W13: Modelling disease progression and economic outcomes of dementia interventions: exploring options for a complex health problem

Tracy Comans, Jasmine Pwu, Kim-Huong Nguyen
Brendan Mulhern

Panellists

• Tracy Comans – Associate Professor in health economics, Centre for Health Services Research, University of Queensland
• Kim-Huong Nguyen, Research Fellow, Centre for Health Services Research, University of Queensland
• Raoh-Fang (Jasmine) Pwu, Director, National Hepatitis C Program Office, Ministry of Health and Welfare, Taipei City, Taiwan
• Brendan Mulhern, Senior Research Fellow, Centre for Health Economics Research and Evaluation, University of Technology, Sydney
Funding organisations

- A/Prof Comans is supported by a NHMRC Boosting Dementia Research Leadership Fellowship
- A/Prof Comans and Dr Nguyen receive research funding through the NHMRC cognitive and related functional decline research centre
- Mr Mulhern receives research funding from the NHMRC, the UK MRC (DEMQOL) and a UTS scholarship

Impacts (World)

- Close to 50 million people, doubling every 20 years estimated to be 131.5 million in 2050
- Much of the increase will be in low and middle income countries
- More than 50% of residents in Australian government-subsidised aged care facilities (RACF) have dementia
  - 44% of RACF residents with dementia also had a diagnosis of a mental illness
- In high-income countries only 20-50% of people with dementia are recognised and documented in primary care.
  - This rate is much lower in low- and middle-income countries where statistical reporting systems are less comprehensive
The decades long search for effective ways to treat or prevent Alzheimer's disease is littered with failures …

But precision medicine—an approach that is changing the treatment of cancer and spawning targeted therapies for a wide range of diseases—may open new avenues for the treatment of Alzheimer's disease.
Treatment - drug

• There is no cure and limited treatments available for dementia
  • Current treatments for AD are not considered disease modifying because they only provide symptomatic improvements and are not associated with improvements on patient survival
  • Over 200 drugs have undergone clinical trials, however only 3 cholinesterase inhibitors (donepezil, galantamine and rivastigmine) and 1 receptor antagonist (memantine) have shown sufficient safety and efficacy
• Blow to future hopes for a better treatment this year:
  • Pfizer announced it was halting research efforts in this area after many years of failed trials
  • Others may follow

Experts: Try non-drug treatment first to manage dementia

BY ABC News Radio | August 2, 2018
Future treatments

• Targets now being sought in mild cognitive decline and pre-dementia states
• As there is a larger population:
  • Cost likely to be high
  • Number needed to be treat likely to be high
  • There will be an imperative to show high value

Current work happening

• Even though there is no current therapy to evaluate, some groups of researchers and funders are preparing models for dementia:
International Pharmaco-Economic Conference on Alzheimer’s Disease

• IPECAD is the only conference that exclusively addresses issues related to the economic evaluation of drug treatments for Alzheimer’s disease.
  • Group of people are developing an open access model for health economic evaluation of AD

• The model will describe progression from pre-dementia states such as at-risk or Mild Cognitive Impairment to dementia and death. The goal of the model is to enable the estimation of the impact of various innovations in Alzheimer’s disease.
  • http://www.ronhandels.nl/category/projects/

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Welcome to ROADMAP!
The “Real world Outcomes across the Alzheimer’s Disease spectrum for better care: Multi-modal data Access Platform” (ROADMAP) project provides the foundation for an integrated data environment and framework for real-world evidence (RWE in Alzheimer’s disease).

This includes the development of consensual key outcome measures and enabling data integration tools for dataset characterisation and outcome classification, as well as guidelines on the handling and interpretation of RWE data. ROADMAP has a budget of EUR 8.21 million and 26 partners led by the University of Oxford and Novartis.
MODELLING DISEASE PROGRESSION AND ECONOMIC OUTCOMES OF DEMENTIA INTERVENTIONS: EXPLORING OPTIONS FOR A COMPLEX HEALTH PROBLEM

Jasmine R. F. Pwu, PhD
Director, National Hepatitis C Program Office, MOHW
An early exercise in Taiwan

Cost-effectiveness analysis of donepezil for mild to moderate Alzheimer’s disease in Taiwan

Jong-Ling Fuh§ and Shuu-Jien Wang

Neurological Institute, Taipei Veterans General Hospital and National Yang-Ming University School of Medicine, Taipei, Taiwan

The choice of disease states

Figure 1. Model structure for the study.
RWE used

V1~V2: data abandoned
V2~a: at risk of moderate
a: presumed time moderate-severe occurs
a~1999/1/1: severe state

Transition probability estimation

Measuring Alzheimer’s disease progression with transition probabilities in the Taiwanese population

Jong-Ling Fuh¹*, Raoh-Fang Pwu², Shuu-Jian Wang¹ and Yu-Hsin Chen²

¹Neurological Institute, Taipei Veterans General Hospital and National Yang-Ming University School of Medicine, Taipei, Taiwan
²iStat Healthcare Consulting Co., Ltd. Taiwan
Table 1. Demographic and neuropsychiatric measures

<table>
<thead>
<tr>
<th>Measure</th>
<th>Patients taking CEIs (n = 194)</th>
<th>Patients not taking CEIs (n = 171)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Follow-up (months)</td>
<td>30.2 ± 17.9</td>
<td>27.4 ± 15.2</td>
<td>0.14</td>
</tr>
<tr>
<td>Male:Female</td>
<td>96:98</td>
<td>73:98</td>
<td>0.19</td>
</tr>
<tr>
<td>Education (years)</td>
<td>8.2 ± 5.2</td>
<td>7.8 ± 5.9</td>
<td>0.45</td>
</tr>
<tr>
<td>Age</td>
<td>73.1 ± 7.4</td>
<td>73.6 ± 8.6</td>
<td>0.58</td>
</tr>
<tr>
<td>MMSE score</td>
<td>16.9 ± 6.9</td>
<td>12.0 ± 7.9</td>
<td>&lt;0.001*</td>
</tr>
<tr>
<td>CDR score of 1/2/3 or above</td>
<td>130/38/3</td>
<td>86/63/45</td>
<td>&lt;0.001†</td>
</tr>
<tr>
<td>Delusion or hallucination (%)</td>
<td>18.0</td>
<td>39.2</td>
<td>0.003†</td>
</tr>
</tbody>
</table>

MMSE = Mini-Mental State Examination; CDR = clinical dementia rating scale.
*The finding was statistically significant via student t-test, p < 0.05.
†The finding was statistically significant via Chi-square test, p < 0.05.

Table 2. Estimated annual transition probabilities

<table>
<thead>
<tr>
<th>Beginning state</th>
<th>Ending state</th>
<th>Total patients (n = 365)</th>
<th>Patients not taking CEIs (n = 194)</th>
<th>Patients taking CEIs (n = 171)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mild</td>
<td>Moderate</td>
<td>Severe</td>
<td>Dead</td>
</tr>
<tr>
<td>Total patients</td>
<td>0.690</td>
<td>0.234</td>
<td>0.054</td>
<td>0.022</td>
</tr>
<tr>
<td>Patients</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>not taking</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CEIs (n = 194)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patients</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>taking CEIs (n=</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>171)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 3. Hazard ratios associated with sex, age, psychotic symptoms, and CEI use

<table>
<thead>
<tr>
<th>Transition</th>
<th>Male sex</th>
<th>Age ≥ 75 years</th>
<th>Psychotic symptoms</th>
<th>CEI use</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild to moderate</td>
<td>0.96 (0.62–1.48)</td>
<td>1.00 (0.97–1.03)</td>
<td>0.99 (0.60–1.62)</td>
<td>0.35* (0.22–0.55)</td>
</tr>
<tr>
<td>Mild to severe</td>
<td>0.71 (0.35–1.43)</td>
<td>0.98 (0.94–1.02)</td>
<td>0.98 (0.45–2.11)</td>
<td>0.13* (0.05–0.34)</td>
</tr>
<tr>
<td>Moderate to severe</td>
<td>0.78 (0.46–1.32)</td>
<td>0.99 (0.96–1.01)</td>
<td>1.03 (0.81–1.31)</td>
<td>0.28* (0.15–0.52)</td>
</tr>
<tr>
<td>Mild to dead</td>
<td>4.03* (1.10–14.74)</td>
<td>1.08 (0.99–1.17)</td>
<td>1.71 (0.52–5.58)</td>
<td>NA</td>
</tr>
<tr>
<td>Moderate to dead</td>
<td>2.53 (0.83–7.66)</td>
<td>0.99 (0.93–1.05)</td>
<td>1.05 (0.74–1.49)</td>
<td>NA</td>
</tr>
<tr>
<td>Severe to dead</td>
<td>2.95 (0.85–10.21)</td>
<td>1.03 (0.96–1.10)</td>
<td>2.97 (0.85–10.38)</td>
<td>NA</td>
</tr>
</tbody>
</table>

Numbers in parentheses are 95% confidence intervals.
CEI = cholinesterase inhibitors; NA = not applicable.
*p < 0.05.
Results

<table>
<thead>
<tr>
<th>Comparison</th>
<th>Total cost</th>
<th>Incremental costs</th>
<th>QALY</th>
<th>Incremental QALYs</th>
<th>Incremental cost-effectiveness ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>non-pharmacological</td>
<td>65,373</td>
<td></td>
<td>1,687</td>
<td>0.525</td>
<td>Dominant</td>
</tr>
<tr>
<td>Donepezil</td>
<td>57,220</td>
<td>-8,153</td>
<td>2,211</td>
<td></td>
<td>7,009</td>
</tr>
</tbody>
</table>

QALY = quality-adjusted life years.

Challenges faced

- Model structure
- Model types
- Data
  - Transition probability
  - Costs
  - Endpoint choices – QALYs?
- Perspectives
Review of the modeling CEA studies

Modeling: targeted population

- Mild-to-moderate (or moderately severe) AD
- Moderate-to-severe AD
- Mild-to-moderate and Moderate-to-severe AD
- General AD living in the community
- Mild cognitive impairment (MCI) due to AD
## Concept models

<table>
<thead>
<tr>
<th>By disease severity according to:</th>
<th>Modeling techniques</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Cognitive function</td>
<td>Markov models, microsimulations</td>
</tr>
<tr>
<td>□ CDR</td>
<td></td>
</tr>
<tr>
<td>□ MMSE</td>
<td></td>
</tr>
<tr>
<td>• Cognitive function and activities of daily living (DAL)</td>
<td>Markov models</td>
</tr>
<tr>
<td>□ MMSE and basic ADL (B-ADL) / instrumental ADL (I-ADL)</td>
<td></td>
</tr>
<tr>
<td>• Patients’ location of care</td>
<td>Markov models, Survival partition model</td>
</tr>
<tr>
<td>□ Not institutionalized and institutionalized</td>
<td></td>
</tr>
<tr>
<td>• The need of FTC</td>
<td>Markov models</td>
</tr>
<tr>
<td>• Continuous interrelated changes over time in cognition, behavior, and function</td>
<td>Discrete event simulation</td>
</tr>
</tbody>
</table>

(Hernandez et al, 2016)

![Diagram](image-url)

**Fig. 1.** Outline view of the cost-effectiveness model. ADAS-cog = Alzheimer’s disease assessment scale-cognitive subscale; FTC = full-time care.

*Pharmacoeconomics 2005; 23 (12)*
Data source

Mix of the following...

- RCT (and placebo arm)
  - And open-label extension study
- Longitudinal study

Endpoints of CEA

- Non-severe life years gained
- QALY gained

Utility – big issue!
What years did the data used for modelling disease progression come from?

Hybrid approach to model dementia progression and evaluate dementia interventions

Kim-Huong Nguyen, Tracy Comans and Dylan Knowles
Research rationale

Need to evaluate economic values of support programs for people with dementia and their informal caregivers

Searching for economic models in the literature

Literature review of model-based economic evaluations (*in press*)

Developing an economic model to evaluate dementia interventions

Objectives of the model

• Originally, we wanted a model that can evaluate both pharma and non-pharma interventions:
  • For pharma interventions, the intervention cost is often contained within the cost of medication → so scaling up is not a real issue
  • For non-pharma intervention (NPI): largely labour cost + issues like availability of services in a particular geographic location (equity) + more variability in intervention delivery due to human factors (efficacy) → scale-up is more challenging
Objectives of the model

• Then we wanted something more because:
  • We think the role of carers is more than just a passive “collection of costs and QALYs” (they impact the progression and likelihood of the person with dementia moving into a residential aged care facility)
  • There is a real substitution effect between NPI and care time/resources spent by informal carers (regardless of intervention efficacy/effectiveness)
  • The trade-off between funding entities are also evident (not just in dementia): high quality / comprehensive aged care and primary care provision often benefits hospitals and EDs by reducing demand; but high and more comprehensive care means higher spending …

Modelling choices

Our obvious option – Markov model

- **Person with dementia** → dementia progression modelled by a standard Markov method (with health states)
  - Accumulate costs and outcomes (LYs, QALYs) for each health states (average costs and outcomes per state plus events)
- **Carers** → changes of health status (dependent on disease progression of the person with dementia)
  - If using a Markov method, they can accumulate costs and outcomes by health states
  - Or a simpler option, they can be treated as a cost or quality accumulator for the person with dementia (currently done in the literature)
- All services can be modelled as average costs (severity-adjusted) per HS or average event cost (e.g. hospital admission, temporary respite care)

Challenges

- Model two Markov processes and allow them to interacts with each other
  - This means expanding the disease progression model into a large number of health states or branches with the carer’s health state nested within the person with dementia’s health states
- Allow for resource constraints (i.e. patients competing for resources and queuing) within a Markov model
  - When we looked for modelling options, TreeAge does not offer this function yet – now you can do some quasi-DES
  - If one DES process is difficult to do, don’t know how we can manage 2–3 of these (hospital, aged care services in the community, nursing home)
- Understand requirements for scale-up or complementary and substitutionary effects between services
Modelling choices

“Everything should be made as simple as possible. But not simpler.”
Albert Einstein

So we revised our objective

Need to evaluate economic values of support programs for people with dementia and their informal caregivers

Searching for economic models in the literature

Literature review of model-based economic evaluations (in press)

Developing a hybrid model to capture dementia progression + service utilisation to evaluate dementia interventions

Adjacent activities

Scoping study: bilateral impacts of dementia dyad

Modelling dementia progression accounting for multidimensional heterogeneity progression
Hybrid (multi-method) modelling

These methods are the different viewpoints that a modeller can take when mapping the real world system into the world of models.

Agent based model
Discrete event simulation
System dynamics

Model applications …

Core dementia component

The disease model (agent / environment)

Population (SD)
- Aging → MCI
- MCI → dementia

Dementia Dyads (ABM)
- Progression in different domains → care needed → living situation
- Progression → mortality
- Progression → events (hospitalisations)

Person with Dementia

Informal carer
- Patient progression → carer burden, stress → events
- Self care, working

Population pyramid (system dynamics)

Flow: number of people who died within this age group

Stock: number of people in an age group
Flow: number of people developed dementia
Stock: new dementia patients
Dementia dyads

Variables controlling behaviour of carers or people with dementia from the “outside”

Agent “living inside” the dyad

Remove the dyad from the population (event of dead)

Person with dementia (ABM)

- 27 health states using 3 state charts
- Transition probabilities informed by a table function
- Dementia patients can enter the disease process at any severity level
- (They are generated from the population pyramid)
Person with dementia (ABM)

- They are able to live either at home (community) or RACF (nursing home) or temporarily in hospital.
- The location depends on:
  - Their health states (red-green-yellow)
  - The carer’s ability to support them at home → interaction with the carer “agent”

Informal carers (ABM)

Functions, variables control how the carer recharge and remains providing care

Functions, variables that allow dementia progression impact on informal carers
Future plan – next model iteration

• ABM can accommodate continuous changes in health conditions (by changes in clinical indicators such as MMSE, ADL, NPI, etc.)
  • We will change the discrete (27) health states (statecharts) using table functions that incorporate a system of questions estimating dementia progression over time
  • This will allow us to incorporate trial data directly to the models if trials collect clinical indicators used in the model (there is always the possibility to having extra functions and to turn them off when not needed)

• Incorporate bilateral impacts of dementia patients and carers
  • Using the links identified in the literature and using results of the literature as cross-validation data

• Develop the remaining components

Hybrid model challenges

• Complex models are data hungry and computational expensive
  • Ours is no different: at the moment, we have a lot of place holders and most inputs are sourced from the literature – this can be improved gradually when more data becomes available

• Building a hybrid model is time consuming
  • It has been a steep learning process for us. The software is very visual with lots of functions (great) but allowing for complex rules and interactions requires extra Java coding (challenging)

• If the question is “whether or not a intervention is cost-effective, this method is possibly unnecessary …
  • But if we want to generate knowledge on what works and what doesn’t – and to understand economic impact (welfare analysis) then maybe it is not so?
Introduction

• Measuring health and quality of life outcomes in dementia is challenging:
  • Difficulty in self and proxy report
  • Difficulty in measuring subjective concepts
  • Wide range of impacts of condition on the person's life
  • Interaction of co morbidities

• Valuation of outcomes also requires careful consideration

• Both generic and condition specific measures used in dementia, and both have advantages and disadvantages

• This may lead to issues with the accuracy of QALYs used in dementia
Generic measures used in dementia

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Domains</th>
<th>Number of health states</th>
<th>Number of studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>EQ-5D</td>
<td>Mobility, self-care, usual activities, pain/discomfort, and anxiety/depression</td>
<td>243/3,125</td>
<td>45</td>
</tr>
<tr>
<td>HUI 2/3</td>
<td>Vision, hearing, speech, ambulation, dexterity, emotion, cognition, and pain</td>
<td>24,000/975,000</td>
<td>15</td>
</tr>
<tr>
<td>QWB</td>
<td>Mobility, physical activity, and social activity</td>
<td>1,170</td>
<td>4</td>
</tr>
<tr>
<td>15D</td>
<td>Mobility, vision, hearing, breathing, sleeping, eating, speech, elimination, usual activities, mental function, discomfort and symptoms, depression, distress, vitality, and sexual activity</td>
<td>31 billion</td>
<td>3</td>
</tr>
<tr>
<td>AQuoL</td>
<td>Illness, independent living, social relationships, physical senses, and psychological well-being</td>
<td>16.8 billion</td>
<td>2</td>
</tr>
</tbody>
</table>

Psychometric properties of generic measures

<table>
<thead>
<tr>
<th></th>
<th>EQ-5D</th>
<th>HUI2/3</th>
<th>QWB</th>
<th>AQuoL</th>
<th>15D</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feasibility</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Average patient-rated completion time (min)</td>
<td>4.5</td>
<td>16.3</td>
<td>18.7</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>Average proxy-rated completion time (min)</td>
<td>2.3</td>
<td>7.7</td>
<td>11.3</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>Average missing items</td>
<td>1%</td>
<td>19%</td>
<td>24%</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>Precision</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shows ceiling effect</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>NA</td>
</tr>
<tr>
<td>Shows floor effect</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>NA</td>
</tr>
<tr>
<td>Reliability</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Test-retest reliability</td>
<td>Moderate</td>
<td>Moderate</td>
<td>Strong</td>
<td>Weak</td>
<td>Weak</td>
</tr>
<tr>
<td>Inter-rater agreement</td>
<td>Weak</td>
<td>Weak</td>
<td>Weak</td>
<td>Weak</td>
<td>Weak</td>
</tr>
<tr>
<td>Validity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of relevant attributes included</td>
<td>10</td>
<td>11</td>
<td>25</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>Convergence validity</td>
<td>Strong</td>
<td>Inconclusive</td>
<td>Moderate</td>
<td>Moderate</td>
<td>Weak</td>
</tr>
<tr>
<td>Known-group validity according to MMSE</td>
<td>Moderate</td>
<td>Inconclusive</td>
<td>NA</td>
<td>Moderate</td>
<td>NA</td>
</tr>
<tr>
<td>Responsiveness</td>
<td>Responsiveness</td>
<td>Medium</td>
<td>Low</td>
<td>Low</td>
<td>Low</td>
</tr>
</tbody>
</table>
EQ-5D-5L - Improving generic measurement?

- English value set derived using TTO and DCE
- Ranges from -0.285 to 1 (Devlin et al 2018)
- Easton et al (2018) - 5L demonstrated strong known group validity in relation to clinically recognised cognition/physical functioning thresholds


What about condition specific measures?

- Condition specific measures have been developed in many areas where generic instruments have been shown not to perform well
- A range of instruments available/being developed in dementia:
  - DEMQOL-U and DEMQOL-Proxy-U (Mulhern et al 2012)
  - Dementia Quality of life Index (DQI; Arons et al 2016)
  - Alzheimers Disease – Five Dimension (AD-5D; Nguyen et al 2017)
- Each has different criteria, development methodology and valuation method
- Evidence of psychometric performance is limited at present


### How do they compare?

<table>
<thead>
<tr>
<th>DEMQOL-U</th>
<th>DQI</th>
<th>AD-5D</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Developed from 29 item DEMQOL using psychometric and Rasch analysis</td>
<td>• Used conceptual framework, qualitative work and expert input</td>
<td>• Developed from 15 item QOL-AD using psychometric and Rasch analysis</td>
</tr>
<tr>
<td>• 5 dimensions, 4 levels (1024 states)</td>
<td>• 6 dimensions, 3 levels (729 states)</td>
<td>• 5 dimensions, 4 levels (1024 states)</td>
</tr>
<tr>
<td>• Valued using TTO with UK general population</td>
<td>• Valued using paired comparisons with professionals and general population</td>
<td>• Valuation using DCE with duration and Best Worst Scaling ongoing in Australia</td>
</tr>
<tr>
<td>• Range from 0.986 to 0.243</td>
<td>• Range from 1 to -0.103</td>
<td>• Initial model range 1 to -0.7</td>
</tr>
</tbody>
</table>

### Valuation of dementia health states

- Range of approaches used for valuation in the general population and people with dementia
- Each has specific methodological features that impact value set characteristics

![Image of Table 1: Presentation of a DCE task](image)

<table>
<thead>
<tr>
<th>Health description A</th>
<th>Health description B</th>
</tr>
</thead>
<tbody>
<tr>
<td>You have poor physical health</td>
<td>You have excellent physical health</td>
</tr>
<tr>
<td>You have poor mood</td>
<td>You have fair mood</td>
</tr>
<tr>
<td>You have fair memory</td>
<td>You have fair memory</td>
</tr>
<tr>
<td>You have fair living situation</td>
<td>You have fair living situation</td>
</tr>
<tr>
<td>You have good ability to do things for fun</td>
<td>You have good ability to do things for fun</td>
</tr>
<tr>
<td>You live in this state for 4 years and then you die.</td>
<td>You live in this state for 7 years and then you die.</td>
</tr>
</tbody>
</table>

![Image of Table 2: Presentation of a BWS task](image)

<table>
<thead>
<tr>
<th>Health description</th>
<th>Best</th>
<th>Worst</th>
</tr>
</thead>
<tbody>
<tr>
<td>You have good memory</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>You have poor mood</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>You have excellent physical health</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>You have fair living situation</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>You have good ability to do things for fun</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>You live in this state for 4 years and then you die.</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>You live in this state for 7 years and then you die.</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>
Valuation by people with dementia

• Evidence that valuation tasks are cognitively complex and difficult to complete. Can lead to incomplete data and compromised data quality
• Evidence of differing preferences (people with dementia value states lower than the general population using TTO). Leads to different value sets?
• Further comparisons with other methods ongoing

Discussion (1)

• Measurement of QoL in dementia an ongoing challenge given population and range of impacts of condition
• Ongoing qual work to understand how the measures perform.
• Condition specific measures should be more sensitive given content is directly related to condition. Further psychometric evidence at descriptive and value set level is required
• Using condition specifics can compromise comparability, so an option is to use both types of measures
• What about wider outcomes? ASCOT? ICECAP? eQALY?
Discussion (2)

• Valuation is also a challenge. Further work to understand the limits of the methods in patient populations is required
• Collecting a sample large enough for full patient value set is
• May lead to revised methods/protocols that are amenable to completion
  • e.g. valuing small numbers of states or partial health states?

Your thoughts?

• Should there be new inter-country projects to update estimates of disease progression?
• Is it appropriate to use generic utility measures for dementia?
• Should we incorporate carer QALYs in economic models? Why or why not?
• How will we be able to fund new therapies for pre-dementia?