Epidemiology and Social Impact of Early Onset Dementia in the Province of Modena, Northern Italy

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Aims of the study. Early onset dementia (EOD), defined as onset of dementia <65 years, has a much higher social impact compared to the more common late onset dementia. EOD epidemiologic data in Italy are extremely scarce, and international estimates of prevalence are considerably variable, ranging between 15.1 and 153/100.000 in the age 45-65.

We present data from an ongoing study aimed at establishing EOD epidemiology in a Northern Italy community (Modena province, around 700.000 inhabitants).

Materials. We retrospectively recruited all patients residing in Modena province referred to the Modena Baggiovara Hospital Neurologic Clinic CDCD (Centro disturbi cognitivi e demenze), by family practitioners and geriatricians of the province. Eligible patients were those affected by EOD from 2012 to January 2019. EOD was diagnosed in patients <65 years presenting with cognitive/behavioral symptoms, following a comprehensive neurological examination by a cognitive neurologist, as well as brain MRI, FDG PET scanning and CSF analyses when appropriate.

Methods. We collected clinical data such as age at onset, disease severity at time of diagnosis, time delay from onset to diagnosis, and epidemiologic data including residence and occupational status.

Results. We identified 223 patients with an EOD diagnosis from 2012 to January 2019. Of these, 103 are males (46,2%). 97 patients have AD (21 lvPPA, 13 PCA, 2 frontal variant), 47 have FTD (33 bvFTD, 14 svPPA), 6 have leucoencephalopathy. Mean onset age was 58,6 years (SD 5,1). Median time from symptoms onset to diagnosis was 3.1 years (SD 29,83). Mean MMSE score at diagnosis was 22,63/30 (SD 5,2). 24 patients were working at time of diagnosis (10,76%) and had to quit working due to the cognitive impairment. Two patients (0,89%) had young children (<18) at time of diagnosis.

Discussion. We provide the first epidemiological data on EOD in Italy. These are consistent with the estimates calculated by transposing European data to the population of Modena province (estimated prevalence=200 patients, detected prevalence=223 patients)¹. Our data show a higher percentage of atypical AD phenotypes and FTD in the EOD group compared to late onset disease². Also, CAA and leucoencephalopathies were over-represented compared to LOD. From a social perspective, EOD has significant impacts on patients and their families: patients are generally forced to leave work, and their children are expected to need psychological support, currently not routinely available.

Conclusions. Our population study provides the first data regarding EOD epidemiology and social impact in Italy.