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

May 4, 2014 (8:30 - 11:30 PDT)

HPM216: Quality Assessment/ Making the Business Case for Quality



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## Examples of Health-Related Quality of Life in Pubmed

- Int J Public Health, 2014, in 8,743 coronary patients
- J Cancer Surviv, 2014, SF-36 in cancer survivors
- JAMA Otolaryngol Head Neck Surg, 2013, laryngopharyngeal reflux-HRQOL laryngopharyngeal reflux patients
- JAMA, 2011, "sexual HRQOL" in men with prostate cancer

## Health-Related Quality of Life (HRQOL)

#### How the person FEELs (well-being)

- Emotional well-being
- Pain
- Energy

#### What the person can DO (functioning)

- Self-care
- Role
- Social





I was grouchy [1<sup>st</sup> question]

- Never	[39]
- Rarely	[48]
- Sometimes	[56]
- Often	[64]
- Always	[72]

Estimated Anger = 56.1 SE = 5.7 (rel. = 0.68)

#### I felt like I was ready to explode

### [2<sup>nd</sup> question]

- Never
- Rarely
- Sometimes
- Often
- Always

### Estimated Anger = 51.9 SE = 4.8 (rel. = 0.77)

- I felt angry [3<sup>rd</sup> question]
  - Never
  - Rarely
  - Sometimes
  - Often
  - Always

Estimated Anger = 50.5 SE = 3.9 (rel. = 0.85)

#### I felt angrier than I thought I should [4<sup>th</sup> question]

- Never
- Rarely
- Sometimes
- Often
- Always

### Estimated Anger = 48.8 SE = 3.6 (rel. = 0.87)

- I felt annoyed [5<sup>th</sup> question]
  - Never
  - Rarely
  - Sometimes
  - Often
  - Always

Estimated Anger = 50.1SE = 3.2 (rel. = 0.90)

- I made myself angry about something just by thinking about it. [6<sup>th</sup> question]
  - Never
  - Rarely
  - Sometimes
  - Often
  - Always

Estimated Anger = 50.2 SE = 2.8 (rel = 0.92)

## Computer Adaptive Testing (CAT)









www.nihpromis.org

## Reliability Target for Use of Measures with Individuals

- Reliability ranges from 0-1
  - 0.90 or above is goal
     >SEM = SD (1- reliability)<sup>1/2</sup>
  - ➢ 95% CI = true score +/- 1.96 x SEM
    - if true z-score = 0, then CI: -.62 to +.62
      Width of CI is 1.24 z-score units
- Reliability = 0.90 when <u>SE = 3.2</u>
  - T-scores (mean = 50, SD = 10) T = 50 + (z \* 10)
  - Reliability =  $1 (SE/10)^2$

## PROMIS Physical Functioning vs. "Legacy" Measures



#### Physical Functioning and Emotional Well-Being at Baseline for 54 Patients at UCLA-Center for East West Medicine



MS = multiple sclerois; ESRD = end-stage renal disease; GERD = gastroesophageal reflux disease.

#### Significant Improvement in all but 1 of SF-36 Scales (Change is in T-score metric)

	Change	t-test	prob.
PF-10	1.7	2.38	.0208
RP-4	4.1	3.81	.0004
BP-2	3.6	2.59	.0125
GH-5	2.4	2.86	.0061
<b>EN-4</b>	5.1	4.33	.0001
SF-2	4.7	3.51	.0009
<b>RE-3</b>	1.5	0.96	.3400 ←
EWB-5	4.3	3.20	.0023
PCS	2.8	3.23	.0021
MCS	3.9	2.82	.0067

### Effect Sizes for Changes in SF-36 Scores



PFI = Physical Functioning; Role-P = Role-Physical; Pain = Bodily Pain; Gen H=General Health; Energy = Energy/Fatigue; Social = Social Functioning; Role-E = Role-Emotional; EWB = Emotional Well-being; PCS = Physical Component Summary; MCS = Mental Component Summary.

## Effect Size

#### (Follow-up – Baseline)/ SD<sub>baseline</sub>

Cohen's Rule of Thumb:

ES = 0.80 Large

## Amount of Change Needed for Significant Individual Change



PFI = Physical Functioning; Role-P = Role-Physical; Pain = Bodily Pain; Gen H=General Health; Energy = Energy/Fatigue; Social = Social Functioning; Role-E = Role-Emotional; EWB = Emotional Well-being; PCS = Physical Component Summary; MCS = Mental Component Summary.

## 7-31% of People in Sample Improve Significantly

	% Improving	% Declining	Difference
PF-10	13%	2%	+ 11%
RP-4	31%	2%	+ 29%
<b>BP-2</b>	22%	7%	+ 15%
GH-5	7%	0%	+ 7%
<b>EN-4</b>	9%	2%	+ 7%
SF-2	17%	4%	+ 13%
<b>RE-3</b>	15%	15%	0%
EWB-5	19%	4%	+ 15%
PCS	24%	7%	+ 17%
MCS	22%	11%	+ 11%

## Defining a Responder: Reliable Change Index (RCI)



 $SEM = SD_{hl} \times \sqrt{1 - r_{xx}}$ 

*Note:*  $SD_{bl}$  = standard deviation at baseline  $r_{xx}$  = reliability

# Amount of Change in Observed Score Needed To be Statistically Significant



*Note:*  $SD_{bl}$  = standard deviation at baseline and  $r_{xx}$  = reliability

"Implementing patient-reported outcomes assessment in clinical practice: a review of the options and considerations"

Snyder, C.F., Aaronson, N. K., et al. <u>Quality</u> of Life Research, 21, 1305-1314, 2012.

- HRQOL has rarely been collected in a standardized fashion in routine clinical practice.
- Increased interest in using PROs for individual patient management.
- Research shows that use of PROs:
  - Improves patient-clinician communication
  - May improve outcomes

Your scores for the CATs you completed are shown below.

The diamond + is placed where we think your score lies. This diamond is placed on your T-Score, which is a standardized score that is based on an average score of 50, based on responses to the same questions in the United States general population. The T-score also has a standard deviation of 10 points, so a score of 40 or 60 represents a score that is one standard deviation away from the average score of the general US population.

The Standard Error (SE) is a statistical measure of variance and represents the possible range of your score. The lines on either side of the diamond in your profile report show the possible range of your actual score around this estimated score. It is very likely that your score is in the range of these lines.



24





# U.S. Health Care Issues



• Access to care

 $- \sim 50$  million people without health insurance

- Costs of care
  - Expenditures ~ \$ 2.7 Trillion

• Effectiveness (quality) of care

### How Do We Know If Care Is Effective?

- Effective care maximizes probability of desired health outcomes
  - Health outcome measures indicate whether care is effective

Cost ↓

Effectiveness ↑

## Health Outcomes Measures

- Traditional clinical endpoints

   Survival
  - Clinical/biological indicators
    - Rheumatoid factor
    - Blood pressure
    - Hematocrit
- Patient-Reported Outcomes

# Types of HRQOL Measures



- Generic vs. Targeted
- Profile vs. Preference-based

## Generic Item

In general, how would you rate your health?

Excellent Very Good Good Fair

Poor

# Targeted Items Assessing "Burden of Kidney Disease"

- My kidney disease interferes too much with my life.
- Too much of my time is spent dealing with my kidney disease.
- I feel frustrated with my kidney disease.
- ✤I feel like a burden on my family.

#### Is CAM Better than Standard Care (SC)?



#### Is Acupuncture Related to Worse HRQOL?

Subject	Acupuncture	HRQOL
	(0-100) 1	
	2 3 No 50	
	4 No 75 5 No 100	
	6 Yes0 7 Yes25	
	8 Yes50	
	9 fes75 10 Yes100	
Group	n	HRQOL
	No Acupuncture375 Yes Acupuncture550	

### Quality of Life for Individual Over Time



## Goal is Access to Cost-Effective Care

Cost ↓

Effectiveness ("Utility") ↑

#### http://www.ukmi.nhs.uk/Research/pharma\_res.asp



## "QALYs: The Basics"

Milton Weinstein, George Torrance, Alistair McGuire (Value in Health, 2009, vol. 12 Supplement 1)

- What is value?
  - Preference or desirability of health states
- How are QALYs used?
  - Societal resource allocation
  - Personal decisions such as decision about whether to have a treatment
  - Societal or program audit
    - Evaluate programs in terms of health of the population.

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#### **Utility Assessments**

An important issue in medical decision making is how to measure people's preferences for health states in a way that will facilitate comparisons of health states. The most important measure of preference is the "utility" of the health state to the individual who will experience it, which is a value from 0 (representing death) to 1 (perfect health and well-being).

This page allows you to assess the utility for a health state using three techniques: rating scale, standard gamble, and time tradeoff.

Enter the health state that you'd like to assess the utility of: amputation of your left hand at the wrist

Select the assessment method to use:

- Rating scale
- Standard Gamble
- Time Tradeoff

Let's do it!

#### http://araw.mede.uic.edu/cgi-bin/utility.cgi

## SG>TTO>RS

#### ➤ SG = TTO<sup>a</sup>

#### ➤ SG = RS<sup>b</sup>

Where a and b are less than 1

The EQ-5D-3L descriptive system should be scored as follows:

By placing a tick in one box in each group, please indicate which statements best describe your health today.

#### Mobility

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

#### Self-Care

I have no problems with selfcare I have some 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 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



Π



NB: There should be only <u>one</u> response for each dimension.

#### 0.435

## HRQOL in SEER-Medicare Health Outcomes Study (n = 126,366)

SF-6D (0-1 possible range) by Condition



Controlling for age, gender, race/ethnicity, education, income, and marital status.

# Distant stage of cancer associated with 0.05-0.10 lower SF-6D Score



**Figure 1.** Distant Stage of Disease Associated with Worse SF-6D Scores (Sample sizes for local/regional, distant, and unstaged: Breast (2045, 26, 347); Prostate (2652, 61 and 633), Colorectal (1481, 48 and 203), and Lung (466, 47 and 65).

# Questions?

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Powerpoint file at: <u>http://gim.med.ucla.edu/FacultyPages/Hays/</u>