Developing and evaluating Huntington Partner in Balance: An online self-management program for caregivers of people with Huntington's Disease

Maud Daemen[1], Lizzy Boots[1], Annelien Duits[1], Mayke Oosterloo[2], Marjolein de Vugt[1].

[1] Department of Psychiatry and Neuropsychology/Alzheimer Center Limburg, School for Mental Health and Neuroscience, Maastricht University, The Netherlands
[2] Department of Neurology, Maastricht University Medical Center, The Netherlands

Caring for a person with Huntington's Disease (HD) and compromising own needs in everyday life becomes more and more challenging as the severity of the disease progresses. Overburdening caregivers of HD patients can lead to anxiety and depression and ultimately to inability to maintain their role as a caregiver. It is of great importance to preventively increase the resilience of caregivers and prevent overloading at a later stage of the care process. The Alzheimer Centre Limburg has developed the blended online self-management program 'Partner in Balance' to help relatives of people with dementia develop skills to prevent overburdening. The program is proven effective in terms of increased self-efficacy, perceived control, and quality of life compared to usual care[1]. Especially relatives of HD patients have a high load of stress and concerns and would benefit from such a program[2]. Therefore, the Partner in Balance program will be adapted to HD caregivers (HPiB). The project aim is to (1) develop HPiB with caregivers and healthcare professionals, (2) evaluate its feasibility and initial effects, and (3) prepare implementation in the existing healthcare context.

The development and evaluation of HPiB take place according to the steps of the Medical Research Council Framework[3], using the principles of the Experience-Based Co-Design approach[4]. Professionals and HD caregivers were brought together in four focus groups to discuss their experiences and needs. These data were used to inform the decision-making process for the content of HPiB. After the modules are developed, a pilot will be conducted to evaluate the feasibility and preliminary effects of HPiB. Ten participants will be recruited and offered the intervention during eight weeks. Before and after eight weeks, questionnaires are administered focusing on levels of stress (PSS)[5], anxiety and depression (HADS)[6], self-efficacy (CSES)[7], experienced control (PMS)[8], capability (ICECAP-O)[9], and quality of life (EuroQol-5D)[10]. Individual in-depth interviews (semi-structured) will be conducted after eight weeks with all the participants and their coaches to evaluate the feasibility of HPiB. Finally, an implementation plan for HPiB within the regular healthcare will be drafted. There will be an orientation on current initiatives where coordination and possible connections can be sought.

Keywords: Huntington's Disease – Caregivers - Support

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