

# Experience sampling in dementia care

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## KNOWLEDGE VALORIZATION

The main aim of this thesis was to investigate the application of the experience sampling method (ESM) within an intervention to support spousal caregivers of people with dementia in daily life. In this valorization paragraph, we describe how the obtained knowledge from our research can be made valuable for clinical and societal use.

### Societal relevance

Today, 47 million people live with dementia worldwide. With the numbers of people with dementia expected to double in the next 30 years and predicted costs likely to rise to a trillion dollars by 2018, we are facing one of the biggest global health and social care challenges of our time. There is an urgent need to improve the coverage of health care around the world, for people living with dementia now and those who will be in the future. For this reason, the World Health Organization and the European Union (EU) have indicated that dementia should be regarded as a global public health priority.

Dementia has a considerable impact on the quality of life of persons with dementia as well as on their caregivers. The majority of the people with dementia are living at home and are cared for by their relatives. Providing years of extensive care for a person with dementia is associated with increased levels of stress and a higher risk of developing physical and psychological symptoms, such as stress and anxiety. In the upcoming years, the care for people with dementia will depend even more on informal caregivers, as people with dementia will be urged to live at home for longer periods due to the rising costs of formal care. This calls for psychosocial interventions that effectively support caregivers in daily life and help them endure their care responsibilities for as long as possible.

Recent technological developments provide new opportunities to extend interventions beyond the clinical setting into people's everyday lives. These interventions are also referred to as ecological momentary interventions (EMIs) and reflect a high ecological validity, because they provide real time support in the real world. This thesis described the development and evaluation of the EMI program 'Partner in Sight', which was based on the experience sampling method (ESM). The ESM is an innovative approach that can be used to self-monitor subjective experiences in the flow of daily life and to provide both the caregiver and the health care professional with unique detailed information, which could not have been captured using conventional retrospective methods. Accurate assessment of caregiver functioning is of great importance to provide care more efficiently, at times and in situations when its most needed. This might save costs in the long-term, as caregivers can be prevented from becoming overburdened and institutionalization of the person with dementia can be delayed.

### **Target audience**

The findings of this thesis are relevant for caregivers of people with dementia, health care professionals, and policy makers.

Caregivers of people with dementia can benefit from our research as the ESM intervention 'Partner in Sight' effectively increased caregivers' feelings of being capable to care for the person with dementia, and reduced perceived stress and negative feelings. By asking caregivers to monitor their daily functioning, they become more aware of implicit daily patterns of emotions and behavior. Our ESM intervention specifically aimed to give caregivers more insight into those situations that elicit positive emotions, such as relaxation and social activities. Results showed that our focus on empowerment of positive experiences helped to protect caregivers against stress and negative feelings. Existing interventions often put emphasis on negative experiences in order to reduce negative caregiver outcomes, such as stress and feelings of burden. This thesis, however, demonstrates that targeting on positive rather than negative experiences can be beneficial to increase caregiver resources and might be a promising direction in future caregiver interventions.

Dementia health care professionals should consider introducing ESM interventions for informal dementia caregivers in addition to already provided care as usual. This thesis proves that the ESM is a highly feasible method in caregivers of people with dementia and offers new possibilities to tailor interventions more to their personal situations. Previous studies confirmed caregiver interventions to be more effective if they are tailor-made and meet the needs of the caregiver. Moreover, the ESM actively involves caregivers in their own empowering process, which is considered as another important aspect in effective psychosocial interventions. The results of this thesis show that, next to using the ESM as an intervention tool, the ESM can be a valuable tool for assessment and screening in the field of dementia care. For health care professionals, ESM assessments can be a useful complement to standard retrospective questionnaires and clinical interviews, as they take into account fluctuations in caregivers' feelings and provide a more comprehensive and dynamic view of caregiver functioning. The use of the ESM in dementia care, therefore, should be stimulated as it allows for more accurate screening of caregiver functioning and helps health care professionals to detect caregivers that are in need of support.

Our findings could be of great interest to insurance companies and policy makers, given that the future care for persons with dementia will depend increasingly on informal caregivers. When policy makers involved in health care regulations invest in effective caregiver support programs, such as 'Partner in Sight', aimed at strengthening caregivers to continue their care responsibilities for as long as possible, this could contribute to the sustainability of health

care for people with dementia. However, to make this a success, insurance companies and policy makers should be more aware of differences in personal circumstances and should take into account individual needs and wishes when providing support to informal caregivers of people with dementia. To this end, the ESM could offer a valuable contribution.

### **Activities and products**

Based on the feasibility results of our exploratory study and evidence from previous research, the EMI program ‘Partner in Sight’ was developed. The program consists of six weeks of ESM self-monitoring, including personalized feedback from a coach on daily life situations that elicit positive emotions. The program is tailored to the individual situation of the caregiver and stresses the positive aspects of caregiving to strengthen caregivers throughout the caretaking process.

Participants of the study and involved care facilities were updated about the study progress and results through a bi-annual newsletter. Furthermore, results were presented at several national and international congresses, symposia, senior centers, and Alzheimer Cafés. Feedback from informal caregivers, health care professionals, and researchers was taken into consideration throughout the study process.

### **Innovation and implementation**

This thesis is the first to present the effects of an ESM intervention to support caregivers of people with dementia. ESM interventions have been successfully implemented in a wide variety of health-related areas. However, the application of the ESM in the field of dementia care is still in its infancy. This thesis, therefore, provides a valuable contribution to our knowledge of delivering caregiver interventions in real life, based on experience sampling techniques. Incorporating ESM interventions in regular health care for dementia caregivers seems to be promising, but the barriers for further implementation should be carefully considered. Future research is essential to make ESM interventions accessible to a wider range of caregivers and more attractive to implement with respect to time and costs.

Within our division ‘Cognitive Neuropsychology and Clinical Neuroscience’, this was the first project in which we explored the application of the ESM. Throughout the project we closely collaborated with the division of ‘Mental Health’, who extensively studied the ESM technique in diverse psychiatric populations. With their help, our knowledge about this innovative method has been extended and the method is now being adopted in other research projects with different populations, including persons with acquired brain injuries and persons with mild cognitive impairment.

