

Measurement differences in the assessment of functional limitations for cognitive impairment classification across geographic locations

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Keywords: measurement, functional limitations, dementia, aging, cross-national comparisons, global health

### Abstract

**INTRODUCTION:** The measurement of dementia in cross-national contexts relies on the assessment of functional limitations. We aimed to evaluate the performance of survey items on functional limitations across culturally diverse geographic settings.

**METHODS:** We used data from the Harmonized Cognitive Assessment Protocol Surveys (HCAP) in five countries (total N=11,250) to quantify associations between items on functional limitations and cognitive impairment.

**RESULTS:** Many items performed better in the US and England compared to South Africa, India, and Mexico. Items on the Community Screening Instrument for Dementia (CSID) had the least variability across countries (SD=0.73 vs. 0.92 [Blessed] and 0.98 [Jorm IQCODE]), but also the weakest associations with cognitive impairment (Median OR=2.23 vs. 3.01 [Blessed] and 2.75 [Jorm IQCODE]).

**DISCUSSION:** Differences in cultural norms for reporting functional limitations likely influences performance of items on functional limitations and may affect the interpretation of results from substantive studies.

### 1. Introduction

Dementia research in geographically and culturally diverse settings is needed to understand

variation in the causes and consequences of dementia. Although high-quality cross-national research

is important, establishing methods to measure dementia comparably across geographic contexts is This is the author manuscript accepted for publication and has undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the [Version of Record](#). Please cite this article as [doi: 10.1002/ALZ.12994](https://doi.org/10.1002/ALZ.12994).

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challenging [1,2]. The assessment of functional limitations (limitations in both basic and instrumental activities of daily living) is a key component of dementia measurement and an important input into adjudication-based or algorithmic diagnoses of dementia [3]. However, cultural factors surrounding the expectations of older adults can affect the reporting of functional limitations in everyday activities [4,5]. This suggests that for some instruments standardization may not be enough. Instead, careful attention is needed to select the specific instruments and items that have the highest validity and comparability across cultures.

Survey items on functional limitations that have strong associations with cognitive impairment across settings would be expected to have strong associations with dementia as well and should be recommended for use in future research. In contrast, items with weak associations with cognitive impairment and high levels of missing data may lack cultural relevance. In prior work, we showed variability in the performance of items for measuring cognition across countries using data from the Harmonized Cognitive Assessment Protocol (HCAP) surveys [2]. In this paper, we extend this work by assessing the performance of items on functional limitations for the ascertainment of dementia in cross-national research.

## **2. Methods**

### **2.1 Study populations**

This study used baseline data from the HCAP studies in the US [6], England [7], South Africa [8], India [9], and Mexico [10] (total N = 11,364). HCAP study participants were sampled from participants of the larger ongoing Health and Retirement International Partner Studies (HRS IPS) in each country. Samples were nationally representative of private households in countries of interest with the exception of the South African sample, which was representative of the rural Agincourt sub-district. All participants gave informed consent. We excluded data on participants with missing data which precluded the estimation of cognitive impairment, resulting in an analytic sample size of 11,250

(excluded N=62 [US], 18 [England], 46 [South Africa], 1 [India], 56 [Mexico]; total % excluded=1.6%)

(details in Appendix A).

### 2.2.1 Items on functional limitations

Items on functional limitations included across the HCAP surveys included the Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) scales (answered by the respondent), and the Community Screening Instrument for Dementia (CSID), the informant portion of the Blessed Dementia Scale, the Jorm IQCODE, and items from the 10/66 assessment (answered by an informant) (Table 1) [11–14]. All tests were adapted for each HCAP survey and were translated and back-translated into the relevant languages. ADL and IADL items were only included in the England and India HCAP surveys. To ensure consistency between studies, for each HCAP study we used items on ADLs and IADLs from the prior wave of the HRS IPS study. Eight of 11 items on the Blessed test asked if loss in functional limitations was due to physical reasons, mental reasons, or both. We classified individuals with decline due to physical reasons as not having decline as our interest was in cognitive impairment. A sensitivity analysis that instead treated these responses as missing yielded similar results (Appendix A). All items containing more than two response categories (Jorm IQCODE, CSID, Blessed and 10/66) were collapsed to two categories (limitation or decline vs. no limitation or decline) due to small cell counts.

### 2.2.2 Cognitive impairment

We defined cognitive impairment as performance below expected levels based on demographic-specific cognitive norms (robust neuropsychological norms approach) [2]. We used confirmatory factor analysis to estimate cognition in the orientation, executive functioning, memory, and language domains. Using items on functional limitations, self-reported health conditions, and depressive symptoms, we excluded individuals from the normative sample at high risk of having

cognitive impairment [15]. Within this sample, we used multivariable regression to estimate cognitive norms by key demographic variables (details of procedure in Appendix A).

### 2.3 Statistical analysis

Age- and sex-adjusted logistic regression models were used to evaluate associations between each item and cognitive impairment. Individuals with missing data on the item of interest were excluded to ensure evaluations of item performance contained only the information collected; the magnitude of missing data was separately evaluated. Models were not fit if there were fewer than five participants in a given combination of response category and impairment status (details in Appendix A Figure S2). We used heatmaps to compare and contrast patterns of associations. We used the median to summarize across countries or items to avoid outliers having outsized influence. We calculated the standard deviation of effect sizes to quantify variability. We directly compared medians and standard deviations to assess broader patterns of findings.

We conducted two sensitivity analyses. First, we repeated all analyses restricted to participants 65 years and older because some HCAP studies included younger participants. Second, to test the sensitivity of findings to methods used for classification of cognitive impairment we conducted analyses using Latent Class Analysis (LCA) as an alternative data-driven approach (details in Appendix A).

## 3. Results

### 3.1 Samples and items included

All samples included older adults, although the average age was higher in the US and England compared to South Africa, India, and Mexico (Table 1). The US and England had higher numbers of individuals with post-secondary education.

### 3.2 Associations for items on functional limitations

Pooling across countries and comparing the three informant batteries with more than 5 items (Jorm IQCODE, CSID, and the Blessed test), items from the Blessed test (Median OR=3.01; Interquartile range [IQR]=1.72-3.98) and the Jorm IQCODE (Median OR=2.75; IQR=2.29-4.05) both had higher median associations with cognitive impairment compared to the CSID (Median OR=2.23; IQR=1.86-3.08) (Figure 1). However, median variability, as assessed by the standard deviation of the estimated odds ratios between HCAP studies, was highest for the Jorm IQCODE (0.98) compared to the Blessed test (0.92) or the CSID (0.73).

Estimated odds ratios across self-reported IADL limitations for the US (Median OR=5.23), England (Median OR=3.87), and Mexico (Median OR=4.03) were higher compared to India (Median OR=1.71). India also had lower estimated odds ratios across ADL items (Median OR=1.95), than the US (Median OR=2.32), England (Median OR=2.77), and Mexico (Median OR=2.45). However, the median standard deviation between countries in estimated odds ratios was higher for IADL (1.30) compared to ADL items (0.93).

Many of the items with the strongest consistent associations across countries asked specifically about cognitive symptoms (Forgets when saw informant from the CSID; Median OR = 3.77; Range = 2.47 – 5.46), or asked about limitations indicating severe decline (Ability to dress from the Blessed test; Median OR = 3.67; 3.45 – 3.94).

Despite generally strong associations across studies, observed associations were strongest in South Africa (Median OR=3.12), the US (Median OR=3.40), and England (Median OR=2.78), compared to India (Median OR=2.10) or Mexico (Median OR=2.43) (Figure 1). However, in South Africa variability in items was low overall (very few informants reported functional limitations) (Appendix A Figure S3). Therefore, stronger associations in South Africa may not be helpful for classifying a large number of individuals. Sensitivity analyses showed results consistent with primary analyses (Appendix A Figures S4-5).

#### 4. Discussion

We found that the association between items on functional limitations and cognitive impairment varied across geographic contexts. For items from informant reports, it is possible that differences are due to the content of the item in the context of varying cultural expectations, differences in the role and knowledge of informants across countries, or differences in reporting biases of informants.

Of the three batteries of items on functional limitations, the CSID was the only one designed for use in cross-national research [13]. The CSID had lower levels of missing data compared to the Jorm IQCODE (Appendix A Figure S1), and had lower variation in estimated associations with cognitive impairment across countries. However, CSID items had a weaker median association with cognitive impairment. While the CSID measures current difficulties or limitations, items from the Jorm IQCODE and Blessed test largely focus either on a comparison to performance from 10 years earlier or the presence and absence of decline from prior ability. These item characteristics may influence the observed strength of associations, although more direct comparisons are needed to evaluate the influence of specific phrasing characteristics on item performance.

Observed differences in education or differences in the cultural environment (skill patterns, cultural values and expectations, familiarity, and language) likely led to some of the observed differences in associations between cognitive impairment and items on functional limitations. Factors including differences in family patterns and religious practices or other societal values that alter how individuals live, perceive, and think about cognitive impairment can impact responses to items assessing functional limitations due to cognitive decline. Given prior work showing differences across cultures in gender norms or beliefs about personal control can impact reporting of functional limitations [16,17], future work should evaluate the relevance of such factors to specific items administered in the HCAP battery. Findings of consistent associations for items specifically asking about cognitive symptoms (forgets when saw informant), or asking about tasks related to basic daily

functioning (ability to dress), suggest that such items have less cultural variation and should be recommended for future studies.

We found larger differences across countries in the associations between cognitive impairment and IADL items as compared ADL items. This suggests that the IADL scale, which measures behaviors important to functioning in everyday society, may be more likely to require adaptations. This aligns with past work which found significant differential item functioning in IADL items, even when comparing across similar high-income countries [18]. Prior efforts to adapt scales on functional limitations to local cultural contexts may serve as examples to guide future work [19,20].

The first study limitation to consider is that there is no gold-standard adjudication of dementia in the HCAP studies; therefore, we used cognitive impairment as the outcome. However, the neuropsychological norms approach was shown to be valid and has been used in prior research [2,21]. While some items on functional limitations were used in this process, their role was limited to the definition of the normative sample which would not be expected to induce spurious associations. Sensitivity analyses using LCA for classification yielded consistent results. Second, differences in self-report vs. proxy-reports of functional limitations may affect comparisons between self-reported items (ADL/IADL scales) as compared to proxy-reported items (all other items). However, study conclusions limit comparisons between these two distinct sets of items. Third, we focused on one way to assess item quality: the association between cognitive impairment and individual items. However, other metrics such as the magnitude of missing data, variability of binary items, and comprehensive content coverage are also important.

In summary, we found variability in the performance of items on functional limitations for the classification of cognitive impairment. This variation may affect findings from substantive studies. In particular, cross-national studies of dementia rely on the comparable measurement of functional limitations; cultural variability in measurement could lead to bias in such studies. Results provide

concrete guidance on the design of future measurement tools and also motivate the need for more comparable, novel measures of functional limitations.

**Acknowledgements:** The Health and Retirement Study: Harmonized Cognitive Assessment Protocol survey is sponsored by the National Institute on Aging (grant number U01 AG058499) and is conducted by the University of Michigan. The MHAS (Mexican Health and Aging Study) is partly sponsored by the National Institutes of Health/National Institute on Aging (grant number NIH R01 AG018016) in the US and the Instituto Nacional de Estadística y Geografía (INEGI) in Mexico. Data files and documentation are public use and available at [www.MHASweb.org](http://www.MHASweb.org). The LASI-DAD project is funded by grants R01 AG051125, RF1 AG055273, and U01 AG064948 from the National Institute on Aging and the National Institutes of Health. The HCAP substudy in ELSA was funded by R01 AG017644 from the National Institute on Aging. The Dementia substudy of the HAALSI cohort was funded by R01 AG054066 from the National Institute on Aging. The HCAP international network is supported by National Institute on Aging grant R24 AG065182.

**Funding Information:** This work was supported by the National Institutes of Health [grant numbers T32AG000247 and 1F31AG074599 to ELN, R01AG051125 and 2R01AG030153 to JL, K01AG054693 to JAD, and K01AG050699 to ALG].

**Conflicts of Interest:** The authors declare no competing financial interests.

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**Figure 1.** Associations between each item on functional limitations and cognitive impairment by domain for each Harmonized Cognitive Assessment Protocol Studies (HCAP) conducted in the United States (N = 3,329), England (N = 1,255), South Africa (N = 560), India (N = 4,095), and Mexico (N = 2,011) from logistic regression models, controlling for age and gender. Odds ratios are displayed for significant associations. For example, the number 1.90 in the upper left corner indicates that in the United States, individuals who had difficulty dressing had an odds of cognitive impairment that was 1.90 times the odds of dementia for those who did not have difficulty dressing. Grey boxes represent instances where an item was not administered or an odds ratio was suppressed due to small cells. Color scale shows differences in associations on the log odds scale

**Table 1.** Characteristics and items administered in the US, England, South Africa, India, and Mexico Harmonized Cognitive Assessment Protocol (HCAP) samples

Characteristic/Item	United States	England	South Africa	India	Mexico
Number of Participants (N)	3329	1255	560	4095	2011
Years of Data Collection	2016-2017	2018	2016-2017	2017-2019	2015
Age (Mean [SD])	75.8 (64-102)	75.9 (65-90)	69.2 (49-95)	69.0 (60-104)	68.1 (54-104)
Percent Female (N)	60.5% (2014)	54.9% (689)	56.2% (315)	53.9% (2207)	59.3% (1193)
No education - primary education (% [N])	18.2% (607)	33.1% (416)	92.7% (519)	75.3% (3085)	72.9% (1467)
Some secondary - completed secondary education (% [N])	53.0% (1766)	53.9% (676)	5.4% (30)	20.6% (845)	20.8% (419)
Post-secondary education (% [N])	28.7% (956)	13.0% (163)	2.0% (11)	4.0% (165)	6.2% (125)
<b>ADLs</b>					
Difficulty Dressing	X	X	X	X	
Difficulty Walking Room	X	X	X	X	X
Difficulty Bathing	X	X	X	X	X
Difficulty Eating	X	X	X	X	X

Difficulty Transfer Bed	X	X	X	X	X
Difficulty Toileting	X	X	X	X	X
<b>IADLs</b>					
Difficulty Map	X	X			
Difficulty Hot Meal	X	X		X	X
Difficulty Shopping	X	X		X	X
Difficulty Phone Calls	X	X		X	
Difficulty Taking Medications	X	X		X	X
Difficulty Managing Money	X	X		X	X
Difficulty Doing Work Around The House		X		X	
Difficulty Getting Around				X	
<b>Jorm IQCODE</b>					
Remember Family, Friends, Dates	X	X	X	X	
Recall Recent Happenings	X	X	X	X	
Recall Conversations	X	X	X	X	
Recall Address And Telephone Number	X	X	X	X	
Day And Month	X	X	X	X	
Where Things Are Kept	X	X	X	X	
Where To Find Things	X	X	X	X	
How To Work Machines	X	X	X	X	
How To Use New Gadget	X	X	X	X	
Learn New Things	X	X	X	X	
Follow A Story	X	X	X	X	
Everyday Decisions	X	X	X	X	
Handling Money	X	X	X	X	
Financial With Bank	X	X	X	X	
Everyday Math	X	X	X	X	
Intelligence To Reason	X	X	X	X	
<b>Community Screening Instrument for Dementia</b>					
General Decline	X	X	X	X	X
Difficulty Remembering	X	X	X	X	X
Forgets Where Put Things	X	X	X	X	X
Forgets Where Things Kept	X	X	X	X	X
Forgets Friends Names	X	X	X	X	X
Forgets Family Members Names	X	X	X	X	X
Forgets Thoughts	X	X	X	X	X
Hard Time Finding Words	X	X	X	X	X
Uses Wrong Words	X	X	X	X	X
Talks About Past Not Present	X	X	X	X	X
Forgets When Saw Informant	X	X	X	X	X
Forgets What Happened Yesterday	X	X	X	X	X
Forgets Where Is	X	X	X	X	X
Gets Lost In Community	X	X	X	X	X
Gets Lost At Home	X	X	X	X	X
<b>Blessed Test</b>					

Ability To Feed Self	X	X	X	X	X
Ability To Use Toilet	X	X	X	X	
Ability To Dress	X	X	X	X	X
Perform Household Tasks	X	X	X	X	
Coping With Small Sums Of Money	X	X	X	X	
Remember A Short List Of Items Such As A Shopping List	X	X	X	X	
Find Way Around Home	X	X	X	X	
Finding His Her Way Around Familiar Streets	X	X	X	X	
Grasping Situations Or Explanations	X	X	X	X	
Recalling Recent Events	X	X	X	X	
Tending To Dwell On The Past	X	X	X	X	
<hr/>					
<b>10/66 Items</b>					
Household Chores	X	X	X	X	
Special Skill	X	X	X	X	
Handle Money	X	X	X	X	
Adjusting Change	X	X	X	X	
Ability To Think	X	X	X	X	

