The Dementia Outcomes Measurement Suite: Tools for Practice Improvement

Jan Sansoni, Nick Marosszeky, Emily Sansoni
Project Aims

- Develop a set of recommended measures for routine use in the assessment, diagnosis, screening and outcomes monitoring of dementia conditions and the evaluation of treatments that are applicable for the Australian health care context.

- Standardise the assessment and evaluation procedures used in this field to enhance comparability of findings across research and practice settings.

- Make recommendations concerning the clarification and standardization of the clinical terminology applicable in this field.
Why Outcomes Monitoring?

• More common in research applications and pharmaceutical evaluation – not common in routine practice

• How do we know whether our interventions work unless we evaluate them?

• Do we know whether our routine care practices are delivering acceptable outcomes to our clients?

• Objectives – maintenance of function; slowing in the rate of deterioration
Project Team: Principal Investigators

- Ms Jan Sansoni (Project Manager)
- Assoc Prof Marc Budge (Senior Clinical Advisor)
- Prof Lynn Chenoweth (clinical, dementia, BPSD and cognitive)
- A/Prof Graeme Hawthorne (utility, social isolation, patient & carer satisfaction)
- Dr Madeleine King (HRQOL, cognitive, BPSD)
- Dr Yun-Hee Jeon (clinical, dementia, BPSD and cognitive)
- Mr Nick Marosszeky (all – function, CALD, Proxy)
Associate Investigators

- Ms Siggi Zapart, CHERE (Instrument Reviews)
- Ms Emily Sansoni, AHOC/CHSD (Instrument Reviews; Editing)
- Dr Kate Senior, CDU (Indigenous Health)
- Ms Patsy Kenny, CHERE (Carer Burden)
- Dr Lee-Fay Low, UNSW (Instrument Reviews)

Project

Advised by National Expert Group for Dementia
Advised by Expert Measurement Group
Categories of Instrument Review

- Dementia Staging and Descriptive Instruments
- Health-Related Quality of Life
- Cognition
- Social Isolation
- Associated Behavioural and Mental Symptoms (BPSD; Delirium; Individual Symptoms)
- Functioning
- Economic Utility
- Patient and Carer Satisfaction
Review Processes

- Initial overall literature search (MEDLINE, PsycINFO) on 20 terms (e.g. dementia, cognition, memory, function, Qol etc)
- Examined major texts in the field (e.g. psychometric review texts, Burns, Kane & Kane, Lezak, McKeith etc)
- Identified list of instrument categories and names and then searched on these names
- Developed database with comparative data for instruments in each category
- Developed CD containing papers and abstracts for each category of instruments
Review Processes

- Developed an impact sheet for the EMG and the review team – Medline, text and web impacts, presence in instrument databases, use in clinical practice (based on field surveys, NEP and clinical feedback)
- Identified a shortlist of about 12 leading contender instruments for each category
- Categories: Dementia staging and descriptive instruments, Cognitive, Associated symptoms (e.g. BPSD; delirium; individual symptoms e.g. apathy), Function, HRQOL, Multi-attribute utility measures, Social isolation, Patient and carer satisfaction)
Review Processes

- Applied additional criteria to reduce to 5-6 instruments per category
- Produced decision summary sheet justifying selection or non-selection of contenders for the short list
- Undertook more extensive searches for short-listed instruments e.g. other databases – CINAHL, Cochrane etc and commenced review
Additional Selection Criteria

- Whether there is a copy of the instrument and the original article available for review
- The number of citations found (save new instruments)
- The amount and range of the published psychometric evidence
- Whether the instrument used in clinical practice (searches, surveys) & applicability to Australian context
- Availability of normative and clinical reference data
Additional Selection Criteria

- Administration time (< 30 minutes and shorter preferred)
- Applicability for patients / clients with varying levels of severity of dementia.
- Proprietary considerations (e.g. prohibitive cost)
- Applicability for use in routine care – does not require specialist skills for administration (e.g. as for many neuropsychological/medical assessments)
AHOC Review Sheet

- Author, publication information, availability
- Cost
- Training requirements
- Purpose & who developed for
- Administration time
- Structure
- Scoring
- Applications, normative and clinical reference data
- Psychometric criteria – reliability, validity, responsiveness
- Cultural applicability and cultural adaptations
- Gender and age appropriateness
Review of Instruments

With all instruments we considered

- Type and stages of dementia
- Purpose of instrument (assessment, screening, outcomes monitoring and evaluation of interventions)
- Self-reporting and proxy reporting
- Respondent and staff burden
- Appropriateness for CALD and indigenous groups
- Appropriateness for setting (e.g. acute, primary, community and residential care; specialist; research)
Instrument Scores and Weights

- Availability of comparison data (3)
- Length/feasibility (2)
- Complexity of administration / cognitive burden (3)
- Ease of obtaining score (2)
- Cultural Appropriateness (1)
- Sensitivity to dementia (3)
- Reliability evidence (3)
- Validity evidence (3)
- Cost of instrument (2)
- Cost of instrument administration (2)

Scores: generally 1 = poor, 2 = moderate 3 = good
– refer to detail in the paper

Multiply the score by the weight and then sum to get a total instrument score
Example: Cognitive Assessment

- 93 instruments identified
- Abbreviated Mental Test, Addenbrookes, ADAS, Blessed IMC Test, Cambridge Cog, Cambridge Mental Disorders, Cog. Capacity Screen, Cog. Abilities Screen, Clock Drawing, Geriatric Mental State, GP Cog, Informant Q on Cog, KICA-Cog, Mattis DRS, Mini Cog MMSE, Memory Impairment Screen, Mental Status Q, RUDAS, and Short Portable Mental amongst contenders
- Proprietary issues some instruments – e.g. some forms of MMSE
- Excluded neuropsychological specialist instruments (focus is routine care)
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<tr>
<th>Cognitive Assessment</th>
<th>W</th>
<th>MMSE 3MS</th>
<th>ADAS COG</th>
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Recommendations: Cognitive

- The instruments with the highest scores were the MMSE-3MS and the ADAS-Cog
- 3MS was selected from the MMSE family for routine settings; better psychometrics and less proprietary issues
- ADAS-Cog may be preferred if more in depth assessment required (e.g. clinical research)
- GP-Cog most appropriate for primary care
- MDS-Cog can also be considered for residential care settings
- RUDAS (Interim) for CALD and…
- Kimberley Indigenous Cognitive Assessment (Interim) for Indigenous
Descriptive and Staging Measures

Five instruments were selected for comprehensive review from twelve contender measures:

- Blessed Dementia Rating Scale (BDS)
- Clinical Dementia Rating Scale (CDR)
- Dementia Severity Rating Scale (DSRS)
- Global Deterioration Scale (GDS)
- Sandoz Clinical Assessment for Geriatric (SCAG)

These descriptive instruments are useful in providing a common language concerning severity and stage of dementia.
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<tr>
<th>Staging &amp; Descriptive</th>
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<th>GDS</th>
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Descriptive and Staging Measures

Recommendations:

- **Global Deterioration Scale (GDS) / Functional Assessment Staging (FAST)** – ease of use
- **Clinical Dementia Rating (CDR)** - more comprehensive – second stage of assessment
- **The Dementia Severity Rating Scale (DSRS)** (Proxy application in community settings – caregiver rating scale)
Example: Dementia-HRQOL

- Seven leading dementia – HRQOL contenders identified

- QOL-AD, QUALID, DEMQOL were chosen for in depth review. Proxy versions were also available for these instruments. (DQOL a runner up)

- Preferred instruments were the QOL-AD and the DEMQOL for mild to moderate dementia and the QUALID for late stage dementia

- Australian reference data required for all instruments
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HRQOL Measures: Generic

- Also examined generic HRQOL instruments re their applicability for use with people with dementia (e.g. global indices, Dartmouth COOP, SF-12V2 & SF36V2, WHOQOL-OLD, SIP, NHP etc.).
- The review concluded that most instruments are not appropriate for use with moderate to severe dementia patients as they involve self-rating or contain inappropriate/complex items particularly for those in residential care. Many are too long.
HRQOL Measures: Generic

- A chapter reviews the leading contenders and discusses key issues concerning the cognitive capacity required to self-rate and the use of proxies.
- It is most likely these generic instruments would be used with dementia carers to assess their HRQOL rather than with dementia patients per se.
Behavioural and Psychological Symptoms of Dementia

- Neuropsychiatric Inventory (NPI)
- Behavioural Pathology in Alzheimer’s Disease Rating Scale (BEHAVE-AD)
- Consortium to Establish a Registry for Alzheimer’s Disease – Behaviour Rating Scale for Dementia (CERAD-BRSD) (research only - until the shortened version is available and assessed)
- The Dementia Behaviour Disturbance Scale and the Neurological Rating Scale were not preferred
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Delirium

- **Confusion Assessment Method (CAM)** – simpler with superior utility but does not capture severity of symptoms and hence cannot be used for repeated measures of delirium severity.

- **Delirium Rating Scale (DRS-R-98)** - more comprehensive as assesses both the presence and severity of symptoms; requires training and a 24 hour observation period.
Individual Symptoms

- Rating Scale for Aggression in the Elderly (RAGE)
- Cohen Mansfield Agitation Inventory (CMAI) and Pittsburgh Agitation Inventory (PAI)
- Rating Anxiety in Dementia (RAID)
- Apathy Evaluation Scale (AES)
- Cornell Scale for Depression in Dementia (CSDD) and Geriatric Depression Scale (GDS) – the latter for community settings
Function

- Function instruments can be ADL, IADL or a combination of these. They can also be generic or dementia specific measures.

- 19 instruments examined were reduced to a short-list of 12 instruments and the following instruments were recommended

**Function Generic:**

- FIM (ADL) – acute and residential
- Barthel (ADL) – community
- OARS-IADL – adapted for primary and community care in Australia
Function

Function & Dementia:

- Alzheimer’s Disease Cooperative Study-ADL (proxy report)
- Disability Assessment for Dementia (proxy report)
- Cleveland Scale-ADL (observation; acute and residential)
Issues: Function

• Absence of research consensus for measurement of function in dementia
• High degree of overlap between items – need for streamlining
• Item Response Theory could be used to cross calibrate items from the recommended measures
• Could then examine item redundancy and coverage across the range of severity levels to develop better tools
Social Function

Focus of measurement falls into 2 categories

- Social participation, networks, support, social contact (sometimes includes ‘objective’ items such as no. of social contacts)
- Social isolation, loneliness (satisfaction with social contacts or feelings of loneliness)
- The MOS Social Support Survey is a blend

Fifteen instruments were identified and seven were selected for detailed examination
Social Function

Recommendations:

- Social participation, networks, support, social contact (no instruments recommended; problems with instrument and item design; need for further research)
- Social isolation, loneliness (De Jong Gierveld Loneliness Scale, Friendship Scale)

The top performer was the De Jong Gierveld Loneliness Scale but it requires linguistic adaptation to its response categories (Yes! Yes). The MOS and the Friendship Scale were runners up.
Multi-attribute Utility Measures

- MAU measures are largely used for economic evaluation and are also known as health indexes.
- The permutations and combinations of responses to a number of questions about health generate numerous ‘health states’ which can be rated on a scale from 0-1.
- By this method we can derive one total health score (e.g. 0.60 for a health state) and thus can compare the valuations for different health conditions (burden) and of the effect of different treatments on a condition.
EuroQol EQ-5D

- **MOBILITY**
  - I have no problems in walking about
  - I have some problems in walking about
  - I am confined to bed

- **SELF-CARE**
  - I have no problems with self-care
  - I have some problems washing or dressing myself
  - I am unable to wash or dress myself

- **USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)**
  - I have no problems with performing my usual activities
  - I have some problems with performing my usual activities
  - I am unable to perform my usual activities

- **PAIN/ DISCOMFORT**
  - I have no pain or discomfort
  - I have moderate pain or discomfort
  - I have extreme pain or discomfort

- **ANXIETY/ DEPRESSION**
  - I am not anxious or depressed
  - I am moderately anxious or depressed
  - I am extremely anxious or depressed

Score type = 1,1,1,2,3 = health state
MAU Instruments for Economic Evaluation

- Multi-attribute utility measures (MAU) such as the EQ-5D (5 items) and the AQoL (12 items) are preferred when undertaking economic evaluations.
- Both instruments require adaptation – EQ-5D has scoring distribution & scoring algorithm issues and the AQoL requires shortening.
- There are issues of self-report/cognitive burden and proxy assessment for these instruments.
Patient Satisfaction

Theories of patient satisfaction suggest instruments should cover 7 areas:

- Access to health services and the treatment environment;
- Provision of health information;
- The relationship with care providers;
- Participation in making health care choices;
- The technical quality of care;
- Treatment effectiveness (helping the daily life of the patient); and
- General satisfaction

Patient dissatisfaction occurs where there are multiple transgressions or catastrophic failure in one area.
Patient Satisfaction

Eleven instruments and single item assessments were selected for review. Measures were also assessed for their coverage of the dimensions of patient satisfaction.

- Generic Measures: Short Assessment of Patient Satisfaction (SAPS – a 7 item generic measure developed for the National Continence Management Strategy) and the Consultation Satisfaction Questionnaire were the standout out measures.
- No self report dementia specific patient satisfaction measures were identified.
The Construction of the SAPS

Final model of a unidimensional Short Assessment of Patient Satisfaction scale (SAPS)

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<td>GUTSS</td>
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<td>Information</td>
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<td>Satisfaction with explanations of treatment results</td>
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<td>Technical skill</td>
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<td>The clinician was careful to check everything</td>
<td>Consult SQ</td>
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<td>Participation</td>
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<td>Satisfaction with health care choices</td>
<td>PSI</td>
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<td>Relationship</td>
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<td>How much were you respected</td>
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Patient Satisfaction

- The 7 item SAPS has an excellent coverage of the dimensions of patient satisfaction (e.g. the best) and was the recommended instrument.
- SAPS is the shortest PS instrument and has excellent psychometric properties.
- Psychometric evidence indicates that SAPS is a strong uni-dimensional scale.
- SAPS needs to be further tested and validated with dementia samples (e.g. patients and carers).
Single Items: Patient Satisfaction

- Two single item patient satisfaction measures showed promise from prior continence research
  - How satisfied are you with the outcomes of your treatment?
  - How satisfied are you with the amount of help received?
- These need to be tested with samples of people with dementia and their carers
- Need for a single item measure for routine use
Carer Satisfaction

- Six measures examined – most were generic measures with poor to weak psychometric properties
- The **Satisfaction with Care at the End of Life in Dementia Scale** was the only dementia specific measure and was the most promising instrument
- An Australian study is required to further test its measurement properties
- Examination of carer burden, carer appraisal and carer wellbeing were outside the scope of this project
Proxy Issues: Definition

“Proxy data refer to those collected from someone who speaks for a patient who cannot, will not, or is unavailable to speak for him or herself, whereas we use the term other-rater data to refer to situations in which the researcher collects ratings from a person other than the patient to gain multiple perspectives on the assessed construct.” (Snow, et al. 2005a)
Proxy Issues

- Proxy reports seen as complementary to patient self-reports, especially when it is not possible or feasible to assess a patient with severe dementia.

- Need to be aware of Content issues:
  - More objective constructs easier and more accurate to rate than subjective constructs (e.g. physical symptoms vs. depressive symptoms). There is more agreement between carer and patient ratings for the more objective/observable constructs.
Proxy Issues

- Need to be aware of **Methodological issues**:
  - Cognitive status of proxy
  - Health status of proxy
  - Level of caregiver burden
  - Usually a trade-off between those in close contact with the patient and those with more clinical training
  - Should be based on usual behaviour rather than extreme behaviour

- Need to be aware of biases and limitations when using proxy ratings (e.g. socially desirable responding, negative information over positive information, filtering)
Indigenous Issues

• Senior with regard to remote communities noted – *a general reluctance to talk about mental health issues and a high level of community anxiety about people who exhibit symptoms*

• Stigma was associated both with the outward display of symptoms (e.g. aggressive and unpredictable behaviour) and beliefs about causation e.g. sorcery
Indigenous Issues: Assessment

- Difficulty in using measures developed for Western populations particularly in rural/remote communities
- Problems with instruments include:
  - Concepts of functioning being related to career and employment.
  - Concepts of independence as being a positive value (rather than valuing the level dependence an individual may have on their family).
  - Measures that include concepts of time (last week, last year) and also volume (a lot, a little).
  - Examples that may have little meaning, especially in a remote context (solving financial affairs, remembering the name of the high school from which they graduated).
Indigenous Issues: Assessment

- Cognitive tests – barriers for those with limited education, numeracy and literacy.
- Inappropriate questions – name of monarch; day of week; month of year.
- Even RUDAS judgement item – refers to crossing busy streets, traffic lights.
- For these reasons KICA-Cog was preferred but it needs further assessment of its psychometric properties.
- Appendix 14 provides numerous examples of problem items.
- Recommended measures need to be assessed with Indigenous populations.
Some Identified Research Gaps

- Need for further research to assess the point at which people can no longer self-rate (e.g. MMSE score) under different modes of administration (e.g. self report, interview, interview assisted) for each instrument

- Some measures need pilot testing in Australia to obtain reference data (e.g. HRQOL)

- Some of the newer measures (GPCOG, RUDAS, KICA-COG, SAPS) need further psychometric data

- Need for further research to streamline measures of function
Some Identified Research Gaps

- Social function/social support areas may need follow up research if we wish to focus on more than just social isolation.
- Further research required to address identified problems with Multi-attribute Utility measures: AQoL (shorten) and/or EQ-5D (scoring and distribution issues).
- Carer satisfaction is addressed in this project but not other informal care measures – this will require a follow up project.
- CALD and ATSI applicability of instruments needs further research.
Implementation Issues

- Mandating measures – not recommended
- The report provides a guide to the use of recommended instruments with regard to stages of assessment and settings for assessment
- Training Issues – audit curricula, develop certified modules
- A Dissemination Strategy (e.g. toolkit, brochures, workshops, videos, papers etc) is needed!
Report Details


- Report available shortly via jan.sansoni@bigpond.com