# How to Measure Quality of Life

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**UCLA**

June 9, 2008, 2:15-2:45pm

*American Diabetes Association*

*San Francisco, CA*

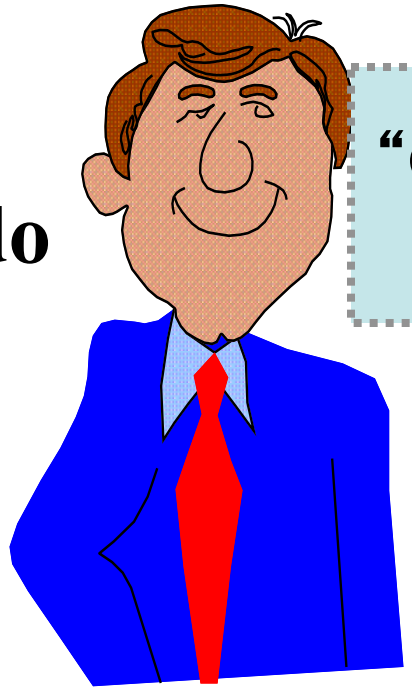
# Presenter Disclosure Information

**Ron D. Hays**

**Disclosed no conflict of interest.**

# How is the patient doing?

**What they are able to do**



**"QOL is determined by its activities"**

**Aristotle**

**And how they feel about their life**

# Health-Related Quality of Life (HRQOL) is …

What the patient can DO (*functioning*)

- Physical (self-care -> vigorous activities)
- Role
- Social

Does your health now limit you in walking more than a mile?

*No*
*Yes, limited a little*
*Yes, limited a lot*

# … and …

How the patient FEELs (*well-being*)

- Emotional well-being
- Pain
- Energy

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*

# 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)

# HRQOL is not

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

# Types of HRQOL Measures

- 1) Generic Profile
  - SF-36
- 2) Disease-targeted ("specific") Profile
  - Audit of Diabetes-Dependent Quality of Life (ADDQoL)
  - Diabetes-39
- 3) Preference-based
  - EQ-5D, HUI, QWB

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VALUE IN HEALTH

# Diabetes-Specific or Generic Measures for Health-Related Quality of Life? Evidence from Psychometric Validation of the D-39 and SF-36

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## ABSTRACT

Objective: There is a debate regarding the use of disease-specific versus generic instruments for health-related quality of life (HRQOL) measures. We tested the psychometric properties of HRQOL measures using the Diabetes-39 (D-39) and the Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36).

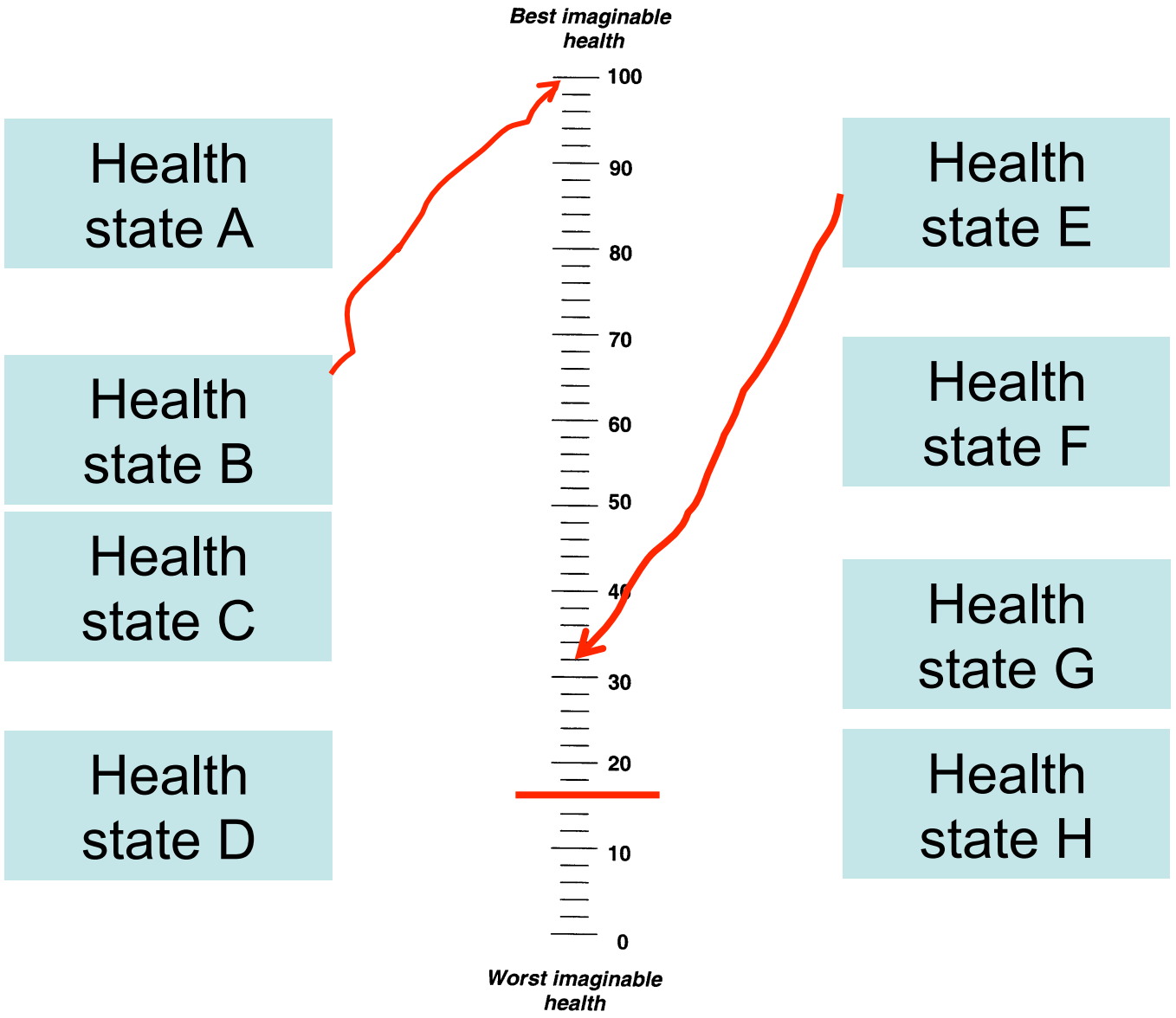
Methods: This was a cross-sectional study collecting data from 280 patients in Taiwan. Exploratory factor analysis was conducted to evaluate construct validity of the two instruments. Known-groups validity was examined using laboratory indicators (fasting, 2-hour postprandial plasma glucose, and hemoglobin A1c), presence of diabetic complications (retinopathy, nephropathy, neuropathy, diabetic foot disorder, cardiovascular and cerebrovascular disorders), and psychosocial variables (sense of well-being and self-reported diabetes severity). Overall discriminative power of the two instruments was evaluated using the C-statistic.

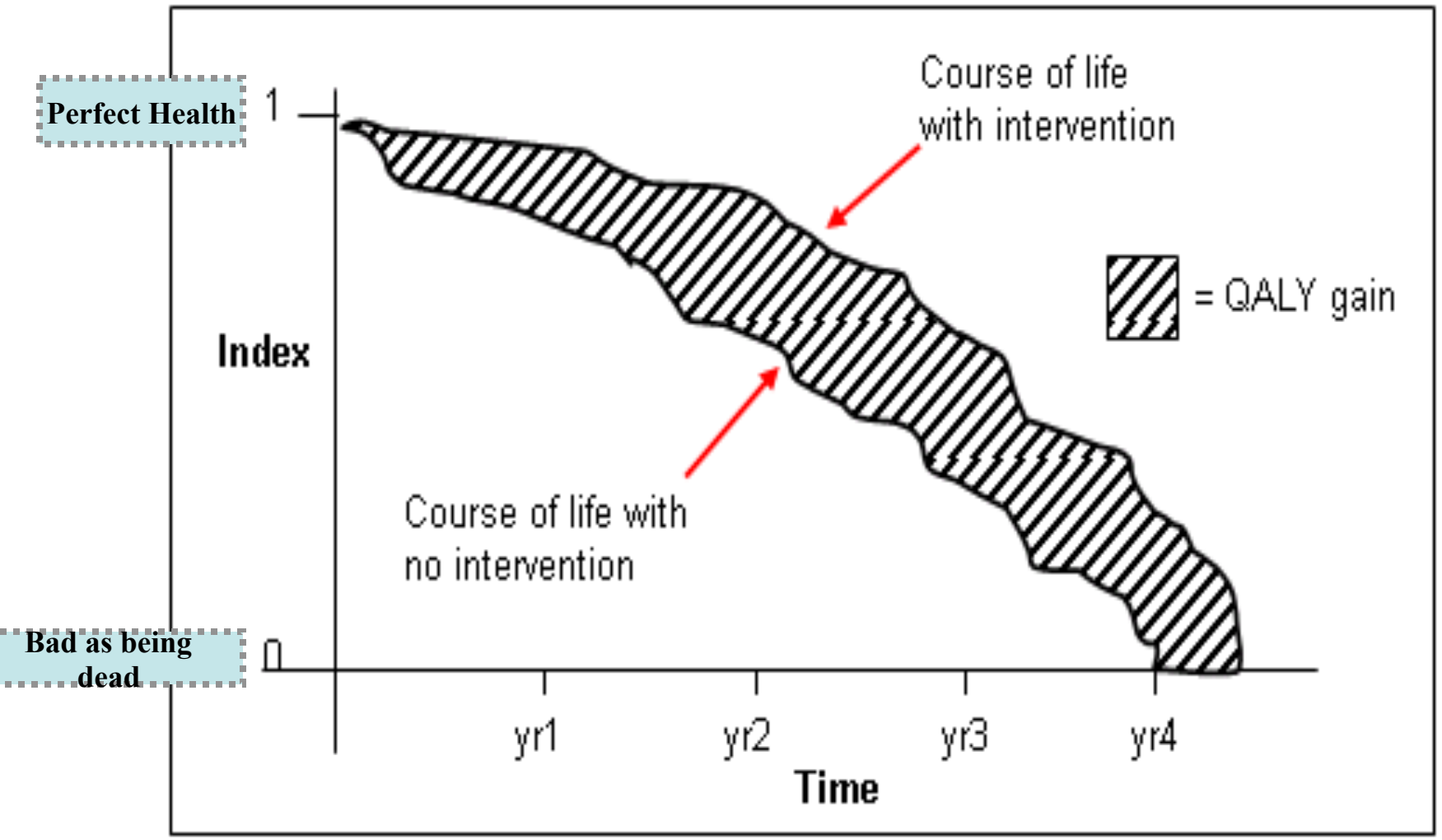
Results: Three distinct factors were extracted through factor analysis. These factors tapped all subscales of the D-39, four physical subscales of the SF-36, and four mental subscales of the SF-36, respectively. Compared with the SF-36, the D-39 demonstrated superior known-groups validity for 2-hour postprandial plasma glucose groups but was inferior for complication groups. Compared with the SF-36, the D-39 discriminated better between self-reported severity known groups, but was inferior between well-being groups. In overall discriminative power, the D-39 discriminated better between laboratory known groups. The SF-36, however, was superior in discriminating between complication known groups.

Conclusions: For psychometric properties, the D-39 and the SF-36 were superior to each other in different regards. The combined use of a disease-specific instrument and a generic instrument may be a useful strategy for diabetes HRQOL assessment.

*Keywords:* diabetes, health-related quality of life, psychometric property.

# Preference-based Measures

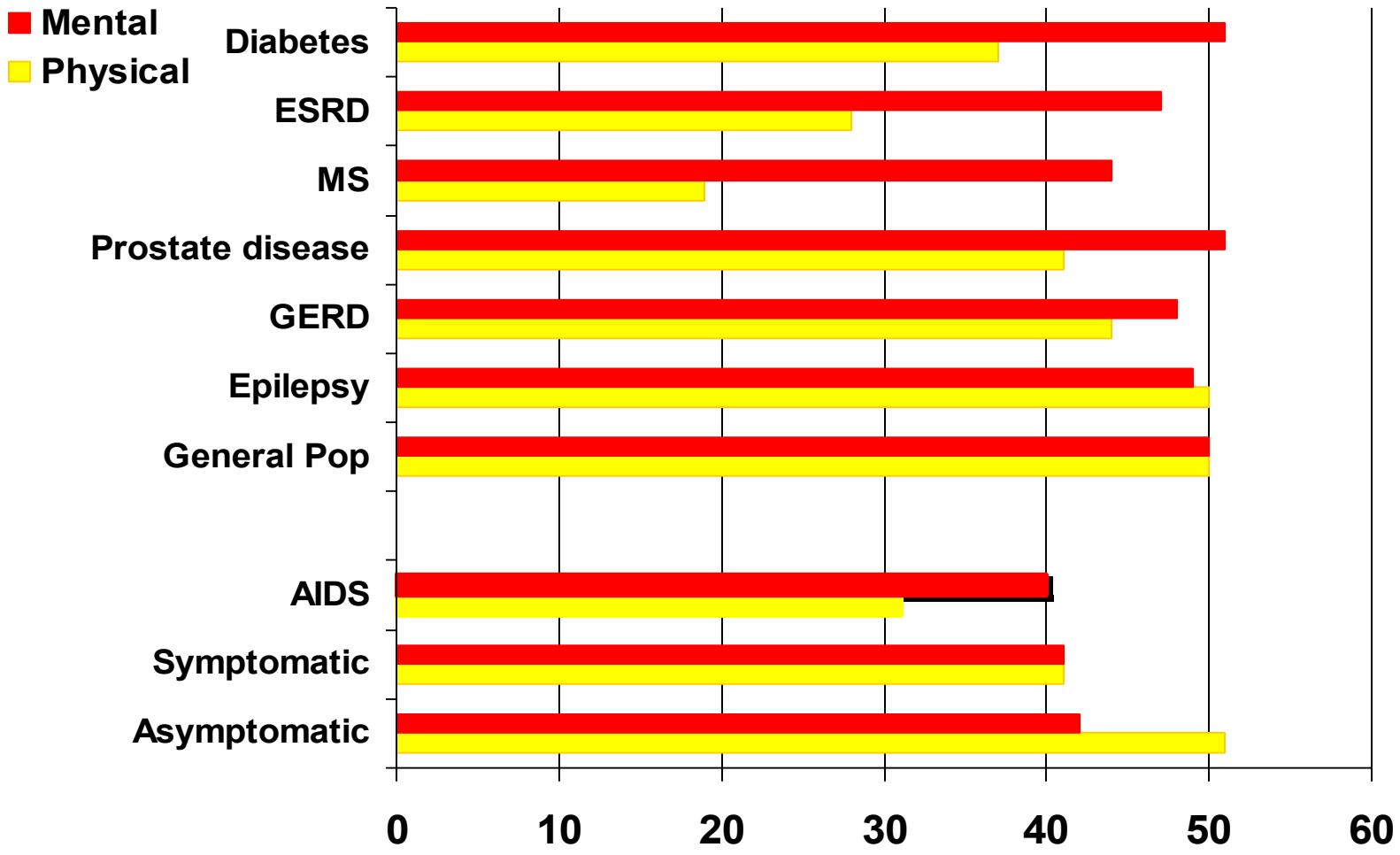



Perfect Health
1
Course of life
with intervention
= QALY gain
Index
Course of life with
no intervention
Bad as being
dead
yr1
yr2
yr3
yr4
Time

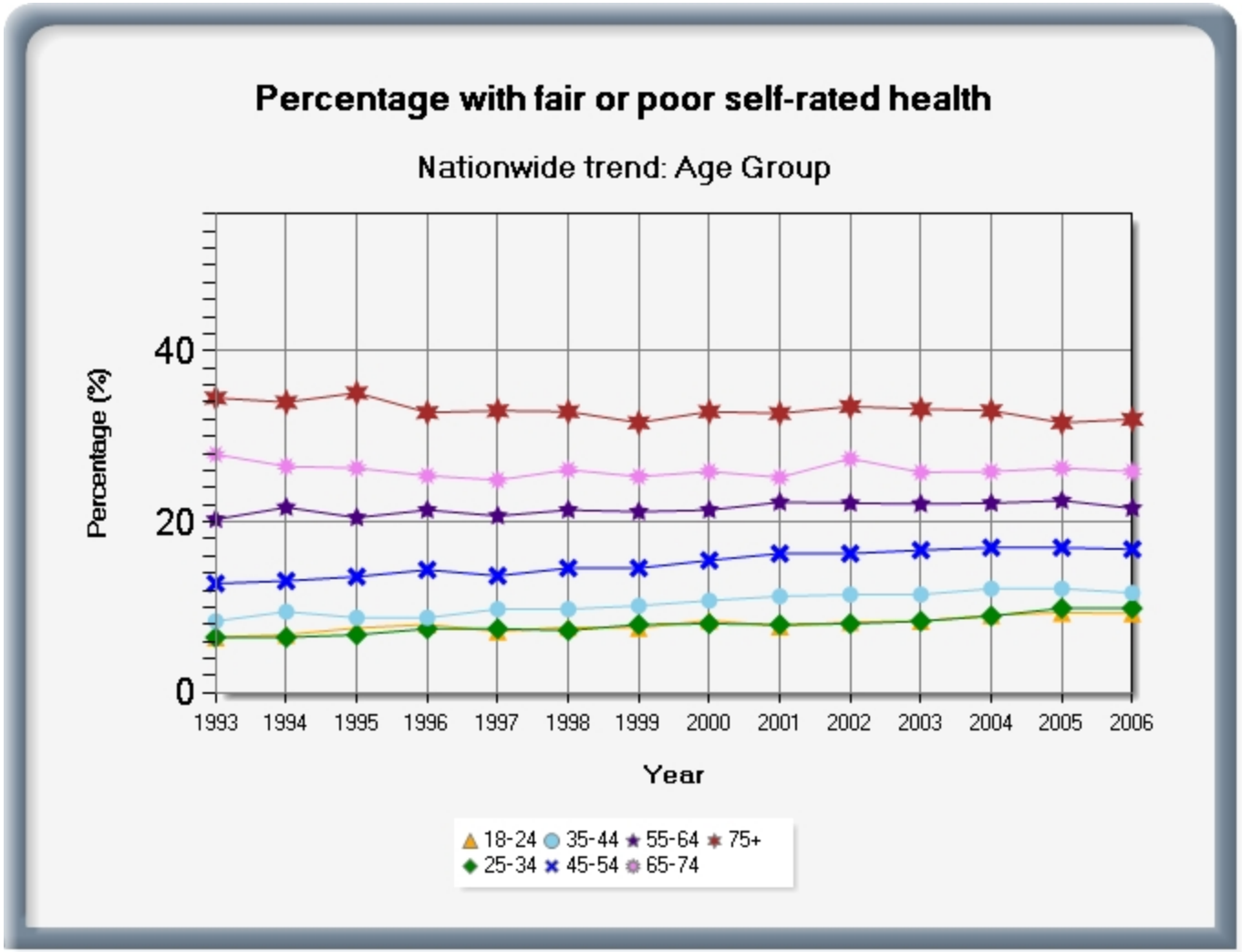
# Uses of Patient-Reported Outcomes (including HRQOL)

- **Monitoring population (and subgroups) ←**
- Observational studies
- Clinical trials
- Clinical practice

# Burden of Diabetes Compared to other Conditions and General Population




*Hays et al. (2000), American Journal of Medicine*




**Greater % of fair or poor health reported by older adults (33% for 75+ vs. 9% for 18-34)**

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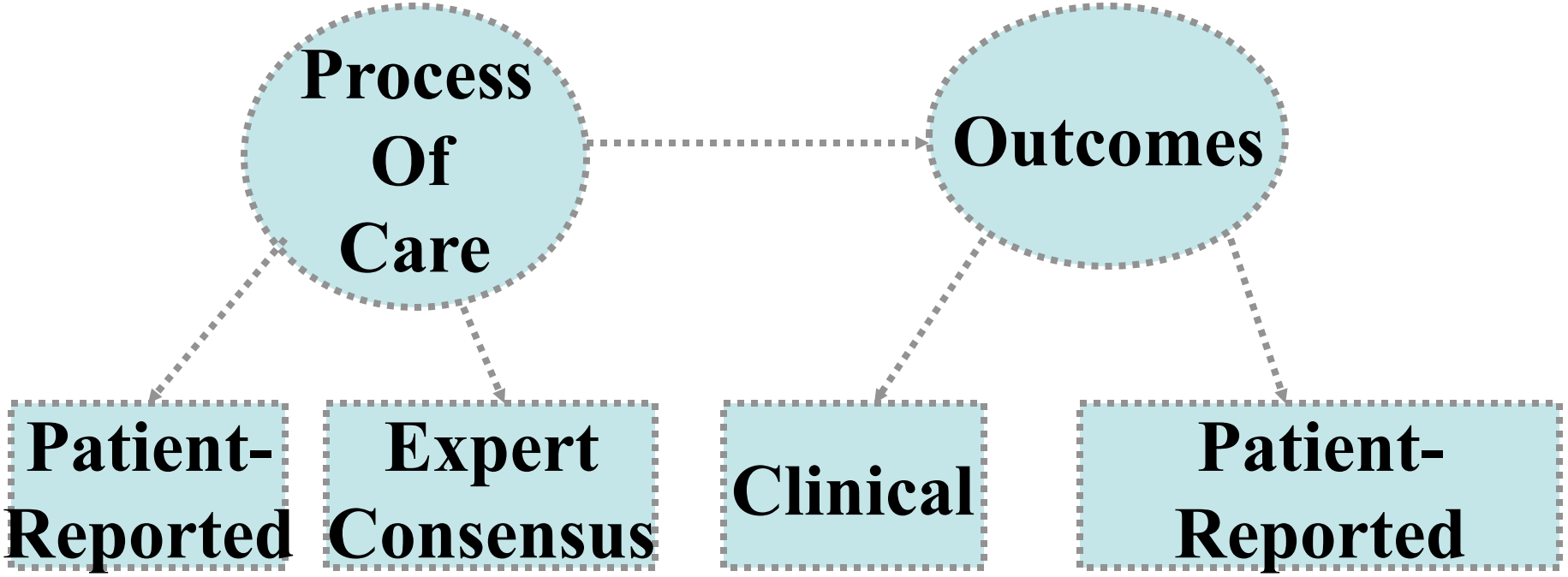
# Observational Studies



# Process of Care

- Expert Consensus
  - Quality of Care "If Then" Indicators
    - % of patients with diabetes with one or more HbA1c tests annually

- Patient reports about communication
  - In the last 12 months, how often did your doctor explain things in a way that was easy to understand?

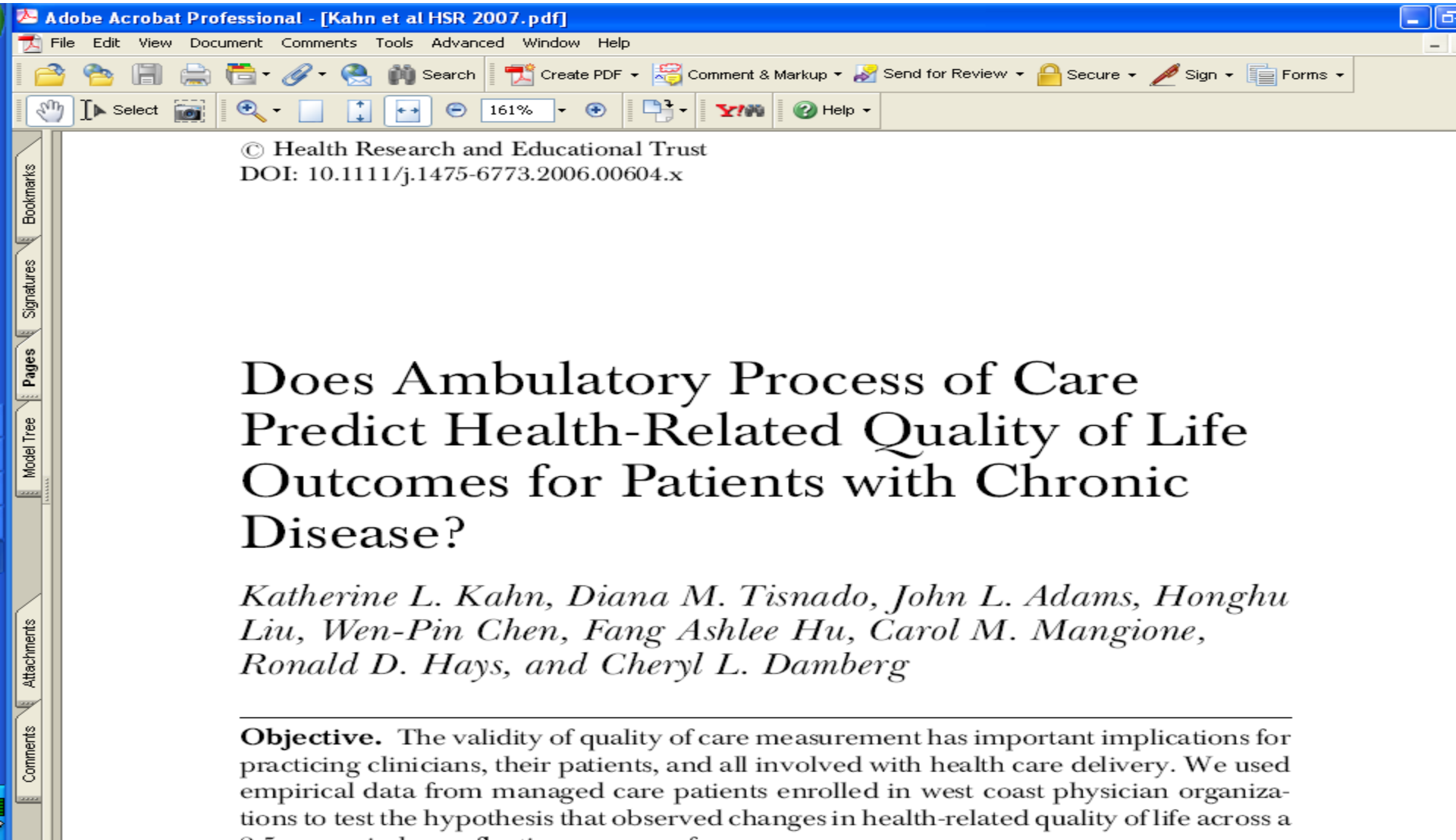
# Outcomes of Care

- Clinical
  - % of patients with diabetes with most recent HbA1c level >9.0% ( poor control)

- Patient global rating of health
  - Would you say that in general your health is:

    - Excellent
    - Very good
    - Good
    - Fair
    - Poor

# Health Services Research
# 2008 Eisenberg Award





DOI: 10.1111/j.1475-6773.2006.00604.x

## Does Ambulatory Process of Care Predict Health-Related Quality of Life Outcomes for Patients with Chronic Disease?

*Katherine L. Kahn, Diana M. Tisnado, John L. Adams, Honghu Liu, Wen-Pin Chen, Fang Ashlee Hu, Carol M. Mangione, Ronald D. Hays, and Cheryl L. Damberg*

**Objective.** The validity of quality of care measurement has important implications for practicing clinicians, their patients, and all involved with health care delivery. We used empirical data from managed care patients enrolled in west coast physician organizations to test the hypothesis that observed changes in health-related quality of life across a

# Uses of Patient-Reported Outcomes (including HRQOL)

- Monitoring population (and subgroups)
- Observational studies
- **Clinical trials ←**
- Clinical practice

# Gandhi, G. Y. et al. (*JAMA*, 2008)

"Patient-Reported Outcomes in Registered Diabetes Trials"

Patient-important = death, major morbid events such as stroke, myocardial infarction, amputation, loss of vision, and end stage renal disease; minor morbid events such as hypoglycemic events, delayed wound healing, infection, and visual disturbances; and painand functional status.

Of 436 registered RCTs, primary outcomes were

*** Patient-important (18%)+**

* Surrogate (61%):
Endpoints that may indicate disease progression and increased risk for patient-important outcomes

* Physiological and laboratory (16%)

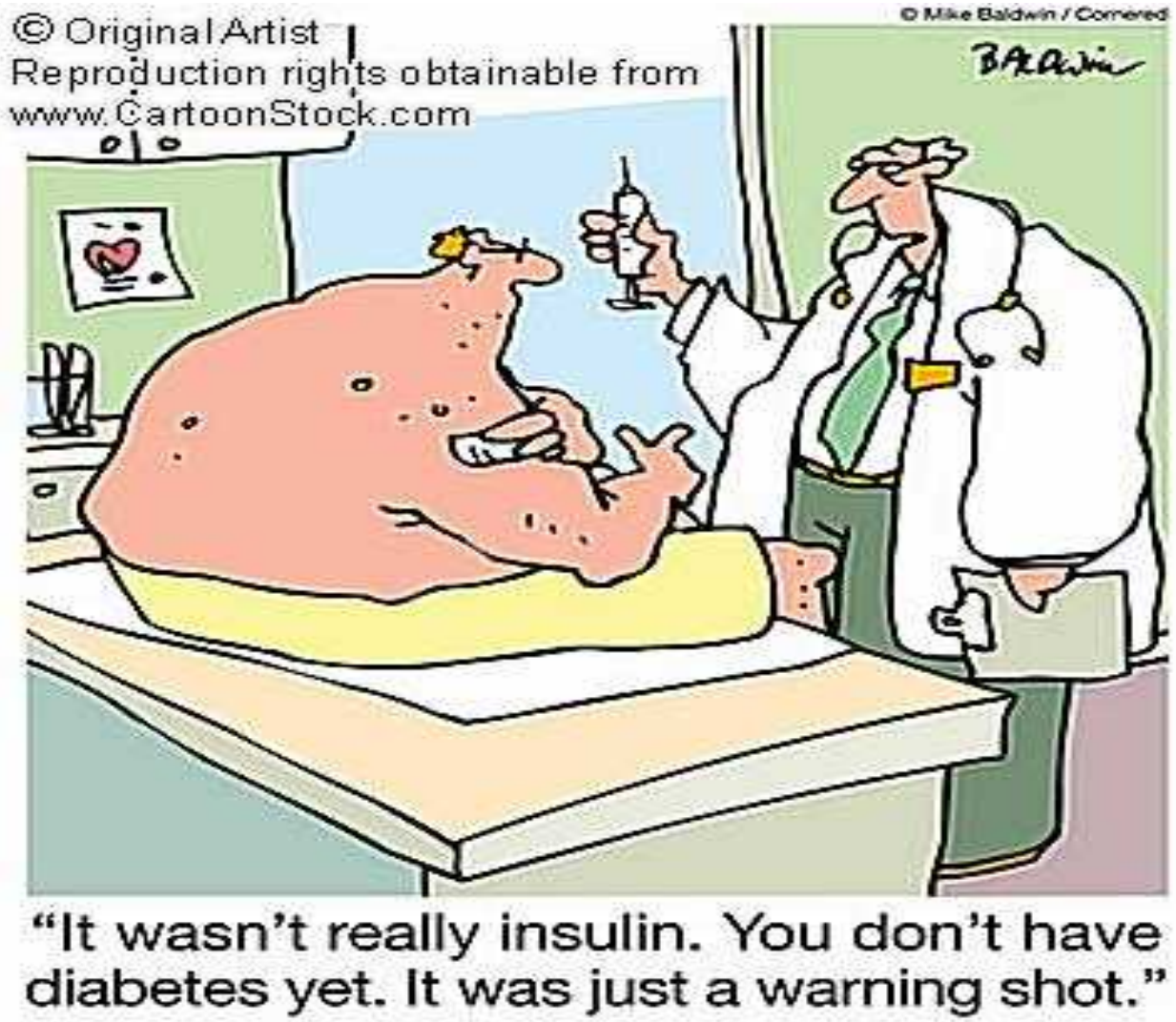
* Other (5%)

+ Primary or secondary in 46% of the trials.

# Uses of Patient-Reported Outcomes (including HRQOL)

- Monitoring population (and subgroups)
- Observational studies
- Clinical trials
- **Clinical practice ←**


**"What fits your busy schedule better, exercising one hour a day or being dead 24 hours a day?"**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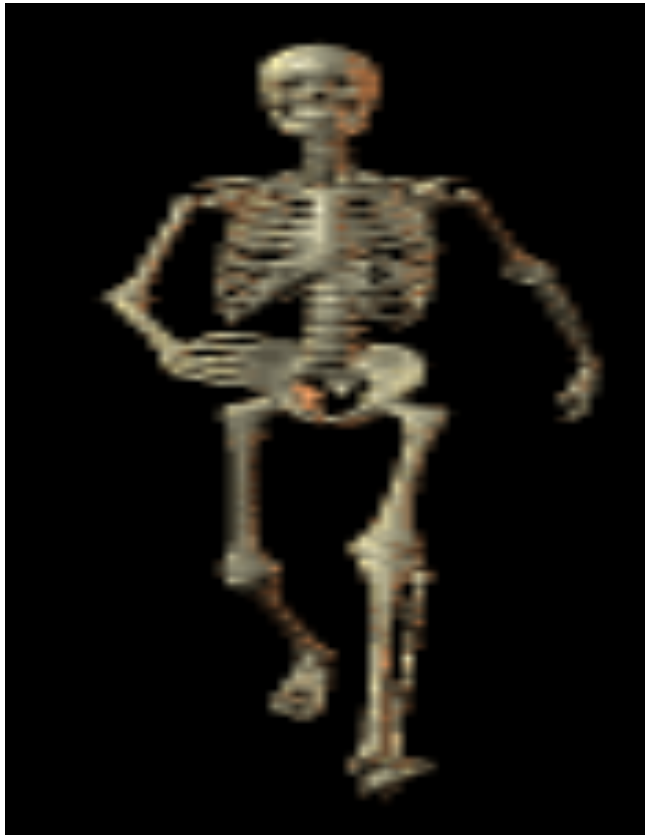
BALDWIN
"It wasn't really insulin. You don't have diabetes yet. It was just a warning shot."

# Diabetes Distress Scale

- Assessing degree to which distressed by feeling:
  - (1) Overwhelmed by the demands of living with diabetes
  - (2) That I am often failing with my diabetes regimen.

L. Fisher et al., "Development of a brief diabetes distress screening instrument," *Annuals Fam Med*. 6(3):246-252, 2008.

# Thank you



# Appendix: EQ-5D

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 self-care
- ❑ 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

http://www.euroqol.org/