RHAPSODY - Internet-based support for caregivers of people with young onset dementia: program design and methods of a pilot study.

Abstract:
Young Onset Dementia (YOD), defined by first symptoms of cognitive or behavioral decline occurring before the age of 65 years, is relatively rare compared to dementia of later onset, but it is associated with diagnostic difficulty and heavy burden on affected individuals and their informal carers. Existing health and social care structures rarely meet the needs of YOD patients. Internet-based interventions are a novel format of delivering health-related education, counseling, and support to this vulnerable yet underserved group. The RHAPSODY (Research to Assess Policies and Strategies for Dementia in the Young) project is a European initiative to improve care for people with YOD by providing an internet-based information and skill-building program for family carers. The e-learning program focuses on managing problem behaviors, dealing with role change, obtaining support, and looking after oneself. It will be evaluated in a pilot study in three countries using a randomized unblinded design with a wait-list control group. Participants will be
informal carers of people with dementia in Alzheimer's disease or behavioral-variant Frontotemporal degeneration with an onset before the age of 65 years. The primary outcome will be caregiving self-efficacy after 6 weeks of program use. As secondary outcomes, caregivers' stress and burden, carer health-related quality of life, caring-related knowledge, patient problem behaviors, and user satisfaction will be assessed. Program utilization will be monitored and a health-economic evaluation will also be performed. The RHAPSODY project will add to the evidence on the potential and limitations of a conveniently accessible, user-friendly, and comprehensive internet-based intervention as an alternative for traditional forms of counseling and support in healthcare, aiming to optimize care and support for people with YOD and their informal caregivers.