Performance of the Informant Questionnaire on Cognitive Decline for the Elderly (IQCODE) in a nationally representative study in India: the LASI-DAD study

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ABSTRACT

Background: Low and middle-income countries like India anticipate rapid population aging and increases in dementia burden. In India, dementia screening scales originally developed in other contexts need to be assessed for feasibility and validity, given the number of different languages and varying levels of literacy and education.

Method: Using data from the Longitudinal Aging Study in India-Diagnostic Assessment of Dementia (N = 4,028), we characterize the performance of the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE). We described patterns and correlates of missingness, evaluated the psychometric properties of the scale, and assessed criterion validity against the Hindi Mental State Examination (HMSE) using linear regression.

Results: Several IQCODE items had high levels of missingness, which was associated with urbanicity, respondent's gender, and informant's generation (same vs. younger generation). Full IQCODE scores showed strong criterion validity against the HMSE; each 1-point increase in IQCODE score was associated with a 3.03-point lower score on the HMSE, controlling for age, gender, and urbanicity. The statistically significant association between IQCODE and HMSE was stronger in urban than rural settings (p-value for interaction = 0.04). Associations between IQCODE and HMSE remained unchanged after removing the three items with the highest levels of differential missingness (remembering addresses and telephone numbers, ability to work with familiar machines, ability to learn to use new gadget or machine).

Conclusion: Findings raise questions about the value of including items with high proportions of missingness, which may signal cultural irrelevance, while removing them did not affect criterion validity.

Key words: developing country, cognitive assessment, elderly, functional assessment, aging, dementia, LMIC, informant report

Introduction

With population aging comes a rising number of people with age-related chronic diseases, including dementia. In particular, low- and middle-income countries (LMIC) are experiencing faster aging, on a population level, than are high income countries, where most dementia research is conducted (Livingston *et al.*, 2020). India is forecasted to have one of the largest populations of older adults with dementia. In 2015, an estimated 4.1 million persons aged over 60 years had dementia in India (Nulkar *et al.*, 2019). This count is projected to rise to 6.35 million by 2025 and to triple to 13.33 million by 2050. Thus, better characterization of the distribution and determinants of dementia in India has been a focus of several studies in the last two decades. This challenge for public health research faces two barriers: properly sampling from the community and developing culturally appropriate screening measures of dementia. Extant dementia research from India consists of either small-scale independent studies, or

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studies that were part of international research collaborations following common protocols (Kumar *et al.*, 2019). There remains a need for large-scale studies designed expressly for the Indian population because India is a diverse and multiethnic country with a multitude of languages and dialects and vastly varying literacy and educational levels, and considerable disparities in resources and lifestyle between urban and rural areas. Accordingly, dementia screening scales adapted from other settings for Indian research must be scrutinized for feasibility and validity (Ravindranath and Sundarkumar, 2021).

A key diagnostic criterion for dementia is selfreported or informant-reported evidence that cognitive functioning has declined from a previous level (American Psychiatric Association, 2013). The Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) is a well-established screening tool designed to assess changes in the everyday cognitive functioning of the respondent (study participant) from the perspective of an informant who knows the respondent well. Outside India, the IQCODE's construct, criterion, and content validity as a screening instrument for dementia have been established in cross-sectional and longitudinal studies (Jorm, 2004). It has been translated into several languages (Del-Ser et al., 1997; Fuh et al., 1995; Isella et al., 2002; Law and Wolfson, 1995; Senanarong et al., 2001; de Jonghe et al., 1997).

While the IQCODE is well-known and validated, its performance in LMIC like India is understudied. A key consideration in any setting is that the IQCODE is administered to proxy informants, rather than to the individuals being assessed (study respondents). Thus, the validity of IQCODE data depends not only on the respondents' actual everyday functioning but also, in large part, on the sociocultural contexts of the Indian population being studied (Siri *et al.*, 2006), as well as the validity of the informant's perspective, which in turn depends on characteristics of the informants and their relationships and familiarity with the respondents. If valid, the ability to compare IQCODE responses between India and other settings would allow for important cross-national and cross-cultural comparisons.

Here, we report on our experience with the IQCODE in a nationally representative survey of older people in India, specifically examining the effects on test results of the demographic characteristics of both of study respondents and of their informants. We examined the distribution of IQCODE scores particularly focusing on the magnitude of missing data, both overall and stratified by respondent and informant characteristics. We also evaluated the criterion validity of IQCODE scores against global cognitive screening scores on the

Hindi Mental State Exam (HMSE) (Ganguli *et al.*, 1995). We discuss the relevance and feasibility of implementing the IQCODE in studies in countries like India and review potential modifications to the scale to enhance cultural validity.

Method

Respondents

The Longitudinal Aging Study in India-Diagnostic Assessment of Dementia (LASI-DAD) study (Lee et al., 2019) is a sub-study of the Longitudinal Aging Study in India (LASI) (LASI wave 1 India report, 2020), a nationally representative survey of older adults in India. LASI-DAD extends LASI's cognitive data collection to include additional in-depth cognitive tests and informant interviews to a subsample of 4,096 LASI respondents aged 60 or older, closely following the Harmonized Cognitive Assessment Protocol (HCAP) (Langa et al., 2020) The study employed a two-stage stratified sampling approach to recruit respondents from 18 states across the country; the methodology has been described previously (Lee et al., 2019). Respondents were administered neuropsychological tests and were each asked to nominate an informant for a brief interview. In 49 cases, neuropsychological testing was completed but no informant interviews were administered (Lee et al., 2020). Additionally, for 19 informant interviews, responses to all IQCODE items were missing. Therefore, this study included data from the remaining 4,028 informant interviews.

Informants

To conduct informant interviews, LASI-DAD asked respondents to nominate a close family member or friend (18 years and older) who knew the respondent well, interacted with the respondent frequently, and thus was knowledgeable regarding the respondent's everyday functioning. Interviewers were trained to help respondents select the informant who knew them best, leaving the final choice to the respondent. When respondents nominated two informants, interviewers contacted the first person, followed by the second if the first person was unavailable.

Demographic categories of respondents and informants

For both respondents and informants, place of residence was categorized as rural or urban based on the most recent Indian census (Census of India, 2011). Genders of the respondent and informant were selfreported as male or female. Educational attainment is self-reported as either no school, or the completion of less than primary school, primary school, middle school, secondary school, higher secondary school, a diploma or certificate, a graduate degree, a postgraduate degree, or a professional degree, which we aggregated to categories of no formal school, primary school, secondary school, and college and more. Due to differences in the distribution of educational attainment between respondents and informants, for respondents, we compared participants without formal education to all other participants, whereas for informants, we compared those with secondary education and above to those with educational attainment of primary school or below. We categorized relationships with respondents based on the informant's generation: children/children-in-law and grandchildren ("younger generation"), spouses/siblings/friends ("same generation"), and other (e.g. parents, other relative).

Assessments

In 7 of 18 states, the national language Hindi was used for assessments; for the remaining states, the tests and questionnaires were translated into 11 different regional languages and back-translated into English (Banerjee *et al*, 2019); 10 participants were assessed in English, for a total of 13 languages.

The informant interview consisted of questions about the informant's demographic characteristics and relationship to the respondent, the respondent's functional status, social engagements, and memory, including the IQCODE (Jorm and Jacomb, 1989), and other scales. It took on average 20 minutes to complete the interview. Most were conducted face to face, but telephone interviews were allowed at the request of the informants. Further details of the study protocol and methodology have been described previously (Banerjee *et al.*, 2019).

INFORMANT QUESTIONNAIRE ON COGNITIVE DECLINE IN THE ELDERLY (IQCODE)

The IQCODE is a brief informant-rated screening questionnaire for dementia. It was originally developed as a 26-item informant questionnaire to retrospectively measure changes in cognitive and functional performance over a 10-year period (or less than 10 years if the informant has not known the respondent for that long) (Jorm and Korten, 1988). For each item, the selected informant rates the respondent's cognitive change on a five-point ordinal scale, with responses ranging from 1: 'has become much better' through 3 = unchanged to 5: 'has become much worse'. A shortened 16-item version, previously recommended for clinical use, was used in LASI-DAD (Jorm, 1994). Scores from individual non-missing items were averaged together to give a final score between 1 and 5, where higher scores indicate greater decline. Informants were also offered a response category of "Never did," which they were instructed to select when participants' lack of engagement with an activity precluded the evaluation of decline (i.e. they had never performed that activity). When describing patterns in responses on the IQCODE both overall and across demographic characteristics, we collapsed the response options into no decline (1-3), decline (4-5), "Never did," and otherwise missing as there were very few informants who endorsed improvements, and our primary goal was to assess missingness and correlates of missingness. However, for the purposes of factor analysis and other quantitative assessments, we used the full 1-5 score.

HINDI MENTAL STATE EXAMINATION

All participants were administered the Hindi Mental State Examination (Ganguli *et al.*, 1995). Where data were missing, we imputed scores based on demographic characteristics, health characteristics, and other cognitive test scores, as previously described (Gross *et al.* 2020).

CERAD WORD LIST MEMORY TASK

The Consortium to Establish a Registry for Alzheimer's Disease (CERAD)Word List Memory Task (Morris *et al.*, 1989) assesses the ability to learn and remember verbal information. The test consists of three learning trials, a delayed recall trial and a recognition trial. A 10-item word list is presented over three trials with a different word order each trial. In LASI-DAD, where many of our respondents were illiterate, the interviewers read the words aloud to the respondents who were then asked to repeat as many words as they could remember.

Analysis plan

We first described the characteristics of the sample overall and by state by using means and SD for continuous variables, and counts and percentages for categorical variables. For each of the 16 items of the IQCODE, we cross-tabulated responses and paid careful attention to rates of "Never did" and missing responses. We then examined responses to each IQCODE item by key demographic characteristics of informants and respondents: respondent gender, urbanicity, and informant's generation in relation to the respondent's generation. We conducted chi-squared tests to assess the statistical significance of differences of select comparisons. Informant's generation is likely strongly related to respondent's age and gender. Therefore, we also used linear regression for binary data with robust standard errors to evaluate the magnitude of risk differences by informant generation for whether a respondent "Never did" a given activity, after controlling for respondent age (as a categorical variable [60–69,70–79,80+]), gender, and years of education. We used these models to calculate the adjusted marginal proportion of informants responding "Never did" by informant's generation. We then calculated alternative partial IQCODE scores after excluding specific items which showed large concerns regarding differential missingness by demographic characteristics.

We established the equivalence of the IQCODE across the 12 different languages used in LASI-DAD, by testing for measurement invariance by language of administration. We compared each language group to Hindi, which was used by the largest number of participants. We excluded from this analysis the N = 10 English language interviews for model identifiability, the first item for "Remembering things about family/friends", was used as an anchor item in this analysis and assumed to be invariant to allow the means and variances of the latent variable to vary across language group. We tested for configural, metric, and scalar levels of invariance (Bontempo and Hofer, 2007).

To evaluate dimensionality of the set of IQCODE items in this sample, we used scree plots with parallel analysis. To assess the proportion of total variance explained by the factor both using the full IQCODE scale and the partial IQCODE scale, we used a principal components analysis (PCA) of the items based on polychoric correlations among the items. Parallel analysis was conducted using the psych package in R (Revelle and Revelle, 2015). We conducted confirmatory factor analysis (CFA) using a robust maximum likelihood estimator in Mplus version 8.

We evaluated the criterion validity of IQCODE scores against HMSE scores, and compared the relationship between the partial IQCODE scores and HMSE to the relationship between the full IQCODE score and the HMSE. The criterion validity findings were also replicated using the CERAD word recall task.

In situations with missing data, LASI-DAD has imputed scores on the IQCODE and HMSE. In this study, we used unimputed IQCODE data for descriptive analyses and models because we sought to evaluate the IQCODE responses as they were collected and explore patterns of missingness. Primary analyses used imputed HMSE data for criterion validity analyses to maximize data availability. We conducted two sets of sensitivity analyses. First, we repeated analyses that were not focused on patterns of missingness (factor analysis and criterion validity analysis) using imputed IQCODE scores. Second, because the general imputation method applied to the HMSE uses IQCODE scores, among many other variables, for the imputation of the HMSE, we repeated the criterion validity analysis using pro-rated HMSE scores, wherein scores of those with missing data were scaled to the full 30-point range to avoid this potential source of circularity. In both sets of sensitivity analyses, inferences were unchanged. We did not account for survey weights in analyses, as the goal of our work was to assess the performance of the IQCODE in the sample to which it was administered, not to make population-level inferences. However, we did test the sensitivity of our findings to this choice in additional analyses by applying weights and accounting for the complex survey design in PCA and CFA models as well as criterion validation analyses.

Results

Demographic characteristics

Across 18 states (see map in Figure S1 published as supplementary material online), we had a total of 4028 respondent and informant pairs with at least one non-missing response to items on the IOCODE. The number of respondent and informant pairs ranged from 100 (Madhya Pradesh) to 351 (Maharashtra). On average, 53.8% of the respondents were women, ranging from 45.0% in Madhya Pradesh to 59.7% in Kerala (see Table S1 published as supplementary material online attached to the electronic version of this paper). Mean age of the respondents was 69.7 years, ranging from 67.5 years of age to 71.1. The sites varied in rurality from 0% in the capital city of Delhi to 96% in Madhya Pradesh. The highest levels of illiteracy (81.5%) as well as the lowest proportion of respondents with formal education (25.2%) were observed in Jammu and Kashmir, whereas the lowest levels of illiteracy (21.6%) and the highest proportion of respondents with some formal educations (89.6%)were observed in Kerala.

The proportion of female informants was highly variable between states, with 31.2% women in Rajasthan, whereas 83.3% were women in Assam (see Table S1 published as supplementary material online). Overall, levels of educational attainment among informants were higher and with less variability between states than among respondents. However, informants' generation did vary substantially among states; the proportion of informants in the same generation as respondents ranged from 10.4% (Uttar Pradesh) to 44.1% (Kerala), and the proportion of informants of a younger generation varied from 52.4% (Kerala) to 83.4% (Uttar Pradesh). The proportion of informants who were not either children, grandchildren, spouses, siblings, or friends was generally low in most states, except Rajasthan (14.8%) and Punjab (8.8%).

Observations during fieldwork

During fieldwork, a sizable proportion (31%) of informants found it difficult to answer the question about the respondent's "Ability to use a new gadget or machine", saying they could not easily think of new gadgets used by the participant over the preceding 10 years. Similar difficulty was encountered with the item about "Learning new things in general." Thus, interviewers were explicitly trained to probe further regarding these items. They helped the informant with examples of gadgets like smartphones, TV remote controls, or newer gas stoves used in some houses. For the item "Learning new things in general," interviewers provided examples of learning new words or skills. Additionally, for the item about "Remembering addresses or telephone numbers", the interviewers emphasized addresses rather than telephone numbers because of the increasing prevalence of smartphones where telephone numbers are saved.

IQCODE responses by respondent and informant characteristics

Items for which informants reported the highest rates of decline included "Remembering where to find things" (48.3%) and "Remembering where things are usually kept" (42.7%), whereas items with the lowest reported rates of decline included "Ability to follow a story in a book or on TV" (22.9%) and "Ability to work with familiar machines" (25.6%) (Table 1). However, high levels of missingness were observed. In addition to the 19 interviews that were missing data on all IQCODE items, which were excluded from our analyses as mentioned before, 2,012 participants (50%) had missing data on at least one item, 1,376 (34%) had missing data on at least two items, 898 (22%) had missing data on at least three items, and 100 (2%) had missing data on at least half of the items. Missingness due to "Never did" responses were concentrated among a subset of the items, including "Remembering addresses and telephone numbers," "Ability to work with familiar machines," "Ability to learn to use a new gadget or machine," "Ability to learn new things in general", "Ability to follow a story in a book/TV", and "Ability to handle financial matters." Measurement invariance testing results are consistent with the hypothesis that the translations of the IQCODE into different languages did not measurably affect the reliability or bias of the instrument (see Table S2 published as supplementary material online).

There were large differences in the patterns of missingness, particularly "Never did" responses, by demographic characteristics of the respondent. In many cases, the proportion of "Never did"

responses was higher among those in rural areas compared to urban areas (Figure 1). For example, 18% of informants in rural areas reported that respondents did not follow stories in books or on TV, whereas only 7% of informants in urban areas reported that this item was not applicable ($\chi^2 = 7.2$, p = 0.007). Additionally, the discrepancy was high for the items "Ability to learn to use a new gadget or machine" (33% vs. 22%; $\chi^2 = 13.2$, p < 0.001), and "Ability to work with familiar machines" (22% vs. 12%; $\chi^2 = 8.4$, p = 0.004). Examination of responses on the IQCODE items by respondent gender revealed similar patterns (Figure 2). Items including "Ability to learn to use a new gadget or machine" $(31\% \text{ vs. } 25\%; \chi^2 = 4.7, p = 0.029)$, "Ability to work with familiar machines" (22% vs. 15%; $\chi^2 = 5.3$, p = 0.022), "Remember address and telephone number" (13% vs. 7%; $\chi^2 = 2.9$, p = 0.090) were missing more often among women, although differences in "Remember address and telephone number" were not statistically significant. The item "Ability to handle financial matters" showed the strongest differences in "Never did" responses by gender (25% for women vs. 11% for men; $\chi^2 = 16.7$, p < 0.001).

Informants' generation was also related to IQCODE items and the proportion of "Never did" responses (Figure 3). Informants who were of a younger generation than respondents, and also those included in the "other" informant category (e.g. parents, other relative), were more likely to report that informants "never did" the activities assessed in the IQCODE questionnaire. These patterns held in a few items even after adjusting for respondent age, gender, and education in linear regression models (see Table S3 published as supplementary material online).

The items with the largest adjusted marginal differences, comparing younger informants to informants of the same generation, were "Ability to work with familiar machines" (20% vs. 15%; risk difference = 0.05, p < 0.001) and "Ability to learn to use a new gadget or machine" (30% vs. 27%; risk difference = 0.03, p = 0.05) (see Table S3 published as supplementary material online). Across each of these informant and respondent characteristics, as well as informant gender and both respondent and informant educational attainment, items including "Remembering addresses and telephone numbers," "Ability to work with familiar machines," "Ability to learn a new gadget or machine," and "Ability to handle financial matters" showed differential missingness (see Figures S2-S4 published as supplementary material online).

Based on these results, we calculated partial IQCODE scores after removing three items: "Remember address and telephone number,"

	NO DECLINE (%)	decline (%)	NEVER DID (%)	missing (%)
Remember things about family/friends (1)	58.1	39.1	1.0	1.8
Remember recent events (2)	60.4	37.3	0.3	2.0
Remember recent conversations (3)	59.4	38.4	0.2	2.0
Remember address and telephone number (4)	57.0	30.9	10.1	2.0
Remember day and month (5)	63.2	32.2	2.7	1.9
Remember where things usually kept (6)	54.6	42.7	0.8	1.9
Remember where to find things (7)	48.9	48.3	0.9	2.0
Ability to work with familiar machines (8)	53.8	25.6	18.3	2.3
Ability to learn a new gadget or machine (9)	41.0	27.9	28.6	2.5
Ability to learn new things in general (10)	46.0	38.9	12.7	2.4
Ability to follow a story in book/TV (11)	61.4	22.9	13.6	2.1
Ability to make decisions on everyday matters (12)	61.2	30.2	6.6	2.0
Ability to handle money for shopping (13)	61.7	27.8	8.6	1.9
Ability to handle financial matters (14)	53.4	26.0	18.6	2.0
Ability to handle everyday arithmetic (15)	60.6	29.1	8.2	2.1
Ability to reason through things (16)	66.4	29.8	1.8	2.1

Table 1. Distribution of informant response to the 16 IQCODE items administered in the LASI-DAD sample	ole
(N = 4,028)	

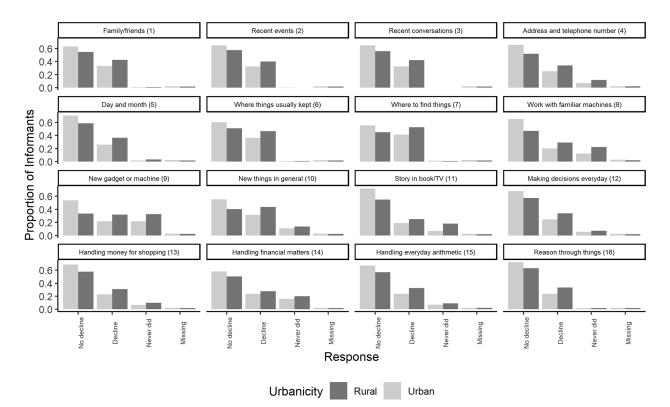


Figure 1. Informant responses to IQCODE items by urbanicity of respondents in the LASI-DAD (N = 4,028) sample. A larger proportion of informants in rural settings reported that participants "never did" specific activities compared to informants in urban settings, including following stories in books or on TV, learning to use a new gadget or machine, and working with familiar machines.

"Ability to work with familiar machines," and "Ability to learn to use a new gadget or machine." We retained the item for "Ability to handle financial matters" as differences in this item could be explained by differences across respondent gender, which are expected due to societal gender norms. Further, we are interested in gender effects.

Factor analysis

Parallel analysis and the examination of scree plots (see Figure S5 published as supplementary material online) suggested a one-factor solution. Based on PCA, the factor explained 62.0% of the total variance in the IQCODE item. Use of partial IQCODE scores

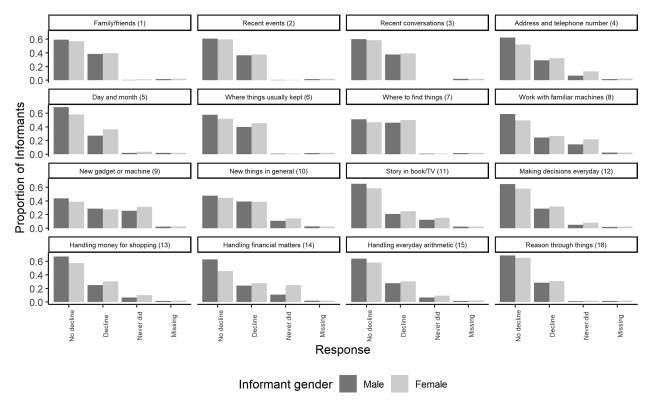


Figure 2. Informant responses to IQCODE items by respondent gender in the LASI-DAD (N = 4,028) sample. Informants for female respondents were more likely to report that informants never learned to use new gadgets or machines, worked with familiar machines, or remembered addresses and telephone numbers.

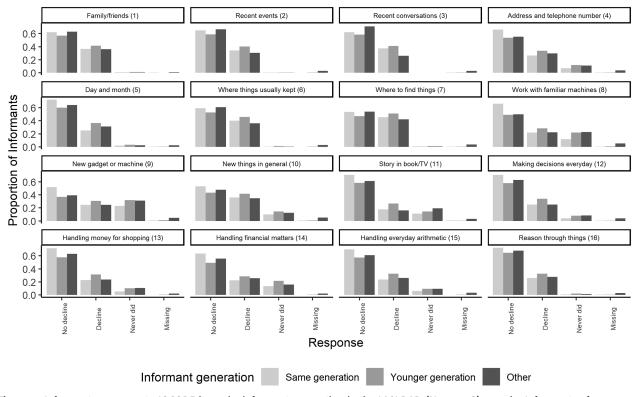


Figure 3. Informant responses to IQCODE items by informant generation in the LASI-DAD (N = 4,028) sample. Informants of a younger generation than respondents were more likely to report that informants "never did" activities including learning to use new gadgets or machines, and working with familiar machines.

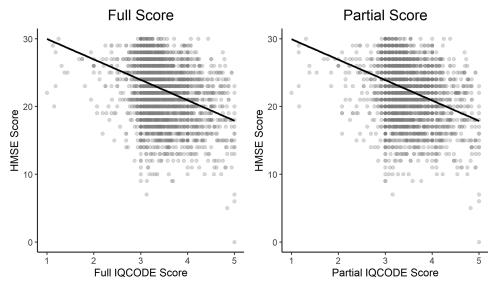


Figure 4. Relationship between the IQCODE (Full Score and Partial Score excluding items with the strongest evidence of differential missingness) and the Hindi Mental State Examination (HMSE) based on linear regression models. There was a strong relationship between IQCODE score and HMSE using either the Full IQCODE Score or the Partial IQCODE Score.

did not substantially change the proportion of total variance explained (62.7%). All items had moderate to high standardized loadings (above 0.7) (see Table S4 published as supplementary material online). CFA further indicated that item thresholds were largely overlapping (see Figure S6 published as supplementary material online); therefore, excluding potentially problematic items should not affect the information contained in the overall IQCODE scale.

Criterion validity

We observed a strong, negative association between the full IQCODE score and the HMSE, such that each 1-point increase in IQCODE score was associated with a 3.03-point lower score on the HMSE after controlling for age, gender, and urbanicity (Figure 4). All criterion validity findings using the HMSE were replicated using the CERAD word recall task, an alternative objective measure of cognition (see Table S5 and Figure S7 published as supplementary material online).

However, there was a significant interaction in the association between IQCODE score and HMSE score with urbanicity (interaction coefficient = 0.57, p = 0.04): a 1-point difference in IQCODE score was associated with a 3.41 (95% Confidence Interval = 2.97–3.86)-point difference in HMSE score among respondents in urban settings, but a 2.84 (2.53–3.15)-point difference in HMSE score among respondents in rural settings. There were no significant interactions by respondent gender or informant generation. The association between IQCODE score and the HMSE remained unchanged when using partial IQCODE scores and the interaction with urbanicity was still present (interaction coefficient = 0.58, p = 0.03) (see Table S6 published as supplementary material online).

Sensitivity analyses using imputed IQCODE scores or pro-rated HMSE scores did not impact study conclusions. Additionally, inferences from PCA and CFA models well as criterion validity analyses were unchanged after accounting for the complex survey design (see Tables S7–S9 published as supplementary material online).

Discussion

We administered the 16-item IOCODE scale to 4028 informants of study respondents, representing a diverse cross-section of older adults in India with respect to age, education, and urban/rural place of residence. The IQCODE score seems to work as intended, being strongly related with HMSE despite the widely varying socio-cultural determinants and demographic characteristics of our large multisite study population. However, we found a large amount of missingness among certain IQCODE items, and some of it was missing in systematic patterns related to location (urban/ rural) and demographic characteristics of both respondents and their informants. Additionally, the strength of the association between the HMSE and IOCODE score varied by urbanicity, with a weaker association observed among rural participants. This finding raises doubt on the value of including frequently missing items in the assessment. Further, we found that eliminating items with the most evidence of systematic missingness

did not reduce the proportion of variation in the HMSE explained by the IQCODE.

Some of the activities involving gadgets and financial matters were difficult for informants to assess in 20-30% of respondents, in patterns that suggest systematic bias. The urbanicity, gender, and educational levels of respondents, as well as the generation to which informants belonged relative to the respondents, affected some item distributions, and missingness. For example, the item related to financial matters showed the strongest differences in responses by respondent gender, and women were more likely than men to be reported as never having handled finances. This discrepancy is likely due to differences in societal gender roles and expectations around money and finances. In contrast, missingness for the items about "Remembering address and telephone number," "Ability to work with familiar machines," "Ability to learn a new gadget or machine," "Ability to learn new things in general", "Ability to follow a story in a book/TV" were not related to gender but were concentrated among illiterate and rural-residing respondents. These discrepancies seem most likely related to literacy, socioeconomic status, and characteristics of the rural environment.

Our results are broadly consistent with a previous study in Lebanon that examined IQCODE performance in 236 Arabic-speaking older adults from hospital-based neurologic and geriatric clinics and community-based primary care clinics in which half the population was illiterate (Phung et al., 2015). That study excluded individuals with severe physical or mental illness and those with mild cognitive impairment. Despite sampling differences compared to our study, they too reported a higher decline on the IQCODE in older and illiterate respondents. For the Lebanese subjects living in the community (not in the hospital or nursing home), informants were mainly relatives (spouses: 24.9%; children: 49.7%) very similar to those in our study (spouses: 29.8%; children: 48.4%). However, in the Lebanese study, the relationship between respondents and informants did not influence mean IQCODE scores, whereas in our study we found differences in missingness on some items between informants of the same and younger generations, even after adjustment for respondent age, gender, and education.

Regarding missingness, the Lebanese study found the same IQCODE items as we did to be most frequently missing. However, the proportion of missing items was much lower than in our study ('learning how to operate a new gadget/machine in the house': 3.3%, 'learning new things in general': 2.8%, 'handling financial matters': 2.8%, and 'handling everyday arithmetic problems': 3.2%). This discrepancy could reflect characteristics both of the study sample and of the study setting. Possibly the informants accompanying respondents to the clinical settings where they were recruited were more attentive to health and functional changes in the respondents than in our study where we recruited participants by geographic area and asked them to nominate informants.

Various previous studies have reported principal components analyses of the IQCODE items, covering a diversity of populations and languages (Fuh et al., 1995; de Jonghe et al., 1997; Jorm et al., 1989; Jorm and Jacomb, 1989; Morales et al., 1997). All have found a large general factor accounting for between 42 and 61% of the variance (median 48%). In our study, the single factor explained 61.9% of the variance in the IQCODE items. In our study, PCA with parallel analysis suggested a one factor structure with highest standardized loadings for items: Handling everyday arithmetic (0.85), Making decisions on everyday matters (0.84), Handling money for shopping (0.82), and Handling financial matters (0.81). This is similar to prior findings (Fuh et al., 1995). In the study by Fuh et al., two items alone were found to have excellent accuracy as a screening test, namely, recalling a conversation a few days later, and handling financial matters, e.g. one's pension, dealing with the bank.

Previous studies have suggested using different numbers of IOCODE items from the IOCODE scale to screen participants depending upon their education levels (Fuh et al., 1995; Perroco et al., 2009; Tang et al., 2003). A German study (Ehrensperger et al., 2010) demonstrated that a 7-item IQCODE had equally high diagnostic discriminability as that of the 16-item IQCODE, allowing for more economical screening. By removing three items for "Remembering address and telephone number," "Ability to work with familiar machines," and "Ability to learn a new gadget or machine," we created a partial IQCODE score which explained the same amount of variance in our cognitive screening (HMSE) score as the full IQCODE score. This finding suggests that we could maintain criterion validity while reducing both missingness and informant burden by eliminating these three frequently and systematically missing items.

Strengths and limitations

A major strength of the LASI-DAD study is the size of the population-based cohort and its reach over many parts of India, including both urban and rural sites and with a range of education/literacy. The enormous effort we devoted to standardizing training and translation processes appears to be justified. Results can therefore be cautiously generalized to India as a whole and potentially to other LMIC countries. However, the price that population-based studies pay for their large size, scope, and representativeness is that respondents and informants cannot be individually examined by expert clinicians with the experience and skill to probe beyond the standardized assessment protocol. A more detailed assessment of the informants, including their own mental states (e.g. anxiety/depression/ cognition), and of the quality of their relationships with the respondents, might have been informative but was beyond the scope of study.

Conclusions and implications

In summary, the IQCODE appears to perform as intended in a large, multisite population study in India, despite methodological challenges associated with low educational levels, a range of socioeconomic status and urbanicity, and the need to be administered in multiple Indian languages. Some items with lower response rates than others were more likely to be missing by gender or by rural/urban residence. A reduced IQCODE scale with fewer items performed as well as the full version. Thus, our data invite a discussion of whether or not (1) a shorter version of the scale should be used in studies of rural populations in low-income and middleincome countries, (2) informant characteristics should be incorporated in models analyzing informant data, (3) studies might reduce measurement error by imposing a preference order for informant, e.g. consistently using a spouse, or an adult child, as the preferred informant, rather than leaving the choice to the respondent. Our data also highlight the value of examining the distribution of scale performance in novel study populations and making appropriate adjustments before deploying them to screen for dementia.

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Conflict of interest

None.

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Description of authors' role

P. Khobragade and E. Nichols contributed equally and worked together to write this paper. P. Khobragade and M. Ganguli formulated the research questions and wrote the first draft of the paper. E. Nichols and A.L. Gross analysed the data and participated in writing and revising further drafts. J. Lee obtained funding; J. Lee and AB Dey developed the overall research study design. P. Khobragade and J. Banerjee were involved in data collection and study management. All authors substantially contributed and commented on the manuscript and approved the final version.

Supplementary material

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