

Saturday

Consistency of drug treatment decisions for behavioral disturbances in frontotemporal dementia within the Frontotemporal Dementia European Rare Disease Network (ERN-RND)

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State of the art: Consistency in decision making among practitioners is a key indicator of the maturity of a clinical field. Here we examined the consistency of drug management decisions for behavioral disturbances in patients with frontotemporal dementia (FTD). Behavioral disturbances have a severe impact on the patient and the caregivers.

Methodology: The FTD group of the European Reference Network-Rare Neurological Diseases (ERN-RND) consists of 34 centres of excellence belonging to 19 European countries. The primary goals of ERN-RND are to improve and harmonize care of RND patients and to develop, share and implement care pathways and guidelines for RND represented in the networks. The FTD expert physicians of the sites were invited to take part in a survey to evaluate current clinical practice regarding drug and non-drug management options at their sites. Thirteen common behavioral problems were queried and a list of 24 drug options (including also 'none') and non-drug management options were provided for each.

Results: Twenty-one respondents from 19 centres from 13 countries participated. Consistency in drug management was highest for the treatment of verbal aggression, physical aggression and delusions of obsessive nature. Consistency was lowest for the treatment of motor unrest and sexual disinhibition. Consistency was intermediate for impulsivity, self-harm due to repetitive behavior, intentional auto-mutilation, hyperphagia with excessive weight gain, rigidity of thought, perseverative somatic complaints, nightly unrest, apathy, and loss of empathy.

Conclusion: The survey data can inform prioritization and design of therapeutic studies of existing drugs for behavioral disturbances in FTD.

Conflicts of interest

RV: Clinical trial agreement between institution (RV as PI) and Prevail; Clinical trial agreement between institution (RV as PI) and Wave;