The Canadian Journal of Neurological Sciences (2025), **52**, 129–131
doi:10.1017/cjn.2024.18

Canadian Journal of Neurological Sciences
Journal Canadien des Sciences Neurologiques

Brief Communication

Translation of the Preference-Based Amyotrophic Lateral Sclerosis Scale into French

Ava Mehdipour[1], Lizabeth Teshler[2], Vanina Dal Bello-Haas[1], Vanessa Bouchard[3] and Ayse Kuspinar[1]

[1]School of Rehabilitation Science, Faculty of Health Sciences, McMaster University, Hamilton, ON, Canada, [2]Department of Arts and Science, McMaster University, Hamilton, ON, Canada and [3]Hôpital de Chicoutimi, Centre intégré universitaire de santé et services sociaux du Saguenay-Lac-Saint-Jean, Chicoutimi, QC, Canada

ABSTRACT: The objective of this study was to translate the Preference-Based Amyotrophic Lateral Sclerosis Scale to French-Canadian. After the scale underwent forward and back translations, the expert committee examined the translated versions and found minor grammatical errors and suggested idioms to be changed to better represent French-Canadian language. Cognitive debriefing interviews were carried out to assess the pre-final version for clarity, and minor changes were made. Consensus from the expert committee and people with amyotrophic lateral sclerosis on the measure's clarity, word choice, and meaning were achieved, resulting in the final French version of the Preference-Based Amyotrophic Lateral Sclerosis Scale.

RÉSUMÉ: L'objectif de cette étude était de traduire vers le français du Canada l'échelle de la sclérose latérale amyotrophique basée sur les préférences (*Preference-Based Amyotrophic Lateral Sclerosis Scale*). Après avoir effectué une traduction aller-retour ou récursive de cette échelle, un comité d'experts a tout d'abord examiné les versions traduites et relevé des erreurs grammaticales mineures. Ce même comité a ensuite suggéré des expressions idiomatiques à modifier pour mieux coller à la réalité du français du Canada. Plus encore, des entretiens cognitifs ont été menés pour évaluer la clarté de la version pré-finale, ce qui a entraîné en bout de ligne des modifications mineures. Enfin, un comité d'experts ainsi que des personnes atteintes de sclérose latérale amyotrophique sont parvenus à un consensus quant à la clarté, au choix des mots et à la signification de la mesure, ce qui a permis d'obtenir la version française finale de l'échelle de la sclérose latérale amyotrophique basée sur les préférences.

Keywords: amyotrophic lateral sclerosis; cognitive debriefing; preference-based measure; translation

(Received 24 November 2023; final revisions submitted 27 January 2024; date of acceptance 29 January 2024; First Published online 20 February 2024)

Introduction

Preference-based measures are health-related quality of life measures that provide a single index score from death to perfect health, generated from general populations or patients' preferences for health states.[1] This score can be multiplied by the life expectancy from an intervention to give its quality-adjusted life years, which can be used to compare interventions with cost-utility analyses.[1] One of the most widely used preference-based measure for people with amyotrophic lateral sclerosis (ALS) (PALS) is the EQ-5D-3L,[2] however, it is generic and does not encompass specific health concerns and areas of life affected in PALS.[3] The majority of generic preference-based measures encompass less than 75% of life domains important to PALS.[3] Thus, the development of an ALS-specific preference-based measure was undertaken to develop a health-related quality of life measure that can be used to evaluate the effects of treatments and most importantly, capture domains important to people living with ALS.[4]

The initial development of an ALS-specific preference-based measure (Preference-Based Amyotrophic Lateral Sclerosis Scale) included identifying areas of life important to PALS using the Patient-Generated Index[3] and asking PALS to give each area an importance rating to determine which items to include in a preference-based measure.[4] Cognitive debriefing interviews were then completed to refine the items and response options, and finalize the scale. The Preference-Based Amyotrophic Lateral Sclerosis Scale includes the following domains/items: Recreation and leisure, Mobility, Interpersonal interactions and relationships, Eating and swallowing, Handling objects, Communicating-speech, Carrying out routine activities, and Mood. The next phase of the project involves adapting the English version of the Preference-Based Amyotrophic Lateral Sclerosis Scale into French. French is one of two official languages in Canada, with more than 20% of the population having French as their first official spoken language (i.e., Francophones).[5] Furthermore, over 70% of the population living in the province of Quebec consists of French-Canadians.[6]

Corresponding author: Ayse Kuspinar; Email: kuspinaa@mcmaster.ca

Cite this article: Mehdipour A, Teshler L, Dal Bello-Haas V, Bouchard V, and Kuspinar A. (2025) Translation of the Preference-Based Amyotrophic Lateral Sclerosis Scale into French. *The Canadian Journal of Neurological Sciences* **52**: 129–131, https://doi.org/10.1017/cjn.2024.18

Thus, a French version of the Preference-Based Amyotrophic Lateral Sclerosis Scale is important to ensure the scale's availability and accessibility across Canada, for both English and French-speaking individuals. The objective of this study was to translate the Preference-Based Amyotrophic Lateral Sclerosis Scale from English to French following standardized translation guidelines to ensure content equivalence between the original and target language.

The translation of the English Preference-Based Amyotrophic Lateral Sclerosis Scale into French was completed using the cultural adaptation process outlined by Beaton et al.[7]:

1. *Initial translation*: Two bilingual translators with French as their mother tongue translated the original English Preference-Based Amyotrophic Lateral Sclerosis Scale into French, independently. Each translator highlighted areas of uncertainty and challenges. One translator had a healthcare background and the other was strictly a translation expert, providing two distinct translation perspectives. The following two translations were created respectively: T-1 and T-2.
2. *Synthesis:* Discrepancies between both forward translations were identified, assessed, and resolved through consensus between the two translators and research team members (AK, LT, VB) resulting in a synthesised French version: T-12.
3. *Back translation:* Working from the synthesized version of the Preference-Based Amyotrophic Lateral Sclerosis Scale, back translations were carried out by two additional translators (BT-1 and BT-2). These translators were blind to the study and had English as their mother tongue. This helped avoid bias and ensured the items truly represented the original meaning of the English scale.
4. *Expert committee review:* An expert committee consisting of 7 members, with English/French language proficiency, clinical experience, and/or research expertise, discussed discrepancies between the original English questionnaire and the two back translations (BT-1 and BT-2). In addition to reviewing the translations, the committee was asked questions around clarity and repeated concerns. This stage led to the pre-final version of the French Preference-Based Amyotrophic Lateral Sclerosis Scale.
5. *Pretesting*: Francophone PALS were invited to complete the pre-final French Preference-Based Amyotrophic Lateral Sclerosis Scale and to participate in individual cognitive debriefing interviews, held through videoconferencing. A semi-structured interview guide published previously[4] was used to conduct the cognitive debriefing interviews. During the interviews, participants were probed to comment on the clarity and their understanding of five randomly selected items from the pre-final scale. Participants were also provided the option of being probed about more items. An item was finalized when it was endorsed 3 consecutive times.

For the pretesting stage, PALS were recruited from the ALS Quebec Society in Quebec, Canada. Participants had to be at least 18 years of age, have a clinical diagnosis of ALS, and be fluent in speaking and writing French. This study was reviewed and approved by the Hamilton Integrated Research Ethics Board (HiREB #5664). Prior to participating in cognitive debriefing interviews, participants filled out a series of questionnaires, including the pre-final French Preference-Based Amyotrophic Lateral Sclerosis Scale.

During the initial translation, minor discrepancies in grammar and clarity were identified between the two translators. These discrepancies included semantic inconsistencies, such as grammatical differences, differences between literal and contextual translation in the context of healthcare (e.g., using the correct terminology when referring to walking devices (item 2: Mobility)), and idiomatic incongruencies, such as terminology and phrasing that needed to be changed to reflect the French language (e.g., different ways of saying 'feeding tube' (item 4: Eating and Swallowing)). These discrepancies were resolved by the research team with input from the translators, creating T-12. Through back translation, item meanings were found to be similar across the BT-1, BT-2, and the original English Preference-Based Amyotrophic Lateral Sclerosis Scale.

Experts expressed that items and response options on the French pre-final version were conceptually consistent with the English versions (original and back translations), clinically easy to understand, and suitable for patient understanding. Minor spelling and grammar mistakes were identified and corrected. Word choice for items were discussed and changed to better reflect the construct and French adaption. For example, 'To mobilize yourself' ('À vous mobiliser') was changed to 'Your ability of moving' ('Votre capacité de mouvement') to capture mobility in the context of movement.

Eleven individuals with ALS were interviewed to meet the endorsement criterion. Each item was endorsed 5 to 9 times. Majority of the items were found to be clear, easy to understand, and detailed. Concerns were raised around item and response option wording for items 3 (Interpersonal Interactions and Relationships), 4 (Eating and Swallowing), 6 (Communicating-Speech), and 8 (Mood). However, revisions were only made for item 4 as suggestions would have changed the meaning of the items and not reflect the original English version. The concern was raised for the phrase 'to supplement what I ate by mouth' ('enrichir ce que j'ai mangé par la bouche') as it did not reflect the general French dialogue, and was changed to 'to supplement my diet' ('pour enrichir ma diète') to better represent the French language.

The Preference-Based Amyotrophic Lateral Sclerosis Scale was translated and adapted into French, to broaden its use in Canada and make it accessible for both English and French speaking Canadians. Beaton et al.[7] outlines a 5-stage process to ensure the scale is not only being translated linguistically, but also adapted culturally to ensure conceptual relevancy to the target population (e.g., French Canadians living with ALS). The French Preference-Based Amyotrophic Lateral Sclerosis Scale (Appendix) is the culturally adapted version of the English Preference-Based Amyotrophic Lateral Sclerosis Scale, after undergoing forward and back translation, expert committee feedback, and pretesting. Cultural adaptation allows initial validity testing (i.e., face and content validity)[7] of the French Preference-Based Amyotrophic Lateral Sclerosis Scale and permits comparisons to be made between the English and French version. Translation of the Preference-Based Amyotrophic Lateral Sclerosis Scale into French can increase the accessibility of the scale for clinical and research settings and facilitate the inclusion of Francophone Canadians in clinical trials and research studies involving the Preference-Based Amyotrophic Lateral Sclerosis Scale, the only ALS-specific preference-based measure.

The cross-cultural adaptation process allowed for the Preference-Based Amyotrophic Lateral Sclerosis Scale to be translated considering semantic, idiomatic, and conceptual equivalency.[8] The main issue that arose during expert committee feedback and pretesting were issues with literal translations of phrasings from English to French. These issues were resolved, and idiomatic and conceptual equivalencies were created with the help of a diverse expert committee, including language experts, clinicians, researchers, and those with lived experiences. Idiomatic

https://doi.org/10.1017/cjn.2024.18 Published online by Cambridge University Press

equivalence was reached for item 4 (Eating and Swallowing) regarding eating by mouth, and conceptual equivalence was reached for items 2 (Mobility) and 6 (Communicating-Speech) to ensure applicability of movement and communication in a clinical context. Culture plays an important role in language;[9] thus, the cross-cultural adaptation method allows the Preference-Based Amyotrophic Lateral Sclerosis Scale to be translated considering the context of use, unlike other translation methods that focus only on linguist translation (i.e., forward translation).[10]

Supplementary material. The supplementary material for this article can be found at https://doi.org/10.1017/cjn.2024.18.

Acknowledgments. We would like to acknowledge the expert committee that provided feedback, participants for engaging in cognitive debriefing interviews, and Kate Busch from the ALS Society of Quebec for helping with participant recruitment.

Author contributions. LT, VDBH, and AK contributed to the study conceptualization, design and data collection. VB provided feedback on the translation of the scale and finalizing of words in French. LT was responsible for data collection and analyzing the cognitive debriefing interviews. AM and LT contributed to result presentation and led writing of the manuscript. All authors reviewed the manuscript and provided feedback on it.

Funding statement. This project was funded by the 2018 ALS Canada Project Grant.

Competing interests. There are no competing interests.

Disclosure. AK and VDBH are Principal Investigators on the 2018 ALS Canada Project Grant.

References

1. Brazier J, Ratcliffe J, Saloman J, Tsuchiya A. Measuring and valuing health benefits for economic evaluation. Oxford University Press; 2007.
2. Peters N, Bello-Haas VD, Packham T, Mehdipour A, Kuspinar A. Psychometric properties of preference-based measures for economic evaluation in amyotrophic lateral sclerosis: a systematic review. Neurol Res Int. 2021;2021:6681554.
3. Peters N, Dal Bello-Haas V, Packham T, et al. Do generic preference-based measures accurately capture areas of health-related quality of life important to individuals with amyotrophic lateral sclerosis: a content validation study. Patient Relat Outcome Meas. 2021;12:191–203.
4. van Damme J, Kuspinar A, Johnston W, et al. Refining items for a preference-based, amyotrophic lateral sclerosis specific, health-related quality of life scale. Amyotroph Lateral Scler Frontotemp Degener. 2022;23:508–516.
5. Office of the Commissioner of Official Languages. Fast figures on Canada's official languages.(2016). Accessed January 9, 2023. *Available at:* https://www.clo-ocol.gc.ca/en/statistics/canada.
6. Low-Kam C, Rhainds D, Lo KS, et al. Whole-genome sequencing in french Canadians from quebec. Hum Genet. 2016;135:1213–1221. DOI: 10.1007/s00439-016-1702-6.
7. Beaton DE, Bombardier C, Guillemin F, Ferraz MB. Guidelines for the process of cross-cultural adaptation of self-report measures. Spine, 2000;25:3186–3191.
8. Guillemin F, Bombardier C, Beaton D. Cross-cultural adaptation of health-related quality of life measures: literature review and proposed guidelines. J Clin Epidemiol. 1993;46:1417–1432. DOI: 10.1016/0895-4356(93)90142-N.
9. Mills CW. Language, logic, and culture. Am Sociol Rev. 1939;4:670–80.
10. Hambleton RK, Merenda PF, Spielberger CD. Adapting Educational and Psychological Tests for Cross Cultural Assessment. Erlbaum; 2004.