

Moving Forward with Dementia

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Impact Paragraph

The findings described in this thesis are relevant for people with dementia, informal caregivers, healthcare professionals, researchers and policymakers. The main findings will be discussed followed by the scientific impact, societal impact and dissemination activities undertaken.

Main findings

This thesis describes experiences from diagnosis and post-diagnostic support and integrates the perspectives of people with dementia, informal caregivers and healthcare professionals. For people with dementia, the social network emerged as an important source of support in making decisions on diagnostic testing and coming to terms with dementia. Perceptions of post-diagnostic support differ between people with dementia and informal caregivers, highlighting differing priorities. For informal caregivers, supporting the person with dementia sometimes negatively affects their mental health and wellbeing. This was sometimes worsened by negative experiences with accessing and using care. Specifically, navigating healthcare systems was deemed complex. High-quality information and signposting services are crucial in supporting informal caregivers. Healthcare professionals express dissatisfaction with the transition between diagnosis and support and healthcare professionals involved in both diagnosis and post-diagnostic support demonstrate a greater capacity to bridge this gap. Overall, the thesis underscores the need for tailored information provision and support to enable people with dementia and informal caregivers to live well with dementia.

Scientific impact

This thesis adds to our increased understanding of how people with dementia and informal caregivers can be supported to live well with dementia. It offers several implications and recommendations for dementia research.

First, this thesis developed an innovative approach for conducting qualitative research with people with dementia. This method was deemed feasible, meaningful and manageable for people with dementia. The published article provides all materials needed such as the interview guide and materials used by participants. Researchers can use these as inspiration to further aid the development of creative approaches in qualitative research that enable

people with dementia to share their experiences in dementia research. In addition, the Cognisance Consortium had a team member who had dementia and was able to provide the lived experience and contribute valuable input around designing data collection methods and recruitment.

Second, this thesis consisted largely of international research that was conducted across countries strengthening its impact. The findings of this thesis showed that it is feasible to identify common experiences whilst not neglecting the subtleties that exist across countries. Quantitative research in multiple countries can easily compare and contrast answers across countries when sample sizes are large enough. Qualitative research is often concerned with subjective experiences and in dementia, these are not independent of cultural factors and the organization of healthcare systems. Collecting, analyzing and interpreting data across countries can be challenging. Research could develop standardized qualitative analysis strategies for cross-country data to strengthen the impact of this type of valuable research.

Our mixed methods study highlighted that healthcare professionals utilize strategies to foster the connection between diagnosis and support but also encounter several barriers to bridging the gap between a dementia diagnosis and subsequent support. Future research can expand on these findings and take into account the role of policymakers in formulating concrete actions and strategies to bridge the gap between diagnosis and support.

Societal Impact

The findings of this thesis are relevant to a broad audience and several implementation and dissemination activities have been undertaken.

First, people with dementia and informal caregivers can benefit from the website 'Forward with Dementia' that was developed based on findings from this thesis. This is an information website for people living with dementia, informal caregivers and healthcare professionals. The website is available in Australia, Canada, The Netherlands, Poland and the United Kingdom. The website was co-designed with people with dementia, informal caregivers and healthcare professionals. The co-design groups emphasized it was important to re-frame the picture of dementia to counter-act stigma. This was achieved by using active language and optimistic and realistic pictures of older people. Within the content, people with dementia were directly addressed, which was

previously missing in online information filling an important gap. This website has been positively evaluated by people with dementia, informal caregivers and healthcare professionals.

Second, the findings are relevant to healthcare professionals. Just like people with dementia and informal caregivers, they can benefit from Forward with Dementia as it has a specific section relevant for them. In addition, it provides healthcare professionals with a trustworthy and easily accessible website that they can refer people with dementia and informal caregivers to, potentially fulfilling their informational needs. This thesis highlighted that healthcare professionals who work across the diagnostic process and post-diagnostic support are more satisfied with the transition between the two. This suggests that a broad range of knowledge and skills can be beneficial in guiding people with dementia and informal caregivers from diagnosis to support, potentially lessening the perceived support gap right after diagnosis.

Thirdly, the findings of this thesis are relevant to policymakers. This thesis demonstrated that people with dementia and informal caregivers perceive the healthcare systems as complex. This can delay the onset of appropriate support services and cause additional burden for informal caregivers. A need for signposting and navigational services were identified as possible solutions to support the process of accessing support services. Findings also highlighted that limited time for consultations with healthcare professionals is a barrier to the provision of person-centered care. The healthcare system should provide healthcare professionals who work with people with dementia with sufficient time for consultations and visits as it can support them in providing person-centered care.

Dissemination

To disseminate Forward with Dementia, a campaign was organized and promotional materials such as flyers, brochures and posters were distributed. These promotional materials described the Forward with Dementia website and were aimed at people with dementia and informal caregivers. In the Netherlands, we collaborated with six regional healthcare organizations in the field of dementia to distribute promotional materials to people with dementia and their informal caregivers. In addition, flyers and promotional materials were distributed at the National Memory Clinic Conferences (2021). Over 1000 brochures and flyers have been distributed so far.

Within the campaign of Forward with Dementia, several dissemination activities were undertaken such as a local radio interview and a webinar. The webinar (2020) discussed the importance of post-diagnostic support and introduced the audience to the website of Forward with Dementia. Approximately 200 people attended. Several lay talks were given at Alzheimer Cafes (2021 and 2022) and the Dementia Dialogues at the MUMC+ (2022). In addition, a workshop was held at a conference of regional case-managers (2022).

The co-design process of the website was of interest to policymakers and researchers. We discussed the development process of Forward with Dementia with the National Dementia Networks in 2022. In addition, an interview on co-designing with people with dementia was published on a Dutch website that promotes the participation of patients in research (2022). A presentation was given to researchers of the EMGO Institute for Health and Care Research (2022). A short video on the implementation of research findings was recorded for the National Dementia Conference (2021).

Lastly, findings from this thesis were communicated to the scientific community. They have been published in international open-access peer-reviewed articles. Findings were also discussed at several national and international conferences in the form of poster and oral presentations (Jaarevent Deltaplan Dementia 2020, Alzheimer Europe 2020 - 2023, Alzheimer's Association International Conference 2021, Alzheimer Disease International 2022, JPCo-fuND2 Midterm Symposium 2022, International Psychogeriatric Association 2023).