

Neuropsychological assessment at the memory clinic

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KNOWLEDGE VALORIZATION

Knowledge resulting from the studies described in this thesis have, next to scientific value, both clinical and societal value. This paragraph addresses how the acquired knowledge can be made valuable in the social and clinical contexts.

Societal relevance

Worldwide, around 50 million people live with dementia. The next 25 years, these numbers will double as a result of the aging population. Dementia is the main cause of disability and dependency in the elderly population. The impact of dementia is present on several domains (e.g., physical, psychological, social, economic) in both patients and their family members, and can lower their quality of life. Furthermore, dementia has a significant social and economic impact due to the high medical and social care costs. In 2018, the global cost of dementia was one trillion US dollars, and this number is expected to further increase as more people live with dementia. This was argument for both the World Health Organization and the European Union to declare dementia a global public health priority.

Currently, no curative pharmacotherapy is available. However, psychosocial interventions and support during the prodromal and early phases of dementia have been shown to be effective (e.g., by lowering caregiver burden). Due to the huge impact of a dementia diagnosis it is important to carry out high-quality diagnostic assessment. Findings in this thesis showed that memory clinics have become a mainstream facility for the diagnosis of dementia and that almost all clinics used a neuropsychological assessment. Our results also showed that both patients and family members experienced high levels of uncertainty during their visit at the memory clinic. They appreciated a follow-up consultation with the neuropsychologist focused on providing neuropsychological feedback. It is important to offer support after receiving the diagnosis and offer insight into what their cognitive performance means for their daily life functioning. However, the studies in this thesis confirmed that the recall of medical information is low. Therefore, a web-based visual tool was developed to explain neuropsychological results to improve the understanding and retention of results.

Target audience

The findings in this thesis could be relevant to a broad audience. Our findings are relevant for people with cognitive complaints that visit a memory clinic. They can benefit from this research as the visual tool developed in this thesis was reported to improve understanding of neuropsychological assessment results. Furthermore, the insight resulting from the other studies might lead to improvements in clinical practice which is beneficial to patients (e.g., more awareness for feelings of uncertainty and low information retention).

The findings are also relevant for clinicians, especially for neuropsychologists working in memory clinics. The clinical implications reported in several chapters might be specifically informative. For example, they might pay extra attention to which cognitive tests they use and might adhere to the harmonized cognitive core

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battery described in the monodisciplinary guideline for Dutch psychologists. They might also pay attention to the way they provide neuropsychological feedback, use communication aids or involve a family member to ascertain that the information is better remembered. Furthermore, psychologists can use the visual tool to more easily explain neuropsychological results to patients and family members. During the feasibility study the visual tool was introduced in three memory clinics during which they used the tool in their daily practice. Results showed that patients, family members, and psychologists were positive regarding the tool. It was easier to understand results, they received (or gave) an overview of their cognitive performance at one glance, and implications of the results for their daily life.

Our results are also relevant for scientists as more scientific evidence was gathered regarding the benefit of using a neuropsychological assessment in a memory clinic. The visual tool also contains a database which can be of interest to collect data while also being part of routine clinical practice. Furthermore, the guideline developed in this thesis might lead to more harmonization between memory clinics and therefore making it easier to conduct research across clinics and compare findings.

Due to the increasing number of patients visiting a memory clinic and patients with dementia our findings might also be of interest to policy makers. Our studies showed that carrying out a neuropsychological assessment with a separate neuropsychological feedback session after receiving the diagnosis was of added value. For policy makers, it might be interesting to learn that neuropsychological feedback is recommended to be included as part of clinical routine.

Activities, innovation, and products

Based on the user input from patients, family members, and professionals the web-based visual tool was developed to explain neuropsychological assessment results. The visual tool comprises of multiple modules (psychologist modules, patients/family members modules) which can be tailored to the findings of the individual patient. The visual tool is also tailored to the experiences and needs of all users, while stressing the translation of the neuropsychological findings to daily life. The visual tool was piloted in the Maastricht UMC+, Radboudumc Nijmegen, and Catharina Hospital Eindhoven. We also developed a monodisciplinary guideline neuropsychological assessment in mild cognitive impairment (MCI) and dementia to harmonize neuropsychological procedures in the Netherlands. Another product resulting from this thesis is an overview of the development of memory clinics in the past twenty year which was distributed among all participating Dutch memory clinics. We also visited meetings of the national psychologist association and the Dutch memory clinic network to present preliminary findings of our studies. We also gave presentations at Alzheimer Cafés, client panel meetings of the Alzheimer Center Limburg, Dialogues around Dementia, and several international conferences (Alzheimer-Europe, FESN).

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Schedule and implementation

Overall, the visual tool was evaluated positively. Therefore, the next step is to implement the tool for a longer period in the Maastricht memory clinic to evaluate the experiences and needs during a longer period of use. Feedback gathered after this period can be used to optimize the tool. To be implemented in other memory clinics more cognitive tests and corresponding normative data have to be added. Also, a long-term and self-sustaining business model has to be developed to make sure the visual tool can be adapted in the future or when other needs arise. The first step is now to implement the tool in the Maastricht memory clinic as all tests used there are available in the tool. Future steps will be adapting the tool with more commonly used tests in other in other Dutch memory clinics. Financial means might also have to be obtained to translate the tool to other target groups (e.g., other tests or daily life recommendations).