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## The use of proxy / informant reports for people with dementia

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### Abstract

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## The Use of Proxy / Informant Reports for People with Dementia

### Abstract

The progressive deterioration of cognitive and functional abilities in people with dementia presents a number of practical problems for the measurement of health outcomes using self-report or direct questioning methods. These include: a poor psychometric evidence base for the use of self-report health status instruments for people with cognitive impairment; the need for better survey design for older people using universal design principles; the time constraints involved with assessment; as well as test administration issues like test-taker inattention and compliance, or alternatively, test-taker burden and distress. In response to these and other problems an alternative measurement approach has been developed. This approach, here described as proxy measurement, uses proxy or surrogate reports of symptoms by carers or clinical informants in close contact with the person with dementia.

This example of knowledge transfer from the Dementia Outcomes Measurement Suite (DOMS) project is designed to help busy clinicians and researchers ensure best practice with the application of proxy measurement. It highlights the key issues in relation to proxy measurement, including:

- 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 the available instruments;
- and the latest research developments in the field.

### Introduction

This paper reports on a literature review into proxy or informant based measurement in the Final Report of Dementia Outcomes Measurement Suite (DOMS) project for the Australian Government, Department of Health and Ageing (Sansoni, et al. 2007). This review summarises a number of important works on proxy measurement from the general research literature (Snow, et al., 2005a), as well as the aging and dementia literature (Harper 2000 in Kane and Kane 2000; Neumann, et al. 2000; Novella, et al. 2001, 2006), and includes consideration of a psychometric review by Jorm (2004).

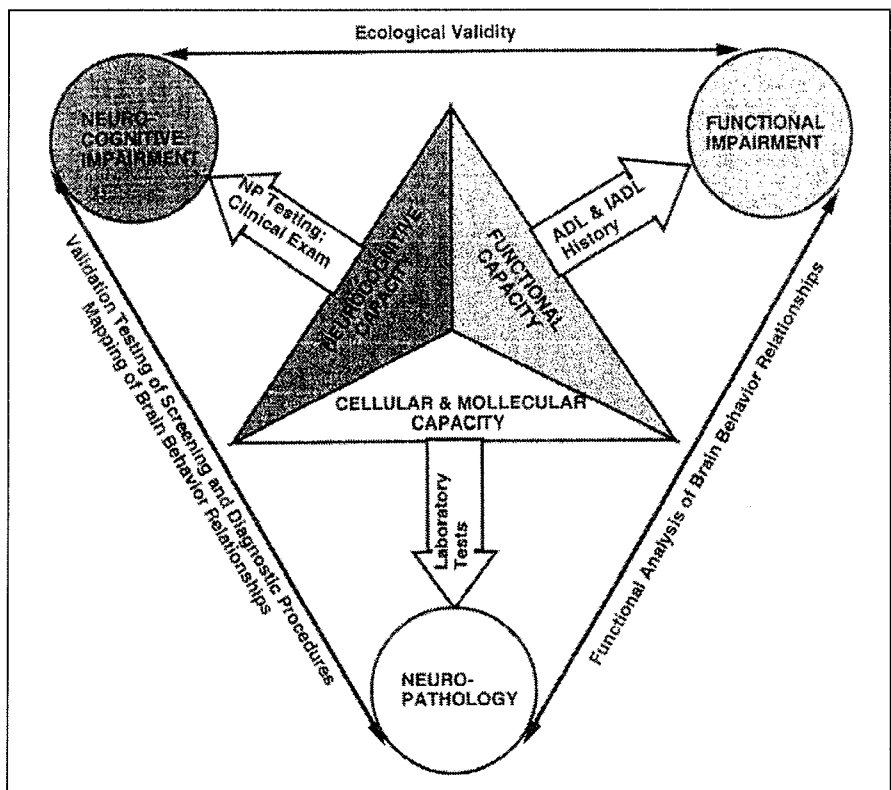
This paper highlights a number of key issues for clinicians and researchers in relation to proxy measurement, including: when to use proxy measures; best practice in the use of proxy informants; factors affecting proxy ratings; the advantages and disadvantages of proxy reports; a survey of the available instruments; and the latest research developments in the field.

As a starting point, a useful definition of proxy measurement is provided by Snow et al. (2005a) who makes the important distinction between proxy data and other-rater data “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.” This definition is thus related back to the measurement model underlying the data collection: Proxy measures need to correspond with patient self reports, while other-rater data measures need to correspond with an overarching construct where the patient and the other-rater data are component parts.

### When to use proxy measures

The progressive deterioration of cognitive and functional abilities in people with dementia presents a number of practical problems for the measurement of health outcomes using self-report or direct questioning methods. The figure below by Oxman (2003) highlights the defining characteristics of dementia and stresses the importance of ecological validity in our assessment and measurement of these characteristics.

*Figure 1 - Interrelationships among the defining features of dementia by Oxman (2003)*



These practical problems primarily concern the validity of using self-report measures with people with dementia, and they include the following issues: a 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 (Iezzoni 2002 and Wingfield 1999); the time constraints involved with assessment; as well as test administration issues like test-taker inattention and compliance, or alternatively, test-taker burden and distress.

In response to these and other problems an alternative measurement approach has developed. This approach, here described as proxy measurement, uses proxy or surrogate reports of symptoms by carers or clinical informants in close contact with the person with dementia.<sup>1</sup>

However, a number of recent papers have challenged the heavy reliance upon proxy measurement to assess the health related quality of life (HRQOL) for people with dementia. The focus group (n = 25) paper by Byrne-Davis, et al. (2006), showed that dementia patients can talk and report on their quality of life in meaningful ways. Other papers have also made important methodological and empirical advances. For instance, Mozley, et al. (1999) has established a number of criteria for interview-ability of dementia patients - including orientation to place, attention and language skill. While Snow, et al. (2005b) found that inaccurate self-reports of depression seem to be related to a lack of insight (or deficit unawareness) rather than the presence of dementia per se. As Riemsma, et al. (2001) recommended, further research work is needed in the area of the assessment of the severity of cognitive impairment and subsequent performance on health status measurement across a number of neurological conditions.

In light of these findings and the central importance of the patient's perspective in health outcomes measurement, the DOMS Final Report by Sansoni, et al. (2007) states, this report "supports the viewpoint that 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." (page 369). Thus where it is possible and feasible HRQOL, and other subjective phenomena, should be assessed by patient (self report) rather than by proxy report. However, it is understood that where patient's experience severe dementia it may not be possible to assess such phenomena by patient self report and the use of proxy measures may be unavoidable.

While there is limited evidence on when to use self-report health status measures for people with cognitive impairment, there is more evidence on when to use proxy measures. From the scientific literature it is clear that proxy measurement is more suitable for certain domains than for others. The review paper by Neumann, et al. (2000) makes the following findings about the scientific literature. These findings are presented in the table below:

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<sup>1</sup> For those interested in alternative methods of data collection to self-report, Harper (2000) also reviews other types of measurement including: observational assessment (laboratory or naturalistic); medical chart review; physiological (e.g. blood pressure or saliva testing); and technological (e.g. video cameras).

**Table 1 - Main Findings from the Literature Review of Neumann, et al. (2000)**

<ul style="list-style-type: none"> <li>• Proxy and subject reports are often comparable in describing levels of functioning, although proxies tend to identify more impairment</li> </ul>
<ul style="list-style-type: none"> <li>• Researchers generally report good agreement in comparisons of proxy and subject assessments in describing overall health, chronic physical conditions, and physical symptoms</li> </ul>
<ul style="list-style-type: none"> <li>• Relatively little is known about the comparability of proxy and subject reports on healthcare utilization or in the concordance between responses and data from medical records or claims</li> </ul>
<ul style="list-style-type: none"> <li>• Limited evidence shows high agreement between proxies and patient preferences for type or setting of care and lower agreement for preferences for health states</li> </ul>
<ul style="list-style-type: none"> <li>• There is low to moderate agreement between proxies' and subjects' reports of depressive symptoms and psychological well-being, with proxies describing more problems</li> </ul>
<ul style="list-style-type: none"> <li>• Proxies are often in agreement with subjects on reports of cognitive status, although proxies may overestimate cognitive abilities</li> </ul>
<ul style="list-style-type: none"> <li>• Proxies tend to describe more functional impairment among persons with dementia compared with self-reports, especially with respect to instrumental functions</li> </ul>
<ul style="list-style-type: none"> <li>• Spouses, children, and other close family members tend to be capable proxies, although proxy reports may be influenced by caregiving burden</li> </ul>

In summary, Neumann, et al. (2000) found that there is evidence to support the use of proxies for the measurement of function, physical health and cognition; while there are some problems with the measurement of emotional / behavioural symptoms and depression. Proxy ratings, on the whole, were more negative for functioning and mental health, than those provided by the patients. This pattern of reporting was most apparent for patients with cognitive impairment and for proxies who reported more caregiver burden and stress.

This view of the literature is supported by Snow, et al. (2005a) who stressed that the more objective the construct the more amenable it is for the proxy measurement approach. They argue this is why there is less discrepancy between proxy and patient reports for physical symptoms and functional activity, than for depression symptoms and quality of life. This view makes a certain amount of sense as the proxy rater can see the outward signs of depression (e.g. irritability, tiredness) but does not have access to the patient's inner life, therefore making it harder for them to report on the condition properly. This is not the same for measures of functional activity where the proxy rater can see or experience the patient's performance directly on everyday tasks. <sup>2</sup>

<sup>2</sup> Snow, et al. (2005a) also outlines analysis techniques and interpretation guides for assessing the level of agreement between patients and proxies; as well examining the theories that attempt to explain the differences between proxy and patient reports (including the concepts of response shift, favourable ratings of self, cognitive dissonance theory, self-awareness theory and self-schema theory).

## Best practice in the use of proxy informants

Responding to the need to use proxy reports in the measurement of dementia conditions, the DOMS review into proxy measurement made a number of important recommendations regarding the use of proxy reports. These were:

- Proxy reports should be examined for three potential biases: (1) the cognitive status of the proxy (as many elderly people are cared for by an elderly spouse carer, who may themselves be impaired or unwell, but to a lesser degree); (2) the health status of the proxy; and (3) the level of carer burden and stress (Harper, 2000);
- There is usually a trade-off between those with close contact to the patient and those with more clinical training (Harper, 2000). However, generally, where a proxy report is used information should be collected from the family member / carer or care staff member that is closest to the patient and has the greatest degree of interaction with the patient;
- Proxy reports should be based on usual behaviour rather than on extreme or rare behaviours (Harper, 2000);
- Proxy reports should be based on observable phenomena like physical symptoms and functioning, rather than subjective phenomena like depression, social isolation and quality of life (Snow, 2005a).

## Factors affecting proxy measurement

Snow, et al. (2005a) neatly summarizes the characteristics affecting scores for patients and proxies. These are outlined in the figure below.

**Figure 2 - Characteristics Affecting Patient Scores and Proxy Ratings as Outlined by Snow, et al. (2005a)**

Characteristics affecting patient scores
<ul style="list-style-type: none"><li>• age</li><li>• cognitive impairment</li><li>• awareness of symptoms</li><li>• depression</li><li>• personality variables</li></ul>
Characteristics affecting proxy ratings
<ul style="list-style-type: none"><li>• education</li><li>• knowledge of construct</li><li>• time spent with patient</li><li>• nature of the relationship</li><li>• response precision*</li><li>• differing schema*</li></ul>
* = The last two characteristics reflect differences between family members and care staff / clinicians.
Also need to include:
<ul style="list-style-type: none"><li>• Carer burden and stress, as well as physical and mental health</li><li>• Severity of condition(s)</li><li>• Possible demand characteristics of the assessment situation</li></ul>

The additional issues of carer burden and stress, as well as physical and mental health have also been added to this Figure. Also included is the severity of the condition(s) and possible demand characteristics of the assessment situation.

This figure provides a useful guide to the analysis and interpretation of data produced from proxy reports. However, the literature is unclear as to the selection of the most appropriate person to act as proxy informant between family members or care staff / clinicians. Novella, et al. (2006) using the SF-36 studied the agreement between different types of proxies (family members, care staff) with the dementia patient's own ratings.

In this study although all proxies rated the patient's health status as poorer on almost all dimensions, the care staff ratings actually had greater agreement with the patient ratings than did those provided by family members. In the selection of the most appropriate proxy to use perhaps the key issue to consider is the closeness to the patient and the frequency of their interaction. Although Cummins (2002) suggests that proxies, where used, should be partners or peers in a nursing home setting it is quite possible that family members may not relate to the dementia patient as often as a formal carer and there may be substantial differences between family carers concerning how often they visit their family member. 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 and disadvantages of proxy reports**

Proxy reports have well-established validities in the scientific literature (Harper, 2000) and add a number of major benefits to the design of projects and information gathering. These include improving the response rate, lowering the cost of data collection, as well as providing another view of the situation or the impact of a disease.

Specifically, proxy ratings help improve the design of projects, as they are a way to examine a patient's premorbid ability (McDowell, 2006) and are useful in longitudinal studies - when a patient dies and there is a need to ascertain whether the patient developed dementia before their death (Waite, et al. 1999). As Neumann, et al. (2000) comments, proxies also permit longer follow-up periods as data collection is not dependent on the patient's capacity to respond. This allows individuals to be included in projects who otherwise may have been left out (Harper, 2000) - either because of acute illness, lack of co-operation, death or low education and literacy (Jorm, 2004).

Proxy ratings have advantages over laboratory tests and naturalistic observation, as they are not as time consuming or expensive (Harper, 2000). These judgements are also said to be unaffected by the patient's education or premorbid ability and language proficiency (Jorm, 2004). However, it should be noted that this approach assumes that the proxy informant comes from a different background to the patient. Proxy questions and items can be constructed in the same format for proxies and patients, thus making comparisons easier (Harper, 2000). As Novella, et al. (2006) points out using different instruments between proxies and patients can be another source of variation with obtained scores.

Finally proxy instruments can be used as a complementary piece of data to improve test accuracy. For example, proxy data can be used with brief cognitive tests to improve screening accuracy (Jorm, 2004, with a specific example provided from Tierney, et al. 2003) or with the assessment and performance of instrumental activities of daily living (Li, et al., 2006).



This is also the logic behind the development of the GPCOG (Brodaty, et al. 2000) and the Community Screening Instrument for Dementia interview (CSI-D) (Hall, et al. 2000) instruments.

The disadvantages of proxy measurement can be broken down into issues related to project design, issues related to the proxy rating judgments and issues concerning contextual factors that influence proxy ratings.

In terms of project design, proxy raters need to have significant exposure to the patient and the “best” informants for the project may not be available (Harper, 2000). Also proxy raters may be subject to sampling bias as some groups are more likely to have proxies than others (Harper, 2000). Harper (2000) also comments that phone interviews with proxies are more likely to result in missing information.

With regard to the rating judgements proxy ratings tend to be impressionistic and dispositional, rather than being based on behavioural observations or situations (Harper, 2000). They also usually rely on a high degree of inference (Harper 2000), as well as a good recall of events (Harper, 2000).

Finally, proxy ratings may also be subject to a number of overlapping contextual factors, which include:

- an emphasis on negative rather than positive information (Novella et al. 2006);
- a conflict of interest between the patient and the proxy - for example in terms of nursing home admission (Harper, 2000);
- the influence of caregiver burden and stress (Novella, et al. 2006; Sands, et al. 2004, especially when the patient has worse health and worse cognitive status (Novella, et al. 2006);
- the filtering of impressions through the past problems and behaviours or premorbid personality, rather than the current situation (Harper, 2000);
- adaptation to caregiving workload and patient behaviours; socially desirable responding, and a context dependent bias to respond in certain ways in relation to perceived benefits or access to services;
- the quality of the relationship between the patient and the proxy, as well as the proxy’s mental health (Jorm, et al. 2004).

Formal carers may also be subject to the effects of labelling of patients, the numbing of certain behaviours and the time of day effects, as a result of the timing of their shift work.

Jorm (2004) in relation to the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) summed up the issue of potential biases rather well: “The major weakness of the IQCODE is that some informants provide less valid data than others. However, little is known about which informants provide the best data. More information is needed on how validity is affected by variables like age, education, frequency of contact, and not living with the subject. Furthermore, little is known about how the purpose of the screening might affect informant ratings. For example, in a clinical situation where a carer wants support services, they might overrate cognitive decline, whereas in a community screening situation they may be reluctant to support a diagnosis of dementia in a loved one. There is also a need for the development of approaches to handling any lowered validity, whether by exclusion of certain informants or by adjustment of IQCODE ratings” (page 15).

## **A survey of published instruments**

From the DOMS literature review, the following table is a list of available proxy / informant instruments. These can be used as a resource for finding informant questions. It should be noted that this list focuses on published measures rather than measures used for one off studies or papers. A number of these measures have been developed by Australian researchers and clinicians.

**Table 2 - List of published proxy / informant instruments with a brief description**

<b>Instrument</b>	<b>Original Article Citation Author(s) + Publication Date</b>	<b>No. of Items</b>	<b>Description of Items</b>	<b>Response Categories</b>	<b>Time Taken (min.)</b>	<b>Proxy instrument used in combination with another instrument</b>
<b>Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) *</b>	Jorm, et al. (1989)	16 (short form)	Items on memory, learning, handling money, making decisions, following a story and reasoning. Compares a person to what they were like 10 years ago.	5 point scale (much improved, a bit improved, not much change, a bit worse and much worse)	10 - 15	No
<b>AD8</b>	Galvin, et al. (2006)	8	Ask has a change occurred in the last several years? Contains items on judgement, reduced interest, repetition, trouble learning, forgetting the date, money management, remembering appointments, trouble thinking.	Yes / No	5	No
<b>Behavioural and Psychological Symptoms (BPSD) Checklist</b>	Snellgrove and Hecker (2005)	14	During the last week have you observed the following symptoms of dementia. Grouped into four factors: behavioural / psychological, psychosis, initiation, disinhibition and aggression.	5 point Likert scale	5	No
<b>Community Screening Instrument for Dementia (CSI-D) Interview</b>	Hall, et al. (1996)	26	Questions about functioning and health.	Unknown	15	Yes, combined with a cognitive test for the patient.

<b>Activities of daily living questionnaire (ADLQ)</b>	Johnson, et al. (2004)	28	Examining everyday functioning in six categories: Self Care Activities; Household Care; Employment and Recreation; Shopping and Money; Travel; and Communication.	4 point scale: 0 (no problem) to 3 (no longer capable of performing the activity)  <i>Different anchor points for different functional items</i>	10 - 25	No
<b>Revised Memory and Behaviour Problem Checklist (RMBPC)</b>	Teri, et al. (1992)	24	Examining the frequency of behaviours and carer's reaction to the behaviours. Includes items on memory, depression and disruptive behaviours.	5 point frequency scale  5 point reaction scale	15 - 20	No
<b>Psychogeriatric Assessment Scales (PAS) Informant interview – Cognitive Decline and Behaviour Change *</b>	Jorm, et al. (1995)	31	Covers the three areas of stroke / cerebrovascular disease (6 items), cognitive decline / everyday functioning (10 items) and behavioural / personality change (15 items).	Yes / No  Plus other types of items e.g. No, not much worse = 0; A bit worse = 1; Yes, a lot worse = 1; Does not know =?	15 - 20	Yes, combined with patient self report measures of stroke and depression, as well as a test of cognitive impairment.
<b>GPCOG Informant Interview</b>	Brodsky, et al. (2000)	6	Questions on event and conversation recall, word finding difficulty, money management, medication management and the need for transport assistance.	Yes / No	5 - 6	Yes, combined with a test for item cognitive impairment.

\* = related instruments

In addition to this list there are those measures with informant sections or interviews used in diagnostic application, most notably the Cambridge Mental Disorders of the Elderly Examination (CAMDEX) - Informant Section (Roth, et al. 1986) and the Canberra Interview for the Elderly (CIE) Informant Interview - Cognitive Decline and Behaviour Change (Henderson, et al. 1992) (The CIE is also related to the IQCODE). Harper (2000) also notes that there are also informant versions of numerous behavioural and psychological symptoms of dementia (BPSD) instruments like the Cornell Scale for Depression in Dementia (CSDD) and the Geriatric Depression Scale (see Snow, et al. 2005b); as well as for measures of function like the Blessed Dementia Scale, the Cleveland ADL scale, Functional Assessment Staging, and Lawton and Brody's IADL instrument (see Kemp, et al. 2002).

Further examination of the brief descriptions of instruments provided in Table 2 shows a range of proxy instruments from screeners / checklists / epidemiological measures (like the GPCOG, AD-8, IQCODE, Behavioural and Psychological Symptoms of Dementia [BPSD] Checklist and the CSI-D) to more detailed instruments suitable for individual clinical application (like the Revised Memory and Behaviour Problem Checklist (RMBPC), Activities of Daily Living Questionnaire [ADLQ], and the Psychogeriatric Assessment Scales [PAS] informant interview). This table also shows that a number of instruments use simple binary (i.e. Yes or No) responses (GPCOG, AD8, PAS) to ease administration. Another noteworthy feature is that a few instruments combine proxy reports with self-reports or tests of cognitive impairment into the one measure (GPCOG, PAS, CSI-D).

### **Latest research developments in the field**

A key paper by Snow, et al. (2005b) examining self-reported depression in dementia, suggests that it is the lack of awareness of the symptoms of dementia, rather than the presence of dementia that affects the accuracy of patient self-reports. This paper is significant in that it represents a new way of examining the discrepancies between proxy and patient reports, namely it highlights the issue of deficit awareness which covaries with dementia.

Other papers have shown that agreement between proxy and patient reports can be improved by using symptom present / absent questions, as opposed to intensity ratings (Magaziner 1997, in Snow, et al. 2005b). Recent work has also showed the importance of co-residency in improving agreement between proxies and patients (Neumann, et al. 2000).

Recent research supports the view that there are professional differences between proxy raters due to clinical training (Novella, et al. 2001) and that there is a poor relationship between a proxy carer's rating of internal states, like memory and cognition, when compared to actual neuropsychological test results (Kemp, et al. 2002, Watson, et al. 2004). These results again highlight the need for greater research into the best content areas to be covered by proxy ratings, especially with regard to those taken from clinicians (Neumann, et al. 2000).

Other research developments include the application of generic outcome measures (like the SF-36) for people with dementia (Novella, et al. 2006), as well as studies comparing staff informants, direct observation and patient perspectives using disease specific quality of life measures (eg. Quality of Life – Alzheimer's Disease [QOL-AD], Dementia Quality of Life [DQoL], Alzheimer's Disease-Related Quality of Life [ADRQL]) (Edelman, et al. (2005). Additional improvements in study design include a paper by Yasuda, et al. (2004) which used a specific performance based measure to compare proxy and patient reports in recovering hip fracture patients; and a paper by Eslinger, et al. (2006) which used the degree of discrepancy between proxy and patient ratings of behaviour to differentiate between assess various sub-types of Alzheimer's Disease (e.g. frontotemporal dementia versus probable Alzheimer's disease).

However, there are a number of areas that require further research work for the field of proxy measurement in dementia to progress. These include:

- To study whether the training of proxies to make structured observations, improves the quality of their ratings (Harper, 2000).
- To examine how the framing of questions, the use of terminology and the administration of instruments influences the results of proxy reporting. For instance, asking a proxy about how the person with dementia performs an everyday task, like using the telephone, could be either broad and general, or broken down into a number of specific and observable component activities (i.e. getting the telephone number, dialling the telephone number, etc). These two different approaches to the question might generate different proxy answers based on how the proxy rater interprets the term “using the telephone”. The same definitional problems apply when professional terms are used to make severity ratings as these may not be fully understood by proxy carers (Neumann, et al. 2000).
- To compare proxy reports with performance based measures and information from medical records and health care utilization (Harper, 2000; Neumann, et al. 2000).
- Many of the recent papers use single or dual item informant measures (e.g. Tierney, et al. 2003; Watson, et al. 2004; Li, et al. 2006). Further research is required to ascertain whether these items have the requisite accuracy as compared to longer proxy measures.

## **Conclusions**

The DOMS Report (Sansoni, et al. 2007) recommended that proxy reports be seen as complementary to patient self-reports, especially when it is not possible or feasible to assess a patient with severe dementia. In this regard, it is vital that further research be undertaken, using recognised markers of severity (like the MMSE-3MS), to determine at what severity level and under what conditions can a patient provide a valid self-report of their symptoms; and whether using different modes of test administration (e.g. self report, interview, interview assisted) can assist.

Areas for further research concerning proxy reports have been outlined. These include determining who are the most appropriate proxy raters for different practice settings (e.g. acute care, primary care and community care, and residential care) and examining how the training of proxies, as well as the framing and administration of questions, influences proxy reports. Additional validation issues include, comparing proxy reports with performance based measures and information from medical records, and the evaluation of the application of single or dual item proxy measures.

## **References**

- Brodsky H, Pond D, Kemp NM, et al. (2000) *The GPCOG: A new screening test for dementia designed for general practice*. Journal of the American Geriatrics Society. Vol. 50, pp. 530-534.
- Byrne-Davis LMT, Bennett PD and Wilcock GK (2006) *How are quality of life ratings made? Toward a model of quality of life in people with dementia*. Quality of Life Research. Vol. 15, pp. 855-865.
- Cummins RA (2002) *Proxy responding for subjective well-being: A review*. International Review of Research in Mental Retardation. Vol. 25, pp. 183-207.
- Edelman P, Fulton BR, Kuhn D, et al. (2005) *A comparison of three methods of measuring dementia-specific quality of life: perspectives of residents, staff, and observers*. Gerontologist. Vol. 45, Spec No. 1, pp. 27-36.
- Eslinger PS, Dennis K, Moore P, et al. (2005) *Metacognitive deficits in frontotemporal dementia*. J Neurol Neurosurg Psychiatry. Vol. 76, pp. 1630-1635.
- Galvin JE, Roe CM, Xiong C, Morris JC (2006) *Validity and reliability of the AD8 informant interview in dementia*. Neurology. Vol. 67, pp. 1942-1948.

Hall KS, Ogunniyi AO, Hendrie HC, et al. (1996) *A cross-cultural community based study of dementias: methods and performance of the survey instrument in Indianapolis, U.S.A. and Ibadan, Nigeria.* International Psychogeriatrics. Vol. 6, pp. 129-142.

Hall KS, Gao S, Emsley CL, Ogunniyi AO, Morgan O and Hendrie HC (2000) *Community screening interview for dementia (CSI 'D'): performance in five disparate study sites.* International Journal of Geriatric Psychiatry. Vol. 15, No. 6, pp. 521-31.

Harper GJ (2000) *Assessing older adults who cannot communicate.* In Kane RL, Kane RA, (eds). Assesing older persons: Measures, meaning, and practical applications. Oxford University Press, Oxford.

Henderson AS (1992) *The Canberra Interview for the Elderly: A new field instrument for the diagnosis of dementia and depression by ICD-10 and DSM-III-R.* Acta Psychiatrica Scandinavica. Vol. 85, No. 2, pp. 105-113.

Iezzoni LI (2002) *Toward universal design in assessing health care experiences.* Medical Care. Vol. 40, No. 9, pp. 725-728.

Johnson N, Barion A, Rademaker A, et al. (2004) *The Activities of Daily Living Questionnaire: A validation study in patients with dementia.* Alzheimer Disease and Associated Disorders. Vol. 18, No. 4, pp. 223-230.

Jorm AF (2004) *The Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE): A review.* International Psychogeriatrics. Vol. 16, No. 3, pp. 275-293.

Jorm AF and Jacomb PA (1989) *An Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE): Socio-demographic correlates, reliability, validity and some norms.* Psychological Medicine. Vol. 19, pp. 1015-1022.

Jorm AF, MacKinnon AJ, Henderson AS, Scott R, Christensen H, Korten AE, Cullen JS, Mulligan R (1995) *The Psychogeriatric Assessment Scales: A multidimensional alternative to categorical diagnoses of dementia and depression in the elderly.* Psychological Medicine. Vol. 25, No. 3, pp. 447-460.

Kemp NM, Brodaty H, Pond D, et al. (2002) *Diagnosing dementia in primary care: The accuracy of informant reports.* Alzheimer Disease and Associated Disorders. Vol. 16, No.3, pp. 171-176.

Li M, Ng TP, Kua EH, et al. (2006) *Brief Informant Screening Test for Mild Cognitive Impairment and Early Alzheimer's Disease.* Dementia and Geriatric Cognitive Disorders. Vol. 21, No.5-6, pp. 392-402.

Magaziner J (1997) *Use of proxies to measure health and functional outcomes in effectiveness research in persons with Alzheimer disease and related disorders.* Alzheimer Disease and Associated Disorders. Vol. 11, Suppl. 6, pp. 168-74.

McDowell I (2006) *Measuring health: A guide to rating scales and questionnaires.* Oxford University Press, Oxford.

Mozley CG, Huxley P, Sutcliffe C, et al. (1999) *'Not knowing where I am doesn't mean I don't know what I like': Cognitive impairment and quality of life responses in elderly people.* International Journal of Geriatric Psychiatry. Vol. 14, No. 9, pp. 776-83.

Naglie G, Tomlinson G, Tansey C, Irvine J, Ritvo P, Black SE, Freedman M, Silberfeld M and Krahn M (2006) *Utility-based quality of life measures in Alzheimer's disease.* Quality of Life Research. Vol. 15, No. 4, pp. 631-43.

Neumann PJ, Araki SS and Gutterman EM (2000) *The use of proxy respondents in studies of older adults: Lessons, challenges and opportunities.* JAGS. Vol. 48, pp. 1646-1654.

Novella JL, Boyer F, Jochum C, et al. (2006) *Health status in patient's with Alzheimer's disease: An investigation of inter-rater agreement.* Quality of Life Research. Vol. 15, pp. 811-819.

Novella JL, Jochum C, Ankri J, et al. (2001) *Measuring general health status in dementia: practical and methodological issues in using the SF-36.* Journal Ageing-Clinical and Experimental Research. Vol. 13, pp. 362-9.

Oxman TE (2003) *The Spectrum of Dementias: Construct and nosologic validity.* In Emery VOB and Oxman TE (eds). Dementia: Presentations, differential diagnosis and nosology. (2nd Ed.) The Johns Hopkins University Press, Baltimore.

Riemsma RP, Forbes CA, Glanville JM, et al. (2001) *General health status measures for people with cognitive impairment : Learning disability and acquired brain injury.* Health Technology Assessment 2001. Vol. 5, No. 6.

Roth M, Tym E, Mountjoy CQ, Huppert FA, Hendrie H, Verma S and Goddard R (1986) *CAMDEX: A standardised instrument for the diagnosis of mental disorder in the elderly with special reference to the early detection of dementia*. British Journal of Psychiatry. Vol. 149, pp. 698-709.

Sands LP, Ferreira P, Stewart AL, et al. (2004) *What explains differences between dementia patients' and their caregivers' ratings of patients' quality of life*. Am J Geriatric Psychiatry. Vol. 12, No. 3, pp. 272-280.

Sansoni J, Marosszeky N, Jeon Y-H, Chenoweth L, Hawthorne G, King M, Budge M, Zapart S, Sansoni E, Senior K, Kenny P, Low L (2007) *Final Report: Dementia Outcomes Measurement Suite Project*. Centre for Health Service Development, University of Wollongong.

Snellgrove CA and Hecker JR (2005) *Brief checklist for non-cognitive symptoms of dementia*. Australasian Journal on Ageing. Vol. 24, No. 2, pp. 88-93.

Snow AL, Cook KF, Lin P-S, et al. (2005a) *Proxies and other external raters: Methodological considerations*. Health Services Research. Vol. 40, No. 5, pp. 1676-1693.

Snow AL, Kunik ME, Molinari VA, et al. (2005b) *Accuracy of self-reported depression in persons with dementia*. JAGS. Vol. 53, pp. 389-396.

Teri L, Truax P, Logsdon R, Uomoto J, Zarit S and Vitaliano PP (1992) *Assessment of behavioral problems in dementia: the revised memory and behavior problems checklist*. Psychology and Ageing. Vol. 7, No. 4, pp. 622-631.

Tierney MC, Herrmann N, Geslani DM, et al. (2003) *Contribution of Informant and Patient Ratings to the Accuracy of the Mini-Mental State Examination in Predicting Probable Alzheimer's Disease*. Journal of the American Geriatrics Society. Vol. 51, No. 6, pp. 813-818.

Waite L, Grayson D, Jorm AF, et al. (1999) *Informant-based staging of dementia using the Clinical Dementia Rating*. Alzheimer Disease and Associated Disorders. Vol. 13, No. 1, pp. 34-37.

Watson LC, Lewis CL and Fillenbaum GG (2004) *Asking family about memory loss: Is it helpful?* J General Internal Medicine. Vol. 20, pp. 28-32.

Wingfield A (1999) *Comprehending spoken questions: Effects of cognitive and sensory change in adult aging*. In Schwarz N, Park DC, Knauper B, Sudman S, (eds). Cognition, ageing, and self reports. Psychology Press, Taylor and Francis Group, Philadelphia.

Yasuda N, Zimmerman S, Hawkes WG, et al. (2004) *Concordance of proxy-perceived change and measured change in multiple domains of function in older persons*. JAGS. Vol. 52, pp. 1157-1162.