#### SPECIAL ARTICLE

# Practical issues in cognitive screening of elderly illiterate populations in developing countries. The Indo-US Cross-National Dementia Epidemiology Study

V. Chandra<sup>1,3</sup>, M. Ganguli<sup>2,3</sup>, G. Ratcliff<sup>2,5</sup>, R. Pandav<sup>1</sup>, S. Sharma<sup>1</sup>, S. Belle<sup>3</sup>, C. Ryan<sup>2</sup>, C. Baker<sup>4</sup>, S. DeKosky<sup>2</sup>, and L. Nath<sup>6</sup>

<sup>1</sup>Center for Aging Research in India, New Delhi, India, <sup>2</sup>School of Medicine, Department of Psychiatry, <sup>3</sup>Graduate School of Public Health, <sup>4</sup>Office of Measurement and Evaluation, and School of Education, <sup>5</sup>Health South Harmarville Rehabilitation Hospital, University of Pittsburgh, Pittsburgh, Pennsylvania, U.S.A., <sup>6</sup>Center for Community Medicine, All India Institute of Medical Sciences, New Delhi, India

ABSTRACT. The study of the epidemiology of dementia. specifically Alzheimer's disease, in developing countries requires specialized instruments and personnel. Cultural and sub-cultural differences among populations are highly relevant to the design of such instruments. Over and above the cultural issues. it is widely recognized that low education and illiteracy pose considerable challenges to reliable and valid cognitive screening. The overall objectives of the Indo-US Cross-National Dementia Epidemiology Study were: a) to determine the prevalence and incidence of, and risk factors for, Alzheimer's and other dementias in a defined Indian community; and b) to compare these results with those found in a defined American community. To achieve these epidemiological objectives, our first task was to develop, systematically and empirically, suitable cognitive and activities assessment screening instruments for use in India, which would 1) be culturally fair, psychometrically sound, and valid for a population with little or no education; 2) be optimally sensitive and specific for dementia; and 3) allow not only the identification but also the more detailed characterization of dementia, and of normal and abnormal cognitive aging. In this paper we address the practical issues involved in the development and administration of the modified cognitive screening battery in our rural Indian context. (Aging Clin. Exp. Res. 10: 349-357, 1998)

<sup>©</sup>1998. Editrice Kurtis

#### INTRODUCTION

A growing number of research groups are developing new or significantly modified tests for the assessment of cognitive function in elderly populations around the world. Cultural and sub-cultural differences among populations are highly relevant to the design of such instruments. Over and above the cultural issues, it is widely recognized that low education and illiteracy pose considerable challenges to reliable and valid cognitive screening.

In a previous report, we discussed the general principles of studying dementia epidemiology in developing countries, and of making cross-cultural comparisons between developed and developing countries (1). We addressed the conceptual and methodological problems likely to be encountered in cognitive screening. We also reported descriptions of, and norms for, the cognitive screening instruments developed for an ongoing study in Northern India, the Indo-US Cross-National Dementia Epidemiology Study (2, 3). This is a collaborative project between the University of Pittsburgh and the Center for Aging Research in India (CARI), and is funded by the National Institute on Aging (NIA), US Department of Health and Human Service. The overall objectives of the project are: a) to determine the prevalence and incidence of, and risk factors for, Alzheimer's and other dementias in a defined Indian community; and b) to compare these results with those found in a defined American community.

Key words: Alzheimer's disease, cognitive screening instrument, dementia, developing countries, epidemiology. Correspondence: V. Chandra, M.D., Ph.D., Center for Aging Research, F-1/3, Vasant Vihar, New Delhi 110 057, India. Received and accepted April 15, 1998.

To achieve these epidemiological objectives, our first task was to develop, systematically and empirically, suitable cognitive and activities assessment screening instruments for use in India, which would:

- a) be culturally fair, psychometrically sound, and valid for a population with little or no education;
- b) be optimally sensitive and specific for dementia;
- c) allow not only the identification, but also the more detailed characterization of dementia, and of normal and abnormal cognitive aging; and
- d) allow meaningful cross-national comparisons with an ongoing study of the epidemiology of dementia in a rural community in the U.S.A.

#### STUDY SITES AND POPULATIONS

Rural site in Ballabgarh, India

The community being studied is near the town Ballabgarh which is 22 miles from New Delhi. India. It consists of 28 villages which are generally representative of rural Northern India in terms of socioeconomic status, literacy, caste, age and gender distribution. The majority of elderly community members have no formal education and are illiterate. The language spoken is the Haryanvi dialect of Hindi, an Indo-European language written in Devanagiri script and pronounced phonetically.

The community receives its health care from the Center for Community Medicine of All India Institute of Medical Sciences (AIIMS) and participates in several ongoing research projects with minimal if any refusals. The elderly are not burdened by other research projects and appear happy to participate, a situation strikingly different from that experienced by epidemiologists conducting community surveys of the elderly in developed countries. Thus, the Ballabgarh study population, already defined and enumerated and with a history of cooperation with research, is an ideal community for an epidemiological study of rural Indian elderly.

A study of dementias in this population is particularly interesting scientifically because of the many unique features of this population. The elderly are largely illiterate, which has widely been reported as a risk factor for dementia and AD (4). They do not consume medications such as non-steroidal anti-inflammatory drugs (5), estrogen supplements (6), anti-oxidants (7), which are reported to be "protective" factors for AD. They do not smoke cigarettes as in western countries but instead smoke "bidi" (tobacco rolled into a plant leaf) and "hookah" (in which tobacco smoke is filtered through rose water before inhaling). In some studies (8-10), smoking has also been found to be a "protective" factor for AD. Thus,

a study of this population which smokes a different kind of tobacco product can further elaborate on this association.

The first phase of the study, which involved developing instruments for cognitive screening, functional capability in activities of daily living, and a protocol for clinical assessment of suspected dementia, was conducted between July 1, 1991 and January 1995. The instruments developed are currently being used in an ongoing study to determine the prevalence and incidence of dementias in this population. 5126 subjects aged 55 years and older have been selected for study (53.1% males). Each subject will be administered a cognitive screening instrument, and a next-of-kin will be administered an Activities of Daily Living assessment questionnaire (11). Subjects performing poorly on either of these instruments will be referred to a team of clinicians for intensive evaluation to determine if they are demented, and if so the cause of the dementia.

#### Site near Pittsburgh, U.S.A.

A requirement of the NIA "Cross-national Investigations of Dementia Epidemiology" grant program under which we were funded was that epidemiological data from our study population had to be compared to data from a reference population in the U.S. (12). Our Ballabgarh study was designed to be compared to a study in the Monongahela Valley. The Monongahela Valley Independent Elders Survey (MoVIES) is an ongoing prospective study of dementia epidemiology in a rural Southwestern Pennsylvania blue-collar community, approximately 25 miles south of Pittsburgh (13). The MoVIES project is linked with the University of Pittsburgh Alzheimer's Disease Research Center (ADRC), and uses assessment protocols adapted from the ADRC and from CERAD, the Consortium to Establish a Registry for Alzheimer's Disease, a multicenter data-pooling project (14), both funded by the NIA.

# ISSUES IN SELECTION AND TRAINING OF PERSONNEL TO ADMINISTER THE SCREENING BATTERY

In developed countries, neuropsychological tests are administered by qualified neuropsychologists who are highly trained. Such personnel are scarce in developing countries, and a practical approach is to use lay workers who are specially trained to administer such tests. Their performance will depend entirely on their training, and on the clarity and specificity of the project's operational procedures, rather than pre-existing knowledge of, or sophistication in, neuropsychological testing or research methodology.

#### Recruitment of personnel

In our project, Field Workers were hired from those who had previously worked in public health projects of the Comprehensive Rural Health Services Project of AIIMS within the same community, and were residents of the Ballabgarh community. They were required to be fluent in Hindi and Haryanvi (local dialect of the state of Haryana) in reading and writing. Thus, they were familiar with the area and the language, and acceptable to the community. A minimum education of 10th grade was required. They could all read English easily, while their spoken English was limited. This knowledge of English was helpful to the project scientists during the development phases of the cognitive screening test for the translation of instruments written in English employed in the MoVIES project for use at the Indian site. In addition. Field Workers were selected based on their demeanor and interpersonal style, such that they would be likely to interact appropriately with elderly individuals and their family members.

#### Training of Field Workers for test administration

Trained neuropsychologists even in developed countries are required to administer tests in a standard fashion. However, they are assumed to be able to exercise some judgement at the time of conducting the interview, and can be trained to score tests reliably. If lay health workers are used, it is necessary to reduce reliance on the Field Worker's judgement to an absolute minimum by making the rules for administration as explicit as possible, and by including instructions for dealing with all foreseeable situations that might arise during testing, so that standardized responses are given to each situation. This attempts to maximize inter-rater reliability.

We prepared a detailed instructions manual in the form of an elaborate "script" to allow Field Workers to administer the tests reliably and consistently. The manual was modified during the instrument development and staff training phases of the project. Feedback from the Field Workers themselves was valuable to the process. The manual was translated into the local language/dialect both for ease of comprehension by the staff, and to avoid their providing subjects with idiosyncratic translations of the instructions. The instructions manual contained all the variations permitted in test administration, and the appropriate response to a number of potential behaviors on the part of the subject.

No further deviation from the instructions manual was permitted. Field Workers were taught not to be tempted to help over and above the clarifications provided in the instructions manual; they were made

to understand that by being "kind" to the subject by offering extra help, they were doing the subject more harm than good. Finally, a consistent style of communication and interpersonal behavior among the interviewers was encouraged.

We developed a close understanding between Field Workers and project scientists. In most developing countries, scientists (particularly physicians) are held in high esteem, and community workers maintain a respectful distance because of the social hierarchy. We ensured that the Field Workers felt that they had access to the scientists, rather than being intimidated. At the same time, Field Workers were instructed not to speak or behave in a condescending or intimidating manner with subjects or other community members.

Lay Field Workers in developing countries generally do not have the skills to score responses. This is better done by an experienced neuropsychologist using clinical experience/judgement within the scoring guidelines developed for the project.

We used the following sequence in the training of Field Workers:

- a) Intensive study of the instructions manual and questionnaires by all Field Workers.
- b) Demonstration of cognitive testing by an experienced clinical neuropsychologist, followed by questions and discussion.
- c) Administration of tests by Field Workers to other project staff. These were observed by the neuropsychologist, and the Field Workers were given feedback by the neuropsychologist.
- d) Administration of tests by Field Workers to community members not participating in the study, under the observation of the neuropsychologist.
- e) A project scientist role-played a particularly difficult subject to be interviewed by the Field Workers.
- f) Establishment of reliability between Field Workers and clinicians.

#### Establishment of reliability

Inter-rater reliability is largely a matter of adequate training and consensus development. During the pilot phases of instrument development, the India-based and U.S.-based neuropsychologists spent extensive periods arriving at a scoring consensus between them. During field-testing, the neuropsychologist and medical officer independently scored the cognitive test forms of the same subjects to establish inter-rater reliability of scoring. Similarly, multiple Field Workers independently completed the test forms of the same subjects to establish inter-rater reliability between themselves. Finally, each subject in the pilot phase was tested by a Field Worker who recorded the subject's responses on a test form. The neuropsychologist observed the same testing, and in-

dependently completed a second form. The Field Worker's form was then scored by the neuropsychologist, while the neuropsychologist's form was scored by the medical officer (R.P.). For 24 out of 30 subjects in this test, agreement was 100% on total HMSE scores; in the remaining six subjects there was a discrepancy of one point, which was related to scoring of the praxis diagram. These discrepancies were resolved by discussion, and further guidelines were added to the operations manual (2).

# ISSUES IN OBTAINING CONSENT TO PARTICIPATE

Voluntary consent must be obtained from all participants and next-of-kin. In our project, a standard consent form was developed, and we followed procedures approved by the Human Volunteers Protection Committees of CARI and the Institutional Review Board (IRB) of University of Pittsburgh. As most subjects were illiterate, they could not read the form for themselves. The form was thus read to them by the Field Worker. It informed them of the objective of the study, the methodology of the study, that they were free to participate or refuse, that there would be no repercussions on them if they refused to participate, adverse effects, if any, of the study, and their right to contact the Project Director of the study for any additional information or clarification.

Each subject and next-of-kin were requested to sign the consent form, or put his/her thumb print on it implying consent to participate. However, many subjects refused to do this, as they could not read the form on which they were putting their thumb print, and being an agricultural society they were concerned that the documents might have something to do with land dealing. So verbal consent to participate was obtained. Moreover, being a questionnaire-based study, answering questions freely implied the subject's willingness and consent to participate. Thus, issues related to consent to participation in research should be carefully worked out in accordance with local customs, as well as international ethical standards.

# ISSUES IN PROVIDING INCENTIVE TO PARTICIPATE

Incentives to participate in research projects are a common practice. Many research programs will provide a token gesture of appreciation to the participants for their time spent in participating. Incentives should not be so large as to coerce the subjects to participate. The amount and type of incentive are usually decided based on the local practice.

In our project, many considerations guided the selection of incentive. Our initial desire was to give

something of use to older subjects, such as a blanket or shoes. However, our local field staff felt that in this conservative society the older people would either give away these items, or store them indefinitely for future use. A cash incentive was considered, but rejected because its direct use to older subjects who have minimal needs is limited, and it might be taken away forcibly by some unscrupulous younger members. We also considered post-cataract eyeglasses, but this proved to be beyond our budget, and also not everyone would need them. Finally, it was decided that we would give a walking stick (cane) to those who needed assistance while walking, vitamins to those in frail health, and simple analgesics to subjects with fever or pain from arthritis at the time of the examination. In addition, we gave all subjects and the next-of-kin a box of sweets as a token of appreciation for their participation. The box of sweets was an appropriate and successful incentive because it is a traditional gift, and was immediately consumed by the entire family. particularly the children, and their enjoyment gave great pleasure to the older subjects.

# ISSUES IN THE ASSESSMENT OF IMPORTANT PARAMETERS INFLUENCING COGNITIVE TESTING

Co-morbidity, such as hearing loss or poor vision, can affect performance in cognitive testing, and must be taken into consideration when administering tests. This issue is particularly important in developing countries where these conditions are not only common, but also uncorrected.

#### Hearing assessment

The method used in our project was for the interviewer to say a sentence in a normal tone, and ask the subject to repeat it. If the subject repeated the sentence verbatim, hearing was assumed to be normal, and the interview proceeded. If the subject did not repeat verbatim, but conveyed the correct message of the sentence, and the Field Worker felt that they didn't repeat verbatim because of a reason other than hearing difficulty, again hearing was assumed to be normal.

If the subject did not repeat verbatim or convey the contents of the sentence, and the Field Worker felt that the reason was due to hearing difficulty or had doubts about the reason, then the volume of speech was raised and the subject was asked to repeat the same sentence. If the subject then repeated the sentence verbatim or its contents, hearing was then assumed to be impaired, and the interview conducted using a louder tone of voice.

If the subject still did not convey the meaning of the

sentence despite a louder tone of voice, and the Field Worker felt hearing loss was substantial, then the cognitive assessment was not completed by the Field Worker, and the subject was referred for clinical assessment by the project scientists.

#### Vision assessment

Vision impairment is extremely common in the elderly in most developing countries. Causes can vary from trachoma to comeal opacity, to cataracts. Frequently, the deficits are not corrected, leading to severe vision impairment. An assessment of vision must be made and taken into consideration in administering tests requiring vision, and also in scoring the responses.

In our project, as most subjects were illiterate, the standard letter chart used to assess vision could not be used. We used a card with the English letter "E" (3" x 2 1/47) printed on it. The card was held at 18 inches, and the subject asked to identify the open side of the "E". If successful, vision was assumed to be normal, and the interview proceeded. If the subject was unsuccessful. the same procedure was repeated at 9 inches. If the subject could identify the open side at 9 inches, vision was considered to be slightly impaired, and all tests requiring vision were conducted holding the test material close to the subject's eyes. If even at 9 inches the subject could not correctly identify the open side of the "E", vision was considered to be too impaired for testing by Field Workers, and the subject was referred to the project scientists for assessment.

In case the subject was untestable by the Field Worker due to substantial vision or hearing loss, the clinicians evaluated the subject by taking a detailed history from the next-of-kin regarding the patients cognitive functioning and performance in the usual activities of daily living. The subject was also observed in his/her home environment as he/she performed the daily household activities. A general physical and neurological examination was performed. For visually impaired subjects, verbal responses to orally presented questions were assessed. For subjects with impaired hearing, responses to visually presented questions usually with the next-of-kin using sign language were assessed. This form of testing highlights the importance of using experienced clinicians for diagnostic evaluation.

# ISSUES IN ASSESSMENT OF AGE AND LITERACY IN RURAL POPULATIONS

Age assessment

In many developing countries, older members of the population do not know their exact dates of birth, and there are no official birth records. We used the pro-

cedure for estimating age by enquiring about "sentinel events", which were well-known historical events or events in the subjects' or family's personal history, such as whether a subject was born before or after a well known national event, a major natural disaster or disease epidemic; or how old he/she was at the time of this event; whether he/she had been married or had started working at the time of the event, etc. Another method used was to determine the age of a subject's adult child, and the subject's age at the time of this child's birth. This was used to estimate the subject's current age.

#### Literacy assessment

In studying the epidemiology of dementia, literacy is an important variable, not only in terms of cognitive function test performance, but also as a potential "risk factor" for Alzheimer's disease as implicated in some studies (4).

A considerable segment of the elderly population in most developing countries is largely illiterate. Very few people have formal education. A few subjects can read and write. Many subjects are able to read, but not to write. Generally, women have had little or no education, as education has not been considered to be useful for women in their role in later life, which was essentially to be a home-maker and sometimes help in the farms.

In assessing education in our project, we first enquired about the level of formal education, if any. Regardless of formal education, they were asked if they were "able to read". In our project, this was defined as the ability to read a paragraph from a local Hindi newspaper. They were also asked if they "could write", which in our project was defined as the ability to write one full sentence, and not just sign their name.

# ISSUES IN SCREENING BATTERY ADMINISTRATION

Preparing for the interview

The interview was conducted in a pre-selected room. In the rural setting, a visit of medical personnel collects a crowd. However, no onlookers or observers were permitted to be present in the room. No watch or wall clock which the subject could see was allowed while the subject was being interviewed. The subject was made to feel comfortable and relaxed. The Field Worker was respectful and considerate of the elderly subject, while at the same time extraneous conversation was discouraged, and strict compliance with the study procedures was gently required. Refreshments (e.g. tea, water) were not permitted to be served dur-

ing the interview, even though it was customary to honor guests by doing so.

Administration of cognitive tests and general rules for recording responses

In testing illiterate subjects who have never been exposed to test-taking situations, the respondents will frequently request clarifications of the instructions. Field Workers were instructed to refer to the instructions manual for how to respond. All responses were neatly recorded verbatim in the spaces provided. No blanks were permitted on the response sheets.

Some special situations which frequently arose during testing, and the responses are illustrated below:

- If a subject for any reason was unable to complete all the tests, the Field Worker administered as many questions as the respondent was able to complete.
- If a subject asked for a judgement on his/her performance during the interview, he/she was told that this would be discussed at the end.
- If a subject said he/she was "tired" and wanted to take a short break, he/she was allowed to do so for 2 to 3 minutes.
- If a subject decided that he/she did not want to continue the interview, the Field Worker first tried to persuade him/her to continue by telling him/her: "It won't be much longer and you are doing well". If he/she still insisted on leaving, the Field Worker terminated the interview politely and thanked the subject for his/her participation.
- If a subject gave more than one answer to a specific question, he/she was asked to select only one. Spontaneous self-corrections were permitted unless otherwise stated, if they were given before the next question.

During the testing, if it appeared that the subject could answer a question but did not spontaneously do so, especially in memory testing, non-specific encouragement was given to encourage the subject to perform as best as he/she could. Statements such as: "It is all right if you do not recall everything; tell me at least one or two things that you are able to remember", or "If you recall something wrongly, it does not matter, but you must try", or "It is in your mind, speak it out", were permitted. Reassurance was also given about his/her performance saying: "You are doing well". Reassurance in the middle of a test was avoided as it could be distracting.

No indication of approval of correct responses or disapproval of incorrect responses was permitted. However, in order to maintain communication with the subject, a non-specific sound such as "hun" was vocalized whenever a task involved a lengthy procedure. If, even after non-specific encouragement, the re-

sponse was vague, e.g., "I am not sure", "I think so", or "perhaps", it was recorded exactly as given.

#### Guidelines for repetition of questions

Cognitive testing of any population requires that the subject's best possible responses are obtained in a uniform and standardized manner. This can be a major challenge in studying illiterate populations. Field experience in the early phases of instrument development in our project suggested that the respondents were not always clear about what was required of them in certain tests. Thus, it was decided to repeat certain questions in the format as given in Table 1. Questions could be repeated only when permitted.

#### Source amnesia

When multiple tests are being administered, subjects may display source amnesia; for example, on Word List Recall, the subject may not be sure of which specific words he/she is being asked to recall. Thus, in our project it was decided to read out the word list from a green colored paper, drawing the subject's attention to the green paper. The green paper was held up prominently each time words on it were used.

#### Penmanship

Tests requiring penmanship pose a special problem in illiterate populations. In our project, subjects required a great deal of persuasion to do tests of praxis since many subjects in these rural areas had never held a pen or pencil in their life. They were gently encouraged to do their best, and many subjects themselves were surprised at how well they could perform.

# ISSUES RELATED TO CONTENT OF SCREENING INSTRUMENTS

General principles and comparison with other studies

Some general principles of neuropsychological tests should apply to any test administered. In our project, the individual tests were selected to be comprehensible and acceptable to the local population, and tap the desired cognitive domain(s). They could not have significant floor or ceiling effects, and their distributions of scores should be comparable to those found among other similar populations. Tests and sub-tests were required to have culturally fair items in terms of names, contexts and words. Existing tests were simplified, while retaining the basic format of the test. This was required to suit the performance and comprehension abilities of uneducated, older subjects, previously unexposed to any kind of test-taking situation.

Table 1 - Guidelines for repetition of questions and instructions.

ie iir

Subject's response	Field Worker's response
Correct answer	Proceed to next question
Incorrect answer	Do not repeat question; proceed to next question
No response (e.g., stone-faced, quizzical expression of face)	Repeat question
Wrong category (e.g., says 'Tuesday' when asked for month)	Repeat question (unless manual says not to)
Irrelevant or evasive response (e.g., for month says: "There are so many months. Months come and go"; for calculation says: "There are no buses in our village" or "I never go by bus")	Check manual for:  (a) alternate words or rephrasing of question; (b) examples or cue
If in doubt about response	Repeat question
If says "I do not know"	Do not repeat the question; try non-specific encouragement

Making the subject at ease with the test-taking situation

The elderly populations in developing countries have rarely been subjected to test-taking situations. This makes it crucial to minimize stress/anxiety which can impair performance. In addition, the instructions given to the subjects in order to make them understand what is required of them in this unfamiliar situation become very important, and need to be tailored to local customs.

Since initial anxiety with the test-taking situation is common, it is advisable to begin with a "Dummy Test" as the first test to obtain the necessary mind-set for performing the rest of the test battery. Ideally, such a test should actually be a known standardized neuropsychological test; it should be scorable, simple, not require literacy, have a high probability of success, be arranged in increasing order of difficulty, and such that the subject listens and responds.

In our project, the Form Discrimination Test was selected as the first to be administered. It is a test on a subject's ability to discriminate between various simple forms (shapes) by matching similar shapes. The subject was required to match a shape shown on a card with a similar shape shown on a sheet of paper.

#### Appropriateness of test content

Commonly used tests frequently require modification for use with illiterate rural subjects.

Confrontation Naming of objects is a frequently used test of language capability; inability to name

these familiar objects is a sign of language impairment, specifically of expressive language. In the standard Confrontation Naming Test, subjects are asked to name objects depicted in line drawings.

In the first phase of instrument development, line diagrams were used after first deleting those line diagrams used in the original Boston Naming Test (CERAD version), which were considered inappropriate for the Indian setting, and then substituting them with more locally appropriate items. In subsequent phases, various substudies tested the use of line diagrams, photographs and actual objects (3 dimensional models) for the naming test.

In the final battery in use in Ballabgarh, objects were used for the test because the sub-studies established that line diagrams and even photographs were too abstract for the subjects. The subject had to name 15 objects. These 15 objects were divided into 3 groups (high, medium and low frequency), depending on how frequently they were presumed to occur in the Hindi language, and how familiar they were to the target population.

The standard Serial Subtraction from 100 by 7's is commonly used as a sub-test of attention. However, for illiterate subjects the task should be made less abstract by formatting it as a story or word problem. For example, our target population was familiar with bus travel. They were asked to assume they had a fixed sum of money (Rs. 20), and that they spent Rs. 3 for bus fare every day. They were then asked to calculate how much money they would have left at the end of each day for 5 consecutive days. The number

20 was chosen, as there was a concept of counting up to 20 and then multiples of it. With this modification, this test of attention was successfully applied to most subjects including women who had minimal exposure to schooling.

In the Word List Memory, the format of presentation was changed from a visual format, i.e., reading, to an auditory format, i.e., hearing, with the list of words being read out aloud by the examiner. The subjects were asked to repeat each word after the examiner, to ensure that they had heard the word and were attentive, and then to repeat the list.

The final battery used for door-to-door screening in our study consists of the following tests: the Hindi Mental State Examination, which is a brief global cognitive scale based on the Mini Mental State Examination (MMSE) (15); Word List Learning, Recall, and Delayed Recognition Tests; Object Naming Test; Verbal Fluency; and Praxis/Simple Construction. These tests and population normative values are described in another publication (3).

# ISSUES RELATED TO TESTS WHICH COULD NOT BE ADAPTED

Many neuropsychological tests used in developed countries cannot be successfully adapted for use with illiterate subjects. The reasons for failure of some tests in our project are explained below.

#### Verbal Fluency for Initial Letters

As a marked discrepancy was noted between uneducated subjects' verbal fluency for initial letters vs fluency for categories, a sub-study was conducted comparing younger subjects with three levels of education. The results showed that the test for verbal fluency for letters was substantially affected by literacy, and as such, this test cannot be conducted in a rural illiterate population (16).

#### Story Recall and Delayed Story Recall

In the initial phases of instrument development, scores in immediate and delayed story recall were found to be very low. This came as a surprise to us because story telling is a popular pastime in rural India. The reasons considered for these low scores included: 1) the story content was inappropriate; 2) the story was "boring" to an average elderly subject; and 3) the sentence structure was too complex syntactically.

Thus, the story content was modified, and different stories, which were more "interesting" and locally appropriate with short sentence structure, were tested. However, there was only a marginal improvement in scores in spite of these changes. The possible reasons for the low scores could be:

- the subjects tended to give what they considered the salient features of the story, rather than repeat i verbatim. However, this was unacceptable for stan dardized scoring; and
- 2) they perceived the story task as too complex which could have resulted in a poor motivatior level to do well.

Despite substantial modifications and revisions the scores on this test remained at floor, and hence this test was deleted from the final battery.

#### "Draw a Clock" test

A frequently used test of praxis which also tests executive functions is to ask subjects to draw a clock. The Clock Test was considered unsuitable for the population in our project as many of them do not know how to read time from a clock (most of them do not even wear a watch or have a wall clock).

#### **CONCLUSIONS**

The study of the epidemiology of dementia, specifically Alzheimer's disease, in developing countries requires specialized instruments and personnel. Development of such instruments and training of personnel requires a substantial investment in time and money. If appropriate methodology is used, results can be compared to other studies, including those conducted in developed countries. Such cross-cultural studies may be very informative in identifying unique populations with a higher or lower risk of AD, compared to other populations. This could lead to new hypothesis and advance our knowledge of AD.

#### **ACKNOWLEDGEMENTS**

This work was supported in part by grants #AG09202, AG07562, and AG00312 from the National Institute on Aging, U.S. Department of Health and Human Services. The authors acknowledge the following individuals whose efforts and support made this work possible: in New Deihi and Ballabgarh, L.M. Nath, A. Mehta, B.S. Nair, R.K. Kaushik, R. Lal, G. Singh, D. Raj, S. Kumar, M. Ram, and V. Ram; in Pittsburgh, J. Gilby, C. Ryan, C. Baker, S. DeKosky, D. Echement, J. Johnston, T. Meshanko, and C. Moran. We are also grateful for the cooperation provided by S. Kapoor, G. Kumar, and other staff of the Comprehensive Rural Health Services Project (Center for Community Medicine, All India Institute of Medical Sciences, New Delhi) for giving us access to their Ballabgarh facilities and census database.

#### REFERENCES

 Chandra V., Ganguli M., Ratcliff G., Pandav R., Sharma S., Gilby J., Belle S., Ryan C., Baker C., Seaberg E., DeKosky S., Nath L.: Studies of the epidemiology of dementia: comparisons between developed and developing countries. Part 1: General al conceptual and methodological issues. Aging Clin. Exp. Res. 6: 307-321, 1994.

- Ganguli M., Ratcliff G., Chandra V., Pandav R., Sharma S., Gilby J., Belle S., Ryan C., Baker C., Seaberg E., DeKosky S., Nath L.: A Hindi version of the MMSE: The development of a cognitive screening instrument for a largely illiterate rural elderly population in India. *Int. J. Geriatr. Psychiatry* 10: 367-377, 1995.
- Ganguli M., Chandra V., Gilby J.E., Ratcliff G., Sharma S.D., Pandav R., Seaberg E.C., Belle S.: Cognitive test performance in a community-based non-demented elderly sample in rural India: the Indo-US Cross-National Dementia Epidemiology Study. Int. Psychogeriatr. 8: 507-523, 1996.
- 4. Katzman R.: Education and the prevalence of dementia and Alzheimer's disease. *Neurology* 43: 13-20, 1993.
- McGeer P.L., Schulzer M., McGeer E.G.: Arthritis and antiinflammatory agents as possible protective factors for Alzheimer's disease: A review of 17 epidemiologic studies. Neurology 47: 425-432, 1996.
- Birge S.J.: The role of ovarian hormones in cognition and dementia. Neurology 48 (Suppl. 5): S1-S41, 1997.
- Aisen P.S., Davis K.L.: The search for disease-modifying treatment for Alzheimer's disease. *Neurology* 48 (Suppl. 6): \$35-\$41, 1997.
- Graves A.B., van Duijn C.M., Chandra V., Fratiglioni L., Heyman A., Jorm A.F., Kokmen E., Kondo K., Mortimer J.A., Rocca W.A.: Alcohol and tobacco consumption as risk factors for Alzheimer's disease: a collaborative re-analysis of case-control studies. *Int. J. Epidemiol.* 20: S48-S57, 1991.
- Brenner D.E., Kukull W.A., vanBelle G., Bowen J.D., McCormick W.C., Ten L., Larson E.B.: Relationship between

- cigarette smoking and Alzheimer's disease in a population-based case-control study. Neurology 43: 293-300, 1993.
- Lee P.N.: Smoking and Alzheimer's disease: A review of the epidemiological evidence. Neuroepidemiology 13: 131-144, 1994.
- Fillenbaum G.G., Chandra V., Ganguli M., Pandav R., Gilby J.E., Seaberg E.C., Belle S., Baker C., Echement D.A., Nath L.M.: Development of an activities of daily living scale for an illiterate rural older population in India. Age Ageing (In press).
- Cross-National Investigations of the Epidemiology of Alzheimer's Disease and Other Dementias of Late Life: National Institute of Aging Ongoing Program Announcement, July 1988.
- Ganguli M., Belle S., Ratcliff G., Seaberg E., Huff F.J., von der Porten K., Kuller L.H.: Sensitivity and specificity for dementia of population-based criteria for cognitive impairment: The MoVIES project. J. Gerontol. 48: M152-M161, 1993.
- Morris J.C., Heyman A., Mohs R.C., Hughes J.P., van Belle G., Fillenbaum G., Mellitus E.D., Clark C., and the CERAD investigators: The consortium to establish a registry for Alzheimer's disease (CERAD). Part I. Clinical and neuropsychological assessment of Alzheimer's disease. *Neurology* 39: 1159-1165, 1989.
- Folstein M.F., Folstein S.E., McHugh P.R.: Mini-Mental State: A practical method for grading the cognitive state of patients for the clinician. J. Psychiatr. Res. 12: 189-198, 1975.
- Ratcliff G., Ganguli M., Chandra V., Sharma S., Belle S., Seaberg E., Pandav R.: Effects of literacy and education on measures of word fluency. *Brain Lang.* 61: 115-122, 1998.