

311 - A step forward understanding the burden on caregivers of older patients with Parkinson Disease – an ICF-based approach.

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Background: Burden of care might be highly dependent of specific characteristics of the disease (Lee et al., 2019). Uncertainties remain about factors that influence burden of care in Parkinson Disease (PD). Aim: To identify a list of ICF-related domains identified by caregivers of older patients with PD. Methods: Caregivers of people with PD were recruited in Portugal Parkinson Foundation, if they take care of someone with PD older than 65 yrs, and for more than 6 hours/day. A focus group was video recorded, based on the following questions: Can you please tell us how did you spent your day before you're a caregiver; there are any differences in your daily routine now? How do you feel or think when you're caring for a relative? Can you tell us if there is any kind of daily activity more pleasant or more embarrassing? Verbal interactions during focus group were transcribed and codified using International Classification of Functioning and Disability (ICF) domains. Results: Seven caregivers (5 females; 40-73 yrs; 5 were spousal) were enrolled. Thirty-six caregivers' references were about body functions and structures (91.67% - mental functions: "I feel tired...it is a constant monotony"); fifty-seven references were about activities and participation ("I need to assist him with bathing"; "when he wants to standing from his favourite chair, he always need help...and his body is very stiff");eleven references were about environmental factors, mostly about medication and family/health professionals assistance. Discussion: Our results demonstrated that caregivers are worried about their mental health and routine preservation, which is in accordance with previous studies in this topic (Tessitore et al.,2018). However, new caregivers' perceptions were found in our study, which are very specific domains in PD: body motion rigidity and medication for patients' psychomotor agitation. A previous study stated that control of mental symptoms in PD are the most powerful predictors of caregivers' burden (Hooker et al., 2000), but do not consider the importance of Parkinson's motor symptoms. Conclusion: Burden of care in PD is mostly associated with the need of preservation in daily routines, but also with management of mental and motor symptoms in PD.