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

Ron D. Hays, Ph.D. HS249F

January 30, 2008 (3:30-6:30 pm) RAND Conference Room, 1232



- 1. What is the difference between symptoms and health-related quality of life?
- 2. How does one estimate the minimally important difference in health-related quality of life measures?
- 3. How do you know if a measure is responsive to change?

Contact Information

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How do you know how the patient is doing?

Temperature

Respiration

Pulse

Weight

Blood pressure



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

Symptoms

- Have you had a fever in the last 7 days?

No

Yes

What they are able to do

And how they feel about their life



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

-> 80% prostatectomy (-) vs. 45% waiting

- Urinary leakage

-> 49% prostatectomy (-) vs. 21% waiting

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

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

Physician observation

Physical performance

<u>Self-report indicators</u>

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



In general, how would you rate your health?

Excellent

Very Good

Good

Fair

Poor

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

How much of the time during the past 4 weeks have you been happy?

None of the time

A little of the time

Some of the time

Most of the time

All of the time



HRQOL is Not

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



Are self-reports reliable?

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

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

In general, how would you rate your health?

Excellent

Very Good

Good

Fair

Poor

Hospitalized Patients Report Worse General Health (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, 267</u>, 1617-1623.

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



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

Types of HRQOL Measures



Profile: Generic vs. Targeted

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

Formula for Transforming Scores

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

Microsoft Excel - transforming-scores.xls						~		_ & ×
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2	2	25	39.5285	-0.63246	43.6754			
3	3	50	39.5285	0	50			
4	4	75	39.5285	0.63246	56.3246			
5	5	100	39.5285	1.26491	62.6491			
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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

T-score Transformation

$PCS = (PCS_z*10) + 50$ MCS = (MCS_z*10) + 50

SF-36 Survey Version 1

http://www.sf-36.org/demos/SF-36.html

http://www.sf-36.org/demos/SF-36v2.html

http://www.assessmentcenter.net/ac1/

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)





HRQOL for HIV Compared to other Chronic Illnesses and 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.

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. <u>Journal of Clinical Epidemiology</u>, <u>47</u>, 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, JAMA)*

Sexual, Urinary and Bowel Function



HRQOL Measures Helpful in Ensuring Access to Cost-Effective Care





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Summarize overall results of health care:

Cost

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SF-36 Physical Health



SF-36 Mental Health



Treatment Impact on Physical Health



Treatment Impact on Mental Health



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.

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MCS-z = (PF-z*-.23) + (RP-z*-.12) + (BP-z*-.10) + (GH-z*-.12) + (EN-z*.24) + (SF-z*.27) + (RE-z*.43) + (MH-z*.48)

 $PCS-z = (PF-z^*.42) + (RP-z^*.35) + (BP-z^*.32) + (GH-z^*.25) + (EN-z^*.03) + (SF-z^*.01) + (RE-z^*.19) + (MH-z^*.22)$

(orthogonal) two factor (physical and mental health) solution introduces – and + weights into scoring algorithm

Summary scores for SF-36 derived from uncorrelated

Weights

536 Primary Care Patients Initiating Antidepressant Tx

♦ 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



n = 194 with Multiple Sclerosis

Scores than general population on Emotional well-being (1 0.3 SD) \diamond Energy (\downarrow 1.0 SD) \diamond 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



Farivar et al. alternative weights

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)

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



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http://www.ukmi.nhs.uk/Research/pharma_res.asp



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	No	dead
2	Νο	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 Medicin	e 5	50

Do a Survival Analysis?

Marathoner and person in coma = 1.0



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?



Brazier et al. SF-6D

Srazier 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) 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 no pain

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

You have a lot of energy all of the time

Health state 424421 (0.59)

- Your health limits you <u>a lot</u> in moderate activities (such as moving a table, pushing a vacuum cleaner, bowling or playing golf)
- You are <u>limited in the kind of work or other activities</u> as a result of your physical health
- Your health limits your social activities (like visiting friends, relatives etc.) <u>most of the time</u>.
- You have pain that interferes with your normal work (both outside the home and housework) <u>moderately</u>
- You feel tense or downhearted and low <u>a little of the time</u>.
- You have a lot of energy <u>all of the time</u>

Indirect Preference Measures--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



Quality of Well-Being States and Weights

Component	Measures	States	Weights
Physical activity	Physical function	In bed, chair, couch, or wheelchair*	<u>077</u> - 060
		stooping, using stairs, walking, etc	000
Mobility	Ability to get around or	In hospital, nursing home, or hospice	ice. <u>090</u> 062
	transport oneself	Did not drive car or use public transportation	062
Social activity	Role function and self-care	Did not feed, bath, dress, or toilet	<u>106</u>
		Limited or did not perform role	061
Symptom/problem	Physical symptoms and	Worst symptom from loss of	<u>407</u>
	complexes problems	consciousness to breathing	smog or
unpleasant air			

* moved vs. did not move oneself in wheelchair



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 ä

On each dimension, respondent gets three choices of level.



Mobility

Self-care

Usual activities

Pain/discomfort

Anxiety/depression

243 states, 3 levels per attribute



Vision

Hearing

Speech

Ambulation

Dexterity

Cognition

Pain and discomfort

Emotion

972,000 states, 5-6 levels per attribute

Quality-adjusted life-years (QALYs)



Tengs, T. Presented at Health Services Research Seminar, VA Hospital, San Diego, July, 2000

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Quality of Life for Individual Over Time



Direct Preference Measures Time Tradeoff (TTO)

- Choice between two certain outcomes
- Years of life traded for quality of life
- Simple to administer alternative to SG
Time Trade-off approach:



Alternative 1: intermediate health state x, for time t, followed by death. Alternative 2: full health for time s where s<t, followed by death.

Time t is given and the individual is asked to state s. The preference score is then worked out as s/t.

Time Tradeoff

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

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

Time Tradeoff

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-<u>X</u>=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).



Alternative 1: probability (p) of living full health for individual's remaining life expectancy otherwise immediate death.

Alternative 2 is the certainty of living in a given intermediate health state x.

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]

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Standard Gamble (SG)

X probability of complete mobility

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

Questions?



For further information

http://gim.med.ucla.edu/FacultyPages/Hays/ http://www.rand.org/health/surveys.html http://www.qolid.org/ www.sf-36.com http://www.nihpromis.org/ http://www.chime.ucla.edu/measurement/measurement.htm http://www.dartmouth.edu/~coopproj/more charts.html http://medicine.ucsd.edu/fpm/hoap/index.html http://www.mapivalues.com/ http://healthmeasurement.org/ http://openhealthmeasures.org/repository/index.html http://www.facit.org/ http://www.eortc.be/ http://www.uclaurology.com/site uo/pdf/PCI short scoring.pdf

Appendix: Generic Child Health Measures

Landgraf, J. M., & Abetz, L. N. (1996). Measuring health outcomes in pediatric populations: Issues in psychometrics and application. In B. Spilker (ed.), <u>Quality of life</u> and pharmacoeconomics in clinical trials, <u>Second edition</u>. Lippincott-Raven Publishers.