

# Perceived needs and support services of families of people with dementia

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## Abstract

**Background:** Dementia is one of the most important causes of dependency worldwide. These patients require constant care. This care is mainly provided by the families. Each family has specific needs and demands specific support services. To improve their quality of life, the family should be considered in the development of strategies that contribute to the provision of support services for them. Considering this, the objectives of this work are to analyse the support needs of these families, as well as the services they access.

**Method:** The FQOLS-NDs instrument (Badía et al., 2020) was applied by telephone to a sample of 163 relatives of people with dementia in the Spain-Portugal cross-border area. The main characteristics of the research participants are: 69.9% are women, aged between 28 and 87, and do not work (63.8%). They are mainly daughters/sons (59.5%) or partners (32.5%) of the person with dementia. In addition, they are mostly their main carers (95.1%) and live with them (74.8%).

**Results:** The main research findings reveal that: 1) The support services most needed by families are information about the disease (53.4%); information about support services (52.8%), and information about where to get them (44.8%). 2) Family members report not being able to access the support services they need. Among them, those to which more than 80% of families do not have access stand out. These are support groups (92.3%), psychological help (90.3%), family respite (85.5%) and spending money (81.1%). 3) There are few support services that families need and consider that they have sufficient access to. The most positive data reveal that only 18.4% of participants perceive the information they receive about the disease as sufficient; only 16.3% consider that they have enough help to run the household, and only 12.8% claim to have access to sufficient information about legal rights.

**Conclusion:** Families are not receiving the support services they most need. Moreover, they do not value the services they access as sufficient. References: Badía, M., Orgaz, M.B., González, E., Vicario-Molina, I., Gómez-Vela, M. and NEUROQUALYFAM group (2020). Family Quality of Life Scale - Neurodegenerative Diseases.