# Health Related Quality of Life and Health Status

Robert M. Kaplan University of California, Los Angeles Dennis G. Fryback University of Wisconsin (Retired) Prepared for Economic Analysis of Nutrition Interventions: Methods, Research and Policy National Institutes of Health February 23, 2010



# What Methods Can Be Used to Measure Health?



# **Summary Measures of Population Health**

- Preference-based, generic measures of health-related quality of life (HRQoL)
  - Main focus of this talk:
    - What these are
    - Their role in a population health data system
    - How they might be implemented in public health

# Mortality-based measures

- death rates, life expectancies, etc.
- All the familiar stuff

- Mortality-based measures
  - death rates, life expectancies, etc.
- Morbidity-based measures
  - indicators

# • Indicators:

- Single, countable things
  - TB rate
  - C-section rates
  - % population who exercise
- Examples:
  - Healthy People 2010 "Leading Indicators"
  - WHO "Core Health Indicators"
  - America's Health Rankings
  - Wisconsin County Health Rankings

- Mortality-based measures
  - death rates, life expectancies, etc.
- Morbidity-based measures
  - indicators
  - health status measures
    - disease-, organ-specific

Health Status Measures: point in time summaries of state of a person's health

### Disease-, organ-specific ....

Created to be sensitive to changes in symptoms or functional impairment due to a particular disease process

### Examples:

- Arthritis Impact Measurement System (AIMS)
- Vision Function Questionnaire (VFQ-25)
- McGill Pain Questionnaire
- NY Heart Association Classification

Some physician-reported, others patient-reported \*Many of these are scored by summing across questions in a questionnaire\*

# **Mortality-based measures**

 death rates, life expectancies, etc.

### **Morbidity-based measures**

- indicators
- health status measures
  - disease-, organ-specific
  - "Generic" health status

### IIII The Health Measurement Research Group www.healthmeasurement.org

**Generic Health Status Measures** Most famous: SF-36 health profile

One questionnaire with 36 questions  $\rightarrow$ 

Several questions about each of 8 different domains of health

KEY: multiple scales to cover broad scope of health, not tied to one disease or organ system

### Scoring:

Psychometric scales based on summing responses to multiple questions Separate scores for each subscale or health concept PF, RP, BP, GH, VT, SF, RE, MH PCS MCS

- Mortality-based measures
  - death rates, life expectancies, etc.

# Morbidity-based measures

- indicators
- health status measures
  - disease-, organ-specific
  - "generic"
- health-related quality-of-life (HRQoL) indexes

### HRQoL indexes

Like generic health status – try to comprehensively cover conceptual basis of health with multiple questions about health

### <u>Scoring</u>

- not simple sums--these are not psychometric scales!
- <u>econometric methods</u> used to elicit utility weights ("preferences") for health states
- 0 = dead, 1= perfect health
- average preference weights from community sample of people

# Data Pyramid for Population Health (after Wolfson)



- Two areas of concern in population health Morbidity and Mortality
  - <u>"Morbidity"</u>: how do people feel, how health problems affect them
    - ability/disability
    - functional capacity
    - independence
    - other aspects of health & well-being
  - <u>"Mortality"</u>: how long people live
    - mortality rates and survival rates
    - life expectancy
- One summary measure, HRQoL, combines all the aspects of morbidity
- A second summary measure, QALE, combines HRQOL and mortality into a single number

III The Health Measurement Research Group www.healthmeasurement.org

# How do we measure quality of life?





# Traditional

# Life Expectancy Infant Mortality Disability Days

# Measuring Effectiveness

# What is the meaning of life?



# Tell Me Old Wise one ... What is the meaning OF Life?









If widely different interventions are to be compared....

 The measure of health must be able to encompass not only differences in length of life but differences in the quality of that life, in symptoms and ability to function.

# Survival Analysis

# Alive 1.0 Dead 0.0

# Problem with Survival Analysis Tennis player 1.0 Man in coma 1.0

III The Health Measurement Research Group www.healthmeasurement.org



# Purpose of Quality Adjusted Survival Analysis

# To summarize life expectancy with adjustments for quality of life

# **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

# What is a QALY?

 The QALY is a measure of health outcome which assigns to each period of time a weight, ranging from 0-1, corresponding to the quality of life during that period, where 1 corresponds to perfect health and a weight of 0 corresponds to a health state judged equivalent to death (Peter Neumann, Tufts Medical Center)

# The concept of a QALY



### IIII The Health Measurement Research Group

www.healthmeasurement.org

# Using QALYs to measure the impact of a treatment



www.healthmeasurement.org

# **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



# Cross-sectional samples of individuals HRQoL at a point in time can be used for meaningful population measures

- Community averages for HRQoL summarize health at a point in time
- Cross-sectional HRQoL data can be combined with mortality data
  - old idea, attributed to Sullivan at Bureau of the Census in 1960s
  - elaborated by others since

# Summary Measures of Population Health (Molla et al, NCHS Statistical Note, 2001)



### |||| The Health Measurement Research Group

www.healthmeasurement.org

		NCHS Table of Health-adjusted Life Expectancy			
		(US females from 2000 census and NHIS)			
		Age bracket	LE	HALE	HALE/LE
		0-4 years	79.5	69.8	87.8%
		5–9 years	75.0	65.4	87.2%
		10-14 years	70.1	60.5	86.3%
		15–19 years	65.1	55.7	85.6%
		20-24 years	60.3	51.0	84.6%
20.5 HALYs		25–29 years	55.4	46.4	83.8%
		30–34 years	50.5	41.8	82.8%
-13.8 HALYs		35–39 years	45.7	37.2	81.4%
6.7 HALYs		40-44 years	40.9	32.8	80.2%
10-year HALE		45-49 years	36.2	28.5	7 <mark>8.</mark> 7%
for 55-59 yo		50–54 years	31.6	24.3	76.9%
female	-	55–59 years	27.1	20.5	75.6%
		60–64 years	22.9	17.0	74.2%
	-	65–69 years	18.9	13.8	73.0%
		70–74 years	15.2	10.8	71.1%
		75–79 years	11.8	8.1	68.6%
		80-84 years	8.7	5.8	66.7%
I I I I The Health Measurement Research Group					

www.healthmeasurement.org

# What has held us back?

# Distractions

- Disagreements on which measure is best
- Disagreements on general philosophy of outcome measurement
  - Generic vs disease specific
  - Psychometric vs. utility based
  - Disciplinary differences statistics, economics, medicine, psychology, anthropology....

# We do agree on some of the core issues

- Most measures can be traced back to Sullivan (1966)
  - Sullivan rarely cited
- Content of items is remarkably similar
- Most measures combine measures of life length and life quality
- Most quality of life measures are hybrid health status/utility measures
  - Health states and health weights (Erickson)

# John Ware

 Think of different approaches as brand names of products designed to measure the same underlying construct... health

# **Preference and Utility Assessment**

# Standard Gamble

- Time Trade-off
- Rating Scales
- Think scoring systems

# Small set of potential HRQOL indexes available today

- EQ-5D
- HUI2, HUI3
- SF-6D
- QWB-SA
- HALex

Each has an associated questionnaire varying from 5 to nearly 60 questions; varying times to complete from 2 min to 15 min on average.

# Health Domains addressed by these HRQoL indexes

### QWB-SA

- Mobility
- Physical activity
- Social activity
- Symptoms

### **HALex**

- Self-rated health
- Physical activity limitations

<u>SF-6D</u> (from SF-36 questionnaire)

- Physical function
- Role limitation
- Social function
- Pain
- Mental health
- Vitality

### <u>HUI2</u>

- Sensation
- Mobility
- Emotion
- Cognition
- Self-care
- Pain

## EuroQol EQ-5D

- Mobility
- Self-care
- Usual activities
- Pain/discomfort
- Anxiety/depression

### <u>HUI3</u>

- Vision
- Hearing
- Speech
- Ambulation
- Dexterity
- Emotion
- Cognition
- Self-care
- Pain

# Scale ranges for these HRQoL indexes

## QWB-SA

- Mobility
- Physical activity
- Social activity
- Symptoms

**0** ... [0.09 ... 1.0]

## HALex

- Self-rated health
- Physical activity limitations

**0** ... [0.10 ... 1.0]

**SF-6D** (from SF-36 questionnaire)

- Physical function
- Role limitation
- Social function
- Pain
- Mental health
- Vitality
- 0 ... [0.31 ... 1.0]

### <u>HUI2</u>

- Sensation
- Mobility
- Emotion
- Cognition
- Self-care
- Pain
- [-.02 ... **0** ... 1.0]

## EuroQol EQ-5D

- Mobility
- Self-care
- Usual activities
- Pain/discomfort
- Anxiety/depression
- [-.11 ... **0** ... 1.0]

# <u>HUI3</u>

- Vision
- Hearing
- Speech
- Ambulation
- Dexterity
- Emotion
- Cognition
- Self-care
- Pain
- [-.36 ... **0** ... 1.0]

## IIII The Health Measurement Research Group

www.healthmeasurement.org



# IIII The Health Measurement Research Group

www.healthmeasurement.org

# US Norms for Six Generic Health-Related Quality-of-Life Indexes From the National Health Measurement Study

Dennis G. Fryback, PhD,\* Nancy Cross Dunham, PhD,\* Mari Palta, PhD,\* Janel Hanmer, PhD,\* Jennifer Buechner, AB,\* Dasha Cherepanov, BS,\* Shani A. Herrington, MS,\* Ron D. Hays, PhD,†§ Robert M. Kaplan, PhD,‡ Theodore G. Ganiats, MD,¶ David Feeny, PhD,||\*\* and Paul Kind, MPhil††

**Background:** A number of indexes measuring self-reported generic health-related quality-of-life (HRQoL) using preference-weighted scoring are used widely in population surveys and clinical studies in the United States.

Objective: To obtain age-by-gender norms for older adults on 6 generic HRQoL indexes in a cross-sectional US population survey and compare age-related trends in HRQoL.

Methods: The EuroQol EQ-5D, Health Utilities Index Mark 2, Health Utilities Index Mark 3, SF-36v2<sup>TM</sup> (used to compute SF-6D), Quality of Well-being Scale self-administered form, and Health and Activities Limitations index were administered via telephone interview to each respondent in a national survey sample of 3844 noninstitutionalized adults age 35–89. Persons age 65–89 and telephone exchanges with high percentages of African Americans were oversampled. Age-by-gender means were computed using sampling and poststratification weights to adjust results to the US adult population.

Results: The 6 indexes exhibit similar patterns of age-related HRQoL by gender; however, means differ significantly across indexes. Females report slightly lower HRQoL than do males across all age groups. HRQoL seems somewhat higher for persons age 65-74 compared with people in the next younger age decade, as measured by all indexes.

**Conclusions:** Six HRQoL measures show similar but not identical trends in population norms for older US adults. Results reported here provide reference values for 6 self-reported HRQoL indexes.

Key Words: health-related quality-of-life, health status, EQ-5D, SF-6D, QWB-SA, SF-6D, Health Utilities Index, HUI2, HUI3, SF-36, population survey, adults, aging, patient-reported outcomes, health outcomes measures, comparative studies

(Med Care 2007;45: 1162-1170)



### www.healthmeasurement.org

# US data sets with HRQoL index

# One-time data sets

- National Health Measurement Study
  - EQ-5D, HUI2, HUI3, SF-6D, QWB-SA, HALex
- US Valuation of the EQ-5D (USVEQ)
  - EQ-5D, HUI2, HUI3
- Joint Canada US Survey of Health (JCUSH)
  - HUI3

# Continuing data sets

- Medical Expenditure Panel Study (MEPS)
  - EQ-5D (2000-2003)
  - SF-12 (a reduced form of SF-36 that can still be used to compute the SF-6D HRQoL index) (2000-present)
- National Health Interview Survey (NHIS)
  - data subsuming HALex

### NHMS: Relation between summary health and 6 HRQoL indexes



www.healthmeasurement.org

# Summary

- Utility-based measures are available to estimate the impact of nutrition at the population level and nutritional interventions at the individual level
- Generic methods allow the comparison of investments in nutrition with investments in other aspects of health care
- There are very few applications at present
- We look forward to the development of these methods for studies in comparative effectiveness.