Published in final edited form as: Alzheimer Dis Assoc Disord. 2010 ; 24(3): 296–302. doi:10.1097/WAD.0b013e3181d5e540.

The predictive validity of the 10/66 Dementia diagnosis in Chennai, India – a three year follow-up study of cases identified at baseline

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Abstract

INTRODUCTION: Dementia prevalence according to DSM-IV criteria tends to be very low in less developed settings. The 10/66 Dementia Research Group's cross-culturally validated diagnosis returns a considerably higher prevalence. Assessing the predictive validity of the 10/66 dementia diagnosis will assist in establishing the best criterion for estimating the population burden of dementia.

METHODS: In a population-based study in Chennai, India, we aimed to follow up after three years 75 people with 10/66 dementia and 193 with cognitive impairment but no dementia (CIND), reassessing diagnostic status, clinical severity, cognitive function, disability and needs for care.

RESULTS: We traced 54 people with dementia of whom 25 (46.3%) had died, double the mortality rate among those with CIND. Twenty-two of the 24 people with 10/66 dementia that were re-examined still met 10/66 dementia criteria. There was clear evidence of clinical progression and increased needs for care. Only one 'case' had unambiguously improved. Cognitive function had deteriorated and disability increased to a much greater extent than among those with CIND.

CONCLUSION: The strong predictive validity of the 10/66 dementia diagnosis is consistent with a lack of sensitivity of the DSM-IV criterion to mild to moderate cases, which may underestimate prevalence in less developed regions.

INTRODUCTION

Two-thirds of older people, and by implication a similar proportion of people with dementia live in low and middle income countries (LAMIC), with rapid increases forecast 1. However, studies applying DSM-IV criteria to diagnose dementia suggested an age-specific prevalence that is only one quarter to one fifth that typically seen in developed countries 2-4. In the 10/66 Dementia Research Group's population-based studies, the prevalence of DSM-

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Martin Prince leads the 10/66 Dementia research group and originated the idea for the analyses reported in this paper. A.T Jotheeswaran and Martin Prince conducted the analyses and wrote the first draft. A.T. Jotheeswaran and Joseph Williams were responsible for the field work in the Chennai 10/66 centre. Joseph Williams has reviewed the manuscript, provided further contributions and suggestions. All authors read and approved the final manuscript.

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IV dementia in urban Latin America was similar to that previously observed in Europe, while that in rural Latin America and in India was very low 4. Conversely, the prevalence of dementia according to the 10/66 Dementia Research Group's own cross-culturally validated criterion was more consistent across sites and higher than that of DSM-IV dementia. For the less developed sites in India and rural Latin America, the discrepancy between the two sets of criteria was particularly striking, the prevalence of 10/66 dementia being four to 16 times higher than that of DSM-IV dementia 4. We need to clarify which is the more appropriate criterion for determining the extent of the burden in LAMIC.

The 10/66 dementia algorithm was carefully developed, calibrated and validated in an extensive pilot study conducted in 25 centres in India, China and southeast Asia, Latin America, the Caribbean, and Africa with an overall sensitivity of 94% and a specificity of 97% for those with higher, and 94% for those with lower levels of education 5. In a further criterion validation nested in the prevalence study in Cuba, 10/66 dementia corresponded more closely to Cuban clinical interviewer dementia diagnoses than did DSM-IV dementia, which selectively missed mild and moderate cases 6. In our prevalence studies, 10/66 dementia cases not confirmed by the DSM-IV criterion were consistently disabled compared with non-cases, in which respect they could not be distinguished from DSM-IV dementia cases in most sites 4. The underestimation by the DSM-IV dementia criterion in less-developed sites seemed to be attributable to underreporting by family informants of intellectual and functional decline 4.

Surprisingly, the predictive validity of survey diagnoses of dementia has not been assessed, other than in relation to neuropathology on autopsy 7. Lishman's classic definition of dementia syndrome 'An acquired global impairment of intellect, memory and personality, but without impairment of consciousness' includes the important exegesis that 'Dementia is nearly always of long duration, usually progressive, and often irreversible, but these features are not included as part of the definition' 8. Nevertheless, the commonest underlying pathologies in older people, Alzheimer's Disease, Vascular Dementia, Dementia with Lewy Bodies and Frontotemporal Dementia tend to be inexorably progressive, and the only available treatments are symptomatic. An important rationale for early diagnosis is that it alerts patients, clinicians and carers to the likelihood of progression. We therefore set out to test the predictive validity of our 10/66 dementia diagnosis in a three year follow-up conducted in our centre in Chennai, India. Our predictive hypotheses were that, if valid

- 1. 10/66 dementia cases would have a high mortality rate, as previously shown for dementia in many studies 9
- **2.** 10/66 dementia cases would have experienced in absolute terms, and relative to those with cognitive impairment but no dementia (CIND).
 - a. decline in cognitive function,
 - b. an increase in disability and needs for care, and
 - c. an increase in overall clinical severity

Validity would be challenged by survival with lack of progression, or clinical or functional improvement.

METHODS

Settings and study design

The urban Indian site for the 10/66 population-based study comprised five geographically defined catchment areas, Kandhanchavadi, Perungudi, Thoraipakkam, Palavakkam, and Kottivakkam located in South Chennai around the Voluntary Health Services (VHS)

Community Health Centre. Tamil is the predominant local language. The design of the baseline and follow-up phases of the 10/66 study have been described in detail elsewhere 10. The baseline catchment area survey in Chennai, carried out between 2004 and 2006, included 1005 people aged 65 years and over, representing a response rate of 72% of all those eligible to participate 11. The follow-up was conducted between Dec 2007 and July 2008 under the auspices of the VHS Institute of Community Health; we sought to reinterview all those with 10/66 or DSM-IV dementia at baseline (n=75), together with a larger group with cognitive impairment but no dementia (CIND - n=193). The CIND group comprised all those meeting Petersen criteria for amnestic mild cognitive impairment (MCI n=33), or pure non-amnestic MCI (n=101) and those with significant cognitive impairment (scoring 1.5 standard deviations below age and education norms on two or more out of three memory tests), but not meeting either MCI criterion (n=59). Three field investigators were thoroughly trained with study protocol and inter-rater reliability exercises were performed before the field work. All interviewers were masked as to the baseline status of the followup participants. Ethical approval for baseline and follow-up surveys was obtained from the King's College London Research Ethics Committee, and from the Research Ethics Committee, Voluntary Health Services, Taramani, Chennai, India. Participation was on the basis of written (signed) informed consent.

Measures

Identical assessment procedures were used for cognitive assessment and dementia diagnosis at baseline and follow-up. These have been described previously in more detail 10. Briefly:

Cognitive function and informant interview—The Community Screening Interview for Dementia (CSI 'D') 12 consists of a 32 item cognitive test administered to the participant (20 minutes) and a 26 item informant interview, enquiring after the participant's daily functioning and general health (15 minutes). The cognitive score (COGSCORE), is a summary score from the participant cognitive test. The informant score (RELSCORE) is a total score from the informant interview. The adapted CERAD ten word list learning task was developed in the Indo-US Ballabgarh dementia study 13. Six words were taken from the original CERAD battery English language list; butter, arm, letter, queen, ticket, and grass. Pole, shore, cabin, and engine were replaced with corner, stone, book and stick, which were deemed more culturally appropriate 13. In the learning phase, the list is read out to the participant, who is then asked to recall the words that they remember. This process is repeated three times, giving a total learning score out of 30. Five minutes later the participant is again asked to recall the 10 words, giving a delayed recall score out of 10.

Clinical interview—A structured comprehensive clinical mental state interview, the Geriatric Mental State, processed using a computer algorithm (AGECAT - Automated Geriatric Examination for Computer Assisted Taxonomy)14 to generate case levels of organicity (probable dementia), depression, anxiety and psychosis and a single hierarchically determined diagnosis.

Final dementia diagnosis was made in two ways:

a) The 10/66 dementia diagnosis was originally developed, calibrated and validated against the gold standard of a local clinician's diagnosis of DSM-IV dementia in pilot studies in 26 centres in Latin America, India, China and Nigeria 5. A logistic regression equation predicting the gold standard criterion diagnosis was developed in one half of the sample and tested in the other, applying coefficients from the GMS/ AGECAT final diagnosis, CSI-D informant and cognitive test interviews and the modified CERAD 10 word list learning tasks 5. Calibration in the development half of the data set showed that a threshold probability of > 0.25 optimised sensitivity and specificity. Overall

b) DSM-IV dementia diagnosis was obtained by applying the relevant criteria (1. development of multiple cognitive deficits manifested by both memory impairment and one or more of aphasia, apraxia, agnosia and disturbance in executive functioning, 2. each causing significant impairment in social or occupational functioning and representing a significant decline from a previous level of functioning, 3. not occurring exclusively during a delirium, and 4. not better accounted for by another axis I disorder) using a fully operationalised computerised algorithm 6

We assessed the severity of dementia (no dementia, questionable dementia, mild, moderate or severe dementia) using a computerised operationalisation of the Clinical Dementia Rating (CDR) 15. The sum of the ratings across the six CDR domains, known as the 'sum of boxes' has been reported to be a reliable indicator of the progression of dementia 16.

Disability and dependency: Disability was measured using the 12 item World Health Organization Disability Assessment Schedule (WHODAS II) 17, developed by the WHO as a culture-fair assessment tool for use in cross-cultural comparative epidemiological and health services research. Dependency (whether the participant needed no care, some care or much care) was ascertained through a series of open-ended questions administered to the informant.

Statistical analysis

We describe the tracing and vital status of participants according to their cognitive status at baseline. We tested for differences in the baseline characteristics of those re-examined and not re-examined (not traced, deceased or not available for interview), using t-tests, or Chi squared tests as appropriate. For all those that were re-examined we describe, separately for all dementia cases, 10/66 dementia cases not meeting DSM-IV criteria and those with CIND, the distribution at baseline and follow-up (mean and standard deviation) for cognitive test scores (CSI'D' COGSCORE and 10 word recall), informant reports of cognitive and functional impairment (CSI'D' RELSCORE), and disability scores (WHODAS II). Paired t-tests were performed to quantify the changes from baseline in each measure, again separately for the dementia and CIND groups. Finally, we calculated change scores for each measure and performed independent sample t-tests to compare the extent of change between dementia and CIND groups.

RESULTS

We re-examined 131 participants, 24/75 (32.0%) of those with dementia, and 107/193 (55.4%) of those with cognitive impairment. Re-examinations took place a mean of 3.1 years after baseline interviews (range 2.4 to 4.7 years). Loss to follow up was mainly accounted for by participants having moved away because of a major urban infrastructure project. This accounted for 68 participants (25.4%), whose vital status could not be determined (Table 1). A further 12 participants were traced but were not available for interview. No participants refused re-examination. Proportions not traced varied according to cognitive group status at baseline (see Table 1), but not to a statistically significant degree (Chi squared =3.1 p=0.37). A further 57 participants (21.3%) were known to have died, or 28.5% of those whose vital status could be determined. Among those with CIND, those not re-examined had a slightly more impaired COGSCORE at baseline (Table 2). Among those with dementia, those not-re-examined were considerably more disabled at baseline. Otherwise there were no differences in baseline cognitive function, age, gender, educational level, physical illness or disability.

Outcome for those with 10/66 dementia

An outcome could be determined for 54 out of 75 10/66 dementia cases at baseline. Twentyfive (46.3%) had died before the follow-up (Table 1). The mortality rate increased with dementia severity; from CDR questionable dementia (15/38, 39.5%) to mild dementia (7/13, 53.8%) to moderate or severe dementia (3/3, 100%), chi squared test for trend = 3.8, p=0.05. The mortality rate was non-significantly higher among 10/66 dementia cases that met DSM-IV dementia criteria (4/6, 66.6%) compared with those not meeting that criterion (21/48, 66.6%)43.8%); Fisher's exact, p=0.40. In all, 24 10/66 dementia cases were re-examined, of whom two had also had symptoms meeting criteria for DSM-IV dementia at baseline. Both of these DSM-IV cases still met DSM-IV criteria at follow-up; one had declined by 15 points on the COGSCORE, and the other by 16 points. Twenty two out of the 24 10/66 dementia casses (91.6%) showed signs of cognitive deterioration, with lower COGSCORE at follow-up than baseline. Twenty-two were still given a 10/66 dementia diagnosis at follow-up. One of the two cases that no longer met 10/66 criteria had clearly improved, with a seven point increase in COGSCORE and a decline in WHODAS II disability score to zero. The other showed a four point decline in COGSCORE, stable WHODAS II, worsening cognitive and functional impairment according to informant report (RELSCORE) and a one point increase in CDR sum of boxes; this participant no longer met 10/66 criteria because of a change in status from 'organic' case to non-case according to the GMS/ AGECAT clinical interview.

According to the Clinical Dementia Rating, 13/24 of the baseline 10/66 dementia cases that were re-examined had shown deterioration, 10 remained at the same level and one had improved (Table 3). The mean CDR sum of boxes score increased from 2.4 (SD 1.8) to 4.4 (SD 3.1), paired mean difference = 2.1 (1.0 to 4.1), t=-4.1, df=23, p<0.001. According to interviewer rated needs for care, $18/24 \ 10/66$ dementia cases had increased needs for care, five were rated at the same level and one had moved from needing care much of the time to needing care only some of the time (Table 4). Seventeen of the twenty cases who were rated as needing no care at baseline now needed care at least some of the time.

Differences in outcome between those with dementia and those with CIND

Mortality was significantly higher among those with dementia at baseline (46.3%), compared with those with CIND (Table 1); pure non-amnestic MCI (21.3%), amnestic MCI (26.9%) and other cognitive impairment (22.5%); chi squared = 11.1, 3 df, p=0.01. Performance on the CSI'D' COGSCORE deteriorated significantly in both groups, more for those with dementia (7.4 points) than for those with CIND (2.0 points) (Table 5). Performance on the CERAD 10 word recall improved slightly for those with CIND (by 0.9 of a word recalled) and remained stable among those with dementia (an insignificant increase of 0.3 of a word recalled), but with no significant difference in the change between the two groups. Informant reports of cognitive and functional decline as indexed by the CSI'D' RELSCORE increased in both groups, by 0.7 points for those with CIND and by 2.1 points among those with dementia, the difference between the two groups being statistically significant. The WHODAS II disability score increased over the follow-up period in both groups, by 5.1 points among those with CIND and by 19.4 points in those with dementia. The difference in change between the two groups was statistically significant. We repeated the above analyses excluding from the dementia group the two 10/66 dementia cases who had also had symptoms meeting criteria for DSM-IV dementia at baseline (Table 5). The change scores, and mean differences with the CIND group were slightly attenuated.

DISCUSSION

Our data must be interpreted with caution, given the relatively small number of dementia cases at baseline, of whom only 24 could be re-examined at follow-up. While mortality (an

important endpoint in itself) was the main cause of loss to follow-up, our estimates of cognitive and functional decline lacked precision. The general similarity of baseline characteristics among those re-examined and not re-examined does not preclude the possibility of significant bias tending either to over-estimate or under-estimate the differences in course between dementia cases and those with CIND. Nevertheless, this follow-up study provides reasonably strong evidence in support of the validity of the 10/66 dementia diagnoses at baseline. Nearly half of those with 10/66 dementia for whom followup information was available had died, almost double the mortality rate for those with CIND. For the survivors, there was strong diagnostic stability. Overall dementia severity (CDR) had progressed in just over half of the cases. There was clearer evidence of progression in terms of needs for care. In only one of the 24 cases that were re-examined was there clear evidence that the original diagnosis was misapplied. Those with 10/66 dementia showed a marked increase in cognitive impairment according to the CSI'D' COGSCORE and in disability according to WHODAS II, with effect sizes of nearly 1.3 in each case. The lack of decline in the 10 word list recall score was probably accounted for by a floor effect, with the slight increase in the CIND group arising from this together with a probable learning effect. Perhaps most impressive was the ability of the 10/66 dementia criterion to discriminate accurately between those with cognitive impairment who were and were not likely to show subsequent cognitive and functional decline. It must be borne in mind that other studies of clinical course and outcome show considerable variation in rates of progression. For example, in the Canadian Study of Health and Ageing, 15% of mild dementia cases reviewed after five years had not yet progressed to having any limitations in personal activities of daily living 18. Similar findings have been reported in a clinical case series from the United Kingdom, in which participants had received full clinical diagnostic work up at entry to the service -25% of survivors had not progressed at three years followup 19.

DSM-IV dementia criteria prioritise reliability by restricting the diagnosis to more severe and incontrovertible cases; multiple domains of cognitive function must be affected, each with clear evidence of social or occupational impairment. By contrast, the 10/66 diagnosis is derived from a probabilistic algorithm; scores on two cognitive tests (CSI'D' COGSCORE and CERAD 10 word list delayed recall), an informant interview for evidence of intellectual and functional decline, and the diagnostic output from the Geriatric Mental State structured clinical interview, all contribute to the probability that a participant is considered a case. As such, there is no requirement for specific patterns of cognitive impairment or for any specific degree of disability. Greater degrees of impairment in one element can compensate for lesser degrees in another. Empirically, in the validation of the 10/66 algorithm in the pilot phase of our project, the GMS clinical interview helped to distinguish between dementia and depression, and the informant interview between dementia and CIND in those with low education. DSM-IV dementia is thus a relatively narrow, but specific criterion. DSM-IV criteria have been criticized for the primacy accorded to memory impairment (which is not an early feature in some dementia subtypes) and for the lack of specificity of the secondary cognitive criteria 20. There is evidence from several studies 4, 6, 21 that the DSM-IV dementia criterion may lack sensitivity for mild and moderate cases, and hence underestimates true dementia prevalence. Our current study supports the earlier impression that the extent of the underestimation might be particularly important in least developed regions 4. Our methods have highlighted a substantial prevalence of dementia that may, hitherto, have been missed and developed/ developing country prevalence differences may not be as large as previously thought. In Chennai the prevalence of DSM-IV dementia was only 0.9%, all of whom were also 10/66 Dementia cases. However a further 6.6% met 10/66 dementia criteria but were not confirmed by DSM-IV 4. If, as our follow-up study suggests, these additional cases were all, or nearly all valid cases of dementia, and the consequent higher prevalence could be generalised across the country then previous estimates of the

number of people with dementia in India 1 would need to be revised upwards by a factor of 2.8 4, from 1.8 to 4.9 million for 2005, and from 6.3 to 17.5 million for 2040.

There are at least three mechanisms by which misclassification might have occurred in the application of the DSM-IV criteria 4, 22; 1) objective cognitive impairment may be less likely to lead to noticeable impairment in the performance of normal social roles, because of the high levels of instrumental support routinely provided to all older people, 2) impairment/ decline may have been noted by informants, but they may have been reluctant to disclose this because of the culture of respect towards older people, or 3) impairment/ decline may have been noted, but attributed to 'normal ageing'. We have recently completed a qualitative study of family informants in Chennai which may cast further light on these processes.

It is important to note that our observations of the limitations of the DSM-IV criteria apply to the specific context of survey methodology, with structured assessments and highly standardised diagnostic algorithms. It is unclear how much these concerns would apply to routine clinical practice. Skilled and experienced clinicians would perhaps be more able to tease out through detailed patient and informant interviews the nature and extent of any decrements in performance consequent upon any cognitive impairments identified through formal testing. However, the social and occupational functioning criterion in DSM-IV has always been controversial. Evidently, it is difficult to operationalise, particularly across cultures. Such pitfalls are implicitly recognised in the guidelines attached to the ICD-10 classification 23, which state:

"Dementia produces an appreciable decline in intellectual functioning, and usually some interference with personal activities of daily living, such as washing, dressing, eating, personal hygiene, excretory and toilet activities. How such a decline manifests itself will depend largely on the social and cultural setting in which the patient lives. Changes in role performance, such as lowered ability to keep or find a job, should not be used as criteria of dementia because of the large cross-cultural differences that exist in what is appropriate, and because there may be frequent, externally imposed changes"

Those involved in the development of the new DSM V criteria have highlighted the need for substantial revision of existing dementia diagnostic criteria, stating that "the boundaries between healthy ageing, MCI and dementia are the subject of much debate" 24. The current requirement for clear evidence of functional decline ensures high specificity, and may well be adequate for the identification of more advanced dementia cases. We suspect that a more sensitive set of criteria might ultimately be based around identification of either progressive cognitive decline, or functional decline, possibly backed up by suggestive changes in biomarkers. We also suspect that many specialist diagnostic centres already in effect practice such an approach to facilitate early diagnosis. The clinical validity of such early diagnoses will, again, be best established through empirical observation of their predictive characteristics. 10/66 follow-up studies are now in the field in China, Cuba, Dominican Republic, Peru and Mexico, which, once completed, will provide further evidence on the predictive validity of the 10/66 dementia diagnosis.

Acknowledgments

This study was funded by the Wellcome Trust as a Health Consequences of Population Change Programme Master's level fellowship for A.T. Jotheeshwaran (GR081343). The baseline phase of the project was supported by the World Health Organisation. The Rockefeller Foundation supported our dissemination meeting at their Bellagio Centre. Alzheimer's Disease International has provided support for networking and infrastructure.

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Table 1

diagnosis.
baseline
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up,
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Status

Status at follow up	Could not be traced	Traced at fo	llow up		Died (among those who
Diagnostic group at baseline		Deceased	Not available for interview	Re- interviewed	courd be traced)
Non- amnestic MCI (N=101)	21 (20.8%)	17 (16.8%)	3 (3.0%)	60 (59.4%)	17/80 (21.3%)
Cognitive impairment (N=59)	19 (32.2%)	8 (13.6%)	2 (3.4%)	30 (50.8%)	8/40 (22.5%)
Amnestic MCI (N=33)	7 (21.2%)	7 (21.2%)	2 (6.0%)	17 (51.5%)	7/26 (26.9%)
Dementia (N=75)	21 (28.0%)	25 (33.3%)	5 (6.7%)	24 (32.0%)	25/54 (46.3%)
All groups (N=268)	68 (25.4%)	57 (21.3%)	12 (4.4%)	131 (48.9%)	57/200 (28.5%)

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Baseline characteristics of participants interviewed and not interviewed in the follow-up phase

		Cogni	live impairmer	1			ementia	
Characteristic	All (n=193)	Re- examined (n=107)	Not re- examined (n=86)	Statistical test for re-examined vs. not re-examined	All (n=75)	Re- examined (N=24)	Not re- examined (n=51)	Statistical test for re-examined vs. not re-examined
Age (mean)	71.2 (5.5)	71.1 (5.2)	71.3 (5.7)	T=0.3, 190 df, p=0.80	75.3 (8.1)	75.3 (8.5)	75.5 (7.5)	T=-0.1, 73 df, p=0.93
Female Gender	103 (54.2%)	56 (52.3)	47 (56.6%)	Chi sq = 0.2 , 1 df, p= 0.66	47 (62.7%)	18 (75.0%)	29 (56.9%)	Chi = 1.6 , 1 df, p= 0.21
Education								
None	75 (39.1%)	41 (38.3%)	34 (40.0%)	Chi sq=0.0, 1 df,	44 (58.7%)	15 (62.5%)	29 (56.9%)	Chi sq = $0.6, 1$
Some	49 (25.5%)	28 (26.2%)	21 (24.7%)	p=0.80	9 (12.0%)	3 (12.5%)	6 (11.8%)	dI, p=0.40
Primary	33 (17.2%)	18 (16.8%)	15 (17.6%)		19 (25.3%)	6 (25.0%)	13 (25.5%)	
Secondary or tertiary	35 (18.2%)	20 (18.7%)	15 (17.6%)		3 (4.0%)	0 (0.0%)	3 (5.9%)	
Number of limiting physical impairments								
None	109 (56.5%)	64 (59.8%)	45 (52.3%)	Chi sq = $0.0, 1$ df, p= 0.90	49 (65.3%)	15 (62.5%)	34 (66.7%)	Chi sq = $0.3, 1$ df, p= 0.59
One or two	74 (38.3%)	36 (33.6%)	38 (44.2%)		24 (32.0%)	8 (33.3%)	16 (31.4%)	
Three or more	10 (5.2%)	7 (6.5%)	3 (3.5%)		2 (2.7%)	1 (4.2%)	1 (2.0%)	
CSI'D' COGSCORE	27.6 (4.3)	28.3 (3.1)	26.6 (5.3)	T=-2.7 131.8 df, p=0.008	20.5 (7.5)	21.9 (5.9)	19.9 (8.1)	T=-1.1, 73 df, p=0.27
CERAD 10 word list recall	2.8 (2.1)	3.0 (2.1)	2.5 (2.0)	T=-1.8, 191 df, p=0.08	1.0 (1.3)	1.2 (1.5)	0.9 (1.2)	T-0.8, 73 df, p=0.45
CSTD' RELSCORE	(6.0) 6.0	1.0 (0.9)	0.8 (0.9)	T=1.6, 191 df, p=0.11	3.6 (3.5)	3.6 (2.5)	3.6 (3.9)	T=0.0, 73 df, p=0.99
WHODAS II disability score	9.3 (11.6)	8.2 (10.8)	10.6 (12.4)	T=1.4, 189 df, p=0.15	23.4 (22.7)	13.8 (15.4)	27.9 (24.2)	T=3.1, 66.2 df, p=0.003

Change in Clinical Dementia Rating (CDR) from baseline to follow up for 10/66 dementia cases (n=24)

CDR at FU	No dementia	Questionable	Mild	Moderate/
CDR at Baseline				severe
No dementia	0	2	0	0
Questionable	0	10	5	2
Mild	0	1	0	4
Moderate/ severe	0	0	0	0

Change in needs for care from baseline to follow up for 10/66 dementia cases (n=24)

Needs for care at follow-up	Does not	Needs care	Needs care
Needs for care at baseline	need care	time	time
Does not need care	3	15	2
Needs care some of the time	0	1	1
Needs care much of the time	0	1	1

Changes from baseline in cognitive function, informant reports of cognitive and functional impairment, and disability compared between those with dementia and those with cognitive impairment but no dementia

	Baseline mean (SD)	Follow-up mean (SD)	Paired t-test for difference between baseline and follow-up	t-test for difference in change score between cognitive impairment and dementia groups
CSI'D' COGSCORE				
Cognitive impairment no dementia (N=107)	28.3 (3.1)	26.3 (5.1)	-2.0 (-2.9 to -1.1) P<0.001	
All dementia cases (N=24)	21.9 (5.9)	14.6 (8.8)	-7.4 (-10.9 to -3.9) P<0.001	-5.4 (-9.0 to -1.8) T=-3.1, df=26.5, p=0.005
10/66 dementia cases not confirmed by DSM-IV (n=22)	22.4 (6.0)	15.7 (8.3)	-6.7 (-10.3 to -3.0)	-4.7 (-8.4 to -0.9) T=5.8 df=24.0, p=0.02
Total (N=131)	27.2 (4.5)	24.2 (7.5)	-3.0 (-2.0 to -4.0) P<0.001	
CERAD 10 word list recall				
Cognitive impairment no dementia (N=107)	3.0 (2.1)	3.9 (2.1)	0.9 (0.3 to 1.4) P=0.001	
All dementia cases (N=24)	1.2 (1.5)	1.4 (1.6)	0.3 (-0.7 to 1.2) P=0.58	-0.6 (-1.7 to 0.5) T=1.0, df 129, p=0.30
10/66 dementia cases not confirmed by DSM-IV	1.3 (1.5)	1.6 (1.6)	0.3 (-0.7 to 1.3)	-0.7 (-1.8 to 0.5) T=1.1 df 130, p=0.26
Total (N=131)	2.7 (2.1)	3.4 (2.2)	0.7 (0.3 to 1.2) P=0.001	
CSI 'D' RELSCORE				
Cognitive impairment no dementia (N=138)	1.0 (0.9)	1.7 (2.9)	0.7 (0.1 to 1.2) P=0.01	
All dementia cases (N=48)	3.6 (2.9)	5.7 (4.7)	2.1 (1.1 to 3.1) p<0.001	1.4 (0.4 to 2.5) T=-2.5, 73.9 df, p=0.02
10/66 dementia cases not confirmed by DSM-IV (n=43)	3.0 (2.1)	4.8 (3.7)	1.7 (0.7 to 2.8) P=0.002	1.1 (0.0 to 2.2) T=-1.9, 179 df, p=0.05
Total (N=186)	1.7 (2.0)	2.7 (3.9)	1.0 (0.6 to 1.5) p<0.001	
WHODAS II disability score				
Cognitive impairment no dementia (N=103)	8.2 (10.8)	13.2 (16.3)	5.1 (1.5 to 8.6) P=0.005	
All dementia cases (N=19)	13.8 (15.5)	30.0 (23.5)	19.4 (9.3 to 29.6) P=0.001	14.4 (5.2 to 23.6) T=-3.1, 120 df, p=0.002
10/66 dementia cases not confirmed by DSM-IV (n=18)	11.1 (10.2)	28.4 (23.1)	17.3 (7.6 to 27.0) P=0.002	12.2 (2.9 to 21.5) T=2.6, 119 df, p=0.02
Total (N=122)	9.2 (11.9)	15.8 (18.5)	7.3 (3.9 to 10.8) P<0.001	