Overview

- HRQOL
- Stages of dementia
- Challenges of assessing HRQOL in dementia
- Instruments for measuring HRQOL in dementia
- DOMS recommendations
- Next steps
Conceptual model
Adapted from Wilson & Cleary JAMA 1995

Proximal Effects
Causal variables

Disease-specific HRQOL
• Physical
• Emotional
• Social Functioning

Other Health issues
Other aspects of life

Distal Effects
Indicator variables

 Generic HRQOL
• Physical
• Emotional
• Social Functioning

QOL
Well being

Health-related QOL

• A board umbrella, many definitions
• “The effect of disease and treatment on a person’s ability to function physically, socially & emotionally”
• 3 key features
  – Multi-dimensional
  – From the patient’s / person’s perspective
  – Health-related
• Operational definitions
  – Domains & items
  – Context-specific
• What are the effects of dementia?
Dementia

- Acquired decline in memory and thinking (cognition) due to brain disease that results in significant impairment of personal, social or occupational function (WHO 2003)
- Progressive
- Impacts on HRQOL differ by stage

Early or mild dementia

- Consistent cognitive deficits but still functional
- Short-term memory impairment
- Disorientation in time & space
- Word-finding difficulties (aphasias)
- Problem-solving
- Social functioning – shopping, finances
- House-hold tasks, hobbies & personal care
- Personality & behavioural changes
- Acute confusional episodes
  - hallucinations & delusions
Moderate/middle stage

- Memory function severely affected
- Disoriented in time & place
- Language, comprehension & calculation
- Executive & intellectual function
- Judgment & insight poor
- Self-care & functional capacity declines
- Marked behavioural changes
- Psychological symptoms
  - Misinterpretations, illusions, delusions, psychosis, depression, anxiety
- Social function severely affected
- Carer stress, placement in residential care

Severe/late stage

- Profound memory impairment
- Disorientation in time, place & to self
- Language
  - Unable to speak coherently or write
- Intellectual function very limited
- Further decline in self-care & functional capacity
- Psychological symptoms
  - Difficult to tell
- Social function no longer possible
- Challenging behaviours reach a peak
  - Activity disturbances, problems eating & swallowing, uncooperative & disinhibited behaviour
Challenges to HRQOL assessment in dementia

- HRQOL is typically self-reported
  - Complex cognitive task - comprehend, evaluate, concentrate
  - Cog fn decreases with disease stage
- Typical time frames is ‘the past week’
  - Short-term memory, progressive loss
- How best to operationalise for measurement?
  - Which domains should be assessed?
  - Relevant ones vary with disease stage
  - Subjective (perceptions) vs objective (behaviours)

Proxy assessment

- Who? Carer - formal or informal
  - Needs to have good knowledge & insight
  - Informal carers may also have some mild cognitive decline
  - Respondent burden – short, simple forms
- Own v Proxy perception of own-HRQOL
  - Is it really the same thing?
  - More agreement for observable behaviours than feelings & global assessments of HRQOL
  - Can we understand nature, size & direction of proxy bias?
- Carer HRQOL
  - Not covered by DOMS
DOMS review

- **Generic instruments**
  - Good for comparison across diseases
  - But don’t capture particular effects / range of relevant issues
  - Self-assessed, often not developed/validated for proxy
  - Prone to floor effects with frail elderly
  - Too long & complex, respondent burden
    - SIP-68, SF-36/12
    - WHO-QOL-BREF (26 items) + WHO-QOL-OLD (26)

- **Disease specific instruments**
  - 6 reviewed
  - 3 recommended

Quality of life in Alzheimer's Disease (QoL-AD)

Logsdon et al, Journal of mental health and Aging, 1999

- **Oldest, most widely cited**
- **Brief - 13 items (1 total score)**
  - Physical health & condition
  - Energy - Mood - Memory
  - Living situation - Self as a whole
  - Interpersonal relationship with family and friends
  - Ability to participate in meaningful activities – chores, fun
  - Financial situation
  - Life as a whole

- **Easy to administer, by interviewer**
  - Detailed script, no formal training
  - ~10 mins
  - Patient-rated version - mild to moderate
  - Proxy (caregiver)-rated version - all stages
- **Free**
- **11 languages**
Dementia Related Quality of Life (DEMQOL)
SC Smith et al, Health Technology Assessment, 2005

- New, developed by world-renowned dementia team
  - As yet, limited psychometric evidence, but promising
- Interviewer administered, manual (website), 10-20 mins
- Patient version - mild to moderate (MMSE ≥ 10)
  - 28 (1 total score) + 1 global QOL question
- Proxy version – all stages
  - 31 items (1 total score) + 1 global proxy perception of pt QOL
  - Overlap of only 14 items! (& poor correlation!)
- Recommend use both - complementary
- Domains
  - **Patient**
    - Daily activities
    - Memory
    - Negative emotion
    - Positive emotion
  - **Proxy**
    - Functioning
    - Emotion
- Free for academic use, cost for commercial

Quality of life in Late-Stage dementia (QUALID)
Weiner et al, JAMDA, 2000

- Late stage, long-term care facilities
  - Based on observable behaviours
- 11 items (1 total score)
  - Smiles    - appears sad    - cries
  - facial expression of discomfort
  - appears physically uncomfortable
  - verbalisations suggest discomfort
  - Is irritable or aggressive
  - enjoys eating   - enjoys touching/being touched
  - enjoys interacting with others
  - appears calm & comfortable
- Easy to administer, by interviewer
  - no training, standardised instructions
  - ~ 5 mins
  - Proxy rated (caregiver 3/last 7 days)
The other 3 …

- **D-QOL**
  - No proxy form
  - relatively long
  - available only in English

- **ADR-QOL**
  - No patient version
  - much longer than others
  - significant costs associated with training and administration

- **CBS**
  - No patient version

Next steps

- Australian field testing & large reference datasets needed
  - Use QoL-AD or DEMQOL concurrently
    - patient and proxy versions
    - mild and moderate
    - Document patient-proxy score comparisons subgroups
  - Use QoL-AD-proxy & DEMQOL-proxy with QUALID
    - in advanced dementia

- Sensitivity to group differences
- Responsiveness to interventions
  - Pharmacologically active, psychosocial, models of nursing care
- Relationship to other clinical & outcome measures
  - Which measures are ‘best’ for what purpose/context
Thank you