

Neuropsychiatric symptoms in dementia

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IMPACT PARAGRAPH

The impact paragraph describes the scientific and societal impact of the results presented in this thesis. In addition, target groups are identified for whom the findings are relevant. Moreover, it is pointed out how these specific target groups can be reached and informed about the research findings.

Aim and key findings

Dementia has a huge impact on affected persons, their family and society. The worldwide prevalence will expand to approximately 82 million in 2030¹ and this has important consequences for health care. Neuropsychiatric symptoms (NPS) – as covered in this thesis - play a role in the aforementioned upcoming increase of numbers of people with dementia, as they can cause various negative outcomes for the patient. NPS are behavioral changes that commonly develop during the different stages of dementia and include for example anxiety, depressive symptoms, psychosis and sleep disturbances. NPS are associated with patient-related factors, but also with the physical and psychosocial environment.² NPS can also lead to negative health effects in the informal caregiver³ and are an important risk factor for transferring from living at home to a nursing home admission. Considering the high dementia prevalence, the role of informal caregivers will only increase and the pressure on nursing homes will grow. In light of the above, the aim of this thesis was to gain more insight into the relationship between the psychosocial context and neuropsychiatric symptoms in the different stages of mild cognitive impairment (MCI) and dementia.

The first study of this thesis focused on the association between depressive symptoms and the progression from MCI to dementia. A systematic review and meta-analysis of the existing literature (Chapter 2) showed that depressive symptoms are associated with an increased risk in the progression from MCI to dementia in community-dwelling persons, but not in clinical populations. The other studies in this thesis focused on the understanding of the relationship between neuropsychiatric symptoms in cognitive disorders and the psychosocial environment. In MCI, the quality of life of the informal caregiver and its potential determinants, including caregiver and person with MCI characteristics such as NPS, were studied (Chapter 3). In this study being a spouse was associated with a lower caregiver quality of life. In addition, the quality of life of the informal caregiver was mainly influenced by caregiver characteristics. However, in dementia, NPS influence the quality of life of the informal caregiver. In line with this, in the following study NPS were associated with a decrease in relationship quality between a person with dementia and his or her informal caregiver over a year (Chapter 4). In the same study social support was associated with maintaining a good relationship. In another study the concept of *expressed emotions* was used to capture the interaction between the caregiver and the person with dementia (Chapter 5). High scores on caregiver expressed emotions, especially critical comments, were associated with more hyperactivity scores in persons with dementia. In addition, critical comments were also

associated with more nursing home admissions. In the last study in this thesis, in a nursing home setting, the results showed that more social support between nurses and supervisors may lead to less agitation in residents with dementia (Chapter 6). Altogether, the results of this thesis confirm the hypothesis that NPS in cognitive disorders and the psychosocial environment interact in a dynamic multidirectional way.

Scientific relevance

This thesis provides more insights into the complex association between the psychosocial environment and NPS in MCI and dementia. The systematic review and meta-analysis (Chapter 2) contribute to the knowledge about the relationship between depressive symptoms and cognitive disorders, specifically the progression from MCI to dementia. The fact that depressive symptoms increased the risk for progression to dementia is not only important because of its consequences for the prognosis of the person with MCI, but also for researchers, as they want to better identify which people with MCI have higher risks of eventually getting dementia, and which will not. This might also lead to more starting points for setting up intervention studies.

In Chapter 3, 4 and 5 different measurements were used to analyze interactions between the psychosocial environment and NPS in cognitive disorders in persons living at home. We used concepts as caregiver quality of life and relationship quality. Also, we used expressed emotions to measure the interaction between the informal caregiver and person with dementia. The results showed that the association is complex and consists of dynamic multidirectional interactions. It is important that in future research these interactions will be further unraveled to come to a more complete understanding. The measurements used in this thesis were feasible, and the studies demonstrate that these measurements are important to take into account in dementia research.

In a nursing home setting, the influence of job characteristics of the nursing team on agitation in residents with dementia was explored (Chapter 6). These job characteristics are described in Karasek's Job Demands-Control-Support model^{4,5}, which is a relevant framework to take into account when studying the psychosocial context in a nursing home setting. Our explorative study showed the importance of social support and researchers can use this study as a stepping stone for a larger longitudinal study on social support within nursing teams.

Societal relevance

As described above, NPS have a huge impact on quality of life of the affected person and result in higher levels of burden for the caregiver. NPS are a major reason for nursing home admission and for the prescription of psychoactive drugs. Lowering the prevalence of NPS could delay or prevent nursing home admission and result in a better quality of life. This thesis confirms the importance of the psychosocial environment in dementia and the complex interaction with NPS. Policy makers in health care should

therefore focus on the psychosocial environment by giving attention to both informal and formal caregivers. Social support for informal caregivers, but also social support within a nursing team could make it easier to cope with challenging behavior. Moreover, paying attention to the interactions between a person with dementia and a caregiver, for example by means of expressed emotions, could result in less hyperactive behavior.

In dementia, NPS seem to influence caregivers' quality of life, this highlights the importance of the interaction between the psychosocial environment and NPS. The finding that relationship quality declines in dementia, and that this is mediated by NPS and (a lack of) social support might be a lead for more targeted interventions. However, the finding that the quality of life of the informal caregiver in MCI and mild dementia is relatively good, and mainly depends on caregiver characteristics is principally a positive and encouraging finding. While MCI and mild dementia can place a burden on a caregiver, it does in the same time not affect caregiver's reported quality of life in general. It is important that also these positive outcomes are communicated to the persons concerned, as they may have a supporting and encouraging effect.

The thesis is also relevant for educational purposes to build more awareness about the importance of the psychosocial environment in dementia and the possible relationship with NPS. Health care professionals such as case managers, nurses and doctors can be made more aware that for reducing NPS, instead of looking primarily at psychoactive drugs, one should also pay more attention to the people around a person with MCI or dementia. Finally, students should be made aware that coaching and supporting caregivers not only may result in better outcomes for the persons with MCI or dementia, but also for the caregivers themselves.

Target groups

The results of this thesis are relevant for various groups. Firstly, the findings are relevant for researchers in the field of dementia as the different studies in this thesis give suggestions for further research. Secondly, policy makers could use the results of this and other research as a reason to improve the support and coaching of informal caregivers. Also, policy makers should take notice of the importance of the wellbeing of nursing teams, as this will result in better job satisfaction, but probably also in better patient outcomes. Thirdly, the results of this thesis are important for health care professionals such as nurses, doctors and psychologists. They can be made more aware that the health and wellbeing of persons with MCI and dementia is not only affected by the disease itself, but results from a complex interaction with dynamic psychological and social factors. Lastly, but certainly not least, the results are relevant for persons with dementia and caregiver groups. Raising awareness for the importance of the interaction between the psychosocial environment and NPS is beneficial for these groups since this could lead to more understanding and new developments.

Activity

The target groups of the results of this thesis are informed in several ways. Four of the studies in this thesis are already published in international medical journals, and one of the studies is submitted for publication in an international medical journal. Some of the published studies already have been cited multiple times. Furthermore, the results of this thesis will be presented at multiple regional conferences for clinicians. Lastly, in education I fulfill a personal role as a trainer of old-age psychiatry and clinical geriatrics residents, where I make sure that sufficient attention is paid to the importance of the psychosocial context in patients with cognitive disorders.

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