

Informant questionnaires as screening measures to detect dementia

A pilot study in the South African context

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Objectives. There is currently no appropriate cognitive screening test available to diagnose dementia cross-culturally in South Africa. The aim of this pilot study was to investigate the efficacy of an informant questionnaire in detecting cognitive decline in the elderly.

Design. The Détérioration Cognitive Observée (DECO), an informant questionnaire previously used abroad, was administered to relatives of elderly patients. Relatives were also asked a series of open-ended questions about the patient's cognitive abilities and behaviour. The DECO results were compared with patients' scores on the Mini-Mental State Examination (MMSE), the cognitive measure currently used to assess a patient's level of cognitive decline, as well as with the clinicians' diagnosis.

Setting. The interviews were completed at the Groote Schuur Hospital Geriatric Clinic during the months of May and June 1994.

Subjects. The subjects were patients ($N = 20$) and their relatives ($N = 20$) attending the Geriatric Clinic.

Results. DECO scores correctly predicted normal functioning in 7 patients and dementia in 8. The DECO scores correlated with the MMSE scores ($r = 0.625$; $P < 0.01$) and MMSE scores correlated with the clinicians' diagnosis ($\chi^2 = 0.114$; $df = 1$; $P = 0.73$). Open-ended questions confirmed the clinicians' diagnosis.

Conclusion. The DECO was found to predict dementia correctly in all but the severely demented patients. As the DECO appears to be a suitable alternative to cognitive testing, it should be considered as a possible screening measure for dementia in elderly people in South Africa.

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Instruments currently used in South Africa to determine cognitive decline have been developed for the assessment of culturally homogeneous Western populations, and it therefore cannot be assumed that they are testing universal

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abilities.¹ These measures are in fact testing specific, learnt abilities that people develop through formal Western education, and their applicability to populations in non-Western countries is highly questionable.

The cognitive screening measure most commonly used by South African clinicians to determine the cognitive status of elderly patients is the Mini-Mental State Examination (MMSE),² despite the fact that studies have shown that it is educationally biased and that education level contributes significantly to variations in MMSE scores.³⁻⁵ Three items on the MMSE have literacy requirements, and failure on these items result in scores below the standard cut-off score for dementia.

Given that 50 - 60% of the population is illiterate,⁶ it is understandable that clinicians in South Africa have found the MMSE inadequate for clinical use and for cross-cultural research. It is expected that for at least the next few decades a significant proportion of the elderly will remain illiterate. Consequently, it is imperative that alternative measures are developed that do not prejudice unschooled/illiterate people.

The purpose of this pilot study was to evaluate the use of an informant questionnaire, the Détérioration Cognitive Observée (DECO), to detect cognitive decline in literate, semi-literate and illiterate elderly people in South Africa. Informant questionnaires have the advantage of gaining direct information about decline in everyday functioning over time as observed by relatives who know the elderly person well. In contrast, cognitive screening tests provide no historical information and serve at best as an indirect technique to estimate likely daily functioning. Abilities measured on currently available screening tests may have little or no direct bearing on an unschooled individual's daily activities.

Methods

Subjects

The subjects were patients ($N = 20$) and relatives ($N = 20$; 1 per patient) attending the Geriatric Outpatient Clinic at Groote Schuur Hospital, Cape Town, during May and June 1994. Patients and relatives (informants) were chosen randomly, the only criterion being that the relative had been in frequent contact with the patient for at least the preceding 3 years.

Of the patients, 12 were female and the age range was 60 - 88 years. The level of education was known to the informants in 17 cases: 1 patient had received no schooling and was illiterate, 8 had 4 - 7 years of schooling, and 8 had 8 - 12 years.

Nineteen relatives were female, the age range was 20 - 75 years, and education ranged between 6 and 12 years of schooling. Five subjects had 8 or less years of schooling. All informants gave informed consent for the research interview.

Assessment instruments

1. The MMSE.

2. The DECO. The DECO was developed by Ritchie and Fuhrer.^{7,8} They based items of the DECO on retrospective data from 147 interviews and items from the Blessed Scale,

the Camdex Family Interview and the Informant Interview. The DECO was chosen for this study because it has high internal consistency and high test-retest reliability. Further, it has been well validated within a case-control study using the *DSM-III (R)* and Clinical Rating Criteria.^{7,8} In addition, receiver operating statistics were used to demonstrate its criterion validity. The DECO was as effective as the MMSE and the IOWA Test (which consists of three subtests of the Benton Battery: Orientation, Visual Retention and Verbal Fluency) in early case identification. Most importantly, results were not significantly influenced by education or place of residence in the validation studies.⁷ The DECO is a 19-item questionnaire with a 3-point Likert scale (Fig. 1) ranging from 'better or about the same' to 'much worse'. The questionnaire is completed by a relative of the patient and asks about changes in memory, language, visuo-spatial skills, praxis and activity level over the past year, thus covering domains implicated in dementia.

	better or about the same	not as well	much worse
Does he/she remember as well as before which day of the week and which month it is?			
When he/she goes out of the house, does he/she know her way around as well as before?			

Fig. 1. Items from the DECO.

The DECO items are scored 2 for 'better or the same', 1 for 'not as well' and 0 for 'much worse'. The highest score on the DECO is 38 and the minimum is 0, with lower scores indicating a decrease in performance. In the validation study⁷ a cut-off score of 30 was used, giving the DECO a specificity of 90% and a sensitivity of 89%.

After translation into Afrikaans by the second author, the DECO was back-translated by the third author to ensure that the meaning of items had not been changed. When there was disagreement, consensus was reached between the two translators.

3. Ten open-ended questions were added to investigate relatives' knowledge of dementia and to gain additional information regarding their observations of cognitive and behavioural changes in the patients. This supplementary information was intended as data for possible substitute items should items on the DECO prove to be non-discriminating in the local context.

Procedure

The DECO and the open-ended questionnaire were administered by the first author to each informant in an individual interview. Although the DECO is usually self-administered, it was decided to read the items (in the informant's mother tongue) and record responses in order to prevent problems which could occur because respondents were poorly educated or illiterate. Twenty-two interviews

were completed, and owing to missing hospital files, 20 of these were later used for analysis.

The MMSE is routinely administered in the Geriatric Clinic. A minor alteration in procedure is made in this clinic to improve its diagnostic properties: a third option is presented for the most educationally biased item, Serial Sevens or the spelling of 'world' backwards. Patients are asked to repeat 'Every dog has its day' (Afrikaans: 'Elke hond kry sy dag') and then asked to say this backwards. The best score of the three options (maximum score = 5) is included in the total score. The MMSE is often criticised for lack of standardised scoring procedures. To minimise subjectivity in scoring patients' copies of the pentagons, clear guidelines are provided on the answer sheet. The suggested cut-off score of 24/30 is used to diagnose dementia.²

At the time of the interview, the administrator was blinded to both measures; the MMSE scores and clinicians' diagnosis were retrieved from patients' folders on completion of the interviews.

The DECO and MMSE scores were subjected to statistical analysis using Pearson's product-moment, Pearson's biserial, and partial and semi-partial correlations.³ Partial and semi-partial analyses were done to correct for possible false-negative or false-positive scores on the DECO. A third variable (correct diagnosis) was created; each patient was given a score of 1 if demented and 0 if not demented, based on the three measures, the DECO, the MMSE and the clinicians' diagnosis. The correlation matrix of variable one (MMSE scores), variable two (DECO scores) and variable three (correct diagnosis) was then calculated (Pearson's product-moment and Pearson's biserial correlations). Further, the patients' level of education was correlated with MMSE scores (Pearson's product-moment correlation), while the association between the clinicians' diagnosis and MMSE scores was examined using Pearson's chi-squared test.

Results

Of the 20 patients included in the sample, 8 received a score below 30 on the DECO (Fig. 2). Fourteen patients obtained scores less than 24 on the MMSE (including 4 patients who were untestable and received scores of 0). The clinicians diagnosed 13 patients as demented; 9 as having possible multi-infarct dementia and 4 as having possible senile dementia of the Alzheimer type.

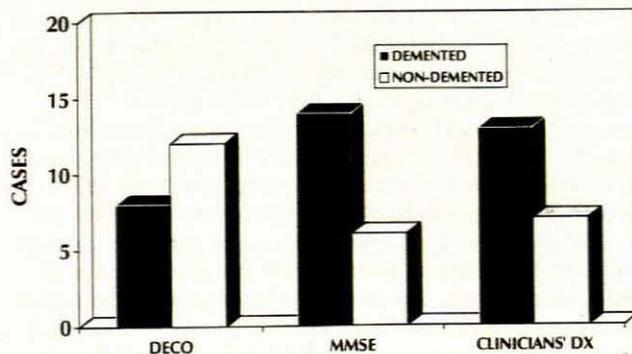


Fig. 2. Graphs showing number of patients classified as demented and non-demented on the DECO and the MMSE and by clinicians' diagnosis.

One patient who scored below the cut-off score on the MMSE was deaf and illiterate. Both the DECO and the clinician diagnosed him as cognitively intact. Five patients who were diagnosed as normal on the DECO were diagnosed as demented by both the MMSE scores and the clinicians' diagnosis. These false negatives on the DECO occurred in patients who were severely demented and had shown no change over the past year.

In the partial correlation analysis, variable three was partialled out from variable one (MMSE scores) and variable two (DECO scores). The correlation between the MMSE and the DECO was statistically significant ($r = 0.713$; $P < 0.01$). In the semi-partial correlation, variable three (correct diagnosis) was only excluded from variable two (DECO scores) and the correlation was found to be statistically significant ($r = 0.625$, $P < 0.01$). The semi-partial correlation was seen to be the more reliable indicator of the relationship between the DECO and MMSE scores.

To ensure that patients had not been misdiagnosed on the MMSE due to their level of education, MMSE diagnosis was tested against the clinicians' diagnosis. Chi-squared analysis of results showed that the null hypothesis of no association between these diagnostic measures could not be rejected ($\chi^2 = 0.114$; $df = 1$; $P = 0.73$).

Finally, the patients' level of education was correlated with MMSE scores using Pearson's product-moment correlation. There was no correlation between education and MMSE scores ($r = 0.235$; $P > 0.01$).

Discussion

In comparing DECO scores with patients' MMSE scores and the diagnosis of the clinicians, this study has shown that the DECO informant questionnaire correctly predicts normal cognitive functioning in non-demented patients, and mild to moderate dementia in cognitively impaired patients. The DECO was found to be insensitive in detecting severe dementia in patients who had reached a plateau. This is because of the relatively short time (1 year) over which relatives were required to comment on cognitive and behavioural changes on this instrument. Researchers in other studies have attempted to overcome this problem by asking informants to compare their relative's current performance over a longer time period. On the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE),¹⁰ for example, informants are asked to compare subjects' present performance with their performance 10 years ago, but this has created problems for a few reasons. Firstly, researchers have found it difficult to locate relatives who have been in close contact with the patient for that length of time.¹⁰ Secondly, relatives are hard-pressed to remember a person's performance 10 years previously.

The problem of misclassifying severely demented patients was noted by the authors of the DECO in the validation study.⁷ However, they correctly point out that severe cases are easy to recognise clinically, and in field studies, adding a few general health questions in the data-gathering interview will identify such cases. Since the mildly to moderately demented subjects are more difficult to identify both clinically and in epidemiological studies, an instrument that is sensitive at this end of the spectrum is of more value.

Aside from consideration of the 1-year time period, the DECO seems preferable to other informant questionnaires because of the shortness of the 3-point Likert scale. The IQCODE has a 5-point scale. A 3-point scale was considered to be less daunting, and consequently more user-friendly. However, the 3-point scale was confusing to some informants, requiring repetition of instructions with every question. This can be attributed to two factors, the respondents' possible unfamiliarity with scales of this type, and the fact that the questionnaire was administered verbally; instructions were not constantly visible to the informants as when self-administered. In collaboration with the author of the DECO, it was decided that in future studies, after reading each item, respondents will be asked whether there is a change in that function, and only if so will they be asked whether this is a 'little change' or a 'big change'. This method has been shown to be a satisfactory alternative when respondents have visual impairments (K. Ritchie — personal communication). Despite the above problems, all respondents in this sample responded favourably to the DECO, regardless of their level of education or literacy level.

Given the high illiteracy rate and widespread poverty in this country, informant questionnaires developed for local use in cross-cultural studies in dementia should fulfil at least two requirements: (i) they must be effective when either the informant or the person under investigation, or both, are illiterate; and (ii) they must be equally effective across the socio-economic spectrum of this society. Admittedly, no informant in this opportunity sample had less than 6 years of education; all could read and write. Although the validation study showed that the DECO is not educationally biased,⁷ we suspect that most respondents in the study had at least some education (education was reported as less than 8 years and more than 8 years), as did respondents in our study. The efficacy of the DECO when the informant cannot read or write and is entirely unschooled still needs investigation.

The DECO was shown to be more effective than the MMSE in one illiterate patient in this sample. He obtained a score of 18/30 on the MMSE. In contrast, his high score of 36 on the DECO correctly classified him as cognitively intact. The absence of dementia was confirmed by the clinicians' diagnosis.

Contrary to our expectations, there was no correlation between MMSE scores and education level. It is not clear whether this was due to the alternative to the Serial Sevens or spelling of 'world' backwards item provided, the small sample size (4 patients who were unable to complete the MMSE were given scores of 0), or the fact that virtually all patients had at least some schooling. It is often erroneously assumed that educational level is a continuous variable; however, there is a measurable difference in MMSE test performance between people who have remained at school long enough to acquire basic literacy, and those who have not.¹¹

Since approximately 45% of the South African population lives below the minimum living level,⁶ it was predicted that several items on the DECO would not be applicable to some patients because they assume that subjects own or have access to luxury items. However, these did not present a problem in this study. One item gave the option of remembering either his/her telephone number or address,

and informants chose whichever was applicable. On another item, which concerned the use of household appliances such as the washing machine, informants spontaneously substituted appliances such as the kettle, stove or iron for the example given. (The example of the washing machine was, however, not applicable in one particular case, in which the male patient had never used such an appliance.) In future versions of the DECO, when applied to the South African population, this item should be modified to include simpler appliances used by both sexes.

It was further anticipated that the item that refers to a change in the ability to write letters for business or to friends might be problematic. This was true in 6 cases. However, in only 1 case was this attributable to illiteracy. In the remaining 5 cases the reasons were that the patient was retired from work, did unskilled (domestic or factory) work that did not require him/her to write business letters, or lived in a close community with family and friends and therefore did not need to communicate by writing letters. When the patient was illiterate, or never wrote letters, the item was scored as 'better or the same', as prescribed by the compilers of the DECO prior to the study (K. Ritchie — personal communication).

Finally, 5 respondents did not understand the question dealing with alterations in activity level. The reason for this was a combination of the way the question is phrased and the complex terms used (e.g. 'reduction in activity level'). This item needs modification. It is a particularly important item, as it is the only item on the DECO which assesses behavioural changes such as apathy. Changes in behaviour and mood state are poorly covered in the DECO. Responses to the open-ended questions suggest that informants are particularly aware of such changes. Ten of the respondents regarded mood and behavioural changes as salient features of the patient's decline in everyday functioning.

The usefulness of a standardised instrument administered to relatives was confirmed during the semi-structured interview. The open-ended questions revealed that although relatives tended to have a generally poor understanding of the clinical concept of dementia, all were clearly aware of the changes in the patient's everyday functioning.

This study has shown that the DECO, with minor modifications, may prove to be a useful instrument to diagnose dementia cross-culturally within South Africa. The fact that it was developed in an European country facilitates cross-national comparison. However, in order to do so, the item with literacy requirements discussed above will have to be retained and scores adjusted accordingly when illiterate elderly people are assessed. This means that scores may be falsely inflated in some instances. Consequently, the cut-off score used in previous studies may not be optimal. However, as with all measures used in a population other than for the one for which it was intended, the DECO needs to be validated in a community study for the South African population and the most effective cut-off score determined by using receiver operating statistics. Test performance may be lower if an assessment instrument is administered in an institutional setting.⁷ The fact that interviews were conducted in a hospital clinic could have affected scores on the DECO, as informants were often observed to be nervous before the clinical consultation. Future studies on the DECO should be conducted in the informant's home environment.

Conclusion

Despite its European origin, the DECO was found to be well accepted in this pilot study and to be a sensitive instrument to diagnose mild and moderate dementia. Further investigations among community-based populations, with minor modifications, appear justified.

REFERENCES

1. Ardila A, Rossellii M, Rosas P. Neuropsychological assessment in illiterates: visuospatial and memory abilities. *Brain Cogn* 1989; **11**: 147-166.
2. Folstein MF, Folstein SE, McHugh P. Mini-mental state: a practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res* 1975; **12**: 189-198.
3. Fillenbaum GG, Hughes DC, Heyman A, George LK, Blazer DG. Relationship of health and demographic characteristics to Mini-Mental State Examination score among community residents. *Psychol Med* 1988; **18**: 719-726.
4. Jagger C, Clarke J, Anderson T, Battock T. Misclassification of dementia by the Mini-Mental State Examination — are education and social class the only factors? *Age Ageing* 1992; **21**: 404-411.
5. O'Connor DW, Pollitt PA, Treasure FP, Brook CPB, Reiss BB. The influence of education, social class and sex on Mini-Mental State scores. *Psychol Med* 1989; **19**: 771-776.
6. Dawes A, Donald D. Understanding the psychological consequences of adversity. In: Dawes A, Donald D, eds. *Childhood and Adversity*. Cape Town: David Phillips, 1994: 1-27.
7. Ritchie K, Fuhrer R. A comparative study of the performance of screening tests for senile dementia using receiver operating characteristics analysis. *J Clin Epidemiol* 1992; **45**: 627-637.
8. Ritchie K, Fuhrer R. The development and validation in France of a screening test for senile dementia. *Rev Geriatr* 1994; **19**: 223-242.
9. Kerlinger FN, Pedhazur EJ. *Multiple Regression in Behavioural Research*. New York: Holt, Rinehart & Winston, 1973: 81-93.
10. Jorm AF, Scott R, Cullen JS, MacKinnon AJ. Performance of the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) as a screening test for dementia. *Psychol Med* 1991; **21**: 785-790.
11. De Villiers JC. Problems in assessment procedures in the local context. Paper presented at the Annual Conference of the Neurology Association of South Africa, Cape Town. 10-12 March 1994.

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