Knowledge valorization

The general aim of this thesis was to gain insight into the mechanisms of mindfulness on aging and to explore the applicability of a mindfulness-based intervention (MBI) to support people with dementia and their caregivers. This valorization addendum describes the societal relevance of the obtained knowledge based on the research described in this thesis.

Relevance

Dementia is a global health challenge. Worldwide, approximately 50 million people are currently living with dementia. This number is expected to reach 115 million in 2050. Dementia has an enormous impact both on the people with dementia and their families. People with dementia often feel isolated and marginalized. Those who care for someone with dementia often feel exhausted and strained. The impact of dementia is also a social and economic one; in 2015, the global societal cost was estimated to be more than 800 billion US dollars. According to the World Health Organization, dementia should be regarded as a global public health priority. Despite significant resources spent on finding a pharmacological treatment, there is no cure for this neurodegenerative condition. Therefore, other avenues to face dementia should be explored, such as prevention as well as improvement of the support of those currently living with dementia. This thesis investigated the role of mindfulness as a possible link with age-related cognitive decline and whether mindfulness could delay the onset of such decline. For example, mindfulness-based interventions (MBIs) might influence risk factors of dementia such as depression, diabetes, obesity, physical inactivity, hypertension, and smoking. Mindfulness could modify these risk factors and prevent or delay the neuropathological cascade leading to cognitive decline. The studies described in this thesis provide insight into these mechanisms, but the cross-sectional nature precludes causal statements. Moreover, this thesis looked into the use of mindfulness-based intervention to support people with dementia and their caregivers. People with dementia and caregiver have expressed a clear need for positive support that goes beyond the diagnosis itself. Questions such as ‘How do you live with the diagnosis?’ and ‘How do you find a new balance together?’ play an important role. MBIs might be the intervention that can effectively help dyades cope with dementia.

Target audience

The findings described in this thesis are relevant for people with dementia, caregivers, dementia health care professionals, and health insurance companies. Informal caregivers fulfill an important role in the care for people with dementia. Unfortunately, most caregivers experience caregiving as stressful. In comparison with caregivers of physically frail elderly people and non-caregivers, caregivers of people
with dementia show higher levels of psychological distress. Caregivers often struggle with acceptance, although they have reported that this is very important to be able to adapt to the situation. Difficulty to acknowledge changes interferes with acceptance. MBIs are able to work on the one hand to reduce stress, and on the other hand to learn how to deal with changes and therefore stimulate acceptance. Moreover, caregivers that have participate in an MBI will learn how to take better care of themselves; a process that is often overlooked because of a focus of care on their partner. Our research also indicates that participating with their partner together could have added benefits for their relationship such as improved communication and increased connectedness.

Similarly, people with dementia might benefit from participating in MBIs. In particular, a program as described in this thesis in which people with dementia participate together with their caregiver. It gives them the tools to learn how to live with the diagnosis and deal with difficult situations. Our research shows that people with early-stage dementia are capable to participate in MBIs. Because the materials of the TANDEM project are made available to certified trainers throughout the Netherlands, more people might be reached.

Results from this thesis could be of interest for health insurance companies and policy makers. In particular, it can be part of a prevention strategy for both general health. More specifically, it can support people with dementia and their caregivers. When people with dementia and their caregivers can participate in an MBI shortly after the diagnosis, it is expected that they will experience less distress. Moreover, it seems reasonable to assume that by investing in the ability to cope with the life changing diagnosis, the caregiver will be able to maintain their supporting role longer. Also other categories of older individuals might benefit from MBIs. People with diabetes that have higher levels of mindfulness show lower levels of diabetes related distress. Perhaps MBIs can reduce distress in people with diabetes. Although more research is needed, it is a relatively low-cost intervention that could prevent or slow down diseases such as diabetes.

Dementia health care professionals should consider MBIs as an option for both caregivers and people with early stage dementia. On the project's website www.tandemproject.nl certified trainers can be found who may provide the TANDEM training. The results of this thesis indicate that MBIs can help people cope with the diagnosis.
Activities and products

With the input of dementia experts and mindfulness trainers, the TANDEM training was developed. The program was based on a standard Mindfulness-Based Stress Reduction program and consists of an 8-week group training of 2,5 hours each week. It was adapted to better suit people with dementia and their caregivers. A manual for the trainer and the accompanying workbook were developed and distributed among certified mindfulness trainers in the Netherlands.

Results of the research in this thesis were presented at several conferences, symposia and Alzheimer Café’s. Moreover, the TANDEM project has been visible through both specific websites (e.g. www.alzheimer-nederland.nl) as well as mainstream media (Psychology Magazine and the local newspaper De Limburger).

Innovation and implementation

The TANDEM project was one of the first projects that included people with dementia and their caregivers together in a single mindfulness training. Certified trainers in the Netherlands can request the materials of the training free of cost. Almost 200 trainers have done this so far, with the majority having the intention to start a TANDEM group. The study has contributed to a wider acceptance of MBIs in the care for people with dementia and their caregivers.

Our study involving Experience Sampling Method is one of the few that have investigated state mindfulness and the association with positive affect. This in combination of short meditation exercises provides new possibilities for people to maintain their practice after a training. It also contributed to the understanding of different facets of mindfulness in daily life. The ESM technique may help us in the future to elucidate the underlying mechanism of mindfulness intervention programs by enabling insight into moment-to-moment causal pathways.

In addition, the link between inflammation and mindfulness opens a new avenue for early intervention. Future research can further investigate whether MBIs can influence inflammation.