Knowledge valorization

The aim of this thesis was to investigate the specific needs in care and guidance for people with YOD and their caregivers, and to explore the impact of young onset dementia (YOD) on informal caregivers and other family members during the different stages of the disease. With this valorization paragraph we describe how the results are of value for societal and economic application.

Societal relevance

Dementia is a worldwide public health priority. In 2015 the number of people with dementia is estimated at 47.5 million and is expected to increase in the upcoming years with a new case every four seconds implying a total number of 7.7 million new cases each year worldwide. In 2015, the total estimated cost of dementia is 818 billion dollars which is predicted to rise to a trillion in 2018. In addition to the expenses for the society, the disease has an enormous impact upon the quality of life of the person with dementia as well as their family and caregivers. Because age is the most important risk factor for developing dementia, it is most prevalent in the elderly and mostly associated with advanced age. However, some people develop symptoms of the disease before the age of 65. According to estimations of the Dutch Alzheimer society there are around 12.000 individuals with YOD in the Netherlands but unfortunately there is no solid information available about the number of people with YOD.

Dementia at a young age has gained more attention over the last years, however, people who are involved still experience feelings of stigma. As dementia in the young is rare it is not always recognized by the environment and the individuals with dementia and their caregivers often feel misunderstood and left on their own. As described in this thesis, most dementia services are often specifically designed for the elderly, and might have difficulties in addressing the needs of younger individuals. Therefore it is important to raise awareness about YOD in the general population and to educate healthcare professionals on how to support people with YOD and their family members.

Since there is no cure available, an important aspect of care for persons with dementia is promoting well-being and maintaining an optimal quality of life (QOL). The informal caregivers play a crucial role in enhancing the well-being of the person with dementia as they provide the greater part of care and are often dedicated to do this by themselves for as long as possible. Unfortunately, these caregivers often do not feel sufficiently prepared for their role as caregiver and this might be even more common in YOD compared to late onset dementia (LOD) as it is more rare. The daily care for someone with dementia requires continuous adaptation to changing and demanding situations for an
extensive period of time and can result in adverse physical and psychological outcomes. In order to support people with YOD and their caregivers and provide effective and efficient care, knowledge about their needs and experiences is essential. This knowledge can be used to develop effective interventions which may save costs in the long-term, by postponing early nursing home placement.

**Target groups**

Our findings are relevant for people with YOD and their caregivers, health care professionals and policy makers. Our studies emphasize that these younger individuals have specific needs and therefore it is important to raise awareness about the occurrence of YOD and the accompanying issues, as it has consequences for service provision. Better support from health care professionals is necessary and difficulties in essential areas in service provisions are described in this thesis. This is not just important for the problematic diagnostic period but for providing guidance after receiving the diagnosis as well.

The findings of this thesis are important for informal caregivers as well as they provide an in depth perspective on the caregivers experiences and emphasize specific themes that could be addressed in future interventions. The caregivers experience high levels of burden and a considerable number of psychosocial problems related to their younger phase of life, including relational difficulties, family conflict, employment and financial issues. The increasingly time consuming tasks together with other responsibilities such as working and being a parent cause double demands. Knowledge about the problems these young caregivers face are important to improve support for informal caregivers. Our results are relevant for people with YOD as well as it describes encountered problems throughout the disease trajectory and identifies factors to improve their QOL. Caregivers should try to find the right balance between providing sufficient help and respecting the autonomy of the person with dementia as the experienced loss of autonomy negatively affects their QOL. This asks for a shift in focus from disability and loss towards the possibilities in daily lives and the empowerment of people with YOD in directing their own care.

**Products**

Based on the recommendations of this thesis an e-health intervention to assist caregivers in coping with YOD was developed (http://www.rhapsody-project.eu). The program consists of multiple modules that address the specific issues people with YOD and their caregivers face. This program is now evaluated in a pilot study conducted in England, France and Germany. The development of the RHAPSODY program also provided some important insights for the adaptation of a blended e-health intervention that was recently developed and evaluated by Alzheimer Centre Limburg (Partner in Balans).
This program aims to enhance caregivers’ sense of competence in dealing with the caregiving situation. Our knowledge will be used to tailor the program to the needs of younger individuals. Presenting such a program complementary to formal care, shortly after receiving the diagnosis might help the caregivers with the acceptance process, and to regain control over the caregiving situation. Specifically in YOD alternative ways to provide care might be necessary as establishing regular dedicated services can be challenging, for example in low populated areas or for people who are still working and have limited availability during the day.

**Innovation**

The NeedYD study is a unique large scale cohort study which resulted in practical information for daily practice to improve care for people with YOD and their caregivers. The combined use of both qualitative and quantitative measures provided a thorough understanding of their experiences and needs. Our work is the result of a good combination of different disciplines, experts, and networks, through several national and international collaborations. Multiple Alzheimer centers, care facilities, and research groups were involved to enhance our knowledge about YOD and to accelerate the progress in YOD research. Our work is also a good example of how previous results can be used to design new projects. By doing this we aim to make a difference for everyone involved by using their own experiences to improve care.

**Implementation**

The participants of the NeedYD study and involved care facilities were updated about the study progress and the results through a newsletter. Furthermore, results were presented at several national and international congresses, symposia, and Alzheimer café’s. Workshops were provided to health care professionals to raise awareness about the experiences of people with YOD and the caregivers and also specifically about the needs of the children. In addition, our findings were used for the content development of an informative YOD website for people in the Netherlands and Belgium www.jongdementie.info. To translate our findings to specific guidelines for clinical practice and to further disseminate our work, we have close connections with the YOD knowledge center. This Dutch knowledge center aims to improve the quality of YOD care by connecting specialized caring facilities, developing specific guidelines, supporting scientific research, and through the dissemination of research findings.