



**Book of Abstracts**

# First Krems Dementia Conference Erste Krems Demenz Konferenz

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„Timely Detection of Dementia“  
Coordinated Efforts in Europe Between East and West

**November 5–7, 2019 | Krems, Austria**

Danube University Krems  
Department of Clinical Neurosciences and Preventive Medicine  
[www.donau-uni.ac.at/dementia-conference](http://www.donau-uni.ac.at/dementia-conference)



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## ABSTRACTS – KEY NOTE LECTURES

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### Dementia Prevention

Demenzerkrankungen sind die große Herausforderung im 21. Jahrhundert. Ein oft zitiertes Statement. Zurecht, denn weltweit leiden derzeit etwa 50 Millionen Menschen an Demenz und diese Zahl wird sich bis 2050 verdreifachen. Die zunehmende Lebenserwartung wird als Hauptgrund dafür angesehen. Demenzerkrankungen sind nicht nur für Betroffene belastend, sondern auch eine extreme Herausforderung für Angehörige und Freunde, die im Verlauf ihrer Betreuungsarbeit ein deutlich erhöhtes Krankheitsrisiko für Depression & Angsterkrankung u.a. haben. Darüber hinaus sind damit soziale Kosten in Höhe von weltweit jährlich mehr als € 800 Milliarden verbunden. Diese Summe wird sich ebenfalls bis 2050 verdreifachen. Die „Lancet-Kommission“ für Demenz publizierte im Sommer 2017 Empfehlungen für Demenzmanagement und -prävention. Es wird betont, dass Demenzsyndrome nicht unbedingt schicksalhaft mit der Alterung einhergehen, sondern, dass durch zeitgerechte (Early-Mid-LateLife) Vermeidung / Beeinflussung von Risiko- und Lebensstilfaktoren die klinische Progression verzögert werden kann. Wir haben in den nächsten 20 bis 30 Jahren eine deutliche Zunahme der über 80-Jährigen in Österreich. Wir wissen, dass ein großer Anteil der österreichischen Bevölkerung damit im Demenz-Risikoalter liegen wird. Die Demenzerkrankungen nehmen mit zunehmendem Alter deutlich zu - keine lineare Zunahme. Wir wissen auch, dass jeder vierte über 85-jährige Mensch von der Alzheimer oder einer anderen Demenzform betroffen ist. Wenn Risikofaktoren beachtet und der Lebensstil modifiziert wird, könnte bei einem Drittel der Betroffenen die klinische Demenzsymptomatik um Jahre hinausgezögert werden. Ergebnisse aufwändiger Langzeit-Präventivstudien geben Hinweise, dass Lebensstilfaktoren wie Neugierde, ein körperlich und kognitiv aktiver Lebensstil, mediterrane Kost und soziale Kontakte einen präventiven Effekt auf die klinische Demenzentwicklung hat.

#### Key-Message

Der geistige Abbau lässt sich im Alter verzögern falls es gelingt, den eigenen Lebensstil zu modifizieren und die Risikofaktoren zu minimieren.

## Subjective Cognitive Decline

Barry Reisberg, Mesum Moosavi, Sunnie Kenowsky

The entity, “Subjective Cognitive Decline” (SCD), was first described in 1982 (Reisberg, et al., *American Journal of Psychiatry*, 1982). This publication described 7 stages in the evolution of brain aging and Alzheimer’s disease using an instrument termed the “Global Deterioration Scale (GDS).” Stage 1 of the GDS was described as a condition in which older persons have neither subjective complaints nor objective evidence of impairment. Stage 2 was described as a stage in which persons have subjective deficits only. It was stated that in this stage, persons commonly have complaints of not recalling names as well as formerly. Another common complaint of GDS stage 2 persons is not recalling where they have placed things as well as formerly. This stage was distinguished from a subsequent stage of “Mild Cognitive Decline,” (GDS stage 3), in which “the earliest clear-cut clinical deficits appear” and “objective evidence of memory deficit is obtained only through an intensive interview.” In this GDS 3 stage, “decreased performance [may become] manifest in demanding employment and social situations.”

In 1986, we estimated that the GDS 2 stage of SCD lasts a mean of 15 years in otherwise healthy persons (Reisberg, *Geriatrics*, 1986). Twenty years later, in 2006, we and our collaborators confirmed this estimate in a longitudinal study of 44 of our GDS stage 2 subjects followed over  $8.9 \pm 1.8$  years (Pritchep, et al., *Neurobiology of Aging*, 2006). The observed percentage of subjects declining over the 8.9 year mean interval (61.36%), and the hypothesized percentage of subjects declining over the 8.9 year mean interval, for a stage lasting precisely 15 years (59.33%), differed by only 2.03%. In 2010, we published a study in which we compared outcomes of healthy subjects with (N= 166), and without (N=47), subjective impairment, over mean follow-up intervals of  $6.8 \pm 3.4$  years and  $6.7 \pm 3.1$  years, respectively. During this period, subjects were followed biannually (Reisberg, et al., *Alzheimers and Dementia*, 2010). There was no significant between group difference in follow-up time. Of the GDS stage 1 subjects who, by definition, were free of subjective complaints and free of objective evidence of impairment, 14.9% declined to MCI or dementia. In contrast, of the GDS stage 2 subjects, by definition with subjective complaints of cognitive impairment only, 54.2% declined to MCI or dementia. The between group differences in the percentage of decliners was highly significant ( $p < 0.0001$ ). After controlling for age, gender, education, and follow-up time, the hazard ratio of the GDS stage 2 (SCD) subjects declining, was 4.5x the risk of decline for the subjects without subjective complaints and without objective impairments (GDS stage 1).

Recently, we published 2 year outcomes of healthy older persons with SCD (GDS stage 2), (Reisberg, et al., *Journal of Alzheimer’s Disease*, 2019). Ninety-eight SCD persons, mean baseline age 67.1 years, mean baseline MMSE,  $28.9 \pm 1.2$ , were followed for  $2.13 \pm 0.3$  years. After adjusting for age at baseline, the change in GDS stage at follow-up (to GDS stage 2.16  $\pm$

0.59), was significant ( $p < 0.01$ ). The rate of progression observed over the 2.13 year follow up interval was very close to that which would be predicted for a stage lasting precisely 15 years (specifically, the observed annual progression rate was 6.701% per year and the estimated annual progression rate for a 15 year stage, in which subjects are uniformly progressing, is 6.667% per year). Therefore, the observed annual progression rate differed from the estimated annual progression rate for a stage lasting 15 years by only 0.034% per year. The MMSE did not show significant changes over the 2.13 year mean follow-up interval.

We conclude that Subjective Cognitive Decline is an entity which is robustly evident using the Global Deterioration Scale and other elements of the GDS staging system. Healthy persons in this stage move towards MCI at a rate very close to 6.67% per year. Strategies for mitigating this progression should be identified in future studies.



## Timely Diagnosis of AD

The lack of success of clinical trials using monoclonal antibodies targeting amyloid at a mild or moderate dementia stage of the illness is a further encouragement to shift the attention to the early stages of the disease. Early intervention would offer the best chance of therapeutic success because the intervention would target less established and extensive pathological processes, which may be therefore potentially reversible. AD can now be identified at a prodromal stage based on a clinical-biological framework characterized by an amnesic syndrome of the hippocampal type associated with in vivo evidence of Alzheimer pathology, e.g. a biological or molecular "signature" of AD (Dubois et al, Lancet Neurology 2014). Turning to the left, subjects can also be identified earlier at a preclinical state of AD by the positivity of pathophysiological biomarkers in cognitively normal subjects. This new category of subjects at a preclinical state of the disease is important to consider for studies aimed at preventing progression to the clinical state, and also aimed at discovering reliable biomarkers for early detection for successful development of therapeutic disease modifying agents. However, it is not established that the presence of Alzheimer lesions is enough to certify a further progression to a clinical AD. The presence of lesions is necessary but it may not be sufficient. Biomarker positive cognitively unimpaired individuals may only be at at-risk of developing. For instance, INSIGHT-study (a follow-up of cognitively normal elderly individuals) showed that only 10 subjects out of 88 with amyloid brain lesions (mean age of 82 years) converted to a clinical AD after 5 years. Besides the presence of AD lesions, additional modulating factors should be taken into account for the determination of the risk to develop the disease. To conclude, such a move forward presupposes that we are able to precisely define the status and the risk for a further progression of those cognitively normal individuals who are biomarker positive.



## Long term care in Europe

Long-term care in Europe is a topic of increasing importance. According to the Report of the Social Protection Committee and the European Commission we need to improve the social protection against the risk of long-term care, also for equity and efficiency reasons. This will be even more difficult in the coming decades because of the increasing gap between the increasing need and limited supply, due to limits both in financial and human resources. As we all know, the Europe is ageing very quickly and the most rapid increase of older persons is among those over 80. These are persons who often need long-term care because of chronic conditions and dependency.

In my presentation I will provide an insight into the situation in long-term care in Europe. Based on my experience from the Long-term care Special interest group of EuGMS (European Geriatric Medicine Society) I would like to highlight also medical and health care aspects of long-term care, and finally I would discuss possibilities, opportunities and challenges of long-term care for persons with dementia.



## How Academia and Alzheimer Associations can work together in promoting diagnosis

For many years, dementia care in Croatia was provided traditionally by the family, without no organized support, and many people with dementia were undiagnosed. Treatment for people with dementia presenting with serious behavioural and psychiatric symptoms was provided on psycho-geriatric wards in psychiatric hospitals. Alzheimer Croatia, founded in 1999, provides information, support, and education to caregivers, and also raises public awareness of Alzheimer's disease and other dementias. The continuing voluntary work of Alzheimer Croatia has helped to encourage the development of other types of services for people with dementia in Croatia.

Although Alzheimer Croatia was established in 1999 and since than we were all time dementia friendly, the whole society became more aware about that need since 2012, when World Health Organization proclaimed Dementia as a public health priority. So, in the last six years various dementia friendly initiatives and activities happened. Many years ago, we started with celebrating the World Alzheimer's Day, now we are doing events through the whole September e.g. Alzheimer Month. During the year, we are organising the Alzheimer Café and *MemoryWalk*, Run for Memory together with numerous educative lectures for lay people. We know that Alzheimer's disease has impact on the whole family, so we offer caregivers and other members of the family to visit our Counselling center, to participation in self-help groups and a lot of information on web-site, blog and social media network.

We are trying to ensure timely diagnosis of dementia, so we are in the public promoting the illustrative version of ten early signs of dementia. We know that great majority of people with dementia are living at home, so we are trying to help them with offering services such as: day care centres, daily hospitals, patronage nurse services, geronto-housewives, meals-on-the-wheels, etc. As standard pharmacological treatment has its limitations, we are offering people with dementia participation in international multicentric clinical trials with potential disease modifying medication.

Through activities of Croatian Alzheimer Alliance, we promote the idea of Dementia friendly communities, so already three towns (Zagreb, Umag and Lipik) have sign that they are willing to become dementia friendly. Through Dementia friends Croatia project, we ensure that each person can become part of dementia friendly movement. Finally, on our Congresses and Conferences which are devoted to dementia, we bring together all professionals which are dealing with dementia, and make plans for the better future of people with dementia, their carers and families.

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## Dietary treatments of dementia

T. Hartmann, A. Solomon, P.J. Visser, A.M.J. van Hees, S.B. Hendrix, K. Blennow, M. Kivipelto, H. Soininen, on behalf of the LipiDiDiet clinical study group.

Diet is one of the major and most accessible risk factors for AD. It is believed that a change towards a healthy dietary pattern, if applied well before onset of overt dementia, will slow cognitive decline and possibly reduce the dementia risk.

For the last two decades the LipiDiDiet consortium has been investigating the role of nutrients and their synergism action on key AD pathological features. Based on preclinical results obtained 11 nutrients were selected which, when applied in this specific combination, gave the most promising results in APP/PS transgenic AD-mouse models. These nutrients are the omega-3 fatty acids DHA and EPA, phospholipids, vitamins B6, B12, folic acid, C and E, as well as choline, selenium, and UMP, collectively this combination is now known as Fortasyn Connect (Souvenaid). Notably, when applied as composite formulation, synergistic effects are observed. We evaluated Fortasyn Connect extensively in preclinical studies, and eventually tested it in a 6-year clinical trial with MCI-AD / prodromal AD participants with biomarker confirmed presence of AD pathology.

The currently available results cover the first 3 years of treatment and reveal long-lasting continuous cognitive benefit and reduced brain pathology in the multinutrient treated participants compared to the placebo control participants. Notably, benefit increased with early and long-term intervention.

## How to cooperate across borders?

Western Balkan Region, in the last 30 years, had have focus on developing of the national states and passed through the period of war. That fact is in the all established states had have impact on the creating of health and social policy which in the focus of their care and financial alloactions puts „war veterans and invalids, civilian victims of war, families whose male member are missing, childrens without one/both parents". This group bind for theirselves the all health and social state resources. On that way, state policy, make compensation for their non-creativity in creating of better and more righteous society with opportunities for that group of society. The fact that at the same time dementia has become an epidemic of all newly-established societies goes unnoticed. The state systems and different institutions are absolutely not prepared to face with dementia which they "push under carpet". They don't develop the new policies and not creating the new solutions and on that way, they complicate already hard situation and position of PwD. In that clime is very hard talk and is still harder work on the dementia field.

Presenting of Sarajevo Statement which is originated as result of meeting on the high level where participated: WHO Regional office for Europe, Government representatives from Western Balkan States, experts and NGO under patronate of ADI and in organization of Alzheimer Association AiR. This is an historic document which originated on base "Global action plan on the public health response to dementia 2017-2025". Declaration defined dementia as a public health and social challange of Western Balkan societies and seek sistematic support which need to be implemented through three linked approaches: policy, service delivery and information and research. The goal of Sarajevo Statement is to give tool to all stakeholders in promotion of dementia and in developing of National Dementia Plans(NDP) through the authority support of ADI and WHO and their endeavor that the all countries in the world adopt NDP till 2025. and using of positive possibilities in WB Region created by the close cooperation of experts and NGO's how they could change trends and include dementia issue in the health and social system in the all societies and initiate the common solutions or initiate competition between WB countries to make better solution through adoption of NDP.

As result of Sarajevo declaration, today BiH has: the medications for dementia is free of charge, the state changed view on PwD and in the procedure is new classification where dementia will be bearer of disability, mixed working group prepare document "Program of doing on dementia field" which will be official Government document to adopting of NDP which will be part of a wider strategy as "Strategy on public health



## Empowerment for people with dementia

There needs to be attention for how both formal and informal carers can contribute optimally to the wellbeing of persons with dementia, so that persons with dementia can live their life as they want to, for as long as possible. Yet, the focus in care has traditionally been on alleviating problems and care professionals often have difficulties in connecting with the capabilities of persons with dementia. In this regard, the concept of empowerment may be helpful. Empowerment is considered a process that supports health and wellbeing and is expected to increase the extent to which people can manage their life and their illnesses. For applying this concept in health care, it is important to specify what empowerment means and includes for people with dementia, and how it can be shaped in the relationship between the individual and people in their environment. Thereto, new research efforts focus on the content and meaning of empowerment and wellbeing in people with dementia and the association between the two.

One of these efforts is a large study aiming to develop an effective empowerment intervention for elderly people with dementia at home and in care homes. To develop this intervention, information from a literature review on empowerment in people with dementia was integrated with information from a European survey of empowerment interventions, and focus group meetings with people with dementia, family caregivers and health care professionals about their needs and wishes concerning the theme empowerment. Applying this knowledge, four empowerment domains were identified that are the basis of a conceptual model of empowerment for elderly people with dementia: "having a sense of choice and control", "retaining a sense of worth", "having a sense of usefulness and being needed" and "being the person who you are". Based on these domains, two empowerment interventions are currently being developed. The findings indicate that it is important for people with dementia that their capabilities are addressed, they can make their own choices and are seen as a person with an own identity who has something to offer to others.

## ABSTRACTS – PARALLEL SESSIONS

### Brigitte Juraszovich

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### The Austrian Dementia Strategy “Living well with dementia”

Around 130,000 people are currently living in Austria with dementia. As a result of demographic developments and rising life expectancy, this number is expected to double by 2050. In addition, 30% of cases on the long-term care benefit registry cite dementia as the responsible factor.

The Austrian Dementia Strategy „Living well with dementia“ provides a framework of objectives and recommendations for taking action to improve the lives of people with dementia as well as their families and carers.

With its seven objectives, the Strategy aims at creating a system in which people affected by dementia and their carers

- live in a community that promotes participation and autonomy to the greatest possible extent,
- get the information they need as early as possible,
- know where to go for help and which services are available,
- get high-quality care irrespectively of their place of residence
- and are actively involved in decisions about their care.

The Strategy intends to assist everyone in the community to develop a better understanding of dementia and to defeat the stigma attached to it. Another key message of the strategy is the need for better education and training of professionals as well as informal carers.

Success of the Strategy depends not only on the commitment of (political) decision makers as well as service providers to work together to coordinate and provide (specific) services tailored to the needs of people with dementia and their caregivers, but also on the involvement of people with dementia in planning and implementing further services.

In order to support a coordinated approach, the dementia strategy platform was set up in 2016 and up to now, the federal government, the states, and social insurance authorities have implemented more than 70 measures to achieve the goals of this strategy.

The presentation will give a summary of the seven objectives of the strategy and the implementation and then highlight current measurements to include, support and strengthen people with dementia as well as their caregiving relatives.

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## Forming an active Dementia community within the Austrian administration

### Background

Information about Dementia needs to enter all levels of society in order enable persons with dementia to staying integrated within our society. Following the successful project “Mission Dementia”( Fonds Gesundes Österreich Project Nr 2442) which was established in 2016 within the E- learning platform of the Federal Ministry of the Interior. The Project “Dementia Active Community” is the follow up project which continuous to involve important professional groups in order to develop a dementia friendly society.

### Methodology

The Austrian county of Burgenland was selected as a pilot region for the project. In a co-creation process, focus groups within the different administrative levels were organized. In a first step, public administration was selected as the main target group for the E-learning program. The focus group discussions which last approximately two hours are recorded and transcribed. The content of the focus group discussions are the basis for real life scenarios used within the E-learning tool.

### Results

Currently, results of 3 focus group interviews are transcribed and the content is analysed. Based on the analysis, scenarios are constructed. After prioritizing the scenarios, these scenarios will be implemented into the E-learning program. The E-learning program will be tested in the pilot region at the beginning of 2020. After a successful trial phase and after implementing suggested changes, a roll out for Austria is planned in 2020.

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## Mission Dementia: an E-learning program for the Austrian Police taskforce: long term experience and certification process

### Background

One of the major aims of most dementia strategies is the inclusion of people with dementia into society. In this context, also public organisations such as the police are of importance. Police officers often serve as a first point of contact in critical situations for both persons with dementia and their relatives. In order to be sensitive to the special needs of persons with dementia, special training for this population is essential. Therefore, the project “Mission Dementia” was initiated by the Austrian M.A.S. Alzheimerhilfe and the Sicherheitsakademie of the Ministry of Internal Affairs. The project was supported by the “Fonds Gesundes Österreich” (Project Nr 2442) and the BVA (the insurance company for governmental employees).

### Methodology

Three internet based learning modules were developed (“basics”, “competence” and “understanding”). After the development of the training modules, a certification process for police stations was added. This involved the development of a testing module within the E-learning tool. In order to be certified, this testing module in addition to the learning modules must be successfully completed. 70% of all police officers working within one police station must successfully complete the E-learning and the testing module. Further networking with other organizations such as nursing homes or community centres, Dementia service Centres must be proven. After this process is completed, a police station can be labelled as “Dementia friendly”. The learning modules are continuously promoted by the minister of internal affairs.

### Results

For the initial evaluation, a questionnaire was developed assessing the following areas: (1) usability, (2) relevance to practice, (3) increase in competence (4) sustainability, (5) didactic. 221 Police officers completed the training program and 23 filled in the questionnaire anonymously. 78% were very satisfied with the learning program, 20% were satisfied and 2% were not satisfied. Officers mentioned that the usage of media (film and drawings) was very positive. They emphasized that they would use the program again if they would need it. Some resources such as the checklists (recommendations for a person search) were printed out for continuous use. To date, 10.500 Police Officers have been trained with the modules. 150 Police Stations have been certified as “dementia friendly. This is about half of the Austrian Police task force. The learning program received several national and international awards (Sozialmarie 2018, E-Award 2019, Austrian Price for Public Administration 2019 and Mission Dementia was nominated for the European Price for Public Administration and was included into the toolbox of the WHO in 2019.

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## The SiDECar (“Skills in DEmentia Care”) project: the role of psychosocial care into the European dementia policies

### Background

Although psychosocial interventions are receiving increased validation, actions to translate evidence into practice are inconsistent. This study is one pillar of the Erasmus+ project entitled “Skills in DEmentia Care - Building psychosocial knowledge and best practice in dementia care” (SiDECar). In light of the importance of policies in establishing what is needed to meet dementia challenges, the aim of this study was to analyze European national strategies/plans to check whether they include references or full sections devoted to psychosocial care. The amount and content of the information along with its coherence with scientific evidence were investigated.

### Methodology

European strategies/plans were searched on the “Alzheimer Europe” and the “Alzheimer Disease International” websites and, if not available, Google and Google Scholar were used. Keywords were: “psychosocial care”, “psychosocial interventions”, “non-pharmacological care”, “non-pharmacological interventions” and “non-medical”. A thematic analysis was carried out to identify: a) main dimensions associated with the topic of psychosocial care, and b) ways of psychosocial interventions delivery. An ad-hoc table was also developed to collect information on the following features relevant to clinical practice: a) type of psychosocial interventions; b) target population(s); c) staff qualifications; d) agencies or services involved in the provision of psychosocial care.

### Results

The area of psychosocial interventions was addressed by 18 documents out of 28 found across Europe. Main dimensions were: “Quality of care” and “Education/Training”. Psychosocial interventions were just mentioned as an appropriate care in Finland, Israel, Switzerland and Wales. The remaining documents provided information on ways of psychosocial interventions delivery which were classified as follows: “Referral of non-pharmacological approach”, “Person-centred diagnosis and care”, “Guidelines implementation”, “Education and training programs”, “Networking and strengthening of health and social services”. As for the other categories, almost no mention was made of type of interventions, professionals and services involved and, if available, it was not in line with scientific evidence.

## **Discussion**

Overall, European dementia policies are characterized by high fragmentation, incompleteness and low systematization. Indeed, in 10 out of 28 policy documents no mention of psychosocial interventions was found and, as for remaining documents, it is still unclear what such provision would actually look like, how it would be enabled, and how it would be assessed. In order to improve people with dementia and their carers' quality of life, multiple and simultaneous actions are needed. Among them, as to be effective, policies should be based on a comprehensive and well-integrated system of care where the topic of psychosocial care and interventions is embedded.

## Technology and Innovation

### Background

Caregivers of a person with dementia (PwD) are faced with unique challenges when combining paid work and unpaid care. Technology has the potential to address some of these challenges, enabling caregivers to stay in work, achieve better wellbeing outcomes for carer and PwD and delay or avoid institutionalisation of the PwD. The aim of this project is to develop a Working Carer's Technology Toolkit (WCTT), a resource which connects existing technologies to the needs of working caregivers of PwD and identifies areas where further innovation is required.

### Methodology

This project uses a participatory design approach to develop the WCTT. Here we present the findings of 16 semi-structured interviews conducted with working caregivers of PwD between March and July 2019. Working caregivers' challenges when combining work and care and their experience and priorities regarding technology have been explored along with how their autonomy at work impacts on technology usefulness and their ability to respond to care-related emergencies. Interviews were analyzed following an inductive thematic analysis approach. Findings are used as the basis of the WCTT framework onto which existing technologies are mapped.

### Results

Interviews have identified several challenges working caregivers face. These include i) worrying about PwD's safety and wellbeing, ii) attending appointments, iii) coordinating the care network, iv) access to information, v) psychosocial & -emotional stressors, vi) keeping PwD company/providing entertainment and vii) personal care. Four autonomy at work scenarios could be discerned which impacted on caregivers' ability to use technology and respond to care-related emergencies and which have to be considered when using technology to facilitate work/care reconciliation:

- a) complete autonomy;
- b) limited autonomy;
- c) no autonomy;
- d) working & caring from home.

### Discussion

Working caregivers of PwD face multiple challenges which impact on their wellbeing and ability to remain in paid work. Many technologies exist which have the potential to help. The WCTT, co-developed by working caregivers of PwD and other relevant stakeholders (including PwD), will be a resource which connects currently available technologies to work/care reconciliation challenges thus empowering working caregivers to find solutions for their individual circumstances. It will also act as a guide for technology developers seeking to understand the requirements of working caregivers by highlighting how existing technologies should be modified and where further innovation is needed.

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## Tablet-based playful multimodal training for activating people with dementia: Practical experiences of two field studies (8 month and 2 month) in home and hospital environment

### Background

The combination of cognitive, physical and social stimulation promises significant potential for success. Serious games can support behavioural changes in a playful way. JOANNEUM RESEARCH and Sozialverein Deutschlandsberg have developed a tablet-based serious game in a series of research projects, which is used for personalized and guided trainings by dementia trainers and caregivers. Each training unit starts with movement exercises for warm-up, followed by various theme-based cognitive and creative exercises, such as quizzes, closes, puzzles, spot-the-difference, pairs, picture details, math, and sound riddles. The difficulty can be adjusted according to the person's actual constitution.

### Methodology

This serious game has 2018 been tested by the Austrian Red Cross in an 8-month pilot study in 3 different Austrian regions. The University Hospital Graz has tested the serious game in a 1-month pilot study at the department of neurology. At each visit/session the patients have been conducted through a tablet-based training unit of 50 minutes following a specific theme (e.g. spring, professions, water, past times).

### Results

The professional caregivers at the Austrian Red Cross have been trained in the multimodal approach of M.A.S. dementia trainings (train-the-trainer). These professional caregivers have then instructed several persons working in their regions. In total 49 persons, men and women, with different stages of cognitive impairment have been visited frequently in their respective home or residential care environment by the volunteers of the Red Cross.

At the University Hospital Graz 14 patients have tested the serious game, the evaluation has focused on usability and acceptance aspects and the practicability in a clinical setting.

### Discussion

On a subjective basis the caregivers of the Austrian Red Cross observed increased cognitive and communicative capabilities, more activation and a more stable emotional status of the participants. Therefore they would like to use the serious game on a regular basis for their visiting service for people with dementia in the future.

In the clinical setting it has been observed, that patients are able to handle the tablet with touch interface very well, nevertheless they need assistance by a caregiver. The content could be adapted to the cognitive abilities and personal interests, which is necessary and very welcome.

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## The Application Potential of the Humanoid Socially Assistive Robot AMIGO for Motivation and Assessment in Dementia Care

### Background

The increase in dementia causes an increase of the use of health care resources. At the same time there is a decreasing number of available caregivers. Consequently, technologies, like socially assistive robots, have been developed to assist caregivers and persons with dementia (PWD) in promoting independence. Most robots were tested in laboratory settings with mainly elderly people without dementia. Therefore, there is a lack of knowledge about their use in real care situations of persons with dementia, such as, the potential for motivating PWD to perform meaningful activities and furthermore to analyse the PWD's mental state.

### Methodology

The project AMIGO explores the experience of PWD, relatives, caregivers and dementia trainers in applying the humanoid socially assistive robot Pepper in private households. In Companion mode Pepper provides entertainment, reminders and tailored dialogues. In Coach mode it specifically motivates to use a tablet computer based, playful multimodal stimulation for intervention, by commenting, applauding and comforting during gameplay. In a first stage pilot study about the usability of the application, Pepper spent 1 week in each of 3 Austrian households. In total 12 participants (3 of each target group) were included to collect questionnaire and interview data.

### Results

The results of the Technology Usage Inventory (4-28 points span) demonstrate that caregivers and dementia trainers are mainly curious about using Pepper (21.3 and 20.7 points). Relatives emphasize the application of Pepper (18.3 points) but also pronounce skepticism (17 points). PWD most often see the usefulness of Pepper (20 points) with some anxiety in the application (15.3 points). Qualitative results show that most of the participants describe positive feelings, like curiosity, interest and surprise. Pepper's principal support was seen in the areas of communication/social contacts, recreational activities, learning ability and mobility.

### Discussion

Overall, the AMIGO application was experienced as positive and opportunities for support were seen by all participants. The results of this first pilot study support the further development of socially assistive robots to enhance motivation for playful training for persons with dementia in private households. Furthermore, we will present first qualitative, very positive results of the main study in which AMIGO stayed 3 weeks in each of more than 10 households.

## Wolfgang Staubmann for the SCOBES-AR study group

Health Perception Lab, Institute Dietetics & Nutrition, FH JOANNEUM University of Applied Sciences, Graz, Austria

## SCOBES-AR / Smart Cognition & Behavior Screening powered by Augmented Reality. A 5-year multidisciplinary project contributing to the early detection of changes in cognitive function in older people

### Background

Improved living conditions and health care enabling people in Austria to get older and older. However, OECD data show that this happens with lower quality of life. Personal cognitive abilities have an influence on one individual's quality of life, whereby the latency phase of cognitive deficits might be very long. In addition, due to the absence of efficient pharmacological therapies the primary aim is to stabilize neurocognitive deficits. Therefore, assessments for the early detection and prevention strategies of these deficits move into focus in order to improve the quality of life in old age in the long term.

### Methodology

The main aim of the SCOBES-AR project is to develop a multimodal screening instrument based on Augmented Reality (AR) technology for early detection of functional and cognitive decline in people between 60 – 75 years. AR techniques form the basis for assessment procedure development. The benefits of AR technology - unlimited body perception, real world experience, augmentation of virtual objects – will be used. Parallel measurements of multiple parameters and automatic action recording will provide more detailed results. The finalized instrument will be a mobile set consisting of a Tablet PC and Smartphone with AR application integrated in an AR headset.

### Results

Based on previous systematic identification of factors contributing to the development of functional deficits and their assessments the evidence base for a valid instrument is established in Project Phase I. One focus will be assessment validation against a reference test battery (Vienna Test System NEURO, Schuhfried, Vienna). Phase II addresses the prototypical testing in an AR environment by means of a feasibility study. The implementation of User Centered Design guarantees optimal usability. Iterative evaluation of assessments and AR environment allows the consolidation of existing expertise. A business model for use in the healthcare system will be developed in Phase III.

### Discussion

Early detection of changes in cognitive function by means of screening and timely interventions based on results can contribute to a more favourable lifestyle and possible prevention regarding cognitive decline. Taking into account one individual's reserve capacity, existing personal resources move into the focus. Therefore, a comprehensive assessment of these individual functional reserves is of high priority. Not least in order to be able to offer individualised interventions and preventive measures.

## Care Management in people with dementia: it is effective and cost-efficient!

### Background

Evidence-based interventions alleviate the burden of disease, as no curative treatment is currently available. A Cochrane review analyzing 13 randomized clinical trials revealed beneficial effects of care management, specifically in reducing patients' behavior disturbance, and caregivers' burden and depression as well as in improving caregivers' well-being and social support. Dementia care management (DCM) uses a well-defined, computer-supported, and model-based intervention implemented by specifically trained nurses.

The aim of this study was to:

- describe the effectiveness of DCM on relevant patient- and caregiver-oriented outcomes,
- determine the cost-effectiveness of DCM

### Methodology

This pragmatic, GP-based, cluster-randomized intervention trial compared the intervention with care as usual at baseline and at 12-month follow-up. In total, 6838 patients were screened for dementia (eligibility: 70 years and older and living at home) from January 1, 2012, to March 31, 2016. Overall, 1167 (17.1%) were diagnosed as having dementia, and 634 (9.3%) provided written informed consent to participate. The cost-effectiveness analysis was based on the data of 444 patients. Health-care resource use, costs, quality-adjusted life years (QALYs), and incremental cost per QALY gained were measured over a 24-month time horizon.

### Results

DCM significantly decreased behavioral and psychological symptoms of dementia ( $b=-7.45$ ; 95% CI,  $-11.08$  to  $-3.81$ ;  $P<.001$ ) and caregiver burden ( $b=-0.50$ ; 95% CI,  $-1.09$  to  $0.08$ ;  $P=.045$ ) compared with care as usual. Patients with dementia receiving DCM had an increased chance of receiving antidementia drug treatment (DCM, 114 of 291 [39.2%] vs care as usual, 31 of 116 [26.7%]) after 12 months (odds ratio, 1.97; 95% CI, 0.99 to 3.94;  $P=.03$ ). Dementia care management significantly increased quality of life ( $b=0.08$ ; 95% CI, 0 to 0.17;  $P=.03$ ) for patients not living alone but did not increase quality of life overall.

DCM increased QALYs (+0.05) and decreased costs (-569€) due to a lower hospitalization and a delayed institutionalization (7 months) compared with usual care. The probability of DCM being cost-effective was 88% at willingness-to-pay thresholds of 40,000€ per QALY gained and higher in patients living alone compared to those not living alone (96% vs. 26%)

### Discussion

Dementia care management provided by specifically trained nurses is an effective collaborative care model that improves relevant patient- and caregiver-related outcomes in dementia DCM is likely to be a cost-effective strategy in treating dementia and thus beneficial for public health-care payers and patients, especially for those living alone.

## Psychological adjustment to Mild Cognitive Impairment: the role of illness perceptions, cognitive fusion and cognitive impairment.

### Background

People diagnosed with Mild Cognitive Impairment (MCI) are at increased risk of developing dementia, particularly Alzheimer's disease. Patients diagnosed with MCI are challenged with managing the practical, social and emotional consequences of living with cognitive impairment, in a context of having limited information regarding the cause or prognostic course of their difficulties. There has been limited research investigating the psychological or social implications, such as how people adjust to the diagnosis. Addressing this research gap is important, as anxiety and depression symptoms significantly increase risk of progression from MCI to dementia by around 18% and 25% respectively (Mourao et al, 2016; Li & Li, 2018).

### Methodology

A cross-sectional mediation analysis in 34 patients with MCI (47% female and 53% male, mean age 76.4 years) evaluated the relationships between cognitive impairment, illness perceptions and cognitive fusion on levels of distress and quality of life (QoL). Participants completed standardised measures for cognitive assessment, illness perceptions, cognitive fusion, depression, anxiety and QoL. Relationships between variables were analysed using correlation, regression and conditional process analyses.

### Results

Illness perceptions were found to be a stronger predictor of depression and QoL in the current sample than objective cognitive impairment. Illness perceptions did not directly predict anxiety, rather cognitive fusion significantly mediated this relationship. Cognitive fusion also significantly mediated the relationship between illness perceptions and depression. Illness perceptions had a significant, direct effect on QoL, however there was no significant indirect effect via cognitive fusion. Greater fusion with threatening illness perceptions was significantly related to increased anxiety and depression.

### Discussion

The current study demonstrates additional support for the role of illness perceptions in psychosocial adjustment to MCI. Moreover, the study indicates that cognitive fusion, a construct central to Psychological intervention such as Acceptance and Commitment Therapy (ACT), which targets cognitive fusion, could warrant further investigation and application. The results need to be replicated in a larger sample, however the study provides promising evidence to suggest that ACT-based interventions, which cultivate defusion from cognitive content (e.g. illness perceptions), could have utility with individuals experiencing distress in relation to an MCI diagnosis. Furthermore, our findings suggest that illness perceptions could be modified, from within a theoretically consistent ACT-model, to improve QoL amongst patients adjusting to MCI.

Juanita Hoe

University of London, United Kingdom

## Effectiveness of an intervention to facilitate prompt referral to memory clinics in the

### United Kingdom: Cluster randomised controlled trial

#### Background

Most people with dementia do not receive timely diagnosis, preventing them from making informed plans about their future and accessing services. Many countries have a policy to increase timely diagnosis, but trials aimed at changing general practitioner (GP) practice have been unsuccessful. We aimed to assess whether a GP's personal letter, with an evidence-based leaflet about overcoming barriers to accessing help for memory problems aimed at empowering patients and families - increases timely dementia diagnosis and patient presentation to general practice.

#### Methodology

Multicentre, cluster-randomised controlled trial with raters masked to online computer-generated randomisation system assessing one-year outcome. We recruited 22 general practices (August 2013-September 2014) and 13 corresponding secondary care memory services in London, Hertfordshire and Essex, United Kingdom. Eligible patients were aged  $\geq 70$  years, without a known diagnosis of dementia, living in their own homes. There were 6387 such patients in 11 intervention practices and 8171 in the control practices. Primary outcome was cognitive severity on Mini-Mental State Examination (MMSE). Secondary outcomes were proportion of patients consulting their GP with suspected memory disorders and proportion of those referred to memory clinic.

#### Results

We analysed 223/266 (83.8%) diagnosed patients. There was no between group difference in cognitive severity at diagnosis (99 intervention, mean MMSE=22.04, 95% confidence intervals (CI) =20.95 to 23.13; 124 control, mean MMSE=22.59, 95%CI=21.58 to 23.6;  $P=0.48$ ). GP consultations with patients with suspected memory disorders increased in intervention versus control group (odds ratio = 1.41; 95% CI= 1.28, 1.54). There was no between group difference in the proportions of patients referred to memory clinics (166, 2.5%; 220, 2.7%;  $P= .077$  respectively). No adverse events from the intervention were reported in relation to patient distress or difficulty with increased volume of work.

#### Discussion

Our intervention to access timely dementia diagnosis resulted in more patients presenting to GPs with memory problems, but no diagnoses increase. We are uncertain of the reason for this and do not know whether additional patients presenting to GPs had objective as well as subjective memory problems and therefore should have been referred. In addition, we aimed to empower patients but did not do anything to change GP practice. We do not know whether empowering the public and targeting GPs would have resulted in a successful intervention. Future interventions should target both patients and GPs.

## Harriet Falk

University of Nottingham, United Kingdom

### Post diagnostic support after a diagnosis of dementia

#### Background

Current research appears to suggest that despite the expected increase in the number of British Ethnic Minority elders (BME) older than 65 years living with dementia and thus consequently an increased need for culturally appropriate dementia services in this population, today and in the decades to come, there hasn't been an equivalent amount of research looking to evaluate how well or not the currently available dementia services across the UK are meeting the dementia health care needs of the British Ethnic Minority elders (BME) older than 65 years (Osman et Carare, 2015, Parveen et al, 2016, APPG, 2013). Secondly, to date and to the best of our knowledge, no qualitative or quantitative research in the UK-midlands, has been conducted that seeks the experience of living with dementia from the perspective of the BME across different sections of the dementia pathway.

THE AIM OF THIS RESEARCH PROJECT is to explore the experiences and dementia care needs of the British Ethnic Minority elders (BME) by specifically studying one ethnic Group within the BME who are British Africans individuals older than 65 years individuals living with dementia in the UK. (Osman et Carare, 2015, Parveen et al, 2016, APPG, 2013)

#### Methodology

This is a qualitative multiple-case study design with a maximum of 10 cases. Each case comprises of the following people: person with dementia, their family care givers and their professional care givers. Data was collected using semi-structured interviewing. People with dementia, their family care givers and professional care givers were each interviewed for a time period of one hour.

DATA ANALYSIS: Qualitative data was analyzed via NVIVO, thematic analysis and the use of research participants' feed-back

#### Results

Several themes regarding the experience of living with dementia by British Africans/Caribbeans in the UK emerged from this study. One of the themes that emerged was: the post-diagnostic support of the British African person with dementia living in the midlands in the United Kingdom. NHS memory clinics across the UK, including the midlands, routinely provide post diagnostic support to all people with dementia such as: appropriate support after a diagnosis of dementia and signposting people to seek the appropriate treatments for dementia. The researcher undertook a placement in a midlands memory clinic and witnessed first-hand that indeed post diagnostic support for dementia was routinely offered to the people living with dementia in the midlands. What struck the researcher, though, during her placement at the memory clinic, was the fact that the majority of attendees receiving dementia post diagnostic support were the British Caucasian population. When the researcher later conducted interviews with British Africans/Caribbeans people living with dementia who attended a day care cultural center, the results of the interviews suggested that this population was not

receiving appropriate post-diagnostic support after a diagnosis of dementia along several points on the dementia pathway. The lack of post diagnostic support to the British African population living with dementia had negative consequences for both the family caregiver and the person living with dementia. I shall discuss what the negative consequences were in my presentation.

### **Discussion**

This study appeared to suggest that British Africans and British Caribbean people who have received a diagnosis of dementia are not receiving the appropriate post-diagnostic support to help them live well with dementia. The reasons for the lack of dementia post diagnostic support to this population were multifold. However, the most common reasons that participants cited included: the discriminatory tendencies of personnel in dementia services who deliberately omitted giving this population the support that they needed after a diagnosis of dementia. Another common reason for lack of post diagnosis support was due to the fact that the British Africans/Caribbean population's perception of dementia grossly differed from British Caucasian perception of dementia. As a result, that made the person with dementia and their families choose to not seek dementia post diagnostic support to help them live well with dementia. Eventually, British Africans/Caribbean people with dementia sought the use of dementia services but only when a major crisis had occurred with the person with dementia. The UK National dementia strategy of 2009 advocates that all people with dementia in the UK live well with dementia which will ensure that they have a quality life. Having appropriate post diagnostic support is one way of ensuring that people with dementia live well with dementia. Therefore, immediate action is urgently needed to ensure that the British African/Caribbean person with dementia receive the appropriate post diagnostic support to help them live well with dementia.

## Alexander Kurz, Lea Pfaeffel

Department of Psychiatry and Psychotherapy, Technical University of Munich School of Medicine Munich, Germany

### The INDEED-Project

According to a recent survey among dementia experts in 10 countries (Mehrabian et al., Neuropsychiatr Dis Treat 2019) the most important gaps in dementia care are low public awareness of dementia, insufficient dementia-related knowledge and skills among health and social care professionals, poor interprofessional collaboration and coordination, and lack of specialised services for people with dementia and informal carers. The EU-funded project „Innovation for Dementia in the Danube Region“ (INDEED) responds to these gaps by an educational and skill-building strategy which addresses health and social care professionals as well as entrepreneurs. The goals of the project are to improve dementia care with the scope of enhancing the quality of life of people with dementia and their informal carers, and to contribute to the development and implementation of national dementia plans. Contents are delivered in a blended-learning format, combining traditional in-person workshops and a multi-media interactive online platform. The multi-professional educational strategy will be field-tested in pilot actions in four countries which include public awareness activities. The project promotes detection and timely diagnosis by outlining the borderline between normal ageing and dementia, the benefits of early diagnosis and intervention, the logic of the diagnostic process, the contribution of different professions, and appropriate ways of disclosure.

## WORKSHOPS

Marc Wortman

### WORKSHOP: Raising Awareness about dementia

Awareness is a key condition for an environment in which people with dementia are detected, understood and treated, both medical and non-medical. There are many ways in which awareness can be raised, from information provision by health care professionals to personal stories of people living with dementia or their families. Alzheimer associations have done a lot of these and learned about the power of tools like the 10 Warning Signs, the Alzheimer Café or the development of Dementia Friendly Communities. In this session we will give an overview of awareness activities and tools as well as examples from activities in Czech Republic, Hungary, Indonesia and The Netherlands.

#### Speakers:

Anežka Prokopová, Czech Republic

Tamas Tatai, Hungary

Amalia Funk-Utomo, Indonesia

Marc Wortmann, Netherlands

## Karl Matz

Department of Clinical Neurosciences and Preventive Medicine, Danube University Krems, Austria

### WORKSHOP: Life style oriented interventions and prevention of vascular and non-vascular cognitive decline

In this workshop we will address the question how vascular risk factors contribute to the development of dementia and possible strategies to influence personal risk factors and life style to reduce tendencies for cognitive decline that may ultimately lead to dementia. Karl Matz will give an overview about trials that tested interventions on risk factors and life style habits in order to reduce the risk of or the extent of cognitive decline. Yvonne Teuschl will highlight the importance of diabetes as a particularly frequent vascular risk factor with a known association with dementia and how the population of diabetic patients is a candidate group for interventions that might reduce this risk. Finally, Thomas Töll from Innsbruck will present the stroke card project as an example of a successful intervention program that showed to reduce the incidence of various stroke sequelae with implication also for cognitive outcomes. Participants are encouraged to engage in an active discussion in how to proceed in research about risk factor control and dementia prevention and how beneficial intervention could be transferred successfully into daily routine.

#### Speakers:

Yvonne Teuschl, Danube University Krems Austria

Thomas Töll, MD, Medical University Innsbruck, Department of Neurology

Karl Matz, Danube University Krems, Austria

## Christian Bancher

### WORKSHOP: Differentialdiagnose demenzieller Erkrankungen (Workshop in German)

## ABSTRACTS – POSTER

Alžběta Bártová, Hana Bláhová, Vladimíra Dostálová, Iva Holmerová

Charles University, Faculty of Humanities – Longevity Studies, Czech Republic

### The needs of people with dementia: a person with dementia as important informants about personal needs

#### Background

The aging population brings with it an increased need to care for particularly vulnerable older patients, both for professionals and informal carers, including a large group of people with dementia. Therefore, it is very important to know and recognize the needs of people with dementia when providing care. Most publications summarize theoretical principles, but do not provide sufficient information on the needs of particularly vulnerable older patients such as those with dementia. The aim of the poster is to present the scoping review results of available studies reporting self-perceived needs of people with dementia receiving home care and also to present the needs reported by vulnerable older people in home care who have not been diagnosed with dementia.

#### Methodology

To achieve the aim, a scoping review of articles published between 2009 and 2018 was chosen as an appropriate method. Databases were searched in order to identify relevant studies exploring the needs of particularly vulnerable older people receiving home care, including those diagnosed with dementia and those without it. Thus, two scoping reviews were conducted. The method of thematic synthesis was used to analyze data from retrieved articles.

#### Results

Based on the search, qualitative and quantitative studies have been identified. Qualitative studies used semi-structured interviews; whilst most quantitative studies used the Camberwell Assessment of Needs for the Elderly (CANE) as an assessment tool. Other quantitative studies utilized the Johns Hopkins Dementia Care Needs Assessment (JHCNA). To categorize reported needs, we used a biopsychosocial model (Engel, 1997), extended by the area of environmental needs (Schmid, 2012). Thematic synthesis revealed areas in which people with dementia and those who have not been diagnosed with dementia reported their needs.

#### Discussion

Generally, vulnerable older people receiving home care are able to express their needs and wishes, with or without dementia. It is therefore important that care professionals are aware of these needs and tailor care to their needs and wishes. Typically, people with or without dementia report a significantly lower number of unmet needs than their carers.

## How much does dementia cost? Experiences from the Dementia Service Centres in Upper Austria

### Background

There is growing evidence that the severity of dementia is one of the main cost drivers of society. The rationale is a reduction of the scarce evidence, for: (1) The costs of dementia care in a community setting. (2) The progression of dementia as observed under the influence longitudinal treatment with non-pharmacological methods. (3) Following this framework this study is going to calculate the transition probabilities for dementia and develops a Discrete Time Markov Chain (DTMC) for estimating the costs of the services of the Dementia Service Centres (DSC) in Austria.

### Methodology

For the cost simulation, the administrative data from over 1,569 clients of the DSC were used. Based on two assessments with the Global Deterioration Scale (GDS) a DTMC model displayed the progression of dementia and formed the basis for the cost simulation. Using the friction cost method this economic simulation could infer the cost development over 10 years. To cope with the uncertainty and identify the main cost drivers a one-way-sensitivity-analysis was undertaken.

### Results

The total costs for treating a person with mild dementia are 50,243 EUR per year. The costs for persons with severe dementia are almost twice as high (91,130 EUR). Thereby 78.4 per cent of these costs are indirect costs for informal care. The DTMC-simulation shows an increase within five (ten) years by the 6.5-fold (12.8-fold). Further, the study shows that the normal progression of dementia is one of the main cost drivers and the share of severe dementia increases from 15.8 per cent to 32.3 per cent within ten years. Overall, the total costs per year are 78,104,793 EUR after one year.

### Discussion

The study presents that the indirect costs are quite important. Beside the fact that indirect costs represent an essential part of the total costs, it is crucial for further policy decision making to develop special facilities to support relatives in coping with the caring challenge and help them to compensate the indirect costs. The cost simulation also showed, that keeping the patient in a mild or moderate level as long as possible will keep the cost increase manageable. So the simulation displayed that the cost increase of severe dementia comes abruptly after three years which could be prevented by a clear clinical pathway for outpatient service and support for caring relatives.

Klaus Dittrich<sup>1</sup>, Martin Litzenberger<sup>1</sup>, HenkHerman Nap<sup>2</sup>, Ivan Rigamonti<sup>3</sup>, Wil Wintjens<sup>4</sup>, Georg Weidmann<sup>5</sup>, Birgit Unger-Hrdlicka<sup>6</sup>, MilanR. Vosko<sup>7</sup>, Matthias Zeller<sup>7</sup>, Stefanie Auer<sup>8</sup>, Matthieu Arendse<sup>9</sup>

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## AAL- Freewalker Project

### Background

Wandering and getting lost is one of the most dramatic problems of persons with dementia. An example would be someone who may take what would normally be a routine walk and then suddenly be unable to find his or her way. GPS trackers are already in use to solve the problem, but they are not adaptable because they rely on fixed predefined geographic zones. This results in alarms, even if a person is intentionally exploring new regions, or is visiting a friend, limiting his or her freedom and often causing extra worry to the caregiver.

### Methodology

The AAL project “FreeWalker” develops, tests and validates a monitoring and warning system based on GPS tracking that addresses the specific deficiencies of older adults with dementia and frailty. The FreeWalker system realizes walking route and habits learning to automatically generate an adaptive save-zone around the home. It comprises of a logic engine which connects walking habits with time of the day and entries in the personal calendar to provide temporary save-zones or save corridors. Additionally, it will monitor movement patterns to warn on critical situations, should a person get lost or disoriented inside a safe-zone.

### Results

A usability analysis has been performed within co-design groups comprising of primary (persons with deficiencies) and secondary (caregivers) users. It provides the basis for the development of the processes (warning and alarming schemas) and the user interfaces of the mobile app and a web portal that will be available to the caregiver informing on the status of the primary user. A study has been designed that will measure as the primary outcome if FreeWalker increases the independence and feeling of safety of the primary client and decreases worrying of the caregiver about the whereabouts and safety of the primary client.

### Discussion

The FreeWalker system will allow elderly persons with cognitive impairment - or who feel insecure in the outside environment - an increased freedom and self-determined way of moving in the outside environment. It is aiming at giving caregivers piece of mind by supporting them in tightly monitoring the primary user, on one hand, when needed (e.g. when he or she is getting lost or is moving towards a dangerous area) but, on the other hand,

empowering the primary user by making decisions him- or herself, if no imminent danger is detected by the system.

Margit Höfler<sup>1</sup>, Paulina Kurzmann<sup>1</sup>, Anna Beránková<sup>3</sup>, Doris Prieschl<sup>2</sup>, Michal Šteffl<sup>3</sup>, Iva Holmerová<sup>3</sup>, Stefanie Auer<sup>1,2</sup>

<sup>1</sup>Danube-University Krems, Austria <sup>2</sup>MAS Alzheimerhilfe Bad Ischl, Austria <sup>3</sup>Charles University Prague, Czech Republic

## Characteristics of Residents in Austrian and Czech Nursing Homes: Open Epidemiological Data from the DEMDATA Project

### Background

Epidemiological data on prevalence and severity of dementia as well as functioning and behavioral problems for residents in European nursing homes is still sparse although these data are crucial in order to provide optimum care. Furthermore, such data should be made accessible to researchers to facilitate interdisciplinary research. In the DEMDATA project, cognitive, functional, behavioral and other health related information of residents in Austrian and Czech nursing homes were collected and environmental factors as well as the situation of the relatives and the care team assessed. Here we describe the data set which was collected during the evaluation of the residents' status and transferred to a public repository.

### Methodology

The sample consisted of 571 residents of eight Austrian and 514 residents of 14 Czech nursing homes. All nursing homes were drawn randomly. Inclusion criteria for participation in the study were that the resident was living permanently in the nursing home and that he/she or a legal representative had signed an informed consent. During the study which was conducted between August 2016 and August 2017, the cognitive, functional, and behavioral status of every resident was assessed with standard test instruments (e.g., MMSE, GDS, BEHAVE-AD-FW, FAST, KATZ Index, Timed-get-up-and-go Test). Also further health-related factors such as quality of life (QOL-AD, Euroquol 5D-3), pain (PAIN-AD), nutritional status, activities of daily living status, numbers of falls and hospital stays were assessed.

### Results and Discussion

The residents' mean age was 84.4 years (SD = 8.33; Austria) and 84.6 years (SD = 7.51, Czech Republic), respectively, and the majority of the residents was female (AUT: 73.4%, CZ: 77.8%). Residents lived in the respective nursing home for 3.4 years (Austria, SD = 4.5) and 3.1 years (Czech Republic, SD = 3.6). To guarantee anonymity of the study participants, we did not include any sociodemographic data such as age, gender or nationality or data that was assessed in one of the countries only i.e., VAS pain scale, QOL-AD) in the data set. Data regarding the environmental factors and the situation of the relatives and the care team will be transferred to a public repository in order to further enhance the cooperation between researchers.

Emina Kučuk

## Burnout syndrom at caregivers

Objective: Familiarity with burnout syndrome, causes and consequences of burnout syndrome, consequences for caregivers. Pointing out the need for more detailed and extensive research on this topic and taking the necessary activities to prevent burnout with caregivers, and timely and adequate education of caregivers as prevention.

Problem: Although there is still no official research on burnout syndrome in caregivers, research shows that the incidence of psychological problems in psychiatric wards is higher than in the general population. This phenomenon is referred to in recent psychological literature as burnout or burnout at work, and is defined as the exhaustion of progressive energy and the will to do the job, the onset of serious fatigue, cynicism, indifference, a sense of inadequacy for the job, and the cessation of investing effort into productive work. Combustion occurs in a complex interaction of situational and personal factors. Situational factors include the characteristics and organization of work, and personal factors, personality traits and attitudes toward work. For caregivers, these are the conditions of working long hours, shift and night work, and they have a great responsibility. Access to people with dementia must be active, never passive. The caregiver must be flexible in all activities interacting with the person with dementia. The caregiver is expected to prepare every situation in communication with the person with dementia, realistically consider the person's with dementia capabilities, break down all situations into individual activities and simpler steps that are easier, praise and encourage the person without criticism or opposition, and the caregiver is expected not to quit if the person with dementia refuses the action he or she must perform. The caregiver must accept that his reality is not the reality of a person with dementia. In addition, depending on the type of dementia, there are problems with movement that becomes difficult, and in the later stages can lead to immobility. From this we can conclude that caregivers are required to have complete psychological, intellectual and physical fitness and involvement in the work they do. Performing these tasks and tasks leads to physical and intellectual exhaustion, which deepens with each passing day and with the new demands of their work.

Conclusion: It is important that mental health research and recognition of psychological exhaustion, in addition to affecting their private and professional functioning, can significantly affect the quality of patient care. Caregiver job characteristics are grouped into many stressful stimuli during one working hour, ranging from endangering and demanding people with dementia, verbal abuse, negative feedback, potential aggressive attacks, lack of staff in potentially dangerous situations. People with dementia are often aggressive, unpredictable and violent. Perhaps the most important predictor of burnout and what increases the stressful stimuli that are in the job description of the caregiver is the inadequate preparation and education for the job.

## The Dementia Service Centre Model Database

### Background

Evidence-based care models are crucial for handling the increasing numbers of persons affected by dementia. In Austria, the Dementia Service Centre (DSC) model provides psychological screenings and psychosocial support for persons with dementia and their support providers. The three main goals of the DSC model are early detection of dementia, delaying institutionalisation of persons with dementia and reducing the burden for support providers. For evaluating the model, a study protocol is in use and the associated data are collected in a database. This paper presents the strategy for generating the evidence base for the DSC model, as well as the structure and content of the DSC database.

### Methodology

The data are collected during the daily work at the DSCs. The database holds variables on the sociodemographic background of the clients, the results of the standardised psychological screening protocol, data on medication and diagnoses, as well as information on patient care and stage specific training. The database runs on Open Source technologies and encompasses a number of error handling and data security measures.

### Results

Database contains baseline data on 4,295 persons in different stages of memory impairment and dementia, and their support providers. Of those who attended the DSC, 2,825 persons (65.8%) were female and the mean age was 79.3 years (SD= 9.3), males (n=1,470; 34.2%) were 77.0 years old (SD= 9.0). The age ranged between 26 and 105 years. The median score of this population on the BEHAVE-AD was 13 points. Information with respect to the medical diagnosis was available for 4,178 of the 4,295 assessed persons. Upon entering the services of the DSC, the majority of persons (n=2,509, 58.4%) had not received a medical dementia diagnosis. The most frequent dementia type diagnosed was Alzheimer's disease (n=737, 17.2%), followed by the diagnosis of "unspecified dementia" which was attested to 538 persons (12.5%).

### Discussion

In the near future, newly acquired clients and follow-up screenings are expected to produce an increasingly rich and comprehensive database. Additionally, a major future objective is to expand the data collection through collaborations with similar initiatives. The potential of the DSC model for rollout all over Upper Austria is currently being evaluated by the federal state of Upper Austria and the Upper Austrian branch of the health insurance company Oberösterreichische Gebietskrankenkasse (GKK).

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### Training and Education of Care Professionals

#### Background

The aging population and the growing migration to Norway affects health services increasingly. Today, health professionals are dependent on communication with both patients and relatives in order to ensure quality healthcare.

Oftentimes, health personnel and patients suffering from dementia do not share a common language due to different cultural backgrounds. At the same time, we also know that conditions and expectations of elderly immigrant patients can be highly divergent from the majority population.

Health professionals in training need experience in meeting complex situations with patients suffering from dementia with varied cultural backgrounds. Medical simulation has previously been shown to be a suitable didactic approach to improving health professional's performance in such situations.

The aim of the study was to explore whether simulation as a didactic approach is suitable for the training of interaction in a multicultural setting.

#### Methodology

The project is based on an action research design during a training program including simulation with 48 health workers. The training course was developed for municipal home services (health care service) at the Bærum Municipality (Norway).

#### Results

Our results show the importance of simulation training between patient and health personnel when they do not share a common language. Our data also showed that simulation contributes to self - reflection skills.

Encounters in multicultural settings must be practiced, and simulation as a didactic approach can be experienced as a suitable interactive training scheme in improving health backgrounds.

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