

Blended web-based Acceptance and Commitment Therapy for Informal Caregivers of people with dementia (ACT-IC study): Result of social health aspects

Authors: Golnaz Atefi¹, Rosalie J.M. van Knippenberg¹, Sara Laureen Bartels¹, Frans R.J. Verhey¹, & Marjolein E. de Vugt¹

Affiliations: 1 Department of Psychiatry and Neuropsychology and Alzheimer Centre Limburg, School for Mental Health and Neurosciences, Maastricht University, Maastricht, The Netherlands

Objective: Numerous e-health programs have shown the potential to enhance psychological and social health outcomes in informal caregivers of People with Dementia (PwD). However, there is still a need for evidence-based interventions tailored to the specific needs of this population, such as maintaining self-management and participating in meaningful activities. This mixed-methods study aims to evaluate the feasibility, acceptability, and preliminary effectiveness of a blended intervention based on acceptance and commitment therapy for informal caregivers of PwD, leading to a better understanding of intervention refinements for future controlled trials.

Method: A single-arm clinical trial design is conducted. A total of 20 informal caregivers of PwD are recruited through memory clinics and social media platforms in the Netherlands. The ACT-IC intervention is delivered over a 9-week period and consists of a collaborative goal-setting session, nine online modules, and nine telephone-based motivational coaching sessions. Feasibility and acceptability are assessed using the attrition rate, adherence to, and engagement with the intervention, the proportion of missing data, and semi-structured interviews. Clinical outcome measures assess depression, anxiety, stress, sense of competence, burden, and self-efficacy at baseline and post-intervention.

Results: Data collection will be completed by May 2023, and analyses are ongoing. Of the 20 caregivers, 19 completed the baseline assessment, and 3 dropped out. Results of an ANOVA investigating the effect of ACT-IC on the outcome measures at post-intervention will be reported, as well as the results of post-hoc analyses that explored the effect on outcomes of goal attainment and meaningful activities, observed use of the website, and reported adherence to the recommended frequency of website use.

Conclusion: The result will contribute to the need for further research on supportive e-health interventions for informal caregivers of PwD. The ACT-IC study is the first trial to apply an evidence-based blended approach to address and evaluate the specific shared needs of caregivers. The mixed-method approach may offer a better understanding of reasons for dropouts, as well as barriers and facilitators that informal caregivers experience over the course of the intervention. Furthermore, social interaction (telephone-based motivational coaching) might improve the feasibility and acceptability of the online ACT intervention.

Online peer support for people with Young Onset Dementia: development of a Best Practice Guidance

Authors: Esther Gerritzen, Orii McDermott & Martin Orrell University of Nottingham, School of Medicine, Academic Unit 1 Mental Health and Clinical Neuroscience, Institute of Mental Health, Nottingham, United Kingdom

Objective: Peer support can be very valuable for people with Young Onset Dementia (YOD) (diagnosis before the age of 65). People with YOD often experience stigma, putting them at a higher risk of social isolation. In the United Kingdom, availability of age-appropriate, in-person peer support services is inconsistent, and as a result many people may miss out on the potential benefits. Online peer support could be a solution, as it overcomes geographical barriers, and offers a variety of platforms and modes of communication. This study aimed to explore how people with YOD experience online peer support, identify potential barriers to online peer support, and get insights into how online peer support can be optimized. The findings were used to develop a Best Practice Guidance on online peer support for people with YOD, and specific guidelines for facilitators of online peer support groups.