

Are caregiver's perceptions a reliable source for rating functional performance of a dementia client?

Prepared by: Colette Steel

Date: 06/06/08

CLINICAL SCENARIO:

Dementia can cause impairment of a person's functioning and occupational performance. Occupational therapists (OT) work collaboratively with caregivers and the person with the illness (Toth-Cohen, 1999). Due to the pathology of degenerative dementia-type illnesses, there comes a time when the client is unable to give the therapist the correct information about their Activities of Daily Living (ADL) due to confusion and forgetfulness (Brangman, 2006). The therapist's then work with the caregivers to find out what their perceptions are about the individual whom they are caring for. The author wanted to investigate whether the perceptions of caregivers are a reliable source for rating functional performance.

FOCUSSED CLINICAL QUESTION:

For the client with dementia, what is the evidence for the effectiveness of a caregiver's perceptions, as opposed to occupational therapists, as a means of rating functional performance?

SUMMARY of Search, 'Best' Evidence' appraised, and Key Findings:

- Two studies were located which addressed the focused clinical question, both studies were appraised.
- The systematic review Tullis & Nicol (1999) was supplied by the lecturer.
- This systematic review focused on finding evidence for the value of functional assessment of older people with dementia the findings focused on three key areas. The findings were: 1) the functional performance of a person with dementia should be assessed at home in their natural setting; 2) the views of the person with dementia should be elicited where possible, especially in the early stages of the illness; 3) the use of a proxy respondent is acceptable in severe dementia; 4) validated/standardised scales are useful, although no one scale emerged as the definitive instrument.
- The quantitative study Cotter, Burgio, Roth, Gerstle and Richardson (2008) was deemed the "best" evidence and most recently published.
- This quantitative study assessed the validity of relying on the caregiver's report for activities of daily living (ADL) functioning, compared to occupational therapist for a care recipient with dementia.
- Clinically significant results were found showing no significance difference between the caregivers' ratings and the occupational therapists.

CLINICAL BOTTOM LINE:

There is evidence that a caregiver's perception is an effective means of rating the functional performance of a client with dementia.

Limitation of this CAT: This critical appraisal has been peer reviewed by one lecturer as part of an assignment.

SEARCH STRATEGY:

Terms used to guide Search Strategy:

| Databases and sites searched | Search Terms | Limits used |
|--|--|--|
| 1. CINAHL 2. ProQuest 3. PubMed 4. Manual search of the references in the studies | Dementia OR Alzheimer* AND judgment OR perception* AND comparison AND caregiver*. | - Peer reviewed - Published after 1998 - Publications available in English |

INCLUSION and EXCLUSION CRITERIA

Inclusion:

- After 1998
- Studies published in the English language that:
 - Investigated the value of the perceptions of a caregiver in relation to functional performance.
 - Focussed on elderly (65+) patients with dementia.

Exclusion:

- Before 1998.
- Not related to dementia.
- Not specific to key words.

RESULTS OF SEARCH

A total of two relevant studies were located and categorised as shown in Table 1

Table 1: Summary of Study Designs of Articles retrieved

| Study Design/ Methodology of Articles Retrieved | Level | Author (Year) |
|--|-------|---|
| Systematic Review | I -1 | Tullis & Nicol, 1999. |
| Did not state but presumed a Cross-section design study | II-2 | Cotter, Burgio, Roth, Gerstle and Richardson, 2008. |
| Unclear as did not state: The study is a comparison of the proxy reports and objective measures. | – | Loewenstein, Argüelles, Bravo, Freeman, Argüelles, Acevedo and Eisdorfer, 2001. |

BEST EVIDENCE

The following study/paper were identified as 'best' evidence and selected for critical appraisal: Tullis and Nicol (1999) and Cotter et al. (2008). The reasons for selecting these studies were:

- Systematic review was selected by the lecture as part of the assignment

The Quantitative study:

- met all the inclusion and exclusion criteria,
- best addressed the clinical question,
- the most recent research article (it was published this year - 2008),
- focused on specific population; caregivers of people with dementia,
- provided the highest level of evidence for answering the clinical question.

SUMMARY OF BEST EVIDENCE

SYSTEMATIC REVIEW:

Tullis, A. & Nicol, M. (1999). A systematic review of the evidence for the value of functional assessment of older people with dementia. *British Journal of Occupational Therapy*, 6(12), 554-563.

Questions for this section have been sourced from Taylor (2007).

1. Are the results valid?

Did the review address a clearly focused issue?

Yes

The focus question of this review is: to find evidence for the value of functional assessment of older people with dementia.

It is a very broad topic and the authors could have split the focus question into smaller questions. In saying that, through the research they found there were three strands of enquiry that were kept separate through the discussion. These were:

1. The design or evaluation of functional performance measurement tools for specific use with older people with dementia.
2. The exploration of the influence of context
3. The exploration of the views held by family, caregivers and the person with dementia.

The population was clearly stated: people aged 65 years and over with a diagnosis of dementia. The study used the International Classification of Disease 10.

Do you think the important, relevant studies were included?

Yes

The published literature was broadly researched and using a combination of electronic databases (CINAHL, Medline and PsychLit) as well as the internet and manual searching. They did not specify what information they used from where. The authors did not specify if the reference lists were used on the located articles. They may have missed vital articles for this research topic. However the researched articles that were found were relevant to the topic.

Relevant key words were used in the search 'elderly, dementia, functional assessment'. The search may have been restricted by not using terms such as 'aged' as well as 'elderly'.

Did the reviewers establish clear inclusion and exclusion criteria for the identified studies?

Yes

The inclusion and exclusion criteria were clearly stated.

Inclusions:

- Published material, research or based on research
- 1989 onwards
- Specific to key words, including dementia of Alzheimer's-type, vascular dementia and suspected dementia.
- Articles that related to the above and outlined factors that appeared to enhance or diminish the value of functional assessment.

Exclusion:

- Not specific to key words
- Dementia under 65 years of age

The two authors did not state who undertook the databases, internet and manual searches or who decided what studies were to be included or excluded in the review. There was also no mention of the number of studies excluded or why or whether they used only articles written in English. They also do not state what research types they included.

Because of this not being stated the reader is unsure on the process of the research: results could be biased and important information may have been missed.

Did the review's authors do enough to assess the methodological quality of the included studies?

No

There appears to be no evidence of any assessment of the methodological quality of the studies included. Therefore, this review needs to be viewed with caution. The quality and rigour of the review is uncertain. Because of this, the review is presumed to be poor quality. It was also not stated that the articles were shared with another reviewer. Taking all these factors into account there could be many biases.

If the results of the review have been combined, was it reasonable to do so?

No

The studies were not combined. The studies were displayed in a table; they were separated under the three different themes.

Table 1. Research articles that design/evaluate functional performance measurement tools for specifies uses with people with dementia.

Table 2. The exploration of the influence of context

Table 2. The exploration of the views held by family, caregivers and the person with dementia.

Due to the diversity of the three focus groups, to form any synthesis of the findings would not be appropriate.

2. What are the results?

If a meta-analysis and synthesis was used, were the methods of meta-analysis appropriate and clearly justified?

No - not used

A meta-analysis was not completed and it was not appropriate to form any synthesis for the findings. As stated above, this is due to the diversity of the three groups. The results were presented in narrative form.

What is the overall result of the review?

N/A

The overall conclusion does address the research question. However the various studies were discussed in narrative form so no results are shown. The review showed little specific or strong evidence to support or to prove wrong the current home assessment strategies. Not one of the individual studies showed statistical significance or stated what measures of clinical significance had been used.

How precise are the results?

N/A

As already stated above, there is no statistical evidence given for the individual studies and no overall synthesis was carried out. Therefore, it is not possible to conclude whether there is high-quality evidence for the effectiveness or value of functional assessments with older people with dementia.

Are the conclusions and recommendations based on the review findings?

Yes

The authors suggested that occupational therapy literature shows that there is a tendency to dwell singularly on the use and evaluation of standardised scales. Other equally important factors to consider are the influence of context and environment on the patient's performance, and the relevance of the proxy perceptions and views on the person with dementia.

The review concluded that:

- The functional performance of a person with dementia should be assessed at home in their natural setting.
- The views of the person with dementia should be elicited where possible, especially in the early stages of the illness.
- The use of a proxy respondent is acceptable in severe dementia.
- Validated/standardised scales are useful, although no one scale emerged as the definitive instrument.

Of interest to my practice question the authors concluded that the use of caregivers reports are an acceptable resource for OTs and other clinicians; however, this conclusion was not statistically significant.

The review also concluded that more research and evaluation was needed for this topic in future as it showed limitations in quantity and strength.

QUANTITATIVE STUDY

Critical Review Form – Quantitative Studies

©Law, M., Stewart, D., Pollock, N., Letts, L. Bosch, J., & Westmorland, M.
[McMaster University](#)

- Adapted Word Version Used with Permission –

The EB Group would like to thank Dr. Craig Scanlan, University of Medicine and Dentistry of NJ, for providing this Word version of the quantitative review form.

| | |
|---|--|
| CITATION | <p>Cotter, E.M., Burgio, L.D., Roth, D.L., Gerstle, J. & Richardson, P. (2008). Comparison of caregiver and occupational therapist ratings of dementia patients' performance of activities of daily living (Electronic version). <i>Journal of Applied Gerontology</i>, 27(2), 215-225.</p> |
| STUDY PURPOSE Was the purpose stated clearly? Yes | <p>Outline the purpose of the study. How does the study apply to occupational therapy and/ or your research question?</p> <p>The research had a clear objective/purpose: to assess the validity of relying on the caregiver's reports for activities of daily living (ADL) functioning, compared to clinical ratings for a care recipient with dementia.</p> <p>This study is related to occupational therapy and my research question as the clinical rating that was being compared to proxy reports was an occupational therapist's. The authors researched the exact question this OTCAT was asking.</p> |
| LITERATURE Was relevant background literature reviewed? Yes | <p>Describe the justification of the need for this study:</p> <p>The background literature is very clear and thorough with a wide range of research that has been found ranging from 1984 - 2006. Some of the findings showed agreement between caregiver and care recipients on estimating ADL function. Various studies used standardized instruments. One showed similarities between results, while in contrast others showed poor similarities yet they concluded it was because of different types of assessments used. It was noted in a study that caregivers found more ADL problems than staff at a day-care centre. The authors noted that the background research had a focus on nurses and adult day care providers as the professionals in question; therefore, they saw a need to do a further study with an OT. This study was developed from a previous study in 2002 and it used an OT as an alternative resource for data collection to make it more reliable.</p> |
| DESIGN cross-sectional study | <p>Describe the study design. Was the design appropriate for the study question? (e.g., for knowledge level about this issue, outcomes, ethical issues, etc.):</p> <p>A cross-sectional study was used for this research question; they used a group of people with dementia and evaluated the validity of the caregivers perceptions by exploring what perceptions the caregiver had as well as an OT on assessing specific ADLs. A cross-sectional study was appropriate for this study as little was known about the comparison of these two subject's perceptions and</p> |

| | |
|---|---|
| | <p>if it is a reliable source. All care recipients were assessed by their caregiver and assessed by an independent OT who was blinded to the study data. The OT was blind to all the data and was instructed to rate the performance that was shown. However it did not state whether the OT was aware of the nature of the research.</p> <p>Appropriate to outcomes? Outcomes and outcome measures were clearly defined: caregiver reports, OT ratings, direct observation with computer-based scoring system. All three sources were used in a modified version of the Functional Independence Measure (FIM) self-care subscale to measure the outcomes.</p> <p>Ethical issues were avoided by receiving consent from all participants.</p> <p>Specify any biases that may have been operating and the direction of their influence on the results:</p> <p>There is the potential for bias as it is unknown whether the OT was blind to the nature of the study.</p> <p>Rating perceptions of the ADLs were not standardised therefore, the results from each individual caregiver could form a bias.</p> |
| <p>SAMPLE</p> <p>N = 21 dyads</p> <p>Was the sample described in detail? Yes/no</p> <p>Was sample size justified? No</p> | <p>Sampling (who; characteristics; how many; how was sampling done?) If more than one group, was there similarity between the groups?:</p> <p>21 adults with dementia (determined by a Mini-Mental State Exam [MMSE] score or medical diagnosis) 21 caregivers - those selected had to be a relative of the dementia patient. Care recipients were required to be living with the family caregiver The care recipient had to require assistance with at least one activity of daily living (ADL)</p> <p>They displayed a table of 'demographic characteristics of the participants' showing the variable such as age, female, culture and spouse. However, the table only said the 'mean' not what the ages ranged from and to for example.</p> <p>This study was modelled and modified from an earlier study in 2002. To get further information regarding the selection and characteristics of the sample the reader was referred to the earlier study. This presumes the reader had the other article at hand or had read it before.</p> <p>The small sample size was not justified.</p> <p>Describe ethics procedures. Was informed consent obtained?:</p> <p>Informed consent was discussed for both the caregivers and patients with dementia. The study was approved from the institutional review board. However, it is not discussed whether confidentiality or other ethical issues were addressed.</p> |

| | | | |
|--|---|--|---|
| <p>OUTCOMES</p> <p>Were the outcome measures reliable? Not addressed</p> <p>Were the outcome measures valid? Not addressed</p> | <p>Specify the frequency of outcome measurement An outcome measure was only used once as a way to rate the perceptions of the caregiver and OT.</p> <p>It was explained that the outcome measure had been as it is a seven point scale that measures ADL performance and is therefore relevant to OT practice. However, the outcome measure was not described; the authors' presumed the reader knew how it works.</p> <table border="1" data-bbox="501 488 1426 891"> <tr> <td data-bbox="501 488 959 891"> <p>Outcome areas:</p> <p>Perceptions of caregivers and OT measuring ADLs.</p> </td> <td data-bbox="959 488 1426 891"> <p>List measures used:</p> <p>Functional Independence Measure (FIM). The Functional Independence Measure was modified. An additional assessment focussing on transferring in and out of a chair or bed was completed. The authors did not report if the measure is valid or reliable.</p> </td> </tr> </table> | <p>Outcome areas:</p> <p>Perceptions of caregivers and OT measuring ADLs.</p> | <p>List measures used:</p> <p>Functional Independence Measure (FIM). The Functional Independence Measure was modified. An additional assessment focussing on transferring in and out of a chair or bed was completed. The authors did not report if the measure is valid or reliable.</p> |
| <p>Outcome areas:</p> <p>Perceptions of caregivers and OT measuring ADLs.</p> | <p>List measures used:</p> <p>Functional Independence Measure (FIM). The Functional Independence Measure was modified. An additional assessment focussing on transferring in and out of a chair or bed was completed. The authors did not report if the measure is valid or reliable.</p> | | |
| <p>INTERVENTION</p> | <p>There is no intervention in a cross-section design study</p> | | |
| <p>RESULTS</p> <p>Results were reported in terms of statistical significance? Yes</p> <p>Were the analysis method(s) appropriate? Yes</p> | <p>What were the results? If there were multiple outcomes, was that taken into account for the statistical analysis?</p> <p>The tables displayed the correlations among the three sets of FIM scores (caregiver reported, OT reported and observation derived) as well as a table displaying the means of the individual ADL FIM scores. All correlations were positive and statistically significant at $p \leq .005$ or better, showing very high significance.</p> <p>Because the study had a small sample size, a 'power analysis' of the correlation data was conducted. This indicated that the smallest of correlations had a power of .884 at an alpha level of .05, showing that even with a small sample size it has very significant correlations.</p> <p>Other analysis methods were Analysis of Variance (ANOVA) and Post hoc Scheffé. The ANOVA showed good results by having no significant difference overall, therefore the Post hoc Scheffé was not necessary to do as they had already proved their point. These analysis methods are well known and very appropriate but the article did not justify why these methods were used.</p> | | |
| <p>Drop-outs were reported? No</p> | <p>Did any participants drop out from the study? Why? (Were reasons given and were drop-outs handled appropriately?)</p> <p>There were no drop-outs in the study: twenty-one caregivers and 21 care recipients were involved in the study. The data was only gathered once having no follow up. Therefore all participants were accounted for throughout the study.</p> | | |
| <p>CONCLUSIONS AND IMPLICATIONS</p> <p>Conclusions were appropriate given study methods and results? Yes</p> | <p>What did the study conclude? What were the main limitations or biases in the study?</p> <p>The aim of the study was to assess the validity of relying on the caregiver's report for activities of daily living (ADL) functioning, compared to clinical ratings for a person with dementia. The study</p> | | |

| | |
|--|--|
| | <p>found as it hypothesized; that the FIM scores obtained from the OT, caregivers, and computer-based observation system did not show significant differences. Therefore the study supports the idea that caregivers of people with dementia can provide accurate information about what the patients can do in ADL functioning.</p> <p>One limitation to the study is a question that is not answered: do the caregivers provide appropriate assistance during ADL interactions? The caregivers may provide either too much or too little assistance. Another limitation is the factors that caregivers may misinterpret the person with dementias functional ability.</p> <p>This study concluded the answer of this OTCAT question.</p> |
|--|--|

IMPLICATIONS FOR PRACTICE, EDUCATION AND FUTURE RESEARCH

It is known throughout the profession that occupational therapists work collaboratively with caregivers as well as the dementia patients in order to gather the data on functional performance on ADLs. Many therapists rely on the caregiver reports of performance and status of patient, particularly when the reports from the person with dementia are unreliable and/or unavailable.

The two studies showed that relying on the caregiver's reports is a reliable source for occupational therapists and other clinicians to use. The systematic review results stated that proxy reports are a reliable source for people with severe dementia; though this study is viewed with caution as it was more like a qualitative study where they formed an opinion by reading other articles and bringing the information together but having no statistical evidence to back up their opinions. The quantitative cross-sectioned design study results said that there is no statistical significant difference between the proxy reports compared with the OT; though this is not such a high level study, the results showed very good statistical significance and trustworthiness. Therefore the overall effectiveness of trusting the validity of caregivers' reports appears to be clear. As it is a family member's personal perceptions these can be clouded by biases, judgements and/or preconceived notions; therefore, a clinician should always use their own discretion and professional judgement in order to determine whether the report is dependable.

Future research about using caregiver's perceptions and view as a means of rating functional performance is required but from a different angle:

- Are the caregivers providing appropriate assistance during ADL interactions, they may provide inappropriate assistance either too much or too little (Cotter et al., 2008).
- Caregivers may misinterpret the person with dementias actual functional ability. Therefore teaching the caregiver skills in order to assess functional ability may be an intervention needed (Cotter et al., 2008).
- Through the stages of dementia when should a clinician start listening to the caregiver over the dementia patient?
- A randomised control trial methodology to give more rigorous research study and provide a stronger form of evidence.
- A larger sample size to give even more statistical significance.

REFERENCES

- Brangman, S.A. (2006, December). Alzheimer's disease focusing on the caregiver (Electronic version). *Patient Care*. Retrieved May 3, 2008. from <http://www.patientcareonline.com>.
- Cotter, E.M., Burgio, L.D., Roth, D.L., Gerstle, J. & Richardson, P. (2008). Comparison of caregiver and occupational therapist ratings of dementia patients' performance of activities of daily living (Electronic version). *Journal of Applied Gerontology*, 27(2), 215-225.
- Hyde, P. (2004). Fool's gold: examining the use of gold standards in the production of research evidence. *British Journal of Occupational Therapy* 67(2), 89-94.
- Loewenstein, D.A, Argüelles, S., Bravo, M., Freeman, R.Q., Argüelles, T., Acevedo, A. & Eisdorfer, C. (2001). Caregivers' judgement of the functional abilities of the alzheimer's disease patient: A comparison of proxy reports and objective measures. *The Journal of Gerontology* 56B(2), 78-84.
- Taylor, M.C. (2007). *Evidence-Based Practice for Occupational Therapist* (3rd ed.). Oxford: Blackwell Publishing Limited.
- Toth-Cohen, S. (2000). Role perceptions of occupational therapists providing support and education for caregiver of persons with dementia. *The American Journal of Occupational Therapy*, 54(5), 509-515.
- Tullis, A. & Nicol, M. (1999). A systematic review of the evidence for the value of functional assessment of older people with dementia. *British Journal of Occupational Therapy*, 6(12), 554-563.
-