Linguistic validation of the Aneurysm Dependent Quality of Life (AneurysmDQoL) and Aneurysm Treatment Satisfaction Questionnaire (AneurysmTSQ) into Spanish and Catalan

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Abstract

This study addresses the translation and linguistic validation of two questionnaires on quality of life (AneurysmDQoL) and treatment satisfaction (AneurysmTSQ) for Catalan and Spanish-speaking patients with abdominal aortic aneurysms. The translation and cross-cultural adaptation process involved several phases, including forward translations, backtranslations, revisions, and cognitive debriefing with patients to ensure equivalence to the original English version, and comprehensibility for individuals without specialized medical knowledge. In this article, we set out the methodology for the linguistic validation of the questionnaire translations and its effectiveness assessment, under the supervision of Health Psychology Research (HPR), United Kingdom, who manage the questionnaires. We analyse the linguistic validation process, highlighting the main challenges and difficulties posed by these texts. The goal of this validation is the implementation of these questionnaires in clinical studies conducted in hospitals across Spain. This will enhance the care provided to patients with aneurysms by improving our understanding of their concerns and difficulties, and provide insight into their opinions of their treatment. However, obtaining clinical data accurately and making meaningful cross-country and

cross-linguistic comparisons is only possible with questionnaires that are accurate, equivalent to the original, easily understandable, and free from ambiguities.

Keywords: Linguistic validation, medical translation, determinologization, healthcare communication, quality of life.

Resumen

Validación lingüística de los cuestionarios "Aneurysm Dependent Quality of Life" (AneurysmDQoL) y "Aneurysm Treatment Satisfaction" (AneurysmTSQ) al español y al catalán

Este estudio aborda la traducción y validación lingüística de dos cuestionarios sobre la calidad de vida (AneurysmDQoL) y la satisfacción con el tratamiento (AneurysmTSQ) para pacientes de habla catalana y castellana con aneurisma de la aorta abdominal. La traducción y adaptación transcultural se han desarrollado a través de diversas fases: traducciones directas, traducciones inversas, revisiones y entrevistas cognitivas con pacientes para garantizar la concordancia con el original inglés y la comprensibilidad de los cuestionarios por parte de personas sin conocimientos médicos especializados. En este artículo, explicamos la metodología utilizada para la validación lingüística de las traducciones de los cuestionarios y la comprobación de su eficacia bajo la supervisión de Health Psychology Research (HPR), Reino Unido, entidad que gestiona los cuestionarios. Analizamos el proceso de validación lingüística y destacamos los principales retos y dificultades que plantean estos textos. El objetivo de la validación es la implementación de estos cuestionarios en estudios clínicos realizados en otros hospitales españoles. Esto permitirá mejorar la atención a los pacientes con aneurismas gracias a una mejor comprensión de sus preocupaciones y dificultades y permitirá conocer su opinión sobre el tratamiento. Sin embargo, solo es posible obtener datos clínicos fiables y comparables entre diferentes países y lenguas si disponemos de cuestionarios fidedignos, equivalentes al original, fácilmente comprensibles y sin ambigüedades.

Palabras clave: Validación lingüística, traducción médica, desterminologización, comunicación sanitaria, calidad de vida.

1. Introduction

This interdisciplinary study, bridging linguistics and medicine, addresses a growing social concern: patients' quality of life. When assessing the impact

of a specific disease on patients' lives, questionnaires designed and validated for this purpose are essential (Peach et al., 2016; Romaine et al., 2019). These questionnaires are often created in English, with no Spanish or Catalan versions available, requiring a rigorous translation and validation process.

An abdominal aortic aneurysm (AAA) is an abnormal, localized dilation in the aorta, the primary artery that carries blood from the heart to the abdominal organs and lower limbs. This dilation leads to a widening of the aorta in the abdominal region, and can pose a significant health risk. While this condition may not be widely known to the general public, it is one of the leading causes of death worldwide among men aged over 55 (Anagnostakos & Lal, 2021; Ying & Affan, 2019). The clinical significance of this issue is underscored by a relatively low mortality risk in elective surgery (2-5%) but can exceed 50% in emergency surgery for ruptured aneurysms (Godo Pla et al., 2023). Furthermore, there has been a recent increase in the incidence of ruptures, accounting for around 1-2% of total deaths (Sakalihasan et al., 2018).

This pathology may have a significant impact on various aspects of life. Patients' ability to express their concerns and evaluate their satisfaction with treatment, including the information provided and their level of comprehension of disease-related aspects, is considered an essential component of a social process known as "patient empowerment" (García-Izquierdo & Montalt, 2013; Cushing, 2015; Toledo-Chávarri et al., 2016; Hong & Oh, 2020; Vainauskienė & Vaitkienė, 2021). This concept primarily focuses on the patient's right to receive information enabling active participation in treatment and making relevant decisions regarding their health.

In this context, questionnaires to assess the impact of AAA on quality of life and satisfaction with treatment for AAA promote a patient-focused perspective and serve as an initial step for physicians to identify ways in which the condition may affect quality of life (such as worries about the future, sex life and physical activity) and to evaluate satisfaction with treatment (including diagnostic tests, postoperative follow-up, and information provided by healthcare professionals).

2. Objectives

To translate and linguistically and culturally adapt the AneurysmDQoL (Aneurysm-Dependent Quality of Life Questionnaire) and AneurysmTSQ (Aneurysm Treatment Satisfaction Questionnaire) questionnaires, managed

by Health Psychology Research (HPR) (©Prof. Clare Bradley: 27.3.13), into Spanish and Catalan.

To linguistically validate those questionnaires, in order to achieve a Spanish and Catalan version that is as faithful to the original as possible to enable studies of this condition across countries and languages, while ensuring it is understandable for patients and does not generate ambiguities or misinterpretations (Escobar-Bravo, 2004). Patients must therefore comprehend the questions and response options exactly as in the original.

To present the methodology developed by Health Psychology Research (HPR) for the linguistic validation of the questionnaire translations and to verify its effectiveness. This is a time-consuming task involving numerous professionals for relatively concise texts. We examine the overall process, its phases and results, as well as iterative interactions among translators, the questionnaires provider and patients.

3. Methodology

To assess the actual impact of abdominal aortic aneurysm from the patients' perspectives, we selected two questionnaires focusing on two fundamental aspects: first, the quality of life of patients with current or recent experience of this condition, and second, their satisfaction with the treatment. AneurysmDQoL is one of several -DQoL measures for different conditions, the first of which was the ADDQoL (Audit of Diabetes Dependent Quality of Life, Bradley et al., 1999). The AneurysmTSQ is one of several -TSQ measures based on the template of the DTSQ (Diabetes Treatment Satisfaction Questionnaire) (Bradley & Lewis, 1990).

The first questionnaire, AneurysmDQoL (HPR, 2014a), examines how this condition affects aspects of life that are often important for quality of life, including work, family, sex life, dependence on others, and enjoyment of food. The second, AneurysmTSQ (HPR, 2014b), focuses on the patient's experience of treatment including support from healthcare workers, the information provided about surgical procedures and the length of hospital stays, among other aspects. The AneurysmTSQ can be valuable for assessing the impact of endovascular technologies in aneurysm repair compared to open surgery (Peach et al., 2016).

The AneurysmDQoL questionnaire comprises 24 questions subdivided into 66 items, while the AneurysmTSQ questionnaire consists of 11 questions

distributed in 53 items. Typically, each item corresponds to a sentence, which can be a question, a response, or an instruction for completing the questionnaire. HPR delineates the items in an annexed report to each questionnaire, and this delineation must be adhered to throughout the translation and validation process (HPR, 2022).

Although there are various methods for translating such documents (Danielsen et al., 2015; Herdman, Fox-Rushby & Badia, 1997; Ware et al., 1995), one of the primary strategies to ensure equivalence to the original while incorporating all the necessary linguistic and cultural adaptations is to follow the MAPI Guidelines methodology (MAPI, 2017) and the International Quality of Life Assessment (IQOLA) Project guidelines (Aaronson et al., 1992). These guidelines ensure semantic, linguistic, conceptual, and technical equivalence.

The linguistic validation and cross-cultural adaptation procedure followed in this study adheres to HPR's recommendations, consisting of five phases (as shown in Figure 1), which are similar to those of the two aforementioned organizations.

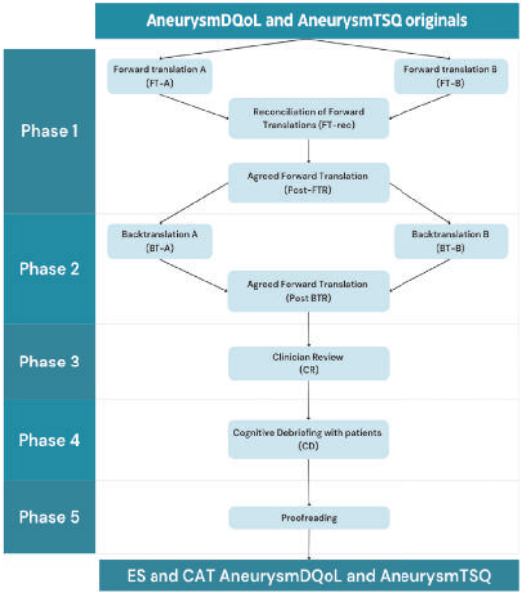

Figure 1. Algorithm including the various steps in linguistic validation.

3.1. Phase 1

a) *Forward Translations (FT):* Two native Spanish and Catalan translators (one professional translator and one linguist) translated the English version of the questionnaires independently.

b) *Reconciliation of Forward Translations (FT-rec):* The coordinator, a linguist specializing in healthcare communication, reviewed both translations and created an intermediate forward translation proposal.

c) *Agreed Forward Translation (Post-FTR):* The provisional version underwent review and agreement with a trilingual (Spanish, Catalan and English) member of the linguistic validation team at HPR, the company which manages the licensing and linguistic validation of the AneurysmDQoL and AneurysmTSQ (and related measures for other conditions) to ensure translation fidelity, prevent misinterpretations, and maintain consistency with other questionnaires containing similar questions or sections.

3.2. Phase 2

a) *Backtranslations (BT):* For each questionnaire and each language version, two professional native English translators (one provided by HPR) performed a blind backtranslation (i.e. with no help or information about the original English questionnaires) and independently of each other. Different translators for Spanish and Catalan versions ensure blind translations to avoid contamination from the information contained in the provisional translation of the other language.

b) *Agreed Backtranslations (Post BTR):* Comparison of the two backtranslations with the original English version to ensure semantic, linguistic, conceptual, and technical equivalence. Review and correction of potential discrepancies and decisions made by HPR and the translation coordinator. Creation of a new agreed-upon version.

3.3. Phase 3

Clinician Review (CR): Each item was reviewed by an experienced vascular surgeon, focusing primarily on the correctness and suitability of the terminology used. Words that might pose comprehension challenges for patients are anticipated to be identified, and replaced with commonly used terms or expressions used in patient interactions, avoiding medical jargon. The clinical expert may propose changes on any subject. The changes are agreed upon with HPR.

3.4. Phase 4

Cognitive Debriefing with patients (CD): Five patients with abdominal aortic aneurysm completed the questionnaires in each language to verify the comprehension of instructions, questions, and response options. Individual cognitive debriefings were subsequently conducted for each questionnaire. If items that hindered comprehension or were interpreted differently were identified, corrections were proposed and agreed upon with HPR. This preliminary testing of the provisional translations took place at the Hospital Universitari i Politècnic La Fe in Valencia.

3.5. Phase 5

Proofreading: An external linguist who has not previously been involved in the process, with native Spanish or Catalan proficiency and excellent English, reviewed the preformatted questionnaires for possible errors or mistakes. The proposed changes were then agreed upon with HPR.

4. Results and discussion

4.1. Forward translations

The numerical and percentage results of the three steps comprising Phase 1 are presented in Table 1. In the first step (1a), a comparison is made between the two forward translations, FT-A and FT-B, to determine the percentages of discrepancies. The items are then classified based on the degree of difficulty in translation. The data clearly indicate that the AneurysmTSQ questionnaires present more complications than the AneurysmDQoL ones (19.81% vs. 1.52% of literal and conceptual discrepancies). This is primarily due to the vocabulary used. While the AneurysmDQoL questionnaires focus on aspects of daily life (with the corresponding vocabulary), the AneurysmTSQ contains many relatively technical items about medical tests and follow-ups. Second, within the Reconciliation of Forward Translations (1b), four options are available: A) if FT-A and FT-B are the same and the coordinator identifies no need for correction, it remains as is; B) one of the two forward translations is selected; C) an intermediate version is created, taking elements from both forward translations; D) the coordinator must intervene to make some improvements or corrections, and an intermediate version is not sufficient. Once again, a substantial difference is evident in the

last category *D) Intervention of coordinator*, with the AneurysmTSQ questionnaires exhibiting greater complexity compared to the AneurysmDQoL equivalents, at 21.70% and 8.33%, respectively. Finally, in the third step (1c), an HPR member of the linguistic validation team with access to all previously validated questionnaires and experience in the field proposes changes to the reconciled version. As observed from the data, the interventions were numerous: on average, nearly half of the items had to be corrected or adapted.

	CAT TSQ	ES TSQ	TSQ CAT+ES	CAT DQoL	ES DQoL	DQoL CAT+ES
1a. Forward translation-A = Forward translation-B?						
A) No discrepancies	13 (24.53%)	11 (20.75%)	**22.64%**	23 (34.85%)	25 (37.88%)	**36.36%**
B) Literal discrepancies, same meaning	30 (56.60%)	31 (58.49%)	**57.55%**	42 (63.64%)	40 (60.61%)	**62.12%**
C) Literal and conceptual discrepancies	10 (18.87%)	11 (20.75%)	**19.81%**	1 (1.52%)	1 (1.52%)	**1.52%**
1b. Reconciliation of forward translations (FT-rec)?						
A) FT-A = FT-B = FT-rec	13 (24.53%)	11 (20.75%)	**22.64%**	22 (33.33%)	25 (37.88%)	**35.61%**
B) FT-A or FT-B = FT-rec	19 (35.85%)	18 (33.96%)	**34.91%**	31 (46.97%)	26 (39.39%)	**43.18%**
C) FT-A + FT-B = FT-rec	12 (22.64%)	10 (18.87%)	**20.75%**	8 (12.12%)	9 (13.64%)	**12.88%**
D) Intervention of coordinator	9 (16.98%)	14 (26.42%)	**21.70%**	5 (7.58%)	6 (9.09%)	**8.33%**
1c. FT-rec = Agreed forward translation (forward translation round)?						
A) No changes	20 (37.74%)	34 (64.15%)	**50.94%**	36 (54.55%)	40 (60.61%)	**57.58%**
B) Literal changes	25 (47.17%)	11 (20.75%)	**33.96%**	30 (45.45%)	24 (36.36%)	**40.91%**
C) Meaning changes	8 (15.09%)	8 (15.09%)	**15.09%**	0	2 (3.03%)	**1.52%**

Table 1. Results of phase 1: Forward translations. Number of items and percentages.

In the first step (1a), these data can be understood as a scale where the category *C) Literal and conceptual discrepancies* is particularly relevant, as it reveals some of the items that will be the most challenging to translate and adapt during the process. This category includes possible mistranslations due to misinterpretation or ambiguity. For example, *not being anxious* is translated by the first translator (FT-A) as *no estar ansioso/a*, and by the second translator (FT-B) as *no tener ansiedad* (ES-AneurysmDQoL), as *ansioso/a* can be ambiguous (it can mean to feel longing or anxiety). However, the intended meaning of the questionnaire was the latter. All these discrepancies, especially those in category (C), needed to be resolved by the coordinator. They include the translation and interpretation of *convenient* (*adecuado*

'adequate' or *fácil/cómodo* 'easy/comfortable') or *bothered*, as exemplified by the question: *How bothered are you...? (¿Está usted preocupado/a por...?* 'Are you worried about...?' or *¿En qué medida siente molestias relacionadas...?* 'To what extent do you feel discomfort related to...'), etc.

In the second step (1b), regarding the coordinator's interventions (D), the coordinator's role primarily focuses on enhancing the questionnaire's consistency and employing more appropriate terminology and expressions for the patients, rather than solely addressing inaccuracies. An example is *aortic aneurysm*, which is translated more literally in both forward translations as *aneurisma aòrtic/aórtico* (CAT/ES), but it was decided that in oral communication with patients, its synonym *aneurisma de l'aorta/la aorta* (CAT/ES) is more commonly used, and its adjectivization avoided as it was considered more complicated.

In the third step (1c), there is a large percentage of modifications in *B) Literal changes* in the case of Catalan, especially for CAT-AneurysmTSQ. This is because in Catalan, there are two formal ways of addressing a person (*vós* + second person plural or *vostè* + third person singular) (Example 1). The *vós* form was considered more inclusive (fewer dialectal differences, less gender differentiation, and less distance from the interlocutor), but *vostè* was ultimately preferred because it had been used in previous validated questionnaires. In Spanish, there is only one form (*usted* + third person singular), so not as many items needed to be edited.

(1) CAT *vós* (proposal): El que ens agradaria saber és com us sentiu amb la vostra vida actualment.
CAT *vostè* (agreed version): El que ens agradaria saber és com se sent amb la seva vida actualment.
ES *usted*: Lo que nos gustaría saber es cómo se siente con su vida actualmente.

In the case of the final category *C) Meaning changes*, which as previously discussed, reveals possible errors or inaccuracies, *How satisfied are you with your understanding of the treatment...?* was modified from the reconciliation proposal FT-rec: *¿En qué medida está usted satisfecho/a con la explicación de su tratamiento...?* (How satisfied are you with the explanation of your treatment...?) to *¿En qué medida está usted satisfecho/a con lo que sabe y entiende de su tratamiento...?* (How satisfied are you with what you know and understand about your treatment...?) because this question specifically refers to the degree of satisfaction patients have with their understanding of their treatment.

Patients sometimes receive a great deal of information and explanations about their illness and treatment, but they do not necessarily understand it. In this case, the patient would be satisfied with the amount of information they have been given, but they are not satisfied with their understanding of this information. In contrast, a physician might give a poor explanation of how a treatment works, but the patient may not care because they prefer not to have too much information as they find it overwhelming.

4.2. Backtranslations

Two independent backtranslations of each questionnaire are performed in the second phase. In the first step of this phase (2a), we compare the differences between the two backtranslations (BT-1 and BT-2). The first category, *A) No discrepancies*, indicates the simplest items, as they have been translated in the same or nearly the same way (changes in word order, preposition without a change in meaning, etc.). The second category, *B) Literal discrepancies, same meaning*, contains translations that are no longer identical or nearly identical, but confirm that the meaning of the proposed translation should be correct. The third category, C*) Literal and conceptual discrepancies*, includes translations that are not entirely equivalent, have some changes in meaning or nuance. In the second step (2b), the two backtranslations are compared – this time not with each other but instead with the English original to examine semantic, linguistic, conceptual, and technical equivalence. If any inconsistency is detected, the proposed translation must be adjusted to provide a better match for the English original. We distinguish only two categories: *A) No changes*, where the proposed translation remains the same, and *B) Changes*, where improvements need to be made.

As observed in Table 2, during the first phase (2a), only 5 items (4.72% AneurysmDQoL) presented conceptual discrepancies, resulting in differences in the meanings of the backtranslations. Additionally, translator agreements encompass approximately half of the items, with the exception of CAT-AneurysmDQoL, where the agreement reaches as high as 75.76%. In the second phase (2b), there are minimal changes in the AneurysmTSQs (averaging 1.89%). However, there is a notably high incidence of changes necessary in the AneurysmDQoLs (averaging 35.61%).

	CAT TSQ	ES TSQ	TSQ CAT+ES	CAT DQoL	ES DQoL	DQoL CAT+ES
2a. Backtranslation-1 (BT-1) = Backtranslation-2 (BT-2)?						
A) No discrepancies	24 (45.28%)	27 (50.94%)	**48.11%**	50 (75.76%)	35 (53.03%)	**64.39%**
B) Literal discrepancies, same meaning	27 (50.94%)	23 (43.40%)	**47.17%**	16 (24.24%)	31 (46.97%)	**35.61%**
C) Literal and conceptual discrepancies	2 (3.77%)	3 (5.66%)	**4.72%**	0	0	**0%**
2b. Agreed backtranslations (back translation round)?						
A) No changes	53 (100%)	51 (96.23%)	**98.11%**	43 (65.15%)	42 (63.64%)	**64.39%**
B) Changes	0	2 (3.77%)	**1.89%**	23 (34.85%)	24 (36.36%)	**35.61%**

Table 2. Results of phase 2: Backtranslations. Number of items and percentage.

In the first step (2a), the category *A) No discrepancies* primarily includes single-word answers (*follow-up*) or short sentences with simple vocabulary and no technical terminology (*Do you have or would you like to have a sex life?*). These are generally items that have not elicited any discrepancies since the initial phase. For these items, we have confirmed that the proposed translations in Catalan and Spanish are understood in a similar manner, suggesting their equivalence to the original. However, this equivalence is validated further in the subsequent step.

In the case of *B) Literal discrepancies, same meaning* it is necessary to review the reasons for the variations in the backtranslations: whether it is simply a different way of saying the same thing (synonyms, different expressions) (Example 2), or if there is some nuance that is not as transparent in the proposed translation and needs editing.

(2) Original: How much energy I have is:
ES translation proposal: La cantidad de energía que tengo es:
BT-1: The energy levels I have are:
BT-2: The amount of energy I have is:

The third category *C) Literal and conceptual discrepancies* is the one that should be analysed in detail, as it can indicate a meaning error. These discrepancies only occurred in the AneurysmTSQ questionnaires, and out of the 5 cases, 4 involved inconsistencies in verb tenses because one of the backtranslations was in the past tense and the other in the present (Example 3). Given that these are questions about satisfaction with quality of life, these nuances can be very important. In the subsequent step, these inconsistencies are reviewed in detail, showing that the proposed translation is correct and adheres to the

original, and that there was an inaccuracy in one of the backtranslations. The fifth case is similar: the inconsistency is that one question is posed negatively (*bothered*), and the other positively (*satisfied*) (Example 4). Again, in the next step, the proposed translation in Catalan is found to adhere to the original and an error is found in BT-2.

(3) ES translation proposal: ¿En qué medida le molestan los efectos secundarios o las secuelas del tratamiento del aneurisma?
BT-1: To what extent are you afflicted by side effects or other ramifications of the aneurysm treatment?
BT-2: How bothered were you by the side effects or after effects of the treatment for the aneurysm?

(4) CAT translation proposal: Fins a quin punt li molesten els efectes secundaris o les seqüeles del tractament del seu aneurisma?
BT-1: How bothered are you by the side effects or sequelae of your aneurysm treatment?
BT-2: To what extent are you satisfied with the side effects or aftereffects of your aneurysm treatment?

In the second step (2b), in the AneurysmTSQ questionnaires, there are only two items in Spanish where some changes had to be made. These are minor issues: the backtranslations revealed that the proposed Spanish translation was missing a minor element (*es decir* 'i.e.'). In the AneurysmDQoL questionnaires, more than a third of items had to be edited in both Catalan and Spanish. This is because the backtranslations revealed that in 23 questions (=23 items in each language) starting with *If I had never had an aneurysm...*, the word *nunca/mai* 'never' was omitted (Example 5) in both Catalan and Spanish. Although the proposed translation (Forward Translation Round) already implies this meaning (*no hubiera tenido/no hagués tingut* 'had not had'), since some patients will no longer have an aneurysm susceptible to rupture (because they have been operated on or have a stent), HPR felt that there could be a risk of interpreting it differently, and it was preferred to explicitly include *nunca/mai* 'never.'

(5) Original: If I had never had an aneurysm, my quality of life would be:
ES translation proposal: Si no hubiera tenido un aneurisma, mi calidad de vida sería:
CAT translation proposal: Si no hagués tingut mai un aneurisma, la meva qualitat de vida seria:
ES/CAT BT-1: If I had not had an aneurysm, my quality of life would be:

ES/CAT BT-2: If I hadn't had an aneurysm, my quality of life would be:
ES agreed translation: Si nunca hubiera tenido un aneurisma, mi calidad de vida sería:
CAT agreed translation: Si no hagués tingut mai un aneurisma, la meva qualitat de vida seria:

In ES-AneurysmDQoL, there was one more case of change, as the Catalan translation was considered to be closer to the original, and this change (Example 6) was also applied to the Spanish version.

(6) Original: For me, local or long distance journeys are:
CAT translation proposal: Per a mi, els desplaçaments locals/urbans o de llarga distància són:
CAT BT1: For me, local/urban or long distance travel is:
CAT BT2: For me, local/urban or long-distance journeys are:
CAT agreed translation: Per a mi, els desplaçaments locals/urbans o de llarga distància són:
ES translation proposal: Para mí, hacer trayectos o viajes (cortos o largos) es:
ES BT1: In my view, making journeys or trips (long or short) is:
ES BT2: For me, making journeys or trips (short or long) is:
ES agreed translation: Para mí, los trayectos locales/urbanos o de larga distancia son:

This also ensures greater consistency between the questionnaires that could be used simultaneously in the same hospital in bilingual regions.

4.3. Clinician review

As shown in Table 3, for the AneurysmDQoL questionnaires (with limited terminology) the clinician expert only proposed changing one item containing the term *monitoring*, which is also present in the AneurysmTSQ. In contrast, for the AneurysmTSQ, the expert suggested revising one-fifth of the items (20.75%), which is a substantial figure. In all cases, these revisions were undertaken with the primary objective of enhancing terminology in order to facilitate a higher level of patient comprehension.

	CAT TSQ	ES TSQ	TSQ CAT+ES	CAT DQoL	ES DQoL	DQoL CAT+ES
3. Post clinician review						
A) No changes	42 (79.25%)	42 (79.25%)	**79.25%**	65 (98.48%)	65 (98.48%)	**98.48%**
B) Changes	11 (20.75%)	11 (20.75%)	**20.75%**	1 (1.52%)	1 (1.52%)	**1.52%**

Table 3. Results of the phase 3: Clinician Review. Number of items and percentage.

In Table 4, the terms that were considered potentially challenging for patients are presented. For example, two alternative translations were included for the term *monitoring*: ALT1 (more literal, precise, and technical) and ALT2 (more general but easier to understand). The clinical expert improved ALT2 to make it less generic but equally easy to comprehend. It was decided that in all cases where two alternatives were available, neither would be discarded in this phase. Instead, patients in cognitive debriefings would provide feedback to determine the optimal choice. For all items containing the term *scan*, it was decided to retain the literal part *escáner/escàner* with the clarification *(TAC)* '(CT)' to enhance comprehension, and to await patients' reactions during the debriefings. All the changes were agreed upon with the translation coordinator and HPR.

Original	Proposed translation ES / CAT	Clinician expert's proposal ES / CAT	Comments	Agreed version for Cognitive Debriefing
Monitoring	ALT1: monitorización ALT2: control / ALT1: monitoratge ALT2: control	visitas de control / visites de control	*Monitoring* is a specialized term and it is not commonly used in conversations with patients. It may be more understandable for regular people 'control visits'.	ALT1: monitorización ALT2: visitas de control / ALT1: monitoratge ALT2: visites de control
Operation (stent or open-repair)	Operación (stent o cirugía abierta) / Operació (stent o cirurgia oberta)	Operación (endoprótesis o cirugía abierta) / Operació (endopròtesi o cirurgia oberta)	*Stent* is usually associated with cardiac catheterism. *endoprótesis/endopròtesi* 'stent graft' is perfectly understandable even for patients who had not yet had aneurysm repair.	✓
Scan results	resultados de los escáneres? / resultats dels escàners?	resultados de las TAC? / els resultats de les TAC?	The patients may not understand the term *escáner/escàner* correctly. We propose using the term *TAC* 'CT' instead, as this is what clinicians use when communicating with patients, and is more familiar to Spanish and Catalan speakers.	resultados de los escáneres (por ejemplo, de las TAC)? / resultats dels escàners (per exemple, de les TAC)?

Table 4. Evolution of selected term translations.

4.4. Cognitive debriefings with patients

The cognitive debriefings involved asking a series of questions about each item (not only those considered problematic) and recording the patients' literal responses and interpretations in report templates prepared by HPR:

1. Was this difficult to understand?
2. What do you understand this wording to mean?
3. Could this be worded better?
4. Which alternative did you prefer?

It is essential to be consistent, persistent, and rigorous, and to genuinely ask all the questions for each item. Even if patients respond that they had no trouble understanding a question or response, it does not necessarily mean they interpreted it correctly. This decision and work are the responsibility of the coordinator. In fact, in numerous cases, a patient claimed not to have had any issues with an item, but was then either unable to explain it in their own words, or explained it differently.

Patients helped us identify items that generated comprehension problems, but they also proposed other versions with words or word orders they considered better due to being easier or more familiar. After collecting the data, we made a distinction between three categories: *A) No changes* (the item's translation is considered successful and does not require modification), *B) Change for ALT2* (patients had difficulty understanding ALT1 and preferred ALT2), and *C) New changes* (patients identified other items that did not have an ALT2 and they needed further adaptation).

In the data in Table 5, there is considerable symmetry between the two languages. Throughout the translation and adaptation process, efforts were made to make the two linguistic versions (Catalan and Spanish) as similar as possible. This also demonstrates that both groups of patients (Catalan-speaking and Spanish-speaking) identified the same problems (or very similar ones) both quantitatively and qualitatively. Items that did not need editing amount to around 80% for the AneurysmTSQ, and around 90% for the AneurysmDQoL. Nevertheless, there remains a significant percentage of items which needed further discussion.

	CAT TSQ	ES TSQ	TSQ CAT+ES	CAT DQoL	ES DQoL	DQoL CAT+ES
4. Post-CD						
A) No changes	42 (79.25%)	42 (79.25%)	**79.25%**	59 (89.39%)	61 (92.42%)	**90.91%**
B) Change for ALT2	6 (11.32%)	6 (11.32%)	**11.32%**	2 (3.03%)	3 (4.55%)	**3.79%**
C) New changes	5 (9.43%)	5 (9.43%)	**9.43%**	5 (7.58%)	2 (3.03%)	**5.30%**

Table 5. Results of the phase 4: Cognitive debriefings with patients. Number of items and percentage.

In the second category, *B) Change for ALT2*, we decided on ALT2 in all cases following the patients' comments. It was confirmed that the more literal translation of *monitoring* to *monitorización/monitoratge* was not well understood by patients. Although the word sounded familiar to them and it was not

initially identified as complicated, when asked about its meaning or how they would explain it in their own words, they either did not know what to say, or they guessed that it was somehow related to tests and examinations. Proposal 2 (ALT2) also needed improvement, because *visitas/visites de control* 'control visits' made patients think of *monitoring after the operation*, but to ensure equivalence in the questionnaires, it needed to be understood as before the operation as well. In the final solution, this specification therefore had to be made clear: *visitas preoperatorias y de control/visites preoperatòries i de control* 'preoperative and control visits'.

An issue unrelated to medical terminology was the adaptation of questions about the *partner*. In English, *partner* is polysemic, and can refer to "one of the owners of a company", "one of a pair of dancers or one of a pair who are playing a sport or a game together" or "the person you are married to or living with as if married to them, or the person you are having a sexual relationship with." The English version of the questionnaire asks all questions related to partner satisfaction (third meaning) in a very descriptive and explicit manner to avoid these confusions (Example 7). However, neither Spanish nor Catalan has the same problem with the polysemy of the word *pareja/parella*. Nevertheless, the priority is always to translate as closely to the original as possible, provided that this does not break any rules applicable to the target language or hinder comprehension. We therefore tried both alternatives (ALT 1 and ALT2), and the patients mostly assured us that they preferred ALT2 due to being shorter and clearer, and that they did not need the parenthesis with examples. Additionally, we considered that the danger with the parenthesis with examples was its exclusion of some types of partner, which could have offended some patients.

(7) Original: Do you have or would you like to have a close personal relationship (e.g. husband / wife, partner):
ALT1: Té o li agradaria tenir una relació de parella (per exemple, marit / muller, parella)?
ALT2: Té o li agradaria tenir una relació de parella?

The questions related to *partner* might have seemed straightforward from a semantic standpoint, but the interpretations of some patients during the debriefings led us to ensure that the proposed meaning included everything according to HPR's instructions. For example, one patient understood all questions about their partner in a sexual context (even though the questionnaire later included questions related to their sex life). This

prompted us to consider a third alternative, by adding *relació afectiva de parella* 'emotional partner relationship', but this was too exclusive because if a patient thinks about sex when responding to this item, it is because it affects their relationship. In the end, we therefore preferred to retain the broader question in order to not exclude any experience.

In the third category, *C) New changes*, the patients showed some items that despite efforts at adaptation were still not comprehensible to everyone. In the AneurysmTSQ questionnaire, it was terminology (*stent*, *scan*, and the questionnaire's English name, *AneurysmDQoL*), and in the AneurysmDQoL, there were more changes in the Catalan version due to some words not being widely known in all Catalan sub-dialects (*lleure* 'leisure', *emplenar* 'to fill'). We present the proposed solution we arrived at as a result of debriefings with the patients in Table (6) below.

Original	Version for Cognitive Debriefing	Comments	Final version
Operation (stent or open-repair)	Operació (endopròtesi o cirurgia oberta)	One patient did not understand *endopròtesi* 'endoprosthesis'. To avoid this problem for others, we propose adding *stent*, since there are patients who are more familiar with this term, because their doctor has used it.	Operación (endoprótesis/stent o cirugía abierta) / Operació (endopròtesi/stent o cirurgia oberta)
scan results	los resultados de los escáneres (por ejemplo, de las TAC)? / resultats dels proves escàners (per exemple, de les TAC)	Some patients think that *escáner/escàner* 'scan' can lead to confusion, as they do not know exactly what it refers to. In Spanish and Catalan, many people may associate it with the document scanner in the office. As the acronym *TAC* 'CT' was understood correctly by all, we propose adding an easier and more descriptive wording of 'results of imaging tests (for example CT scans)'.	los resultados de las pruebas por la imagen (por ejemplo, de las TAC)? / resultats de les proves per la imatge (per exemple, de les TAC)
scans	escáneres como la TAC / escàners com la TAC	As above. 'imaging tests such as CT'	pruebas por la imagen como la TAC / proves per la imatge com la TAC
AneurysmDQoL (Aneurysm-Dependent Quality of Life)	AneurysmDQoL (Aneurysm-Dependent Quality of Life)	Patients affected by AAA are usually elderly and do not understand English.	AneurismaDQoL
my leisure activities	activitats de lleure	The word *lleure* 'leisure' is widely used in Catalonia, but not in the Valencian Community. The patients were unsure of its meaning. *Oci* is a synonym and is known to everyone.	activitats d'oci
If **yes**, complete **(a)** and **(b)**	Si la resposta és ***sí***, empleni **(a)** i **(b)**	Although only one patient had problems with *empleni* 'fill/complete', we consider it to be a rather formal verb, and not familiar to everyone. It would be better to use a synonym that is easier to understand.	Si la resposta és ***sí***, contesti **(a)** i **(b)**

Table 6. Improvements made as a result of cognitive debriefings.

4.5. Proofreading

Phase 5 entails proofreading by an external linguist who has not previously been involved in the present process. Our expert confirmed the adequacy of all four questionnaires, and suggested only minor changes related to formatting errors (Table 7), rather than in the translation and adaptation: consistency in the use of capital letters in a list of items (four items) in the AneurysmTSQ and a different font size in one of the CAT-DQoL responses.

	CAT TSQ	ES TSQ	TSQ CAT+ES	CAT DQoL	ES DQoL	DQoL CAT+ES
5. Post proof-reading						
A) No changes	49 (92.45%)	49 (92.45%)	**92.45%**	65 (98.48%)	66 (100%)	**99.24%**
B) Minor changes	4 (7.55%)	4 (7.55%)	**7.55%**	1 (1.52%)	0	**0.76%**
C) Changes	0	0	**0%**	0	0	**0%**

Table 7. Results of phase 5: Proofreading. Number of items and percentages.

5. Conclusions

This study on the translation and adaptation of questionnaires related to abdominal aortic aneurysms into Spanish and Catalan has highlighted a series of critical processes and challenges that have a substantial impact on both linguistic and translation research and clinical practice. The various stages of this research, ranging from the initial translation to the final proofreading, have provided a profound insight into how subtle linguistic and cultural differences can influence patients' understanding and interpretation of health questionnaires.

The process of linguistic validation required obtaining the license for the questionnaires from HPR, and approval from the Ethics Committee of the Hospital Universitari i Politècnic La Fe. The participants were experts from various fields, including humanities professionals specializing in linguistics and translation, as well as vascular surgeons and psychologists in the field of healthcare sciences. This diversity of experts was essential to ensure the quality of the questionnaires. The need for this study is evident when the focus is on the patient in the healthcare setting. Communication with patients was through written words, attempting to gather information on how they experience a specific medical condition, their concerns, and complications, as well as their satisfaction with their treatment. The choice

of words is crucial. In addition to contributions by experts from various fields, cognitive debriefings with patients were essential to identify and address specific comprehension issues and to ensure that the questionnaires can be effectively used in clinical practice.

The main challenges we faced included finding a balance between a faithful translation of the original and a translation that is understandable, natural, and respectful to patients; avoiding words or expressions with potential semantic ambiguities; adjusting politeness to avoid invasive or overly complex questions resulting from an overly literal translation from English; steering clear of unnecessary use of Anglicisms, and finally, adapting the terminology to make it understandable even to patients without specialized knowledge.

As regards terminology, all the technical terms in the questionnaires were translated in the available dictionaries, but this did not ensure understanding. We found that terms needed to be adapted rather than simply translated. Furthermore, concerning determinologization, there are notable differences between languages and countries. Achieving this adaptation successfully requires an interdisciplinary team, and is essential for verifying the final testing with real patients. There are often expressions or terms that professionals assume are understandable or cannot be misinterpreted, but this must be verified. Each minor nuance can affect the patient's perception, and even invalidate a clinical study.

With our data on the linguistic validation process, we have been able to justify the utility of the HPR procedure. At each stage of the process, we identified items that did not guarantee suitability for the patient, precision, consistency with other items or questionnaires, and fidelity to the original. The number of items requiring editing decreased as the phases progressed. The HPR procedure and its supervision ensure that the questionnaire is equivalent to the original and at the same time, understandable and adapted to patients in a specific language and country, as is the case with Spanish and Catalan in Spain.

This work made it possible to implement QoL and treatment satisfaction questionnaires in both languages for clinical studies in several hospitals in Spain, and to make them available through HPR for other healthcare institutions that may need them. This is a significant breakthrough in improving care for Catalan and Spanish-speaking patients with abdominal aortic aneurysms. These questionnaires can now be used to assess quality of

life and satisfaction with treatment, to identify patients' needs and concerns, and to contribute to more personalized and effective care for this population.

The primary limitations encompass the potential for bias in patient selection, as recruitment was conducted over the phone, necessitating prior consent as well as considerations regarding physical availability and scheduling for the testing date. Conversely, the sample size for the final cognitive debriefing comprised only five patients, which might have been insufficient for detecting other potential issues. This limitation arises from the lack of assurance regarding diverse educational levels in this critical assessment. It is important to note that the focus of this assessment was not on comprehension but rather on the interpretation of certain concepts.

In summary, this study highlights the complexity of translating and adapting health questionnaires in a multilingual and multicultural context. Collaboration between translators, clinical experts, and patients was essential in achieving a final version that is both faithful to the original and comprehensible to users. The implications of this work go beyond linguistics, and have a direct impact on clinical practice, as it ensures that healthcare professionals can collect meaningful and accurate data from Spanish and Catalan-speaking patients.

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Access to questionnaires

Please visit www.healthpsychologyresearch.com to request access to the AneurysmDQoL and AneurysmTSQ and related measures for other conditions.

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