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## Measuring health related quality of life in persons with dementia

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## Measuring health related quality of life in persons with dementia

### Abstract

*Background:* Dementia affects many aspects of the quality of the lives of people with dementia, particularly their ability to function socially and to live independently. Measuring health related quality of life (HRQOL) in this area poses unique challenges. This paper briefly outlines these challenges and describes instruments considered to be the most useful and appropriate.

*Methods:* A literature search of CINAHL, EMBASE, MEDLINE and PSYCINFO was conducted to identify papers reporting the development, testing or application of instruments measuring HRQOL in persons with dementia. Review criteria were: availability; cost and ease of administration; suitability across disease stage; psychometric properties; and the availability of clinical and comparison data.

*Results:* Six instruments were considered to be the most useful and appropriate: Quality of Life in Alzheimer's Disease (QOLAD), DEMQOL, Quality of Life in Late-Stage dementia (QUALID), Dementia Quality of Life instrument (DQOL), Cornell Brown Scale for Quality of Life in Dementia (CBS), and the Alzheimer Disease-Related Quality of Life (ADRQOL). All are readily available, short and easy to administer. Psychometric properties are good and clinical data is available. QOLAD and DEMQOL are the most sensitive to disease stage and both have patient and proxy versions. QUALID is the only instrument specifically suited to late stage dementia.

*Conclusion:* Measuring HRQOL in dementia poses difficulties relating to disease stage, self report vs. proxy measures, and subjective vs. objective measures. Several instruments have been found to be appropriate; however QOLAD and DEMQOL are the most suitable for use across a range of disease stages and have the advantage of having both patient and proxy versions available. QUALID is well suited for the nursing home setting.

### Keywords

life, quality, related, health, persons, measuring, dementia

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# Measuring health-related quality of life in persons with dementia

## DOMS results & recommendations

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(DOMS) team

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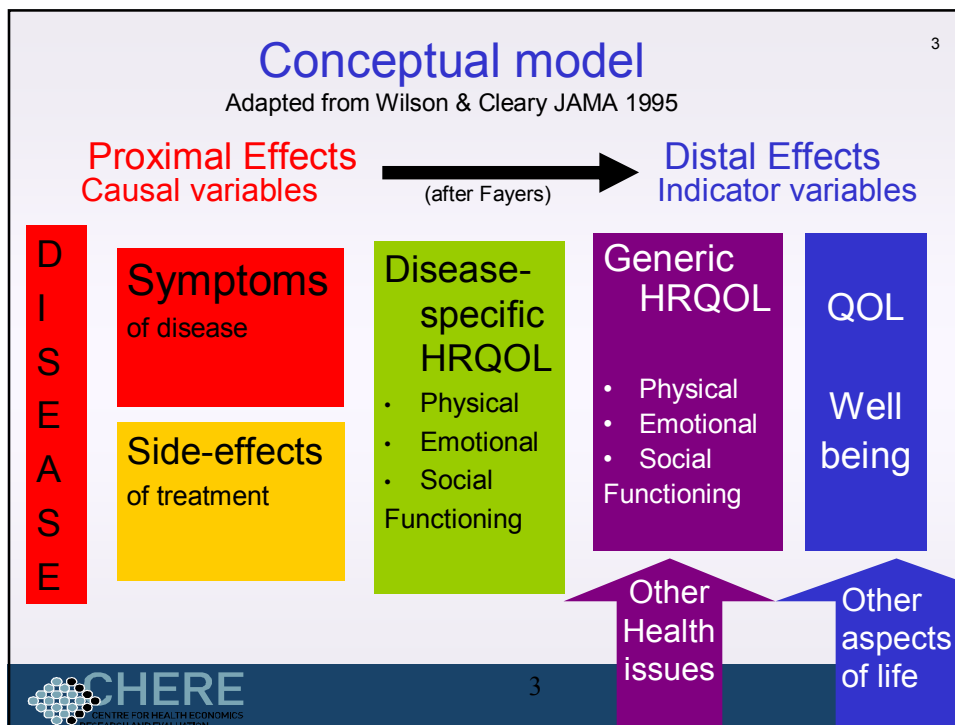


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## Overview

- HRQOL
- Stages of dementia
- Challenges of assessing HRQOL in dementia
- Instruments for measuring HRQOL in dementia
- DOMS recommendations
- Next steps





- ### Health-related QOL
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- 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?
- CHERE
- CHSD

## 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 Alzheimers 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  $\geq$  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**

<u>Patient</u>	<u>Proxy</u>
– Daily activities	Functioning
– Memory	Emotion
– Negative emotion	
– Positive 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

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