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Dementia care research (research projects; nonpharmacological)/Instrument development, program evaluation and translation

Spanish translation and adaptation of a family quality-of-life survey for families of people with a neurodegenerative disease

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Abstract

Background: One of the main objectives of NEUROQUALYFAM Project is to assess the quality of life and the needs of support of families of people with a neurodegenerative disease (ND) in Spain. For this purpose, The *Family Quality of Life Survey-Adapted for Main Caregivers of Persons with Dementia* (FQoLS; DiZazzo-Miller & Samuel, 2011) has been translated and adapted to the Spanish context.

Method: The "International Test Commission guidelines for test translation and adaptation" were taken into account, thus considering the following phases: 1) Two initial and independent translations of FQoLS; 2) Review and synthesis of the translations; 3) Focus groups with families of people with a ND, as well as with health, social and third sector professionals, in order to assess the relevance, clarity and appropriateness of items; 4) Synthesis and agreement by a committee of experts; 5) Backtranslation and comparison with the original items; 6) Pilot study of the consensual version with a sample of families with an individual with a ND.

Result: After the translation and adaptation process, the comprehension and appropriateness of items and response options in the preliminary version were verified. The application of the final version of the instrument and the assessment of its psychometric properties will be conducted in a subsequent phase of the study.

Conclusion: Preliminary results indicate that the instrument has been successfully translated and adapted to the Spanish context. Moreover, this questionnaire seems to be a useful tool for assessing the quality of life of families of patients with ND as well as for designing intervention strategies aimed to optimize support resources and improve families' health and wellbeing outcomes.

Reference: DiZazzo-Miller, R., Samuel, P.S. (2011). *Family Quality of Life Survey: Main Caregivers of Persons with Dementia*. Detroit, MI, USA: Wayne State University.