Caregivers of patients with frontotemporal lobar degeneration: a review of burden, problems, needs, and interventions.

Abstract:
Frontotemporal lobar degeneration (FTLD) is a relatively rare disease compared to Alzheimer’s disease (AD), but nevertheless causes higher burden and stress to caregivers. Only little is known about the problems and needs of the caregivers of patients with FTLD. Such information is crucial for the development of caregiver support interventions. The aim of the current study is to systematically review publications on (1) burden, problems, and needs of FTLD caregivers, and (2) the feasibility and efficacy of caregiver interventions in FTLD. A systematic review was conducted. Medical, psychological, and social sciences databases were searched for publications on burden, problems, needs of FTLD caregivers, and support interventions. Very little published data are available on burden, problems, and needs of FTLD caregivers. Burden among FTLD caregivers is higher than among AD caregivers and correlated with neuropsychiatric symptoms. Specific problems include delayed diagnosis, young age of patients, behavioral disturbances, lack of information and suitable care facilities, caregivers’ depression, social isolation, and neglect of personal needs. Hardly any literature is available on the actual needs of FTLD caregivers. Regarding interventions for caregivers, no randomized controlled trials exist. Eight publications could be identified that provide narrative reports on structured caregiver support groups or
respite care in combination with caregiver support intervention or advanced practice nursing. More research and funding are needed to elucidate the complex construct of burden of FTLD caregivers to identify and quantify their problems and needs in order to develop helpful interventions and services.

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