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Carer Informants for Dementia Sufferers: Carer Awareness of Cognitive Impairment in an Elderly Community-resident Sample

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Summary

By comparing data obtained from the carers of 170 community-resident dementia sufferers with the results of objective cognitive testing, we assessed carer awareness of a range of cognitive deficits in their dependants. Spouses living with demented patients were the best at estimating the overall severity of cognitive impairment, whereas both first-degree (particularly if living with the dementia sufferer) and second-degree relatives were better at identifying and reporting the severity of memory impairment and topographical disorientation. Only one carer was aware of problems with object recognition, although a definite problem was detected in at least 40% of the study group. The testing instruments used (MMSE and CAMCOG) probably under-detected dysnomia and appeared to be inconclusive when compared with carer reports of difficulties that could be attributable to dyspraxia, highlighting the problem of sole reliance on either these instruments or informant accounts to obtain accurate clinical information.

Introduction

Obtaining clinical information from dementia sufferers can be fraught with difficulties. In particular, it appears that, while positive responses made by patients with dementia to enquiries about symptoms may be accurate, negative responses are frequently erroneous [1]. This results in under-reporting of clinically relevant details. To overcome this difficulty, informant interview has become an integral component of the assessment of patients with dementia living in the community. Carers, most of whom are close relatives familiar with patients' premorbid and current levels of functioning, are usually well placed to report on the cognitive symptoms of dementia exhibited by their dependants. However, despite the widespread use of and reliance upon such reports for both clinical and academic purposes, relatively little is known about how comparable carer perceptions of cognitive deficits are with objective ratings of patient performance and what factors might affect the quality of such data gathered from informants.

Proxy ratings of memory function in head-injured patients [2] and dysmnesic alcoholic patients [3] have been found to correlate well with tested memory performance. Koss *et al.* [4] and Fischer *et al.* [5] have found the carers of patients with Alzheimer's disease to be reliable informants of their dependants' memory deficits. Jorm and Korten [6] have developed an instrument, based on informant assessment, known as the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) and have found it to be a valid and reliable screening measure for dementia and useful for charting cognitive decline in dementia patients. O'Connor *et al.* [7] compared informant accounts, as documented using the CAMDEX informant interview [8], with results obtained from cognitive testing and found these to be 'highly consistent'. These studies, however, have primarily concentrated on comparing assessments of memory and orientation and have excluded other important cognitive deficits such as dysphasias, agnosias and dyspraxias. Furthermore, detailed information is rarely provided about the kinship of the informants and the frequency of contact they have with dementia sufferers.

This study, which takes into account both kinship and frequency of contact, reports carers' abilities to identify a range of cognitive abnormalities in community-resident dementia sufferers in comparison to objective raters applying standardized testing procedures.

Methods

Patients and carers: All patients in the present study were drawn from the Camberwell Dementia Case Register, the overall methodology of which has been previously described [9, 10]. This is an ongoing community-based register of elderly persons with dementia who are in contact with the

psychiatric and hospital-based medical health and social services provided by the inner London boroughs of South Southwark and East Lambeth. The register was started in 1992 and in its first 30 months 469 cases were enrolled. Of these, 227 were resident in the community and living in private accommodation; the remainder were living in local authority accommodation, had nursing-home placements or were hospital inpatients. To avoid floor effects on neuropsychological assessment, 32 individuals scoring 0 on the Mini Mental State Examination (MMSE) [11] were excluded from the analysis. A further 25 cases were excluded due to immobility or sensory deficits (i.e. blindness and/or deafness) that would confound assessment of cognitive function by both carers and investigators. Analyses were performed on the remaining 170 cases.

Kinship of the carers was identified and divided into three groups as follows: spouses; first-degree relatives, most of whom were adult children; second-degree relatives and some unrelated carers. We also documented the frequency of contact between carers and patients (carer lives with the patient; visits 1–7 days weekly; visits less than once weekly).

Carer interviews: All patients enrolled in the Camberwell Dementia Case Register and their carers underwent the same standardized assessment procedures [9, 10]. The CAMDEX informant interview [8] was used to obtain information about the onset, symptom profile, course and duration of the dementia. The purpose of the informant interview is to document the carer's observations, not to obtain the carer's opinions about the neuropsychological abnormalities underlying these observations. Questions about the following specific problems were selected from the interview schedule that paralleled test items from the objective assessments of patients: dysmnesia, topographical disorientation, dyspraxia, dysnomia and visual agnosia. These are detailed in the Appendix. The higher the score, the more evidence there was to suggest the presence of a specific cognitive deficit and its severity.

Part 1 (sections A and B) of the Blessed Dementia Rating Scale (BDRS) [12] provided an index of the patient's general functional ability at the time of the interview. The higher the score, the greater the degree of disability. The BDRS score was arrived at by carer interview and for the purposes of this study was based upon informant's observations of the patient during the previous 4 weeks.

Patient assessments: Patients' cognitive function was assessed using the MMSE [11], the Abbreviated Mental Test Score (AMTS) [13] and by a selection of tests from the CAMCOG component of the CAMDEX [8], including those examining praxis and visual agnosia. From these data it was possible to generate objectively measured sub-scores for variables that paralleled the above five domains of cognitive function (see Appendix). Scores were adjusted to enumerate the errors made. Therefore, the higher the score the worse the performance.

Statistical analysis: The data were analysed using the Statistical Package for the Social Sciences (SPSS/PC+ 5.0 for Windows) [14]. Correlation analyses between carers' observations and investigators' assessments were performed using Spearman's rank correlations as these data were not normally distributed. Comparisons of ordinal data between groups were made using Mann–Whitney's U test. Results are presented as mean (standard deviation). Analyses were not performed if more than 10% of the data were missing. To allow for multiple comparisons, Bonferroni corrections were used to determine significance.

Table I. Kinship and frequency of contact of informants with patients (n = 170)

Kinship	Lives with	Contact (days/week) 1–7	<1
Spouse	50	1	0
1st-degree relative	27	35	19
2nd-degree relative	5	16	17

Results

The carers' kinship and frequency of contact with the dementia patients are presented in Table I. The mean age (SD) of patients at interview was 79.3 (7.4) years. Of the 170 patients, 60% were female; 52% lived alone, 29% with a spouse, 16% with a first-degree relative and 3% with a second-degree relative. They all had established dementing illnesses with a mean duration of 4.0 (3.0) years, MMSE score of 14.4 (5.5) and BDRS of 6.6 (3.1).

The carers' global impressions of the functional severity of dementia, as measured by the BDRS, correlated moderately well with patients' total MMSE score ($r^s = -0.41$, $p < 0.00001$). When the carers were stratified by kinship, this correlation remained significant for spouses ($r^s = -0.40$, $p = 0.01$) and first-degree relatives ($r^s = -0.45$, $p < 0.0001$), but was no longer significant for second-degree relatives ($r^s = -0.31$, $p = 0.17$). When stratified by frequency of contact, there was a significant correlation for those carers living with the patients ($r^s = -0.38$, $p = 0.001$) but not for carers in contact with patients 1–7 days per week ($r^s = -0.24$, $p = 0.24$) or for carers seeing the patients less than once weekly ($r^s = 0.29$, $p = 0.27$). On stratifying the carer group by both kinship and frequency of contact, the only significant correlation was for spouses living with patients ($r^s = -0.40$, $p = 0.03$).

Memory, orientation and praxis: Correlation coefficients between carer reports and objective tests of memory, orientation and praxis for the whole group of

Table II. Coefficient values (r^s) for correlations between informant observations and objective measurements on tests of memory, orientation and praxis

Carers	n	Memory	Orientation	Praxis
Total	170	0.31***	0.31***	0.13
Kinship:				
spouse	51	0.16	0.19	0.03
1st-degree rel.	81	0.32*	0.47***	0.13
2nd-degree rel.	38	0.51**	0.14	0.30
Contact:				
lives with	82	0.35**	0.27	0.06
1–7 days/week	52	0.24	0.22	0.30
<1 day/week	36	0.33	0.34	−0.02

*$p < 0.01$, **$p < 0.005$, ***$p < 0.0001$.

Table III. Coefficient values (r^s) for correlations between informant observations and objective measurements on tests of memory, orientation and praxis

Carers	n	Memory	Orientation	Praxis
Spouse living with patient	50	0.17	0.16	−0.01
1st-degree relative				
living with patient	27	0.65**	0.55*	0.18
sees patient 1–7 days/week	35	0.14	0.24	0.13
sees patient <1 day/week	19	0.21	0.53	−0.09
2nd-degree relative				
living with patient	5	0.79	n/d	0.35
sees patient 1–7 days/week	16	0.53	−0.03	0.58
sees patient <1 day/week	17	0.41	0.08	0.02

*$p < 0.05$, **$p < 0.005$; n/d = analysis not done.

carers and for the group stratified by kinship and frequency of contact are shown in Table II. The carers' impressions of difficulties with memory and orientation correlated significantly with objective examination of these cognitive domains. These significant correlations extended to first- and second-degree relatives and also to carers living with patients, for reports and objective measures of memory, but only to first-degree relatives for orientation. These correlation values were very low for the spouse group. On simultaneously stratifying the carer group by both kinship and frequency of contact (Table III), the only significant correlations occurred in first-degree relatives living with patients, for both memory ($r^s = 0.65$, $p < 0.005$) and orientation ($r^s = 0.55$, $p < 0.05$). The group comprising second-degree relatives living with patients was excluded from the analysis for orientation as 20% of the data were missing.

There were no significant correlations between carers' reports and objective measurements of dyspraxia. There was no difference in test scores for dyspraxia between patient groups identified by carers as having some (n = 99) or no difficulties (n = 67) with feeding and/or dressing (Mann–Whitney $U = 2855$, $Z = -1.76$, $p = 0.08$).

Naming: There was no difference in test scores for dysnomia between patient groups identified by carers as having (n = 89) or not having difficulties (n = 78) naming objects (Mann–Whitney $U = 3202$, $Z = -1.26$, $p = 0.21$). Of the 89 subjects observed by carers to have word-finding difficulties, 69 were able to name the four test items. On stratifying the carer group, as described above, no significant differences were found between groups.

Object recognition: Only one carer expressed an awareness of difficulties in recognizing objects and what they were used for, whereas out of 168 patients tested 130 (77.4%) could not identify or misidentified at least one of the photographed objects presented to them; 68 (40.5%) of the patients could not identify at least two photographs and 16 (9.5%) were unable to identify any of the objects.

Discussion

As in earlier studies [4, 7], we also found that carers were relatively good at estimating the overall severity of cognitive impairment in dementia. It was perhaps not surprising that spouses and first-degree relatives were better at reporting on overall disability, as were carers residing with dementia sufferers, compared to those with less frequent contact. All of the spouses, with one exception, lived with their dependants and therefore it was perhaps also predictable that the subgroup which comprised spouses living with patients provided the most accurate overall assessments. However, this pattern changed on examination of individual cognitive domains.

Carers were good at identifying the presence of both memory impairment and topographical disorientation and were relatively good at estimating the severity of these deficits. Interestingly, it was not spouses but first-degree relatives, and also second-degree relatives in the case of memory, who were more aware of these particular deficits. The subgroup of carers comprising first-degree relatives living with the care recipient were the most adept at identifying memory impairment and disorientation. It may be that, for spouses living with their dementing partners, close proximity makes gradual decline less obvious. Another possibility may be that, to some extent, denial by spouses of the severity of their partner's condition leads them to minimize deficits or alternatively, at a more conscious level, spouses may feel that they are letting their partners down by informing others of their deficits.

The results of this study also suggest that there are some specific cognitive deficits which are less apparent to carers, most notably visual agnosia. This can be a subtle abnormality which in the restricting world of the dementing person may not be given much opportunity for expression and hence observation by a carer. None the less, it is striking that difficulty with object recognition was identified by only one of the carers, whereas, when tested, a large proportion of the dementia group (40.5%) misidentified objects in at

least two out of three photographs. Such a cognitive deficit may manifest itself in the misidentification and subsequent inappropriate utilization of objects leading to bizarre behaviours which perplex carers and contribute to the burden of care.

Carer ratings of difficulty with feeding and/or dressing appeared to have no relationship to test scores on the praxis items. This finding may be explained partially on the basis that subtle problems with praxis, as detected by instruments such as the MMSE or the CAMDEX, may not translate into overt difficulties in activities of daily living. Of course such difficulties may not be attributable solely, if at all, to dyspraxia and may be secondary to a range of cognitive deficits including dysmnesia, sequencing impairment, neglect and perceptual abnormalities. Another possible explanation, albeit less likely, is that carers may genuinely not be aware of, or consider problematic, difficulties with dressing and/or feeding.

When compared with evidence of dysnomia detected on testing, carers seemed to over-identify naming difficulties. This suggests that the test words employed are too easy and probably of too high frequency usage and hence they may not reveal early or mild problems that are apparent to carers.

An important methodological issue of this and other studies [1, 4, 7] is that for any particular cognitive deficit investigated both the source of information, i.e. carer or objective investigator, and the mode of ascertainment vary. Consequently, high levels of correlation were not expected to be obtained. When a correlation is low it may mean either that the informant is not very observant or that they are observing something different to that being assessed by the investigators. This raises the methodological issue of how more directly comparable information might be obtained. Although possibly the most ideal solution, it would be impractical to have investigators live with dementing patients and then have their observations documented in the same manner as carer informants. Alternatively, carers themselves could apply the test instruments but this might result in unacceptable bias.

In conclusion, the findings of this study provide some support for the clinical practice of seeking informant data as part of patient assessment. However, it appears that there are some cognitive deficits, for example visual agnosia, that are not readily apparent to carers. Furthermore, it is clear from our findings about praxis and language that sole reliance upon the results of cognitive testing, applying the commonly used instruments employed in this and many other dementia studies and also in clinical practice, would result in an inaccurate portrait of the patient. To provide ecologically meaningful information they need to be corroborated and supplemented by either observation or carer report. Education on the whole range of cognitive deficits that can arise in dementia is particularly important for carers to enable them to make sense of the disturbed behaviour of their dependants [15]. Appropriate information about subtle deficits such as agnosias and dyspraxias may help to explain some of the more unusual behavioural abnormalities in dementia and invest carers with a greater sense of control.

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Appendix

Carer interviews

Memory: Two questions were used that addressed difficulties in remembering short lists and when the patient last saw the informant (Camdex items 248 and 249); combining the responses gave a possible total score of 4.

Orientation: Likewise, scores for topographical orientation were calculated from questions about observed difficulties in patients finding their way around their homes and neighbourhoods (Camdex 251 and 252). The maximum score was 4.

Praxis: Scores for dyspraxis were generated by combining the responses to informant observations about patients' difficulties in feeding and dressing themselves (Camdex 267 and 268) as these activities are dependent on intact motor and visuo-spatial skills. This gave a maximum score of 12.

Naming: The Camdex item (258) about difficulty in finding the right words or using wrong words was used to provide a dichotomous variable for informants' awareness of dysnomia.

Object recognition: As part of the informant interview, carers were also asked about difficulties with object recognition from which was generated a dichotomous variable for carers' awareness of visual agnosia.

Patient interviews

Memory: Scores for delayed memory (recall of the words apple, table and penny) and remote memory (identity of reigning UK monarch and year World War I began) were used to provide an aggregate score, maximum of 5, for memory.

Orientation: A possible total score of 5 was calculated for topographical orientation from the responses to the MMSE items about name of place, two nearby streets, town, district and floor of building.

Praxis: A maximum score of 3 was generated by combining the responses to the MMSE constructional ability item (copying intersecting pentagons) and the ideomotor praxis items ('show me how you wave goodbye' and 'show me how you brush your teeth with a toothbrush') from the CAMCOG.

Naming: Patients were asked to name four objects presented in a simple manner (wrist-watch, pencil, elbow and shoulder) giving a maximum score of 4.

Object recognition: Patients were presented with three photographs of familiar objects (spectacles, a woman's shoe and a pipe) taken at unusual angles and were asked to identify the objects depicted. One point was allocated for each incorrectly identified photograph.