

Diagnosing Dementia in Primary Care: The Accuracy of Informant Reports

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Summary: In the diagnosis of dementia, information obtained from informants or proxies is important; however, little is known about the circumstances under which informants' reports lack accuracy. This study compares informant reports of cognitive status against psychometric tests to identify the degree of, and factors associated with, discrepant reporting. Four areas of patient cognitive ability were examined: memory of recent events, ability to remember a short list of items after a delay, language/naming abilities, and working memory. Primary care practitioners recruited 248 community-dwelling patients aged 75 years or more or aged 50–74 years with suspected memory complaints; 248 friends or relatives acted as informants. More than half of the informants (60%) gave responses consistent with psychometric testing. Informants who underreported patient difficulties tended to report on patients who were diagnosed as having subclinical dementia, were less educated, and had poorer remote memory. Informants who overreported difficulties were more likely to report on those diagnosed with dementia. While informant accounts are critical for the assessment of dementia, we found that in 40% of cases these reports may be inaccurate, particularly when the patient has low education and poor remote memory or when overall cognitive difficulties are mild. **Key Words:** Dementia—Informants—Primary care—General practice—Proxy.

Informant or proxy assessments of a person's cognitive status are useful in aiding diagnosis, assessing degree of decline, and anticipating future decline (Corey-Bloom et al., 1995; Tierney et al., 1996; Gauthier et al., 1997; Jorm et al., 1997; Cipolli et al., 1998; Ippen et al., 1999, Jorm et al., 2000). However, the reliability of informant reports may be limited, as patient and informant characteristics may potentially bias informant reports (Magaziner, 1997).

Few studies have focused on the accuracy of infor-

mants' reports on patients' cognitive status (Neumann et al., 2000). In the Honolulu-Asia Aging Study (Ross et al., 1997), family informants failed to recognize cognitive problems in 21% of community-dwelling persons subsequently found to have dementia. Problems were more likely to go undetected by family members if patients were older, less educated, had intact remote memory, or had few behavioral or daily functioning problems. Accuracy increased with greater frequency of patient-informant contact (Bassett et al., 1990). The type of patient-informant relationship may (McLoughlin et al., 1996) or may not (Bassett et al., 1990; Tierney et al., 1996; Ross et al., 1997) influence accuracy of reports.

We aimed to investigate the accuracy of informants' reporting on patient cognitive status. To achieve this, informant reports of cognitive status were compared with psychometric tests to identify the degree of and factors associated with discrepant reporting.

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METHODS

Overview

We conducted a prospective primary practice-based study that incorporated informant reports and cognitive assessments of patients, examining four areas: memory of recent events, i.e., events occurring in the past week (*recent memory*), ability to remember a short list of items after a delay (*delayed memory*), language and naming abilities (*language*), and working memory or ability to concentrate (*concentration*). Informant reports were compared with psychometric testing for these domains and classified as consistent with testing, indicating more problems than shown in testing (*overreporting*), or indicating fewer problems than shown in testing (*underreporting*) (see Table 1 for decision rules).

Informants were categorized into four groups: “minimizers” gave one or more underreporting response and no overreporting responses; “maximizers” gave one or more overreporting response and no underreporting responses; “consistents” were informants whose responses were all consistent with testing; and “mixed” informants gave a combination of minimized, maximized, and consistent responses. As there were only four mixed informants, they were excluded from further analyses.

Participants

A convenience sample of 67 general practitioners (GPs) from three metropolitan regions in Sydney and one in Wollongong recruited 380 community-dwelling par-

ticipants of whom 248 completed the study. Subjects were included if they were aged ≥ 75 years regardless of cognitive status or aged 50–74 years and their GP suspected memory difficulties. Patients were excluded from the study if they resided in a nursing home, the GP considered them to be depressed or delirious, or poor English language abilities, sight, or hearing precluded testing. Of the 132 subjects who did not complete the study, 47 withdrew, 24 did not meet the study’s inclusion-exclusion criteria, 35 did not have appropriate informants, and 26 were unable to receive home visits. At subsequent consensus case conferences, 79 of the 248 participants (32%) received a diagnosis of dementia according to Diagnostic and Statistical Manual of Mental Disorders (4TH edition) (DSM-IV) criteria (American Psychiatric Association, 1994), and 38 (15%) were considered subclinical cases (likely to have dementia but not meeting all criteria).

Assessment Measures

Demographic data comprised patient age, informant age (by 10-year age group), patient and informant gender, patient’s years of formal education, relationship to informant (spouse/de facto, sibling/child/parent, friend/other), and frequency of informant contact with patient (living with patient, sees patient 4–7 times per week, sees patient 1–3 times per week, sees patient every 2–4 weeks).

The Cambridge Examination for Mental Disorders in the Elderly (CAMDEX) (Roth et al., 1986) comprises a

TABLE 1. Questions used for analyses, and decision rules for informant response classification

	CAMDEX Questions Used		Informant Response Classification	
	CAMCOG (Patient)	Informant Interview	Under-reporting	Over-reporting
Recent memory	q157 – Describe a recent news event score range: 0–1	q248 – Degree of difficulty remembering recent events. responses: ‘no difficulty’ to ‘great difficulty’	Patient unable to answer. Informant response: ‘no difficulty’	Patient answers correctly. Informant response: ‘great difficulty’
Delayed memory	q161 – Repeat names of three objects after a delay score range: 0–3	q247 – Degree of difficulty remembering short list of items. responses: ‘no difficulty’ to ‘great difficulty’	Patient able to recall no more than one object. Informant response: ‘no difficulty’.	Patient able to recall all three objects. Informant response: ‘great difficulty’.
Language	q137 – Name pencil and watch q138 – Name six pictures of objects score range: 0–8	q256 – Difficulty finding the right word or using the wrong word more often. responses: ‘yes’ or ‘no’.	Patient names no more than 5 of 8 items. Informant response: ‘no difficulty’.	Patient names all 8 items Informant response: ‘yes, has difficulty’.
Concentration	q159 – Count backwards q160 – Serial subtractions score range: 0–7	q254 – Decline in mental functioning? q259 – Does thinking seem muddled? responses: ‘yes’ or ‘no’.	Patient scores no more than 3 of a possible 7. Informant response: ‘no’ to both mental decline and muddled thinking.	Patient scores 6 or 7 out of a possible 7. Informant response: ‘yes’ to both mental decline and muddled thinking.

structured psychiatric interview with the patient and a test of cognitive abilities (CAMCOG). A remote memory score was calculated by adding the “retrieval of remote information” items in the CAMCOG, items 148–153, (maximum score = 6; higher scores indicate better retrieval of remote information). A Mini-Mental State Examination score (MMSE) (Folstein et al., 1975) was also obtained from the CAMCOG items.

For the instrumental activities of daily living (IADL) scale (Lawton and Brody, 1969), informants are asked to rate the patient’s day-to-day functioning in eight areas, including shopping, laundry, housekeeping, and ability to handle finances. Scores range from 8 to 31, with higher scores indicating greater impairment; scores were prorated if individual items were not applicable.

Procedure

General practitioners recruited consecutive eligible patients. An average of 5 weeks later, a research psychologist administered the CAMCOG to patients at home interview, and the CAMDEX informant interview and the IADL scale to informants face-to-face (49.2%) or by telephone (50.8%). Although the research psychologist saw both patient and informant, we believe that this did not introduce a significant bias since the patient and informant sections were highly structured.

Analyses

All analyses were performed using SPSS for Windows version 10.0.5, (SPSS Inc., Chicago, IL). Student *t* test or chi-square analyses were used to test for differences between minimizer, maximizer, and consistent groups. The suggested *p* value required for significance after Bonferroni corrections for multiple tests is 0.008.

“Minimizers” were compared with “consistents” using binary logistic regression analysis. Based on previous research, patient age, education, remote memory, IADL score and dementia status, amount of patient-informant contact, and type of patient-informant relationship were the predictor variables in this regression, and entry to the model was forced. In addition, “maximizers” were compared with “consistents” using binary logistic regression analysis, and patient’s IADL score, dementia status, patient-informant relationship, and patient-informant degree of contact were used as predictor variables, with forced entry into the model.

RESULTS

Sample Characteristics

Of the 248 patients, 6 were excluded (2 due to missing data and 4 in the “mixed” category). The remaining 242

participants were aged 56–94 years, (mean, 79.6 years; SD = 6.02), and 58.3% were female. Formal education ranged from 2 to 30 years (mean, 9.3 years; SD = 2.98); MMSE scores ranged from 7 to 30 (mean, 24.4; SD = 4.0), and IADL scores from 8 to 30 (mean, 11.2; SD = 5.2). In regards to dementia, 52.9% of participants did not meet DSM-IV criteria, 31.4% met criteria, and 15.7% did not meet criteria but were considered to be subclinical. The severity of dementia, according to CAMDEX criteria, was minimal in 14 (18.4% of those with dementia), mild in 39 (51.3%), and moderate in 23 (30.3%).

The 242 informants were mainly female (75.6%) and ranged in age from 20 to 90 years. Their modal age was 70–79 years (29.3%); 22.5% were aged between 50 and 59. Most informants were either the patient’s spouse/de facto (40.9%) or child/sibling/parent (39.3%); remaining informants were friends, other relatives, or others (19.8%). Most informants (55.8%) lived with the patient, 10.8% visited the patient more than 4 times a week, 27.3% visited 1–3 times a week, and 6.1% visited once every 2–4 weeks.

Informant Responses

Very few informants underreported “short-term recall” or overreported “naming/word finding” (Table 2). Responses consistent with psychometric testing in all four domains were given by 59.5% of informants; 33.4% gave a response discrepant with testing in one domain; 5.4% gave a discrepant response in two domains; and 1.7% gave a discrepant response in three domains.

The means (for continuous predictors) or percentages (for categorical predictors) and differences between minimizers, maximizers, and consistent groups are shown in Table 3. Patients who were reported on by minimizing informants were significantly more likely to have subclinical dementia and have poorer remote memory than patients reported on by consistent informants. In contrast, patients reported on by maximizing informants were more likely to meet DSM-IV criteria

TABLE 2. Informant responses (under-reporting, over-reporting and consistent) by cognitive domain (*n* = 242)

	Number of 'under-reporting' responses (%)	Number of 'consistent' responses (%)	Number of 'over-reporting' responses (%)
Recent memory	9 (3.7)	224 (92.6)	9 (3.7)
Delayed memory	38 (15.7)	199 (82.2)	5 (2.1)
Language	2 (0.8)	225 (93.0)	15 (6.2)
Concentration	22 (9.1)	201 (83.1)	19 (7.9)

TABLE 3. Predictor variables examined by informant group

	Minimizer n = 59	Consistent n = 144	Maximizer n = 39	Min* vs Con – test of significance†	Max vs Con – test of significance†
Patient age (years)	80.3 (SD 4.65)	79.0 (SD 6.48)	80.3 (SD 6.02)	t = -1.32 df = 201 p = 0.187	t = -1.10 df = 181 p = 0.274
Patient years of education	8.5 (SD 2.42)	9.7 (SD 3.27)	9.2 (SD 2.42)	t = 2.59 df = 201 p = 0.010	t = 0.93 df = 181 p = 0.212
Patient's remote memory score	4.0 (SD 1.54)	4.6 (SD 1.35)	4.3 (SD 1.32)	t = 2.47 df = 201 p = 0.006	t = 1.25 df = 181 p = 0.212
Patient's IADL score	10.00 (SD 3.18)	10.72 (SD 5.05)	14.50 (SD 6.62)	t = 1.01 df = 201 p = 0.313	t = -3.82 df = 181 p = 0.001
Informant's relationship to patient (%)					
spouse/defacto	37.3	40.3	48.7	$\chi^2 = 1.02$	$\chi^2 = 3.10$
sibling/child/parent‡	44.1	36.8	41.0	df = 2	df = 2
friend/other	18.6	22.9	10.3	p = 0.602	p = 0.213
Mode of interview (%)				$\chi^2 = 2.30$	$\chi^2 = 0.84$
Face-to-face	39.0	50.7	59.0	df = 1	df = 1
Telephone	61.0	49.3	41.0	p = 0.129	p = 0.358
DSM-IV dementia status (%)					
absent	40.7	64.6	28.2	$\chi^2 = 18.76$	$\chi^2 = 18.98$
sub-clinical	33.9	9.7	10.3	df = 2	df = 2
present	25.4	25.7	61.5	p = 0.001	p = 0.001
Frequency of contact between patient and informant (%)					
Lives with patient	46.4	57.2	64.9	$\chi^2 = 4.82$	$\chi^2 = 1.37$
Sees patient 4–7 times per week	16.1	8.7	10.8	df = 3	df = 3
Sees patient 1–3 times per week	26.8	29.0	21.6	p = 0.185	p = 0.714
Sees patient every 2–4 weeks	10.7	5.1	2.7		

*Min = minimizer, Max = maximizer; Con = consistent

†Suggested p-value of significance is 0.008.

‡There was one parent in this group.

for dementia, and these informants also rated patients as significantly more dependent in activities of daily living than consistent informants.

Multivariate Logistic Regression: Predicting “Minimizers”

Multiple regression results are presented in Table 4, showing the odds ratios and significance levels of predictors. The patient-informant relationship and patient-informant frequency of contact were highly correlated since informants who were spouses/de facto were very likely to also be living with the patient. For this reason, the informant-patient relationship and the frequency of contact variables were entered in separate regressions alternately.

The model including patient dementia status, patient age, patient education, remote memory, IADL score, and patient-informant relationship successfully classified

75.7% of informants. Substituting the frequency of informant contact variable for the patient-informant relationship variable did not substantially change the model's accurate classification rate (78.5%) but did alter the significance of the IADL score. In the model including frequency of patient-informant contact, IADL score was not significant because of the relationship between these variables (patients who saw the informant more often were more likely to be rated as functioning poorly). Belonging to the minimizer group was significantly predicted by reporting on a patient with subclinical dementia, lower education, and greater remote memory impairment.

Multivariate Logistic Regression: Predicting “Maximizers”

Membership of the maximizer group was more likely if the patient met DSM-IV criteria for dementia (Table

TABLE 4. Odds ratio and significance levels of predictors in logistic regression analyses, comparing minimizers to consistents, and maximizers to consistents

	Predictors	Odds ratio (95% CI)	DF	p-value
'Minimizers' (n = 59) compared to 'consistents' (n = 144)	Patient's dementia status:		2	0.002
	<i>absent vs present</i>	1.17 (0.42–3.2)		0.540
	<i>absent vs sub-clinical</i>	5.21 (1.98–13.68)		0.001
	Patient age (years)	1.03 (0.96–1.10)	1	0.400
	Patient years of education	0.82 (0.70–0.97)	1	0.019
	Patient's remote memory	0.69 (0.51–0.94)	1	0.019
	Patient's IADL	0.92 (0.82–1.02)	1	0.098
	Informant's relationship to patient:		2	0.326
	<i>spouse/defacto vs friend/other</i>	1.62 (0.59–4.44)		0.351
	<i>sibling/child/parent vs friend/other</i>	2.14 (0.79–5.76)		0.134
	Frequency of patient/informant contact	1.19 (0.86–1.66)	1	0.298
'Maximizers' (n = 39) compared to 'consistents' (n = 144)	Patient's dementia status:		2	0.016
	<i>absent vs present</i>	3.77 (1.52–9.37)		0.004
	<i>absent vs sub-clinical</i>	2.50 (0.68–9.20)		0.167
	Patient's IADL	1.06 (0.99–1.13)	1	0.121
	Informant's relationship to patient:		2	0.602
	<i>spouse/defacto vs friend/other</i>	1.84 (0.54–6.5)		0.331
	<i>sibling/child/parent vs friend/other</i>	1.46 (0.41–5.14)		0.556
	Frequency of patient/informant contact	0.97 (0.67–1.39)	1	0.845

4). Correct classification was achieved in 80.0% of cases. Substituting the patient-informant relationship variable with the frequency of informant contact variable did not substantially change the model's accurate classification rate (78.5%).

DISCUSSION

Informant reports are pivotal for clinicians diagnosing dementia. In this study, informants were generally accurate in assessing patients' cognitive abilities on any particular domain. However 40.5% of informants gave responses discrepant with the ratings by independent psychologists in at least one of the four cognitive domains examined (24.3% underreported and 16.1% overreported).

When should clinicians suspect the veracity of informant reports? Underreporting tended to occur in patients with subclinical dementia. These patients usually had mild difficulties but did not meet criteria for dementia because they were still able to function independently. Consistent with previous findings (Ross et al., 1997), underreporting of difficulties was predicted by lower levels of patient education. This may be because deficits are less noticeable in less-educated persons who have fewer cognitive demands placed on them, because lack of education may affect test performance, or because patient education acts as a proxy for informant education, which in turn predicts underreporting.

In contrast to Ross et al. (1997), we found that underreporting of problems was associated with poorer patient

remote memory. Perhaps these patients have long-standing poor memory, making memory problems less easily detectable to informants. We found no support for a relationship between patients' age, frequency of contact with informant or relationship to informant, and minimizer response bias in informants.

Overreporting of patient cognitive problems was more likely to occur when the patient's symptoms met criteria for dementia. There are several possible reasons for this. If a patient is impaired in some areas of cognitive functioning, the informant may assume that the patient is impaired in all areas. Alternatively, as dementia progresses and patients become more dependent, informants are likely to be more burdened and perhaps less reliable in their reports (Jorm, 1996). Some informants may even (knowingly or otherwise) exaggerate their reports because they need assistance. A limitation of this study is that we did not collect information about informants' affective state or burden.

Other limitations are conceded. Psychometric testing, our "criterion standard," may in some situations be less accurate than informant reports (McLoughlin et al., 1996). The performance of some patients in the structured testing environment may not reflect their day-to-day abilities, and testing may not be able to detect the small changes in cognition observed by informants. Finally, several factors potentially affecting informant accuracy were not included: informant's culture or ethnicity, level of depression, education, and cognitive abilities (Ross et al., 1997, Long et al., 1998; Ippen et al., 1999).

In conclusion, the current study has several implica-

tions for clinicians. Informant reports should be obtained regardless of the informant's relationship to or degree of contact with the patient—these factors do not significantly affect the accuracy of informant reports on cognitive status. However, patient factors such as fewer years of education, milder degree of dementia, and poorer remote memory ability may indicate less reliable informant reports. Such patients may require more careful diagnostic assessment.

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