Carer Appraisal Scale: A Carer-Based Assessment of Patient Functioning

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Delirium

- CAM
- CAM with MiniCog
- NEECHAM Confusion Scale
- Delirium Rating Scale
Single question in delirium:

• “Do you think [name of patient] has been more confused lately?”
• Question posed to patient friend or family.
• Administered by medical student, together with CAM
• Measured against interview by a psychiatrist
Results

• SQiD sensitivity and specificity of 80% (95% CI 28.3-99.49%) and 71% (41.90-91.61%) respectively.
• The CAM demonstrated a negative predictive value (NPV) of 80% (51.91-95.67%) and the SQiD showed a NPV of 91% (58.72-99.77%).
• Kappa correlation of SQiD with the Psil was 0.431 (p = 0.023).
• The CAM had a kappa value of 0.37 (p = 0.050).
• CAM had only 40% sensitivity in this study.
Collateral

• The value of collateral history is regularly impressed upon students and clinical staff of all levels

• However, there is a surprising paucity of standardised tools designed to take advantage of this.
Role of the carer

• Carers play a vitally important role in supporting family members, friends and neighbours to live at home and remain connected to their communities.
Assessing the carer

• 2008: AMHOCN undertook a literature review of available instruments for measuring carer outcomes
• Undertook stakeholder consultations with carers from the public and private sector and from non-government organisations
• 7 tools identified
  – Carer Wellbeing, Burden and need
  – Carers’ Quality of Life-7D + Visual Analogue Scale (CarerQol-7D+VAS)
  – Carers’ Needs Assessment for Schizophrenia (CNA-S)
  – Involvement Evaluation Questionnaire (IEQ)
  – Carers Assessment of Difficulties Index (CADI)
  – Carers’ Assessment of Satisfaction Index (CASI)
  – Burden Assessment Scale (BAS)
  – Carers Need Assessment Measure (CaNAM)
• Carer Wellbeing and Burden have been extensively examined, less attention has been paid to the issue of carer needs
• Only the CarerQol-7D+VAS assessed carer needs, in addition to burden and wellness
  – Issues with terminology
  – Lack of a reference time period
  – Administration considerations
  – Overly simplistic nature of the scale
  – Lack of explanation regarding what the scale means
• Available tools felt neither practical nor feasible to be introduced
Older Adult Behaviour Checklist (OABCL)

• Brigidi et al, 2010
• To identify discrepancies between informant and self-reports to assist clinicians pinpoint areas for further evaluation and intervention
• 123 items and is based on clinician interview of carers, not intended to be filled out by carers themselves.
Carer Recognition Act 2010 (NSW)

• This legislation aimed to increase the recognition and awareness of the role carers played in providing daily care and support to people with disability, medical conditions, mental illness or who were frail and aged.

• Section 5 of the Act: a carer is defined as “an individual who provides personal care, support and assistance to another individual who needs it because that other individual: (a) has a disability; or (b) has a medical condition (including a terminal or chronic illness); or (c) has a mental illness; or (d) is frail and aged”.

• An individual is not a carer in respect of care, support and assistance he or she provides: (a) under a contract of service or a contract for the provision of services; or (b) in the course of doing voluntary work for a charitable, welfare or community organisation; or (c) as part of the requirements of a course of education or training.
• The Act continues to state that carers are to be considered as partners with other care providers in the provision of care, and acknowledged the unique knowledge and experience of carers.
Aim: to develop an outcome measure that...

• Provides useful collateral information regarding patient functioning
• Acknowledges the importance of the carer
• Primarily measures patient functioning, but also looks at patient needs
• Assists in service evaluation
• Is simple enough to be used regularly and routinely
Care planning

• Currently driven by clinician assessment, at best informally guided by adhoc discussions with family members.
• Structured clinician-based functional assessments only provide for 'snapshot' assessments of patient (during time of interview) and therefore can not be comprehensive.
• Carers are better placed to identify the care needs of patients due to their intimate knowledge of the client and their history and their daily contact, information which can assist to provide a more comprehensive picture of the client's current functioning, and thus provide more targeted and appropriate information.
• Most importantly in terms of realistic goal setting and recovery-focused care, carers have the best understanding of the patient’s optimal or baseline functioning.
Old Age Community Mental Health

- Carers of older patients tend to have at least a moderate level of contact and provide some form of care assistance, and therefore can better evaluate their day-to-day functioning.
# The Scale

### Carer Appraisal Scale

**Date:** 

<table>
<thead>
<tr>
<th>Item</th>
<th>Worst Ever</th>
<th>Much Worse</th>
<th>Worse</th>
<th>Little or No Change</th>
<th>Better</th>
<th>Much Better</th>
<th>As Good As They Can Get</th>
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<tbody>
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<td>1. How do you feel? (Please tick)</td>
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<td>2. Please tick how concerned you are with the patient’s functioning in each of the following areas:</td>
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<td>3. Depression or Low Mood</td>
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<td>6. Appetite</td>
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<td>7. Concentration &amp; Memory</td>
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<td>8. Swaying / Swaying / or Believing things that are not real</td>
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<td>9. Aggression</td>
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<td>13. Physical Health</td>
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<td>14. Mobility</td>
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<td>15. Interacting with Family &amp; Friends</td>
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<td>16. Shopping, Finances &amp; Using the telephone</td>
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<td>17. Toiletting / Self Feeding and Dressing</td>
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<td>18. Living in a clean place</td>
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<td>19. Self-talking</td>
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<td>20. Worries about the patient</td>
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<td>21. Changes in the patient's personality</td>
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<td>22. Changes in the patient's appearance</td>
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<td>23. Changes in the patient's speech</td>
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<td>24. Changes in the patient's movement</td>
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<td>25. Changes in the patient's eating</td>
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<td>26. Changes in the patient's sleeping</td>
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### Additional Comments

5. Any comment on interventions the team has implemented?

6. Any other comments:

*Acquiring.com (2012), developed with assistance from LHS SMB1919*
Carer Appraisal Scale

- Section 1: Broad impression of patient overall progress, on 7 point likert scale
- 2 week period chosen for consistency with RUG-ADL, HONOS, Kessler
Section 2

• 18 point checklist, 4 point likert scale

<table>
<thead>
<tr>
<th>Categories</th>
<th>Depression or Low Mood</th>
<th>Aggression</th>
<th>Interacting with Family &amp; Friends</th>
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</thead>
<tbody>
<tr>
<td>Anxiety</td>
<td>Wandering</td>
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<td>Shopping, finances and using the telephone</td>
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<tr>
<td>Sleep</td>
<td>Alcohol or Prescription Drug Overuse</td>
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<td>Toileting/Self-feeding and Dressing</td>
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<tr>
<td>Concentration &amp; Memory</td>
<td>Pain</td>
<td></td>
<td>Living in a clean place</td>
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<tr>
<td>Seeing/Hearing or Believing things that are not real</td>
<td>Physical Health</td>
<td></td>
<td>Hobbies &amp; Pastimes</td>
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<tr>
<td>Trying to harm themselves</td>
<td>Mobility</td>
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<td>Appetite</td>
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</tbody>
</table>
• Includes IADLs (Shopping, Finances and Using the Telephone) and Basic ADLs
• Scaled from “Not at all concerned” to “Very concerned”
• No qualifiers
• Scorable
  – Each item 0 to 3
  – Minimum 0, Maximum 54
Sections 3-6

• Qualitative open-ended questions
• “What changes have you noticed with the patient?”
• “What is the most important issue you would like the team to focus on at this time?”
• “Any comment on interventions the team has implemented?”
• “Any other comments”
Analysis

• Not possible to validate this scale against a ‘gold standard’, as we are unaware of any other carer-based evaluation of patient functioning scale

• We assessed the extent of agreement between the CAS and HONOS assessments completed by ourselves
Results

- 23 patient-carer dyads
- 3 patients refused to allow carers to complete scales
- 13 were completed by a son or daughter of the patient, 6 were completed by the patient's spouse, 1 completed by a sibling.
- 15 were completed with giving the form directly to the carer, and 5 were completed over the phone.
• No negative feedback regarding the form.
• Five carers reported specifically positive feedback, grateful for the opportunity to contribute in a more concrete fashion to their loved one's care.
Qualitative completion

• 19/20 completed Question 3 (Changes noticed)
• 17/20 completed Question 4 (Important Issue)
• 12/20 completed Question 5 (Team Intervention)
• 5/20 completed Question 6 (Any other comments).
Analysis against HONOS

- Weighted $\kappa(w)$ of 0.276 (95% CI 0.22 to 0.33) indicates statistically significant “fair” inter-rater agreement

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<tr>
<th>Carer score</th>
<th>Clinician score</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
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<td>13</td>
<td>8</td>
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Analysis against Living Skills Profile

- Item 4 (Appetite) against LSP Item 7 (Diet)
  - Weighted Kappa 0.039 (poor correlation)
- Item 14 (Interacting) against LSP Items 1-3 (Withdrawal)
  - Weighted Kappa 0.098 (poor correlation)
Analysis against RUG-ADL

- Item 16 (Toileting/Self-feeding and Dressing) against RUG-ADL Items 2 (Toileting) and 4 (Eating)
  - Weighted Kappa 0.211 (Fair correlation)
    - Standard Error 0.09, 95% CI 0.0335 to 0.388
Findings

• A lot of ‘hidden’ information
• It was useful to know whether the scale would be completed
• High rate of compliance and ease of administration
• Very high rate of acceptance by carers
• Fair agreement with HONOS, less with assessment tools that require more knowledge of daily social functioning (LSP, RUG-ADL)
Practical Issues

- When should the scale be given?
- When should it be repeated?
- What does ‘team’ mean?
- Consent?
- Documentation?
- Anonymous?
Practical Use

- Private Practice

CAS

2/02/2012
2/03/2012
2/04/2012
2/05/2012
2/06/2012
2/07/2012

CARER APPRAISAL OF PATIENT FUNCTIONING

How do you feel today? (2/4/12)

1. The patient has been in the past two (2) weeks.

Please circle one of the following:

Worse Ever / Much Worse / Worse / Little or No Change / Better / Much Better / As Good as you can get

Please tick here concerned you are with the patient’s functioning in the following areas:

<table>
<thead>
<tr>
<th>Area</th>
<th>Not at all concerned</th>
<th>Slightly concerned</th>
<th>Moderately concerned</th>
<th>Very concerned</th>
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<tbody>
<tr>
<td>Depression or Low Mood</td>
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<td>Anxiety</td>
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<td>Sleep</td>
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<td>Appetite</td>
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<tr>
<td>Concentration &amp; Memory</td>
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<td>Seizures &amp; grand mal</td>
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<td>Scarcity</td>
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<td>Blackouts</td>
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<td>Physical Health</td>
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<td>Mobility</td>
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<td>Intimacy</td>
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<td>Intimacy with Family &amp; Friends</td>
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<td>Seizures, finances &amp; using the telephone</td>
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<td>toilet / self-care and dressing</td>
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<td>Living in a clean place</td>
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<td>Bathing &amp; dressing</td>
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What changes have you noticed with the patient? (2/4/12)

- the patient is still very depressed. Today (2/4/12) he slept in and did not want to get out of bed.

What is the most important issue that needs assistance with? (2/4/12)

- Mobility

The patient wants to take it at his leisure and suffer.

Trying to get the attention from the care room is to the Dr's Magazine. The Dr. needs him to accept himself. Anyway, call the telephone once or twice. The Dr. or maybe be settled.
Modifications

• Word “Team”
• Word “Hobbies & Pastimes” changed to “Occupation”, or “School Performance”
• Sexual functioning
Plans for future research

• Trial in larger numbers of patient-carer dyads
• Consider testing in different areas of Sydney, including NESB
• Validation against OABC, carers trialling the HONOS
Thanks

• Royal North Shore Specialist Mental Health Services for Older Persons
• RNSH Ethics Department
• Associate Professor Carmel Peisah
• Professor Gin Malhi