# Health-Related Quality of Life

Ron D. Hays, Ph.D. (hays@rand.org) February 4, 2004 (3:00-6:00 pm) Main conference room

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## Health Care System Concerns



Access

### Affordability

Accountability

#### **Resource** Allocation Problem

Everyone in health care wants reimbursement for their services

Options range from acute surgery, prevention, to long term care

But there is a limited amount of money

How do we spend limited resources to enhance population health?

# **Cost Effective Care**





# "Outcomes" How is the Patient Doing?

#### **Physiological**

- Hematocrit
- Albumin

**Physician observation** 

Physical performance

<u>Self-report indicators</u>

Functioning and well-being



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



### **HRQOL** is Not

- Quality of
  environment
- Type of housing
- Level of income
- Social Support





More important to patients than physiological measures or physician observations.

Summarize overall results of health care:

Cost

# Types of HRQOL Measures



Profile

– Generic

– Targeted

Preference-based

#### **Powerpoint Slides**

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

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#### Advantages of Generic Measures

Allow comparisons across different people

- Across disease groups
- Sick versus well
- Young versus old

**Can detect unexpected side effects** 

# Generic HRQOL Item



In general, would you say your health is:

Excellent

Very Good

Good

Fair

Poor

#### **Overall Health Rating Item**

#### Overall, how would you rate your <u>current health</u>? (Circle One Number)



#### **Overall Quality of Life Item**

Overall, how would you rate your quality of life?



### Health versus Quality of Life

"In general, how would you rate your health?"

"Overall, how would you rate your quality of life?"

# Generic HRQOL: 8 SF-36 Scales



- Physical functioning
- Role limitations/physical

Pain

- General health perceptions
- Social functioning
- Energy/fatigue
- Role limitations/emotional
- Emotional well-being

# SF-36 Physical Health



# SF-36 Mental Health



# **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 very nervous? None of the time A little of the time Some of the time Most of the time All of the time

🚰 The SF Community - offering information and discussion on health outcomes - Microsoft Internet Explorer					
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From: lélie Date: 10-21-2002 Subject: Stydy only one dimension of the SF 36

Is it possible to administer only some questions of the SF 36 if we want to study only one dimension or should we administer the entire questionnaire ? Thanks for your help,

Lélie

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#### Scoring Generic HRQOL Scales

Average or sum all items in the same scale.

Transform average or sum linearly to

0-100 possible range

T-score metric

## Formula for Transforming Scores

$$Z_{X} = \frac{(X - \overline{X})}{SD_{x}}$$

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#### Uses of Generic Measures

#### **Cross-Sectional**

- Comparison of Different Samples
- Profiles of Different Diseases
- Longitudinal
- Profiles of Different Diseases
- Examining Antecedents
- Predicting utilization or mortality

# HRQOL Scores of Clinical Trial and Non-Clinical Trial HIV Patients

Cunningham et al. (1995)



# HRQOL of Those with Chronic Illness Compared to General Population



Hays, et al. (2000), <u>American Journal of Medicine</u>

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



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. <u>Archives of General Psychiatry</u>, <u>52</u>, 11-19.

#### Association of Exercise with Physical Functioning 2-years After Baseline in the MOS



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.

# Generic Health Ratings Associated with Hospitalizations (N = 20,158)



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

# Five-Year Mortality Rates by Levels of Physical Health



### Targeted HRQOL Measures

- Designed to be relevant to particular group.
- Sensitive to small, clinically-important changes.
- Important for respondent cooperation.
- More familiar and actionable.

# 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, <u>Archives of Physical Medicine and</u> <u>Rehabilitation</u>)

## Mattson-Prince (1997)

Dropped 10 physical functioning items because of perception that they were demeaning to people with SCI



#### 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 to Extremely)
### **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

#### **NEI-RQL-42** Far Vision Item

How much difficulty do you have judging distances, like walking downstairs or parking a car?

No difficulty at all A little difficulty Moderate difficulty A lot of difficulty

#### Spinal Cord Independence Measure

Self care (feeding, bathing, dressing, grooming)

**Respiration and sphincter management** 

Mobility (in bed and preventing pressure ulcers, bed-wheel chair, wheelchair-toilet-tub transfers)

#### **Kidney Disease-Targeted Scales**

- Symptoms/problems (12 items)
- Effects of kidney disease (8 items)
- Burden of kidney disease (4 items)
- Work status (2 items)
- Cognitive function (3 items)
- Quality of social interaction (3 items)
- Sexual function (2 items)
- Sleep (4 items)

HRQOL in Men Treated for Localized Prostate Cancer

**Cross-sectional study of managed care pop.** 

Sexual, urinary and bowel function and distress

214 men with prostate cancer

**98 radical prostatectomy** 

56 primary pelvic irradiation

60 observation alone

273 age/zip matched pts. without cancer

### **Sexual, Urinary and Bowel Function**



## Sexual, Urinary, and Bowel Function Outcomes



Litwin, et al. (1995, JAMA)



#### **Generic Profile Measures**

#### **Targeted Profile Measures**

-> Summarizing Profile Information

# Physical Health



# Mental Health



#### 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)

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)

#### SF-36 PCS and MCS

# $MCS = (MCS_z*10) + 50$

#### $PCS = (PCS_z*10) + 50$

**T-score Transformation** 

# 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. <u>Quality of</u> <u>Life Research, 10</u>, 405-413.

•Taft, C., Karlsson, J., & Sullivan, M. (2001). Reply to Drs Ware and Kosinski. <u>Quality of Life Research</u>, <u>10</u>, 415-420.

# 536 Primary Care Patients Initiating Antidepressant Tx

S-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. (Med Care, 1998)



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



# n = 194 with Multiple Sclerosis

Scores than general population on Emotional well-being (1 0.3 SD)  $\diamond$ Energy ( $\downarrow$ 1.0 SD)  $\otimes$  Social functioning ( $\downarrow 1.0$  SD) ♦ Yet SF-36 MCS was only 0.2 SD lower. 

Nortvedt et al. (Med Care, 2000)

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



### **Treatment Impact on Physical Health**



#### **Treatment Impact on Mental Health**



### Is New Treatment (X) Better Than Standard Care (O)?



# 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 = <u>0.20</u> Physical functioning + <u>0.15</u> Pain + <u>0.41</u> Energy + <u>0.10</u> Emotional well-being + <u>0.05</u> Social functioning + <u>0.09</u> 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. <u>Medical Care</u>, <u>32</u>, 716-731.

#### Is Use of Medicine Related to Worse HRQOL?

Person	Medication Use	HRQOL (0-100 scale)
1	Νο	dead
2	No	dead
3	Νο	50
4	Νο	75
5	Νο	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	e 5	50

### **Survival Analysis**

## Marathoner 1.0 Person in coma 1.0



### Profile + Mortality Outcomes for Acute MI (n = 133)



## Preference-Based Measure--Quality of Well-Being Scale

- Summarize HRQOL in QALYs
  - -- Physical activity (PAC)
  - Mobility (MOB)
  - Social activity (SAC)
  - Symptom/problem complexes (SPC)



# Quality of Well-Being Weighting Procedure

Each page in this booklet tells how an imaginary person is affected by a health problem on one day of his or her life. I want you to look at each health situation and rate it on a ladder with steps numbered from zero to ten. The information on each page tells 1) the person's age group, 2) whether the person could drive or use public transportation, 3) how well the person could walk, 4) how well the person could perform the activities usual for his or her age, and 5) what symptom or problem was bothering the person.

Example Case #1

#### Adult (18-65)

Drove car or used public transportation without help Walked without physical problems Limited in amount or kind of work, school, or housework Problem with being overweight or underweight



#### **QWB** Physical Activity Levels

1) In wheelchair and moved oneself or had difficulty:

lifting stooping using stairs walking, etc.

2) In bed, chair, couch, or wheelchair and did <u>not</u> move oneself

### QWB Mobility Levels

Did not drive car or use public transportation
 In hospital, nursing home, or hospice

#### **QWB** Social Activity Levels

1) Limited or did not perform role activities

2) Did not feed, bath, dress, or toilet oneself

### QWB Symptom/Problem Complexes

Worst Symptom/problem complex experienced

Breathing smog  $\rightarrow$ Loss of consciousness

## Quality of Well-Being States and Weights

Component	Measures	States	Weights
Physical activity	Physical function	In bed, chair, couch, or wheelchair* In wheelchair* or had difficulty lifting, stooping, using stairs, walking, etc	<u>077</u> 060
Mobility	Ability to get around or transport oneself	In hospital, nursing home, or hospice Did not drive car or use public transportation	. <u>090</u> 062
Social activity	Role function and self-care	Did not feed, bath, dress, or toilet Limited or did not perform role	<u>106</u> 061
Symptom/problem	Physical symptoms and complexes problems	Worst symptom from loss of consciousness to breathing	<u>407</u> smog or

unpleasant air

\* moved vs. did not move oneself in wheelchair



#### Mobility

**Self-care** 

**Usual activities** 

**Pain/discomfort** 

**Anxiety/depression** 

243 states, 3 levels per attribute



#### Your own health state today

By placing a tick in one box in each group below, please indicate which statement best describes your own health state today.

Do not tick more than one box in each group.

#### Mobility

have no problems in walking about	
have some problems in walking about	
am confined to bed	

#### Self-Care

have no problems with self-care	
have some problems washing and dressing myself	
am unable to wash or dress myself	

Usual Activities (eg. work, study, housework, family or leisure activities)
I have no problems with performing my usual activities
I have some problems with performing my usual activities
I am unable to perform my usual activities

#### Pain/Discomfort

I have no pain or discomfort I have moderate pain or discomfort I have extreme pain or discomfort

#### Anxiety/Depression

I am not anxious or depressed I am moderately anxious or depressed I am extremely anxious or depressed On each dimension, respondent gets three choices of level.



#### Vision

Hearing

Speech

Ambulation

**Dexterity** 

Cognition

Pain and discomfort

Emotion

972,000 states, 5-6 levels per attribute

## SF-6D Summary Measure

• 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

### Quality-adjusted life-years (QALYs)



Tengs, T. Presented at Health Services Research Seminar, VA Hospital San Diego July 2000
Cost/QALY (1993 US dollars) •\$0 Seat belt laws

•\$2k Pneumonococcal vaccine

\$6k Smoking cessation counseling

•\$12k Oral gold for rheumatoid arthritis

•\$40k CABG, 2-vessel disease; hemodialysis

•\$167k Mammography screening

•\$293k Hip replacement

•\$663k CABG, 1-vessel disease

#### **Questions?**

#### www.rand.org/health/surveys.html

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

## Next Week's Reading

Hays, R. D., Anderson, R. T., & Revicki, D. (1998). Assessing reliability and validity of measurement in clinical trials. In M. Staquet, R. Hays, & P. Fayers (eds.), <u>Quality of Life Assessment in Clinical Trials:</u> <u>Methods and Practice</u> (pp. 169-182). Oxford: Oxford University Press.

#### Ad Hoc Preference Score Estimates

Comprehensive Geriatric Assessment (n = 363 community-dwelling older persons) lead to improvements in SF-36 energy, social functioning, and

Physical functioning (4.69 points) in 64 weeks

Cost of \$746 over 5 years beyond control group

## 

Cost/QALY: \$10,600+

<\$20,000 per QALY worthwhile

#### Limitations of Preference Measures

**Complexity of task** 

**Coarseness of health states** 

Sensitivity to method of elicitation

## Time Tradeoff (TTO)

- Choice between two certain outcomes
- Years of life traded for quality of life
- Simple to administer alternative to SG



Choice #1: Your present state (e.g., paralysis) Life Expectancy: 10 years Choice #2: Complete mobility How many years (x) would you give up in your current state to be able to have complete mobility?

# $\begin{bmatrix} 1 - \frac{X}{10} = QALY \end{bmatrix}$



How many years (x) would you give up in your current state to be able to have complete mobility?

 $X = 0 \rightarrow QALY = 1$ 

X = 1 -> QALY = 0.9

X = 5 -> QALY = 0.5

X = 10 -> QALY = 0

[1 - X = QALY]10

#### Standard Gamble

#### **Classical method of assessing preferences**

- Choose between certain outcome and a gamble
- Conformity to axioms of expected utility theory
- Incorporates uncertainty (thus, more reflective of treatment decisions).

## Standard Gamble (SG)

**<u>Choice #1</u>**: Your present state (e.g., paralysis)

#### Choice #2: X probability of complete mobility 1-X probability of death

Preference Value: Point at which indifferent between choices, varying X
[X = QALY]

#### Standard Gamble (SG)

X probability of complete mobility

 $X = 1.00 \rightarrow QALY = 1.00$  $X = 0.50 \rightarrow QALY = 0.50$  $X = 0.00 \rightarrow QALY = 0.00$ 

## Hypothetical Health States

#### **Physical Health**

P3 P2 P1 Mental Health	0.00 -0.20 -0.50	High Medium Low
M3	0.00	High
M2	-0.30	Medium
M1	-0.40	Low

## Mapping Health States into Quality of Life

**Exists** 

Measured

