The use of proxy / informant reports for people with dementia

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Outline

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- When to use proxy measures
- Best practice in the use of proxy informants
- Factors affecting proxy ratings
- The advantages and disadvantages of proxy reports
- A survey of available instruments
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Useful 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)
Problems with self-report measures

- Poor psychometric evidence base for the use of self-report health status instruments for people with cognitive impairment (Riemsma et al., 2001)
- The need for better survey design for older people using universal design principles
- The time constraints involved with assessment
- Test-taker inattention and compliance
- Test-taker burden and distress

However

- Recent focus group research by Byrne-Davis, et al. (2006) suggests that dementia patients (including those in the moderate to severe range) can talk about their quality of life in meaningful ways

- “… proxy measurement should be seen as complementary to the direct assessment of patients. Where possible the direct assessment of people with dementia should be attempted.” (DOMS Final Report)
When to use proxy measures

- From the Literature Review of Neumann, et al. (2000)
  - Comparable agreement with self-report measures of functioning, overall health, physical symptoms, cognitive status
  - Little known about the relationship of proxy reports with health utilisation / medical records data
  - Low to moderate agreement with self-report measures of depressive symptoms and well-being
  - Some under-reporting of cognitive impairment (less impaired)
  - Some over-reporting of functional impairment, especially IADLs (more impaired)
  - Influence of caregiver burden on spouse, children and other family member proxies

Best practice in the use of proxy informants

- The more objective the construct the more amenable to proxy measurement, the less discrepancy there is between proxy and patient reports (Examples - physical symptoms vs. depression symptoms; functioning vs. quality of life) (Snow, et al. 2005a)

- Advice from Harper, 2000 on proxy reports
  - Examine three possible biases
    - 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
Factors affecting proxy ratings

Characteristics affecting patient scores
- age
- cognitive impairment
- awareness of symptoms
- depression
- personality variables

Characteristics affecting proxy ratings
- education
- knowledge of construct
- time spent with patient
- nature of the relationship
- response precision*
- differing schema*

* = The last two characteristics reflect the differences between family members and care staff / clinicians

Also need to include:
- Carer burden and stress, as well as physical and mental health
- Severity of condition(s)
- Possible demand characteristics of the assessment situation

Based on Snow, et al. (2005a)

Rule of thumb

“Naglie, et al. (2006) only used family / informal carer proxies who visited their relative with dementia 3 or more times per week and this might be used as a rule of thumb. However, in community settings the partner or close family member may be the best proxy, and in some cases, they may be the only viable source of information. There appears to be a need for further research to provide advice concerning the selection of appropriate proxies across settings and with regard to the severity of illness of the person with dementia.”
The advantages of proxy reports

- Improve follow-up rate / response rate – can assess people in a project who would be normally excluded due to acute illness, lack of co-operation, low education or death
- Not as time consuming or as expensive as the alternatives – laboratory tests or naturalistic observation
- Complementary piece of data – questions can be in the same format, used in combination with the direct questioning of patients to improve test accuracy (e.g. GPCOG, CSI-D)

The disadvantages of proxy reports

- Design issues
  - Need exposure to patient, the best informant may not be available
  - Sampling bias some groups more likely to have proxies than others
- Ratings
  - Judgements tend to be impressionistic and dispositional rather than based on behavioural observations or situations
  - Rely on a high degree of inference and a good recall of events
The disadvantages of proxy reports

- Overlapping contextual factors
  - Emphasis on negative rather than positive information (Novella, et al., 2006)
  - Conflict of interest between patient and proxy (e.g. nursing home admission)
  - Influence of caregiver burden and stress
  - Filtering of impressions through past problems and behaviours, rather than present events
  - Adaptation to the caregiving workload, socially desirable responding, responding to get some perceived benefit
  - Quality of relationship between patient and proxy
  - Formal cares: labelling, numbing of behaviours and time of day effects because of shift work

- Some informants provide less valid data than others, we need ways to handle this lowered validity – either by the exclusion of certain informants or the adjustment of scores (Jorm, 2004)

Survey of available instruments

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Original Paper</th>
<th>Items</th>
</tr>
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<tbody>
<tr>
<td>Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE)*</td>
<td>Jorm, et al. (1989)</td>
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<td>AD8</td>
<td>Galvin, et al. (2006)</td>
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<tr>
<td>Behavioural and Psychological Symptoms (BPSD) Checklist</td>
<td>Snellgrove and Hecker (2005)</td>
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<td>Community Screening Instrument for Dementia (CSI-D) Interview</td>
<td>Hall, et al. (1996)</td>
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<td>Revised Memory and Behaviour Problem Checklist (RMBPC)</td>
<td>Teri, et al. (1992)</td>
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<tr>
<td>Psychogeriatric Assessment Scales (PAS) Informant interview – Cognitive Decline and Behaviour Change*</td>
<td>Jorm, et al. (1995)</td>
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<tr>
<td>GPCOG Informant Interview</td>
<td>Brodaty, et al. (2000)</td>
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</tbody>
</table>

* = related instruments
Red = used in combination with another instrument
Survey of available instruments

◆ Other instruments with informant sections
  – CAMDEX
  – Canberra Interview for the Elderly*

◆ Instruments with informant versions
  – Cornell Scale for Depression in Dementia
  – Geriatric Depression Scale
  – Blessed Dementia Scale
  – Cleveland ADL Scale
  – Functional Assessment Staging instrument
  – Lawton and Brody’s IADL instrument

Latest research developments

◆ A paper on self-reported depression in dementia by Snow, et al. (2005b) suggests that it is the lack of awareness of symptoms, rather than the presence of dementia per se that effects the accuracy of self-reports (i.e. deficit unawareness / lack of insight co-varies with dementia)
Major Research Gaps

- Can we improve proxy reports by training and structured observation?
- How does the framing of questions influence proxy reports? (Example – using the telephone)
- Need to compare proxy reports to performance based measures and health utilisation / medical records data
- The use of single or dual item proxy measures. Are they as accurate as longer proxy measures?

Conclusions

- Proxy reports seen as complementary to patient self-reports, especially when it is not possible or feasible to assess a patient with severe dementia
- We need to be aware of Content issues:
  - More objective constructs than subjective constructs (physical symptoms vs. depressive symptoms)
- We 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
Conclusions

- We also need to be aware of their biases and limitations when using proxy ratings (e.g. socially desirable responding, negative information over positive information, filtering)

- Research guidance:
  - Work on the major research gaps (e.g. training, framing of questions)
  - Plus the continuous process of examining proxy report validity and discrepancies with self-reports
  - Who are the most appropriate proxy raters for different practice settings?
  - And we need ways to handle lowered validity - either by the exclusion of certain informants or the adjustment of scores

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