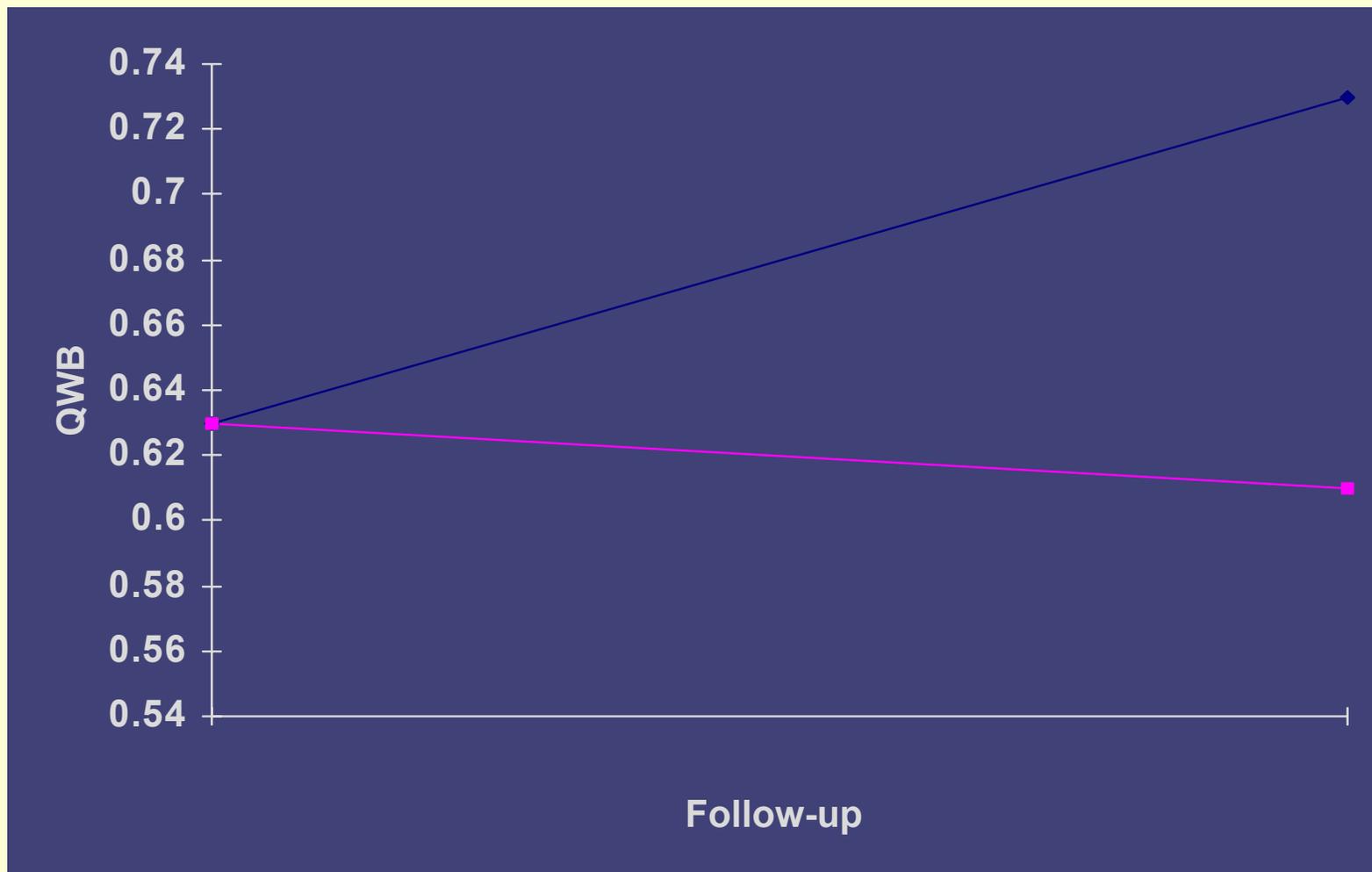
QWB and Survival in HIV



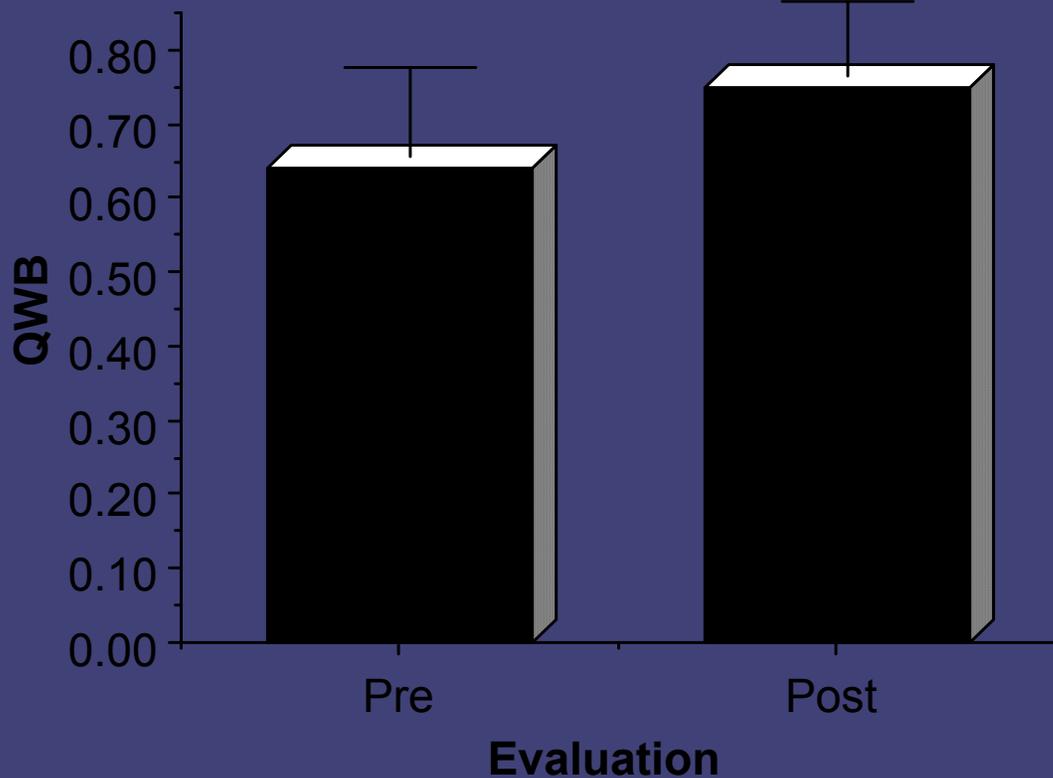
Estimating treatment effects



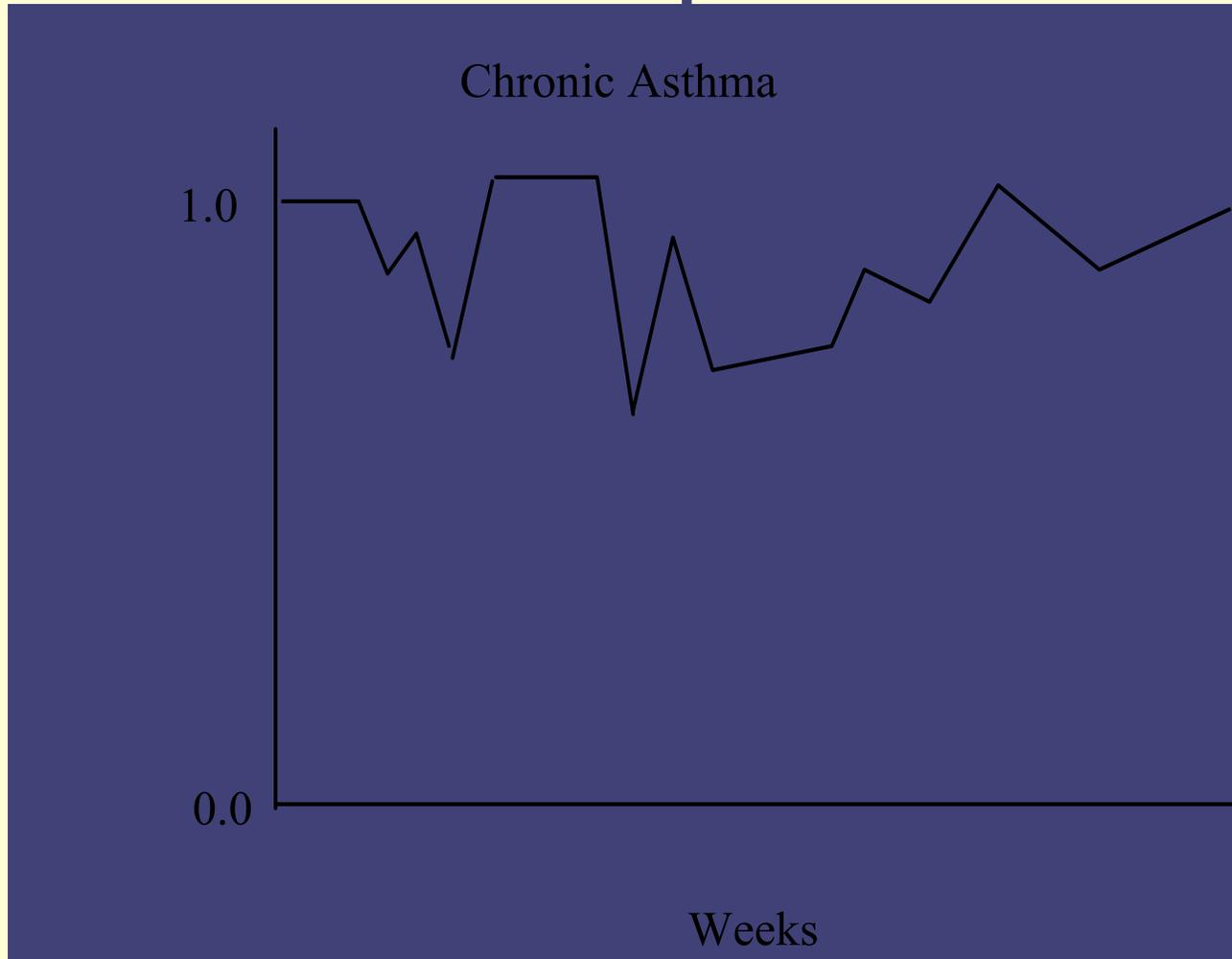
Patients Undergoing Sinus Surgery Vs Control (Hodgson, 1994)



QWB Before and After Ciprofloxacin Treatment for Exacerbations of CF (Orenstein et al, 1990)



Issues in Child Health: Chronic Episodic





QWB has been criticized for

- Excluding mental health
 - Excluding sensory function
 - Excluding social health
 - Excluding disease specific information,
and
 - Being too long
- 

Is Mental Health Excluded from the QWB?



QWB by SAPS Patient Groups and Controls

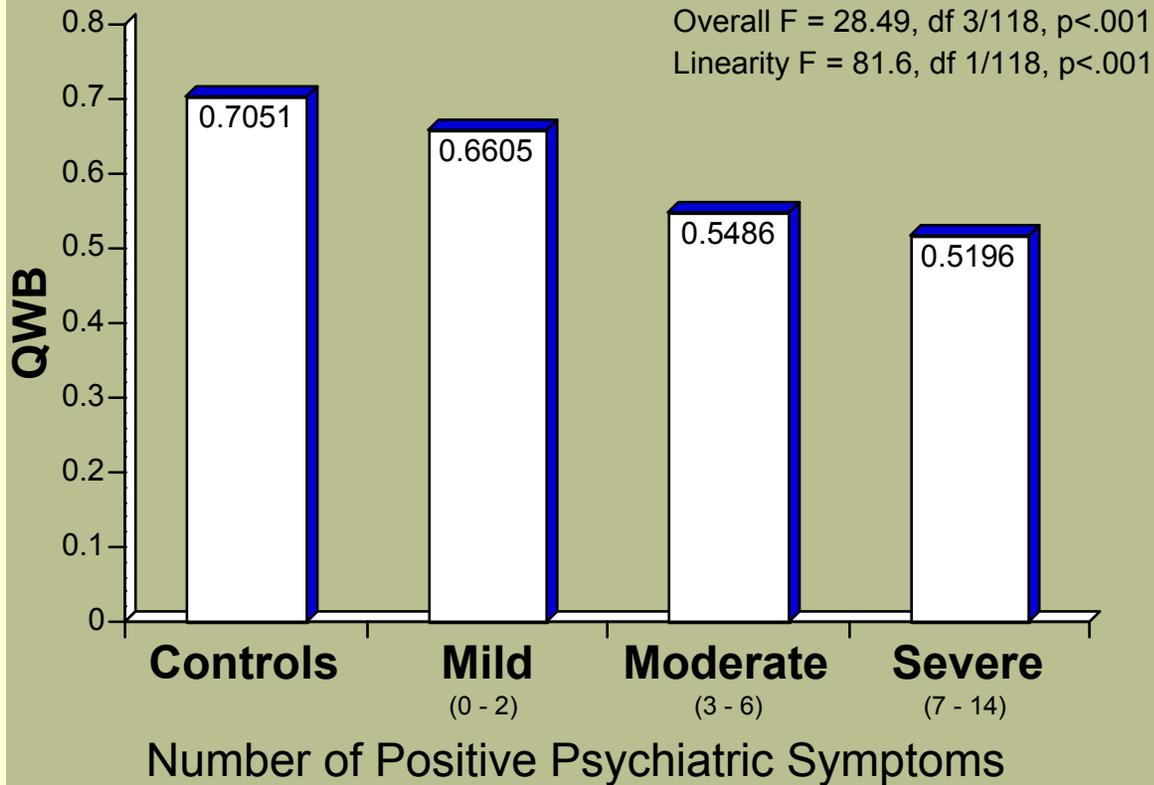
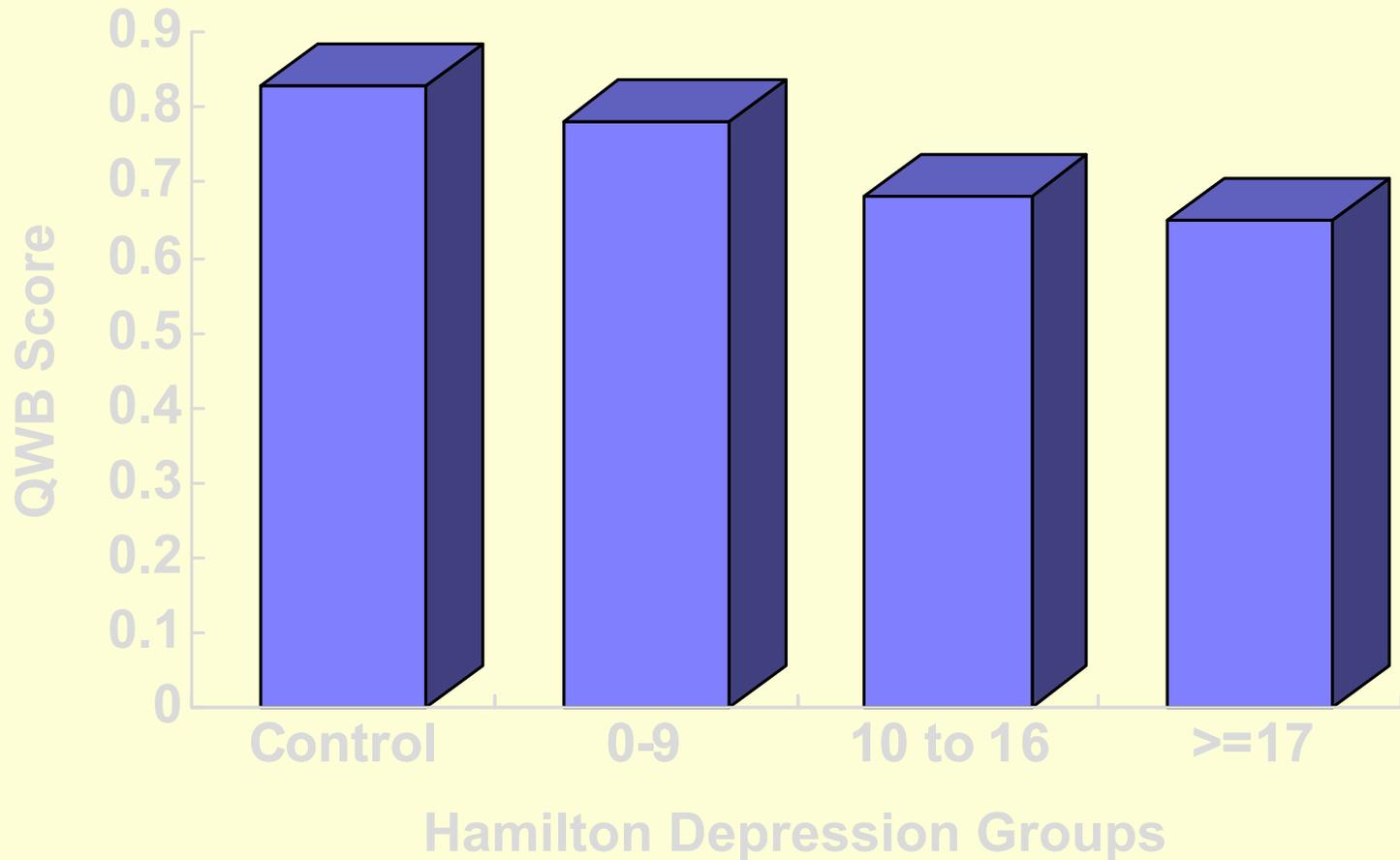


Figure 1

QWB by Hamilton Depression

(from Rubin et al 1994)





QWB-SA Mental Health

- trouble sleeping
 - feeling upset and blue
 - excessive worry
 - feeling no control
 - feeling lonely
 - frustration
 - hangover
 - change in sexual interest or performance
 - memory loss
 - thoughts images
 - mediation
 - loss of appetite
-



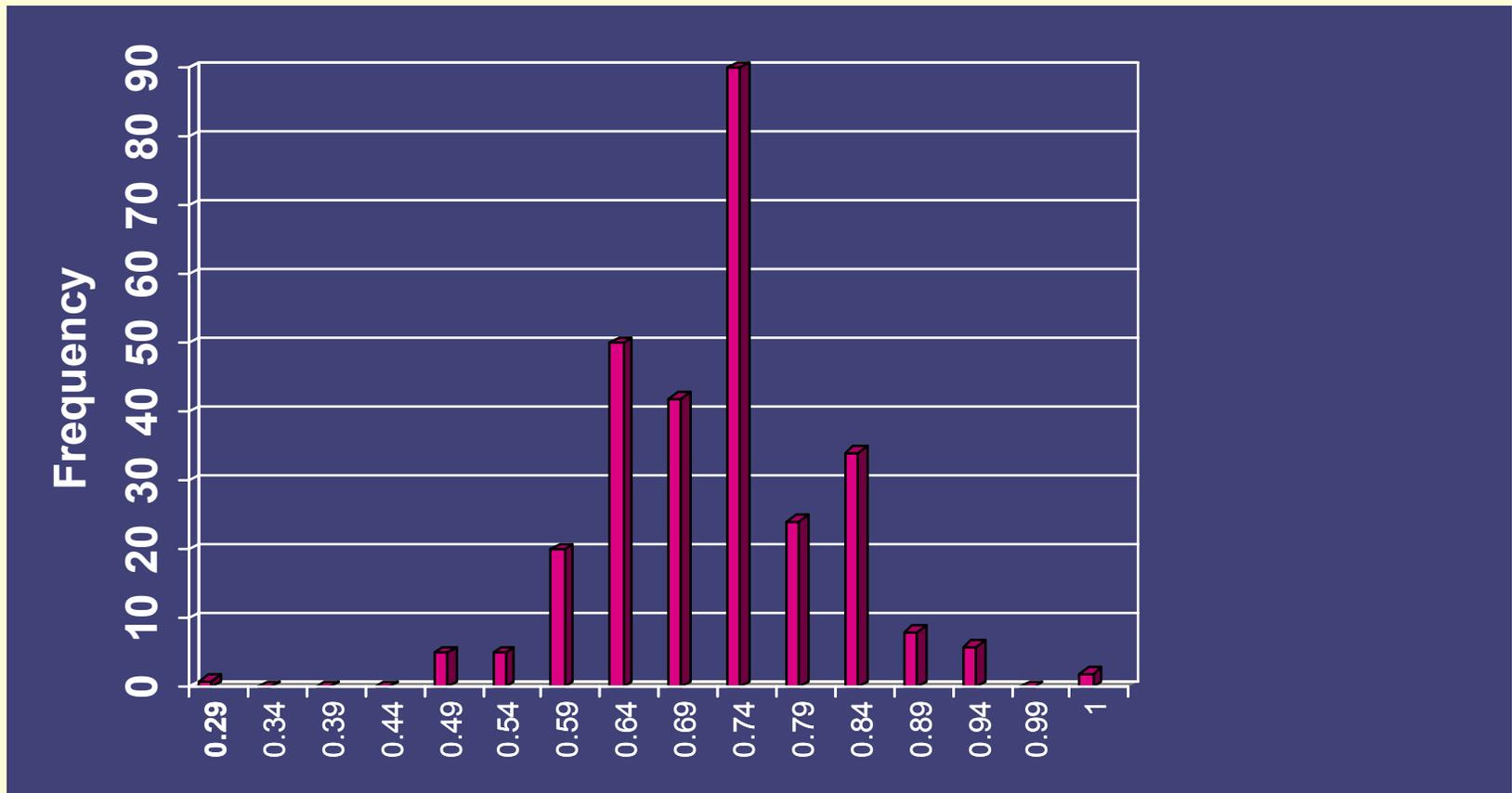
Correlations with Depression

| | |
|-----------------|-----|
| ● QWB-Hamilton | .70 |
| ● QWB-Beck | .58 |
| ● Beck-Hamilton | .69 |

Using older QWB weights r
HamD=.33, Beck=.30



QWB-SA Distribution (Andresen 1998, N=301)





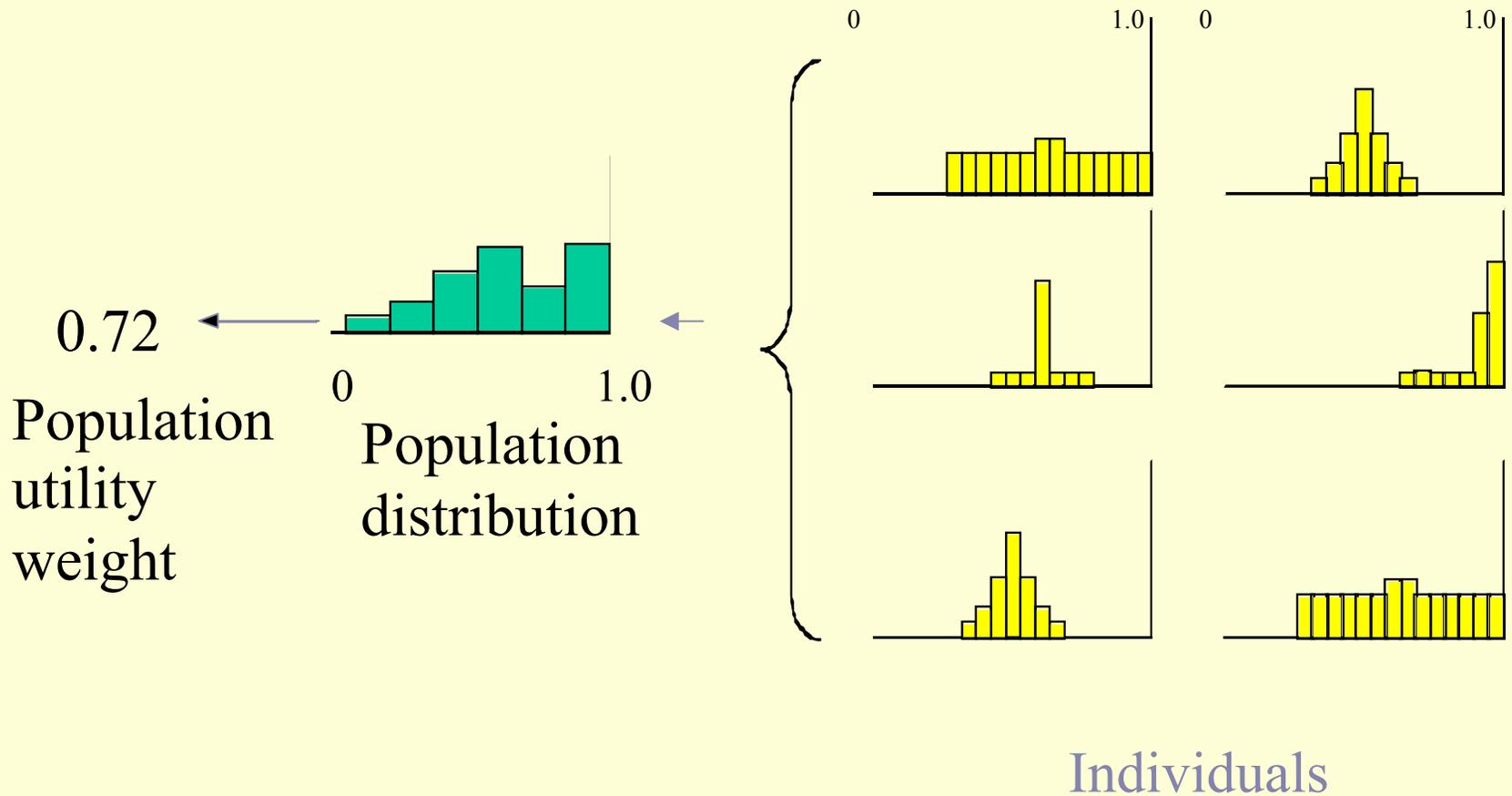
Summary

- QWB and SF-36 have some common roots
 - Correlations between QWB and some SF-36 components are substantial
 - QWB now can be self-administered
 - QWB can be used to estimate QALYs for policy analysis
 - Several theoretical and technical issues must be resolved in future studies
- 



Utility Assessment Issues

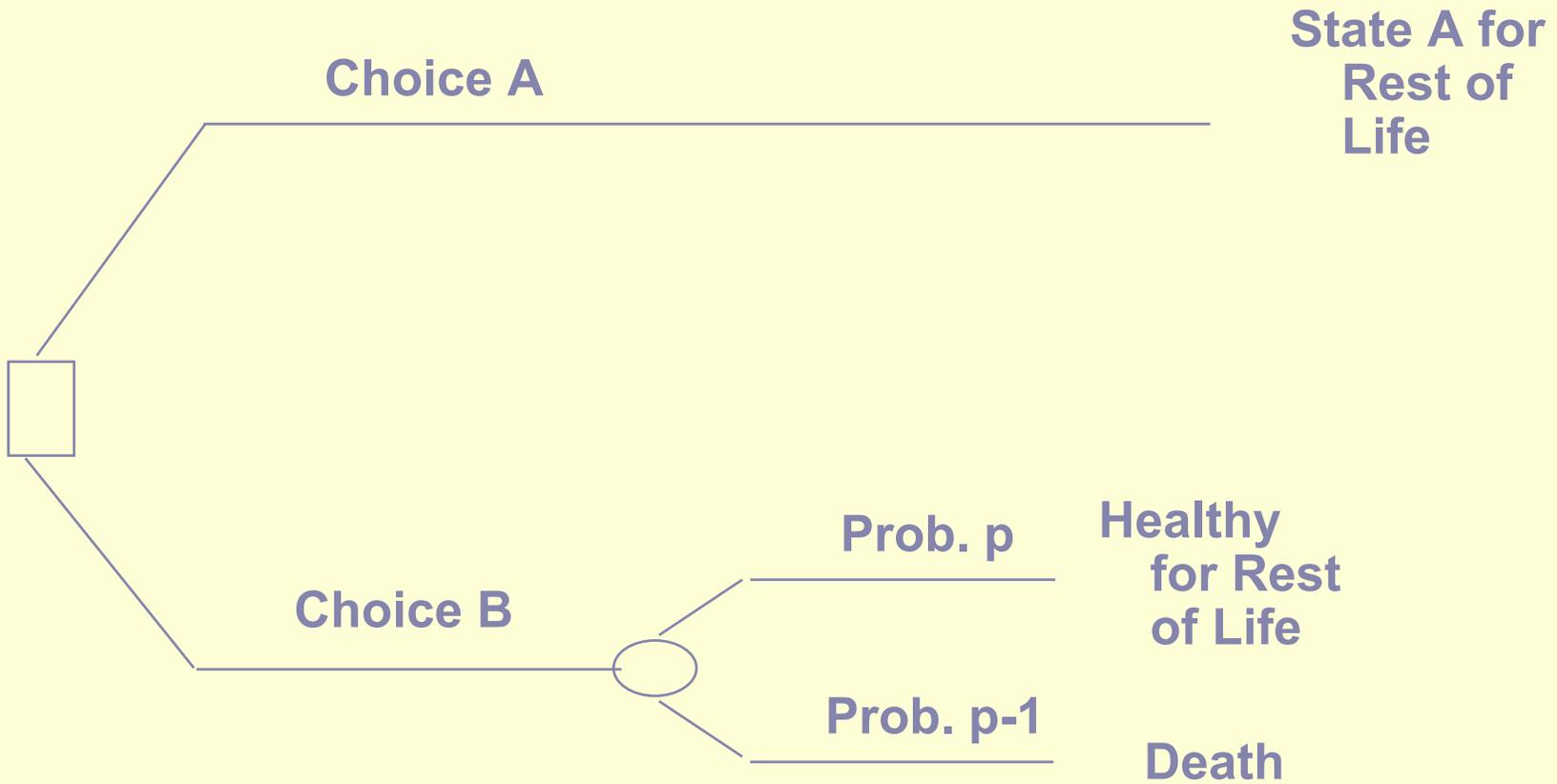
*The difficult task of development
of population utility weight
for a health condition*





Preference and Utility Assessment

- Standard Gamble
 - Time Trade-off
 - Rating Scales
- 

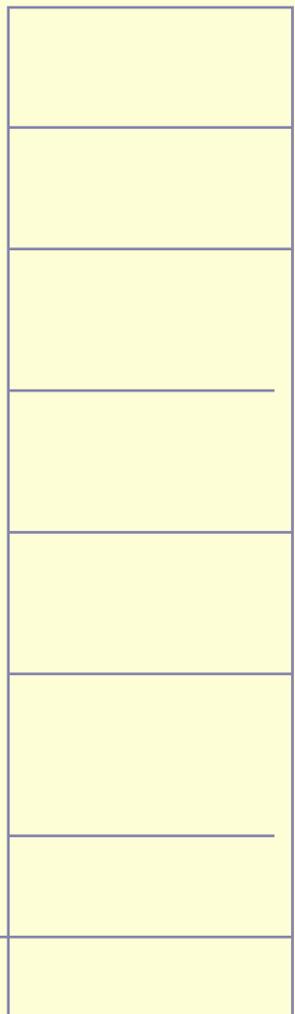


Example of Standard Gamble (Torrance & Feeny, 1989)

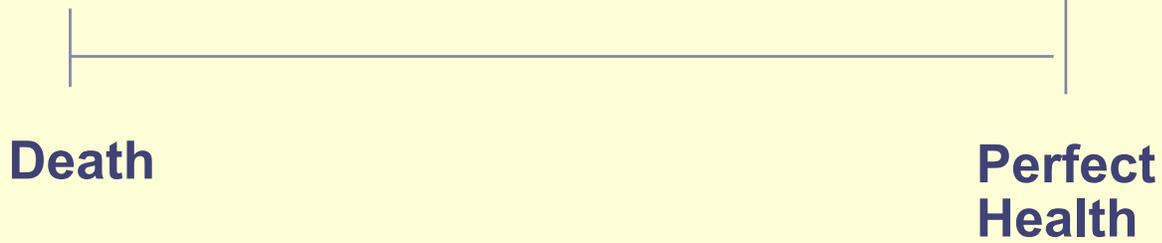
Category Scale



Perfect Health



Visual Analog



Death



Approaches for describing health states

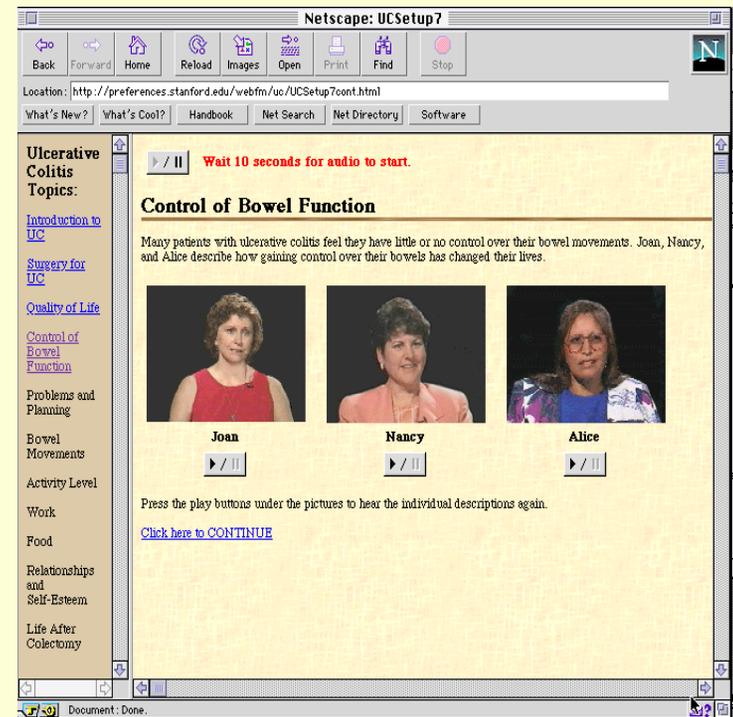
Brief Outline

Age: 40-65 yr. old employee housekeeper
Mobility: in house
Physical activity: walks but has limitations.
Social activity: did not perform but performed self-care activities
Symptoms/problems: sick or upset stomach, vomiting, or diarrhea

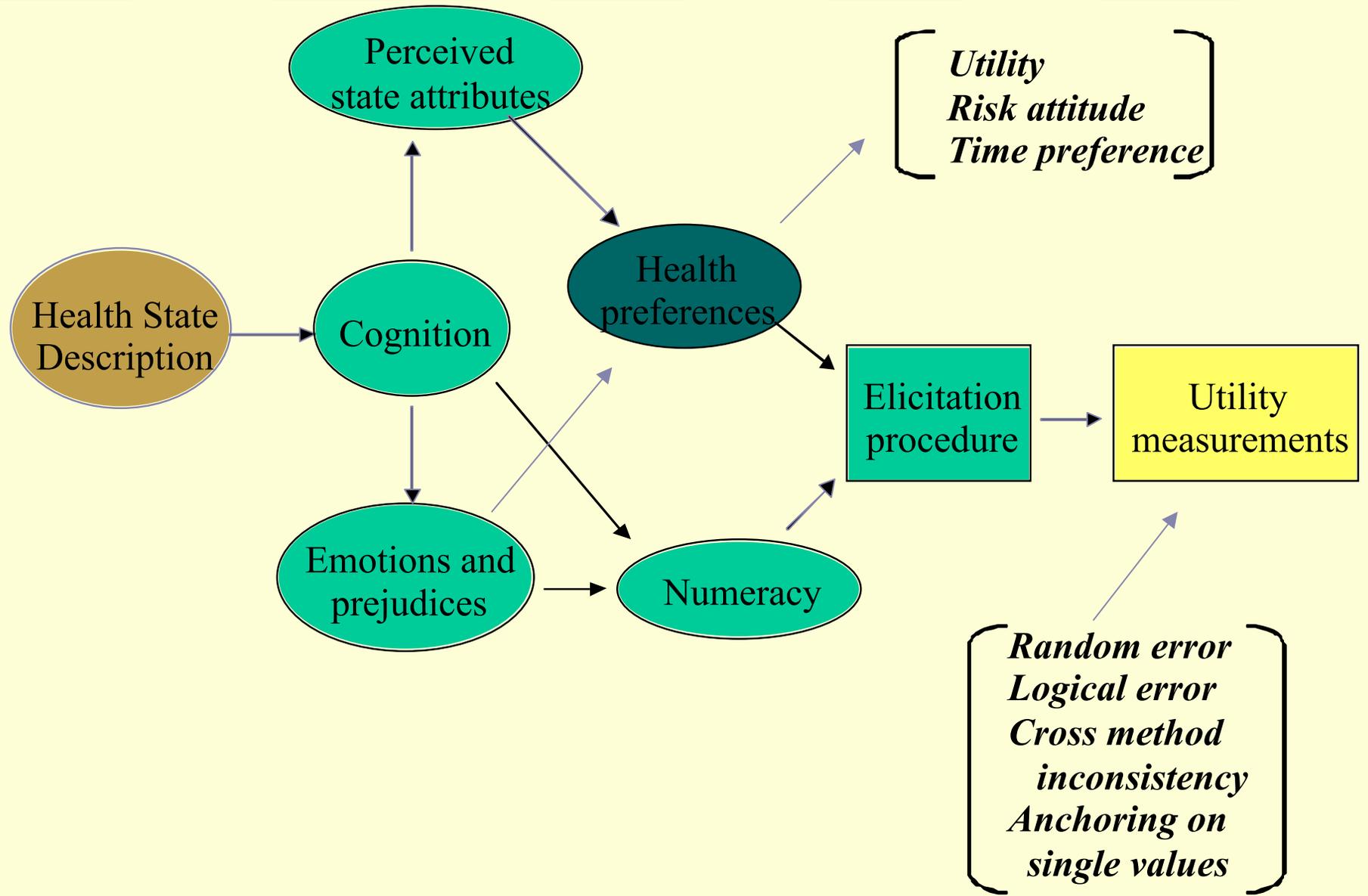
Narrative text

I am in the age range of 40-64 years I live alone and am confined to my home. I have lost 35 pounds in the last 6 months. I am able to only eat small amounts of food at present and I vomit occasionally. I am tired and weak and walk with the aid of a walker. I require assistance to get into and out of the bathtub. Social contact with my family and friends is infrequent.

Multimedia



What is an appropriate strength of stimulus to form preferences?





Potential Sources of Variability In Preference Measurements

- Descriptions of states
 - Scaling methods
 - Measurement or assignment procedures
 - Health Status and Social factors
- 

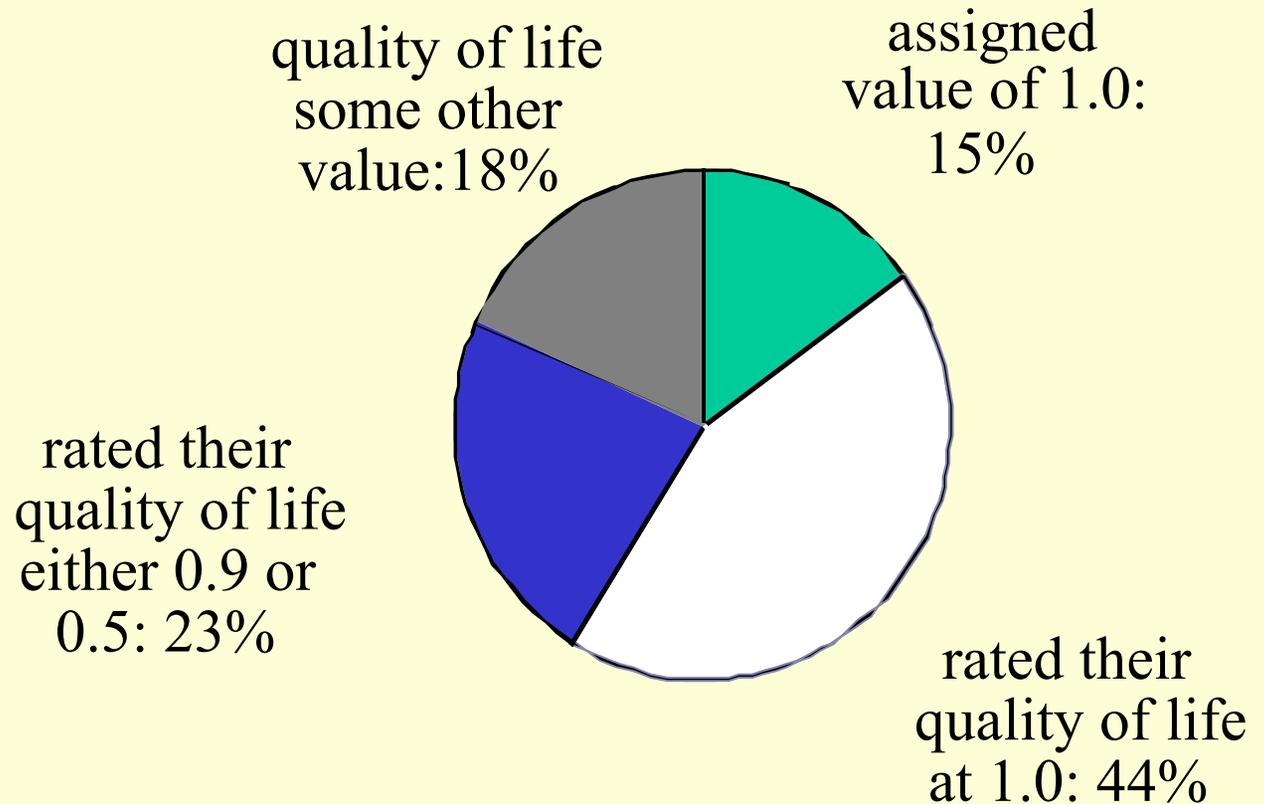


Validity

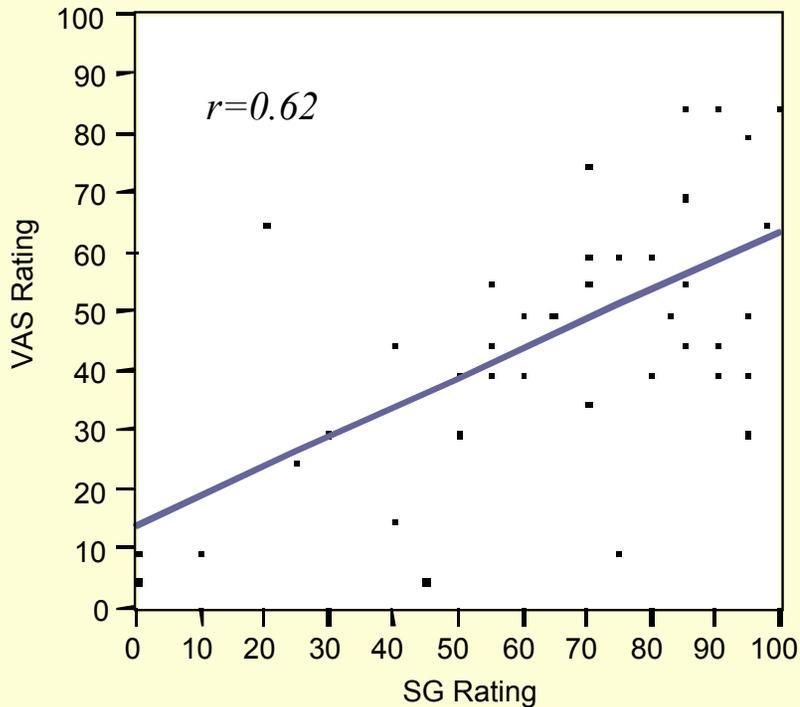
- No absolute standard or threshold
 - Valid aggregate utilities can only arise from valid measurements within individuals
 - Validity of measurements within an individual measurable by
 - Ability to discriminate among states within the protocol
 - Internal consistency of individual responses
- 

Discrete distributions of utilities make can assessment of reliability difficult.

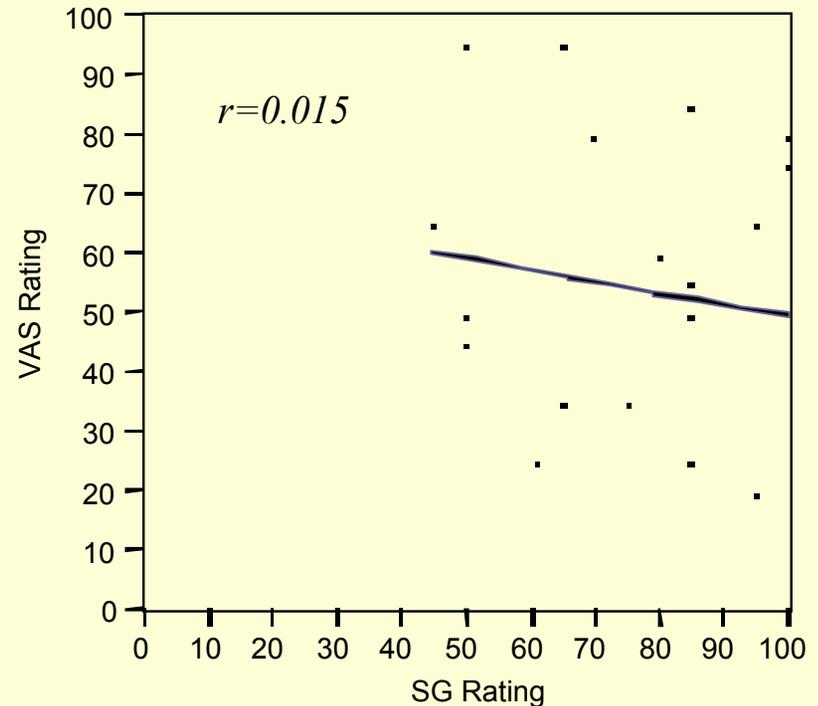
Results of the
Beaver Dam study
(Fryback et al.
Medical Decision
Making
1993)



Procedural Invariance and the Organization Of Preferences within an Individual



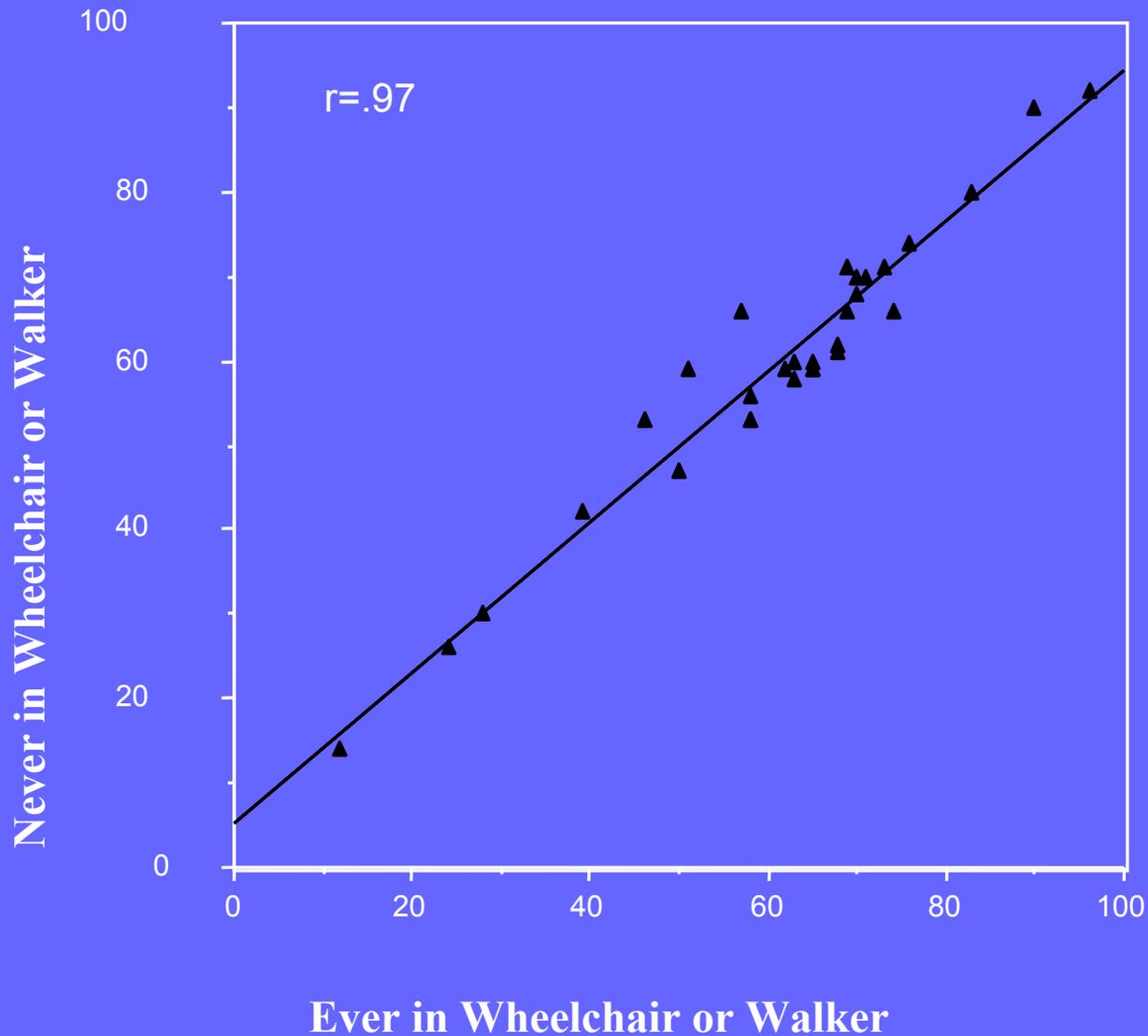
Satisfy

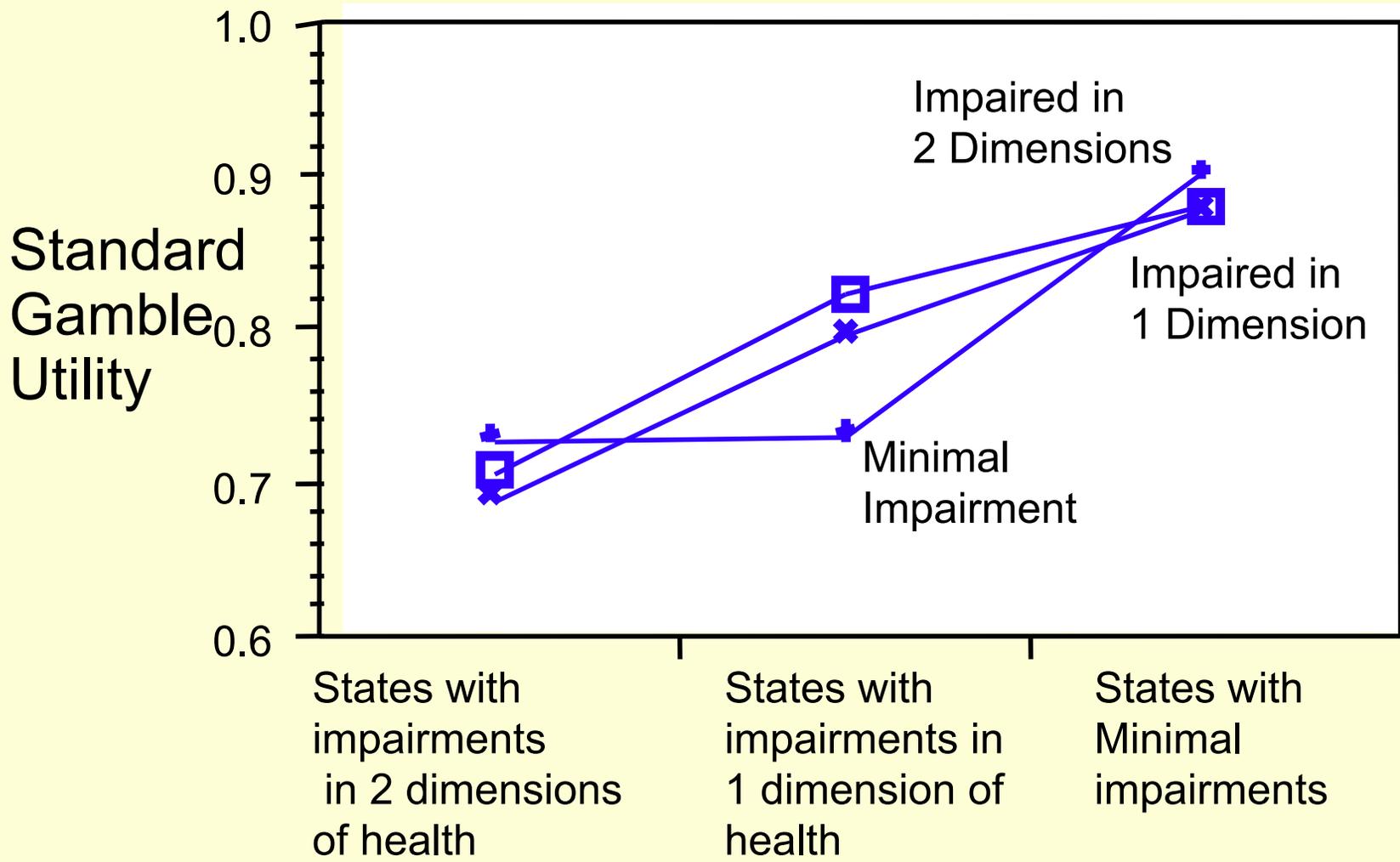


Fail

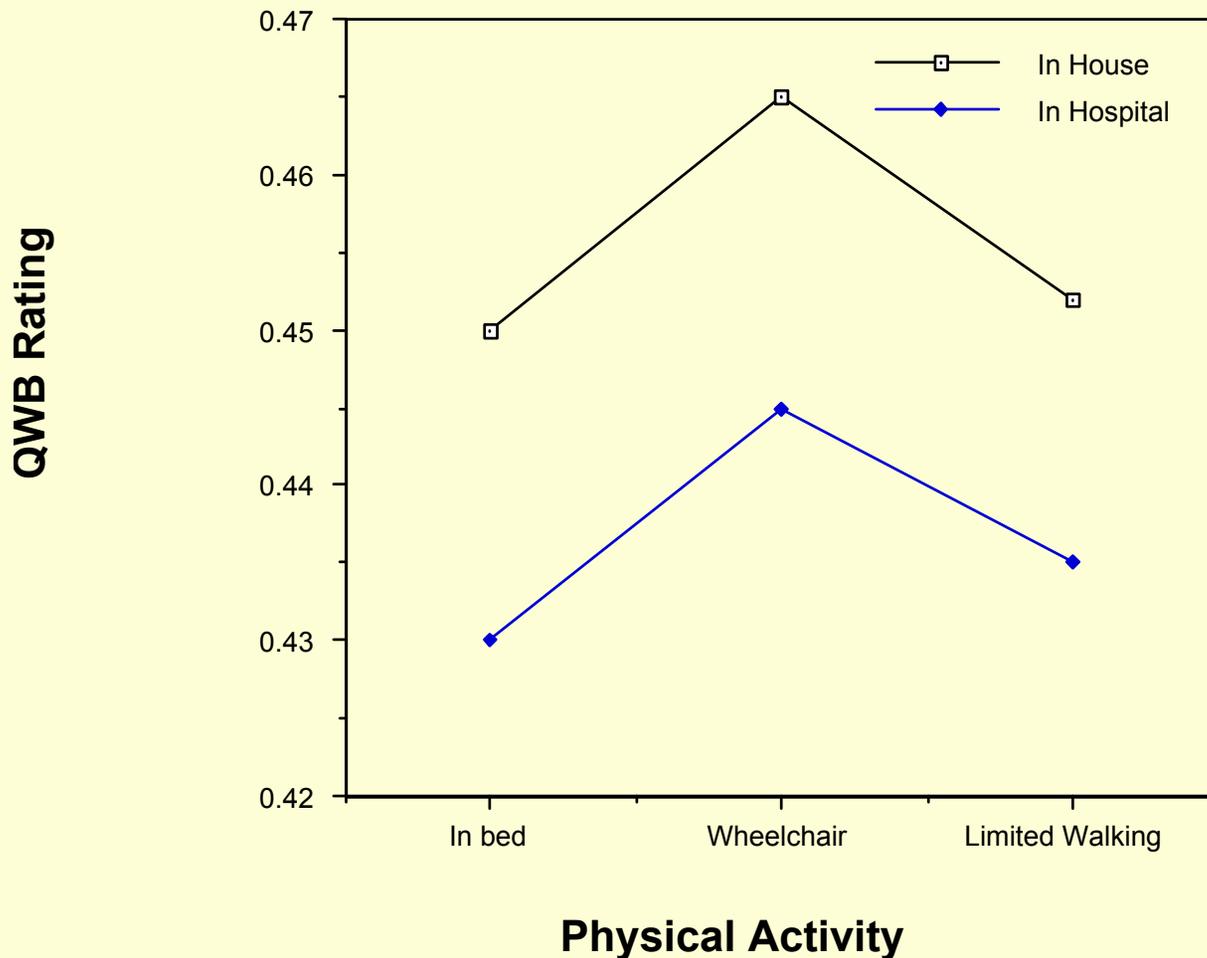
Lenert and Treadwell, Medical Decision Making, 1999

Comparison between ever and never in wheelchair or walker for 31 items:
Data from Oregon Health Services Commission

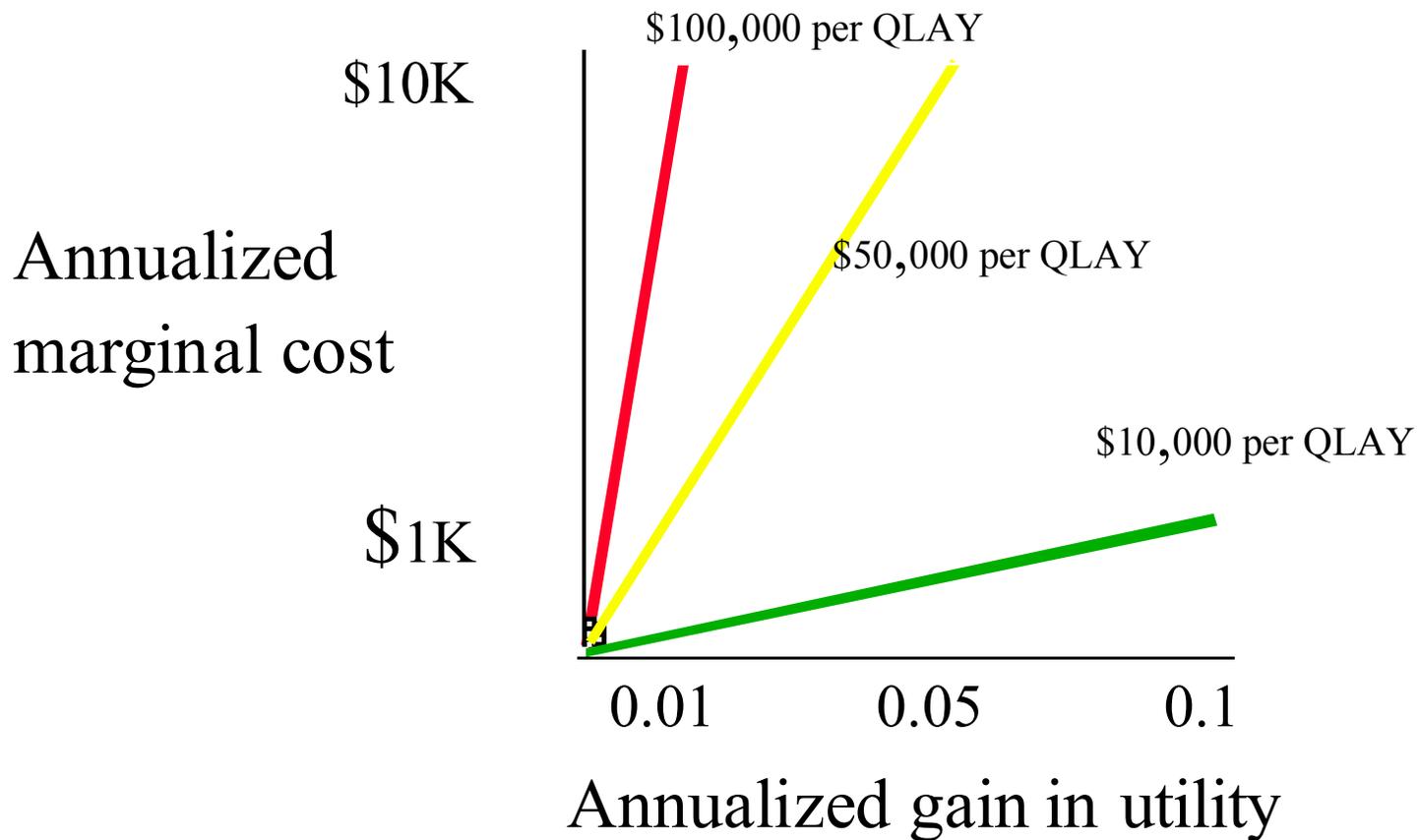




Additive Independence and Interval Scaling



Potential minimally important differences





Summary

- Competing methods (RS, TTO, SG) are really Complementary methods
 - all have some evidentiary basis.
 - Each capture different aspects of preferences.
 - There is no gold standard for measurement of preferences.
 - The focus of research needs to be:
 - understanding of the implications of choice of a particular scaling method
 - effects of changes in procedures for elicitation.
- 