

# Quality of Life Outcomes in Translation Research

K.M.Venkat Narayan, MD, MPH, MBA  
Ping Zhang, PhD  
Centers for Disease Control & Prevention

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## Outline

\$ Why is quality of life (QOL)  
important?

\$ What factors are related to QOL?

\$ How is QOL measured?



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## Outline

\$ Why is quality of life (QOL)  
important?



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- \$ Growth of chronic disease is shifting emphasis from objective (mortality and morbidity) to subjective (SRH, HRQL) health measures.
- \$ The perspective of the person/patient is gaining importance.
- \$ Growing importance of economics
- \$ Changes in organization and delivery of health care



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## In Diabetes.....

- \$ Importance of psycho-social factors
  - ▣ Psycho-social factors affect self-monitoring
  - ▣ Depression predicts mortality, hospitalization



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## Rise to prominence of the patient's point of view

- \$ Bioethics phase (1940's-1980's)
  - ▣ respect for patient autonomy
  - ▣ patient chooses among medical care options
- \$ Outcomes phase (1980's-2000's)
  - ▣ turn to patient-centered outcomes
  - ▣ patient defines goals of medical care



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## Outline

**\$** What factors are related to QOL?



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**\$** People with diabetes have

- Worse QOL than people with no diabetes
- Better QOL than people with other serious chronic illness



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## Among people with Diabetes

**\$** QOL

- Not associated with duration and type
- Not impaired by intensive treatment
- Strongly impaired by complications
- Associated with some demographic factors (e.g., gender, age, education)
- Associated with health status and perceived ability to control disease



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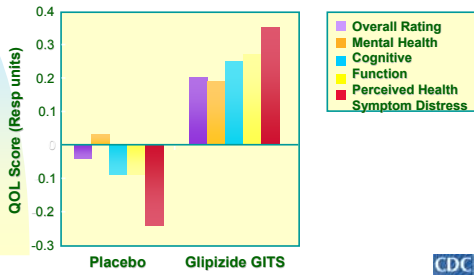
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## Change In QOL Scales With Therapy in Type 2 Diabetes



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## Outline

\$ How is QOL measured?

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\$ QOL is a multi-dimensional construct comprising the individual's subjective perception of physical, emotional and social well-being, including both a cognitive component (e.g., satisfaction) and an emotional component (e.g., happiness)

▲ Campbell A, et al. The Quality of American Life, New York, Russell Sage, 1976

CDC

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## Measuring QOL

### \$ Illness-specific

- ☐ Focus on specific problems
- ☐ Hypoglycemia, insulin injections, self-monitoring of blood glucose, dietary restrictions
- ☐ DQOL, Diabetes-39, PAID, DTSR

### \$ Global

- ☐ Use across health & illness groups



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## Concepts related to health outcomes (Global)

- \$ Health related Quality of life (HRQOL)
- \$ Quality-adjusted life years (QALY)
- \$ Willingness-to-pay for health benefits (WTP)



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## Health related Quality of life (HRQOL)

HRQOL refers to the impact of health aspects of an individual's life on that persons' quality of life, or overall wellbeing, or refers to the value of a health state to an individual



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## Global HRQOL Ways of measuring

- \$ Health Profile -- non-preference-based approach (e.g., SF-36, SIP)
  - ▣ Can't produce a single score
  - ▣ Can't be used for economic evaluation
- \$ Utility measure -- preference-based approach (e.g., QWB, HUI, EUROQOL)
  - ▣ Can produce a single score
  - ▣ designed for economic evaluation



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## Methods for Assigning Preferences to Health States

- \$ Standard gamble
- \$ Time trade-off



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## Sources of Preferences

- \$ Community
  - ▣ Used for public funded programs
  - ▣ Ethical issue of discrimination against people who are ill or disabled
- \$ Patients
  - ▣ Appropriate when evaluating alternative interventions for the same condition
- \$ Health professionals



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## Quality-adjusted life years (QALY)

A summary outcome measure that incorporates the quality or **utility** of a health state with the duration of **survival**.



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## QALY Matrix

\$ Two possible effects of a disease or an intervention:

- Extending life or
- improving the health related quality of life.

\$ QALY combines the two effects in a multiplicative way



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## How to calculate QALY

1. assigns a number that corresponds to the quality of health state during each period during the survival.

e.g., 1= optimal health; 0= Death; blindness =0.80.

2. add the utilities across time periods



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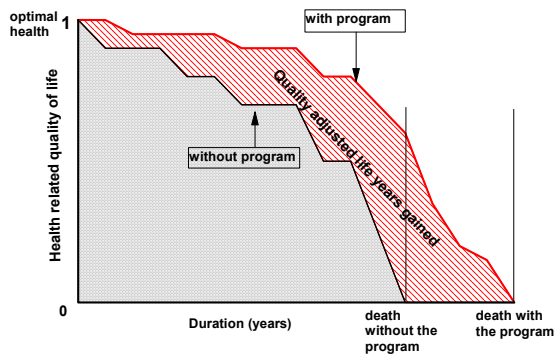
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## QALYs Gained from an intervention



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## Willingness-to-pay for health benefits (WTP)

A method of measuring the value an individual places on reducing risk of death or illness by estimating the maximum dollar amount an individual would pay in a given risk-reduction situation

Prevention Effectiveness, by Haddix et al.



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## Willingness-to-pay: how to do it?

- Using survey methods, respondents are
- presented with hypothetical scenarios about the health benefit and
  - asked to think the contingency of actual market existing for a health benefit and
  - asked to state the maximum they would be willing to pay for such a health benefit



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## Conclusion

- \$\$\$ QOL is an important outcome
- \$\$\$ Data on impact of interventions on QOL are scarce
- \$\$\$ Future research
  - ▣ QOL as primary outcome
  - ▣ Different ways of measuring QOL



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## Global Measures of QOL (Non-preference based)

- \$\$\$ Medical Outcomes Study Short-Form General Health Survey (SF-36, SF-20, SF-12)
  - ▣ Physical, social and role functioning capture behavioral dysfunction
  - ▣ Mental health, perceptions of overall health, and pain reflect subjective components
  - ▣ Available in many languages



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## Willingness-to-pay: an example

- Willingness-to-pay for *in vitro* fertilization
- Assume you are infertile and want to have a baby
  - IVF can help if purchased
  - Mean WTP of \$17,730 (if 10% chance of success)
  - Mean WTP of \$28,054 (if 25% chance of success)
  - Mean WTP of \$43,576 (if 50% chance of success)

Implied for WTP of \$177,730 per statistical baby

Source: Neumann and Johannesson. Medical Care, 1994



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## Standard Gamble

§ An elicitation method that is rooted in the axioms of expected utility theory.

- ✓ An individual is asked to choose between a less desirable (but certain) chronic health state, & a gamble offering a certain probability of a worse health state (dead) or having an improved state of health (healthy)



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## Standard Gamble Continued

For which value of X would a person be indifferent between an X% probability of dying with a (100-X)% probability of living in perfect health, vs. a 100% probability of living with diabetes?

- Utility of death = 0
- Utility of perfect health = 1
- Utility of diabetes =  $1 - X$
- $X = 30 \Rightarrow$  utility of diabetes is .7



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## Standard Gamble Continued

Ask sequentially for different values of the probability of dying: Which would you prefer: 100% certainty of living with [diabetes] or having an operation that has an X% probability of dying but a (100-X)% probability of a cure (perfect health)?

The value at which the rater says "I'm indifferent is the value assigned to [diabetes/other condition under study]."



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## Time trade-off

- \$ Used to determine how many years of life in excellent health are equivalent to life in a less desirable health state.
- ✓ Presents rater with a choice: between 2 alternatives that both have a certain outcome.
  - ✓ Better health has shorter lifespan.
  - ✓ The choice is how many years of life the rater would be willing to give up to be in the healthier state.



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## Time-Tradeoff

Continued

“Suppose you are faced with a year in health state S (diabetes). Taking into account your age, pain and suffering, immobility, and lost earnings, what fraction of a fully healthy year of life would you be willing to accept in exchange for the state S (with diabetes) for a full year?”

If answer is 9 months, then HRQOL associated with diabetes =  $9/12=0.75$



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