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Spanish translation and linguistic validation of the quality of life in neurological disorders (Neuro-QoL) measurement system

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Abstract

Introduction—The quality of life in neurological disorders (Neuro-QoL) measurement system is a 470-item compilation of health-related quality of life domains for adults and children with neurological disorders. It was developed and cognitively debriefed in English and Spanish, with general population and clinical samples in the USA. This paper describes the Spanish translation and linguistic validation process.

Methods—The translation methodology combined forward and back-translations, multiple reviews, and cognitive debriefing with 30 adult and 30 pediatric Spanish-speaking respondents in the USA. The adult Fatigue bank was later also tested in Spain and Argentina. A universal approach to translation was adopted to produce a Spanish version that can be used in various countries. Translators from several countries were involved in the process.

Results—Cognitive debriefing results indicated that most of the 470 Spanish items were well understood. Translations were revised as needed where difficulty was reported or where participants' comments revealed misunderstanding of an item's intended meaning. Additional testing of the universal Spanish adult Fatigue item bank in Spain and Argentina confirmed good understanding of the items and that no country-specific word changes were necessary.

Conclusion—All the adult and pediatric Neuro-QoL measures have been linguistically validated with Spanish speakers in the USA. Instruments are available for use at www.assessmentcenter.net.

Keywords

Neuro-QoL; Translation methodology; Linguistic validation

Introduction

The quality of life in neurological disorders (Neuro-QoL) measurement system was developed to assess symptoms and concerns of adult and pediatric patients with neurological disorders. This compilation of 470 self-report items covers 13 adult and 10 pediatric domains across physical, mental, and social health, making it possible to assess concurrently various aspects of a patient's functioning that traditionally would be measured with condition-specific tools [1, 2]. The Neuro-QoL instruments comprise calibrated item banks that can be administered as computerized adaptive tests (CAT), and fixed-length short forms and scales. Table 1 lists all available instruments.

The Neuro-QoL measures were originally developed in English, following extensive work to review existing item pools and determine relevant content across neurological disorders. The quality of life domains for five priority adult neurological conditions (stroke, multiple sclerosis, Parkinson's disease, epilepsy, and ALS) and two pediatric conditions (epilepsy and muscular dystrophy) were identified through a comprehensive review of the literature, expert interviews, and patient and caregiver focus groups [3, 4]. Since one of the aims of the project was to make the final instruments available in Spanish and appropriate for multilingual translation, linguistic and cultural translatability was assessed during the item development phase. Translation experts reviewed the wording of the items and identified potential translation difficulties and ambiguities, and subsequent revisions were made where possible [4]. Additionally, input from native Spanish-speaking patients residing in the USA was also incorporated in the item development process. Subsets of the best items from the final item pool for each domain (126 adult and 60 pediatric items) were debriefed with English speakers and translated into Spanish for use in cognitive debriefing interviews with Spanish-speaking patients in the USA. The goal was to assess content validity and verify that the item wording was culturally appropriate for the Spanish-speaking population. Subsequently, some changes were made to the English source items (e.g., going from present tense to past tense), some items were dropped, and others were modified. Once the item pools were finalized for field testing, all new and revised items were translated into Spanish. In this paper, we describe the Spanish translation and linguistic validation process.

Translation methodology

The items were translated according to the FACIT translation methodology [5–7], a validated and widely used iterative method consisting of forward and back-translations, multiple reviews, and testing with cognitive debriefing. The main purpose of this rigorous methodology is to ensure conceptual and measurement equivalence between language versions. Translators and reviewers from a variety of Spanish-speaking countries or regions (e.g., Puerto Rico, Mexico, Argentina, Colombia, Spain) participated in the process to produce a language version as universal as possible [5, 8]. Given the large number of items translated at one time, the translators were not the same for all the item banks. However, an attempt was made to have representation from Europe, USA, South America, Central America, and the Caribbean in all cases. The universal approach to translation presupposes that languages spoken in more than one country not be treated as country-specific. Given the heterogeneity of the Spanish-speaking population in the USA, it makes sense to have translated tools appropriate for a wider audience, rather than creating multiple country-specific versions of the same language. Figure 1 outlines the steps used to produce the final Spanish translation:

Prior to beginning the translation, item definitions were developed to clarify the intended meaning of the concepts. Item history tables were created to facilitate documentation of all the steps of the translation process item by item.

Redundancies between the adult and pediatric banks were identified to avoid duplicated translations. Pediatric and adult banks for each domain were included in the same history to ensure consistency where possible. The items previously translated for use in cognitive debriefing during item development were updated to match the revised English through a minimal methodology (i.e., one forward translation, one back-translation, one review, and finalization by the language coordinator). Revisions were also made to items previously translated by others to ensure accuracy and consistency of Spanish terminology across Neuro-QoL banks.

Some translation issues worth noting include difficulty to make culturally meaningful distinctions between “tired,” “fatigued,” and “exhausted,” which is a problem across languages. The multidimensional concept “upset” was also challenging. Issues identified and resolved during quality review and proofreading included (a) no grammatical agreement between the recall period “lately” and the past tense used in the items (the solution was to translate “lately” as “recently”); (b) resolution of discrepancies between items previously translated by others and the Neuro-QoL English source; and (c) universality considerations (if a Spanish word was too country-specific or would not be understood in a specific country, another word was added in parenthesis to make it more easily understood by all Spanish speakers).

Cognitive debriefing

Translated banks were divided into sets and debriefed with 30 adults and 30 children (ages 8–17). Fifteen adults were recruited from the general population and 15 from a clinical population (10 with any neurological disease and 5 diagnosed with stroke). The debriefing

scripts focused on items pertinent to the subjects' groups. For example, the Stroke group reviewed items from assisted device and personality and behavior banks, while general population groups reviewed Positive Physical Function and Cognition banks. For the pediatric group, the plan was to recruit 20 subjects from the general population, and 10 from a clinical population (5 diagnosed with epilepsy and 5 with muscular dystrophy), and items were grouped accordingly (e.g., Stigma and Walking Aid items were meant to be debriefed only with the clinical sample). However, due to difficulty finding Spanish-speaking children with the specific diagnoses, the items assigned to the epilepsy and muscular dystrophy groups were tested with general population. Three interviews had already been conducted with MD patients, and the data were combined.

Subjects completed the Neuro-QoL items independently before answering the interviewer's probes on item difficulty, the meaning of specific words/phrases, or reasons for selecting a specific response option. In some instances, subjects were also asked to consider alternative wording for an item. Interview scripts were compatible with the principles proposed by Willis [9].

Analysis and finalization

Participants' comments were analyzed to determine whether any item(s) needed to be revised. More pediatric items than adult ones were revised, but no item bank stood out as being more problematic than another. The issues encountered can be grouped in three main categories, although they sometimes overlap: (1) *Universality*: e.g., the word "inodoro" (toilet) is not used in all countries, so the word "excusado" was added in parentheses in adult items; for pediatric items, the English word "*toilet*" was added in italic in parenthesis, since the issue of universality was coupled with children's lack of Spanish vocabulary. (2) *Register or limited vocabulary*: e.g., "rendimiento en la escuela" (doing well in school) was not well understood by all children, so it was revised to "ir bien en la escuela." Similarly, it was unclear from adults responses if some had misunderstood "Me sentí indefenso/a" (I felt helpless), so an explanatory text ("sentí que no podía hacer nada para ayudarme") was added in parenthesis to clarify the intended meaning. (3) *Influence of English language*: this was evident in the understanding of the Spanish word "tutores" (guardians) in pediatric items. Some children interpreted it as "teachers." The final translation was revised with the more descriptive but unambiguous wording, "los que están legalmente a cargo de mí" (those who are legally in charge of me).

The translation was revised as appropriate where difficulty was reported or where there was a mismatch between understanding of the item and its intended meaning. Revisions were applied consistently for the same wording within and across banks, except in cases where a differentiation between pediatric and adult terms was needed (e.g., if children did not understand a certain word/phrase, while adults did, the revision was made only to the pediatric item).

Discussion and conclusion

The adult and pediatric Neuro-QoL measures have been linguistically validated with a diverse Spanish-speaking population in the USA. Following a rigorous multi-step translation

methodology which incorporated the input of translators from various countries and included pretesting with cognitive debriefing to assess understandability of each translated item, both the adult and pediatric Spanish items were considered conceptually equivalent to the English source. The adult Fatigue item bank has subsequently been linguistically validated also in Spain and Argentina, confirming that the universal Spanish version of this measure is appropriate for other countries besides the USA.

After the translation was considered final, the Spanish items were administered to a calibration sample of over one thousand Spanish-speaking individuals in the USA. Discussion of the calibration study and psychometric properties of the Spanish item banks will be reported elsewhere. Currently, computer adaptive tests (CAT) for all domains can be administered online through Assessment Center (www.assessmentcenter.net) to English speakers, and the Spanish version will soon be made available as well.

All Spanish fixed-length short forms are already available for use and can be downloaded via the Neuro-QoL Web site (www.neuroqol.org). Selected instruments have been translated into other languages, and additional translations are currently in progress. The same rigorous translation methodology described in this paper is being used for all languages.

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Fig. 1.
FACIT translation methodology

Table 1Neuro-QoL instruments available in assessment center (www.assessmentcenter.net)

Domain	Adult # items		Pediatric # items	
	Bank	Short form/scale	Bank	Short form/scale
Anxiety	21	8	19	8
Depression	24	8	16	8
Anger				8
Fatigue	19	8	13,11	8
Upper extremity function—fine motor, ADL	20	8		40 (scale)
Lower extremity function—mobility	19	8		39 (scale)
Cognitive function	28	8	14	8
Emotional and behavioral dyscontrol	18	8		
Positive affect and well-being	23	9		
Sleep disturbance		8		
Ability to participate in social roles and activities	45	8		
Satisfaction with social roles and activities	45	8		
Social relations—interaction with peers			16	8
Stigma	24	8	18	8
Pain				10
Communication		5 (scale)		