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# The Spanish Translation and Adaptation of the Uniform Data Set of the National Institute on Aging Alzheimer's Disease Centers

Amarilis Acevedo, PhD<sup>\*</sup>, Kristin R. Krueger, PhD<sup>†</sup>, Ellen Navarro, MA<sup>‡</sup>, Freddy Ortiz, PhD<sup>§</sup>, Jennifer J. Manly, PhD<sup>||</sup>, Margarita M. Padilla-Vélez, PhD<sup>||</sup>, Sandra Weintraub, PhD<sup>‡</sup>, Oscar L. López, MD<sup>¶</sup>, and Dan Mungas, PhD<sup>#</sup>

\* Department of Psychiatry and Behavioral Sciences, University of Miami Miller School of Medicine, Miami, FL

<sup>†</sup> Department of Behavioral Sciences, Alzheimer's Disease Center, Rush University Medical Center

<sup>‡</sup> Cognitive Neurology and Alzheimer's Disease Center, Northwestern University, Chicago, IL

<sup>§</sup> Department of Neurology, Alzheimer Disease Research Center, David Geffen School of Medicine at UCLA, University of California, Los Angeles

<sup>#</sup> Department of Neurology, University of California, Davis, CA

 $^{\parallel}$  Taub Institute for Research on Alzheimer's Disease and the Aging Brain, Columbia University Medical Center, New York, NY

<sup>¶</sup> Department of Neurology & Psychiatry, University of Pittsburgh School of Medicine, Pittsburgh, PA

# Abstract

Researchers from Alzheimer's Disease Centers (ADCs) across the United States with expertise in the assessment of Spanish-speaking elderly collaborated to create the official Spanish version of measures in the Uniform Data Set of the National Institute on Aging Alzheimer's Disease Center Program. The present article describes this project, whose primary goal was to create Spanish instruments with cultural and linguistic equivalence to the English versions. The resulting Spanish versions make provisions for variations among Spanish-speaking groups in the United States of different nationalities, socio-cultural, linguistic, and educational backgrounds. A consensus-based translation and adaptation approach was used, and guiding principles and specific components of this process are summarized. The Spanish translation and adaptation of the Uniform Data Set measures became available online to ADCs in April 2007. Its creation is important, as the resulting effort provides standardized measures for the collection of cross-sectional and longitudinal data on a large cohort of Spanish-speaking elders across the country and facilitates collaborative research among ADCs.

#### Keywords

Alzheimer disease; mild cognitive impairment; aging; neuropsychologic; Spanish; Hispanic

Reprints: Amarilis Acevedo, PhD, Department of Psychiatry and Behavioral Sciences, University of Miami Miller School of Medicine, MRI Building, 2nd Floor, 4300 Alton Road, Miami Beach, FL 33140 (aacevedo3@med.miami.edu).

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The demographic landscape of the aging population in the United States has changed considerably during the past 50 years, a trend that is expected to continue into the coming decades. Although the largest proportion of older adults in the United States is non-Hispanic White, comprising 83% of the elderly at present, this proportion is expected to decrease to 61% by 2050.<sup>1</sup> Conversely, the proportion of older adults in the United States who are individuals of Latino background (In this article, the term individuals of Latino Background (ILB) is used instead of "Hispanic" to emphasize the heterogeneity that characterize this rapidly growing segment of the population.) is expected to increase from 6% at present to 18% by 2050.<sup>1</sup>

In the United States, about 28 million people from over 20 countries of reference speak Spanish at home and about half of them speak English less than "very well."<sup>2</sup> Individuals of Mexican ancestry constitute 67% of all ILB in the United States, followed by individuals from Puerto Rico (9%) and Cuba (4%), with the remaining 20% tracing their origin to other Spanishspeaking countries.<sup>3</sup> The different Spanish-speaking groups are not homogeneously distributed across the United States. For example, 55% of individuals of Mexican descent live in the West of the United States, 58% of individuals of Puerto Rican background live in the Northeast, and 75% of individuals of Cuban descent live in the South of the country.<sup>3</sup> Demographic characteristics such as age and educational attainment, which have been associated with the likelihood of developing dementia in older age, also vary among the different groups of ILB in the United States. Specifically, individuals of Cuban descent comprise the largest group of ILB over the age of 65 years in the United States, whereas those of Mexican descent comprise the youngest cohort.<sup>3</sup> In addition, among ILB residing in the Unites States, individuals of Cuban descent have the highest educational attainment whereas those of Mexican descent have the lowest.<sup>3</sup> These between-group differences underscore the need for cognitive and functional measures that have wide applicability to groups of older Spanish speakers in the United States from varied nationalities and socio-demographic backgrounds.

The study of older adults of Latino background in the United States is important for a number of reasons. Older ILB residing in the United States have a high prevalence of diabetes,<sup>4</sup> stroke, <sup>5</sup> uncontrolled hypertension,<sup>6,7</sup> vascular pathology,<sup>8</sup> and factors known to increase the risk for cognitive decline and dementia.<sup>9–14</sup> ILB in the United States have limited access to adequate medical care,<sup>15–17</sup> which hinders the medical management of these conditions. In addition, as a result of various socio-political and geo-historical factors, a considerable proportion of ILB residing in the United States have relatively low educational and occupational attainment and low socio-economic status,<sup>3</sup> which may increase the likelihood of developing dementia in old age.<sup>10,18,19</sup> These risk factors and the increasing life expectancy of ILB in the United States<sup>20</sup> and in their respective countries<sup>21</sup> suggest that the number of older ILB who will develop age-related dementias is likely to increase in the United States and in Spanish-speaking countries in the next decades.

At present, there are 29 federally funded Alzheimer's Disease Centers (ADCs) in the United States, with an increasing number of Spanish-speaking ILB being assessed at these centers. In an effort to collect uniform data on Spanish-speaking ADC participants, a Work Group of experts was selected to generate Spanish-translated and adapted versions of the measures used at the ADCs. This report describes the process of translation and adaptation into Spanish of a set of behavioral, functional, and neuropsychologic measures used by the ADCs across the country.

#### **METHODS**

#### **General Background**

In 1984, the National Institute of Aging (NIA) established a program for the creation of the ADCs in the Unites States. In 1999, NIA created the National Alzheimer's Coordinating Center

(NACC) under the direction of Walter Kukull at the University of Washington in Seattle to promote the creation of a database that would integrate data from ADCs across the country. For this purpose, in 2002, NIA selected a Clinical Task Force (CTF) under the direction of John Morris from Washington University in St Louis that would select a set of clinical, behavioral, and neuropsychologic measures known as the Uniform Data Set (UDS).

The purpose of the UDS was to promote the collection of data on a consistent set of measures, to be administered and scored in a uniform manner, which would allow the characterization of ADC participants across the nation. The UDS was implemented at all ADCs in September 2005 and a website was created to collect and manage UDS data and to serve the public (see Ref. <sup>22</sup>). From its inception, one of the goals of the UDS was to describe the clinical features of Alzheimer disease (AD) not only in English-speaking older adults but also in individuals of varied ethno-cultural/linguistic backgrounds (see Ref. <sup>23</sup>).

Over the past few years, the number of ILB assessed at ADCs has increased considerably. Because there was no official Spanish translation of the UDS for the assessment of Spanishspeaking participants, ADCs had to resort to local translations generated at the individual sites, resulting in varied versions of the instructions, item content, and scoring procedures. In 2005, the CTF recommended the creation of a Work Group that, under the direction of Dan Mungas from the University of California at Davis, would create a uniform Spanish translation of the neuropsychologic measures and other measures of the UDS. The official Spanish version of these instruments would then allow the uniform collection of data of Spanish-speaking participants from across the country and would allow comparative analyses with respect to their English-speaking counterparts. This would provide cross-sectional and longitudinal data, to be submitted to NACC, on a large cohort of Spanish-speaking older adults with mild cognitive impairment, mild dementia, or normal cognition. The Spanish versions generated by the Work Group would then constitute the standard protocol to be adopted by the ADCs to assess Spanish-speaking participants and to facilitate collaborative research among these centers. The purpose of the current report is to present the rationale and process of translation and adaptation of the UDS protocol into Spanish, which may serve as a model to guide similar efforts by other research groups across the country.

#### Procedure

In the summer of 2005, Dan Mungas contacted ADCs to identify investigators with expertise in the assessment of Spanish-speaking older adults who may be interested in joining the Spanish Translation and Adaptation Work Group (STAWG). The STAWG, constituted in September 2005, was composed of investigators from ADCs that assess varied groups of Spanish-speaking older adults in the United States, particularly those whose country of reference is Mexico, Puerto Rico, Cuba, Dominican Republic, and other Latin American countries. In addition to Dan Mungas (chair), the members most directly involved in the present effort were, in the alphabetical order, Amarilis Acevedo (University of Miami Miller School of Medicine), Kristin Krueger (Rush University Medical Center), Jennifer Manly (Columbia University), Ellen Navarro (Northwestern University), Freddy Ortiz (University of California, Los Angeles), Margarita Padilla-Vélez (Columbia University), and Sandra Weintraub (Northwestern University).

The mandate to STAWG was to generate Spanish versions of the neuropsychologic measures in the UDS and of 3 questionnaires that are completed by patients or informants who participate in the ADCs (Table 1). The latter consist of the 15-item Geriatric Depression Scale (GDS-15), <sup>34</sup> the brief version of the Neuropsychiatry Inventory Questionnaire (NPI-Q),<sup>32,33</sup> and the Functional Assessment Questionnaire (FAQ).<sup>24</sup> Materials to be translated included instructions to the participant or informant, the content and/or items of the measures, and where appropriate, translation of the scoring guidelines. Selecting tests that were different from those in the English

Page 4

UDS protocol was not an option, as the primary goal of the project was to generate analogous Spanish versions of the existing measures, thus allowing comparative analysis of Englishspeaking and Spanish-speaking ADC participants. In addition, there were legal agreements already in place between NACC and the publishing companies of the instruments that limited the type and nature of changes that could be made to the measures. Given that the examiners administering the Spanish version of these instruments would be English-Spanish bilinguals, translation of the form instructions to the examiners was deemed unnecessary.

The first step undertaken by STAWG was the identification of published translations of the target instruments and local translations of the same that were available to members of the group. In October 2005, STAWG circulated existing translations of the instruments for broad review and discussion. In the first conference call in November 2005, STAWG determined that the group at large would review the distributed versions of the Mini-Mental Status Examination (MMSE),<sup>31</sup> Trail Making Test (TMT),<sup>26</sup> Category Fluency,<sup>25</sup> Digit Span,<sup>30</sup> and Digit Symbol.<sup>27</sup> Subcommittees were created to conduct in-depth analyses of available versions of Logical Memory<sup>30</sup> and the Boston Naming Test (BNT)<sup>35</sup> as well as of the GDS-15, NPI-Q, and the FAQ. The subcommittees would then generate working versions of these measures to be distributed to the group at large for discussion at consensus conference calls.

After extensive review and discussion in a series of conference calls, in March 2006, STAWG assembled working versions of the TMT, Category Fluency, Digit Span, Digit Symbol, and the BNT. During subsequent months, working versions of Logical Memory, FAQ, GDS-15, and NPI-Q were generated, and all working versions were modified to be consistent with version 1.2 of the UDS, which was released in April 2006. In June 2006, the working versions of the Spanish-adapted instruments were sent to NACC for formatting. After further fine-tuning by STAWG, in November 2006, the formatted versions of the target instruments were submitted to the CTF, which distributed them to the ADCs for feedback. Following feedback, additional revisions were made by STAWG, with the revised instruments submitted in January 2007 to NACC for formatting and, subsequently, to the CTF for approval. Approval by the CTF followed and the first official version of the measures were made available online in April 2007 for immediate implementation in ADCs across the nation.

#### General Guidelines Adopted for the Translation and Adaptation of Measures

As part of the process of translation and adaptation, STAWG established 5 general principles to guide its work:

- 1. The STAWG effort would be one of translation and adaptation of the instruments rather than literal translation. The distinction between literal translation and adaptation is important, as the former usually results in a word-for-word translation of the instrument that may result in expressions that may be unnatural and difficult to understand in the target language whereas the latter aims for conceptual and cross-cultural equivalence of the instrument's content. Procedurally, STAWG would rely on successive review and revision of the working drafts of the instruments instead of backward translation as suggested by Stanfield,<sup>36</sup> and final decisions would be made by consensus.
- 2. The ultimate goal of STAWG was to create Spanish versions of the instruments with cultural and linguistic equivalence to the English versions and that, although aiming for some degree of universality, would make provisions for variations among Spanish speakers of different nationalities, socio-cultural/linguistic backgrounds, and regions of residence in the United States. The latter is important given the differential geographic distribution of ILB from different countries of origin across different

regions of the United States (see above) and the resulting dissimilar demographic characteristics of Spanish speakers seen at different ADCs.

- **3.** STAWG would follow the administration instructions of the English UDS protocol closely, unless it was determined that specific modifications would facilitate comprehension of the instructions by Spanish speakers, particularly those with limited schooling.
- 4. Given the heterogeneity of Spanish speakers in the United States and their lexical diversity, the dictionary of the Royal Spanish Academy (ie, Diccionario de la Real Academia Española) would be used as a guide along with dictionaries with a broader representation of words and idiomatic expressions used in Latin American countries.
- 5. Special guidelines would be created for UDS measures that presented unique challenges in the translation and adaptation efforts. This particularly applied to the BNT and, to a lesser degree, Logical Memory, which presented the most challenges regarding linguistic equivalence and cultural relevance in relation to the English version and to generalizability when used with Spanish speakers of varied nationalities and backgrounds (see below). Given that it was impossible to present all conceivable correct responses for all measures in the UDS Coding Guidebook for the Spanish Module, it was agreed that the Guidebook would advise examiners to query unfamiliar responses provided by ADC participants and to consult with a comprehensive Spanish dictionary and a reliable source that is knowledgeable about the participant's group of reference.

#### Translation and Adaptation of Individual Instruments

**BNT**—The BNT is a widely used measure of confrontation naming that consists of 60 black and white line drawings of objects that the examinee is asked to name. The English UDS version of the BNT consists of the 30 odd-numbered items of the test, which are administered in order starting with item 1 and with semantic and phonemic cues provided as needed. In the English UDS version, testing is discontinued after 6 consecutive trials where the subject is unable to name the item spontaneously or after the provision of the stimulus cue. The BNT is frequently used by neuropsychologists to assess Spanish speakers in the United States.<sup>37</sup>

Variables related to cultural, educational, and/or linguistic factors can have a substantial impact on performance in the BNT.<sup>38–44</sup> In addition, naming difficulty of the items varies as a function of their written and oral word frequency for a given language, the age at which the examinee learned the item's name, the examinee's familiarity with the depicted object, and the cultural meaningfulness of the item. Because of this, translation and adaptation of the BNT to other English-speaking<sup>45</sup> and non-English-speaking samples have resulted in the elimination, substitution, or reordering of BNT items.<sup>28,39,41,46–48</sup>

The BNT has been officially translated into Spanish by Editorial Médica Panamericana (Panamerican Medical Publishing Company) in agreement with Pro-ED. The first official Spanish edition<sup>29</sup> substituted 12 items of the standard BNT (ie, the 60-item English BNT version by Kaplan et al<sup>35</sup>) for 12 items created de novo that were considered more culturally and/or linguistically appropriate when used with Spanish speakers. The order of presentation of the 60 items of the official 1996 Spanish edition mirrors the order of presentation of the standard BNT, except that each of the 12 new items takes the place of the item it was created to substitute. The second official Spanish edition of the BNT was published in 2005,<sup>49</sup> where 5 of the 12 items of the standard BNT that had been substituted in the 1996 Spanish edition were reincorporated into the test.

In its translation and adaptation efforts, STAWG selected the 1996 official Spanish version of the BNT as the starting point. This decision was based on 3 characteristics of the 1996 version. First, it had already identified and eliminated items that could be problematic when used with Spanish speakers. Second, it had provided 12 alternate, more appropriate items from which to choose. Third, it offered the highest degree of flexibility for STAWG in the selection of items that would be applicable for the use with older Spanish-speaking ADC participants from different nationalities and backgrounds. The latter is important, as most of the studies that have used the official Spanish BNT versions have been based on the samples from Spain and Argentina.<sup>50–53</sup> It is noted that existing agreements between NACC and the BNT publishing companies required that the order of presentation of the items in the resulting UDS Spanish BNT version.

For the selection of the 30 items for the UDS Spanish version of the BNT, STAWG followed a multistep process based on the following 5 criteria, presented in order of importance as set by STAWG:

- **1.** Only items in the official 1996 Spanish BNT that seemed appropriate for Spanish speakers in the United States would be considered.
- 2. Precedence would be given to items that had high name agreement among individuals of different Spanish-speaking countries and to items that would require only 1 phonemic cue, even if more than 1 correct label was identified (eg, the phonemic cue "pe" would apply to the correct words "peine" or "peinilla" for "comb"). Alternate correct responses, including those whose difference lies on the prosodic and thus orthographical accent (eg, "dominó" and "dómino" for "dominoes") would be identified and scored as correct if produced spontaneously or after a semantic cue.
- **3.** Precedence would be given to items that, in conjunction with the other selected items, would provide a range of naming difficulty when used with Spanish speakers. Although in the standard English BNT, the items are presented in ascending order of difficulty, previous agreements with the corresponding publishing companies (see above) required that the order of presentation of items in the Spanish UDS version followed that of the official 1996 Spanish BNT version.
- 4. Special consideration would be given to the 12 items of the 1996 BNT Spanish version that were shown by Serrano et al<sup>53</sup> to have high sensitivity and specificity in the identification of Spanish-speaking elderly AD patients versus those who were cognitively normal and that, in addition, were not biased by education.
- 5. If appropriate, preference would be given to items that were part of the English UDS version of the BNT to facilitate item analyses between the English-speaking and Spanish-speaking ADC samples.

To make the above-mentioned determinations, STAWG conducted an extensive review of the literature in cross-cultural and linguistic issues on the BNT in general, and on individual BNT items in particular. Preference was given to studies that examined performance on the BNT of Spanish speakers in the United States, <sup>28,39–42,54,55</sup> Latin America, <sup>50,53</sup> and Spain. <sup>51,56</sup> In addition, STAWG surveyed its members for additional information generated at their ADCs (eg, BNT item analysis data) that could assist in this process. Word frequency was taken into consideration, although a word corpus of Spanish could not be identified that included all BNT items, that was based on a diversified sample of Spanish speakers from various Spanish-speaking countries, that was current, and was based on both written and spoken media.

The application of the above-mentioned selection criteria resulted in the 30-item UDS Spanish version of the BNT. Of the 30 items, 17 (57%) are included in the English UDS version of the BNT. The Spanish version also includes 8 of the 12 items shown by Serrano et al<sup>53</sup> to have

Acevedo et al.

high degree of discrimination for AD versus normal cognition in Spanish-speaking elderly. It is noted that 5 of the 30 items (17%) in the UDS Spanish version have Spanish alternate correct responses.

**Logical Memory, Story A**—The English UDS battery of tests includes Story A of the Logical Memory subtest of the Wechsler Memory Scale-Revised (WMS-R).<sup>30</sup> In this subtest, examinees were asked to read a short story and then asked to recall the information (immediate recall). The examinee is then instructed to try to remember the story because she/he will be asked to recall it later. After a 20-minute filled delay, the participant is asked to recall the story (delayed recall). For both immediate and delayed recall of the story, the participant's recall is recorded and recall units are scored according to standard test procedures.

In translating and adapting this test, STAWG paid particular attention to issues of cultural and linguistic equivalence to the English version while aiming for a product that would be acceptable to a diverse population of Spanish speakers in the United States. This resulted in the substitution of some story elements with new words or phrases. For example, in determining the term to be used for "south Boston," STAWG agreed to maintain the descriptor of "south," to select a state rather than a city, thus increasing the likelihood that the name would be familiar to ILB residing in different states across the country, and to select a word with a Spanish origin that could be easily understood by Spanish speakers and easily pronounced according to Spanish language rules. On the basis of these criteria, "sur de Tejas" (South of Texas) was selected. Special attention was also paid to scoring criteria that if translated literally from English would result in scoring errors. For example, the English scoring criteria for "small children" stipulate that "sons" (translated as "hijos" in Spanish) is a 0-point response. However, the words "sons" and "children," when the latter refers to offspring of 2 people rather than an underage individual, can be translated into Spanish as "hijos". Thus, the term "hijos" in Spanish corresponds to a 1-point response, unless the examinee uses words to exclusively refer to male children (eg, "hijos varones").

**Category Fluency Test**—The Category Fluency Test is a timed task that assesses the ability to produce words that belong to a specified semantic category. In the UDS version of the test, the subject is allowed for 60 seconds to retrieve words that belong to the category of "animals," followed by a 60-second trial for retrieval of words from the category of "vegetables." A brief practice trial, where the subject is asked to produce words belonging to the category of "articles of clothing," followed by feedback, precedes the administration of the actual test. The UDS manual includes specific scoring guidelines to examiners.

For the translation and adaptation of the Category Fluency Test, STAWG followed the general guidelines mentioned above. For example, in a previous study with 316 English-speaking and 237 Spanish-speaking adults in the United States (see Ref. <sup>57</sup>) it was noted that, in contrast to their English-speaking peers, Spanish-speaking adults with limited schooling did not fully understand the word "category." Thus, STAWG modified the instructions in the Spanish version by including the words "grupo" (ie, "group") and "categoría" (ie, category) to eliminate this potential confound.

**MMSE**—The MMSE is a commonly used screening tool for cognitive impairment. The test includes a brief assessment of orientation, attention, registration, recall, and language. Previous research suggests that demographic variables such as age, educational attainment, and/or ethnicity affect performance on the MMSE.<sup>58–60</sup> It should be noted that the UDS had a preexisting agreement with Psychological Assessment Resources (PAR) to use their English and Spanish versions of the MMSE. The PAR Spanish MMSE, developed in Argentina, did not match one-for-one with the English version and included region-specific items that were not inclusive enough for the diverse cohort of ILB that participate in the ADCs across the

**TMT**—The TMT is a timed test that consists of Part A and Part B, both of which assess psychomotor and visual tracking speed. Part B is more complex than Part A because, in addition, it assesses cognitive flexibility, requiring the examinee to alternate between numbers and letters in sequence. The UDS version of the test follows standard administration procedures. It is noted that the TMT is the second most frequently used test by neuropsychologists when assessing Spanish speakers in the United States.<sup>37</sup>

the MMSE to translate and adapt, was agreed upon based on its non-region-specific words and

on its utility in previous studies with Spanish-speaking elderly (see Ref. <sup>61</sup>).

For the translation and adaptation of the TMT, STAWG followed the general guidelines mentioned above. For example, the present subjunctive form of the Spanish verbs "comenzar" or "empezar" can be used to translate the verbs "start" and "begin" in the English TMT. Word frequency dictionaries in Spanish were consulted<sup>62</sup> and the verb with higher frequency (ie, empezar) was selected to facilitate comprehension of the instructions by Spanish speakers with low educational attainment.

**Digit Span**—The Digit Span test is a measure of auditory attention and working memory where the subject is asked to repeat strings of numbers of increasing length. In the first portion of the test, the subject is required to repeat the numbers in the same order as the examiner. In the second portion of the test, the subject is asked to repeat the numbers in backward fashion. The UDS version of the test is based on the WMS-R.<sup>30</sup> The UDS version differs from the WMS-R version in that, before starting to read each string of numbers, the UDS examiner alerts the subject that a new string of numbers is about to be read.

For the translation and adaptation of Digit Span, STAWG followed the general guidelines mentioned above. As mentioned by other investigators (see Ref. <sup>63</sup>), because of linguistic and cultural factors, individuals raised and educated in Spanish-speaking countries are frequently unfamiliar with tasks that require spelling or repeating digits, especially in backward fashion. To ensure that Spanish-speaking participants understood the instructions on the digit backward condition, the words "hacia atrás" (ie, backwards) in combination with "al revés" (ie, the other way around) were used to emphasize the backward nature of the test and to use terms that would be understandable to Spanish speakers of different nationalities and backgrounds.

**Digit Symbol**—The Digit Symbol test is a timed task that assesses visual attention, scanning, and coding as well as graphomotor speed. The UDS version of the test corresponds to the revised edition of the Wechsler Adult Intelligence Scale-Revised.<sup>27</sup> For the translation and adaptation of Digit Symbol, STAWG followed the general guidelines mentioned above.

**The FAQ**—The FAQ is an informant-based questionnaire designed to measure the ability of older adults, over the previous 4 weeks, to perform 10 activities of daily living (eg, writing checks, paying bills, and balancing a checkbook). Information is rated on a 4-point scale, were 0 is "normal" and 3 is "dependent." In translating and adapting this questionnaire, STAWG reviewed published Spanish translations by other groups (see Ref. <sup>64</sup>), in addition to Spanish translations of the instrument compiled by STAWG members. For the translation and adaptation of the FAQ, STAWG followed the general guidelines mentioned above. For example, in one of the items, the informant is asked to rate the degree of difficulty of the participant when playing bridge. As a large number of Spanish speakers from Latin America

Acevedo et al.

are not familiar with the game bridge, the item was adapted to refer to "jugar cartas o canasta" (ie, play cards or bridge). In addition, as STAWG members considered that there was no universal translation into Spanish of the word "hobby," the term "pasatiempo" (ie, pastime) was selected.

**The GDS-15 Items**—The GDS-15 consists of 15 items that are responded in a yes-no fashion by the examinee based on how she/he has felt in the past week. In working with this measure, STAWG examined studies that have published Spanish versions of the GDS (see Refs. <sup>65,66</sup>) and local translations of the instrument compiled by STAWG. For the translation and adaptation of the GDS-15, STAWG followed the general guidelines mentioned above. For example, the group agreed on using the terms "inútil" and "sin remedio" in the Spanish translation of the terms "pretty worthless" and "hopeless," respectively, to convey the corresponding meaning in English, while ensuring that the terms would be understandable to individuals from different countries of reference and varied socio-cultural and educational backgrounds.

**The NPI-Quick Version (NPI-Q)**—The NPI is a validated instrument that assesses psychopathology in individuals with dementia.<sup>33</sup> Similar to the original NPI, the abridged version of the instrument, known as NPI-Q (see Ref. <sup>32</sup>), assesses 12 core neuropsychiatric domains (ie, delusions, hallucinations, agitation, dysphoria, anxiety, euphoria, apathy, disinhibition, irritability/lability, aberrant motor behavior, night-time behavior disturbances, and appetite/eating abnormalities) that may be present in dementia. The instrument rates the severity and frequency of each neuropsychiatric symptom based on scripted questions administered to the patient's informant. The NPI and NPI-Q have been translated and validated in several languages, including Italian, Greek, Korean, and Spanish (see Refs. <sup>67–70</sup>).

To translate and adapt the NPI-Q, STAWG examined studies that had validated the measure in Spanish-speaking samples (see Ref. <sup>68</sup>) and local translations of the instrument compiled by the group. Special consideration was given to the translation of idiomatic expressions in the NPI-Q. For example, one of the items in the instrument queries about whether the participant "become[s] upset," a phrase that can be translated into Spanish in different ways. After considering various options, the STAWG agreed on the term "se molesta" to ensure that the question would be understood by individuals of diverse socio-cultural and educational backgrounds. Another item in the instrument uses the expression to be "in low spirits" which, if translated literally, would be "bajos espíritus," a meaningless term in Spanish that could have been interpreted by examinees as referring to spiritual or religious influences or experiences. In this case, STAWG reached consensus between their different ADC bilingual bicultural members on using the term "moral baja," as in the context of the sentence, this idiomatic expression in Spanish conveys a meaning akin to "low spirits" in American English.

## CONCLUSIONS

For years, ADCs across the country have collected longitudinal data in a large number of English-speaking older adults with normal cognition, mild cognitive impairment, AD, or other dementias. Efforts to collect comparable data in Spanish-speaking ADC participants were limited by the lack of a uniform Spanish version of measures in the UDS battery. To address this limitation, STAWG was constituted in September 2005 and after extensive analysis, discussion, and revisions, in April 2007, the Spanish UDS module was made available online to ADCs. The Spanish version of the UDS battery allows consistent administration and scoring of the measures and the collection of data that would allow the characterization of the clinical features of normal and abnormal cognitive aging and of dementia risk factors among ILB in the United States. A parallel exciting development is the Spanish language packet, currently under development by NACC (see Ref. <sup>71</sup>), which will allow investigators to retrieve and

analyze data collected at ADCs using the Spanish UDS instruments. The work described in this report is an important first step in furthering our understanding of aging and dementia among ILB. Future studies are needed to examine the psychometric properties of the Spanish UDS instruments, including their reliability, validity, discriminative ability, and sensitivity to longitudinal cognitive change, as well as the impact of socio-demographic variables on progression to clinically significant end points. In addition, the possibility of differential validity of the measures across different groups of ILB residing in the United States needs to be systematically assessed. Collaboration among ADCs that assess large numbers of Spanish speakers will allow us to characterize ILB, the fastest growing segment of older adults in the United States.

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Acevedo et al.

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#### TABLE 1

## Measures in the English Uniform Data Set That Were Translated and Adapted Into Spanish

Domain	Measures
Neuropsychologic/cognitive tests	
Overall Cognitive Screen	Mini-Mental State Examination (Folstein et al) <sup>24</sup>
Verbal Episodic Memory	Logical Memory-Immediate (Wechsler) <sup>25</sup>
	Logical Memory-Delayed (Wechsler) <sup>25</sup>
Attention	Digit Span-Forward (Wechsler) <sup>25</sup>
	Digit Span-Backward (Wechsler) <sup>25</sup>
Semantic Memory and Language	Category Fluency (Morris et al) <sup>26</sup>
	Boston Naming Test (Kaplan et al) <sup>27</sup>
	Test de Vocabulario de Boston [Boston Naming Test] (Kaplan et al) <sup>28,29</sup>
Psychomotor Speed and Visuospatial Function	Digit Symbol (Wechsler) <sup>30</sup>
	Trail Making Test-Part A (Adjutant General's Office) <sup>31</sup>
Executive Function	Trail Making Test-Part B (Adjutant General's Office) <sup>31</sup>
Functional Status, Neuropsychiatric Status, and Depression	Functional Assessment Questionnaire (Pfeffer et al) <sup>32</sup> Neuropsychiatric Inventory Questionnaire-Brief Version (Kaufer et al) <sup>33</sup> Geriatric Depression Scale-15 Item (Sheikh and Yesavage) <sup>34</sup>