Improving quality of life for people with dementia: the ADI-Stroud symposia

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Understanding quality of life
Quality of life

- Intuitively understood
- Part of common discourse
  - personal
  - political
- Broad, unifying and holistic concept
- Continuous and fundamental human process
Health related quality of life

...an individual’s perception of their position in life...in relation to their goals, expectations, standards and concerns

– WHOQOL

...the impact of a perceived health state on [living] a subjectively fulfilling life

– Bullinger et al 1993
Quality of life -- particularly important in dementia

- Dementias are more complex than simple disorders
  - coronary heart disease
  - diabetes
  - surgical care

- Non-linear and unpredictable process

- Multiple pathologies

- Link between symptoms and qol is not clear, simple or predictable

- Interventions are usually complex
  - need to avoid OSPD syndrome
Quality of life in dementia

- What really matters to people with dementia and their carers
- What really matters to clinicians
- The true goal of intervention
- What should really matter to policy makers and researchers
- More than just a combination of health assessments
  - cognition and behaviour are not very good proxies for quality of life
How to measure it

• Different levels require different approaches
  – individual level
  – population level

• Measurement derived from the experiences and values of people with dementia rather than the preconceptions of “experts”

• Patient Reported Outcome Measure (PROM)
Measurement of quality of life

Individual level – DEMQOL
Measurement at the individual level

- Much excellent work in instrument development eg
  - QOLAS Selai et al (2001)

- Evolving field with progressive refinement of methodology
Development of the system

Initial field test
111 pairs

Psychometrics
Item reduction

Final field test
105 pairs

Conceptual framework
bottom up + top down

DEMQOL
DEMQOL-Proxy
Measurement of health-related quality of life for people with dementia: development of a new instrument (DEM-QOL) and an evaluation of current methodology

SC Smith, DL Lamping, S Banerjee, R Harwood, B Foley, P Smith, JC Cook, J Murray, M Prince, E Levin, A Mann and M Knapp

March 2005

Health Technology Assessment
NHS R&D HTA Programme

The system

- Two interviewer administered self-report instruments
  - different items work in the two groups
  - measuring the same thing
- DEMQOL
  - 28 item self report for people with dementia
  - 5 to 30 minutes
  - Score 28 to 112
- DEMQOL-Proxy
  - 31 item carer report on qol of person with dementia
  - 5 to 10 minutes
  - Score 31 to 124
- Administration manuals for each
Instructions: Read each of the following questions (in bold) verbatim and show the respondent the response card.

I would like to ask you about your life. There are no right or wrong answers. Just give the answer that best describes how you have felt in the last week. Don’t worry if some questions appear not to apply to you. We have to ask the same questions of everybody.

Before we start we’ll do a practise question; that’s one that doesn’t count. (Show the response card and ask respondent to say or point to the answer.). In the last week, how much have you enjoyed watching television?

a lot      quite a bit      a little      not at all

Follow up with a prompt question: Why is that? or Tell me a bit more about that.
**First I’m going to ask about your feelings. In the last week, have you felt……..**

1. cheerful? **
   - a lot
   - quite a bit
   - a little
   - not at all

2. worried or anxious?
   - a lot
   - quite a bit
   - a little
   - not at all

3. that you are enjoying life? **
   - a lot
   - quite a bit
   - a little
   - not at all

4. frustrated?
   - a lot
   - quite a bit
   - a little
   - not at all

5. confident? **
   - a lot
   - quite a bit
   - a little
   - not at all

6. full of energy? **
   - a lot
   - quite a bit
   - a little
   - not at all

7. sad?
   - a lot
   - quite a bit
   - a little
   - not at all

8. lonely?
   - a lot
   - quite a bit
   - a little
   - not at all

9. distressed?
   - a lot
   - quite a bit
   - a little
   - not at all

10. lively? **
    - a lot
    - quite a bit
    - a little
    - not at all

11. irritable?
    - a lot
    - quite a bit
    - a little
    - not at all

12. fed-up?
    - a lot
    - quite a bit
    - a little
    - not at all

13. that there are things that you wanted to do but couldn’t?
    - a lot
    - quite a bit
    - a little
    - not at all

**Next, I’m going to ask you about your memory. In the last week, how worried have you been about……..**

14. forgetting things that happened recently?
    - a lot
    - quite a bit
    - a little
    - not at all

15. forgetting who people are?
    - a lot
    - quite a bit
    - a little
    - not at all

16. forgetting what day it is?
    - a lot
    - quite a bit
    - a little
    - not at all
DEMOL system results

- High acceptability
- High feasibility
- High internal consistency
- Good test retest reliability
- Good evidence of validity
  - content
  - convergent (SF12 MCS)
  - discriminant (no effect age and gender)
- More work needed on responsiveness

**DEMQOL-Proxy: Linear regression of clinical variables with DEMQOL-Proxy**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Beta coefficient</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>NPI total</td>
<td>0.52</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Patient age</td>
<td>0.32</td>
<td>0.016</td>
</tr>
<tr>
<td>MMSE</td>
<td>-0.16</td>
<td>0.281</td>
</tr>
<tr>
<td>Carer GHQ</td>
<td>0.07</td>
<td>0.623</td>
</tr>
<tr>
<td>ADL (BI)</td>
<td>0.02</td>
<td>0.924</td>
</tr>
</tbody>
</table>

Quality of life measuring quality of care -
Croydon Memory Service Model Evaluation
What is good quality care? - data on first 780 cases

95% acceptance rate

94% appropriate referrals

18% minority ethnic groups

19% under 65 years of age

Outcome: improvement in self-rated quality of life - DEMQOL

- Part of routine assessment
- Preliminary data
- 109 cases
- 6 month follow-up
- p=0.029

Banerjee et al (2007) IJGP
Outcome: improvement in proxy-rated quality of life – DEMQOL-Proxy

- Part of routine assessment
- Preliminary data
- 141 cases
- 6 month follow-up
- p=0.041
Change in DEMQOL for those below mean (<90)

- 6 month DEMQOL change 8.3pt, paired t=4.99, p<0.001, Cohen’s $d = 0.79$
- 12 month DEMQOL change 7.8pt, paired t=3.88, p<0.001, Cohen’s $d = 0.60$
Distribution of DEMQOL scores by CDR score

- Drive up the quality of life for those with poor quality of life.
- Maintain a good quality of life for those with good life quality.

DEMQOL score

CDR score
Changes over time in real world clinical practice, DEMQOL scores from the Croydon Memory Service

- routine practice
- data from patients remaining in service
- baseline, 6 months and 12 months
- indication of the possibility of change
- one element of responsiveness
GENERATION OF PREFERENCE-BASED INDICES FROM DEMQOL AND DEMQOL-PROXY FOR USE IN ECONOMIC EVALUATION
Introduction

- Economic evaluation using cost utility analysis can inform resource allocation between emerging interventions

- Cost per Quality Adjusted Life Year (QALY) can be used

- The ‘Q’ or utility requires a health state value scored using preference information

- Typically generic preference based measures (PBM) of health (eg EQ-5D/SF-6D) are used

- Generally these animals do not work well in dementia
Five linked stages

- Adapt DEMQOL and DEMQOL-Proxy using psychometric and Rasch analysis to develop a health state classification system with one item per dimension
- Classification system amenable to preference valuation and the subsequent generation of QALYs using dementia specific preference based measures

1. **Derivation of the health state classification**
   - **Step I** Establish dimensions using EFA
   - **Step II** Eliminate items per dimension using Rasch analysis
   - **Step III** Select items per dimension using Rasch analysis and clinical input
   - **Step IV** Exploration of item level reducing per dimension
   - **Step V** Validation – repeat steps I to IV on other datasets

2. **Main population valuation survey**
3. **Patient/carer valuation survey**
4. **Modelling**, and
5. **Application to trial data**
Lots of scientific stuff...

Disordered response levels

Differential item functioning

Fit to Rasch models
Results

- Mean observed TTO values range from 0.18 to 0.95 for DEMQOL-5D and from 0.33 to 0.96 for DEMQOL-P-4D.
- The best performing models for each measure were main effects models estimated using individual level data.
- Overall the regression models have:
  - good predictive ability (for example MAE 0.043-0.067)
  - consistent coefficients, and
  - comparable in their performance to other measures including:
    - generic EQ-5D (MAE 0.039)
    - SF-6D (MAE 0.073-0.079)
    - asthma-specific AQL-5D (0.046-0.057 and
    - cancer-specific EORTC-8D (0.046 to 0.054)
Conclusions

• A system ready to use.
• It is feasible to estimate preference-based single index measures from the DEMQOL and DEMQOL-Proxy for use in economic evaluation.
• These measures will enable economic evaluation using (good) QALYs to be undertaken on people with dementia across the full severity range of dementia.
What individual measures can’t do...

• Constrained by measurability
  – The tyranny of the four point scale
  – Love, touch, choice, liberty, personhood, dignity, respect

• Many of the big questions out of range
  – Strategy
  – Policy
  – Choice (eg of care home)
Use of a population level quality of life framework in dementia

• Framework with which to judge policies and practice
  – internationally, nationally, locally

• Design services, systems and policies that truly meet the needs of people with dementia and their carers
  – designed to maintain and enhance life quality

• Operationalise broad political and policy statements
  – help to turn rhetoric into reality
A population framework for understanding quality of life in dementia and evaluating public policy and service

Stroud symposia ADI-QOL
Rationale for the series

• To develop a cross-national understanding of what
  – determines good and bad quality of life in dementia
  – improve or impair quality of life in dementia

• To generate a cross-national framework with which to judge services and policy for people with dementia
The ADI/Stroud workshops

- Washington 100 participants
  - the nature of quality of life in dementia
- Christchurch 150 participants
  - what makes quality of life in dementia better and worse
- Barcelona 50 participants
  - practical actions to promote or inhibit quality of life
- Dominican Republic 100 participants
  - relationship between carer and the person with dementia
- Kyoto 170 participants
  - the role of choice in quality of life in dementia
- Istanbul 40 participants
  - spirituality and quality of life
- Berlin 50 participants
  - effect and timing of diagnosis
- Singapore 50 participants
  - review and future use
Contributors
Methodology for generating the ADI-QOL model – the small print!

- NVivo 2 qualitative data handling computer package used to aid storage, coding, and retrieval of the data.
- Transcripts analysed using qualitative thematic analysis.
- They were coded in detail for concepts using open coding.
- Codes derived directly from data, not from pre-determined theory.
- Two people (RW, SB) read the transcripts thoroughly, worked to develop a coding framework.
- Any discrepancies discussed until consensus reached.
- All of the transcripts were coded at a detailed conceptual level, with new codes emerging.
- Once all coded, transcripts read again from the beginning to ensure that instances of concepts defined by later codes were captured.
- Detailed codes were re-examined and codes were grouped into themes, forming conceptual domains drawn from the text itself to ensure the themes were fully grounded in the data.
Elements of quality of life in dementia: frequency of endorsement

- Respect
- Education
- Spirituality
- Love
- Communication
- Time
- Choice
Background themes

- Subjective
- individually-defined
- Important cultural elements, but...
- Possible to find supra-cultural transcendent themes
- not the same as disease progression
- inter-dependence of quality of life for carer and person with dementia

- Five domains
  - Personhood
  - Communication
  - Environment
  - Health
  - Quality of Care
Making it better -- personhood

- Choice/decision making (43)
- love (33)
- cultural appropriateness (19)
- respect (18)
- knowing personal history (13)
- spirituality (11)
- treat as individual (10)

- Involvement
- creativity
- belonging
- genuineness
- feeling useful
- tolerance
- independence
- dignity
- work with retained skills
- treat like an adult
- freedom/autonomy
- trust
- acceptance
Making it worse -- personhood

- Infantalisation (17)
- treating as a disease (10)
- being stopped doing things (9)
- forced to do things (9)
- denying choice (7)
- rejection/exclusion (6)

- abuse
- role stripping
- over-organisation
- over protection
- denial of individuality
- disrespect
- made to feel not worthwhile
- indifference
- loss of autonomy
- disgust
- dishonesty
- laughing at people with dementia
Making quality of life better in dementia

- Communication
  - touch
- Environment
  - security
- Personhood
  - choice
- Health
  - physical care
- Quality of life
- Quality of care
  - carer support
Making quality of life worse in dementia

- Communication
  - Lack of time
- Environment
  - restriction
- Personhood
  - infantilisation
- Health
  - medication
- Quality of life
- Quality of care
  - denial
ADI-QOL model of quality of life in dementia

**Inner ring**
- Quality of care
- Health
- Communication
- Environment
- Personhood

**Outer ring**
- Service funding
- Public attitudes
- Policy
How we might use the framework?

- Systematic framework to judge
  - service eg care home
  - policy eg NSF
- Assess by domain
  - then domain content
- Who can use it?
  - service themselves
  - inspectors
  - customers

- What do you do?
  - Use any information you have
    - enquiry
    - observation
    - consensus
- Useful information where there is none
- Tells you where to look and what to look for
- Value in repetition
Quality of care in dementia: challenges and solutions informed by and judged by the ADI-QOL framework
National Dementia Strategy - England

• Published 2 Feb 2009
• Five year plan
• 17 interlinked objectives
• £150 million extra funding
• Four key themes
  • Improving awareness
  • Early and better diagnosis
  • Improved quality of care
  • Delivering the Strategy
National Dementia Strategy - England

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Objectives of the National Dementia Strategy - England

Raising awareness and understanding

- O1 public information campaign

Early diagnosis and support

- O2 memory services
- O3 information for people with dementia and carers
- O4 continuity of support for people with dementia and carers
- O5 peer support for people with dementia and carers

Living well with dementia

- O6 improved care in general hospitals
- O7 implementing carer’s strategy for people with dementia
- O8 improved community personal support
- O9 improved intermediate care for dementia
- O10 housing including telecare
- O11 improved care home care
- O12 improved EOLC

Making the change

- O13 workforce competencies, development and training
- O14 joint local commissioning strategy and world class commissioning
- O15 performance monitoring and evaluation including inspection
- O16 research
- O17 effective national and regional support for implementation of the strategy
Objectives of the National Dementia Strategy - England

- Environment
- Personhood
- Health
- Communication
- Quality of Care
- Government & Social Policy
- Public Attitudes & Understanding
- Funding for Services
- Quality of Life

Making the change:
- Workforce competencies, development and training
- Joint local commissioning strategy and world class commissioning
- Performance monitoring and evaluation including inspection
- Research
- Effective national and regional support for implementation of the strategy

Diagram showing the interconnection between various objectives and strategies.
Living well with dementia in care homes

Reduced use of antipsychotic medication
Ministerial review of use of antipsychotics in dementia

- Published November 2009
- Comprehensive review
  - Negative effects
  - Positive effects
- Analysis of reasons for current clinical behaviour
- Practical clinical plan to deal with problems found
New data and extrapolation

- NHS Information Centre for Health and Social Care completed analyses using the IMS Disease Analyzer.
- Practices from England, Wales, Scotland and Northern Ireland a representative UK sample by age and sex.
- 1,098,627 patients 12-month period from 1 April 2007 to 31 March 2008.
  - 192,190 people (17.5%) over the age of 65
  - 10,255 (5.3%) received a prescription for an antipsychotic.

Estimates for the report

- 25% people with dementia receiving an antipsychotic
- 180,000 people with dementia receiving an antipsychotic
- Includes people with dementia at home as well as people in care homes
Summary of risks and benefits at a population level of the use of antipsychotics for BPSD in people with dementia

- data suggest that treating 1,000 people with BPSD with an atypical antipsychotic drug for around 12 weeks would result in
  - an additional 91–200 patients with behaviour disturbance showing clinically significant improvement
  - an additional 10 deaths;
  - an additional 18 CVAEs,
    » around half of which may be severe;
  - no additional falls or fractures; and
  - an additional 58–94 patients with gait disturbance.

- For UK
  - 1,800 deaths per year
  - 1,620 severe CVAEs per year
Analysis of why

- Symptom of underlying system failure in health and social care for people with dementia
- 1960s response to a 21st century challenge
- Why lack of response to clear warnings
  - It is complicated
  - System does not allow change
    - Knowledge
    - Attitudes
    - Provision
- Simple stuff eg specialists shouting at GPS does not work
- Need to treat the cause as well as the symptoms
Action

- Provision of specialist input
- Use quality improvement mechanisms
- Improve skills in primary and social care
Action

Provision of specialist input

Use quality improvement mechanisms

Improve skills in primary and social care
Final thoughts

• Concepts of quality of life are important and useful
  – everything we do for people with dementia and their carers is about enhancing or maintaining good quality of life

• Intervention at multiple levels likely to lead to the greatest quality improvement
  – international, national, local, individual

• Different levels need different interventions and measures

• We now have the materials and methods to plan, assess and improve QoL in dementia
Thank you!