

Psychosocial factors and environmental design / Living with dementia and quality of life

Enhancing family quality-of-life outcomes:
The NEUROQUALYFAM project

Eva González Ortega | NEUROQUALYFAM group

University of Salamanca, Salamanca, Spain

Correspondence

Eva González Ortega, University of Salamanca,
Salamanca, Spain.Email: evagonz@usal.es

Abstract

Background: Neurodegenerative diseases (ND) have a great impact on both patients and their relatives, since the latter play an essential role in the care process. Consequently, the families require support to perform this function with higher levels of well-being. The objective of the NEUROQUALYFAM project (Interreg V-A Spain-Portugal, POCTEP) is to analyze the quality of life of families of people with ND, to identify their needs and to plan family-centered support resources in order to offer high-quality social health services for people with ND and their families.

Method: The study sample will consist of 300 families from the Spanish-Portuguese cross-border area. The *Family Quality of Life Survey - Dementia* (FQoLS) will be translated, adapted and validated (DiZazzo-Miller & Samuel, 2011) to assess their quality of life. Focus groups with families and professionals from health, social services and the third sector will be conducted to identify needs and support resources. The "section 2-Support and Services" of the validated Spanish version of the *Beach Center Family Quality of Life Scale* (Verdugo, Rodríguez and Sainz, 2012) will be adapted for families of people with ND to identify the types of support needed and to what extent they are provided. A confirmatory factor analysis will be conducted to examine the validity of the construct FQoLS- ND. A top-down content analysis will be undertaken for qualitative data.

Result: The project will provide: (a) a procedure to evaluate the quality of life of families of people with ND; (b) the identification and mapping of unmet support needs regarding the health and social system; (c) the planning of a family-centered support system for the improvement of health and wellbeing outcomes, and (d) the design of a comprehensive ICT platform of support resources that enhances training, information exchange and collaborative networks between and among families and professionals.

Conclusion: The project NEUROQUALYFAM provides a research and intervention model that might be applied in other regions and countries. It strengthens cooperation between the institutions (health and social services, third sector) to improve the quality of family life and optimize support resources for family caregivers.