

Domains and dimensions of family quality of life among families with a member with neurodegenerative diseases

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Abstract

Background: Family quality of life (FQoL) is a recent construct to be applied in neurodegenerative diseases (NDs). In this context, there is interest in advancing in the measurement of the FQoL as a first step to determine the supports that families need to perceive quality of life. The aim of this study was to test the validity of the *Family Quality of Life Survey- Dementia* (DiZazzo-Miller & Samuel, 2011) in order to assess FQoL among family members of individuals with NDs who live in the cross-border area of Spain-Portugal.

Method: Three hundred family members of people with NDs completed the *FQoL-NDs Survey* (Badia et al., 2020). The mean age was 62.4 years ($SD = 13.34$). Most were males (70%), married (79.7%), not working (64.7%), with low income (66.1%), and had elementary/high studies (73.1%). The majority were the spouse/partner (40.9%) or son/daughter (51.7%) of the care-recipient and played the role of primary caregiver (93.3%). Sixty percent of care-recipients were females ($M = 79.3$ years; $SD = 11.7$). Sixty two percent presented dementia, 30.4 % Parkinson's disease, and 7.6% multiple sclerosis. Construct validity was tested by correlation analysis to examine associations between domain level outcomes (i.e., health, financial well-being, family relationships, support from others, support from services, influence of values, careers, leisure and recreation, and community integration) and global FQoL. Likewise, t-tests were used to compare the outcome measures (attainment and satisfaction) within each of the nine family domains.

Result: Global *attainment* and *satisfaction* with FQoL-NDs was found to be significantly correlated with composite *attainment* and *satisfaction* from nine domains ($r = .489$, $p < .001$ and $r = .536$, $p < .001$, respectively). *Attainment* and *satisfaction* were positively correlated within the nine domains (ranging from $r = .83$ to $r = -.69$, $p < .001$). There was a significant difference between domain-level *attainment* and *satisfaction* ratings [$t(299) = 12.28$, $p < .001$, $h^2 = .34$]: the mean level of *satisfaction* experienced ($M = 3.71$, $SD = 0.49$) was significantly higher than that of *attainment* ($M = 3.52$, $SD = 0.49$).

Conclusion: This study demonstrates that FQoL-NDs has good validity properties and it is a useful tool to establish FQoL profiles for family caregivers of people with NDs.