

SYMPOSIUM PRESENTATION 1: HOUSING AND DAILY LIVING

Living at home with dementia beyond care: A perspective on the day and night situation

C. A. M. Huisman (Convener)

Participants: A.A.G. Sponselee (the Netherlands), C.A.M. Huisman (the Netherlands), T.M. Raymundo (Brazil), L.D. Bernardo (Brazil), M.A. van Tilborg (the Netherlands). **ISSUE** Worldwide around 55 million people live with dementia and this number will increase to 139 million people in 2050 (WHO, 2021). People with a disability or older age depend on support of an informal caregiver. Informal caregivers can experience a higher level of depression and stress and the risk of developing physical health problems are greater compared to non-caregivers. When caring for someone with dementia, the care can be even more demanding because of behavioral and psychological symptoms of dementia (BPSD). Research shows that informal caregivers perceive their situation as permanent and they experience a sense of being tied-in, the feeling to be always alert, unappreciated, feeling trapped, pulled in all directions, and sometimes being in an unreal situation. The care burden may result in a decrease in quality of life of the informal caregiver. **CONTENT** Our symposium is designed to bring together speakers from the Netherlands and Brazil on the theme living with dementia at home. The speakers will highlight: 1) a project conducted in the Netherlands with method and results 2) visual functioning at home 3) living with dementia at home in Brazil. **STRUCTURE** Huisman will introduce the project 'a good night for a better day'. A project performed in the Netherlands, the central issue is how can technology support a better sleep for people with dementia and their informal caregiver living at home. In the project we assume existing technology and examine what is needed to match these technologies to the context. Sponselee will talk about the perspectives of different stakeholders in the Netherlands on challenges during the night for people with dementia and their informal caregivers living at home. Van Tilborg will talk about visual functioning of people with dementia in and around home, possible solutions will be discussed. Raymundo and Bernardo (duo presentation) will present the Brazilian scenario and the initiatives aimed at the prevention of dementia, especially those linked to the training of community health agents (which are part of the Brazilian Unified Health System) for the early recognition of signs and symptoms of illness, and those related to the support of family caregivers in the management of behavioral and psychological changes resulting from the disease. In a complementary way, the symposium will present actions aimed at the elderly with a focus on technologies that can be used for cognitive training and cognitive stimulation. **CONCLUSION** The use of the technology and home modifications can support people with dementia and their caregiver to live at home as long as possible. The implementation is a challenge. This symposium will inspire people to think how we can realize ageing in place with dementia.

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Keywords: dementia, sleep, technology, age in place, eye care

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Available technology applications to support sleep for people with dementia and their informal caregiver

C. A. M. Huisman, H. S. M. Kort

Purpose In Europe, estimates suggest that around 80% of all long-term care is provided by informal caregivers (Zigante, 2018). Caring for a person with dementia can be difficult because of the BPSD (Behavioral and Psychological Symptoms of Dementia) (Chiao, Wu & Hsiao, 2015). Hereby, sleep disturbance is common (Bubu et al., 2017) and an important factor for a higher care burden for the informal caregiver. We performed a project to find out in which way supportive technologies can be implemented in people's homes. **Method** In the two-year project, people with cognitive problems, informal caregivers and care professionals will be examined in a participatory way to find out how the night can be supported. Research will be performed from a person-centered perspective that takes the person and the unique aspects as a starting point to find appropriate solutions. The perspective of "warm technology" is the starting point, where the intention is to use appropriate, non-stigmatizing and person-enhancing technology with the target group. **Results and Discussion** The project consists of four phases. The first phase is to get a better understanding of the situation around the night of people with cognitive problems and the informal caregivers. To make clear where there are opportunities to support with existing technology and related services. Considering the ethnic and cultural differences. Phase two is a scoping review of the available technology which can support and to gain insight in the barriers and facilitators of the implementation of technology in people's homes. In this phase the existing technology is also matched to the context and adjustments of the technology will be made as needed, in this way solution directions emerge. In phase three the solution directions will be demonstrated to the target group, in an iterative process changes can be made if necessary. In this phase, also materials will be developed together with the target group to support the implementation of the technology solutions, e.g. instruction materials. In the last phase a pilot study will be performed and evaluated. Technology solutions will be implemented in people's home and the implementation and technology solution will be evaluated. The project is started in September 2021 and will be finalized in August 2023.

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A multi-stakeholder perspective on challenges during the night for people with dementia and their carers

A. G. Sponselee, M. E. Nieboer, R. G. A. Brankaert

Purpose Behavioral changes, such as wandering, sundowning, as well as related agitation, are important predictors for caregiver burnout and subsequently some of the major causes of institutionalization of people with dementia (Volicer, Harper & Manning, 2001; Hope et al., 2001). Insights into what influences a good quality of sleep is increasing. Nevertheless, knowledge on and attention to the importance of sleep on quality of life for people with dementia is limited by both informal and formal caregivers. The aim of this study was to gain insight into the challenges people with dementia living at home and their informal caregivers experience during the night, that can contribute to the development of technological interventions. **Method** Semi-structured interviews were conducted with people with dementia and their informal caregivers to gain insight into their problems and challenges during the night in relation to sleep and sleep quality. Participants were also asked to keep a sleep diary for 2-7 days, based on the NHG (Dutch College of General Practitioners) guideline (NHG, 2014), before the visit. During the visit, open questions were posed, using topics based on literature and the guideline 'Care for Healthy sleep and sleep problems' (V&VN, 2021) (day/night rhythm; evening routine; causes and effects of sleep disturbances). In addition to the home visits, a focus group with formal caregivers was organized. The goal was to extend or confirm the results of the home visits from a multi-stakeholder perspective. Both home visits and focus group were recorded. The interviews were transcribed and analyzed resulting in an experience flow of people with dementia and their informal carers. **Results and Discussion** Eleven people were interviewed in this study. Three women suffering from dementia [59-83; mean age: 75], five informal caregivers [1 male, 4 female; 74-86; mean age: 82] and three formal caregivers [all female]. People with dementia have difficulty in accepting the loss in abilities. They may worry during day and night. They may even feel anxious. They experience less need for sleep; leave their bed to visit the toilet or even take a shower. Activities during the day and fresh air in the bed room may increase their quality of sleep. Informal carers have to be alert day and night being afraid something might go wrong. They have to reassure the person with dementia. An afternoon nap by the person with dementia gives the informal carer a moment to recharge. Dementia and old age complicate the ability perform daytime activities. Improving the knowledge about the importance of good sleep and opening up the discussion about sleep will increase the potential for tackling problems related to sleep for both people with dementia and their carers. Technologies may support in structure in day and night activities, taking into account personal habits and behaviors, to improve sleep quality.

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Visual functioning and home modifications at home

M. A. van Tilborg

Purpose During this session all the visual challenges with the use of the technology in and around the house will be discussed. These days home modifications for patients with dementia are extremely important for the ability to live independently at home. People living with dementia do have a 5-time risks to fall (Rubenstein & Josephson, 2006). Fear of falling is also a reason of not want to leave their homes, or even reducing their mobility in their home situation. Visual functioning is broader than only the visual acuity. Visual acuity is the ability to see well at a certain distance recognizing high contrast visual targets. Seeing well of better doesn't mean that frail people will fall less, people who sees better are able to be mobile with enlarged the risk to fall (Cummings et al., 2007). Visual functioning is the ability how well the person functions in vision-related activities. In the literature the importance of good hearing and good vision for promoting activities during the day are known. In reality specialized eyecare for people living with dementia and aging people in general (Saftari & Kwon, 2018), is getting more and more attention, although more awareness could me be made towards the use of home modifications in general. **Methods** Literature and observations are used to shows the top range of ability to see and to functioning in and around the home situation with the technology used. With the focus on the necessity of light, contrast, color and the use of magnified instructions or banners as the reduction of glare. **Results and Discussion** the outcome will be a take home message for more awareness of the complexity of good vision and visual functioning, the need of attention towards eye care and the understanding of the problems arising with use of certain technology.

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Brazilian initiatives aimed at the prevention and care of dementia

T. M. Raymundo, L. D. Bernardo

Purpose Worldwide around 55 million people live with dementia and this number will increase to 139 million people in 2050 (WHO, 2021). Specifically in relation to the Brazilian scenario, in 2016, the country ranked second (behind Turkey) in relation to the age-standardized prevalence of Alzheimer's Disease and other dementias per 100,000 people (GBD 2016 Dementia Collaborators, 2019). The increase in the number of cases of dementia leads to a greater need for care. People with a disability or older age depend on support of an informal caregiver. Informal caregivers can experience a higher level of depression and stress and the risk of developing physical health problems are greater compared to non-caregivers. When caring for someone with dementia, the care can be even more demanding because of behavioral and psychological symptoms of dementia (BPSD). Research shows that informal caregivers perceive their situation as permanent and they experience a sense of being tied-in, the feeling to be always alert, unappreciated, feeling trapped, pulled in all directions, and sometimes being in an unreal situation. The care burden may result in a decrease in quality of life of the informal caregiver. In view of the above, countries have developed plans to meet the needs and demands of the elderly population with dementia and their caregivers. The initiatives depend mainly on the development of each country as well as on their public policies and strategies for coping with dementia. **Method** At this stage of the symposium, the aim is to present and discuss with the participants, through a conversation, the Brazilian initiatives in the prevention and care of dementia. Low-income countries still lack political, financial, and social incentives for diagnosis, support, and care plans for the population with dementia. Brazil is presented as a country of continental dimensions and with significant population aging, but which still have rates of underdiagnosis and undertreatment in the context of dementia. Only in 2020, a law project was introduced in the Senate that established the National Policy to Combat Alzheimer's Disease and other dementias, but care, risk reduction, prevention, and support actions for elderly people with dementia and their families have not yet been implemented. What is observed is the existence of specific and regional policies or actions (projects linked to universities) for the care of the person with dementia, which is still insufficient to carry out an adequate situational diagnosis of the country and to establish national priorities. **Results and Discussion** Detailed presentation of Brazilian initiatives and scenario followed by group discussions about them and presentation of points of view, and possible actions aimed at the older people with a focus on technologies will be discussed and will compose this stage of the symposium.

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