

## 203 - FAMILY QUALITY OF LIFE IN NEURODEGENERATIVE DISEASES: EXPLORING NEEDS AND SUPPORTS IN THE CROSS-BORDER AREA SPAIN-PORTUGAL

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Neurodegenerative diseases often have an impact on both patients and their family caregivers. Given that families are an important support resource for people with neurodegenerative diseases, it is important to ensure their own quality of life. This symposium aim to present the NEUROQUALYFAM project funded by Cross Border Cooperation Programme Spain–Portugal 2014–2020 (POCTEP). The main objective of this project is to improve the quality of life of family caregivers who care people with neurodegenerative disease at home through the assessment of their needs and support resources, and the subsequent design and optimization of high-quality resources and services that are family-centered.

Communication #1:

### **THE NEUROQUALYFAM PROJECT: AN OVERVIEW**

**Speaker 1: Eva González Ortega**

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The care of individuals with neurodegenerative diseases is often delivered in family settings, so it is important to understand the needs of the family unit involved in this care to determine the factors that contribute to family quality of life. A qualitative study using focus groups was conducted to identify the unmet needs of family caregivers from their own perspectives.

Communication #2:

### **NEURODEGENERATIVE DISEASES: ANALYSIS OF THE SITUATION IN THE CROSS-BORDER REGION OF SPAIN PORTUGAL**

**Speaker 2: Ermelinda Marques**

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Neurodegenerative diseases are one of the main causes of disability and dependence in the world, which have a strong impact on the physical, psychological and social health and well-being of the people with these diseases and their families. The neurodegenerative diseases addressed in this investigation are Alzheimer's and other dementias, Parkinson's and Multiple Sclerosis. The first two are related to age, which makes its prevalence very high, thus justifying the development of projects in this ageing region, in order to know the magnitude of the problem and subsequently implement strategies that aim to increase the quality of life of families of people with these pathologies and delay as much as possible the evolution of the diseases and sequelae.

Communication #3:

### **FAMILY QUALITY OF LIFE SURVEY- NEURODEGENERATIVE DISEASES**

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Despite the growing interest in the topic of family quality of life, this construct has not been assessed yet in families of people with neurodegenerative diseases, because none of the existing instruments has been adapted to the Spanish context. Consequently, the goal of this study is to present the results of the translation, adaptation, and validation of the Spanish version of Family Quality of Life Survey-Neurodegenerative Diseases.

Communication #4:

**HEALTH CARE FOR PEOPLE WITH NEURODEGENERATIVE DISEASES AND THEIR CAREGIVERS IN THE HEALTH SYSTEM OF CASTILLA Y LEÓN (SPAIN)**

**Speaker 4: María Antonia Martín Delgado**

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The strategy of neurodegenerative diseases of the National Health System of Spain includes, among its objectives, providing the best health and social care to the affected population, their caregivers and their families. Castilla y León, in its IV Health Plan, wants to improve the care of people with neurodegenerative diseases, by considering them as a priority health problem that must receive integral health care due to their implications for the patient, and its social and family environment. To this end, measures have been taken regarding prevention and early detection through the development of training, awareness-raising programmes for health professionals, including specific assistance guides in the electronic clinical history of Primary care, attention to these pathologies in the Portfolio of Services (Primary and Specialized Care), development and updating of integrated healthcare processes, cooperation and integrated operation between the health and social systems implicated in the improvement of the integral attention to these people and their families, channels of civic participation and research development that allows to transfer knowledge to improve the health care practice in Castilla y León.