



Book of Abstracts

# 3<sup>rd</sup> Krems Dementia Conference

## From Reaction to Action

28-30 October 2021

Krems, Austria



Danube University Krems  
Department for Clinical Neurosciences and Preventive Medicine  
Center for Dementia Studies  
Dr. Karl Dorrek Straße 30  
3500 Krems / Austria

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# ABSTRACTS – KEYNOTE LECTURES

## Where we are with the science

### **van der Flier, Wiesje**

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Knowledge of Alzheimer's disease (AD) is developing at an increasingly fast rate. Increasing insights in the putative benefits of a healthy lifestyle and approval by the FDA of the first disease modifying therapy for AD show that opportunities for prevention are coming closer. In finding solutions for AD, prevention is key. Intervening using both pharmacological and/or non-pharmacological approaches will ultimately have most benefit in the Alzheimer-stages before dementia. One of the key questions is; what works for whom? In answering this question, we need to address both biological differences between patients and variability in preferences, wishes and needs.

To prepare for a future with personalized prevention of dementia due to AD, timely diagnosis is crucial, with tools that are both accurate and scalable. Blood-based biomarkers and digital tools are both promising in this respect. When we diagnose AD before dementia, diagnosis becomes prognosis. And this means that we need to be able provide patients with individual risk profiles. So people know what they can expect. And in addressing these topics of diagnosis, prognosis and prevention, we need to make sure that patients and their families are at the steering wheel of the management of their own health and disease.

To prepare for a future with personalized medicine for AD, we need to work together across all sectors in society. The ABOARD project is a Dutch consortium of >30 partners, from academia, health care, industry and societal organizations. All work together to shape the future journey of AD patients, where we can actually improve the lives of AD patients.

## The Costs of Dementia in Austria

Czypionka, Thomas<sup>1</sup>, Reiss, Miriam<sup>1</sup>, Reitzinger, Stephanie<sup>1,2</sup>, Riedel, Monika<sup>1</sup>

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**Background:** In Austria, an estimated 147,000 people have dementia, although underdiagnosis and – partly arising from this – underprovision of appropriate care do not allow to determine the exact number of dementia patients. Despite increasing relevance, evidence about dementia in Austria is sparse, particularly in the context of the economic costs of dementia. The aim of the study is to contribute to the stream of research about costs of dementia. We demonstrate the magnitude of the burden of disease affecting patients, caregivers, and the entire society.

**Methodology:** The study uses the approach of population dementia-attributable fractions; intangible costs are discussed based on international literature. The health costs estimation includes costs of dementia per se as well as dementia-attributable fractions of secondary diseases, calculated from relative risks from epidemiological studies. We transfer cost shares of the German disease-related cost accounts to Austrian health expenditures by age and sex. Dementia-attributable costs for residential-, home-, and 24-h-care as well as for work loss of caregiving relatives rely on different data sources. The cost estimation of informal care, using a substitution approach, reflects total (not dementia-attributable) notional costs.

**Results:** The monetary costs of dementia for the year 2019 amount to a total of EUR 2.7 billion. About half of these costs are medical costs. Approximately 3.9% of health care expenditures (excl. long-term care), 15.8% of residential care expenses and 22.5% of home care expenses were attributable to dementia in 2019. The production loss due to reduced working hours of caregiving relatives is estimated at EUR 31 million. In addition to monetary costs, total notional cost of informal care for dementia patients living at home account to EUR 4.9 billion including all supervision time or EUR 3.0 billion without supervision time.

## **Preventing cognitive decline online: The Maintain Your Brain randomised controlled trial**

**Brodaty, Henry**

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**Background:** The lack of disease modifying interventions for Alzheimer's disease (AD) and other dementias plus the accumulating evidence that environmental factors can delay the onset of dementia, have led to increased interest in dementia prevention. Potentially modifiable environmental factors account for 40 percent of the population attributable risk of dementia. Achieving reduction in risk factors at a population level is a challenge. I will describe risk factors, the advantages and disadvantages of digital strategies and the progress of an internet based multicomponent randomised controlled trial being conducted in the state of New South Wales, Australia.

**Method:** Invitations to participate in MYB were emailed or posted to 96,418 persons aged 55-77 years from the 45 and Up study, a population-based cohort study of one in ten people aged 45 years and older (n = 267,000) recruited from Medicare lists between 2006-2009. Participants were required to have risk factors rendering them eligible for two to four of the following modules: physical activity, nutrition, cognitive training and depression. Within each module activities were designed to address individual risk factors. For example, physical activity could target, aerobic fitness, strength or balance; nutrition could target poor adherence to a Mediterranean-type diet, being obese or underweight, or having a history of high cholesterol, high blood pressure, diabetes, alcohol excess or cardiovascular disease.

The 3 years RCT randomised participants into an active coaching group with 1-2 weekly exercises for each eligible module and an information group who receive static information on the web. In year 1, modules run for ten weeks followed by a 2-week break including testing. Participants in both groups receive booster sessions for their eligible modules until the end of Year 3.

**Results:** Of 14,064 who consented to the trial, 6,236 completed all baseline assessments and were randomised. Over 97% of participants met criteria for at least two risk factors: 16% met criteria for all four, 51% for three, 31% for two; 2% for one module and <1% (n = 21) were not eligible for any module. The trial will be completed in November 2021.

**Conclusion:** Most persons aged 55-77 years old have risk factors for cognitive decline that may be amenable to preventative interventions. Lifestyle interventions have capacity to reduce the risk of cognitive decline and ultimately delay the onset of dementia. If successful, this study evaluating the efficacy of delivering and monitoring a multipronged internet intervention, is scalable nationally and internationally.

Keynotes FRIDAY 30<sup>th</sup> OCTOBER 2021

## **Kunst- und Kulturvermittlung im Museum: Eine Möglichkeit der Prävention (Talk in German)**

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Seit einigen Jahren ist die Kulturvermittlung für Menschen mit dementiellen Veränderungen in vielen Museen Teil des Programms. Dass die vielfältigen Herausforderungen eines Museumsbesuchs motorisch, geistig und sprachlich aktivieren ist erwiesen. Dabei gilt es, die Inhalte der Vermittlungsarbeit immer wieder auf den Prüfstand zu stellen. Der Vortrag beschäftigt sich mit Praxisbeispielen und liefert Anregungen zur Diskussion.

## **Dignity and Dementia**

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A growing number of people suffer from dementia. This is due to the sweeping demographic change our society has been going through in the past few decades. Life expectancy and the life span are increasing, consequently also the probability to experience one's dementia. The inclusion of people with dementia in all domains of society is a perspective, a vision, oft he UN Convention on the Rights of Persons with Disabilities. Maintaining dignity is considered prerequisite of care of people with physical and cognitive impairments. Dignity is given a high priority in health and social care but there still is no unifying concept of dignity, no agreed definition. The presentation will attempt to address this question.



# ABSTRACTS – INDIVIDUAL SESSIONS

## SESSION 1: New Treatments

### Aducanumab – facts on evidence

#### Gräßel, Elmar

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**Background:** For several years, various pharmaceutical companies have been conducting intensive research into antibodies against beta-amyloid, which clumps together to form insoluble plaques in the brains of patients suffering from Alzheimer's disease. So far, all randomised controlled trials on this have failed to prove efficacy, i.e. without demonstrating a significant, clinically meaningful improvement in symptoms compared to control group. In the summer of 2021, the US Food and Drug Administration (FDA) has now provisionally approved the antibody Aducanumab for the treatment of Alzheimer's disease.

**Methods:** A source search was conducted to obtain background information in the form of reliable primary and secondary sources related to the approval of Aducanumab in the USA. The analysis of the accessible information mainly relates to four aspects: (1) History of the results. (2) Effect of Aducanumab on cognitive abilities, since the decline of cognitive abilities according to ICD-10 represents the core symptomatology of the dementia syndrome. (3) Adverse effects. (4) Treatment costs.

**Results:** (1) Biogen conducted two randomised controlled trials (started in 2016, designated ENGAGE and EMERGE) with the antibody Aducanumab in patients with early Alzheimer's disease. Both trials were stopped in 2019 because no clinical benefit was apparent (Deutsches Ärzteblatt online 2021). Biogen then allowed the participants to continue the study. Now (2021), one of the two studies (EMERGE) showed partially significant results, however, the continuation of the ENGAGE study did not lead to significant differences between treatment group and control group (Deutsches Ärzteblatt online 2021).

(2) Cognitive abilities were measured using the ADAS-cog 13 (range 0 - 85 points, i.e. the larger the values, the lower the cognitive abilities, as the test adds up errors in the test items). In 547 (Aducanumab group) versus 548 cases (placebo group), the decrease in cognitive abilities in the Aducanumab group after 1.5 years was on average 1.4 points lower than in the placebo group. The cognitive abilities decreased in both groups, in the Aducanumab group by 3.8 points, in the placebo group by 5.2 points (see Table 1). This number of cases (in total more than 1000) resulted in a significance value of  $p = 0.010$  (Haeberlein et al. 2021; slide presentation for the Food and Drug Administration). The estimation of the effect size (Cohen's  $d$ ) results in a value of about 0.2.

Table 1. ADAS-cog values in the EMERGE study (intention to treat;  $n = 1095$ )

	baseline	follow-up (after 18 months)
Placebo group (n = 548) m ± SD	21.9 ± 6.7	27.1 ± ?
Aducanumab high-dose group (n = 547) m ± SD	22.2 ± 7.1	26.0 ± ?

?: not reported by Biogen (Haeberlein et al. 2021)

p = 0.010 (univariate analysis, no multivariate controlled calculation)

Cohen's d ≈ 0.2 (author's own calculation based on incompletely reported data; i.e. missing information on standard deviation at follow-up; assumption for estimation: same standard deviation at follow-up as at baseline)

(3) Among the adverse effects, the most striking is that brain oedema (in imaging described as ARIA-E, E for "edema") was observed in 35 % of those treated with Aducanumab compared to 3 % in the placebo group (Haeberlein et al. 2021). The cerebral oedema is to be understood as a consequence of a damage to the blood-brain barrier.

(4) The treatment costs for 12 months (monthly infusions) are indicated as rounded 56,000 US dollars (Deutsches Ärzteblatt online 2021).

**Discussion:** The effect size on cognitive abilities after 18 months of treatment is not considered as clinically relevant. Ten out of eleven experts had stated at a hearing organised by the Food and Drug Administration (FDA) that the results presented did not provide evidence for the efficacy of Aducanumab in the treatment of Alzheimer's disease (Deutsches Ärzteblatt online 2021). With this fact and the facts presented above, everyone can draw her / his own conclusion.

**Declaration:** The author has no conflict of interest. He received no grant for research or any other purpose from a pharmaceutical company during the last 10 years.

## References

Haeberlein SB<sup>1</sup>, von Hehn C<sup>1</sup>, Tian Y<sup>1</sup>, Chalkias S<sup>1</sup>, Muralidharan KK<sup>1</sup>, Chen T<sup>1</sup>, Wu S<sup>1</sup>, Li J<sup>1</sup>, Skordos L<sup>1</sup>, Nisenbaum L<sup>1</sup>, Rajagovindan R<sup>1</sup>, Dent G<sup>1</sup>, Harrison K<sup>1</sup>, Nestorov I<sup>1</sup>, Zhu Y<sup>1</sup>, Mallinckrodt C<sup>1</sup>, Sandroock A<sup>1</sup> (2021). EMERGE and ENGAGE topline results: Two phase 3 studies to evaluate Aducanumab in patients with early Alzheimer's disease. <https://investors.biogen.com/static-files/8e58afa4-ba37-4250-9a78-2ecfb63b1dcb> (Accessed 14.06.2021)

<sup>1</sup> Biogen, Cambridge, MA, USA

Deutsches Ärzteblatt (Newsletter online: Tuesday, 8 June 2021). Morbus Alzheimer: FDA lässt Antikörper Aducanumab entgegen negativem Expertenvotum zu. [Alzheimer's disease: FDA approves antibody Aducanumab despite negative expert vote.] (Accessed 14.06.2021)

## **Aducanumab – the patient’s perspective**

**Mimica, Ninoslav**

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First antedementia drug was introduced to the market about 30 years ago and till now only 6 molecules (tacrine, donepezil, rivastigmine, galantamine, memantine, aducanumab) were approved by Food and Drug Administration (FDA) for treatment of AD. First five drugs were registered in about 10 years and from that time people with dementia (PWD) were waiting, almost 20 years, for a new (inovative) treatment. So, we all were facing a huge need and desire for a new antedementives - from patient’s side, but also from the side of professionals. Everybody was highly frustrated because in all other fields of medicine, every few years the new drug was produced. First four antedementives came from group of Ace-inhibitors while memantine is NMDA antagonist, and were so called symptomatic treatment. Last approved AD drug has different mechanism of action, namely this medication clears amyloid plaques. The amyloid theory of AD is (was) probably most popular so a lot of people believe this intervention may be disease modifying; next years will approve or disapprove this concept. The FDA approval of aducanumab was controversial and pretty unique, it happens on June 7, 2021, despite disagreement of Advisory panel. While in clinical trials aducanumab didn’t show clinical benefit only demonstrate reducing of amyloid-beta, it was concluded that the brain with less plaques may function better. From clinical practice, we are aware that there are a lot of people who demonstrate AD symptomatology while not having amyloid plaques - they for sure need to wait for another drug. There is an information that the aducanumab yearly treatment will cost 56.000 USA\$ and probably will not be covered by Medicare, or so. Many PwD, will for sure, be interested in buying aducanumab, but majority of people in need will not be able to afford this experimental treatment.

In Europe, we must wait for EMA decision on aducanumab, but PwD in Croatia are also hopping that this regulatory agency will also approve the aducanumab for AD. When that happens the aducanumab will be on EU-market, but it is not probable that it will be on reimbursement regime, because in Croatia, the group of antedementives, are only class of pharmaceuticals which do not have at least one representative on A list, which is completely reimbursed. Namely, all three antedementives (donepezil, rivastigmine, memantine), although are not considered expensive medication, are on B list e. g. patients need to pay participation.

## SESSION 2: Dementia Policies

### The Austrian Dementia Strategy „Living well with dementia“ – Participation and involvement of people affected by dementia

**Juraszovich, Brigitte**

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**Background:** The Austrian dementia strategy “Living well with dementia” provides a framework of 7 objectives and 21 recommendations for taking action to improve the lives of people with dementia as well as their families and friends. Goals 1 to 3 consider dementia as a public health issue by promoting participation and autonomy of people affected to the greatest possible extent. But this requires an open society that also makes participation possible.

**Methodology:** To ensure participation from the beginning, people affected by dementia, self help groups and informal carers were part of a platform. People affected are involved in workshops and conferences. During the last years, the self-help groups started to work together and to cooperate under an umbrella organisation. In 2021, a federal working group of people with dementia was established with the objective to involve people with dementia in the implementation process of the dementia strategy and to make them visible and to bring their needs and opinions into public.

**Results / Next steps:** The next step would be the establishment of a structured participation and self-determination process in the form of dialogue forums with people affected by dementia, their relatives and informal carers and changing third partners. The basic principles of these forums are:

Exchange of subjective perspectives

Dismantling mutual prejudices and bringing about open understanding

Development of a common language

Empowerment

**Discussion:** Within the participation process, the challenge arises that people with dementia are a heterogeneous group and individuals represent a fraction of the totality. There is the difficulty of actually reaching the target group, as they are not present in public (but on the contrary "hidden"). However, the results of the work have a higher practical relevance and are more relevant for the people themselves.

## **The Netherlands: National Dementia Strategy 2021 – 2030**

**Hoogendam, Jacqueline**

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On World Alzheimer's Day 2020 the government of The Netherlands presented its fourth dementia plan the National Dementia Strategy 2021-2030. A ten-year plan to underline the importance to act on dementia. An issue that will not be solved in three or four years.

The National Dementia Strategy has three main themes:

- 'A world without dementia', on funding ground breaking research to cure, prevent and treat dementia
- 'Persons with dementia matter', on dementia friendly society and social participation by persons with dementia, the concept of 'dementia friendly 2.0'
- 'Tailor made support when living with dementia', on person centred and integrated dementia support and care

In addition to the main themes, the strategy has four cross-cutting themes: innovation, young-onset dementia, international activities and communication. The National Dementia Strategy can be downloaded at [National Dementia Strategy 2021-2030 | Publication | Government.nl](#)

## **SESSION 3: Post-diagnostic support**

### **Dementia Care Case Management | The Netherlands, Amsterdam**

#### **Tuinhof de Moed, Annemiek**

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The conference theme: From Reaction to Action beautifully underlines the facility of dementia care case management in the Netherlands. Each person diagnosed with dementia is entitled to receive this form of care, which is part of the basic health insurance. Dementia care case management aims to support people with dementia to continue living at home as long as possible with a good quality of life for both the person with dementia and their informal caregivers.

The presentation provides an introduction into the Dutch context, followed by a sketch of dementia care case management and its impact on informal caregivers and ends with mentioning some of the challenges which are currently faced and addressed in Dutch society.

[www.tuinhofdemoed.com](http://www.tuinhofdemoed.com) | [annemiek@tuinhofdemoed.com](mailto:annemiek@tuinhofdemoed.com) | [www.mantelzorgendementie.nl](http://www.mantelzorgendementie.nl)

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[www.bensajetcentrum.nl](http://www.bensajetcentrum.nl)

## **SESSION 4: Promenz e.V. – Online self-help group discussion (Session in German)**

**Moderator: Schönborn, Raphael, Austria**

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Aktiv trotz Demenz

Von Menschen mit Vergesslichkeit und ihren Bezugspersonen können wir am besten lernen, was sich diese für ein aktives und selbstbestimmtes Leben wünschen. Sie sind die Expert\*innen in eigener Sache, das anzuerkennen und den Betroffenen und ihren Nahestehenden zuzuhören, kann Barrieren in ihrer Bewältigung des Alltags und sozialer Teilhabe offenlegen. Dadurch können Verbesserungen für ihre Lebensumstände abgeleitet und entwickelt werden. Durch ihre Expertise leisten sie einen unersetzbaren gesellschaftlichen Beitrag und sie erfahren durch die Selbstvertretung Wertschätzung und Anerkennung.

Im Rahmen eines moderierten Online-Trialogs mit Betroffenen, An- und Zugehörigen und Expert\*innen gehen wir der Frage nach, wie ein aktives und selbstbestimmtes Leben für Menschen mit Demenz und ihren Bezugspersonen möglich sein kann. Der Trialog stammt aus der Selbstbestimmungsbewegung der Psychiatrie-Reform und wurde von PROMENZ bereits für die „Task Force Pflege“ des Bundesministeriums für Soziales, Gesundheit, Pflege und Konsumentenschutz 2020 und für die Entwicklung der Wiener Demenzstrategie 2021 erfolgreich durchgeführt. Der Trialog stellt ein interaktives Format dar, bei dem die Kongressteilnehmer\*innen den Selbstvertreter\*innen auf Augenhöhe begegnen und mit ihnen in Austausch treten können.

Der Trialog zielt auf einen Kulturwandel im Demenzbereich durch Sensibilisierung und Bewusstseinsbildung ab. Die bisherige Defizitorientierung soll von Ressourcenorientierung abgelöst und Stigmatisierung und Tabu aufgebrochen und umgebaut werden. Neue Zugänge und Betrachtungsweisen, die sich an der Anerkennung und den Ressourcen der Betroffenen und An- und Zugehörigen ausrichten, sollen dadurch eröffnet werden. Die Ergebnisse des Trialogs werden im Anschluss als Positionspapier für ein aktives und selbstbestimmtes Leben trotz Demenz veröffentlicht und den Kongressteilnehmer\*innen zur Verfügung gestellt.

Angeregt durch die Inputs von Betroffenen und ihrer Bezugspersonen sollen im interaktiven Austausch mit den Kongressteilnehmenden die Bedeutung der Selbstgestaltung erörtert, Barrieren identifiziert und Lösungswege erarbeitet werden.



## **SESSION 5: Dementia-competent Communities**

### **Dementia Meet – An European Community Building Project**

**Dominik, Isler**

Dementia Meets, Switzerland

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Dementia is on the rise. Dementia cannot be cured. That is why the topic is as taboo as it is challenging. It is the "elephant in the room". However, the open discussion of dementia in our society is becoming more and more important. Appropriate offers are completely lacking or remain in old patterns. After diagnosis, people are left alone.

We changed that in 2014 with Dementia Meets, casual and enriching events in the middle of cities with 150 people. Here, those affected can exchange views at eye level, here an open dialogue between doctors, carers and relatives is created that would otherwise not exist.

The Dementia Meet events solve dementia from self-help groups in basements or from expert panels. Our events bring dementia to the centre of our cities, to the centre of our society.

The more attention and love those affected and their relatives receive, the more successful our handling of this disease as a society will be. And the better known Dementia Meet is, the stronger our voice will be in the political arena.

Dr. Dominik will talk about this effective social franchising pioneer project by his company LINDEN to spread Dementia Meets in Europe.

## Mission Dementia & Dementia.Active Community

**Richter, Markus<sup>1</sup>, Auer, Stefanie<sup>2</sup>, Bauer, Lisa<sup>1</sup>, Dernes, Eduard<sup>1</sup>, Warisch, Petra<sup>3</sup>, Stöflbauer, Martina<sup>3</sup>, Drexler, Paolo<sup>1</sup>, Sarikaya, Deniz<sup>1</sup>, Pürcher, Paul<sup>2</sup>, Höfler, Margit<sup>2</sup>, Wortmann, Marc<sup>4</sup>**

<sup>1</sup>E-learning centre of the SIAK, E-Learning Centre, Federal Police Academy, Federal Ministry of the Interior, Vienna, <sup>2</sup>Danube University Krems, Centre for Dementia Studies, <sup>3</sup>Federal Ministry of the Interior, <sup>4</sup>Marc Wortmann Consultancy

**Background:** Persons who work in the public administration and police officers often serve as a first point of contact in critical situations for both persons with dementia and their relatives. To be sensitive to the special needs of persons with dementia, training is essential. We therefore initiated two e-learning programs for these important groups.

**Methods:** In a first step, we organized focus groups in which the experiences and needs of the professional groups (police officers, community employees) were discussed. Based on these groups, important topics were defined, and teaching contents were developed. Then, the learning programs were implemented on the E-learning platform of the Federal Ministry of the Interior. We also developed two different certification processes for the different groups.

**Results:** To date, over 13.000 Police Officers have been trained and 242 Police Stations are certified as a "Dementia-friendly police station". Results from a pre-liminary evaluation showed that the E-learning program was well-accepted by the police officers. A similar certification process for community employees just started.

**Discussion:** Providing E-learning programs may be an effective and economically interesting method for awareness building regarding dementia. Hence, this method could be further extended to other professional groups and even the general public.

## The INDEED online platform as an example for digital and interdisciplinary dementia education

**Pfaeffel, Lea<sup>1</sup>, Popovici, Georgeta<sup>2</sup>**

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<sup>2</sup>Romanian Alzheimer Society/Romania

**Background:** The quality of care for people with dementia and their carers falls short of European care standards in several South-eastern European countries. In particular, there is a lack of updated knowledge about dementia among professionals, inadequate interprofessional cooperation, and a lack of dementia-related services such as day care centres. Vocational training for professionals has proven to increase necessary skills and enlarge professional care networks. Thus, it will likely contribute to better dementia care and contribute to improving the quality of life of people with dementia and their informal carers (Mehrabian et al. 2019\*).

**Methodology:** The INDEED Project (Innovation for Dementia in the Danube Region) is co-funded by the European INTERREG-Danube Transnational Programme. This project has created an educational intervention which addresses multiple occupations. The intervention is delivered in a blended-learning format including a multilingual, online learning platform and workshops and complements existing occupation-specific trainings and lifelong learning courses. The educational intervention has been piloted from 2020 to 2021 with exceptionally favourable results, being overall rated by participants with 4.5 out of 5 points.

**Results:** Overall, 16 workshops piloting the online learning platform, with more than 200 participants, were organised in Bulgaria, Romania, Slovakia and Slovenia. Evaluation by the workshop participants and users of the online platform show that the INDEED intervention is a valuable complement to existing vocational trainings, helps to enlarge knowledge about dementia, contributes to the enhancing and strengthening of the interprofessional collaboration with real benefits for professionals and improves knowledge on business-related aspects of providing services for people with dementia.

**Discussion:** The project group is now working on developing an additional chapter to the online learning platform. This chapter will feature good-practice examples from South-eastern Europe showing how effective dementia care can be provided despite COVID-19 constraints.

\* S Mehrabian, L Schwarzkopf, S Auer, I Holmerova, MG. Kramberger, M Boban, E Stefanova, C Tudose, N Bachinskaya, T Kovacs, P Koranda, T Kunchev, L Traykov, J Diehl-Schmid, K Milecka, A Kurz (2019) Dementia care in the Danube region. A multi-national expert survey. *Neuropsychiatric Disease and Treatment* 15:2503-2511.

## **Accompaniment of people with dementia in the hospital by volunteers from Klinikbrücke Tirol - Begleitung von Menschen mit Demenz im Krankenhaus durch Freiwillige der Klinikbrücke Tirol**

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**Background:** The Klinikbrücke was created in 1997 to support relatives and to offer patients an "extra" of interpersonal support. The services are offered in cooperation with the initiative „Demenz braucht Kompetenz“ of the tirol kliniken and are free of charge for patients. Volunteers come where patients need support: on wards, outpatient departments or as accompaniment through the clinic area. The offer can be requested by patients, their relatives or employees of the tirol clinics. Klinikbrücke volunteers are specially trained for their work in the hospital. In order to provide support to people with dementia or delirium, they specialize in additional training.

**Results:** Klinikbrücke volunteers give away time out from everyday hospital life, accompany patients into the fresh air, listen to music together with patients with dementia, read aloud and stand by - individually tailored to the needs of the patients. Networking with the memory nurses as a part of the initiative „Demenz braucht Kompetenz“ of the tirol kliniken, the Klinikbrücke offers voluntary services for people with dementia at the LKH Innsbruck, at the LKH Hall, LKH Hochzirl-Natters and at the Landespflegeklinik Tirol. With the background of a special training for dementia assignments at the clinic, the volunteers have a relieving effect on staff and relatives and enriching ones for the patients.

## Krems Arts Education & Dementia Initiative Symposium – KAEDI (in German)

### Zeitlos schön - Kunstbetrachtung mit Menschen mit Vergesslichkeit im Belvedere: Ein Praxisbericht

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**Background:** Die Abteilung Kunstvermittlung des Belvedere setzt sich bereits seit vielen Jahren mit ihren Fachkompetenzen für ein vielfältiges Angebot für Besucher\*innen ein und kann auf umfangreiche Erfahrungen in der Gestaltung und Durchführung von Vermittlungsformaten für Menschen mit Demenz und Vergesslichkeit aufbauen. Aus der Museumspraxis ergeben sich wichtige Fragenstellungen, die im Austausch und Wissenstransfer mit Universitäten, innovative Zugänge und neue Handlungsmöglichkeiten schaffen können.

**Methodology:**- Dialogorientierte, multisensorische und partizipative Rundgänge durch das Museum- Interne Bewusstseinsbildung durch Fortbildungen im Bereich Inklusion für die Mitarbeiter\*innen des Museums - Austausch mit Institutionen im wissenschaftlichen Bereich

**Results:** Inklusion und kulturelle Teilhabe ermöglichen den Abbau von Barrieren und Stigmatisierung. Museum als öffentlicher Raum und Abbild der Gesellschaft. Vermittlungsformate für Menschen mit Demenz und Vergesslichkeit und Begleiter\*innen werden als konstante Angebote für die Besucher\*innen gefördert. Ein Booklet mit einfach zugänglichen Erklärungen liegt im Oberen Belvedere zur freien Entnahme auf. In Echocast-Schulungen im Museum werden Mitarbeiter\*innen im Umgang mit Menschen mit Demenz und Vergesslichkeit geschult.

**Discussion:** Wie können betroffene Expert\*innen involviert werden? Wie kann Raum für einen Diskurs entstehen, an dem Menschen mit Demenz und Vergesslichkeit von Anfang an teilhaben? Wie kann Mitgestaltung im Museum stattfinden? Wie lässt sich ein nachhaltiges Format etablieren, das die Dialoggruppe erreicht und Vertrauen schafft? Immer wieder stellt sich die Frage nach Assistenz für den Museumsbesuch. Wie kann dies ermöglicht werden? Welche unterschiedlichen Formen von Angeboten braucht es für die verschiedenen Stadien von Demenz mit denen Betroffenen ins Museum kommen? Wie können Kooperationen und Projektarbeit mit anderen Institutionen wie Bibliotheken, Theatern, Kinos, etc., umgesetzt werden? Wissenschaftliche Begleitung und Evaluation, als wichtige Grundlage für eine Weiterentwicklung. Vorurteile verlernen. Die Kraft des Verlernens als Potenzial - nicht als Verlust!

## **One hit wonder? Die Herausforderung der Überführung von Pilotprojekten zur Demenz-Vermittlung in den Dauerbetrieb am Beispiel des Museum Arbeitswelt**

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2019 führten das Museum Arbeitswelt und die Volkshilfe Oberösterreich ein innovatives Pilotprojekt durch. Im Rahmen einer speziell auf Menschen mit Demenz ausgerichteten Führung wurde die Ausstellung ARBEIT IST UNSICHTBAR gemeinsam erkundet. Im Mittelpunkt der Kulturvermittlung stand an diesem Tag nicht die Wissensvermittlung, sondern die Aktivierung und Einbindung der Teilnehmer\*innen und ihrer individuellen Erfahrungen und Erlebnisse. Unterschiedliche Materialien der Sinneswahrnehmung wurden in dem gemeinsamen Rundgang eingesetzt, um Brücken in die Vergangenheit zu legen und den Besucher\*innen Erinnerungsimpulse zu ermöglichen. Im Vordergrund an diesem gemeinsamen Halbtage stand der persönliche Kontakt, das Kennenlernen der Menschen und das Erzählen der individuellen Lebensgeschichte.

Mit Doris Reitmayr, der Leiterin des Tageszentrums „Lichtblick“ für Menschen mit Demenz, in Steyr war von Anfang an eine kompetente und engagierte Ansprechperson gefunden. Mit ihr gemeinsam konnte der Besuch geplant und durchgeführt werden. Das Pilotprojekt wurde von allen Beteiligten als Erfolg betrachtet und eine Wiederholung für 2020 ins Auge gefasst. Ausschlaggebend für den Erfolg war, dass persönliche Vorbesprechungen stattgefunden hatten und auf deren Basis für alle Teilnehmer\*innen in der Ausstellung individuelle Anknüpfungspunkte gefunden wurden. Die damals 80-jährige Anna Pechar zum Beispiel erzählte über ihre Arbeit in der Kugellager-Abteilung, in der sie als junge Frau in den Steyr-Werken gearbeitet hatte. Die Erinnerungen wurden geweckt über Kugellager aus der Ausstellung, die als taktile Objekte angegriffen werden konnten, sowie über Riechdosen mit Schmieröl, die den Fabrikgeruch wiedergeben sollten. Ähnliche taktile Objekte wurden für alle Teilnehmer\*innen in der Ausstellung zur Verfügung gestellt und teilweise nur für diesen einen Besuch vorbereitet. Die geplante Wiederholung konnte bisher aufgrund der COVID-19-Pandemie nicht durchgeführt werden.

Im Vortrag werden einerseits aus Sicht der Kulturvermittlung die Stärken wiedergegeben, die ein Besuch birgt, der individuell auf die Teilnehmer\*innen und ihr jeweiliges Arbeitsleben eingeht. Des Weiteren werden vor allem die Herausforderungen hervorgehoben, Pilotprojekte mit einem erhöhten Aufwand in den Regelbetrieb zu integrieren, noch dazu in Zeiten einer Pandemie, die es aktuell erschwert die bewährten Mittel von Riechdosen und taktilen Objekten einzubauen.

## **Gemeinsam eine schöne Zeit verbringen. Generationen – Workshops zu Alltagsthemen im Volkskundemuseum**

**Martos, Daniela, Richter-Kovarik, Katharina**

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**Generationenbegegnung, Kinder und Menschen mit Demenzdiagnosen, Pilotprojekte im Volkskundemuseum Wien**

**Intergenerational meetings, Children together with people having Dementia, Pilotprojects in Volkskundemuseum Wien**

Das Volkskundemuseum Wien (VKM Wien) ist aufgrund seiner Sammlungsbestände (viele Alltagsgegenstände aus dem 18. – 20. Jahrhundert im Vergleich zu heute) ein Ort des generationsübergreifenden Austausches. Verstärkt kommt es dabei auch zu Begegnungen von Kindern mit Menschen mit Vergesslichkeit und Demenzdiagnosen. Für das aktuell laufende Erasmus + Projekt UNLOCK werden Konzepte für mehr Inklusion in diesem Bereich erarbeitet.

Bereits seit 2018 bietet das VKM Wien Menschen mit Vergesslichkeit und deren Angehörigen einen Ort des Wohlfühlens, der Inspirationen und des Austausches an. Es war Partner im Projekt „Freizeitbuddys für Menschen mit Demenz“ der Caritas und hat im Rahmen der Initiative ACHTSAMER 8. in Kooperation mit Format 60+ Atelier der PensionistInnenklubs, Promenz und der Caritas Workshops im Sinne der Generationenbegegnung angeboten, die auch wissenschaftlich begleitet werden. Es handelt sich um Pilotprojekte, in denen Erfahrungen gesammelt werden und das Programm nach Feedbackrunden adaptiert wird. Die Learnings aus diesen Workshops möchten wir gerne präsentieren.

## SYMPOSIUM

### **Demography and migration - impacts on a life habits and housing requirements of families PwD in SEE**

**Kučuk, Osman, Kučuk, Emina**

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**Background:** Due to demographic changes in SE Europe ageing have accelerate pace. Until 2030., percentage of older adults will be 30% of total population what is twice as big as average world percentage and almost twice more than 2010. In the same time life expectancy will be 78 years and it is 17 years more than 1991. when happened social changes in SE Europe(SEE). Expect age of population is 47 years and it is on top of functional adjusted environment. Until 2030. SEE will lose 15% of population due to migration and deaths(UN DESA 2015). BiH has 150.000 peoples living with dementia(Kučuk 2015).

**Methodology:** Demographic changes has led people in changing of life habits and they have the new housing requirements now. The research will compare today's way, organisation and opportunities for life of people living with dementia(PwD) versus possibilities by the system in regarding with recommendations by WHO (Global strategy on Ageing and Health 2016.-2020.) extended for the new requirments regarding Covid-19. We shall compare current level of services and offers versus needs of PwD that will be satisfied through self-sustainable system, the system that will be functional for the time of emergency conditions, on base of non-pharmacological approach and in accordance with needs of elderly.

**Results:** In considered cases, we'll see that today's systems do not provide the essential services that are in accordance with principles of good health, well being for PwD and don't reduce inequalities with other groups. We made the new model of housing that ensure foster the abilities of PwD, deliver person centred integrated care as well as long-term care and offer solutions for everything what current systems can not. Model has a cheaper services than current models.

**Discussion:** Considered new housing system offer new hope for PwD and it's in accordance with the recommendations of WHO, Covid-19 recommendations and needs of PwD. This model require pilot that will help to decision makers and politicians to make datas analyses, afterwhat they can support solution and adopt for wide using that will be supported and included through the systems: health and social care and insurance.



## Live-in-care and Dementia

Leder, Anna<sup>1</sup>, Durisova, Simona<sup>2</sup>, Romocea, Anca-Ioana<sup>3</sup>

<sup>1</sup>Co-Founder of IG24 - Platform for the interests of migrant 24/24 care workers in Austria ([kontakt@ig24.at](mailto:kontakt@ig24.at))

<sup>2</sup>Co-Founder of IG24/Austria

<sup>3</sup>IG24 Activist/Austria

**Background:** Without any appropriate professional qualification caregivers often take care of people with dementia and other serious illnesses. Since placement agencies recruit and match participants together and create job opportunities for caregivers, they force caregivers to take care of clients with high care level. Not only suffer caregivers from stress and work overload but as self-employee they also take all the responsibility for the wellbeing of their clients. The subordination to placement agencies and people in need of live in care accompanied with the non-recognition of care work results directly from the problematic of the false self-employment and the laissez faire policy.

**Methodology:** With our presentation and following discussion we want to rise attention on the lacking quality of the live in care as well as on bad working conditions of caregivers. The opening part contains of the introduction of speakers and the IG24. In the second part we will deliver overall information about the live in care system. The third part will be more specific – we will introduce two examples respectively real cases of two caregivers covering the care work. The aim is to show problems of caregivers in taking care of people with dementia.

**Results:** The expected outcome of the presentation is to strengthen the awareness about the topic among the conference participants. Participants will get an overview about the functioning of the live in care, the main problems and interests of migrant caregivers alike. Regarding to taking care of people with dementia together with participants we will try to suggest and gather ideas how to improve the status quo of unregulated care work. A further cooperation with participants interested in the topic is highly welcome.

**Discussion:** The subject of the discussion are real cases of two caregivers, who sought out help of the IG24. By analyzing these two cases and searching for possible solutions we would like to point not only at care work carried out by laypersons but also at the structural problem of the false self-employment. The complexity of this problem shows difficulties and shortcomings in the live in care on many levels. The analysis of the restricted possibilities of caregivers may also encourage participants to think about an alternative live in care model.

## **EXPERT STATEMENT**

### **Dementia: assessment of working ability and determination of disability in bosnia and herzegovina**

#### **Dzumhur, Jasminka**

Human Rights Ombudsperson of Bosnia and Herzegovina, former Vice President of the UN Working Group on Enforced and Involuntary Disappearances and the UN Committee on the Rights of Migrant Workers

The aim of this paper is to present some legal aspects of dementia, as a disease, with special reference to its impact on work ability and importance in the process of determining disability.

Dementia is a common name for a group of symptoms caused by a brain disorder that affects thinking, behavior, and the ability to perform daily tasks. The very notion of dementia is often associated in public with the age factor and there is a low awareness that dementia is a consequence of brain disease. The most important characteristic of dementia is the inability to carry out daily activities. This raises the question of the social response to the needs of a person with dementia, both in terms of exercising rights and fulfilling obligations, especially if it is a working person. The assessment of working ability, ie determination of disability is performed by a medical expertise, most often for the purpose of exercising the rights from the pension and disability insurance, but it can also be performed due to the exercise of other rights.

The research, through the analysis of international standards, the legislation of Bosnia and Herzegovina, and the institutional mechanisms for the assessment of working capacity and determination of disability, intends to show the current situation in Bosnia and Herzegovina. Special attention is paid to the issue of harmonization of national legislation and practice with international standards governing this area. The result of the work should contribute to the improvement of the legislative and institutional framework which regulates the assessment of working ability and the determination of disability, with special emphasis on the specifics related to people with dementia.

## SESSION 6: Diagnostics

### 20 Years of the “Ten-Word-List with Encoding Enhancement”

#### Strotzka, Stefan

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**Background:** Episodic memory is the most developed and complex form of memory. It is therefore lost early in the emergence of dementia. For diagnosing the latter, it is especially suitable to focus on the operation of the episodic memory. The “Ten-Word-List with Encoding Enhancement” of Friedel M Reischies of Berlin, Germany is a practical, readily administered and informative test of the episodic memory. In this test, clients hear ten words. Upon hearing each, they should consider whether what is designated is larger or smaller than a table, and they should then recall the words.

**Methodology:** A retrospective evaluation of 4,079 female and male clients of the Gerontopsychiatric Center (GPZ) of the Psychosocial Services of the City of Vienna, using the “Ten-Word-List”, took note of persons without cognitive impairment, persons in the stage of mild cognitive impairment and in the stage of dementia.

**Results:** Persons without cognitive impairment reached an average of 6.9 out of ten possible words. In the stage of mild cognitive impairment 5.3 words could be recalled and in the stage of dementia 2.5. The sensitivity and specificity for the diagnosis of dementia were 89% and 84%.

**Discussion:** The results of the first study of the “Ten-Word-List” involving 116 subjects were confirmed in the investigation of the GPZ. The procedure is a practical, quick, and very precise test for early discrimination, especially helpful in diagnosing a pre-senile dementia.

Strotzka S (2021) 20 Jahre „Zehn-Wort-Merkliste mit Imaginations-Einspeicherhilfe“. *psychopraxis.neuropraxis*, 24(2):110-115

## **Spontaneous speech analyses as an early detection method for dementia: possibilities and limitations**

**Lafenthaler, Sandra**

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**Background:** Linguistic features (phonetic, semantic-lexical and syntactic variables) in the spontaneous speech of patients in the pre- or early stages, or both, of dementia have emerged as promising and reliable indicators. However, these results, which are promising across languages, differ greatly in terms of classification accuracy. This is due to heterogeneous methodological approaches.

**Aim:** The oral presentation aims to give an insight into the current state of research regarding spontaneous speech analysis as a possible early detection method for dementia. In addition, an ongoing study will be presented. This is to clarify whether linguistic markers in spontaneous speech samples are potential predictors in the early detection of Alzheimer's disease. In addition, it is to be evaluated whether an automatic early detection method using a Support Vector Machine (SVM), which is based on a selected set of linguistic markers, is a reliable method for detecting early neurocognitive disorders.

**Methodology:** A state-of-the-art regarding early detection of dementia from spontaneous speech analysis is given. A systematic search was carried out using PubMed, ScienceDirect and Google Scholar. The ongoing study was designed based on this literature review. It should include at least 50 healthy and 50 cognitively impaired participants (mild cognitive impairment and early-stage Alzheimer's disease). First, picture description tasks are used to elicit semi-spontaneous speech. After the orthographic transcription of the spontaneous speech samples, linguistic features are extracted from the text corpora with the help of manual and computer-aided methods (including PRAAT software) and the potential of the linguistic discriminators is validated using statistical methods. Finally, the early detection potential of the linguistic markers is to be checked with the help of a classification algorithm (artificial intelligence, AI).

**Discussion:** This oral presentation presents the current research on this topic and gives an insight into the ongoing study (data collection, extraction of linguistic features based on already recorded spontaneous speech sequences).

Contributors to the ongoing study mentioned in the oral presentation:

Mag. Dr. Sandra Lafenthaler – Department of Linguistics, University of Salzburg, Austria

Prof. Dr. Yvonne Höller – School of Humanities and Social Sciences, University of Akureyri, Iceland

Mag. Dr. Jürgen Bergmann – University Clinic for Neurology, Christian-Doppler-Klinik Salzburg, Austria

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Vanessa Frey, MSc PhD - University Clinic for Neurology, Christian-Doppler-Klinik Salzburg, Austria

Dr. Isabella Gostner - University Clinic for Neurology, Christian-Doppler-Klinik Salzburg, Austria

Mag. Dr. Margarita Kirschner - University Clinic for Neurology, Christian-Doppler-Klinik Salzburg, Austria

Dr. Fabio Rossini - University Clinic for Neurology, Christian-Doppler-Klinik Salzburg, Austria

Assoc. Prof. Dr. Wolfgang Staffen - University Clinic for Neurology, Christian-Doppler-Klinik Salzburg, Austria

Prof. Mag. Dr. Eugen Trinka - University Clinic for Neurology, Christian-Doppler-Klinik Salzburg, Austria

## **SESSION 7: Agitation**

### **Report of the IPA Agitation Group**

**Splaine, Michael**

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Persons with Alzheimer's disease and related disorders have other health issues as an estimated 75% have at least one additional chronic condition. Flare ups of these conditions, made more difficult by the underlying cognitive impairment, may lead to emergency department visits and unplanned hospital visits.

A hospital stay for any aged person results in loss of muscle mass and tone, some function and increased risks of acquired infection and institutional care. In the US a person with ADRD who is hospitalized likely will have another 2 visits in that same year. In the US persons with ADRD in their medical record comprise 40% of rapid (under 30 day) readmissions back to hospital, resulting in more loss of ability and risk of institutionalization.

Recognizing the risks to its clients, a community-based senior serving organization senior services organization has created a hospital readmission reduction for persons with dementia program by developing Hospital2Home, by adopting an evidence based through RCT model of transitions in care, coupled with respite coaching and additional educational activities for persons living with dementia and their families about preventing hospitalization/coping better with hospital stay and for more successful post hospital care.

This symposium will share the story of identifying and selecting an evidence-based intervention and adopting it into practice at Nevada Senior Services, core educational objectives and information about the caregiver and staff education programs and preliminary evaluation results indicating a 2% rapid readmission rate among Hospital2Home clients vs 35% among all seniors in the community served. Special emphasis on building stakeholder engagement and negotiating the formal collaborations between hospital and community-based organization.

## SESSION 8: New Skills

### Oral health association with dementia: a case control study

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**Background:** Dementia is recognised worldwide as a major public health. Due to improved healthcare, the number of people with dementia and natural dentition is increasing problem. As dementia progresses the capability of self-care decreases which lead to increase in oral infections. Some studies supports that poor oral health (periodontal disease and tooth loss) increases the risk of dementia while other studies do not. The aim of this study was to investigate the association between oral health conditions and risk of dementia in elderly Chinese population.

**Methodology:** Data from the hospital case-control study conducted in Guangzhou Hui'ai Hospital in China, which included n=233 cases and 233 controls were analysed. Cases were enrolled from Community Neurology Management Department and Physical Examination Department in Hui'ai Hospital. Dementia was diagnosed by the neurologist through ICD-10 criteria. The control group were healthy people without neurological disease (dementia). Oral health data was collected using self-administered questionnaires included self-perceived oral health status, oral hygiene, number of teeth present and periodontal disease (PD).

**Results:** Of 466 participants, the average age was 73.6 years (SD 9.46), 77.2% were cases (dementia) and 70.0% were control (non-dementia). Logistic regression models were applied to estimate the relationship of cases compared to the control group adjusted with confounders exhibited, (1) there was significant association between self-reported poor oral health and risk of dementia OR (odds ratio) 1.98 (1.01-3.87), (2) edentulous versus =>25 teeth OR 6.63 (2.51-17.52) and 1-8 teeth versus =>25 teeth OR 3.00 (1.36-6.60), (3) mild/moderate PD 4.13 (1.49-1.42), (4) brushing OR 23.37 (10.14-53.88) and (5) non-significant association of severe PD 1.50 (0.70-3.23) was found.

**Discussion:** In this study we not only looked at oral diseases but also included oral hygiene indicators which most of the previous studies did not include. Positive association of poor oral health with dementia risk was found. Of the oral health parameters studied, the strongest association was between not brushing OR 23 times greater dementia risk in cases. Poor oral

hygiene causes plaque formation leading to chronic inflammatory disease (PD) resulting alveolar bone loss and eventually tooth loss. The oral hygiene and health of older people with dementia needs to be improved. Preventing (brushing) and treating (PD) may help reduce the global epidemic of dementia.



## Competences and skills of social care staff: improvement of dementia care in social home care service

**Bártová, Alžběta<sup>1</sup>, Dostálová, Vladimíra<sup>1</sup>, Holmerová, Iva<sup>1</sup>, Pojarová, Martina<sup>2</sup>**

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**Background:** Most people prefer to live independently in their home environment despite reduced self-sufficiency. It is therefore necessary to pay sufficient attention to home care provided to frail older people, including people living with dementia. Although informal carers usually play a central role in providing care of home dwelling person with dementia, it is essential to ensure optimal opportunities to benefit from professional services. Sufficient qualifications and skills of caring staff are then necessary to ensure the quality of professional service. The main aim of this presentation is to introduce key activities supporting professional development and skills of formal carers providing social care to home dwelling people with dementia.

**Methodology:** Qualitative research was chosen to identify key activities. The research was performed in an organization providing field social care (Pečovatelské centrum Praha 7). Seven semi-structured interviews were conducted with social workers and 3 focus groups (n=18) with workers involved in personal care for people with dementia. Data obtained from the interviews were analysed through thematic analysis.

**Results:** Based on the thematic analysis, the main areas of key activities needed to support the professional development and skills of formal carers were identified: 1) identification and evaluation of dementia; 2) coordination of care and support needs including collaboration with other stakeholders, and 3) communication skills. Specific activities in these areas vary between social workers and workers involved in personal care.

**Conclusion:** The activities are fulfilled through training. As part of the training, guidelines for both social workers and direct care workers have been developed, presented and implemented. A total of seven training programs were conducted, which included: 1) introduction to a tool for identifying warning signs of cognitive changes ; 2) assessment of cognitive function using valid tools; 3) introduction to the principles of functional geriatric assessment; 4) introduction to the individual care plan including training in its use in practice; 5) introduction to the principles of case management; 6) specifics of communication with people with dementia and 7) specifics of communication with family carers of people with dementia.

Project was supported by European Social fund.

## SESSION 9: Dementia and COVID-19

### **Environmental stimuli in nursing homes during the Covid-19 pandemic: Lessons learned for future management of challenging behavior**

**Gerritsen, Debby, Knippenberg, Inge, Nijsten, Johanna, Bakker, Christian, Koopmans, Raymond , Leontjevas, Ruslan**

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**Background:** Challenging behavior is common in nursing home residents, especially in those with dementia. The observed decrease in environmental stimuli during the COVID-19 pandemic due to applied restrictions has affected residents differently. To improve future care, the experience of professionals can be used to learn about the effects of environmental stimuli on challenging behavior in specific resident groups during the pandemic. Our study aimed to learn from successful initiatives and observed effects of decreased environmental stimuli on challenging behavior in residents during anti-pandemic measures, from the perspective of professionals.

**Methodology:** An online survey among 199 Dutch nursing home professionals was conducted from November 2020 to January 2021. Professionals were asked about alleged effects of diminished environmental stimuli in residents with different types of challenging behavior (i.e., psychotic, depressed, anxious, agitated, apathic behavior) and with mild vs. advanced, or without, dementia. Also, their opinion about strategies to limit environmental stimuli was explored.

**Results:** Residents with advanced dementia and those with psychotic and agitated behavior seemed to benefit from diminished environmental stimuli. In contrast, residents without dementia and those with depressive and apathic behavior seemed to be negatively affected by decreased environmental stimuli. Professionals indicated that they would like to preserve various strategies to limit environmental stimuli in the future, such as reducing the use of corridors adjacent to residents' rooms. Also, they planned to keep using new initiatives regarding organized activities (e.g., increased use of small-scale and person-oriented activities). Opinions were divided on receiving visitors in the living room and instating visiting hours.

**Discussion:** Various strategies and initiatives in nursing homes during the pandemic seem promising to meet individual needs in the future. While many residents may be negatively affected by restrictions during the pandemic, specific resident groups may benefit from a

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decrease in environmental stimuli. These findings underline the importance of a good balance between stimuli and rest in the nursing home, tailored to an individual resident.

## **Are visits allowed? The impact of the COVID-19 pandemic on care home visitation and care delivery in the UK**

**Giebel, Clarissa**<sup>1,2</sup>, **Hanna, Kerry**<sup>1,2</sup>, **Cannon, Jacqueline**<sup>3</sup>, **Tetlow, Hilary**<sup>2,4</sup>, **Marlow, Paul**<sup>2</sup>, **Shenton, Justine**<sup>5</sup>, **Mason, Stephen**<sup>6</sup>, **Rajagopal, Manoj**<sup>7</sup>, **Gabbay, Mark**<sup>1,2</sup>

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7 Lancashire & South Cumbria NHS Trust

**Background:** COVID-19 has caused the sudden closure of care homes to the outside world, to stem the virus from infecting some of the most vulnerable groups of people – older adults residing in care homes. With very little knowledge to date, we aimed to explore the impact of COVID-19 on care provision and visits in care homes from staff and family members' perspectives.

**Methods:** Care home staff and family carers of people living with dementia (PLWD) across the UK were recruited via convenience sampling and participated via telephone or Zoom. Participants took part in a semi-structured remote interview. Baseline data were collected between October and November 2020, and follow-up interviews were collected throughout March 2021. Anonymised transcripts were analysed separately by two research team members using thematic analysis, with codes discussed and themes generated jointly, supported by research team input.

**Results:** 42 participants (26 family carers and 16 care home staff) took part in the baseline interviews, and 20 purposefully sampled participants (11 family carers and 9 care home staff) were followed up. Prior to vaccination roll out in the UK, at baseline, family carers expressed concern about a lack of clear guidance throughout the pandemic, with care homes delivering care differently and disparities noted in the levels and types of visiting allowed for family members. Lack of communication between care homes and family members, but also government and care homes, led to family carers feeling excluded and concerned about the well-being of their relative. Data on follow-up interviews are still being analysed.

**Conclusions:** This is the first empirical evidence to show how the pandemic has caused severe difficulties in providing adequate care for care home residents, with not only residents, but also care home staff and family carers being negatively affected. Follow-up data will shed light onto the impact of vaccination and eased visitation rights put in place since March 2021 on care delivery and connections between family carers and residents.

## **Public involvement of people with dementia and carers in research**

**Giebel, Clarissa<sup>1,2</sup>, Gabbay, Mark<sup>1,2</sup>**

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We present our approach to public involvement in dementia research. This builds on the principles of public involvement, defined as embedded co-production, as opposed to collaboration or consultation- engagement, or help with recruitment and participation. We discuss this within the context of our Public and Community Involvement programme within the National Institute for Health Research Applied Health Collaboration North West Coast. This is a 62 member organisation research and implementation collaboration focusing on health inequalities. The approach embeds capacity building among the member organisations' workforce and co-production including robust public involvement in all elements, from defining the problem and research question, study design, delivery analysis to dissemination, with parallel approaches in implementation and its evaluation. We co-developed a toolkit for researchers to embed equity and public involvement in research design and delivery [www.hiat.org.uk](http://www.hiat.org.uk). Finally, we focus on how we work with the public, people living with dementia and carers and a variety of health and social care providers in our work, linked to the Liverpool Dementia and Ageing Research Forum.

# AIDEM Workshop

## **Presentation of the EU-Japan Project E-VITA, a Virtual Coach for Smart Aging**

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E-VITA: EU-Japan Virtual Coach for Smart Aging. The combination of the socio-technology excellence “Made in Europe” with the excellence of technology “Made in Japan” will produce an innovative coaching system based on the needs and wishes of older adults. The virtual coach will provide personalized recommendations and interventions to improve the quality of life of older adults in Europe and Japan while offering opportunities to SME’s and NGO’s to explore the feasibility of a new ecosystem. The impact should be Empowering older adults to better manage their own activities will have an impact on increasing the wellbeing of older adults and will improve their quality of life via socio-technological support of “Active and Healthy Ageing” in Europe and Japan.

Wieching, Rainer; Taki, Yasuyuki; Ogawa, Toshimi; Browne, Ryan.

thanks to:

Jokinen, K., Homma, K., Matsumoto, Y., Fukuda, K. (2021). Integration and Interaction of Trustworthy AI in a Virtual Coach – An Overview of EU-Japan Collaboration on Eldercare. In: Matsushita and Takama (Eds.): *Advances in Artificial Intelligence – Selected Papers from the Annual Conference of Japanese Society of Artificial Intelligence (JSAI 2021)*. Springer Nature Series Advances in Intelligent Systems and Computing.

## The Treacherous Language of Alzheimer: Exposed by Agent AI

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Alzheimer's disease (AD) is known to impact on language production. For example, typical phenomena throughout progress of the disease include during early stage reduced fluency, slower speaking, or increase in usage of fillers; during moderate phase, problems often occur to form basic phrases or follow conversations, while in late stage, one can often observe incoherent and illogical speech production, frequent repetitions, or even singing, babbling, or unrelated content interjection. Less is known about the acoustic correlates of AD, however, from the above, it seems obvious that also by purely acoustic measurement, cues of AD must be accessible to a well-trained AI.

Based on traditional features brute-forced by the openSMILE tool such as the 6k-large ComParE set, log-Mel features, or MFCCs and bags-of-audio-words derived thereof, as well as based on CNN/LSTM-RNN end-to-end learning from the raw speech signal or zero-frequency filtered (ZFF) signals, acoustic analyses were fulfilled on the Interspeech 2020 Alzheimer's Dementia Recognition through Spontaneous Speech (ADReSS) challenge task (54 AD, 54 control, 50-80 years, roughly balanced). In addition, linguistics were represented by hierarchical attention networks and BiLSTM-RNN with attention. In extensive test runs, the baseline of the challenge is exceeded both by the chosen acoustic and linguistic representations, where linguistics are slightly ahead, and the fusion of these two leads to the best results of 85.2% accuracy and 85.4% F1-measure. The root mean square error is 4.65 for the Mini-Mental State Examination score in [0,30].

While this is a highly encouraging result, potential for improvement may be found in the co-modelling of typical AD comorbidities. Such include several tasks which have equally been targeted successfully by audio intelligence. These include based on prevalence and frequency hypertension, osteoarthritis, depression, or cerebrovascular disease, as well as Parkinson's disease, cardiac arrhythmia, insomnia, anxiety, or neurosis. In a suited multitarget learning framework, an overall improved detection is assumed due to further data and by that knowledge injection. With such, next steps foremostly will include realising trustable applications in smart devices for real-life usage.



## Social Robot Pepper Coaches and Promotes the Quality of Life of Persons with Dementia: The AMIGO Study

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**Background:** The evidence of social robots for people with dementia (PwD) living at home is unclear. The aim was to explore the effects of Coach Pepper (social assistive humanoid robot system “AMIGO” combined with external Tablet-based training) versus an exclusively Tablet-based training on various physical-, mental- and psychosocial outcomes as well as the user experience with Coach Pepper.

**Methods:** The study (2019-2020) includes a randomized controlled trial with complementary interviews using content analysis. The intervention group (16 PwD) received Coach Pepper and the control group (16 PwD) an exclusively Tablet-based training for three weeks. Data were collected using standardized questionnaires and interviews.

**Results:** In both groups, PwD were >80 years old and mainly female. The mild stage of Alzheimer's was predominant in both groups. The comparison of quality of life (DEMQOL questionnaire) between the groups showed a significantly greater increase in the Coach Pepper group ( $\bar{X}$ : 5.48 vs. -0.31; med: 4 vs. 2 points,  $p = 0.0226$ ). All other outcomes did not differ significantly. Main qualitative results: *Attitude/feelings* - PwD reacted mainly positively to Pepper. The PwD were generally not afraid of Pepper and did not feel repulsed. They found Pepper nice/pleasant and funny. *Communication, social contacts* - Pepper was well received and integrated as a family member. His presence was not disturbing, more an enrichment. PwD regarded Pepper as a friend, child and contact person. He promotes communication in PwD. The life of PwD “bloomed” and they bonded with Pepper, which caused feelings of sadness after Pepper moved out. *Meaningful activities*- Music and dance activities stimulated PwD particularly positively.

**Conclusion:** Coach Pepper significantly increased the quality of life of the PwD in the robot group. As the additional qualitative results demonstrate, this increase can be attributed in particular to the promotion of communication and social contacts by Pepper. Further research should focus on the increase of Pepper's communication skills and program content.

### Contact

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## **On the Use of Sensor Technology for Early Notification of Stress in People with Impaired Cognition**

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Challenging behavior in people with intellectual disabilities is a widespread and persistent problem in intramural care. It has negative consequences on the quality of life and happiness, and it increases sick leave and drop-out of care professionals. Early notification of stress enables caregivers to better understand and respond to the needs of their clients, thereby preventing further escalation and reducing the number of incidents against significant health care cost savings.

We present the results of an extensive validation study in which sensor technology and artificial intelligence models were used for early notification of stress in people with impaired cognition. 25 intramural clients living in care institutions across the Netherlands were included in the study. During events of challenging behavior, the physiological response (skin conductance, heartrate, and movement artefacts) of the client was measured with wearables and, via trained artificial intelligence models, converted into stress levels. These stress levels were validated against behavioral analysis from video observations. The stress detection model was trained with over 500 hours of labelled physiological data from competent test persons, performed in a reference setting in which emotions were prompted. The study showed that the trained model was well capable of notifying stress in people with impaired cognition.

## Using AI to Move Towards Better Individualized Treatment

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Despite strong efforts in research, the past decade has not yielded any substantial improvement in treatments of Alzheimer's Disease (AD). While there are currently more than 120 compounds tested in clinical trials, the disease is still treated with the same compounds as >15-20 years ago, which have only a small symptomatic effect and do not modify disease progression. Recent failures in clinical trials and the highly controversial approval of aducanumab highlight the need for new and better drugs. Given the progressive, neurodegenerative nature of the disease it is of utmost importance to therapeutically intervene as early as possible. At the same time the high heterogeneity of the disease is a challenge that needs to be addressed.

Based on examples from own work I will point out the tight connection between the needs for earlier diagnosis, patient stratification and prediction of disease progression and the development of modern machine learning algorithms, which can integrate multiple data modalities, such as genetic factors, cognitive function and brain pathophysiology. In conclusion, the access to sufficiently large, multi-modal patient-level data is of utmost relevance to realize the vision of a more effective and better individualized treatment of AD driven by AI.

## Dementia Risk Reduction: Applied Epidemiology and Public Health

**Deckers, Kay<sup>1</sup>**

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**Background:** From a public health perspective, those at increased risk of dementia should be identifiable based on readily available risk factors that are truly amenable to change. To this end, the “Lifestyle for BRAin Health” (LIBRA) score was developed after triangulation of results from a systematic literature review on risk and protective factors for dementia and an expert consensus study. LIBRA quantifies an individual’s potential for dementia prevention by flagging their ‘room for improvement’.

**Methodology:** LIBRA consists of 12 risk and protective factors which can be targeted by lifestyle interventions and risk management in primary care. Risk factors are coronary heart disease, diabetes, hypercholesterolemia, hypertension, depression, obesity, smoking, physical inactivity and renal disease. Protective factors are low-to-moderate alcohol use, high cognitive activity and healthy diet. A weight is assigned to each factor based on the factor’s relative risk from meta-analyses (total score: -5.9 to 12.7), with higher scores indicating higher dementia risk.

**Results:** In pooled analyses from six prospective studies, a one-point change in LIBRA increased dementia risk by 15% (95%CI=9%-21%) in people aged <65 years and by 11% (95%CI=7%-15%) in those aged 65-75 years, but not at older ages. Higher LIBRA scores were also associated with cognitive decline in middle-aged individuals (Doetinchem Cohort Study), correlated with cognition scores in a health-seeking sample, related to intervention effects in early dementia prevention trials (preDIVA, FINGER) and associated with brain atrophy and cerebrovascular changes (The Maastricht Study). Further, LIBRA is currently used by several international partners to give middle-aged individuals from the general population insight into their own lifestyle in order to promote brain health in later life.

**Discussion:** There is a public need for knowledge transfer on brain health and potential for delaying dementia. LIBRA might be a useful tool to inform individuals of their profile and identify target behaviors.

## **Multimodal Interventions for Persons with Age-related Cognitive Impairments in Long-term Care Settings**

**Saran, Nikoleta**<sup>1</sup>

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Due to the symptomatology of these pathological changes, people with age-related cognitive impairment (ACI) often experience mobility difficulties and impairments in the independent performance of activities of daily living. As well individuals with ACI, as the health care system could benefit from Mobility- or ATL-enhancing interventions, by increasing the independence and preventing the need for further care of affected individuals. Current pharmacological treatments have not shown any promising success yet and are associated with risks of side effects. Therefore, nursing staff should be able to assess the impact of cognitive-motor interventions on activities of daily living and mobility in people with ACI and be able to apply these interventions. Research question: How does the combination of physical and cognitive interventions affect the activities of daily living and mobility of people with age-related cognitive impairment in long-term care facilities? To answer the research question, a structured literature search was conducted in the Pubmed, Cochrane, and CINAHL databases. The search resulted in 715 hits. Five randomized controlled trials were included in the quality assessment of the literature with subsequent synthesis of results and discussion. The results show that cognitive-motor interventions have positive effects on activities of daily living of institutionalized individuals with ACI. Results were inconsistent in the category of mobility. The small number of included heterogeneous publications limits the significance of the results, which is why further research in this area must be carried out. However, as some positive effects were found and no negative events were observed during the interventions, a recommendation for the implementation of cognitive-motor interventions in practice can be given.

## **Virtual Technologies and Eye-Tracking Measurements for Mindfulness and Activation in Long-Term Care**

**Paletta, Lucas<sup>1</sup>, Pszeida, Martin<sup>1</sup>, Andreu, Jean-Philippe<sup>1</sup>, Dini, Amir<sup>1</sup>, Schüssler, Sandra<sup>2</sup>, Lodron, Julia<sup>2</sup>, Zweytik, Elke<sup>3</sup>, Steiner, Josef<sup>3</sup>, Grabher, Andrea<sup>4</sup>, Kober, Silvia<sup>5</sup>, Wood, Guilherme<sup>5</sup>**

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Recent studies underline the importance of the cognitive reserve for mental health, especially in dementia care, which is supported by stress reduction, joyful experience and meditation. Mindfulness training has previously been successfully applied to dementia and indicates a lasting positive effect on well-being and motivation (Chiesa et al., 2011). We investigated the potential of unobtrusive technology for the measurement of eye movements in Virtual Reality (VR)-based mindfulness training. The objective of this research is to develop software estimators for cognitive assessment and mindfulness trait in order to apply VR technology in the future as a screening instrument, monitoring tool and thereby serving for decision support in mental health care. Eye movement analysis within a pilot study demonstrated significantly different results for persons with Alzheimer's dementia and healthy controls. These results indicate that significant conclusions are drawn on relevant mental health parameters even within a very short eye movement measurement period applying few minutes of observation of carefully selected video-based stimuli

### **Contact**

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## **Memorytainment as an Assistive Technology Approach**

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<sup>1</sup>Memorytainment by Kosmas o Etolos E.C.U., Athens, Greece

The Memorytainment services are applied in two elderly care units in Greece, Kosmas o Etolos, as a non-pharmaceutical dementia inhibitor. This attempt started four years ago with the implementation of the Bike Memories service and evolved into today's form of Memorytainment. During the pandemic of COVID-19 and the difficult conditions we had to overcome, Memorytainment developed a group of services that work as an assistive technology approach of dementia and related conditions. These practical services are applied to the guests of the two elderly care units and combine memory stimulation, limb mobilization and entertainment. We continuously develop innovative approaches aiming at diminishing the obstacles and restrictions of the pandemic. Our main concern is the maintenance of the levels of dementia to the minimum through our innovative assistive technology services adjusted to a personalized session program for everyone. Memorytainment is a non-pharmaceutical form of intervention to the person with dementia, causing a mental and physical stimulation. After 4 years of study, there have been observations of slowing the progression of dementia with the use of Memorytainment services.

## **DIGITAAL life - The Innovative App for the Multimodal Activation of Cognitive Performance**

**Fellner, Maria**

digitAAL Life GmbH, Graz, Austria

digitAAL Life GmbH specializes in the development of innovative digital solutions for health and care. Together with strategic partners from research, medicine and practice, digitAAL Life has developed a tablet-based training game for multimodal activation of cognitive performance (see <https://youtu.be/D-ie9glO5k>), which has already been launched on the German-speaking market and is now transferred to several European languages (especially CEE region and Italy). The app can be tested for free, see [www.DIGITAAL.life/test](http://www.DIGITAAL.life/test).



## **CogVis GmbH**

### **Planinc, Rainer**

cogvis software und consulting GmbH, Vienna, Austria

Cogvis combines 3D sensors together with Artificial Intelligence to actively support care-taker and residents in their daily activities. Our product cogvisAI already provides support in nursing homes, hospitals, rehabilitation clinics etc. Current research activities focus on assisting residents suffering from dementia when using the toilet – with the help of our virtual assistant, they are able to use the toilet again on their own!

## **Combining Nurse Call, Wander Control and Mobile Call Functionalities in One System that Works Seamless Indoors as well as Outdoors and Provides Safety for Older Adults and Reduces Burden on Care Givers**

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The number of people suffering from dementia will rise significantly within the next decades worldwide. Although this is widely known wander control systems are mainly stand alone or only partly integrated solutions, either working indoors or outdoors. In the 2010s the market was not yet requesting holistic solutions since people suffering from dementia were often kept in closed facilities. From an ethical and legal perspective this way of handling is seen very critical. During the first development phase of the Personal Protection and Caring System (2PCS) – based on an AAL Joint Programme Project from 2011-2014 – the focus was on being able to trigger social alarms (actively or based on detected falls and geo-alarms). During the go to market phase it got more and more clear that fully integrated solutions with seamless functionalities were requested. Therefore, the R&D focus was to fulfil this requirement by combining nurse call, wander control and mobile call functionalities in one system that works indoors as well as outdoors and provides safety for older adults and reduces burden on care givers taking under consideration a maximum of freedom, mobility, and self-determination.

## **DigniSens GmbH**

### **Werba, Simon**

DigniSens GmbH, Graz, Austria

DigniSens GmbH, a medical technology company based in Graz, is engaged in the development, certification and marketing of digital care assistance systems. The first product, ASCA 1 (which stands for "advanced sensoric care assistance"), is a reusable, rechargeable sensor device that is attached to the outside of a nursing nappy and uses the latest sensors to detect urinary and faecal incontinence episodes as well as distinctive movements (e.g. getting out of bed at night). In case of an emergency, the nursing staff is notified via the local call system, a smartphone or browser app or via SMS, so that the nursing staff can implement quick, adequate and individual nursing measures. The added value generated in this way manifests itself on the one hand in the sphere of the users (care staff), who benefit from an increase in the efficiency and quality of care as well as a reduction in workload, and on the other hand in the sphere of those in need of care, since the use of ASCA 1 minimises health risks and generally increases the quality of life. In addition, ASCA 1 enables home operators to save follow-up costs due to a lack of nursing care. ASCA 1 is currently being tested in pilot projects in Styria and Vienna - the market launch is planned for the first quarter of 2022.

## **Project VR4 Mind& Motion: Virtual Training for People with Dementia**

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When people talk about VR glasses, they usually think of video games and the gaming scene. The use of virtual reality is now also interesting for other areas. Currently, the project VR4 Mind&Motion is investigating the use of VR glasses in the therapy of people with dementia. Regularly shown 3D videos - combined with relaxing music - are intended to help improve the mental and physical abilities of people suffering from dementia and maintain them for as long as possible.

Based on the user requirements the project consortia identified a comprehensive image and software concept, which will now be tested in a pilot study starting in autumn 2021. In training units of 15 minutes, the patients will regularly test the combination of ergometer training and a visual reality display. In order to assess the possible success, the ergometer training with VR-glasses will be evaluated by various measurement methods such as heart rate variability, balance measurement and cognitive tests.

## **Old Brains, New Tricks: Can Environmental Enrichment Improve Aging Memory?**

**Stark, Craig E.L.<sup>1</sup>**

James L. McGaugh Chair in Neurobiology of Learning and Memory Professor, Department of Neurobiology and Behavior, Director, Facility for Imaging and Brain Research (FIBRE) & Campus Center for Neuroimaging (CCNI), School of Biological Sciences, University of California, Irvine

Memory complaints are the most common cognitive concern of individuals as they age, and it's no wonder people are worried about it. Problems with memory are a hallmark feature of Alzheimer's disease and other forms of dementia. However, memory lapses are a normal part of memory, even when we're young. What's more, these lapses get more common as we age, even when there are no clinical signs of dementia. The first part of the talk will cover my laboratory's research into these age-related changes and how we can use sophisticated neuroimaging and behavioral techniques to study the effects of aging on our brains and our memory. A question naturally arises from this work: Can we do anything to slow or reverse these changes? The second part of the talk will describe my lab's recent efforts to adapt rodent studies on "environmental enrichment" to humans. These studies show how engaging in and exploring large virtual worlds can actually improve memory ability and may ameliorate age-related memory decline.

Poster

# ABSTRACTS – POSTER

## Depression and loneliness among residents living in nursing homes and residential homes: a scoping review

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**Background:** Loneliness is a subjective phenomenon. It is experienced a lack of satisfying relationship to others, whether because the subject has too few relationships or because their existing relationships do not provide the desired form of closeness (Svenderson, 2017). As defined by Peplou and Perlman (1982), the definitions of loneliness share the same concept: an unpleasant, subjective experience resulting from inadequate social relationships. Loneliness and rumination are remarkable risk factors of depression among the elderly in the both community and nursing homes (Gan at al.,2015). A Norwegian study found that 56% of nursing home residents are feeling lonely (Dragaset et al.,2011). The study from Poland found that depression was observed in 33.8% long term care facility (Horwath, Scerbinska,2017). Furthermore, another study from China shown that 14.9% residents in long term facility reported suicidal ideation (Zhang at al.,2020). Associated with one being depressed in nursing homes include pain, risk of stroke, risk of heart attack, decreased cognitive function and is also linked to increased morbidity in nursing home residents, a relationship it has been also suggested for medical inpatients (Zammit, Fiorini, 2015).

**Methodology:** The scoping review has been selected as the appropriate methodology for this study. The general purpose for conducting scoping reviews is to identify and map the available evidence (Arskley,O'Malley, 2005). Scoping reviews can be useful tools to investigate the design and conduct of research on a particular topic and conducted to review current research an identify knowledge gaps on the topic (Munn at al.,2018). According to Arksey and O'Malley (2005) the scoping review methodology is divided into six steps framework: identifying the research question, searching for relevant studies, selecting studies, charting the data, collecting the data, summarizing and reporting results and consulting with stakeholders to inform or validate study findings.

**Results:** A total of 27 studies were included in the final synthesis, mixed designed studies (n=7) including questionnaires, surveys, Geriatric depression Scales, Satisfaction with life Scale, Loneliness Scale, face to face interviews and observations. Furthermore, were included quantitative studies (n=10) included one longitudinal study with 6 years follow up. Finally, were also included qualitative studies (n=10), the studies used a mixture of approach of interviews an observation. The majority of the participants were from long-term facilities (n=24), medical students and nurses were included (n=1) study and mixture of participants such as residents, family members and staff were included in (n=1) study. The most of the studies are from Norway (n=7), China (n=3), Finland (n=2), Turkey (n=2), Poland (n=2), US

(n=2), Belgium (n=1), Sri Lanka (n=1), South Korea and Japan (n=1), Hong Kong (n=1), Malta (n=1), Taiwan (n=1), Iran (n=1), New Zealand (n=1) and Sweden (n=1). In Table 1, we provide a summary of the individual studies.

**Discussion:** This scoping review highlights the importance to continue support residents' well-being in the long-term care facilities, support their mental health and also to continue educate and support healthcare staff as they have the major impact on resident's welfare. Previous studies indicated the correlation between loneliness and depression with demographics factors such as being married, unmarried or widowed for that reason it was recommended by Mahammadi et al. (2016) pay more attention on reducing feeling of loneliness and anxiety by increasing their life satisfaction. We found that only one study was focused on resident's suicidal ideation (Zhang et al., 2020) who concluded from his cross-sectional study with 538 participants, age above 60 years old, from 37 nursing homes in China that 14.9% reported current suicidal ideation but we are worried that this number could be higher and we believe that needs to be done more research for the future to prevent any risk of suicide among elderly. One reason for the lack of information on suicide risk in long term facilities is that prior 2010, universal screening for suicidal ideation in these facilities had not been widely adopted nor recommended as an approach to prevent suicide (Mezuk et al.,2014).



## **Building an Evidence Base – the Krems Arts Education & Dementia Initiative (KAEDI)**

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**Background:** In May 2021, we established the Krems Arts Education & Dementia Initiative (KAEDI). This Austrian initiative aims to encourage the exchange between universities, museums as well as institutions and associations for and by Persons with Dementia. A major emphasis will be on the potential impact of museums and arts education in the field of Dementia prevention. There is scientific evidence that engagement in arts and culture can improve the quality of life of Persons with Dementia and their support providers (Thomson et al., 2018).

**Methodology:** More and more museums are offering inclusive programs to encourage the participation of people with dementia in culture. Especially art can arouse emotions, evoke memories, stimulate conversation, inspire, visually provoke, and trigger associations. To gain an overview of available programs in different museums, we organized the online symposium “Arts Education and Dementia. Enabling cultural participation in museums” on May 11th, 2021 (see <http://www.donau-uni.ac.at/kunstvermittlungunddemenz>). 15 abstracts were submitted and finally 12 art programs from Austria, Germany, Romania, and the USA were presented.

**Results:** Some museums already have long-standing experience in arts education for Persons with Dementia (Ganß et al., 2016), others have just started their programs. Due to the current health crisis (COVID 19), programs in digital form were developed and two digital approaches were presented. Scientific evidence for the benefits of arts educational programs is largely missing. Strengthening the cooperation of museums with organizations from the social and care sectors is important. Furthermore, academic knowledge is necessary to jointly implement and evaluate these programs in order to increase scientific evidence and acceptance for effective programs.

**Discussion:** In order to build an evidence base, KAEDI will initiate interdisciplinary research studies to evaluate specific arts educational programs. It aims to combine academic research with experience from art museums that provide such programs for Persons with Dementia and Persons at risk for Dementia. The study results will form a basis for the development of future initiatives of museums to enhance the quality of life of Persons with Dementia and their support providers.

## The needs of informal carers of people living with dementia: qualitative study

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**Background:** The ageing population requires the higher attention to challenges in providing care for frail older people including people living with dementia. The most of these people prefer to live independently in their home environment. In ensuring such opportunity family and other informal carers play a central role. Therefore, their needs and experiences have to be well explored in order to provide tailored support and care. The main aim of poster presentation is to provide evidence of the wide range of needs and experiences of family carers of home dwelling people living with dementia.

**Methodology:** A qualitative research method was chosen. Data was collected by means of semi-structured interviews with family carers providing informal care of person living with dementia. The thematic analysis process involved several steps that were continuously discussed by the team of all authors. Based on the thematic analysis, nine sub-themes were identified and then grouped into four main themes based on their similarity.

**Results:** The main themes were: 1) Information and Services, 2) Safety, 3) Integrity and 4) Personal Time. None of the family carers interviewed in this study expressed the intention to place their loved one in a residential facility in their current stage of dementia. However, all carers formulated their need for help with actual caregiving in various areas to ensure the person living with dementia will be able to stay at home. Sufficient access to information and services, ensuring safety of relative with dementia, supporting their integrity and sufficient free time for themselves were identified as key factors in coping with care.

**Discussion:** The needs and experiences of informal carers of people living with dementia need to be carefully ascertained. Ensuring appropriate support for informal carers, based on their experience of providing care, is essential to minimise caregiver burden and leads to a better quality of life for carers and those they care for.

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## How do relatives of people with severe dementia experience episodes of lucidity?

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**Background:** There are no studies to date on episodes of lucidity (EL) in people with severe dementia that describe the experience of relatives. The present study aims to learn more about EL in people with severe dementia and how they are experienced by relatives, and to draw conclusions for practice. EL are defined: "Patients with severe dementia sometimes surprise the care providers because they seem to be much more aware of their situation and function much more adequately than usual. Such episodes are labelled 'episodes of lucidity'." (Normann et al., 2002, S. 370).

**Methodology:** For data collection, 10 problem-centred interviews according to Witzel [2] were conducted with 10 relatives of people with medically diagnosed dementia who experience EL, with severity GDS/FAST 6 and 7 according to Reisberg [3].

For the data analysis, we chose the content-structuring qualitative content analysis according to Mayring [4]. For the purpose of communicative validation, all relatives were sent the results for assessment. Study questions: How do the relatives of people with severe dementia experience EL? In which situations have EL appeared? Which triggers or promoting/inhibiting factors do relatives state for the occurrence of EL?

**Results:** Both the experience of the patients from the perspective of the relatives and the experience of the relatives themselves were almost exclusively described with positive feelings (most frequently "happiness and joy"). The lucid moments experienced had a positive effect on relationships and further encounters. Several relatives refer to themselves as a possible trigger. Other triggers and facilitating factors are animals (dog, cat), children, emotions, "not being afraid", biographical topics of conversation, "soul or near-death experience" (mentioned for the longest EL), "person-centredness" and communication/conversation skills. Inhibiting factors include the opposite of person-centredness, environmental factors and the use of medication (antipsychotics/benzodiazepines).

**Discussion:** From the perspective of relatives, knowing the facilitating and inhibiting factors for the occurrence of EL is of great importance for competent care and support of people with severe dementia. In practice, these promoting factors should be used as a guideline in dealing with dementia patients. In order to describe people with severe/very severe dementia more comprehensively, the expansion of the Reisberg stages GDS/FAST 6 and 7 [3] to include a description of EL is recommended. Anyone working with people with severe dementia should be aware that complex consciousness is maintained for longer than is often assumed.

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## Dementia and its problems in Nepal

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**Background:** Dementia has become an alarming problem not only in developed countries but the low and middle income countries like Nepal also could not remain far from this disease. Upliftment in the life style of the people, availability of nutritious food, increase in the people access to the health care sector, the population of the elderly people is increasing. With an increase in the population of elderly people (60 years and above) in Nepal, it is expected to increase the population of people suffering from old age disease like dementia. Currently it is estimated that 50 million people worldwide are suffering from this chronic disease and in Nepal there are more than 135000 people estimated to be suffering from this disease. Thus dementia has become a major challenge for Nepal because there is lack of enough manpower working in this sector and the health care system is not equally accessible to all the people. And the next thing the government does not have any effective plans, policies and programs to tackle with this problem.

**Aim:** to find out the situation of the dementia in Nepal, problems created by it and the effective measures for tackling with this disease

### **Methodology:**

- a. Review of the literature
- b. Consultation with experts
- c. Analysis of the secondary data

**Results:** With the increase in the number of elderly people in Nepal, the disease like dementia is also increasing. Since the country lack farsighted strong plans, policies and programs as well as manpower working in this sector, the situation of dementia patients in Nepal is going to be vulnerable. Thus the government of Nepal must immediately put effective efforts in this sector, seek help from international bodies to fight with this disease.

**Discussion:** It is seen that government of poor countries like Nepal is not paying attention to the non-communicable chronic and neurological disease like dementia. There is lack of governmental special care homes for the person suffering from dementia. However there are some private care house for such patients but these houses are very expensive and behind the access of the normal people. Thus the government must pay attention and give priority for this problem and formulate effective plans, policies and programs in the concerned sector.

## **ART WITH THE SENSES. Enabling social and cultural participation for people with dementia**

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**Background:** The number of people with demential changes will double by 2050. Museums can greatly improve the quality of life of people with dementia and their relatives. They can help raise awareness on the subject and enable participation in social and cultural life. Numerous international studies confirm the positive effects of art. Since 2018, the Tyrolean State Museums have been operating a format titled “Art with the senses. Enabling social and cultural participation for people with dementia”. It builds on the findings of a study conducted at the Lehmbruck Museum in Duisburg and uses the guide to art education for people with dementia published by the Museum of Modern Art in New York. “Art with the senses” comprises a sensorial introduction, the direct experience in front of the artwork, and a creative session in the studio. The programme has been developed in co-operation with the VAGET day therapy centre as a new format of the Tyrolean State Museum in response to societal changes.

## **DAS MOBILE MUSEUM - Kunstbesuche für Menschen mit Demenz**

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Seit 2018 finden im Museum Ostwall im Dortmunder U Workshops und Führungen statt, die sich gleichermaßen an Menschen mit Demenz und ihre Begleitungen richten. Die Kulturgeragogin und Künstlerin Jutta Schmidt initiierte und konzipierte ein umfangreiches Angebot inklusiver Formate für diese Zielgruppe und erhielt für deren erste Umsetzung und Evaluation eine Förderung des Förderfonds für Kultur und Alter des Land NRW.

Da die Museumsbesuche für viele Senioreneinrichtungen eine personelle und organisatorische Herausforderung sind, hat Jutta Schmidt 2019 ein neues ergänzendes Format entwickelt, um die Einrichtungen zu überzeugen, dass sich der Aufwand lohnt: DAS MOBILE MUSEUM. Dieses sucht über die Kunstvermittlung auch die intensive Vernetzung von Pflege und Museum. Ebenso werden Vorbehalte und mögliche Hemmschwellen bezüglich Museumsbesuchen für Menschen mit Demenz abgebaut. Seit 2020 bietet das Museum Ostwall dieses Angebot als reizvollen Einstieg in die Begegnung zwischen Kunst und Menschen mit Demenz an. Das Museum kommt zum Hausbesuch!

Geschulte Kunstvermittler\*innen gestalten in den Senioren-Einrichtungen einen Nachmittag rund um die Kunstwerke des Museums Ostwall. Ein Koffer voller Anregungen zum Fühlen, Riechen, Hören und Staunen machen die Kunst zum Erlebnis und bieten einen sinnlich orientierten Zugang zu ausgewählten Werken des Museums. Auf diese Weise lernen die Senioren und ihre Betreuenden das Museumsteam und dessen Arbeit mit Menschen mit Demenz kennen und erleben gemeinsam einen anregenden Nachmittag rund um die Kunst in vertrauter Umgebung. Ein Besuch des „Mobilen Museums“ ist kostenlos. Allerdings kann er nur stattfinden, wenn ein oder mehrere Museumsbesuche im Museum Ostwall im Dortmunder U mit gebucht werden.

Mit einer großen Akquise-Offensive wurden in 2019 rund 50 Einrichtungen in Dortmund persönlich angesprochen und - sofern Interesse bestand - von Jutta Schmidt und ihrem Team persönlich in der Einrichtung für ein Informationsgespräch besucht. Daraus haben sich rund 45 Buchungen generiert. Durchschnittlich buchte eine Einrichtung, wenn sie für das Projekt gewonnen werden konnte, ein „Mobiles Museum“ und zwei Museumswshops.

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See you at the

**4<sup>th</sup> Krems Dementia Conference  
“Dementia on the Move”**

Autumn 2022 (exact date to be announced)  
<https://www.donau-uni.ac.at/dementia-conference>

