Book of Abstracts

2nd Krems Dementia Conference VIRTUAL

Dealing with Dementia: Prevention, Timely Detection and Awareness

Coordinated Efforts in Europe Between East and West

16-18 November 2020
Krems, Austria

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ABSTRACTS – KEYNOTE LECTURES

Social health and dementia prevention

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Background: We human beings need other persons to function well. Framing social functioning under the umbrella of social health profiles the role of interactions between persons in managing health. A striking finding is that social health is associated with incident dementia. However, the study of social health is in its infancy and more clarity on the concept and constituent domains is needed to facilitate epidemiological research on the relation between social health to dementia.

Aim: To study the strengths and gaps in epidemiological research on the relation between social health, cognitive functioning and incident dementia.

Methods: A systematic literature review was performed to identify social health markers associated with incident dementia. We development a framework on the social health concept, its constituent domains and markers and used it to scrutinize the epidemiological databases of the European Joint Programme Neurodegenerative Diseases project Social Health And Reserve in the Dementia patient journey (SHARED) project.

Results: The literature review indicated that experiencing combinations of unfavourable social characteristics (i.e. social isolation and living alone) forms a risk factor for both development of dementia and worse cognitive functioning while the opposite (i.e. participating in leisure activities or favourable social relationship) seemed to be protective.
The analytic framework focuses on the two levels in social interaction, the individual and the social environment. Scrutinizing the epidemiological datasets included in the SHARED project identified important gaps: the identified markers mainly related to the social environmental level and not to the individual level in social interaction.

Conclusion: The conceptual framework paves the way to investigation of the relation between social health and cognitive decline and dementia. It allows to systematically identify relevant social health markers. The finding that the social capacities of the individual are not considered in epidemiological databases requires the use of other methodologies to identify and operationalize these markers and feed them into epidemiological databases.
The social health framework can contribute to bridging the gap between social and biomedical sciences. It stimulates to no longer taking human interactions for granted but to engage in unravelling the contribution of social health to cognitive decline and dementia.

The NYU Caregiver Program: Years of Experience

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To address the needs of caregivers who provide help selflessly to their relatives and friends, researchers and clinicians at NYU developed The NYU Caregiver Intervention (NYUCI), which was evaluated by Mary Mittelman and colleagues in a randomized controlled trial funded for two decades by the National Institutes of Health. This study and its replications and translations demonstrated that enhancing social support through a multicomponent intervention tailored to individual strengths and needs has numerous long-term benefits for family caregivers and people with dementia.

The intervention includes a comprehensive evaluation, 6 sessions of individual and family consultation within four months of enrollment, and ad hoc counseling -- additional consultation as needed - as well as encouragement to participate regularly in a support group. The potential cost savings attributed to improving caregiver well-being so that they could keep their relatives with dementia at home rather than placing them in residential care led to the funding of nine caregiver support programs in New York State in 2016.

One of these programs, The NYU Alzheimer's Disease and Related Dementias Family Support Program (FSP) is directed by Dr Mittelman at NYU Langone Medical Center. The grant from New York State makes it possible for caregivers and their relatives with dementia in New York City to receive, at no cost, ongoing care consultation, evidence-based services, referrals, support as well as novel interventions designed to improve quality of life and reduce the negative effects of dementia and caregiving. More than 1500 caregivers and their relatives with dementia have benefitted from the services of the FSP since its inception.

Research leading to better diagnosis and care in memory clinics – findings from the ABIDE project

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The advances in diagnosis of AD using MRI, markers in Cerebrospinal Fluid (CSF), and amyloid-imaging using PET are among the largest successes of AD research. Nonetheless, in a large proportion of patients, a diagnosis is only made in a late disease stage. A better and timely diagnosis would be very beneficial, as patients can receive help quicker and more effectively. ABIDE is a Dutch project that aims to improve AD diagnosis in memory clinics, by promoting effective application of MRI, CSF, and PET for diagnosis of MCI and AD in memory clinics, taking into account patients' perspective and wishes on their use.

In this lecture, innovations in diagnosis will be discussed with a focus on practical implications at everyday memory clinics. We developed individualized risk models that allow estimation of probabilities of progression from MCI to dementia, taking into account patients' characteristics. The risk models are integrated in an easy to use app, called the ADappt. An audiotape study provides a sneak preview in the consulting room with patients, caregivers and professionals, and shows that patient-doctor communication to date is a rather one-direction street and only limited information is provided on a patients' personal prognosis. A Delphi study resulted in a core topic list on which patients, caregivers and professionals agree that these should be discussed during the diagnostic process, and this could help to empower patients/caregivers and provide doctors with a guideline on how to incorporate shared decision making in the AD diagnostic process.

With the development of new diagnostic tests, we enter an era where we can actually start to translate findings from science to everyday clinical practice. Tools to support the diagnostic process, may act as a catalyst for quicker and more effective diagnosis. Diagnosis of AD should be personalized, in terms of both patient biology and preferences.

Prevention of stroke and dementia

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Currently, 14 million stroke occur every year and 80 million people are living with the consequences of stroke. While vascular brain lesions contributing to the appearance of dementia are quite frequent, at least one third of all dementias are a direct consequence of stroke. The World Stroke Organisation has published a Declaration of Prevention of Stroke and Dementia (Lancet Neurology 2020) which focuses on major changes of prevention: It is argued that in order to reduce incidence rates of both stroke and dementia, population-based prevention measures must become effective. Mostly only individual high-risk prevention is established as a medical practice, whereas the very more frequent stroke numbers caused by low and medium-risk persons are hardly ever the focus of attention. It is postulated that heat maps showing differing risks by colour in a population or showing risk attributes such as 'low risk' and 'medium risk' should be abandoned in favor of a continuum of risk. The attribute 'low risk' gives false assurance that there is no risk. Population-based prevention also includes the need for bolder activities by governments focusing on increased sugar, tobacco and alcohol taxation (STAX). Moreover, the project 'Cut Stroke in Half' has been developed that is estimated to prevent 50% of strokes and 30% of dementias occurring in a population. Initial experiences are already ongoing and encouraging. With use of community health workers, e-health measures and polypill applications these population-wide prevention effects can be seen and become effective for the reaching the sustainable developmental goals to reduce excess mortality by NCDs by 2030.

Developing, sustaining, and spreading rural primary care memory clinics in Saskatchewan, Canada

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Background: Limited access to specialists and services in rural areas results in greater responsibility for dementia diagnosis and management in primary health care (PHC), yet there are few evidence-based practices for rural dementia care. This presentation will describe the collaborative work done by the Rural Dementia Action Research (RaDAR) team and rural PHC teams in Saskatchewan, Canada to develop, implement, sustain, and spread an intervention to address this practice gap.

Methodology: The development and implementation process was informed by a five-step approach for adapting innovations to local settings. Seven principles of effective PHC for dementia from the literature were organized into the domains of team-based care, decision support, and specialist-to-provider support. In partnership with one rural PHC team (nurse practitioner, home care nurse, occupational therapist, physical therapist, Alzheimer Society First Link Coordinator) we iteratively co-designed and implemented strategies for operationalizing these principles in ways that were feasible and sustainable in the rural context.

Results: This work resulted in an ongoing monthly full day interdisciplinary Rural Primary Health Care Memory Clinic. Flow sheets based on best practices for dementia assessment and management were adapted for team-based care and embedded in the electronic medical record. A process evaluation informed by the Consolidated Framework for Implementation Research identified contextual factors influencing intervention development. Facilitators included the intervention's relative advantage, tension for change, and engagement of champions; barriers included intervention complexity, lack of co-location of team members, and workload.

Discussion: After developing a working model for the memory clinics in the first team, we gradually spread to four other communities, making adaptations as needed to fit the local context and PHC team composition. To facilitate further spread we have developed a plan involving a one-day training workshop, mentorship, education, and organizational support for new teams. Multiple studies to evaluate clinic outcomes are planned or underway.

Are high-income countries prepared to deliver a disease-modifying Alzheimer's treatment? Findings from a global surveillance program

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Background: We may see the first disease-modifying Alzheimer's treatment as early as 2021. However, the complexity of identifying treatment-eligible patients, diagnosing them formally and administering the treatment combined with the large backlog of prevalent cases may overwhelm the existing infrastructure for memory care. Our research program analyzes the capacity of health systems in terms of dementia specialists, imaging equipment and infusion sites to estimate wait times for a treatment. The program also looks into institutional arrangements, such dementia policies, payment and care delivery models and regulation, in memory care, as well as emerging technologies.

Methodology: Desk research, expert interviews and simulation modeling.

Results: All G7 are expected to have substantial wait times when a treatment first becomes available exist in all G7 countries. Peak wait times are projected to be similar between 11 months in Germany, 14 months in the U.K. and Japan, 19 months in the U.S. and 28 months in Canada. Substantial numbers of patients might progress to a disease-state, in which a treatment will no longer be effective. Many countries functionally operate their healthcare systems under global budgets, either directly as in tax-funded countries, like the U.K or Italy, or indirectly through a combination of price regulation and volume controls in social insurance countries, like Germany. This approach limits the growth in healthcare spending but make it difficult for the system to absorb unanticipated substantial increases in demand for services, even if they are temporary. Improved diagnostic technology, such as blood based biomarkers for Alzheimer's disease, has the potential to reduce wait lists and costs.

Discussion: As the COVID-19 pandemic has taught us, even the most sophisticated healthcare systems can be overwhelmed by sudden surges in the demand for services. The arrival of a disease-modifying treatment for Alzheimer's disease may result in a similar scenario, in which current health system capacity is insufficient to cope with the expected influx of patients, who will seek diagnosis and treatment. Unlike the COVID-19 pandemic, there is still time for healthcare systems to prepare to ensure the needed capacity is in place to provide access to new DMTs when they arrive. Time, however, is limited as recent trial results suggest that we may see the first disease-modifying treatments as early as 2021.

Challenging behavior of nursing home residents during COVID-19 measures in The Netherlands

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Background: Our objectives were to gain understanding from the perspective of the nursing home (NH) practitioners, of (1) whether challenging behavior in NH residents changed during the COVID-19 measures, (2) whether the practitioners' involvement in the treatment of challenging behavior changed, (3) what can be learned from the experience of NH staff.

Methodology: We conducted a mixed methods study with a survey in 323 NH practitioners (psychologists, elderly care physicians, nurse practitioners) in the Netherlands, and in-depth interviews in 16 NH practitioners. Non-parametric analyses were used to compare estimated proportions of residents with increased and with decreased challenging behavior. Content analyses were conducted for open-ended questions and in-depth interviews.

Results: Participants reported slightly higher proportions for increased than for decreased challenging behavior. Although it seemed that the extent to which practitioners were involved in the treatment of challenging behavior did not change considerably, half of them reported that their work load increased and work satisfaction worsened during the measures. Different strategies and person-tailored solutions were reported and suggested.

Discussion: Because COVID-19 measures resulted in both increased and decreased challenging behavior in NH residents, it is important to monitor for their potential longlasting effects. Increased work load and worsened work satisfaction of the NH staff, together with the changes in type of the challenging behavior, indicate that the harmful effects of the anti-pandemic measures should be taken seriously.

Dementia and long-term care in COVID-19 times

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Background: The COVID-19 epidemic brought new challenges and highlighted somme problems that were known but still insufficiently addressed. New topics and needs for knowledge have emerged. In addition to biomedical ones, these are issues of care and organization, adequate support and psychosocial interventions in the care of people with dementia, but also preventing the spread of infection and optimizing measures to be minimally restrictive but effective against spread of the infection. One of the problems that the coronary crisis also accentuated in the Czech Republic was care in institutional facilities.

Methodology: In the Czech Republic, data on patients in various types of long-term and residential care facilities are not fully available yet. Therefore, case studies of care facilities and their responses to various degrees of anti-epidemic measures were chosen.

Results: Most restrictions were applied to long-term and residential care facilities. These included lock-down, bans on visits etc. Moreover, some facilities responded by voluntarily preventive quarantine of all clients and employees for various lengths of weeks to months. Other facilities applied a strict anti-epidemic regime with minimal restrictions (applied only mandatory ones according to the current situations and updating their anti-epidemic plans and maintaining preventive measures).

Discussion: The COVID-19 epidemic is still ongoing and we do not yet know what impact it will have in individual countries. However, initial experience and case studies of institutions providing care to vulnerable groups, including people with dementia, indicate that the pandemic has revealed and accentuated many challenges, also the need for better health care for people with dementia and other vulnerable groups in residential long-term care facilities. This can contribute also to better setting of anti-epidemic measures and thus preventing the spread of the virus.

ABSTRACTS – INDIVIDUAL SESSIONS

SESSION Community Projects (Part 1): How can integration be made possible?

"The Dementia-friendly library Wiener Neustadt" – Health promotion for and with people with dementia and their carers in non-health settings

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Background: People with dementia and their caregivers may experience restrictions in social participation. Public organizations need to provide good health information to support citizens and improve their health literacy when living with cognitive impairment. There is little knowledge about how non-health organizations in a city can contribute to enhanced health literacy and foster social participation of people living with dementia and their carergivers. Libraries are spaces of education and learning and thus have an important function in a city. They offer possibilities to participate in public life but can also provide information and offer space for connection and collaboration.

Methodology: We aim to create a dementia-friendly library in collaboration with two other organizations in the community: the information service point of the city hall and a museum. Using a participatory health research design based on needs assessments with mixed methods with management and staff from all three organizations ensures sustainability. All interventions are developed collaboratively in the steering group with the local self-help group Alzheimer Austria including the perspective of caregivers of people with dementia and an activist living with cognitive impairment as well as the management of all three organizations.

Results: We will present findings from the needs assessment including online focus groups with staff and real life focus groups and interviews with people with dementia and their carers.

Discussion: The need for health promotion with people with dementia is even greater during the COVID-19 pandemic and challenges and chances will be discussed.

Dementia friendly police: An update

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

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

Results: For the initial evaluation, a questionnaire was developed assessing the following areas: (1) usability, (2) relevance to practice, (3) increase in competence (4) sustainability, (5) didactic. 221 Police officers completed the training program and 23 filled in the questionnaire anonymously. 78% were very satisfied with the learning program, 20% were satisfied and 2% were not satisfied. Officers mentioned that the usage of media (film and drawings) was very positive. They emphasized that they would use the program again if they would need it. Some resources such as the checklists (recommendations for a person search) were printed out for continuous use. To date, almost 11.000 Police Officers have been trained with the modules. 241 Police Stations have been certified as "dementia friendly. This is about half of the Austrian Police task force. The learning program received several national and international awards (Sozialmarie 2018, E-Award 2019, Austrian Price for Public Administration 2019 and Mission Dementia was nominated for the European Price for Public Administration and was included into the toolbox of the WHO in 2020.

Dementia Active Community

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Background: Persons working in the public administration such as community administration often serve as a first point of contact in critical situations for both persons with dementia and their relatives. In order to be sensitive to the special needs of persons with dementia, training is essential. Therefore, the follow-up project of "Mission Dementia", "Active Community" was initiated.

Methodology: Using a focus group methodology involving different professional groups within the public administration, current understanding and the needs and wishes for a Dementia teaching tool were assessed and discussed.

Results: The concept and content of 3 learning modules and one evaluation module was developed and is in the process of technical implementation. After the completion, the teaching tool will be made available to the Pilot region of Burgenland, one of the nine regions of Austria and tested for (1) usability, (2) relevance to practice, (3) increase in competence (4) sustainability, and (5) didactic strengths. A certification process for communities is currently developed.

The dementia Network Upper Austria

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The presentation introduces the „Network DEMENTIA Upper Austria" and its goals and services. The guiding Idea of our program is „dementia – detect – talk about – act!"

It takes a closer look at the steering mechanisms as part of the "Zielsteuerung" (a nationwide and regional strategic health steering process) and the link between politics, social insurance and the organisations that provide the services.

Some of the benefits of a network such as the pooling of knowledge and common development leading to an Upper-Austrian-wide standardised service are highlighted. I also address the framework needed to put up such a federal state wide service.

The goals set provide opportunities for both the persons with dementia and their carers and for the health- and social system.

These goals are:

For the people with dementia and their carers
▫ Increase of life quality for both groups
▫ Reduction of behavioural problems
▫ Delay of progression of the disease due to training of the persons resources and abilities
▫ Decrease the burden of care

For the health- and social-system
▫ Comparable quality standard within the network in Upper Austria
▫ Increase of target group specific take-up
▫ Optimize medical resources
▫ A framework for effective and affordable services

The Upper Austrian dementia program is built on two columns one offers easily accessible services for people living at home the so-called "Dementia Service Centers" and one focuses on nursing homes in Upper Austria providing dementia specific services for the setting and a collaboration of professions.

I'm focusing on the offerings, evaluations and numbers of our "Dementia Service Centers" and the nursing home Program.

To summarize the presentation up, I reflect on how the program – that has its roots before the creation of the Austrian Dementia Strategy „living well with dementia" – fits into the goals of this nationwide platform.

Why social care matters. The economics of dementia care in Austria.

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Background: There is overwhelming evidence that the number of persons with dementia will increase rapidly in the next years. Economic simulations forecast an increase for pharmaceutical treatments and as far as there is no cure for dementia in sight, the fast deterioration of the dementia severity level is a crucial cost driver. Further, the cost for informal care could be a game changer to reduce the yearly cost increase. Therefore, it is crucial to estimate the total cost to elaborate how the informal care cost will increase relatively to the direct cost of a non-pharmaceutical treatment.

Methodology: Based on the administrative and clinical data of the Dementia Service Centres (DSC) in Upper Austria, we deployed a time-discrete Markov-chain model to simulate the cost development of dementia by using two assessments with the Global deterioration scale of 1,341 clients within one year and display the progression in transition probabilities. The cost assessment was undertaken with the administrative data of the DSC and was entered in the simulation model. Thus, this model helps to extrapolate the costs with the progression of dementia and could simulate how the direct and indirect costs increase within 10 years.

Results: In total we see that a cost increase from EUR 69 million in year one to EUR 139 million in year ten. The cost of informal care takes 74% of the total cost share. Hence, the cost of hours needed to care are double in ten years. Also, the direct cost increases by the 1.5-fold within the same time. In total the costs of informal care per person with a mild (severe) form is EUR 39,933 (EUR 69,746) per year, compared to the treatment cost of EUR 3,533. One crucial insight is, that the cost share of people with severe dementia prevails the costs of mild forms – ceteris paribus – after four years.

Discussion: Our cost simulation shows that the costs of informal care exceed the treatment cost by far. Taking care of a relative with dementia is highly associated with the severity level and is one of the main cost drivers beside the deterioration of the dementia status. We want to stress that the social support could help to remain in mild or moderate dementia severity level. Hence, the support of the social environment and social support systems could help delay the deterioration of dementia and could therefore thwart the cost increase.

SESSION Diagnostics

Cognitive Assessment for Immigrants

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Background: In the calendar year 2002, only one percent of those evaluated at the Geronto-Psychiatric Center for Psychosocial Services of Vienna consisted of those born in another country. At present, the figure stands at 20% of all neuropsychological examinations.

Methodology: Selection of suitable testing procedures and investigation of the question whether immigrants respond differently to the tests than subjects born and raised in Austria.

Results: What has proven reliable are the "Quick Clock Three-Word Combination" which is independent of education and culture, the "Mini Mental State Examination," and the "Ten Word Test with Encoding Enhancement." For those who have enjoyed no educational opportunity there is the transcultural, non-verbal "EASY-Test." Although immigrants undergoing their first assessment at the Gerontopsychiatric Center are on average several years younger than the native-bred Austrians, they come for assessment in a considerably more advanced state of dementia.

Discussion: Because of burdens specific to migration, such as traumatic experiences, insufficient financial resources, and unfulfilled expectations, immigrants of the first generation are subject to processes of ageing that incur a higher risk of dementia earlier in life. Cognitive assessment for this population will acquire greater significance in the future.

Strotzka, S. (2015). Kognitives Assessment für Migrantinnen und Migranten. *Zeitschrift für Gerontologie & Geriatrie, 48*, 10-14.

How can we examine the patients with Subjective Cognitive Decline?

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Background: Subjective cognitive decline (SCD) is a common among elderly population and despite that it has been associated with an increased risk of future progression to Alzheimer's disease (AD) is still unexplored. The examination of this stage of AD spectrum is among the most important research subjects currently.

Methods: The literature review was performed across a number of electronic databases in October 2020, including Medline (via PubMed), EMBASE, PsycINFO (Psychological Abstracts), Cochrane Database, and CINAHL Database. Among the several terms, thee search included the following: ''subjective cognitive decline'', ''memory complaint'', "neuropsychological assessment", "tests", "Subjective memory/cognitive impairment", "and ''subjective memory loss'', "EEG", "MRI", "APOE4", "neuroimaging". The searches were not limited by date of publication or study design. Only English studies were included.

Results: 875 citations were identified, 432 papers were obtained, of which 80 were selected for containing neuropsychological examination, neuroimaging assessment and biomarker detection of SCD. Although they may not present detectable signs of disease, SCD score lower on several neuropsychological tests than the healthy controls (HC), and they also have a higher incidence of future cognitive decline. Regarding the APOE4, the results provide mixed evidence linking coincident APOE4-positive genotype and SCD. On the other hand, magnetic resonance imaging studies in SCD reveal a pattern of hippocampal atrophy similar to that of amnestic mild cognitive impairment, while brain connectivity as found after EEG examination shows aberrant connections and local dysfunction in several network metrics in the SCD compared to HC.

Conclusions: Narrative review provided mixed evidence linking worse neuropsychological performance, brain atrophy and brain network organization in SCD compared to HC. Though there was little evidence to suggest that a particular test predisposes individuals to developing SCD, several assessments found to be promising in order to discriminate this population.

SESSION Community Projects (Part 2): How can integration be made possible?

Alzheimer Cafés in Hungary – Response to the COVID-19 pandemic

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Background: Alzheimer Cafés (ACs) are regular informal social gatherings with the ultimate goal of improving the quality of life of those living with dementia and of their caregivers. In March 2020 the COVID-19 pandemic almost brought Hungary to a total standstill for a few months. At the same time many public health- and social services – including day care for people living with dementia – were suspended temporally, and ACs followed suit by ceasing in-person operations indefinitely. "Social" distancing advices added a further blow to the availability of (informal) supporting resources. It seemed only natural for some activities to go online – public and higher education, some health services, telework, retail, etc. –, and the option to continue or move some of their activities to online platforms was available for ACs as well.

Methodology: (In order to understand the online activities and strategies of ACs, a desk research method was employed. The data collection covers 12 months in total from September 2019 until August 2020 providing sufficient amount of data, a time period that is split into two roughly equal periods of six months immediately before and after that watershed moment of COVID-19 outbreak in early-mid March, 2020. All Hungarian ACs with an online presence were mapped, and the content they shared on a webpage or on Facebook were categorised according to their perceived functions (intended or unintended), a list of 10 benefits that an online platform could potentially enable realising from basic to more strategic long-term community goals.

Results: Most Hungarian ACs are present on the internet, and content- and format-wise there is a wide variety of what they are sharing and how they are operating there. Most ACs refrain their online activities to the bare minimum of informing their community about their actual on-site (in-person) AC-event series, their overarching rationale of existing, of course. After the COVID-19 outbreak and the suspension of on-site activities most ACs informed their community about it, and while some of them ceased online operations, others kept posting about the pandemic and other miscellaneous content. A couple of ACs even offered personalised support, and one moved their meetings online. However, there were hardly any

attempts in the entire scene to realise additional community-level benefits via their online platforms, regardless of the pandemic.

Discussion: There is a need for a reflection on and improvement of online practices and methods used by ACs in Hungary. Some ACs have no online presence whatsoever, while many others use only a static website that provides no real opportunity for online community engagement. However, available technological means themselves are no guarantee of a lively and solidarity-based online community either, as it probably requires active facilitation. ICT-training for key personnel and a community-building strategy might be needed, but such investments could eventually pay off at individual and community levels by for example reinforcing solidarity and peer-support; outreaching for underrepresented target groups (like e.g. middle-aged carers from the "sandwich" generation); or enhancing the empowerment of its members.

The MAKS® therapy: effects of a multimodal, non-pharmacological intervention for people with mild to moderate dementia

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Background: In view of the low effect sizes of pharmacological therapies for Alzheimer dementia, non-pharmacological therapies are gaining in importance.

Methodology: The multimodal, non-pharmacological MAKS-therapy® consists of four components: motor (M), everyday practical (A) and cognitive (K) training in a social-communicative (S) environment [1]. MAKS® is conducted as a group therapy with 10 to 12 participants with mild to moderate dementia and two therapists in day care facilities and nursing homes. The effects of MAKS® were investigated in two randomised controlled trials [2, 5].

Results: The five (a to e) most important results are: stabilisation of cognitive (a) and everyday practical (b) skills in the intervention group and significant decrease in the control group already with regular use of 1 to 2 days per week (c) [5]. In addition, there were significantly effects on emotional symptoms (reduction in depression) and behavioural symptoms, in particular improvement in social behaviour (d), both in comparison with the control group [3]. A detailed health economic analysis in day care facilities concludes that the MAKS® intervention is cost-effective in the care of mild and moderate dementia patients (e) [4].

Discussion: According to Steinbeißer et al. [4] MAKS® should be introduced as standard treatment in day care facilities.

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Evaluating a complex intervention in integrated dementia care: a mixed methods research and design approach

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Background: Evaluations of complex interventions for people with dementia (PwD) are often hampered by data gaps (e.g. lack of diagnose coding in ambulatory care). Also, the multidimensional approaches required to cater for the needs of PwD are hardly captured with a single empirical method. The focus of this study is on integrated care for PwD provided at the Geronto-Psychiatric Center for Psycho-Social Services Vienna (PSD), which works in a multi-professional team as an ambulatory institution with the objective to enable PwD to ensure care at the best point of service, and high quality of care, while considering also needs of informal carers.

Methodology: The study uses a mixed methods research and design (MMRD) approach adapted from Bergman. MMRD emphasises the role of individual researcher(s) in considering different epistemiological and methodological perspectives. The qualitative part included 8 semi-structured interviews with informal caregivers, 6 expert interviews with care professionals, 1 group interview with the multi-professional team at PSD, and a qualitative analysis of 200 evaluation forms from professionals who participated in trainings at PSD. The quantitative part included a quasi-experimental analysis of administrative data (propensity score matching), quantitative analysis of training evaluation forms, and a descriptive analysis of data on PSD patients. The study period was April 2016 to December 2019.

Results: While the quantitative analysis of the study is still ongoing, qualitative results shows that PSD's multiprofessional approach in dementia diagnostics has been successful in ensuring care at the best point of service for PwD, in particular the possibility of home visits on behalf of professionals. Interviews with informal carers clearly highlight that respite effects have been achieved. Integrated care is enabled by functioning relations between network partners, coordinated by PSD. Similar initiatives should be extended across Vienna to cater for the increasing need for multidimensional approaches in dementia care. Qualitative and quantitative elements mutually benefited from the analysis by identifying additional elements to be considered, or clarifying underlying mechanisms.

Discussion: The qualitative part of the study provides indications of the successful elements PSD's approach to dementia care. Support for informal caregivers and home visits as well as functioning collaborations with network partners in long-term care and health care are key elements for success. In evaluating the project, the intervention's complexity could not have been grasped empirically without MMRD, which was integrated at the research design stage, and during analysis. As opposed to monomethod studies in evaluating complex interventions for PwD, MMRD thus presents several advantages in gaining a deeper understanding of the multidimensionality inherent in many integrated care interventions.

Perception of professional carers on quality of care of home dwelling people

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Background: The number of people with dementia and the demand for long-term care provided in person's home environment is increasing. The aim of such care is to enable the person to stay at home as long as possible and to prevent hospitalization or other institutional care. When providing care in the home environment it is necessary to focus on patient's needs and experiences. The aim of this presentation is to provide our findings on quality of care of home dwelling people from the perception of professional carers. This study was funded by the Grant Agency of Charles University, project n. 760219 (Met and unmet needs of vulnerable older patients receiving healthcare at home and in hospital).

Methodology: A total of 3 focus groups with home health care nurses and 9 face to face semi-structures interviews with social care workers were conducted. An exploratory-descriptive qualitative approach was chosen. During data collection, the researchers focused on the areas of "what" and "why". Data were analysed in the means of content analysis. To ensure the trustworthiness of this study, the recommendation of Graneheim, Lindgren and Lundman (2017) was followed.

Results: According to content analysis three main areas were identified. 1) Needs assessment method; 2) Settings for a care plane; 3) Communication with other carers including professionals. The starting point for ensuring all three areas is 1) to targeted education of (not only) caring professionals and 2) following the principles of case management.

Discussion: Professional caregivers are aware of the need to provide patients in home care of the best possible quality. These caregivers consider as important to identify the needs of their patients and to tailor care to those needs. The key is therefore undoubtedly the setting of individualized and person-centred care. High-quality communication between caring professionals and mutual information sharing is essential.

Digital Storytelling in Dementia Care

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Background: Supporting caring relatives is one of the most important factors to reduce caregivers' burden to ensure high-quality primary care for people with dementia. Recent studies have shown that the knowledge of family carers in terms of dealing with the disease must be improved. This work aims to enhance the knowledge sharing process among informal caregivers together with healthcare professionals to help affected people and their families on getting appropriate help and social support without spending hours on research or ending up in despair.

Methodology: The storytelling method has been shown to be particularly suitable to record personal experiences and to encourage involvement. Digital storytelling is an innovative technique that can improve knowledge translation by utilizing multimedia content, such as short videos, pictures or audio. A prototype for sharing stories in an online environment with a user-centered design approach will be developed based on analysis and benchmarking of existing systems as well as semi-structured interviews with informal caregivers and professional stakeholders focusing on questions of how they want to share their stories and what factors affect their participation.

Results: The emerging stories show different situations and how people deal with them. The know-how of laypeople is complemented with expertise from healthcare professionals. Firstly, suitable types to record experiences are introduced. Secondly, approaches to structure and distribute these narratives for an adequate representation, navigation and search are developed. Finally, solutions are proposed to keep this user-generated content up-to date and accurate. A high-fidelity prototype based on the theoretical and empirical results will be implemented and evaluated by the end of 2020.

Discussion: This work aims to contain the increased risk of loneliness and mental illness of caring relatives. In rural areas, there is often no possibility to participate in support groups or some carers may not have time due to their permanent care obligations. An online community

for sharing experiences based on real-life conditions is supposed to close this gap. The stories intend to encourage and help other informal caregivers in coping with difficult situations. Feeling competent and connected to others contributes to an improved quality of life. Moreover, the platform can serve as a network to exchange and motivate dementia-friendly initiatives.

AAL-technologies for/with people with dementia – the user's perspective

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Background: Living with dementia changes everyday routines and need growing support by care persons. Specific technologies can facilitate certain challenges coming along while living with dementia (e.g. in the area of safety or orientation). There are numerous technological developments, but they often have difficulty meeting the needs of the target group. Therefore, the project aims to identify the needs, wishes and requirements of people with dementia and their caregivers with regard to the use of assistive technology in their daily lives and to make them available for technology development in Austria.

Methodology: For this purpose, a literature search, qualitative-empirical surveys with people with dementia and their caregivers were conducted throughout Austria. Two focus groups with care experts were carried out face to face. With respect to Covid 19, the focus group with persons with dementia in collaboration with PROMENZ were carried out via zoom. Problem centered interviews with relatives mostly were conducted via telephone. A first thematic analysis has been carried out.

Results: Research results of literature review show that products do not systematically take into account the needs, requirements and everyday routines of people with dementia in the development of new technologies. Concerning people with dementia it becomes obvious that technology already is part of everyday living. There are different needs for technological development and basically it is important that use of technology is easy to understand and affordable. Women are disproportionately represented both in the very old age population and among caregivers. In this respect, the question of gender-specific requirements is also relevant.

Discussion: The question of how technological support systems can best support and facilitate the life of people with dementia and their care persons has to be answered in different dimensions. First it has to be acknowledged that the individual living situation and social structure influence the access to new technologies. Daily routines often already are supported by technologies. Gender effects as well as the experience with technology influence the use of new technologies. Different needs of people with dementia and their caregivers have to be taken seriously.

SESSION What did we learn from COVID-19?

People with dementia and covid-19 pandemic – actual croatian condition

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In Croatia, we are still lacking such kind of officinal state plan although there is an initiative of Croatian Alzheimer Alliance (HAA) for several years ago. HAA has now 31 members, e.g. different societies or NGOs who are working for better life of PwD and supporting the need of developing national dementia strategy. Although a national strategy or an action plan for a fight against dementia has yet to be adopted by Croatia, there are numerous friendly initiatives for people with dementia, primarily non-profit organisation such as the Croatian Society for Alzheimer's Disease, societies such as the Croatian Society for Alzheimer's Disease and Old Age Psychiatry, and referral centres of the Ministry of Health supported by the Croatian Alzheimer Alliance, which gathers numerous relevant participants and therefore aids people with dementia and their families.

Soon after the pandemic of COVID-19 has entered in our country, Croatian Society for Alzheimer's Disease and Old Age Psychiatry started to provide information and advice for people with dementia and their carers. In April 2020, we published Recommendations for people with dementia - how to stay healthy during COVID-19 pandemic (1). Due to high risk of coronavirus infection while coming to hospital and siting in waiting rooms we offer our patients video/audio counselling and virtual program in Day hospital (via Zoom). All our activities were modified on daily basis - when the daily number of new corona cases was low we open again Day hospital and live counselling, with all epidemiological precautions. As far it is possible we try to promote physical distance but not the social distancing among people with dementia (2).

In October 2020, due to worsening of pandemic, and regarding the high number of new COVID positive (asymptomatic) cases the personal visits to inpatients and to nursing homes are forbidden. So, nowdays we are trying to resolve all worsening of psychic state of persons with dementia through outpatient clinic. We hospitalise much less, only urgent cases, keep hospitalization brief, because we are aware that isolation of persons with dementia, without allowing regular visits from carer is not benefitial for mental status of persons with dementia.

COVID crises is shoving us how important is to develop multiprofessional kind of help which can be provided at home of person with dementia.

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COVID-19 and Dementia - exchange of experiences and chances for the future

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Background: The annual conference by the Austrian Dementia Strategy focuses on challenges and chances for people living with dementia in the context of the current COVID-19 pandemic. Therefore, four online talks are held between September 21st and November 5th. For each talk, a specific audience is invited to talk about their experiences during (March 16th – May 1st) and after the lockdown in Austria.

Methodology: The first online talk has already taken place. The target group were people living with dementia themselves as well as their relatives, partly represented by support groups. They were invited to talk about their personal experiences. The upcoming talks will focus on:

- the view and experiences of institutions that provide either care for people living with cognitive impairment or have an advocacy role for those
- chances for the future with a focus on digitization: presentation of a recent study regarding dementia and digitization, conducted by the university of Vienna. Furthermore, there will be discussions on benefits of the use of technical options as well as ethical aspects and challenges.
- summary of all talks and derivation of needs for action, also in accordance with results from the currently running reform in long-term-care.

Results: The first online talk showed different perspectives on the beginning of the pandemic and the lockdown. One dementia-affected person told about coming to rest in the first days of the lockdown and that a certain deceleration and relaxation could be achieved. She was also able to learn about how to use modern technology (video meetings). However, in the further course of the lockdown she suffered increasingly from social isolation and felt a deterioration in her cognitive and physical abilities. Other topics in this talk were about difficulties that carers had and (dis)advantages of online meetings that support groups identified.

SESSION Update on dementia plans from different countries

The Austrian dementia strategy "Living well with dementia"
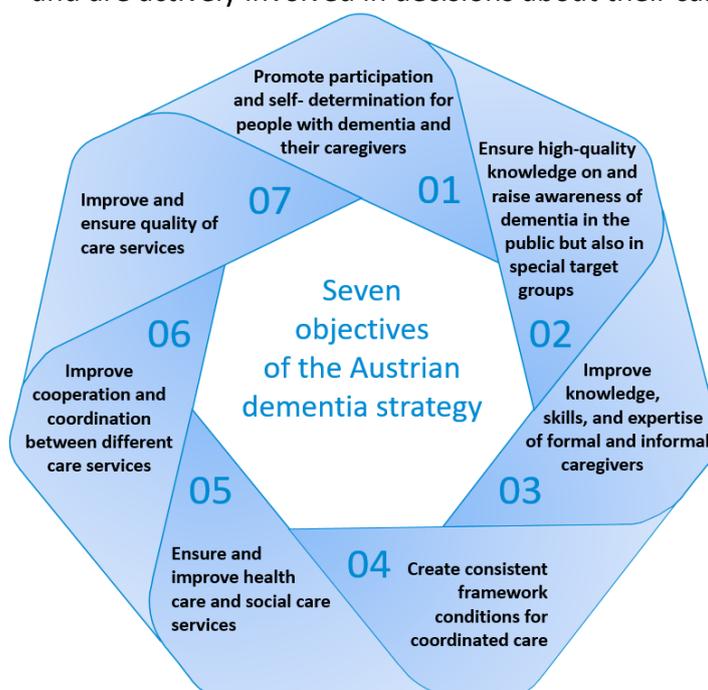
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The Austrian dementia strategy "Living well with dementia" provides a framework of objectives and recommendations for taking action to improve the lives of people with dementia as well as their families and friends.

7 Objectives and recommendations

The strategy aims to create a system in which people affected by dementia and their families and friends

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

The strategy intends to assist everyone in the community to develop a better understanding of dementia and to break down the stigma attached to it.

The first five years period: 2016 - 2020

The dementia strategy is intended to form **a joint orientation framework** for targeted cooperation between the stakeholders.

During this first period, a Dementia Strategy Platform was established. The platform is intended to facilitate coordinated action and the realisation of joint framework conditions and recommendations. To this end, political decision-makers, those realising the actions, researchers and those affected form a joint platform, whereby existing structures are taken into account. It is recommended that similar platforms should be established at a provincial level (particularly in order to involve local authorities).

Tasks:
- Providing impulses for the implementation of the dementia strategy
- Coordination between the federal government and the provinces
- Annual conferences to evaluate the realisation of the strategy
- Coordination and transfer of knowledge via offers, new projects and research results
- Advice on realisation on the basis of research findings
- Support in the development of recommendations and framework specifications – e.g. the main points of specific care concepts
- Knowledge transfer

To ensure participation from the beginning, people effected by dementia, self help groups and informell carers were part of the platform.

Next steps

The current government's program attaches great importance to the dementia strategy. The goal is to provide measures with resources and roll them out throughout Austria.

The Task Force Nursing, a nursing care reform process, is currently working on those measures that are to be given priority in the coming years and are to be implemented in cooperation with many stakeholders.

Website www.demenzstrategie.at

The website www.demenzstrategie.at documents and presents all the measures taken in the federal states to implement the recommendations.

Dementia Policies And Strategies On The Balkan And See

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Although dementia is not direct linked with aging, still most number of dementia cases outbreak after 65. Person can live with Alzheimer 15 maybe 20 years what occupie the whole old age. Countries of Western Balkan as well as whole South East Europe have no developed or adopted National Dementia Strategies/Plans. Besides, dementia is situated very low on the list of priorities all Governments that Region although dementia was health priority for 4 repeatedly EU mandates. For the Regional Governments demographic changes and pressure which they make on health, social system and housing system, social flows are not reason for concern and serious access for tackle with that issues.

Considering that the whole region of SE Europe quite equable by the social-economic aspects and that internal patency rate is very high, we ran international discussion to draw attention of competent policy makers, experts and NGO's on the dementia issues and problems with which people living with dementia faced and how we could with a common engagements of all stakeholders make stronger pressure on a policy makers that they see adoption of National Strategies as project with whose solving they can help to people living with dementia and their caregivers but that they will open unknown niches for business developing in social and health sectors what is not practice in region of the SE Europe. In that way, they could interested younger or middle-aged generation and return confidence in system and to create theirselves future in own countries.

Therefore, at 2018. we had organize Expert meeting for Western Balkan countries with participation of Austria and Slovenia as the positive sample and as countries with adopted National Dementia Strategies to prove potential and to transfer their experience. Through the Sarajevo Statement we invited Governments to participate and encourage developing of National Dementia Strategies. Sarajevo Statement stated that „Systematic support for people with dementia should be implemented through three linked approaches: -policy; -service delivery; - information and research. These approaches can be accomplished through seven action areas which Statement listed. But in the same time, we wanted to point out to the fact that Strategy without Action is not useful and do not help to sides in the realization of their rights.

At 2020. We had organize the second meeting „Dementia Care and Policies of extended Danube Region" with the goal to identify issues of the all societies in the Danube Region and show their connection and causal-consequence relationship between richer and poorer part

of the Danube Region. Conference brought together eminent experts from renowned institutions across almost the entire Danube region. Conference had 34 lecturers in the 11 sessions. The presented topics, created on the basis of scientific research work of lecturers and their teams within renowned institutions and financed by public funds implemented throughout the wider Danube region, confirmed and indicated the following: - Discrimination with regards of human rights; - Outdated and misaligned legislation; - misaligned health care system to needs of PwD; - Social neglect; - Insufficient support of caregivers; -Absent or national Dementia Strategies without actions.

In conclusion, Every solution have to be comprehensive and self-sustainable and treat the all aspects of life. Obviously countries of SE Europe, alone, can not solve accumulated problems in their societies regarding dementia. They need help to develop self-sustainable National Dementia Strategies which will not be dead letter on paper

European and Greek projects about the Research in Dementia in Greece

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Research is the only way for new Knowledge. European Projects: 1."How to best meet the needs of people with dementia with severe behavioral disturbances. Toward a respectful and cost-effective model" – RECAGE" **The RECAGE project** will tackle one of the most challenging problem arising during the clinical course of dementia: the so-called Behavioral and Psychological Symptoms of Dementia (BPSD). European Union's Horizon 2020 research and innovation program. http://www.recageproject.eu/   2. "A global ecosystem for the independent and healty living of elder people with mild cognitive impairments" (ehcoBUTLER). Pilot-based, multidisciplinary, collaborative study designed to test the socio-economic benefits from the deployment of several innovative and user led ICT pilot projects based on different business models in order to be able to translate promising results into scalable practice across Europe. https://cordis.europa.eu/project/id/643566 3. "Remote Assessment of Disease and Relapse- Alzheimer's Disease" (RADAR-AD). A European project to assess the use of Remote Monitoring Technology in detection of impairments in functional components of tasks of daily living that occurred below the threshold of clinical scale detection or disability questionnaires in patients in various stages of AD. https://www.radar-ad.org/ 4. "Story2remember: Using Drama and Storytelling in Dementia Care" An innovative Erasmus+ project that proposes a methodology based on creative drama and storytelling, by creating a training program for health care professionals in Dementia care settings. Story2remember aims to improve quality of life of both Patients with Dementia (PwD) and their caregivers, to improve health care professionals' skills, to increase social inclusion of PwD and to raise social awareness on dementia issue. https://story2remember.eu/. 5. "Intergenerational CONtact between studeNts and people with dEmentia through CreaTive education". The iCONNECT project is comprised from six European Organizations/ Institutions, is funded by the Erasmus+ funding program (KA2 - Cooperation for innovation and the exchange of good practices) and focuses on innovative practices in supporting the social engagement of Higher Educational Institutions in promoting via interculture and intergenerational support the social inclusion of older people with dementia. https://www.iconnectdementia.eu/.

The National Dementia Strategy for Germany

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Background: Currently, about 1.6 million people in Germany are living with dementia. Due to demographic trends, this number is expected to rise to about 2.8 million by 2050.[1] For this reason, there is a need for raising public awareness and understanding of dementia. Germany has already made good progress in recent years on its road to a dementia-friendly society and offers a wide range of services for people with dementia and their relatives. However, there is still a need for further action.

Methodology: In order to tackle the social challenges in a sustainable manner, the Federal Government has agreed to develop a National Dementia Strategy for Germany together with the German Alzheimer's Society and representatives of the federal states, municipalities, social security institutions, the scientific and research community, the leading welfare organisations, professional and trade associations, civil society, associations of health care and long-term care professionals, and health and long-term care insurance providers. The process of development of the National Dementia Strategy took place between January 2019 and April 2020.

Results: The National Dementia Strategy aims at fostering the participation of people with dementia in society, supporting people with dementia and their relatives, improving the provision of medical and nursing care for people with dementia, and promoting outstanding research in the field of dementia. The strategy also takes into account inter-sectoral cooperation within the health care system, current developments in digitalisation and the support of people with dementia and their relatives with a migration background. Altogether 27 aims were defined and 162 measures were agreed, to be implemented in the coming years.

Discussion: The stakeholders will implement the measures in the coming years within the scope of their competences, at their own responsibility and according to the available resources. The strategy is designed for the long term and thus opens up the possibility of continuously reviewing the objectives, addressing current developments, such as the COVID-19 pandemic, and setting new priorities. A monitoring system will be introduced to support the implementation of the strategy. Furthermore, a network will be established to strengthen the cooperation between the participating stakeholders. The aim is to take stock after 2026 and further refine the National Dementia Strategy.

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SESSION Awareness building and common projects

Interprofessional educational intervention in the Danube Region

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Background: In many countries of the Danube Region the quality of care for people with dementia and their families falls short of international standards. There is a lack of dementia-related knowledge among professionals in the health and social care sector, insufficient cooperation and care coordination, as well as a shortage of important services such as day care centres.

Methodology: Vocational education of all occupational groups involved in dementia care is considered to be crucial for improving dementia care and thus enhancing quality of life of people with dementia and their informal carers (Mehrabian et al. 2019*). In 2017, dementia experts from ten South Eastern European countries teamed up with policy makers and businesses to develop and pilot an educational intervention that addresses multiple professions from the health and social sectors which makes it unique in providing a joint knowledge base on person-centred, holistic dementia care, and a platform for collaboration.

Results: The intervention is now available in a blended-learning format consisting of in-person workshops and an e-learning programme. The e-learning programme features various media such as videos, infographics and quizzes to complement existing occupation-specific trainings. All materials are currently available in five languages (English, Bulgarian, Slovenian, Slovakian, Romanian).

Discussion: The intervention is co-funded by the European INTERREG-Danube Transnational Programme from 2018 to 2021.

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

The Bike Memories service

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The Bike Memories service is an innovation of "Kosmas Etolos" care units for the elderly, based in Athens. The service is performed by an occupational therapist. It combines memory stimulation, limb mobilization and entertainment. The service is offered through a passive exercise bike which is arms and feet operated and fits into a wheelchair based on each patient's body type. It includes a large screen, through which edited videos are displayed that are created based on pleasant memories and favorite activities of the patient. These are selected from a "history of patient's life" questionnaire, which is completed both by the individual itself and close relatives.

The procedure begins with the patient sitting in a wheelchair. The necessary measurements of blood pressure, oxygen and pulse are monitored and the patient adjusts to the bicycle. The questionnaire from which the videos are created includes the following information: place of birth, origin, places one lived, favorite destinations, the jobs he/she worked in, studies, religion. Art, theater, cinema, music, sports and politics are taken into consideration. Favorite animals, plants and objects add up to the list. The session ends with the repetition of the aforementioned measurements, as well as the evaluation of the whole session, is recorded to special reports.

The Bike Memories service is a non-pharmaceutical form of intervention to the person with dementia, causing a mental and physical stimulation. The mental stimulation is caused by the audiovisual experience of watching pleasant memories of his/her life. This stimulates the hippocampus, the part of the brain associated with memories and emotions. Physical stimulation is caused by the simultaneous or non-simultaneous movement of upper and lower limbs. The use of the bicycle helps to mobilize the joints, avoid possible thrombosis, partially recover musculoskeletal disorders and intestinal motility.

This process can be described as a memory virtual walk. The duration lasts about 10 minutes and the arms and feet speed is adjusted by the bicycle software. The creation of the videos highlights favorite destinations, music and especially comic excerpts from movies that used to make the patient laugh. The information gathered from the special reports helps the doctor

understand the change in the stage of dementia. The service recommended frequency is up to 3 times a week depending on the patient and can be used either to confront upper or lower limb problems, or hearing or vision problems.

The voices of people with dementia and their carers: A strategy for public participation and involvement in a multinational psychosocial intervention trial

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Background: The importance of involving users in research to improve impact, relevance, and applicability of findings is increasingly recognised. Active music-making has shown potential to benefit older adults through multiple biological, psychological, and social pathways. The multinational randomised controlled trial MIDDEL aims to determine the effects of two **M**usic **I**nterventions (group music therapy, recreational choir singing) for **D**ementia and **D**epression in **EL**derly care. The trial's development was informed by the priorities, experience and preferences of residents and carers. To ensure the relevance and applicability of findings in each participating country, user representatives will continue to be actively involved throughout the trial.

Methodology: Guided by Normalisation Process Theory (NPT), a specifically developed template for public participation and involvement (PPI) will be implemented by local researchers. In each participating country (Germany, Netherlands, Norway, Turkey, UK), key stakeholders will be identified whose personal lives or working practice may be impacted by the research findings (care home managers, music practitioners, care home staff, relatives, residents). Members of these groups will be recruited to form local PPI groups that will periodically meet and send delegates to study management meetings. Selected PPI representatives will be trained to assist with recruitment of care homes and interviewing of individual residents.

Results: By understanding, acknowledging and systematically incorporating users' perspectives and their expertise by experience, researchers will be enabled to better anticipate and overcome any impediments to implementation of study procedures and of trial findings into routine practice, especially considering additional challenges caused by the COVID-19 pandemic and ensuing restrictions on social gatherings and singing. This will increase the efficiency of the study, accelerate dissemination, and help to ensure its impact in each participating country.

Discussion: PPI strategies as implemented within this international trial can help to underpin research with lived experience of dementia that is culturally appropriate; bring the voice of people with dementia and their carers to the research process, potentially challenging academic assumptions; and ensure the relevance and applicability of research findings as pertinent to each country.

Trial registration: NCT03496675

DEMEDARTS Dementia.Empathy.Education.Arts

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Background: Artistic-Research on Patterns of Perception and Action in an Aging Society. Around 10 million people are living with dementia in Europe. Where social policy and medicine come to an end, artistic strategies aim to open up new perspectives for people living with dementia with regard to their own abilities and the situation in their social environment. It's not only those affected who need support, but above all society must be sensitized. DEMEDARTS (Austrian-Science-Fund (FWF) A-609 PEEK), located at the Center for Didactics of Art and Interdisciplinary Education, University of Applied Arts, addresses challenges to sensitize society through artistic-& educational projects.

Methodology: Consisting of art- &design-educators, artists, teachers, movement- &art-therapists, authors, designers, we are developing the first art-based-teaching-concept to sensitize young people in schools & universities, since there is no school strategy for dementia education (through art). Questions of how art-&design-workshops can help secondary school students to develop empathy for people with dementia and how artistic research can affect the cross-generational well-being of people with dementia are addressed. Practicing *phenomenon-based-learning*, artistic interventions/workshops to change the perception of the society are developed, achieved through art-based-methods, and collaboration between people with mild to moderate dementia, people without dementia, artists, therapists, teachers, university- & secondary- students.

Results: Especially in Covid-19-times, where isolation and constraints dominate every-day, dealing with sensual experiences evoke well-being. Reid & Hartzell (2013) believe that "Art therapy provides a novel way to enhance social support [...], while aiding emotional and creative expression." The applied methods' focus was on salutogenetic perspectives (Antonovsky 1979;1996), where positive thinking skills are emphasized. This approach corresponds to research findings of Positive Psychology (Seligman&Csikszentmihaly 2000) and the SDG- Goal-3 "Good-Health" and "Well-Being". Workshops resulted in positive feedback and knowledge about dementia by all participants (N=281, aged 13-65). Most of them were students, others engaged in family care and isolation.

Discussion: Training future art & design teachers and educators to engage with the topic is relevant. The workshops allowed investigation with own isolation, focusing on the well-being and resources and a non verbal communication tool and expression of an estimated value. The stress on sensual tasks is in the light of perception of people with dementia. Doing art strengthens empathic abilities for people with & without dementia. By experienced embodiment, feelings and sensual attention become more sensitive. Art-based research facilitated a creative approach, awareness of one's own resources, and an increase of empathy as well as knowledge growth on dementia.

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Learnings on dementia friendly-communities based on experiences in two networks "Gut leben mit Demenz in Klosterneuburg" (Lower Austria) and "MITEINANDER im demenzfreundlichen Hietzing" (Vienna)

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Background: There are various factors that require us to rethink dementia care as a communal task. The number of people with dementia is growing but they live in different settings: the number of single households is growing fast, more women are in the work force and stay longer / have their children later in life and children increasingly move to cities / abroad. The care sector is confronted with a shortage of personnel to staff nursing homes and mobile services. Loneliness is a real threat for people with dementia and their immediate family. Austria'a national dementia strategy defines community care as one way to meet these challenges.

Methodology: Two networks show how communities can be empowered and encouraged to make "living well with dementia" possible. In Klosterneuburg, a network („Gut leben mit Demenz in Klosterneuburg") was founded by Caritas Vienna in 2017 and managed through 2019. Evaluation was carried out for process and impact. The network is now being run by a "Verein". In Vienna, "MITEINANDER im demenzfreundlichen Hietzing" has been coordinated by Kardinal König Haus since 2017.

Both networks address a wide variety of players and explore both personal contributions for a good life with dementia as well as communal frameworks. Participation is key in all formats used, from surveys through focus groups, one-on-one consulting to large events and media work.

Results: The authors present their learnings from three years of coordination in the networks. For Klosterneuburg, a sustainability report shows success factors and challenges. In March 2020, a panel discussion („Sorgende Gemeinden / Demenz-Netzwerke als ein zukunftsfestes Sozialmodell?") asked more than 20 experts throughout Austria to share their insights on the possibilities and obstacles to establish community care as a new way to deal with dementia in both urban and rural settings. While the possibilities vary with the settings, there are common denominators to establish sustainable networks.

Discussion: The Austrian government quotes "Strengthening civil society and self-help" as a cornerstone of care settings. Are dementia-friendly networks a sustainable setting to make this happen? Do we see such networks as important and politically desired actors?

Austria has a very diverse landscape of age-friendly and dementia-friendly initiatives and projects. The authors have explored at what these have in common, where differences are vital and where a common agenda might be useful. The pros and cons of such networks in general are discussed on the basis of success stories and instances of failure or disappointed hopes. A list of good practice items will conclude the session.

The dementia's notebook

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The science of occupational therapy is concerned with improving the quality of life of the person with dementia, helping to increase functionality, self-image, self-esteem and good psychological mood. It is known that dementia, causing memory problems leads people to states of anxiety and confusion. Some times stress occurs during the day when the person does not have or does not know what to do. Based on the data of dementia, an auxiliary solution is to create a notebook of two parts, which will contain elements of the person that are considered important so that the person is at calmness.

Before creating the notebook it is important to make an assessment by an occupational therapist during which data related to the person will be recorded. More specifically, the first part of notebook will contain basic information, such as name, date of birth, occupation or former occupation, family status, origin and place of residence and interests. It is equally important to have marked dates that have some significance for the person, such as birthdays, weddings and even deaths, in order to remember which people are alive. It would also be helpful to have photos of people, places he has visited and happy stories to stimulate memories.

Continuing, the second part of the notebook will be the individual's daily schedule. The daily routine includes daily activities that should be done during the day, such as eating, personal hygiene, sleep schedule, medication or household chores. Additionally, regular appointments will be listed either with a doctor, or a friendly meeting or any other outdoor activity. The person will also be able to record emotions, or something remarkable that happened during the day. In this way the person with dementia will be able to organize his daily life, will not neglect his obligations and will regulate his routine.

In summary, a basic condition for creating such a notebook is that it addresses an early stage of dementia, so the person can manage most of it. In many cases the occupational therapy evaluation and creation of the notebook requires the presence of a relative in order to have credibility. We must not omit the registration of emergency telephones. The notebook will help the person with dementia to be organized, focused, aware of himself and his environment and to recall memories. Anxiety is reduced as he looks back at the notebook solving the confusion that prevails in his mind.

AIDEM Workshop

mHealth for Neuro Degenerative Diseases: Something to Remember

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Mobile Health (mHealth) and potentially even its combination with ambient devices in the Internet of Things (IoT) holds great promises in earlier detection of neurodegenerative disorders when combined with recent means of Artificial Intelligence (AI). A rich range of sensors on today's smart phones and watches can be exploited to recognise early onset, for example, of the two most prevalent examples of Alzheimer's Disease (AD), or Parkinson's Disease (PD). A key advantage is that such an approach can help monitor users anywhere, anytime, in real-time, and hence potentially lead to the earlier diagnosis. However, noise, missing data, unknown signal specification and forced pre-processing and inaccessibility of the raw sensor data in hardware sensing devices are challenging to AI methods. This holds also, as hardware tends to change rapidly on the market, and AI constantly needs to adapt to new sensor signals. Recent deep learning, however, makes it possible to well cope with denoising such as by target and interference embedding (e.g., the N-HANS toolkit), package loss concealment for signal restauration by recurrent neural networks, or end-to-end learning (e.g., by the end2you toolkit) directly from the signal sample values. In addition, transfer learning, and generative approaches help overcoming hardware changes and coping with little data, as is often the case in medical applications. Overall, holistic approaches will be needed to best separate neurodegenerative disorders from other health state information. Once a diagnosis has been made, it needs to best be explainable. In addition, new methods of compression of data and squeezing of deep neural networks help increasing privacy in distributed settings or by directly allowing for local processing of personal data on small devices. Recent competitive challenge events have shown that assessing, e.g., the Mini-Mental State Examination (MMSE) score for AD seems well feasible from acoustic or linguistic user cues ready for mHealth embedding. Additional multisensorial combination can lead to a rich selection of future use-cases in the context of neurodegenerative disorders.

AI for Dementia Diagnosis: Imaging, Generalizability and Open Science

Bron, Esther

Erasmus MC Rotterdam, The Netherlands

Neuroimage analysis and machine learning can play a crucial role in early diagnosis and prediction of dementia. In this talk, Dr. Esther Bron will present some of her group's research on machine learning approaches for aiding diagnosis of brain diseases and novel approaches for modeling and predicting disease progression. But most importantly, she will focus on the validation of such methods and how proper validation is essential for translation to clinical practice and use in clinical trials. Therefore, Dr. Bron will also present the international TADPOLE grand challenge that compared state-of-the-art prediction methods and the TADPOLE-SHARE project in which various international research teams collaborate to make the prediction algorithms available for the scientific community.

AI for Dementia Diagnosis: Imaging, Generalizability and Open Science

Guilherme Wood & Silvia Kober

University of Graz, Austria

Brain oscillations are associated with specific aspects of cognition and emotion regulation and modulated by brain pathologies such as dementia. Mindfulness practices are known to have a positive impact on health and emotion regulation in healthy people as well as in dementia patients. In the present study, we investigated the impact of a VR-based mindfulness training on the brain oscillations of dementia patients. Twelve dementia patients (64-84 years of age) and 12 age-matched typical elderly persons (74-90 years of age) participated in the study. Measurements took approximately 60 minutes are consisted of 2 minutes of resting states EEG (Nexus-10 amplifiers, three electrodes easily mounted on the head), 10 minutes of questionnaire filling, 2 further minutes of resting states, VR intervention for 20 to 30 minutes, 2 minutes of resting states EEG and finally, 10 minutes of questionnaire filling for a second time. Results showed an increase in the power of upper alpha oscillations from pre to post-test in both dementia patients and typical controls. Furthermore, EEG coherence was also stronger in both groups after the VR based intervention. These results suggest that the VR-based mindfulness intervention is associated with positive changes in brain activity in both typical elderly individuals as well as patients with dementia.

Assistive Technology for Home-Dwelling People with Dementia in Times of COVID-19

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The COVID-19 restrictions affect daily living in Norway, including home-dwelling people with dementia, and researchers conducting clinical trials in dementia. My talk will 1) describe the development of a pandemic cohort (PAN.DEM) incorporated in the LIVE@Home.Path, an ongoing clinical intervention trial on resource utilization including home-dwelling people with dementia and their caregivers (N=438 dyads) and 2) describe pre-pandemic use of assistive technology and explore to which extent COVID-19 restrictions increase caregivers interest in innovation in the PAN.DEM cohort (N=126). Our main finding is that assistive technology is in regular use among 75% pre-pandemic, the vast majority utilized traditional stove guards and safety alarms, only few operate sensor technology, including GPS, fall detectors or communication aids. In response to COVID-19, 17% show increased interest in technology; the ability to operate a telephone and higher cognitive functioning are associated with increased interest. We conclude that wearable and sensing technology is not yet established among people with dementia in Norway, and few caregivers consider increased interest under the restrictions. Complying with the process evaluation of complex interventions has provided valuable information on how the unexpected intervention in terms of pandemic restrictions affects everyday life of home-dwelling people with dementia and their caregivers.

Body and Brain Training with Big Data & AI for Seniors with Dementia

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We developed playful technology for seniors to perform fun and entertaining interactive physical play, which can be shown to have significant effect on physical functional abilities and cognitive functional abilities of the seniors. Utilizing a Big Data and AI approach, we developed a novel playful method for screening people for potential physical and cognitive shortages. The method creates a body and brain performance map for each individual, and the Big Data analysis provides a basis for automatically identifying the particular abilities, which may be underperforming in an individual. Further, several studies including randomized controlled trials with the Moto Tiles system have shown that particular Moto Tiles game play will increase performance of particular abilities, even after short-term play. Thereby, the proposed system can automatically generate personalized training protocols for the individual by selecting and providing the right Moto Tiles games for the individual to play to improve the underperforming abilities. The suitability of the method was tested in a small effect test with seniors with mild dementia at a care institution in Denmark. The results show that the seniors with dementia who were screened to be at high risk of falling, within the short period of training with the automatically generated personalized protocol increased their skills to no longer be at risk of falling.

Integrating Artificial Intelligence in a Web-based Interactive Educational Tool to Support People with Dementia and their Caregivers: An Explorative Feasibility Study

Buffel, Connor & Vander Stichele, Geert

Mindbytes, Edmonton, Canada

A web-based interactive educational tool consisting of person with dementia- and caregiver-facing components was previously developed. The interactive educational tool was developed to provide insights and advice on coping and interacting with a loved one in the context of dementia. The interactive educational tool, which is comprised of 30 decision points (3 options per decision) is packaged into 10 modular narratives. The objective of the present work was to evaluate the feasibility of integrating an AI engine that could (1) compute the multiparametric, interdependent inputs reflecting the psychosocial reality in dementia and (2) tailor educational content based on user characteristics and decisions. The key emotional, psychological, and social parameters in the domain of dementia were mapped followed by a systematic structuring of contextual data. A computational model was externally validated and an early-stage engine was created around which AI algorithms could be developed. Preliminary simulations were performed to assess feasibility to generate tailored (1) scenarios (2) decision options (3) and feedback. Key challenges were identified in interoperability with existing visual design software.

Multimodal Activation for Cognitive Performance in Dementia Care: Towards AI-enabled Decision Support

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Research on prevention and intervention of dementia has recently focused on the impact of risk factors starting already in early life (Livingston et al., 2020). Lack of cognitive, physical and social stimulation, depression, among other lifestyle aspects, are modifiable risk factors for dementia. The FINGER Study (Ngandu et al., 2015) demonstrated that multimodal intervention is capable to provide a significant decrease in the cognitive decline for MCI. Recently, playful Tablet-PC based training was developed for multimodal activation in a home care setting (Paletta et al., 2020) where physical and sensorimotor exercises are complemented by a gaze-based serious game called MIRA. MIRA game scores indicate a significant correlation with reference cognitive assessment scores. First results in an exploratory pilot study demonstrate promising indication of users' neuropsychological profiles and project to future personalised assessment and intervention. Finally, we sketch an overview on planned AI-based methods for time series prediction of cognitive decline.

Dementia, Diversity, and Disparities: A Perspective from the United States

Schlesinger, Jennifer
Healthcare Services and Community Education, Alzheimer's Los Angeles

Ethnically, culturally, and linguistically diverse communities have different views of dementia as well as different barriers to care and information. This can impact disease identification, diagnosis, and post-diagnostic care and support. Low literacy and low health literacy leaves many individuals unable to comprehend and act on health-related information. When individuals are affected by dementia and family caregivers are under stress, plain language materials can help them absorb information more easily, improving their ability to manage challenging caregiver situations and dementia-related behavioral symptoms.

ABSTRACTS – POSTER

POSTER

Screening for Dementia with the Vienna Visuo-Constructional Test 3.0 Screening (VVT 3.0 Screening)

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Background: Visuo-constructive functions are one important cognitive domain for the diagnosis and early detection of the dementias. Using the Vienna Visuo-constructional Test 3.0 Screening (VVT 3.0 Screening), we assessed visuo-constructive performance in subjective cognitive decline (SCD), mild cognitive impairment (MCI), Alzheimer's disease (AD), and healthy control (HC) groups to determine whether VVT scores can be used to distinguish the mentioned diagnostic groups and predict disease progression to more advanced stages.

Methodology: We analyzed the data of 422 patients referred to the Department of Neurology, Medical University of Vienna, for assessment of neurocognitive status. We also examined 110 of these patients in a follow-up with regard to stability of performance and disease progression. We compared VVT performance across diagnostic groups and explored associations with relevant sociodemographic and clinical variables. Predictive validity was assessed using Receiver Operator Characteristic (ROC) curves and Multinomial Logistic Regression analyses.

Results: We found that most diagnostic groups differed significantly regarding VVT scores. These were shown to reliably identify cases suffering from visuo-constructive impairment but were not sufficient for classification into all diagnostic groups. Progression to more advanced disease stages could not be predicted reliably using VVT scores, possibly because subsamples of progressors were quite small.

Discussion: In summary, VVT scores are useful indicators for identifying visuo-constructive impairment but are limited by factors such as similar disease manifestations when used to discriminate between several diagnostic groups. The same factors complicate the use of VVT scores for predicting disease progression to more advanced stages.

Further Information: www.psimistri.com – global psychometric test and intervention systems

Reference: Valencia N, Lehrner J. Screening for dementia with the Vienna Visuo-Constructional Test 3.0 screening (VVT 3.0 screening). Neuropsychiatr. 2018 Dec;32(4):196-203. doi: 10.1007/s40211-018-0279-9. Epub 2018 Jul 9.

Caregivers perception on association between oral health and dementia: A focus group study

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Background: In the United Kingdom (UK), estimates show that there are around 850,000 people live with dementia, and 700,000 friends and family are caring for a person with dementia[1]. Professional carers and family members play a vital role in supporting people with dementia in their oral care. In this qualitative study, the researcher explored the perceptions and experiences of professional and family carers on association between oral health and dementia when caring for people with dementia.

Methodology: Data was collected from a sample of 16 caregivers using three focus group sessions in Wolverhampton, UK. Participants in this study were recruited through word of mouth from community areas especially community groups such as church or care homes. The data collection was done by the focus group topic guide and short questionnaire. Each focus group session lasted for average 70 minutes and had different participants. The focus group were audio-recorded during the focus group and throughout the session, brief field notes were taken. Audio recording were later transcribed which were entered into NVivo V.10 for data analysis.

Results: Out of 16, ten of the participants were professional caregivers and six were family caregivers. They had been carers for <1 year to >10 years. Five were male and eleven were females with educational status from primary to postgraduate. There were seven sub-themes which were grouped into three main themes from the findings. First, perceived relationship between dementia and oral health described about general view of caregivers. Second, caregiver perception regarding dementia care about barriers and support provided to people with dementia. Third, external factors for dementia and oral health in people with dementia mentions socio-cultural and lifestyle factors.

Discussion: The study, to the best of knowledge, is the first qualitative focus group study that examined the caregiver's perception on association between dementia and oral health of people with dementia. Recent evidence reported in literature it has been shown that poor oral health (tooth loss and periodontal disease) could increase dementia risk[2,3]. Similarly, dementia could lead to poor oral health[2]. This study increases our understanding about the views and beliefs of family and professional caregivers of dementia risk leading to poor oral health and other confounding factors role in association between dementia and oral health.

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Basic Needs Management in Time of COVID Crisis in Local Level

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Background: The Covid-19 emergency, which initially hit the developed world, is presently spreading into developing nations. Developing nations will in general be less fortunate, attempting to turn out to be further developed monetarily and socially. Their frameworks aren't as set up as those you find in Europe and the US. They additionally depend on essential area jobs. All exercises that comprise of abusing characteristic assets, like farming, mining, and ranger services. Thus, they are especially affected by disrupted supply chains and lower demand for their goods. In this paper, the condition of accomplish of basic need of the people due to Covid-19 emergency is investigated in remote areas of Nepal.

Methodology: The digital survey is conducted for the people of Nepal residing in remote areas using different social medias. The questioners include the fulfilment of the basic needs of people and around them during the COVID breakout. The condition of financial situations of the people in the community below average economic line are focused for the query in the survey. Source of income of the people is mentioned to identify the social status of the people. The role of local government and private authorities and their transparency in providing the basic need is also mentioned. Furthermore, the psychological effect is also reviewed.

Results: Addressing the basic needs of people like food, shelter and clothing by local authorities seems poor in managerial level. Transparency of work ethics of the government and private authorities in the local level seems satisfactory. Most of the peoples in remote areas are below poverty line and their source of life is daily income through labor work. Due to lack of the work environment, most of this category of people are relying on the donation package of government, local authorities and social workers. Furthermore, the psychological effect is found to be more on children and old age group.

Discussion: The Covid-19 emergency is gradually hitting in the developing countries like Nepal in remote areas. Due to large poverty line, people are unable to even meet their basic needs of food, clothing and shelter. Daily wages works are mostly affected. The private authorities,

local government bodies and social workers are the main pillars of management in this sort of crisis. Their work ethics is satisfactory and need to be more precise on proper long-term management of basic needs for people with the guidance of expertise of managerial field.

POSTER

Utilization of occupational therapy services and relation to survival in people taking dementia-specific medication in Austria - a retrospective population based study with a 13-year observation period

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Objectives: Evidence-based treatment of dementia includes pharmacological and nonpharmacological methods of which psycho-social interventions are an important component, commonly administered by occupational therapists. The aim of this study was to investigate the utilization of occupational therapy (OT) services and its association with survival in people taking dementia-specific medication in a population-based Austrian dataset compared to a two times as large control group without dementia-specific medication.

Methods/Design: A retrospective study with a 13-year observation period (2003-2016) was conducted on real-world data covering 98% of all insured Austrians. We used descriptive statistics, Chi-squared/Fisher's Exact Tests and survival analyses including three Cox models.

Results: Data from 286,553 participants were analysed. Only 4.5% (n=12,950) received OT services. In the dementia-medication group (n=111,033), participants who received OT services (3.6%; n=4,032) had significantly more comorbidities (4.7%) compared to those without OT (3.5%; p<0.001) and were also more likely to be male (4% versus 3.5%; p<0.001). While persons taking dementia-specific medication showed a slightly reduced survival with OT

(p<0.001) compared to those without, the result in the control group without dementia specific medication showed a slightly better result of the participants who received OT (p<0.001). The reduced survival in the dementia-medication group with OT is likely to be related to the higher number of comorbidities in this group.

Conclusion: The small number of people who received OT in both groups shows that OT services might not have been accessible to all people who needed them. Moreover, people with dementia-specific medication were more likely to receive OT when they had comorbidities.

ICOS – a new method for early dementia detection

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Background: Early dementia detection is still a problem in everyday clinical practice. Hence I developed an internet based method for early dementia detection which goes by the acronym ICOS (Internet based COgnitiv Score) that allows fast, easy and sensitive relevant testing on that matter. The test is provided as a progressive web app that can be started – preferably on a mobile phone – at the url https://braining.app.

Methodology: In order to validate the test I did so far a single centered comparison of the ICOS results compared to Mini Mental score results and Demtect score results of the relevant patients in my doctor´s office, which showed so far a significantly higher sensitivity for dementia detection by using ICOS than using Mini Mental Score and a slightly higher sensitivity for dementia detection by using ICOS than the Demtect score, whereas I have to grant that the number of patients is yet too small to give good statistic power to that comparison.

More data is being gathered and a new study is currently being developed to be sourced by several different medical centers in Styria.

Results: So far results show that ICOS (https://braining.app) could be a good screening test for early dementia detection, that can be done in an uncomplicated way from home with as little as an internet connection and a standard mobile phone. It seems to be giving a good idea whether there exist indicators for an early dementia and could be used by general practitioners as well as patients themselves independently.

Discussion: Even though the collected scientific data is not yet fully sustainable for good scientific/statistic power I still believe this app/development could be of interest at the upcoming second dementia congress in Krems in order to show potential future ways on how to improve early dementia detection in everyday clinical practice.

List of Contributors

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