

•
•
•
•
•
•
•
•

Importance of Health-Related Quality of Life & Introduction to Measures

William Cunningham M.D., M.P.H.

Professor of Medicine and Public Health, UCLA

Wcunningham@mednet.ucla.edu

Rm 31-254A CHS

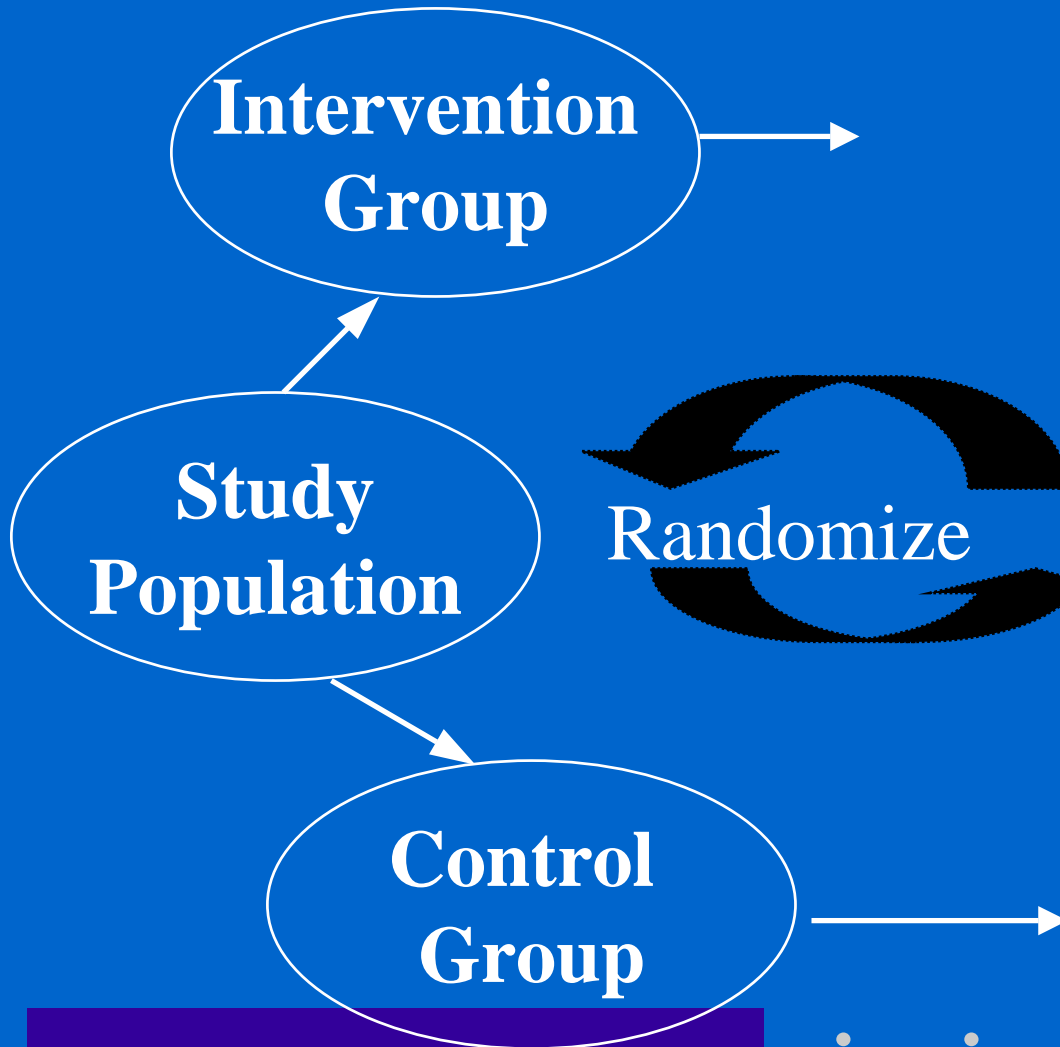
Ron Hays, PhD

hays@rand.org

Two Major Teaching GOALS:

- Measure Health-Related Quality of Life (HRQOL)
- Design an outcomes study

Randomized Trial Design



- Measure and Compare Outcomes
 - HRQOL
 - Symptoms
 - Mortality
 - Complications
 - laboratory data
- Less control for case-mix required

Analytic Model for an Outcomes Study

- Observation of groups OR
- Nonrandom intervention vs. comparison group

- *Control for case-mix crucial
- severity
- comorbidity
- socio-demographics
- other covariates

Outcomes

- HRQOL
- clinical
- symptoms
- mortality
- utilization

Course Overview

- Health status, quality of life and health services:
 - needs, outcomes and policy
- Conceptualizing health: HRQOL
- Measuring health: HRQOL
 - reliability, validity, acceptability
- Applications to health services research

Key Problems With US Health Care System

- Access to care
 - ~ 44 million people without health insurance
- Cost of care
 - expenditures ~ \$1.2 Trillion
- Effectiveness (quality) of care
 - not all care delivered is beneficial
 - not all needs are met

Why Is Health Status Important?

- Reflects need for services
- Effective services improve health outcomes

Defining Health Needs

- Defines objectives of health care
- A lack (illness) of desired goal (health)
- Implies a means of attaining goal
- Necessarily implies value judgment

Types of Health Needs

- Perceived (Individual)
- Evaluated (Professional)
- Normative (Expert/Empirical)
- Need ~ Demand

Defining Health Outcomes

- Health and Disease vs. illness
- Related to Needs
- Function of Use and Process
- Focus is on Intervention
 - Policy
 - Community-Based
 - Clinical

History of Health and Quality of Life Concepts: A Paradigm Shift

- Changes in survival, epidemiology
- Limits of medical technology
- Public health and policy: populations
 - social indicators of health status, QOL
- Chronic disease treatment: individuals
 - measures of function and well-being (HRQOL)
- Cost-containment and consumerism
 - demonstration of health care value

WHO Definition of Health

- Health is a total state of physical, mental and social well-being, and not merely the absence of disease

– WHO, 1949

Goals of Care System

- Provide equitable, cost effective care
 - Maximize access to needed care
 - Minimize costs
 - Maximize effectiveness (quality)

Health Services Research: Improving Health Systems

- Criteria
 - Equity - needed care provided
 - Efficiency - costs are minimized
 - ➔ – Effectiveness - quality of care improves health
- Application
 - Evaluate policy, interventions, secular trends

How Do We Know If Care Is Effective?

- Effective care maximizes probability of desired outcomes
- Outcomes are markers of whether or not care is effective

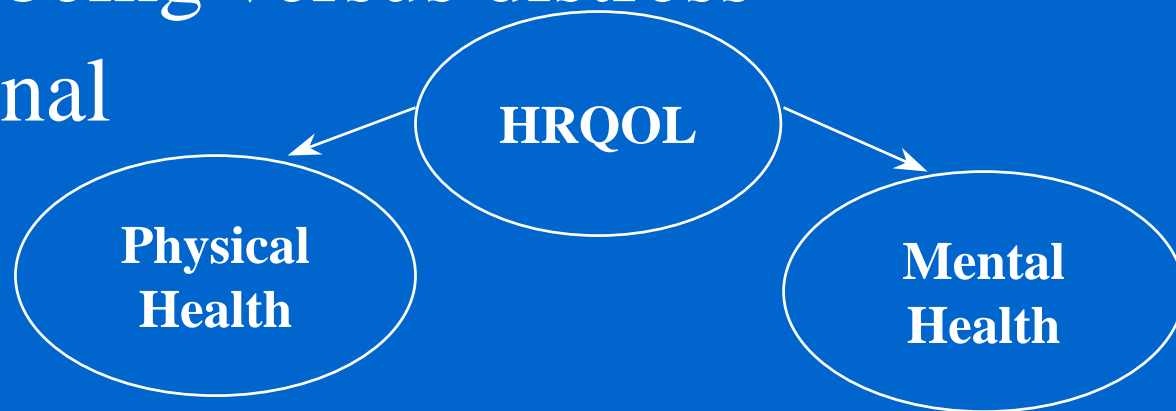
What Are Health Outcomes?

- Traditional clinical endpoints
 - Death, disease occurrence, other adverse events
 - Clinical measures/biological indicators
 - blood pressure
 - blood hemoglobin level
 - symptoms, (e.g. fever)
- Health-Related Quality of Life



Definition of Health-Related Quality of Life (HRQOL)

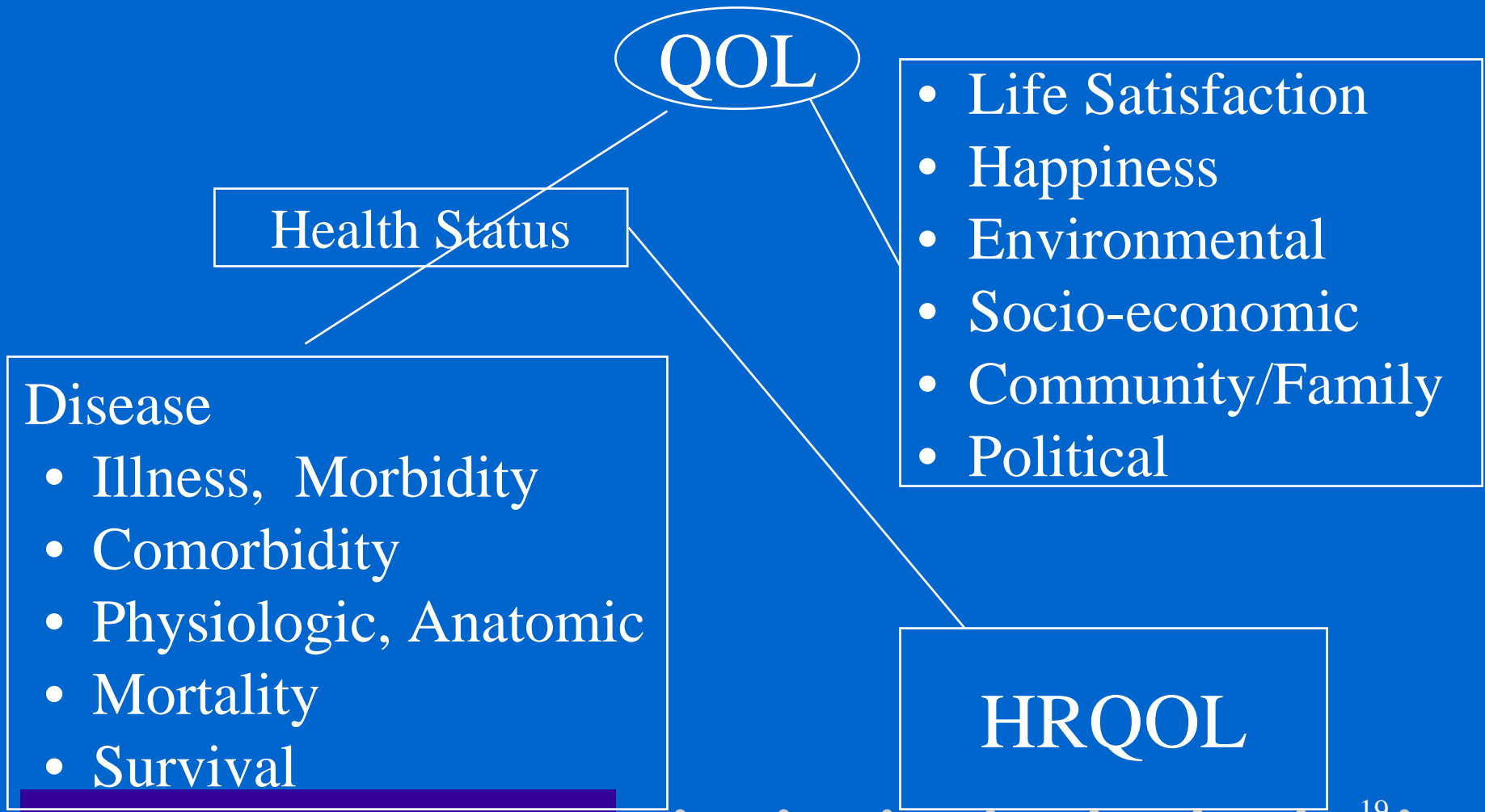
- Ability to engage in daily functions:
 - physical (e.g. self-care)
 - role
 - social
- Perceived well-being versus distress
- Multi-dimensional



HRQOL is not

- Quality of environment
- Political freedom
- Adequate housing
- Level of income

Quality Of Life, Health Status, & Health-Related Quality of Life (HRQOL)



Valid Measurement of Health Is Critical

- Develop/ select HRQOL measures for specific purpose
- Evaluate performance of measures in target group, disease, or context
 - acceptability
 - reliability and validity

Example of HRQOL Measure

Overall, how would you rate your current health?
(Circle One Number)



Worst possible health
(as bad or worse than
being dead)

Half-way
between worst
and best

Best possible
health

Part 2 Overview

- Conceptualizing HRQOL
- Operationalizing HRQOL

Conceptualizing Health

- Biomedical Model
- WHO definition: bio-psychosocial model
- HRQOL: consumer perspective
- Domains, dimensions, concepts, items

Concentric Model of Health Domains (Ware 1984)



Three Views of Chronic Physical Illness

- Impairment (biological)
- Disability (psychological)
- Handicap (social)

– WHO, 1980

How do you measure HRQOL? (1)

- Define constructs
 - conceptual definition
 - operational definition
 - domains, dimensions, items

How do you measure HRQOL? (2)

- Operationalize constructs
 - Questions reflect health concept
- Conceptual - operational links
 - Content: breadth and depth
 - Response concepts (options)

How do you measure HRQOL? (3)

- Standardization
 - Item content and responses
 - Score answers (assigning numbers)
 - Summarize and analyze answers
- Individualization
 - Qualitative

Advantages of Standardized Measurement

- Objectivity
- Quantification
- Communication
- Economy
- Scientific generalization

• Adapted with permission from Ron Hays @ RAND

Example HRQOL Measure: SF-20 (# items)

- Function
 - Physical function (6)
 - Role function (2)
 - Social function (1)
- Well-Being
 - Emotional well-being (5)
 - Low pain (1)
 - Current health (5)

Measurement Approach Depends on Domain

- Function: potentially observable
 - Self report
 - Observer report
- Well-being: subjective, unobservable
 - Reports
 - Ratings

Observable Physical Function (self-care) Item

- How much does your health now limit you in bathing or dressing yourself?

Example Content of HRQOL Measure (#items) (SF-36)

Dimension

- Physical Health
 - Physical function (10)
 - Bodily Pain (2)
 - Role limitations / physical health (4)
- Mental Health
 - Emotional distress / Positive affect (5)
 - Role limitations / mental health (3)
- Both
 - General Health (5)
 - Energy (4)
 - Social Function (2)
 - Change in health status

Range of HRQOL content

- Positive vs. negative well-being states
- Strenuous vs. basic activities

Positive and negative well-being items

- How much of the time ...
 - Have you felt calm and peaceful?
 - Have you been a very nervous person?

Example Range of Physical Function Items

- How much does your health now limit you in these activities?
 - Bathing or dressing yourself
 - Lifting or carrying groceries
 - Running a few miles

Gradations (range) of Content

- Fine gradations detect subtle differences among similar subjects
- Broader ranges detect differences between dissimilar subjects
- Measuring both requires many items

Example Range of Physical Function Items

- How much does your health now limit you in these activities?
 - Bathing or dressing yourself
 - Moving in or out of a bed or chair
 - Walking indoors, e.g., around your home

Example Range of Physical Function Items

- How much does your health now limit you in these activities?
 - Bathing or dressing yourself
 - Lifting or carrying groceries
 - Running a few miles

(Limited: a lot, a little, not at all)

Example Item and Response Options (rating)

- In general, how would you say your health is now:

Excellent, very good, good, fair , poor

Contrasting Dichotomous and Graded (frequency) Response Options

- Have you felt depressed during the past 4 weeks?

Yes

No

- How often during the past 4 weeks have you felt depressed?

All of the time, most of the time, some of the time, a little of the time, none of the time

Response Options: Severity vs. Duration

- How much does your health now limit you in these activities?

- Running a few miles
- Lifting or carrying groceries
- Bathing or dressing yourself

(Limited: a lot, a little, not at all)

- more than 3 months, less than 3 months, not at all

Reports vs. Ratings

- Reports: imply “objective” metric
 - level, state, occurrence, frequency
- Ratings: evaluation (judgment)
 - “subjective”, “weights”, “importance”

Example Rating Item

- In general, how would you say your health is now:
 - Excellent, very good, good, fair, poor

Example Report vs. Rating Items

- Does your physical health limit you?
 - Yes or No
- Overall, how would you rate your physical health?
 - Excellent, very good, good, fair, poor

Design Issues

- Study design
 - intervention
 - follow-up
 - cross-sectional survey
- Sample morbidity
- Acuity/ chronicity of conditions
- Item content

Health Measurement Terminology

- Scale
- Items
- Instrument
- Scales
- Scores
- Profile
- Index
- Measure