

Balanced and prepared

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KNOWLEDGE VALORIZATION

This thesis described the development and evaluation of the supportive e-health intervention 'Partner in Balance' for caregivers of people with early-stage dementia. In this valorization paragraph we aim to describe how the obtained knowledge from our research can be made valuable in social and economical contexts.

Relevance and innovation

The global cost of dementia was estimated at 604 billion dollars in the 2011 World Alzheimer Report.¹ Due to the rise of people with dementia in the near future, it is expected that the cost of care for dementia will increase by 85% in 2030, possibly making it the most expensive disease of our society.¹ Efficacious pharmacotherapies are not yet available to cure dementia, but previous studies showed that psychosocial interventions aimed at reducing caregiver burden and increasing their self-efficacy might reduce (indirect) dementia care costs, as they improve caregiver mood, caregiver quality of life and delay the institutionalization of the care recipient for up to 1.5 years.²⁻⁴ These results are noteworthy, considering that a single day at a nursing home costs approximately 200 Dollars in the US.⁵

Most caregiver interventions focus on the mild to moderate stages of dementia, but timing of these interventions might be crucial in maximizing the effects. Our results showed that early support could help caregivers adapt to the changes of early dementia and feel more competent to care. Next to intervention timing, intervention delivery can also be essential to maximize intervention effects. E-health technology offers an opportunity for easy accessible and tailored interventions and could be an efficient alternative to continue to provide education and support for the informal caregivers at reduced costs.⁶⁻⁸ Our literature review confirmed this by presenting the promising results Internet interventions for dementia caregivers have on caregiver confidence, self-efficacy, stress, burden, and depression. However, existing e-health programs for dementia caregivers are mainly aimed at dealing with dementia related problems in the later stages of dementia, and results of our needs assessment showed that support should fit the stage-specific needs of the caregiver. E-health self-management interventions could suit the caring role transition caregivers face during the early stages and help future informal caregivers cope with the challenges of caring for a person with dementia.⁹⁻¹⁰ The studies in this thesis confirmed this hypothesis, as the newly developed e-health self-management intervention for caregivers of people with early-stage dementia 'Partner in Balance' is effective in increasing dementia caregiver self-efficacy, mastery, and quality of life.

Target groups

The findings in this thesis are relevant for caregivers of people with early-stage dementia, dementia healthcare professionals, and policy makers.

Caregivers of people with early-stage dementia can profit from our research as the 'Partner in Balance' program effectively increased caregivers' self-efficacy, mastery and quality of life. Dementia healthcare professionals could consider online support for informal dementia caregivers in addition to the already provided care as usual. In their care considerations they could take the stage of the disease, individual characteristics and coping mechanism of the caregiver, and relationship with the care recipient prior to the disease into account and adapt the care accordingly to suit the situation and needs of the individual caregiver. Furthermore, the results show that many difficulties in the early stages can be attributed to difficulties accepting the changes in family roles and relationships, therefore targeting acceptance of these changes in early interventions such as the currently developed program 'Partner in Balance' might prove to be beneficial. During the feasibility and effectiveness study, 'Partner in Balance' was introduced in some institutions in the southern part of the Netherlands. If interested, the institutions could participate in the study, delivering the intervention in their care practice under regular supervision of the research team. The Academic Hospital Maastricht, the Riagg Maastricht, all 5 chains of 'Hulp bij Dementie' (Integrated Dementia Care in Limburg), Elkerliek Hospital Helmond, Catharina Hospital Eindhoven and Metgcz Roermond have agreed to participate and already use the program in their daily practice. Results showed that caregivers who followed the program reported an increase in self-efficacy, mastery, and quality of life. As the number of people with dementia will increase in the future, this finding could be of great interest to insurance companies and policy makers. When policy and practice in the formal care system invest in improving the capability of informal carers to help them continue to care for their family member with dementia with effective programs such as 'Partner in Balance', this could contribute to the sustainability of the healthcare for people with dementia and their carers. Furthermore, the policies of the formal care system are conceptualized in rational and general terms, whereas effective care should fit the expectations and experiences of informal family carers that emerge out of a unique set of personal circumstances. If insurance companies and policy makers take these personal circumstances into account this could increase the effectiveness of support for informal carers.

Activities and products

Based on the user- and professional input, evidence from previous research, and feasibility findings the online self-management program 'Partner in Balance' was developed. The program comprises of multiple components, is tailored to the individual and includes interaction with a coach and the possibility to interact with other caregivers. The program is tailored to individual differences in caregivers based on their needs, while stressing the positive aspects of caregiving and focusing on adjusting expectations to be able to facilitate acceptance during the early stages.

The different institutions who offered the program during the study period were updated of the study progress through a bi-annual newsletter. Furthermore, we visited Alzheimer Cafes, senior centers and mental health insitutions in the southern part of the Netherlands to present our study and preliminary findings and to ask feedback from both caregivers and professionals.

Schedule and implementation

As the intervention proved to be effective on caregiver self-efficacy, mastery and quality of life, the institutions that offered the program during the study and followed the coach training will focus on implementing the program in their daily care. Currently, we are exploring the possibilities to implement the program on a larger scale, by focusing on municipalities within the scope of Dementia Friendly Communities. We are currently discussing the option of implementing 'Partner in Balance' within the EU Prevent project (www.euprevent.eu), in which German and French regions have also expressed their interest. We are currently investigating (financial) opportunities for translating and implementing 'Partner in Balance' on a European level. Furthermore, as spousal- and child caregivers of people with young-onset dementia may benefit from other topics and examples, financial means were obtained to develop additional modules to meet the needs of this specific group.

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