

PRoF Award abstract – Call 2015

Living well with dementia

1. Research Outline

Acronym	
Project name in English	Living well with dementia
Pitch (1 sentence)	<i>Living well with dementia</i> focuses on how environmental factors can contribute to a reduction of (nightly) agitation of persons with dementia.
Executive summary (max. 10 lines)	
<p>Persons with dementia often present agitated behaviour. Agitation has multiple causes and there is a growing interest in environmental interventions to complement the social and pharmacological care that is provided. This study intends to check the validity of environmental interventions for the prevention or treatment of agitation by listening to the experiences of professional and family caregivers. Our main intention is to understand and reduce the nightly agitation of home dwelling elderly because disorientation during the night, having an impact on burden of the family carer, is an important reason for early transfer to nursing homes. The psycho-education website, currently developed by the research group will help family member to find individualized solutions based on (science and experience based) expert knowledge.</p>	

2. Cause and context of the research

A definition of agitation frequently used in dementia research is the one of Cohen-Mansfield & Billig (1986): *“An inappropriate verbal, vocal or motor activity that is not judged by an outside observer to be an obvious outcome of the needs or confusion of the individual”*. Although agitation probably results from a combination of needs and confusion, these are not apparent. Caregivers (professionals as well as family) stress the impact of agitation on their working and living. Our research started with a personalized analysis of possible individual causes of this agitated behavior and an exploration of carers' experiences with sensory and spatial interventions concerning daylight, familiar and domestic smells, music and noise, nature elements and glare. The existence and influence of bright light therapy is innovative and there is interest in research about light, sound, temperature and spatial design.

3. Innovation results achieved

Useful results for home care resulted from a **literature review** and **focus groups** of family carers, followed by an exploratory study **in 8 nursing homes**. In **ongoing research** a website is developed to support family carers of home dwelling persons with dementia in their search for solutions.

Results of the literature review: a clear overview of determinants and pathways for change

A first step in managing agitation is to determine possible causes. These can be used to start up sequential interventions that relate to these bio-psycho-social factors. Agitation, as other symptoms of dementia, can have multiple causes. The bio-psycho-social model of dementia incorporates four groups of determinants of symptoms in dementia: biological fixed factors, psychological fixed factors, biological tractable factors & psychological tractable factors (Spector & Orrell, 2010). Recent research has investigated the effect of spatial and sensory interventions on agitation. Although we do not aim comprehensibility, we found seven major themes that are important determinants of agitation in dementia: light, smell, sound, temperature, nature, colour and spatial configuration. Each of these determinants leads to a number of strategies that might be helpful to reduce nightly agitation.

Professional and family carers' view on how to handle nightly agitation

Each situation of a person with dementia is personal and so individual solutions must be developed. Carers in focus groups learned a lot about the individual strategies that home dwelling elderly and their family members use to have an impact on nightly agitation behaviour. All caregivers stressed the impact of agitation on their quality of life and on the quality of life of the person with dementia. Most of them are familiar with the impact of daylight, natural elements and smell. However they wanted to learn more about other possibilities to influence the agitation at night. Mutual exchange processes prove to be very helpful and inspiring.

Van Vracem M., Spruytte, N., Declercq A., Van Audenhove, Ch. (2015). Agitation in dementia and the role of spatial and sensory interventions: Experiences of professional and family caregivers (accepted - Scandinavian Journal of Caring Sciences)

Results of the exploratory study in 8 nursing homes

In the exploratory study participatory observation was realized in 8 nursing homes. By observing what happened at night the researcher learned that noise made by working staff members, light in the rooms and corridors and organizational factors urging persons with dementia to go to sleep very early, can be considered the main causes for nightly agitation. The study has an impact on how nursing homes work and improve their approach to nightly agitation.

Van Vracem M., Spruytte, N., Declercq A., Van Audenhove, Ch. Nachtelijke onrust bij personen met dementie in woonzorgcentra: een verkennende veldstudie. (submitted - Tijdschrift voor Gerontologie en Geriatrie)

Results of the online tool (to be expected)

Starting from the knowledge and insights that were gained by the three previous steps, we now develop an online psycho-education programme that brings together all the information. First, the user of this tool finds an overview of the different causes of nightly agitation, including scientific background. Second, a number of possible non-medical approaches is presented so that the user can choose which intervention to first try out. Third, experiences of other family members will be included. The website is currently in development together with supplementary questioning of family members, confronted with the problem, in different parts of the country. In this stage we ask them also to tell us about their expectations of the

online tool and we ask them to participate in further research on its effectiveness and feasibility. We expect a positive effect on the hours of sleep of the person with dementia and of the family carer. Furthermore, we expect the tool to have a positive influence on the self-competency and on the burden of the family member. The online tool fulfils the need of family carers to learn through the experience of other family carers, and this without losing privacy. The ongoing study aims to develop the tool, to implement and evaluate it in a pilot study. It is our ambition to implement it afterwards on a larger and sustainable scale.

4. Link to the PRoF values

Awareness

Living well with dementia focusses on a better awareness of nightly agitation as being something that can be handled by the family carer, by focussing on personalized solutions in their own environment, including light, noise, smells, etc. It will lead to a more positive self-competency and less sleepless nights, which will have a positive influence on the carers' burden and health.

Comfort

Large scale use of the tool can bring more comfort and serenity in the life of many persons with dementia and their family carers.

Safety

Nightly agitation leads to very unsafe situations, and is often cause of accidents and fixation. An adapted environment will result in more safety in home situations of persons with dementia and their family carers. It will permit a longer stay at home without irresponsible risk.

Privacy

Dementia is for many people still a source of shame and stigma. Very often persons with dementia don't talk with professionals or with the GP, about their most urgent problems because they fear to be institutionalized. Instead they behave as if everything is OK. Similarly, many family carers believe that they have to be strong and just 'try harder', without asking for help. An online tool brings evidence-based knowledge in the house of each person, without interference of others.

Loneliness

Very often a person with dementia is living alone. In that case the nightly agitation might be caused by anxiety and loneliness. This situation is particularly unsafe. Introducing individualized solutions in these circumstances is above all useful, taking always into consideration the persons' past history and possible periods of grief or depression as causes of nightly agitation.

Non-stigmatizing

The approach by an online psycho-education tool implies that there is nobody else involved except the family carer and the person with dementia. Reducing stigmatization is a significant advantage of this tool. Particularly because by learning about the experiences of others and various possible solutions, the user will understand that his problem is not uncommon for his situation. It will hopefully lead to more acceptability in asking for help.

Intergenerational

Often, elderly people do not use the internet. However, their children do. Therefore, the family member suffering from the problem of nightly agitation can take advantage of the experience of others, often younger family members, who are finding the way to the internet more easily.

Flexibility

The online tool is a very flexible instrument, offering very individualized solutions for each user. It will not be a guide with standard approaches, since each situation is very different from others. Every pathway to a solution will be unique.

Empowerment

The website starts from the premise that for each individual case of nightly agitation an adapted approach can be found. This vision on hope and expectancy of positive results as well as the experience that others have the same troubles, are very meaningful for the users of the tool. They find inspiration to work on their own project and to believe in their own strengths.

5. Applicable IPR rules

The research is intellectual property of the KU Leuven.

6. Information on the partners

Partners

The research is elaborated in the context of VIND: the Vlaams Impulsnetwerk Dementie Onderzoek, financed by IWT.

The Alzheimer Liga (a federation of family members) is partner in the collaboration with family members and in the valorisation of the tool.

Expertise Center Dementia Sophia & Expertise Center Dementia Foton participated in the expert panels 'Living well with dementia'.

Interdisciplinary and interuniversity collaboration

This study is part of the Vlaams ImpulsNetwerk voor Dementie-onderzoek (VIND). Since February 2014 this network gathers expertise in two Flemish universities and stimulates collaboration in the search for a more effective treatment and care in dementia. This network aims to integrate clinical research and fundamental research.

The collaborating groups are

Co-ordinators of VIND are:

- Rik Vandenberghe (Laboratorium Cognitieve Neurologie, KU Leuven en geheugenkliniek UZ Leuven) and Christine Van Broeckhoven (Departement Moleculaire Genetica, Universiteit Antwerpen),

with as co-coördinators:



- Bart De Strooper (Laboratorium voor Onderzoek naar Neurodegeneratieve Aandoeningen, KU Leuven) and Stuart Maudsley (Departement Moleculaire Genetica, Universiteit Antwerpen) and Chantal Van Audenhove (LUCAS KU Leuven, Center for Care Research and Consultancy) as co-ordinator for the Care programme in VIND.

Addendum: Contact information

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