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### Permalink

<https://escholarship.org/uc/item/8kg9j94c>

### Journal

The patient, 10(1)

### ISSN

1178-1653

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### Publication Date

2017-02-01

### DOI

10.1007/s40271-016-0191-y

Peer reviewed

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**The Patient - Patient-Centered Outcomes Research**

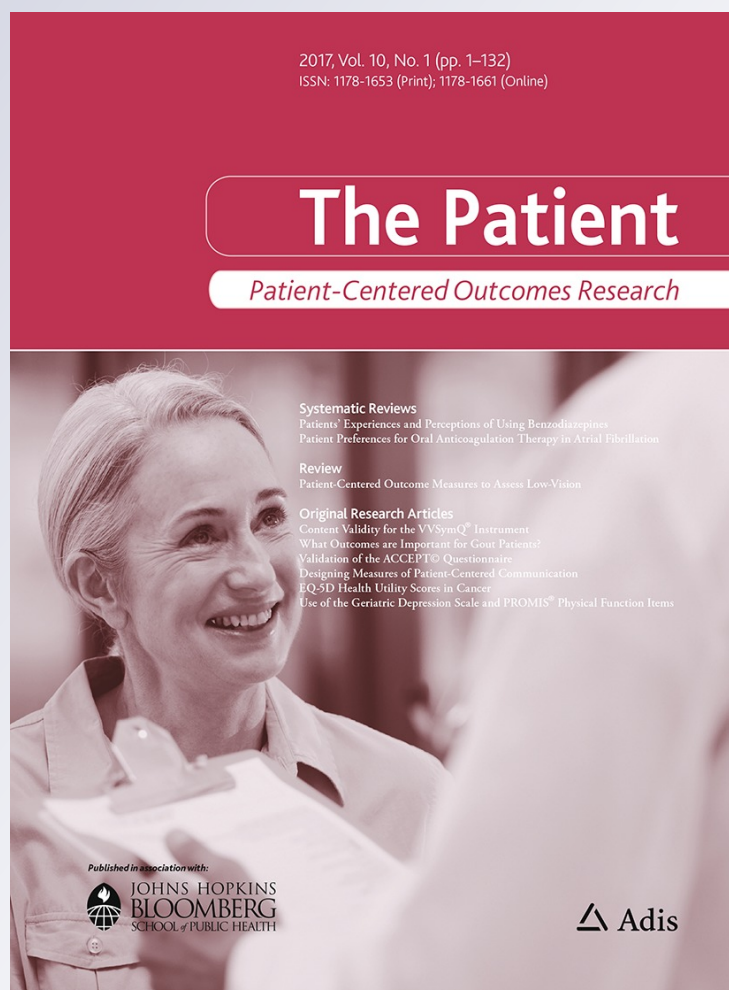
ISSN 1178-1653

Volume 10

Number 1

Patient (2017) 10:117-131

DOI 10.1007/s40271-016-0191-y



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# Readability and Comprehension of the Geriatric Depression Scale and PROMIS<sup>®</sup> Physical Function Items in Older African Americans and Latinos

 Sylvia H. Paz<sup>1</sup> · Loretta Jones<sup>2,3</sup> · José L. Calderón<sup>1</sup> · Ron D. Hays<sup>1,4</sup>

 Published online: 7 September 2016  
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## Abstract

**Background** Depression and physical function are particularly important health domains for the elderly. The Geriatric Depression Scale (GDS) and the Patient-Reported Outcomes Measurement Information System (PROMIS<sup>®</sup>) physical function item bank are two surveys commonly used to measure these domains. It is unclear if these two instruments adequately measure these aspects of health in minority elderly.

**Objective** The aim of this study was to estimate the readability of the GDS and PROMIS<sup>®</sup> physical function items and to assess their comprehensibility using a sample of African American and Latino elderly.

**Methods** Readability was estimated using the Flesch–Kincaid and Flesch Reading Ease (FRE) formulae for

English versions, and a Spanish adaptation of the FRE formula for the Spanish versions. Comprehension of the GDS and PROMIS<sup>®</sup> items by minority elderly was evaluated with 30 cognitive interviews.

**Results** Readability estimates of a number of items in English and Spanish of the GDS and PROMIS<sup>®</sup> physical functioning items exceed the U.S. recommended 5th-grade threshold for vulnerable populations, or were rated as ‘fairly difficult’, ‘difficult’, or ‘very difficult’ to read. Cognitive interviews revealed that many participants felt that more than the two (yes/no) GDS response options were needed to answer the questions. Wording of several PROMIS<sup>®</sup> items was considered confusing, and interpreting responses was problematic because they were based on using physical aids. **Conclusions** Problems with item wording and response options of the GDS and PROMIS<sup>®</sup> physical function items may reduce reliability and validity of measurement when used with minority elderly.

**Electronic supplementary material** The online version of this article (doi:10.1007/s40271-016-0191-y) contains supplementary material, which is available to authorized users.

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## Key Points for Decision Makers

The Geriatric Depression Scale (GDS) and Patient-Reported Outcomes Measurement Information System (PROMIS<sup>®</sup>) physical function item bank are commonly used surveys to measure important health domains in the elderly.

Problems with readability, item comprehension, and incorrect responses were revealed in this study.

Caution is needed when using these two surveys with minority elderly.

## 1 Introduction

Depression is projected to be the leading cause of global disability by 2020 and is independently associated with poor physical functioning [1–5]. The prevalence of depression is as high as 15–20 % for community-dwelling elderly persons in the US and is disparately higher for race/ethnic minority elderly [1, 2, 4–6].

The number of elderly persons in the US (age  $\geq 65$  years) is rising at a historically unparalleled rate [7, 8]. The Latino elderly population represented 6 % of all elderly in 2005 and is projected to comprise 17 % by 2050 [7–9] while African Americans represented 8 % of all elderly in 2005 and are projected to comprise 12 % by 2050 [7–9].

Race/ethnic minority elderly (African American and Latinos) currently comprise approximately 68 % of all elderly persons living in poverty [10–13]. Race/ethnic minority elderly living in poverty tend to have limited educational attainment, poor reading skills and limited access to quality healthcare [14–17]. Consequently, they have limited health literacy that is further impaired by cognitive decline associated with aging, poorly controlled chronic disease, and polypharmacy.

An important challenge facing investigators and healthcare delivery systems is monitoring symptoms of depression and physical functioning with high rates of non-response to surveys by older race/ethnic minorities. The cognitive demands of completing surveys is an important factor influencing survey non-response. High levels of survey readability that require higher levels of education to be understood are associated with item missing data [18]. US norms recommend that surveys do not include items that require more than 8 or 9 years of formal schooling for the general population, and more than 5 years of formal schooling for vulnerable populations [16, 17].

Two commonly used measures are the Geriatric Depression Scale (GDS) and the Patient-Reported Outcomes Measurement Information System (PROMIS<sup>®</sup>) physical function item bank [19–25]. The purpose of this study was to assess (1) cognitive demand for completing the GDS and the PROMIS<sup>®</sup> physical function item bank by measures of readability; and (2) comprehension of these surveys by Latino and African American elderly using cognitive interviews.

## 2 Methods

### 2.1 Study Surveys

#### 2.1.1 Geriatric Depression Scale (GDS)

Extensive support for the reliability and validity of the GDS has been reported [26–28]. The GDS has shown a

92 % sensitivity and 89 % specificity to clinical diagnoses of depression among the elderly. Because most Spanish-speaking participants of this study were of Mexican background, this study used the original Spanish translation based on Mexican Spanish [29]. The GDS asks participants to respond ‘yes’ or ‘no’ to 30 questions about how they have felt during the past week. The score is calculated by giving one point to each of the following responses: ‘NO’ to items 1, 5, 7, 9, 15, 19, 21, 27, 29, and 30; and ‘YES’ to items 2, 3, 4, 6, 8, 10, 11, 12, 13, 14, 16, 17, 18, 20, 22, 23, 24, 25, 26, and 28 (see Supplementary Appendix A). Scores of 0–9 are considered ‘normal’, 10–19 are considered ‘mild depressive symptoms’, and 20–30 are considered ‘severe depressive symptoms’ [29].

#### 2.1.2 Patient-Reported Outcomes Measurement Information System (PROMIS<sup>®</sup>) Physical Function Item Bank

The PROMIS<sup>®</sup> physical functioning item bank is a relatively new instrument consisting of 124 items that assess mobility (lower extremity), dexterity (upper extremity), axial or central (neck and back function), and daily living activities using five response options. The bank was developed and evaluated using state-of-the-science item response theory methods that enhance precision and efficiency of administration [22–25, 30–33]. Multiple PROMIS<sup>®</sup> physical functioning short-forms of varying length have been created, with the number of items ranging from 4 to 20. The subset of items administered were those most likely to be administered in future studies because they are included in the longest physical functioning short-form and other short forms [25, 33]. English and Spanish-language versions of the instruments included in this study are provided in Supplementary Appendix A.

### 2.2 Study Population

Individuals were eligible for inclusion in the study if they self-reported being African American, Spanish- or English-speaking Latino, and were 65 years of age or older. The goal was to obtain a sample of people who lived in under-resourced communities, and who represented diversity in terms of age (65 years or older) and sex. We also wanted a sample with similar numbers of individuals belonging to the groups we were studying: African Americans, and Spanish- and English-speaking Latinos. Subjects who completed a cognitive interview were given a Target gift card valued at \$50 as a token of appreciation for their time. All those in the study verbally agreed to participate after having read an information sheet approved by the University of California, Los Angeles (UCLA) Office of the Human Research Protection Committee on 13

December 2013 (Institutional Review Board [IRB] number 13-001562).

### 2.2.1 Readability Measurement

Most formulae used to evaluate the readability of written text are based on the number of syllables per word and the number of words per sentence [34]. The Flesch–Kincaid (F-K) readability index yields an estimate of the grade level needed to read and comprehend the material; the Flesch Reading Ease (FRE) formula yields a rating on a scale where 100 represents the easiest text and 0 represents the hardest text. For Spanish, an adaptation of the FRE formula is available that yields an estimate of the age that is needed to read and comprehend the material [35].

Readability estimation for survey items is challenging because the items do not necessarily conform to the grammatical structure of complete sentences or questions. Furthermore, response options influence readability but are not sentences and were excluded from readability estimates in this study. The readability of English-language items was estimated using the F-K and FRE indices available in Microsoft Word (Microsoft Corporation, Redmond, WA, USA), while the readability of Spanish-language items was manually calculated following the scoring adaptation of the FRE formula mentioned above.

### 2.2.2 Cognitive Interviews

Comprehension refers to the cognitive processes and prior experiences that are necessary to respond to the different items, and can be ascertained using one-on-one cognitive interviews [36]. In these interviews, respondents can be asked about the understanding of questions and the process by which answers are selected.

Cognitive interviews were conducted with 30 individuals aged 65 years or older recruited in senior centers or community organizations in three locations: (1) Theresa Lindsay Multi-Purpose Senior Center serving South Central Los Angeles ([http://www.la4seniors.com/theresa\\_lindsay.htm](http://www.la4seniors.com/theresa_lindsay.htm)); (2) Mexican American Opportunity Foundation serving East Los Angeles (<http://www.maof.org/>); and (3) Ward Villas in the West Adams district south of downtown Los Angeles (<http://www.ward-edc.org/>). Interviews were conducted between 21 July and 15 August 2014. The study was advertised using bilingual (Spanish and English) informational flyers posted on bulletin boards at the three locations. The first author's telephone number was provided for interested subjects to call for further information.

The interviewer used a guide with intermittent probes embedded to evaluate a respondent's understanding of the intent of the questions. Items were evaluated for content, reading level, relevance to the individual, and

comprehension. All comments that were repeated by at least five participants were included in the report [37, 38]. The cognitive interview guides in English and Spanish are available in Supplementary Appendix B. The average time to complete the 30-item GDS was 7 min, and 10 min for the 26 PROMIS® physical function items. Retrospective probes were used in which the cognitive interview followed immediately after the subject had responded to each instrument. The order of the instruments was interchanged so that half of the participants completed the GDS first, and half completed the physical function items first. The average time of the entire interview, including the time to complete the GDS and PROMIS® items, was 46 min, with a range of 31–62 min.

## 3 Results

The sociodemographic characteristics of the sample are shown in Table 1. The average age was 76 years and 60 % of the sample were female.

### 3.1 Readability

#### 3.1.1 GDS Reading Ease

The mean and median F-K grade level scores for the English version of the GDS were 3.8 and 3.7, respectively,

**Table 1** Sample sociodemographic characteristics ( $n = 30$ )

	Mean (SD)	$n$ (%)	Range
Age, years	76 (8.1)		65–90
Sex			
Male		12 (40)	
Female		18 (60)	
Race/ethnicity			
Black or African American		12 (40)	
Spanish-speaking Latinos		12 (40)	
English-speaking Latinos		6 (20)	
Education			
Could not read one or both questionnaires <sup>a</sup>		5 (17)	
Six or less years of formal education		11 (37)	
Between 7 and 12 years of formal education		7 (23)	
Some college education or higher		7 (23)	

SD standard deviation

<sup>a</sup> For these subjects, the items were administered via interview conducted by the first author. Two of these subjects could read the Geriatric Depression Scale but could not read the physical functioning items due to the length of each item and the response options

with a range of 0.1–7.6. Nine items (30 %) scored above the 5 years of formal schooling for vulnerable populations [16]. The mean and median on the FRE readability index for the English version of the GDS were 81.3 and 85.0, respectively, with a range of 49.4–100.0. Six items (20 %) fell into the categories of ‘fairly difficult’, ‘difficult’, or ‘very difficult’ according to the FRE scores [39].

The mean and median of the adapted FRE for the Spanish version of the GDS were 7.9 and 7.6, respectively, with a range of 5.6–12.2.

### 3.1.2 PROMIS<sup>®</sup> Physical Function Reading Ease

The mean and median F-K grade level scores for the PROMIS<sup>®</sup> physical function items in English were 4.3 and 3.0, respectively, with a range of 0.6–12.0. Six items (23 %) scored above the recommended 5 years of schooling. The mean and median on the FRE readability index for the physical function items in English were 70.7 and 94.3, respectively, with a range of 34.2–100.0. Three items (12 %) fell into the categories of ‘fairly difficult’, ‘difficult’, or ‘very difficult’ according to the FRE scores.

The mean and median of the adapted FRE for the Spanish version of the physical function items were 9.7 and 9.8, respectively, with a range of 6.5–15.2. All readability estimates for both instruments, in both Spanish and English, are shown in the Appendix.

## 3.2 Scores

### 3.2.1 GDS

The mean score of the GDS was 6.1, with a range of 0–22. A total of 123 responses were missing (14 % of all possible responses). The three items with the most missing responses were: ‘Do you feel full of energy?’; ‘Do you often feel downhearted and blue?’; and ‘Do you often get restless and fidgety?’ Twenty-four participants scored within the ‘normal’ range of 0–9; five participants scored in the ‘mild depressive’ range of 10–19; and one participant scored in the range of 20–30, suggesting ‘severe depressive symptoms’.

### 3.2.2 PROMIS<sup>®</sup> Physical Function Item

The average PROMIS<sup>®</sup> physical functioning scale score was 40, with a range of 25–63. A total of 101 responses were missing (13 % of all possible responses). The three items with most missing data were: ‘Does your health now limit you in doing vigorous activities, such as running, lifting heavy objects, participating in strenuous sports?’; ‘Does your health now limit you in bending, kneeling, or

stooping?’; and ‘Does your health now limit you in walking more than a mile (1.6 km)?’ This measure is scored so that a higher score represents better functioning and the mean is 50 for the US general population. Hence, participants in this sample reported a noteworthy level of limitations in physical functioning.

## 3.3 Cognitive Interviews

### 3.3.1 GDS Perceived Ease of Use and Comprehension

The GDS items were generally easier to read and respond to than the PROMIS<sup>®</sup> physical functioning items. The stems of the items were short and clear, and ‘yes’ and ‘no’ response options were considered very easy to understand. However, 20 participants (67 % of the total sample) indicated that ‘yes’ and ‘no’ were not a sufficient number of response options. Participants remarked that other response options such as ‘sometimes’, ‘most of the time’, ‘probably’, ‘maybe’, ‘not always’, ‘not all the time,’ or ‘rarely’ were preferred. In addition, nine participants (30 % of the total sample) commented that their answers depended on the day and how they felt. A few participants said that short questions, large font, and space between questions made the questionnaire easy to read and respond to. Two Spanish-speaking subjects suggested adding a question about having ever thought of committing suicide.

### 3.3.2 PROMIS<sup>®</sup> Physical Function Item Perceived Survey Ease of Use and Comprehension

Several of the PROMIS<sup>®</sup> physical functioning items were considered long and many subjects forgot the beginning of the stem when reading the response options. This produced confusion and errors in choosing a response. In addition, many respondents use physical aids inside and/or outside their home. Some mentioned using wheelchairs, canes, bars, stools in the bathroom, and raised toilet seats. The ‘with a little difficulty’ response option was sometimes interpreted to mean “Yes, with help of a walker with a little basket, and buying just 1 or 2 items at the store, I can go shopping and carry groceries”.

Topics missing, according to participants, were problems with fingers and hands and how these affect daily life and writing, problems specific to lower-back issues and legs, general arthritis problems, hearing problems, and questions about cooking a meal, which is hard for most people. Given the small sample size of the study, we could not analyze the data by race/ethnicity; however, we included the different groups to try to have a representative sample of the main group components of minority elderly. Comments on selected items are summarized in Table 2.

## 4 Discussion

The results of this study reveal that minority elderly may not interpret the items in the GDS and the PROMIS® physical function in the way intended. This makes comparability of the data collected from different subgroups potentially problematic. This is important since both instruments measure domains that are especially relevant for older individuals.

Under-resourced subgroups in the US consistently have worse health outcomes than other individuals [10–12]. Health literacy and limited reading skills are known to be important barriers to improving health outcomes, while difficult-to-read health materials are a key barrier to garnishing information that may inform investigators, health-care delivery systems, and policy makers about how best to address rising rates of depressive symptoms and physical functioning dysfunction for this population.

The appropriate use of survey measures requires respondents to be able to read and comprehend survey items, including the item stems and response options. Poor-quality data can result if survey items are administered to those who lack literacy levels or the education necessary to fully comprehend them [40]. Given that Latino and African American elderly tend to have limited educational attainment and also experience cognitive decline from aging, chronic diseases and polypharmacy, measures targeting them must be designed to be very easy to engage and very easy to read in order to be comprehended by them.

Many national surveys have readability scores that require post high school- to graduate-level reading skills to engage and complete, making them difficult to comprehend for most people, particularly the elderly. Difficult survey readability is a key determinant of survey and item non-response by race/ethnic minorities in general, and for minority elderly in particular [18]. Even though concerns about readability formulae have been raised, an important aspect of a survey is its reading ease [41].

Readability analysis performed for this study included only the item stems, not the response options. Including these would almost certainly affect the readability level, indicating that the items are harder to read and comprehend. In addition, readability formulae do not take into account other variables that are related to text comprehension. For example, interest, motivation, and previous experience and knowledge are all factors that may affect the subject's ability to comprehend [42, 43]. Less commonly used vocabulary and the effect of new material may also affect reading ease in a way not captured by readability formulae.

Furthermore, in this study, different formulae were used for different languages, which makes it harder to make any

comparison. For English, we used one formula that yields a corresponding grade level that is needed to read the material, and another formula that rates text based on a 0–100 scale. For Spanish, the formula yields information on age needed to read and comprehend written text. Results of this formula need to be interpreted with caution because it is based on the Flesch English-language formula; however, it has been used in other studies about readability in Spanish due to its simplicity [44].

Computerized calculations were used for English items, while the readability for Spanish items was manually calculated. Despite these limitations, these formulae provide some information about the skills needed to read and comprehend survey items. They also provide some information as to the items that require higher levels of schooling to be correctly comprehended. For example, “Have you dropped many of your activities and interests?” (¿Ha usted abandonado muchos de sus intereses y actividades?) and “Does your health now limit you in doing vigorous activities, such as running, lifting heavy objects, participating in strenuous sports?” (¿Limita su salud en este momento su capacidad para realizar actividades vigorosas, como correr, levantar objetos pesados o participar en deportes enérgicos?) have high readability scores. These items were misunderstood by many subjects in the cognitive interviews and, as a result, some participants selected response options that did not represent their health accurately.

Item 17 in the GDS “Do you feel pretty worthless the way you are now?” (¿Se siente usted inútil, echadizo?) had very low readability in both English measurements, yet a very high readability score in Spanish. In the cognitive interviews, this item had no problems in English but presented problems for Spanish-speaking subjects as some did not understand the wording (see Table 2). There are a paucity of readability formulae in Spanish, in part due to the fact that readability formulae were originally developed for English language and only some have been adapted to Spanish. Among the most common adaptations is the Spaulding formula developed in 1956, the Fernandez Huerta adaptation of the FRE developed in 1957, and the adaptation developed by Garcia-Lopez and Arcos-Cebrian in 1999 [35]. The latter is of interest because it provides information on age. However, these formulae provide different estimates rather than one absolute readability score.

Other factors that affect the ease with which surveys are comprehended and responded to, and that are not measured in readability formulae, are related to format and design, which should take into consideration cultural appropriateness and other social characteristics of the population to be studied. For this study, both surveys were printed double-spaced and with large fonts, which made it easier for participants to read. Cognitive design principles have been



**Table 2** Selected comments<sup>a</sup> of the Geriatric Depression Scale and the PROMIS<sup>®</sup> Physical Functioning Items

Item	Comments
<i>Geriatric Depression Scale</i>	
Response options: yes/no	
1. Are you basically satisfied with your life?	Item was primarily related to health The word 'basically' can be deleted 'Sometimes' should be added as a response option Spanish speakers related item to family life
3. Do you feel that your life is empty?	Item referred to family life and religion or faith 'Sometimes' or 'Maybe' should be added as response options
4. Do you often get bored?	'Sometimes' should be added as a response option The word 'frecuentemente' (frequently) was not known to two Spanish-speaking respondents
6. Are you bothered by thoughts you can't get out of your head?	'Sometimes' should be added as a response option
7. Are you in good spirits most of the time?	'Most of the time' and 'Sometimes' should be added as response options
11. Do you often get restless and fidgety?	The words 'restless' and 'fidgety' do not mean the same The Spanish translation 'intranquilo' was correctly understood as restless
13. Do you frequently worry about the future?	The response 'NO' was frequently used because "nothing can be done about it" For some, this was the same as the item "Are you hopeful about the future?" and can therefore be deleted
14. Do you feel you have more problems with memory than most?	'Somewhat' should be added as a response option 'Than most people your age' should be added to the stem of the item For some, this was the same as item "Is your mind as clear as it used to be?" and can therefore be deleted
16. Do you often feel downhearted and blue?	Additional response options were necessary for this item The words 'downhearted' and 'blue' mean the same and refer to feeling sad, worried, and depressed
17. Do you feel pretty worthless the way you are now?	The Spanish word 'echadizo' was not understood Additional response options were necessary since this is not a permanent state
21. Do you feel full of energy?	Additional response options such as 'sometimes', 'not all the time', and 'most days' were necessary
23. Do you think that most people are better off than you are?	It was not clear if this question only referred to finances, to health, or in general. Could be offensive The Spanish translation 'suerte' (luck) was better understood and clearer
24. Do you frequently get upset over little things?	Additional response options were necessary
25. Do you frequently feel like crying?	Additional response options such as 'sometimes' were necessary
27. Do you enjoy getting up in the morning?	Additional response options were necessary as this depends on the day, therefore it is not always the same
30. Is your mind as clear as it used to be?	Additional response options were necessary and therefore many could not respond
<i>PROMIS<sup>®</sup> Physical Function Item Bank— Short Forms</i>	
Response options:	
Without any difficulty	
With a little difficulty	
With some difficulty	
With much difficulty	
Unable to do	
PFA11: Are you able to do chores such as vacuuming or yard work?	The word "chores" was mostly understood as household chores. Sweeping, dusting, and doing dishes were given as examples

**Table 2** continued

Item	Comments
PFA16: Are you able to dress yourself, including tying shoelaces and buttoning your clothes?	'Without any difficulty' was selected by many who only wear slip-ons because they cannot bend and do not wear shoes with shoelaces
PFA34: Are you able to wash your back?	More specifics were necessary. Some of the comments were: only take baths, just let water run, only with the use of a special brush, cannot raise their arms, and others use a towel or washcloth Since most find a way to do this activity, the response options 'without any difficulty' or 'with a little difficulty' were selected The same comments were repeated for the item asking about 'drying your back'
PFA56: Are you able to get in and out of a car?	The following comments were given by persons who responded 'with a little difficulty': "It is the same to get in or out of a car. I feel neck and back pain when moving and twisting" "Both are equal to me. You learn tricks; like to get out you turn around first" "Physical therapy teaches you how to do all these things" "No problem, but sometimes kind of hard" "My daughter's car is very low so it is harder; the other car is higher so it is hard for me to lift my leg. So it depends on how I am feeling that day, and on the car and height" "It is difficult for me. My arms hurt so I have a system of first my left hand, then I turn and I sit close to the door. Getting out is harder" "Depends on the car. Especially if you are in a back seat, it is very hard to get out"
PFB19: Are you able to squeeze a new tube of toothpaste?	Question was understood as asking about 'Twisting the cap open when the tube is new' and many people added "it is much harder toward the end when there is little left" Arthritis was mentioned as a common problem that affects this activity One person who selected 'with some difficulty' commented "I can't do that; it is very difficult to open"
PFB22: Are you able to hold a plate full of food?	More specifics were necessary regarding how heavy and how full the plate is Shaking of the hands was mentioned as a problem with this activity Many Spanish speakers who commented that they could not do this or it was very hard for them selected 'With a little difficulty or with some difficulty'
PFB24: Are you able to run a short distance, such as to catch a bus?	Many who commented "I can't run" selected 'With much difficulty' One person who selected 'With little difficulty' commented: "I can't run at all; I can walk fast but not run. But why would I when another bus will come". For this person, running is a physical problem, but it does not create a big problem in daily life 'Short distance' was described in multiple ways: "Half a block" "One block" "Like 2 blocks" "Very short like from here to the parking lot" "From here to the corner" (building was a corner building) "From here to the dining room" (dining room being the room next door) "From here to the door" Other examples suggested were: "Running after my dog" "Cross the street because the light is going to change" "If a scary dog is running toward me" "Trying to catch up with mailman who just left and you had a letter to give him"
PFC45: Are you able to sit on and get up from the toilet?	Most people mentioned some kind of aid in the bathroom 'Without any difficulty' was selected by many who commented on having bars and raised toilets

**Table 2** continued

Item	Comments
PFC46: Are you able to transfer from a bed to a chair and back?	<p>'Without any difficulty' or 'With a little difficulty' were selected by people who made comments such as:</p> <p>"No problem if the chair is next to the bed"</p> <p>"I am very careful and hold on to something so that the chair does not slide"</p> <p>"I don't have any problem because I can hold on to special handles and bars I have next to my bed"</p>
PFA23: Are you able to go for a walk of at least 15 minutes?	<p>'At least 15 minutes' was understood as exactly 15 minutes</p> <p>'With a little difficulty' was selected by people who made the following comments:</p> <p>"I can but it is very hard"</p> <p>"Walking until I get exhausted", "breathing very heavy—like a block and a half"</p> <p>"Yes, I can but stopping several times to rest"</p>
PFA53: Are you able to run errands and shop?	<p>Most people correctly understood this item as asking about going to the bank, paying bills, or going to the market</p> <p>'With a little difficulty' was selected by people who could only do this activity because they used a walker or a wheelchair</p> <p>Most Spanish-speaking respondents referred to food shopping and said that they could only do this activity if they bought one or two small things at a time. These people selected 'with a little difficulty' or 'with some difficulty'</p>
Response options:	
Not at all	
Very little	
Somewhat	
Quite a lot	
Cannot do	
PFA1: Does your health now limit you in doing vigorous activities, such as running, lifting heavy objects, participating in strenuous sports?	<p>People who incorrectly selected 'very little' commented:</p> <p>"I can lift some objects if they are not too heavy, but I don't participate in any sports and I don't run"; "I don't do any of that"; "Maybe lifting heavy things around the house, but that is very hard for me"; "Depends how far I run. I guess I have some limitations with age and it is hard work for me"</p> <p>People correctly understood 'strenuous sports' giving the following examples: basketball, baseball, riding a bike, football, or running</p> <p>The word 'strenuous' seemed not necessary and could be deleted</p> <p>Some Spanish speakers did not know the meaning of the words 'vigorosas' or 'enérgicos'</p> <p>Some people who selected 'nada' (not at all) commented they could not do these activities</p>
PFA3: Does your health now limit you in bending, kneeling, or stooping?	<p>Both words 'bending' and 'stooping' meant the same and referred to 'bending forward to pick up something'</p> <p>Some people commented "Seniors can bend but can't stop or kneel"</p> <p>Two Spanish speakers suggested using 'incarse' instead, or, in addition, 'arrodillarse'</p> <p>Most comments referred to kneeling done only at church</p>
PFA5: Does your health now limit you in lifting or carrying groceries?	<p>People who incorrectly selected 'Very little' made the following comments:</p> <p>"Depends on how heavy and if I have to bend"</p> <p>"No problem" said a 90-year-old with a walker</p> <p>"I can't, but I don't have to carry groceries because a lady who helps me in the house does it"</p> <p>"Sometimes but I don't carry them. I use a cart and walk 2 blocks, but I don't lift them. Somebody comes and helps me"</p> <p>"Depends on how heavy the groceries are. I use several bags to make them lighter"</p> <p>One person who incorrectly responded 'Somewhat' commented "My neck and shoulders hurt. I limit the weight so I don't overload myself. I use many bags, each one with only one or two things, and that way they are lighter"</p> <p>Several Spanish-speaking respondents who incorrectly selected 'Not at all' commented that they cannot do this</p>

Table 2 continued

Item	Comments
PFC12: Does your health now limit you in doing two hours of physical labor?	<p>People who responded 'Very little' or 'Somewhat' commented that 'physical labor' means:</p> <p>"Digging ditches or lifting heavy objects"</p> <p>"Does that mean like exercising on a treadmill?"</p> <p>"Like moping or waxing the floor—somebody else does that for me"</p> <p>"Moping the floor or cutting the grass"</p> <p>"Like working in the yard—I cut my roses"</p> <p>One subject who incorrectly selected 'Not at all' commented "I can't do any of that – like shovel to fix the road or mix concrete"</p> <p>For most subjects, physical labor referred to house chores</p>
PFC36: Does your health now limit you in walking more than a mile (1.6 km)? (SF-PF20) PFC36: Does your health now limit you in walking more than a mile?	<p>All the people agreed that there was no need to add kilometers</p> <p>Nobody could define 'More than a mile' accurately. All except one person understood 'More than a mile' as one mile</p> <p>Most defined a mile incorrectly, giving examples such as:</p> <p>"Walking around the block"</p> <p>"From here to the corner"</p> <p>"About 4 blocks"</p> <p>"One long block"</p> <p>"Around the corner or walking inside a big mall"</p>
PFC37: Does your health now limit you in climbing one flight of stairs?	<p>'Climbing one flight of stairs' was correctly understood as going from one floor to the next with something between 10 and 22 steps</p> <p>Few people thought this item referred to five or less steps</p> <p>One person who incorrectly responded 'Not at all' commented "No; I can't, but if I have to, I have to stop every couple of steps to catch my breath"</p> <p>Some respondents who incorrectly selected 'Somewhat' commented:</p> <p>"I can't go upstairs"</p> <p>"That is about eight steps and I use elevators because I can't do that"</p> <p>"That is very tough for me—like 10 steps only, but I can't do"</p>
PFA7: How much do physical health problems now limit your usual physical activities (such as walking or climbing stairs)?	<p>One person who commented "It is very hard for me, but I use a cane or walker that help me" incorrectly responded 'Very little'</p> <p>'Physical health problems' were correctly understood as, for example, 'arthritis', 'high blood pressure', 'asthma', 'back problems', or 'knee problems'</p> <p>Some examples given for 'Usual physical activities' were:</p> <p>"Climbing a hill"</p> <p>"Playing basketball"</p> <p>"Cutting grass"</p> <p>"Going on a long walk"</p> <p>One person asked whether these referred to activities inside or outside the home</p> <p>One Spanish-speaking person suggested simplifying this question to: "¿Cuánto le limitó su salud física para hacer sus cosas usuales?" (How much did your physical health limit you in doing your usual things?)</p> <p>The response selected depended on the day and if they had depression or osteoporosis</p>

Table 2 continued

Item	Comments
PFB1: Does your health now limit you in doing moderate work around the house like vacuuming, sweeping floors or carrying in groceries?	<p>Several people who incorrectly responded 'Not at all' or 'Very little' commented:</p> <p>"I can't do any of those things"</p> <p>"I can do them but it is very hard"; "Sometimes I can, it depends on my arthritis because some days are better than others"</p> <p>"I use a walker, but only when I go out of the house, so I can do most of the house work"</p> <p>"Very little because I do most of my work like doing the dishes"</p> <p>'Moderate work around the house' meant:</p> <p>Vacuuming</p> <p>General house cleaning</p> <p>Washing dishes</p> <p>Sorting and folding clothes</p>
PFA4: Does your health now limit you in doing heavy work around the house like scrubbing floors, or lifting or moving heavy furniture?	<p>People who commented they could not do heavy work, incorrectly selected 'Not at all' or 'Very little'</p> <p>Examples given of heavy work around the house were:</p> <p>Moving furniture</p> <p>Washing windows</p> <p>Vacuuming</p> <p>Mopping the floors</p>

PROMIS<sup>®</sup> Patient-Reported Outcomes Measurement Information System

<sup>a</sup> At least five respondents commented on each item included in the table

shown to help make surveys simpler, clearer, and more attractive, thus improving the validity of the data [45]. These principles are based on state-of-the-art formatting methods for self-administered questionnaires [46].

As the study by Krosnick and Alwin revealed, the order of response options can also impact the response selected, and this effect varies depending on whether the survey is self- or interviewer-administered [47]. While the likelihood of choosing the first response choices increases when the survey is self-administered (primacy effect), the likelihood of selecting the last choices increases with interviewer-administered surveys (recency effect). Furthermore, individuals with lower levels of education are more likely to be influenced by the order of response options [47]. Even though readability would be higher when response options are included, an interviewer could be helpful in explaining items that are not clear, but this is not possible in self-administration.

By probing comprehension, this study found that some items were not understood. While many participants did not understand some words, others words meant different things to different participants. Even though "Does your health now limit you in walking more than a mile?" is a relatively easy item to understand, most subjects gave wrong examples of a mile. In the item "Are you able to run a short distance, such as to catch a bus?", multiple different examples of 'short distance' were given that were very different distances.

Most participants suggested adding response options to items in the GDS. On these items, many subjects selected a response option and then commented in the interview that it was not accurate, or did not respond at all because, to them, it was not a 'yes/no' question. Adding response options such as 'sometimes' would have been helpful. However, interesting to note is that many of these items include the word 'frequently' in the stem. Adding a response option such as 'sometimes' to the descriptor 'frequently' could make these items more confusing. Furthermore, many participants mentioned that responses depended on the time of the day, and that days were not all the same. Having only two response options might also be a factor affecting the low specificity rates, with this instrument having difficulty discriminating among the different diagnostic groups [48]. However, the scale may still be useful for those with some cognitive impairment [48, 49].

Some of the PROMIS<sup>®</sup> physical functioning items use wording that might not be relevant to older individuals. For example, "Are you able to do chores such as vacuuming or yard work?" created problems because yard work seemed vague and harder to perform than some house-related chores; however, because some participants live in an urban area or in a senior center with no yard work at all, this item might not be universally relevant. These items are especially not applicable to urban dwelling older adults who either live in apartments or with younger family

members who would not expect the older adults to do this work.

Many respondents selected ‘without any difficulty’ to some tasks after commenting they had multiple assistive devices. It might be better to add instructions at the beginning about how one should answer if a task can be easily performed, but only with an assistive device. There is an existing PROMIS® physical functioning measure that incorporates mobility aids, but the measure refers to the use of aids such as canes and walking sticks [50]. Other aids that are helpful for physical functioning items, such as bars or raised toilets, are not included. The addition of instructions could help with uniformity of responses and comparability of results.

Many of the items that start with “Does your health limit you in ...” were too long. In many cases, respondents forgot that the question was asking about their health limiting their activities, and thus responded with the first response option, “Not at all” because they were thinking that they could not do this activity at all.

Several of the physical functioning items that were confusing to study participants were also flagged for differential item functioning (DIF) in a comparison of English- and Spanish-speaking respondents [51]. This means that respondents with the same level of physical functioning respond differently to these items depending on whether they respond in English or Spanish. The same is true in a DIF analysis comparing older versus younger respondents [52]. Older and younger subjects responded differently to these items depending on the language used. This is important as this qualitative study may help explain some of the problems found in the DIF analyses. For example, a study of individuals with knee impairments documented that some of the PROMIS® items dealing with higher levels of physical functioning (‘athletic activities’) were perceived by older individuals to be less relevant to them [53].

The generalizability of these results requires further study. There may be discordance in the way items were developed and the way they are understood by some. Future studies need to incorporate qualitative analysis of items before surveys are developed to ensure the target subgroups will adequately respond to all items and results can be appropriately generalized.

A limitation of this study was that the sample size was too small to draw any conclusions regarding group differences. Further studies would have to evaluate and compare any differences based on race or ethnic group. In addition, further studies could include samples with other age

groups, and different health status and conditions. A second limitation is that we do not know if under-resourced minority subjects are similar or different from other elderly people in the way they responded to these two instruments or the questions they had.

In summary, it is important to ensure that PROs are reliable and valid across different subgroups and populations. Poor literacy skills, poor disease management, and poor physical and mental health are all interrelated symptoms that ultimately affect the health of a society. As the less-educated aging population continues to grow, future studies need to focus on specific physical functioning and emotional attributes that decline with aging, as well as particular attributes that are affected in this specific population. Furthermore, surveys need to be developed ensuring that this population can read and understand all the items appropriately.

**Author contributions** Sylvia H. Paz helped design the study, collected and analyzed the data, wrote the first draft of the manuscript, and wrote intermediate versions following co-author revisions. Loretta Jones helped design the study and provided input for the manuscript. José L. Calderón provided input in several revisions of the manuscript. Ron D. Hays helped with the study design and provided input throughout the study and writing of the manuscript.

#### Compliance with Ethical Standards

Sylvia H. Paz, José L. Calderón, and Ron D. Hays received support from the UCLA and Charles Drew University (CDU), Resource Centers for Minority Aging Research/Center for Health Improvement of Minority Elderly (RCMAR/CHIME) under National Institutes of Health/National Institute on Aging (NIH/NIA) grant P30-AG021684. Sylvia H. Paz was also supported by the UCLA Clinical and Translational Science Institute (CTSI) under NIH/National Center for Advancing Translational Sciences (NCATS) grant number UL1TR000124. Ron D. Hays was also supported by NCI (No. 1U2-CCA186878-01), and the UCLA/CDU Project EXPORT, National Institute on Minority Health and Health Disparities (NIMHD; 2P20MD000182). Loretta Jones was supported in part by NIH/NIMHD grant numbers U54MD007598 (formerly U54RR026138), P20MD00182, S21 MD000103, MD000182, U54RR022762, and R01MD007721-01A1, NIH/NCATS grant number UL1TR000124, and NIH/NIA RCMAR/CHIME grant number P30-AG021684. The Los Angeles Community Academic Partnership for Research in Aging (L.A. Capra) Center and Ward Economic Development Corporation (WEDC) were instrumental in providing community organizations. The contents of this article are solely the responsibility of the authors and do not necessarily represent the official views of the NIH.

**Conflict of interest** Sylvia H. Paz, Loretta Jones, José L. Calderón, and Ron D. Hays have no conflicts of interest to declare. The study was approved by the UCLA Institutional Review Board (IRB) Research Ethics Committee and has been performed in accordance with the ethical standards of the Declaration of Helsinki.

**Appendix**

English Instruments and Readability Scores

PROMIS® Physical Function Short Form (20a)

		FRE	F-K
PFA11	Are you able to do chores such as vacuuming or yard work?	81.8	4.8
PFA12	Are you able to push open a heavy door?	84.9	3.6
PFA16	Are you able to dress yourself, including tying shoelaces and buttoning your clothes?	63.4	7.6
	Are you able to dress yourself, including tying shoelaces and doing buttons?	67.7	6.7
PFA34	Are you able to wash your back?	100.00	0.6
PFA38	Are you able to dry your back with a towel?	95.1	2.4
PFA51	Are you able to sit on the edge of a bed?	100.0	1.5
PFA55	Are you able to wash and dry your body?	94.3	2.3
PFA56	Are you able to get in and out of a car?	100.0	1.5
PFB19	Are you able to squeeze a new tube of toothpaste?	95.1	2.4
PFB22	Are you able to hold a plate full of food?	100.0	1.2
PFB24	Are you able to run a short distance, such as to catch a bus?	95.9	3.3
PFB26	Are you able to shampoo your hair?	90.9	2.3
PFC45	Are you able to sit on and get up from the toilet?	95.9	2.8
	Are you able to get on and off the toilet?	95.1	2.4
PFC46	Are you able to transfer from a bed to a chair and back?	96.0	3.0
PFA1	Does your health now limit you in doing vigorous activities, such as running, lifting heavy objects, participating in strenuous sports?	34.2	12.0
PFA3	Does your health now limit you in bending, kneeling, or stooping?	80.3	4.7
PFA5	Does your health now limit you in lifting or carrying groceries?	72.6	5.8
PFC12	Does your health now limit you in doing two hours of physical labor?	83.0	4.9
PFC36	Does your health now limit you in walking more than a mile (1.6 km)?	83.8	5.0
	Does your health now limit you in walking more than a mile?	95.9	2.8
PFC37	Does your health now limit you in climbing one flight of stairs?	95.9	2.8

Additional Items to Complete Short Forms 4a, 8a, 10a, and PROMIS® PF-57

		FRE	F-K
PFA21	Are you able to go up and down stairs at a normal pace?	96.0	3.0
PFA23	Are you able to go for a walk of at least 15 minutes?	89.8	4.1
PFC53	Are you able to run errands and shop?	94.3	2.3
PFA7	How much do physical health problems now limit your usual physical activities (such as walking or climbing stairs)?	40.0	9.6
PFB1	Does your health now limit you in doing moderate work around the house like vacuuming, sweeping floors or carrying in groceries?	57.6	10.6
PFA4	Does your health now limit you in doing heavy work around the house like scrubbing floors, or lifting or moving heavy furniture?	65.7	9.7

Geriatric Depression Scale

		FRE	F-K
Q.1	Are you basically satisfied with your life?	54.7	7.3
Q.2	Have you dropped many of your activities and interests?	56.7	7.5
Q.3	Do you feel that your life is empty?	100.0	0.8
Q.4	Do you often get bored?	100.0	0.5
Q.5	Are you hopeful about the future?	59.7	6.4
Q.6	Are you bothered by thoughts you can't get out of your head?	100.0	1.2
Q.7	Are you in good spirits most of the time?	100.0	1.0
Q.8	Are you afraid that something bad is going to happen to you?	81.8	4.8
Q.9	Do you feel happy most of the time?	100.0	0.8
Q.10	Do you often feel helpless?	83.3	2.8
Q.11	Do you often get restless and fidgety?	66.7	5.6
Q.12	Do you prefer to stay at home, rather than going out and doing new things?	95.7	3.6
Q.13	Do you frequently worry about the future?	54.7	7.3
Q.14	Do you feel you have more problems with memory than most?	87.9	3.7
Q.15	Do you think it is wonderful to be alive now?	86.7	3.6
Q.16	Do you often feel downhearted and blue?	78.8	3.9
Q.17	Do you feel pretty worthless the way you are now?	95.1	2.4
Q.18	Do you worry a lot about the past?	92.9	2.2
Q.19	Do you find life very exciting?	73.8	4.4
Q.20	Is it hard for you to get started on new projects?	95.6	2.6
Q.21	Do you feel full of energy?	87.9	2.4
Q.22	Do you feel that your situation is hopeless?	71.8	5.2

	FRE	F-K
Q.23 Do you think that most people are better off than you are?	95.9	2.8
Q.24 Do you frequently get upset over little things?	61.2	6.7
Q.25 Do you frequently feel like crying?	87.9	2.4
Q.26 Do you have trouble concentrating?	49.4	7.6
Q.27 Do you enjoy getting up in the morning?	82.3	3.7
Q.28 Do you prefer to avoid social gatherings?	54.7	7.3
Q.29 Is it easy for you to make decisions?	82.3	3.7
Q.30 Is your mind as clear as it used to be?	100.0	0.1

Spanish Instruments and Readability Scores  
PROMIS® Physical Function Short Form (20a)

	FRE <sup>a</sup>
PFA11 ¿Puede realizar tareas, como pasar la aspiradora o trabajar en el jardín?	10.1
PFA12 ¿Puede abrir una puerta pesada empujándola?	11.8
PFA16 ¿Puede vestirse sin ayuda, incluso amarrarse los zapatos y abotonarse la ropa?	11.4
PFA34 ¿Puede lavarse la espalda?	8.8
PFA38 ¿Puede secarse la espalda con una toalla?	8.2
PFA51 ¿Puede sentarse en el borde de una cama?	6.5
PFA55 ¿Puede lavarse y secarse el cuerpo?	7.3
PFA56 ¿Se puede subir y bajar de un automóvil?	6.5
PFB19 ¿Puede apretar un tubo nuevo de pasta de dientes?	6.8
PFB22 ¿Puede sujetar un plato lleno de comida?	7.6
PFB24 ¿Puede correr una distancia corta, como para alcanzar un autobús?	9.6
PFB26 ¿Puede lavarse el cabello con champú?	7.3
PFC45 ¿Puede sentarse y levantarse del inodoro (excusado)?	12.1
PFC46 ¿Puede pasar de una cama a una silla y volver a la cama?	6.5
PFA1 ¿Limita su salud en este momento su capacidad para realizar actividades vigorosas, como correr, levantar objetos pesados o participar en deportes enérgicos?	15.2
PFA3 ¿Limita su salud en este momento su capacidad para inclinarse, arrodillarse o agacharse?	12.3
PFA5 ¿Limita su salud en este momento su capacidad para levantar o llevar las bolsas del supermercado?	10.5
PFC12 ¿Limita su salud en este momento su capacidad para realizar dos horas de trabajo físico?	10.9
PFC36 ¿Limita su salud en este momento su capacidad para caminar más de una milla (1.6 km)?	8.9
¿Limita su salud en este momento su capacidad para caminar más de una milla?	10.0
PFC37 ¿Limita su salud en este momento su capacidad para subir un piso de escaleras?	10.0

Additional Items to Complete Short Forms 4a, 8a, 10a, and PROMIS® PF-57

	FRE <sup>a</sup>
PFA21 ¿Puede subir y bajar escaleras a un paso normal?	7.4
PFA23 ¿Puede salir a caminar durante 15 minutos por lo menos?	8.3
PFA53 ¿Puede hacer mandados y compras?	7.1
PFA7 ¿Cuánto le limitaron sus problemas de salud física sus actividades físicas usuales (como caminar o subir escaleras)?	12.6
PFB1 ¿Limita su salud en este momento su capacidad para realizar trabajos moderados en el hogar, como pasar la aspiradora, barrer el piso (suelo) o entrar a la casa las compras del mercado?	13.8
PFA4 ¿Limita su salud en este momento su capacidad para realizar trabajos pesados en el hogar, como fregar (restregar) los pisos (el suelo), o levantar o mover muebles pesados?	13.4

Geriatric Depression Scale

	FRE <sup>a</sup>
Q.1 ¿Esta usted satisfecho con su vida?	7.3
Q.2 ¿Ha usted abandonado muchos de sus intereses y actividades?	10.7
Q.3 ¿Siente usted que su vida esta vacia?	6.9
Q.4 ¿Se siente usted frecuentemente aburrido?	12.2
Q.5 ¿Tiene usted mucha fe en el futuro?	5.6
Q.6 ¿Tiene usted pensamientos que le molestan?	8.6
Q.7 ¿La mayoría del tiempo esta usted de buen humor?	6.8
Q.8 ¿Tiene miedo que algo malo le vaya a pasar?	6.1
Q.9 ¿Se siente usted feliz la mayoría del tiempo?	7.2
Q.10 ¿Se siente usted a menudo impotente?	8.6
Q.11 ¿Se siente usted a menudo intranquilo?	8.6
Q.12 ¿Prefiere usted quedarse en su cuarto en vez de salir?	6.4
Q.13 ¿Se preocupa usted a menudo sobre el futuro?	8.5
Q.14 ¿Cree usted que tiene mas problemas con su memoria que los demas?	6.9
Q.15 ¿Cree usted que es maravilloso ester viviendo?	9.5
Q.16 ¿Se siente usted a menudo triste?	6.0
Q.17 ¿Se siente usted inutil, echadizo?	9.7
Q.18 ¿Se preocupa usted mucho sobre el pasado?	8.2
Q.19 ¿Cree usted que la vida es muy interesante?	7.2
Q.20 ¿Es dificil para usted empezar proyectos nuevos?	9.5
Q.21 ¿Se siente usted lleno de energla?	7.3
Q.22 ¿Se siente usted sin esperanza?	7.1
Q.23 ¿Cree usted que los demas tienen mas suerte que usted?	5.7



	FRE <sup>a</sup>
Q.24 ¿Se siente usted muy nervioso sobre cosas pequeñas?	7.8
Q.25 ¿Siente usted a menudo ganas de llorar?	6.9
Q.26 ¿Es difícil para usted concentrarse?	9.7
Q.27 ¿Esta usted contento de levantarse por la mañana?	8.5
Q.28 ¿Prefiere usted evitar grupos de gente?	8.6
Q.29 ¿Es fácil para usted tomar decisiones?	8.6
Q.30 ¿Esta su mente tan clara como antes?	5.6

PROMIS<sup>®</sup> Patient-Reported Outcomes Measurement Information System, *F-K* Flesch–Kincaid, *FRE* Flesch Reading Ease

<sup>a</sup> For Spanish, an adaptation of the FRE formula was used

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