

# Adaptation and Validation of the World Health Organization Quality of Life-BREF for people with aphasia

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Abstract ID: 82

Event: SoA 2023 Nice

Topic: Clinical and experimental work on aphasia and related disorders

## Introduction and aims

The World Health Organization has developed an instrument to assess quality of life (QoL) at various levels (Canavarro et al., 2003; WHO, 1994) - The World Health Organization Quality of Life-BREF instrument: WHOQOL-BREF. It is not, however, adapted to the difficulties of understanding and expression of people with aphasia (PWA). The objective of the present study was to create an aphasia-friendly version of the WHOQOL-BREF, which is adapted to the needs of PWA and to validate it.

## Methods

The WHOQOL-BREF was adapted to address the linguistic difficulties of PWA, resulting in an aphasia-friendly version based on the existing international literature on the subject, and to study its content validity according to an expert panel of PWA. Participants were recruited at the Portuguese Institute of Aphasia (IPA) in Matosinhos, Portugal, according to the following inclusion criteria: Both sexes; over 18 years of age; European Portuguese (EP) as their first language; literate; people living at home; having at least 3 months post onset; with no hearing problems that interfered in the communication process; having an aphasia diagnosis according to the Lisbon Aphasia Assessment Battery - BAAL (Caldas, 1979; Damásio, 1973; Ferro, 1986), a reliable yes/no response (no less than 7 on the BAAL yes/no questions, with a total score of 8 points); no presumed cognitive disorder according to the Language Mini Mental State Examination - LMMMSE (Pashek, 2008) EP version (Matos and Jesus, 2011) and also according to the information in the clinical history of the person; no presumed depression according to the Center For Epidemiologic Studies Depression Scale - CES-D (Radloff, 1979) EP version (Gonçalves and Fagulha, 2004); be able to understand simple sentences according to the sub-test of the Language and Aphasia Assessment Tests in Portuguese - PALPA-P (Castro et al., 2007). For the adaptation processes, two participatory workshops were held with a group of five PWA and then, individual interviews were carried out with the same experts. The second phase consisted of the analysis of the concurrent (Stroke and Aphasia Quality of Life Scale - 39 - SAQOL-39; Hilari et al. 2003; Rodrigues and Leal, 2013) and discriminant validity (PWA and neurologically healthy control participants - NHP) of this new aphasia-friendly version. For this phase, the study included a sample of 45 people (15 PWA and 30 age and sex-matched NHP). For the experimental group (PWA), the same inclusion criteria described earlier in phase 1 were considered. For

the control group (NHP) the following inclusion criteria were established: No history of cerebrovascular or neurological disease; EP being their first language; sufficient hearing and vision ability for paper and pen assessment; living independently in the community; without concomitant mobility problems.

## Results

Regarding the font type, the Geneva (*sans-serif font*) was preferred (80%), capital letters were the preferred option (60%) for highlighting and all experts considered the use of images to be relevant and to facilitate understanding. To test discriminant validity of the adapted WHOQOL-BREF, the results obtained for the two groups were compared. Statistical analysis (t-test) showed that the physical domain was best in differentiating experimental and control groups, since it was the only domain in which statistically significant differences were observed. To test concurrent validity, the adapted WHOQOL-BREF and SAQOL-39 results were compared and Pearson Correlation values between domains were calculated. The correlations between the adapted WHOQOL-BREF and SAQOL-39 domains ranged from 0.19 to 0.55.

## Discussion

The results obtained through the application of the adapted WHOQOL-BREF to both groups (PWA and NHP), have shown that there were only statistically significant differences for the physical domain of the instrument, with controls obtaining higher scores. These results were not expected since several studies report a negative impact of aphasia on QoL (Hackett et al., 2000; Monteiro, 2011; Rodrigues and Leal 2013). These results could be explained by some motor impairments in our group of PWA or pain associated with their aphasia. In the remaining domains and in the total adapted WHOQOL-BREF score, no significant differences were observed between the two groups and the scores obtained were relatively high. This may be because more than half of the participants (53%) have an Anomic aphasia and a high Aphasia Quotient ( $77.07 \pm 14.55$ ), which could translate into greater functionality and, consequently, a lower impact of deficits on day-to-day activities and QoL. In addition, most PWA (73%) were accompanied at the IPA, benefiting from a person-centred approach and an intervention according to the Life Participation Approach to Aphasia, with a focus on the active participation and empowerment of PWA (IPA, 2022; Chapey et al., 2000). Finally, another reason that may underline the results obtained in our study is related to the fact that PWA with signs of depression were excluded from the study, while NHP did not undergo a formal screening test to analyse their emotional status.

In this study, it was also possible to observe, that although the WHOQOL-BREF and the SAQOL-39 are both instruments for assessing QoL and are divided into the same domains, there is only correlation in the physical domain. This may have happened because the

WHOQOL-BREF focuses on activities and participation, never focusing on the deficits of the PWA.

## Conclusions

Through the present study, it was possible to obtain a consensus about the adaptations to be carried out to facilitate the understanding and expression of PWA and to produce aphasia-friendly support materials for WHOQOL-BREF. Contrary to what was expected, the results showed that the Portuguese PWA involved in the study have a good QoL and that the values obtained are close to those of the control group, with only a significant difference in the physical domain. In the future, it is suggested to increase the sample size and its diversity and to perform a psychometric study with the adapted WHOQOL-BREF version to establish standardised values for the Portuguese population of PWA.

## References

Canavarro, M. C., Vaz Serra, A., Pereira, M., Simões, M. R., Quartilho, M. J., Rijo, D., ... Paredes, T. (2010). WHOQOL disponível para Portugal: Desenvolvimento dos instrumentos de avaliação da qualidade de vida da Organização Mundial de Saúde (WHOQOL-100 e WHOQOL-BREF). In M. C. Canavarro, & A. Vaz Serra (Eds.), *Qualidade de vida e saúde: Uma abordagem na perspectiva da Organização Mundial de Saúde* (pp. 171-190). Lisboa: Fundação Calouste Gulbenkian.

Hackett, Maree L., John R. Duncan, Craig S. Anderson, Joanna B. Broad, and Ruth Bonita. 2000. "Health-Related Quality of Life Among Long-Term Survivors of Stroke." *Stroke* 31(2):440-47. doi: 10.1161/01.STR.31.2.440.

IPA. 2022. "Instituto Português Da Afasia." *O Contexto Em Que Surgiu o IPA*.

Monteiro, Andreia. 2011. "Qualidade De Vida (QV) Em Indivíduos Com Sequelas de Acidente Vascular Cerebral (AVC)." Undergraduate Honors Thesis, Instituto Politécnico do Porto, Porto.

Rodrigues, Inês Tello, and Maria Gabriela Leal. 2013. "Portuguese Translation and Psychometric Properties of the Portuguese Version of the Stroke and Aphasia Quality of Life Scale-39 (SAQOL-39)." *ACR* 18(4):339-44.

WHO. 1994. "Development of the WHOQOL: Rationale and Current Status." *International Journal of Mental Health* 23:24-56.



## Abstracts