

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

**Authors:** Golnaz Atefi<sup>1</sup>, Rosalie J.M. van Knippenberg<sup>1</sup>, Sara Laureen Bartels<sup>1</sup>, Frans R.J. Verhey<sup>1</sup>, & Marjolein E. de Vugt<sup>1</sup>

**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.

**Method:** This study was conducted between October 2019 and December 2022. It followed the Medical Research Council (MRC) guidelines on complex interventions and focused on the development stage. The study consisted of multiple sub-studies, which all contributed to the Best Practice Guidance. The sub-studies included literature reviews, focus groups, an online survey, and interviews. All participants were people living with YOD.

**Results:** Participants described online peer support as their lifeline which gave them hope and a sense of purpose again, after an often very difficult diagnostic and post-diagnostic period. For people in rural areas or who were unable to travel, online was the only way in which they could connect with their peers. However, many were unaware that online peer support exists, what it entails, and how they could get involved. This indicates a need for better advertisement of and signposting to (online) peer support.

**Conclusion:** Online peer support can be beneficial for people with YOD. The Best Practice Guidance provides people with YOD with evidence-based information on what online peer support entails, facilitators with guidelines on how to optimize online peer support for people with YOD, and healthcare professionals with an opportunity to signpost people with YOD to online peer support.

### **User experience and analytics inform the development of an innovative telehealth curriculum: ROAD MAP (Recovery-Oriented Approach to Dementia through Meaningful Activity Participation)**

**Authors:** Lesley Garcia, Martin Orrell, Justine Schneider University of Nottingham, School of Medicine, Academic Unit 1 Mental Health and Clinical Neuroscience, Institute of Mental Health, Nottingham, United Kingdom

**Objective:** To user-test a recovery-oriented, clinician-facilitated, web-based, self-management intervention accessible via mobile device: ROAD MAP. The initial programme theory underlying this research is that supporting the experiences of CHIME (connectedness, hope and optimism, identity, meaning in life and empowerment), in persons living with dementia (PLWD) will have health-promoting benefits for the PLWD.

**Method:** The intervention will be delivered to 20 dyads of community-dwelling PLWDs and their carers via a five-week, online, recovery-based curriculum. Five convenience-sampled occupational therapists (OT) will be trained online in a 10-hour training programme to deliver the intervention. All data collection instruments are informed by realist evaluation (RE) methodology and enquire into initial programme theories (IPTs) used to develop the curriculum and the ROAD MAP digital tool. Data collection, between January and March 2023, will occur during both the OT training and the five-week pilot study. The OT facilitators will provide qualitative feedback on the ROAD MAP technology. Data will be collected via pre-post self-completion forms, semi-structured interviews, a focus group, and weekly guided reflective journal. PLWD's self-reported, user experience will be live polled within the weekly one-hour long sessions of the pilot. Their digital usage analytics will be generated by the MyGuide platform on which the ROAD MAP intervention is built. These data will be manually screened for IPT relevance and used to test emerging programme theories.

**Results:** All data will be collected by end of March 2023 and analysed by end of May 2023. NVivo will be used to generate refined programme theories according to RE methodology. This will provide evidence of plausible, causal context-mechanism-outcome configurations which may optimize the refined version of the ROAD MAP digital intervention, curriculum and facilitator training methods.

**Conclusion:** This study will increase knowledge of a methodology for developing useable and acceptable recovery-oriented telehealth tools for PLWD. This intervention could directly enhance the education of health care professionals and improve the equitable delivery of dementia services.