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PRELIMINARY DATA FROM FAMIDEM SURVEY: CAN WE ASSUME WHO IS AT RISK REGARDING INFORMAL CAREGIVING IN DEMENTIA ?

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Background and aims: In meridional European countries such as Portugal, informal caregivers are almost always close relatives, either key-relatives (those more involved) or not. There are few systematic comparisons between the experience of key-relatives/primary caregivers (PC) and other/secondary caregivers (SC) in psychogeriatrics. We present some preliminary data from the FAMIDEM (Families of People with Dementia) survey.

Methods: Non-randomised cross-sectional study comparing two related samples of caregivers (PC versus SC) of 41 patients with DSM-IV dementia from outpatient practices in Lisbon (Portugal). Caregivers' assessments included: Zarit Burden Interview, Caregiver Activity Survey (CAS), Positive Aspects of Caregiving, GHQ-12, Social Network Questionnaire and Dementia Knowledge Questionnaire.

Results: Patients' mean age was 78,7 years (SD 7,9). 24 (58,5%) were women and 58,5% had Alzheimer disease. PC were older than SC ($p=0,000$) and tended to live with the patient ($p=0,000$). They reported less emotional support ($p=0,021$) but higher objective burden-CAS ($p=0,002$). Regarding all other outcome variables, significant differences between groups were not found. Within the global sample, comparing spouses ($n=23$) and adult children/other relatives ($n=59$) yielded interestingly different preliminary results, eg higher GHQ-12 levels ($p=0,010$).

Conclusions: The experience of caregiving is possibly different regarding PC and SC, but further research is warranted in order to define who really is at risk. Being a spouse may be much more determinant, although most spouses are PC as well. For the moment, it seems prudent not to exclude SC from risk assessments. The final FAMIDEM results, even lacking generalizability, will probably provide interesting clues.