Quality of Life and Health of the Public

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with special thanks to Ivan Barofsky, Shirley Beresford, Michael Buenafe, Paula Diehr, Yuki Durham, Todd Edwards, David Grembowski, Jean Mbassi, Carol Moinpour, Gayle Reiber, Bob Shimambukuro, Tari Topolski, and Gooloo Wunderlich
“The health of the people is really the foundation upon which all their happiness and all their powers as a state depend.”

- Benjamin Disraeli
Number of SSDI Applications, Awards, Beneficiaries, and Terminations, Aged 18-64 Years, 1960-2000

Increase in work disability?

Objectives

- Define quality of life and its determinants
- Describe uses in public health & health care
  - Monitoring populations and disparities
  - Allocating health resources
  - Improving treatment effectiveness
- Suggest future directions
What are we talking about?

- Cost
- QALYs
- ADL
- Discomfort
- Symptoms
- Bother
- HRQL
- Productivity
- Satisfaction
Patient Outcomes Assessment Sources and Examples

- Clinician - Reported: For example, Global impressions, Observation & tests of function
- Physiological: For example, FEV$_1$, HbA1c, Tumor size
- Caregiver - Reported: For example, Dependency, Functional status
- Patient - Reported: Global Impression, Functional status, Well-being, Symptoms, HRQL, Satisfaction with TX, Treatment adherence
Quality of Life: la Carte des Vins

- **Health Status**: death, disease, disability, discomfort, dissatisfaction (5 D’s)
- **Functional Status**: performance of social roles and valued activities
- **Well-Being**: wellness, feelings
- **Quality of life**: safe environment, adequate housing, guaranteed income, respect, love, freedom, spirituality, meaning and purpose
- **Health-related quality of life**: those aspects of quality of life attributed to health
- **Patient-reported outcomes**: all of the above plus adherence and satisfaction with care
Perceived Quality of Life is ....

- an evaluation of personal experience and position in life
- best conceived as a subjective view about one’s life based on what is important
- a measure of goals, standards, expectations and concerns (needs)
- related to health and illness but also broader
- related to well-being, happiness, depression but also more inclusive of position in life
Determinants of Health and Quality of Life

- Patrick et al, *Medical Care* 2000

**Environment (extrinsic)**
- Social & Cultural
- Economic & Political
- Physical & Geographic
- Health, Education & Social Care

**Health Status and Health-Related Quality of Life**
- Symptoms
- Functional Status
- Health Perceptions
- Opportunity

**Person (intrinsic)**
- Biology & Life Course
- Lifestyle & Health Behavior
- Illness Behavior
- Personality & Motivation
- Values & Preferences

**General Quality of Life**

**Survival**
Social Determinants of Health

- Health Behaviors and Personal Risk Factors
- Access to Health Services
- Mental Health and Social Support
- Economic Opportunity and Equity
- Education Background and Opportunity
- Language and Other Cultural Factors
- Environmental Risk
- Stress due to Social Factors
- Trust in Health System and Research
- Institutionalized biases (racism, sexism, etc.)
Best fit Model explaining Self-rated Health at Age 33  
\( n = 6,463 \)

<table>
<thead>
<tr>
<th>EARLY LIFE</th>
<th>Odds Ratio (top to bottom category)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Socio-emotional status at age 7</td>
<td>1.56</td>
</tr>
<tr>
<td>Parents read to child at age 7</td>
<td>1.26</td>
</tr>
<tr>
<td>% of adult age at age 7</td>
<td>2.56</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>CUMULATIVE</th>
<th>Odds Ratio (top to bottom category)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Socio-economic circumstances at birth, 7, 11, 16 years</td>
<td>1.72</td>
</tr>
<tr>
<td>Socio-emotional adjustment at ages 11 and 16</td>
<td>2.02</td>
</tr>
<tr>
<td>End of school qualifications</td>
<td>1.77</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>MACRO: SOCIOECONOMIC</th>
<th>Odds Ratio (top to bottom category)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current material circumstances at age 33</td>
<td>1.87</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>MESO: CIVIL SOCIETY</th>
<th>Odds Ratio (top to bottom category)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social trust</td>
<td>1.25</td>
</tr>
<tr>
<td>Psychosocial job strain</td>
<td>1.64</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>INTERSECTING</th>
<th>Odds Ratio (top to bottom category)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Job insecurity at age 33</td>
<td>1.33</td>
</tr>
<tr>
<td>Level of control in life</td>
<td>2.88</td>
</tr>
</tbody>
</table>

Source: Statistics Canada
POOR GUY CAN'T WALK AND CHEW GUM AT THE SAME TIME!
Correlations between Perceived Quality of Life and Sickness Impact Profile (SIP)\(^a\)

<table>
<thead>
<tr>
<th>Sample</th>
<th>N</th>
<th>Pearson Correlation (^b)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mobility limitations – wheelchair use</td>
<td>60</td>
<td>-0.57</td>
</tr>
<tr>
<td>Mobility limitations – no wheelchair use</td>
<td>38</td>
<td>-0.62</td>
</tr>
<tr>
<td>Younger well adults</td>
<td>50</td>
<td>+0.09</td>
</tr>
<tr>
<td>Older well adults</td>
<td>49</td>
<td>-0.73</td>
</tr>
<tr>
<td>Chronic illness</td>
<td>49</td>
<td>-0.67</td>
</tr>
<tr>
<td>Terminal cancer</td>
<td>48</td>
<td>-0.69</td>
</tr>
<tr>
<td>AIDS</td>
<td>50</td>
<td>-0.44</td>
</tr>
<tr>
<td>Stroke</td>
<td>45</td>
<td>-0.73</td>
</tr>
<tr>
<td>Nursing Home</td>
<td>50</td>
<td>-0.53</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>439</strong></td>
<td><strong>-0.69</strong></td>
</tr>
</tbody>
</table>

\(^a\) Higher PQoL scores indicate better quality of life and higher SIP scores indicate poorer functional status.

\(^b\) All are significant at 0.001 except for younger well adults, which was nonsignificant.

Objectives

Describe uses in public health & health care

*Monitoring populations and disparities*
Satisfaction with health and physical condition, General Social Survey, U.S.

Percentage

A very great deal
A Great Deal
Quite A Bit
A Fair Amount
Some
A Little
None

Source: http://www.icpsr.umich.edu/GSS/index.html
Self-Assessment of health by color, U.S.
Percent with fair or poor health

NCHS “Health, United States, 2000 with Adolescent Health Chartbook” table 58
Percentage of persons with perceived fair or poor health status by household income

Source: United States, 1995
Education

Figure 1. Mean number of “healthy days” among adults with less than a high school education,* by state—United States, Behavioral Risk Factor Surveillance System, 1993-1996

- Age-adjusted to the 1990 U.S. population aged ≥18 years.
Percent in Each Health State at Year 4 – *A Healthy Future*

![Chart showing health status distribution at Year 4](chart.png)
QoL in Youth Health Appraisal
www.yqol.org

- QoL a useful framework for integrating internal and external influences from perspective of the adolescent her/himself
- Qol is both outcome of behavior and determinant of behavior
- Absence of a health-risk behavior cannot be considered equivalent to overall QoL
YQOL Conceptual Model

“My Evaluation Of....”

Social Relationships

“...my relationships with others”

Sense of Self

“...my feelings about myself”

Culture and Community (Environment)

“...my opportunities and obstacles”

General Quality of Life

“...my life”
Perceptual and Contextual Items

- **Known only to adolescent:** “I feel I am getting along with my parents or guardians” (Perceptual)
- **Potentially verifiable:** “How often have your family members had serious arguments?” (Contextual)
Perceptual Item Means Controlling for Age and Gender

- Get Along with Parents
- Forward to Future
- Alone in Life
- Good about Self
- Life is...
- Total Perceptual Score

With Disability
No Disability
Perceptual Item Means Controlling for Age, Gender and Depression

- Get Along with Parents
- Forward to Future
- Alone in Life
- Good about Self
- Life is…
- Total Perceptual Score

With Disability and No Disability
Perceptual Items Means Controlling for Age, Gender, Depression and Contextual

- Get Along with Parents
- Forward to Future
- Alone in Life
- Good about Self
- Life is...
- Total Perceptual Score

With Disability
No Disability
Health-risk Behaviors and Groups

- Smoking, alcohol use, illicit drugs, sexual activity and engagement in unsafe sex
- Three groups:
  - abstainers (never)
  - experimenters (once, twice or sometimes)
  - engagers (often)
Perceptual Items by Smoking Status

- Abstainer
- Experimenter
- Engager

Get along with parents, forward to future, alone in life, good about self, life is...
Objectives

Describe uses in public health & health care

Allocating health resources
Applications

- DALYs or DALES or Disability Adjusted Life Years (Expectancy): measures of “burden of disease” and health system performance
- YHLs or Years of Healthy Life: monitored for achieving goals of Healthy People 2000/2010
- QALYs or Quality Adjusted Life Years used in cost-effectiveness analyses/resource allocation
QALYs

- Discount quantity of life (e.g. life expectancy) by a measure of health sometimes referred to as quality of life but usually function or symptom status
  - i.e., Persons living 10 years in perfect health are calculated as having 10 QALYs. Persons in less than perfect health, perhaps .4, who live 20 years have 8 QALYs
QALYs Gained by Intervention

What about vulnerability and vulnerable populations?

- In this context, to be vulnerable is to be at risk for unequal opportunity to achieve maximum possible health and quality of life because of differences in intrinsic or extrinsic resources associated with “the good”

- Vulnerable populations are those at risk at any point in time, for example, persons with lower chance of improvement than others for any environmental or personal reason
Proposed Solutions

- Abandon use of cost-effectiveness in resource allocation
- Leave vulnerable populations out
- Replace individual utilities with societal utilities, e.g. person trade-offs
- Use “equity weights” or adjust on technical basis
- Use outcome measures that go beyond “functioning” to include “opportunity”
Amartya Sen:

- Human diversity necessitates that the demand for equality with regard to any single chosen domain, leads to inequality in other domains.
- The domain worthy of concern is the domain of capability to achieve.
- Goal is to achieve capacity to “be” and “do”.
Goal of Health Policy on Vulnerability

- Health policy should aim to provide resources to individuals and populations in proportion to their vulnerability with the goal of maximizing individuals' capacity to achieve their potential.
Maximizing capacity to achieve potential suggests

- Definitions of health beyond functional status that incorporate opportunity
- Inclusion of individual’s evaluation of health or function in health states being evaluated — how are you doing and how do you feel about how you are doing?
- Societal weighting of capabilities judged by individuals and aggregated
Sample Values for the HaLex and YHL

Value assigned to health states defined by activity limitation and perceived health for persons 18 years and older, NHIS 1990

<table>
<thead>
<tr>
<th>Limitation</th>
<th>Excellent</th>
<th>Very Good</th>
<th>Good</th>
<th>Fair</th>
<th>Poor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not Limited</td>
<td>1.00</td>
<td>0.92</td>
<td>0.84</td>
<td>0.63</td>
<td>0.47</td>
</tr>
<tr>
<td>Limited-other</td>
<td>0.87</td>
<td>0.79</td>
<td>0.72</td>
<td>0.52</td>
<td>0.38</td>
</tr>
<tr>
<td>Limited-major</td>
<td>0.81</td>
<td>0.74</td>
<td>0.67</td>
<td>0.48</td>
<td>0.34</td>
</tr>
<tr>
<td>Unable-major</td>
<td>0.68</td>
<td>0.62</td>
<td>0.55</td>
<td>0.38</td>
<td>0.25</td>
</tr>
<tr>
<td>Limited in IADLs*</td>
<td>0.57</td>
<td>0.51</td>
<td>0.45</td>
<td>0.29</td>
<td>0.17</td>
</tr>
<tr>
<td>Limited in ADLs**</td>
<td>0.47</td>
<td>0.41</td>
<td>0.36</td>
<td>0.21</td>
<td>0.10</td>
</tr>
</tbody>
</table>

*IADL: Instrumental Activities of Daily Living
**ADL: Activities of Daily Living

## A Suggested Table of Outcomes

<table>
<thead>
<tr>
<th>Countries</th>
<th>Life expectancy at birth 1999 (in years)</th>
<th>Health expenditure 1998 (% of GDP)</th>
<th>DALE 2000 (years)</th>
<th>Perceived Quality of Life</th>
</tr>
</thead>
<tbody>
<tr>
<td>Argentina</td>
<td>73.2</td>
<td>10.3</td>
<td>66.7</td>
<td>?</td>
</tr>
<tr>
<td>Bolivia</td>
<td>62.0</td>
<td>6.5</td>
<td>53.3</td>
<td>?</td>
</tr>
<tr>
<td>Brazil</td>
<td>67.5</td>
<td>6.6</td>
<td>59.1</td>
<td>?</td>
</tr>
<tr>
<td>Chile</td>
<td>75.2</td>
<td>5.8</td>
<td>68.6</td>
<td>?</td>
</tr>
<tr>
<td>Paraguay</td>
<td>69.9</td>
<td>5.3</td>
<td>63.0</td>
<td>?</td>
</tr>
<tr>
<td>Uruguay</td>
<td>74.2</td>
<td>9.1</td>
<td>67.0</td>
<td>?</td>
</tr>
</tbody>
</table>

Objectives

- Describe uses in public health & health care

*Improving treatment effectiveness*
I'm worried and concerned about GI symptoms that bother me! I can't bend over or exercise. My whole life is affected. Heartburn disturbs my sleep. I can't eat and drink whatever I like.
QOL Scores (higher = worse) for Patients with Extremity Sarcoma

* * p < .05; ** p = .051

Sugarbaker 1982
Change in SF-36 Domain Between Baseline and Post-Amputation Interval Diabetes Ulcer Outcome Study

△ SF-36 Score

- Physical functioning
- Role physical
- Bodily pain
- General health
- Vitality
- Social functioning
- Role emotional
- Mental health

Amputated <12 wk (n=19)
Amputated >12 wk (n=10)

* (zero)
## Quality-of-Life Outcomes in the Evaluation of Head and Neck Cancer Treatments

<table>
<thead>
<tr>
<th>Type of significance</th>
<th>Percentage of Studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Statistical</td>
<td>90.1</td>
</tr>
<tr>
<td>Clinical</td>
<td>26.7</td>
</tr>
<tr>
<td>Anchors</td>
<td>21.7</td>
</tr>
<tr>
<td>Minimally important difference</td>
<td>3.3</td>
</tr>
<tr>
<td>Both</td>
<td>1.7</td>
</tr>
</tbody>
</table>

Table 2. Percentage of the 61 Studies Using Method for Establishing Significance

*Schwartz et al., Arch Otolaryngol Head Neck Surg. 2001;127:673-678*
“I am looking forward to becoming humus myself buried naked without coffin under a tree on my land in Ao Tea Roa”

- Hundertwasser

b 15 December 1928 Wien
d 19 February 2000 Aboard QEII
End of Life Research and Practice

http://depts.washington.edu/eolcare/

- Develop outcome measures of the quality of dying and death
  - patient-clinician communication about end-of-life care, including loved ones
  - quality of end-of-life care

- Examine relationship between quality of care, communication & quality of dying and death

- Develop and test interventions to improve the quality of care and dying and death
Lessons learned: How to improve the quality of dying and death

- Improve communication between patient and family and between patients and providers
- Improve pain & symptom management
- Increase continuity of care
  - evening/weekend coverage
  - primary MD responsible for care
- Increase access to care coordinator
Objectives

Suggest current and future directions

- **Environment**: Finding the determinants
- **Person**: extending the scope
## Health Plan Level

### Physician Referral Project

<table>
<thead>
<tr>
<th>Improvement in:</th>
<th>Managedness Index</th>
<th>In-Network Benefits Index</th>
<th>Out-of-Network Benefits Index</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain interference</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Pain bothersomeness</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Restricted activity days</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Satisfaction with primary care physician</td>
<td></td>
<td>NS</td>
<td></td>
</tr>
</tbody>
</table>

NS: Not Significant
Breast Cancer Biobehavioral Model

- Intervention
- Psychobehavioral Functioning
  - Modifiable Mediating
  - Exogenous immune
- Neuroendocrine
- Immune Functioning
- Exogenous clinical/demo
Threats to validity of self-report

- Social desirability
- Cultural variation
- Adaptation and response shift
- Cognitive processes
- Emotional affect
Take away messages

- Determinants of QoL in the person and in the environment
- Functional status and QoL not synonymous
- QoL improvements through promotion of opportunity to achieve—social environment
- QoL useful outcome for public health
- Progress in measurement outpaces application in outcomes assessments
Quality of Life for Quality of Life Researchers