Well-Being and Quality of Life of Patients with Chronic Physical Illness

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Health-related quality of life

• The impact of disease and treatment on people’s lives and their capacity to perform the usual daily activities for their age and major social role (Guyatt)

• The functional effects of an illness and its therapy on the patient, as perceived by the patient (Sprangers)
Quality of life

• An individual’s perception of his or her position in life in the context of the culture and value systems in which he or she lives, and in relation to his or her goals, standards and concerns

Autonomy and freedom, prosperity, safety, respect, social functioning, well-being, fulfillment, self-actualization

- Stiglitz Commission
- National well-being accounts
Well-being in people with health problems

- Health-related quality of life
  - Disease-specific measures
  - Generic measures: SF-36, EQ5D, QWB, SIP

- SF-36

  Physical health status     Mental health status
  Physical functioning     Mental health
  Role limitations (physical)     Role limitations (emotional)
  Pain     Social functioning
  General health perception     Vitality
Well-being in people with health problems

• Health-related quality of life
  ➢ Disease-specific measures
  ➢ Generic measures: SF-36, EQ5D, QWB, SIP

• EQ-5D
  Mobility: No problem
  Self-care: Some problem
  Usual activities: Extreme
  Pain/discomfort
  Anxiety/depression
Well-being in people with health problems

- Health-related quality of life
  - Disease-specific measures
  - Generic measures: SF-36, EQ5D, QWB, SIP

- Identify problems that may not be central to the patient’s specific illness
- Evaluate treatments
- Allocate resources
Well-being in people with health problems

• How do different illnesses compare?
• Health-related quality of life:
Large-scale SF-36 studies

Sprangers (2000)

Hobbs (2002)

Singh (2005)

Wee (2005)
Well-being in people with health problems

• How do different illnesses compare?
• Health-related quality of life:
  • Physical components
    - Mild/moderate: diabetes, heart disease, cancer
    - Severe: musculoskeletal, chronic lung disease, stroke
  • Mental components
    - Mild/moderate: diabetes, heart disease, cancer, musculoskeletal
    - Severe: chronic lung disease, stroke
Well-being in people with health problems

• How do different illnesses compare?
• Health-related quality of life:
• Pain, disability
• Adaptation and response shift
  ➢ Change in internal standards (recalibration)
  ➢ Change in values (reprioritisation)
  ➢ Change in meaning (reconceptualisation)
Well-being in people with health problems

- Health-related quality of life
  - Disease-specific measures
  - Generic measures: EQ5D, SF-36, QWB, SIP

- General quality of life
- Subjective well-being
Well-being in people with health problems

- Negative states of well-being
  - Depressed mood

- Positive states of well-being
  - Positive affect, enjoyment, happiness
  - Evaluative aspects: autonomy, self-realisation, purpose in life
Well-being in people with health problems

- Is general quality of life and positive well-being impaired in people with health problems?

ELSA Wave One 2002
Interview (11,050) aged 50 and over

Wave Two 2004
Interview (9,432)
Nurse (7,666)

Wave Three 2006
Interview (9,771 core + refreshment group)

Life history (7,855)

Wave Four 2008/9
Interview (10,860 core + refreshment group)
Nurse (8,641)
ELSA measures

• CASP-19: control, autonomy, self-realisation and pleasure
• CES-D depression scale
• Happiness (two items)
  ➢ Have you recently been able to enjoy your normal day-to-day activities?
  ➢ Have you recently been feeling reasonably happy, all things considered?
General quality of life and chronic illness

ELSA wave 1, adjusted for Age, gender and wealth
Happiness and chronic illness

ELSA wave 1, adjusted for Age, gender and wealth
Depression and chronic illness

ELSA wave 1, adjusted for Age, gender and wealth
General quality of life and number of illnesses

ELSA wave 1, adjusted for Age, gender and wealth
Well-being and number of illnesses

ELSA wave 1, adjusted for
Age, gender and wealth
Well-being in people with health problems

• Is general quality of life and positive well-being impaired in people with health problems?
  ➢ Cross-sectional associations between all illnesses and compromised general quality of life and well-being
  ➢ Multiple conditions associated with greater impairment
General quality of life and illness onset

<table>
<thead>
<tr>
<th>Wave</th>
<th>Onset 1</th>
<th>Onset 2</th>
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<tbody>
<tr>
<td>Wave 1</td>
<td>✗</td>
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<tr>
<td>Wave 4</td>
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General quality of life and CHD

Adjusted for age, gender and wealth (ELSA)
General quality of life and stroke

Adjusted for age, gender and wealth (ELSA)
General quality of life and chronic lung disease

Adjusted for age, gender and wealth (ELSA)
Depression and chronic lung disease

Adjusted for age, gender and wealth (ELSA)
Depression and CHD

Adjusted for age, gender and wealth (ELSA)
Well-being in people with health problems

• Is general quality of life and positive well-being impaired in people with health problems?
  ➢ Cross-sectional associations between all illnesses and compromised general quality of life and well-being
  ➢ Multiple conditions associated with greater impairment
  ➢ Longitudinal analyses show mixed picture. Impairments may be present before diagnosis
Measurement of well-being

- Recollected affect
  - CES-D depression scale
  - General Health Questionnaire
  - Diener life satisfaction scale

- Problems of retrospective accounts
  - Recall errors
  - Recall biases (salience memory heuristics, etc)
  - ‘Memory – experience gap’

- Ecological momentary assessment
- Day reconstruction method

ELSA Wave One 2002
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Nurse (8,641)
Ecological momentary assessment

- 4,732 participants in wave 2
- Mean age 64.39, range 52 - 79
- Four assessments
  - Waking
  - 30 minutes after waking
  - 7:00 pm
  - Bedtime
- 4-point ratings (1 = not at all; 4 = extremely)
  - Happy, excited, content
  - Anxious, worried, fearful
  - Tired
## EMA and questionnaire measures

<table>
<thead>
<tr>
<th></th>
<th>CESD</th>
<th>CASP19</th>
<th>Life satisfaction</th>
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<tbody>
<tr>
<td>Positive affect</td>
<td>$r = -0.282$</td>
<td>$r = 0.354$</td>
<td>$r = 0.375$</td>
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<tr>
<td>Negative affect</td>
<td>$r = 0.296$</td>
<td>$r = -0.288$</td>
<td>$r = -0.201$</td>
</tr>
</tbody>
</table>

Adjusted for age, gender, and wealth
EMA positive affect and age

Positive affect vs. time of day for different age groups:

- Red circles represent individuals aged <64 years.
- Purple triangles represent individuals aged 65+ years.

Key points:
- Positive affect increases from wake to wake+30.
- There is a peak in positive affect at 7:00pm.
- Positive affect decreases after bed-time.
EMA negative affect and age

![Graph showing negative affect over time with age groups](graph.png)

- **Age <64**
- **Age 65+**

*X-axis: Wake, Wake+30, 7:00pm, Bed-time*

*Y-axis: Negative affect*
EMA positive affect and arthritis

Adjusted for age, gender, wealth, marital status, and work status
EMA positive affect and arthritis

Adjusted for age, gender, wealth, marital status, and work status
EMA negative affect and arthritis

Adjusted for age, gender, wealth, marital status, and work status
Adjusted for age, gender, wealth, marital status, and work status
EMA negative affect and CHD

Adjusted for age, gender, wealth, marital status, and work status
Adjusted for age, gender, wealth, marital status, and work status.
EMA negative affect and cancer

Adjusted for age, gender, wealth, marital status, and work status
Well-being in people with health problems

• Is general quality of life and positive well-being impaired in people with health problems?
  ➢ Cross-sectional associations between all illnesses and compromised general quality of life and well-being
  ➢ Multiple conditions associated with greater impairment
  ➢ Longitudinal analyses show mixed picture. Impairments may be present before diagnosis
  ➢ EMA analyses show adaptation in some conditions, and cumulative impairment of well-being in others
Well-being in people with health problems

- Is general quality of life and positive well-being impaired in people with health problems?
- Is it useful to measure positive as well as negative mood states in physical illness?
Happiness in CHD

- 147 patients tested 3 weeks after discharge from hospital following acute coronary syndrome
  - 127 men, 20 women, age 61.8 ± 10.9 years

- EMA 6 times over the day
  - Waking, waking+30 minutes; 10:00 am, 2:00 pm, 7:00 pm, bedtime

- Happiness rating
  - Not at all, somewhat, very much, extremely

- Depressed vs non-depressed
  - Hamilton rating scale for depression
Happiness and depression in CHD

147 patients
3 weeks after acute coronary syndrome
Happiness and depression in CHD

Adjusted for age, gender, ethnicity, social deprivation, marital status and Grace risk score
3 weeks after acute coronary syndrome
Measurement of well-being

• Recollected affect
  CES-D depression scale
  General Health Questionnaire
  Diener life satisfaction scale

• Problems of retrospective accounts
  Recall errors
  Recall biases (salience memory heuristics, etc)
  ‘Memory – experience gap’

• Ecological momentary assessment
• Day reconstruction method
Happiness during everyday activities

Mood rating

- Social
- Exercise
- Relax
- Eat
- TV
- Work
- Travel

40+ years
< 40 years
Well-being in people with health problems

• General well-being and positive affect impaired in people with chronic health problems

• Absence of depression and anxiety does not mean complete well-being

• Concurrent activities are critically relevant to experienced well-being
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